



City Research Online

City, University of London Institutional Repository

Citation: Wilson, C. J. (2007). Cancer nurses' assessment practice in the outpatient chemotherapy unit: a realist evaluation of the introduction of an assessment tool. (Unpublished Doctoral thesis, City University London)

This is the submitted version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/12060/>

Link to published version:

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

City Research Online:

<http://openaccess.city.ac.uk/>

publications@city.ac.uk

St Bartholomew School of Nursing and Midwifery
Department of Public Health and Primary Care
City University
London

Cancer Nurses' Assessment Practice in the
Outpatient Chemotherapy Unit: A Realist Evaluation
of the Introduction of an Assessment Tool

Catherine Julia Wilson

PhD

June 2007

Author: Catherine Julia Wilson

Title: 2007

Year: Cancer Nurses' Assessment Practice in the Outpatient Chemotherapy Unit: Evaluation Of the Introduction Of And Assessment Tool

Deposit agreement signed? no

Page	Item	Cause for Concern
59	Fig 3.1	Adapted from other source, but cited
60	Table 3.1	Adapted from other source, but cited
75-79	List of participants	List of participants but author later states that all have been given pseudonyms.
93	Fig	Adapted from other source, but cited
285	Appendix 5	Assessment tool – copied from elsewhere?
325	Appendix 14	Toxicity proforma – copied from hospital
341	Appendix 17	Appears to have been downloaded from website – can't find on web;, i think the web addresses are in the nature of references. (SP)

Table of Contents

Table of Contents	1
List of Tables	5
List of Figures	7
List of Flowcharts	9
List of Graphs	11
Acknowledgements	13
Abstract	17
Glossary	19
Introduction	21

Part One

Chapter 1	Literature Review: Assessment in Cancer Care	27
1.1	Introduction.....	27
1.2	Assessment in cancer care: the problem	28
1.3	Developments in oncology nursing: the role of the chemotherapy nurse	30
1.4	Nurses' assessments of palliative care patients	32
1.5	Improving assessment in cancer care	34
1.6	Chapter Summary	39
Chapter 2	Assessment in Nursing.....	41
2.1	Introduction.....	41
2.2	Assessment in nursing: an historical overview	41
2.3	Assessment as a cognitive activity	42
2.4	Assessment as a social activity	45
2.5	Summary of social aspects of assessment.....	52
2.6	Conclusion.....	53

Part Two

Chapter 3	Methods.....	57
3.1	Introduction.....	57
3.2	Research Design.....	57
3.3	Aims and Objectives.....	58
3.4	Methodological framework.....	59

Table of Contents

3.5	Realist Evaluation	62
3.6	Methods	65
3.7	Into the Field: The Conduct of the Study.....	73
3.8	Process of Data Collection.....	80
3.9	Ethical issues	82
3.10	Data analysis.....	85
3.11	Credibility and Rigour.....	88
3.12	Summary.....	89
Part Three		
Overview of Part Three: Findings.....		93
Chapter 4	Findings Phase 1: Describing Nurses' Assessment Practice	95
4.1	Introduction	95
4.2	Assessment at The Northern.....	95
4.3	Testing Context-Mechanism-Outcome Configurations	96
4.4	Summary of findings from The Northern	114
4.5	Assessment at The Southern: A Comparison	117
4.6	Revised Context-Mechanism-Outcome1.....	119
4.7	Summary.....	131
Chapter 5	Explaining nurses' assessment practice.....	133
5.1	Understanding assessment talk	133
5.2	Working in the Dark: overview.....	134
5.3	Control of the interaction	149
5.4	Summary of conceptual framework.....	153
Chapter 6	The impact of the assessment tool.....	155
6.1	Overview:	155
6.2	CMO Configuration for Phase 2	157
6.3	Summary.....	174
Chapter 7	Explaining the impact of the tool	175
7.1	Introduction	175
7.2	Awareness	176
7.3	Clarifying the issue.....	179
7.4	Interpreting.....	181

7.5	Supporting	183
7.6	Reframing	186
7.7	Summary of Conceptual Explanation	188
Part Four		
	Overview of Part 4	191
Chapter 8	The social organisation of assessment talk	193
8.1	Introduction	193
8.2	Realism and causation	193
8.3	Social organisation	194
8.4	Understanding Assessment as 'Information work'	195
8.5	Summary	207
Chapter 9	Discussion	209
9.1	Introduction	209
9.2	Assessment according to a hierarchy of appropriateness	209
9.3	Impact of the tool: creating discordant discourses in the chemotherapy unit	219
9.4	Assessment or screening?	224
9.5	Limitations of the study	225
9.6	Recommendations for policy and practice	227
9.7	Recommendations for future research	229
9.8	Summary	229
Chapter 10	Concluding the Realist Evaluation	231
10.1	Introduction	231
10.2	What worked for the patients?	231
10.3	What worked for the nurses?	234
10.4	What did not work for the nurses?	237
10.5	In what circumstances?	240
10.6	Reflections on the Realist Evaluation	244
10.7	How to test in the future	246
10.8	Conclusion	250

Table of Contents

References	251
Appendix 1 Research Studies	275
Appendix 2 Patients Interview Schedule	279
Appendix 3 ECOG classification	281
Appendix 4 Sociodemographic form	283
Appendix 5 ART Assessment Tool.....	285
Appendix 6 Ethics Committee	291
Appendix 7 Patient Invitation Letter.....	297
Appendix 8 Patient Invitation Sheet	299
Appendix 9 Nurses Interview Schedule.....	307
Appendix 10 Poster.....	309
Appendix 11 GP Letter.....	311
Appendix 12 Audit Trail.....	313
Appendix 13 Data from ART	319
Appendix 14 Toxicity Proforma The Southern.....	325
Appendix 15 Interim Phase Field Notes Extracts	327
Appendix 16 Patients' Professional Support	337
Appendix 17 Theory of Planned Behaviour.....	341
Appendix 18 Nurse Information.....	343
Appendix 19 Nurse Invitation Letter	349
Appendix 20 Consent Forms.....	351
Appendix 21 Examples of Transcripts.....	359

List of Tables

Table 1-1	Comparison of two studies using the EORTC QLQC 30 in clinical practice.....	38
Table 3-1	Principles of Realism	60
Table 3-2	Context-mechanism-outcome configurations which guided the study	65
Table 3-3	Details of participating nurses at The Northern.....	76
Table 3-4	Patients' details: Phase 1, The Northern.....	77
Table 3-5	Patients' details Phase 2 The Northern.....	77
Table 3-6	Details of nurse participants at The Southern.....	78
Table 3-7	Patients in Phase 1: The Southern	79
Table 3-8	Patients in Phase 2: The Southern	79
Table 3-9	Addressing issues of rigour and credibility.....	88
Table 4-1	Context-mechanism-outcome configurations for Phase 1.....	97
Table 4-2	Evidence for the unit's relaxed and friendly approach.....	98
Table 4-3	Use of the anchor question	99
Table 4-4	Evidence for mechanism of trust from follow-up interviews	101
Table 4-5	Mechanism of Trust	102
Table 4-6	Examples of patients' descriptions of rapport	103
Table 4-7	Mechanism of rapport.....	105
Table 4-8	Context-Mechanism-Outcome 1	105
Table 4-9	Safety and administrative issues in assessments.....	106
Table 4-10	Side effects raised during assessments.....	107
Table 4-11	Symptoms discussed during assessments	107
Table 4-12	CMO 2 Phase 1	111
Table 4-13	Summary unit workload, Phase 1	112
Table 4-14	Summary of issues discussed during assessment.....	113
Table 4-15	Revised Phase 1 CMOs for nurses at The Northern.....	115
Table 4-16	Revised Phase 1 CMOs for Patients at The Northern.....	116
Table 4-17	CMO 1	119
Table 4-18	Revised context: relaxed and friendly approach	119
Table 4-19	Mechanism of rapport	120
Table 4-20	Mechanism: Trust	121

List of Tables

Table 4-21	Mechanism of emotional control	122
Table 4-22	Issues discussed during the assessments at The Southern	124
Table 4-23	Revised outcome for CMO1.....	125
Table 4-24	CMO1: Revised outcome of assessment.....	126
Table 4-25	CMO2: Contextual influences on assessment	127
Table 4-26	CMO2 Influence of workload and busy-ness on communication in assessment	128
Table 4-27	Mechanism of Time on assessment	129
Table 4-28	Outcome: satisfaction	130
Table 5-1	Nurses' post-registration training and experience.....	140
Table 5-2	Working in the dark: facets of knowledge as a disabling mechanism	144
Table 6-1	CMO Phase 2	157
Table 6-2	Mechanism: Articulation.....	161
Table 6-3	Mechanism: Engagement outcomes.....	162
Table 6-4	Disabling mechanisms.....	163
Table 6-5	Reasons for patients declining offers of help	166
Table 6-6	CMO Phase 2	168
Table 6-7	Referrals and interventions	170
Table 10-1	Nurses' feedback about using the assessment tool.....	235
Table 10-2	Learning from the circumstances of what worked.....	241
Table 10-3	What worked for Myra and Sue	248

List of Figures

Figure 3-1	The Research Design (adapted from Crotty 1998)	59
Figure 3-2	The Realist Evaluation Cycle	62
Figure 3-3	Core category in Phase 1: Confirming treatment tolerability	86
Figure Overview-1	The Realist Evaluation Cycle	93
Figure 4-1	Conduct of the assessment conversation at The Northern (Phase 1).....	96
Figure 4-2	Conduct of the assessment conversation at The Southern (Phase 1)	118
Figure 4-3	Revised CMOs from Phase 1	131
Figure 5-1	Model of assessment talk in the outpatient chemotherapy unit.....	134
Figure 6-1	Pattern of assessment interaction in Phase 2.....	156
Figure 6-2	Revised CMOs, Phase 2.....	174
Figure 7-1	A model of structured quality of life assessment.....	175

IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

List of Flowcharts

Flowchart 3-1 Overview of Case Study 1..... 67

Flowchart 3-2 Overview of Case Study 2..... 68

IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

List of Graphs

Graph 4-1	Patients' issues from follow-up interview	108
Graph 4-2	Length of assessments or contact with the nurses in Phase 1	112
Graph 4-3	Length of assessments Phase 1, The Southern	129
Graph 6-1	Graph of high scores on the assessment tool: The Northern	165
Graph 6-2	Graph of high scores on the assessment tool: The Southern	165
Graph 6-3	Pie chart to show patients' emotional and existential concerns	169
Graph 6-4	Social issues identified	169
Graph 6-5	Graph to show average length of assessments, Phase 1 and Phase 2	171
Graph 6-6	Number of issues raised by patients	173

IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Acknowledgements

My thanks go first and foremost to the nurses and patients who kindly agreed to participate in this study. My pledge to preserve their anonymity prevents me from naming them, but I am most grateful to them for letting me observe and listen to their assessments, and for sharing their thoughts so willingly in order to help me in this work.

In addition, I am indebted to the following:

Professor Rosamund Bryar, and Dr Anne Lanceley, my academic supervisors, whose wisdom, patience, guidance, and support have been invaluable

Professor E Jane Maher, for encouraging me to undertake this project, and for her generous financial support of the work

West Hertfordshire Hospitals NHS Trust for part-funding my salary

The Band Trust/The Florence Nightingale Foundation for the award of three scholarships to pay my academic fees

The John Laing Foundation for two donations to help with the expenses of the project

The League of Nurses, St Bartholomew's Hospital, for a grant to buy the mini disc recorders

My colleagues (past and present) in the Supportive Oncology Research Team, especially Teresa Young, for her support and advice on the analysis of the assessment tool

Sajjad Shah for being able to interpret my 'drawings' and for producing the graphics of the two models

The Librarians at The Les Cannon Memorial Library, for their help in retrieving articles and journals

Lloyd Allen for giving me clinical supervision in 2005 and for his insight into the effect of the research process

Gay Walker, for proof reading the draft thesis

My husband, David, for his encouragement, support, patience and much needed IT expertise. Thanks go also to Oliver, Andrew and Emma without whom this project would have been completed much sooner, although without whom it might never have been undertaken

My friends, Kirsty Cottle, Jenny Plumb and Antonia Scott, who have 'been there' in the wings. Special thanks to my 'PhD buddy' and friend, Kathy French, for sharing the journey

Finally, I should like to acknowledge all those who have influenced my clinical practice and thinking over the years, especially patients (in particular Ruth, Linda, Edna and Patricia) in the 'second line chemotherapy breast cancer study' who taught me so much about structured assessment. Dr Gisela Field was my clinical supervisor from 1999-2002, and was instrumental in recognising the potential therapeutic effect for patients of the assessment tool.

IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

Declaration

I grant powers of discretion to the University Librarian to allow this thesis to be copied in whole or in part without further reference to me. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement

IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Abstract

Assessment tools have been shown to increase the accuracy of professionals' assessment of patients (Heaven and Maguire 1997; Söllner et al 2001; Horton 2002; Hill et al 2003; Farrell et al 2005). Whilst structured assessment of patients with advanced cancer is recommended to enhance patients' experiences of illness and treatment and improve service provision to meet their needs (NICE 2004, p24), little is known about the actual practice of using structured assessment tools. There is limited evidence that nurses have the skills required to use assessment tools. Evidence also suggests that nurses may be ill prepared and inadequately supported to deal with the consequences of more comprehensive assessment of patient need.

This case study used realist evaluation to identify the impact of introducing a quality of life assessment tool in two outpatient chemotherapy units. Qualitative methods of non-participant observation, audio-recording, and individual interviews were used. 38 patients attending for palliative treatments and 10 nurses were recruited; 6 nurses completed all stages of the study. Data was collected in two phases with an interim period of training in between. In Phase 1, nurses assessed patients as usual. In Phase 2 the assessment tool was used. The nurse-patient assessment interaction was observed and tape-recorded. Interpretive interviews were conducted with nurses and patients to ascertain their perspectives of the assessment. Consistent with realist evaluation, data were analysed thematically to test and refine context-mechanism-outcome configurations. Social organisation as an underlying causal mechanism provided an explanatory framework for data analysis.

Findings reveal that, prior to the introduction of the assessment tool, nurses' assessments were brief and treatment-related. After the introduction of the tool, assessments were patient-led, and focused on patients' experiences. Whilst patients valued this shift in focus, results demonstrate that the assessments were time-consuming and did not necessarily prompt appropriate multi-disciplinary team referrals. The use of the tool was problematic for nurses, exposing them to emotionally challenging issues, and revealed gaps in their cancer and palliative care knowledge. These findings have been underplayed in recent policy and assessment guidance. Recommendations for practice, training and future research are made which may help to ensure that guidance is successfully rolled out in the future.

IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Glossary

Abbreviation / Term	Definition and Explanation
ENB 237	English National Board Course 237 is a post-registration certificate in Cancer Nursing, covering issues relating to the principles and practice of nursing patients throughout the illness trajectory. It is not specifically designed to enable nurses to administer chemotherapy.
N59	A short post-registration course to prepare nurses for and enable them to give chemotherapy. Originally designed for experienced cancer nurses to give them extra skills in the administration of chemotherapy (How 2006, personal communication), it is now used as a stand-alone course to prepare nurses for this role. A requirement for working in the outpatient chemotherapy unit. Curriculum covers: safety; emergencies; toxicity of specific drugs; practical skills; and an overview of psychological and social issues
Macmillan nurse Mac nurse	A nurse specialist in cancer care, either with specific tumour-related expertise and case load or as more widely used in the thesis, a palliative care specialist nurse. Macmillan Cancer Relief pump-primes these posts for three years, after which they become funded by the NHS Trust, but the name persists. The term has been used in this thesis as all the patients and nurses referred to such post holders as the Macmillan, or Mac nurse.
DN	District nurse. A nurse working in the patient's home, based in primary care, not necessarily with any special expertise in palliative care matters
MDT	Multi-disciplinary team involved with cancer patients and can include: Oncologist; GP; social worker; district nurses, palliative care nurses (Macmillan nurse); hospice day care; dietician
N:	Nurse
P:	Patient
Rel:	Relative
QoL	Quality of life
OP	Out patient (sometimes also referred to in the literature as: day-care or ambulatory care)

Glossary

Transcription notes

The transcripts have been provided to convey the conversation. They have not been transcribed with full discourse analysis symbols and terminology. However, where patients and nurses speak at the same time, the following symbols have been used: for example:

N: Well how are you

=today

P: =fine

Introduction

This thesis describes a study which explored cancer nurses' assessment practice in the outpatient chemotherapy unit. The research was concerned with the way in which patients' 'needs' are interpreted in this setting, and with identifying the implications of changing assessment practice in line with policy recommendations from the National Institute of Health and Clinical Excellence (NICE) (2004). Specifically, the thesis is about the impact of introducing a quality of life assessment tool into two outpatient chemotherapy units in different hospitals, and the consequences arising from this intervention.

Three areas of interest underpin this work. Firstly, assessment has long been the focus of practice development initiatives in cancer nursing and oncology because of its importance in directing patients to timely and appropriate support (NICE 2004). Recent research, however, identifies that patients' needs and concerns are not recognised or addressed in clinical practice (Hill et al 2003; Farrell et al 2005). This is not only disappointing but cause for concern, because cancer patients are known to have multiple and complex needs (Botti et al 2006); assessment is therefore acknowledged to be an important aspect of cancer patients' care (Wilkinson et al 2002).

The remedy for inadequacies in assessment is perceived to be the improvement of professionals' skills. Over the past two decades, assessment skills training programmes have been developed, refined, and provided for nurses and doctors working in cancer care (Heaven and Maguire 1996; Parle et al 1997; Fallowfield et al 1998; Department of Health 2000; Fallowfield et al 2001; 2002; Parle et al 2001; Maguire et al 2002; Wilkinson et al 2002); indeed, communication and assessment skills training is a requirement of continuing professional development (Department of Health 2001). It appears, however, that significant improvement in practice is yet to be seen (e.g. Horton 2002; Hill et al 2003; Farrell et al 2005); in spite of the emphasis on assessment in cancer care, fundamental difficulties remain in transferring skills into practice. The question to be asked is why the *status quo* persists. Extensive research has been carried out in this area (e.g. Fallowfield et al 2002; Maguire et al 2002; Wilkinson et al 2002), but the answers remain elusive. This is partly because the majority of studies investigating assessment have been designed to compare clinically-based assessment conversations against a 'gold standard'; such an approach can (and does) reveal the deficits between the actual and the ideal, but cannot explain assessments in terms of underlying mechanisms which shape their form and conduct. A different focus of research is required which moves away from describing deficiencies in nurses' assessments, to one which explores the structures that both constrain and facilitate practice.

Of particular interest is the recommendation by NICE (2004) that structured approaches to assessment should be adopted as means to improve outcomes. Research findings demonstrate a strong correlation between the use of an assessment tool and the accurate identification of patients' problems (e.g. Newell et al 1998; Horton 2002; Hill 2003; Farrell et al 2005; Kruijver et al 2006). Assessment tools are being enthusiastically embraced in cancer care (McGrath et al 2005); much improvement is expected to follow from their adoption into clinical settings, for they are seen as 'an unqualified good' (McGrath et al 2005 p691) and as 'best practice' (McGrath et al *ibid* p691). This degree of faith in assessment tools reveals a simplistic understanding of their possible effect. For instance, although one study suggested that their use was therapeutic for patients (Annells and Koch 2001), another identified that patients

Introduction

disliked them (McGrath et al 2005). Worryingly, using an assessment tool had a negative impact on nurses' ability to give patients holistic care (McGrath and Phillips 2007). Such findings indicate that, contrary to expectations in policy, introducing assessment tools into clinical practice might have equivocal outcomes.

There is a paucity of research into the effect of assessment tools on cancer nurses' practice (most has examined oncologists' use of tools). Redressing this is important not only because nurses are pivotal to providing cancer care (Richardson 2004), but also because studies which have explored day-to-day communication between cancer nurses and patients (i.e. nurse-patient talk which does not have a specific assessment aim) identify that the more patients are encouraged to share their anxieties, the more nurses 'block' such disclosure (Booth 1993; Heaven and Maguire 1997; Lanceley 2000; Kruijver et al 2001a; 2001b). Assessment tools, being more accurate in identifying patients' concerns, might produce a similar effect, and therefore their effectiveness would be compromised. The potential difficulties of using tools have not been adequately acknowledged by policy makers.

Secondly, major changes are taking place in the way cancer care is organised and delivered in the UK, with new priorities for care and treatment (Department of Health 2000a; 2000b; 2001; 2005). Policy shapes *systems* of care; it is practitioners who incorporate initiatives into their day-to-day work. It is therefore important to explore the impact of policy on clinical areas, because currently in the NHS, there is an inherent contradiction between a target-driven commitment to efficiency and effectiveness, and an emphasis on the individual patient as 'consumer' and 'partner' in care. How this tension is managed in practice is of interest and relevance to this study: assessment necessarily involves patients' own interpretations of need and meaning, which have to be accommodated within the existing service; support has to be provided within the constraints of available resources. Thus, introducing assessment tools, which are known to identify a greater number of patients' needs than 'usual' assessments, might have far-reaching implications both for practitioners and for the organisation of cancer care.

Thirdly, developments in oncology have increased optimism for treatment outcomes (The 2002). Patients with incurable disease can benefit from anti-cancer treatments, such that the 'palliative' and 'terminal' phases of a cancer illness are increasingly merged with the treatment phase (Schou and Hewison 1999; The et al 2000; The 2002). Most patients receive anti-cancer treatments in out-patient or day care settings (Sitzia and Wood 1997), characterised by rapid patient throughput. How patients' distress or symptoms are acknowledged in clinical areas such as these is unclear (Corner 2001); evidence is emerging that in outpatient chemotherapy units there is a dichotomy between 'treatment' and 'support' (McIlfratrick et al 2006), thus separating 'care' from 'work' (James 1992b). This division might be exacerbated by the notion of 'supportive care', which gives the remit of 'support' and 'care' to skilled and trained professionals based in offices or centres removed from clinical settings and in-patient wards. On the one hand these developments relieve the pressure on those working in busy treatment areas and ensure that time and space are given to patients who require or desire support, but on the other hand, such services reduce the responsibility taken by individual professionals for providing psychosocial care (Seymour et al 2002). This issue has two potential implications for assessment: firstly, patients need to be assessed in clinical areas in order to access support and specialist care. Secondly, the proliferation of 'specialist' support might affect individual practitioners' priorities for assessment, narrowing its focus to areas of clinical relevance. Rather than see this as a

failure, it might be timely to re-configure assessment as a bridge between the holistic approach to care to which cancer nurses espouse (Seymour et al 2002; Williams and Payne 2003), and the reality of everyday clinical practice.

These themes are the foci of this thesis, which describes how introducing an assessment tool into the outpatient chemotherapy unit changed assessment from a question-and-answer conversation constituted by the rituals and functions of the treatment setting, which permitted only a narrow exploration of patients' problems, to a dialogue facilitated by the tool in which patients' experiences and concerns were articulated and acknowledged. In the process, the tool disrupted the smooth running of the chemotherapy units, and exposed tensions between the rhetoric in cancer care relating to holism, and the reality of practice which demands efficiency and accountability. The research approach adopted by this study identifies why the introduction of assessment tools into current practice is unlikely to be a panacea, and elucidates the reasons for the way cancer nurses' assessments in contemporary clinical settings are currently conceived and conducted.

The thesis is divided into four parts. Part 1 outlines the background to the study, and is comprised of two chapters. Chapter 1 critically reviews the literature on assessment in cancer care, and identifies that there is a need for an alternative approach to researching assessment practice, to include the patients' voice and embrace the context of care. Chapter 2 explores assessment in nursing, and discusses how assessment practice is affected by the contradiction between professional and managerial discourses in health care. These two chapters provide the justification for the study and set the work into its policy and practice context.

Part 2 of the thesis concerns the empirical phase of the research. Chapter 3 presents the realist evaluation approach, which was the methodological framework for the study, and describes the methods used to collect and analyse the data.

Part 3 of the thesis is comprised of four chapters. Chapter 4 is concerned with Phase 1 of the data collection, in which context-mechanism-outcome hypotheses (CMOs) devised at the outset of the study were tested and refined. Chapter 5 brings these findings together into a model of assessment in the outpatient chemotherapy unit. The model provides a conceptual explanation for nurses' assessment practice as part of the realist evaluation. Chapter 6 is concerned with the findings from Phase 2 of the data collection, in which assessments were conducted using the tool. Hypothetical context-mechanism-outcome configurations were tested, and revised, before being presented in the form of a model of structured assessment in Chapter 7.

Part 4 of the thesis concludes the realist evaluation. This is achieved in three stages. Firstly, in Chapter 8, the reasons for the limited impact of the tool are explained in terms of an underlying causal, or generative, mechanism in the setting, identified as social organisation. Secondly, Chapter 9 discusses the implications of the findings for practice, policy and future research, and acknowledges the limitations of the study. Thirdly, Chapter 10 answers the question: what worked, for whom and in what circumstances (Pawson and Tilley 1997 p216). Reflections on the realist evaluation approach are presented, and a suggestion made for how the revised CMOs from Phase 2 of the study might be re-evaluated. Finally, conclusions from this work are drawn.



IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

Part One



IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Chapter 1 Literature Review: Assessment in Cancer Care

1.1 Introduction

Cancer is a major cause of illness and death in the UK: one in three people will be diagnosed with cancer in their lifetime, and one in four will die from it (Department of Health 2002). The diagnosis of cancer, its treatment and subsequent effects, impact upon every aspect of patients' lives (Wright et al 2002); accordingly, 'supportive care' services have developed to help patients and their families cope. These services include information, counselling, complementary therapies, rehabilitation, spiritual support, specialist psychiatric and psychological care and symptom control (Richards 2003). Supportive care, however, is reliant upon assessment; without it, professionals cannot provide, or direct patients to, appropriate help and information. Thus, assessment is the key, the 'critical first step' (NICE 2004 p 39) in ensuring that patients can access available or required supportive care services.

This chapter presents a critical review of the literature relating to assessment in cancer care, with specific reference to assessment in cancer nursing. It is important to clarify what is meant by 'assessment', as the term encompasses many concepts. The definition of assessment which guided the selection of literature for this review was:

'Assessment is ... to identify the patient's most important needs and concerns and decide upon a plan of care in collaboration with other health care professionals where appropriate.'

(Alfaro-LeFevre 2004 p76)

This definition forms the framework for the discussion and description of nurses' assessment practice throughout this thesis.

The literature presented in this chapter was identified from a search of the following computerised databases from 1991-2006 unless otherwise stated:

CINAHL, OVID, PSYCHLIT, RCN Journal Data base (1985-1996), British Nursing Index (1991-2006).

The search terms were:

assessment; nurse-patient assessment; assessment skills; communication; cancer nursing; oncology; outpatient; day care; ambulatory care; chemotherapy; palliative care; patient needs; concerns; symptom assessment; assessment tools; quality of life; quality of life tools; chemotherapy toxicity; advanced cancer.

These terms were used as subject headings, keywords, in combination, exploded and imploded.

Hand searching of references and theses was also carried out.

Initially, 116 articles were retrieved; those with an empirical base were selected. Articles were rejected if the contents related to: the assessment of a specific symptom (e.g. pain); 'assessment' pertaining to nurse education; 'needs assessment' (in policy terms); and assessment in advanced nursing practice. As the thesis has progressed, further literature was accessed and reviewed.

The chapter is divided into two main sections. The first considers the issue of assessment in cancer care in general, and cancer nursing in particular. Firstly, the extent of the problem of assessment in cancer care is detailed, based on research evidence which has identified that health professionals are poor at identifying cancer patients' problems. This is followed by a critique of the way in which assessment in cancer care, and cancer nursing in particular, has been constructed and researched. The discussion is centred on three areas: the focus on analysis of the linguistic skills required for and used in assessment; assessment practice in chemotherapy nursing; and assessment of patients in the palliative phase of their illness. This discussion provides the context for the research that is presented in subsequent chapters. To a large extent, research into assessment in each of these areas has focused on the gap between the number and type of patients' concerns identified by nurses in practice, and the number and type of concerns identified from the analysis of the data. I will argue that this perspective has a narrow focus, and has limited our understanding of why problems in assessment practice persist.

The second section of the chapter is divided into two parts and contains a critical review of initiatives introduced to improve professionals' assessments of cancer patients, namely assessment skills training and the use of assessment tools. The first part explores the impact of assessment skills training on nurses' ability to elicit patients' concerns; the second looks at the use of assessment tools in cancer care. The chapter concludes by identifying where further research is needed.

1.2 Assessment in cancer care: the problem

Cancer patients have high levels of need (Osse et al 2002), but professionals are not effective in eliciting or identifying concerns and distress (Butow 2001). For instance, cancer patients have a much higher rate of depression and anxiety (reported at between 47% and 58%) compared with the general population (where it is 5.8%) (Butow 2001), yet few psychological problems are detected in routine oncology practice (Ford et al 1994; Heaven and Maguire 1997; Söllner et al 2001; Soothill et al 2001; Pruyn et al 2004; Farrell et al 2005). Doctors' identification of patients' anxiety and depression is reported as no more accurate than by chance (Newell et al 1998). Nurses' assessment skills have been shown to be similarly lacking in accuracy. In a study comparing community-based palliative care nurses' assessments with a patient-completed palliative care outcome scale, there was only a 'poor' correlation for anxiety: nurses underestimated patients' worries. The severity of other problems was overestimated (Horton 2002). Another study which examined nurses' assessment records of patients admitted to a palliative care unit found that anxiety and depression were recognised in, at best, less than two thirds of cases, and at worst, in a fifth; sleeplessness was not recognised or assessed at all (Strömberg et al 2001). Research to identify whether cancer nurses had assessed the key concerns of women receiving in-patient chemotherapy treatment in a short-stay ward (Farrell et al 2005) found that each patient had an average of 10.3 concerns, 80% of which had not been identified by the nurses. A study (Hill et al 2003) exploring the needs of patients newly diagnosed with lung cancer found that only 43% of the patients' worries and concerns had been discussed with members of the care team. Those issues which had been addressed were more likely to be related to physical issues and symptoms even though the patients rated their psychological concerns more highly.

Despite weaknesses of design, where real-life practice is compared with documentary evidence or researcher assessments (which are assumed to be the more accurate), the failure of professionals

working in cancer and palliative care to identify and elicit patients' need is a concern. Consequently, efforts are being made to remedy the situation. The National Institute for Health and Clinical Excellence (NICE 2004) have recommended two key policy initiatives with regard to assessment of cancer patients to enhance practice. These are: for professionals to have access to assessment skills training; and for structured approaches to assessments to be adopted, for example, the use of tools.

However, the research on which such policy is based provides only a partial picture of professionals' assessment practice because the design of the studies cannot account for the apparent paucity of professionals' skills. For example, Söllner et al (2001) found that oncologists were able to detect moderate, but not severe, levels of psychological distress among their patients attending outpatient clinics. The reasons for this were unclear, but possible explanations could include a reluctance to become involved in complex management issues when working in the outpatient clinic, or that the mid-point of the rating scale was selected as a convenient way of providing data for the study. Unfortunately, it is not possible to gain insight into possible contextual reasons for the findings, because typically, the study design 'renders the organisation transparent' (Strong 1979 p5); the primary focus is on deficiencies in individual practitioners, rather than exploring assessment practice in the context in which it occurs. A lack of understanding of the reasons for oncology professionals' assessment practice in general, and cancer nurses' in particular, is a significant gap in knowledge.

1.2.1 Assessment: linguistic analysis

I alluded earlier to the focus of the majority of research into professionals' assessments of cancer patients, which has been to highlight their inaccuracies and shortcomings. This has been achieved by analysing the communication skills used by health care professionals to elicit patients' concerns. The overwhelming evidence from these studies (for example Wilkinson 1991; Booth 1993; Heaven and Maguire 1996; 1997; Maguire et al 1996a; 1996b; Parle et al 1997; Tanghe et al 1998; Kruijver et al 2001a; Söllner et al 2001; Horton 2002; Farrell et al 2005) is that many nurses and doctors lack the skills to be proficient in assessment: ignoring patients' cues, blocking questions, and controlling the agenda of the assessment interview. As a result, the majority of patients' concerns, particularly psychosocial ones, are ignored or remain undisclosed.

Wilkinson's (1991) seminal research in which the linguistic content of nurse-patient assessments was analysed to produce a typology of nurses' assessment verbalisations and style, is a case in point.

Wilkinson's (*ibid*) study was conducted in the in-patient wards in two different hospitals; one was a cancer hospital, and the other a district general hospital. Nurses were asked to assess patients at different stages of their cancer illness (newly diagnosed, relapsed, and in the palliative phase); these assessments were tape recorded and analysed to identify the type of linguistic techniques the nurses used. The nurses were interviewed afterwards, and field notes were collected. The assessments were scored according to how many of seven topics had been covered in the assessment, and the type of 'verbalisations' in the conversation. Verbalisations were divided into 'facilitative utterances' such as: open questions, reflection, empathy, clarification, and 'blocking behaviours': premature false reassurance, inappropriate advice, jolly along, and personal chit chat. Wilkinson identified that the assessments were superficial, and scored low in every category, such that she concluded that nurses 'were planning care on little more than assumptions' (p686).

This study provided the evidence base for much of the assessment skills training in cancer care over the past 15 years. It identified the type of linguistic techniques that nurses used to control the assessment conversation, and offered some tentative explanations for nurses' practice, based on individual characteristics (such as religious beliefs, activities outside of work) and on environmental factors (such as the role of the ward sister). However, the predictive variables identified are largely descriptive. For instance, nurses with more hobbies, atheists, and those frightened of their own death were found to use more blocking techniques than Protestants or Roman Catholics, or nurses with greater self awareness. Because these links are descriptive, the conclusions reached concerning the factors which affect nurses' assessments of patients should be interpreted cautiously. It is unfortunate that subsequent research has ignored this aspect of Wilkinson's work, focusing instead on ways to improve individuals' assessment skills. However, this is interesting in itself: locating the problem in the individual may offer a more 'fixable' solution than trying to address some other possible explanations for deficits in assessment practice.

Wilkinson's (*ibid*) scoring of the nurses' assessments rested primarily on the validity of the seven categories identified as 'necessary' to assess, and against which the quality and content of nurses' practice was judged. These categories include: discussion of patient's understanding of the reason for admission; patient's history of previous illnesses and present illness; patient's understanding of diagnosis. Two decades on, cancer care has changed; fewer patients are being admitted to in-patient wards for treatment and care, so these categories may be less relevant to contemporary assessment practice. Work is required which identifies and explores the role of assessment in the context of today's patient care settings (such as day care, short stay wards) and newer nurse roles (where additional or different information may be required). The research presented in this thesis will provide a contemporary perspective on cancer nurses' assessment practice.

1.3 Developments in oncology nursing: the role of the chemotherapy nurse

The expansion of cancer nursing roles reflects the development of nursing *per se* in the UK. For example, nurse practitioner roles have developed to enable some nurses to substitute for junior doctors in endoscopy, primary care, midwifery, mental health and learning disability (Furlong and Smith 2005). Similarly, in cancer care, nurses' roles and responsibilities have expanded, partly to help meet government targets and reduce waiting times for treatments (Fitzsimmonds et al 2005), and partly to make better use of cancer nurses' skills and knowledge (Department of Health 2000b). Oncology nurses are now in posts such as tumour-specific specialist nurses (Porter 1998; Twomey 2000; Campbell et al 2000; Parle et al 2001); are running clinics for: symptom management (Moore et al 2002), follow-up care (Faithfull et al 2001; Loftus and Weston 2001; Cox and Wilson 2003), psychological support (McArdle et al 1996; Maughan and Clarke 2001); and providing nurse-led chemotherapy services (Fitzsimmonds et al 2005). Cancer nurses are therefore in the fore-front of helping patients and families cope during treatment (Richardson 2004), and have the most insight into patients' problems (Richardson 2004). What remains unclear, however, is the impact of these newer roles (many of which have been assumed from junior doctors) on cancer nurses' assessments of patients.

To date, the majority of studies of nurses' assessments of cancer patients have focused on the admission interview, carried out when patients require in-patient care for treatment or symptom control. However, developments in radiotherapy, and improvements in the management of the side effects of chemotherapy enable the majority of patients to receive their treatment without having to stay in hospital overnight (Sitzia and Wood 1998); many services are now provided on an outpatient or ambulatory care basis (Pearce et al 2001; McIlfatrick 2003). As a result, cancer treatment settings are 'becoming much less institutions and much more centres of expertise' (McIlfatrick 2003 p 4), with shorter, more episodic contact between patients and members of the cancer care team. There is a paucity of research into nurses' assessments of patients in contemporary cancer treatment settings.

One such setting is the outpatient chemotherapy unit, an important focus for research, because more than half of patients diagnosed with cancer will receive chemotherapy (Sitzia and Dikken 1997), the majority of which will be given on an outpatient basis (Pearce et al 2001).

A large proportion of chemotherapy is prescribed with a palliative intent (Kendall et al 2000; Kim et al 2005; Lagman and Walsh 2005). Palliative chemotherapy, which is the focus of this thesis, is prescribed for patients whose disease can no longer be cured; the aim of the treatment is to control or relieve troublesome symptoms and improve patients' quality of life (Kendall et al 2000). The most common cancers for which palliative chemotherapy is prescribed are breast; lung; colorectal; ovarian; head and neck, and myeloma (Archer et al 1999; Davis 2005a).

Survival gains for patients receiving palliative chemotherapy are modest (Kearsley 1992; The et al 2000; Calhoun et al 2001); despite treatment, the majority of patients will die within twelve months (Ramirez et al 1996; Kendall et al 2000; Young and Rea 2000). Moreover, palliative chemotherapy may result in 'significant' toxicity (Glimelius et al 1997; Earle et al 2000; Carelle et al 2002; Lagman and Walsh 2005), lead patients to misinterpret their prognosis (Payne 1992; Schou 1993; The 2002), and delay referrals to the palliative care team (Lidstone et al 2003; Willard and Luker 2005). Research indicates that anti-cancer treatment may limit palliative patients' access to supportive care services (Browner and Carducci 2005), and leave them with symptoms that are poorly managed (Calhoun et al 2001; Carelle et al 2002) or unaddressed (Lidstone et al 2003; Willard and Luker 2005). Differentiating treatment toxicity from deteriorating disease or increasing symptom burden (Kendall et al 2000; Lagman and Walsh 2005) requires careful assessment.

Thus, there is an onus on professionals to assess and direct patients attending for palliative treatment to appropriate support and care (Butters et al 2003); for many patients, this responsibility will lie with nurses in the outpatient chemotherapy unit.

1.3.1 Chemotherapy nurses' assessments

There is a paucity of research into outpatient chemotherapy nursing roles, and even less into assessment of patients. A survey (Clarke et al 2004) of outpatient chemotherapy units identified that the majority of nurses' assessments were conversational; nurses assessed patients informally whilst administering treatments. Few units had adopted the routine use of more formal approaches such as patients' diaries and checklists. This is an interesting finding, because studies by Dennison (1995) and Arantzamendi and Kearney (2004) suggest that conversation might not be an effective means of

assessing patients. Indeed, Dennison (1995) questioned whether nurses are able to carry out anything other than a superficial conversation with patients at the same time as giving chemotherapy, although other research identified that nurses were satisfied with their assessments (Arantzamendi and Kearney 2004). All of the eight nurses interviewed in Arantzamendi and Kearney's study believed that conversational assessments were adequate to meet patients' needs, although they admitted that patients rarely expressed any. Unfortunately, despite the study's design, the nurses' explanations for this were not explored. This issue requires further investigation; it appears to contradict findings from other studies into nurse-patient communication in cancer care, which identified that patients do express concerns (Hunt 1991; Booth 1993; Jarrett and Payne 1995; Heaven and Maguire 1996; Wilkinson et al 1998; Lanceley 2000; Williams et al 2001; Osse et al 2002; Hill et al 2003). Greater insight into the patients' contribution to assessment in the outpatient chemotherapy department is required.

1.4 Nurses' assessments of palliative care patients

So far, the assessment practice of two different aspects of cancer nurses' work has been reviewed: assessments of cancer patients being admitted to in-patient wards, and assessments of patients being given chemotherapy. The third type of assessment to be discussed is the assessment of patients admitted to a hospice for palliative care. Heaven and Maguire's (1997) research into the assessments of hospice nurses is particularly interesting, because hospice care is premised upon an holistic approach, and therefore it might be expected that nurses working in such a setting would be able to identify patients' physical, social and psychological needs. However, only 40% of the patients' concerns disclosed during the assessment interview were registered and documented by the nurses (Heaven and Maguire 1997). The researcher identified twice as many concerns as the nurses, who had failed to elicit and document the patients' main concerns in 65% of cases. Such findings were taken as an indication of poor practice, and the need for assessment skills training.

These conclusions should be interpreted with caution, because of weaknesses in the design of the study. For instance, the research interview, carried out up to twelve hours after the nurse's assessment, was preceded by the patient completing a concerns checklist and the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983). It seems reasonable to assume that the patients, after being in the hospice for 12 hours (and in receipt of medical and nursing attention), and after completing a concerns checklist (which may have itself brought new problems to the fore), may have been prompted to identify different or additional issues with the researcher. Moreover, the study was designed on the supposition that the researcher's information and interpretation of the patient's concerns were the correct versions, which is impossible to verify.

However, the nurses were aware that they were taking part in a study which was looking at their assessments (which were being tape recorded). Therefore, the findings might not be representative because the assessments might have been *more* comprehensive than usual. No attempt was made to enable the nurses to interpret their practice; they may have been carrying out their assessment in stages, for example, which may have led them to identify additional needs at a later assessment interview. That nurses perceive assessment to be a process, with an initial identification of urgent problems, postponing other issues for subsequent meetings, was confirmed by Kennedy (2004) in a study of community nurses' practice.

An alternative to the predominant skills-deficit model of researching assessment, which has focused on 'judging' assessments in terms of their contents and 'accuracy', is to invite participants to be involved in interpreting the data. Lanceley (2000) invited cancer nurses to reflect on tape recorded conversations they had with patients during day-to-day care (i.e. conversations which were not specifically patient assessments), and used nurses' own interpretations of their communication work when analysing her data. Her findings reveal that nurses had the skills to elicit patients' emotions, but lacked confidence to deal with the psychological effects such conversations aroused. Lanceley did not involve patients in this interpretive analysis, and there is limited understanding of patients' perspectives on, expectations of, and contributions to, assessment in cancer care. To date, the patients' role in assessment has been marginalised; their contribution has been seen as a cue for the nurse, not as part of a conversational dyad (Jarrett and Payne 1995), even though patients are not passive participants in conversations with cancer nurses (Jarrett 1996), and their contribution is influenced by the context of care and by the nurse's own style of conversation (Hunt 1989).

The importance of exploring the patients' contribution to assessment is illustrated by an interesting finding in Heaven and Maguire's (1997) study, which was that patients had 'deliberately withheld psychological, social and spiritual concerns' (p288). The authors interpreted this as indicative of limitations in the nurses' skills, but other explanations are possible. Latimer (2000) has argued that the identification of need is 'interactively constituted'; therefore, it may be erroneous to assume that patients want to tell nurses their problems and concerns, and will do so if the nurse facilitates this (Jarrett and Payne 1995). The patients in Heaven and Maguire's study may have been exercising some control of the conversation, although this notion could not be explored within the design of the study. Alternative research approaches may enable any such evidence to emerge.

By concentrating on communication-related cues, Heaven and Maguire ignored other means by which nurses elicit information about patients' problems and symptoms, for instance, observation of patients' physical signs; non-verbal signals; and 'concrete' information such as medical diagnosis and medical notes (Hedberg and Larsson 2003). Thus, whilst linguistic skills are important, they are not the sole influences on assessment. Other factors, such as intuition (Benner 1982), experience (Crow et al 1995), and attitudes and beliefs (Parle et al 1997) have been recognised as important in assessment in other branches of nursing (for example community nursing (Bryans and McIntosh 1996; Kennedy 2004)). However, cancer nurses' assessments remain poorly understood, and more work is required using a broader approach than the assessment skills focus which has predominated.

1.4.1 Summary of gaps in knowledge

To summarise, the review of the literature has highlighted three gaps in knowledge with regard to assessment in cancer care. Firstly, that research to date has largely de-contextualised the assessment conversation. Thus, although the predominant approach to researching assessment to date has identified the skills that are required to perform a 'good' assessment, much less is known about the reasons for nurses practising as they do.

Secondly, nurses' roles in cancer care have changed and expanded in recent years, and to date, research into cancer nurses' assessments has been set in in-patient wards. Fewer patients are now being admitted for in-patient care; instead, the majority of treatments are given in short stay and

outpatient settings (Sitzia and Wood 1998), and therefore it is more relevant to patients' and nurses' current experiences to explore and understand assessment work in these clinical areas. Nurses working in such settings have taken on more autonomous, technical roles, and are not required to carry out traditional, ward-based work. Research is needed to explore assessments that are being carried out in these roles and settings so that current practice can be identified and developed where necessary.

Thirdly, the patients' contribution to assessment has been marginalised in research to date; much less is known about their expectations and experiences of assessment than has been explored from nurses' perspectives. Moreover, since work into patient-nurse communication has identified that patients play an important role in the dyad, it is timely to explore and acknowledge the patients' part in the assessment encounter.

1.5 Improving assessment in cancer care

Two recommendations have been made by policy makers, researchers and academics to address the problems of assessment in cancer care. These are: assessment skills training, and the use of assessment tools. The following paragraphs review the literature in these areas, beginning with assessment skills training, to illustrate the progress that has been made in developing professionals' practice, and to highlight the gaps in knowledge that remain.

1.5.1 Training and skills development

Assessment skills training involves practitioners attending workshops where they are taught communication skills for assessment through role play, increasing self awareness, reflection, and exploration of their attitudes and anxieties with regard to cancer patients. It produces equivocal results; training has a positive effect on professionals' use of communication strategies to help elicit patients' concerns, but does not necessarily translate into improved assessments in the clinical setting (Heaven and Maguire 1996; Kruijver et al 2001b; Parle et al 2001). Heaven and Maguire (1996) found that training had little effect on hospice nurses' ability to identify patients' concerns, despite the nurses employing better assessment skills, which should have led to an increase in patient disclosure. It appeared that the more patients talked about their emotional concerns during the assessment, the more the nurses 'blocked' the conversation to prevent further disclosure of these issues, suggesting that blocking techniques may not only be a communication strategy, but also a defence against anxiety (Menzies Lyth 1988; Lanceley 2000).

Neither does training lead to sustained improvements in the assessment of patients' psychological needs over a long period of time (Booth et al 1996; Wilkinson et al 2002). Given the prevalence of cancer patients' anxiety and depression (see section 1.2), this is disappointing, and warrants further research using an explanatory approach to identify some possible reasons for this finding.

Thus, assessment skills training has had mixed success. Training has some influence on the type of utterances (Kruijver et al 2001b) and linguistic techniques (Booth et al 1996; Wilkinson et al 2002) nurses use in their assessments, but these changes do not necessarily result in nurses identifying

patients' concerns. Improving the assessment skills of individual practitioners through training, although important and valuable, is therefore insufficient to produce sustained change in clinical practice.

1.5.2 Structuring Assessment

The Guidance on the Configuration of Supportive and Palliative Care Services for Adults with Cancer (NICE 2004) recommended that structured approaches to assessment (including the use of tools) be developed and adopted into clinical practice to enhance professionals' assessments of patients' needs. Two main bodies of evidence formed the basis for this recommendation; one was the findings from studies which demonstrated that using assessment tools in clinical practice is feasible, improves doctors' consultations (Detmar et al 2002; Velikova et al 2004), and reduces patients' symptom distress over time (Sarna 1998). This research is discussed in sections 1.5.3 and 1.5.4.

The other was the large body of research which has identified that using a tool is a more 'accurate' means of identifying patients' concerns and problems when compared with professionals' 'usual' practice (for example: Ford et al 1994; Heaven and Maguire 1997; Newell et al 1998; Tanghe et al 1998; Söllner et al 2001; Hill et al 2002a; Horton 2002; Farrell et al 2005; Kruijver et al 2006). These research studies are summarised in Appendix 1.

Evaluations of assessment tools show that they: improve symptom management (Rhodes et al 1998; Tanghe et al 1998; Braud et al 2003; Boyes et al 2006); help to identify more concerns and problems when compared with professionals' assessments (Roth et al 1998; Söllner et al 2001; Strömberg et al 2001; Lidstone et al 2003); improve patients' quality of life (Hill 2002a; Velikova et al 2004); improve communication between patient and doctor (Detmar et al 1998; 2002; Bruera et al 2003; Velikova et al 2004).

It is important to emphasise a limitation in the design of the majority of these studies (see Appendix 1), which are premised on the assumption that assigning a high score to questions on the assessment tool indicates a 'need' requiring an intervention or care. Other research has identified that this is not the case (McLachlan et al 2001; Curry et al 2002; Osse et al 2002; Velikova et al 2004).

The findings from studies which compare professionals' assessments with patient-completed tools (see Appendix 1) were predictable: a patient's self-report based on a questionnaire is almost certainly going to identify more and different symptoms or problems than practitioners working in a clinical setting. What is more worrying perhaps, is that professionals, including nurses, are not identifying patients' main concerns when assessing patients (Farrell et al 2005), and that research published in 2005 (Farrell et al 2005) is demonstrating a similar discrepancy between patients' and professionals' perceptions of problems to that published in 1994 (Ford et al 1994). Thus, although we know that professionals' assessment practice is flawed and less than accurate, the reasons for the continuing status quo remain largely unexplored. Research to date has concentrated on the extent of the problem and describing the limitations of professionals' practice; fewer studies explore possible reasons for this. As a result, the solution offered by NICE (2004) to the problem of 'poor assessment' is focused on individual practitioners: if individuals are more skilled and more effective communicators, better able to identify patients' concerns using a tool, then the problems in assessment practice will have been addressed. This is a simplistic response to a complex issue in practice.

Structured assessment may not be the panacea for inadequacies in professionals' practice that the findings from the studies summarised in Appendix 1 would suggest. Already, anecdotal evidence is appearing which suggests that using a tool in clinical practice is problematic: nurses are too busy to use them routinely (Dikken 2003); staff find them burdensome (Hill et al 2002a); and forget to use them (Dikken 2003); patients find them a burden (McGrath et al 2005), whilst other patients decline because 'no one looked at it last time' (Dikken 2003 p 51). Such first-hand accounts of the problems of using assessment tools in a clinical setting indicate that careful preparatory work is required before they are introduced to staff and incorporated into routine care. Preparatory work requires an understanding of the impact of the tool on practitioners, practice, and patients. Moreover, it is not known in which clinical settings assessment tools are practical and most beneficial (Levine and Ganz 2002), and whether they are more helpful to specialists (such as clinical nurse specialists, counsellors, consultants) or those working 'on the front-line' in more general settings (such as staff nurses, junior doctors, and information officers; in outpatient, day care, and in-patient areas), or indeed, whether tools are equally helpful to everyone.

1.5.3 Structuring nursing assessments

A different research focus was provided by Sarna (1998), in which the impact of an assessment tool on patients' symptom distress over a period of six months was investigated. Sarna (1998) used a randomised trial to demonstrate that structured nursing assessment reduced patients' symptom distress over time. Her study involved the recruitment of 48 patients newly diagnosed with lung cancer who were randomized to 'usual' or 'structured' assessment. Patients were receiving outpatient treatment with chemotherapy and/or were monitored regularly in clinic, depending on their oncologists' clinical decisions. Baseline data was obtained using the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983), performance status and physical functioning status. Both groups completed the Symptom Distress Scale (SDS) (McCorkle and Young 1978) each month for six months, but patients in the control group placed their completed SDS in an envelope for the researcher. Nurses of patients in the intervention group were given a synopsis of patients' problems identified on SDS to enhance their assessments. Over six months, patients receiving chemotherapy who had had their needs assessed based on the Symptom Distress Scale had less symptom distress than other patients.

This study formed part of the evidence for the policy recommendations from NICE (2004) for improving assessment practice in cancer care. However, questions can be asked of the validity of Sarna's findings. Firstly, there was a high attrition rate: at the end of the study, almost half of the patients had withdrawn (26 patients remained). It is not clear if the attrition rate was the same across both the intervention and control groups. Secondly, the research was based on a dubious premise that palliation was directly linked to assessment. Unfortunately, there was no data to support this claim nor information about the support services available to, or used by, patients. Thirdly, the SDS scores were compared with nurses' documentation, assuming that these latter records accurately captured the details of the nurses' 'usual' assessments. Other researchers have shown that nurses' records are a poor reflection of 'nursing' (Davis et al 1994; Hyde et al 2005; Irving et al 2006). Fourthly, it is not clear whether the same nurses were assessing both groups in the study – there may have been a cross-over effect if some of their assessments were structured and some not. Thus, although Sarna concluded that structured assessment enhances palliative care, the mechanism of this relationship remains unexplained. There was, however, a suggestion that structured assessment was a 'proxy for the

benefits of increased support' (p1048). More recently, Annells and Koch (2001) made a similar link: patients with advanced cancer taking part in a study to validate an assessment tool were felt to have had 'therapeutic gains' (p808) from the assessment interview. This conclusion deserves further research to verify it, by evaluating 'process' changes and incorporating patients' views, in order to capture some of the wider possible benefits that a tool may bring to an assessment conversation.

Policy makers (NICE 2004; Richardson et al 2006) recommend that assessment tools and structured approaches to assessment should be developed and adopted at national and local levels. There is a wide range of assessment tools available, ranging from symptom-specific tools (such as pain, fatigue) through more general social, psychological assessment or screening tools (Wright et al 2002), to quality of life assessment tools. Symptom-specific assessment tools and screening tools have generally been researched from the perspective of 'do they work?' i.e. do they elicit more concerns than professionals' usual assessments; are they effective; and are they valid and reliable. The evidence for the 'effectiveness' of symptom and screening tools is well established (see Appendix 1), although few have been adopted into routine practice (Levine and Ganz 2002). The reasons why not are not clearly understood.

Work to ascertain whether the use of assessment tools is feasible in clinical practice and the differences they make to the assessment encounter has been undertaken using quality of life tools (Detmar and Aaronson 1998; Greenhalgh and Meadows 1999; Detmar et al 2002; Velikova et al 2002; 2004). This group of studies will be critically reviewed in the following paragraphs, since addressing questions of feasibility and additional value are important if structured assessment is to become routine practice in oncology care settings.

1.5.4 Assessing quality of life in cancer care

Quality of life - or more specifically, health-related quality of life (Kassa and Longe 2003) - is an important construct in cancer and palliative care. Since the 1980s, a variety of valid and reliable tools have been developed to 'quantify', measure and capture patients' quality of life. To date, the main focus of quality of life measurement in cancer care has been confined to clinical trials, to provide an additional and alternative endpoint from the traditional ones of survival, tumour response and toxicity. Using quality of life information in a clinical setting is different (Greenhalgh and Meadows 1999; Higginson and Carr 2001; Osse et al 2002), and work is required which will identify: the added value of a quality of life tool in terms of process as well as outcomes (Greenhalgh and Meadows 1999); which tools are feasible and acceptable (to patients and professionals); the barriers to their routine use and how these might be overcome (Greenhalgh and Meadows 1999). Some of this work has been carried out, but mainly in the USA and within non-oncology settings (Greenhalgh and Meadows 1999). The benefits of using quality of life tools in the clinical setting are said to include: identification of patients' problems and preferences for treatment; patient-doctor communication and decision-making; enhancing access to supportive care services; managerial activities, such as staff training and clinical audit (Coates 1997; Greenhalgh and Meadows 1999; Higginson and Carr 2001; Sprangers 2002). In the light of these potential benefits, there have been calls to stop developing new quality of life tools and to concentrate research efforts on identifying which tools can most effectively be introduced into clinical settings (Levine and Ganz 2000).

In cancer care, there is a paucity of work exploring the impact of using a quality of life tool in practice, especially with regard to oncology nursing. Two studies have evaluated the use of the EORTC QLQ-C30 (Aaronson et al 1993) in clinical practice; both demonstrated the EORTC QLQ-C30 was feasible in a medical outpatient setting, did not lengthen consultation times, yet facilitated discussion of patients' quality of life concerns (Detmar et al 2002 and Velikova et al 2004). These studies are compared in Table 1-1 below:

Study	Detmar et al	Velikova et al
Aim	To identify effect of QoL tool on communication in oncology outpatient consultations	To examine: effect of QoL on process of care and patients' well being in oncology outpatient departments.
Method	Randomised Controlled Trial: cross over design Longitudinal study: used in 3 consecutive out-patient visits Intervention group: completed QoL form in waiting area; graphical summary shared with oncologist Audio-taped consultations: content analysed	Randomised Controlled Trial: 3 groups: intervention (QoL graphical summary shared with oncologist), control (no QoL measurement) and attention control (patients filled in QoL but information not shared with physician) Longitudinal study: used in 4 consecutive out-patient visits Audio-taped consultations: content analysed
QoL tool	EORTC QLQ-C30	EORTC QLQ-C30
Patients	214 patients seen at 4 consultations prior to palliative chemotherapy treatments in out-patient clinic, Netherlands	286 patients about to commence treatment attending out-patient oncology clinics in UK
Doctors	10 oncologists	28 oncologists
Findings: effect of tool	Statistical significant difference between groups in discussion of: social functioning; fatigue; dyspnoea (↑in intervention group) Improved physician awareness of moderate-severe problems in intervention group No differences in management; prescription of medications; referrals Increased counselling from physicians on how patients could manage problems in intervention group No difference in satisfaction between groups No difference in length of consultations	Statistically significant improvement in QoL in intervention and attention control groups compared with control group Positive effect on emotional functioning in intervention group More frequent discussion of chronic non-specific symptoms in intervention group No prolongation of consultations No detectable effect on patient management
Conclusions	QoL assessment in palliative cancer treatment setting facilitated discussion of QoL issues Heightened physicians' awareness of patients' problems	Routine assessment of QoL had an positive impact on doctor-patient communication and resulted in benefits for patients in intervention group who had improved emotional functioning and improved QoL
Comments	Cross over design: some 'contamination' of physicians' assessment of patients in group who used QoL tool first.	Few details given about changes in communication during the consultation High non-responder rate: 30% patients declined to take part

Table 1-1 Comparison of two studies using the EORTC QLQ 30 in clinical practice

Both these studies used computers to create graphical summaries of patients' responses which were compared with normative scores, to identify the 'abnormal', but this interpretation of the scores may not have corresponded with patients' perceptions of their problems (Osse et al 2002; Cox 2003). The conclusion from both studies was that using a quality of life tool in clinical practice was beneficial: it improved doctor-patient consultations and did not lengthen consultation times. Interestingly, however, using the tool did not lead to any changes in patients' management: the use of a structured tool influenced consultations but not medical decisions. The reasons for this are unclear, although it should be noted that no mention was made as to whether nurses were present in the clinics, and what impact the intervention had on their workload. It may have been that discussing the problem with the doctor was sufficient. In any case, this is an interesting finding, and needs further research.

1.5.5 Summary: assessment tools

Assessment tools are more accurate in identifying patients' symptoms and problems than professionals' usual assessments. Some evidence has emerged to suggest that using an assessment tool in clinical practice may be helpful to patients, not only because of outcomes, but because the process of structured assessment is beneficial, although further work is required to explore this in more depth. The EORTC QLC-30 quality of life tool has been shown to be practical and helpful to doctors and patients in oncology outpatient clinics, but little work has been carried out exploring the impact of an assessment tool on cancer nurses' assessments in the UK. If benefits were identified, adopting a tool common to both nurses and doctors might aid multi-disciplinary communication and continuity of care. Using an assessment tool may be 'therapeutic' (Annells and Koch 2001) for patients, although this assertion requires further corroboration, since subsequent research has identified the opposite: patients found completing tools a burdensome activity (McGrath et al 2005). Thus, there are several possible directions for future research to examine the proposals by policy makers (NICE 2004; Richardson et al 2006) for structured assessment in cancer care.

1.6 Chapter Summary

The importance of assessment in cancer care is not in question. Many patients need support to help them cope with the effects of their disease and treatment: accessing this depends on assessment, but despite efforts to enhance practice through assessment skills training, research demonstrates that professionals are generally poor at identifying patients' concerns and distress. Most studies, however, have focused on the gap between what should be assessed and what is identified; few studies have sought to understand the reasons for apparent deficiencies in professionals' practice.

Assessment tools have been recommended as a means to enhance assessment practice, and appear to benefit doctors and patients. However, because so little is understood about assessment, and cancer nurses' assessment in particular, a key question remains: whether there are other influences, as yet under-acknowledged, which sustain the *status quo*, and which, left unaddressed, would compromise any and all policy initiatives to improve assessment practice. Research is needed to explore assessment from a different perspective, moving away from the focus on linguistic skills, and directing attention to understanding assessment in its contemporary clinical context, acknowledging the patients' contribution to the encounter. The limited focus of research into cancer nurses' assessments contrasts with wider methodological approaches adopted by researchers in other branches of nursing,

Literature Review: Assessment in Cancer Care

where more research evidence is available concerning the conduct of, influences on, and rationale for, this complex area of practice. Cancer nursing has much to learn from this work, as the next chapter demonstrates.

Chapter 2 **Assessment in Nursing**

Nursing assessment is 'characterised by the struggle to understand what is happening to a patient or client'

(Gadow 1995 p 32)

2.1 Introduction

This chapter explores nursing assessment as a professional activity, particularly as it is configured in practice. The chapter is divided into two main sections, beginning with the cognitive aspects of assessment, and a critical exploration of research findings which describe *how* nurses assess. The second explores assessment as a social activity, and identifies its importance in enabling nurses to 'know' their patients. Research studies are used as exemplars to illustrate how a third aspect of assessment, its bureaucratic function, underlies and shapes much of nurses' clinical assessment activity (Latimer 2000; Powers 2002; Irving et al 2006). The exemplars expose the tension between the rhetoric of academics and educators, and the reality of assessment practice.

2.2 Assessment in nursing: an historical overview

The following brief résumé of nursing assessment provides an historical overview of nursing assessment in the UK to highlight its role in nurses' care of patients. Placing the development of nursing assessment in its historical context helps to explain why certain research approaches to assessment have been adopted.

The nursing process was imported to the UK from the USA in the 1970s, and was hailed as a means to transform nursing (Walton 1986). The nursing process sees the 'unique function' (Henderson 1966) of the nurse as dependent on a systematic problem-solving approach to care, involving four (or five) stages, the first of which is assessment.

Traditionally, nursing care was carrying out doctors' orders and the management of a patient's primary medical problem (O'Connell 1997) but this began to change in the 1960s. Five areas of professional concern arose (Walton 1986; O'Connell 1997); namely, the need to: identify and clarify the role of the nurse; achieve professional status for nursing; improve nurses' job satisfaction; narrow the gap between theory and practice; and create a clinical career ladder. The nursing process was seen as a means to address all these concerns: in other words, the nursing process was a 'strategy for professionalisation' (Walton 1986 p6; O'Connell 1997).

In addition to the systematic approach to care, the nursing process was underpinned by the ideology of holism (Salvage 1990), which significantly changed the nature of nurse-patient relations (see section 2.4). Importantly, therefore, the nursing process contained an inherent contradiction, between the scientific rationalist approach that its format required, and the philosophy of individualised, patient-centred care that it espoused.

Assessment, as the first stage in the nursing process, involves taking the patient's history, to identify his or her physical, social, psychological and spiritual problems. Today, the assessment of patients is

considered to be a crucial and 'normal' part of nursing, and is carried out whether or not the nursing process is in use in a particular care setting.

2.3 Assessment as a cognitive activity

Gadow (1995, page 26) states that nurses come to understand patients' experiences and needs through the 'co-authoring' and 'synthesis' of two kinds of knowledge: general (based on theory and empirical research), and particular (based on knowing the individual patient; see section 2.4). Understanding how nurses obtain, interpret, and utilise such knowledge is important to an overall appreciation of assessment practice. Language is a key part of this process; research exploring linguistic elements of assessment was discussed in Chapter 1. The focus of the following paragraphs is a critical review of research approaches to nurses' cognitive assessment work. A selected review of the literature is divided into those studies which have used rationalist, phenomenological and ethnographic perspectives to describe and explain how nurses assess patients.

2.3.1 Rationalist Perspective

The rationalist perspective rests on the premise that human behaviour is logical and consistent (Bucknall 2000), and therefore research methods are experimental, to 'test' certain skills and attributes in assessment. Central to a rationalist study is the belief that it is necessary to separate, control, or remove, extraneous variables so that the particular variable in question can be identified or 'revealed' (Bryans and McIntosh 2000 p1244). Two theoretical approaches have underpinned the majority of rationalist research into cognitive aspects of nursing assessment: decision-theory and information processing theory. Both approaches require the nurse taking part in the study to make her internal thought processes explicit using case simulation and/or think-aloud techniques based on hypothetical patient management problems (for example Cioffi and Markham 1997; Hedberg and Larsson 2003; Funkesson et al 2006), and can be criticised for assuming that it is possible to achieve this (Taylor 2000).

Studies identify that nurses use an internally driven search strategy for gathering and organising information in assessment (Tanner et al 1993; Bryans and McIntosh 1996; Salantero et al 2002; Lee et al 2006). Nurses' memories of previous patients play a part in the cognitive activity of assessment (Crow et al 1995; Taylor 1997; Sbaih 1998) to help interpret cues and generate hypotheses. These memories form 'conceptual maps' (Kitson 1993), heuristics (Cioffi and Markham 1997; Buckingham and Adams 2000), and 'encyclopaedias of knowledge' (Sbaih 1998 p6) to enable nurses anticipate patients' problems and plan future care needs (Crow et al 1995; Kennedy 2002).

Several criticisms can be made of the rationalist approach to researching nurses' assessment practice using simulation and think-aloud techniques. Firstly, the approach confines nurses' cognitive assessment skills to linear, sequential steps, whereas other studies have identified that expert nurses do not follow this format (Benner 1982; Benner and Tanner 1987; Tanner et al 1993). Secondly, although simulated case studies avoid the ethical problems associated with conducting research in the clinical environment, other problems are created, such as the questions of transferability and representativeness. Simulated scenarios are devoid of the emotion and anxiety (Lanceley 2000) found in clinical settings, where nurses have to rely on interaction (Cowley et al 2000; Potter et al 2004), and

filter contextual noise (Carr 2004). These factors add complexity and uncertainty to nurses' work (Tanner et al 1993; Bucknall 2000). Moreover, nurses' reasoning is, to a great extent, context specific (Crow et al 1995; Thompson 1999), therefore, the usefulness of exploring assessment practice away from the settings in which nurses work is questionable.

The scenarios used in case simulation and think-aloud situations tend to be based on specific nursing problems (such as pressure sore, recording a patient's blood pressure, identifying ante-partum haemorrhage) (Cioffi and Markham 1997; Taylor 1997) which lend themselves to certain lines of questioning, and lead to clear-cut types of decisions or diagnoses. Some studies which used more complex scenarios applied *a priori* criteria to judge the accuracy of nurses' assessment decisions (e.g. Cioffi and Markham 1997); others compared nurses' assessment questions and topics with the researchers' 'gold standard' (e.g. Junnola et al 2002), or with patients' self-reports (e.g. Florin et al's study 2005). Such approaches have limited usefulness, because in practice, assessment is a subjective, situational process (Locsin 2001), made in a client encounter (Lee et al 2006) with mutual input from both nurses and patients (Fuller and Schaller-Ayers 2000). By excluding the patient, rationalist approaches fail to embrace one of the key aims of assessment practice, which is to benefit the patient or client (Harbison 2001). In addition, by artificially creating a value-free situation in order to research assessment, any sense of moral reasoning is removed.

The benefits of the rationalist approach lie in the objectivity of the research, which makes the findings more easily communicable. The weaknesses outlined above raise questions as to the relevance of this approach to clinical practice: its prescriptive approach lacks descriptive fit (Thompson 1999).

2.3.2 Phenomenological approach

The phenomenological approach to assessment is based on a premise that the 'lived experience of the nurse in context' (Benner 1984 p369) builds up a form of expertise and knowledge, which leads her to make accurate judgements. The phenomenological perspective rejects the rationalist approach, by arguing that nurses do not make assessment decisions using linear thought processes when faced with clinical problems and situations, but instead, use unconscious intuitive judgements to identify patients' needs.

Benner (1982; 1984) carried out an influential study which adopted phenomenology to research this topic. Similarities between expert nurses' judgements and Dreyfus' six key aspects of intuition (Dreyfus 1979 cited in Benner 1982) were identified. Intuition is a 'sixth sense' (Benner and Tanner 1987), a form of perceptual awareness, strengthened by familiarity with the patient and the ward or care setting (English 1993).

Benner's work has been criticised because the notion of intuition has an 'uncomfortable connotation with 'mysticism'' (English 1993 p390), against which there can be little argument (English 1993), with potential, therefore, to be an excuse for poor care. For example, a study found that the majority of community nurses made intuitive decisions about wound management (Hallett et al 2000), even though there is a large body of evidence on which to base this practice.

A second criticism is that the theory of 'intuition' arose out of the narratives of a few 'expert' nurses, all of whom were coached and 'drilled' on the type of narrative required and desired for the study (Nelson and McGillion 2004 p635). These were not 'typical' assessments; indeed participants were discouraged from choosing examples which might be considered 'ordinary'. Not surprisingly, the narratives chosen to describe nurses' intuitive assessment practice are striking - Lanceley (2000) has commented on their 'almost Hollywoodian sense of drama' (p25) - such as dealing with an emergency exsanguination. Thus, although Benner's work has been adopted and accepted as a generalised theory (Paley 1996), a question remains as to how far these narratives of lived experience help to illuminate nurses' practice in general (Nelson and McGillion 2004). Rather, they illustrate certain features of *one nurse's* practice, and therefore should be seen as a description rather than a generalised theory (English 1993). Moreover, recent research suggests that nurses use a dual form of reasoning in assessment: intuition *and* analytical thinking (Lee et al 2006), suggesting that a phenomenological perspective is a narrow lens through which to view assessment.

2.3.3 Ethnographic approaches

Ethnography is a method which involves the study of people in their natural environment to provide a detailed description and interpretation of the phenomena being studied (Robson 2002). The advantage of this method is that the findings are concerned with practice observed in the natural setting. The disadvantage is that it is limited in its ability to draw causal inferences.

Several ethnographic studies of nurses' clinical practice have included assessments of patients (Latimer 2000; Jones 2003; Wong 2004). Kennedy (2002) used ethnography and interviews to describe district nurses' first assessments of patients, and identified that assessment had multiple aims including: building the bigger picture (looking beyond the referral task); establishing trust and building rapport; and prioritising care needs.

District nurses used theoretical and experiential knowledge in their assessments to facilitate the exploration of a wide range of issues. Assessments were characterised by a multiple agenda, their uniqueness and their temporal nature. A key aim was to 'know' the patient and carer through the establishment of rapport and trust.

The strength of Kennedy's research is that it demonstrates the importance of context to the study of nursing assessment. An additional advantage of the ethnographic approach is that it embraces multiple perspectives, so that Kennedy reported the nurses' as well as her own views, although the patients' voice is absent. Nonetheless, the descriptions of assessment practice serve as a 'social microscope' (Bowers 1992 p65) to make visible the ways in which district nurses work.

2.3.4 A methodological alternative

The limitations of rationalist, phenomenological and ethnographic research approaches highlight the need for an alternative methodological framework to research this area. An approach is needed which can encompass the interactional nature of assessment as well as the unique perspectives and contributions of the individuals concerned (Rashotte and Carnevale 2004), and which can explain the findings in relation to underlying concepts (Craib 1992). Neither pattern recognition (as in the rationalist

approach), nor intuitive models (as in a phenomenological approach) addresses the gap between theories of assessment and nurses' practice; neither of these positions is able to reconcile the apparently different worlds of theory and clinical reality (Rashotte and Carnevale 2004). A possible solution lies in the epistemology of realism, which does not place rationalist and phenomenological approaches at opposite ends of a continuum, but accepts that they occupy the same theoretical plane (Thompson 1999). A realist approach would aim to discover the mechanisms involved in assessment (required by the hypothetico-deductive, or rationalist, system); embrace tacit knowledge (as in the phenomenological approach); and include social context (as in ethnography). Realism seeks to explicate implicit knowledge and practice in terms of a causal, explanatory mechanism (Rashotte and Carnevale 2004), but accepts that the explanatory mechanism chosen is only one of a number of possible choices. Thus, realism embraces 'socially mediated' phenomena (Rashotte and Carnevale 2004, p 38), interpretation, and explanation in terms of mechanisms, and therefore offers an alternative lens for viewing nurses' assessment practice. The tenets and further justification for adopting a realist stance for this study are outlined in Chapter 3.

2.3.5 Summary of cognitive aspects of assessment

This section of the chapter has reviewed research approaches to describe and explain how nurses assess. In spite of the wealth of research in this area, limitations in study design mean that nurses' assessment practice remains poorly understood. More research is required; especially work that is rooted in real-world clinical settings, to study this complex but important aspect of nurses' practice.

2.4 Assessment as a social activity

Assessment is not solely a cognitive, decision-making activity. Another aspect of assessment, 'knowing the patient', has become a tenet of professional discourse in nursing (May 1995b). It is during assessment that the patient as a 'person' can emerge, and non-medical, psychosocial issues can be identified (Wong 2004). The following discussion highlights the tension between the espoused ideology of 'knowing the patient' and the out-working of it in practice, demonstrating the relevance of this particular theory-practice gap to the empirical work that follows.

2.4.1 Knowing the patient: an ideology shared in health care practice and policy

Knowing the patient is valued in many branches of nursing, including, for example: primary and community care (Gerrish 2000; Luker et al 2000; Kennedy 2002; Seale et al 2006), medical and surgical nursing (Johnson and Webb 1994; Latimer 2000; McQueen 2004; Parker 2004; Martin and Hewitt-Taylor 2006;), cancer and palliative care (May 1995b; Corner 1997; Willard and Luker 2005; McIlfatrick et al 2006), intensive care (Bucknall 2000; Seymour 2001; Coombes 2004), accident and emergency nursing (Byrne and Heyman 1997; Sbaih 1998), care of the elderly (Jones et al 1997), and midwifery (Hart and Lockey 2002). The widespread adoption of this philosophy of care is testament to its acceptance, although research has identified difficulties in transferring it to practice (Redfern 1996; O'Connell 1998; Gerrish 2000; Latimer 2000).

The importance of knowing the patient and the provision of individualised care are also emphasised in UK health care policy, which embraces the notion of patient as consumer. Consumerism in the health

service has had three effects (Allen 1998, 2004; Meerabeau 1998). Firstly, patients are involved in the debate about how services should be provided, for example the consultation exercise 'Our Health, Our Choice, Our Say' (Department of Health 2006); secondly, there is greater use of economic terminology (value for money, rationing, targets); thirdly, protection of patients' rights has increased complaints, and fear of litigation has formalised and standardised care. Whether patients can ever truly be consumers, however, is doubtful: by definition they are vulnerable, and therefore unable to be equal partners (especially as power and knowledge are related). Patients are not directly responsible for purchasing their care in the NHS, and do not have an alternative if they are dissatisfied. Most consumerist activities, therefore, have been concerned with 'hotel' aspects of hospitalisation (Allen 1998), of delivering choice and achieving 'standards', leaving nurses at the 'sharp end' of policy change (Allen 1998). The following paragraphs illustrate the impact of consumerist principles and policy on nurses' work, using a study conducted in an accident and emergency department as an exemplar

2.4.1.1 Impact of consumerist policy on practice: The Patients' Charter as an exemplar

The Patient's Charter (Department of Health 1995), which was introduced into accident and emergency departments in 1996, included a set of standards that patients could expect to receive in respect of information, waiting times, a named nurse, and access to immediate initial assessment. However, because nurses and patients interpreted the commitments in the Charter differently, some conflict and difficulties arose (Sbaih 2002), particularly as neither patients nor nurses had been involved in discussions as to how such a policy could be implemented.

Sbaih (2002) identified that some of the problems in fulfilling and sustaining the standards in the Charter resulted from the unpredictable nature of the work in accident and emergency. Many of these difficulties arose because patients interpreted the term 'immediate' to relate not only to assessment, but to their treatment and progress through the department. Because these expectations were not met, there were many complaints.

The Charter required nurses' assessments to be formalised so that documentation could be audited and used as evidence that targets were being met. Thus, a triage system was implemented, but this isolated 'assessment' from other aspects of nurses' work in the department, which compromised the overall working of the unit. Formalising one aspect of work in the setting had a 'knock-on' effect on other aspects, but this impact was not anticipated when the Charter was written.

This exemplar demonstrates that when implementing policy several factors should be considered: account needs to be taken of the ways in which nurses work, and their role as a healthcare mediator (Allen 2004) recognised. Secondly, before introducing change, patients' views and understandings should be obtained and considered in relation to nurses' versions of their work (Sbaih 2002). To date, patients appear not to have been involved in how policy is implemented; this is an area where their views about changes to a service need to be heard. Thirdly, problems arise when standards and policy are formalised and imposed on work settings, which are 'fundamentally local organisations' (Dyke 1998, p12), without consulting those providing the service. If such issues are not addressed by future studies, a balanced description of the impact of policy in health care settings will not be achieved, and an opportunity for useful insight into the work both of, and in, particular health care settings will be missed (Sbaih 2002).

2.4.2 Knowing the patient individualises care

Evidence indicates that although nurses value patients as individuals and endeavour to treat them as such, it is difficult to transfer this philosophy to practice. One reason is that the majority of nurses do not care for only one patient; they manage a case load or look after a group of patients. Multiple members of the nursing team (including health care assistants) are involved in providing patient care; nurses are therefore relative strangers who come into close proximity to, and interact with, patients in order to carry out nursing activities (de Raeye 2002; Jones 2003).

The difficulty in providing individualised care in an in-patient setting is illustrated by mapping one nurse's use of the nursing process, which identified that although she began her shift by conducting a 'round' of her six allocated patients to assess their conditions, identify problems, and for three patients, immediately start interventions, she almost immediately 'began to be interrupted' (Potter et al 2004 p107). Ebright et al (2003) identified similar findings; in a three hour period of observation, nurses were interrupted up to 31 times by people (such as patients' visitors, doctors, physiotherapists) arriving on the ward and asking for information and help. During these interruptions, patients' needs were subordinated to the demands of other work: patients' call bells remained unanswered, requests for attention were ignored, and other nurses were sent to complete unfinished nursing procedures (O'Connell 1997; Ebright et al 2003; Potter et al 2004).

Another limitation in the provision of individualised in-patient care is the ward routine (Bertero and Eriksson 1996; Waters and Easton 1999; Latimer 2000), nurses having limited influence over timing of meals, ward cleaning, other professionals, and doctors' rounds (Allen 2002). Nurses report feeling pressure to complete their work before the shift change, and do not like to handover unfinished 'admissions' (O'Connell 1998; Latimer 2000). Consequently, assessment practice appears to have less to do with 'knowing the patient' than with a need to meet a bureaucratic requirement to complete the necessary paperwork and other formal records (O'Connell 1992; Brown 1995; Jones 2003).

Wong (2004) suggests that assessment of patients' needs is no longer the means by which nurses provide individualised care, but functions to organise and distribute resources to facilitate speedy treatment and discharge. This concurs with Latimer's (2000) conclusion that nurses are the 'conduits through which the complex and conflicting demands of current health and professional policy are accomplished and translated in care settings' (p8). This emphasises the importance of involving practising nurses in discussions and evaluations about the implementation of professional and policy ideals.

2.4.3 Knowing patients aids expert decision making

Radwin (1996) correlates assessment (the means by which nurses come to know patients), with nurses' ability to make informed decisions about patients' care. Empirical studies, however, identify that nurses' assessments and decision making are based on biomedical issues, or constrained by standardised diagnostic coding and management protocols (Heartfield 1996; Allen 1997, 1998; Latimer 2000; Hyde et al 2005; Irving et al 2006). This dual role of assessment reflects a paradox in health care in general, and nursing in particular: the complementary and contradictory positions of the managerial discourse which is concerned with clinical governance, audit, value for money but which also requires

patients' experiences of care to be optimal, and the nursing discourse, which values expertise, holism, individualised care, but which is also striving to achieve professional status and embracing extended and expanded roles. This tension is captured in the debate concerning nursing diagnosis and its possible contribution and relevance to patient care.

2.4.3.1 Assessment and nursing diagnosis

Nursing diagnosis originated in the USA in the 1970s with a dual agenda: to advance the professional status of nursing, and to define and organise nursing care (Lutzen and Tishelman 1996). The term is often used interchangeably with 'nursing problems' (Hogston 1997); others classify it as a fifth stage of the nursing process, between assessment and the planning stage (O'Connell 1992). Nursing diagnosis has not been adopted widely in the UK; its value is hotly debated, with views on both sides of the argument being strongly held.

Those who advocate its adoption in the UK state that it is 'the end product of assessment' (Hogston 1997 p468), others argue that the '*outcome*' of an assessment is not a label (Powers 2002), but effective care.

Clark (1999) argues that nursing would be advantaged by the adoption of nursing diagnosis. It is interesting, however, that the benefits perceived are for management, research, and policy, illustrating how this debate is the concern of 'Nursing'. Patients' and relatives' voices are silenced, and there is no suggestion of any advantage for practising nurses (Powers 2002). Empirical work supports the argument that adoption of nursing diagnosis is not for the benefit of clinical nurses. Research (O'Connell 1992; 1997) identified that nurses had difficulty assigning a diagnosis to patients' problems because nurses worked in a 'state of not knowing' (O'Connell 1997; p46). Moreover, nurses commented that patients' situations were fluid, so they were unable and unwilling to classify and formalise patients' problems with a label.

Those who oppose the notion of nursing diagnosis criticise its rationalistic approach to care, which goes against the nursing ideal (Mason and Webb 1993). Nurses do not work in isolation from other professions who play a role in the management of patients' problems (Jones et al 1997), and therefore a *nursing* diagnosis is inappropriate.

The debate over nursing diagnosis may soon be redundant (Hogston 1997), as the use of computers in health care becomes more widespread. Information technology will facilitate and even require nurses to select and apply a diagnostic category to patients' problems. Currently in the UK, developments in standardised assessment and decision making are focused not on nursing diagnoses, but on protocols and care pathways, which are becoming more widespread (Ilott et al 2006). Nurses working in expanded roles using advanced assessment and (medical) diagnostic skills usually work according to, and within, agreed protocols (Ilott et al 2006). It is ironic that the more expanded a nurse's role, the more constrained it is by protocols. The danger is that the regular use of protocols can result in a 'tick box approach' to care, with practitioners slavishly following the protocol rather than endeavouring to know their patients, or using decision-making skills (Ilott et al 2006).

2.4.3.2 Exemplar of nurses' decision making: assessment documentation

Nursing diagnoses are purported to be the means of making nursing and nurses' decisions about patients' care more visible (Clark and Lang 1992; Clark 1999) to others in the health care team (Clark 1999). Visibility is required, because analyses of nurses' documentation do not demonstrate nursing activities (Irving et al 2006). Instead, a biomedical discourse predominates (Crow et al 1995; Latimer 2000; Hyde et al 2005; Irving et al 2006). Discourse analyses of nursing documentation reveal that nursing, and its philosophical underpinnings, such as holism, were largely absent (Wigens 1997; Allen 1998; Hyde et al 2005). Adopting the biomedical model (with its focus on bodily functions and activities of daily living) meant that there was no language for nurses to document patients' psychological or sexual problems (Hardy et al 2002; Latimer 2000; Hyde et al 2005; Irving et al 2006). Nurses' attention to these issues was recorded in general terms such as 'reassurance given'; as a result, the assessment and care of these issues were invisible (Hardy et al 2000; Latimer 2000; Irving et al 2006). In the context of managerialism, which relies on 'evidence' and 'audit' to assign value, the absence of non-physical aspects of patients' care, and the invisibility of nursing's response to these, are a concern. There is a danger that nursing's contribution to the care of patients will be lost, and its role limited to that of organising and mediating (Allen 2004) patient care, rather than providing it.

It is worth noting that analysis of nursing documentation has been carried out from a Foucauldian perspective (Foucault 1972; 1975). A limitation is that the relationship between 'discourse' and 'reality' cannot be assumed (Mills 2003), because the structures, systems and meanings that create and sustain discourse are not named (Heartfield 1996). Another limitation is that Foucauldian analysis presents the researcher's interpretation: the subjects' voices are not included (Mills 2003). Therefore no attempt is made to uncover tacit meanings or intentions, leaving the nurses who wrote the accounts of their care powerless in the analysis. This is an interesting outcome, given Foucault's writings on power and knowledge. Research is therefore needed which adopts alternative explanatory approaches to add new insight into nurses' assessments and decision making.

2.4.4 Knowing the patient in contemporary health care

Radwin (1996) states that developments in contemporary health care are threatening nurses' ability to know their patients, but that empirical evidence of the benefits of this relationship is such that nurses will resist further change. The following paragraphs explore these assertions using three exemplars of nurses' work in contemporary UK health care settings.

Health care in the UK in recent years has changed. Throughout the NHS, two discourses, managerialism and consumerism predominate (Allen 1998; Traynor 1999; Department of Health 2000a; 2006; Gilbert 2005). In practice, these are exemplified by the need to ensure: evidence based care; audit; efficiency and value for money; patient choice and user involvement (Allen 1998; Hewison 1999; Traynor 1999; Wong 2004; Gilbert 2005). There has been a huge increase in the amount of ambulatory, short stay and day care treatment being provided (McIlfrack 2003), requiring different nursing roles and new priorities (RCN 2005). The absorption into the nursing role of tasks previously carried out by doctors has blurred the medical-nursing boundary (Allen 1997; Wigens 1997; Jones 2003). As a result, changes in the division of labour in health care and nursing have ensued, including

greater use of health care assistants to perform the less skilled aspects of nursing (Jones 2003; Spilsbury and Meyer 2004).

Two potential effects on the way in which nurses might come to know their patients follow from these changes in health care: firstly, nurses spend less time with patients, having to prioritise other aspects of care; secondly, the type of care nurses are carrying out allows for less intimacy and fewer opportunities to use the 'nursing gaze' (Lawler 1991 p37). There are implications for nurses' assessment practice arising from these changes, as the evidence from the following three exemplars illustrate.

2.4.4.1 Exemplar: Assessment dilemmas in the day care surgical unit

Nurses working in a day care surgery unit (Wigens 1997) perceived their assessments of patients to be constrained by: the use of protocols (e.g. analgesia); shortage of time and rapid patient turnover; repetitive, routine surgery, with little variation in patients' diagnoses or pre- and post-operative care; staff shortages. One of the nurses who took part in the study talked of 'processing' patients on a 'conveyor belt' (Wigens 1997 p1119) because patient turnover and throughput was so high. Consequently, there were limited opportunities to become emotionally involved with patients.

Interestingly, two of the nurses in the study had chosen to work in surgical day care because in-patient nursing had 'drained' (p1118) them, suggesting that day care surgical nursing gave permission to some nurses to work in an emotionally distant way (Allan 2001b). Similar findings were identified by a small number of nurses working in an outpatient chemotherapy unit (McIlfratrick et al 2006), although a larger proportion felt frustrated by the gap between their aspirations for patient care, and their actual practice. Thus, ambulatory care settings impact on the quality of nurse-patient relationships because of the priorities and choices of the nurses who work in them and the clinical role demanded by the service. Little is known of patients' expectations of nursing in day care settings, although evidence is emerging which suggests that they do not desire or expect to be 'known' (Allan 2002; McIlfratrick 2003; McIlfratrick et al 2006).

2.4.4.2 Exemplar: Nursing the clinic vs nursing the patient

Balancing the competing demands of service and patients, requires nurses to make decisions about the priorities for care (Willard and Luker 2005; McIlfratrick et al 2006). Research (Willard and Luker 2005) in an oncology outpatient clinic identified that nurse specialists compromised their desire to assess and provide patients with supportive care in order to comply with the clinic's treatment agenda (waiting time targets, improved treatment outcomes). As a result, nurse-patient consultations were restricted to treatment-related concerns; only (nurse selected) priorities were addressed; privacy and space were limited to curtail lengthy conversations. One of the nurses described the dilemma thus:

'You're constantly juggling, you just have to choose what you think are the important things to deal with at the time and that's at the expense of maybe other things that are bothering patients and if they're not vocal and articulate, they get missed' (interview, nurse practitioner.)

(Willard and Luker 2005, p330. Emphasis added)

This quote provides an interesting insight into the tension felt by the nurse in her work. There is no evidence of the nurses resisting the culture of the clinic, nor of using their experience to fight to change the system, as Radwin (1996) suggested might happen. One way, however, in which resistance to

change might be facilitated is to provide *evidence* of patients' needs and the value of addressing these in clinics. The routine use of an assessment tool might supply this evidence and enable patients to prioritise their concerns, thus promoting the 'subordinate position of support' (Willard and Luker 2005 p331) in cancer clinics.

2.4.4.3 Exemplar: Assessment and technical care: depersonalising the patient

Jones (2003) conducted a focus group study to explore the consequences for nurses of taking on technical tasks (such as inserting intravenous cannulae, male catheterisation, and recording ECGs) from junior doctors. These extra tasks had not expanded therapeutic skills, because staff shortages and an increasing workload had created a task-based system of care. Qualified nurses were meeting patients solely to perform a particular activity; the rest of the patient's care was delegated to health care assistants. The new way of working left nurses with less time to spend with patients and fewer opportunities to get to know them as individuals, therefore, patients received less emotional and social care. Jones (2003) concluded that nurses' care had become fragmented and depersonalised.

However, these conclusions should be treated with caution, as the data comprised nurses' perceptions of how they used to care for patients, compared with their current practice. It is possible that they over-emphasised the amount of time they used to spend with patients. As Redfern (1996) observed when carrying out an ethnographic study of individualised care on wards which purported to practise this:

'Interactions between nurses and patients were often centred around accomplishing particular nursing care tasks. [...] Patients' needs were often subordinated to demands of other aspects of ward work'

(Redfern 1996 p24-25)

Thus, it is not necessarily the technical activities that led the nurses in Jones' study to give depersonalised care. Research is needed which can elucidate how nurses are attempting to reconcile the technical aspects of care with the profession's ideology, and what impact newer, extended nursing roles have had on 'knowing the patient'.

2.4.5 Knowing the patient facilitates positive patient outcomes

Although the ideology of individualised care is embedded in policy and in nursing, there is limited evidence that it leads to positive patient *outcomes*. Evidence is either anecdotal or concentrates on patient satisfaction (Avis et al 1995), and although satisfaction is an important outcome, it is difficult to define and therefore to research, so the validity of findings are questioned. Faithfull et al (2001) identified that nurse-led follow-up of men following pelvic radiotherapy increased patients' satisfaction with care and was cost effective compared with a control group who had usual outpatient follow-up. However, there was no significant difference between the two groups in a key outcome: the severity of patients' symptoms.

A contemporary form of 'knowing the patient' is 'patient-centred nursing', which is gaining recognition among researchers and academics (Binnie and Titchen 1999; McCormack 2003; Clark and Ross 2006; McCormack and McCance 2006), but there is limited research on the outcomes (as opposed to process changes) of this approach.

Nurses greatly value 'knowing the patient', individualised care, and the nurse-patient relationship, and believe that these enhance the quality of care provided (Bailey 1995; Redfern 1996; Faithfull et al 2001; Ross 2006):

'the nurse-patient relationship is central to quality of nursing. Nurses spending time with patients, talking with them, [...] are activities which were valued. It is important that nurses take a personal interest in patients as individuals'

(Redfern 1996 p24-5)

The links between assessment, intervention and positive outcomes are illustrated by nurses' work with breathless lung cancer patients (Bailey 1995; Bredin et al 1999; Krishnasamy et al 2001). Two randomised studies demonstrated that nurses, by working in a therapeutic, close relationship with patients, can make a significant difference to patients' quality of life (Bredin et al 1999; Moore et al 2002). Interestingly, this approach to managing breathlessness rested upon assessment.

2.4.5.1 Exemplar: Cancer nursing as therapy

The study (Bailey 1995; Bredin et al 1999; Krishnasamy et al 2001) involved specially trained nurses carrying out a detailed, semi-structured assessment of patients with lung cancer who were breathless. The assessment included: the meaning of the breathlessness; factors which ameliorated or exacerbated it; 'breathing retraining'; emotional issues; problems warranting pharmacological or medical intervention. The control arm of the study was 'supportive care', which consisted of 'usual' assessment of breathing problems (i.e. based on biological and physical mechanisms). Therefore, this 'nursing approach' (Corner 1997) to the management of breathlessness, was a 'therapeutic assessment' of the symptom.

Corner (1997; 2001) links this approach to assessment and intervention with a need to 'reframe' care through the 'radical deconstruction' of existing (and restricting) environment and approach in health care (Corner and Dunlop 1997 p298-299), to facilitate the reconstruction of context and symptoms. This would suggest, like Radwin (1996), that knowing the patient and therapeutic assessment are not possible in health care settings where managerialism predominates. For as Rodger (2002) argues, the positive outcomes identified as arising from this 'therapy' (Bailey 1995) and subsequently confirmed in randomised study (Moore et al 2002) may have been the result of the extra time and contact afforded the patients; something which is not available to the majority in the current climate in the NHS.

2.5 Summary of social aspects of assessment

The preceding paragraphs have identified that assessment as a social activity is valued in Nursing, and by nurses. The importance of 'knowing the patient' is shared with UK government health care policy in which consumerist and managerial discourses predominate. Whilst the tenet of knowing the patient is central to nursing and important in health care policy, it is not easily transferred into practice. Exemplars have illustrated the wide gap between espoused ideals about the benefits of knowing the patient, in ensuring individualised care, improved outcomes and empowering nurses, and the reality of clinical nursing. Developments in health care and changes in nursing roles and care settings appear to limit nurses' ability to know their patients. The paradox between the aims of assessment in theory, and its apparent role in clinical nursing was identified, but work is required to explore this tension further.

2.6 Conclusion

This chapter has drawn on published research to highlight the importance of assessment in nursing, and the role that it plays in enabling nurses to care for patients. Assessment is a complex activity; the quote from Gadwo at the beginning of the chapter indicates the difficulties faced by nurses when trying to assess and interpret their patients' situation. Assessment is not only concerned with 'outcomes', such as decisions, diagnoses, and interventions, but is also advocated as a means by which patients can become known to nurses. The complexity and role of assessment in patient care makes it an important focus for research.

A key issue has been the paradox in assessment between its clinical and managerial functions, with academic rhetoric stressing its importance to theoretical and espoused goals of knowing the patient and making competent decisions or diagnoses. For management, nurses' assessments play an important role in providing bureaucratic, demographic, medical and auditable information about patients' care. The literature indicates that nurses' assessments are less a reflection of professional rhetoric, and are shaped more by managerial and bureaucratic issues, but this is not acknowledged by politicians and academics, who continue to advocate individualised, person-centred care. A problem, as the exemplars used in this chapter have illustrated, is that many nurses find their work does not facilitate anything but brief, superficial nurse-patient relationships, highlighting the gap between theory and practice. Thus, current understandings of assessment maybe outdated. There is a dearth of research exploring nursing assessment in contemporary care settings, by 'ordinary' (i.e. not specialist or expert) nurses; few studies have invited nurses to participate in interpreting their own assessment practice, and no studies have included patients in this work.

IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

Part Two

IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Chapter 3 Methods

3.1 Introduction

This chapter is divided into two main sections, commencing with the rationale for the research design, and the realist evaluation methodology. Data collection methods are presented and explained. The second section describes the conduct of the study; how data were collected and analysed, and introduces the two case study sites and participants. Ethical considerations and the issue of trustworthiness are addressed.

3.2 Research Design

This study was concerned with initiating and evaluating change in cancer nurses' assessment practice in outpatient chemotherapy settings. Specifically, the research set out to evaluate the impact of a quality of life assessment tool on nurses' assessments of patients attending for outpatient palliative treatments. A participative, interpretive, realist evaluation provided an alternative approach to exploring cancer nurses' assessments of patients; most work in this field has focused on linguistic analyses of nurses' skills (see Chapter 1).

My aim was to focus the research in the wider context of meanings brought to the assessment encounter and created by those participating in it, rather than limiting the study to uncovering the experience of assessment per se. Therefore, the philosophical framework and methodological choices were influenced by a desire to give a voice to the participants and provide a patient-practitioner directed view of what was important or valuable in assessment.

I wanted to root the evaluation in the complexities of real life practice (see Chapter 2). Therefore, controlling variables for the purposes of a randomised controlled trial (which might have been an alternative approach to test the introduction of the assessment tool) was felt to be fraught with difficulty and unhelpful, for two reasons. First, such an approach would only answer the question 'does this work?', and tell us little more than we already know (Pawson and Tilley 1997) (see section 1.5.2; Appendix 1). As the literature review has indicated, assessment is not only concerned with outcomes, and it was important to identify process changes arising from introducing the assessment tool. Second, I wanted an epistemological framework that would go beyond identifying satisfaction with, or dislike of, the assessment tool. Rather, I wanted the research to generate unexpected findings, to identify issues from nurses and patients, which might influence managers and educators as they seek to use structured assessment tools and implement the NICE guidelines (NICE 2004) within the local cancer network. Thus, a realist methodological framework was chosen.

A realist evaluation methodology asks 'what (in an intervention) worked, and how, for whom, and in what circumstances?' (Pawson and Tilley 1997 p216; Mark and Henry 1998 p 83; Kazi and Spurling 2000 p4). The evaluator and the practitioners work collaboratively to decide what is effective and which aspects of the intervention to implement in order to change practice. These premises fitted with the aims of the study.

An interpretive perspective was incorporated into a realist evaluation (See section 3.4) to gain insight into the: context and conduct of nurses' practice; patients' contribution to the assessments; implications of the intervention.

3.3 Aims and Objectives

The overall aim of the study was to identify the impact of introducing a quality of life assessment tool to structure nurses' assessments of patients receiving outpatient palliative treatments. The study set out to understand assessment practice in context, and take account of nurses' and patients' views of assessment and using the tool.

The objectives of the research were to:

- Describe, explain and evaluate chemotherapy nurses' assessments in context
- Determine the impact of introducing an assessment tool to structure assessments
- Increase understanding of the patients' perspectives of the assessment encounter
- Identify organisational and educational implications of introducing an assessment tool, in order to inform future practice development

These objectives were translated into the following research question:

'How does the use of a tool to structure cancer nurses' assessments of patients receiving outpatient palliative chemotherapy affect the assessment process?'

A case study was carried out in two sites. Realist evaluation was combined with an interpretive approach to data collection and analysis. Non-participant observation of the nurses at work provided the contextual information required for the realist evaluation, and interviews with the patients and nurses provided interpretive, reflective insights into assessment practice. The relationship between the methodology and the methods is illustrated in Figure 3-1.

Figure 3-1 The Research Design (adapted from Crotty 1998)

3.4 Methodological framework

A combination of realist and interpretivist perspectives formed the methodological framework for the study. An integration of realism (which is the basis for realist evaluation) and interpretivism was necessary to achieve the aims of the study, and provide potential to offer new insights into cancer nurses' assessment practice.

3.4.1 Realism

A realist view of science states that reality exists, independent of observations or thoughts (Porter 1998b), and meaningful patterns are present in this reality (Julnes and Mark 1998). A realist scientist's task is to formulate and test theories to explain how structures and mechanisms produce outcomes (Robson 2002). For example, iron filings, when brought into close proximity with a magnet, form certain patterns. At one level, the reality is the actual filings which can be seen and touched, but at another level, the reality is the magnetism which cannot be seen or felt, although its effects can be seen. The theory of magnetism explains the patterns created in the iron filings when near to a magnet, and proves the existence of magnetism (Porter 1998b). A realist methodology, therefore, involves the construction of theories which account for, and explain, appearances.

Social reality, from a realist perspective, is socially constructed and experienced (Robson 2002). Thus, when people speak and interact, they do so within the bounds of conventions, rules and other influences governing social behaviour. A realist approach to social research seeks to identify and acknowledge these influences, because it is through these rules and conventions that experience is mediated (Julnes and Mark 1998). Pre-existing social structures (Robson 2002) are context-sensitive mechanisms (Julnes and Mark 1998) which affect the outcomes of research in social and practice

settings (Kazi 2003), and help to explain why particular effects of an intervention are seen in some contexts and not in others. Unlike a positivist evaluation, which would seek to artificially control or eliminate the variables in the research environment, to prove that 'x' caused 'y', a realist evaluation sets out to identify the context-specific mechanisms (e.g. social structures and hidden meanings) which affect behaviour (Pawson and Tilley 1997; Proctor 1998). These mechanisms are used to explain the research findings in the light of contextual influences. The principles of realism are summarised in Table 3-1 below.

Table 3-1 Principles of Realism

(adapted from Pawson and Tilley, 1997; Proctor 1998; Robson 2002; Kazi 2003)

The tenets of realism were important for this study, because my nursing experience is that patients give different accounts of their situation, symptoms and feelings to different people. These accounts are perceived, understood and interpreted in different ways (Bryans and McIntosh 1996); some interpretations will be more accurate than others. Those that match most closely the reality of the patient's situation are the ones which can be said to be more 'real' (Hussey 2000).

On its own, however, realism was not sufficient to encapsulate the breadth and variety of nurses' assessment practice. Of particular importance in assessment is the patient's own view of the matter, based on subjective interpretation of what is being experienced. An additional, complementary methodology was required.

3.4.2 Interpretivism

Interpretivism was crucial to understanding how meaning was shared and understood in the assessment encounter. Interpretivism lies within a constructionist epistemology (See Figure 3.1 above). The principal characteristic of constructivism is its view that 'knowledge, both everyday and

scientific, is a construction shaped by its context' (Delanty 1997 p129). Accordingly, a constructionist view of reality is:

'...contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context'

(Crotty 1998, p42)

Knowledge therefore, is socially constructed meanings, derived through interaction with objects or people in the world, and interpretation of them (Berger and Luckman 1966). The task of the social researcher is to understand people's constructions of reality and interpret their meanings (Blaikie 1993).

This premise was important to the research, because it enabled assessment of 'need' to be constructed by the patient as well as the nurse, rather than be seen as a 'given' (Latimer 2000 p127). Assessment is concerned with understanding, interpreting, and negotiating the meaning of patients' experiences and symptoms. Language is a key medium through which that interpretation takes place and through which reality is constructed (Hussey 2000). Hence the need for a constructionist, interpretivist epistemology, where language, meaning and understanding are socially constructed, negotiated and interpreted. Bringing realism and interpretivism into dialogue provided a new approach to the study of cancer nurses' assessment practice.

3.4.3 Integrating realist and interpretivist perspectives

Intuitively, realism and interpretivism perhaps seem incompatible (Wainwright 1997) but 'realism in ontology and interpretivism in epistemology are quite compatible' (Crotty 1998 p 11), with common premises and complementary differences (Delanty 1997; Crotty 1998). These are outlined below.

First, realism does not deny a dimension of constructivism in knowledge (Delanty 1997), as its premise is that social reality is socially constructed (Proctor 1998). This is similar to the interpretive perspective that knowledge is a complex interplay of interpreted, socially constructed meanings (Blaikie 1993). The main difference is that a realist explanation can choose between rival interpretations, and judge one to be 'better' than another, because realists assert that experience is constructed through pre-existing structures (Robson 2002), and not, as interpretivists would argue, solely dependent upon inter-subjective agreement (Hussey 2000). A key aim of realist study is to identify the pre-existing structures which affect behaviour. These are known as explanatory or causal mechanisms, responsible for the effect of an intervention. These tenets were important for this research, to provide insight into contextual influences on cancer nurses' assessments.

Second, in social settings, 'reality' is only relative to language (Hussey 2000). Thus, whilst realists argue that 'reality' exists, and interpretivists argue that 'knowledge' is constructed, neither is premised on an unmediated truth or theory-neutral starting point (Hussey 2000). Both realists and constructivists share the premise that social reality is communicatively constructed (Delanty 1997): language is the bridge between descriptions (experience) and the world. Assessment is dependent on communication, so, for this study, it was important to include the communicators in the interpretation of assessment conversations.

Third, both realism and interpretivism accept that meanings are negotiated through language, but realists accept that other factors influence the transmission of meaning (Crotty 1998) and are independent of the events to which they give rise (Delanty 1997). The status of the listener, time, context and social convention may affect what is said: these factors are 'as much a part of reality as the building in which drama is enacted' (Hussey 2000 p 107). In exploring the influence of these factors on nurses' assessments, it would be possible to view assessment as an interactive process, and not merely a cognitive exercise, where the successful 'outcome' is believed to depend on reasoning or linguistic skill (Latimer 2000). This would be a new perspective on cancer nurses' assessments.

3.4.3.1 Summary

The pragmatic methodological framework of realism and interpretivism enabled an original approach to be used to explore cancer nursing assessment. Consequently, the study embraced the subjective interpretation of patients' symptoms and problems, the negotiated understanding achieved through the assessment conversation, the biological reality of the patients' illness and treatment, and the context of care.

3.5 Realist Evaluation

A realist evaluation uses evidence from practice, literature and policy to produce hypotheses about how change or outcomes may be brought about by an intervention. These hypotheses are then tested and refined. Research is situated in context, and relies on a cyclical linking of theory and empirical data (see Figure 3-2).

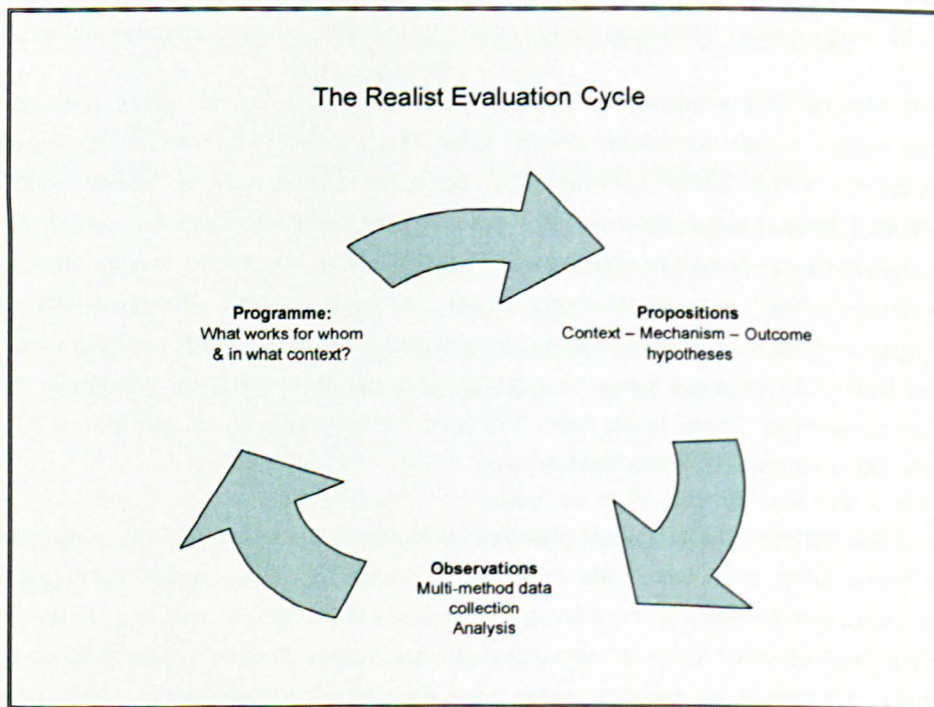


Figure 3-2 The Realist Evaluation Cycle adapted from Sayer (2000) and Pawson and Tilley (1997)

Realist evaluation is concerned with social programmes and social systems (Pawson and Tilley 1997). In this case, the programme was the introduction of an assessment tool into the chemotherapy outpatient department (the social system). Realism has a particular way of describing the operation of a social programme under five subheadings: embeddedness, regularities, mechanisms, contexts and outcomes (Pawson and Tilley 1997).

3.5.1 Embeddedness

Within realism, social reality has a stratified nature (see Table 3-1): the empirical; the actual and the real. The relationship between social reality and behaviour is encapsulated in the term 'embeddedness', meaning that it is not possible to change behaviour without it affecting social reality: they are interrelated. Thus, a realist evaluation differs from a positivist evaluation in that it does not seek to control variables. Rather, it embraces the research context, and seeks to identify the ways in which an intervention affects social relations (the real) that underpin or generate events (the actual) which are observed and experienced in practice (the empirical) (Kazi 2000 p23).

3.5.2 Regularities

Realist evaluations are concerned with the identification of a causal or generative mechanism that can explain the outcomes of an intervention (Pawson and Tilley 1997; Kazi 2003). In order to explain the effects of an intervention, the mechanisms and contexts which are involved in producing the outcomes observed have to be identified and their relationships explained. For example, gunpowder causes explosions; this is a regularity; explosions which occur in the presence of gunpowder can be explained in terms of gunpowder's causal effect. However, gunpowder will only ignite in particular circumstances (Robson 2002). If the gunpowder is wet, or if there is no oxygen, then applying heat will not result in an explosion. Thus, the contextual conditions necessary for the explosion also have to be identified in order to explain different outcomes in different conditions: for instance, why on one occasion the gunpowder did not explode, but on another, there was a violent explosion (more heat, more powder, stronger mixture). Similarly, in social settings, the goal of realist explanation is to explain social regularities which are generated by an underlying causal mechanism. Explanation therefore consists of how the interplay between contexts and mechanisms constituted the regularity:

The basic task of social inquiry is to explain [...] socially significant regularities. Explanation [...] consists of propositions about how the interplay between structure and agency has constituted the regularity. Within realist investigation there is also investigation of how the workings of such mechanisms are contingent and conditional, and thus only fired in particular local [...] or institutional contexts.

Pawson and Tilley (1997 p71)

3.5.3 Mechanisms

A mechanism is a theory to explain how the process of change, brought about by an intervention, is related to the outcome (Pawson and Tilley 1997). The aim of realist evaluation is to understand how an intervention worked, through identifying the mechanisms which produced the outcomes (Mark and Henry 1998). There are many different types of mechanisms (Pawson and Tilley 1997), depending on the level of reality which is being explained. For instance, social mechanisms are people's choices, their reasoning, and capacities; programme mechanisms are propositions about the intervention to

Methods

explain how it worked; and the causal mechanism is the underlying explanatory mechanism which provides an account of the hidden structures and processes which affect an intervention (Pawson and Tilley 1997). In this study, asking the question: 'what is it about the assessment tool that makes it work?' could provide an account of how the tool affected the social relations of the chemotherapy unit; the choices of the nurse and patients in selecting which aspects of the structured assessment process to accept, and which to reject; and the capacity of the nurses to use the assessment tool.

At the outset of the study, it was not clear exactly how the assessment tool would bring about change. Therefore, the tool was identified as the mechanism, with the aim of refining this in the light of the findings.

3.5.4 Context

Realist evaluators state that the relationship between causal and programme mechanisms is not fixed, but dependent on context (Proctor 1998). Programmes are introduced into pre-existing social situations with rules, relations and cultural systems, which can limit the efficacy of programme mechanisms (Pawson and Tilley 1997). An important task of evaluation therefore, is to include, via hypotheses and research design, an account of the extent to which pre-existing structures enable or disable the intended mechanism of change (Pawson and Tilley 1997). Therefore, the study had a before-and-after design. In Phase 1, I set out to identify and understand the social rules in the chemotherapy department; the attitudes of the nurses and patients to assessment; nurses' current, individual assessment practice; the philosophy, policy, and managerial style of the unit; and patient and nurse roles in assessment. In Phase 2, assessments were structured using a tool, and any changes in the issues identified in Phase 1 were evaluated in the light of the intervention.

The nurses at the first case study site and I considered the following to be potentially important contextual influences on assessment:

1. An open, friendly approach would enable patients to voice their concerns
2. Time is an important factor influencing assessment: when time is short, assessment is less holistic
3. The work-load of the chemotherapy unit impacts on assessment: being busy or short of staff curtails assessments, and affects nurses' interactions with patients

These contextual issues were based on practice wisdom. Their relevance to the mechanisms and outcomes were explored in the first phase of data collection.

3.5.5 Outcomes

Realist enquiry explains social outcomes and patterns. Outcomes were tentatively proposed at the outset of the study to guide the analysis of the data. These were generated from three sources: the NICE Guidelines (2004) which formed the policy background to the study; my own experience of using an assessment tool, and the beliefs of the nurses in the first case study site who volunteered to participate in the study. The nurses and I hypothesised that the tool would:

1. Identify more psychosocial issues than usual assessment
2. Increase the number of referrals to the multi-disciplinary team, particularly the palliative care team
3. Switch the initiative in the assessment encounter from the nurse's to the patient's agenda
4. Lengthen the assessment process

Evidence for these outcomes was sought in the data.

3.5.6 Context-mechanism-outcome configurations

Realists attempt to capture what works, for whom, and in what circumstances, through generating sets of context-mechanism-outcome (CMO) propositions, which are then tested empirically and refined (Pawson and Tilley 1997). The context-mechanism-outcome propositions developed for this study are detailed in Table 3-2:

CONTEXT	MECHANISM	OUTCOME
Relaxed, friendly atmosphere	Trust Communication: Expressing and eliciting issues of concern	Patient raises issues of importance Written documentation of patient's concerns and nurse's actions
Busy nurse: heavy workload Unit short of staff	Reluctance to 'bother' nurse Reluctance to explore non-chemotherapy related issues	Not willing to raise psycho-social concerns Psycho-social concerns not identified
Context Phase 2	Mechanism Phase 2	Outcomes Phase 2
Nurse willing to use assessment tool Patient willing to use assessment tool	Assessment tool (enables nurse to elicit patient's concerns)	More psychosocial concerns elicited. Patient-led agenda in assessment ↑Written documentation of patient's concerns & nurse's actions More referrals to multi-disciplinary team Longer assessment time

Table 3-2 Context-mechanism-outcome configurations which guided the study

In summary, Pawson and Tilley (1997 p 215-9) state that a realist evaluation does not hypothesise that x will result in y , but identifies the reasons why an initiative works, and what it is about the intervention that enables change.

3.6 Methods

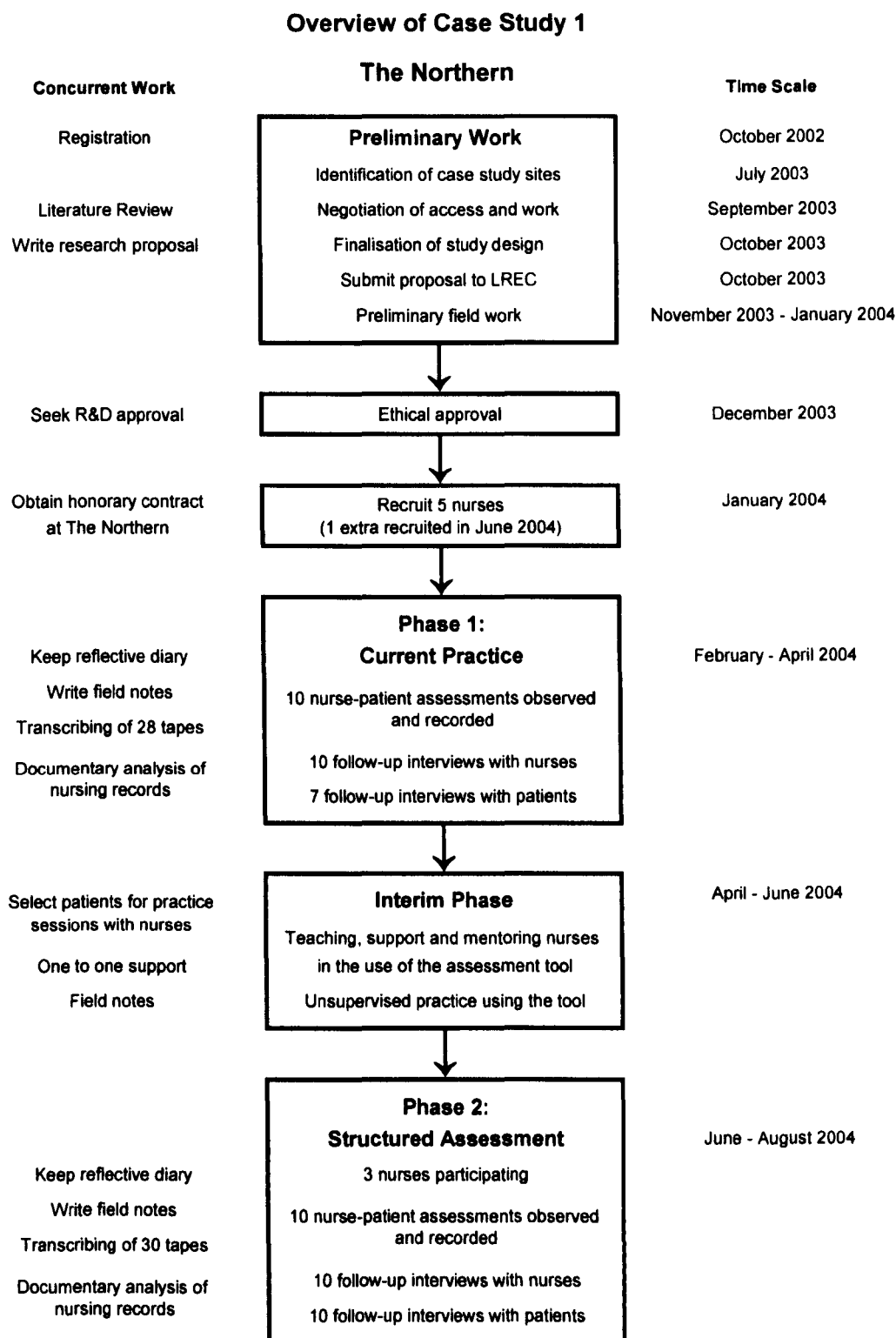
3.6.1 Case Study

The preceding explication of realist evaluation has emphasised the role of context and multiple methods of data collection. The case study method was chosen as a manageable means of organising and collecting the data. There is much debate about how 'case study' should be defined: whether it is a method, an approach, a tool or a design (Bryar 1999). For Yin (1994), an early exponent of case study research, its advantage is the investigation of a phenomenon within its real-life context, using *a priori*

Methods

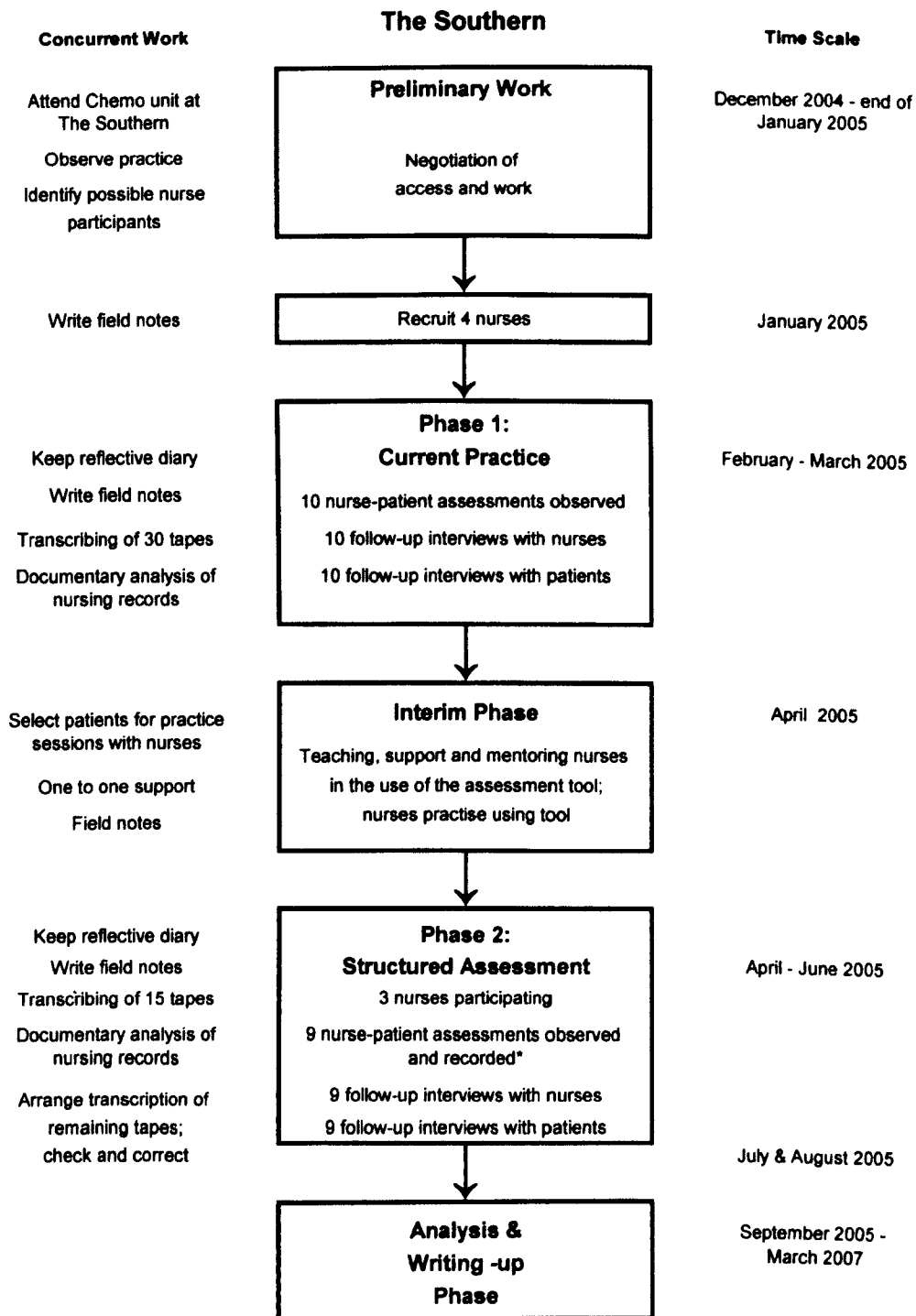
theoretical propositions to guide data collection and analysis and multiple sources of evidence. These factors were relevant to this study as they fitted with the realist evaluation methodology. Thus, I understood case study to be research strategy (Yin 1994) that provided an organising framework for data collection and analysis.

The flow charts overleaf give an overview and timetable of the study.



Flowchart 3-1 Overview of Case Study 1

Overview of Case Study 2



Flowchart 3-2 Overview of Case Study 2

Two case study sites were used to test the preliminary context-mechanism-outcome configurations (see Table 3-2). This enhanced the relevance of the study to the local cancer network.

3.6.2 Data collection methods

Multiple methods of data collection were used. These were: audio-recording of the nurse-patient assessments; observation; interviews; analysis of documentary evidence.

3.6.2.1 Audio recording of nurse-patient assessments

Audio-taping the assessment encounter provided an accurate record. Other researchers have used this to good effect when researching nurse-patient conversations (Lanceley 2000), but the disadvantage is that the nuances of non-verbal cues, facial expression and posture are lost (Van Cott 1993). Video recording was an option, but technically and financially prohibitive. Audio-taping was therefore combined with participant observation so that non-verbal cues could be observed.

Problems with the sound quality of tape recording alone led to the purchase of a Sony mini-disc recorder, with a clip-on microphone which was attached to the patient, but which also gave sufficiently clear sound to pick up the nurse's speech.

3.6.2.2 Participant observation

Participant observation has been described as one of the most important approaches to data collection in practice-based professions, such as nursing (Moore and Savage 2002). It is especially useful for observing the ways people relate to each other (Punch 1998), and for capturing data about the research setting (Bonner and Tolhurst 2002); both important considerations for this study. Moreover, this method of generating data for research parallels the processes by which nurses produce knowledge for practice, in which there is a relationship between their interpretations of a patient's situation, and the patient's 'lived experience' of it (Savage 2000b p330). Both attempt to understand the world-view of others (Pellatt 2003). In studying nurses' assessments of patients, I was mirroring the ways in which the nurses participating in this study identified knowledge *for* practice (through observing, interacting and interpreting), by being 'situated' in the field, identifying knowledge *about* practice.

It is important to clarify the role (Rolfe 2006) I adopted in the study. Participant observation enables a researcher to take on various roles (Spradley 1979), ranging from complete observer, to observer as participant, participant as observer, and complete participant, although they are not necessarily as clearly delineated as these categories imply (Moore and Savage 2002; Robson 2002).

In Phase 1, when my concern was to gather data about nurses' usual practice, I set out to be a non-participant (or complete) observer, because I wanted to minimise my influence on the nurse-patient assessment. I employed several strategies to reduce as much as possible the observer effect. For example, when the patient and nurse were talking, I sat slightly behind the nurse and to the side, so that I was not directly in the sight-line of the patient, to avoid affecting the dynamic of the assessment or drawing attention to myself. It was not always a successful strategy, however, as patients would sometimes include me in the interaction, by looking at me and saying 'I did, you know' or 'do you know what I mean', to which I felt it was only polite to reply. Whether I affected the interactions in Phase 1 is difficult to ascertain. Only on one occasion was I asked to sit at the nurses' station instead of near the

Methods

patient's chair. I was able to observe the interaction from this seat, although I was not able to hear what was being said.

In Phase 2, however, my role was more of observer as participant, because I was frequently brought into the assessment conversation to assist the nurses during the completion of the paperwork connected with the tool, or to help answer a difficult question. There were occasions (in both Phases) when I felt obliged to intervene during the assessments, as part of my professional responsibility to the duty of care to the patients (see section 3.9).

The dual role of nurse and researcher requires exploration and is important (Northway 2002). The term insider-outsider is used to describe the position of the researcher (Bonner and Tollhurst 2002), and although this is the focus of the following discussion, the notion could be usefully explored from the perspective of the research participants' view of my role, in which I was seen as moving from outsider to insider. At the beginning of the study, I was viewed as a 'stranger', an 'outsider' who had arrived in the unit to 'research' assessment practice. The nurses were initially anxious as I watched them work, but, once they realised that I was not going to 'judge' or criticise their practice, they were open and friendly towards me. As the research progressed, and my role became a facilitator and mentor, I became more of an 'insider', being included in the nurses' discussion of day-to-day problems, and sometimes being asked for advice and support. All the while, however, I strove to maintain the focus of my study, to remain objective about the practice I was observing so that I did not make assumptions about what I was seeing, whilst at the same time remaining non-judgmental, seeking to understand the reasons for what was taking place.

Whether I saw myself as an 'outsider' or an 'insider' (Bonner and Tolhurst 2002; Allen 2003) is debatable. I felt neither. I was not an insider, because the administration of outpatient chemotherapy is not an area of expertise for me, and I had no formal role within the nursing team. But nor was I an outsider, because I had experience in oncology and palliative care nursing. On balance, I was probably more of an insider than an outsider, and as such, was able to explore the process of practice (Bonner and Tolhurst 2002). There were times when this blurred role led to difficulties, especially if I was concerned about poor or unsafe practice. Being an insider made it easier for me to be privy to nurses' private work-space and conversations, but in my outsider role, it sometimes left me feeling uncomfortable if what I heard or saw contradicted my own beliefs and philosophy about the care of patients in the palliative phase of their illness. I had to work hard to ensure I did not overstep the boundaries of my researcher role, but at the same time, I had to maintain my professional code of conduct.

In my role as observer, I did not administer chemotherapy or perform any technical nursing duties connected with the chemotherapy, but I would pick things up if they were dropped, fetch a glass of water, or if required, answer the telephone to take a message.

I tried not to take notes whilst I was observing assessments, to avoid appearing to inspect practice. I made mental notes, and when the nurse left the patient to collect equipment, or seek help from a colleague, I wrote key words down in a note pad placed on my knee, as an *aide-memoire*. Notes and reflections were then written up more fully straight away in a diary, and later entered into a Word document on my computer.

3.6.2.3 Interviews

Interviews can take many forms (Robson 2002), varying in structure, depth (Patton 1990) and purpose (Pawson and Tilley 1997). There were two aims to the interviews with the participants in my study. One was to explore my theoretical assumptions about assessment, and to test them with the participants to see if the context-mechanism-outcome configurations (see Table 3-2) developed at the outset of the research were accurate or not. This theory-driven approach to the subject matter of the interview is in keeping with realist evaluation (Pawson 1996; Pawson and Tilley 1997). I sought information about the participants' impressions of the context of care (relaxed, friendly, informal); the mechanisms of assessment (trust, time); and the outcomes. (See interview schedule in Appendix 2).

The second aim was to enable the nurses and patients to interpret their understandings of assessment. During the interview, sections from the recorded assessment conversation were re-played, to allow the nurse or patient to interpret or comment on the extract. The aim was to ensure I understood as far as possible the nuances and meanings of the conversation, and captured the emotions and responses that were aroused during the assessment. I selected the extracts to play. This approach fitted with the realist evaluation methodology, which asserts that the:

'researcher's theory is the subject matter of the interview and that the interviewee is there to confirm or falsify, and above all to refine that theory'

(Pawson and Tilley 1997 p159).

This was also practical: preparing the extracts was time consuming; the mini disc recorder was less flexible than a cassette recorder for selecting short extracts to re-play. Although this premise fitted with the recorded extracts, my interpretivist approach sought to allow the nurses and patients to volunteer new insights. Thus, both were invited to select from the transcripts, or from their memories, aspects of the assessment which they wanted to talk about. The mixture of pre-planned selection of discussion points, and participant-led interpretation worked well.

The majority of the patients' interviews took place in the patients' homes, at their invitation; six took place in rooms adjacent to the chemotherapy units. The interviews with patients lasted from 15 minutes to over an hour. I was sensitive to patients' non-verbal cues and physical status and aimed to avoid overtiring them.

All the nurse interviews took place in a room away from the treatment areas. My third aim in these interviews, in addition to the testing of theoretical assumptions discussed above, was to uncover tacit understandings and impressions of the encounter, to identify decision-making and clarify how those clinical judgments had been made. These follow-up interviews were audio-recorded, and lasted between 30 minutes and an hour. Examples of the interview schedules can be found in Appendix 2.

3.6.2.4 Documentary evidence

A photocopy of the nurses' documentation was made. Details of patients' socio-demographic status, performance status (using the ECOG score – see Appendix 3), diagnosis, sites of metastases and symptoms, previous treatment, and existing supportive care services were recorded on a socio-demographic data sheet (see Appendix 4). In Phase 2, the completed assessment tool, ART, was also photocopied (see Appendix 5).

3.6.2.5 Assessment tool

There were many assessment tools available for possible use in the study, ranging from chemotherapy toxicity scales (which are completed by the nurse or doctor), general and specific symptom assessment scales (e.g. fatigue, nausea, pain), to quality of life questionnaires (as discussed in Chapter 1).

A disadvantage of toxicity scales is that they are completed by health care professionals, so may not be an accurate reflection of the patient's experience (Levack et al 2004). Furthermore, patients with advanced, incurable cancer may have a wide range of illness-related symptoms (Lidstone et al 2003; Echteld et al 2006), such as pain, depression, weakness, anorexia (Poole and Froggatt 2002; Butters et al 2003) which may not be adequately captured in a toxicity scale.

The tool therefore had to accommodate the needs and concerns of a diverse group of patients. I chose between C-SAS (Brown et al 2001b), developed to assess patients receiving chemotherapy in outpatient settings and the Assessment Response Tool (ART) – a combination of EORTC QLQ-C30 (Aaronson et al 1993) and a Symptoms and Problems Checklist validated in a palliative population (Lidstone et al 2003). Both the EORTC QLQ-C30 and the Symptoms and Problems Checklist are validated and have been used separately in clinical practice (Detmar et al 2002; Butters et al 2003; Lidstone et al 2003; Velikova et al 2004).

I chose ART (see Appendix 5) for four reasons. Firstly, it is a cancer-specific quality of life tool, important because the effective management of symptoms experienced by patients receiving chemotherapy improves their quality of life (Brown et al 2001b), and 'quality of life' is the main end point of palliative chemotherapy (Richards 2003). Thus, attention to quality of life and its facets in the assessment of patients with advanced cancer was important.

Secondly, ART incorporates the EORTC quality of life questionnaire, which is widely used in cancer clinical trials, and has been shown to improve the quality of communication in oncologist-patient consultations when used as a clinical instead of a research tool (Detmar and Aaronson 1998; Detmar et al 2002; Velikova et al 2002; 2004). It seemed appropriate to use a tool which could be shared and used effectively (although differently) by other health care professionals caring for the patient.

Thirdly, there are growing calls for the incorporation of well established, validated, reliable quality of life tools into clinical practice, rather than developing new ones (Detmar and Aaronson 1998; Levine and Ganz 2002). Collecting research data and clinical information using one questionnaire saves patient time, and increases the utility of the quality of life assessment (Levine and Ganz 2002). For use with palliative patients, it is recommended that an appendix of questions validated for palliative care is added (Groenvold et al 2006) to provide additional questions relating to symptom-related and existential issues (Echteld et al 2006).

Fourthly, ART is cancer-related, not just chemotherapy related: using ART meant that some understanding of the patient's experience of illness and palliative treatment would be achieved (Annells et al 2001; Bruera et al 2003). At the outset of the study, this was an important principle in assessment of patients with incurable cancer.

Assessment tools for use in clinical practice must combine clinical usefulness with ease of completion, ideally by the patients themselves (Brown et al 2001b), and have an intelligible scoring system (Brown et al 2001b). ART fulfilled both of these criteria for patients with advanced breast cancer (Wilson et al 2002). The assessment tool has two parts. The first part is completed by the patient, and has 48 questions, comprising the quality of life questionnaire and a symptoms and problems checklist. It takes between five and fifteen minutes to complete. Patients score their responses from 1 (not at all) 'no problem', to 4 (very much). The second part of ART is the nurse's assessment, which concentrates on those issues to which the patient has given a score of 3 or 4. First, the patient is invited to discuss the issue further. The nurse then completes a short 'intervention checklist', recording whether the patient finds the issue distressing, and if so, how much (on a scale of 1-4 (not at all - very much)), and whether the patient would like an intervention or a referral to help them manage or deal with the problem. There is space for the nurse to write details about the action taken, or what existing services are being provided to assist the patient. At the outset of the study it was expected that this assessment approach would enhance the identification of 'need' and would lead to patients being referred or 'sign-posted' to relevant support services.

3.7 Into the Field: The Conduct of the Study

3.7.1 Negotiating Access

In August 2003, I invited myself to the Network Chemotherapy Nurses' Meeting to introduce my proposed research to the managers of the outpatient chemotherapy units in a particular cancer network. At the end of the meeting, the sister at The Southern approached me and volunteered her staff to take part.

Within a week, the senior sister at The Northern emailed to say that she and her staff were interested in being involved. After meeting the staff to discuss the project further, the team volunteered to participate. I decided to carry out the first case study at The Northern.

In September 2003, I began to visit the unit at The Northern two days a week, to enable the nurses to become accustomed to me shadowing them. In the light of this experience, several changes were made to the proposed research design. For instance, changes were made to the way in which possible patient recruits were identified.

In October 2003, ethics committee approval was requested (see Appendix 6), and whilst waiting for the committee's decision, I continued to visit the unit several times a month. A total of 52 hours of observation and contact time with the nurses at The Northern was completed during this pre-study phase.

Data collection was completed in August 2004. In December 2004, after my MPhil/PhD upgrade examination, I returned to meet the Sister at The Southern to re-negotiate access, having already obtained ethical approval from the Local Research Ethics Committee at The Southern earlier in the year. A total of 48 hours of pre-study contact time was spent in the chemotherapy unit at The Southern before data collection commenced in early February 2005.

3.7.2 Research Setting

In describing and introducing the setting and the participants, I am using pseudonyms to preserve the anonymity of the nurses, patients and hospitals. These pseudonyms will be used throughout the thesis.

3.7.2.1 The Northern

Case study 1 was the outpatient chemotherapy department in the cancer unit of The Northern. The Northern was situated to the north of the cancer network, and served a population of 300,000, which had social, cultural and ethnic diversity. In addition to the chemotherapy unit, the department had outpatient consultation facilities, offices for two breast care nurse specialists, a colo-rectal nurse specialist and three palliative care nurse specialists (one hospital based). There were no dedicated in-patient beds for cancer treatment or care at the hospital. Cancer patients requiring admission were nursed on general medical wards. Two oncologists each travelled 25 miles from the Cancer Centre to run clinics at The Northern once a week, thus the chemotherapy nurses had responsibility for deciding whether a patient was well enough to receive treatment, based on blood test results and protocols. A consultant haematologist offered emergency medical cover for all oncology outpatients.

At the outset of the study, there was no complementary therapy service at The Northern, although towards the end of data collection, a hand aromatherapy massage service commenced for patients attending for chemotherapy treatments on Friday mornings. There was a small room located in the waiting area where cancer information could be obtained.

The chemotherapy unit, housed in a purpose-built extension to the main hospital, treated approximately 150 patients per month, or up to 10 patients a day. In 2002, approximately 70 patients per month were treated, indicating how the service was developing and expanding. During the course of the study, patient numbers and referrals increased; sometimes 15 patients per day were treated. In September 2003, there were 6 part time nurses in the unit, two of whom were sisters. In November 2003 (the month preceding the granting of ethical approval for this study), both sisters and two staff nurses gave notice that they were leaving. Two new staff nurses were recruited, and one of the existing staff nurses was promoted to F grade sister to be in charge until a new G grade was appointed. This G grade appointment took five months to complete. Following these staff changes the unit's staffing quota was revised, and reduced to 5 nurses, 3 of whom were part time.

By the end of the study there was a full complement of staff, comprising two sisters, one G grade (unit manager – full time), the other F grade (sister – part time); they were assisted by 3 E grade staff nurses (one full time; two part time).

3.7.2.2 The Southern

Case study 2 was the outpatient chemotherapy unit at The Southern, a cancer centre at the south of the cancer network, based in a small hospital which also had general medical outpatient facilities, a minor injuries unit, specialist plastics and burns unit and two wards for the rehabilitation of elderly patients. In the grounds of The Southern was an in-patient palliative care unit, with day hospice and outpatient facilities. Eighteen consultant oncologists, with their respective medical teams, treated more than 3,000 new patients per year with radiotherapy, and an additional 1,500 with chemotherapy. The

cancer centre had two in-patient wards, and a five day ward as well as the outpatient chemotherapy unit, which treated an average of 45 patients per day. Patients travelled from a wide area to receive their treatment, with the oncologists visiting 15 district general hospitals each week to hold clinics and receive referrals. Each consultant oncologist had a specialist site-specific interest in oncology, and many had their own research nurses to help recruit patients to clinical trials; any intravenous trial drugs were administered in the chemotherapy unit by research nurses working alongside the regular staff.

There was no formal palliative care team or social work support within the cancer centre at the time of data collection; specialist palliative care advice was sought from the palliative care unit as necessary.

The outpatient chemotherapy unit was housed in a separate building away from the oncology outpatient and radiotherapy areas, but attached to a Support and Information Centre which provided information, telephone help line, drop-in support, complementary therapies and counselling services to patients. The chemotherapy unit had a complement of ten nurses: a G grade manager; 3 F grade sisters/charge nurses; and 6 E grade staff nurses, 3 of whom worked part time.

3.7.3 Participants: Case Study 1 The Northern

3.7.3.1 Nurses

Six nurses participated in Phase 1. Two were F grade sisters; two were E grade staff nurses, and one was an agency nurse who worked four days a week in a different hospital as a haematology specialist nurse, and regularly worked one day a week in the chemotherapy unit at The Northern. The sixth nurse was the newly appointed G Grade sister who arrived as Phase 2 of the data collection was commencing. She kindly embraced the research, and volunteered to take part. However, due to restrictions on her time, she was only able to carry out one 'baseline' assessment for Phase 1, and it was not possible for her to participate in Phase 2. Thus, three nurses (marked with an asterix in the table below) were involved in both Phases of data collection (see Table 3-3).

**Table 3-3 Details of participating nurses at The Northern
(see glossary for explanation of abbreviations)**

3.7.3.2 Patients

Patients with advanced or incurable cancer were identified from treatment schedules in the appointment diary, using my knowledge of chemotherapy regimes. I did not limit selection of the patients by diagnosis, sex or age, as I wanted to include a diverse range of patients, to reflect nurses' usual practice. Patients receiving palliative treatment were chosen, reflecting the recommendations in the Guidance on Supportive and Palliative Care (NICE 2004).

After identifying possible patients, I confirmed their suitability for the study by checking in the medical notes for a diagnosis of metastatic cancer or an indication that the intent of the treatment was palliative. Initially, I was asked to verify possible patient recruits with the Sister or staff nurse. There were some patients that I was advised not to approach – e.g. because they were known to have severe anxiety or language problems.

Six patients who were approached in Phase 1 declined to participate; 3 patients declined in Phase 2. Reasons given were; 'not wanting to criticise the nurses' (n = 3); feeling too ill (n = 4); not wanting to be tape recorded (n = 2). In addition, four patients agreed to take part, but three were not well enough to have their treatment, and no assessment took place; and the fourth I judged to be too ill to take part, and did not offer to obtain consent from him. From a total of 33 patients approached, 19 were recruited. One patient, Amar, took part in both Phases of data collection. In Phase 2, he was attending for his second treatment of a different chemotherapy regime because his disease had progressed in spite of the treatment he had been receiving when he took part in Phase 1. Thus, 10 assessments were observed and recorded in each Phase of the data collection.

Table 3-4 and Table 3-5 provide details of the patients recruited to the study. Details of the ECOG performance scale can be found in Appendix 3.

Table 3-4 Patients' details: Phase 1, The Northern

Table 3-5 Patients' details Phase 2 The Northern

3.7.4 Participants Case Study 2: The Southern

3.7.4.1 Nurses

Four nurses of the ten nurses working at the Southern participated in Phase 1; three of these participated in Phase 2 (marked with an asterisk in the table below). Tina withdrew from the study prior to the interim phase. Table 3-6 provides details of the nurses at The Southern.

**Table 3-6 Details of nurse participants at The Southern
(see glossary for explanation of abbreviations)**

3.7.4.2 Patients

Patients who were potential recruits to the study were identified from the appointment schedule, and their suitability checked by verifying the intent of treatment or their advanced disease from the hospital notes. The nurses were not involved in the recruitment process. Once patients had been identified, the information leaflet about the study was posted to them, along with a letter inviting them to take part in the study (see Appendix 7). When patients attended for their treatment, they were asked if they wished to take part. 25 patients were invited to participate in Phase 1; 10 assessments were obtained although 11 patients were recruited; there was one recording failure. The most frequent reason for not taking part (n=9) was patients not attending for their scheduled treatment; 2 patients arrived in the unit earlier than scheduled and I missed their assessments; 3 patients declined.

Three patients declined to take part in Phase 2; all gave the reason that they felt 'too ill'. Nine patients were recruited in Phase 2. Recruitment to the study ended slightly early, as there were only 3 nurses participating: Penny carried out two structured assessments and two follow-up interviews in Phase 2 before leaving the unit to work elsewhere in the NHS. This left Kim and Sue. Kim completed two assessments, but was not available to carry out any others, leaving Sue, who completed five structured

assessments. In consultation with my supervisors, recruitment finished after 9 patients. Table 3-7 and Table 3-8 give details of the patients:

Table 3-7 Patients in Phase 1: The Southern

Table 3-8 Patients in Phase 2: The Southern

3.8 Process of Data Collection

The data was collected in two phases in both case study sites.

3.8.1 Phase 1

Nurses' usual, current assessment practice was observed and audio-recorded. Patients were invited to take part in the study by letter during the week preceding their chemotherapy appointment, and gave consent on the day of their treatment. The nurses consented to take part each time they were tape-recorded; this 'process consent' was important, as they were involved in the research for several months, and I wanted to ensure that their commitment and involvement remained voluntary.

Once the patient had been called through from the waiting area into the treatment room, and was seated, a microphone was clipped to their clothing, and the mini disc recorder switched on. The assessments were observed and mental notes taken whilst they were in progress. Before the patient left the department, arrangements were made to meet for the follow-up interview, and information about the content and conduct of that was given (see Appendix 8). In the patient interview I stressed I was not checking up on the nurse, and wanted to understand what the patients had felt and thought when they had been talking to the nurse. Patients were given a transcript of the assessment at the beginning of the interview. During the interview, patients were invited to listen to extracts from the recorded assessments, to clarify my understandings, and interpret their intentions and meanings.

A total of 16 follow-up interviews with patients were carried out in Phase 1, and 19 in Phase 2.

Follow-up interviews with the nurses were carried out as soon as it was possible. In most instances, this was within two weeks of the assessment, although due to staff sickness, holidays, and work load, there were five instances when the interviews were more than a month from the assessment. The format of the follow-up interviews with the nurses was similar to that of the patients although the context and questioning was slightly different. (see Appendix 9). The nurses were given a transcript of the assessment at least two days before the interview was held. During the interview, excerpts from the mini disc recording were played. The intention was that hearing extracts from the assessment would remind the nurse of contextual issues, and allow her to reflect on the particular assessment. Replaying sections of the assessments was difficult to sustain over time, as the nurses disliked hearing their voices, and became resistant to listening to the assessments, preferring to read and reflect from the transcript only. Two of the nurses at The Northern had difficulty reflecting on their practice; the nurses at The Southern were more practised in reflection, and the follow-up interviews were less problematic.

At all times I was careful not to seem judgemental, and not to be critical, but rather, inquiring. Sometimes, when the nurse seemed unsure of my motive, I would say that I found what the patient was saying was unsettling (or confusing); sharing my thoughts seemed to help. After the first interviews, the nurses were more willing to be interviewed, and there was less difficulty in identifying time to meet. Two of the nurses at The Northern said they had found the follow-up interviews 'very helpful'.

3.8.2 Interim Phase

During the interim phase, the nurses were shown how to use ART (see Appendix 5). Initially, I had intended to teach this formally in two sessions, taking the nurses away from the unit to explain how structured assessment might be implemented, allow them ask questions, and practise with each other. I had also planned to use role play, video, and other more formal teaching approaches to introduce the assessment tool. Unfortunately, by the end of Phase 1 at The Northern, there was a serious shortage of staff, and it was impossible to carry out my plans. Following discussion of the problem with my supervisors, I worked with the nurses on a one-to-one basis, mentoring and supporting them as they learned to assess patients using ART. Field notes and a reflective diary were kept during this time, as this phase provided rich data about the experience and impact of introducing an assessment tool into a busy unit. This one-to-one approach was successful, and was also used at The Southern, where it would have been impossible to remove the nurses from the clinical area to carry out a more formal introduction to ART.

During the interim phase, any patients being treated by the nurses participating in the study were asked on arrival in the unit if they would mind completing ART in order to enable the nurses to practise structured assessment. At The Northern, there was a high refusal rate with 21 patients declining to complete a questionnaire, and 28 agreeing. The most frequently cited reason (n =10) for not being able to complete a questionnaire was that the patient did not have their spectacles with them; other reasons included feeling too ill (n = 8), not wanting to (n =2) and one lady said, after looking at the tool, that she could fill it in, but 'the nurses have never wanted to know anything about me before, and I'm not going start telling them now'. There were no refusals at The Southern, probably because most of the patients there had been, or were, involved in clinical trials, and were familiar with the EORTC quality of life questionnaire which formed part of ART.

I supported the nurses during the assessment conversation, and, if required, suggested interventions, and role modelled questions and responses to the patients. Following several sessions of intensive support and role modelling, I left the nurses to practise using ART on their own. Each nurse used ART to assess up to ten further patients before Phase 2 began.

3.8.3 Phase 2

Recruitment and data collection in Phase 2 mirrored that of Phase 1; observation and recording were of assessments structured by the assessment tool. Once the patients had signed a consent form in the waiting area, they completed the questionnaire. After they had been called into the treatment room, I attached a microphone to their clothing, and the patient handed the questionnaire to the nurse. She used the questionnaire as a tool to guide her assessment, asking the patient more about any of the items on the questionnaire which had been given a score of '3' or '4' ('quite a bit' or 'very much').

Follow-up interviews with the patients and nurses were carried out as in Phase 1.

19 patients were recruited to Phase 2, and all participated in a follow-up interview.

3.9 Ethical issues

There were many ethical considerations to be addressed in this study.

3.9.1 Autonomy

The issue of informed consent was important to enable patients and nurses to make their own decision as to whether they wished to take part in the study. Careful steps were taken to ensure participants understood what was entailed, and what their contribution involved.

3.9.1.1 Consent

Informed consent was a key element of the study. In particular, I was concerned that patients and nurses should be taking part voluntarily, with sufficient information to make a decision. I wrote to prospective patient recruits approximately one week before they were due to attend for their treatment inviting them to take part in the study, and enclosed written information about the research (see Appendix 8). The study was designed in this way to safeguard the validity of patients' consent (Cassarett and Karlawish 2000).

The information was presented in booklet form to facilitate reading, and included details to help potential participants make an informed decision about the research, including the aims of the study; what would be required; who was involved; sources of funding; and that consent could be withdrawn at any point without jeopardising care (Wilkie 1997; Seymour and Skilbeck 2002). Formal ethical approval was obtained from the Local Research Ethics Committees in both hospitals. The ethics committee at The Northern had concerns about audio recording process and the accidental recording of conversations of patients who had not consented to this. In response to this concern, a poster was made (see Appendix 10) giving information about the study, and advising patients that recordings were to take place. Each time there was to be a recorded assessment a poster was displayed in the waiting area, another in the treatment room.

When prospective patients attended for their scheduled treatment, any questions they asked were answered, and written consent was obtained from those who were willing to take part.

Permission was sought and obtained from patients and nurses (separately) after each audio-recording to ensure they consented to the use of the audio recorded assessments and follow-up interviews. This was a requirement of the approval granted by the Local Research Ethics Committees in both case study sites, and is considered good practice (Wilkie 1997).

As in other studies of health care settings in which ethnographic approaches, particularly observation, have been used (Savage 2000a), I was careful not to assume that the nurses' initial consent to participate in the research was a 'one off' permanent agreement, as the study took six months in each case study site. Therefore prior to and following each assessment written consent was obtained.

3.9.2 Harm

3.9.2.1 Patients

The group of patients I was researching was vulnerable (Mount et al 1995; Casarett and Karlawish 2000), and steps were taken to minimise harm and protect those taking part in the study. For instance, the phrasing of the patients' invitation letter and information sheet avoided the term 'palliative' as this may have caused distress (Addington-Hall 2002).

Patients' conditions were unstable, and potentially could deteriorate, so before each planned interview I telephoned to check that they were well enough and still willing for me to visit them. Five patients were unable to be interviewed at the first appointment because they were unwell; three interviews were re-arranged. Some of the patients were quite unwell, and I was at pains to ensure I did not overtire them. Some follow-up interviews were therefore shorter and less detailed than others.

Patients were asked whether they were willing to listen to extracts from the assessment before hearing them; the transcript of the assessment served as a guide to and pre-warning of the content. This meant I did not force patients to tell me about 'difficult' issues which they might not have wanted to explore (Addington-Hall 2002). There were two interviews which did not cover 'my agenda'. One was because the patient was in great pain, and the priority was to seek help. The other patient had a story to tell which was at odds with my focus. This was an issue identified by other researchers interviewing dying patients (Seymour and Skilbeck 2002), although I had not anticipated this at the outset of the study. Interestingly, as I left his home, he turned to his daughter, who had joined us, and commented that he had enjoyed the interview, and that he felt better for meeting me. I do not think this comment was intended for my hearing.

If, during the interview, patients indicated that they needed help or symptom advice, I sought their permission to make a referral for appropriate support, for instance, the GP, oncologist, the chemotherapy nurses, or palliative care nurse.

At the end of the interview, all patients were given a business card with my contact details, and the telephone number, opening hours and website address of the cancer support and information centre at The Southern. This was the main information centre for the Cancer Network, and therefore services were available to patients at The Northern. When necessary, I advised patients to contact their GP, district nurses or Macmillan nurse to discuss medication or any concerns they had raised during the interview. The patient's GP was informed, by letter, of the patient's participation in the study (see Appendix 11).

3.9.2.2 Issues in practice

Avoiding harm also guided the decisions to be made when I observed, or was party to, 'inappropriate' or unsafe care. The support of my academic supervisors was important to help me reflect on my role in such situations. Although I had no responsibility for the day-to-day management of the chemotherapy units or patient care, there were times at The Northern when there were only inexperienced nurses on duty, and at such times, I would try and offer support, by suggesting a particular course of action (telephoning the doctor, for instance), or offering to perform a task if (such as carrying out

Methods

observations) if I suspected that it had been forgotten and if I considered it to be important (as in the case of neutropenic patient, who had become septic). Balancing my role as a non-judgemental observer with my professional code of conduct was sometimes problematic and uncomfortable; keeping a reflexive diary was helpful in recording my feelings and learning from my experiences.

3.9.2.3 Nurses

Consideration of potential harm for the nurse participants was also vital. I strove to build and sustain good relations with the nurses. Sensitivity was required when the nurses were busy, especially during the interim and second phases of data collection, as the study reduced the flexibility of the workload in the units, causing additional work for all the nurses, whether taking part in the research, or not.

The follow-up interviews had potential to cause harm, and although I intended and aimed for the interview to be an opportunity for nurses to interpret their assessments, it was sometimes difficult for the nurses to re-visit their practice. I tried always to respond sensitively, sometimes sharing my experiences of having my practice assessed by an 'outsider', reminding the nurses that the aim of the interview was to understand, not judge their assessments.

During the interim phase and Phase 2, many of the nurses found the structured assessments stressful and upsetting. Process consent was very important during these phases of the study. I provided support, feedback, and encouragement, as well as an openness to allow any anger and fear to be expressed. By the end of Phase 2, these emotions had largely dissipated; the nurses all said they had learned and gained a great deal from taking part in the study.

3.9.2.4 Transcriber

Having experienced various emotions whilst transcribing the audio-recorded assessments and patient follow-up interviews, I was concerned that the secretary transcribing the remaining tapes might be similarly affected (Lalor et al 2006). Although she was accustomed to transcribing individual and focus group interviews with cancer patients, I considered it important to offer an opportunity to 'de-brief' and talk about any emotions the tapes had aroused. She declined offers of support, citing her skill as an audio-typist which meant she had not listened in depth to the tapes.

3.9.2.5 Researcher

I underestimated the impact of the research on me. The interim phase, the follow-up interviews with nurses and patients, and the volume and content of material to transcribe and analyse, and therefore engage with, were particularly draining. I was also saddened by the news that so many of the patients had died or deteriorated soon after the study; this added poignancy to the data and highlighted the commitment of the patients and their relatives to the research.

Pressure of time and limited financial resources prevented me from arranging regular clinical supervision, but in August 2005, after data collection was complete and analysis was commencing, I contacted a former colleague experienced in providing clinical supervision to specialist nurses. We met twice; he helped me explore my role in the research process, and allowed me to re-think some of the difficulties I had faced.

One oversight was the issue of personal safety when interviewing patients in their homes. This was highlighted when, during one interview, the patient's daughter arrived, and explained that she always attended when a health professional visited her father, as he had a violent temper. This experience taught me to inform a family member or colleague of my planned whereabouts and at the end of each interview, to 'report in' to confirm my safety.

3.9.3 Privacy, confidentiality and anonymity

All participants were assured of confidentiality and anonymity. After each audio recorded assessment and interview, the tapes and mini-discs were labelled with a number relating to the patient and the nurse; the key to this numbering system was kept in a separate file on my computer. Pseudonyms were assigned to the participants and case study sites at the write-up stage.

The audio-recorded material has been stored in a locked cupboard, away from the computer where the identity codes and pseudonyms are stored; the mini-discs and cassette tapes will be wiped clean after the thesis has been examined, in line with Local Research Ethics Committee guidelines.

3.9.4 Summary of ethical issues

Conducting this study of nurses' assessments of patients receiving palliative treatments required sensitivity. Balancing my need to conduct sound, good quality research in a busy clinical environment involving patients with advanced cancer and nurses working under pressure, presented many ethical challenges. The study was exploring an important area of practice, and included the participants' voices which are ethically sound principles for palliative care research (Addington-Hall 2002; Skilbeck and Seymour 2002). In addition, the regular support of my academic supervisors, who monitored my progress and sometimes challenged my decisions, helped me to remain sensitively aware to the needs of the study's participants. As an ethical principle, I endeavoured at all times to engage and work collaboratively with the participants, and be reflexive in the process.

3.10 Data analysis

Data were analysed in several different ways and stages in order to answer the research question. Firstly, the data were analysed by case, followed by a cross case analysis. A manual approach to data analysis was combined with the use of NVivo (Richards 1999) to identify codes and themes, and to generate the conceptual models.

3.10.1 Audio-recorded data

3.10.1.1 Coding and Identifying themes

I transcribed each nurse-patient assessment recording; a copy was given to the nurse and patient. Each follow-up interview was transcribed, and copies given to the participants (if desired). I transcribed all the Phase 1 nurse interviews and patient follow-up interviews at The Northern, and five of those at The Southern. All the Phase 2 nurse follow-up interviews and the remaining patient interviews were transcribed professionally. These transcripts were checked and corrected.

Methods

The length of the assessment interactions was timed using a stop-watch.

A preliminary analysis of the data was carried out manually, adapting Burnard's (1991) method for analysing tape recorded data. First, the transcripts were re-read whilst listening to the tapes, in order to become immersed in the data (Burnard 1991) and to correct any errors in the transcription. Secondly, themes were identified, using an adaptation of Burnard's method (1991) of analysing interview transcripts. This involved six steps:

1. Categories were generated, e.g. 'nausea' ; 'fatigue'
2. These categories were collapsed into broader categories, such as 'technical issue'; 'toxicity'
3. The transcripts were re-read and revised where necessary to ensure that the broader categories were covering all the aspects of the assessments.
4. Each transcript was marked with coloured pens to identify the coded categories (for example, red for symptom; yellow for toxicity).
5. These colour-coded sections were then 'cut and pasted' into a Word document on the computer to collect the examples from each code.
6. A core category was identified which encapsulated and linked the sub-categories.

Figure 3-3 illustrates the themes and core category from Phase 1:

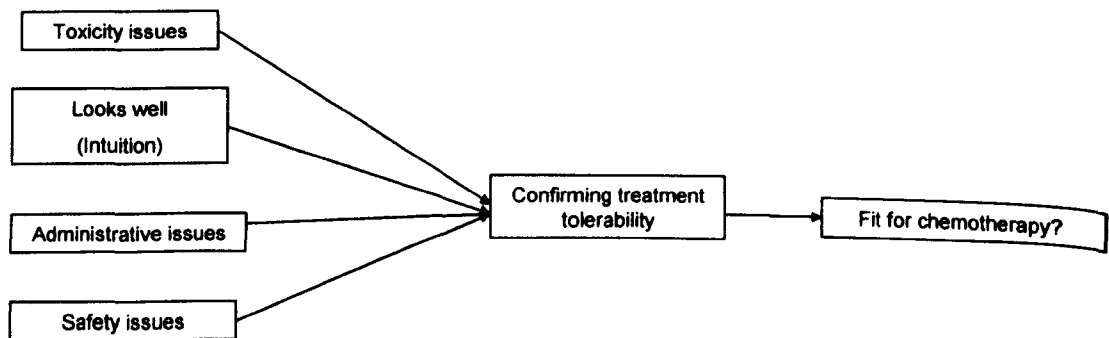


Figure 3-3 Core category in Phase 1: Confirming treatment tolerability

NVivo (Richards 1999) analysis software was used to re-code all the data, and enabled identification of additional codes, such as: use of humour; patients' cues; negotiation work in the assessments; existing support from family and professionals.

Using the context-mechanism-outcome (CMO) configurations generated at the outset of the study as a guide, the transcripts were searched for comments referring to contextual information, such as unit short staffed, or from patients about the friendliness of the unit and the nurses. Mechanisms and outcomes were coded and relationships between them tested. Each theme and its subcategories were stored in NVivo. Once the codes had been identified, they were collapsed into related themes.

Appendix 12 contains the audit trail and examples of the data and analysis.

Using my field notes, reflective diary, and Pawson and Tilley's book (1997) as a guide, data were analysed three further times, as the different levels of theoretical analysis were carried out.

Firstly, flow charts of the assessment conversation were made, which helped to identify the pattern of assessment. Contextual influences were sought and identified for each case study site, and a cross case check performed; mechanisms were identified relating to patients, nurses, setting, and the tool; outcomes were identified. These elements were brought into revised context-mechanism-outcome configurations for each Phase of the data collection.

Secondly, these CMOs were conceptualised into a model representing each Phase of the data collection. This was achieved through a cognitive mapping exercise: key themes were written onto 'Post-It notes' and stuck on a large piece of paper on a white-board easel. The themes were moved around until a model of the assessment conversation for the specific Phase had been generated; different coloured Post-it notes for contextual influences and mechanisms (arising from the follow-up interviews and field notes) were placed in proximity to the outcome themes. Arrows were drawn between the contextual influences, the mechanisms and the outcomes of the assessments to assist the testing and refining of the propositions. Once the models and CMOs had been refined and I felt they represented the data, they were transferred into a PowerPoint format. The paper version remained in view, as the refinement of the models and relationships between the themes continued during the early stages of writing of the results, which were firstly written as individual case studies. This was repeated for Phase 2 data. The simultaneous writing and refinement of the models as my thinking developed enabled me to compare and contrast the cases and to immerse myself thoroughly in the data. The analysis and writing of the findings took eight months.

Finally, after a period of reflection and reading, the generative, causal mechanism was inferred, and data placed into the new categories relating to social organisation.

The nurses' feedback from Phase 2 was tabulated, and the positive and negative effects of the tool identified.

3.10.1.2 Documentary evidence

The nurses' documentation of their assessments was analysed descriptively. The number of referrals documented was counted, and the service to which the patient had been referred was recorded. This data was collated in an Excel workbook.

3.10.1.3 Analysis of the assessment tool

The data from ART was entered into an Excel programme. Firstly, all the question scores were entered into a spreadsheet.

Secondly, each question on each patient's questionnaire was assigned a new variable: if the answer to the question had been given a score of 3 or 4 ('quite a bit' or 'very much' of a problem), it had a variable of 1; if the score had been 1 or 2 ('not at all' or 'a little'), it was assigned 0. This was because the structured assessments had focused on issues which the patients had given a score of 3 or 4, and not those which had been rated as less of a problem.

Methods

The global quality of life and health questions were not analysed, as these had not been discussed in the assessments, but had been perceived as an indicator of the patients' health status.

Each case study site had a separate spreadsheet; the results from both cases were combined into a new cross-case analysis spread sheet. An extract from one of the spreadsheets is presented in Appendix 13.

3.11 Credibility and Rigour

Lincoln and Guba (1985) suggest that there are five techniques which enable a researcher to 'persuade his or her audience that the findings of an inquiry are worth paying attention to, worth taking account of' (p290). These techniques are listed in Table 3-9, along with the strategies used in this study to fulfil these criteria.

Recommended by Lincoln and Guba	Used in this study
Activities which increase the probability of producing credible findings	<p>Prolonged engagement in the field</p> <p>Participant observation</p> <p>Triangulation of data from multiple sources (nurses, patients, documents, observations, audio recordings)</p>
An external check of the inquiry process	Regular academic supervision jointly with both supervisors throughout the study which involved checks on the conduct of the study as well as discussion of the findings and my analysis of them
Checking preliminary findings and interpretations against archived raw data	<p>Data re-analysed using NVivo</p> <p>Refining CMOs</p>
Refinement of working hypotheses as more information becomes available	<p>Re-analysing data three times manually and using NVivo</p> <p>Testing and refining CMO propositions</p> <p>Interrogating the data during the writing up phase</p> <p>Analysing at 3 different levels of theoretical abstraction</p> <p>Reflection during data analysis phase</p>
Testing the findings with the human sources from which they have come	Involving patients and nurses in interpretation of assessments

Table 3-9 Addressing issues of rigour and credibility

Patients and nurses were involved in checking my interpretation of the assessments. Their involvement was key to the testing and refinement of the CMOs. The preliminary findings from the testing of the CMOs were fed back to the nurses for their comments. They were surprised by certain findings; for example, that their assessments were not affected by 'being busy', but were pleased that other CMOs had been 'proved', for example, that the assessment tool led to longer assessments. The analysis of all the data took longer than anticipated, by which time many of the patients had died. I was concerned that contacting patients still living might be problematic, and so further member checks with patients were not attempted. A report summarising the findings will be written for patients and any relatives to read, as part of a requirement for the local research ethics committee at The Northern.

The conceptual (actual) and real (causation) levels of analysis are my interpretations of the data. The nature of the findings, staff changes in the units, and the length of time taken to analyse the full set of data resulted in limited feedback being given to the nurses to date. This, however, should not lessen the credibility and quality of this work (Rolfe 2006). Reality, according to the ontological and epistemological stance of this study, is fallible, constructed and interpreted through language.

Some academics question the need for, and relevance of, Lincoln and Guba's (1985) strategies (see Table 3-9) to 'prove' the rigour of qualitative research (Morse et al 2002; Rolfe 2006), arguing that rigour does not rely on special procedures external to the research process itself (Morse et al 2002), but more on methodological coherence (Morse et al 2002) and the reader's appraisal (Rolfe 2006) of the nature and merits of a work (Sandelowski and Barroso 2002). Thus, qualitative research should not be evaluated against external criteria, but appraised in terms of its presentation and coherence (Rolfe 2006):

Quality judgements entail a subjective 'reading' of the research text, and the responsibility for appraising research lies with the reader rather than with the writer of the report

(Rolfe 2006, p 309)

To assist the reader in this appraisal, I have provided: extensive extracts from the transcripts in the presentation of the findings (Chapters 4-7); extracts from my reflective diary and field notes; and a decision (audit) trail (see Appendix 12) which includes not only details of decisions taken during data analysis, but those which appeared to have potential (Morse et al 2002), but were subsequently abandoned because the data did not support them

3.12 Summary

This chapter has identified the methodological focus which guided the design and conduct of the study. The complementary nature of realist and interpretive philosophies has been identified, and the implications and advantages for the study of this pragmatic stance emphasised. Data collection methods and the conduct of the study have been outlined. Issues relating to data analysis and ethical considerations have been made explicit. The findings are presented in the chapters that follow, and demonstrate how the realist evaluation methodology enabled the research question to be answered.



IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

Part Three

IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Overview of Part Three: Findings

The realist evaluation approach relies on the building of theoretical models to explain the effects of an intervention (Kazi 2000) in a social or practice setting. Taking a model of existing practice as a starting point, a programme of change is introduced and evaluated. The model serves as an approximation of reality, in which practitioners' tacit knowledge and practice wisdom are incorporated to illustrate how existing contexts, mechanisms and outcomes in the setting are influencing practice (Kazi 2000). Based on this model, hypotheses are generated as to where the impact of the proposed change will be or was felt. The evaluation tests and refines these hypotheses, as well as offering explanations for the success or otherwise of the intervention (Pawson and Tilley 1997; Kazi 2000). Moreover, a realist evaluation accepts that not everyone involved in the programme will benefit from the change; that is why a key task of a realist evaluation is to answer the question: 'what worked, (and how), for whom, and in which contexts' (Pawson and Tilley 1997 p216; Mark and Henry 1998 p83; Kazi and Spurling 2000 p4). Evaluation of the intervention and its impact leads to a refinement of the original model; further hypotheses are developed, the intervention is honed and tested, and so the cycle continues. Figure Overview-1 below illustrates this process (Kazi 2000):

Figure Overview-1 The Realist Evaluation Cycle
(adapted from Kazi 2000).

Since there was no pre-existing explanatory model of nurses' assessment practice in the outpatient chemotherapy department to use as a basis for the realist evaluation, the study commenced at a phase in the realist evaluation cycle at which existing contexts, mechanisms and outcomes would be identified (as marked in Figure Overview-1 above). The aim of this phase of the data collection was to

Overview of Part Three : Findings

build a preliminary model of existing practice to form a baseline against which any changes arising from the intervention could be compared.

The realist evaluation is presented over the next two parts of the thesis. This part contains four chapters. Chapters 4 and 6 are concerned with the presentation of the empirical data for Phase 1 and Phase 2 respectively. The contents of these chapters form the first of three elements of 'realist theory building' (Pawson and Tilley 1997 p 122) in which the context-mechanism-outcome (CMO) configurations are explored to provide a detailed description of the attributes and processes of assessment practice.

The findings from Phase 1 are brought together in Chapter 5 within a conceptual framework, or model (the second element of theory building), to illustrate the relationship between the contexts, mechanisms and outcomes identified in Chapter 4. Similarly, in Chapter 7, a model of structured assessment is presented, to illustrate the mechanisms and processes which were involved in assessment when based on a tool. Chapter 7 provides the answer to the question of 'how' the assessment tool worked.

First, however, the findings from Phase 1 are presented.

Chapter 4 Findings Phase 1: Describing Nurses' Assessment Practice

4.1 Introduction

This chapter concerns the findings from Phase 1 of the data collection, and is divided into two main parts. The first concerns the analysis of data from case study site 1, the chemotherapy unit at The Northern Hospital. In the second part, the findings from The Southern are presented.

The first part of the chapter, relating to the findings from The Northern, is divided into two halves, and is structured around the testing and refinement of the two preliminary context-mechanism-outcome (CMO) configurations described at the outset of the study.

Throughout the following chapters, pseudonyms have been used.

4.2 Assessment at The Northern

The chemotherapy service at the Northern was nurse-led, as each oncologist was in the hospital one day per week (two days in total). The nurses worked autonomously in terms of managing the appointment system and the service, although treatment-related decisions were protocol-based. An average of 45 patients per week, approximately 10 of whom were prescribed palliative chemotherapy, attended the unit for treatment. The number of patients was limited to ensure patients did not have to wait to receive their chemotherapy. Most chemotherapy treatments were administered mid-late morning; blood transfusions, monoclonal antibody treatments and Pamidronate infusions were administered at other times. The service was flexible: if there were delays (such as problems in pharmacy), patients were warned by telephone and asked to come later. If the unit was short staffed, some patients' appointments were cancelled and re-scheduled. Patients lived locally; all attended the pathology department the day before their scheduled treatment to have a blood test; these results were sent to the chemotherapy unit the same afternoon, to enable the nurses to order chemotherapy for the following day. Consequently, when patients arrived at their appointment time, their treatment was invariably waiting to be administered. Patients appreciated this efficiency.

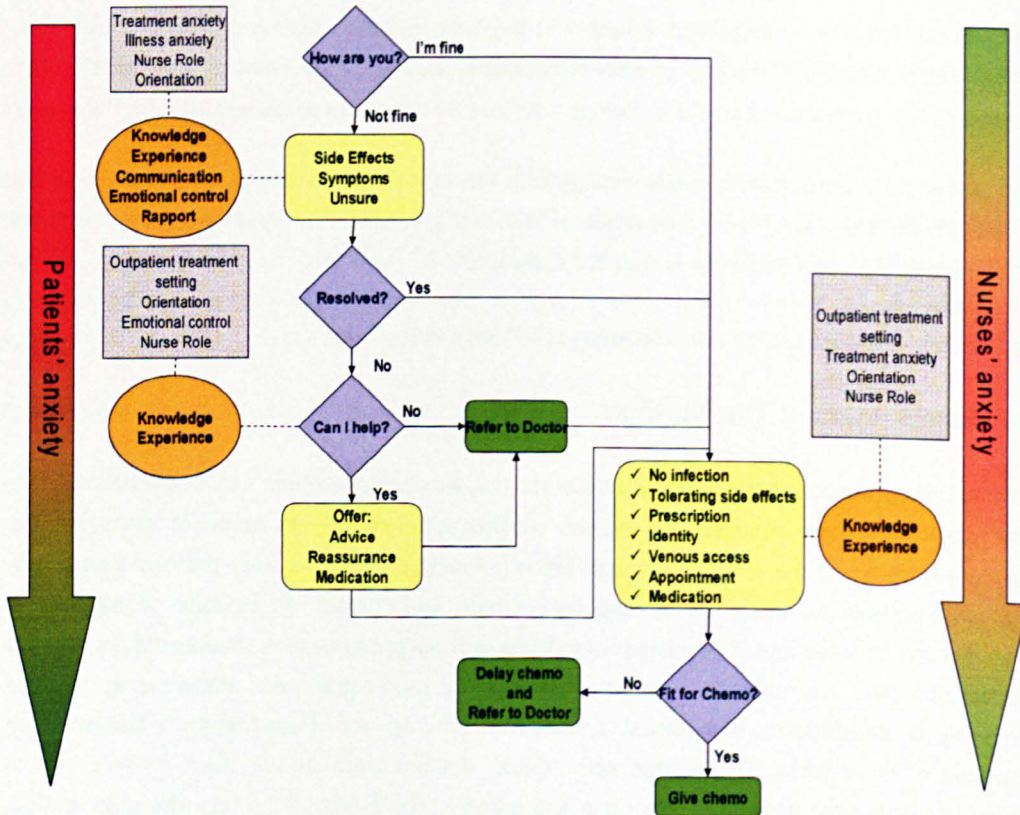
Assessment at The Northern was primarily to confirm the decision made 24 hours earlier that the patient could receive their treatment and to identify any other issues. When analysing this data, it was sometimes difficult to identify an 'assessment': the nurses' approach was conversational, and in half of the audio-recorded interactions, there appeared to be little in the way of an 'assessment' prior to the commencement of the patients' chemotherapy.

There were two notable features of the assessment interactions. One was the presence of anxiety. Nurses' anxiety was noted to rise during the assessment especially if patients asked about symptoms, or the nurse misunderstood the patient's meaning. Patients' anxiety, though high at the outset, lessened as the assessment progressed, especially once the cannula had been inserted.

The second feature of the assessments was their similarity, in format and content, among the nurses, as illustrated in Figure 4-1, which represents the conduct of the assessments.

4.2.1 The conduct of assessment: The Northern

The assessment conversation between the nurses and patients is summarised in Figure 4-1:



Key:

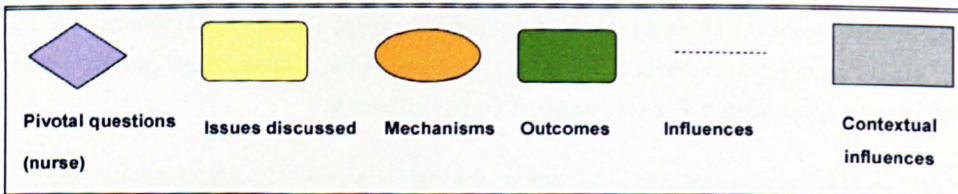


Figure 4-1 Conduct of the assessment conversation at The Northern (Phase 1).

The following paragraphs present the data as it was used to test and refine the context-mechanism-outcome (CMO) configurations devised at the outset of the study (see section 3.5.6); the findings offer an explanatory, not a judgemental, view of nurses' practice.

4.3 Testing Context-Mechanism-Outcome Configurations

The two CMOs were based on the nurses' practice wisdom and beliefs about the factors which facilitated assessment (see sections 3.5.4; 3.5.5; 3.5.6). The first CMO concerned the creation of an informal, relaxed atmosphere in the unit. The nurses believed that a friendly setting (context) would fire

the mechanism of trust; if patients felt relaxed, they would feel safe enough to raise issues that concerned them, and that, having done so, the nurses would deal with these appropriately.

The second CMO concerned the issue of time. The nurses believed that having sufficient staff and time enabled them to carry out more detailed assessments, and that when time and staff were short or limited, the assessments would be shorter and more treatment focused than holistic. The CMOs are summarised in Table 4-1:

No.	Context	Mechanism	Outcome
1	Relaxed, friendly atmosphere (+)	Trust (+)	Patient raises issues of importance and concern (+) Nurse documents concerns and advises/refers patient as required (+)
2	Having sufficient time to carry out assessments (+) Busy nurse; heavy workload; short of staff (-)	Communication Patient reluctant to 'bother' nurse (-)	Satisfaction with assessment (pt and nurse) (+) Shorter assessments when busy, focused on chemotherapy issues only (-) Patient does not raise concerns (-)

Table 4-1 Context-mechanism-outcome configurations for Phase 1

Each CMO has been tested, and evidence to support or refine them is presented in turn, commencing with CMO1.

4.3.1 Context 1: The creation of a relaxed, friendly atmosphere

Evidence came from four sources: documentary evidence (the unit philosophy); analysis of the assessments; nurses' comments in the follow-up interviews; patients' feedback about their assessment and care (See Table 4.2):

Source	Example	
Documentary Evidence	We aim to care for patients [...] in a friendly professional way. [...] We aim to give holistic, family-orientated care <i>(Unit Philosophy)</i>	
Conduct of the Assessment	Introductions/first name terms	N: Hello Mrs. H my name is Judy. I'm one of the chemo nurses P: Hi would you like to call me Janet, everybody else does N: Hello Janet, please call me Judy <i>(Judy to Janet)</i>
	Opening question	Anyway how are you today? <i>(Noreen to Clive)</i>
	Banter	N: Are you OK there? P: Yeah. I just passed out three times [...] P: Cheers sweetheart

Findings

		N: That's 50quid (Kate and George)
	Chat	N: Even Brian Lara isn't playing well P: He's gone right off hasn't he? Last time he got 300 and something off us, but he's not had a very good test series (Noreen and George)
Nurse follow-up interviews	I want to get to know them, I want to tell them a little bit about me (Brenda Follow-Up Phase 1)	
Patient follow-up interviews	It's not too bad there. It's a very friendly place, that's what I like. I like being in a relaxed [place] and larking around (Charlie Follow-Up)	

Table 4-2 Evidence for the unit's relaxed and friendly approach

Each of these sources will be explored in greater depth, starting with the unit's philosophy:

4.3.1.1 Philosophy of Care

The unit's philosophy of care stated that:

'We aim to care for patients and their families in a friendly professional way. We aim to use our skills to give treatments in a professional manner at all times, and strive to give the best care we can. We aim to give holistic, family-orientated care to our patients, ensuring that we are available to answer any questions and give appropriate support.' (Emphasis added)

The statement was typed on a laminated piece of card, and was pinned on the wall at the entrance to the Unit, available for all to read.

4.3.1.2 The 'anchor question'

Nine of the ten Phase 1 assessments contained a 'how are you' question, coded as an 'anchor question' because it ended any conversation between the patient and his/her companion, changed the tone and direction of the interaction, signalling the opportunity to exchange information. It was used in three ways. One patient, Clive, interpreted it solely as a social greeting, and answered it as such, failing to disclose to the nurse that he had experienced a serious adverse event since his last treatment. In two instances, the nurses asked the anchor question and immediately asked a more focused follow-up question, to which a treatment-focused reply was given. The majority of the patients used the anchor question as an opportunity to open an information-exchange about their concerns and experiences. Table 4-3 summarises how the anchor question was used:

Use of the anchor question	No. of instances	Example from the transcripts
Social	1 Clive	N: Anyway how are you today? P: Not bad. Not bad at all. (Noreen and Clive)
Chemotherapy-related (response to closed question)	2 Charlie	N: How are you by the way? How are you doing today? I mean do you feel anything do you have cough, colds P: No (Myra and Charlie)

	George	N: How you've been. OK? P: Actually I didn't even know I'd had chemo this last time. No reaction at all <i>(Noreen and George)</i>
Patient took opportunity to share problems	6 Edwina Frances Janet Jim Hazel Amar	N: How are you today? P: Very well actually. The tiredness after three courses has been worse than I had experienced and I wasn't expecting it to be quite so bad. <i>(Judy and Janet)</i>

Table 4-3 Use of the anchor question

In the six instances when patients used the opening anchor question to share their problems, a second anchor question was subsequently asked, to which patients responded with treatment-related information. The extract below illustrates this:

Extract from transcript	Analysis notes (C=context; M= mechanism; O = Outcome)
<p><i>[Brenda is making Edwina comfortable and positioning her arm on a pillow and placing a heat pad over it as she commences the assessment]</i></p> <p>N: We'll put this on and get you warm going. [pause]. Mrs. X isn't it? It's this this arm isn't it? Put this [pillow] so. This [drink of water] is over there. Here. Have you had any problems in the last¹</p> <p>P: Um only the usual side effects, oh one of the things is my umm left fore arm the veins have come up sore</p> <p>N: [Nurse sits down] Mmm [discussion of which vein to choose]</p> <p>N: And everything else has been alright?²</p> <p>P: Yes everything else has been fine, just the usual side effects just general side effects really. Things like muscular and skeletal aches and pains. [patient talks about taking Vioxx analgesia]</p> <p>N: Lovely. I'll go and get everything checked</p> <p>P: Thank you <i>(Brenda and Edwina)</i></p>	<p>¹Anchor question Pt answer – treatment focus; veins (C=treatment anxiety)</p> <p>²Follow-up anchor question Patient continues treatment focus (C=treatment anxiety)</p> <p>Safety (C = treatment anxiety; nurse role)</p>

The nurses wanted and expected the patients to use the 'anchor question' as a prompt to share their concerns, and in the majority of instances, this was the case.

4.3.1.3 Banter

Banter was noted in three of the assessments, all of which involved Kate, the most experienced nurse in the unit. In general, there was an easy relationship between the patients and all but one of the nurses at The Northern. The exception was Myra who had some difficulties with the English language

Findings

and was unable to banter with patients in the same way as the others. Nevertheless, patients were noted to try to engage Myra in banter and social conversation, illustrating how the nurses and patients worked jointly to create a friendly setting for their care.

4.3.1.4 Chatting

'Chatting' was identified in three assessments, demonstrating the informality of nurse-patient relationships. Chatting was different from conversation aimed to elicit assessment information (e.g. fatigue, nausea and activity levels), which took place during the administration of chemotherapy. Chatting involved discussion of news, family matters, sport, the weather, and involved the nurses in sharing some personal details with the patients.

Thus, the data confirm that the context of the chemotherapy unit was relaxed and friendly and that both nurses and patients were involved in the creation of this atmosphere. The CMO proposed at the outset of the study predicted that this context would fire (Pawson and Tilley 1997) the mechanism of trust in order to lead to the outcome (enabling patients to share their concerns). Whether or not this hypothesis was accurate forms the basis of the findings presented in the following section.

4.3.2 Mechanism 1: Trust

The evidence for trust came from the patient follow-up interviews. In line with the principles of realist interviewing (Pawson and Tilley 1997) the questions set out to refine the theoretical concepts of the study. Patients were asked whether trust was an issue of relevance, and about the factors which were involved in developing or having a feeling of trust. Examples of the questions asked are given below:

CW: If I asked you to talk about 'trust' in relation to the nurses or the chemotherapy unit, what would you say?

CW: Am I understanding you correctly - are you saying that you trust the nurses? ... In what way?

CW: What factors are important to you when thinking about the assessment conversation you had with [nurse]? ... Did you feel you trusted her?

In response to these questions, seven patients responded positively, and indicated that trust was indeed a mechanism, but described trust in terms of nurses' technical competence and nurses' know-how about the treatment and equipment. Trust was not fired by contextual influence of the relaxed and friendly atmosphere.

Table 4-4 summarises the components of trust identified from the data:

Mechanism	Components of Trust	Identified by	Example from the data
Trust	Technical competence	Doreen Charlie Hazel Edwina Lesley Frances	Being able to get the needle in the first time (Doreen). If they get the needle in OK then I can trust them (Charlie) You don't want to see that you think that they're afraid of actually doing it [giving chemo], but none of them are, so I wouldn't expect that. I have every confidence in them. (Hazel)
	Know-how	Edwina Jim Doreen Frances Hazel	I don't know what's going to happen and so I trust that they do and I need to know that they do (Edwina) [it's technical skill] and being able to say what the side effects are (Frances)

Table 4-4 Evidence for mechanism of trust from follow-up interviews

An extract (below) from one patient's follow-up interview details the mechanism of trust. The column on the right hand side includes some of the analysis notes:

Extract from transcript	Analysis notes
<p>CW: And this was your 3rd treatment. Did you have any expectations about the way, how the chat would go?</p> <p>P: No I was surprised and delighted I think by the attention and the warmth¹ as well, and the pace</p> <p>CW: Was there anything different about this chat because it was a different nurse wasn't it than the previous times?</p> <p>P: ²Um she was different and um that isn't about better or worse literally. I've had P for half of a treatment and S for the other half. I had M for a treatment and now Brenda for a treatment. Um I think the child in me wants that contact with the same person so when I knew that it wasn't going to be S, I was disappointed because I thought that she was quite my nurse as it were, but um Brenda was very competent and very knowledgeable so that was fine. This reassured me right away so I could relax and trust her to get on with it safely. She worked confidently³.</p> <p>There was something about the way - for me it's the way nurses work whether they gingerly put in the ..what's it called?</p> <p>CW: Cannula</p> <p>P: Cannula - and so I'm very conscious of how confident they are in their working practice and I like to see it and she was, ⁴and if the nurse is confident then I'm fine. I judge their competence by the things they say and how they say it and the confidence by which they apply whatever they're doing so that they're not tentative but they seem to be very assured - practised I guess is the word isn't it - and that installs my confidence in them because I don't know what's going to happen⁵ and I trust⁶ that they do, and I need to know that they do. That's important to me. If someone wasn't very confident I'm immediately conscious of it, and there was ⁷one nurse when I was having my cold cap who didn't seem to quite know about it. I needed to go to the loo and she didn't quite know how to undo the equipment and how to make it mobile and I just didn't like it. I didn't - you know - that hesitancy, that ⁸knowing what to do is such a vital part of the confidence or trust in the nursing staff. I think it portrays a sense of you know what you're doing you're taking care of me and relax</p> <p>(Follow up interview with Edwina)</p>	<p>¹M=Rapport</p> <p>²C=Treatment setting: Organisation of unit; different nurses each time</p> <p>³Technical know-how</p> <p>C=Treatment anxiety; M=Trust</p> <p>C=Nurse role: technical</p> <p>⁴C=treatment anxiety</p> <p>⁵C=treatment anxiety: unsure of plan/uncertain side effects ⁶M=Trust</p> <p>⁷C=Nurse role: pt values nurse's competence with equipment</p> <p>⁸M=Trust</p>

Findings

From this extract, it is clear that 'trust' was a mechanism which was important for Edwina, and that trust was in the nurse's technical ability and her competence (her know-how). Trust was important because of the anxiety felt with regard to the treatment process, the equipment, and potential dangers ('I could trust her to get on with it safely').

Thus, the mechanism of trust was fired by contextual influences other than the relaxed and friendly atmosphere which had been predicted. The influences firing trust were: nurses' extended role and skills; and patients' anxiety about their treatment and the dangers and risks associated with it. These influences are summarised in Table 4-5 below:

Mechanism	Fired by Context (other sub-mechanisms)
Trust : (nurses' technical competence and know-how)	Extended role: <ul style="list-style-type: none"> • technical skill • navigator for patient; knowing what will happen next (e.g. out-patient appointments) • knowledgeable (to prevent emergencies; recognise serious problems and refer back to oncologist)
	Treatment Anxiety: <ul style="list-style-type: none"> • Trust in nurses' knowledge of side effects (to warn patients; education role; give support)

Table 4-5 Mechanism of Trust

4.3.2.1 Refining Mechanism 1: Rapport as an alternative mechanism

Further analysis of the data revealed that an alternative mechanism, rapport, was directly related to the relaxed and friendly context of the treatment setting. Evidence to support this claim is presented below.

In the follow-up interviews patients stated that it was easy to talk to the nurses because of the informality of the unit (the relaxed and friendly atmosphere). This mechanism has been labelled rapport:

Extract from transcript	Analysis notes
CW: How would you describe the unit then? P: Friendly, that's right, yes. CW: You clearly like that. P: Yes, that's right. Well, that's the only two treatments that Lindsey's ever given me because she's relatively new there, and I, straight away I found her easy to talk to, well I found them all easy to talk to, you know? It is relaxed I must admit. But apart from being told what I'd got and then going in there and being treated, the surprise of that as well, it does take you back quite a bit, it sort of spaces you out a little bit and you know, you think "It's a hospital, it ain't supposed to be like this". You probably find that's a bit strange. But that's the way I find it, you know, hospital's normally a formal place and you go into that unit and you're at home, it's totally different, it really is different, it's amazing. (Follow up interview, Jim)	C=Friendly M=Rapport C=Relaxed and friendly C=Illness anxiety C=Relaxed and friendly

This extract from Jim's follow-up interview demonstrates the link between the relaxed unit and the feeling of rapport that he felt he had with Lindsey. For, although she was relatively new in post, he

'straight away' found her easy to talk to. Table 4-6 summarises the meaning of 'rapport' as described by the five patients who felt that they had this with the nurses at The Northern:

Patient	Example
Edwina (re. Brenda)	I was surprised and delighted I think by the attention and the warmth
Frances (re. Kate)	..she's very friendly. They [the nurses] just do the job but at the same time they make you feel comfortable with, you know, if you need to ask anything.
Hazel (re Judy)	Yes, I just think we [Judy and I] got on quite nicely together.
Lesley (re Judy)	I felt she understood me, oh, very much so. [...] I like the friendliness and the familiarity without being over-familiar. I like the fact that people try to learn each other's names and that 'we're all in this together' is the atmosphere that's been created and that 'let's all pull on the same oars together'.
Jim (re. Lindsey)	..straight away I found her easy to talk to

Table 4-6 Examples of patients' descriptions of rapport

Two patients (both of whom Myra assessed) did not describe rapport. One of these was Charlie; the other was Doreen, who volunteered that she did not want a rapport with the nurses, partly because the 'original' nurses had all left and been replaced by newer ones, and partly because she felt she was less needful of such a relationship because she knew what to expect from her treatment, having had it for so long:

Extract from transcript	Analysis notes
<p><i>[has been talking about her positive relationship with one of the nurses who has left].</i></p> <p>CW: But what about now? What about rapport now?</p> <p>P: I don't think so much now, I think at the beginning it's nice to have it, but now I've had six of the Herceptin and then six of the Taxol. You do get an old hand, you know, and say "Well, no, leave me alone I'll just sit here and eat my dinner". [...] But it's like when you go to the hairdressers, you just want to be pampered and just left alone and "I don't want to speak to anyone for an hour and a half" or whatever. Just sit and read a magazine, you just get on with it quietly.</p> <p><i>(Doreen, follow-up interview)</i></p>	<p>?does rapport require continuity of contact; familiarity?</p>

Doreen's comments raise the question of whether rapport requires other contextual elements, such as familiarity arising from length of contact, or shared intimacy, or a confident nurse (e.g. Charlie had found Myra to be 'nervy') in order to be fired. Data which supports the notion of familiarity came from Myra herself, who, in the follow-up interview spoke of how difficult it was to assess Doreen:

Extract from nurse follow-up interview: Myra talking about her assessment of Doreen
<p>CW: I wonder if you can tell me what you thought about this meeting with Mrs. H.</p> <p>N: In what way?</p> <p>CW: Well, was there anything that struck you about it, from reading the transcript? <i>[NB: had declined to listen to the tape]</i></p> <p>N: No not really. I didn't say very much <i>[laughs]</i></p> <p>CW <i>[Laughs]</i> – yes, you could say that. Do you think that this silence was typical – or were there things which affected you that day?</p>

Findings

<p>N: Yes, yes, it was difficult. It was my first time meeting her. We are really getting along now. She's lovely. I need time to get to know patients, to know what to ask them. I didn't know what to ask her. I couldn't think of anything.</p> <p>CW: Mmm. And yet with other patients, I've heard you chatting away. <i>[laughs]</i></p> <p>N: <i>[laughs]</i> Yes, but I find it difficult to pass the time of day with some patients. I didn't know what to say to her. I found it hard to get in, to start things off. I find it hard to ask questions, I don't want to seem nosy</p> <p>CW: Do you think asking questions is being nosy?</p> <p>N: Sometimes it is. It's very difficult to get the conversation going if the patient doesn't want to talk. I don't want to have to ask the same question, to keep on asking the same questions, so I sometimes find it easier to be silent.</p> <p>CW: And is that what you felt – did you feel Mrs. H didn't want to talk?</p> <p>N: Yes, I think she didn't want to. She just wanted the treatment started and for me not to be nosy</p> <p>CW: Did you – were you worried about being seen as being nosy?</p> <p>N: Well. I couldn't think of anything to ask. I felt she knew the other nurses and I could feel my confidence going down. I wanted to run away, in case I asked or said something wrong.</p> <p>CW: Something wrong?</p> <p>N: Something she didn't want to talk about or something that would upset her</p> <p><i>(Follow-up interview, Myra)</i></p> <p>Notes:</p> <p>C=Illness anxiety (Nurse + Patient. Nurse anxious not to raise issue of breathlessness with patient – suspected pt anxious)</p> <p>M=Knowledge (did not know where breast cancer could spread – lack of theoretical knowledge: disabling mechanism)</p> <p>M=Emotional control – to reduce anxiety</p>
<p>Extract from Doreen's follow-up interview</p> <p>P: What do I expect from the nurses? Not a lot anymore.</p> <p>CW: Why's that?</p> <p>P: Well I think, because this is the second lot, you know, and it doesn't seem to be taking effect, yes I just wonder whether it's doing me any good, I'm just going through all this lot for nothing. I think my trouble is, when they say "How are you feeling?" and I say "Fine, I'm well" because I am, I don't really make a fuss and that's just me. You know, I put things down to other things, like the breathlessness I put down to the operation I had last year. But now it's sort of getting on for six or seven months since I've had it done and it's not getting any better, then it's starting to worry me and I think "What's going wrong?"</p> <p><i>(Follow-up interview, Doreen)</i></p> <p>Analysis notes:</p> <p>C=Illness anxiety; Orientation: coping with limitations (not making a fuss)</p> <p>?M=emotional control</p>
<p>Field Notes from assessment:</p> <p>I felt very uncomfortable watching this assessment; the patient commenced it by stating she was 'a bit breathless' (and if Myra had been able to watch her settle herself into the chair, she would have seen how short of breath she was. But, she was checking the Herceptin with L (other nurses at lunch so L called in from research office to help)). However, the subject of the breathlessness was never raised or discussed again. Listening to Doreen's cough, she sounds like she has a pleural effusion. She coughed - a tickly cough - throughout the assessment. Most of this 'assessment' was in silence; (must remember to time these). Assessment mainly about veins; nothing else. Myra seemed very anxious and ill at ease with Doreen. Was it because L was the checking nurse and Doreen and she bantered a bit at the beginning? Or was it because Myra (subconsciously) wanted to avoid getting involved in a discussion about prognosis and disease progression?</p>

Doreen's comments in the follow-up interview reveal that Myra's hunch about Doreen's anxiety was correct; and Doreen, feeling anxious, and not relaxed, did not want to build rapport with Myra, whom she only vaguely knew. Myra indicates in her interview that her own anxiety about Doreen's illness may have prevented her from building rapport; her reluctance not to be 'nosy', to ask a question which might open up some difficult issues led her to keep the interaction very 'closed'. Thus, her ability to create

rapport was hampered by her own anxiety about what would happen if the new symptom was discussed. This indicates that the individual nurse and patient as well as the dyad (c.f. Charlie and Myra) needed to feel relaxed and comfortable in order to fire the mechanism of rapport.

Myra's anxiety about Doreen's illness fired a disabling mechanism: emotional control. Doreen, too, used emotional control to hide her fears about the treatment's success, and her prognosis. The mechanism emotional control was tested and confirmed from data at The Southern (See Section 4.4.3.4 and Chapter 5). The new mechanism of rapport is summarised in Table 4-7:

Mechanism	Components	Fired by Context	Disabled by contexts:	
Rapport	Warm and friendly relationship	Relaxed and friendly atmosphere in the unit	?Nurse anxiety re patient's illness	
		Extended role – inspires confidence (knowledgeable – can answer questions; skilful & technically competent)	Role: lack of (self) confidence in nurses' skills/knowledge	
	Feeling understood Being able to ask questions	Orientation: Personal liking of the nurse and style of interaction	Illness anxiety: advanced cancer: meaning of symptoms	Lack of knowledge: (patient and nurse) Nurses' lack of experience with discussion of illness issues
			Perception of limited nurse role	
		Relaxed patient Relaxed nurse	Anxiety; treatment; illness; nurse's lack of knowledge or skill	

Table 4-7 Mechanism of rapport

4.3.3 Outcomes 1

The CMO configuration proposed at the outset of the study predicted that there would be two positive outcomes from the context of a relaxed, friendly approach. These are highlighted in the Table 4-8 below:

No.	Context	Mechanism	Outcome
1	Relaxed, friendly atmosphere (+)	Rapport (+) Trust (+)	Patient raises issues of importance and concern (+) Nurse documents concerns and advises/refers patient as required (+)

Table 4-8 Context-Mechanism-Outcome 1

Patients did raise concerns. There was little evidence, however, of a causal relationship between the patient raising his/her concerns, and the nurse responding to them. Nurses' responses were found to be dependent on their interpretation of the seriousness of the patient's issue and their knowledge and experience of its likely cause, progress or solution. Patients' experience of their concerns, and their interpretation of the seriousness of them influenced whether or not they mentioned them to the nurse.

Findings

The presentation of these findings begins with a summary of the analysis of patients' concerns raised during the assessments.

4.3.3.1 Patients' concerns

Table 4-9, Table 4-10 and Table 4-11 summarise the type and number of concerns addressed in the assessments. Safety was a key concern for both patients and nurses; the greatest number of concerns related to the safe administration of the treatment (see Table 4-9):

Issue	Number patient-initiated	Number nurse initiated	Example
Safety (treatment-related)	6	12: 10=identity checks 2 other	Blood tests; patient's identity and correct prescription; patency of vein I thought we had eight [syringes] but we've only got six (<i>George</i>)
Administrative issues	5	6	Outpatient appointments; tablets to take home I haven't heard about my appointment yet, how long should I wait before phoning Dr K's secretary? (<i>Hazel</i>)
Total	11	18	

Table 4-9 Safety and administrative issues in assessments

Table 4-10 and Table 4-11 illustrate that the number of treatment-related issues out-numbered symptoms or illness-related issues:

Treatment-related issue	Number patient initiated	Number nurse initiated	Example
Veins	6	3	I'm worried because they've take out my Hickman line and I don't know which vein you can use (<i>Hazel</i>)
Infections	1	1	I got a bit chesty and sore throat and I rang here on Friday, came in, and it was just the flu – I saw one of the doctors and she just put me on some antibiotics (<i>Frances</i>)
Nausea/vomiting	1	1	And how did the anti-sickness tablets – did you need to take many of those (<i>Brenda to Edwina</i>)
Diarrhoea	1	1	Any diarrhoea or anything like that? (<i>Lindsey to Jim</i>)
Appetite	0	2	So you've been eating all right? (<i>Lindsey to Jim</i>)
Joint aches	4	0	.. just general side effects really, things like muscular and skeletal aches and pains (<i>Edwina</i>)
Fatigue	2	1	The tiredness after three course has been worse than I had experienced and I wasn't expecting it to be quite so bad (<i>Janet</i>)
Dry eyes	1	0	..this time my eyes were really dry and sore. I don't know if that's - is that anything to - can you get that with the chemo (<i>Frances</i>)

Sore mouth	0	1	Any mouth problems? (<i>Kate to Frances</i>)
Total	16	10	

Table 4-10 Side effects raised during assessments

Table 4-11 illustrates that the nurses asked patients very few questions about their symptoms; the patients volunteered five times as many symptom-related issues to the nurses in the assessments as they were asked about, although neither nurses nor patients raised or discussed psychological issues or concerns:

Symptom	Number patient-initiated	Number nurse initiated	Example
Pain	2	1	..last week[...]the pain was unbelievable I was getting an hour's sleep a night (<i>Jim</i>)
Constipation	2	0	I suffer badly with constipation [...]my bowels haven't moved for about 4 days now (<i>Amar</i>)
Oedema	1	0	..my GP seems to think I've got water retention in my feet (<i>Jim</i>)
Breathlessness	2	1	I'm not too bad apart from a cough and breathlessness when I'm rushing around (<i>Doreen</i>)
Cough	2	0	I had no coughing nor anything this time. Normally I'm coughing up blood (<i>George</i>)
Rash	1	0	Actually I woke up with a really red face this morning [...] and all across here [chest area] it's bright red (<i>Frances</i>)
Sweating	1	0	I'm having awful head sweats (<i>Jim</i>)
Total	11	2	

Table 4-11 Symptoms discussed during assessments

In the two instances when the nurses asked patients about their symptoms, the talk was framed within a treatment perspective, reflecting the nurses' knowledge and orientation. The extract below is taken from the assessment between Lindsey and Jim (who had lung cancer), and demonstrates how Lindsey confines her discussion of Jim's breathlessness to his blood count:

Extract from assessment transcript	Analysis notes
<p><i>[Nurse is inserting the cannula; patient panting, breathing heavily]</i></p> <p>N: Have you noticed any breathlessness or anything</p> <p>P: Sometimes yeah but I put it down to me legs, I put it down to my leg. Yeah because it's spread to my pelvis. That's why I had to have radiation. That's what Dr K said anyway</p> <p>N: Just sometimes if your blood counts are a little bit low you can find that you might get a little bit breathless, because obviously your haemoglobin is a bit low so the oxygen's not getting round your body as well</p> <p><i>Lindsey and Jim</i></p>	<p>?is pt breathing like this to relax or is he getting more breathless (was short of breath on walking) <i>Field notes</i></p> <p>Illness progression</p> <p>C=orientation to treatment</p> <p>M=emotional control; ignores information re RT and disease spread</p>

Findings

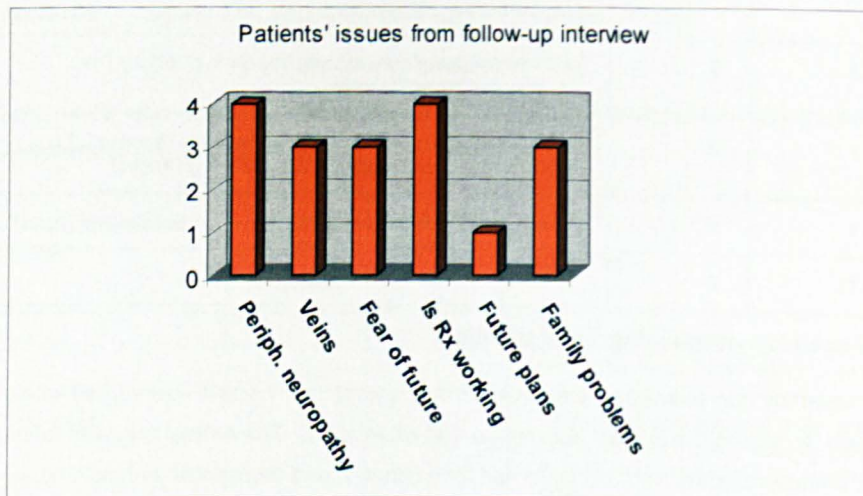
In this extract, although Lindsey noticed Jim's breathlessness, she talked about it solely from a treatment-related perspective (anaemia), not from his illness (lung cancer), precluding any discussion of the impact of the breathlessness on Jim or his family.

Nurses relied upon the patients to volunteer information about their side effects or treatment-experiences. Patients raised issues about which they were unsure; which were extreme or unexpected; and which they felt the nurse should know about in order to deliver the planned treatment safely:

<p>P: Oh and I tell you what else this time my eyes were really dry and sore. I don't know if that's - is that anything to - can you get that with the chemo?</p> <p>N: Um you can get that with some chemos but I'm actually not quite sure with this one to be honest, but I'll look it up for you</p>	<p>P: I'm on some antibiotics. This is [shows arm to nurse] from where the chemo actually went into the soft tissues</p> <p>N: That was?</p> <p>P: The Vinorelbine. On Tuesday when I went down to [The Southern] for something completely different, they saw that and they said 'we'll give you some antibiotics'</p>
<p><i>Kate and Frances</i></p>	<p><i>Judy and Janet</i></p>

4.3.3.2 Patients' concerns at follow-up interview

At the follow-up interviews, patients cited their concerns at the time of the observed assessment as illustrated in Graph 4-1:



Graph 4-1 Patients' issues from follow-up interview

Two of the categories (veins and peripheral neuropathy) were directly related to the effects of the chemotherapy, although peripheral neuropathy was not something which had been discussed or raised with the nurses, and was a surprising finding. The other categories were related to fears for the future; worries about the treatment's effectiveness; and difficulties in the family (communication problems, finances, employment, coping). With the exception of Jim, who had hinted to Lindsey that he understood his prognosis, these issues had not been discussed with the nurses:

Extract from patient follow-up interviews
<p>P: I just tell them things that help them you know? Things they need to know. They're busy people, they dunna want to hear all sorts of rubbish. Once you've had a few treatments, you soon learn what's helpful to them.</p> <p><i>Charlie</i></p> <p>C=Role perception M=Experience (of assessment)</p>
<p>P: [starts to cry] Sorry. I keep crying. Makes you wonder if that's why you are more emotional, because there's so much going, this year, the second time. It's like, it's just like you're in limbo almost, you know? [...] I have felt like that [optimistic] up until this week when, so, but then I keep thinking, "No you're kidding yourself" do you know what I mean? I'm not really accepting what's there. [...] Maybe I just need to talk. [...].</p> <p>CW: Did you think to tell [Kate] about this last week when you were there</p> <p>P: Oh they don't want me weeping and wailing and carrying on in there. It'd spoil it for them all – and the other patients they don't want to see me like this. I'm OK really, it's just my son. I think about my son, but then I keep thinking about [inaudible], it's almost, it's just. It's just what's going on. Waiting for results and things.</p> <p><i>Frances</i></p> <p>C=Illness anxiety; relaxed and friendly unit M=Emotional control</p>

Frances' comments indicate she felt that the ambience of the unit might have been 'spoiled' by her tears or emotional display, suggesting that the relaxed, friendly, happy unit fired a mechanism of emotional control. The findings also confirm the contextual influences underlying emotional control: anxiety about the illness, and worries about the success of the treatment.

Jim was the exception in talking about his prognosis. His treatment took 76 minutes to administer via bolus injections, and whilst it was in progress, he spoke several times about his future, and hinted about his limited prognosis:

Extract from recorded assessment with Lindsey
<p>P: I'm thinking about moving on, what to do with the rest of my life. About going back to work and that. But they might not let me like, what with having cancer. I'll have to wait and see what Prof K says when I see him next time..Every time I see Prof K he gives me bad news. Last time I came out of his office it was thank you very much, I didn't know it was in my pelvis like. But you got to laugh haven't you. You've got to laugh about it haven't you?</p> <p><i>Jim</i></p>

This suggests that, to fire the mechanism of communication to enable discussion of 'deeper' issues, prolonged contact with the nurse is required.

4.3.3.3 Nurse documentation

Assessment documentation did not reflect the number or type of issues discussed or raised by the patients, but was a summary of the patients' overall wellbeing and a record that the chemotherapy had been administered. For example:

Examples of nurses' documentation		
'Feeling well; chemo given no problems.' <i>Noreen re George Brenda re Edwina; Judy re Hazel</i>	'Chemo given. No problems' <i>Myra re Amar; Myra re Doreen; Myra re Charlie</i>	'Premedication given, and observations maintained. Chemo given as prescribed. No problems' <i>Judy re Janet</i>

Findings

The exception was Kate, who recorded that Frances had developed a rash over her chest wall:

Kate's documentation of Frances' treatment visit:
Has steroid rash over chest wall; telephoned Dr K's registrar. No action required. Patient reassured. Chemo given. No problems. Return in 3/52 (<i>Kate's documentation re Frances</i>)

4.3.3.4 Nurses' Advice

Limited advice was given to patients. In response to a patient's issue, nurses would check that the symptom or problem had resolved or that someone else was dealing with it, before moving on to a treatment-related topic:

Extract from assessment	Analysis notes
N: What about your appetite. Do you have?	C=treatment: appetite assessed as a side effect
P: This is not so good so that's what the steroids are for. I suffer badly with constipation. The steroids. I don't eat a lot and then with the constipation I can't eat a lot	Appetite problems = symptom of illness. Constipation
N: Do you always have the constipation	
P: Yeah well like my bowels haven't moved for about four days now	
N: Wow!	Surprised
P: I take Normacol	
N: Do you see the doctor for the constipation? Four days is quite a lot.	C= Nurse Orientation (to doctor)
P: That's what the Macmillan nurse [C] visits for. She's the one who deals with that	C= Pt Orientation (MDT support)
N: Do you have problems with your kidneys or anything like that	No advice given; no further assessment of symptom
P: =No	(D)M=?lack of knowledge; what to advise?
N: =so you can drink	Nurse is anxious & confused re steroid use
P: Yes yes	
[silence]	
N: It says here that the dexamethasone 4mg was for - this is the B - the dexamethasone was for the A cycle only so you won't have them today	(D)M= (lack of knowledge is disabling mechanism)
Pt's sister to Pt: So just take whatever Dr S prescribed	
P: Yes	
N: It's best if you feel nauseated it's best to take the metaclopramide because it prevents the sickness. Does it [the vein] feel OK?	Returns to familiar territory; reduces anxiety
P: Yes but it feels cold. I don't know if that's OK	C=treatment anxiety; M=experience (new – venous spasm)
<i>Myra and Amar</i>	

In the extract above, Amar indicated that he was troubled by two symptoms: loss of appetite and constipation, and earlier in the assessment had talked about his problems with vomiting following his last chemotherapy. Myra's shocked response ('wow!') to the information that he had not opened his bowels for four days did not lead her to offer any advice or help to Amar, although he had indicated that his Macmillan nurse was involved. Her response was to ask if he could drink fluids (it is unclear as to why, but perhaps it was meant to be a means to relieve the constipation and /or to prevent dehydration from his vomiting). She suggested a pharmacological solution (metaclopramide) for the nausea, and immediately returned to focus on the treatment, checking for safety. This move prevented Amar from asking any further questions. An explanation for this was Myra's lack of experience and knowledge

about symptoms and how to manage them, confirming that knowledge and experience are necessary for nurses to assess patients' problems:

Extract from nurse follow-up interview

I didn't really know what to say when he said about his bowels like that. That's what I want to learn. What his Macmillan nurse is doing. I haven't ever nursed cancer patients before, and so I want to learn.

Myra: follow-up interview re. Amar

Symptom advice was in terms of a treatment-related cause (as in Lindsey's comments to Jim, see section 4.3.3.1). In the following extract Brenda talks to Edwina about her bone pain as if its cause were the bone marrow working hard to regenerate cells:

Extract from assessment transcript	Analysis notes
<p>P: I'm feeling nothing wrong. I'm not - in general except for the [mastectomy] scar which is up in the air and that really does feel like someone is rubbing metal on my breast bone [...]</p> <p>N: I'm sure it was said to you at the chat that most of the side effects and the things that you get are because of the way chemo works on the fast dividing cells so its those cells in the fast dividing parts of the body are ones that get affected like the hair follicles and the nose</p> <p><i>Brenda and Edwina. (Original emphasis)</i></p>	<p>C=Illness anxiety: am I getting better?</p> <p>C=Orientation: Treatment focus</p> <p>M (disabling)= lack of knowledge re status of Edwina's cancer</p>

At the follow-up interview, Brenda did not know that Edwina had metastases in her sternum. This illustrates that knowledge of patients' disease status affects the advice a nurse might give regarding a symptom. A lack of such knowledge was a disabling mechanism and prevented Brenda from assessing Edwina's pain more fully.

The extracts presented above illustrate how patients raised issues about which they wanted clarification or information; many of these were related to safety aspects of the treatment and to their experiences of symptoms and side effects. The nurses' treatment-related responses, although aimed at helping patients make sense of what they had experienced, ignored any illness-related anxieties.

4.3.4 CMO 2 Context: Effect of workload and staffing on assessment

The second CMO proposed at the outset to the study predicted that time would be an influencing contextual influence on communication in nurses' assessments: having sufficient time would lead to more in-depth assessments and that a shortage of time lead to more limited, treatment-focused ones: The CMO is presented in Table 4-12:

Context	Mechanism	Outcome
<p>Unit not too busy; adequate staffing (+);</p> <p>Busy nurse; heavy workload; short of staff (-)</p>	<p>Communication</p> <p>Patient reluctant to 'bother' nurse (-)</p>	<p>Satisfaction with assessment (pt and nurse) (+)</p> <p>Shorter assessments when busy, focused on chemotherapy issues only (-)</p> <p>Patient does not raise concerns (-)</p>

Table 4-12 CMO 2 Phase 1

Findings

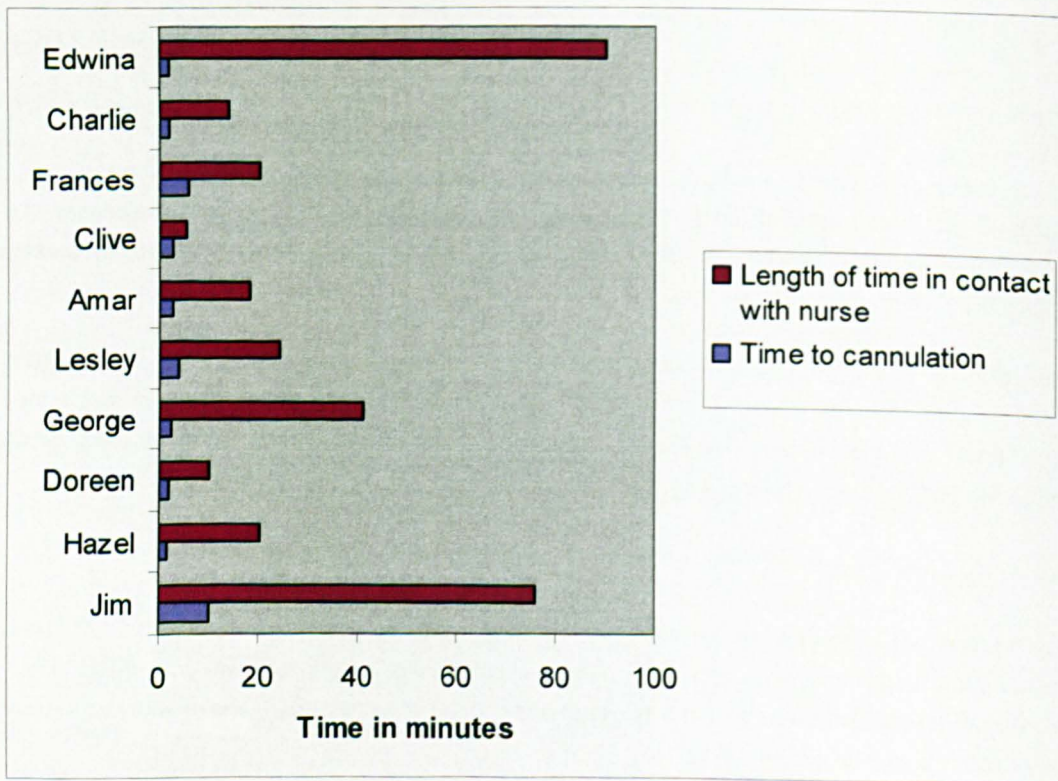
The nurses were asked to classify the sessions when I was present as 'quiet', 'busy' and/or 'short staffed' (see Table 4-13).

No. of observation sessions (Ph 1)	No. of hours spent observing	No. of sessions classed as 'busy'	No. of sessions 'short staffed'(sickness)
23	106	17	15

Table 4-13 Summary unit workload, Phase 1

There were frequent staff shortages, and a high rate of staff sickness rate. On two occasions, Myra was the only nurse on duty, having to rely on a Nurse Specialist to check the patients' chemotherapy prescription.

In terms of the audio-recorded assessments for the study, there were three in Phase 1 which were carried out during busy or short-staffed periods. These were Edwina's, Jim's and George's assessments. There was no evidence to show that the busier or short staffed sessions led to shorter assessments, as Graph 4-2 illustrates:



Graph 4-2 Length of assessments or contact with the nurses in Phase 1

The graph above shows two different timings. The shorter line (bar) relates to the length of time between the nurse first meeting the patient and commencing the insertion of the cannula. The longer bar (line) indicates the total length of time the assessing nurse spent in contact with the patient. This includes the time spent inserting the needle, attaching the infusion bags, and in three instances (Jim, George and Edwina) the length of time that the treatment took to administer via bolus injections.

Jim had the longest assessment before cannulation commenced, and his treatment was given on one of the busiest days I was present in the unit. Therefore, there was no clear link between the unit being busy and the length of an assessment. The two longest assessments prior to cannulation (Jim and Frances) were conducted by the two most experienced nurses (Lindsey and Kate), which suggests that knowledge and experience have an impact on assessment length.

4.3.5 Mechanism 2: Communication

It was predicted that patients would be reluctant to 'bother' the nurse with their concerns, if the unit was busy. There was no data to support this proposition. Table 4-14 summarises the content of the assessments, with an asterisk against the names of the patients whose assessments were carried out when the unit was busy. It can be seen that these were the assessments that covered the most issues:

Patient	No. & type of issues raised by patient	No. & type of issues raised by nurse	Assessment-related topics raised during chat whilst chemo. in progress
Clive	1: side effects	1: Was pain helped by APD?	Activity levels at home (nurse-led)
Charlie	1: Vein	2: Any infections? Next appointment	Previous chemo (patient-led)
Amar	6: Side effects: vomiting; diarrhoea. Safety: vein Symptoms: Constipation; ↓appetite Medication confusion: steroids	2: Fatigue; safety (vein)	-
Doreen	2: cough; breathlessness	1: safety (vein): 'does it feel all right?'	Veins
Edwina *	3: veins; side effects (joint aches; fatigue)	3: medication for joint aches; safety; nausea	Holidays; fatigue; nausea and anti-emetics; sleep problems; constipation
Frances	4: pain & analgesia; skin rash; dry eyes; infection	2: sore mouth; veins	Hormone therapy (patient-initiated)
George *	3: Outpatient appointment; improved cough; safety (correct chemo?)	2: vein; outpatient appointment	-
Hazel	2: veins; Outpatient appointment	1: veins	Hickman lines
Janet	2: safety (reaction to Herceptin); veins	-	Experience of Herceptin
Jim *	6: sweating; side effects; new symptoms; outpatient appointment; pain; safety (blood test)	3: diarrhoea; eating; breathlessness	Anaemia

Table 4-14 Summary of issues discussed during assessment

Table 4-14 illustrates that patients did raise their concerns with the nurses, and that they were not restricted by any perception of the nurses having limited time available to talk to them.

4.3.6 Outcome: Satisfaction

The nurses said they were satisfied overall with their assessments, although Kate said that she could have asked Frances about her emotional concerns, and felt that she had not addressed these in the assessment:

Extract from nurse follow-up interview

Her main issues were her anxiety over her relapse. She may not have mentioned it here but I know that because the conversation was quite different the first time. [...]Although, maybe I should have given her more of an opportunity to follow-up on last time, because I didn't mention how she was, as far as symptoms go I did, but I didn't actually probably ask her how she was in herself.

Kate re Frances

None of the other nurses identified anything they would have improved on or could have extended. Two nurses (Judy and Kate) indicated that they were conscious of being recorded, although they did not think it affected their approach:

Extract from nurse follow-up interview

From a brief discussion with this lady I gained a lot of information which would help manage her care in the future. She tolerated her treatment without problems, her venous access was not as difficult as she had claimed, I personally find it difficult when patients tell me which veins I can or cannot use as quite often they are incorrect, this lady was quite assertive and made me feel that the task of successful cannulation was made into more of a challenge than it actually was. I felt rather self conscious at being recorded however I don't think that I would have changed my approach in any way

Judy re Janet

Seven of the eight patients who had a follow-up interview said they were satisfied with the nurses' assessments. This feeling of satisfaction, however, was related to two issues: successful administration of the chemotherapy and the friendliness of the nurse:

Extract from patient follow-up interviews

I do feel that you can mention any concerns. I wouldn't think "Oh no, I daren't ask them that today because they might be a little bit cross with me because they haven't got time". Sometimes [in hospital] you do feel that, you think "Oh no, I won't mention that today because of" I don't feel that at all. I don't feel as though I could ask them.

Hazel

The patient who was dissatisfied was Clive, who had left the chemotherapy unit after his Pamidronate treatment without any analgesia or any appointment to see the Oncologist. He had expected to have been given information about new pain medication following an allergic reaction to his analgesia six days earlier, but the nurse had not known of his problems, and therefore these were not addressed. He had assumed the information would have reached her, and did not ask her about this. Thus, in Clive's case, satisfaction was not dependent on the issue of time, but on the nurse having relevant information (communication from colleagues), and upon communication from the patient.

4.4 Summary of findings from The Northern

The findings from Phase 1 reveal that patients were actively involved in informing the nurses about their side effects and symptoms. Nurses sought a limited amount and type of information from patients; mostly their focus was on safety and administrative issues, reflecting the technical focus and

responsibilities of their role. Nurses' assessment practice was complex and influenced by more contextual influences and mechanisms than predicted in the original CMOs. Interestingly, the same contexts and mechanisms influenced the patients' contribution to assessment. The findings led to revised CMOs. These are presented in Table 4-15 (nurses) and Table 4-16 (patients) below:

Context	Mechanisms	Outcome
<p>Outpatient Treatment Setting: Patients visiting unit; working in isolation from medical staff Nurse role; safety issues and responsibility of decision making Relaxed and friendly unit</p>	<p>Communication: dependent on patients volunteering problems Rapport: patients regular visitors, familiar faces</p>	<p>Decision: fit for chemotherapy Safety Information exchange Satisfaction</p>
<p>Chemotherapy: treatment-related anxiety Nurse working in extended role: legal and professional boundaries and priorities</p>	<p>Knowledge: drug regime; expected side effects Know-how; technical skill Experience of: Assessment; practice wisdom and beliefs Advice given to previous patients which 'worked' Experience of other patients having same treatment: side effects to expect Confidence in knowledge and skill and assessment</p>	<p>Information exchange: Treatment-related issues identified and clarified Safety Confidence: able to give explanation and education to patients re treatment effects Decision re. fit for chemo Lower anxiety: patients' treatment given safely Satisfaction: enjoy technical skill</p>
<p>Relaxed, friendly atmosphere</p>	<p>Emotional control (?-) Rapport (mutual)</p>	<p>Suppression of anxiety to ensure patient's confidence (?-ve or +ve) Satisfaction</p>
<p>Illness: anxiety Patient's prognosis</p>	<p>Communication Knowledge (of cancer and spread) Emotional control</p>	<p>Information from patient and MDT Reduction of anxiety: avoidance of difficult issues</p>
<p>Role: perception requirements</p>	<p>Communication Trust Experience of MDT involvement</p>	<p>Information: narrow focus of issues raised and/or acknowledged</p>
<p>Orientation to treatment; role</p>	<p>Communication (?limited) Experience of: assessment; of support available : assumed Macmillan nurse involvement</p>	<p>Information Safety Reduced anxiety: keep assessment focused on treatment issues. Avoid 'difficult' topics</p>

Table 4-15 Revised Phase 1 CMOs for nurses at The Northern

Context	Mechanisms	Outcome
<p>Outpatient Treatment Setting: Patients visit unit regularly Nurse role: perception of nurse's role in care Relaxed and friendly unit</p>	<p>Communication: dependent on patients volunteering problems Experience of nurse's role and previous advice Emotional control: hide fear of cannulation Rapport: enjoy banter, chat with nurses 'family' atmosphere</p>	<p>Decision: fit for chemotherapy Safety Information exchange Confidence in nurse Satisfaction with care Lower anxiety: treatment given safely</p>
<p>Chemotherapy: Treatment anxiety</p>	<p>Knowledge: how much has been explained and understood re. chemotherapy drug regime; side effects Experience of: assessment; treatment/side effects (will they be bad?). Expectations of assessment, and distinguishing 'abnormal' to guide what info to volunteer Trust: nurses' technical skill; know how</p>	<p>Information exchange Safety Decision: treatment given Lower anxiety: treatment given safely; increased understanding of experiences, side effects, how to manage problems</p>
<p>Relaxed, friendly atmosphere</p>	<p>Emotional control (?-): hide fears and worries Rapport (mutual)</p>	<p>Suppression of distress (?-ve or +ve) Satisfaction</p>
<p>Illness: anxiety; prognosis Are symptoms sign of worsening illness or effect of treatment; is treatment working; aware of reason for treatment; coping with symptoms</p>	<p>Communication (mutual) Information from patient and MDT Emotional control</p>	<p>Satisfaction: Patient feels nurse listened</p>
<p>Role perception of nurses, what they should know, what they need to know</p>	<p>Communication Trust Experience of nurses' responses; MDT</p>	<p>Information: narrow focus of issues raised and/or acknowledged</p>
<p>Orientation: to oncologist; members of MDT for support</p>	<p>Communication (?limited) Experience of: assessment guides patients' contribution; support available and MDT</p>	<p>Information Safety Confidence ?Reduced anxiety: keep assessment focused on treatment issues.</p>

Table 4-16 Revised Phase 1 CMOs for Patients at The Northern

These revised CMOs were used to guide the analysis of the data from the second case study, the chemotherapy unit at The Southern. The findings from case study 2 are presented in the next part of the chapter.

4.5 Assessment at The Southern: A Comparison

This section of the chapter concerns assessment at The Southern, and is divided into two parts. Although there were many similarities in the findings between the two case study sites in terms of the mechanisms and outcomes, there were important differences in the way that assessments were conducted, and in the nurses' role. These differences will be described in the first section, before the findings to support or refute the CMOs are presented.

4.5.1 Context of Assessment at The Southern

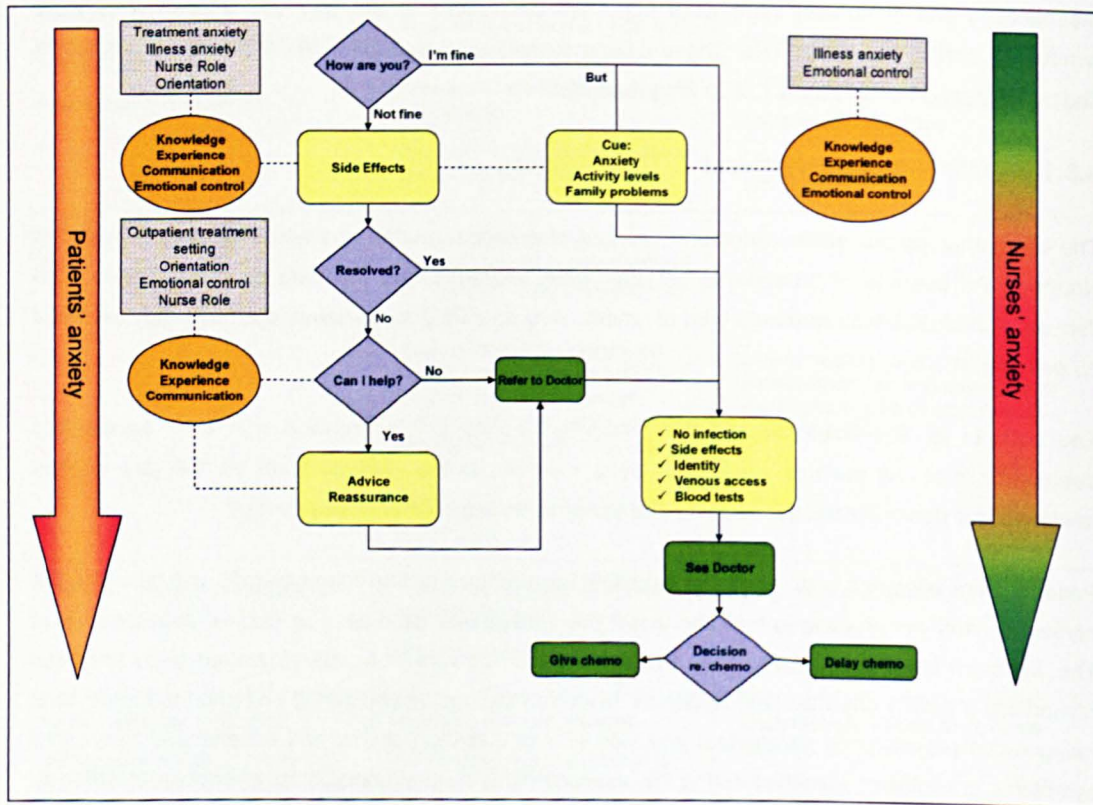
The chemotherapy unit at The Southern was part of a cancer centre, and was much larger than The Northern. An average of 38 patients per day were treated during the data collection period from January – June 2005, more than a third of whom were attending for palliative chemotherapy (average 15 per day).

The patients at The Southern had their treatment scheduled to coincide with their oncologist's treatment clinics. All patients were seen by a member of the medical team on the day of their treatment; the doctors made the decision that the patients were 'fit for chemotherapy'.

Patients were allocated a thirty minute morning appointment in the chemotherapy unit to allow the nurses to carry out an assessment and insert the intravenous cannula. The nurses' assessments at The Southern were a form of 'triage': the assessment conversation was structured by a proforma comprising a toxicity checklist (see Appendix 14) which the nurses completed on behalf of the doctors, rating within pre-assigned parameters any side effects that the patients had experienced. Any other symptoms or problems identified during the assessment were documented for the doctor to address. After the nurse had completed her assessment and the proforma, she inserted the cannula and took a sample of blood to test in the unit. Afterwards, the patients were directed to the doctor's clinic (in a different building), with their blood test results and the completed toxicity proforma, where the doctor confirmed the patient's suitability for treatment, and the chemotherapy was ordered from pharmacy. Whilst the treatment was being prepared, the patient returned to the chemotherapy unit waiting area until the treatment was delivered and a nurse was available to administer it. The average length of this wait for patients in the study was three and a half hours.

4.5.2 Conduct of assessment at The Southern

The flow chart below summarises the assessment conversation between the nurses and the patients at The Southern.



Key:

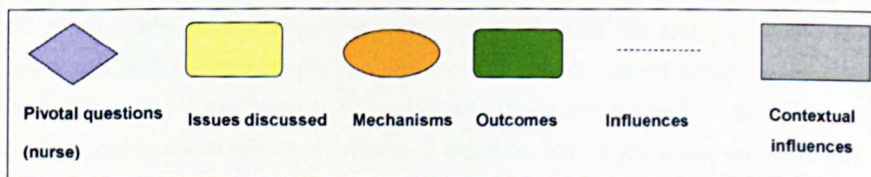


Figure 4-2 Conduct of the assessment conversation at The Southern (Phase 1)

As at The Northern, anxiety was noted to be a component of assessment. At The Southern, however, patients' anxiety did not necessarily lessen as the assessment progressed, because there remained the prospect of receiving 'bad news' from the imminent visit to the doctor's clinic (e.g. following a physical examination or scan results). The nurses' pattern of anxiety, however, was similar to that of The Northern; it rose if and when patients asked questions for which they did not have the knowledge or information to provide the answer.

Data analysis was guided by those CMOs confirmed and generated at The Northern, and by the search for any new ones arising from the different context of the service at The Southern. The findings are summarised in this section to prevent repetition.

4.6 Revised Context-Mechanism-Outcome1

Table 4-17 presents CMO1, revised with the addition of the mechanism of rapport. This revised mechanism guided the data analysis from The Southern.

No.	Context	Mechanism	Outcome
1	Relaxed, friendly atmosphere (+)	Rapport (+) Trust (+)	Patient raises issues of importance and concern (+) Nurse documents concerns and advises/refers patient as required (+)

Table 4-17 CMO 1

4.6.1 Context: Relaxed and friendly atmosphere

There was limited evidence that patients found the chemotherapy unit relaxed and friendly. Seven of the nine patients who had a follow-up interview talked about the unit in negative terms, because of its association with long waiting times; difficulties parking, and other negative connotations with the cancer centre. These comments, however, were dissociated from perceptions of the chemotherapy nurses' approach, which was as 'kind' and 'friendly'.

The nurses stated that they tried to put patients at ease, aware that they were anxious, and that organisational issues (such as waiting times) could cause angst.

The contextual influence was revised to 'relaxed and friendly approach', as summarised in Table 4-18:

Context	Evidence for?	Comments	Revisions
Relaxed and friendly atmosphere	Mixed: Nurses ✓ Patients x	1. Negative association of unit with administration problems in the cancer centre 2. Patients disliked waiting times and the chemotherapy itself, as likely to have unpleasant effects 3. Nurses felt it was important to relax the patients; acknowledged patients were anxious 4. Patients found the nurses friendly	Context revised: Relaxed and friendly approach
Example from patient interviews		[the nurses] are all nice and they have this very much wanting to relax you as much as they can. They're all like that there and they're very sympathetic (<i>Harriet</i>)	
Example from nurse interviews		Many patients are anxious, uptight, don't want to be here, so let's try and make it more enjoyable, relax them a bit (<i>Kim</i>)	
Unit Philosophy		The chemotherapy unit aims to provide an individualised service to patients in a friendly and relaxed environment.	

Table 4-18 Revised context: relaxed and friendly approach

4.6.2 Mechanism: Rapport

The CMO predicted that a relaxed and friendly context would fire the mechanism of rapport. This relationship had been identified at The Northern. There was limited evidence for this at The Southern: seven (of nine) patients said they had rapport with the doctors and the clinical trials nurses, not the chemotherapy nurses.

Rapport was important for the nurses, however, to facilitate assessment. Factors such as: patients' personality; 'chemistry' in the nurse-patient relationship; knowing the patient; and a relaxed patient were said to be important influences in establishing or developing rapport.

Table 4-19 summarises the mechanism of rapport:

Mechanism	Fired by Relaxed and Friendly approach?	Comments	Revisions
Rapport	Mixed response: Nurses: ✓ Patients: x	1. Nurses sought rapport; it facilitated assessment conversation 2. 7 Patients did not feel rapport with many of the nurses (2 did); instead, had rapport with oncologist and/or research nurse	No revisions, but: Rapport felt to have been achieved by the nurses in 8 of 10 assessments Patients said they did not need rapport to give information in the assessment; they knew what was required. They liked the nurses
Example from patients:	the research nurse is quite a key support for me and then there's Dr Y. [oncologist] I think he's very nice, he's very easy to talk to, I have a good rapport with him I think. [...]But the nurses are very nice here (<i>Joanna</i>)		
Example from nurses:	[Ian was] a nice gentleman, I felt like I had a rapport with him immediately (<i>Sue re Ian</i>) [...] your rapport with every patient isn't the same but I do think that plays a big part. Rapport makes assessment easier, definitely (<i>Tina</i>)		

Table 4-19 Mechanism of rapport

Thus, rapport was identified as one of the mechanisms fired by being relaxed and friendly, but it was more important for the nurses than for the patients:

Extracts from nurse follow-up interviews	
I feel that we click together. With some patients you have more of a rapport with than others <i>Penny re Desmond</i>	So quite a cold person I found, and it kind of threw me a bit to be honest with you. I immediately felt uncomfortable with her, whereas a lot of patients I meet for the first time and I naturally warm to them and they to me, hopefully. And they feel quite comfortable that they can, not necessarily open up, but I would like to think that they would be able to confide in me if there was anything that I needed to know. But yes, with her, no smiles, no nothing, there was no warmth from this person at all. It really did knock me off guard really, and I immediately felt very uncomfortable <i>Sue re Barbara</i>

The nurses approached patients in a relaxed (informal) and friendly way, acknowledging that chemotherapy was associated with anxiety and unpleasant effects. Rapport was identified as important

to the nurses; it made assessment more enjoyable and more satisfying. Patients had established rapport with other members of the cancer care team, but valued the chemotherapy nurses' kindness.

4.6.3 Mechanism: Trust

The mechanism of trust was identified to be similar to that at The Northern; trust was not fired by the relaxed and friendly approach, but was connected to technical competence and knowledge.

For instance, one patient (Barbara) said she trusted the nurses not to forget her in the waiting room; another (Ian), trusted that the nurses 'would know what to do that if there was an emergency during the treatment'. Patients also described their trust in the chemotherapy nurses in relation to: accurate and efficient communication with the oncologists; being knowledgeable about side effects; and skilled to ensure the safe administration of treatment.

All four nurses believed their relaxed and friendly approach engendered trust in the patients, and that this enabled patients to share information which would not otherwise be voiced (e.g. to the medical staff). The components and evidence of trust as a mechanism are summarised in Table 4-20:

Mechanism	Fired by Relaxed and Friendly approach?	Comments	Revisions
Trust	Mixed response: Nurses ✓ Patients ✓/x	1. Nurses related friendliness with instilling confidence within patients, to make assessment more effective 2. Patients acknowledged nurses tried to make the treatment as pleasant as possible; but trust more associated with technical competence and 'know-how'=nurses' role	Trust fired by several contexts: 1. Treatment anxiety 2. Nurse role 3. Relaxed and friendly approach
Example from patients:	How I see them is that they need to make sure that everything is done correctly and that the cannula's put in well and the treatment's delivered correctly and to the right person (<i>Rachel</i>)		
Example from nurses:	I find patients don't tell, won't sit down and talk to doctors as much as they will nurses. [...] I think the approach that you take can vary very much from patient to patient. [...] I think if they're comfortable and relaxed with you they are more likely to tell you things. (<i>Tina</i>)		

Table 4-20 Mechanism: Trust

4.6.4 Mechanism: emotional control

The mechanism of emotional control was confirmed by the data from The Southern. Patients worked to hide their anxiety and minimise their problems when they attended the hospital for treatment. Nurses acknowledged that patients were anxious prior to the insertion of the cannula, that chemotherapy was something that the majority of patients disliked and that patients hid symptoms in order to safeguard their treatment. The nurses believed one of their roles in assessment was the detection of hidden concerns during the assessment conversation to alert the oncologist.

Findings

One of the ways in which patients controlled their emotions was to use 'cues' as a means to raise their worries during the assessment conversation. This finding is summarised in the section on 'outcomes' (section 4.6.5), and discussed further in Chapter 5.

The findings from The Southern relating to the mechanism of emotional control are summarised Table 4-21 below:

Mechanism	Fired by relaxed and friendly approach?	Comments	Revised Mechanism?
Emotional control	No But fired by other contextual features: Outpatient setting; treatment anxiety; illness anxiety; nurse role; orientation	<ol style="list-style-type: none"> 1. All patients understood nurses' assessment to be concerned with treatment issues. Did not expect to address other things with the chemotherapy nurses 2. In follow-up interviews, patients spoke of feeling anxious prior to having cannula inserted; worried prior to seeing the Doctor in case given news that disease was progressing or treatment not working. 3. No emotion exhibited by patients during assessments. 4. No assessment of psychological or social issues identified 5. Nurses were anxious, embarrassed, puzzled at times during the assessment; hid these emotions 6. The content of assessment focused on treatment toxicity 	No revisions: but not fired by this context at The Southern
Example from patients:	..basically once you've been over there a couple of times it's just the same thing they ask you every time anyway, so if you haven't taken it in the first or the second time then you must be a bit dim anyway, you know what I mean? <i>(Dave)</i>		
Example from nurses:	<p>I think there's just something about that room [treatment room]. It doesn't lend itself to people opening up. <i>(Sue)</i></p> <p>I think they perhaps, in some cases, they put on their Sunday best and the big smile and actually things are really awful at home but in fact "We're here for today" and whatever and we're going to say "everything's wonderful and we don't need any help". <i>(Kim)</i></p>		

Table 4-21 Mechanism of emotional control

The data confirm that the mechanisms of rapport and trust were partially fired by the relaxed and friendly approach, but that other contextual influences (anxiety over the treatment; the treatment setting and the way it was organised) partially disabled these mechanisms and fired the mechanism of emotional control.

4.6.5 Outcomes

CMO1 (see Table 4-17 above) predicted that the outcomes would be: patients raise issues of importance and concern; nurse documents concerns and gives advice, or refers patients for support, as required. The findings relating to these outcomes will be presented in turn.

4.6.5.1 Patients' issues

Treatment-related issues were primarily those raised and discussed in the assessments at The Southern. This was not surprising, as the nurses' assessment proforma was focused on toxicities and side effects. Both patients and nurses considered this to be a positive finding, an indication of 'good practice': this outcome was considered most important, not a failing. Nurses at The Southern considered the absence of discussion of psychological concerns was because there were none to discuss on the day of the audio-recording.

Toxicity issues were addressed in all of the assessments. The assessment between Barbara and Sue (below) illustrates the way in which the proforma structured the conversation. Although this assessment was atypical because Barbara's answers were monosyllabic (the other patients added details and were more forthcoming with information in answer to the nurses' questions), this transcript is typical of the format and conduct of assessment at The Southern:

Extract from assessment	Analysis notes
N Hello I'm Y	Introduction
P Hello	Anchor question
N How are you	Treatment focus
P Fine	C=organisation of unit
N Good. Any problems since the last chemo	
P No I've been fine	List-like questions: toxicity
N Good. Any nausea or vomiting	
P No	
N Any soreness in the mouth, ulcers or anything	
P No	O=information: no problems
N How have the bowels been	
P Fine	
N Any constipation, diarrhoea	
P No	M=emotional control: nurse is anxious and uncomfortable
N Any hair loss	
P No	
N Any tingling in the hands and feet, numbness or anything	
P No	
N Any infections, coughs, colds, temperature	
P No	
N Any redness or soreness on your hands and feet	
P No	
N Anything else – have you any other problems or anything	
P No – I'm fine	
N OK then, that's OK [laughs]	
<i>Sue and Barbara</i>	

Findings

Patients influenced the assessments, and raised issues of concern. The majority of these concerns were treatment-related, as illustrated in Table 4-22:

Issues identified in response to nurses' questions:		Treatment-related issues raised by patients during the assessment:		Issues not directly related to chemotherapy raised by patients	
Sore mouth	1	Urinary problems	1	Urinary incontinence	1
Dry/cracked skin	3	Fatigue	2	Swallowing problems	1
Fatigue	3	Diarrhoea	1	Sweating	1
Diarrhoea	1	Skin rash	1	Weight loss/dry mouth	1
Constipation	2	Aching joints	2	Swollen leg *	1
Pins and needles	2			Tremor *	1
Vein problems	6	Tingling in ear	1	Improved appetite	1
Taste changes	1	Sores in nose	1	Friction at home	1
Appetite	1	Cough	1		
Nausea	1	Dry/sticky eyes	1	*same patient (Grace)	
Weight loss	1				
Infection/colds	1				
Total:	23		11		8

Table 4-22 Issues discussed during the assessments at The Southern

Some patients used the assessments to inform the nurses about new symptoms (see column 3 in Table 4-22). When asked about these issues in the follow-up interviews, they talked in terms of worries about the meaning and effect of the symptom or problem. Such worries had not been made explicit in the assessment, and were not explored. These issues were subsequently labelled 'cues'. An example is presented below; the use of the cues is explored further in Chapter 5.

Extract from assessment	Analysis notes & extracts from patient follow-up interview
<p>N: And any infections that you've been aware of</p> <p>P: No but I've been generally - my face is really spotty¹ and my skin feels really oily which isn't normal for me</p> <p>N: I think that's probably all to do with = inaudible [?chemotherapy] [...]</p> <p>P: [...] No um my eyes feel like sticky a bit, slightly sticky today</p> <p>N: Are you drinking plenty</p> <p>P: Yeah. I'm going to the toilet all the time - like to urinate and er last night I mean. [small laugh] this sounds daft - my muscles were so lax I had an accident in bed and it was like I've never had that I mean and you know and you know I've been practising my pelvic floor and all that and it is working but sometimes I just you know²</p> <p>N: Do you feel there's any burning or anything related?³</p> <p>P: No no burning or No no no</p>	<p>¹Cue: illness anxiety: new symptom; change in experience & effect on body image: "I have put on a lot of weight since starting the treatment, and so to get spotty like this, to have sort of acne again felt like another assault. It made me think "How much lower have I got to go down before I start coming up"? (Follow-up interview)</p> <p>²Cue: illness anxiety: "I was really scared by that [incontinence] - what caused it - are things getting really bad and I haven't realised it? It was so embarrassing. I was really upset and thought this is the beginning of the end, and if I'm going to lose all dignity I want it to be quick; I'll stop the treatment and</p>

<p>N: OK. [Brightly] Right OK .I think the best thing to do is to check your bloods.</p> <p>P: I hope you get the bungs off [the Hickman line] this week.</p> <p><i>Kim and Rachel</i></p>	<p>just ..[struggles for control]. But anyway, I don't know. Maybe not" (original emphasis)</p> <p>³Context: treatment orientation of nurse; M=knowledge of chemo; DM=knowledge – not aware may indicate spinal cord compression. O=safety (checking to make sure not haemorrhagic cystitis from Cyclophosphamide)</p>
--	---

In summary, one of the outcomes of CMO1 was found to have been triggered: patients did raise concerns during the assessment, although the CMO configuration required revision:

Outcome	Identified	Comments	Revisions
Patient raises issues of importance and concern	Yes	<p>Patients responded to nurses' questions and offered information about side effects or unusual symptoms</p> <p>Patients perceived what was important in terms of how worried they were and in terms of what they thought the nurses 'needed to know'</p> <p>Patients hinted at anxiety through use of cues</p>	Context: patients' perceptions of nurse role; organisation of outpatient treatment setting; orientation of nurses to treatment, and patients to oncologist
Chemotherapy issues identified from nurses' questions:		<p>N: And fatigue. Have you been tired at all?</p> <p>P: I haven't got a lot of energy <i>(Tina and Patrick)</i></p> <p>N: Any nausea or vomiting</p> <p>P: Um yeah a bit. Slight nausea. I get it a lot. It goes off. It just comes and goes. <i>(Penny and Desmond)</i></p>	
Symptom/new experiences not directly related to toxicity identified to nurses:		<p>P: The only thing I do get is I seem to do a lot of sweating in bed</p> <p>N: Is that new</p> <p>P: See tonight, tonight and the next 3 nights it will be like a flood and I won't sleep. I've had that all the time <i>(Dave)</i></p>	

Table 4-23 Revised outcome for CMO1

4.6.5.2 Nurses' responses

The second outcome predicted in CMO1 was that nurses would document patients' concerns and give advice to patients or refer them for support if necessary.

Findings reveal that the nurses responded to patients' concerns in three ways. Firstly, they checked to see how long the patient had been experiencing the problem, (e.g. whether it was 'new', it had resolved, or it 'came and went'). Secondly, and most frequently, they asked if the patient had already informed the doctor (if not, they advised them to do so). Thirdly, they asked a follow up question in terms of treatment toxicity. Little nursing advice was given to patients in the study regarding their concerns:

Findings

Extracts from recorded assessments	
N:	And any problems with the bowels?
P:	Yes [groans]
N:	Yes [laughs]
P:	The other way this time – last time I got constipated and by the time I came back I almost got piles and I did get piles and this time it was the other way. Not not -
N:	You weren't dashing to the toilet or
P:	Not dashing to the toilet but I've had a few explosions [sounds a bit embarrassed] – Saturday but Sunday night -nothing - I had not an accident but
N:	A near accident
P:	Yeah
N:	OK. Any numbness in the fingers?
<i>Kim and Rachel</i>	

There were two exceptions involving Penny and Tina; both nurses found that giving advice left them uncomfortable and embarrassed, for different reasons. Penny, because she was unsure as to her role advising on medication issues; Tina, because the advice she gave proved to be inappropriate when the patient subsequently revealed to her that he was diabetic.

Nurses documented the majority (31/42) of the patients' concerns on the proforma. Of the 31 concerns documented, the medical staff wrote a response in six instances.

The findings in relation to these outcomes for CMO1 are summarised in the Table 4-24:

Outcome	Identified	Comments	Revisions
Nurse documents concerns and advises/refers patient as required (+)	Yes: documentation	Nurses documented patients' concerns; this document was sent to the oncologist.	Contextual influences of nurse role affecting nurses' confidence in giving advice.
	Yes/No: advice	Few examples of advice identified: 3 in total in relation to concerns raised (diarrhoea; weight loss – eat high calorie diet; skincare in the sun)	Also depended on mechanisms of communication (nurses misunderstood the patients' cues), experience; knowledge
	No referrals	No referrals made: at follow-up interviews, 1 patient asked CW for Macmillan Nurse referral; 2 asked CW for dietetic advice	
Example of nurse's documentation: (Also see Appendix 14)	'Feeling asleep until about 5pm. Pain in hands/swollen over weekend. Generally aches. Loose bowels over weekend. Eyes sticky'. (<i>Kim's record of Rachel's assessment</i>)		

Table 4-24 CMO1: Revised outcome of assessment

4.6.6 CMO2: Context: Workload and staffing levels

The second CMO generated at the beginning of the study concerned the impact of workload on the mechanism of communication.

Context	Mechanism	Outcome
Unit not too busy; adequate staffing (+); Busy nurse; heavy workload; short of staff (-)	Communication: Patient reluctant to 'bother' nurse (-)	Satisfaction with assessment (pt and nurse) (+) Shorter assessments when busy, focused on chemotherapy issues only (-) Patient does not raise concerns (-)

It was predicted that when the unit was busy and short-staffed, assessments would become more focused, and patients would raise fewer concerns, reluctant to 'bother' a busy nurse. There was no evidence to support this prediction during the periods of data collection.

Staffing levels and work load at The Southern remained stable during the study. The nurses perceived the unit to be always busy. Time was not a contextual influence on assessment practice during the period of data collection, as Table 4-25 illustrates:

Context	Evidence For?	Comments	Revisions
Having sufficient time to carry out assessments (+) Busy nurse; heavy workload; short of staff (-)	Yes No	30 minutes appointment time was allocated to each patient for assessment and cannulation None of the data collection days (observation or pt recruitment) was classified by the nurses as 'short staffed' or 'abnormally busy'	Alternative Context identified: Outpatient Treatment Setting (the way in which the unit was organised)
Example from patient follow-up interviews:	CW: Did you feel that your main issues were covered? P: Yes, they also, everyone brings up the same things as well. I expect them to ask me that every week. It seems to me, well, as far as I'm concerned they're pretty good. OK? (<i>Desmond</i>)		
Example from nurse follow-up interviews	[...] Mrs. Y didn't want to open up and tell me anything at all. I still felt that I needed to do the assessment, albeit very quick. [...]But I felt it was an OK assessment in that I felt that I had done my part effectively and I had given her the opportunity to say anything she wished (<i>Sue re Barbara</i>)		

Table 4-25 CMO2: Contextual influences on assessment

4.6.7 Mechanism: communication

There was limited evidence to support the prediction that patients would be reluctant to tell the nurse their concerns if she was perceived as 'busy'. Three patients said the nurses were 'always busy' (Barbara, Ian and Dave), so they kept their answers to the assessment questions brief and 'to the point so the nurses can get on with their work' (Dave).

Four other patients perceived the doctors as 'more busy' than the nurses, but said they would tell the doctor their concerns rather than the chemotherapy nurses. Patients' perceptions of the nurses' role, and their orientation to the doctor for support and information rather than busy-ness in the chemotherapy unit, were contextual influences firing the mechanism of communication, Table 4-26 summarises the findings in relation to CMO2:

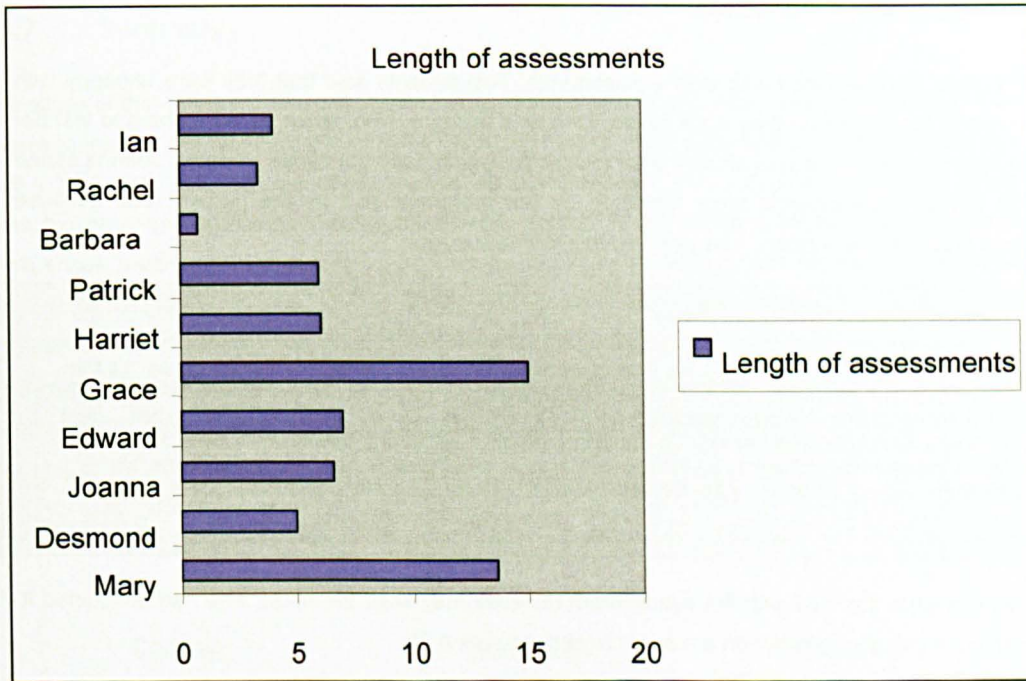
Findings

Mechanism	Fired by busy context; short staff	Comments	Revisions
Communication: Patient reluctant to 'bother' nurse (-)	No	<p>Nurses were perceived as 'busy' by 3 patients. Four others perceived the nurses as 'less busy' than the doctors.</p> <p>All patients said they would tell the nurses whatever they needed to know or would answer any questions they were asked.</p> <p>Seven patients commented that telling the nurses their concerns was 'not worth it' as they only told them to tell the doctor</p> <p>5 patients hinted at worrying issues through the use of cues</p>	<p>Communication was a mechanism involved in assessment, but not related to time issues.</p> <p>The mechanism of communication was fired by:</p> <p>Treatment anxiety; perceptions of the nurses' role; orientation (to treatment issues and the oncologist);</p> <p>Illness anxiety (use of cues)</p>
Example from patient follow-up interview:		<p>CW: What do you expect to talk about?</p> <p>P: Well, just to find out how you've been over that three weeks, yes. Which they do. And they say "Have you got any diarrhoea or sickness" and all that sort of thing. They do that, that's what you'd expect. They're very pleasant there, they really are.</p> <p>CW: And what about any other sort of issues or worries about anything?</p> <p>P: I would probably leave it for the doctor, actually. (<i>Harriet</i>)</p>	
Example from nurse follow-up interview:		<p>But it is important to get the small talk, if you like, to get the whole picture because quite often someone will tell you "No", they haven't had any problems with nausea but actually you discover that in fact they don't eat anyway or they've lost a huge amount of weight, they perhaps haven't associated things that seem obvious to yourself. (<i>Kim</i>)</p>	

Table 4-26 CMO2 Influence of workload and busy-ness on communication in assessment

Kim's comments, in Table 4-24 above, indicate that 'small talk' with patients (to give them more time) was a strategy to allow concerns to be raised and questions asked. Thus, as at The Northern, lack of time did not disable the mechanism of communication in assessment.

The average length of the assessments at the Southern was 12 minutes, 17 seconds, (range 48 seconds – 15minutes 16 seconds). Graph 4-3 illustrates the individual timings for each patient:



Graph 4-3 Length of assessments Phase 1, The Southern

Table 4-27 summarises the findings in relation to the influence of time on assessments at The Southern:

Predicted Outcome	Identified?	Comments	Revisions
Shorter assessments when busy, focused on chemotherapy issues only (-)	No	All assessments were focused primarily on chemotherapy issues: considered good practice Patients' assessments all followed a unit format, and concluded when all questions on the proforma had been asked and answered. The length of time this took varied according to how much patients shared. Nurses felt they gave patients sufficient time to say all they wanted to	Treatment-focused issues were seen as a positive one because this focus ensured safe administration of treatment
Example from patient follow-up interviews		If she had asked the questions I would respond. But I probably wouldn't forfeit that information without being asked for it, probably. It's like "she's asked me what she needs to know and I'll tell her so that I'm not holding her up". I'm very conscious of the appointment time and the others waiting outside (<i>Ian</i>)	
Example from nurse follow-up interviews		I think perhaps he was really came in with "There aren't any problems, I'm absolutely fine" because he started off with very short answers to everything. But, as we got talking, he perhaps relaxed more and actually did a lot more talking and told me a lot more about the fact that he was running out of tablets and the side effects that he was having. (<i>Kim re Edward</i>)	

Table 4-27 Mechanism of Time on assessment

4.6.8 Outcome: Satisfaction

All the nurses were satisfied with their assessments. Two patients said that they were unhappy with one or two of the questions they were asked. One was Barbara, who, when asked if she had lost her hair, looked surprised; she was attending for Herceptin, which does not cause alopecia. Joanna stated that the nurses' assessments were restricted by the proforma, and by the nurses' role, because whenever she raised a concern, she was told to inform the doctor:

Extracts from patient follow-up interviews

I think that perhaps because they have a list of set questions I think, sometimes, if you might have a little problem [...] and you think "Well, is this related to my chemo or not?" and perhaps if you're not asked about it you're not necessarily going to be forthcoming if it's not worrying you, but it actually might be quite critical [gives example of her nose bleeds]. So sometimes having a set list of questions means you don't always offer all the information that may be there. [...] I think maybe it's the style of the questions means that by definition if you ask 20 people a day the same questions you're not going to perhaps probe and push

Joanna

Five patients were satisfied with the assessment because they liked the nurse who had conducted it. The findings relating to satisfaction are summarised in Table 4-28:

Predicted Outcomes	Identified	Comments	Revisions
Satisfaction with assessment (pt and nurse) (+)	Yes	Five of the nine patients interviewed specified they were satisfied with the assessment. Two patients were not. Two did not comment All the nurses were satisfied with their assessments	
Example from patient-follow-up interviews:		I was suppose it was wrong [to ask me about hair loss] really because I was told at the start of the treatment I wouldn't [lose it] so I was surprised when she asked me but then she doesn't know what's going on with individuals, does she? (<i>Barbara</i>) I find most of the nurses are very good. [...] I really do, [...] I've never found anything but helpfulness and people have been good to me, you know what I mean (<i>Dave</i>)	
Example from nurse follow-up interviews		So, I suppose, I think, I started off by saying to [him] "How are you?" because it's quite an open question and then, usually, if there's something that's burning they'll start off by saying, talking about it, and I think then once you've got that major issue out the way you can then just check really, recap that there's nothing else that you might miss. I think it worked, and I think [he] told me everything he wanted to. Yeah, it was OK [laughs]. (<i>Tina re Patrick</i>)	

Table 4-28 Outcome: satisfaction

4.7 Summary

Analysis of the data from The Southern confirms the context, mechanism, outcome configurations that were refined at The Northern. Despite the local differences in the organisation of the patients' day, use of a proforma, and the role of the nurses at The Southern, the underlying contextual influences, mechanisms, and outcomes in assessment were shared. It was not possible to isolate the contextual influences, mechanisms or outcomes, as Pawson and Tilley's (1997) model had been interpreted at the outset of the study. Therefore, the CMO configurations have been revised to reflect the multiple influences and mechanisms and outcomes involved in creating the assessment practice observed and recorded. Interestingly, the findings suggest that the CMO configurations are similar for both patients and nurses. These revised CMO configurations are presented in Figure 4-3:

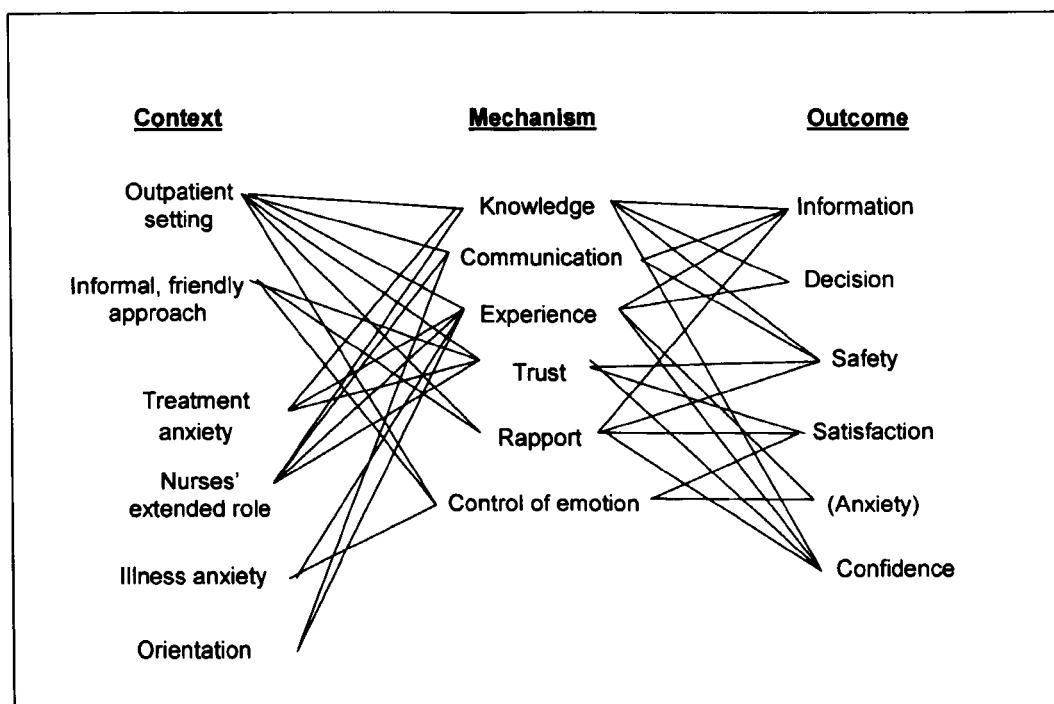


Figure 4-3 Revised CMOs from Phase 1

These will be explained and further explored in the following chapter, where they form the basis of a conceptual model of assessment practice.



IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

Chapter 5 Explaining nurses' assessment practice

I know that you believe you understand what you think I said, but I'm not sure you realise that what you heard is not what I meant.

(Robert McCloskey)

There now follows an explanation of cancer nurses' assessment practice in the outpatient chemotherapy unit. In this chapter, the findings presented in Chapter 4 are brought together into a conceptual framework, or model, to depict the relationships between the contexts, mechanisms, and outcomes of assessment practice. This model allows a more detailed explication of those contexts and mechanisms that were identified from the data (which were additional to the ones tested) as being responsible for nurses' assessment practice.

The aim of this level of theoretical explanation is to increase understanding of assessment talk in the outpatient chemotherapy unit.

5.1 Understanding assessment talk

The model illustrated overleaf is a representation of the relationships between the contexts, mechanisms and outcomes identified and described in Chapter 4. It takes the form of a circle or wheel, bounded by a rim which represents the two attributes of the assessments which influenced, and were influenced by the contexts, mechanisms and outcomes within. These attributes were 'working in the dark' and 'control of the interaction'. They were shaped by, and linked to each other, represented by the shading in the model: a consequence of 'working in the dark' was the control of assessment, and because the assessments were controlled, nurses were observed to be 'working in the dark'.

The spokes of the wheel are the mechanisms, situated within the context. The context encompasses the way in which the chemotherapy units were organised as well as the norms, values and relations between the nurses and patients who were involved in the assessment talk. Contextual influences were responsible for firing the mechanisms (knowledge, experience, communication, trust, rapport and emotional control), which in turn triggered the outcomes of assessment, depicted in the hub of the wheel, the centre of the model.

The circle shape enables multiple contexts to fire (Pawson and Tilley 1997) multiple mechanisms and trigger (Pawson and Tilley 1997) multiple outcomes, reflecting the reality of practice, and moves away from the suggestion of the linear cause-and-effect model in the initial CMO propositions.

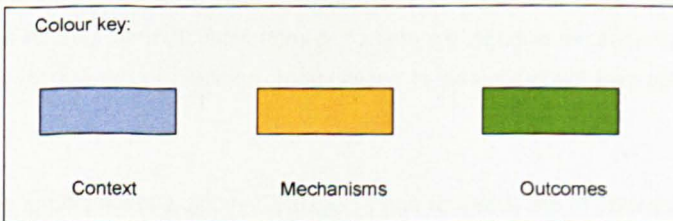
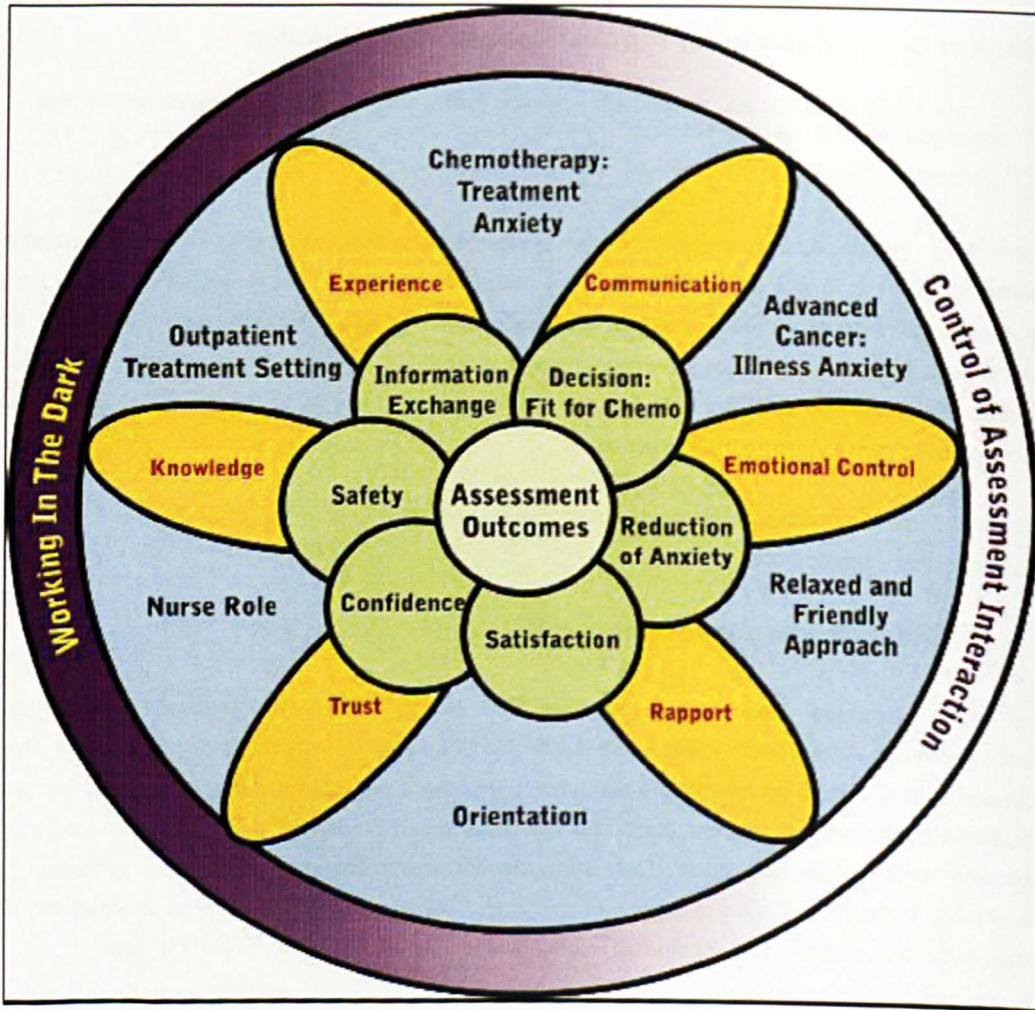


Figure 5-1 Model of assessment talk in the outpatient chemotherapy unit

An explication of the model of assessment now follows, structured by the two attributes contained within the rim: 'working in the dark' and 'control of the interaction' which circumscribed the assessments.

5.2 Working in the Dark: overview

I wrote the phrase 'working in the dark' in my field notes in May 2004, following a period of reflection during the interim phase at The Northern. My impression was that the nurses were 'in the dark': at an individual level (knowledge, experience, patient-nurse communication), at a unit level (resulting from the division of labour, and the way in which it was organised), and in terms of the place of the

chemotherapy unit within the system of cancer care (managerial support and flow of information to the nurses). Ten months later, whilst collecting data at The Southern, an incident occurred which suggested that the nurses there too, were 'working in the dark' - as one of the team put it at the time: 'We're out of the loop here, hidden away' (field notes, March 15th 2005) - fulfilling an important, but narrowly focused role within cancer care. The following discussion uses a more detailed exploration of the contexts and mechanisms outlined in the model (Figure 5-1) to explain how working in the dark affected the nurses' assessments.

For the purpose of illustration, the discussion is structured around one of the assessments from The Southern involving Penny and Grace. I have included some of my reflective field notes to describe the background to the assessment conversation:

<p>Field notes:</p> <p>An assessment between [Penny] and Mrs. P [Grace], a lady with malignant melanoma attending for her second chemo, whom Penny asked me to call into the unit. She came in rather tentatively, followed by her friend. Mrs. P chose to sit in the chair nearest the door, because she said she might need to dash to the loo. I got her a drink of water and explained about the microphone and settled her in whilst Penny collected the treatment trolley and the notes. Mrs. P's friend accompanied her, so I drew up a stool for her to sit on next to Grace and went off to buy a drink for her from the waiting room (Klix machine). As I was bringing it back in, Penny arrived with the trolley, and looked around for something to sit on – and just as I was dragging over a little coffee table to put the coffee and Grace's cup of water on, Penny asked for the stool so she could sit down, leaving Grace's friend with nothing to sit on, standing up and looking very uncomfortable. Penny began to look at the veins on Grace's arms, unaware of the friend's discomfort. I did a quick scan of the unit but couldn't see a vacant chair either - I would have had to go to the nurses' office to borrow one from there, and then struggle with it through the narrow doorway - but Penny had already begun the assessment, leaving me in a dilemma. What was my role here? In the end, I signaled to the friend to perch on the coffee table and she and Grace held their cups of drink. Now I was left standing like a lighthouse, uncomfortable and embarrassed, and with the assessment well in progress, I crouched down to the side of Penny, eventually having to kneel on the floor when my quads gave way. It struck me how invisible the friend was to Penny. I felt quite uncomfortable with this whole scenario (and my decision re the coffee table), but it was good for me to understand how the friend must have been made to feel too.</p>	
<p>Extended extracts from assessment</p>	<p>Field notes; analysis notes and comments</p>
<p>N: Hello I don't think we've met. I'm [Penny].</p> <p>P: Hello. No, we haven't</p> <p>N: [to friend] Are you?</p> <p>F: A friend.</p> <p>N: Right. Did we do you on the right side last time¹</p> <p>P: Yes</p> <p>N: Because you've got a little bruise there. You haven't had any sort of pain or any problems where that was</p> <p>P: No, not where that is² - No</p> <p>N: OK. So how've you been?³</p> <p>P: Awful</p> <p>N: Oh no.</p> <p>P: Um the first week wasn't too bad</p> <p>N: Right</p> <p>P: Um and then I got diarrhoea⁴</p> <p>N: And how long did that last for⁵</p> <p>P: Nearly all the time.</p> <p>N: Right up until today or –</p> <p>P: I ..I hardly ever made it to the loo⁶</p>	<p>Working in the dark: unfamiliar nurse-patient</p> <p>¹Focus on vein</p> <p>Observation</p> <p>²Cue: has had pain elsewhere?</p> <p>³Anchor question</p> <p>⁴Diarrhoea: side effect</p> <p>⁵Temporal assessment of problem</p> <p>⁶Severity of side effect</p>

<p>N: You've still got?</p> <p>P: I've been again this morning. [...] haven't eaten much anyway and um it seems everything I eat goes straight through me [pause] and also my leg's swollen⁷</p> <p>N: OK. I'll have a look at that in a second. I just want to um. ⁸So you took some Imodium [..]</p> <p>N: What I recommended for people who get the diarrhoea really bad is that you take the Imodium on the first bout [...] I'll put it on your sheet to discuss it with your doctor [...] <i>[Discussion as to whether has taken Imodium this morning]</i></p> <p>N: The doctor will probably prescribe you some today</p> <p>P: It's different today because last time I came I picked my notes up and saw the doctor first</p> <p>N: Yes that was your first time [...] ⁹Today we'll put the needle in now - well once I've finished assessing you - and take the bloods and leave the needle in so we don't haven't got to stab you again and put some gauze around it and you go and see the doctor in clinic and he takes your chemotherapy off hold with pharmacy and it takes an hour or two to get here</p> <p>P: Yes</p> <p>N: and then we call you in and start your chemotherapy <i>[Discussion about INR levels; nurse documenting this on the proforma]</i></p> <p>P: Everything's paperwork isn't it¹⁰</p> <p>N: I just want to get the facts straight [little laugh]. OK. So the doctor will discuss the diarrhoea with you¹¹ and he'll clarify with you how you should take the tablets to put a stop to it - so you don't get really bad with it again. So have you had any sort of nausea or vomiting with that¹²</p> <p>P: No</p> <p>N: OK but you've not been eating very much</p> <p>P: Not for the past 2 weeks really</p> <p>N: OK. [...] Any – have you noticed any hair thinning or hair loss at all</p> <p>P: No</p> <p>N: Any tingling or pins and needles in your fingers and toes</p> <p>P: This hand [left] when I get up in the morning shakes¹³. That's why I can't put my make-up on and the mascara's [demonstrates unsteady hand]</p> <p>N: And that's a new thing since starting your chemotherapy</p> <p>P: Yes.</p> <p>N: You've got no numbness or weakness in your fingers¹⁴ – you can still do buttons up on your blouse and things</p> <p>P: Oh yes</p> <p>N: OK. No sort of - did you feel like you had a temperature at all while you had the diarrhoea or</p> <p>P: No</p> <p>N: OK. No flu-y symptoms - coughs colds dizziness or anything</p> <p>P: No no. Just this leg¹⁵ where I've had that op it just feels tight as a drum and then since I've had the chemo that ankle's right up</p> <p>F: You've had quite a lot of pain as well haven't you¹⁶</p> <p>P: Yeah [...] <i>[Discussion about constipation and usefulness of Movicol]</i></p> <p>N: OK. Any soreness of your hands or the bottoms of your feet¹⁷</p> <p>P: No [...]</p>	<p>M=Experience; this was not 'normal'</p> <p>⁷New experience: symptom</p> <p>⁸Nurse keeps focus on diarrhoea</p> <p>Field note: Nurse is uncomfortable here: ?getting unsure, and nervous rash creeping up her neck; begins to sound less sure of herself – why?</p> <p>⁹Nurse role: as navigator</p> <p>¹⁰Nurse a bit put off by this comment</p> <p>¹¹Refers to doctor</p> <p>¹²Nurse brings assessment 'on track' to cover proforma questions</p> <p>¹³New symptom</p> <p>¹⁴Treatment focus of symptom interpretation; safety check for chemo prescription</p> <p>¹⁵Patient returns to concerns over swollen leg</p> <p>¹⁶Friend mentions pain: advocacy</p> <p>¹⁷Nurse returns to treatment agenda</p>
--	--

<p>N: Have you been very tired for a couple of weeks or not too bad</p> <p>P: Not too bad really um I've been tireder! [little laugh]</p> <p>N: Anything else to mention, or any questions for me*</p> <p>P: Um Can't think of anything else. I think I've covered most things</p> <p>N: OK then what I'm going to do then I'm now going to put the cannula in. I might try and have a look a this side if that's OK with you and try and give that side a break</p> <p>[cannulation commences]</p>	<p>Field notes:</p> <p>*Nurse takes patient's arm and is stroking the veins as Grace answers this question</p>
<p>Extract from follow-up interview with Grace:</p> <p>CW: You mentioned your swollen leg to the nurse at the beginning of the assessment; do you want to say a bit more about that?</p> <p>P: Well I was worried about it really, and I'd had a lot of pain from it. And still I am. Part of me wondered whether it was - because I'd only had the one lot of treatment and.. I know what they say about melanoma, and part of me was worried it was to do with the operation where they took the lymph glands out [two months ago] and whether that had gone wrong. And it came up so quickly not long after the chemo last time, so as well, I thought it might have been another clot or something. I thought she might need to know - I mean it - in case it affected the chemo, and whether she could think what else it could be, but she didn't say anything and nor did Dr T, so I'm none the wiser. I am a bit worried though ... [struggles for control], a bit you know -and it's just getting worse but we'll have to wait and see.</p>	

This assessment conversation between Penny and Grace illustrates three aspects of working in the dark which were identified in many of the other assessments. These were firstly, that patients' physical symptoms remained hidden: Grace's swollen leg was physically concealed by the trousers she was wearing, and metaphorically by the focus of the assessment conversation, leaving Penny in the dark about the extent of the swelling and its implications, and Grace in the dark about the possible explanations for her symptom and how to cope with it.

Secondly, patients' social selves and personhood (Corner 2001) were detached from the assessment conversation, as signified by the marginalisation of Grace's friend, leaving the nurses in the dark about patients' lives away from the chemotherapy unit.

Thirdly, patients' underlying anxiety about their illness and prognosis remained hidden from the nurses, because of the ways in which such information was communicated: Grace used her swollen leg as a cue to her real concern, but this was not recognised by Penny, and so it was ignored. Thus, Penny was in the dark about Grace's underlying anxiety and the meanings that she was attaching to the symptom.

In order to explain why these aspects of working in the dark arose from, and resulted in, the nurses' assessments, a more detailed exploration of the contexts and mechanisms depicted in the model (Figure 5-1) now follows.

5.2.1 Working in the dark: symptom assessment

Working in the dark with regard to patients' physical symptoms was a key finding in both case study sites. The practice of 'not looking' at physical symptoms was a feature of the assessments observed in the chemotherapy units; in all, there were eighteen instances (including those recorded in my field notes) when patients asked nurses about physical problems, which were not visually 'inspected' or explored first hand. These included: patients' reports of sore or infected mouths (n=6); infected leg ulcer (n=1); sore toe (n=2); fungating breast/mastectomy scar tumours (n=2); a possible boil (skin infection) (n=1); swollen legs (n=3); split or sore skin on feet (n=3). Ten of these instances were

observed at The Northern, and eight at The Southern. There was only one occasion when a patient's question about a new physical symptom was looked at by the nurse, and this was when Kate looked at a rash across Frances' chest. Thus, nurses were working in the dark with regard to understanding the severity of the symptom, how much discomfort it was causing the patient, and the implications for their practice (e.g. whether infection was present).

However, symptoms were also kept 'in the dark' in a metaphorical sense. The findings in Chapter 4 describe how, although patients mentioned their symptoms to the nurses during the assessments, only those which were primarily or potentially treatment-related were brought out into the open and explored, leaving both nurses and patients in the dark about non-treatment-related symptoms: the nurses, because they did not look into these in detail, and the patients, because they did not receive advice or support. Using Penny's assessment of Grace as an illustration, it is possible to identify some of the reasons to explain why this was the case, commencing with a more detailed description of the contextual influences on assessment practice.

5.2.2 Working in the dark: Context of assessments

5.2.2.1 Treatment Anxiety

The transcript presented in section 5.2 shows how Grace paused briefly at the end of a list-like description of how the diarrhoea had affected her and then broached the subject of her swollen leg. In response, Penny concentrated on the problem of the diarrhoea as her first priority, and promised that she would 'look' at the problem of the swollen leg 'in a second', although she did not return to it. Later in the assessment, however, she did pursue another symptom mentioned by Grace - the unsteady hand - because that had potential implications for the planned chemotherapy treatment if it were to signal the development of peripheral neuropathy. Penny's decisions reflected her role, which was to give chemotherapy; her priority for assessment was to address issues which were affected by the treatment (treatment anxiety):

Extract from Penny's follow-up interview

Primarily [assessment is] to assess the side effects that the patients are having and any problems they've been having with their chemotherapy. And, in that sense, I feel like it's quite a narrow expectation of assessing patients. And, but then also if another problem does arrive in a different area, unrelated to their chemotherapy, then of course I would think it's expected of me to address that too.

This view of assessment was shared by the other nurses who took part in the study, all of whom saw the aim of their assessments primarily in terms of identifying how well (or otherwise) patients were coping with the chemotherapy. For example:

Extracts from nurse follow-up interviews: The Northern	Extracts from nurse follow-up interviews: The Southern
<p>Obviously I need to find out any problems they've had because they may not think to tell me [...] So I need to try and get them to open up just to talk about any worries that they've got for the future of the treatment.</p> <p><i>Brenda</i></p>	<p>I think [assessment's about] probably seeing how they've coped with the chemotherapy, I think, in all ways [...] I think from a nurse we need to know generally that they're coping with the chemotherapy, that it's doing what it's meant to be doing.</p> <p><i>Tina</i></p>

<p>Does he feel OK – has he any cough, colds, sore mouth, diarrhoea. Is it OK to give the chemo.</p> <p><i>Myra</i></p> <p>I need to make a full assessment really of whether they are physically well enough to have chemo.</p> <p><i>Kate</i></p>	<p>Well, obviously I do want to know if they have had side effects, if they have got problems, obvious things like diarrhoea, constipation, whatever, things that we can treat. Are the anti-emetics working, or have they got such terrible nausea they're not eating at all. Really, how things have gone.</p> <p><i>Kim</i></p>
---	--

Grace's problem of the diarrhoea was acute, so it was not surprising that Penny should concentrate on this in the first instance. It was also a symptom for which there was a solution, and for which she could suggest some advice and treatment (Imodium). Kim's comments in the box above indicate that she too, listened out for signals from patients about symptoms or side effects which she could do something about, 'things that we can treat'. This was important to prevent patients developing anxiety about future treatments, as:

'sort[ing] side effects out efficiently and quickly [will] prevent anticipatory problems and help patients get through the course'
(Kim).

Thus, recognising that Grace had suffered a tiresome side effect, anxious to control it and prevent a repeat following the planned chemotherapy, Penny focused on the acute issue first, intending to return later to the problem of the swollen leg.

This respect for the toxic nature of the drugs, and a desire to ensure that patients did not suffer undue side effects helps to explain why nurses prioritised treatment-related issues over other symptoms in assessment. Patients however, shared the nurses' treatment-focused agenda for assessment, reflecting their anxiety about the treatment and their desire for a safe outcome, without complications.

5.2.2.2 Nurse Role

The main aim of assessment was to confirm that the patients were 'fit for chemotherapy'. The nurses at The Northern carried the responsibility for making this decision, although it was primarily based on patients' blood test results which were known in advance of meeting the patients; assessment confirmed that the treatment was being tolerated.

The nurses at The Southern had a different role, and so did their assessments. Their assessment talk was to elicit information to enable doctors to make the decision that the patient was fit for treatment. The nurses were required to complete a toxicity rating scale for each patient (see Appendix 14); this paperwork shaped the assessment conversation.

Nurses in both settings were working in an extended role, performing a task which had once been the remit of junior doctors, which meant their accountability lay in treatment-related issues. Seven of the ten nurses stated that the technical skills required for this role were their prime interest and source of satisfaction, and were the reasons they had chosen to work in this setting. They were most knowledgeable about, and skilled in treatment-related issues, which either consciously or subconsciously took priority when they were assessing patients.

Acknowledging that the nurses' extended role brought with it legal and professional requirements helps to explain the focus of the assessments. There was evidence, however, that the nurses were confused about the boundaries of their role and how much advice they were 'allowed' to give patients. This is illustrated in Penny's assessment of Grace (see section 5.2) and her loss of confidence when advising Grace about the use of Imodium. During the follow-up interview, Penny confirmed that she was unsure whether she was 'allowed' to suggest medication for the diarrhoea; she was 'in the dark' about where the boundaries and limits of her role lay. She said she usually 'avoided' such discussions (mechanism: emotional control) by referring patients to the doctor.

The nurses' role was reflected in the training and education that they had received over the past twelve months. Table 5-1 illustrates how the nurses' on-going education and professional development reflected their role and interests:

Name of Nurse/Grade	Relevant education in the past year	Length of time in current unit	Professional experience post-registration
Brenda (F)	N59	18 months	Ophthalmic outpatients
Noreen (E)	N59	18 months	Medical ward; ENT
Myra (E)	Undertaking N59	4 months	A&E nursing in Philippine Army
Kate (F/bank)	Study day on breast clinical trials	5 years	Oncology ward; Chemotherapy unit in another hospital
Judy (agency)	None	Regularly employed in unit one day a week for past 12 months	Haematology: employed concurrently in another hospital as CNS (4 days per week)
Lindsey (G)	Completed BSc Cancer Nursing degree	1 month	Haematology out-patient chemotherapy service
Tina (G)	To commence haematology course	7 years	Oncology; chemotherapy unit
Kim (F)	Completing BSc Cancer Nursing	4 years	Clinical trials nurse
Sue (F)	None	7 years	Just returned to unit having spent previous 12 months acting up in G Grade post on in-patient oncology ward covering maternity leave
Penny (E)	None	7 months	Medical ward; oncology day ward

Table 5-1 Nurses' post-registration training and experience

None of the nurses had palliative care experience or received any specific post-registration training in symptom control or communication skills, which meant they were 'in the dark'. Their role fired mechanisms of knowledge and experience in treatment-related areas and skills, but when asked to attend to patients' concerns in topics which were outside their primary role, the nurses became anxious, firing the mechanism of emotional control. Limited knowledge and skills in these areas were disabling mechanisms. (See section 5.2.3.1).

5.2.2.3 Outpatient Treatment Setting

The outpatient setting influenced assessments in three ways: the culture of the treatment setting was reflected in the nurses' priorities for assessment; the public arena of the treatment rooms restricted opportunities for observing or looking at patients' bodies; and the organisation of the units limited the opportunities for nurses to 'get to know' the patients.

The nurses' assessments reflected the cultural influence of the treatment setting. This 'web of meaning' (McIlfratrick 2003 p58) (which the patients also shared) was primarily concerned with the administration of anti-cancer treatments. Cox (2000a) identified that the culture and organisation of a cancer clinical trials unit created a unique context for care, in which clinical trials work and 'treatment' became merged. Similarly, in the outpatient chemotherapy units, 'care' was synonymous with 'technical skill', and assessment with treatment-orientated issues, which left the nurses 'in the dark' about patients' 'life world', epitomised by the absence of any acknowledgement or assessment of patients' support networks (lay and professional). Some patients volunteered this information during the assessments, but as no record of this support was made, the next nurse caring for the patient worked in the dark. Thus, the nature of support, the reasons that it was being given, and the context in which patients were living with their illness remained hidden: nurses were working in the dark.

Nurses had opportunities to hear first-hand some details of the patients' support networks, since all of them except Charlie were accompanied by a companion or partner whilst their treatment was given. Yet, as the extract from my field notes and Grace's assessment shows (see section 5.2), these people were marginalised from the assessment. I observed three other incidents at The Southern where relatives or friends stood next to the patient whilst treatment was given, and there were fifteen entries in my field notes across both case study sites where I perceived the patients' companions to be 'sidelined', their interventions and advocacy ignored, as Grace's friend's had been. Understanding why this occurred for reasons other than discourtesy is important. One explanation is that the exclusion of any prolonged exploration of family or personal matters facilitated the work of the units. Nurses were required to process patients throughout the day according to an appointment system; indeed, at The Southern, three of the nurses (two of whom were not taking part in the study) described the unit as a 'sausage factory' quite independently of each other. Thus, the demands of the system and the need to be 'efficient' (Tina) affected the way relatives and friends were tolerated; they were allowed to be present as 'supportive partners' but were expected, and volunteered, to remain in the background during the contact between nurse and patient, as the following example illustrates:

Extract from assessment	Extract from field notes/reflections
<p>N: [To patient] Are you all right there? [opens dressing pack] OK.</p> <p>Wife: Do you want me to move from here?</p> <p>N: No you're fine</p> <p>Wife: Are you sure?</p> <p>N: Yeah</p> <p>Wife: I can move you know</p> <p>N: *[to patient] Anyway how are you today</p> <p>P: Not bad. Not bad at all.</p> <p><i>Noreen and Clive, The Northern</i></p>	<p>As Noreen approaches Clive's chair, Mrs. E gets up from where she has been sitting in front of him, and pulls her chair right back and to the side. But she is still checking she has moved far enough away. It struck me that she had moved too far away – she hardly 'belonged' to Clive now, and couldn't possibly see anything. It seemed like a symbolic gesture but of what? To think about: was it perhaps a handing over of responsibility and care to the nurse; moving away from treatment; not feeling needed anymore?</p> <p>*Noreen ignores Mrs. E's question and addresses Clive. Does not include Mrs. E in the conversation again.</p>

The outpatient setting created and sustained 'working in the dark'. The public arena in which treatment was given prohibited exposure of patients' bodies and there were few opportunities for patients to bring their 'personhood' (Corner 2001) or 'self' into area. In a sense, the outpatient chemotherapy unit was a liminal area (van Gennep 1960), between in-patient and domiciliary settings. So, Jim found the unit 'homely' quite 'unlike a hospital' (see Chapter 4) and both units' philosophies stated that care was given in a 'family atmosphere', but this created difficulties in negotiating access to patients' 'territory': their bodies or their social world. Patients remained dressed in their own clothes, but did not own any space in the unit, even temporarily. The constant movement of patients in and out of the treatment areas, and the fleeting contact between nurse and patient limited the development of intimacy whereby patients might be enabled or encouraged to share their life-world with nurses. Patients' occupation of 'chair space' was temporary and generally brief (the longest a patient was in a chair was two hours), and for most of this time, the patients' only contact with the nurses arose from a need to attend to intravenous infusions. In this liminal setting, therefore, patients' life-worlds were both denied and hidden – nurses were in the dark about the patients' occupations, social situation or support network.

Moreover, there was no continuity of nurse-patient contact between treatments which meant that any social knowledge of the patient did not influence subsequent care; nurses were able to carry out their work without this information. Any curiosity about the patients' life world was in terms of social interest, rather than clinical usefulness. Patients had no expectation that nurses would use any of the information they shared, not least because they realised that a different nurse would most likely be treating them on their next visit. Neither The Northern nor The Southern practised 'named nursing', although in both units there were a few patients who had regular contact with the same nurse (e.g. Penny and Desmond). As Penny's opening words to Grace reveal (see section 5.2), she had not met her before: meeting for the first time, the nurses and patients were 'in the dark'. Penny and Myra said 'knowing the patient' was helpful and made assessment easier (mechanism: rapport: see Chapter 4), but this was not a view shared by the patients. Instead, they thought nurses needed to know about treatment-related issues: safety was their priority.

In both case study sites, a lack of continuity of care was observed not only between treatments, but also within a treatment. At The Southern, there was no continuity between the nurse who assessed the patient and the one who administered or commenced the treatment. This limited nurses' opportunities to 'know' the patients, leaving them in the dark:

Extract from nurse follow-up interviews

N: On the ward [...] you get so much more knowledge of the patient, I don't know, there's just something about seeing them and seeing their families, because that's how you, whereas here it's very it's just sort of like they're separated from the whole. Here you only get a glimpse of what's going on, don't you?

CW: Yes, it seems that way

N: Exactly. But that's it, that is it and it depends what they choose to tell you at that point of contact because after that they're lost then in the system, they go off and see the doctor and they come back and yes, you might have a chance to talk again but it's very rare that I will actually sit there with them and talk then – it's more a question of put the chemo up and go onto the next one.

Sue, The Southern

The third aspect of the treatment setting which resulted in the nurses working in the dark was the way in which the units were organised; specifically, the division of labour, which disabled the mechanisms of knowledge (of the patient and observational knowledge) and communication (e.g. information). These mechanisms are further explored in section 5.2.3. For instance, at The Northern, the division of labour prevented the nurses from observing the patients arriving in the unit: volunteers accompanied patients into the treatment room and made them comfortable. The nurses therefore missed many cues, for example, how breathless patients were, or that they looked as if in pain. Observable symptoms which may have informed the nurses' assessments were missed.

Summary

The treatment setting was a significant contextual influence on the way in which nurses assessed patients, concealing non-treatment-related symptoms and patients' social selves. This, along with the nurses' role, and the underlying anxiety in both patients and nurses about the potential complications of the treatment, helps to explain why the nurses were 'in the dark'. However, as the following section illustrates, contextual influences were only part of the reason for the nurses working in the dark. These contextual factors fired (and/or disabled) the mechanisms of communication, knowledge, experience and emotional control, which reinforced the nurses' assessment practice.

5.2.3 Working in the dark: Mechanisms

Penny's assessment of Grace (see section 5.2) concentrated on treatment-related side effects such as diarrhoea and possible peripheral neuropathy (when Grace talks about unsteadiness in her hand), and overlooked Grace's swollen leg. This focus on the toxicity issues reflected Penny's knowledge and experience (mechanisms):

Extract from Penny's follow-up interview re Grace

I think, at the beginning that she also mentioned, I think, did she say her ankles were swollen? Because also with questions like that I don't have any real theoretical knowledge, so I felt I couldn't answer her question. It would have been wrong to do that as I had no knowledge to allow me to do that. So I thought to concentrate on the diarrhoea and give her some confidence on that, because it had been her first cycle and it is very hard to know what to do. And when you're feeling rough anyway you're kind of grasping at straws and I was very conscious of that but I was then quite confused myself because I'd given her one lot of information about how to take anti-diarrhoea medication and then I thought to myself "Well, I shouldn't have said any of that, am I allowed to say that?" I don't know, so I was feeling unsure already and I thought I can't deal with the swollen leg, I had no idea what to say about it, so I think subconsciously I moved on.

Penny

The extract above illustrates how working in the dark resulted from contextual influences and mechanisms. Penny talks of how her limited theoretical knowledge triggered anxiety, and to reduce her discomfort (emotional control) she chose not to address the problem of Grace's swollen leg. Such mechanisms might explain why so few of the patients' symptoms were addressed in the assessments. The following section explores how limitations in the nurses' knowledge and experience of symptom control, cancer, and palliative care, were disabling mechanisms, and resulted in the nurses working in the dark.

5.2.3.1 Disabling mechanisms: limited knowledge and experience

In the follow-up interviews, the nurses identified that the topic in assessment which caused them most anxiety was patients' symptoms, because they lacked knowledge to address questions about this issue. In four instances, the aspect of knowledge nurses were referring to was theoretical; in five, it was informational; and in three it was knowledge about services or facilities in the hospital and how to access these. Observational knowledge was identified during data analysis. These facets of knowledge and how they influenced nurses' working in the dark are summarised in Table 5-2:

Type of knowledge	Nurses' explanations from follow-up interviews; field notes
<p>Theoretical knowledge (cancer: management, spread; symptom control)</p>	<p>Because also with questions like that [answering a patient's question about mastectomy] I don't have any real theoretical knowledge. The only theory knowledge that I've picked up is things that I've read myself. I haven't done any courses or anything. So I'm very cautious when people ask me questions like that.</p> <p><i>(Penny re Harriet)</i></p>
<p>Informational knowledge (e.g. having information that a patient had diabetes)</p>	<p>And I suppose I was [...]thinking if he's not eating an awful lot, and the things that he was eating weren't sweet things, I'm thinking there was a lot of fat maybe in his breakfast but then not an awful lot the rest of the day, so I was telling him to increase his calories with sweet things and then I suddenly, when he said about the diabetes [...] I felt a bit foolish. I suppose my initial instinct was "Why have you forgotten that? You shouldn't have forgotten that he was diabetic". But then, in all honesty, I didn't know he was a diabetic; it's not in his notes.</p> <p><i>(Tina re Patrick)</i></p> <p><i>(also theoretical knowledge and contextual knowledge about the diagnosis: patient had cancer of the head of pancreas)</i></p>
<p>Service knowledge</p>	<p>It was difficult to know what to say because I didn't know where to send her for advice [for sleeplessness]; she had refused a Macmillan nurse and had tried tablets from the GP. And I don't think there was anything else here to help her like massage and things. I didn't know where to send her</p> <p><i>[Relaxation CDs were available in Information Room, but Judy was an agency nurse and did not know this]</i></p> <p><i>Judy re Hazel</i></p>
<p>Observational knowledge</p>	<p>The division of labour in the unit is interesting. Because the volunteers bring the patients down to the unit, the nurses don't see how patients walk, relationships with their relatives (bad conflict yesterday P and his wife!), the amount of anxiety, and the expectation (faces all alight to say 'hello') [...]and by the time the nurses turn round, the volunteers have put away the wheelchair, done all the positioning and making comfortable, and the breathless patients have had a chance to recover (e.g. Doreen; Amar; Clive; George; Jim).</p> <p>Reflections on Phase 1 of the data collection process at The Northern 5th April 2004.</p>

Table 5-2 Working in the dark: facets of knowledge as a disabling mechanism

These facets of the mechanism of knowledge were important in understanding why assessments took the form they did. The nurses' limited knowledge and experience in palliative care (see section 3.7.3.1; 3.7.4.1) were disabling mechanisms, leaving them working in the dark in relation to patients' non-treatment related concerns.

Another aspect of the mechanism 'knowledge', which kept the nurses 'in the dark', was that they appeared to be unaware of patients' diagnoses and disease status. The nurses at The Northern did not

read the patients' medical notes, and the way in which these were organised made it difficult to gain a cohesive picture of the patients' medical history and cancer journey. The nurses at The Southern did read the most recent summaries in the patients' notes before greeting them, but did not appear to retain or utilise the information during the assessments. Previous studies have shown how nurses perceived patients in terms of their diagnosis (Lawler 1991), for instance, 'the gall bladder in bed 2'; my observations were that the chemotherapy nurses spoke of the patients in terms of the treatment regime, and that a driving force behind many of their assessments concerned the technical implications of the particular drugs the patients were due to receive:

Example from The Northern	Example from The Southern (Field notes)
<p>[Looking at the patients' veins] There's not much doing here. I'm thinking of where I can go, which vein to use because of what he's to have [a vesicant].</p> <p><i>Noreen re George</i></p> <p>(At the follow-up interview did not know where George's primary cancer was)</p>	<p>I'm off to coffee, keep an eye on the FEC in the chair over there; after the cyclo she needs 'Us and Es' please</p> <p><i>Kim, Field notes</i></p>

Focusing on the particular treatment regime, and having less interest in the reasons for the prescription of the chemotherapy, meant that the nurses were 'in the dark' about patients' diagnoses and disease status. Such information might have helped nurses interpret patients' cues (e.g. recognising that patients may have breathlessness from lung metastases, or be symptomatic of hypercalcaemia because they were known to have bone secondaries). Identifying these examples of knowledge and experience as disabling mechanisms illustrates the role of emotional control during the nurses' assessments of patients. This is explored more fully in section 5.3.

In summary, limitations in the nurses' knowledge and experience left the nurses working in the dark, unable, or reluctant, to explore patients' symptoms during assessment.

5.2.3.2 Communication

Communication was an important mechanism in explaining why the nurses were 'in the dark' about patients' symptoms. There were three aspects to this: *how* patients talked to the nurses about their symptoms; *what* was communicated or, more importantly, what was not; and the *nature* of the nurses' communication to each other and from the multidisciplinary team.

Data reveal that patients raised their concerns, both explicitly and more covertly in the form of cues:

Extracts from The Northern	Extract from The Southern
<p>Nurse B: Are you feeling well? Or-</p> <p>P: Not too bad apart from a cough and breathlessness when I'm rushing around but apart from that I feel fine</p> <p><i>Doreen (with Kate as Nurse B, checking the patient's identity)</i></p>	<p>N: Any nausea or vomiting</p> <p>P: Um yeah a bit. Slight nausea. I get it a lot. It goes off. It just comes and goes. [...]</p> <p>N: OK [pause 5 secs]</p> <p>P: It's very slight. It's very slight. It's no problem. It's no problem.</p> <p><i>Penny and Desmond</i></p>

Having voiced these, many patients were quick to minimise their impact (see the extracts above), which lulled the nurses into thinking the patients' problems were not too severe, and did not need addressing. In the follow-up interviews, this was the reason the nurses gave most frequently for their responses to patients' symptoms. This strategy, such as dismissing the apparent severity of a symptom, and denying any associated anxiety, left the nurses in the dark as to the underlying meanings of the patients' comments.

As the extracts from Grace's assessment and feedback show (see section 5.2) there was a 'hidden agenda' in some of the patients' minds when they talked to the nurse about a physical symptom: this was a cue to another issue underlying the patients' verbalised concern. Six patients at The Southern indicated during the follow-up interviews that the physical issue they were speaking of masked an underlying worry about their prognosis, treatment outcomes and ability to cope at home. Because the issue had not been openly mentioned, and the nurses had not picked up the hidden meaning, but had focused on the overt topic, the patients and the nurses were in the dark.

This issue is illustrated in the following extracts from Patrick's follow-up interview which, when shown alongside the assessment conversation with Tina, reveal the gulf between what he said and what he meant:

Extract from assessment	Extracts from patient's follow-up interview
<p>N: Right how are you P: Not too bad N: You've got your arm out ready P: Not too bad N: Not too bad. How's it been P: So far so good. I feel a bit tired¹ N: Still tired. Any worse or P: Not any worse, no N: Not any worse P: No [...] N: Mouth OK P: Well the mouth gets dry sometimes do you know I was up and down the other night for 2 nights in a row because I drank so much and I was peeing all night* N: What so you were drinking because your mouth was dry and then you were up all night weeing P: Yeah N: That's not good is it; we don't want you to be up all night. Are you eating and drinking all right, normally P: Yeah I'm eating all right, I'm getting my appetite back and all N: Really? That's good. Oh lovely [...] P: The only thing is I'm not putting on a lot of weight N: You're putting it on P: No I'm not putting it on I'm eating well, but I'm not putting on weight</p>	<p>¹I wanted to see if she thought I was doing OK like you know? I've been feeling very tired and it's not getting any better, so I wanted to see what she thought. [...]</p> <p><i>*Analysis note: disabling mechanism: lack of knowledge – patient has Ca. head of pancreas: symptoms suggest diabetes</i></p> <p>I wanted to ask you [CW] if you could get me a Macmillan nurse or something. I've got diabetes from the cancer and all, and I've no-one to help me. [...]</p> <p>At the moment I'm still living in a flat and it's four floors up and when I bring up bags of shopping and things like that I find it tough, you know? So, if they could get me a ground floor flat, around the same area, I'd be happy. And if I'm getting better it would be worth putting me in a new flat see [...]</p> <p>And you don't get to see people at all, and</p>

<p>N: Right You saying you're not very active at the moment either</p> <p>P: No no well um you can't be out all day</p> <p>N: But some people don't Have you ever been a big chap</p> <p>P: In what way?</p> <p>N: Weight wise</p> <p>P: Weight wise Yeah</p> <p><i>[Discussion of what Patrick eats during the day]</i></p> <p>N: OK. Well I wouldn't be too overly concerned about your weight I mean you're eating well and um as long as you're not losing it as long as you're maintaining a steady weight and you're eating, I wouldn't worry about it too much</p> <p>P: Yep yep. But a couple of people have said to me in the last couple of weeks since Christmas that I'm looking much better</p> <p>N: I think you look better. I think you look well</p> <p>P: People are saying that to me so</p> <p>N: So let's see we don't want to make it a problem if it isn't</p> <p>P: Oh no no I don't want any problems. I want to get better, go back to work if I can</p> <p>N: Maybe you need to try a Mars Bar everyday and see if that helps</p> <p>P: Well I've got diabetes and all you see</p> <p>N: Oh right OK</p> <p>P: You know. You don't check the diabetes here do you</p> <p>N: No no.</p> <p><i>Tina and Patrick, The Southern</i></p>	<p>it's a long day seeing no-one. Because a lot of people are working and when the people want to come and see me I don't, it's time to go to bed. And when I do see people they're very shocked at how I look. I've lost a lot of weight see.</p> <p>[..]</p> <p>CW: Do you have any family?</p> <p>P: I have, but they don't bother with me because I got divorced and they don't bother with me now. Like they know I'm ill but they didn't even ring me Christmas but you don't worry about it really. You know, they're grown up, they make decisions of their own and it's a long road without turning.</p>
--	---

Tina did not recognise the cues that Patrick was giving: the way he communicated left Tina in the dark. In the example above, working in the dark meant that Tina's advice to Patrick to eat a Mars bar to help boost his weight was incorrect and potentially dangerous in view of his diabetes.

Opportunity to explore the patients' perspectives on their use of cues and the minimalisation of symptoms arose in some of the follow-up interviews. Interestingly, some patients had not realised they were using such strategies until these were highlighted. It appears that fear of the treatment being curtailed, or of confronting 'the dreaded news' (Edwina) led to the suppression of these underlying meanings; keeping such uncomfortable, almost unbearable thoughts hidden: in the dark. This adds to an understanding of the reasons for their style of communication and helps to explain why some issues were communicated in these more obscure ways.

The extract between Tina and Patrick (above) illustrates a problem Tina faced when assessing Patrick, which was the lack of information available concerning his co-morbidity. There was no information in the medical notes of Patrick's diabetes; no mention in the doctors' letters to the GP of this, and no record of any communication from the GP to the oncologist. This example of how little communication there was between the medical staff, the chemotherapy nurses, the primary care team and/or the palliative care team was not an isolated case; a striking finding of the study was how much the chemotherapy nurses were 'in the dark' with regard to information about the patients. There were five instances when patients' care was affected by a lack of information and three more when the nurses

gave what turned out to be inappropriate advice to patients because they did not know what else was being advised or prescribed, or who else was involved in the patient's care. There were no examples of communication to the oncology team from community- or hospital-based palliative care teams or district nurses to outline their input into patients' care.

There were three instances at The Southern where patients were being seen by medical or surgical teams in other hospitals in the same Trust, where communication about patients' management was absent from the patients' notes. For example, Ian told me at the follow-up interview that he had a long psychiatric history, and a month before, had had to have emergency treatment for panic attacks (the hospital was in the same Trust as The Southern). He was, at that time, seeing a psychiatrist each week. This information was not shared with the team at The Southern, and although he hinted to Sue that he had not been coping, Sue had interpreted his comments (which included that he felt 'jittery') as a response to nicotine withdrawal, and reassured him that it was 'OK to have a ciggie from time to time'. Thus, her assessment of his needs/experiences was affected by the lack of information she had about his problems.

Not only was little information flowing to the nurses from outside the chemotherapy units, limited information-sharing was observed within them. Few opportunities existed or were used during the working day to enable nurses to share patient-related information with each other. The majority of information which was passed between the nurses concerned technical details (such as the quality of patients' veins), and administrative issues (such as passing on telephone requests from the clinic for additional blood tests, or outpatient appointments). The observed communication between the nurses was not concerned with patients' social, emotional or illness issues.

In summary, the mechanism of communication is important in explaining why nurses worked in the dark. The patients' use of cues which were misinterpreted; the focus of assessment on treatment-related issues; and the lack of information flowing to the nurses, all resulted in them working in the dark. This affected the way they assessed patients.

5.2.3.3 Orientation

The orientation of the nurses to chemotherapy treatment issues affected their responses to issues raised in the assessments.

The patients' primary orientation to the doctor and/or other people for support affected the type and amount of communication that they gave to the chemotherapy nurses, sometimes leaving them in the dark as a result. For example, ten patients said that they did not share information with the chemotherapy nurses; these patients were orientated to the oncologist, because s/he was perceived as the person who made decisions about treatment and the management of the cancer. This orientation was more noticeable at The Southern, with seven patients there stating this. The oncologists also gave hope; eight patients (across both case study sites) talked of the oncologist having other options available to him or her if this particular course of treatment did 'not work':

Extract from patient follow-up interview	
P	[...] part of me says "Will I see the kids, the grandchildren married or will I see them grown up?" [...] But, no, I don't like thinking about it, you do think about it sometimes. Every time I have it done I'm thinking, you know, but then there's other things coming out each year there's something new that they can try. Doctor X was very nice. He's very nice, very positive, very optimistic when he talks to you, he makes you feel that this isn't it, you've still got all these things, this, this and this to try. Doctor X has told me "If this doesn't work then we've got hormone treatments that's right, some more chemo, this and that [...]"
CW:	So would you say he's your sort of main professional support?
P:	I think so, yes.
<i>Doreen, The Northern</i>	
Orientation to oncologist; treatment	

Six patients said that they withheld or 'played down' the severity of their symptoms to prevent the treatment being curtailed; some patients were afraid that reporting too many problems might jeopardise their treatment. Such orientation to the treatment, as well as to other members of the multidisciplinary team (including community nurses and Macmillan nurses) affected the chemotherapy nurses' knowledge of patients' needs and the support being given. The divide in orientation between 'treatment' and 'care', coupled with the limited information which flowed to the nurses (communication) from the supportive care services and from the patients left them working in the dark.

5.2.4 Summary

Working in the dark was a feature of the nurses' assessments. Explaining the contexts and mechanisms involved in assessment enables a clearer understanding of the reasons for the observed assessment practice in the chemotherapy units.

5.3 Control of the interaction

Control of the interaction was both a cause of working in the dark, and an explanation for it. For instance, Penny's omission of any exploration of Grace's swollen leg illustrated how she worked in the dark. However, this omission was also a means by which she controlled the interaction: by avoiding a discussion about Grace's possible advancing disease, she was able to keep the assessment focused on the areas necessary for her to do her job.

Control of the assessment interaction resulted from the following contexts: treatment anxiety (which required the nurses to identify and exclude toxicity problems); the nurses' role (which shaped the format and aims of the assessment conversation); and the outpatient treatment setting (which was characterised by high patient turnover: retaining control of the interaction facilitated patients' movement through the units).

The mechanisms involved in controlling the assessment interaction were: communication; emotional control; knowledge and experience (these latter two were enabling, not disabling mechanisms in this instance; control was achieved *because* there were gaps and limitations in the nurses' knowledge and experience). Controlling the interaction with these mechanisms enabled the nurses to work in the dark; this was both a legitimate and a subconscious means for them to avoid uncomfortable questions and reduce their anxiety.

The nurses controlled the interactions in three ways, controlling: the conduct of the assessments; the content; and the concerns which were addressed. Each of these aspects will be explored in turn, commencing with a description of how the conduct of the assessments was controlled.

5.3.1 Controlling the conduct of the assessments

Assessments were controlled by: the use of body posture and language, and limiting contact between nurses and patients.

Nurses used body language to signal to patients that they wished to (re-)focus the assessment interaction. They achieved this through changes in posture, such as standing up whilst carrying out the assessments, and the use of movement, to signal that the topic under discussion was to be concluded.

Four of the assessments at The Northern were conducted standing up, with the nurses holding in their hands the tray containing the patients' treatment, prepared and ready to start administering it. Assessment was thus signalled as a formality, to confirm what the blood test results had indicated (that the patient was 'well'), and to fulfil professional, legal and safety guidelines, such as the patient's identity.

A second strategy used by the nurses at The Northern, was activity. Many of the assessments were conducted whilst the nurses were looking for a suitable vein, or whilst inserting the cannula. Although primarily intended as a relaxation strategy, it could be interpreted as a means to control assessment, for it led the nurses to interrupt the patient's conversation with technically-related comments, such as: 'sharp scratch'; 'hold still'; 'does it feel all right'. The effect was that patients' stories were curtailed, and the direction of the conversation changed, as the example below illustrates:

Extracts from assessment at The Northern

[Noreen is preparing to commence the administration of the chemotherapy via bolus injections. Is identifying and rearranging the syringes as George is talking]

- P: I've had no side effects. With the first lot I didn't know what to expect but after the last lot I didn't know I'd had it you know
- N: Good
- P: I had no coughing nor anything this time. Normally I'm coughing up
=blood
- N: =Right I'm just going to double check this
- P: It might come back – maybe not
- N: Does that feel all right
- P: OK sweetheart
- N: Right. You know what to look out for
- P: If it stings or
- N: Burns or just let me know
- Noreen and George*

At The Southern, the nurses sat down to assess the patients, but in all ten interactions, they used movement to signal to the patients that the assessment had come to an end, or that they wished to 'move on' to a different topic. One of these strategies is illustrated in Penny's assessment of Grace (see section 5.2), when Penny takes Grace's hand and begins to tap the veins and stroke her arm as

Grace is speaking. Grace's response is to close the assessment conversation to allow Penny to insert the cannula.

Other signals nurses were observed using were: placing the patient's identity band on the wrist; applying the tourniquet; placing the pen used to complete the assessment proforma in the uniform pocket; clipping the assessment proforma onto the front of the patient's medical notes, and placing them on the bottom of the treatment trolley; taking the notes from the top of the trolley and completing the paperwork. The patients' response in all these instances was to stop talking, and allow the nurse to introduce a new topic of conversation, or to commence inserting the intravenous cannula.

The way in which the chemotherapy units were organised indirectly controlled the amount of contact between the nurses and the patients. Patients understood that they would meet several nurses during their visit to the units, and that each nurse would carry out a particular task. Controlling the amount of time the nurses and patients spent in contact with each other was also a means of creating and maintaining emotional distance (Allan 2000, 2001b), which was reflected in the content of the assessments (see Section 5.3.2). None of the observed assessments in either unit contained a discussion of patients' emotional or social concerns; the overt focus was entirely on physical issues.

5.3.2 Control of the content of the assessment interaction

The mechanisms of communication, knowledge, experience and emotional control were principally responsible for controlling the content of the assessment interactions.

The use of certain communication strategies enabled the nurses to keep or regain control of the content of assessments. Examples of these were: the use of multiple questions to steer the answer to treatment-related issues, and the use of the response 'OK' to patients' answers, which acted like a 'full stop'. For example:

Use of multiple questions	Use of OK
<p>N: How are you by the way? How are you doing today? I mean do you feel anything do you have cough, colds</p> <p>P: No</p> <p><i>Myra and Jim</i></p>	<p>N: Do you feel there's any burning or anything related</p> <p>P: No no burning or No no no</p> <p>N: OK. [Brightly] Right OK. I think the best thing to do is to check your bloods</p> <p><i>Kim and Rachel</i></p>
<p>N: How are you? OK? Any problems?</p> <p><i>Kim and Freddie</i></p>	<p>N: Is it better or worse?</p> <p>P: Probably staying the same</p>
<p>N: Any other problems? Nausea, vomiting?</p> <p>P: No</p>	<p>N: OK. Any flu-y symptoms in the last week, [..]</p> <p>P: No</p>
<p>N: No? Any soreness of your mouth, or tongue, any mouth ulcers?</p> <p>P: No</p> <p><i>Sue and Ian</i></p>	<p>N: OK. And the skin on your hands and feet – is that OK</p> <p>P: but um but not problematically so, just a bit dry</p> <p>N: OK.</p> <p><i>Penny and Desmond</i></p>

One reason why nurses felt the need to retain control of the assessments was the physical environment and layout of the treatment area, which required patients to sit in close proximity to each other. The lack of privacy in the units was mentioned by two nurses in their follow-up interviews as a reason for limiting the discussion of personal or private issues in a public area (context: treatment setting; mechanism: communication). Moreover, all the nurses believed that when patients attended for their treatment, they wanted to have, as Noreen put it, a 'break from talking about cancer', and, mindful that chemotherapy was difficult for many to cope with, the nurses believed that it was 'kinder to avoid the topic and give them a rest from thinking about it' (Noreen). As Sue explained:

Extract from nurse follow-up interview, The Southern

- N: If somebody asked me something about their cancer or about treatment, of course I'll answer it and I'll answer it as truthfully as I possibly can but otherwise I don't necessarily bring up the subject, I really don't. I don't know whether they want to. That's probably part of it as well. Do you want to sit there and talk about cancer all the time? And the answer is no. So I sort of think, sometimes I think they're probably a bit bombarded by it as well. And probably sick to death of it. And I just really don't want to revisit it.
- CW: And I wonder, you say, you said you don't really want to, but part of me says "OK, but why is that?" Is there something else underlying that?
- N: Perhaps. Partly yes, sometimes it's because, it's protecting yourself, isn't it? I mean, I don't like being in awkward situations and sometimes I am and yes, it's kind of, maybe there is a partly -
- CW: Because it's sometimes difficult to do that, isn't it?
- N: Yes, you're opening up a can of worms and it's like "Where do I take this?" you know, "how long have I got if I start stirring things" you know, "I've got another 20 patients in the waiting room I've got to get through". So I think there's just something about that room it doesn't lend itself to people opening up.

Sue, The Southern

Thus, nurses assumed that patients did not want to talk about their illness. Consequently, they controlled the content of the conversation (context: illness anxiety; mechanism: communication) to protect patients from having to discuss 'difficult' issues.

Controlling the assessment interaction resulted from the nurses' limited knowledge and experience in palliative care; these were enabling mechanisms, facilitating control. Thus, when patients talked about issues relating to their illness or asked about non-treatment related issues, the nurses' limited knowledge and experience allowed, enabled, or inevitably led them to ignore the issue. As they said at a feedback session, 'you can't assess what you don't know' (Brenda).

5.3.3 Control of the concerns acknowledged in the assessment interaction

The nurses' main aim for their assessments was safety; this was also shared by patients. Indeed, patients were willing to take control of the assessment interaction when necessary, if they thought the safe outcome they desired was threatened by an oversight on the part of the nurse:

Extracts from assessments

[Nurse is just about to start giving the chemotherapy]

- P: Sorry, I thought you were going to take blood tests first.
- N: No, it's all right, we're going to go ahead.
- P: Oh right, yes, I'm with you yes, do it after sort of, yes.
- N: On your blood test that you had yesterday it's a little bit low, the doctor's happy for you to go ahead but she wants to have another look today and take another test in case they want to do anything else.

[..]

P: I'm very hot and sweaty today as well.
 N: You haven't got a temperature?
 P: Don't think so.
 N: Have you checked your temperature?
 P: No, I haven't done it today

Lindsey and Jim

In the extract above, Jim indicates his concern for safety by intervening to remind and advise Lindsey of issues which may have been important for her to know to ensure the safe outcome of his treatment (Context: illness anxiety; mechanism: communication).

The nurses' interpretation of patients' symptoms from a treatment-related perspective (see section 4.3.3.1) also controlled the depth of discussion (disabling mechanism: knowledge) and prevented a potentially upsetting conversation from ensuing (mechanism: emotional control).

5.3.4 Summary

The type of concerns acknowledged in assessment was controlled through the use of mechanisms: communication, knowledge, experience and emotional control. These mechanisms were fired in response to the contextual influences of role, treatment setting and treatment anxiety.

5.4 Summary of conceptual framework

A model for understanding cancer nurses' assessment practice has been presented based on the contextual influences, mechanisms and outcomes identified in Chapter 4. The conceptual model of a wheel illustrates the inter-relatedness of contexts, mechanisms and outcomes of assessment. A particular strength of the model is that it was developed from data which included the interpretations and understandings of the nurses and patients involved in the assessment conversations. New insight has been gained into nurses' and patients' priorities for assessment, highlighting the outcomes of safety and decision making which explains the focus and process of nurses' practice and patients' contributions to assessment. The model explains the reasons for the assessments described in Chapter 4, and provides a background and baseline to enable an evaluation of the impact of the tool, which is the subject of the following chapter.

IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

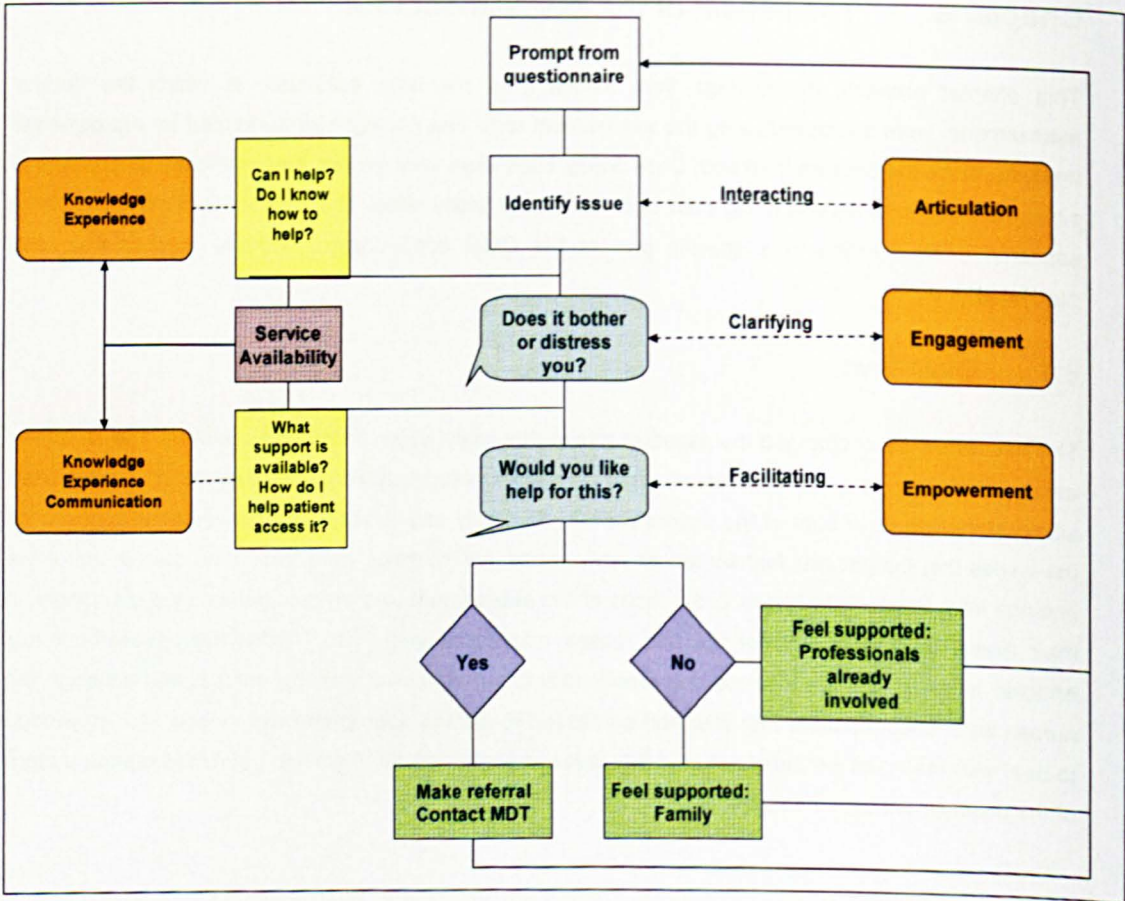
BLANK PAGE IN ORIGINAL

Chapter 6 The impact of the assessment tool

This chapter presents the findings from Phase 2 of the data collection, in which the nurses' assessments were structured using the assessment tool. The findings are presented as a cross-case analysis, since the findings from both Case Study Sites were very similar. Any inter-case differences or similarities are emphasised using data from both case study sites. The chapter is divided into three sections, each referring to a specific part of the CMO configuration: context, mechanisms, and outcomes.

6.1 Overview:

The assessment tool changed the assessments in three key ways: firstly, particularly at The Northern, assessment became a discrete conversation, conducted separately from any other activity, with nurses sitting alongside or in front of the patient's chair. Secondly, the assessment conversation focused on the issues that the patients had scored as problematic; few of these were treatment-related, unlike the findings from Phase 1. In Phase 2, the focus of the assessment was on how patients were coping with their illness, and their experiences and losses associated with this. Thirdly, the assessment tool enabled patients to share intimate and emotionally laden concerns with the nurses, and although the nurses were uncomfortable with this, and confessed to lacking appropriate experience and knowledge to deal with these, all the patients found the assessment beneficial. Figure 6-1 summarises the pattern of the assessment conversation:



Key to Figure 6.1

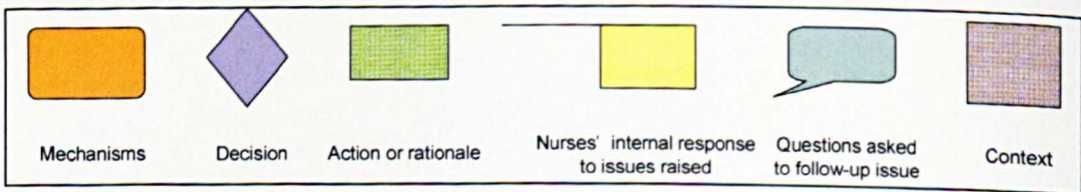


Figure 6-1 Pattern of assessment interaction in Phase 2

Patients completed the questionnaire-part of the assessment tool whilst in the waiting room. After they had been brought into the treatment area, the nurse followed up the questions which had been scored as posing 'quite a bit' or 'very much' of a problem. The items on the questionnaire served as a prompt to the patients and nurses, and enabled them to discuss issues of concern. After the patient had articulated his or her experience of the issue, the nurse asked if it was distressing or bothersome; this enabled the patient to talk about its impact. The nurse and patient engaged with each other, clarifying the meaning of the symptom or problem, which facilitated discussion of the patients' desire or need for any help or support, and involved the patient in decisions as to how the problem could be managed.

During these discussions the nurses' questions and responses were influenced by the mechanisms of knowledge and experience. Communication with the multi-disciplinary team followed in a few instances at The Northern, arising from patients' requests for specialist support or referrals for help.

The chapter begins with the presentation of data to test the CMO proposed at the outset of the research.

6.2 CMO Configuration for Phase 2

At the outset of the study, the CMO predicted that if nurses and patients were willing to use the assessment tool, more psychosocial concerns would be elicited, leading to longer assessment conversations, and more referrals to palliative and supportive care services. Table 6-1 presents the complete CMO:

Context	Mechanism	Outcome
Nurse willing to use the tool Patient willing to use the tool	Tool enables nurse to elicit patient's concerns	More psychosocial concerns elicited More referrals to multi-disciplinary team Documentation of patient concerns and action Longer assessment time Patient-led agenda in assessment

Table 6-1 CMO Phase 2

Data relating to each part of the CMO is presented, commencing with contextual issues.

6.2.1 Context: Willingness to use the assessment tool

6.2.1.1 The Northern

Considering the difficulties in recruiting patients during the interim phase to enable the nurses to practise using ART (see Appendix 15 for further details of the interim phase), identifying patients willing to take part in Phase 2 was relatively straightforward. Three patients approached to take part in Phase 2 declined, giving an improved response rate over Phase 1. A total of ten patients were recruited, and all were interviewed afterwards.

During the interim phase, the nursing personnel in the unit changed: Kate left to take up a new role as a research sister; Judy's employment as an agency nurse ceased because of budget cuts; and Lindsey was appointed the new G Grade manager and arrived towards the end of the data collection period. Although she was willing to participate in the study (and did complete an assessment for Phase 1), there was insufficient time available to introduce the tool to her. Consequently three nurses (Brenda, Noreen and Myra) took part in Phase 2.

6.2.1.2 The Southern

Recruitment to Phase 2 at The Southern was similar to that of Phase 1: there were few difficulties encountered, with only 3 patients declining to take part: all explained that they felt 'too ill'.

As at The Northern, staff changes resulted in some difficulties conducting Phase 2 of the study at The Southern. During the interim phase, Penny gave notice of her intention to leave the chemotherapy unit as she was re-locating; she completed two structured assessments and the follow-up interviews before

leaving. Tina withdrew from the study once the assessment tool had been shown to her and the principles of using the tool explained:

Extract from nurse follow-up interview

N: To be honest Cathy this is not something I want to do. This is not an area of work that I'm interested in; I'd rather leave it to the experts if you see what I mean. I like the acute side, the technical, and I really don't have any experience of this at all. I've never done palliative care. Well, I say never done I obviously did it on the 237 [...] but as for actual palliative care it's never been something that really interests me as such I must admit.

CW: No, that's perfectly reasonable to say

N: It's not been an area that, I don't know, it's just not me really and I think it's best left to those that enjoy it and leave me to focus on what I enjoy.

Tina: End of follow-up interview, Phase 1

Sue and Kim continued to participate, although Kim was not enthusiastic: she declined to take part in the interim training phase, stating that she did not require 'training', because she was familiar with the EORTC QLQ-C30 (having previously worked as a Research Nurse involved in recruiting patients to clinical trials). She completed two assessments, one of which contained no high scores, and the other, very few. There were two further occasions when there were patients available and consenting to take part in Phase 2, but on each of these occasions, she was carrying out administrative tasks which she was unable to leave. I took this reluctance as a tacit withdrawal of her consent to participate.

Sue was an enthusiastic participant, and completed five assessments, after which I felt that it was unfair to ask her to complete any more, especially as the unit was short of staff and was being disrupted by the study. After consulting with my supervisors, recruitment stopped after 9 patients.

6.2.1.3 Contextual influences

The contextual influences (the outpatient treatment setting; nurses' role; underlying anxiety about the illness) which were identified in Phase 1 remained, although there was less emphasis in assessment on 'treatment', and therefore less evidence for patients' and nurses' anxiety surrounding the safety of the chemotherapy. Contextual influences pertaining to the mechanisms and outcomes will be addressed throughout the following sections.

An additional contextual influence emerged during the interim phase, which was the availability of supportive care services. At The Northern, nurses were limited in the range of interventions they could offer patients. The services desired and/or required, but unavailable, were: counselling; complementary therapy and a specialist pain clinic.

6.2.2 Mechanism: Assessment tool

At the outset of the study, the assessment tool was labelled as the mechanism to trigger the outcomes, because neither the nurses nor I understood how the tool would work. We predicted that the tool would elicit patients' concerns (based on the evidence from studies evaluating the effectiveness of assessment tools (NICE 2004) (see section 1.5.2), but the explanatory mechanisms were unknown.

Data analysis identified three mechanisms which explain the tool's effect: articulation; engagement and empowerment. Other mechanisms involved were: communication; knowledge and experience, and emotional control: the use of the tool aroused anxiety in the nurses. The tool exposed gaps in some of the nurses' knowledge and skills which had been concealed by the 'safe' format of the Phase 1 assessments: limited knowledge and experience were disabling mechanisms. Each of these will be described in turn.

6.2.3 Mechanisms

6.2.3.1 Articulation

At the outset of the study, it was expected that the tool would enable the nurses to elicit information and identify patients' 'needs' efficiently and effectively, as in previous research (Detmar et al 2002; Butters et al 2003; Velikova et al 2004) (see also Appendix 1). The way in which this would be achieved was unknown, but was assumed to be a simple cause-and-effect model of change.

Data from this study indicate that the tool 'gave permission' to both patients and nurses to talk about patients' concerns. It enabled patients to articulate their experience through the 'telling of their story' (Wilson et al 2006). Unlike Phase 1, when the nurses and patients were observed to be controlling and suppressing emotional issues (such as illness anxiety), in Phase 2, these issues were raised and discussed. Patients talked about their symptoms, families, work, fears, and hopes, as the following extract from Amar's assessment illustrates:

Extract from Phase 2 assessment	
N:	So it [the breathlessness] has actually improved?
P:	It has improved, you know, but not significantly. Like I couldn't walk from my house to town like I could do before um, I've got to catch a bus or drive there.
N:	And the daily activities and things, if you ever want to do anything you can't do that as well?
P:	Yes, no they are also the same thing. Like washing-up a couple of cups and a plate I can wash-up but anything more than that generally and I'm struggling after a while. Like walking upstairs is OK, I can do two or three and then I'm knackered. I'm lucky because where I'm staying there's a toilet downstairs, for example so I don't need to go up and down so often. Having to go up and down is quite difficult
N:	And you're saying about you're having to spend quite a lot of time sitting in a chair?
P:	I do, I spend a lot of time sitting in a chair because if I stand up and just stand there for just 10 minutes, I feel exhausted. So I need to sit down.
N:	Again, I mean there's nothing we can do?
P:	Not really, I don't think there's much that can be done. I've learned to expect that and learned to manage the illness.
N:	Yes, sort of try to put yourself back into control.
P:	Yes, it's just become a routine now, I know what I can do and what I can't do. I've just adjusted myself to cope with that
N:	You're saying that you're limited in pursuing hobbies and leisure time activities
P:	That's totally gone.
N:	What were your hobbies?
P:	I used to play a lot of sports. Cricket, football, golf, table-tennis, you name any sport, I used to do a lot of that. I used to go and visit friends, to go out socially, friends would come around, visit people, talk to people, mixing quite well, now I've none of that.
N:	Are you managing to get people to come to you? Or do you not feel up to any visits?
P:	No. I've not had a good time, because of the way I look, the way I am, I'm quite different from what I was. I get very nervous about people to visit me now. I'm not so keen for people to see me in this condition. So I'm

a bit stressed with that.
 [...]
 N: You've already actually brought up this one, haven't you, worries about your appearance? I mean we've only ever seen you, this is normal to us.
 P: Yes, I know, that's right, yes. It's become normal to my family as well but it's not normal to friends.
 N: Have you lost a lot of weight then?
 P: I used to be 79 kilos, now I am 65.
 N: That's a huge amount.
 P: My clothes, you can see, my clothes.
 N: Just hanging.
 P: Hanging on me.
Brenda and Amar, The Northern

In the extract above, Amar conveyed the limitations forced on him by his advanced lung cancer. The assessment was not an identification of 'need' or an information-seeking exercise for either the nurse or the patient, but an articulation of his experience of how the illness was affecting him. For Amar, much of this experience was loss: loss of the ability to perform basic household tasks like washing up; loss of his social life; loss of independence (no longer able to catch the bus; having to live with his extended family); a negative change in his body image. All the other assessment transcripts demonstrated a similar pattern, with the tool serving as a prompt for the issue to be explored from the patients' perspective, and an aid to articulation.

Table 6-2 below illustrates how the tool enabled nurses and patients to interact, facilitating the patient to articulate his or her concerns:

Mechanism	Examples from assessment transcripts
Articulation of: Physical Symptoms	N: Number 3, have you had pain, and you've got quite a bit. P: That's right, in my arm. But they say it's because the cancer's affected all of the nerves and the muscles.[...] it's at night that I have most of the trouble. I can't get comfortable. (<i>Noreen and Julia, The Northern</i>)
Articulation of: Emotional, social, existential issues	N: And you've also ticked as a number 3 worries and concerns about the future P: Yeah N: Is that to do with your work and – has it helped now a bit P: It's only just fleeting - like at night you're lying there and you think about the future and you just worry a little bit you know about what's happened, and what's going to happen and is this working - because I haven't had any side effects the last 2 times I've had this chemo, so I'm thinking is it really working. You know. I'm sure it is - but N: [laughs] I'm sure it is (<i>Sue and Daisy, The Southern</i>)
Articulation of: limitations resulting from the illness and treatment	N: And a lot of problems tend to come from sort of physical problems doing shopping and so on. How much does that distress you? P: How much it distresses me? I would say a lot, because my stomach* – it's so big that it's just it's very difficult to stand up rather than go like this, to stoop it really, really hurts my back but it is easier if I use crutches, but I don't use crutches here because I can just about manage. I've got crutches and a wheelchair at home. But it is quite distressing, the fact that you know I get out of breath just going to the kitchen. (<i>Brenda and Elizabeth, The Northern</i>) * had gross abdominal ascites

Articulation of general situation	<p>N: You've got some financial problems</p> <p>P: Yes, well it's to do with transport, I don't drive you see, and I suppose it's beginning now to add up how much I'm using taxis. Even getting into [town] and doing shopping and things like that because I know I'm going to get out of breath getting in and out of the stations because in a hell of a lot of stations you're still walking up steps, having to walk up steps to get out and I suppose I've never noticed it before but now I do – I can't do it</p> <p>N: Does this stop you trying</p> <p>P: Well you do feel less inclined to do it</p> <p><i>(Penny and April)</i></p>
-----------------------------------	--

Table 6-2 Mechanism: Articulation

Thus, the assessment tool enabled patients to articulate not only their symptoms and problems, but also the meaning of these, and to verbalise how these were impacting on their daily lives.

6.2.3.2 Engagement

Engagement was a term which I wrote in my reflective diary after the follow-up interview with Felicity, the first patient to be recruited into Phase 2, to capture her feedback about the assessment tool. In the interview, she spoke of the nurse's 'involvement' with what she had said during the assessment. All the patients identified that when talking about important or troublesome issues, the nurses 'really listened' (June).

Extract from patient follow-up interviews:	
<p>..[the tool] was very good. And then when she came along and asked whether she could do anything to help I felt very good. [..]. I guess it's being able to tell it like it is, to get someone to listen to me and hear how it is</p> <p><i>Amar, The Northern</i></p>	<p>I think it [the tool] was a good thing, because I think sometimes you can end up talking about the nurse, and quite often that's what's happened.[..] I had a nurse once who was telling me all about her wedding and she was planning her wedding and she was having her do and I didn't feel, if I did have a problem, I could encroach on her [..] I didn't feel that I could sort of, if I did have a problem, I don't suppose I would have been able to. But this was different, it made her listen to me</p> <p><i>Daisy, The Southern</i></p>

A combination of factors: the focus on the topics being discussed, the way in which assessment conversation was conducted, plus the effect that the tool had in enabling patients to articulate the impact of symptoms, illness and treatment, resulted in 'engagement'. Engagement had three positive outcomes for both the nurses and patients. These are summarised in Table 6-3 below:

Outcome of engagement	Who benefited?	Example:
<p>Understanding (+)</p>	<p>Patients (n=14)</p> <p>Nurses: overall n=6/6</p> <p>Because ↑ understanding of specific issues: (n= no. of times identified)</p> <p>Of symptoms (n=8)</p> <p>Of restrictions (n=11)</p> <p>Of living with the treatment and illness (n=12)</p>	<p>It [the tool] helped her to understand my position, I think it helped her [Myra] as much as it helped me</p> <p><i>(Muriel, patient, The Northern)</i></p> <p>I think it's a really, really good idea. I think that it makes, on the positive side, first of all I think it allows us to know our patients better and in some respect I think that's a good thing because we can develop a relationship with the patient better and that helps us understand them better</p> <p><i>(Penny, nurse, The Southern)</i></p>

Patients: Feeling supported (+)	Patients (n=16)	When I was talking it made me feel like she [Myra] really cared, it made it all feel not so bad, that she understood and that's why it was really helpful <i>(Patricia, patient, The Northern)</i>
Satisfaction (+)	Patients (n=18) Nurses (n=overall perception: n=5/6)	P: Well yes it [the questionnaire] calms you down a bit, because I hadn't had the chemo then, so I was apprehensive so this was just a slow [...] introduction, that's it, yes. I was very happy with it. <i>(Pauline, patient, The Northern)</i> I think it was excellent, how an assessment should be. It was like being back on the wards again. Definitely an improvement, made a pleasant change from the monotony of this place <i>(Sue, nurse, The Southern)</i>

Table 6-3 Mechanism: Engagement outcomes

One of the main reasons for this sense of engagement was that the nurses had to address the issue that the patient raised. In Phase 1, whether an issue was explored or not, and how much, depended on the nurse's interpretation of what the patient meant when they mentioned a symptom or concern. Issues in Phase 1 could be interpreted in a narrow treatment-focused way or closed down by the nurse. In Phase 2, however, the tool enabled the patients to explain and describe their feelings and experiences, so that the nurse engaged with the patient's experience, instead of moving on:

Extract from recorded assessment	
N:	Intimate relationships. Leave blank if not applicable. Um
P:	What's that? Oh sex oh that's because C [husband] can't bear to come near me when I'm not well he thinks its too much of an intrusion and an imposition and I long for him, but it's been like that ever since we've been married. When he's worried or when he's worried about me whatever, he just doesn't think about that
N:	Yes. I think obviously you have to think about how you're feeling especially as you're starting treatment
P:	Yes that's right
N:	I think men tend to get a bit scared
P:	That's exactly what it is I'm sure
N:	They get a bit worried, don't want to come near you or whatever. Obviously you're quite close anyway so you can talk and discuss about it
P:	Yes yes. No actually, we're not very good at about talking and discussing this particular area unless it's complimentary [laughs]. We're all right with compliments [Laughs]
N:	Yes
P:	But whenever we've had - he was under stress of redundancy for a year so it's his worries as well as about me so it keeps, keeps him - but we're all right loving and cuddling
N:	Mmm. Well maybe keep it like that for a little while, for the time being [nervous laugh]
P:	Well, certainly while I'm on the chemo, I mean there's no way while I'm on the chemo that he's going to come near me
N:	Well perhaps if you take the lead, if you're quite forceful [Laughs hard]
P:	[Seriously] Yes. Well no. I've had to learn over the years we've been married, I've had to learn not to do that because it's pressure
N:	[Seriously] Right right.
P:	So I have to do rather more subtle enticements [laughs]
N:	[laughs]

P: [Laughs] and so at my age it turns out to be a few open buttons. I can't take my clothes off anymore but a few open buttons can be quite enticing [Laughs]
 N: [Laughs] Ohh right
 P: Very subtle
 N: Oh right.
Noreen and Felicity; The Northern. Original emphasis

In the above extract, Felicity was able to set her present experience and feelings about her husband's reluctance to be physically intimate with her in terms of his 'usual' or previous responses to stressful situations during their marriage. Thus, although she was upset and distressed by the situation, and wished it were different, she could put the current experience into context and relate it to other stressful times (such as the threat of redundancy) when her husband had responded similarly. Thus, the high score was re-configured for both Noreen and Felicity from a potential 'need' to an 'experience'.

In the follow-up interview, Noreen identified one of the disabling mechanisms associated with engagement for the nurses, which was where to send patients for help (Mechanism: knowledge (of service availability)). The other disabling mechanism was nurses' limited experience: of cancer and palliative care; and talking with patients about sensitive or 'difficult' issues. These disabling mechanisms triggered anxiety and made nurses aware of their shortcomings, which they found lowered their self-confidence. Table 6-4 summarises the disabling mechanisms: lack of knowledge and experience:

Disabling mechanisms	Issues on the tool associated with triggering disabling mechanisms:	Outcome
Lack of knowledge Identified by three of the nurses: Myra, Noreen and Penny	Financial Sexual Family Anxiety Pain Appetite Fatigue Breathlessness Living with advanced cancer Service availability	Anxiety; ↓confidence
Extract from follow-up interview	I was quite taken aback, you know when she started talking about intimate things and I thought 'Help! I've never done this before'. I've had no training on this. I think we need this. (Noreen)	
Lack of experience	Holistic assessment Referring patients to supportive care services Talking about dying	Anxiety; ↓confidence
Extract from follow-up interviews	I was feeling anxious because I didn't know what was going to be raised [in the assessment]. It causes anxiety because it makes me feel that I'm incompetent in a number of areas, mainly - not necessarily giving medical advice - but giving kind of basic counselling advice to patients and knowing where the resources are for their social, psychological and emotional issues. (Penny)	

Table 6-4 Disabling mechanisms

One of the most powerful examples of a positive outcome of engagement arising from the assessment is illustrated by an extract from field notes which were written after Noreen's assessment of Rose, who was attending The Northern for treatment for advanced stomach cancer:

Extract from field notes

Noreen did another assessment today. A little lady – retired nurse 65 but looked 85 – very frail, thin and ill. Having treatment for Ca. stomach. Poor thing – she was feeling very nauseated, and retched, burped and belched her way through the first part of the assessment. She seemed so ill and nauseated I did wonder a couple of times if it was ethical to continue, or whether we should stop the assessment to give her some anti-emetics at least or to stop completely. However, she said she wanted to carry on. [...] Anyway, about half way through Rose began to speak more strongly, to get her 'wind up' (literally too) and began to really come out of herself. She began to talk about her plans for the future; her hope to go home to the Caribbean, and her faith; of not being afraid to die and she began to 'witness' (she said she was Brethren) to Noreen about her beliefs. It seemed to me that this role reversal, of Rose teaching Noreen something (or thinking that she was), and of affirming the fundamentals about the future (not being afraid to die, of believing in an after-life) had a real effect on her ?making it possible for her to bear the treatment and the illness. For, she seemed to change from being a very ill, vulnerable *patient* to a *person* contributing and having something to say. By the end of the assessment, she had stopped retching and belching, she was much more animated, her eyes were brighter, and when J offered her a lunch box, she readily accepted it, saying she felt hungry. We watched her from the desk, tucking into the sandwich and the soup. J was astonished. Noreen too. It was, in Noreen's words 'a transformation'. [...] It was a really positive outcome from what seemed like a rather unethical start. Interesting.

(Field Notes)

Thus, the assessment tool enabled nurses and patients to engage with the issues and with each other.

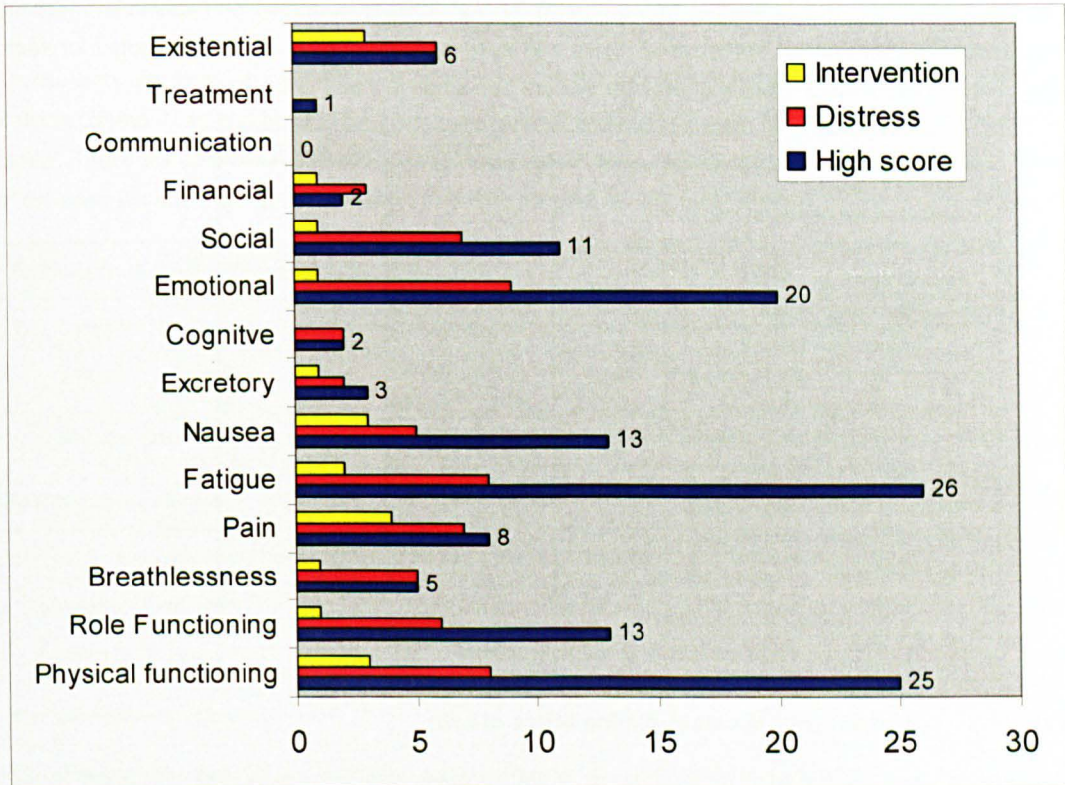
6.2.3.3 Empowerment

Patients were empowered by the tool in three ways: firstly, their issues formed the agenda for the assessment, and the tool gave them permission to bring their concerns out into the open. Twelve of the nineteen patients who took part in Phase 2 stated that they felt they had control of the assessment, and had felt that they had a choice as to whether or not to answer the questions.

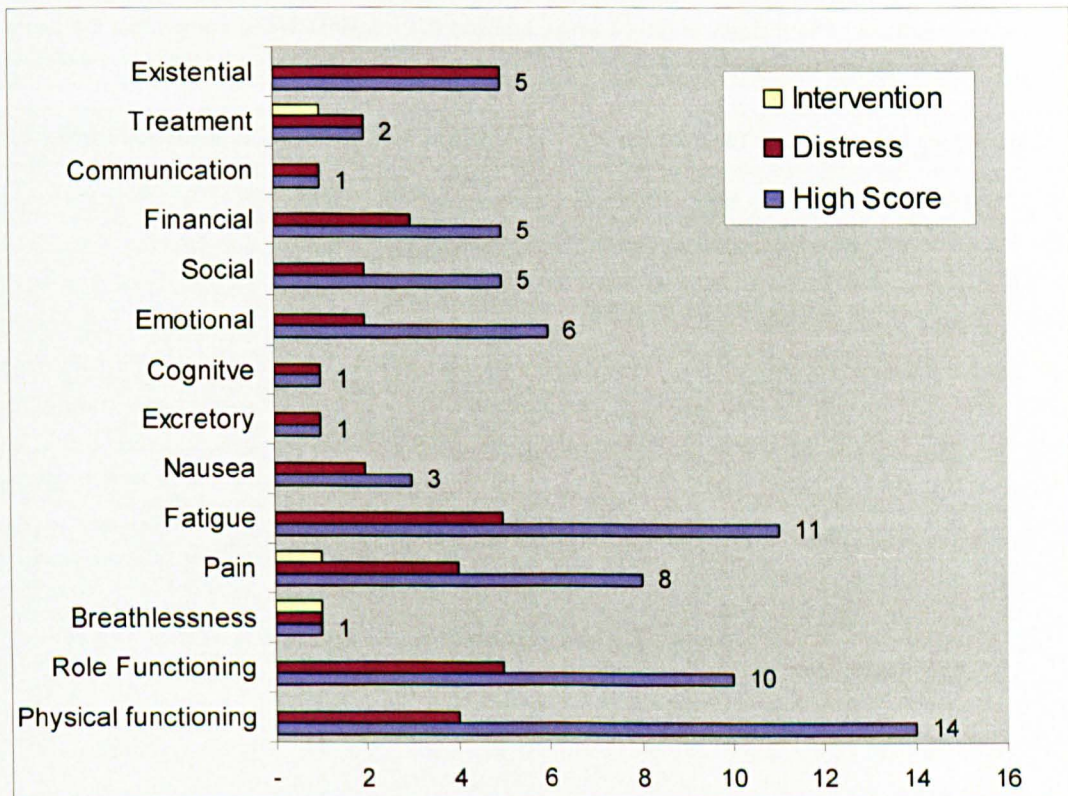
Secondly, patients said they felt in control of deciding whether or not to accept help for their issue. Thirdly, as a result of the structured assessment, said they felt they could take more control in situations where support was already available or in place. The following sections illustrate these last two points more fully, beginning with the response to the offer of help.

6.2.3.4 Choosing whether to accept professional help

At the outset, the assessment tool had been envisaged as a 'sign-post' for nurses to identify need and make the appropriate referral. Thus, when patients gave a high score to an item on the questionnaire, the nurses had been taught to ask a follow-up question about whether the patient needed an intervention, such as referral to a specialist, or written information. Unexpectedly, the tool did not lead to many requests for support or interventions; in the majority of instances, patients declined offers of help, as Graph 6-1 and Graph 6-2 illustrate:



Graph 6-1 Graph of high scores on the assessment tool: The Northern



Graph 6-2 Graph of high scores on the assessment tool: The Southern

The graphs illustrate that in relation to the number of high scoring issues which patients themselves classified as 'distressing' or 'bothersome', there was a low number of offers of help accepted for each item on the questionnaire. Reasons given for this are presented in Table 6-5:

Reasons	The Northern	The Southern
Has family support	10	2
Macmillan Nurse (aware of issue)	9	2
Has new medication	1	2
Chemotherapy might help	5	
Will ask Macmillan Nurse	3	
Has other professional support	7	1
Accepting: this is how it is;expected	13	5
Nothing you can do	10	6
Don't want to talk to professionals	5	
Coping: learned to manage it	2	2
New support to start within 7 days	3	
Already having treatment for it	1	2
Issue is improving	1	
Has analgesia	1	2
Under investigation	2	
Not cancer-related: age	1	

Table 6-5 Reasons for patients declining offers of help

Patients identified support from family, friends, and/or professionals, principally their Macmillan Nurse. The table above, however, shows that for some issues, patients felt that there was nothing that could be done; that their experiences and feelings were 'normal', and that they had to learn to live with the symptom or problem. The majority of issues which aroused this response were: worry about the future, fatigue, role, social and cognitive functioning.

Extracts from assessments at The Northern	Extracts from assessments at The Southern
<p>N: So looking at the past week, really, obviously from what you've said you have been limited doing jobs around the house or even hobbies and things, I would imagine?</p> <p>P: Yes. I've given up playing the piano because I can't sit there.</p> <p><i>(Brenda and Elizabeth)</i></p>	<p>N: Right I'm just going to touch on worries or concerns about the future</p> <p>P: Well I have I mean</p> <p>N: Of course</p> <p>P: Well hopefully the CT scan will say everything's all right but it is a bit of a worry because you don't know do you? We just have to wait and see</p> <p><i>(Sue and Joy)</i></p>
<p>N: And have you had difficulty in concentrating on things, like reading?</p> <p>P: Yes, I skip.</p> <p>N: Oh right, you just flick?</p> <p>P: Yes, I can't concentrate on anything, not for long.</p> <p>N: Does it bother you?</p> <p>P: It does, but not to the extent of the illness itself. It comes with it really. You can't have something like this without it affecting you can you?</p> <p><i>(Myra and Patricia)</i></p>	<p>N: OK and the last thing that you've mentioned is the fact that you're quite worried about the future. Is that related to - um your cancer or related to [slight pause]</p> <p>P: Purely related to the cancer and I suppose over the last week as well, having seen Dr S a couple of weeks ago and she said the CT scan will decide whether to continue treatment or change chemo or discontinue it</p> <p><i>(Penny and April)</i></p>

6.2.3.5 Empowering patients to talk

The second way in which patients were empowered by the tool was that it helped five of them (Felicity, Patricia, Diane, May and Hope) identify issues which they could discuss with their Macmillan Nurse or family. These were issues which they thought had been raised or discussed adequately, but as a result of the assessment tool they had realised that they needed or wanted to discuss further. For example:

Extracts from patient follow-up interviews	
CW:	Some of these things that you brought up [play tape] and Noreen suggested you discuss with your Macmillan Nurse – have you or had you discussed many of these things with your Macmillan nurse to date?
P:	I thought I had. [Laughs]. I've met her twice and I thought I had but again, having thought about them after the questionnaire I realise that I haven't <i>really</i> discussed them with her, but they are at the end of the phone and I feel I can talk to her about things <i>(Felicity follow-up interview; original emphasis)</i>
P:	It [the tool] was really helpful because as I was doing it I realised, I thought I don't want to die at home. I want to go to the hospice you know? It just came to me as I was filling it in. I realized that G [husband] will never cope and I think that's been preying on my mind like and worrying me and so I've worked it all out now. When I go to see them next week I'm going to ask them if I can come in there to die when the time comes. So yes, it was really helpful. Really helpful. I feel as if it's all, all the worry and such has been lifted from me <i>(Patricia Follow-up interview)</i>
P:	The questionnaire was useful because it shows you why you are feeling rotten. You see, patients like me appear happy but we aren't, and no-one really takes notice of what we say, so this questionnaire was useful. And it was helpful because it makes you realise <i>why</i> you are fed up, and that you have reason to be, you see, I reckon ten out of eleven things that I was asked on that form are affecting my life so that explains it; it helps me realise why I'm feeling so crap. And because I understand that, I can explain it to my family now. <i>(May Follow-up interview; original emphasis)</i>

6.2.3.6 Disabling mechanisms

Three disabling mechanisms were fired by the assessment tool. These affected the nurses, and were: a lack of knowledge (e.g. symptom control, service availability, cancer) a lack of experience (in talking to patients about dying and issues related to existential fears); and emotional control (necessary to limit their anxiety whilst carrying out the assessments). The effects of these were mitigated to some degree by the way in which the study was conducted (see Chapter 10) in that I negotiated how much support the nurses wanted, or whether they wished to carry out the assessment on their own. All the nurses asked for me to be ready to do this, and therefore if the nurses looked to me for help, I stepped in to assist:

Extract from Phase 2 assessment	
N:	Do you have any worries or concerns about important people in your life?
P:	Yes, G. My hubby, what's going to happen to him and who's going to look after him properly. Because he's had two strokes, his short-term memory's not good. So it does concern me a lot. I mean I've just decided that when, if, when I get bad I'm not going to die at home I shall go to the hospice and take some of the burden off him, because he won't cope with it. And I wouldn't want him to try. <i>[Long, uncomfortable silence. Nurse looks very shocked; tears in her eyes. Eventually and rather suddenly, gets up and moves to patient opposite to slow infusion rate down. Patient turns to me, with a rather surprised look on her face, and nods as if to seek my approval of her statement.]</i>
CW:	[to patient] That's a very big decision.
P:	Yes, and I've said to G out there [waiting room] about it, and he said "I don't think that I will cope" and I said

"No, I don't think you will" and I said "I wouldn't make you". I said "So when the time comes I'll make it known that I want to go into the hospice and finish my life there". The doctor there said that they don't give you the drugs to knock you out with the pain, they give you the drugs but it doesn't knock you out, you're still aware of people and so, yes, I've decided to do that.

[Nurse returns and sits quietly, picks up the questionnaire and papers whilst patient finishes speaking]

CW: And having made the decision has that helped you?

P: Yes. I said to G "Nothing against you, it's not being nasty or anything, it's just taking some of that burden off you". So he doesn't have to try and cope with it, I think that's fair. So that's that one. *[pause. Myra looks at me, and says to patient:]*

N: About your appearance, do you have worries or concerns?

Myra and Patricia

The extract (above) from Myra's assessment of Patricia, reveals in a very stark way her response to the anxiety created by the assessment tool and the discussion of existential issues. Her movement away from Patricia to the patient sitting opposite, to adjust his intravenous infusion, was a signal that she needed to remove herself from the stressful encounter, and regain a sense of control. Her physical withdrawal removed the need to respond to Patricia; and the act of doing something in which she was skilled enabled her to re-master her confidence. Afterwards, she said she felt 'shocked' by Patricia's comments, and said she had never heard anyone talk like that before.

6.2.4 Hypothesised Outcomes

The CMO proposed at the outset to the study predicted the following the following outcomes, highlighted in Table 6-6:

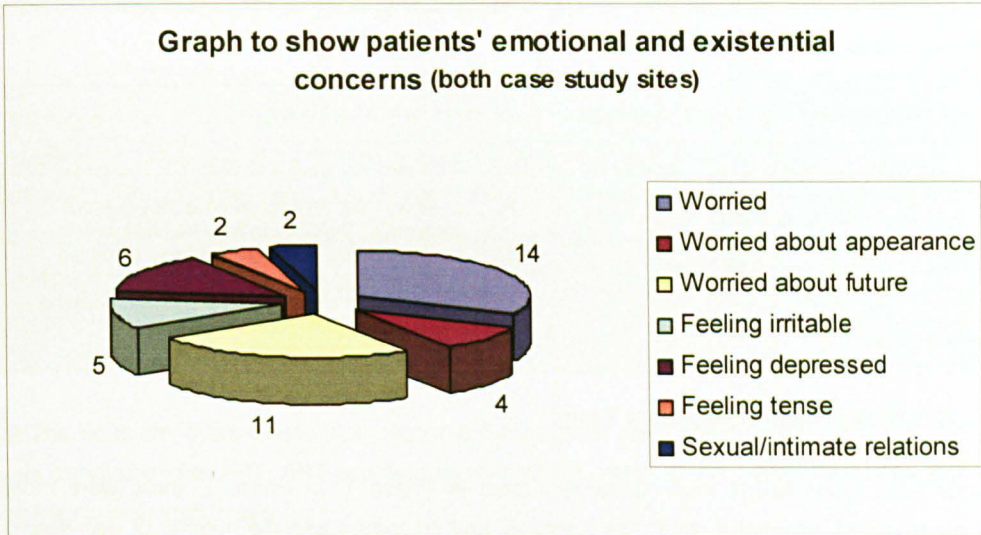
Context	Mechanism	Outcome
Nurse willing to use the tool Patient willing to use the tool	Tool enables nurse to elicit patient's concerns	<ul style="list-style-type: none"> • More psychosocial concerns elicited • More referrals to MDT • Documentation of patient concerns and action • Longer assessment time • Patient-led agenda in assessment

Table 6-6 CMO Phase 2

Each outcome will be addressed in turn.

6.2.4.1 Psychosocial concerns

In Phase 1, no psychosocial concerns were identified in either case study. In Phase 2, 44 emotional/existential concerns were identified (26 at The Northern and 18 at The Southern), as illustrated in Graph 6-3:

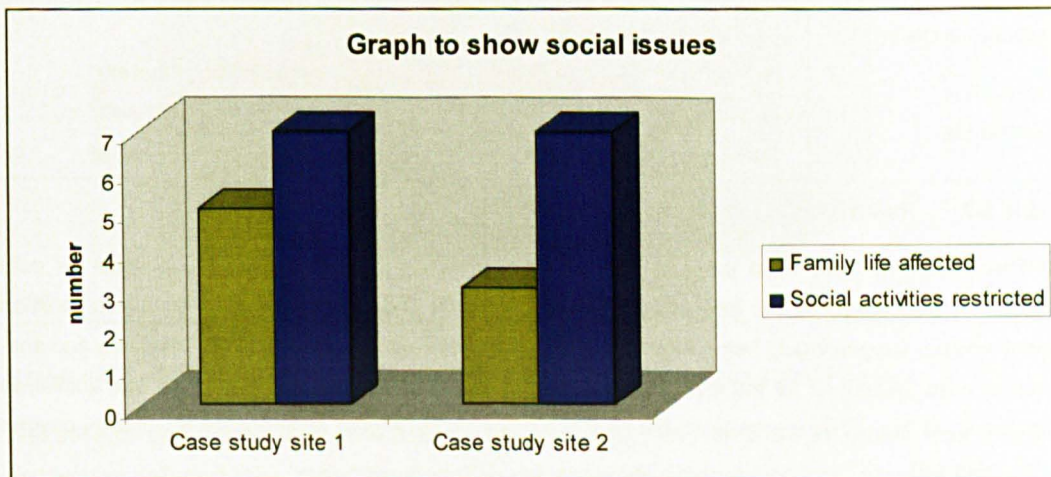


Graph 6-3 Pie chart to show patients' emotional and existential concerns

The assessment tool, however, involved more than merely identifying issues of concern; it facilitated patients' articulation of them, as the following extracts illustrate:

Extract from The Northern	Extract from The Southern
<p>N: Family worries – how much would you says that bothers you</p> <p>P: Oh very much and I feel tearful as soon as I think about it but um I'm concerned about my husband because I don't know how he'll cope - well I'm sure he will cope but in a hermit type of way take himself off to his railways and steam trains and become a complete slob I'm sure, but it's my boys, it's my boys</p> <p><i>(Noreen and Felicity, original emphasis)</i></p>	<p>P: And I worry about him really, my partner, getting on all right, to know that they're anxious, and I worry about my granddaughter because she doesn't know that I'm not going to be better but I'm determined in myself not to let it get me in that sense</p> <p>N: Sure</p> <p>P: Obviously you worry about them, your husband and your family and that</p> <p>N: Of course you do</p> <p><i>(Sue and June)</i></p>

Twenty one social issues were identified in Phase 2, as illustrated in Graph 6-4:



Graph 6-4 Social issues identified

The impact of the assessment tool

In the assessment conversation, patients described the meaning of these issues, and articulated the impact of their illness and treatment on their lives:

Extract from The Northern	Extract from The Southern
<p>P: What it is, it [the treatment] takes over your life what with the blood tests and that. What it means is you can't go swimming and it interferes with what I've got to do with the kids as well and that, but there's not a lot you can do about it</p> <p><i>(Brenda and Diane)</i></p>	<p>N: You said you were a bit limited in social activities</p> <p>P: Well I'm - I'm very very tired. Like yesterday it took me till 5 o'clock to feel like I had woken up and then I was very very tired and then I did manage to go out in the evening for an hour, but all day I didn't have any energy to do anything</p> <p><i>(Kim and Hope)</i></p>

6.2.4.2 Referrals to Multi-Disciplinary Team

No referrals were made to the multi-disciplinary team in Phase 1. In Phase 2, there were more referrals, as predicted, although only at The Northern, and compared with the number of high scores on the questionnaire, these were few in number. The patients' reasons for this were presented in Table 6-5 above.

Eight patients at The Northern required a total of twelve referrals, summarised in Table 6-7:

Referral to:	Reason	Patients requiring/accepting
Doctor on call	Change anti-emetics Aperients Pain control	Rose Rose Muriel
Dietician	Difficulty eating (ascites) Weight loss; no appetite	Elizabeth Amar
Macmillan Nurse	Emotional support Financial help for family holiday	Amar Diane
Pain clinic	Neuropathic pain	Julia
Day Hospice (via Macmillan Nurse)	Social support	Rose
Information Centre	Information on: Eating Fatigue Coping with breathlessness	Amar; Felicity; Elizabeth Pauline; Emily; Elizabeth Felicity

Table 6-7 Referrals and interventions

At The Southern, there were three issues for which patients requested help: these were for pain (thought to be caused by the side effect of Taxol); nausea; and breathlessness (request for opinion about whether oxygen would help). All these issues were referred to the oncologist. Analgesia and anti-emetics were prescribed for the first two issues; the question about the breathlessness was answered with the word 'No'. (Two weeks later, the patient's palliative care team arranged for domiciliary oxygen to be installed).

6.2.4.3 Documentation of Patients' Concerns

The nurses' documentation of the patient's visit to the unit did not change as a result of using the assessment tool. None of the referrals arising from the assessments at The Northern was recorded in the patients' notes; none of the issues raised was noted. The questionnaires were filed into the patients' medical notes, although Brenda filed the ones from her patients in the back of the correspondence section and when I asked her why she said:

'I don't want them getting in the way of the oncology section. They'll clutter up the treatment information'

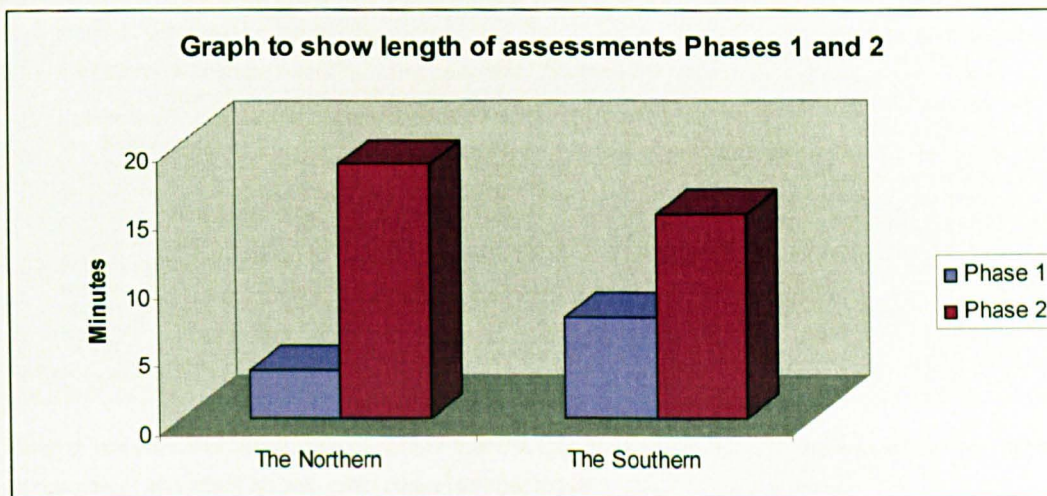
(Brenda) Field notes

At The Southern, three issues (see section 6.2.4.2 above) were noted on the toxicity proforma, which was completed after ART. ART was filed in the patients' notes at the current page, and was available for the medical staff to see.

6.2.4.4 Longer Assessment Time

The assessments in Phase 2 were longer than those in Phase 1. The timings below concern the assessment conversation alone, and exclude any conversation which took place between the nurse and patient during the administration of the treatment. The time taken to cannulate the patients is not included, since this was not being carried out during the assessment conversation.

The average length of the assessments at The Northern in Phase 2 was 18 minutes 58 seconds (range: 11 minutes 12 seconds - 34 minutes 4 seconds). At The Southern the average was 14 minutes 54 seconds (range of 2 minutes 23 seconds (no high scores) - 49 minutes 50 seconds). Graph 6-5 illustrates the change in assessment length between Phase 1 and Phase 2:



Graph 6-5 Graph to show average length of assessments, Phase 1 and Phase 2

The patients stated that the assessments were not too long; the time taken to discuss their concerns and worries reflected the number they had. The nurses, however, found the tool to be impractical, and

The impact of the assessment tool

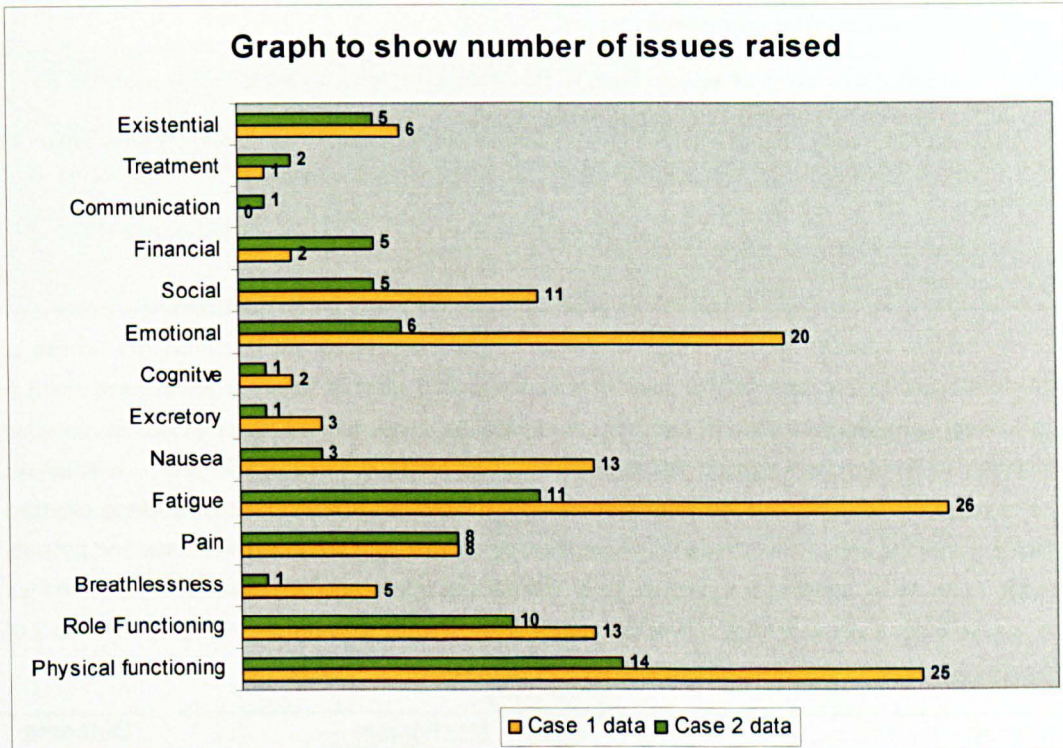
the extra workload resulting from the assessments (making referrals, and accessing information) burdensome:

Extract from follow-up interviews at The Northern	Extract from follow-up interviews at The Southern
<p>N: They're a bit long aren't they? I started to feel panicky as it was going on and on and I kept thinking about all the things I still had to do and all the patients waiting outside, which I know I shouldn't have done but it [the tool] takes so long</p> <p><i>(Noreen, nurse)</i></p> <p>P: Was it [the questionnaire] too long? Well first of all, when I first saw it, I thought 'God this is going to take ages', but it was fine. No it was really fine. It didn't take long at all, and everything was there, I wouldn't take anything out. It only took me about 15 minutes and I think that it was time really well spent. [...] It [the assessment] was long, I can say so, but I didn't feel it was too long.</p> <p><i>(Amar, patient)</i></p>	<p>N: They took a long time to complete and go over, and I don't think they would work in here as a routine. The assessments were long, so I think I'd have to have less patients in a day, loads less, 50% or more less.</p> <p><i>(Penny, nurse)</i></p> <p>P: It wasn't too long. It's quite easy to use and the questions all seem relevant, they're all about the concerns that I have, most things I was concerned about, so that's good that they were being addressed not pushed to one side. I think it's quite good when they're on paper because it means that there are, sometimes when it's verbal it can be missed out and I think it helps when it's on paper.</p> <p><i>(Hope, patient)</i></p>

6.2.4.5 Patient-led agenda

The assessments changed the agenda of the assessment from treatment-related issues in Phase 1, to patients' articulation of experience in Phase 2. However, contrary to the CMO prediction, which assumed that the patients would not be involved in setting the agenda for the assessments in Phase 1, patients were active partners in setting the treatment agenda in Phase 1 (see Chapters 4 and 5). In Phase 2, however, the types of issues raised reflect the patients' experiences of their illness, rather than the narrower treatment and toxicity focus of Phase 1 assessments.

The assessment tool also enabled patients to raise a large number of other issues with the nurses, as illustrated in Graph 6-6:



Graph 6-6 Number of issues raised by patients

Patients confirmed that they felt in control of the assessment agenda; in the follow-up interviews, all eighteen patients who had high scores on the tool stated that content of the assessments reflected their issues and priorities:

Extracts from patients' follow-up interviews	
<p>CW: What I want to ask you first of all is did you have any thoughts about filling in the questionnaire</p> <p>P: Well it's funny because when it was first discussed I thought 'Ooh no I'd rather talk to people rather than fill up a questionnaire' but actually I found that it was really useful. It was a really good <i>aide memoire</i> and I found it gave a construction to the whole session and didn't in any way prohibit me from saying what I wanted to say and I found it very useful. I found it very useful [...] you didn't have to answer a question if you didn't want to, you didn't have to answer the question about on the emotional matters if it was too painful and things, and you can say I can't talk about that today. Well I can, that's the trouble [...] I felt I led it actually, rather than being led</p> <p><i>(Follow-Up interview Felicity; original emphasis)</i></p>	<p>P: I didn't feel as if I was being pushed into anything. Oh no, no, [...] because you've got the choice. You're answering it yourself at your own pace, there's no rush to do it. And then, you just quietly talk to the nurse about anything that's got a higher score. You haven't got to talk about every single question, it's only those that have got a higher score. And all the nurse is doing is just trying to help you so, definitely, I thought it was good.</p> <p><i>(Follow-up interview Elizabeth)</i></p>

Patients not only liked the sense of control that the tool gave them, but also the way which it facilitated discussion of important issues, which then felt supportive:

Extracts from patient follow-up interview

CW: And, when you said [play back section of tape re. Macmillan nurse] about not wanting to talk – yet here we were encouraging you to talk – what did you feel?

P: [Laughs] Well, I know. That's the strange thing – it was different. Different. It wasn't like I was being asked questions, but just being asked to say what things were like for me

CW: And is that better – a better way?

P: Yes. Much. It doesn't feel like it's being forced on you.

(Follow-up interview Amar)

6.3 Summary

The assessment tool changed the format of the assessments from an information-seeking exercise which ensured the safe administration of chemotherapy, to an interaction in which nurses and patients engaged with issues affecting the patients' lives. The patients appreciated the assessment tool, and felt that it gave them a sense of control over the conversation. The revised CMOs arising from Phase 2 of the data collection are summarised below in Figure 6-2 below.

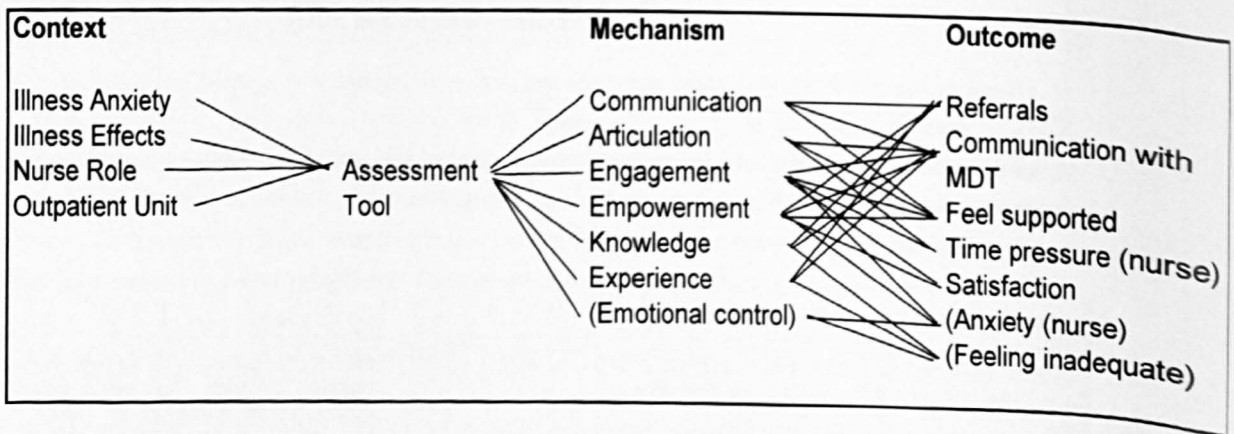


Figure 6-2 Revised CMOs, Phase 2

The next chapter offers an explanation of these findings, by presenting them in the form of a conceptual model, to depict the relationships between the mechanisms and the outcomes identified in the data.

Chapter 7 Explaining the impact of the tool

*How little the real sufferings of illness are known or understood.
(Nightingale 1859)*

7.1 Introduction

This chapter is concerned with drawing the findings from the previous chapter into a conceptual model to explain the impact of the assessment tool. This is consistent with the realist evaluation, which requires three levels of theory building. This is the second level, and aims to portray the relationships between the mechanisms and outcomes identified in the findings, in order to explain the effect of the intervention. The model (see Figure 7-1 below), illustrates the change mechanisms, or processes fired by the tool, and their effect on the assessment conversation.

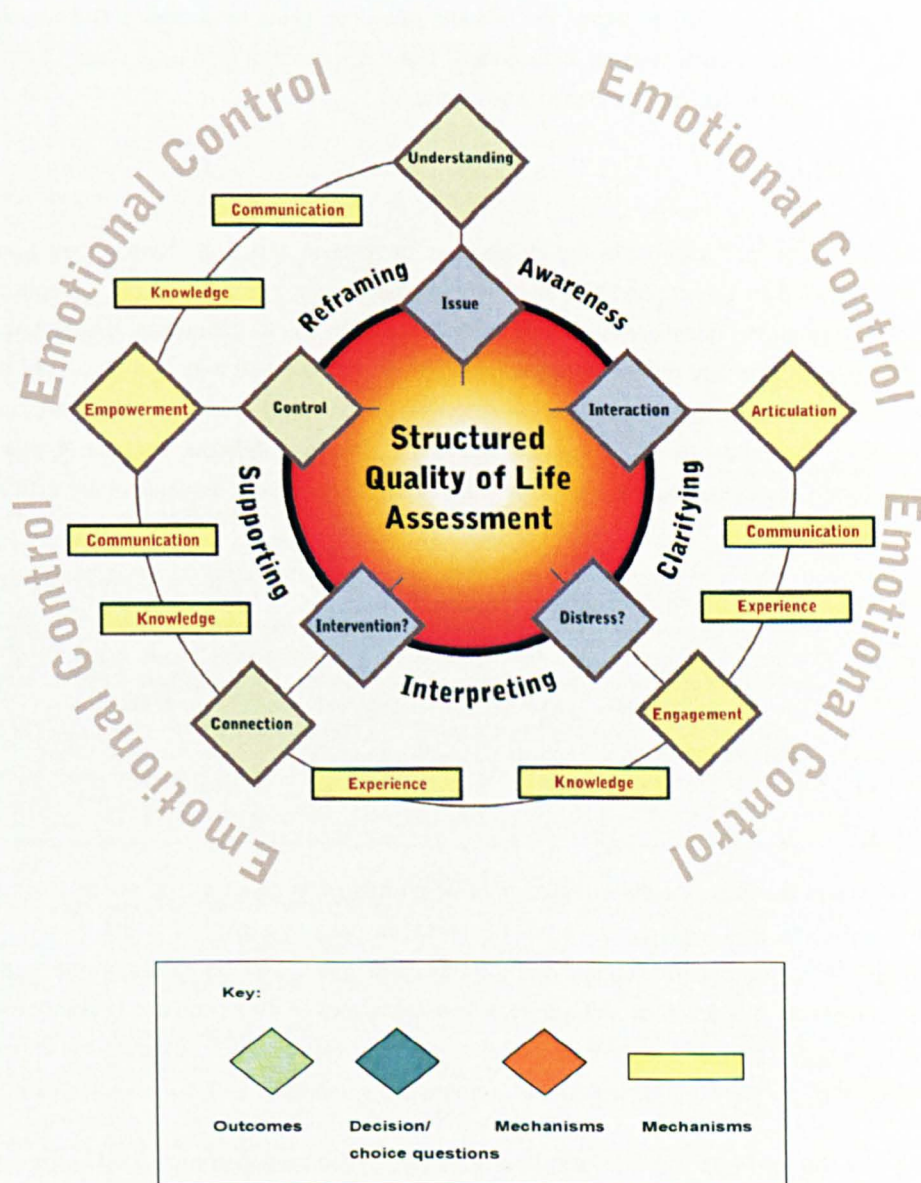


Figure 7-1 A model of structured quality of life assessment

Structured quality of life assessment was based on an 'assessment tool', which comprised two complementary and sequential parts. Firstly, the patients completed a questionnaire; any issues which they felt were pertinent to their situation and experience were given a higher score. These issues formed the agenda for the second part of the assessment, a follow-up interaction, in which the high scores were explored. The interaction had five phases which are depicted in the inner circle of the model: raising *awareness* (of the issue), *clarifying*, *interpreting* and *supporting*. These facilitated a fifth, a *reframing* of the issue from 'problem' to 'experience'. The outcome of these phases was greater 'understanding' for both the nurses and patients of the issue under discussion.

The mechanisms knowledge, experience and communication were fired throughout, although the mechanisms of articulation, engagement and empowerment which were fired specifically by the tool were more powerful in triggering the principal outcome, ('understanding'). All these mechanisms have been detailed in previous chapters, so this chapter is concerned primarily with an explication of each of the processes outlined above. However, the role and relevance of the mechanisms and how they were fired will be clarified as each process is described. The mechanism of emotional control (primarily the nurses) was present throughout the Phase 2 assessments.

7.2 Awareness

The tool raised patients' awareness, by giving them permission and time to voice their worries and sufferings, rather than giving priority to treatment-related issues. For instance, 16 patients said that seeing the issue on the questionnaire made them feel able to talk to the nurses; 8 said they had not talked to the chemotherapy nurses in this way before, and 7 said that they had discussed the issue 'differently' (Daisy) because it was on the questionnaire. By this they meant that they had 'spent time' (Muriel) 'telling the nurse' (Emily) about their concerns. This was different because 'it was not just mentioned and OK, but she seemed to really want to hear' (Joy). Such sentiments are echoed in the following extract:

Extract from patient follow-up interviews

Usually I don't talk about the pain I have with the nurses here, it's something I live with or talk to my Macmillan Nurse or GP about, and I would never really think to talk to the nurses here about my pain. With them I talk about the chemo usually. But having the questions on the questionnaire, seeing the questions written down on a printed sheet was different from just being asked about it, I had a choice about highlighting whatever, and because it was printed it made it seem like it was expected, and that it was something that was sort of normal, not unusual and that it was OK to talk to the nurse about it. I was quite surprised to do that.

Pauline

Having identified the issue on the questionnaire which had been given a high score, the nurse and patient spent some time exploring it. In this conversation patients explained to the nurses how they were living and coping with their cancer and the treatment; this raised the nurses' awareness of such issues. To illustrate this point, an extract from an assessment at The Southern is presented below, between Penny and May. I have chosen to feature Penny's assessment to illustrate the impact of the assessment tool, because her assessment of Grace was the exemplar for the Phase 1 assessments.

Extracts from the follow-up interview with Penny (in the speech marks) are provided in the right hand column of the box below, to show how the assessment tool raised Penny's awareness of the patient's (May's) pain and its impact on her life. May was attending for her second course of chemotherapy for

relapsed breast cancer; five days earlier she had been discharged from hospital after an emergency admission for uncontrolled pain, when a fracture of the pubic remus and multiple bone metastases were diagnosed. Some analysis notes are also included.

Extract from assessment conversation Penny and May (The Southern)	Extracts from Penny's follow-up interview/Analysis notes
<p>N: OK. Another thing you've scored high is pain</p> <p>P: Uh huh</p> <p>N: And the fact that the pain is interfering with your daily activities as well</p> <p>P: Well it's the pain that stops me walking =so -</p> <p>N: =Well, can I ask where you get the pain because I don't know very much about the pain</p> <p>P: Well the pain's there [<i>points to inner thigh</i>] somewhere. It's almost like in the groin but it's not quite. Um but what it is, is that's where the worst bit of bone cancer is and I've also fractured it somehow</p> <p>N: Ooh</p> <p>P: So I think it's - I would assume - and this is a totally uneducated guess - that most of the pain's from the fracture because I can move it. It's just when I put weight on it, it hurts¹</p> <p>N: And what are you - do you take any medication for pain</p> <p>P: Yeah [<i>discussion of tablet's name: Co-Codamol</i>]</p> <p>N: And do you take those regularly</p> <p>P: Yeah</p> <p>N: OK. And do they help</p> <p>P: I don't know because I haven't not taken them². Does that make sense?</p> <p>N: Right. And are you still getting pain at other times do you - they don't take the pain away completely</p> <p>P: =Well no</p> <p>N: =By the sound of things</p> <p>P: Sorry I get ever such a dry mouth I have to keep drinking*</p> <p>N: That's all right</p> <p>P: When I'm sitting here like this I've got no pain</p> <p>N: Right</p> <p>P: But if I stood up it would hurt. Now I would imagine it would be the same without pain killers; it might be worse. I honestly can't comment</p> <p>N: Do you have pain when you're sleeping at all</p> <p>P: Well if I try to move in a silly position³</p> <p>N: So how do you feel about your pain control from sort of a medical point of view? Do you feel like that the tablets are adequate enough or do you feel like -</p> <p>P: Yes because the way I'm also thinking is that if I've got a fracture there it also needs time to mend and if the pain [killers] were blocking it out and I was walking on it, it wouldn't do it any good. So I don't know long a fracture like that does take to mend or should roughly but that's the kind of way I'm looking at it but um</p> <p>N: Yeah</p> <p>P: While the sharp pain is there when I stand on it I shouldn't really</p>	<p>"I wouldn't normally go into pain like this; to me it didn't seem so bad, - she didn't seem uncomfortable or in pain as such - I can usually tell by looking at someone - and it's not something that falls in my job really, so if I'm honest, this was a new way of talking because we don't usually go into patients' medical details, usually we concentrate on chemo issues. When she said she'd fractured it, it sounded horrible for her"</p> <p>¹Articulation of how May understands/has rationalised the issue</p> <p>² "She made me feel stupid; I wanted - I just wished I could leave it and go onto something else but I couldn't"</p> <p>*missed cue: Patient's blood tests results later identified hypercalcaemia (disabling mechanism - lack of knowledge/experience of cancer/palliative care)</p> <p>³ "I was quite uncomfortable when she was talking about how she managed the pain, like I was interfering in something she had sussed for herself. [...] I was feeling anxious when we were talking about the pain medication; I wasn't sure I could advise if she had wanted different analgesia, and then I felt she put me in my place, she was being a bit patronising to me."</p> <p>"At the end I'm afraid part of me thought, 'so what?' What is there for me</p>

<p>block it out so that I don't know it's there</p> <p>N: Mm</p> <p>P: I hope that does make sense</p> <p>N: Yeah [small laugh].</p>	<p>to do? Was there any point discussing this? And in one sense, no, but in another I've learned something new about how patients manage their pain day to day."</p>
--	--

May's articulation of her pain to Penny was a novel experience for both; she said later that she had not talked about her pain in this way with anyone else to date:

'I was surprised at how much I'd thought about it. I didn't think I had but I've worked out how to manage it quite well, haven't I?'

May: follow-up interview

The extracts from Penny's follow-up interview reveal that she felt anxious during the assessment, and a closer analysis of the conversation identifies the effect of emotional control which was fired to help her to manage this anxiety. The following section explores this issue in more detail.

7.2.1 Emotional control of 'awareness'

Penny's anxiety stemmed from two factors: a limited knowledge of pain management, and her discomfort resulting from the role reversal in the assessment. May had become the knowledgeable partner, in control of the interaction; May's experience of her pain, and the strategies she had devised to keep it manageable left Penny feeling 'patronised', superfluous and interfering.

Penny attempted to bring the assessment agenda back to issues in her sphere by asking May to concentrate on the management of her pain from a 'medical point of view', and by inquiring about the tablets, since these were areas where an intervention that she could facilitate would be feasible. However, May continued to explain how she had rationalised the pain and is thus portrayed as an 'expert patient'. The interaction, therefore, legitimised May's experience and gave her control of the agenda, but this left Penny in a role of a listener, not a 'do-er', and she was not comfortable with this.

Elsewhere in the follow-up interview from this assessment, Penny described how she felt she had 'lost control' of the conversation with May, which made her anxious and frustrated. This sense of not being 'in control' of the content of the assessments was also shared by Noreen, Brenda and Kim, who all saw this as a negative outcome of the assessment tool:

Extracts from nurse follow-up interviews	
<p>The questionnaire makes me feel anxious because you never know what they're going to bring up next. What you're going to be asked.</p> <p><i>Noreen</i></p>	<p>You have to be ready for all sorts of things, and although I don't mind, it is kind of stressful. You don't know where the patient's going to take you in these assessments, what you're going to have to talk about. Out of my comfort zone I think!</p> <p><i>[Laughs]</i></p> <p><i>Kim</i></p>

The assessment conversations reveal a number of strategies that the nurses used to try to regain control of the assessment. One strategy was for the nurse to use the assessment tool in a question and answer format, to prevent engagement with the patient's issue; another was to try to close down the topic in order to move the assessment onto another area; and a third strategy was to concentrate

on a medical interpretation of the problem (as in Penny's assessment of May). Despite these attempts by the nurses to control the interaction, all the patients said they felt that they had had an opportunity to 'tell their story' (Wilson et al 2006), and they believed the nurses had a better understanding of their circumstances and experiences.

7.3 Clarifying the issue

'Clarifying' was a process in which patients appraised their concern in terms of how much it 'bothered' them. At the outset of the study it was expected that exploring the problem in this way would serve as a screening process to enable the nurses to identify patients' troublesome issues for which specialist help and support were required. Instead, patients responded by clarifying the issue, using the opportunity to talk further (mechanism = communication) about their interpretation of the issue, and possible explanations. This led, in the majority of instances, to patients articulating their distress, describing to the nurses how the problem or symptom impacted on their lives and relationships.

During the clarification process, patients did not minimise the impact of their symptoms or anxieties, but verbalised their hitherto hidden meanings:

Extract from assessment at The Northern	Extract from assessment at The Southern
<p>N: Your appetite, does it bother you?</p> <p>P: It does bother me because I'm so skinny.</p> <p>N: How much - is it a bit, or quite a lot?</p> <p>P: It worries me a lot that I don't eat properly. I mean, people look at me as if I'm anorexic and I'm not. And you feel like saying "It's not because I'm anorexic, it's because I've got something else" and you just can't say that, can you?</p> <p>[..]</p> <p>N: About your appearance, do you have worries or concerns?</p> <p>P: About my weight yes, about going bald, no. But the weight issue bothers me [...] I daren't get on the scales. I was six and a half stone on the 20th April, but I don't know what I am now. I haven't been on the scales since, and I'm thinner than that now. Nobody's put me on the scales. So that's about it. It's my weight more than anything that bothers me. I think if you've got a bit more weight you are more able to move and do things and you look less ill so you then feel better. But I'm so skinny at the minute that no, I'm all bones.</p> <p><i>Myra and Patricia</i></p>	<p>N: OK and the last thing that you've mentioned is the fact that you're quite worried about the future. Is that related to - um your cancer or related to [slight pause]</p> <p>P: Purely related to the cancer [...] Thankfully [Dr S] told me today that the chemo's doing what it's supposed to be doing</p> <p>N: Excellent</p> <p>P: It's doing the trick and zapping the tumour. It's not got rid of the fluid round the lung yet which is causing all the breathlessness but hopefully that will come with more, but it is zapping the tumour so that's pretty good news. So I'll probably worry a bit less now so. [...] It's the way it's described isn't it like 'aggressive this and that' in the forms for my medical retirement, [...] and [<i>tears welling in eyes</i>] you see 'aggressive' 'incurable', and all these words start adding up in your head don't they</p> <p><i>Penny and April</i></p>

Thus, the assessment tool enabled patients to clarify their worries, symptoms and experiences, through the articulation of their distress. In Phase 2, patients did not feel, as they had said in Phase 1, that talking was 'holding up the nurses' work'. The assessment tool signalled to the patients that talking about such issues was the nurses' work. The problem was that the nurses did not share this; 'assessment' to their minds remained a means to make treatment-related decisions, so the talk generated by the assessment tool was perceived to be a 'waste of time' or 'irrelevant' to their role:

Extract from nurse follow-up interviews	
<p>I can't see the point to this really. I mean I can see that we should assess patients' symptoms more than we do usually, but doing it this way doesn't seem to be helpful. It takes so long and - I just think we need something more related to chemo, like a toxicity scale and side effects. This isn't relevant to what we do here. Sorry to say that.</p> <p><i>Brenda, The Northern</i></p>	<p>The assessments are interesting and I enjoy doing them, but they aren't really helping me in my role here. It takes so long for the patient to tell you what's wrong, and that doesn't work here really. I can't see how this relates to what I do. I can see how it gives me a more holistic picture of the patient, but in here, that's not really necessary and I think I can get that anyway without the questionnaire.</p> <p><i>Kim, The Southern</i></p>

There are two explanations for this response: firstly, that the context the nurses were in meant that they felt pressure to be busy; their work was primarily a technical task, not talk. Thus, to spend time assessing patients' non-treatment-related issues (outside of their role) was using time they believed they did not have. This is discussed further in Chapter 9. A second explanation is that the nurses' need 'to do something' was an emotional response to their own distress when listening to patients' difficulties. It is this aspect which is addressed in the following section.

7.3.1 Emotional control in 'clarifying'

Engaging with, and hearing, the patients' discomfort was difficult for four of the nurses, and left them wanting to 'do' something to relieve or alleviate the patients' distress. Thus, in many instances, particularly at The Northern, the nurses sought to offer an intervention or solution for the patient's difficulty in order to 'fix' the problem and make it better. This is illustrated in the following extract from Brenda's assessment of Diane

Extract from Brenda's assessment of Diane	
N:	I notice you've got down about feeling depressed
P:	Well you know you do, you worry about will it happen again and that, and you do worry
N:	Quite a lot?
P:	Very much
N:	Yes. Is there anything you think we can do to help you with that
P:	[...] - but no, no I've got G my sister here, and my mum and that. But it is a worry because you just don't know what's going to happen at all do you? It is on top of your mind all the time. But then it's not surprising is it? Everyone must feel like this
N:	Do you want me to have a word with S to see about getting somebody back because I can arrange that from here
P:	I think I'm all right at the moment.
N:	I think I probably would do, because you see all the Mac nurses they liaise with each other closely in the district
P:	OK
N:	Any time just say, just say [Assessment moves to financial issues]
N:	So again think about having someone
P:	= Come round
N:	= Come round. It doesn't mean anything's imminent or anything
P:	No no. I know what you mean

N: Some people think "Oh no what is she not telling me" but that's not what I mean
 P: Oh no I know what you mean [Brenda]
 N: There's a good service out there so you could make good use of it
 P: OK
 N: Shall I have a chat and see if S [Macmillan nurse] is free, and she can tell you what's out there
 P: OK. Just to see what's out there
Brenda and Diane

Afterwards, Brenda said:

I wanted her to see S. I didn't like the fact that she wasn't in the system. I feel better now she's going to see S'

(Brenda field notes)

Thus, Brenda 'felt better' for being able to intervene: taking action helped her cope with the anxiety she felt when talking with Diane, who was young, with school-age children, and had a poor prognosis.

This need to 'do' something reflected the nurses' lack of palliative care experience and communication skills, since they were unaccustomed to hearing and 'holding' (Bailey 1995) patients' distress.

7.4 Interpreting

The assessment tool enabled patients to interpret their problems and concerns in terms of their lives and their coping strategies. Thus, thinking about whether the situation distressed them gave them an opportunity to place their experience into their wider life-world and bring to mind situations where they had faced problems and come through them. This applied to half of the patients in the study; all said that being able to put their current experience into their life-time experiences was helpful. The extract below illustrates one such example:

Extract from assessment at The Southern	Extract from Violet's follow-up interview
<p>P: My daughter was here 6 years ago. She was having chemotherapy N: Was she? P: Were you here? N: I was yeah P: Z was her name. She had Hodgkin's [..] N: Oh my Lord so how's that =affected you P: =It's not just that. My son had leukaemia when he was 5 N: Good Lord it's a P: This is why it didn't affect me so much because I was used to it I think N: Sure P: One after the other you learn to cope <i>Sue and Violet</i></p>	<p>I remember how ill my children were when they had their chemo and that helps me to think positively. It's tempting to think that every ache and pain is the cancer you know but I remember my daughter she had dreadful pains. And they got through it and so I will get through it too. The worst part is the treatment. I don't mind, I'm not worried for me whatever happens, but for my children. For them it's hard because they were treated here, and so I try to be positive for them and so that's it. I have to fight it whilst I can. To keep going for them.</p>

Explaining the impact of the tool

Interpreting describes the way in which patients were allowed to talk in their terms about the problem. There were occasions when patients' interpretation of an issue on the questionnaire was unexpected, and, had the nurses not spent time talking with the patients, the assumption about the meaning or interpretation of the high score would have been different. For example, when asked to clarify and interpret a high score for being limited in social activities, the restrictions patients talked about were not only the result of lowered energy levels (which was the expected explanation) but also: their embarrassment about body image (Amar and Patricia); being a visitor to Britain and not knowing many people (Rose); unpredictable symptoms (Pauline); and spouse's cancer illness (John).

Enabling patients to interpret their issues for themselves helped to prevent misunderstandings arising, and ensured that the patients', not the nurses' meanings predominated.

Knowledge and experience affected the interpretation of patients' problems. Limited knowledge led to misinterpretation, or lack of exploration of patients' symptoms, as the example below illustrates:

Extract from Noreen's assessment of Julia

- N: Right, number 11 you've had trouble sleeping, it's because of the pain?
P: Because of the pain, yes that's right.
N: Right. [...] And you feel weak because?
P: Same reason.
N: Yes.
P: Yet I get up early in the morning, I can't sleep in.
N: Right. This is the same thing, during the past week you've felt really tired. If you get a good night's sleep I think that would help.
[...]
N: The pain does interfere with your daily activities quite a bit?
P: Yes, my daughter does my housework for me and the garden. I can't do it now.
N: It's probably best now you've got the smaller garden.
P: That's right.
N: Go out when you please, obviously when the pain and the tiredness gets better but the tiredness also escalates because obviously one problem can affect another. So hopefully if the pain is sorted.
P: Perhaps life would be a lot better.
[...]
N: And here it says number 24 you're feeling depressed.
P: Well yes I am a bit. It gets me down see. I feel flat and fed up a bit. I'm so tired
N: Yes if we could get you a better night's sleep, sort the sleep out, then it would improve I think.

Noreen and Julia

In her assessment, Julia stated she was 'always tired'; she initiated the subject of tiredness five times. On four occasions during the conversation she spoke of how dependent she had become on her husband and daughter; of her irritation with her family; had given depression a score of 4 on the questionnaire, and stated that she was waking early each morning. This collection of symptoms might have been a sign that Julia was depressed, but Noreen did not understand this. Had she done so, she might have interpreted the issues raised in the assessment differently.

7.4.1 Emotional control of 'interpreting'

Although Noreen's missed cue and misinterpretation of Julia's psychological status reflected her knowledge base, there were other instances when the nurses' interpretations of the assessment interaction were a response to the mechanism of emotional control. For example, patients' problems and issues were sometimes consciously (and unconsciously) misinterpreted to limit the depth of the discussion, and keep the focus of the interaction on more neutral matters. In the extract below Brenda combines 'worry', with 'social activities' and 'family' life, and interprets them in terms of 'food', eating and appetite, although Elizabeth does not share this linkage:

Extract from Brenda's assessment of Elizabeth	
N:	I mean obviously you've ticked here things like worrying, how it's interfering with your family life, interfering with social activities. Again social activities is part of the eating, and family we tend to think of it as different.
P:	Yes, I mean I haven't done that with the family thing. Really it's just that I'm, one of my sons is in the army and he's moving back from Germany this year, in October, because I'm ill. That's a big disruption for them, although they think I'm quite happy about it. I didn't mean it like that, I mean that it's a disruption at home.
N:	Right, that what you're telling me about your son actually ties in with worries and concerns about important people in your life, I mean is that one of the issues?
P:	Well that's one of them. Another is my daughter is on her own at the moment with twin boys, 7 year old boys and she's going through absolute hell at the moment. What with separating from her partner and she's left with the children and she's trying to look after me as well. That's why I had to get some help somehow because I live in S, and [daughter] lives in M, and although it's not that far away and she drives, it's far enough, you know? And also they're worried and trying to do their best for me, so it does, it disrupts the whole of the family. I've got another son, he's the youngest, he's 24 going on 16. [laughs]. And I don't think he knows, actually, how to cope with it really. He just doesn't know what or how.
N:	Is he living with you?
P:	He's sort of with me, sort of, but he's just come back from Iraq so when he came back from the army he didn't have anywhere to go so he's with me part time. And having seen all he's seen he just can't take anymore on; he's in denial, but that's understandable.
N:	Just get him, get him involved in the snacks.
<i>Brenda and Elizabeth</i>	

This strategy, in which several issues were linked together, to create a more neutral interpretation before allowing the patient to clarify the score on the questionnaire, was identified in five of the assessments, all involving Brenda, Kim and Penny.

7.5 Supporting

The Phase 2 assessments enabled patients to identify their sources of support. Eleven patients said that talking about their difficulties in the assessment reminded them of how supported they were, and how much effort had been made to help them. This was supportive in itself:

'I realised that although things are really tough and difficult, lots of effort has been made on my behalf. It felt good to be able to do that'

(May).

There were three aspects to the supporting process. These were: patients' articulation of the support they were receiving; acknowledging patients' lay support network; and referring patients to supportive care services.

In the follow-up interviews, 12 patients' support came predominantly from family and friends. Seventeen of the 19 patients said their professional support came primarily from the consultant oncologist, even when they were also in receipt of other palliative or primary care services. This support, however, was concerned with the oncologist's role in making decisions, providing treatment, and mapping the illness trajectory (Strauss et al 1987) rather than any expertise in managing symptoms.

Appendix 16 summarises the professional support which the patients identified, either during the assessment, or during the follow-up interview. The patients at The Northern were in receipt of more professional and specialist palliative care support than the patients at The Southern; the most regular input came from the community nursing service.

Patients used the assessment conversation in Phase 2 to tell the nurses about the help they were receiving from friends and family. This contrasted with the findings from Phase 1. In Phase 2 patients were able to place themselves within a social network, supported professionally (as desired) and by family and friends. The assessment tool enabled the patient to bring their life-world into the chemotherapy unit, through the acknowledgement of the practical support and affection that was being shown to them. For example:

Extract from Noreen's assessment of Rose

- N: At the beginning it asked you if you had any trouble doing strenuous activities like carrying heavy shopping bags or a suitcase, and you do, you circled very much.
- P: Yes, I can't do much.
- N: You can't. Right. Have you got any help at home?
- P: Yes.
- N: You have, so who's at home with you?
- P: My daughter.
- N: Your daughter, yes?
- P: She helps me.
- N: Right, and so who else is at home?
- P: I have a son-in-law and two granddaughters.
- N: Right, and do they help so far as the shopping is concerned?
- P: They do look after that. I can't get out.
- [..]
- N: Are you able to get up to wash yourself and get dressed?
- P: No, I need help with that. Because I have this as well, you see? [points to colostomy]
- N: Oh you've got, right.
- P: I have that to cope with as well.
- N: Yes. Is there any help for that at home?
- P: Yes, my husband and my daughter. They take me to bed.

Noreen and Rose

In contrast to their Phase 1 assessments, when few suggestions were made to patients to help alleviate their discomfort, nurses in Phase 2 (particularly at The Northern) offered to provide information and services in response to patients' concerns. The interventions which the nurses suggested and organised for the patients in Phase 2 were summarised in Chapter 6 (Table 6-7). In addition, nurses gave information informally during the assessment, which patients reported was supportive:

Extract from assessments at The Northern	
N:	Now you're feeling very tired
P:	Yes and whether it's to do with this or whether it's to do with the ongoing state I don't know
N:	What are you doing at home? Are you still trying to do the same amount of -
P:	Yes, yes the housework. I've had two weeks - the doctor gave me the last week off work and the next week off work and I've been doing housework which I know I won't always be able to do but when I get this terrible pain it makes you feel shaky and weak for a little while, and just because I'm at home I notice it more
N:	Have you got anybody in the house at all? Can you share things out with the family?
P:	Yeah oh yeah I can do that. I suppose I just try and see what I can do really, it's me
N:	Have a little nap in the afternoon. Have you ever been given a booklet on fatigue
P:	No
N:	Right we should have one somewhere. I'll have to go down to the information room and get a Handy Hints for you to help you and give you ideas of what to do. OK?
<i>Noreen and Pauline</i>	

The nurses liked the opportunity to 'do' something for the patients, especially Brenda, who was the least enthusiastic of the nurses at The Northern about the assessment tool. Indeed, when an opportunity arose to refer Elizabeth to the dietician, she said:

Extract from Brenda's assessment of Elizabeth	
N:	We can refer you to a dietician if you like?
P:	Oh yes.
N:	If that's a problem
P:	Yes maybe they can do something for me.
N:	That's it, <i>[sotto voce]</i> there is a point to this after all. Sorry, I shouldn't say that <i>[laughs]</i> .
<i>Brenda and Elizabeth: emphasis added</i>	

The nurses' assessment practice at The Southern did not change as noticeably between Phase 1 and Phase 2; fewer interventions were offered and less advice given to patients during the assessments.

7.5.1 Emotional control when supporting

The assessment tool allowed patients to articulate their concerns, fears and difficulties. The engagement that ensued was deemed to be supportive, but for the nurses, this engagement was costly, not only because they experienced distress whilst listening to the patients', but also, because the tool aroused negative feelings, such as anxiety and inadequacy. Phrases, such as:

Extracts from field notes: The Northern	Extracts+ from field notes: The Southern
<p>It's so sad; made me want to cry. She was so nice, and so open. Quite shocking</p> <p><i>Noreen</i></p> <p>That really got to me that one. I'm all wrung out.</p> <p><i>Brenda</i></p> <p>I feel sad. I don't know what to say to her. I've never heard this kind of thing before.</p> <p><i>Myra</i></p> <p>Do you think it's upset her? I'm worried we might have stirred up a wasps' nest and caused her real trauma. Is this type of assessment right?</p> <p><i>Brenda</i></p>	<p>It's really sad. So very sad. How do people cope?</p> <p><i>Penny</i></p> <p>I feel so powerless. What can I do? Why talk about such things when there's nothing to do?</p> <p><i>Sue</i></p> <p>Poor thing. How dreadful for her.</p> <p><i>Kim</i></p> <p>What a mess she's in.</p> <p><i>Sue</i></p> <p>I felt such a fool, not realising his problems were so bad. Did it show?</p> <p><i>Penny</i></p>

Supporting patients was 'draining' for nurses, and raised questions among some of them as to whether this type of assessment was necessary in the chemotherapy unit.

In summary, the assessment tool facilitated patients' articulation of the support they were receiving, from a network of family, friends and in many cases, professional carers. The assessment tool, and the engagement which it enabled, also ensured that nurses were able to offer support (advice), and, through their listening, be supportive.

7.6 Reframing

The final phase in the assessment process was reframing (see Figure 7-1). The issue to which patients had assigned a high score on the questionnaire, perceived at the outset of the study to be a potential 'problem' to be dealt with, was, for the most part, reframed to an 'experience'. Patients found that talking about the problem helped them to better understand it; they valued the nurses' empathy. All the patients appreciated the time and attention given to them to enable them to talk through their concerns: the opportunity and time to talk enabled them to reframe some aspects of their situation.

This approach to assessment was new and different for the nurses, who perceived assessment as an activity related to chemotherapy and solving patients' problems. The 'reframing' phase was not fully appreciated until after data collection had been completed and the analysis had commenced.

Patients appeared to accept that there were many aspects of their illness and treatment that they had to learn to live with. In both case study sites, the most frequent reasons patients gave for declining offers of help were that they 'expected' to feel like they did (n=18) and they did not think there was anything that could relieve the situation or symptom (n=16). Elizabeth's explanation of her experience of her abdominal ascites serves as an illustration of this:

Extract from Elizabeth's follow-up interview
<p>It's not so much pain it's the pressure. You can imagine a balloon and you can pump it up and it'll get bigger and bigger and bigger and you can feel it's really hard, rock hard. Well that's exactly what this is like, and yesterday and today it just seems worse. So it's a convenient thing for me to lie so it falls down the side. I can't sit. Medication I'm fine, that's controlling the pain, surgery type pain. You can't stand up straight because you get breathless with it because it's just pressing on everything that I've got in there, you know? I</p>

don't know whether they'll drain you off. So, as I say, it's not so much pain as just pressure. I feel as if somebody would put a pin in it and it would just explode. [..]

To be honest I don't think there's much that anybody can do at the moment. Just got to plough on. I see the consultant soon, should be next week. So, I think if there is anything that could be done then I'm sure they'll tell me. [..]

It's just that my stomach is so big and everybody thinks I'm pregnant, you know? I managed to go to church yesterday for the first time since I was in [hospital]. And I was wearing that top, that blue top and, although I was on crutches and everything, I know I can see people staring at me thinking "She's too old to be pregnant" you know? And I mean some people in church they actually knew what I had, but it is embarrassing. I think that I'll feel more embarrassed even when my hair falls out. But the Macmillan Nurse is coming tomorrow, maybe she can apply for a grant to help me get some clothes that are just a bit looser so they're not quite so tight and showing my big stomach. Because it is embarrassing, people do look at you. And I've got so old so quickly that what with this [points to abdomen] as well, I mean if I looked 30 I wouldn't care being pregnant, you know? But I'm 57. [..]

You've got to do this sort of thing [fill in the questionnaire] otherwise you're not going to find what patients need, are you? They'll only be guessing, and you're more likely to guess wrong because no-one knows what it's like except me because I'm the one going through it. [..]

So, I understand what's going on for me, why I look like this and feel like this. I accept it and I think the questionnaire helped [Brenda] to understand it too. Not to change anything because she can't, but just to understand. That's helpful in itself, knowing that she knows how it is for me and she wanted to help, I understand that. We both understood each other's view points, where we were both coming from and I think we ended up if not in the same place then near each other. So yes to your question, it was [helpful to talk like that] and that's why, because at the end of the day, I feel I understand and she understands, and as I say not many others who see me do.

Field notes:

Interview was conducted in Elizabeth's flat six days after her treatment. She asked if she could lie down whilst we talked as she was feeling less well, her ascites were worse and very uncomfortable for her. Had some pain also. We talked in her bedroom; two cats on the bed. Bedroom very messy; clothes lying everywhere, dirty crockery and empty glasses next to the bed. Very hot. She was very tired and less well than last Tuesday, and so I kept the interview fairly short (time 35mins). I asked if she wanted me to inform anyone (e.g. the chemo nurses) about her increased symptoms but she declined; Macmillan nurse due to call tomorrow. [..] 5th July 2004

Elizabeth perceived that Brenda understood her situation following the assessment. For Elizabeth, this was a positive outcome. This sentiment was echoed by twelve of the patients across both case studies highlighting the importance of allowing patients to articulate their experience and of engagement with it, in order to achieve a positive outcome of assessment.

Four other patients spoke of feeling reassured by the assessment because the nurses 'see this sort of thing all the time' (Pauline); thus, they believed they did not have a 'problem' because it was not unusual, even if it was unpleasant or tiresome, as April's comments demonstrate:

Extract from April's follow-up interview

I thought it was a really good way of helping the nurse and me to talk. I quite like forms mind you, so maybe that's why. But one thing was I felt that as she was going through it with me that she understood, she seemed to not be surprised by anything and that felt really nice. Things which were relatively minor I guess and which I had never brought up before but even so niggle away at the back of your mind in the night or in a quiet moment and such, she seemed to take in her stride and that left me thinking OK that's OK that's not unusual, she's seen that before. Now of course, whether she has or not I can't tell, but I felt that's what she was saying. She was very calm and kind and seemed to want to help. I think this is an excellent idea. What a shame it's my last treatment. Where've you been [laughs]

7.6.1 Emotional control in reframing

Hearing patients' distress and experiences was difficult and emotionally costly for the nurses. As Chapter 5 explained, in Phase 1, the nurses worked in the dark and controlled the assessments, concealing many of the issues raised and talked about in Phase 2. In Phase 2, however, the assessment tool 'opened Pandora's Box' (Brenda): a wide range of patients' issues were addressed,

which the nurses found difficult to accommodate. The nurses were concerned that the assessment tool was upsetting for the patients; they worried that the patients were experiencing similar reactions to their own. Five of the six nurses had reservations about the relevance of the assessment tool in this setting:

Extract from nurse follow-up interview, The Northern	Extract from nurse follow-up interview, The Southern
<p>I just feel this is for a Macmillan nurse to do. These sorts of things the patients are bringing up are really deep and it's not the place or the time for us to deal with them. Not when they're going to have chemo. They're stressed enough as it is and I don't think they should be asked these things at this time. It's too much for them. It holds them up. I don't really know if they want all this brought out into the open.</p> <p><i>Brenda</i></p>	<p>[..] when you're sort of asking somebody in depth on the quality of life questionnaire, the problem, a simple mouth problem can become horrifically complicated and so many of the symptoms were with regard to their disease rather than their chemotherapy and I had to also advise on handling of social and psychological problems. It doesn't fit here. How can we help patients do that when we're trying to help them through the chemo fog? How can we?</p> <p><i>Penny</i></p>

None of the patients said they found the assessment tool distressing; all appreciated the opportunity to talk about their concerns and experiences. Thus, the nurses' worries about the Phase 2 assessments may have reflected not only a *desire* to protect the patients, but a *need* to protect themselves.

Moreover, the nurses were not able to 'fix' patients' difficulties in Phase 2, leaving them feeling powerless and helpless about improving patients' situations. Neither they nor I had understood that the Phase 2 assessments were achieving something which had to be perceived and appreciated in different terms from usual practice. Consequently, at the time the study was being conducted, there was little apparent gain from the emotional cost of introducing the assessment tool.

7.7 Summary of Conceptual Explanation

To summarise, the model of structured quality of life assessment presented at the beginning of this chapter is a representation of the way in which the quality of life assessment tool facilitated a conversation between nurses and patients to enable greater understanding of cancer illness and/or treatment experience. The assessment conversation was characterised by five processes/phases, which were: raising awareness of the issue and having permission to talk about it; clarifying its impact in terms of the distress it caused; interpreting its meaning and significance, and identifying the positive; acknowledging and identifying support; and reframing the topic of the assessment from 'problem' or 'potential need' to 'understanding illness experiences'.

This chapter has answered the question: 'how did the intervention (the assessment tool) work?' through an explication of the processes and mechanisms fired by the tool. The remaining parts of the realist evaluation question are answered in the following chapters, starting with the third and final level of theoretical abstraction of the data, in which the assessment tool and its effects are embedded in a causal mechanism: social organisation theory.

Part Four



IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Overview of Part 4

Part 4 is concerned with completing the realist evaluation. A realist evaluation seeks to answer the question: What worked, and how, for whom, and in what circumstances (Pawson and Tilley 1997 p216; Mark and Henry 1998 p83; Kazi and Spurling 2000 p4).

The issue of 'how' the assessment tool worked was addressed in the previous chapter. Chapter 8 presents the third level of explication in terms of an underlying, causative generative mechanism identified in the setting: social organisation, which explains the format, content and relations in nurses' usual assessment, to explain the impact of the introduction of the tool.

Chapter 9 is the discussion chapter, and synthesises the main findings of the study with existing literature and theory. Limitations of the study design are acknowledged, and recommendations for practice, policy and research are made.

Chapter 10 concludes the realist evaluation, by answering the question: 'what worked, for whom, and in what circumstances', drawing on feedback from nurses and patients and using insight from analysis of the data. Some reflections on the process of conducting a realist evaluation are made, and a suggestion for how the CMOs generated and refined in this study can be tested in the future is offered. Conclusions of the study are drawn.

Part 4 begins with a theoretical account of how the tool affected the underlying generative mechanism responsible for nurses' usual assessments: social organisation, which explains the tool's mixed effect.



IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

Chapter 8 The social organisation of assessment talk

It is only where nurses place themselves in relation with, not to, the patient as a situated person that his or her needs can emerge accurately and appropriately.

(Latimer 2000 p127)

8.1 Introduction

The following explication of assessment in the chemotherapy unit is based on the 'generative mechanism' (Pawson and Tilley 1997; Kazi 2003) of social organisation, which shaped relations between nurses and patients during 'usual' assessment and was responsible for producing the type of assessments which were observed in Phase 1. Social organisation theory explains why the nurses positioned themselves in relation to the patients in Phase 1 (as in Latimer's quote above) and not *alongside*, which is where the tool tried to bring them.

The findings from the previous two chapters have revealed how the assessment tool changed assessment from a functional activity, concerned with making a decision that the patient was 'fit for treatment', to a conversation in which patients were allowed and enabled to articulate experiences of their illness. In Chapter 7, the way in which the tool achieved this ('how it worked') was depicted in the form of a model to represent the relationships between the mechanisms and outcomes, and the phases of assessment that the tool facilitated. This chapter moves the explanation of the tool's effect to a higher level, that of the real, by addressing the issue of causation.

The chapter is divided into three sections. The first explains the realist approach to causation. The second introduces social organisation theory. The third section explains why the social organisation of nurses' usual assessments was successful, and why the assessment tool was considered by the nurses to be problematic.

8.2 Realism and causation

Realism, from which realist evaluation emerged, is premised on the belief that ultimately, what is observed and experienced is the result of unobserved, underlying causes (Jules and Mark 1998). Reality is stratified into three layers: the empirical (the observed or experienced: presented in Chapter 4 and 6); the actual (an explanation linking the empirical with the real: reflected in the models of assessment presented in Chapters 5 and 7) and the real, which constitutes the realm of:

'..structures, powers, mechanisms and tendencies that underpin, generate or facilitate the actual events which may or may not be experienced.'

(Kazi 2003, p23)

Causation in realist evaluation is concerned with explanation, not prediction (Outhwaite 1987; Sayer 1992; Pawson and Tilley 1997). It is based on the identification of one or more underlying, generative mechanism(s) (Pawson and Tilley 1997; Stickley 2006) responsible for the phenomenon observed (in this instance, the type of assessments). The 'explanatory' or 'generative mechanism' is a metaphor for that which underpins, and can explain, the reasons for the observable appearance of a phenomenon or process (Pawson and Tilley 1997). The analogy of a clock illustrates this notion (Pawson and Tilley

ibid). Looking at a clock's face, it is possible to tell the time (the empirical); looking inside the clock reveals the cogs and springs, which gives an indication of how the hands move (the actual), but to understand how the clock works requires an explanation in terms of the 'oscillation of caesium atoms' (the real) (Pawson and Tilley *ibid*, p65).

This study, with its before-and-after design, has described two types of assessments (see Chapters 4 and 6), and has explicated their form and conduct with the aid of conceptual models (see Chapters 5 and 7). To understand the reasons for the content and conduct of the Phase 1 assessments, and the tool's impact, a causal explanation is required which encompasses the choices, relationships and capacities of the participants, as well as the social structures at work in the setting (Sayer 2000; Kazi 2003):

'the identification and investigation of the potential causal mechanism(s) that influence a programme's desired outcome are a crucial part of realist evaluation. The aim is not to cover a phenomenon under a generalisation (this metal expands when heated because all metals do) but to identify a factor responsible for it, that helped produce or at least facilitated it.'

(Kazi 2003, p 24)

The explanatory or generative mechanism which explains the findings is social organisation theory, which was inferred from the data. In social science, the role of theory is to represent meanings (Outhwaite 1987; Pawson and Tilley 1997); realism abandons positivist assumptions about scientific theory (Outhwaite 1987; Pawson and Tilley 1997; Kazi 2003), in particular, the laws of generalisability and external validity, which aim to prove that 'x' will cause 'y' in every case. Rather, 'truth' is considered in terms of its 'practical adequacy' (Outhwaite 1987; Sayer 1992; Pawson and Tilley 1997). Therefore, the following paragraphs construe, not construct the social organisation of assessment, whilst recognising that this account is a fallible interpretation (Sayer 2000; Tolson et al 2007).

A realist explanation can be considered to be 'good' if: the postulated generative mechanism is capable of explaining the phenomena (see Chapters 4-8 to make a judgement); there is good reason to believe in its existence (see Sudnow 1967; Dingwall 1977; Bloor 1978; Strauss et al 1987; Silverman and Petr kyl  1990; Chambliss 1996; Diaz 2000); there is an absence of equally good alternatives (see Appendix 12 for audit trail) (Outhwaite 1987).

8.3 Social organisation

Social organisation is concerned with the description of the pattern of ordered activity and relations between people in a given setting or within a given task (Firth 1964). Although the term social organisation can refer to a specific entity, such as a hospital or other work place, it can also be a *process*, a part of the whole, which reflects the wider structure and network of relationships in which it is situated (Olsen 1968). It is this narrower definition that is being applied in this instance.

Social organisation theory explains how the assessment talk between nurses and patients was arranged and orientated to reflect and maintain the work of the chemotherapy units. The social organisation of assessment accounts for: the patterns of interaction; nurse-patient relations; the outcomes of usual assessment. In other words, social organisation theory explains the regularities of assessment.

The central focus of the explanation is on the kinds of *work* (Strauss et al 1987) involved in and achieved by the Phase 1 assessments, and in the way nurses and patients positioned themselves in order to accomplish this. Understanding assessment in the outpatient chemotherapy unit as work, or 'task talk' (Strauss et al 1987 p253) explains the tool's impact: assessment was *the* precursor to all the other work which the nurses were required to carry out and take responsibility for. The content and conduct of 'usual' assessments was socially organised to enable the nurses to work: the content ensured safety, efficiency, and accountability through the nurses' narrowly-focused questions and patients' answers; the conduct facilitated this 'information work', by constituting emotionally distant nurse-patient relations.

The tool created disruption because it changed assessment from its socially organised efficiency, to a lengthy, patient-centred, holistic conversation, and, at the same time, engendered anxiety in the nurses, because its content exposed gaps in their knowledge and experience, and forced them to confront emotionally challenging issues.

8.4 Understanding Assessment as 'Information work'

The intrinsic aim of 'usual' assessments was for the nurses to obtain, and patients to give, information. Assessment was thus 'information work', mutually conceived and achieved through interaction. The type of information being sought and given concerned: technical issues (e.g. the quality of patients' veins); treatment-related issues (such as side effects); and administrative issues (e.g. outpatient appointments). Such information was elicited and required to make a decision that patients could receive their planned cycle of chemotherapy.

Patients' information work was crucial to assessment: nurses relied on patients reporting side effects or problems, and believed that their relaxed and friendly approach facilitated information exchange. Patients shared the nurses' understandings of what assessment should involve and achieve. They had learned, from experience, what they would be asked, and what information was necessary or helpful to volunteer. Although much of the information sought and given in assessment concerned 'abnormal' experiences, the information work of the assessment was to verify that 'normality' had returned. Consequently, a 'problem' was not defined in terms of patients' difficulties, but was translated by the assessment process into a temporary inconvenience which was 'normal': i.e. to be expected; not unusual (experienced/met before); or transitory (resolved). If there were no problems, then there was no information to exchange, and nothing to talk about, as Barbara's assessment (Chapter 4, section 4.6.5) illustrates. Thus, the reality of assessment practice was concerned with identifying and confirming 'the normal' through the discounting of problems.

This narrow focus, however, contradicted the beliefs of half of the nurses who took part in Phase 1 of the study, who, although they recognised their priority was to assess chemotherapy-related issues (see section 5.2) also described their aims for assessment in broader terms, for example:

Nurses' beliefs about assessment	
<p>There's more to it [the job] than giving the chemo, isn't it? It's about caring for the whole patient. What I said [earlier] was the act of chemo a technician could do, and that's not what we're doing here really, is it? We're treating the whole patient and the things that surround the actual giving of the chemo are just as important as the actual act of giving it.</p> <p><i>(Kate, The Northern)</i></p> <p>CW: What is your aim in your assessments?</p> <p>N: I want to get to know them [the patients]</p> <p><i>(Brenda, The Northern)</i></p>	<p>I do appreciate that this is a difficult time for patients and that they have lots of other problems to deal with, so it's about identifying those too</p> <p><i>(Sue, The Southern)</i></p> <p>I think everybody here's very conscious of the fact that these people have lives beyond the four walls of the chemotherapy suite.</p> <p><i>(Penny, The Southern)</i></p>

There was, therefore, a discrepancy between the nurses' espoused aims of assessment and the reality of practice; between the nurses' beliefs about what they assessed, and the actual focus of the interaction; and between the values expressed in the units' philosophies (see Chapter 4) and the narrow range of information work which was carried out.

Part of the explanation for this discrepancy lies in the lack of information work which went on between the nurses themselves as they worked, which restricted opportunities for them to mentor or support each other, or share information about patients. Moreover, the limited information which came to the nurses from the wider multi-disciplinary team meant that they had little background information about the patient to inform their assessments. Nurses were working in the dark. As a consequence, the assessments were functional, shaped by the work of the units.

The relentless nature of work of the units was even more marked at The Southern, because the number of patients being treated per day was higher, and because all patients had to be assessed during the morning to enable treatments to be ordered from pharmacy. As the nurses there said, at times they felt as if they worked in 'a sausage factory', exacerbated by the unfamiliarity of the patients. Moreover, the limited opportunity in either unit for nurses to verbally share information about patients increased reliance on written information, but that only contained technical or treatment-related details (see sections 4.3.3.1; 4.3.3.3 and Table 4-24). Thus, nurses were working in the dark, having little information except treatment regime and biomedical details available to them as the basis for their assessments.

In contrast, the information generated by the assessment tool was not primarily chemotherapy-related, but focused on patients' illness experiences and problems. These were not transitory or easily resolved; nor were these issues 'normal' (i.e. familiar) to the nurses, who had limited palliative care knowledge. Moreover, the assessment tool placed patients in control of the agenda for assessment; this fundamentally changed the relations between nurses and patients, which the nurses found difficult. They missed being in control of the content and conduct of the assessments, were afraid of what was going to be asked and raised, and were concerned that patients' safety was being compromised by the wider agenda of the assessment tool. The information exchanged in Phase 2 was not specifically treatment-related, and therefore did not facilitate decision-making or work in the chemotherapy units (indeed, the tool hampered such work by considerably lengthening the assessment conversation). Unsurprisingly, the nurses perceived the tool to be unworkable and unhelpful.

Information work in usual assessment comprised five aspects: safety work; bureaucratic work; temporal work; negotiation work and emotion work. Each will be addressed in turn.

8.4.1 Safety work

Safety was the key issue underlying the information work of Phase 1 assessments. The aim of assessment was to answer the question: 'is the patient fit for chemotherapy?' by excluding reasons why treatment should not be given. Both patients and nurses were concerned for a safe outcome, i.e. that the proposed treatment was given without immediate or late complications. Twelve of the Phase 1 assessments were primarily focused on safety issues, with little else discussed; seven of these were at The Northern. Safety work comprised two elements: technical issues and prevention of complications.

One of the contextual factors influencing the safety work of both nurses and patients was the paucity of continuity of care. Nurses had little prior knowledge or experience of the patients, their veins, or previous reactions to treatment. Patients needed to trust the nurses, who were relative strangers and whose technical skill was 'unknown', to administer the treatment safely and with as little discomfort as possible. This accounts for the information that patients provided in the Phase 1 assessments:

Extracts from assessments: safety work	
<p>P: Sorry, I thought we had eight bottles, there's only six</p> <p>N: No, there's six</p> <p>P: Yes, but usually I have eight</p> <p>N: These are your steroids, the anti-sickness, perhaps pharmacy put it in bigger syringes. There's 1,2,3,4,5,6. Six syringes</p> <p>P: Well I've never had just 6 before. Hope they've got it right.</p> <p><i>Noreen and George</i></p>	<p>N: Anywhere I need to avoid?</p> <p>P: It's sore there</p> <p>N: Nice one on your hand here</p> <p>P: Really? Usually the hand is a problem. What about there [points to vein higher up arm]</p> <p>N: That doesn't feel so good. I think it'll be OK. [inaudible]. I can feel it. It feels nice and bouncy. I'll try here</p> <p>P: I'd rather you went up here, they've had dreadful problems down there, the veins keep collapsing</p> <p><i>Kim and Mary</i></p>

Safety work was not the priority of Phase 2 assessments. The assessment conversation focused on issues which the patient had scored on the questionnaire as troublesome or problematic. Although items relating to treatment (such as nausea, vomiting, dry skin, sore mouth) were available on the questionnaire, most patients gave these questions a low score, which meant that they were not discussed. Nurses in both case studies felt uncomfortable because the content and control of the Phase 2 assessments lay with the patient, which, they believed, prevented them from addressing the treatment agenda in sufficient detail. Even though the nurses were encouraged to ask any supplementary questions necessary to safeguard their practice, and the nurses at The Southern completed the toxicity proforma in addition to ART, the Phase 2 assessments were not perceived as 'safe' for the work that was carried out in the setting.

8.4.2 Assessment as Bureaucratic work

Assessment in the chemotherapy units was primarily concerned with eliciting knowledge for practice, and was less concerned with 'knowing patients' as persons or individuals, which is purported to be the purpose of nursing assessment (Latimer 2000). Although nurses and patients did engage in social

chat, during which patients might intimate their difficulties, none of this information was picked up or used. It was heard but left at the chair: the patients' social chat had no effect on the care given.

The nurses were working in an extended role; their assessments were a 'form-ality' (*sic* Latimer 2000 p81), reflecting the issues for which they were accountable and professionally responsible. These bureaucratic requirements were reflected in the paperwork, which focused on treatment-related and technical issues, providing limited space for other information to be recorded.

There was, however, a paradox in the assessments. Although nurses acknowledged the bureaucratic agenda, they saw this as secondary to managing patients' anxieties about their treatment and illness. They considered they successfully reconciled the tension between the bureaucratic and professional agendas for assessment by adopting a relaxed, friendly approach. They believed that this informality enabled them to assess patients holistically. Thus, the assessment tool was perceived as largely 'unnecessary'; most nurses considered they obtained similar information in their usual assessments, and did not see any added value in the tool, particularly as it caused them discomfort and disrupted the smooth running of the units. Moreover, the tool did not provide opportunity to use banter, chat and humour which nurses believed were the means to assess patients' wider needs. The tool was therefore perceived in terms of what it took away from their assessments: the satisfying (chat) and necessary (bureaucratic), leaving only the stressful, emotionally challenging and irrelevant. Not surprising, then, that the tool was considered not to 'work'.

8.4.3 Assessment as Temporal Work

Phase 1 assessments facilitated the temporal work of the units in two ways. Firstly, they were short (especially at The Northern), which enabled nurses to confirm quickly whether patients were fit for treatment. Such brevity ensured that the shape (Sbaih 2002) of the unit was maintained by constant patient through-put. Secondly, usual assessments limited discussion of patients' problems to the weeks preceding the treatment, thus permitting only a narrow temporal focus to the discussion of problems:

Extracts from The Northern (Emphasis added)	Extracts from The Southern (Emphasis added)
N: How are you this week ? <i>Myra and Amar</i>	N: OK I just want to check first of all whether you have had any problems following your last chemotherapy
N: Anyway how are you today ? P: Not bad. Not bad at all.	P: Er no not really <i>Kim and Edward</i>
N: Not bad. Not bad since your last Pamidronate? <i>Noreen and Clive</i>	N: This is your second one. OK. Any problems since last week ? <i>Penny and Joanna</i>
N: Have you had any problems in the last three weeks ? <i>Brenda and Edwina</i>	N: Any problems since the last chemo ? <i>Sue and Barbara</i>

If patients had any problems, the nurses' response was to identify that these had resolved or had been temporary:

Extract from The Northern (emphasis added)	Extract from The Southern
<p>Nurse B: Did you have any other problems</p> <p>P: Well I had stomach cramps I had vomiting diarrhoea quite severe. [...] And through the night it was bad. I had to ring as I said I had to ring the houseman medical emergency</p> <p>Nurse B: That's all settled now?</p> <p>Kate (Nurse B) with Myra and Amar (emphasis added)</p>	<p>N: Were you actually coughing anything up</p> <p>P: A bit of phlegm and all that [...] - it wasn't colourful or anything it was just clear know what I mean</p> <p>N: OK. And that's all cleared now?</p> <p>P: It's all cleared now</p> <p>Tina and Patrick (emphasis added)</p>

The effect of this narrow temporal focus was to enable the nurses to move on to another topic, and prevent detailed discussion of the issue. Thus, the temporal work of the assessments mirrored and facilitated the temporal work of the units, which required a constant throughput and regular turnover of patients, as an early extract from my field notes at The Northern illustrates:

I am struck by the sheer constancy of the work here. The nurses are not rushed off their feet, as on the wards, but the work never lets up. As soon as Noreen finished one patient and cleared away, there was only time to wash her hands and go on to the next one. Actually, it seems quite monotonous and somewhat lonely. There aren't the opportunities to stop and talk, to share and learn from each other. No 'report' or handover in the middle of the day, no way of sharing information or off-loading stress. Nowhere to hide: everything is so public. There's no private space for the nurses; they drink coffee in the preparation area and eat lunch at the desk [whilst in full view of the patients] – mutual surveillance!

Field notes, The Northern October 23rd 2003

Although the Phase 2 assessment tool asked patients to limit their responses to issues which had been a concern 'over the past week', they ignored this narrow temporal focus, and placed their experiences into a much wider temporal context. The assessment conversations therefore covered patients' past experiences (including how they had coped previously with crises; see section 6.2.3.2; 7.4), their personal and social history, as well as their fears for the future. This meant that assessments took a long time, and disrupted the temporal work of the units. Moreover, at The Northern, the assessments created work in terms of referrals, retrieving information, liaising with the Macmillan nurses. This was time consuming.

The assessment tool also exposed the lack of trajectory work (Strauss et al 1987) in usual assessment. In Phase 2, it became clear that nurses' limited palliative care knowledge and experience hampered their ability mentally to place patients along the cancer journey. Thus, they were unable to anticipate potential problems (e.g. those patients who may have or had had hypercalcaemia), and did not realise the possible significance of some of the patients' cues (in terms of prognosis or illness relapse). As a result, the usefulness of some of the patients' information work in the Phase 2 assessments was not appreciated.

8.4.4 Assessment as Negotiation Work

Assessment in Phase 1 was achieved through informal 'chat'; consequently negotiation work was an essential feature. Selecting a mutually conducive tone for the assessments was important, especially since the majority of nurses and patients were unfamiliar with each other. Sometimes, nurses would choose a topic to chat about, which ostensibly seemed neutral, but which led to some disclosure about prognosis, leaving the nurses feeling guilty and upset. There were instances too, when patients tried to

joke with the nurses, which was inappropriate, and vice versa. Setting the tone for the assessment, and identifying a mutual style of humour was important negotiation work.

Whilst observing Phase 1 assessments, there were numerous occasions when nurses and patients appeared to misunderstand each other, and to talk on 'different wavelengths'. These impressions were checked with participants during the follow-up interviews, and in most instances, misunderstandings were confirmed. The nurses stated that they were keen always to ensure that any misunderstanding had been clarified. The patients, however, indicated that they sometimes left with the confusion unaddressed; sometimes out of sympathy for the nurse, but more often, because they made a judgement as to the importance of 'getting back in step' (Harriet). If patients perceived the issue to be a social, conversational topic, then they did not persist with trying to clarify the confusion, but changed the subject. Other topics of confusion, which they did try to clarify, were sometimes not resolved. Principally these were related to nurses' use of medical terminology (e.g. 'CEA'; 'your counts'; 'blood test'). Patients were frequently confused by abbreviations and medical terms, and were often unable to negotiate an understanding. Another of the most frequently misunderstood topics identified from the data which required negotiation work, was the issue of steroids, which were sometimes prescribed by patients' GPs or the palliative care team for appetite stimulation. The nurses were more accustomed to their anti-emetic action, and consequently, they gave inappropriate advice to patients, or did not understand patients' confusion at all.

Thus, negotiation work concerned three issues: negotiating neutral topics; working to banter and share humour; and clarifying misunderstandings in the assessment conversation.

The Phase 2 assessment tool removed much misunderstanding from assessment, and less negotiation work was required. The nurses noted the tool facilitated discussion of more 'difficult' issues with patients even before they had negotiated a style of interaction or established rapport. In addition, there was little confusion about the topic under discussion, or the patients' meanings: the agenda and control of the interaction lay with the patients.

Negotiation work in Phase 2 involved the nurses and patients making joint decisions about patients' supportive care needs, and what services, if any, they desired in the light of the difficulties they identified on the assessment tool. Where necessary, and particularly for the nurses at The Northern, negotiation work continued as referrals were made, and information passed to members of the multidisciplinary team.

8.4.5 Emotion Work

Both patients and nurses were shown to be involved in emotion work during the Phase 1 assessments. One of the ways in which the nurses', and especially the patients', emotion work was manifested in the assessments was the use of humour. This was particularly evident during the cannulation procedure, a part of the treatment which was dreaded and disliked by all patients:

Extracts from assessments:	
N:	Sharp scratch coming
P:	Have you done it?
N:	Don't speak too soon. Is that hurting?
P:	Mm
N:	It is? It'll have to come out.
P:	I don't believe it [<i>Laughs loudly</i>]
<i>Judy and Hazel</i>	
P:	This isn't my favourite, I'm terrible with this. The famous bit 'only a little scratch'
N:	Never trust a nurse
P:	I've never had a scratch like that in my life
	[Pause]
N:	Sharp scratch
<i>Tina and Dave (original emphasis)</i>	
N:	Right I hope you're going to be good today
P:	Aye I wouldn't bank on it [<i>laughs</i>]
<i>Noreen and George</i>	

Patients who were nervous or needle phobic were perceived as troublesome, and nurses were observed 'sharing' these patients out because they were 'hard work' (Brenda), or 'exhausting' (Penny). Indeed, Noreen's comment to George (above) is a signal to him that he has 'to behave', as a parent might talk to a child, because previous experience (mechanism) told her that his nervousness made the job of cannulation very difficult.

In Phase 2, there was little humour and banter, which the nurses missed greatly, although they noted, with surprise, that they did not have to work to build rapport to enable patients to share personal or private thoughts and fears.

The emotion work of nurses' usual assessments comprised four 'defensive techniques' (Menzies Lyth 1988 p50), to create emotional (and social) distance between nurses and patients, thus constituting the nurse-patient relations required for information work. Some of these defences were reasonable and necessary in view of the nature of the nurses' work and the patients' fears about the treatment, but they also created barriers to emotionally engaged and responsive nursing. The defences were using assessment: as a task to be carried out; to depersonalise and deny the significance of the individual; reduce responsibility for decision making; and allow the denial of feelings (Menzies Lyth 1988).

8.4.5.1 Splitting the nurse-patient relationship into tasks

Patients were in contact with several nurses whilst their treatment was being administered: a particular nurse carried out the assessment and inserted the cannula; different nurses replaced infusion fluids, checked the cannula and discharged patients. Patients therefore understood assessment to be one of several tasks which nurses were required to 'do' in relation to administering chemotherapy; their expectations for assessment were the discussion of practical, treatment-orientated issues.

The lack of nurse-patient continuity between treatments reinforced the message that assessment was a necessary precursor for a particular cycle of treatment: patients did not expect to 'know' the nurses, or to be known by them. Indeed, four of those patients who described 'close' contact with the nurse, and who had talked about having rapport, were unable to recall the nurses' names at the follow-up interviews:

Extract from patients' follow-up interviews:	
<p>P: I felt she understood me. Oh, very much so. I thought she was lovely – er what was her name?</p> <p>CW: [Judy]</p> <p>P: Ah yes Judy, well, I wasn't trying to teach grandmother how to suck eggs obviously [..]</p> <p><i>Janet, The Northern</i></p>	<p>P: Who was I talking to last week?</p> <p>CW: [Penny].</p> <p>P: Penny, yes, that's right. She came out with a thing [..]</p> <p><i>Desmond, The Southern</i></p>

Similarly, for nurses, 'assessment' was an episode of contact, required to enable treatment to be administered. After assessment, nurses' contact with patients was broken down into specific, practical tasks, most of which took only a few seconds to carry out (with the exception of administering certain chemotherapy regimes). As a result, there was little requirement to seek information during the assessments which necessitated or facilitated follow-up actions, because assessment was a task, not a process.

8.4.5.2 Depersonalising the person

Depersonalising the patient as a person, was achieved through: the nurses' focus on the technical aspects of the treatment (veins, the vesicant nature of the drugs); talking about the patient in terms of the treatment regime, rather than their name (see section 5.2.3); the marginalisation of patients' companions in the treatment room (see Section 5.2); the organisation of patients' care (in which nurses were inter-changeable, and the tasks associated with chemotherapy were shared out). All of these signalled the primary focus of assessment to be safety and contact with the nurses to be for technical reasons.

Menzies Lyth (1988) argued that such strategies were defenses to protect nurses against anxiety, but soon after her work was first published in 1959, a practising nurse criticised it for failing to acknowledge nurses' need to be efficient, to 'get through the work' (Anonymous RMN, 1960, cited in Menzies Lyth 1988 p91). In this study, nurses in both case studies asserted that the way care in the units was organised was for a similar purpose, and that this benefited patients: sharing out the tasks, and the absence of a 'named nurse' ensured efficiency, thus reducing delays and cutting the amount of time patients spent in the waiting room. For example, nurses' work was unpredictable, and a nurse might be delayed (e.g. with a difficult cannulation or a problem with a prescription), so any nurse who was available gave treatments to patients waiting in the queue. Moreover, limited continuity of care was explained as benefiting patients by enabling them to have contact with all the nurses in the unit, preventing 'over dependency' on any one nurse which, when she was absent or on annual leave, would create difficulties. Nurses in both units argued strongly that the organisation of care was a means of reducing *patients'* anxiety (and not, as Menzies Lyth suggested, that such a defence was to reduce nurses' anxiety).

8.4.5.3 Reduction of responsibility for decision making

Reduction in responsibility for decision making (Menzie's Lyth 1988) was a feature of the assessments, in that any problem or issue which had not resolved was deferred to another health care professional. Patients were asked to discuss their problems with the doctor, or were given an appointment to enable them to do so; other patients volunteered that they would talk to their GP or Macmillan nurse about the issue. According to Menzie's Lyth (1988), this type of response was a defensive technique to reduce anxiety aroused by the patients' sufferings, but this provides only a partial explanation, since some of the nurses' anxiety in this study arose from working in the dark (See Chapter 5). Importantly, too, deferring to others with more knowledge or responsibility was professionally sound, ensured patients' safety and was a stipulated criterion of the nurses' extended role:

Extract from Tina's follow-up interview re. Dave	
N:	You know, the amount of drugs that we deal with and the amount of patients, certainly from my own point of view, I would rather go and check anything that I wasn't 100% sure of. And I always say that to my patients, whether I know them well or whether I don't know them well, if I'm not 100% sure I'm not, just because I've got the spots on [I'm wearing the sister's dress] it doesn't mean to say I'm too proud to go and check if I'm not 100% sure. I'm not in the business of just doing something because I don't want to not look good. I'll go and check and that's just me. I can't help that, that's just the way I am. I'm human, the same as everybody else, and we all make mistakes. Hopefully one way around not making them is to check, really.

The assessment tool made nurses more accountable for patients' issues, for which there were few solutions, and of which the nurses had limited knowledge and experience. The assessment tool required nurses to engage with patients' issues whereas in Phase 1, nurses had more control over choosing to acknowledge issues or not. Patients were generally advised, and volunteered to inform their Macmillan nurse of their problems.

8.4.5.4 Detachment and denial of feelings

Few of the patients' feelings and anxieties were explicitly acknowledged during 'usual' assessments (see Chapters 4 and 5). The exception was dread of the insertion of the intravenous cannula. With regard to other anxieties, such as prognosis or the meaning of their symptoms, patients *appeared* not to be unduly worried, although at the follow-up interviews, it was clear that these issues were worrying. Six patients volunteered that they would 'never cry' (Rachel) in front of the nurses, and that they kept all those 'sorts of things bottled up' (Hazel).

Patients' emotion work to deny their feelings manifested itself in the assessments in three ways: firstly, the minimalisation of their symptoms, or the use of cues (see section 5.2.3.2); secondly, self-depreciation; thirdly, comments indicating their commitment to 'fight' the cancer. Jim's assessment illustrates all three aspects:

Extract from Lindsey's assessment of Jim	Analysis notes
<p>P: And I went to see my GP and I told him about my feet and he said that looks like water retention from the cancer side and he'll probably refer me back to Dr X like. But I'll see what happens</p> <p>[..]</p> <p>P: So I thought that as I didn't feel so rough this time I thought perhaps I'm getting used to it at last [nurse is getting cannula out from trolley – facing away from patient] .I don't know if your body can ever get used</p>	<p>Dismisses severity of symptom and impact of it</p>

The social organisation of assessment talk

<p>to it</p> <p>N: No. It doesn't really get used to it but you probably got a lot more accustomed to how you = feel</p> <p>P: =I'm fighting it</p> <p>N: =so it's not such a surprise when you feel a bit rough</p> <p>P: I'm sort of fighting it all the time like</p> <p>N: But this is the last one</p> <p>P: Well I was told 6 and that's 6 in my book so I can go out and enjoy myself in a few week's time <i>[laughs]</i></p> <p>[..]</p> <p><i>[confusion over blood test]</i></p> <p>N: No, [the doctor] wants to have another look at it today after I've taken a cross match in case they want to do anything =else</p> <p>P: =Yes. Like shoot me or something</p> <p>[..]</p> <p>P: I started to go off [consultant] I must admit because every time I see him he gives me bad news. It's like my leg, I didn't need to know that, I didn't need to know it was in my pelvis thank you very much. But still, never mind, we have a laugh and a joke, because he said I wouldn't lose my beard. [...] Well, what can you do? You've got to laugh about it then, haven't you? [...] I look like a 106 year old China-man with this. [...] And my hair was in a ponytail half way down my back. Never mind. I'll just move on, don't dwell on the past. [...] So I keep reminding myself it's the last one. Hopefully. That's the other word, isn't it, hopefully?</p> <p><i>Lindsey and Jim</i></p>	<p>Has already said he has been getting worse and new symptoms - here is checking that chemo might be effective still</p> <p>Fighting spirit</p> <p>Repeats fighting spirit as nurse spoke over the last one</p> <p>Humour disguises anxiety about future</p> <p>Metaphor of death</p> <p>Laughter in voice here; light-hearted, indignant tone</p> <p>Self-deprecating</p> <p>Sense of loss here</p> <p>Repetition of 'hopefully': hints about fears for future</p>
--	--

Thus, the Phase1 assessment conversation provided opportunity for patients to deny their feelings or detach any overt emotion from the topic under discussion.

The units, however, were not emotionally neutral (Allan 2000, 2001b). There was a clear demarcation of the areas in which emotions were expressed, and those where they had to be suppressed and concealed. The waiting rooms were places where emotions were aired, whereas they were suppressed and denied (by both patients and nurses) in the treatment rooms. Thus, it was in the waiting rooms that patients cried or voiced their fears (principally to other patients, but also at The Northern, to the volunteers), and in the treatment rooms where patients appeared 'relaxed and happy', and where emotional expression was not often observed.

Denial of feelings, however, was not limited to the patients, but included the nurses. There were few opportunities during the nurses' day when they could share or admit their feelings about patients. On three occasions at The Northern, the nurses were visibly upset by news from the in-patient wards that patients had died. In all three instances, the nurses encouraged each other to 'keep going', 'keep busy and take you mind off it'. Brenda used the analogy of 'falling off a bike' and getting straight back on it to explain the importance of this approach.

At The Southern, the nurses were rarely informed when a patient had died. It was a frequent occurrence for patients not to attend for their booked treatment, and generally, nurses did not know the reasons why. This was a result of poor information flow, and was a sign of the marginalisation of the

nurses within the cancer centre. On one occasion, however, news came through that one of the patients who had been receiving outpatient chemotherapy had died from a cardiac arrest. Sue's account of how she felt when she heard the news indicates how nurses' feelings were denied and detached from the seeming never-ending work in the units:

Extract from Sue's follow-up interview	
N:	I heard a patient yesterday of only 40 had died leaving five children.
CW:	Oh dear.
N:	Yes, she only came in for Hickman Line, she arrested on [ward] and she's dead, and I was like "Oh my God". I was completely floored by that, that's something I've thought about since. But again, it's like "Well, where I take that?" I can't take that to anybody at all. Yes, of course I'm saddened by it, because I knew this lady quite a lot, bless her heart, because she knew I could cannulate her when she came in. She had no veins whatsoever; they were just dreadful which is the reason why she had to go for the Hickman Line. I mean, bless her heart, I don't think her prognosis was terribly good and she had a recurrence of breast cancer, it came back again. But it was just, I think the way the news was delivered as well was quite harsh, because I was told by the pharmacist downstairs and he was just very matter of fact about it.
CW:	He didn't realise you knew the patient?
N:	And I just expected, as I say, "By the way she's come in and had her Hickman Line and she's on [ward]" and he just went "Oh yes, she arrested and died this morning". I was like "Oh my God" it was like somebody had punched me in the head. And I just couldn't believe it. But there you go. [...]
CW:	And are you told when your regular patients die?
N:	No, it's only if you pick it up on the computer. Very occasionally a very nice doctor in clinic might say "Oh by the way I thought you might like to know Mrs. So-and-So hasn't done quite so well as we would have liked". Sometimes if the receptionists know, they'll put it on the sheet of signing paper, put RIP next to it. But even so that's not a very nice way of finding out because you'll be looking down the sheet and you'll be like "Oh my God" and then we'll just say "Oh, So-and-So's died" and a couple of us will go "Oh blimey, really?" That's it, onto the next one. It's hard and it's harsh but what do you do?

None of the nurses in either unit attended clinical supervision. At The Northern, it was not provided. At The Southern, it was sporadically available, but the nurses did not attend: Tina and Sue because it was group supervision and they did not feel comfortable sharing their feelings with colleagues; and Kim, Penny and the other permanent members of the nursing staff because they 'thought it was a waste of time', and that they 'didn't need it'. Nurses were denying their feelings to themselves and detaching themselves from the distress or sadness in their work.

This distress and sadness did not only relate to matters such as the death of patients, but also to emotion work involved in coping with: personal matters, such as the loss of family and friends (Brenda, Noreen and Sue); health and relationship concerns (Myra; Sue; Penny), and mistakes at work, disciplinary issues or complaints (Penny, Sue, Myra and Brenda).

Thus, the way in which the nurses dealt with themselves, with each other and were dealt with by their managers illustrates how their feelings were denied and how much personal emotion work they were involved in when endeavouring to carry out their role. This might help to explain why the Phase 1 assessments of patients were apparently devoid of emotion.

8.4.5.5 Emotion work of the assessment tool

The preceding description of nurses' emotion work in the Phase 1 assessments explains why the introduction of the assessment tool was quite so distressing and difficult for the nurses. They were accustomed to detaching themselves from the patients' life-world, their suffering and problems, in order to focus on treatment and technical tasks; usual assessment facilitated this. The Phase 2 assessments

enabled patients to express emotion; patients were asked to think and talk about whether an issue distressed or bothered them, and if so, how much, and why. Consequently, patients articulated their experiences of loss, and explained how limited they were in their activities and lives, but were apparently able to do this without undue emotional upset. The assessment tool appeared to help patients talk about emotional issues in a controlled way.

The assessment tool required a great deal of emotion work from the nurses, because hearing what patients said was emotionally costly, and all found the content of the Phase 2 assessments upsetting at times. Two of the nurses (Brenda and Kim) were uncomfortable with the degree of emotional disclosure that the tool facilitated. Consequently, they tended to close down the assessment talk, and move off the topic being discussed. The other nurses were more willing to allow patients to express their concerns in more depth, with Sue being the most confident and comfortable in this work. Two contrasting types of nurses' emotion work are illustrated below; on the left are two examples of nurses' controlling work in which patients' emotional expressions are not acknowledged. In the right-hand column is an example of a nurse's facilitative emotion work:

Example of nurses' controlled responses	Example of facilitating responses
<p>P: .. they said they wouldn't use chemo until the very last possible thing, so I know how serious it is, and I know what's going to happen [...] But the future, I will think about once this cancer reduces.</p> <p>N: Nothing we can do to help really, it sounds like you've got all the support there you need, it's just a matter of accessing it if you need it.</p> <p><i>Brenda and Elizabeth, The Northern</i></p> <p>P: Well I'm - I'm very very tired. [...] all day I didn't have any energy to do anything</p> <p>N: And is that getting worse or is that same as usual</p> <p>P: [...] this time it's worse again</p> <p>N: Right. It's particularly bad this time</p> <p>P: Yeah yeah.</p> <p>N: And you said er about pain as well</p> <p><i>Kim and Hope, The Southern</i></p>	<p>P: I've had this problem [breathlessness] for quite some time now and I find that's stopping me from doing quite a lot of things. I have to stop and start a lot. [...] . It's getting worse and I'm out of breath at the moment it's all a bit -</p> <p>N: And how is that impacting on you</p> <p>P: Well I can't do anything really. I just sort of, I don't like sitting around and I want to try and do things I want to be obviously independent but -</p> <p>N: Of course. But that's becoming increasingly difficult</p> <p>P: Yeah it is.</p> <p>N: And how's that making you feel</p> <p>P: Well it makes you feel as if you're -you know - leaving everything to everybody else and you feel a bit - and it you gets down about it</p> <p>N: And obviously it's frustrating isn't it</p> <p>P: Yeah yeah</p> <p><i>Sue and June, The Southern</i></p>

The emotion work of the Phase 2 assessments was markedly different from usual assessment. The assessment tool facilitated patients' emotional disclosure, enabling them to articulate emotionally-laden issues. Such disclosure, however, was emotionally costly for the nurses who were accustomed to working in an environment where emotional issues were concealed and suppressed, and whose practice consciously accomplished this.

8.5 Summary

The existing, underlying generative mechanism in the setting, responsible for shaping the format and content of usual assessments was social organisation, which positioned nurses and patients in assessment in terms of their roles in the chemotherapy units: nurses as the administrators of treatment, and patients as receivers. In social organisation terms, assessment was information work, to enable nurses to administer chemotherapy, and was therefore focused on treatment-related issues. This narrow focus also allowed other issues (such as patients' prognosis, anxiety, symptoms) to be legitimately overlooked. The social organisation of assessment facilitated high patient turn-over, by allowing only brief and superficial exploration of patients' problems; this also protected nurses from patients' emotional distress. Introducing the assessment tool fired new mechanisms, which conflicted with the social organisation of assessment. Since the social organisation of assessment was successful in enabling nurses to do their job, the mechanisms of the assessment tool were partially disabled, limiting the tool's positive effects. This theoretical account, supported by the data, enables the realist evaluation to be concluded, beginning in Chapter 9 with a discussion of the main findings, and in Chapter 10, by identifying what worked, for whom, and in what circumstances.



IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

Chapter 9 Discussion

9.1 Introduction

This chapter draws together the key findings from the study and synthesises them with existing literature to highlight the contribution made by this research to the body of knowledge in cancer nursing. The study set out to evaluate the impact of introducing an assessment tool into the outpatient chemotherapy unit, and had three broad objectives, to: understand nurses' assessment practice in context; to identify the impact of introducing an assessment tool; understand patients' perspectives on assessment in general, and specifically, on using a tool. The aim was to offer an alternative view of assessment, moving away from an emphasis on identifying how nurses *should* assess patients, to understanding the complexities of assessment practice.

The aims of the study (see section 3.3) were met through the adoption of a realist evaluation methodology combined with an interpretivist approach to data analysis (based on nurses' and patients' perspectives of assessment), so that the contexts, mechanisms and outcomes of assessment could be identified. The combination of realist and interpretivist perspectives provides unique insight into assessment in the outpatient chemotherapy unit.

There are three important findings from this study which contribute to knowledge of assessment in cancer nursing. Firstly, nurses' usual assessments were based on a 'hierarchy of appropriateness' (Charles-Jones et al 2003 p76) which prioritised treatment-related issues and safety, reflecting the nurses' role, knowledge and experience. This hierarchy of appropriateness enabled nurses to select, from patients' cues and talk, the issues for which they could be held accountable, or for which they had a possible solution. Patients' contributions to assessment reflected this hierarchy: experience of previous assessments guided their expectations and knowledge of what was required, and they set out to 'be positive' in order to safeguard their anti-cancer therapy. The treatment-related agenda was thus shared and mutually constructed.

Secondly, introducing the tool disrupted the organisation of the units, slowing the flow of patients, and delaying the start of the treatments, highlighting how 'usual' assessments facilitated chemotherapy nurses' work. Introducing an assessment tool into a clinical setting dominated by a treatment-related (biomedical) discourse, characterised by the Phase 1 assessments, was problematic.

Thirdly, the outcomes of the assessment tool did not match policy expectations for increased referrals to supportive and palliative care services, indicating that there is a difference between 'assessment' involving articulation and engagement, and 'screening', which aims to identify 'need'.

9.2 Assessment according to a hierarchy of appropriateness

Nurses' usual assessments of patients were primarily concerned with identifying possible contraindications to chemotherapy, and confirming that patients were 'fit' to be given the proposed treatment (See Chapters 4 and 5). In practice, Phase 1 assessments identified few psychological or symptom-related problems, although in the follow-up interviews, nurses demonstrated an awareness of patients' anxieties and difficulties which had not been apparent in the observed or recorded data. Such findings

emphasise the advantage of involving nurses in the interpretation of their practice, and helped to identify a 'hierarchy of appropriateness' (Charles-Jones et al 2003 p76) which underpinned 'usual' assessments in the setting. This hierarchy of appropriateness arose from contextual influences and mechanisms: the nurses' role; their knowledge and experience; the outpatient treatment setting; and an orientation to action and treatment. This hierarchy was mutually understood and jointly constructed by patients and nurses; it maintained the work of the units, and ensured safe outcomes. Thus, whilst patients did intimate their difficulties, symptoms, and worries during the assessment conversation, they did not expect such issues to be addressed, and accepted that assessment was to enable nurses to administer anti-cancer treatments. In practice, therefore, assessment was different from espoused aims of policy (NICE 2004; Richardson et al 2006), Nursing (Alfaro-LeFevre 2004, see Chapter 1, page 12), and nurses' own beliefs (see Section 8.4). The notion of a hierarchy of appropriateness provides new insight into cancer nurses' assessment practice, and is a contribution to the body of knowledge in this field.

Assessment was complex and multi-faceted, with three priorities in the hierarchy of appropriateness. These were to elicit information concerning treatment-related issues; reassure and relax patients; and identify problems and issues for which the nurses had a possible solution. These areas are discussed in turn.

9.2.1 Assessment to identify treatment-related issues

As described in Chapters 4 and 5, nurses were orientated to treatment: their primary task was to administer chemotherapy and other anti-cancer treatments, and assessment was shaped and constructed to enable them to carry out their work. At one level, therefore, assessment was established as a procedurally conceived interaction (Sudnow 1967) to fulfil bureaucratic requirements, as Latimer (2000) and Wong (2004) suggest. In this study, however, assessment was more than a bureaucratic task: assessment was a functional activity, which facilitated the work of the chemotherapy nurses, by: keeping patients moving through the units; helping to relax patients prior to cannulation; ensuring safe outcomes for the treatment. Understanding assessment in these functional terms highlights its importance in enabling nurses to fulfil their role. Assessment, as it was configured in Phase 1, reflected the priorities of the treatment setting.

In this study, therefore, patients' non-treatment-related concerns were secondary to those associated with chemotherapy. Nurses were wary of becoming 'entangled in conversation with patients' (Tina; Kim), and were reluctant to 'open Pandora's Box' (Noreen; Brenda; Kim), 'stir up a wasps nest' (Brenda; Sue), or 'open a can of worms' (Sue; Penny). The negative imagery used by the nurses to describe the possible content and consequences of assessing patients' non-treatment-related issues reveals the danger, inconvenience, unpleasantness and (emotional) pain they associated with such talk. Nurses preferred the practical side of their job, using their technical skills, which provided a legitimate means of making such talk optional, and avoided any unforeseen consequences of making a wrong move, as Myra had feared when assessing Doreen (see section 4.3.2.1). Not surprising, therefore, that the assessment tool aroused an equivocal response and overall, was considered to be unsuitable in this setting (See Sections 10.3; 10.4).

9.2.1.1 The role of knowledge and experience in the hierarchy

High in the hierarchy of appropriateness was biomedical knowledge, including treatment-related issues. This set the agenda for the Phase 1 assessments, which focused on whether patients were fit for their chemotherapy. Therefore, nurses responded to any signal from patients in the assessments which might affect their decision about whether the patient should be given his/her treatment. Any issue which threatened the safety of the planned treatment was assigned a higher definition of appropriateness than social chat, or cues about other problems.

Nurses relied on their knowledge to distinguish between the relevant, important, or significant and the less important; this enabled them to confidently dismiss and discount patients' treatment-related worries, or provide reassurance. The Phase 1 assessments, therefore, centred the importance and interpretation of patients' reports of their experiences on the nurses' knowledge and understanding.

The importance of knowledge and experience to assessment practice in cancer care has been acknowledged by other researchers (Parle et al 1997; Wilkinson et al 2002), although only in terms of practitioners' knowledge of, and experience in, using communication skills when assessing patients. 'Knowledge' and 'experience' as used in this study was not in terms of nurses' confidence in, for example, using open questions, or facilitating behaviours in order to elicit patients' concerns (Parle et al 1997; Wilkinson et al 2002); rather, the term 'knowledge' refers to *knowing that* certain cues signalled potentially serious problems, or *knowing who* to refer a patient to for support or counselling.

Other researchers have assumed that health professionals working in cancer care have sufficient clinical and theoretical knowledge to enable them to assess patients effectively, and that the problems in assessment are the result of using flawed or limited assessment skills (Maguire et al 1995, 1996a, 2002; Parle et al 1997). Although it is now recognised that achieving change in assessment practice requires more than skills training, and that other influences on assessment need to be addressed (such as whether there is support in the work place, and individual attitudes and beliefs about assessment) (Parle et al 1997; Maguire et al 2002; Wilkinson et al 2002), this study is unique in identifying that cancer nurses' assessment practice was shaped by limited clinical knowledge and experience. Nurses did not recognise the potential or actual importance of patients' cues or symptoms (e.g. that pancreatic cancer can cause diabetes mellitus see section 5.2.3.2); these gaps in knowledge and experience affected assessment practice. Not understanding the importance of patients' symptoms, and being unable to place these on an illness trajectory (such as the prognosis following an episode of hypercalcaemia; knowing where cancers metastasise in order to interpret the significance of a cough) meant that the nurses did not follow-up patients' cues. Working in the dark limited the ability of the nurses to respond to the information patients were divulging during the assessment conversation.

Understanding the importance of knowledge and experience (mechanisms) in the hierarchy of appropriateness explains why the assessment tool was perceived negatively by most of the nurses, for using the tool provided patients with a much wider range of topics to discuss and therefore required the nurses to have a broader knowledge base. As a consequence, most of the nurses lacked the confidence and knowledge to be able to address patients' concerns in Phase 2, which created anxiety. Nurses concluded that the tool was identifying the 'wrong' type of issues for their practice.

This insight into nurses' usual assessments also explains why the assessment tool caused difficulties, for it demanded that the nurses had a wider stock of knowledge than was necessary for their usual assessments. The chemotherapy nurses' education and training, expertise and interests lay primarily in treatment-related issues; thus they had knowledge for their particular practice and were undoubtedly skilled in these areas. This study identified that know-how (Kennedy 2002, 2004) (i.e. technical skill, knowing *for* practice: knowledge of chemotherapy) was an insufficient knowledge base for holistic assessment using a tool. Knowledge *why* (certain issues were important and what they might signify), and knowledge of *who* was involved or could help to support patients with their problems (both lay and professional people, based in the community and in the hospital) was required. The nurses had a narrow range of knowledge, and as a consequence, their assessments had 'become a world of familiar topics and familiar recipes' (Bloor 1978 p40).

This study identified chemotherapy nurses' recipes of knowledge (Sbaih 1997) to be basic, so that patients' signs, symptoms, possible outcomes and management strategies were not connected and organised in a mental reference library (Sbaih 1997; 1998). The findings suggest that expanding nurses' stock of knowledge through action learning circles and/or reflective practice would help to reconstruct the hierarchy of appropriateness and thus improve nurses' recognition of patients' cues.

The hierarchy of appropriateness was also based on the nurses' and patients' experiences of assessment in the chemotherapy units. For instance, several of the nurses had been socialised into believing that patients 'needed a break' from talking about cancer, and that it was kinder to discourage emotional disclosure, or to curtail talk about 'difficult' issues prior to their treatment. Therefore, although most of the nurses in the follow-up interviews recognised many of the patients' cues about illness anxiety (for example), they had interpreted them during the assessment as signals to *avoid* talking about or probing further into patients' fears and worries. These issues were not necessarily ignored because the nurses felt they lacked the skills to deal with patients' psychological issues, but because in the hierarchy of appropriateness, these issues were deemed inappropriate to the setting. Consequently, nurses used the hierarchy of appropriateness to steer assessments clear of the dangerous boundary (Parker 2004) of patients' anxiety and distress, by selectively ignoring certain cues in order to neutralise (Allan 2001b) assessments.

9.2.1.2 Intuition in the hierarchy

All the nurses spoke of the importance of intuition in their assessment work to help to confirm that patients were fit for treatment. Intuition was used to establish and confirm that patients were 'well'. At The Northern, in particular, there was little evidence in the nurse follow-up interviews of rational, problem-solving hypothesis-generating work in assessments. Instead, patients were intuitively perceived as 'well' (especially as their blood test results were already known) and the assessment conversation set out to confirm this 'hunch'.

Nurses' use of the term intuition in this study differed from Benner's (1982; Benner and Tanner 1987), which was based on nurses' ability to interpret signs and changes in patients' conditions which predicted that a catastrophe was imminent. In the present study, nurses' intuition was interpreting the *absence* of signs and symptoms, to ensure that no complications from the treatment would ensue. Intuition explains why so few non-treatment-related issues were identified by the nurses in Phase 1,

because intuition was used to exclude obvious, visible problems, and was reliant on how the patient appeared. Patients' symptoms and worries were not often apparent to the on-looker, particularly as they engaged in face work (Goffman 1971) to safeguard their treatment. When combined with the division of labour in the units (see Chapters 5 and 8) intuitive assessment was risky. The findings suggest that intuition, as it was used in this study, is not a safe notion on which to base assessment practice (Hallett et al 2000).

9.2.2 Assessment to relax patients

Assessment was a precursor to a practical procedure: insertion of an intravenous cannula, and the administration of chemotherapy. The former was painful, and the latter had potentially dangerous consequences, and almost certainly would leave patients feeling (temporarily) worse. One of the main functions of assessment was to relax patients.

The creation of a happy, friendly atmosphere, in which the administration of chemotherapy was seen as a routine activity, was important. Humour and laughter were used to disguise anxiety, which was rarely displayed and acknowledged; any (infrequent) overt displays of emotion by some patients (not taking part in the study) were greeted with dread and irritation by nurses. Nurses re-enforced patients' need to comply with the technical procedures, talking in language which an adult might adopt when addressing a child: 'hold still'; 'be good'; 'prick coming'; 'would you like a sweetie'. In addition, there were many instances of nurses using terms of endearment towards the patients: 'darling', 'sweetheart', 'poor love', 'my dear'. Other researchers (Hewison 1995; Webb and Hope 1995; Pontin and Webb 1996) have noted how the use of these terms increases nurses' power over patients, and causes patients to submit to nurses' routines. Much of the literature on this topic indicates that the majority of patients do not like nurses using terms of endearment although in some cases, it can have a positive effect (Brown and Draper 2003). In this study, nurses needed patients to submit to the cannulation process; patients indicated they liked the nurses to be 'firm' (Joanna) and confident (Edwina). Moreover, all the patients who were asked said they thought the nurses' use of terms of endearment was 'lovely'. The patients stated that they found the use of such terms 'comforting' (Mary), and 'warm' (Lesley), indicating that their anxiety needed a container (Bion 1962 cited in Fabricius 1991) in the way that a mother contains and processes an infant's unmanageable distress, and at the right moment, hands it back in a manageable form (Klein 1946 cited in Halton 2004; Menzies Lyth 1988; Fabricius 1991). A concern arising from the Phase 1 assessments was that although patients were signalling such needs, these were being selectively ignored by the nurses' practice.

Assessment in Phase 1, therefore, was more concerned with preparing patients for their treatment, of relaxing them, rather than identifying and talking about any non-treatment-related problems. The conversational, chatty approach of many of the nurses' assessments confirmed other researchers' findings in this area (Dennison 1995; Arantzamendi and Kearney 2004). Most nurses enjoyed negotiating a style of interaction to put patients at their ease; they spoke of how satisfying it was to build rapport and banter with patients and preferred the informality of the Phase 1 assessments to the structure afforded by the tool. The informality of the assessments enabled nurses sometimes to consciously and selectively ignore certain issues, such as illness anxiety, by changing the subject, or by making a light-hearted comment. Importantly, though, these findings confirm that patients were contributing such concerns to the assessments (see Sections 4.3.3.1; 4.6.5), despite the absence of

obvious 'gold standard' skills (such as facilitative utterances) (Wilkinson 1991; Heaven and Maguire 1996; Wilkinson et al 1998; Kruijver et al 2001b). Nurses' 'blocking behaviours' were not, therefore, the consequence of 'poor' assessment skills, which is the dominant, accepted explanation for the problems of cancer nurses' assessments (Maguire et al 1996b, 2002; Kruijver et al 2001a, 2001b; Wilkinson et al 2002; NICE 2004; Richardson et al 2006). Rather, 'blocking' or ignoring of certain issues occurred *after* patients had disclosed them and was the corollary of the hierarchy of appropriateness, which guided nurses' evaluations of relevance and importance, and enabled them to select, from patients' cues and talk, those issues which they were willing or able to address. This suggests that assessment skills training will have limited impact unless attention is paid to nurses' work and priorities in clinical practice. For instance, when confronted by patients' problems, both in reflecting on their practice in the follow-up interviews in Phase 1, and when using the tool in Phase 2, nurses denied having responsibility for dealing with many of the problems patients identified, believing that such issues fell outside their remit. I return to this topic in section 9.2.4.1.

Nurses' misinterpretation of patients' cues (see Lindsey's assessment of Jim, section 4.3.3.1) and their use of humour (e.g. Kate's assessment of Frances: 'you've had a little bit of everything then haven't you!'), sustained the relaxed, emotionally neutral (Allan 2000) assessments. Nurses did not attempt to clarify patients' possible underlying meanings during the assessments; instead patients' issues were interpreted in 'safe' (and often treatment-orientated) terms. This was also a means by which ambiguity in the assessment was maintained, thus curtailing any disclosure of emotionally challenging issues, since nurses were unsure whether or not patients wanted to 'talk', or whether they should steer clear of such topics. This ambiguity, they said, enabled patients' hopes to be maintained, as it prevented any confirmation of the patients' suspicions that their symptoms were a sign of worsening illness. Unlike Lanceley's (2000) findings, the nurses in this study tried to *prevent* emotional disclosure, whereas Lanceley identified that nurses facilitated but did not sustain emotion talk. In this study, nurses sometimes made deliberate, conscious decisions not to delve more deeply into patients' problems because of the work-load in the units, beliefs about the appropriateness of so doing, and assumptions about their responsibilities and those of other members of the multidisciplinary team. Thus, avoidance of, and a desire to lessen patients' anxiety, were high in the hierarchy of appropriateness in assessment.

9.2.3 Patients' understanding of and contribution to the hierarchy

Assessment in this study was a mutually conceived conversation relating to safety and establishing normality: a desire to be seen to be 'normal' and 'well' was high in patients' hierarchy of appropriateness. This is different from the way assessment is usually perceived; it is more frequently concerned with identifying patients' *problems* and needs (Latimer 2000; Richardson et al 2006).

Patients, particularly at The Southern, brought their concerns into the assessment conversation in the form of cues. Several patients at The Southern indicated in the follow-up interviews that the use of the toxicity proforma constrained their contribution, which explains why they smuggled their worries into the assessment in this covert way. Patients at The Northern were more direct in drawing nurses' attention to their symptoms and side effects, although, in both case study sites, the majority of patients 'mentioned' and then immediately minimised, or dismissed, the significance of a problem. Nurses were deceived by this tactic, taking at face value the patients' 'never mind' approach, assuming this meant

that the problem was not severe. In the follow-up interviews, however, patients explained the reasons why they presented their problems in assessment in these ways: one reason was to 'test the water' (Jim; Patrick) to see what, if any, reaction such information created. Another was because it was difficult to describe the problem in words (Desmond; Charlie); but most frequently, patients wanted to ascertain whether the side effects or symptoms warranted a new appointment with the oncologist, without jeopardising their current treatment, and therefore brought such issues to the nurses' attention in an indirect way.

Such findings make the patients' responses to Phase 2 assessments even more interesting; their appreciation of the opportunity to talk at greater length about problems or difficulties was markedly different from their contribution to, and expectations of, assessments in Phase 1. Partly this was because the issue causing difficulty was already out in the open, printed on the questionnaire, which gave patients permission to articulate such matters. They did not need to negotiate openings to bring such topics into the assessment. There was increasing evidence, however, from my observations and from the transcripts, that, as nurses became more familiar with the structure of the Phase 2 assessments, they were quicker to try to limit patients' articulation work. Other researchers (Booth et al 1996; Heaven and Maguire 1997; Kruijver et al 2001b) have identified that the more facilitative questions nurses are trained to use in assessment, the more blocking behaviours they use. In this study, such practices raised ethical questions about encouraging patients to open up their concerns, only to have them dismissed and disregarded. If an assessment tool is introduced into a clinical setting in the future, it will be important to utilise this finding, by raising practitioners' awareness and acknowledging the emotional investment that using an assessment tool demands. Future studies should adopt a longitudinal approach to data collection to identify how nurses' use of an assessment tool changes over time.

Involving patients in the follow-up interviews highlights the value of the research design. Many patients said they did not know why they had asked certain questions, or why they had dismissed their symptoms in the assessment. Several patients were surprised by the ways in which they had brought their problems to the nurse's attention. For many, it was only after talking and reflecting in the interviews that the underlying agendas surfaced. The type of assessments identified in Phase 1 were therefore a means by which patients 'tested the water' not only with the nurses but with themselves, opening 'Pandora's Box' a little, but allowing it to close soon afterwards. In contrast, the Phase 2 assessments, like the follow-up interviews, allowed patients time to talk through the meanings of their symptoms and problems, and in so doing, allowed the negative emotions trapped inside Pandora's Box to be aired, leaving, as in the Greek myth, positive emotions behind (in this case, feeling supported).

Whether the follow-up interviews caused patients distress is difficult to know; encouraging them to confront and expose hidden feelings might have been traumatic and as a safeguard, all patients were given telephone numbers of people to contact (including me) if they wished to re-visit the issues we had discussed. More obvious were the follow-up interviews which were helpful to patients: letters and telephone calls were sent by some, thanking me for allowing them to be a part of the study; other patients made comments in my hearing to members of their family, saying how helpful it had been to talk. Four patients at The Southern, and two at The Northern, used the follow-up interviews to ask for referrals to members of the multi-disciplinary team, e.g. dieticians, palliative care services, appointments with the oncologist, and for improved analgesia. Overall, the patients appeared more

able and willing to reflect on their assessments than the nurses, indicating perhaps, that they were less threatened by me and by the possible findings. Moreover, as patients stated in the Phase 2 follow-up interviews, they had very few opportunities to 'just talk' (Frances) without upsetting others, highlighting the importance of finding time and space to enable patients to 'tell their story' (Wilson et al 2006). I return to this issue in Chapter 10.

9.2.4 Orientation to action

Nurses were noted to ask follow-up questions in the assessments (in both Phases) if there was something they could 'do' for patients to relieve the problem. For example, the Phase 1 findings illustrate how assessment problems (except constipation) were more likely to be explored if there was a pharmacological solution available, and patients could be given a prescription for the symptom (such as nausea, vomiting). The symptom of constipation was largely ignored because it was not thought to be 'serious' and was expected to be transient, associated principally as it was, with the side effect of anti-emetics, indicating how nurses' repeated exposure to chemotherapy and its effects had desensitised them to its impact on patients. Nurses' experience in this field meant that chemotherapy and its side effects were 'normal' (i.e. familiar) which resulted in them missing patients' cues and failing to follow-up patients' concerns. The significance of the experience of such symptoms and problems for patients was thus overlooked.

In addition, several nurses in the follow-up interviews said they had recognised a patient's cue, or heard what had been said, but had ignored the issue (e.g. anxiety) because they did not know where to refer patients for additional help and support. This finding is similar to previous research by Grande et al (2003) which identified that general practitioners and district nurses were less likely to identify symptoms that they felt least competent to treat. Educating nurses in symptom control, and enhancing their knowledge-base would help improve nurses' assessment practice.

Thus, high in the hierarchy of appropriateness were issues for which there was a potential solution. In general, nurses ignored problems in their 'usual' assessments, for which they had few management strategies, indicating that important in the hierarchy of appropriateness were the issues of role and problem solving. For instance, all the nurses in the follow-up interviews recognised what patients had said about fatigue, but four nurses admitted that they chose not to explore this issue as they did not think there was anything they could do to help. A similar orientation to role and problem solving was noted in doctors' assessments of patients' pain in outpatient oncology clinics (Rogers and Todd 2000), where oncologists were interested only in identifying the 'right kind' of pain to fit their role and stock of treatment options. Such findings suggest that assessing according to a hierarchy of appropriateness might be more widespread than has been recognised to date, and warrant further research.

Identifying that a social worker was available to chemotherapy patients at The Northern added a new priority to the nurses' hierarchy of appropriateness. During Phase 2 at The Northern, we learned that the hospital social worker had been allocated protected time for patients attending the chemotherapy unit; subsequently, the nurses became more pro-active in inquiring about patients' financial situation and whether they were claiming the benefits to which they might have been entitled. This issue has since been incorporated into the nurses' checklist of assessment topics.

9.2.4.1 Role and responsibility in the hierarchy

Issues for which the chemotherapy nurses believed they had responsibility were higher in the hierarchy of appropriateness than those issues (such as symptoms, anxiety about prognosis, coping and anything requiring a prescription for medication) which were perceived to fall within the Macmillan nurse's or the oncologist's remit. Allied to the nurses' desire to 'do' something about patients' problems, was the question of whether there was a service or person to whom the nurse could refer the patient. This has been noted by other researchers, who have identified that the organising framework of decision making in assessment is influenced by factors such as service availability (Gerrish 2000) and service organisation (Carr 2004). At The Northern, for example, there was no complementary therapy and no counselling service, (raising questions about the appropriateness of the model of cancer care established following the Calman-Hine report in 1995); the nurses at The Northern were uncomfortable about probing into patients' psychological concerns because they knew that there was no formal support or help available if a need were identified. None of the nurses in either case study site was aware of which services might be available in primary care, indicating that a service mapping exercise might enhance assessment practice, and is a recommendation arising from this study.

Interestingly, despite identifying that patients in Phase 2 had a high number of problems and distress, the assessment tool did not lead to a linear problem-solving pattern of response, and was one of the reasons the nurses perceived the tool as 'unhelpful'. One posited explanation for there not being a link between patients' apparent concerns and the low rate of interventions is that patients' symptoms or problems were not severe or troublesome; however, their distress scores (see Graphs 6.1, 6.2) did not corroborate this. Alternatively, it could be that the nurses' limited knowledge of symptom management and service provision prevented offers of help being made. The evidence does not fully support this: patients were offered interventions such as referrals to other members of the multi-disciplinary team, but most of these were declined, confirming the findings from other research which identified that assessment tools do not necessarily lead to increased use of services or changes to patients' management (McLachlan et al 2001; Curry et al 2002; Detmar et al 2002; Velikova et al 2004).

One reason for such findings in this study is that the chemotherapy nurses assumed that patients were in close contact with specialist palliative care teams, and that non-treatment-related concerns were being addressed elsewhere in the system, most probably in the community. Although the majority of patients at The Northern had been referred to a Macmillan nurse, this was not the case at The Southern, where only two of the nine patients were known to palliative care teams. Moreover, a referral to the Macmillan nursing service did not necessarily result in close contact or a supportive relationship between the specialist nurse and the patient. In the follow-up interviews, many patients in the present study explained that they had declined offers of help because they had already indicated their problems to most of these professionals, but that nothing had improved, indicating, they believed, that 'this is how it is'. There appeared to be a grey area in service provision for patients receiving palliative chemotherapy, where, once an initial assessment had been carried out, regular face-to-face contact with the specialist palliative care nurse was sporadic, and dependent upon patients admitting during a routine (usually monthly) telephone call that they were having 'problems' and required a home visit. Recent research among district nurses corroborates these anecdotal findings, and has shown that patients in the palliative phase of their illness who have few physical needs do not fit the model of service provision (Griffiths et al 2007). A wider case study approach, incorporating patients'

assessment experiences across the multi-disciplinary team would provide much needed insight into the provision of care during the palliative treatment phase of a cancer illness.

An alternative explanation therefore, for the low take-up rate of offers of interventions in this study (despite the tool's effectiveness in identifying patients' concerns), is that the assessment tool allowed patients to articulate a counter-narrative (Fisher and Goodley 2007) to the problem-solving approach to assessment encapsulated in policy, existing practice and at the outset to the study. The linear, biomedical, 'pathologising' (Corner 1999 p705) model of assessment predominant in cancer care and policy, in which patients' problems are elicited to enable them to be 'solved' by professional intervention, did not fit patients' and carers' interpretations of their illness and its effects. In other words, the tool's lack of impact on service use and interventions can be explained in terms of its ability to enable patients to articulate a 'life-world' counter-narrative (Fisher and Goodley 2007) in assessment, which became the means for patients to identify and select 'acceptable' limitations arising from their illness which could be accommodated through adjustment (reframing; see Chapter 7).

Patients were orientated to the anti-cancer treatment, which gave them hope, allowing them to suppress fears of dying (Cox 2002), and gave patients a short-term focus, of a few weeks, beyond which they did not need to look, and was another reason for them marginalising or declining some of the specialist palliative support on offer. Thus, whilst policy makers speak of 'seamless' care across the cancer journey (Department of Health 2005), the patients in this study did not perceive their care in these terms. Rather than journeying, it seemed as if they were stranded in the world of the clinic (The 2002), in 'immediacy' (Schou and Hewison 1999 p165), where the journey's end 'is rarely made explicit and progression is measured in calibrated bits' (del-Vecchio Good et al 1994, p857). The importance of this is that the treatment, with its associated appointments and scans, provided a less emotionally charged end point (The et al 2000) than patients' long-term prospects. Thus, palliative anti-cancer treatment was 'palliative' in two senses: in terms of relieving symptoms and preventing problems, and also, in 'cloaking or shielding' (Clark and Seymour 1999 p80) patients and health care professionals from the reality of the prognosis:

'It is possible to sail a boat, for example without charts or a compass. However, the absence of a chart prevents the possibility of a journey; one is limited to a 'day' sailing, so that new destinations and new challenges are out of reach'

(Rappaport 1990, p192 cited in Schou and Hewison 1999 p165).

Moreover, some of the patients died whilst still enmeshed in their three weekly chemotherapy regimes, and many more soon afterwards, suggesting that their oncologists, like the patients, could not face 'endings' (i.e. severing clinical relationships and dependencies). This also raises questions as to whether some palliative chemotherapy was prescribed as a substitute for the more difficult task of engaging with the reality of the journey's End (i.e. death) (Crossley 2003).

9.2.5 Summary

The hierarchy of appropriateness was constructed to mirror the nurses' perceptions of how assessment should reflect their role in the cancer service as an administrator of treatment. The hierarchy of appropriateness guided the format and conduct of assessment, focusing on three issues: firstly, functionality. Assessment was perceived and conceived as a pre-cursor to treatment, and therefore

issues which might affect the administration or the safety of the treatment were paramount. Secondly, assessment aimed to relax patients, by creating rapport, and providing nurses with opportunities to instil in patients confidence in their technical skills and know-how. Nurses were aware that patients were anxious prior to their treatment, and were concerned not to cause further upset by introducing 'difficult' or sensitive topics into assessment. These dangerous boundaries were avoided by focusing on every-day topics of conversation, and the 'normal'. Finally, nurses perceived assessment as a means to 'do' something for patients. Consequently, they prioritised issues in assessment which lay within the boundaries of their role, such as treatment-related side effects, or for which they had a possible solution. Other issues, such as patients' symptoms, were ignored, assuming that these were already being addressed by members of the multidisciplinary team.

9.3 Impact of the tool: creating discordant discourses in the chemotherapy unit

Nurses' usual assessments facilitated the work in the chemotherapy units, by maintaining the throughput of patients. This finding highlights the importance of efficiency in cancer care, which, like other branches of contemporary health care, requires nurses to work within the competing demands of policy, service, profession and the individual (Wong 2004). Consequently, the chemotherapy units were organised and structured along industry models (Wong 2004) to ensure efficiency and accountability, contain costs, and to manage risk (Parker 2004). According to Herdman (2004 p99), the outpatient chemotherapy unit is 'a paradigm case of the McDonaldisation of health care', where patients are being nursed or treated in settings organised along similar lines to fast food restaurants. Thus, just as McDonald's discourages customers from lingering in its restaurants, by organising them to ensure maximum efficiency (achieved through functional seating and bright lighting; a 'drive through' option; a strict division of labour; the use of 'scripts', and the provision of a predictable, limited menu), so health care settings are increasingly being organised and developed along similar lines. The result, however, as often in McDonalds, is that efficiency backfires, queues develop, and the experience can seem dehumanising (for both customers and staff) (Ritzer 1996, in Herdman 2004). It appears that some patients may be identifying such effects in cancer care:

'My stay in hospital made me realise how outdated my view of [cancer] nurses was. I had anticipated nurses as rather comforting figures who would relate to their patients as people, rather than bodies in beds. [...] Generally [cancer] nursing seemed to be far more of a technical occupation than I had imagined. [...] all the nurses I came across, without exception, were highly competent but desperately busy [...] I wondered if maybe some of the more traditional caring aspects were being forced out by time constraints'

(Clark 2002 p60)¹

The pessimistic picture of cancer nursing painted by this quote suggests that nurses' ability to care for individual patients (the professional patient-centred discourse) is being compromised by the effects of specialisation and efficiency. Managerialist and not professional discourses in health care and nursing appear to be shaping patients' experiences (Allen 2004; Wong 2004) and practitioners' roles (Bloor 1978; Knight and Field 1981; Wiggins 1997; Allen 2004). This study identified that nurses' assessment

¹ Clark was diagnosed with a head and neck cancer and underwent extensive treatment in Australia and the UK. Her book is an account of her experiences of her illness and treatment.

practice in the outpatient chemotherapy unit was routinised in order for nurses to work efficiently and safely within the setting. The findings reveal how the nurses' role had been developed with a task-oriented, narrow remit, and few opportunities to use any extended skills and knowledge because of working in the dark.

In most areas of nursing characterised by boundary blurring with medicine, the technical and practical are combined (Allen 1997, 2002). For example in intensive care, nurses are involved with high-tech machinery, 'basic' patient care, and a high degree of emotional engagement with patients' relatives (Seymour 2001; Coombes 2004; Peter and Liaschenko 2004). In contrast, the chemotherapy nurses' work contained little variety: paradoxically, the nurses' extended role had restricted their clinical remit and given them a narrow jurisdiction (Hughes 2002) in the service. They were not 'maxi nurses' (RCN 2005), but had taken on a specific task from medicine, and seemingly surrendered other aspects of the nursing mandate (Allen 2004). This is an interesting finding, since policy such as The Cancer Plan and The Nursing Contribution to Cancer (Department of Health 2000a, 2000b), and professional bodies such as the RCN (RCN 2005) claim that such tasks will expand, not constrict nursing roles, although research, like the findings of the present study, identifies that this is not the case (Wigens 1997; Jones 2003; Allen 2004). Interestingly, the nurses in this study (and those who declined to take part) indicated that they were happy with their narrowly focused role, preferring the technical to involvement with patients. This partially explains their responses to the Phase 2 assessments (See Table 10.1). The hierarchy of appropriateness sustained this mode of working, allowing nurses to selectively respond to certain issues, leaving others, which they believed fell outside their remit, for someone else to take care of (see section 9.2.4.1).

Moreover, the nurses' sphere of influence was limited by the clinical control that medicine had retained over the patients' care. Unlike nursing in in-patient areas, chemotherapy nurses did not have prolonged contact with patients, and were not in a position to give detailed information to the medical staff about the patient's life; neither were they involved in clinical decision making – traditional ways in which nurses' assessments can influence patient care (Allen 1997, 2002; Latimer 2000). Consequently, and perhaps unusually (May 1995b; Latimer 2000), it was the medical staff, and not the nurses who had greater knowledge of the patients. Indeed, the patients in this study stated that they shared more information with the oncology doctors, because they asked the 'right' questions, and were the professionals with the power to make decisions about treatment and care management. Contrary to Richardson's (2004) claim, these nurses did not have 'most insight' into patients' problems nor were they at the 'fore-front of helping patients cope with cancer' (p292). These findings support other research which indicates that the 'real life work of hospital nurses is rather different from the kinds of claims which are made by the leaders of the profession and also official job descriptions'. (Allen 2002 p51).

The outpatient setting was an important contextual influence on assessment and the nurses' perceptions of their role. McIlfratrick et al (2006) concluded that chemotherapy nurses either had to 'run the clinic' or nurse the patient; nurses felt 'torn' between attending to the technical aspects of their role, and their desire to spend time talking to and supporting patients. Where the present study differs from McIlfratrick et al's (2006) is that the nurses in this study did not perceive a dichotomy between their technical and nursing skills; they considered their technical skill and their ability to administer chemotherapy to be their way of 'nursing the patient'; they did not see this as 'nursing the clinic'.

Moreover, McIlfatrick et al (2006) imply that nurses were dissatisfied by this tension, but in this study, the nurses did not notice a tension in their role until the assessment tool was introduced. They were, on the whole, satisfied with their usual assessments, and believed that they delivered individualised patient care through the establishment of rapport and the relaxed and informal approach in assessment conversations. The nurses had cultivated and established a comfortable working pattern in which they believed they accommodated patients' individual needs into an efficient system.

This way of working was a successful compromise to balance the demands of: policy, to be efficient; the service, to treat increasing numbers of patients; the nurses, to provide safe care. The majority of the nurses liked what they offered to patients, but felt that they coped with the tensions in their job only because of the narrow focus their role afforded; there was not a great deal of desire to broaden it: the nurses in this study were happy to let others fulfil this role. Such findings beg two questions: Does this matter? Is patient care adversely affected by this way of working? Most of the nurses who completed the study believed that patients benefited from the narrowly conceived assessments of Phase 1, and that these should be valued for what they achieved: safety and satisfaction. Nurses argued that it was the assessment tool which compromised safety and efficiency (i.e. potentially adversely affecting patients' care), and was therefore inappropriate for this setting. This leaves the issue of whether a more holistic type of assessment should be attempted in a treatment setting, or whether the *status quo* in assessment should be accepted for what it achieves, and valued for its functional role.

There is no simple answer. On the one hand, if nurses' usual assessments are acknowledged as 'good enough' (Fabricius 1991; Allan 2001a), in that they were effective (i.e. no-one who took part in the study was given chemotherapy inappropriately) and efficient (they facilitated the nurses' work and kept the units running smoothly), then there needs to be an open acknowledgement that this is the type of assessment taking place. As Allen (2004) suggests, a re-formulation of the nursing mandate may be required, moving away from one which espouses holistic patient care and caring relationships, to one which better reflects what nurses actually *do*, which, in this instance, was work as a skilled technician and as a health care mediator helping patients navigate and be navigated through the treatment-phase of their cancer illness.

On the other hand, there appears to be little enthusiasm or evidence to support this limited role for assessment in cancer care. Policy in this area is encouraging wider, not narrower, assessment of patients' needs (NICE 2004); cancer nursing espouses 'therapeutic' approaches to care (Corner 1997), and nurses find satisfaction in 'knowing' their patients (May 1995b; Luker et al 2000; McCormack and McCance 2006; Griffiths et al 2007); patients dislike impersonal care (Audit Commission 2002), and value caring, personalised interactions (Clark and Ross 2006).

This raises two further questions: should holistic assessments be the remit of specialists? And, should nurses in the front-line of patient care focus their assessments narrowly, ensuring they are 'fit for purpose'? Again, policy suggests not. The National Institute for Health and Clinical Excellence (2004) state that all staff, whether generalists, specialists, and those on the front-line of patient care should be able to assess patients' needs:

Discussion

'Providing supportive and palliative care should be part of every health and social care professional's role'

(NICE 2004 p22)

And:

'Health and social care professionals providing day-day care of patients and carers [...] should be able to assess care and support needs, including needs for palliative care, of each patient and carer, at all stages of the patient pathway and in all domains of care'

(NICE 2004 p35)

A recently published Department of Health document (Richardson et al 2006) following on from the NICE guidance (2004) falls short of suggesting that structured assessments are the remit of specialists, although it does recommend that staff who conduct them should have attained relevant competencies and skills. How these competencies will be 'proved' or assessed and by whom, is unclear. All the nurses in this study, except Myra, believed that their assessments were 'good', and were effective. Thus, it is unclear whose priorities will form the basis for these competencies. Moreover, the findings from this study suggest that proof of assessment competencies is unlikely to be sufficient to ensure the routine adoption of assessment tools into clinical practice. Work is required which involves practitioners in deciding: how tools can be accommodated in a particular setting; how adequate support, emotional care, and opportunities for reflection and action learning can be provided. How such provision can be incorporated into a system which has so little slack remains to be seen.

The problem therefore, is how holistic assessment can be accommodated into a McDonaldised health care setting (Herdman 2004) and whether the effort to achieve this would be 'worth it'. I think that it would, for two reasons. Firstly, although functional assessments may appear more efficient, there may be unwanted and serious consequences. Mistakes can and do happen when professionals assume someone else in the system is identifying problems (Gannon 2005). When professionals have only a partial picture of the patients' experiences and needs, oversights in management (Godlee 2005), and co-ordination of care (Neale and Olsen 2005) occur. In other words, fragmentation of care in the health service makes failures of communication almost inevitable (Gannon 2005).

Secondly, if nurses and other professionals working at the 'coal face' only carry out functional, utilitarian assessments, it is not clear how patients will access specialist services when they need to, or how patients' less 'obvious' needs and concerns will be identified. The Audit Commission (2005) found that 20% of cancer patients felt they had either not discussed the side effects of their treatment during routine clinic visits or had had an unsatisfactory discussion; 25% of patients attending outpatient appointments had experienced anxiety and depression severe enough that they felt they needed help to cope, and 20% of these thought that more could have been done to assist them with this problem. If we state that front-line staff's assessments will be functional and role-related, it is difficult to see how patients such as those highlighted in the Audit Commission's report will gain access to appropriate support and specialist care - unless all patients are to be referred to specialist nurses and/or palliative care services 'just in case'. Such a move would be illogical, both in economic terms and in view of the limitations in service provision.

Removing or restricting assessment opportunities and practice in treatment settings may be economically (as well as ethically) unsound, for, as this study and others have identified (Sarna 1998;

Annells & Koch 2001; Hoekstra et al 2007), patients benefit from the assessment process itself. Such opportunities to talk and be listened to may prevent patients developing complex emotional or social needs which would require (expensive) specialist care. Moreover, patients in this study reported that it was reassuring to be asked about the issue: this validated their problem. And those patients who did not have many concerns or high scores felt very reassured.

Both these arguments support the role of outpatient chemotherapy nurses identifying the wide range of potential problems faced by patients undergoing anti-cancer treatment. Consequently, the issue is not whether these nurses should assess, but how to accommodate such practice into a 'McDonaldised' (Herdman 2004) health care setting. Efforts need to be made to identify where assessments can be accommodated in the cancer service, especially as more and more targets are being imposed, such that finding time and space to assess patients in outpatient clinical areas is increasingly problematic (Willard and Luker 2005). The current climate appears to make it difficult to justify 'supporting patients' as a legitimate form of [nursing] care (Willard and Luker 2005). Nurses at The Southern all said that using the assessment tool on a regular basis would be 'the straw that broke the camel's back' in terms of pushing them beyond their limit. But this need not be so; if practising nurses were involved in the planning of services, and more flexibility was incorporated into working arrangements and the chemotherapy units' opening hours, assessment could be phased across the day, and introduced across the service, shared out among members of the multidisciplinary team, rather than being squeezed into an already packed schedule. Underlying the nurses' comments, was, I felt, an admission that this type of work and engagement was not what they wanted; like the nurses in day care surgery (Wigens 1997), some of the nurses had chosen to work in the chemotherapy unit because they saw it as a place where emotional distance could be maintained. McIlfatrick (2003; McIlfatrick et al 2006) also identified this, which indicates there is a need for research to explore the out-working of espoused nursing ideals in contemporary cancer care settings.

We need therefore to create opportunities to commence a 'radical deconstruction and reconstruction' (Corner and Dunlop 1997 p292) of cancer care in order to enable nurses (and other professionals) to feel 'a re-invigorated obligation to address patients' concerns' (Corner 2001 p11). Initiatives such as: setting up an assessment clinic for outpatient chemotherapy patients; creating a supportive care register for patients undergoing palliative chemotherapy, similar to that in Primary Care, which requires assessment of patients, and discussion of their situation within a multi-disciplinary team; the creation of link-lecturer palliative care nurse practitioner posts in chemotherapy to develop nurses' palliative care skills and knowledge; attending to the physical environment of assessment care, such as comfortable seating and privacy for patients; and the provision of administrative or secretarial assistance to community- and hospital-based nurses, to improve liaison across the primary-secondary care interface, all might help improve the care of patients receiving palliative anti-cancer treatments. The emphasis that has been given to assessment in cancer care by policy makers such as NICE affords an opportunity to debate how care and services might be constructed in order to accommodate their recommendations for introducing assessment tools. Such debate is necessary, for, as the preceding discussion has shown, tools cannot be easily absorbed into current systems and settings of clinical cancer care.

9.4 Assessment or screening?

Using assessment tools is recommended as a means to enhance professionals' identification of cancer patients' needs, and improve access to appropriate supportive and palliative care services (NICE 2004). This study, however, did not find a close association with 'assessment' and 'need' (for service provision), and therefore questions whether the relationship between these two issues is as close as policy makers assume. Such findings have been noted by other researchers (Roth et al 1998; Annells and Koch 2001; McLachlan et al 2001; Curry et al 2002; Detmar et al 2002; Cox 2003; Velikova et al 2004; Aranda et al 2005; Florin et al 2005; Hoekstra et al 2007). Taken together with this growing body of research, the findings from the present study indicate that assigning a high score to an item on a questionnaire does not necessarily imply this symptom/problem is troublesome to the patient. For instance, Hoekstra et al (2007) identified that a third of patients' symptom severity scores were not correlated to their accounts of distress. In this study, patients were distressed by their high scoring issues, but this distress did not translate into a 'need' (i.e. a desire) for professional support.

This indicates that patients have a different perception of what constitutes a 'problem' than professionals (Florin et al 2005). For instance, in this study, patients said in the follow-up interviews that they perceived their situation could not be altered: 'this is how it is'; 'there is nothing you can do'. In addition, most had family to provide support, which was why they did not want professional intervention. These reasons were similar to those given by patients in an Australian study (McLachlan et al 2001; Curry et al 2002) in which 29% of the 202 cancer patients in an ambulatory care setting declined offers of a service intervention because they had friends and family to support them; they preferred to manage the problem themselves. Such findings increase the need for patients' family members to be part of the caring process and be involved in receiving support. Although such an approach was espoused in the chemotherapy units, it was not obvious that such care was taking place. Research into patients' lay support networks is required, to identify whether carers have need of professional support, who is best placed to provide this, and where in the service it can be accommodated.

Patients in this study differentiated between 'feeling' tired and 'being' tired or 'feeling' unwell and 'being' unwell, but this important subjective distinction between the functional capacity of 'being', and identity as 'feeling' (Grenier 2006) was not necessarily captured in the score on the questionnaire (Cox 2003). The benefit of the assessment tool in this study was that patients were able to make this distinction while exploring the meaning of the scores with the nurses. This approach provided more accurate insight into the patients' situation than scores on the quality of life questionnaire alone, by enabling patients to decide how much disruption and discomfort they accepted as being 'normal' or tolerable. Drawing on a narrative distinction between 'being' and 'feeling' therefore, revealed the discrepancy between professional and lay concepts of 'problems', and the lived experience of symptoms in patients' everyday lives (McIlpatrick 2003). Thus, one benefit of the tool was that it did not just provide nurses with a list of patients' symptoms and concerns, but also enabled the patients to place these in the context of their life-world. This approach is considered to be the way forward for assessment (Hoekstra et al 2007) and for using quality of life tools in a clinical setting (Cox 2003). It also raises some interesting questions about the use of normative graphs as the basis for interpreting quality of life scores in a clinical setting, as in Detmar and Aaronson's (1998), Detmar et al's (2002) and Velikova et

al's (2002, 2004) research, and may explain why the consultation times in these studies were not lengthened when the EORTC QLQC-30 was used.

The gap identified in this study between 'concerns' (i.e. high scores on the questionnaire), 'distress' (that the patients were bothered by the issue) and 'need' (whether they accepted an offer of referral for professional support or a specialist service) might also have been because the assessment conversation which followed the tool's completion was supportive. Sarna (1998) also postulated that structured assessment was a proxy for support. One of the explanations for this is that in Phase 2, the relationship between assessment and intervention became more blurred, because during the interpreting and clarifying phases, nurses gave advice and provided written information (such as dietary advice) to help patients, which, in some instances was deemed sufficient as a first offer of support. Providing interventions such as these during the assessment conversation contrasted with the Phase 1 assessments, in which nurses did not address patients' concerns. However, the refusal to document the provision of such advice and information is a worry; nurses did not perceive that information-giving was necessary to record, but in a climate where 'measurable outcomes' are valued for audit and clinical governance, the absence of a record of nurses' care will diminish options for preserving and expanding nursing roles.

Future research should explore the relationship between 'distress' and 'need', and identify whether there is any correlation between these and, for example, coping, self efficacy, and social support. If so, screening patients for coping, or self efficacy, and/or social support may identify those at risk of developing needs, so that extra support can be provided to prevent crises developing. Making the distinction between screening and assessment is important, because the outcomes of each are different. The findings from this study suggest that there is a difference between 'screening' for problems (which is looking for high scores and assuming these mean that the patient has a need), and 'assessment', (which is the engagement and discussion about the meaning of the high scores with the patient). The former requires short, easy-to-complete tools, and leads to targeted referrals. The latter, as this study revealed, is time consuming, leads to discussion, and allows patients to articulate the meaning of their symptoms and problems. Assessment, as practised in this study, was a time consuming exercise, with few tangible outcomes, although patients benefited in more covert ways. Screening, however, might be an efficient means of identifying patients at risk of not coping or not managing their symptoms, allowing resources to be targeted at patients with limited social support networks. Screening patients for coping and social support might be more cost effective than the introduction of assessment tools into clinical areas. In the light of the findings from this study which are shared by several others (Roth et al 1998; McLachlan et al 2001; Curry et al 2002; Detmar et al 2002; Velikova et al 2004; Aranda et al 2005; Florin et al. 2005) work is required in this area, to establish which of these two approaches could and should be adopted for routine use in clinical practice.

9.5 Limitations of the study

There are several limitations of the study which are addressed here. Firstly, the nurses and patients participated voluntarily, and therefore may not represent the general population working in and attending outpatient chemotherapy units. One particular caveat is that the patients who appeared to be ill, i.e. who had obvious symptoms, or who were visibly strained or distressed in the waiting rooms were the ones who declined to take part in the study. Therefore, it is not possible to know whether they

would have shared the views of the patients who took part in the study who all found this type of assessment to be helpful. However, six of the nineteen patients who took part in Phase 2, died within six weeks of the follow-up interview; another three relapsed or were diagnosed with progressive disease within two months; and another four were admitted to a hospice or hospital for care within three months, having deteriorated significantly. Therefore, a large proportion of the patients who took part in the research had a very limited prognosis, and could be considered to have been 'ill' at the time of the study.

Secondly, the choice of the EORTC QLQC-30 as the assessment tool can be criticised, for not being suitable for palliative patients (Echteld et al 2006) as some of the items might be inappropriate (Groenvold et al 2006) and existential issues are not included (Cohen et al 1997). Neither applies to this study. The 'palliative phase' of a cancer illness covers a wide range of debility and morbidity, from patients with few signs or symptoms of their incurable disease, to those dying in a hospice. None of the patients who consented to take part in the study thought the tool was too long or too burdensome (once they had filled it in, although two commented that they thought it looked long when they first saw it); all were receiving palliative chemotherapy, and the EORTC QLQC-30 is the recommended tool of choice in studies which are evaluating the benefits of palliative anticancer therapies and supportive care (Richards and Ramirez 1997). To make the EORTC QLQC-30 more valid for the palliative population an appendix of suitable items should be used (Groenvold et al 2006) to provide the additional items relevant to such patients. ART had a Symptoms and Problems Checklist appendix, a tool validated for a palliative outpatient population (Butters et al 2003; Lidstone et al 2003), containing additional questions relating to existential, symptom, and family issues.

In addition, the EORTC QLQC-30 was feasible and improved patients' quality of life when used in clinical practice by oncologists working in outpatient clinics (Detmar and Aaronson 1998; Detmar et al 2002; Velikova et al 2002, 2004); indeed, Detmar and Aaronson's study (1998) was specifically evaluating its usefulness with palliative patients. Thus, it seemed sensible to ascertain its feasibility for nurses' assessments, to perhaps standardise the assessment tools in use in a particular cancer network in the future. Moreover, given the frequency that the EORTC QLQC-30 is used in clinical trials research, the tool offers potential to provide quality of life information for research and clinical practice without adding to the patients' burden by requiring them to complete multiple questionnaires. However, its feasibility in this study did not corroborate Velikova et al's (*ibid*) findings, and so its applicability to nurses' assessments remains in doubt.

A third criticism of this study is that no linguistic analysis of the nurses' assessments was carried out. Therefore, the mechanism of communication might be considered to be limited in its scope because it does not contain any detailed analysis of the nurses' assessment skills. This study set out to understand, and not judge, nurses' assessments; therefore, an analysis of language and communication strategies was not considered to correspond with the research question or the aims of the study. Much high quality research has already been carried out using linguistic analysis of assessment practice (e.g. Wilkinson 1991; Heaven and Maguire 1997; Wilkinson et al 2002); much is therefore already known about the limitations of nurses' assessment *skills*. What is less clearly understood is why nurses (and other health care professionals) find it difficult to elicit, identify and sustain discussion of patients' concerns in the clinical setting, and there is little insight into how an assessment tool might (or might not) compensate for these difficulties. Moreover, if the transcripts had

been scored in terms of their linguistic quality, critical ingredients of the patient's perspective would have been missed, since it would have been my judgement, as the researcher, which counted. Involving patients (and nurses) in the interpretation of the assessment conversations provided different insights for the analysis, preventing a uni-dimensional researcher-led interpretation. A benefit of this approach was the identification of the hierarchy of appropriateness as a framework for giving and attending to cues in assessment.

Fourthly, the study evaluated individual assessment encounters, and therefore the design of the study could be criticised for perceiving assessment as an episode, not a process. Kennedy (2002, 2004) identified that community nurses assessed their patients in stages, carrying out more detailed and in-depth assessments each time they met, and as they came to know each other better. Although a longitudinal study of using the assessment tool would provide useful insight about its use over a period of time, evaluating its immediate impact provided useful insight into ordinary assessment practice, and therefore was able to explain the tool's impact. Moreover, 'assessment' in the chemotherapy units was itself episodic: there was little continuity of nurse-patient contact within or between treatments: the study reflected practice in the units.

The study also has some key strengths. One of these was the involvement of nurses and patients in the interpretation of the assessments; another was the realist evaluation approach, which resulted in greater understanding of the contextual influences on nurses' assessment practice, and identified the underlying mechanisms. The realist evaluation enabled a model of 'usual' assessment to be generated, and provided a new understanding of how the assessment tool worked (see Chapter 7). The findings in the preceding sections challenge current understandings of cancer nurses' assessments, by highlighting the inconsistencies in policy and professional rhetoric related to assessment, and the difficulties nurses face when attempting to reconcile these contradictions. This study identified that implementing policy recommendations to adopt structured approaches to assessment, such as assessment tools, in clinical areas will not be simple, and that practitioners need to be consulted and involved in discussions to develop assessment practice in cancer nursing.

9.6 Recommendations for policy and practice

Several recommendations arise from this work. Cancer nurses working in chemotherapy units should be better supported by management, to enable them to explore ways in which the service they provide might be improved and developed to incorporate more holistic, structured patient-centred assessments into practice. The provision of clinical supervision, action learning circles, and peer mentoring to enhance learning from practice are required, since this study has identified that such approaches are useful and help raise awareness of patients' contributions to assessment, and nurses' responses to emotional disclosure.

Policy (NICE 2004; Richardson et al 2006) seeks to improve assessment in cancer care, although the recommendations for implementing such policy in practice are less well defined. Findings from research which is rooted in clinical practice, such as these, need to be recognised by policy makers, to ensure that any improvements to assessment care are aimed beyond the fixing of deficits in individual practitioners' skills, and embrace macro and micro contextual issues. Practising nurses need to have a stronger voice in helping to develop cancer care, so that recommendations are realistic, and can be

Discussion

incorporated to benefit patients. However, it is also imperative to listen to patients, and to find ways of embracing changes which they desire, but which may not 'suit' nurses' work. Thus, although the nurses decided that the tool was unsuited to the setting, the patients would like it to become part of their care. Clearly, development of the outpatient chemotherapy service is required in order to accommodate this division of opinion.

Nurses should be consulted about their working arrangements, need for preparation work and on-going service provision before assessment tools are introduced. A debate is required to ascertain chemotherapy nurses' commitment to using assessment tools and the breadth of their nursing role. Assessment practice across the multidisciplinary team should be identified, to prevent overlap and repetition, and to enhance the communication of patients' needs and concerns.

A service mapping exercise is needed, to provide practical information for clinical areas, such as the outpatient chemotherapy unit, to enhance the referral process to supportive care services. Where gaps in supportive care service provision are identified in certain units but not in others, (as at The Northern compared with The Southern), alternative provision should be considered, for example, providing patients with vouchers, to enable them to 'purchase' care in the private sector. Provision of equipment, such as a fax machine would simplify the referral process to other agencies, and there should be consideration of how to enable nurses to access secretarial support. Keeping a stock of blank referral forms and frequently used information booklets in the units would increase nurses' willingness to supply these to patients, without causing extra inconvenience.

The instigation of an holistic assessment clinic is recommended for patients receiving palliative chemotherapy, in which a more detailed assessment, using a tool can be carried out. This could be offered to patients attending for their second and penultimate treatments. Nurses working in the chemotherapy units, who have a special interest in palliative treatments and palliative care should receive relevant training in symptom management and counselling and should become patients' 'named nurses' with responsibility for managing the assessment clinics, and forging links with members of the multi-disciplinary team. The creation of a supportive care register, which would require regular holistic assessment for patients receiving palliative anti-cancer treatments, might enhance liaison across the primary-secondary and oncology-palliative care interfaces. The development of an anticipatory care pathway might also enhance the management of patients receiving palliative anti-cancer treatments.

Routine assessments of all patients attending the outpatient chemotherapy unit should be underpinned by a philosophical model of care. Modifications to the paperwork used to record nurses' assessment conversations would enable nurses to record patients' non-treatment-related needs and social support network.

The creation of a link lecturer-practitioner post in palliative care and chemotherapy would provide mentoring, education and support to nurses, and help develop skills and recipes of knowledge (Sbaih 1998) in the setting.

9.7 Recommendations for future research

This study has generated more questions than it has provided answers, and since realist evaluation is cyclical, further research is recommended.

A realist re-evaluation is required to test the refined CMO configurations (see Chapter 10) in different settings. Professionals, such as therapy radiographers, oncologists, staff in cancer support and information centres, nurses on in-patient wards and nurse specialists could be involved.

A longitudinal study of the use and impact of using an assessment tool in clinical settings is required, to identify how nurses' (or other health care professionals') use of a tool changes with familiarity and over time.

There is a need for further study of assessment across and along the patient's cancer journey and the use of services in relation to concerns and needs. This work is relevant to the key worker debate, and would help to identify how best to manage transitions when key workers change.

This study, along with others (see section 9.4), has demonstrated that there is a difference between patients' 'concerns' and 'needs'. More research is required to explore this distinction further, in order to distinguish 'screening' from 'assessment', so that adequate provision is made to support developments in assessment practice.

9.8 Summary

The discussion has provided new insight into cancer nurses' assessment practice, by identifying how a hierarchy of appropriateness influenced nurses' selection and interpretation of patients' cues during assessment. The emotion work of assessment was highlighted. Emotion work explained why nurses steered away from difficult issues whilst carrying out assessments, in order to avoid a prolonged and potentially uncomfortable conversation which they did not believe patients wanted. Patients understood and shared many of the nurses' priorities in the hierarchy of appropriateness and valued the nurses' friendliness and warmth during the assessment conversation. The notions of 'the cancer journey' and 'seamless care', which feature strongly in policy statements, have been questioned, and further research to further explore these concepts is recommended. The discussion has raised some questions about the nature of the outpatient chemotherapy nursing role, and identified some of the difficulties nurses face when balancing the needs of the service with the needs of assessment policy. The findings indicate that an assessment tool such as ART cannot be easily absorbed into the chemotherapy outpatient unit as it currently functions, and highlight how important it is to involve practising nurses when considering how policy initiatives might be implemented.

These findings provide the context for the conclusion to the realist evaluation which is the focus of the following chapter, which answers the question: what worked, for whom, and in what circumstances.



IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Chapter 10 Concluding the Realist Evaluation

Realistic evaluation is not only for 'engineering' but can serve the ends of 'enlightenment' and advocacy as well

(Pawson and Tilley 1997 p213)

10.1 Introduction

This chapter is concerned with completing the realist evaluation, and answers the question: 'What worked, for whom, and in what circumstances?' (Pawson and Tilley 1997 p216; Mark and Henry 1998 p83; Kazi and Spurling 2000 p4).

The question of 'how' the assessment tool worked was addressed in Chapter 7, and an explanation of why its impact was limited was presented in Chapter 8. The Phase 2 findings (see Chapters 6 and 7) identified that the assessment tool worked for the patients, but was of limited usefulness and acceptability to the nurses, and was considered by them to be unsuited to the setting. This chapter explores the reasons for these conclusions, and therefore addresses not only 'what worked', but also, what did not work.

10.2 What worked for the patients?

All the patients who took part in the study (including the interim phase) stated that they found completing the assessment tool and subsequent conversation with the nurse a positive and helpful experience. There were two aspects to this: firstly, the opportunity to talk was valued. Secondly, patients considered the type of issues which were raised and talked about to be pertinent and important. This contrasted with the feedback from the patients in Phase 1, and the nurses, who considered that treatment-related issues were the priority.

10.2.1 Assessment as a helpful narrative

A total of 55 patients were involved in using the assessment tool and giving feedback (19 in Phase 2, and 36 in the interim phase). All stated that they found this form of assessment very helpful. However, it should be remembered that there were, especially at The Northern, a number of patients who declined to take part in the research, and therefore, only patients who were willing to complete a questionnaire were recruited to the study, although the majority of these commented that they expected to *dislike* the questionnaire-based assessment, and had been surprised to prefer it. All of them reported that the assessment tool was 'better', and thought it should be incorporated into everyday practice.

The findings reveal how the assessment tool enabled patients to 'tell their story' (Drummond 2000; Annells and Koch 2001; Wilson et al 2006), which they found to be supportive. This is different from most other studies evaluating the use of assessment tools (e.g. Strömberg et al 2001b; Allenby et al 2002; Detmar et al 2002; Hill 2002a; Velikova et al 2004; see also Appendix 1) which have focused on the improvement in professionals' ability to identify patients' emotional, social and existential issues. Although these outcomes were also identified in this study, the emphasis and importance that patients

gave to the opportunity to talk was striking. The model of structured assessment presented in Chapter 7 provides a more detailed description of how the assessment tool facilitated this, through the firing of mechanisms: articulation, engagement, connection, empowerment and communication, for both nurses and patients.

The use of narrative in cancer care is increasingly recognised as an important area for research and clinical practice (Hydén 1997; Kleinman 1988; Greenhalgh 1999; Greenhalgh and Herwitsch 1999; Blinderman and Cherny 2005; Shapiro and Ross 2005) because patients can use narrative to make sense of their situation and find meaning. As Frank (1995 p18) states:

'Telling stories of illness is the attempt, instigated by the body's disease, to give a voice to an experience that medicine cannot describe'

The model of structured assessment (see Chapter 7) generated by the realist evaluation analysis provides insight into how the assessment tool enabled patients to share their story and why narrative was so helpful to them. Other research suggested that assessment-tool narrative was satisfying to patients because a professional was interested in finding out what mattered to them; patients felt satisfied because someone had validated their feelings, and listened to them (Annells and Koch 2001). Whilst these findings were corroborated in this study, there were additional benefits from narrative work, because not only did hearing the patients' stories have an effect on the nurses listening, but the process of narrating was helpful to the patients. Thus, it was through the process of talking that patients felt supported; in other words, the linguistic interactions arising from the assessment tool were 'those which occurred not only with others but with the self' (Jordens et al 2001 p1235). In talking about their concerns and problems, patients were able to clarify their feelings, be involved in decisions, and understand and appreciate the help and support that was either already in place, or planned. As Jordens et al (2001 p1235) said, the value of narratives should be considered not only 'in terms of the work they do *on* the interlocutor, [...] [but] in terms of the work they do *for* the narrator' (original emphasis).

The benefit that patients apparently gained from voicing their problems and worries belied the fear that the nurses expressed during the study that such talk would be upsetting. With one exception (a patient in the interim phase – see Appendix 15), none of the patients who took part in the study was distressed when completing the tool or talking about their experiences or fears; they reported at the follow-up interviews that the assessment conversation had been helpful, not upsetting. This finding contrasts with other research (Bertero and Eriksson 1996; Jarrett and Payne 2000) which suggests that cancer patients want a 'break' from thinking about their cancer and do not want to open up and 'purge their emotions' (Hunt and Meerabeau 1993). The patients in this study indicated that fear of their illness was 'omnipresent' (Shaha and Cox 2003), such that 'having a break' from thoughts about it was not possible. Moreover, in the follow-up interviews, they indicated that they had had few opportunities to voice their anxieties to others, whether family or other health care professionals, which was a reason that the assessment tool seemed to be supportive. The assessment tool gave them a welcome opening to discuss such concerns, indicating that, given the opportunity and permission, patients will actively engage in discussion about 'difficult' issues, and do not necessarily require light hearted talk (Langley-Evans and Payne 1997), social chat (Hunt 1991; Bertero and Eriksson 1996; Jarrett 1996), or even rapport to be established prior to divulging their fears and anxieties. Instead, it was the opportunity and permission to talk about such issues which were the catalysts.

The findings from this study also contradict the argument that using an assessment tool has a negative effect upon the assessment conversation, 'medicalising' and restricting its remit (Cowley et al 2004). One reason may be that patients in this study had control over the questions which they answered: they completed the questionnaire in private, away from the nurses and the clinical area, unlike the clients in Cowley et al's (*ibid*) study who were asked verbally about issues by health visitors in a question-and-answer format. A second explanation is that the patients in the present study perceived assessment to be a means to improve their care, and saw the nurses as 'friends', there to help them, whereas some of the clients in Cowley et al's study viewed the health visitors with suspicion. Moreover, the health visitor assessment tool had been imposed by management to identify 'at risk' families and improve the monitoring and documentation of parenting behaviours. A third explanation is that the 'nursing gaze' (May 1992a, 1992b, 1995a, 1997; Locsin 2001) which is often perceived as having the potential to be a negative disciplinary activity because it symbolises the extension of nurses' power, can have beneficial, positive effects (Armstrong 1983; May 1995b; Davies and Allen 2007).

10.2.2 Identifying patients' concerns

Patients' narratives about their illness and experiences, their losses and concerns, provided an alternative view of their problems from the predominant biomedical treatment-orientated perspective identified in the Phase 1 assessments. The type of issues discussed in Phase 2 corroborated other researchers' findings about the problems faced by patients in the palliative phase of a cancer illness such as fatigue, breathlessness, pain, anxiety, and fear of the future (Hill et al 2003; Lidstone et al 2003; Blinderman and Cherny 2005; Hoekstra et al 2007). As previous research has identified, the tool improved the identification of psychosocial issues which were absent from the nurses' 'usual' assessments (Rathbone et al 1994; Söllner et al 2001; Farrell et al 2005). Patients in this study liked the tool for its help in enabling them to clarify their problems. The tool worked as an *aide memoire*, helping patients to recall what they had experienced and felt about their illness. In addition, reading the list of items and assigning a score to each, helped patients separate problems and difficulties from one overwhelming experience into more discrete issues which could be articulated and explained in turn. Similar benefits were identified when the Palliative Outcome Scale (Slater and Freeman 2004), the Symptom Distress Scale (Sarna 1998) and the Client Generated Index (Annells and Koch 2001) were used, suggesting that it is the structured approach of assessment based on a tool, and not the particular tool itself which was helpful.

According to patients in this study, one of the most positive aspects of using the assessment tool was being able to complete the questionnaire-part of the assessment tool themselves. In the follow-up interviews, patients reported that they had not felt obliged to answer questions, and felt able, if so inclined, to assign an incorrect score to an issue to avoid its discussion, although none had apparently chosen to do this. Such a response refutes the argument that a more holistic approach to assessment increases the power of health professionals over patients (Hunt and Meerabeau 1993; May 1997; Locsin 2001). By contrast, several patients in the Phase 1 follow-up interviews confessed to 'hiding' or minimising their symptoms in assessment to present a front which did not necessarily reflect the reality of how they felt. Five patients explained that this was to ensure they did not jeopardise their treatment. That patients minimise their symptoms has been noted by other researchers (Schou and Hewison 1999; The 2002; O'Baugh et al 2003), recognising patients' need to maintain hope, and to be positive. Such attitudes reflect the dominant notion of 'fighting' cancer (Sontag 1978; Frank 1995; de Raeve

1997), not giving in, and coping (O’Baugh et al 2003). In Phase 1, the nurses and patients jointly constructed such an approach; in Phase 2, however, patients were able to be more honest about their problems, because these assessments were not focusing on treatment-related issues *per se*, thus distancing the relationship between treatment decisions and assessment. The Phase 2 assessments were therefore very different to the norm. Most of the nurses struggled to incorporate this degree of change into their practice, and were afraid that in raising issues such as death and dying, we were taking away patients’ hope. Kim and Brenda feared that the tool allowed patients to dwell on their problems and therefore must have led patients to think negative and depressing thoughts. None of the patients reported that they felt upset or depressed by the assessments. All of them commented that they had valued the opportunity to talk about such issues because these were important to them.

The assessment tool therefore gave patients the opportunity to author (Latimer 2000) their worries and concerns, and in the narration of these, patients felt supported and helped.

10.3 What worked for the nurses?

Nurses gave positive and negative feedback about the assessment tool. Some of the feedback was also contradictory, making it impossible to draw a straightforward conclusion about what worked and what did not. In the final follow-up interview with the nurses, each was asked for their thoughts about using the assessment tool. Table 10-1 uses the nurses’ own words to summarise their feedback:

Nurse	Positive aspects : what worked	Negative aspects: what did not work
Brenda	Understanding what patients are going through. I've learned a lot; has made me think about the way I assess patients and I will adapt how I do it – like ask them more about pain	Time consuming Not my role Didn't lead to anything – can't see the point of doing this This is nurse specialist stuff Not relevant to my job
Noreen	Job satisfaction has increased Interesting. Broader than the other assessments we do. Makes me feel like I'm doing something helpful for these patients It's been a really good learning experience and made me think. It was nice to have Cathy helping and showing interest in me.	Stressful – don't have the skills and knowledge for this Can't hide from patients' problems Patient has control - stressful Not really relevant to my work; I'm not really sure this type of assessment is right for here. Time consuming – doesn't work in the outpatient unit Very tiring and a bit upsetting
Myra	It makes the job interesting The tool is really helpful. I think it helps me to know patients better It has been good learning It was amazing to talk to patients like that and about such private things.	
Sue	What I came into nursing to do Wish we could do this all the time: ends the conveyor belt feeling.	Time consuming Not sure it would be possible to do routinely in this setting – takes too long and too emotionally

	<p>Very different: shows how narrow our other assessments were</p> <p>Helpful for the patient – they clearly liked it</p> <p>Made me connect with patients very quickly, which was satisfying</p> <p>Helped me discuss issues in depth with patients: made me give them time</p>	<p>draining: couldn't give like this all the time</p> <p>Made me feel very powerless to help which was difficult for me; would not have been able to do this without Cathy's support</p> <p>I feel I do this type of assessment anyway when necessary: assessment is a key part of my role</p>
Kim	<p>Raised my awareness of patients' problems</p> <p>Think it is a good idea</p> <p>Main benefit was to understand what patients were going through</p> <p>Made me realise I need to find out about services to help patients</p> <p>The study made me think – you couldn't assess like this on automatic pilot</p>	<p>Not sure it added anything to my standard assessments; it was no different really. I don't need a tool to help me do this.</p> <p>It was the same as my usual assessments</p> <p>Patients can always talk about these things anyway if they want to.</p>
Penny	<p>It made me feel I knew the patients better and more quickly: Patients talked very openly even when I didn't know them</p> <p>This is definitely holistic assessment</p> <p>Satisfying: it's like ward nursing in the day care setting</p> <p>It helped the patients which was nice.</p> <p>It gave variety to the work here which is what is lacking sometimes, and gave me permission to spend time talking to the patients, not hurrying off so much.</p>	<p>Emotionally draining and upsetting.</p> <p>I needed Cathy to be there to support me or else I would not have been able to face doing this.</p> <p>Scary</p> <p>Had no idea patients were suffering like this</p> <p>Not really necessary to do this type of assessment in this setting – we're not here for this really, and patients don't come for this</p> <p>Time consuming</p> <p>Made me feel very vulnerable and exposed my lack of knowledge.</p>

Table 10-1 Nurses' feedback about using the assessment tool

The learning and support which the nurses identified as a result of taking part in the study are addressed in sections 10.5.1; 10.5.2. For the purpose of the following discussion, the nurses' responses are divided into two broad areas: the positive aspects of using the tool, and the negative, commencing with 'what worked'.

10.3.1 Bringing nurses and patients closer together

Using a quality of life assessment tool in practice brought nurses and patients closer together. Nurses commented that they felt that they 'knew' and understood patients better. This was perceived as a positive outcome. This finding corroborates other research which identified that 'knowing the patient' gave nurses job satisfaction (May 1995b; Coyle and Williams 2001). However, the nurses who took part in the study volunteered to do so, and might have already been more orientated to closer nurse-patient relationships, and that this finding was to be expected.

Much of what has been written about the benefits of knowing the patient and the importance of holistic assessment are related to improving nurses' ability to care for patients (Radwin 1996; Gerrish 2000; Kennedy 2004). This study identified that the closeness which developed following the Phase 2 assessments did not aid nurses' work in terms of practical care; indeed, the biomedical assessments of Phase 1 were *more* relevant for the nurses' work. Rather, the closeness that resulted from using the assessment tool was an affective closeness: a greater awareness and understanding of the patient and

his or her experiences. The nurses found this, on one level, to be interesting, for it provided them with a different lens through which to view their patients. The narrative proximity (Peter and Liaschenko 2004) which the tool facilitated, raised nurses' awareness of patients' sufferings, and created a sense of intimacy and involvement which they reported to be satisfying. In addition, the obvious benefits of the assessment tool for three of the patients (for example see section 6.2.3.3), gave great pleasure to the nurses involved. The closeness created by using the tool was not reliant on familiarity, and did not require nurses to build rapport with patients. They reported that this was a surprising but positive finding. At another level, however, this narrative proximity (Peter and Liaschenko 2004) was problematic, as it forced nurses to confront emotionally challenging issues. This is further discussed in section 10.4.

10.3.2 Increasing the scope of the nurses' role

A combination of organisational, contextual, individual, social and professional factors produced the biomedical treatment-focused assessments of Phase 1, despite an espoused goal to the contrary in the units' philosophies and the nurses' personal beliefs. The functional, utilitarian nature of the nurses' usual assessments has been described and reasons for this explained, stressing what these assessments *achieved*, for the nurses, patients, and the service (see Chapters 4, 5, 8 and 9). The biomedical focus provided an efficient and effective means of assessing patients, enabling the nurses to practise, but this limited patients' perceptions of the nurses' role. Patients in Phase 1 reported that nurses were 'kind', 'nice', 'good for a laugh', technically skilled, and competent in administering chemotherapy. After using the assessment tool, eight patients said in the follow-up interviews that they saw the nurses in a 'different light', as 'knowledgeable' nurses, able to support and help them.

Chapter 8 referred to the monotony and constancy of the work nurses were carrying out in the chemotherapy units. Unlike ward nursing, there were few opportunities for the chemotherapy nurses to negotiate spaces (May 1992b) to make time for personal encounters with the patients. Interactional space in the chemotherapy units was also limited by the lack of privacy and physical intimacy with patients, who were constantly moving in and out of the treatment rooms. Nurses' task-orientated work thus became a self-fulfilling cycle of functional interactions and emotional and physical distance, which in turn demanded more of the same because such practices created and sustained working in the dark.

The broader focus of the Phase 2 assessments helped nurses see patients from a different perspective, and also led some nurses to see opportunities to use the available time and space in the units in a different way. For instance, at The Northern, some patients are now assessed in an interview room, providing privacy. This has been a longer lasting effect of the study.

All the nurses acknowledged that the assessment tool changed their assessment practice, although Sue and Kim believed that the change was in degree, rather than substance. One benefit identified at The Southern was the variety of talk which the tool generated, which ended the 'sausage factory' feeling of the morning work. Moreover, Penny and Sue spoke of the tool creating interest because the wider remit of the assessments demanded that they used different skills, thus adding a new dimension to their role. There was also a close link in the Phase 2 assessments between 'assessment' and 'support', with nurses offering advice, and suggesting strategies for coping and managing problems in response to some of the patients' issues. This was most marked at The Northern, where the Phase 2

assessments created new opportunities for nurses to provide patients with information, make referrals to the wider multidisciplinary team, and to initiate contact with the palliative care nurses. Although such work was time consuming and on occasion caused friction, the nurses liked the extra responsibility associated with this new dimension to their role.

10.4 What did not work for the nurses?

The nurses concluded that, overall, the assessment tool was not feasible in this particular clinical setting. There were three reasons. Firstly, the assessment tool deconstructed the hierarchy of appropriateness (see Chapter 9) which guided nurses' 'usual' assessments, requiring a broader assessment focus, for which nurses had limited knowledge and experience. The routine nature of Phase 1 assessments had concealed these gaps in the nurses' knowledge, and removed much responsibility for decision making relating to patients' coping and support needs. Secondly, the assessment tool followed patients' priorities for assessment, leaving the nurses afraid that safety issues were not being adequately addressed (see section 8.4.1). This was partly because treatment-related issues on the questionnaire were not often given high scores, and were therefore not discussed. Partly, too, it was because the nurses were ill-prepared for the feelings that losing control of the assessment conversation engendered; expert patients left them feeling superfluous and uncomfortable (see section 7.2). Thirdly, the assessment tool forced nurses to confront emotionally challenging issues, and disabled the mechanism of emotional control which was fundamental to the Phase 1 assessments. Moreover, because nurses perceived their usual assessments to be satisfactory, they regarded many of the changes brought about by the tool as both problematic and unnecessary.

10.4.1 Working with emotions: overwhelming nurses' defence against anxiety

The social organisation of assessment, identified as the generative mechanism underlying assessment work in the chemotherapy units, was responsible for the: content of assessment talk; relations between nurses and patients, and their respective roles in assessment; rules and procedures for assessment; and paperwork. Assessment was routinised, helping nurses control anxiety in, as well as manage the work of, the units. Price (2001) argues that balancing unpredictable and uncertain situations with highly routinised, predictable procedures provides reassurance. For instance, check-in procedures at airports offer a predictable, familiar routine for passengers preparing to fly. Applying this theory to assessment in the chemotherapy unit reveals how their routine nature offered some sense of order not only to the patients (who all spoke of knowing what to expect in assessment) but also to the nurses, who were working in the dark, facing the practical unknowns of the patients' veins and responses, as well as trying to manage the unpredictable workload in the units. This theory does not, however, explain why patients found the assessment tool helpful, and were not made more anxious when 'safe', predictable assessment was replaced by the tool. It may be that the routinised assessments served the nurses' purposes more successfully than the patients' and that, because of the social organisation of assessment, patients were passively accepting of their role.

The findings illustrate how Menzies Lyth's (1988) work remains relevant in the 21st century, even though health care and nurses' work are now very different. Menzies Lyth (*ibid*) identified that the task allocation model of nursing served to defend nurses against anxiety. Since then, the introduction of the

Nursing Process, which espouses and is explicitly orientated to 'knowing' patients as individuals, 'cancer nursing as therapy' (Bailey et al 1995; Comer 1997) and radical changes in nurse education (Fabricius 1991) have been embraced, which, in theory, should have led to improvements in nurses' willingness and ability to provide emotional care to cancer patients. Instead, one defence has been replaced by another (Fabricius 1991): changing the organisation of nursing care has not 'solved' the problem of emotional engagement with patients' sufferings, because these newer ways of delivering nursing care have been incorporated into the system of defences (Fabricius 1991). Thus, 'usual' assessment was a defence used by the nurses to protect themselves from patients' illness and sufferings. The Phase 1 assessments facilitated the 'evasion of anxiety but contribute[d] little to its modification and reduction' (Menzies Lyth 1988, p77). In contrast, in Phase 2, the assessment tool surfaced patients' illness experiences, losses and fears, and enabled patients to talk about these things (and indeed, it shows potential in this area). In so doing, however, it forced nurses to confront emotionally challenging issues. The degree and intensity of patients' suffering as expressed in the Phase 2 assessments was too much for most of the nurses to bear.

These findings suggest that any attempts to improve assessment practice, either through the use of an assessment tool or through assessment skills training, will be unsuccessful unless this issue of emotion work is addressed. Nurses in this study were so unused to hearing and 'holding' (Fabricius 1991) patients' suffering, that they were 'shocked' (Penny) by the type of issues and talk generated by the assessment tool. These findings highlight the importance of addressing the social organisation of health care to enable nurses to 'be with' as well as 'do for' patients if assessment tools are to be incorporated into clinical settings. Indeed, even if tools are not introduced, these findings indicate that nurses need to be in receipt of emotional care to enable them to provide it (Hoekstra et al 2007).

10.4.2 Emotion work not emotional labour

The use of the term 'emotion work' which was described in Chapter 8 was not intended to infer that there was a close association between what I observed and interpreted in this study and Hochschild's (1983) theory of emotional labour. Hochschild's theory, which is concerned with the 'work workers have to do with their feelings to comply with the role(s) that the organisation requires them to play' (Timmons and Tanner 2005 p85), has been used by others in health care and nursing to explain emotional care (James 1992a; Timmons et al 2005), but the term 'emotion work' in this study is more closely associated with Menzies Lyth's (1988) psychodynamic approach. There are several differences from Hochschild's theory, outlined below. Making these distinctions is important, because they reveal how nurses' emotion work helped them to manage the assessment conversation, given all the limits and problems arising from working in this particular clinical setting (such as working in the dark), to protect the organisation, patients, and themselves.

The term 'emotional labour' was used by (Hochschild 1983) to illustrate how air hostesses' emotion work was commodified by airlines as part of the product being sold (Timmons and Tanner 2005). In this study, although emotion work in assessments was shaped by the organisation, it was also an outcome of the work of the individual nurses and patients. Emotion work was actively and subconsciously involved in assessment. For example, nurses' emotion work was a product of: their individual orientation to care; the value they placed on emotional disclosure; their belief that controlling and concealing emotions was the 'correct' response in the setting; a belief that building rapport through

being relaxed and friendly was crucial to disclosure of difficult issues; as well as unconscious defences against anxiety (Menzies Lyth 1988) (see section 8.4.5). Thus, emotion work was not only *socially* organised, but was also shaped, consciously and unconsciously, by individuals.

Hochschild (*ibid*) identified that the emotions displayed by air hostesses were the ones which they 'ought' to feel, and were not those which they actually felt: the hostesses' emotional displays reflected managerial 'rules' of expression of feelings, and were inauthentic. Emotions in this study were also concealed; patients' emotional work mirrored that of Hochschild's emotional labour theory, but the nurses' did not. The rules of emotional disclosure which nurses adopted in their usual assessments were *not* the ones espoused and valued by management, or profession, or policy, in which assessment is purported to elicit patients' distress. Rather, nurses' emotion work concealed feelings of uncertainty and anxiety (working in the dark), reflected the hierarchy of appropriateness in assessment, and protected patients from miscommunication and managerial failures within the system. Thus, nurse's individual responses to the content and direction of the assessment conversation gave rise to emotion work; emotion work did not reflect (because it was contrary to) the philosophy of the units, assessment policy, or any education they had received about assessment.

Moreover, following on from the earlier discussion of the relevance of Menzies Lyth's work to this study, nurses' emotion work was not concerned with avoiding emotional *display*, it was more to do with avoiding 'feelings' in the first place. This explains why the assessment tool was perceived as so emotionally costly: it forced nurses to confront emotionally challenging issues, which they were not accustomed to feeling and managing. Thus, unlike Hochschild's air hostesses, who did not show what they felt, but showed what they ought to feel, the nurses in this study were avoiding feelings *per se*, through the way in which emotion work in assessment was socially organised. As they described themselves, they were 'keeping a lid on Pandora's box' (Noreen, Kim, Brenda).

Finally, Hochschild's theory (1983) fails to acknowledge that emotional labour can be fulfilling (Price 2001). Aspects of emotion work in the Phase 1 assessments were satisfying: for instance, bantering with patients and creating a relaxed and friendly atmosphere. In Phase 2, nurses mourned the lack of banter, and missed the light hearted chat and the humorous exchanges. In their feedback about the assessment tool, however, some of the nurses (Penny, Sue and Noreen) identified that the emotional engagement with patients had been satisfying and rewarding. This was different, but still satisfying, emotion work from that of the Phase 1 assessments.

Using the assessment tool was emotionally costly for the nurses, and revealed how much emotion work their usual assessments entailed. Nurses appeared to be striving for emotional survival (Sandgren et al 2006), so it is timely (once again) to recommend that steps are taken to support nurses (and other health care professionals) in their work. Whether it is possible, or even whether a desire exists, in the current climate of health care economies and policy, to address the emotional care and support of nurses (and other health care professionals) remains to be seen. As yet, there does not appear to be a satisfactory means of 'working the hyphen' (Fine 1994 p70), between managerialist and consumerist (person-centred - whether patient or individual professional) discourses. Work to identify some possible solutions to this dilemma is required.

10.5 In what circumstances?

This study was comprised of two case studies, carried out in different hospitals, although both were outpatient chemotherapy units. Two units were purposively selected with contrasting work-load, nurses' experience in oncology, existing assessment practice and patients' characteristics (ethnicity and social background). At the outset, it was expected that such differences between the units would give divergent findings, and that the answer to the question 'in which circumstances' (did the tool work) might be (for example) the nurses' workload. However, as earlier chapters have revealed, the findings which emerged from each case study site were very similar, which although interesting, provides only a limited answer to the realist evaluation question. This is an issue for further research. In retrospect the second case might have provided additional, alternative insight if it had been situated in a very different setting, such as in primary care, or in specialist nurses' clinics. Nonetheless, identifying that nurses' assessment practice in both case study sites was so similar suggests that this finding may have a wider relevance. Additionally, the findings on emotion work corroborate other research which has explored nurses' emotional labour in ambulatory care settings, such as: outpatient fertility clinics (Allan 2001b); day care surgery units (Wigens 1997); renal dialysis units (Bevan 1998); and accident and emergency nursing (Byrne and Heyman 1997). It is unclear, however, whether the type of emotional care identified was the result of the nurses' orientation, which led them to choose to work in such settings, or whether it was the nature of the settings which created the emotional care identified. Clearly, further research into nurses' work in ambulatory care settings is merited.

10.5.1 The Intervention

Realist evaluations inform the development of policy and practice (Kazi 2000; Tilley 2000) and therefore it is necessary to learn the lessons not only from the effects of the intervention but also from the way it was implemented (Mark and Henry 1998; Weiss 2000). This prevents mistakes being made in future studies, and helps to build evaluations for the future (Pawson and Tilley 1997); it avoids harm (by ensuring that interventions which are counterproductive are not re-introduced in similar contexts); and waste (by not introducing interventions that will not work in specific conditions) (Tilley 2005).

There are two aspects to the circumstances of 'what worked'; one relates to the tool itself, and other, to the way in which the tool was introduced.

The circumstances in which the tool worked are summarised in Table 10-2 (see also Chapters 6 and 7), along with practical recommendations which may be useful when planning future research or practice development with assessment tools:

How the tool worked	Works best if	Considerations
Raised awareness of issues	Support for nurses: emotional and practical	Organisational changes would be required: e.g. appointment system; privacy; time; involve MDT
Articulation: Gave permission to talk Clarified the issue	Mentoring of nurses Patients have energy to talk, and are physically able to talk (e.g. not suited to some head and neck cancer patients)	Supervision and support required for nurses; willing to reflect on practice Organisational disruption will ensue: plan ahead

	Nurses interested in palliative care	Prepare for effect of tool: talk = work?
Engaged nurses with patients' issues	Team approach to care across cancer service Mentoring to support nurses Education to enable nurses to interpret importance of patients' issues	Involve MDT in the change; map service availability and criteria for referrals Educational preparation Action learning or reflective practice groups
Engaged patients with their own issues and with support	Patients are allowed to talk: sufficient time is given for assessment ?Privacy required	Place of assessment: is chemo unit the place to do this? Privacy; timing; frequency of such assessments
Empowerment Gave control to patients	Educational preparation for nurses; communication skills training Feedback positive outcomes to nurses of using the tool for the patients	Increase awareness of nurses' responses to this: use reflection to explore feelings about loss of control Communicate outcomes of decisions re intervention: to check if wishes for professional support change
Led to increased understanding of patients' issues	Support and mentoring for nurses Liaison with MDT Practical issues: privacy; reorganize appointment system; share assessment workload; offer some continuity of care to patients Prepare patients for using tool: information in waiting areas, spectacles; provide time and pens something to lean on Involve volunteers/clinic clerks in handing out assessment forms Offer copy of completed tool to share with family/primary care team	Re-think assessment as 'work' Increase chemotherapy nurses' involvement in MDT and in 'communication loop' across the cancer service Paperwork to document assessments: record members of MDT involved in patients' care; file assessment tool in notes; provide copy for patient if required Fax machine in units to facilitate referrals and information sharing Obtain stock of blank referral forms for Palliative care nurse, Primary care team Service mapping: telephone numbers of roles and titles of MDT Keep stock of regularly used information sheets in treatment areas, e.g. dietary advice, fatigue 'handy hints'

Table 10-2 Learning from the circumstances of what worked.

10.5.2 The programme effect

The programme effect is the combination of the processes and outcomes by which the intervention is achieved (Weiss 2000). Having identified that social organisation was the regularity of assessment (See Chapter 8) and the underlying causal mechanism in the setting (which disabled many of the tool's mechanisms), the following section is concerned with identifying the positive aspects of the research process on the nurses who were learning to use the tool.

The five phases of structured quality of life assessment (depicted in Figure 7-1) were also the change mechanisms at work in the programme. Taking part in the research as it was designed and conducted (see Chapter 3) effected cognitive, affective and behavioural change in the nurses' practice. These change mechanisms are addressed below.

10.5.2.1 Awareness

The assessment tool raised nurses' awareness of the impact of incurable cancer and palliative anti-cancer treatment on patients' lives. Such insight provided a wider focus for assessment than was the norm. Half the nurses in Phase 2 of the study admitted that hearing such stories and being given this insight was the first time they had appreciated patients' lives away from the treatment setting. For two others (Sue and Kim), taking part in the study enabled them to re-visit previously used assessment skills, and gave permission to spend time talking to patients about non-treatment related issues. In addition, the programme effect raised nurses' awareness of their learning needs and revealed some limitations in their practice. The follow-up interviews gave nurses opportunity to reflect on their assessments, and raised awareness of the assumptions and routines that underpinned and shaped assessment work. All the nurses, except Myra, considered themselves skilful and expert; being made aware of gaps in their knowledge, and being self-critical of their usual practice during the follow-up interviews raised uncomfortable feelings about their competence, which required sensitivity. At the end of the study, however, all the nurses reported that they had learned a great deal from taking part, and had become more self-aware when assessing patients.

10.5.2.2 Clarifying

A key feature of the study design was the follow-up interviews during which sections of the assessments were re-played to participants. This stratagem was particularly successful with the patients, who reported that they had forgotten many of the details and nuances of the assessment conversation. Hearing these extracts gave them opportunity to clarify for me their understanding and allowed me to check that I had interpreted their cues appropriately.

The nurses had difficulty listening to the assessment recordings, and the majority preferred to read the transcripts. The purpose of the follow-up interviews was to enable the nurses to interpret their assessments, and supplement, challenge and correct my understandings and interpretations. The follow-up interviews were not easy either for the nurses or for me; with one exception, the nurses said they gained much from these follow-up interviews, and appreciated the opportunity to clarify their practice.

In Phase 2 I clarified with the nurses how much help and support they desired when assessments based on the tool were being recorded and observed. At times, during Phase 2, nurses had difficulty knowing how to respond to what patients were saying either because they did not understand (see Noreen's assessment of Julia, section 7.4), or because the talk was too painful (see Myra's assessment of Patricia, section 6.2.3.6). In these instances, I reflected back to patients a summary of what they had said, asked follow-up questions, modelled responses and made suggestions to the nurses to help them continue with the assessment. This clarifying role ensured that the study remained ethically sound.

10.5.2.3 Interpreting

The follow-up interviews were an opportunity for patients and nurses to interpret their understandings of assessment to me. Allowing them to interpret their feelings and interpret their experiences of assessment was crucial to gaining insight into the impact of the tool as well as into the nurses' usual assessments. However, an unanticipated effect of these reflective sessions was that some of the nurses became upset, and others, defensive and hurt. I had anticipated patients' distress in the follow-up interviews, but not how the nurses might feel. In retrospect, this was an oversight.

Introducing the assessment tool caused some friction, and was disruptive. A realist evaluation is concerned with understanding how the intervention worked, and therefore, understanding what emotions and feelings the assessment tool generated was a key part of my role. The nurses who took part in the interim phase and Phase 2 of the data collection found using the tool to be emotionally draining, and therefore, I was careful to check the nurses' on-going consent to participate in the study before recruiting the patients for the day. I also had to interpret the nurses' anger and upset.

It was difficult to feedback some of the findings about emotion work in assessment, and three of the nurses disagreed with my interpretation. After reflection and re-consideration, I believe that the interpretation is worthy of discussion, and have presented it in the thesis, along with supporting evidence to enable readers to draw their own conclusions about the validity of my claims.

10.5.2.4 Supporting

This was an important aspect of the research process, as the introduction and use of the tool aroused strong anxiety in the nurses, who needed and were given support to help them cope with change. The difficulties the nurses found when using the tool have been described (see section 10.4), for it exposed them to emotionally difficult issues, and highlighted gaps in their knowledge. Support was necessary to compensate for this. After each recorded assessment, the nurse and I would 'de-brief', which enabled me to provide support and information, a cup of coffee, and a listening ear (and on occasion a shoulder to cry on). I felt that this support was necessary to protect both nurses and patients, and ensure safe and ethical practice during the interim phase and Phase 2 of the data collection. My role as container (Fabricius 1991) was important: not only for the patients' sufferings (in my role as a modeller and mentor), but also for the nurses' distress when they had listened to the patients' stories.

10.5.2.5 Reframing

The model of structured assessment presented in Chapter 7, shows how the assessment tool reframed assessment from 'identification of need' to 'articulation of experience'. Much of this insight came after the study had been completed, during data analysis. In retrospect, being able to help nurses reframe the Phase 2 assessments either before or during the interim phase might have helped them to understand what they were achieving with the help of the tool.

10.5.3 Summary

There were several aspects to the circumstances in which the tool worked. One was the research design, in which the 'conditions of normality' were challenged (Danemark et al 1997 p104), removing certain mechanisms and provoking others to appear. The way in which the tool was introduced (the programme effect) was helpful, and was perceived positively by the nurses. The programme effect fired change mechanisms in the nurses to enable them to use the tool, and make judgements about the changes brought about by it. The assessment tool worked for the patients attending for treatment in the outpatient chemotherapy unit, but not in the ways expected at the outset of the study, nor in line with policy directives which suggest that using a tool is an efficient means of matching patients' needs to relevant supportive and palliative care services. Some aspects of the assessment tool worked for the nurses; but, overall, they concluded that the tool was not feasible in the setting, and did not help them in their role.

10.6 Reflections on the Realist Evaluation

Realist evaluation is not prescriptive. This is both a strength, and a weakness. There are few guidelines as to how to proceed; consequently, much of what was learned was from trial and error.

Context and mechanisms are central to a realist evaluation, but both terms are poorly defined (Davis 2005b). Identifying the contextual influences on assessment practice was quite straightforward, particularly after periods of reflection and with the use of field notes to supplement the data coding. Nonetheless, it should be remembered that 'context' as I came to understand it, with its different elements or influences remains my interpretation of the phenomena, and is different from how it has been defined and identified in other studies (for example: Byng et al 2005; Wilson et al 2005).

Defining and identifying 'mechanisms' was more difficult. The term has different meanings and different usages. For instance Pawson and Tilley (1997) describe them as hidden workings (page 65); theoretical propositions (page 66); as sub-processes of a programme (page 75); explanations of what it is about the programme that works (page 66); how the programme (will) work(s) (page 190); and choices and capacities which lead to patterns of behaviour (page 216). Moreover, there are 'change mechanisms', 'causal mechanisms', 'programme mechanisms', 'generative mechanisms', 'problem mechanisms', 'disabling mechanisms' and 'blocking mechanisms' (Pawson and Tilley 1997; Kazi 2003), all of which have a different function and different definitions.

One of the difficulties in interpreting Pawson and Tilley's (*ibid*) model of realist evaluation, was that the CMO configurations generated from the data did not lend themselves to single causal linear pathways, as Pawson and Tilley's examples suggest, for example C1-M1-O1; C2-M1-O2 (p72-76; 134; 140-141). The findings (see Figure 4-3 and Figure 6-2) suggest that they are neither singular nor linear, and that multiple contexts fire multiple mechanisms and trigger multiple outcomes, some of which were negative. This seemed to reflect the complexity of practice and the data, and Pawson and Tilley's subsequent text (*ibid* p216-217). One of the interesting findings was that the same CMO configurations fitted with both the patients and the nurses, perhaps because there was a wide range of possible combinations on offer. A future study could map the CMOs for each individual research participant; in this research, each chemotherapy unit was a case study, because defining the case in

these terms fitted with the research question. In judging the usefulness of the CMO configurations that emerged from the data it should be remembered that they represent approximations; they should reflect the reality of practice, and provide an explanation of why and how an intervention may or may not work (Pawson and Tilley 1997). The CMO configurations arising from the data have achieved these goals.

Deciding when to commence Phase 2 of the data collection was difficult, since evaluating an intervention such as an assessment tool or a new way of working implies that some familiarity in its use and skill is required. There is no guidance on this issue in the literature (Tolson et al 2007). In this study, Phase 2 data collection commenced when the nurses themselves said they felt ready and sufficiently confident to use the tool. As a result, there were differences between the two case study sites: the nurses at The Northern requested and required a longer interim phase in which they could practise using the tool with supervision and on their own, compared with those at The Southern. It could be argued that this was a weakness of the study; however, the aim was not to 'test' the nurses' ability in using the tool, but to evaluate the impact of it on their practice, and to this end, it was important to be guided by their confidence. Moreover, keeping detailed field notes, and reflecting on the study provided rich data about the immediate impact of the tool which helped in the interpretation of what had been observed in Phase 1 but had not been fully understood.

Analysing and presenting the findings in terms of the realist evaluation was complex and time consuming. Data analysis was performed in four stages, since a realist evaluation is not merely concerned with ascertaining 'what worked', but why, how, for whom, and in what circumstances. Moreover, as realism is premised on the existence of a stratified reality in both the physical and social realms (Sayer 1992; 2000; Pawson and Tilley 1997; Bhaskar 1998), it was necessary to do multiple levels of analysis in order to provide the required levels of explanation. The strength of this stratified analysis is the degree of explanation which has been offered for the impact of the tool on practice. This provides useful information for any future practice development work.

The goal of a realist evaluation is the 'betterment of practice' (Pawson and Tilley 1997 p119). This goal was achieved, but feedback from a conference presentation raised the question of the value of such a goal and the outcomes from the tool, since the majority have been inferred from the data to represent what the patients and nurses reported (such as 'satisfaction', and 'feeling supported'). The quantifiable outcomes concerned the number and type of issues identified by the assessment tool. Pawson (1989 cited in McEvoy and Richards 2003) argues that quantitative measures are needed to evaluate contexts, mechanisms and outcomes, although Sayer (2000) advocates qualitative approaches for their ability to identify contextually-grounded (McEvoy and Richards 2003) explanatory mechanisms. Kazi (2003) states that a realist evaluation can accommodate either quantitative or qualitative methods, depending on the intervention being evaluated. Qualitative methods were used in this study, since these fitted the research question and aims of the study. Thus, realist evaluation offers flexibility in the type and range of methods used, which suggests that the approach has a wide range of applicability. From a managerialist perspective, however, the outcomes from the tool are 'soft' and economically unattractive; the tool did not enhance patients' access to supportive care services nor lead to more efficiency, as predicted in policy (NICE 2004). Thus, even though patients found the structured assessments to be supportive and helpful, it is doubtful whether the type of outcomes identified will be considered rigorous enough for cancer networks to embrace. Thus as Tolson et al (2007) question, is

'betterment of practice' (Pawson and Tilley 1997 p119) an adequate goal of realist evaluation, or should there be more concrete outcomes? Whether betterment of practice in terms of care processes is valued by managers of Health Trusts and cancer networks is debatable, but a debate which is worth opening, for although the Health Service is shaped by a managerial discourse which emphasises efficiency and 'value for money' (Wigens 1997; Parker 2004; Wong 2004; Gilbert 2005; Willard and Luker 2005) there is also a consumerist discourse (Gerrish 2000; Radley 2002; McQueen 2004) espousing patient choice and individualised care. These findings add weight to this latter discourse, in that they offer a possible means to bring the patients' voice into health care settings (Radley 2002), and involve patients in decisions about their care.

In summary, the realist evaluation approach provided insight into and new understanding of nurses' assessment practice in the outpatient chemotherapy unit, and the impact of introducing an assessment tool. Realist evaluation provides explanations for these findings which will help to avoid costly mistakes (Tilley 2005) if this policy is rolled out across the cancer network and in other units before underlying issues have been addressed. This is another aim of a realist evaluation (Tilley 2005), and one which is likely to be welcomed by managers and policy makers in the Health Service.

10.7 How to test in the future

Realist evaluations are concerned with developing transferable, cumulative lessons from research, using the refined CMOs from one study and testing them in a new setting so they may be fine-tuned (Pawson and Tilley 1997) to fit different circumstances. In realist evaluation, generalisations are not made in terms of replication, as future settings will be different (Pawson and Tilley 1997). Instead, generalisation concerns the testing of CMO configurations using theory to provide an analytic framework for subsequent studies. In identifying a theory on which to base a future study to test the CMOs refined at the end of this study, the following were considered: nurses' attitudes towards holistic assessment, which was an espoused ideal but proved difficult to practise; the contextual influences on, and mechanisms of, assessment, including working in the dark, the social organisation of assessment (which placed control of the assessment with the nurses and shaped assessment as a functional activity); and the tensions between and within policy and professional ideals for assessment and cancer care.

Social organisation theory was identified as the generative, causative mechanism arising from the context. When analysing 'what worked, and for whom', it became clear that there was a second underlying generative mechanism relating to the nurses (and patients) who took part in the study and their individual responses to the intervention:

Realists do not contend that programmes work, rather it is the action of the stakeholders which makes them work, and the causal potential of an initiative takes the form of providing reasons and resources to enable program participants to change.

(Pawson and Tilley 1997 p213)

This is congruent with theories of practice development and policy implementation (Rycroft-Malone et al 2006), which is the focus of this work. The theory which is suggested to be applied to test the refined CMOs from this study in future research is the theory of planned behaviour (Ajzen 2006), which assumes that intention to perform the behaviour is its most important determinant (Michie and Lester

2005). The intention is determined by three variables: whether the person is in favour of performing the behaviour (attitude) and evaluations of the planned behaviour; how much social pressure they feel to do it (social norm) and their evaluations of these beliefs; and whether they feel in control of performing the behaviour (perceived behavioural control), and how much confidence they have in performing that behaviour. The theory states that generally, the more positive people's attitudes and subjective norms towards the behaviour, and the greater their perceived control over the behaviour, the stronger their intention to carry it out (Michie and Lester 2005; Ajzen 2006). The theory is summarised in Appendix 17.

The theory of planned behaviour may seem at odds with the emphasis throughout the study on the importance of recognising the contextual influences on nurses' assessment practice, rather than 'blaming' them as individuals for any deficiencies in their assessment practice. However, in realist terms, causation is not understood to be external (Pawson and Tilley 1997 p213): i.e. the tool did not produce the outcomes, but it was its *impact* on the social setting, the nurses and patients which led to the outcomes:

Interventions are embedded in a range of attitudinal, individual, institutional processes and the choice making behaviour of individuals in their situations is fundamental to understanding patterns of behaviour. In social settings, there are also the social norms and constraints to consider, power and resource constraints. Programme evaluations need to grasp how changes introduced inform and alter the balance of constrained choices of participants

(Pawson and Tilley 1997 p216)

Chapter 8 has addressed the impact of the tool on the social setting, the norms and nurse-patient relations constituted by the underlying, causal mechanism in the setting: social organisation of assessment. In relation to the individual nurses working in the setting, however, who were able to make choices and change their practice (or to decide not to), there were three effects of the tool:

1. It deconstructed the hierarchy of appropriateness which guided usual assessment practice, challenging nurses' beliefs and assumptions about assessment
2. It confronted nurses' emotional defences and created anxiety, challenging their perceived behavioural control
3. It raised questions about the feasibility of carrying out holistic assessment in the outpatient chemotherapy unit, challenging nurses' attitudes about the value of assessing patients, and the therapeutic nature of talk, and whether this was valued as 'work'

The usefulness and applicability of the theory of planned behaviour is explicated by examining the responses of the two nurses for whom the assessment tool 'worked' most positively. These nurses were Myra and Sue, although the reasons were different. Table 10-3 below contains a summary of their responses to the research study and my interpretations of why the research 'worked' for them, linked to the theory of planned behaviour. This illustrates how the theory can help in future studies to build on and refine the CMOs generated from this research.

Concluding the Realist Evaluation

Nurse	Why intervention worked	Theory of planned behaviour
Myra	<p>Was keen to learn and improve practice; was new in her post, and inexperienced</p> <p>Had no previous experience, and was open to development and mentoring which gave her confidence</p> <p>Was keen to please and receive positive feedback</p> <p>Committed to the assessment tool; saw the advantages but had little insight into the disadvantages</p> <p>Was not fully socialised into the unit's norms and values</p> <p>Was not involved in managerial issues, and was very patient-focused, not affected by organisational disruption arising from the tool</p> <p>Was very keen to help patients and improve her nursing</p> <p>This approach to assessment fitted with the teaching on the post-registration chemotherapy course</p>	<p>Subjective norm</p> <p>Perceived behavioural control; attitude</p> <p>Attitude</p> <p>Attitude; positive appraisal</p> <p>Attitude</p> <p>Attitude; perceived behavioural control</p> <p>Attitude</p> <p>Subjective norm</p>
Sue	<p>Was committed to holistic assessment; felt frustrated with usual assessment practice in the unit – did not feel it was good enough</p> <p>Wanted to take more responsibility for improving practice to match her philosophy and beliefs</p> <p>?Wanted to challenge managerial style of G grade</p> <p>Had recent experience of working on in-patient ward and was more aware of patients' social circumstances and multi-disciplinary working</p> <p>Was not afraid of engagement; was accustomed to talking with patients and relatives on in-patient ward and had recent experience of talking with and caring for the dying. Missed this role having returned to out-patient work</p> <p>Had communication skills: displayed empathy, and felt nurses in chemo unit were in a position to make a difference</p> <p>Found using the tool satisfying</p> <p>?Underlying agenda to prove her worth in the team (?keen to be seen to be a key player in the research)</p>	<p>Positive attitude; behavioural belief</p> <p>Normative belief; perceived behavioural control</p> <p>Perceived behavioural control</p> <p>Perceived behavioural control; normative belief</p> <p>Attitude; normative belief; perceived behavioural control</p> <p>Perceived behavioural control; attitude</p> <p>Attitude</p> <p>Attitude</p>

Table 10-3 What worked for Myra and Sue

10.7.1.1 Summary

In reflecting on the experience of conducting a realist evaluation, I have identified the positive and negative, the strengths and weaknesses of the approach. The realist evaluation approach was valuable, because it provided insight and understanding through the generation of explanatory mechanisms, and placed chemotherapy nurses' assessment work in context. It revealed and explained why the introduction of the assessment tool had an equivocal impact on the nurses; a positive impact on the patients, and a disruptive impact on the setting. Conducting a realist evaluation approach has therefore made a unique contribution to the body of knowledge in cancer nurses' assessment practice.

10.8 Conclusion

This realist evaluation has been concerned with the way chemotherapy nurses assess patients in the palliative phase of their cancer illness attending the outpatient chemotherapy unit for treatment, and in particular, the impact of introducing an assessment tool. The study has exposed the different ways assessment is conceptualised in policy, theory and practice, with each of the domains prioritising a separate agenda. Highlighting these tensions helps to explain why assessment remains stubbornly difficult to 'improve' through the use of assessment skills training.

Assessment practice in the outpatient chemotherapy unit was identified to be a functional activity, structured and bound by the nurses' hierarchy of appropriateness, and by a fear of emotional disclosure, such that the assessment conversation had become a defence against anxiety. Contextual influences on assessment and the mechanisms which these fired combined to leave nurses working in the dark, further constraining their assessment practice, guaranteeing a narrow treatment-focused agenda.

Introducing the tool considerably lengthened assessments, and widened the range of concerns that were addressed, exposing nurses to emotionally challenging issues, which they were largely unable to bear. Moreover, the assessment tool did not necessarily prompt referrals to supportive and palliative care services, indicating that there is limited understanding in policy of assessment in practice. Despite firing powerful and effective mechanisms, the assessment tool was partially disabled by the social organisation of assessment work, the causal mechanism responsible for shaping the conduct and content of usual assessments. The nurses considered the tool to be impractical and largely unsuited to the setting.

Patients preferred the structured approach, welcoming the opportunity to articulate their experiences of illness, and engage with the meanings of their symptoms and problems. The benefits which patients identified highlight the need to find ways of strengthening their voice in assessment and care, and to debate the scope for re-configuring assessment as 'articulation work'.

Assessment tools are therefore unlikely to be the panacea for the problems of cancer nursing assessment.

This study might not provide an answer to the problem of how to transfer assessment policy into practice, but has identified ways in which elements can be translated. This study revealed that nurses' current assessment work in the outpatient chemotherapy unit accomplishes a great deal, and should be valued for its efficiency and effectiveness. Acknowledging the impact of policy on the ability of chemotherapy nurses to balance all that they are being asked to be and achieve is a valuable finding of this study, and worthy of further research.

This study has opened a window on cancer nurses' assessment practice in the outpatient chemotherapy unit. If the realist evaluation serves the ends of enlightenment and advocacy as well as engineering (Pawson and Tilley 1997 p213) then these will be outcomes worthy of the generosity of those who made this study possible.

References

- Aaronson N K; Ahmedzai S; Bergman B; Bullinger M; Cull A; Duez NJ; A Filiberti; Flechtner H; Fleishman SB; de Haes JCJM; Kaasa S; Klee M; Osoba D; Razavi D; Rofe PB; Schraub S; Sneeuw K; Sullivan M; Takeda F (1993) The European Organisation for Research and Treatment of Cancer QLQC-30: a quality of life instrument for use in international clinical trials in oncology Journal of the National Cancer Institute 85:5 365-76
- Addington-Hall J (2002) Research sensitivities to palliative care patients European Journal of Cancer Care 11 220-224
- Ajzen I (2006) Behavioural interventions based on the Theory of Planned Behaviour downloaded from <http://www.people.umass.edu/ajzen/pdf/tpb.intervention.pdf> February 2007
- Ajzen, I. (2005). Attitudes, Personality, and Behaviour (2nd. Edition) Open University Press, Buckingham I.
- Alfaro-le-Fevre R (2004) Critical Thinking and Clinical Judgement: A Practical Approach Saunders, London
- Allan HT (2000) Sister will see you now: managing emotions in a fertility clinic. An ethnographic study. Unpublished PhD Thesis University of Manchester
- Allan HT (2001a) 'A good enough' nurse: supporting patients in a fertility unit Nursing Inquiry 8:1 51-60
- Allan HT (2001b) Nursing the clinic and managing emotions in a fertility unit: findings from an ethnographic study Human Fertility 4 18-23
- Allan HT (2002) Nursing the clinic, being there and hovering: ways of caring in a British fertility unit Journal of Advanced Nursing 38:1 86-93
- Allen D (1997) The nursing-medical boundary: a negotiated order? Sociology of Health and Illness 18 498-520
- Allen D (1998) Record-keeping and routine nursing practice: the view from the wards Journal of Advanced Nursing 27:6 1223-1230
- Allen D (2002) Time and space on the hospital ward: shaping the scope of nursing practice In: Nursing and the Division of Labour in Healthcare (ed: Allen D and Hughes D) Palgrave Macmillan, Bristol p23-51
- Allen D (2003) Ethnomethodological insights into insider-outsider relationships in nursing ethnographies of healthcare settings Nursing Inquiry 11:1 14-24
- Allen D (2004) Re-reading nursing and re-writing practice: towards an empirically based reformulation of the nursing mandate Nursing Inquiry 11:4 271-283.
- Allen D and Hughes D (ed) (2002) Nursing and the Division of Labour in Healthcare Palgrave Macmillan, Bristol
- Allenby A; Matthews J; Bereford J; McLachlan S (2002) The application of computer touch-screen technology screening for psychosocial distress in an ambulatory oncology setting European Journal of Cancer Care 11 245-53
- Annelis M and Koch T (2001) 'The real stuff': implications for nursing of assessing and measuring a terminally ill person's quality of life Journal of Clinical Nursing, 10: 6 806-812

References

- Annels M.; Brown M. & Koch T. (2001) Client relevant care and quality of life: the trial of a Client Generated Index (CGI) tool for community nursing. International Journal of Nursing Studies 38 9-16.
- Aranda S; Schofield P; Wein L; Yates P; Milne D; Faulkner R; Voudouris N (2005) Mapping the quality of life of urban women with metastatic breast cancer European Journal of Cancer Care 14:3 211-222
- Arantzamendi M and Kearney N (2004) The psychological needs of patients receiving chemotherapy: an exploration of nurse perceptions European Journal of Cancer Care 13 23-31
- Archer VR; Billingham LJ; Cullen MH (1999) Palliative chemotherapy: no longer a contradiction in terms The Oncologist 4 470-477
- Armstrong D (1983) The fabrication of nurse-patient relationships Social Science and Medicine 17:8 457-460
- Armstrong D (1995) The rise of surveillance medicine Sociology of Health & Illness 17 (3), 393-404
- Armstrong D (2004) Emotions in organisations: disturbance or intelligence? In Working Below the Surface: The Emotional Life of Contemporary Organisations (ed: Huffingham C; Armstrong D; Halkon W; Hoyle L; Pooley J) Karnac, London 11-27
- Audit Commission (2005) The NHS Cancer Plan: A Progress Report, London
- Audit Commission (2002) NHS Cancer Care in England and Wales National Service Framework Assessments No. 1 HMSO, London
- Avis M; Bond M; Arthur A (1995) Satisfying solutions? A review of some unresolved issues in the measurement of patient satisfaction Journal of Advanced Nursing 22:2 316-322.
- Bailey C (1995) Nursing as therapy in the management of breathlessness in lung cancer European Journal of Cancer Care 4:4 184-90
- Ball J (2005) Maxi Nurses: Advanced and Specialist Nursing Roles Report commissioned by the Royal College of Nursing downloaded from http://www.rcn.org.uk/publications/pdf/maxi_nurses_advanced.pdf - 230.7KB
- Benner P (1982) From novice to expert The American Journal of Nursing 82: 3 402-407
- Benner P (1984) Interpretive Phenomenology: Embodiment, Caring and Ethics in Health and Illness Thousand Oaks, California
- Benner P and Tanner C (1987) Clinical Judgment: How Expert Nurses Use Intuition The American Journal of Nursing 87:1 23-31 Sage, Thousand Oaks
- Benner P; Tanner C; Chelsa C (1992) From beginner to expert: gaining a differentiated clinical world in critical care nursing Advances in Nursing Science 14:3 13-28
- Berger A (1998) Few cancer patients benefit from palliative chemotherapy British Medical Journal 317 1407
- Berger PL and Luckman T (1966) The Social Construction of Reality: A Treatise in the Sociology of Knowledge Anchor Books, New York
- Bertero C and Eriksson BE (1996) Demanding interaction, given routines: an observational study of leukaemia patients and their nursing staff International Journal of Nursing Studies 2:4 201-8
- Bevan MT (1998) Nursing in the dialysis unit: technological enframing and a declining art, or an imperative for caring? Journal of Advanced Nursing 27 730-36

- Bhaskar R (1998) Critical Realism: Essential Readings Routledge, London
- Bhaskar R (1998) Philosophy and scientific realism In: Critical Realism: Essential Readings (ed: Archer MR; Bhaskar R; Collier T; Lawson N; Norrie A) Routledge, London p16-47
- Binnie A and Titchen A (1999) Freedom to Practise: The Development of Patient-Centred Nursing Butterworth-Heinemann, Oxford
- Blaikie N (1993) Approaches to Social Enquiry Polity, Cambridge
- Blinderman C and Cherny NI (2005) Existential issues do not necessarily result in existential suffering: lessons from cancer patients in Israel Palliative Medicine 19:5 371-80
- Bloor M (1978) On the routinised nature of work in people-processing agencies: the case of adenotonsillectomy assessments in ENT outpatient clinics In: Relationships between Doctors and Patients (ed: A Davies) Ilfradrove Ltd, Barry, South Wales 29-47
- Bonner A and Tolhurst G (2002) Insider-outsider perspectives on participant observation Nurse Researcher 9:4 7-19
- Booth C (1993) Helping patients with cancer: Putting psychological assessment skills into practice Unpublished PhD University of Manchester
- Booth J and Waters KR (1995) the multi-faceted role of the nurse in the day hospital Journal of Advanced Nursing 22 700-06
- Booth K; Maguire PM; Butterworth T; Hillier VF (1996) Perceived professional support and the use of blocking behaviours by hospice nurses Journal of Advanced Nursing 24:3 522-7
- Bowers L (1992) Ethnomethodology: an approach to nursing research International Journal of Nursing Studies 29:1, 59-67
- Boyes A; Newell S; Girgis A; McElduff P; Sanson-Fisher R (2006) Does routine assessment and real-time feedback improve cancer patients' psychosocial well-being? European Journal of Cancer Care 15:2 163-171
- Braud A-C; Genre D; Leto C; Nemer V; Cathol J-F; Macquart-Moulin G; Maraninchi D (2003) Nurses' repeat measurement of chemotherapy symptoms: feasibility, resulting information, patient satisfaction Cancer Nursing 26:6 468-475
- Bredin M, Corner JL, Krishnasamy M, Plant H, Bailey C, A'Hearn R (1999) Multi-centre randomised trial for breathlessness in patients with lung cancer British Medical Journal 318 901-904
- Brown ST; Bowman JM; Eason FR (2001) Assessment of nurses' attitudes and knowledge regarding pain International Journal of Palliative Nursing 7 597-603
- Brown A and Draper P (2003) Accommodative speech and terms of endearment: elements of a language mode often experienced by older adults Journal of Advanced Nursing 41:1 15-21
- Brown SJ (1995) An interviewing style for nursing assessment Journal of Advanced Nursing 21 340-343
- Brown V, Sitzia J, Richardson A, Hughes J, Hannon H, Oakley C (2001) The development of the Chemotherapy Symptom Assessment Scale (C-SAS): a scale for the routine clinical assessment of the symptom experience s of patients receiving cytotoxic chemotherapy International Journal of Nursing Studies 38 497-510
- Browner I and Carducci MA (2005) Palliative chemotherapy: historical perspective, applications and controversies Seminars in Oncology 32 145-55

References

- Bruera E Sweeney C Wiley J Palmer L Tolley S Rosales M Ripamonti C (2003) Breast cancer patient perception of the helpfulness of a prompt sheet versus a general information sheet during outpatient consultation: a randomised controlled trial Journal of Pain and Symptom Management 25:5 412-421
- Bryans A and McIntosh J (1996) Decision making in community nursing: an analysis of the stages of decision making as they relate to community nursing assessment practice Journal of Advanced Nursing 24:1 24-30
- Bryans A and McIntosh J (2000) The use of simulation and post-simulation interview to examine the knowledge involved in community nursing assessment practice Journal of Advanced Nursing 31:5 1244-51
- Bryar RM (1999) An examination of case study research Nurse Researcher 7 61-78
- Buckingham CD and Adams AE (2000) Classifying clinical decision making: a unifying approach Journal of Advanced Nursing 32:4 981-989.
- Buckingham, C.D. & Adams, A.E. (2000). Classifying Clinical Decision Making: Interpreting Nursing Intuition, Heuristics, and Medical Diagnosis. Journal of Advanced Nursing 32:4 990-998.
- Bucknall TK (2000). Critical care nurses' decision making activities in the natural clinical setting Journal of Clinical Nursing 9 25-36
- Burkey Y (1997) Comment: the patient and power: sociological perspectives on holistic care Health and Social Care in the Community 5:1 21-22
- Burnard P (1991) A method of analysing interview transcripts in qualitative research Nurse Education Today 11 461-466
- Butow P (2001) The importance of communication skills to effective cancer care and support New South Wales Public Health Bulletin 12:10 272-274
- Butters E; Pearce S; Ramirez A; Richards M (2003) Assessing symptoms and concerns inpatients with advanced cancer: the development of a checklist for use in clinical practice Palliative Medicine 17:7 588-595
- Byng R; Norman I; Redfern S (2005) Using realistic evaluation to evaluate practice-level intervention to improve primary healthcare for patients with long-term mental illness Evaluation 11:1 69-93
- Byrne G and Heyman R (1997) Patient anxiety in the accident and emergency department. Journal of Clinical Nursing 6:4 289-295
- Calhoun EA; Chang C-H; Welshman EE; Fishman DA; Lurain JR; Bennett CL (2001) Evaluating the total costs of chemotherapy-induced toxicity: results from a pilot study with ovarian cancer patients The Oncologist 6:5 441-445
- Campbell J; German L; Lane C; Dodwell D (2000) Radiotherapy outpatient review: a nurse-led clinic Clinical Oncology 12:2 104-7
- Carelle N; Piotto E; Bellanger A; Germanaud J; Thuillier A; Khayat D (2002) Changing patient perceptions of the side effects of cancer chemotherapy Cancer 85:1 155-63
- Carpentio LJ (1993) Nursing Diagnosis: Application to Clinical Practice 5th edition Lippincott Philadelphia
- Carr SM (2004) A framework for understanding clinical reasoning in community nursing Journal of Clinical Nursing 13:7:850-857

- Casarett D, Karlawish J. (2000) Are special ethical guidelines needed for palliative care research? Journal of Pain Symptom Management 20:130-9
- Chambliss DF (1996) Beyond Caring: Hospitals, Nurses and the Social Organisation of Ethics University of Chicago Press, Chicago
- Charles-Jones H; Latimer J; May C (2003) Transforming general practice: the redistribution of medical work in primary care Sociology of Health and Illness 25:1 71-92
- Cheek J (1995) Nurses, nursing and representation: an exploration of the effect of viewing positions on the textual portrayal of nursing Nursing Inquiry 2:4 235-40
- Cheek J and Porter S (1997) Reviewing Foucault: possibilities and problems for nursing and health care Nursing Inquiry 4:2 108-19
- Cioffi J and Markham R (1997) Clinical decision making: managing case complexity Journal of Advanced Nursing 25:2 65-72.
- Cioffi J.(1997) Heuristics, servants to intuition in clinical decision making Journal of Advanced Nursing 26:1 203-208.
- Clark A; Hanson AJ; Ross H (2003) Seeing the person behind the patient: enhancing the care of older people using a biographical approach Journal of Clinical Nursing 12:5 697-706
- Clark D (2002) Between hope and acceptance: the medicalisation of dying British Medical Journal 324 909-907
- Clark D and Seymour J (1999) Reflections on Palliative Care Facing Death Series Open University Press, Buckingham
- Clark J (1999) A language for nursing Nursing Standard 13:31 42-4
- Clark J and Lang N (1992) Nursing's next advance: an internal classification for nursing practice Nursing Standard 13: 31 42-44
- Clark R (2002) A Long Walk Home Radcliffe Medical, Oxford
- Clarke A and Ross H (2006) Influences on nurses' communications with older people at the end of life: perceptions and experiences of nurses working in palliative care and general medicine International Journal of Older People Nursing 1:1 34-43
- Clarke B; Brown V, Harlow W, Hughes J, Sitzia J 2004 The assessment of symptoms experienced by patients receiving cytotoxic chemotherapy – an examination of current practice in outpatient chemotherapy units of acute NHS Trusts. Worthing and Southlands NHS Trust, Unpublished Report
- Clarke L (2006) So what *exactly* is a nurse? Journal of Psychiatric and Mental Health Nursing 13:4 388-394
- Coates A (1997) Quality of life and supportive care Supportive Care in Cancer 5 435-438
- Cohen SR; Mount BM; Bruera E; Provost M; Rowe J; Tong K (1997) Validity of the McGill Quality of life questionnaire in the palliative setting: a multi-centre Canadian study demonstrating the importance of the existential domain Palliative Medicine 11 3-20
- Conlon M (2005) Will the lead clinical please stand up? That'll be the General Practitioner British Medical Journal 330 966
- Coombes MA (2004) Power and Conflict between Doctors and Nurses: Breaking Through the Inner Circle in Clinical Care Routledge, London

References

- Comer J (1997) Beyond survival rates and side effects: cancer nursing as therapy: The Robert Tiffany Lecture Cancer Nursing 20:1 3-11
- Comer J (1999) Interface between research and practice in psycho-oncology Acta-Oncologica 38:6 703-8
- Comer J (2001) Between You and Me: Closing the Gap Between People and Health Care HMSO London
- Comer J (2003) The role of nurse-led care in cancer management The Lancet Oncology 4:10 631-6
- Comer J and O'Driscoll M (1999) Development of a breathlessness assessment guide for use in palliative care Palliative Medicine 13:5 375-84
- Comer J and Dunlop R (1997) New approaches to care In: New Themes in Palliative Care (ed: Clark D; Hockley J; Ahmedzai S) Open University Press, Buckingham p 288-300
- Comer J; Plant H; A'Hearn R; Bailey C (2001) Non-pharmacological intervention for breathlessness in lung cancer Palliative Medicine 10:44 29-305
- Cowley S; Mitcheson J; Houston AM (2004) Structuring health needs assessment: the medicalisation of health visiting Sociology of Health and Illness 26:5 503-26
- Cowley S.; Bergen A; Young K; Kavanagh A (2000) A taxonomy of needs assessment, elicited from a multiple case study of community nursing education and practice. Journal of Advanced Nursing 31, 126-134
- Cox K (2000a) Setting the context for research: examining the environment and philosophy of a cancer clinical trials unit Journal of Advanced Nursing 32:5 1058-65
- Cox K (2000b) Enhancing cancer clinical trials management: recommendations from a qualitative study of trial participants' experiences Psycho-Oncology 9:4 314-22
- Cox K (2002) The hopes of the dying: examining patients' experience of participation in early cancer clinical trials NT Research 7:1 60-73
- Cox K (2003) Assessing quality of life in patients in phase I and II anti-cancer drug trials: interviews versus questionnaires Social Science and Medicine 56 921-34
- Cox K and Wilson E (2003) Follow-up for people with cancer: nurse-led services and telephone interventions Journal of Advanced Nursing 43:1 51-61
- Coyle J Williams B (2001) Valuing people as individuals: development of an instrument through a survey of person-centredness in secondary care Journal of Advanced Nursing 36:3 450-459
- Craib I (1992) Modern Social Theory: From Parsons to Habermas St Martins Press New York
- Crossley ML (2003) Let me explain: Narrative emplotment and patient's experience of oral cancer Social Science and Medicine 56:3 439-448
- Crotty M (1998) The Foundations of Social Research: Meanings and Perspective in the Research Process Sage, London
- Crow R; Chase J; Lamond, D (1995) The cognitive component of nursing assessment: an analysis Journal of Advanced Nursing 22:2 206-212
- Curry C; Cossich T; Matthews JP; Beresford J; McLachlan SA (2002) Uptake of psychosocial referrals in an outpatient cancer setting: improving service accessibility via the referral process Supportive Care in Cancer 10: 549-555

Danemark B; Ekstron M; Jakobsen L; Karlsson JC (1997) Explaining Society: Critical Realism in the Social Sciences Routledge, London

Davies B and Allen D (2007) Integrating 'mental illness' and 'motherhood': The positive use of surveillance by health professionals. A qualitative study International Journal of Nursing Studies 44:3 365-376

Davis BD; Billings JR; Ryland RK (1994) Evaluation of nursing process documentation Journal of Advanced Nursing 19 960-968

Davis MP (2005a) Integrating palliative medicine into an oncology practice. American Journal of Hospice and Palliative Medicine 22:6 447-456

Davis P (2005b) The limits of realist evaluation: surfacing and exploring assumptions in assessing the best value performance regime Evaluation 11:3 275-195

de Raeve L (1997) Positive thinking and moral oppression in cancer care European Journal of Cancer Care 6:4 249-56

de Raeve L (2002) The modification of emotional responses: a problem of trust in nurse-patient relationships? Nursing Ethics 9: 5 466-471

Del Vecchio Good MJ; Munakata T; Kobayashi Y; Mattingly C; Good BJ (1994) Oncology and narrative time Social Science and Medicine 38:6 855-62

Delanty G (1997) Social Science: Beyond Constructivism and Realism. Open University Press, Buckingham

Dennison S (1995) An exploration of the communication that takes place between nurses and patients whilst cancer chemotherapy is administered Journal of Clinical Nursing 4:4 227-33

Department of Health (2005) The Patients' Charter HMSO London

Department of Health (1999) A Policy Framework for Commissioning Cancer Services : A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales Guidance for Providers and Purchasers of Cancer Services (Calman-Hine Report) HMSO, London

Department of Health (2000a) The NHS Cancer Plan: A Plan for Investment, A Plan for Reform HMSO London

Department of Health (2000b) The Nursing Contribution to Cancer Care HMSO London
downloaded from
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4010121

Department of Health (2001) A Health Service of All the Talents: Developing the NHS Workforce - Consultation Document on the Review of Workforce Planning
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003182

Department of Health (2002) Better Cancer Survival And Fewer Post-Operative Deaths Press release Downloaded from
http://www.dh.gov.uk/en/Publicationsandstatistics/Pressreleases/DH_4013137 February 2007

Department of Health (2005) Tackling Cancer: Improving the Patient Journey. Department of Health, London

Department of Health (2006) Our Health, Our Choice, Our Say HMSO London downloaded from
<http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Modernisation/Ourhealthourcareoursay/index.htm>

References

- Detmar SB and Aaronson NK (1998) Quality of life in daily clinical oncology practice: a feasibility study European Journal of Cancer 34:8 1181-1186
- Detmar SB; Muller MJ; Schornagel JH; Aaronson NK (2002) Health-related quality of life assessments and patient-physician communication: a randomised controlled trial Journal of the American Medical Association 288: 23 3027-3034
- Díaz F (2000) The social organisation of chemotherapy treatment consultations Sociology of Health & Illness 22:3 364-389
- Dikken C (2003) Benefits of using a chemotherapy symptom assessment scale Nursing Times 99:39 50-51
- Dingwall R (1977) The social organisation of health visitor training Croom Helm, London
- Donnelly S and Walsh D (1995) The symptoms of advanced cancer Seminars in Oncology 22:2 67-72
- Doyle C; Crump M; Pintilie M; Oza AM (2001) Does palliative chemotherapy palliate? Evaluation of expectations, outcomes, and costs in women receiving chemotherapy for advanced ovarian cancer Journal of Clinical Oncology 19:5 1266-1274
- Drummond N (2000) Quality of life with asthma: the existential and the aesthetic Sociology of Health & Illness 22:2 235-253
- Dyke G (1998) The New NHS Charter – A Different Approach HMSO London
- Earle CC; Venditti LN; Neumann PJ; Gelber RD; Weinstein MC; Potosky AL; Weeks JC (2000) Who gets chemotherapy for metastatic lung cancer? Chest 117 1239-1246
- Ebright PR; Patterson ES; Chalko BA; Render ML (2003) Understanding the complexity of registered nurse work in acute care settings Journal of Nursing Administration 33:12 630-638
- Echteld MA; Deliens L; Orwuteaka-Philipsen B; Klein M; van der Wal G (2006) EORTC QLQ-C15-PAL: the new standard in the assessment of health-related quality of life in advanced cancer? Palliative Medicine 20: 1 1-2
- English I (1993) Intuition as a function of the expert nurse: a critique of Benner's novice to expert model Journal of Advanced Nursing 18 387-393
- Expert Advisory Group on Cancer (EAGC): The Calman-Hine Report) (1995) A Policy Framework for Commissioning Cancer Services. DH, London and the Welsh Office
- Fabricius J (1991) Running on the spot or can nursing really change? Psychoanalytic Psychotherapy 5: 2. 97-108
- Faithfull S; Comer J; Meyer L; Huddart R; Deamaley D (2001) Evaluation of nurse-led follow-up for patients undergoing pelvic radiotherapy British Journal of Cancer 14 1853-1864
- Fall-Dickson J and Rose L (1999) Caring for patients who experience chemotherapy-induced side effects: the meaning for oncology nurses Oncology Nursing Forum 26:5 901-907
- Farrell C; Heaven C; Beaver K; Maguire P (2005) Identifying concerns of women undergoing chemotherapy Patient Education and Counselling 56 72-77
- Field D (1989) Nursing the Dying Routledge Kegan Paul, London
- Fine Y (1994) Working the hyphen: redefining self and other in qualitative research In: Handbook of Qualitative Research (ed: Denzin NK and Lincoln YS) Sage Thousand Oaks, 1st edition.

- Firth R (1964) Essays on Social Organisation and Values Athlone, London
- Fisher P and Goodley D (2007) The linear model of disability: mothers of disabled babies resist with counter-narratives Sociology of Health and Illness 29:1 66-81
- Fitzsimmonds D, Hawker SE, Simmonds P, George SL, Johnson CD, Comer JL (2005) Nurse-led models of chemotherapy care: mixed economy or nurse-doctor substitution? Journal of Advanced Nursing 50:3 244-252
- Fletcher J (1997) Do nurses really care? Some unwelcome findings from recent research and inquiry Journal of Nursing Management 5 43-50
- Florin J; Ehrenberg A; Ehnfors M (2005) Patients' and nurses' perceptions of nursing problems in an acute care setting Journal of Advanced Nursing 51:2 140-149
- Ford S; Fallowfield L; Lewis S (1994) Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? British Journal of Cancer 70:4 767-70
- Foucault M. (1972) The Archaeology of Knowledge. Tavistock, London
- Foucault M. (1975) Discipline and Punish: The Birth of the Prison. Vintage Books, New York
- Frank A (1995) The Wounded Story Teller: Body, Illness and Ethics University of Chicago Press, Chicago
- Fuller J and Schaller-Ayres J (2000) Health Assessment: A Nursing Approach Lippincott Philadelphia
- Funkesson KH; Anbäck EM; Ek AC (in press) Nurses' reasoning process during care planning taking pressure ulcer prevention as an example. A think-aloud study International Journal of Nursing Studies downloaded from http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6T7T-4K8SC68-2&_user=10&_coverDate=06%2F27%2F2006&_rdoc=1&_fmt=&_orig=search&_sort=d&view=c&_auct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=1f6f8b37fcee511958cde6aa590f41c on July 15th 2006
- Furlong E; Smith R (2005) Advanced nursing practice: policy, education and role development. Journal of Clinical Nursing 14:9 1059-1066.
- Gadow S (1995) Clinical epistemology: a dialectic of nursing assessment Canadian Journal of Nursing Research 27:2 25-34
- Gannon C (2005) Will the lead clinician please stand up? British Medical Journal 330 737
- Gerrish K (2000) Individualised care: its conceptualisation and practice within a multiethnic society Journal of Advanced Nursing 32:1 91-99
- Gilbert TP (2005) Trust and managerialism: exploring discourses of care Journal of Advanced Nursing 52:4 454-463
- Glimelius B; Ekstroem K; Hoffman K; Graf W; Sjoeden P.-O; Haglund U; Svensson C; Enander, L.-K.; Linne T; Sellstroem H. (1997) Randomized comparison between chemotherapy plus best supportive care with best supportive care in advanced gastric cancer Annals of Oncology 8:2 163-8
- Godlee F (2005) Heading where exactly? British Medical Journal 330 7493 downloaded from www.bmj.com/cgi/content/extract/330/7493
- Goffman E (1971) The Presentation of Self in Everyday Life Penguin, London

References

- Grande GE; Todd CJ; Barclay SIG (1997) Support needs in the last year of life: patients and carer dilemmas Palliative Medicine 11 202-208
- Grande GE; McKerral A; Addington-Hall JM; Todd CJ (2003) Place of death and use of health services in the last year of life Journal of Palliative Care 19:4 263-70
- Greenhalgh J and Meadows K (1999) The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review Journal of Evaluation In Clinical Practice 5:4 401-16
- Greenhalgh T (1999) Narrative based medicine in an evidence based world British Medical Journal 318: 323-325
- Greenwood J and King M (1995) Some surprising similarities in the clinical reasoning of 'expert' and 'novice' orthopaedic nurses: report of a study using verbal protocols and protocol analyses. Journal of Advanced Nursing. 22:5 907-913
- Grenier A (2006) The distinction between feeling frail and being frail: exploring emotional experiences in health and social care Journal of Social Work Practice 20:3 299-313
- Griffiths J; Ewing G; Rogers M; Barclay S; Martin A; McCabe J; Todd C (2007) Supporting Cancer Patients With Palliative Care Needs: District Nurses' Role Perceptions Cancer Nursing 30: 2 156-162
- Groenvold M; Petersen MA; Aaronson MA; Arraras JI; Blazeby JB; Bottomley A; Fayers PM; de Graeff A; Hammerlid E; Kassa S; Sprangers MAG; Bjorner JB (2006) The development of the EORTC QLQ-C15-PAL: A shortened questionnaire for cancer patients in palliative care European Journal of Cancer 42:1 55-64
- Grol RPTM (2002) Problems to discuss with cancer patients in palliative care: a comprehensive approach Patient Education and Counselling 47 195-204
- Hallett CE; Austin L; Cress A; Luker KA (2000) Community nurses' perceptions of patient 'compliance' in wound care: a discourse analysis Journal of Advanced Nursing. 32:1115-123
- Halton W (2004) By what authority? Psychoanalytical reflections on creativity and change in relation to organisational life In: Working Below the Surface : The Emotional Life of Contemporary Organisations (ed: Huffingham C; Armstrong D; Halton W; Hoyle L; Pooley J) Tavistock Clinic Series Kamaç, London 107-122
- Harbison Jean (2001) Clinical decision making in nursing: theoretical perspectives and their relevance to practice Journal of Advanced Nursing. 35:1 126-133
- Hardy S; Garbett R; Titchen A; Manley K (2002) Exploring nursing expertise: nurses talk nursing Nursing Inquiry 9:3 196-202.
- Hart A and Lockey R (2002) Inequalities in health care provision: the relationship between contemporary policy and contemporary practice in maternity services in England Journal of Advanced Nursing 37:5 485-493
- Heartfield M (1996) Nursing documentation and nursing practice: a discourse analysis Journal of Advanced Nursing 24:1 98-103
- Heaven C and Maguire P (1997) Disclosure of concerns by hospice patients and their identification by nurses Palliative Medicine 11 283-290
- Heaven CM and Maguire P (1996) Training hospice nurses to elicit patient concerns Journal of Advanced Nursing 23 280-286

- Hedberg B; Larsson US (2003) Observations, confirmations and strategies - useful tools in decision-making process for nurses in practice? Journal of Clinical Nursing 12:2 215-222
- Henderson, V. (1966). The Nature of Nursing. Macmillan New York
- Herdman E (2004) Nursing in a post-emotional society Nursing Philosophy 5:2 95-103
- Hewison A (1995) Nurses' power in interactions with patients Journal of Advanced Nursing 21:1 75-82
- Hewison A (1999) The new public management and the new nursing: related by rhetoric? Some reflections on the policy process and nursing Journal of Advanced Nursing 29:8 1377-1384
- Higginson I; Carr S (2001) Measuring quality of life: using quality of life measures in the clinical setting British Medical Journal 322:1297-1300
- Hill KM; Amir Z; Muers MF; Connolly CK; Round CE (2003) Do newly diagnosed lung cancer patients feel their concerns are being met? European Journal of Cancer Care 12:1 35-45
- Hill N (2002a) Use of quality of life scores in care planning in a hospice setting: a comparative study International Journal of Palliative Nursing 8:12 540-47
- Hill N (2002b) Use of quality of life scores in care planning in a hospice setting: the theme of revelation International Journal of Palliative Nursing 8:12 591-3
- Hoekstra J; Vernooij-Dassen MJFJ; de Vos R; Bindels PJE (2007) The added value of assessing the 'most troublesome' symptom among patients with cancer in the palliative phase Patient Education and Counseling 65:2.223-229
- Hogston R (1997) Nursing diagnosis and classification systems: a position paper Journal of Advanced Nursing 26 496-500
- Horton R (2002) Differences in assessment of symptoms and quality of life between patients with advanced cancer and their specialist palliative care nurses in a home care setting Palliative Medicine 16:6 488-94
- Hoschild A (1983) The Managed Heart: The Commercialisation of Feeling Henry Holt, New York
- Hughes D (2002) Nursing and the division of labour: sociological perspectives In: Nursing and the Division of Labour in Healthcare (Allen D and Hughes D ed) Palgrave Macmillan, Bristol 1-22
- Hunt M (1989) Dying at home: its basic 'ordinariness' displayed in patients' and nurses' talk PhD Thesis, University of London
- Hunt M (1991) Being friendly and informal: reflected in nurses', terminally ill patients' and relatives' conversations at home Journal of Advanced Nursing 16 929-938
- Hunt M and Meerabeau L (1993) Purging the emotions: the lack of emotional expression in subfertility and in the care of the dying International Journal of Nursing Studies 30:2 115-23
- Hussey T (2000) Realism and nursing Nursing Philosophy 1:2 96-108
- Hyde A; Treacy MP; Scott A; Butler M; Drennan J; Irving K; Byrne A; MacNeela P; Hanrahan M (2005) Modes of rationality in nursing documentation: biology, biography and the 'voice of nursing' Nursing Inquiry 12:2 66-77
- Hydén L-C (1997) Illness and narrative Sociology of Health & Illness 19:1 48-69
- Ilott I; Rick J; Patterson M; Turgoose C; Lacey A (2006) What is protocol-base care? A concept analysis Journal of Nursing Management 14:7 544-552

References

- Irving K; Treacy M; Scott A; Hyde A; Butler M; MacNeela P. (2006) Discursive practices in the documentation of patient assessments Journal of Advanced Nursing 53:2 151-159
- James N (1992a) Care = organisation + physical labour + emotional labour Sociology of Health & Illness 14:4 488-509
- James N (1992b) Care, work and care-work: a synthesis? In: Policy Issues in Nursing (ed: Robinson J; Gray A; Elkan R) Open University Press Buckingham 96-111
- Jarrett NJ (1996) 'Comfortable Conversation': Nurse-patient Communication in the Cancer Care Context. Unpublished PhD Thesis University of Southampton
- Jarrett NJ and Payne SA (2000) Creating and maintaining 'optimism' in cancer care communication International Journal of Nursing Studies 37:1 81-90
- Jarrett NJ; Payne S (1995) A selective review of the literature on nurse- patient communication: has the patient's contribution been neglected? Journal of Advanced Nursing 22:1 72-78
- Johnson M and Webb C (1994) The power of social judgement: struggle and negotiation in the nursing process Nurse Education Today 15 83-89
- Jones AM (2003) Changes in practice the nurse-doctor interface. Using focus groups to explore the perceptions of first level nurses working in an acute care setting Journal of Clinical Nursing 12 124-131
- Jones M; O'Neill P; Waterman H; Webb C (1997) Building a relationship: communications between staff and stroke patients on a rehabilitation ward Journal of Advanced Nursing 26:1 101-110
- Jordens CFC; Little M; Paul K; Sayers E-J (2001) Life disruption and generic complexity: a social linguistic analysis of narratives of cancer illness Social Science and Medicine 53 1227-1236
- Julnes G; Mark M (1996) Evaluation as sense-making: knowledge construction in a realist world In: Realist Evaluation: An Emerging Theory in Support of Practice (ed: Henry GT; Julnes G; Mark MM) Jossey-Bass San Francisco 33-52
- Junnola T; Eriksson E; Salanterä S; Sirkka L (2002) Nurses' decision-making in collecting information for the assessment of patients' nursing problems. Journal of Clinical Nursing 11:2 186-196
- Kaasa S and Longe JH (2003) Quality of life in palliative care: principles and practice Palliative Medicine 17 11-20
- Kazi M & Spurling L (2000b) Realist evaluation for evidence-based practice downloaded from www.euroopeanevaluation.org/docs/101_kazi.pdf on September 21st 2005
- Kazi MAF (2000) Evaluation of social work practice in England Journal of Social Work Research and Evaluation 1:2 101-9
- Kazi MAF (2003) Realist Evaluation in Practice: Health and Social Work Sage, London
- Kearsley J (1992) Some basic guidelines on the use of chemotherapy for patients with metastatic malignancy Palliative Medicine 6:1 11-16
- Kelly D; Ross S; Gray B; Smith P (2000) Death, dying and emotional labour: problematic dimensions of the bone marrow transplant nursing role? Journal of Advanced Nursing 32:4 952-960
- Kendall C; Elyan S; Jeffrey D (2000) Palliative Chemotherapy Forum for Applied Cancer Education and Training downloaded from www.blackwell publishing.com/facet on 14th August 2006

- Kennedy C.M.(2004) A typology of knowledge for district nursing assessment Journal of Advanced Nursing 45: 4 401-409
- Kennedy CM (2002) The work of district nurses: first assessment visits Journal of Advanced Nursing 40:6 710-720
- Kim A, Fall P, Dajie W (2005) Palliative care: optimising quality of life Journal of American Osteopathic Association 105:5 9-14
- Kitson A (2004) Future vision RCN Magazine Autumn 15
- Kitson A. (1993) Formalizing concepts related to nursing and caring. In: Nursing: Art and Science (ed: Kitson A). Chapman Hall, London p25-47
- Kizer KW (2002) Patient-centred care essential but probably not sufficient Quality Safety in Health Care 11 117-118
- Kleinman A (1998) The Illness Narratives: Suffering, Healing and the Human Condition Basic Books, New York
- Knight M; Field D (1981) A silent conspiracy: coping with dying patients on an acute surgical ward Journal of Advanced Nursing 6 221-9
- Krishnasamy M; Corner J; Bredin M; Plant H; Bailey C (2001) Cancer nursing practice development: understanding breathlessness Journal of Clinical Nursing 10:1 103-108
- Kruijver IP; Kerkstra A; Bensing JM; van de Wiel HB (2000) Nurse-patient communication in cancer care. A review of the literature Cancer Nursing 23:1 20-31
- Kruijver IPM; Kerkstra A; Bensing JM; van de Wiel HBM (2001a) Communication skills of nurses during interactions with simulated cancer patients Journal of Advanced Nursing 34:6 772-779
- Kruijver IP; Kerkstra A; Kerssens JJ; Holtkamp CC; Bensing JM; van de Wiel HB (2001b) Communication between nurses and simulated patients with cancer: evaluation of a communication training programme European Journal of Oncology Nursing 5:3 140-50
- Kruijver IP; Garssen B; Visser AP; Kuiper AJ (2006) Signalling psychosocial problems in cancer care: the structural use of a short psychosocial checklist during medical or nursing visits. Patient Education and Counselling 62:2 163-77
- Legman R; Walsh D (2005) integration of palliative medicine into comprehensive cancer care Seminars in Oncology 32 134-8
- Lalor JG; Begley CM; Devane D (2006) Exploring painful experiences: impact of emotional narratives on members of a qualitative research team Journal of Advanced Nursing 56:6 607-616
- Lanceley EA (2000) The Patient and Nurse in Emotion-Talk in Cancer Care: The Tempest in my Mind Unpublished PhD Thesis University of London
- Langley-Evans A; Payne S (1997) Light-hearted death talk in a palliative day care context Journal of Advanced Nursing 26:6 1091-1097
- Larue F, Colleau S, Brasseur L, Cleeland C (1995) Multi-centre study of cancer and its treatment in France British Medical Journal 301 1034-1037
- Latimer J (2000) The Conduct of Care: Understanding Nurses' Practice Blackwell Science, Oxford
- Lawler J (1991) Behind the Screens: Nursing, Somatology and the Problem of the Body Churchill Livingstone Melbourne

References

- Lawlor MC (2003) Gazing anew: the shift from a clinical gaze to an ethnographic lens American Journal of Occupational Therapy 57:1 29-39
- Lee J; Chan ACM; Phillips DR (2006) Diagnostic practise in nursing: a critical review of the literature Nursing and Health Sciences 8 57-65
- Levack P; Graham J; Kidd J (2004) Listen to the patient: quality of life of patients with recently diagnosed malignant cord compression in relation to their disability Palliative Medicine 18:7 954-601
- Levine MN and Ganz PA (2002) Beyond the development of quality of life instruments: where do we go from here? Journal of Clinical Oncology 20:9 2215-2216
- Lidstone V, Butters E, Seed PT, Sinnott C, Beynon T, Richards M (2003) Symptoms and concerns amongst cancer outpatients: identifying the need for specialist palliative care Palliative Medicine 17 588-595
- Lincoln VS and Guba EG (1985) Naturalistic Inquiry Sage, Newbury Park
- Locsin RC (2001) Nursing practice and the preoccupation of power over death Holistic Nursing Practice 15:2 1-3
- Loftus LA; Weston V (2001) The development of nurse-led clinics in cancer care Journal of Clinical Nursing 10:2 215-220
- Luker K; Austin L; Caress A, Hallett C (2000) The importance of 'knowing the patient': community nurses' constructions of quality in providing palliative care Journal of Advanced Nursing 31:4 775-782
- Lutzen K and Tishelman C (1996) Nursing diagnosis: a critical analysis of underlying assumptions International Journal of Nursing Studies 33:2 190-200
- Maguire P; Booth K; Elliot C; Jones B (1996a) Helping health professionals involved in cancer care acquire key interviewing skills: the impact of workshops European Journal of Cancer 32a:9 1486-1489
- Maguire P; Faulkner A; Booth K; Elliot C; Hillier V (1996b) Helping cancer patients disclose their concerns European Journal of Cancer 32a: 9 78-81
- Maguire P; Parte M; Booth K; Heaven C (2002) Improving health professionals' communication with patients: to change skills, attitudes or personality Psycho-Oncology 11 91-92
- Maguire P; Parte M; Booth K; Heaven C; Trevelyan N (1995) Improving professionals' communication with patients: to change skills, attitudes or personality? Psycho-Oncology 4:2 91
- Mark MM; Henry GT (1998) Social programming and policy-making: a realist perspective In: Realist Evaluation: An Emerging Theory in Support of Practice. New Directions for Evaluation Series (eds Henry GT; Julnes G; Mark MM) 78 73-88
- Martin C and Hewitt-Taylor J (2006) From expert to tasks, expert nursing practice redefined? Journal of Clinical Nursing 16:12 1531-1539
- Mason G and Webb C (1993) Nursing diagnosis: a review of the literature Journal of Clinical Nursing 2:2 67-74
- Maughan K and Clarke C (2001) The effect of a clinical nurse specialist in gynaecological oncology on quality of life and sexuality Journal of Clinical Nursing 10:2 221-229
- May C (1992) Individual care? Power and subjectivity in therapeutic relationships Sociology 26:4 589-602

- May C (1992b) Nursing work, nurses' knowledge, and the subjectification of the patient Sociology of Health & Illness 14:4 472-487
- May C (1995a) Patient autonomy and the politics of professional relationships Journal of Advanced Nursing 21:1 83-87
- May C (1995b) To call it work somehow demeans it: the social construction of talk in the care of terminally ill patients Journal of Advanced Nursing 22:3 556-561
- May C (1997) The patient and power: sociological perspectives on the consequences of holistic care Health and Social Care in the Community 5:1 17-20
- McArdle JM; George WD; McArdle CS; Smith DC; Moodie AR; Hughson AV; Murray GD (1996) Psychological support for patients undergoing breast cancer surgery: a randomised study. British Medical Journal 312 813-816
- McCorkle R and Young K (1978) Development of a symptom distress scale. Cancer Nursing. 1:5 373-378
- McCormack B (2003) Researching nursing practice: does person-centredness matter? Nursing Philosophy 4:3 179-188
- McCormack B and McCance T (2006) Development of a framework for person-centred nursing Journal of Advanced Nursing 56:5 472-479
- McEvoy P and Richards D (2003) Critical realism: a way forward for evaluation research in nursing? Journal of Advanced Nursing 43:4 411-4
- McGrath P and Kearsley JH (1995) Is there a better way? Bioethical reflections on palliative cytotoxic drug use Palliative Medicine 9:4 269-71
- McGrath P; Moore A; McNaught M; Palmer G; Greene A; Atkinson D (2005) Another form to fill in! Clients' reflections on the hospice use of questionnaires Supportive Care in Cancer 13:9 691-701
- McGrath P; Phillips E (2007) Making them more vulnerable: nursing insights on the irony of using questionnaires Nursing Forum 42:2 65-72
- McIlfatrick SJ (2003) Exploring Patients', Caregivers' and Nurses' Experience of Day Hospital Chemotherapy: A Phenomenological Study Unpublished PhD University of Ulster
- McIlfatrick S; Sullivan K; McKenna Hugh (2006) Nursing the clinic vs nursing the patient: nurses' experience of a day hospital chemotherapy service Journal of Clinical Nursing 15:9 1170-78
- McKenna H; McCann S; McCaughan; Keeney (2004) The role of an outreach oncology nurse practitioner: a case study evaluation European Journal of Oncology Nursing 8 66-77
- McLachlan S-A; Allenby A; Matthews J; Wirth A; Kissane D; Bishop M; Beresford J; Zalberg J (2001) Randomised trial of co-ordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer Journal of Clinical Oncology. 19: 21 4117-4125
- McQueen ACH (2004) Emotional intelligence in nursing work Journal of Advanced Nursing 47:1 101-8
- Meerabeau E (1998) Consumerism and health care: the example of fertility treatment Journal of Advanced Nursing 27:4 721-29
- Menzies Lyth I (1988) Containing Anxiety in Institutions Selected Essays Volume 1 Free Association Books, London

References

- Michie S; Lester K (2005) Words matter: increasing the implementation of clinical guidelines Quality and Safety in Health Care 14 367-370
- Mills S (2003) Michel Foucault Routledge, London
- Moore S; Corner J; Haviland J; Wells M; Salmon E; Normand C; Brada M; O'Brien M; Smith I (2002) Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomised trial British Medical Journal 325:7373 1145-1147
- Moore L and Savage J (2002) Participant observation, informed consent and ethical approval Nurse Researcher 9:4 58-69
- Morse JM; Barrett M; Mayan M; Olson K; Spiers J (2002) Verification strategies for establishing reliability and validity in qualitative research International Journal of Qualitative Methods 1:2 Downloaded from http://www.ualberta.ca/~iiqm/backissues/1_2Final/pdf/morseetal.pdf January 2007
- Mount BM; Cohen R; MacDonald N; Bruera E; Dudgeon DJ (1995) Ethical issues in palliative care revisited Palliative Medicine 9:2 165-6.
- National Institute for Clinical Excellence (2004) Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. NICE, London
- Neale G and Olsen S (2005) Will the lead clinician please stand up? We should be promoting total quality care British Medical Journal 330: 966 doi:10.1136/bmj.330.7497.966-c
- Nelson S; McGillion M (2004) Expertise or performance? Questioning the rhetoric of contemporary narrative use in nursing. Journal of Advanced Nursing. 47:6 631-638
- Newell S; Sanson-Fisher RW; Girgis A; Bonaventura A (1998) How well do medical oncologists' perceptions reflect their patients' problems? Cancer 83 1640-1651
- Northway R (2002) Commentary: insider-outsider perspectives Nurse Researcher 9:4 4-6
- O'Connell B (1992) A Comparative Study Evaluating the Effectiveness of Nursing Assessment Formats Unpublished MSc Thesis Curtin University of Technology, Australia Downloaded from <http://adt.curtin.edu.au/theses/available/adt-WCU20020812.105507/12> March 2005
- O'Connell B (1997) A grounded theory study of the clinical use of the nursing process within selected hospital settings Unpublished PhD Thesis Curtin University of Technology
- O'Connell B (1998) The clinical application of the nursing process in selected acute care settings: a professional mirage Australian Journal of Advanced Nursing 15:4 22-32
- O'Connell B (2000) Enabling care: working through obscurity and uncertainty a basic social process in selected acute care settings Australian Journal of Advanced Nursing 17:3 32-39
- O'Baugh J; Wilkes L; Luke S; George A (2003) 'Being positive': perceptions of patients with cancer and their nurses Journal of Advanced Nursing 44:3 262-270
- Olsen ME (1968) The Process of Social Organisation Holt, Rinehart and Winston, New York
- Osse BHP; Vermooij-Dassen MJFJ; Schade E; de Vree B; van den Muijsenberg METC Grol RTPM (2002) Problems to discuss with cancer patients in palliative care: a comprehensive approach Patient Education and Counselling 47 195-204
- Outhwaite W (1967) New Philosophies of Science: Realism, Hermeneutics and Critical Theory Macmillan, Basingstoke

- Paley J (1996) Intuition and expertise: comments on the Benner debate Journal of Advanced Nursing 23:4 655-671
- Parker JM (2004) Nursing on the medical ward Nursing Inquiry 11:4 210-217
- Parle M; Maguire P; Heaven C (1997) The development of a training model to improve health professionals' skills, self efficacy and outcome expectations when communicating with cancer patients Social Science and Medicine 44: 2 231-240
- Parle M; Gallagher J; Gray C; Akers G; Liebert B (2001) From evidence to practice: factors affecting the specialist breast nurse's detection of psychological morbidity in women with breast cancer Psycho-Oncology 10 503-510
- Patton MQ (1990) Qualitative Evaluation and Research Methods Sage, London
- Pawson R and Tilley N (1997) Realist Evaluation Sage, London
- Pawson R and Tilley N (1998) Caring communities, paradigms, polemics design debates Evaluation 4:1 73-90
- Pawson R (1996) Theorising the interview British Journal of Sociology 47:2 294-314
- Pawson R (2003) Nothing as practical as a good theory Evaluation 9:4 471-490
- Payne S (1992) A study of quality of life of cancer patients receiving palliative chemotherapy Social Science and Medicine 35:12 1505-9
- Pearce S; Kelly D; Warren S (2001) 'More than just money' - widening the understanding of the costs involved in cancer care. Journal of Advanced Nursing. 33:3 371-379
- Pellatt G (2003) Ethnography and reflexivity: emotions and feelings in fieldwork. Nurse Researcher 10:3 28-33
- Peter E and Liaschenko J (2004) Perils of proximity: a spatiotemporal analysis of moral distress and moral ambiguity Nursing Inquiry 11:4 218-225
- Pontin DJ and Webb C (1996) Assessing patient satisfaction Part 2: Findings: nursing, the hospital and patients' concerns Journal of Clinical Nursing 5:1 33-40
- Poole K and Froggett K (2002) Loss of weight and loss of appetite in advanced cancer: a problem for the patient, the carer or the health professional? Palliative Medicine 16:6 499-506
- Porter HB (1996) Effectiveness and efficiency of nurse-given cancer patient education Canadian Oncology Nursing Journal 8 229-240
- Porter S (1996) Breaking the boundaries between nursing and sociology: a critical realist ethnography of the theory-practice gap Journal of Advanced Nursing 34:2 413-20
- Porter HB (1998a) Effectiveness and efficiency of nurse-given cancer patient education Canadian Oncology Nursing Journal 8 229-240
- Porter S (1998b) Social Theory and Nursing Practice Houndmills, Basingstoke
- Potter P; Boxerman S; Wolf L; Marshall J; Grayson D; Sledge J; Evanoff B (2004) Mapping the nursing process: a new approach for understanding the work of nursing Journal of Nursing Administration 34:2 101-9
- Powers P (2002) A discourse analysis of nursing diagnosis Qualitative Health Research 12:7 945-965

References

- Price H (2001) Emotional labour in the classroom: a psychoanalytic perspective Journal of Social Work Practice 15:2 161-180
- Proctor S (1998) Linking philosophy and method in the research process: the case for realism Nurse Researcher 5:4 73-90
- Pruyn JF; Heule-Dieleman HAG; Knegt PP; Moosterd FR; van Hest AG; Sinnige HAM; Pruyn ATH; de Boer MF (2004) On the enhancement of efficiency in care for cancer patients in outpatient clinics: an instrument to accelerate psychosocial screening and referral Patient Education and Counseling 53:2 135-40
- Punch K (1998) Introduction to Social Research: Quantitative and Qualitative Approaches Sage London
- Radley A (2002) 'Cases' and 'voices': the changing agenda for doctors and their patients Postgraduate Medicine 78 701-2 downloaded from www.pmj.bmjournals.com on September 23rd 2008
- Radwin L (1998) 'Knowing the patient': a review of research on an emerging concept Journal of Advanced Nursing 23 1142-6
- Ramirez AJ; Towison KE; Leaning MS; Rubens RD (1996) Do patients with advanced breast cancer benefit from chemotherapy? British Journal of Cancer 78:11 1488-1494
- Rashotte J and Carnevale FA (2004) Medical and nursing clinical decision making: a comparative epistemological analysis Nursing Philosophy 5:2 160-174
- Rathbone GV; Horsley S; Goacher J (1994) A self-evaluated assessment suitable for seriously ill hospice patients Palliative Medicine 8:1 29-34.
- Redfern S (1996) Individualised patient care: its meaning and practice in a general setting NT Research 1 22-33
- Reed J; Clarke CL (1999) Nursing older people: constructing need and care Nursing Inquiry 6 208-215
- Rhodes VA; McDaniel RW; Matthews CA (1998) Hospice patients' and nurses' perceptions of self-care deficits based on symptom experience Cancer Nursing 21:5 312-319
- Richards L (1999) Using NVivo in Qualitative Research Sage, London
- Richards M (2003) Priorities for supportive and palliative care in England Palliative Medicine 17 7-8
- Richards M and Ramirez A (1997) Quality of life: the main outcome measure of palliative care Palliative Medicine 11:2 89-92.
- Richardson A; Tebbit P; Brown V; Sitzia J; on behalf of the Cancer Action Team (2006) Assessment of Supportive and Palliative Care Needs for Adults with Cancer Kings College, London
- Richardson A (2004) Creating a culture of compassion: developing supportive care for people with cancer European Journal of Oncology Nursing 8:4 293-305
- Robinson JD and Heritage J (2005) The structure of patients' presenting concerns: the completion relevance of current symptoms Social Science and Medicine 61 481-493
- Robson C (2002) Real World Research Blackwell Publishing, Oxford
- Rodger A (2002) Is it a trial of nurse-led follow-up or plenty of time? Rapid response: British Medical Journal 325: 1145 December 15th

- Rogers MS and Todd CJ (2000) The 'right kind of pain': talking about symptoms in outpatient oncology consultations Palliative Medicine 14:4 325-51
- Rogers PJ; Petrino A; Hubner TA; Hacs TA (2000) Program theory evaluation: practice, promise and problems In: Program Theory in Evaluation: Challenges and Opportunities; New Directions for Evaluation 87 5-13
- Rolfe G (2006) Validity, trustworthiness and rigour: quality and the idea of qualitative research Journal of Advanced Nursing 53:3 304-310
- Ross L (2006) Spiritual care in nursing: an overview of the research to date Journal of Clinical Nursing 15:7 852-862
- Roth AJ; Kornblith AB; Batel-Copel L; Peabody E; Scher HI; Holland JC (1998) Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study Cancer 82:10 1904 - 1908
- Royal College of Nursing (2005) *Maxi Nurses. Advanced and Specialist Nursing Roles*. RCN Publications, London. Available at: http://www.rcn.org.uk/publications/pdf/maxi_nurses_advanced.pdf
- Rycroft-Malone J (2006) The politics of the evidence-based practice movements Journal of Research in Nursing 11:2 95-108
- Rycroft-Malone J; Morrell C; Bick D (2004) The research agenda for protocol-based care Nursing Standard 19:6 33-36
- Rycroft-Malone J; Latter S; Yerrell P; Shaw D (2001) Consumerism in health care: the case of medication education Journal of Nursing Management 9 221-230
- Salanterä S; Eriksson E; Junnola T; Salminen EK; Lauri S (2002) Clinical judgement and information seeking by nurses and physicians working with cancer patients Psycho-Oncology 12 280-290
- Salvage J (1990) The theory and practice of the 'new nursing' Nursing Times 86:4 42-45
- Sandelowski M and Barroso J (2002) Reading qualitative studies International Journal of Qualitative Methods 1:1 1-47 downloaded from: http://www.ualberta.ca/~iiqm/backissues/1_1Final/pdf/sandeleng.pdf January 2007
- Sandgren A; Thulesius H; Friglund B; Petersson K (2006) Striving for emotional survival in palliative care nursing Qualitative Health Research 16:1 79-96
- Sarna L (1998) Effectiveness of structured nursing assessment of symptom distress in advanced lung cancer Oncology Nursing Forum 25:6 1041-1048
- Savage J (2000) Ethnography and health care British Medical Journal 321:1400-1402
- Savage J (2000) Participative observation: standing in the shoes of others? Qualitative Health Research 10:3 324-339
- Sayer A (1992) Method in Social Science: A Realist Approach Routledge, London
- Sayer A (2000) Realism and Social Science Sage, London
- Sbailh L (1997) The work of accident and emergency nurses. Part 1: An introduction to the rules Accident and Emergency Nursing 5:1 28-33
- Sbailh L (1998) Initial assessments: gaining 'impressions' and normal cases Accident and Emergency Nursing 6:2 70-74

References

- Sbait LC (2002) Meanings of the immediate: the practical use of the Patient's Charter in the accident and emergency department Social Science and Medicine 54 1345-1355
- Schou KC (1993) Awareness contexts and the construction of dying in the cancer treatment setting: micro and macro levels in narrative analysis In: The Sociology of Death (ed: D Clark) Blackwell, Oxford 238-263
- Schou KC and Hewison J (1999) Experiencing Cancer Facing Death Series Open University Press, Buckingham
- Seale C; Anderson E; Kinnersley P (2006) Treatment advice in primary care: a comparative study of nurse practitioners and general practitioners Journal of Advanced Nursing 54:5 534-42
- Seymour J (2001) Critical Moments: Death and Dying in Intensive Care Facing Death Series Open University Press, Buckingham
- Seymour J and Skilbeck J (2002) Ethical considerations in researching user views European Journal of Cancer Care 11:3 215-9
- Seymour J; Clark D; Hughes P; Bath P; Beech N; Comer J; Douglas H.-R; Halliday D; Haviland J; Marples R. (2002b) Clinical nurse specialists in palliative care. Part 3. Issues for the Macmillan Nurse role Palliative Medicine 16:5 386-394
- Shaha M and Cox CL (2003) The omnipresence of cancer European Journal of Oncology Nursing 7:3 191-6.
- Shapiro J and Ross V (2005) Applications of narrative theory and therapy to the practice of family medicine Family Medicine 34:2 96-100
- Silverman D and Peräkylä A (1990) AIDS counselling: the interactional organisation of talk about 'delicate' issues Social Sociology of Health and Illness 12 3 293-318
- Sitzia J; Dikken C; Hughes J (1997) Psychometric evaluation of a questionnaire to document side-effects of chemotherapy Journal of Advanced Nursing 25:5 999-1007
- Sitzia J; Wood N (1998) Patient satisfaction with cancer chemotherapy nursing: a review of the literature. International Journal of Nursing Studies 35 1-12
- Slater A and Freeman E (2005) Patients' views of using an outcome measure in palliative day care: a focus group study International Journal of Palliative Nursing 10:7 343 - 351
- Söllner W; DeVriess A; Steixner E; Lukas P; Sprinzi G; Rumpold G; Maislinger S (2001) How successful are oncologists in identifying patient distress, perceived social support, and need for psychological counselling? British Journal of Cancer 84:2 179-185
- Sontag S (1978) Illness as Metaphor Farrar, New York
- Soothill K; Morris SM; Harman J; Francis B; Thomas C; McIlmurray MB (2001) The significant unmet needs of cancer patients: probing psychosocial concerns Supportive Care in Cancer 9 597-605
- Spilsbury K and Meyer J (2004) Use, misuse and non-use of health care assistants: understanding the work of health care assistants in a hospital setting Journal of Nursing Management 12:6 411-418
- Spradley JP (1979) The Ethnographic Interview Holt, Rinehart and Winston, New York
- Sprangers MAG (2002) Quality of life assessment in oncology – achievements and challenges Acta Oncologica 41:3 229-37

- Stickley T (2006) Should service user involvement be consigned to history? A critical realist perspective Journal of Psychiatric and Mental Health Nursing 13:5 570-577
- Strauss AL; Fagerhaugh S; Suczek B; Wiener C (1987) Social Organisation of Medical Work Transaction Publications New York
- Strömngren A (2001b) Does the medical record cover the symptoms experienced by cancer patients receiving palliative care? A comparison of the record and patient self-rating Journal of Pain and Symptom Management 21:3 189-196
- Strömngren AS; Groenvold M; Pedersen L; Olsen AK; Sjogren P (2002) Symptomatology of cancer patients in palliative care European Journal of Cancer Care 38:6 788-794
- Stromgren AS; Groenvold M; Sorensen A; Andersen L (2001) Symptom recognition in advanced cancer. A comparison of nursing records against patient self-rating Acta Anaesthesiologica Scandinavica 45:9 1080-1085
- Strong PM (1979) The Ceremonial Order of the Clinic: Parents, Doctors and Medical Bureaucracies Routledge and Kegan Paul, London
- Sudnow D (1967) Passing On: The Social Organisation of Dying Prentice Hall, London
- Tanghe A; Evers G; Parideans R (1998) Nurses' assessments of symptom occurrence and symptom distress in chemotherapy patients European Journal of Oncology Nursing 2:1 12-26
- Tanner C (2000) Critical thinking: beyond the nursing process Journal of Nursing Education 39:8 338-9
- Tanner C; Benner P; Chelsa C; Gordon D (1993) The phenomenology of knowing the patient Image 25 273-280
- Taylor C (1997) Problem solving in clinical nursing practice Journal of Advanced Nursing 26:2 329-336
- Taylor C (2000) Clinical problem-solving in nursing: insights from the literature Journal of Advanced Nursing 31:4 842-849
- Taylor C (2002) Assessing patients' needs: does the same information guide the expert and novice nurse? International Nursing Review 49 11-19
- The A-M (2002) Palliative Care and Communication Facing Death Series Open University Press, Buckingham
- The A-M; Hak T; Koester G; van de Wal (2000) Collusion in doctor-patient communication about imminent death: an ethnographic study British Medical Journal 321 1376-81
- Thompson C (1999) A conceptual treadmill: the need for 'middle ground' in clinical decision making theory in nursing Journal of Advanced Nursing 30:5 1222-1229
- Tilley N (2000) Realistic Evaluation: An Overview Presentation at the Founding Conference of the Danish Evaluation Society. Downloaded from <http://www.danskevalueringsselskab.dk/pdf/Nick%20Tilley.pdf> March 2003
- Tilley N (2005) Conducting realist evaluations. Presentation at UK Evaluation Society Conference, Manchester, December 2005.
- Timmons S and Tanner J (2005) Operating theatre nurses: emotional labour and the hostess role International Journal of Nursing Studies 11:2 85-94

References

- Tolson D; McIntosh J; Loftus L; Cormie P (2007) Developing a managed clinical network in palliative care: a realistic evaluation International Journal of Nursing Studies 44:2 183-95
- Traynor M (1999) Managerialism and Nursing: Beyond Oppression and Profession Routledge, London
- Twomey C (2000) Telephone contacts with a cancer nurse specialist Nursing Standard 15 35-38
- van Gennep A (1960) The Rites of Passage London, Routledge, Kegan and Paul (originally published 1909)
- VanCott M-L (1993) Communicative competence during nursing admission interviews of elderly patients Qualitative Health Research 3:184-208
- Velikova G; Brown GM; Smith AB; Selby PJ (2002) Computer-based quality of life questionnaires may contribute to doctor-patient interactions in oncology British Journal of Cancer 86: 51-56.
- Velikova G; Booth L; Smith AB; Brown PM; Lynch P; Brown JM; Selby P J (2004) Measuring quality of life in routine oncology practice improves communication and patient well-being: A randomized controlled trial Journal of Clinical Oncology 22:4 714-724
- Wainwright S (1997) A new paradigm for nursing: the potential of realism Journal of Advanced Nursing 26:6 1262-71
- Walton I (1966) The Nursing Process in Perspective: A Literature Review Unpublished Report Department of Social Policy and Social Work, University of York
- Waters K and Easton N (1999) Individualized care: is it possible to plan and carry out? Journal of Advanced Nursing 29:1 79-87
- Webb C and Hope KW (1995) What kind of nurses do patients want? Journal of Clinical Nursing 4 101-108.
- Weiss CH (2000) Which links in which theories shall we evaluate? In: Program Theory in Evaluation: Challenges and Opportunities New Directions for Evaluation (Ed: Rogers PJ; Hecsi TA; Petrosino A; Huebner TA) 87 35-45 Jossey-Bass, San Francisco
- Wells M (1998) The hidden experience of radiotherapy to the head and neck: a qualitative study of patients after completion of treatment Journal of Advanced Nursing 28:4 840-48
- Wigens L (1997) The conflict between 'new nursing' and 'scientific management' as perceived by surgical nurses Journal of Advanced Nursing 26:6 1116-1122
- Willkie P(1997) Ethical issues in qualitative research in palliative care Palliative Medicine 11 321-24
- Wilkinson S (1991) Factors which influence how nurses communicate with cancer patients Journal of Advanced Nursing 16:6 677-688
- Wilkinson S; Gambles M; Roberts A (2002) The essence of cancer care: the impact of training on nurses' ability to communicate effectively Journal of Advanced Nursing 40:6 731-738
- Wilkinson, S. Roberts, A. Aldridge, J. (1998) Nurse-patient communication in palliative care: an evaluation of a communication skills programme Palliative Medicine 12:1 13-22
- Willard C and Luker K (2005) Supportive care in the cancer setting: rhetoric or reality? Palliative Medicine 19, 328-333

- Williams ML and Payne S (2003) A qualitative study of clinical nurse specialists' views on depression in palliative care patients Palliative Medicine 17:4 334-338
- Williams PD; Ducey KA; Sear AM; Williams AR; Tobin-Rumelhart SE; Bunde P (2001) Treatment type and symptom severity among oncology patients by self-report International Journal of Nursing Studies 38 359-367
- Wilson C; Bryar R; Lanceley A; Young T (2006) 'Telling my story': Palliative chemotherapy patients' perspectives of the benefits of an assessment tool Abstract for Oral Presentation at the Palliative Care Congress, Sheffield Palliative Medicine 20:2 135
- Wilson C; Ward P; Field G; Maher EJ; Young T; Vivat B; Grunfeld E; Brown S; Westcombe A; Ramirez A (2002) Assessing the supportive care needs of women with advanced breast cancer in the second line chemotherapy study: the Assessment-Response Tool distinguishes between high scores, concerns and needs Unpublished report
- Wilson VJ; McCormack BJ; Ives G (2005) Understanding the workplace culture of a special care nursery Journal of Advanced Nursing 50: 1 27-38
- Wong WH (2004) Caring holistically within new managerialism Nursing Inquiry 11:1 2-13
- Wright EP; Kiely MA; Lynch P; Cull A; Selby P J (2002) Social problems in oncology British Journal of Cancer 87:10 1099-1104
- Wright S (1995) The role of the nurse: extended or expanded? Nursing Standard 10:9 25-29
- Yin RK (1994) Case Study Research: Design and Methods Sage Thousand Oaks
- Young A and Rea D (2000) ABC of colorectal cancer: Treatment of advanced disease British Medical Journal 321: 7271 1278-1281
- Zigmond A and Snaith R (1983) The Hospital Anxiety and Depression Scale Acta Psychiatrica Scandinavica 67 361-70



IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

1st Author; date & country	Study design & aims	Participants	Findings & conclusions	Comments
Rathbone 1994 UK	Pilot study: testing new assessment tool, comparing patients' own grading of their problems vs. their grading of nurse identified problems	44 patients In-patient Hospice	Average of 5.6 problems per patient 50% of these not identified by nurses 52% of these were psychosocial problems PEP useful in identifying problems underrated or unrecognized in assessment	
Coyle 1996 USA	Quantitative study To validate assessment tool: PNAT = Patient Needs Assessment Tool	36 cancer pts Advanced disease In-Pt, & Out-Pt 1 doctor, 1 nurse	PNAT is valid scale for assessment of range of problems in cancer patient	Burdensome design for patients 9 questionnaires to complete Small sample Focus on 'functional disturbance' Experienced nurse and doctor assessed patient and rated impairment using assessment tool: PNAT Research nurse interviewed patient. Pt completed 9 questionnaires
Stephens 1997 UK	Comparing doctors' ratings of pts QoL and symptoms with patients' QoL questionnaires submitted in lung cancer clinical trials RSCL used	819 patients (lung) palliative treatment	Doctors underestimated severity of pts' symptoms in 15% and overestimated in 7% of completed questionnaires Levels of agreement: 78% Poor level of agreement for cough	The pts' RSCL scores were available to all Drs in the clinic; not all of them used it Drs were asked to rate pts' symptoms since the last assessment; patients, since the last week Retrospective comparison of doctors' assessments of patients QoL in clinical setting
Macquart-Moulin 1997 France	Compare breast cancer pts' self-rated side effects of chemo and global QoL with oncologists' assessments using specially designed questionnaire	50 women undergoing adjuvant CMF chemo 33 of these completed tool for 6 courses	Mean number of symptoms per course >5; high for hot flushes, poor appetite, joint pain: not usually assessed Moderate concordance with physicians' reports except for the above which were underestimated	No details of reliability of tool Comparing with medical records
Tanghe 1998 Belgium	What is the level of agreement between patient and nurse concerning symptom occurrence and distress following chemotherapy?	189 patients 51 nurses Adapted Symptom Distress Scale	Nurses [estimated majority of symptoms Highest agreement in: nausea, vomiting, alopecia Pts highest distress = fatigue	Nurses completed their questionnaires on patients' symptoms at the end of their shift: may not have recalled accurately Not all patients and nurses had matched pairs as nurses limited to 3 q'aires per day

1st Author; date & country	Study design & aims	Participants	Findings & conclusions	Comments
Rhodes USA 1998	Descriptive, correlational study comparing nurses' assessments of hospice pts' symptoms with pts' self assessment. Tool used: adapted Symptom Distress Scale 3 data collection points: 24hrs; 2 weeks & 4 weeks after admission	53 hospice patients 20 RNs 2 Medical social workers	Statistically significant improvement in pts'. symptom distress scores from base line - week 4 Weak correlation between nurses' and patients' scores at both time points Nurses overestimated patients' symptoms	Different nurses carried out the assessments at baseline, week 2 and week 4 Attrition of patients between weeks 2 & 4 Nurses completed their assessments 24 hrs after patients Patients assessment forms were completed by telephone with the researcher
Roth 1998 USA	Intervention study Feasibility of a checklist approach to identify anxiety and depression Referral rate to psychiatrist provision of psychosocial intervention	95 men with advanced prostate cancer	HADs and distress thermometer helped identify 29 patients with depression 12/29 refused referral for specialist help	Choice of psychiatrist as offer of support caused problems for patients: majority declined offer: ?was HADS too sensitive a cut-off or was it the stigma of psychiatrist?
Detmar 1998 Netherlands	Observation of OP consultations Completion of EORTC QLQ-C30 To test feasibility of EORTC tool in clinical practice and identify effects of QoL assessment on consultations	6 oncologists 18 patients OP clinics	Tool was feasible, small increase in no. of QoL issues discussed in clinic but doctors took more responsibility for raising issues with pts. when using tool. EORTC QLQC-30 facilitated communication in OP clinic	Tool facilitated doctors' counselling and advisory role
Taenzer 2000 USA	Did QOL information improve pts satisfaction with consultation; what was the impact of QoL assessment Control group intervention group QoL tool = EORTC QLQC 30 and Satisfaction scale	57 Outpatients Lung cancer	No difference in satisfaction between 2 groups More QoL issues addressed in intervention group (but not significant) No change in outcomes as a result of QoL assessment (referrals)	Data presented was incomplete
Carlson 2001 USA	To determine the utility and acceptability to patients and staff of using computerised QoL tool in OP clinic	48 patients Mixed diagnoses 41% advanced disease Attending pain clinic	Pts had low global QoL scores; main problem areas: role functioning; pain, fatigue, sleep problems Pts found computer very easy to use	50% pts had not used computer before; did not have problems using computer Pts thought it a good use of waiting room time No information on staff views, impact on clinic or management of symptoms

1st Author; date & country	Study design & aims	Participants	Findings & conclusions	Comments
Strömgen 2001 Denmark	Comparison of medical recording of patient symptoms and patients' self reporting using 3 questionnaires HADS; EORTC QLQC-30; ESAS	55 patients	Pain was most correlated between physicians & patients. Considerable quantitative and qualitative differences between doctors' and patients' ratings - patients had many more symptoms than were identified by doctors	Comparison with medical notes: are these a valid comparison c.f. research into nursing notes being a poor reflection of practice
Sollner 2001 Germany	Comparison of oncologists' identification of pt. psychosocial needs vs screening tools To identify how accurate oncologists are in identifying patients' psychosocial needs	8 oncologists 298 patients OP radiotherapy	Weak correlation between doctors and assessment screening tools Correct perception of severe distress in 11 of 30 pts; recommendations for counselling not related to distress but progressive disease and pt denial More education required to help doctors identify distress	Oncologists could detect moderate distress but not severe distress: why?
McLachlan 2001 Australia	Randomised study To determine whether making QoL info. available to HCPs & co-ordinating care ↓ needs, improves QoL and satisfaction	450 cancer patients attending for OP chemo Co-ordination nurse Doctors	No sig. differences in change in needs, QoL or psychosocial functioning or satisfaction with care. Pts with moderate or severe depression at baseline showed sig. ↓ in depression between baseline and follow-up (6 months)	Making this information available routinely does not seem to make a difference except in severe depression Majority of patients with 'needs' declined offers of intervention
Hill 2002	Pre-test post test design Pre-test group completed QOL tool soon after admission; re-test 7 days later; researcher collected results Intervention group: completed forms were shared with nurses to plan care	72 patients 10 nurses Hospice New Zealand	No statistical difference in QoL between control and intervention groups between 1st and 2nd assessments Nurses had difficulty in using QoL data in practice All patients' QoL improved	Benefits of using QoL tool in practice: accessing information that would not usually be obtained; finding out such information more quickly/earlier Increased awareness of patients' experiences
Zhao 2003 China	Comparison study: nurses assess ments vs patients' self-assessed quality of life scores	191 patients Gynaecological cancer 25 nurses	Significant differences between nurses' assessments and patients' self assessment in: cognitive (nurses overestimated problems); fatigue; constipation; finances (nurses underestimated these)	Nurses rated a convenience sample using questionnaire afterwards Ratings were done on day of discharge from hospital

1st Author; date & country	Study design & aims	Participants	Findings & conclusions	Comments
Lidstone 2003 UK	To identify cancer OP clinic pts' needs as they attend(ed) oncology clinic Tools used was Symptoms and Concerns Checklist	480 patients Mixed diagnoses	Mean number of items per patient: 10 83% of pts reported one or more item likely to benefit from specialist palliative care High level of unmet need in cancer outpatients	50% of patients had advanced disease Fatigue most commonly rated problem Survey of concerns, so tool not used in clinical setting: no detail as to whether feasible
Bruera 2003 USA	RCT Prompt sheet vs information sheet Audiotaped consultations To identify if a prompt sheet given to women prior to OP consultation helps them to ask questions more effectively than a general information sheet	60 women with breast cancer	No significant differences between the 2 groups re: no. of questions asked, or length of consultation Prompt sheets may help patients ask questions of doctors and improve communication	Prompt sheet designed for the study Timings were estimated by the doctors
Braud 2003 France	Quantitative evaluation of assessment tool for 5 chemotherapy-related symptoms To investigate the feasibility and acceptability of repeated (12 hrly) measurement of side effects during chemotherapy	49 in-patients no. of nurses unspecified	80% judged assessment as 'not constraining' 55% judged care to be improved Assessment tool was feasible Information generated may increase satisfaction with treatment	Nurses' views not given
Velkova 2004 UK	Randomised study Quality of life tool for assessment of patient concerns vs. medical history To show that QoL tool improves assessment of social and psychological needs and communication skills	Oncologists (Drs) Out patients	Use of EORTC QoL tool significantly improved assessment skills and improved patients' QoL Not all patients required help with problems QoL tool feasible for OP clinic Patients found tool acceptable Length of consultations did not change	Little detail given about impact on doctors' communications with patients No information on whether nurses were present in the clinic and the impact of tool on their workload
Boyes 2005 Australia	Intervention study: pts attending OP clinic for chemo completed computer touch screen assessment. Control group results not fed back to doctors in clinic. Longitudinal study: survey carried out 4 times	Oncologists (Drs) n=4 Outpatients: 42 in intervention group; 38 in control group	Reduction in level of debilitating physical symptom by visit 3 in intervention group; no significant differences in anxiety, depression, perceived needs between the groups	Feedback increased consultation times by 3-5 mins Few patients had 'needs' in either group Not randomised; more of a pilot study Same oncologists saw patients in both groups - contamination problems Feedback did not contribute to patient management

Appendix 2 Patients' Interview Schedule

Patient Interview Schedule

Follow-up interview patient:

These questions were used as a guide, and were not strictly adhered to. There was a degree of flexibility in the interviews; some were more effective than others, with some patients able to recall their thoughts and feelings, and the assessment conversation better than others.

Do you want to tell me about your treatment this time? [Aim to uncover background information about patient's understanding of their symptoms, whether they understand the palliative nature of the treatment, disease trajectory, previous treatment]

When you came for your treatment last week, did you have any pressing worries or concerns? What did you like about it; dislike about it?

Had you had treatment from [nurse] before? How well do you think you know her/him?

Do you want to say anything particular about the conversation you had with [nurse]

Was that conversation typical of others you have had with her or other nurses in the chemotherapy unit? [Length, content, contribution, rapport, laughter]

What do you expect to talk about or to be asked about?

Was there anything you decided not to raise? [Why not?]

Do you have a Macmillan Nurse; district nurse [frequency of contact]

Would you say you had close contact with Macmillan nurse/district nurse/GP

Who would you say was your main source of professional support? Where does your GP fit? What about the chemotherapy nurses, where do they fit?

Who would you say was your main source of support at home? [Family circumstances; social support]

If we talk about trust [rapport], what does that mean to you in terms of the chemotherapy nurses?

What did you mean when you said (play section of tape)?

Do you think the nurse had the right sort of information by the end of the conversation? Enough information?

- Is there anything else you want to add?

The follow-up interviews for Phase 2 covered similar areas, but added the following issues:

- What did you think about the questionnaire? Why? Can you tell me more about that?
- What else was good (or bad) about the questionnaire [and the assessment]
- Was it too long? [Distinguish between questionnaire; conversation with the nurse or both]
- Were there any issues on the questionnaire which you felt were unnecessary/inappropriate; intrusive; upsetting
- Did the questionnaire cover the things/issues which were important/relevant to you and your situation? If not, what was missing?
- Did you find it difficult or embarrassing to talk about these issues in the treatment area which is quite public? Is the treatment area too open for such conversations? (use tape recorded sections). Was it difficult to talk about these things before the treatment?
- Did you think these questions and issues were relevant to your visit for treatment/ the nurse to know about
- Have you discussed the things you raised with the nurse with anyone else to date? Who? Is this type of assessment repeating other conversations you have had with other professionals, eg your Macmillan nurse?
- Do you think this questionnaire is a good idea or a bad idea? Why?
- How often do you think this type of assessment using the questionnaire should be carried out? (Each visit; every other visit; once a course of treatment; at the end; beginning; half way through; never)
- Have you anything else you wish to add or say?

Appendix 3 ECOG Classification

Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature eg light housework, office work
2	Ambulatory and capable of all self-care, but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited self-care, confined to bed more than 50% of waking hours
4	Completely disabled. Cannot carry out any self-care. Totally confined to bed or chair
5	Dead

ECOG Classification

IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Appendix 4 Sociodemographic Form

Socio-demographic Information and Field Notes Form	
Date	
Name	GP:
Address	
Telephone number	GP telephone:
Date of Birth	
Occupation (F/T; P/T) (working/retired/sick leave)	
Social support:	Dependents:
Diagnosis:	
Disease history:	
Sites of metastases:	Treatment regime:

Treatment #

ECOG Score:

Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature eg light housework, office work
2	Ambulatory and capable of all self-care, but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited self care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry out any selfcare. Totally confined to bed or chair
5	Dead

Time assessment commenced

Time ended

Main concerns (CJW)

Contextual Notes

Professional Support:

Appendix 5 ART Assessment Tool



Assessment Response Tool (ART) - (page 1 of 5)

During the past week:	Not at All	A Little	Quite a Bit	Very Much
16. Have you been constipated?	1	2	3	4
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor Excellent

© Copyright 1995 EORTC Quality of Life Group. All rights reserved. Version 3.0

During the past week have you had difficulties as a result of:

	Not at All	A Little	Quite a Bit	Very Much
31. Bladder/Urinary Problems	1	2	3	4
32. Mouth/Taste Problems (e.g. dry/sore).	1	2	3	4
33. Swallowing Problems	1	2	3	4
34. Lack of information about your Illness or Treatment	1	2	3	4
35. The Way in which the Doctors or Nurses Communicated with You	1	2	3	4
36. Anything to do with your Treatment (e.g. Side-effects) or Care	1	2	3	4
37. Caring for Yourself	1	2	3	4
38. Lack of Support From Others	1	2	3	4
39. Your Relationships with Important People In Your Life (e.g. partner, children, family)	1	2	3	4
40. Worries or Concerns about Important People in Your Life	1	2	3	4
41. Worries or Concerns about Your Appearance	1	2	3	4
42. Your Sexual/Intimate Relations (leave blank if not applicable)	1	2	3	4
43. Your Finances	1	2	3	4
44. Your Work (leave blank if not applicable)	1	2	3	4
45. Spiritual/Religious Issues	1	2	3	4
46. Worries or Concerns About the Future	1	2	3	4

Please list any other symptoms/problems you want to talk to the nurse about:

Patient name label

Date :

Existing Support Services

Category	Distress				Intervene ?		Reasons?	Details of existing HCP involvement / medication		Comments? e.g. referrals required Which HCP already involved/referred?
	None	A little	Quite a bit	V much	Yes	No		Yes	No	
	1	2	3	4						
Physical functioning 1 2 3 4 5 37										
Role functioning 6 7 37 39 44										
Breathlessness 8										
Pain 9 19										
Fatigue / Asthenia / Sleep 10 11 12 18										
Nausea / Appetite / Oral problems 13 14 15 32 33										

Category	Distress				Intervene ?		Reasons?	Details of existing HCP involvement / medication		Comments? e.g. referrals required
	None	A little	Quite a bit	V much	Yes	No		Yes	No	Which HCP already involved/referred?
	1	2	3	4						
Excretory problems 16 17 31										
Cognitive functioning 20 25										
Emotional functioning 21 22 23 24 40 41										
Social functioning 26 27 38 39 40 42										
Financial issues 28 43										
Communication 34 35 39										
Treatment / care 36										
Existential 40 45 46										



IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

Appendix 6 Ethics Committee



To: *Cathy Wilson, Nurse Researcher,*

Copy to:

Date of Approval: 05.12.03

Members of the LREC:

Title of study: Enhancing the "palliative care approach" in oncology: the impact of introducing an assessment tool to structure nurses' assessments of cancer patients receiving palliative chemotherapy

SBLREC Ref: Oct03/4d
please quote this reference on all correspondence

Study considered for first time by the Committee	
Study reviewed by the Committee	XX
Study examined by Chairman (preliminary)	
Chairman's action, following examination by the full committee, and subsequent modifications	
Chairman's action only; examination by committee not necessary	

OUTCOME:	Study APPROVED	XX
----------	----------------	----

Study Approval for The Northern - (page 1 of 3)

ADDITIONAL COMMENTS:

The Researcher attended the meeting accompanied by her University Supervisors. Following a long discussion with the Researcher, the Committee were satisfied that all their comments had been answered satisfactorily. This study is approved.

Local Research Ethics Committee conforms to the ICH Guidelines on Good Clinical Practice.

DOCUMENTS CONSIDERED:

Protocol No/Date:

Information for Nurses: Version 1 dated 15.10.03

Information for Patients: Version 1 dated 15.10.03

Patient Letter: Version 1 dated 15.10.03

GP letter pt invitation phase 1 dated 14.10.03

GP pt acceptance Version 1 dated 14.10.03

GP letter pt invitation phase 2 Version 1 dated 14.10.03

GP pt non acceptance Version 1 dated 14.10.03

Consent Form:

Questionnaire:

ONE OF THE CONDITIONS OF THIS APPROVAL IS THAT YOU SUBMIT TO THE COMMITTEE ANNUAL REPORTS ON THE PROGRESS OF THE STUDY. A REMINDER LETTER WILL BE SENT TO YOU A MONTH BEFORE THE FIRST REPORT IS DUE.

FAILURE TO PROVIDE REPORTS MAY RESULT IN APPROVAL BEING WITHDRAWN

Signed _____ (Chairman/Vice Chairman)

Date 17 / 12 / 03

Correspondence to:



Chairman
Administrator

29 April 2004

Mrs Kathy Wilson

Dear Cathy

EC2004-09 Enhancing the 'Palliative Care Approach' in Oncology Nursing:
The impact of introducing an assessment tool to structure nurses'
assessments of cancer patients receiving palliative chemotherapy
Investigator: Cathy Wilson

Thank you for your letter dated 23 April 2004 together with amendments as requested in our letter dated 27 February 2004.

All the matters raised by the Ethics Committee have now been addressed, and acting under delegated authority I am happy to confirm final ethical approval on behalf of the Committee.

The study may commence as soon as management approval has been confirmed by the R&D Directorate on behalf of the Trust. This will be arranged by

Approval conditions

Approval is given on the assumption that you will follow the protocol as agreed, and comply with the standard conditions enclosed

Final list of approved documents

Information about Tape Recording Interviews
Patient Information Sheet Phase 1 Version 2
Patient Information Sheet Phase 2 Version 2

Not dated
22/04/2004
23/04/2004

Statement of compliance

The NHS Trust Local Research Ethics Committee is fully compliant with the International Conference on Harmonisation (ICH) Guidelines for Clinical Good Practice as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its constitution to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice adopted by the Commission of the European Union on 17 January 1997.

Please quote the EC reference above in any correspondence on this study.

With best wishes,

Yours sincerely

Temporary Committee Administrator

cc

R&D

IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Appendix 7 Patient Invitation Letter

Date

Dear

Re: A research study to explore nurses' assessments of patients in the outpatient chemotherapy department

I am a nurse at [...] Hospital, and am studying for a PhD at City University, London. I am trying to find out more about the way nurses identify whether patients need extra help and support as they undergo chemotherapy treatment.

I am working currently with the nurses in the chemotherapy department, and have identified your name from the records of patients scheduled to receive some chemotherapy next week. I am writing to ask if you would consider taking part in the research. I enclose some information about the study to help you make a decision about whether you wish to participate. You do not need to decide straight away. When you come to have your chemotherapy next week, I will ask you what you have decided.

You are under no obligation to take part in this research.

Your hospital consultant knows that I may be approaching you to ask if you would be willing to take part.

If you wish to speak to me before your treatment day, please contact me in the [...] research office, telephone number [...].

Thank you for reading the enclosed information.

With best wishes,

Yours sincerely,

Cathy Wilson
Nurse Researcher

Patient Invitation Letter

IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

Appendix 8 Patient Information

INFORMATION FOR PATIENTS ABOUT A RESEARCH STUDY

Title: A study to explore nurses' assessments of patients in the outpatient chemotherapy department

Researcher: Cathy Wilson MSc, BSc (Hons), RGN, Oncology Nursing Certificate, Diploma in Palliative Care
Nurse Researcher, [...] Hospital, and Honorary Nurse Researcher, [...] Hospital.

Introduction

You are being asked to take part in a research study. Before you decide, it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully, and discuss it with your family and your GP if you would like. Please ask if there is anything you do not understand, or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

The purpose of this study is to find out more about the way nurses identify your needs and make decisions about whether you might require additional help and support from other professionals. Generally, nurses find out this information by talking with you and asking questions, and encouraging you to share your worries and concerns. We particularly want to hear your side of the story, as most research into how nurses' talk with patients has concentrated on the nurses' perspectives.

However, in order for us to keep improving our care, we need to understand better, from your point of view, what goes on in the discussions that take place between you and your nurse before and during the giving of chemotherapy. Such information will help us to plan training courses for nurses, and ensure that we provide appropriate support for them in their work so that they continue to deliver the best possible care to patients.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What does the study involve?

The study involves me observing the nurses give you your chemotherapy, and listening to the nurse talk to you whilst you are in the chemotherapy department the next time you visit. Your conversations with your nurse will, with your agreement, be tape recorded.

A week later, I should like to interview you, to play sections of the tape to you, so that you can explain to me what you thought, and what you understood about the conversation. This interview is to find out your opinion – there are no 'right' or 'wrong' answers, and neither you nor your nurse are being tested or judged.

Patient information phase 1 v1 6/16/2007

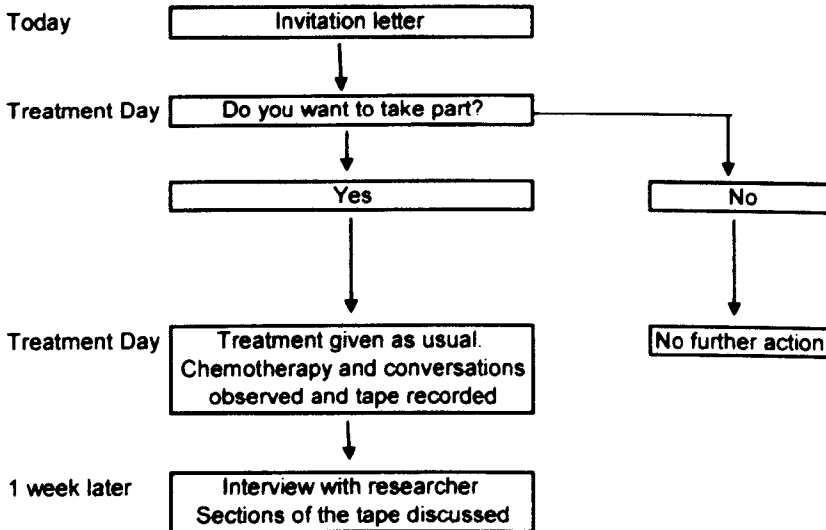
If you were willing to take part in this study, there would be no change in your treatment or chemotherapy. I would be collecting information about your experience in the department and observing the nurses as they give you your chemotherapy.

Your consultant and GP will be informed if you take part in this study.

If at any time, you identify a need for support or care that is not being dealt with, I will, with your permission, refer you to a relevant member of the health care team, so that any worries you have can hopefully be sorted out.

The flow-chart below summarises the plan of the research and what will happen if you decide to take part in the study. When you arrive for your chemotherapy next week, you will be asked if you have received this information, whether you wish to ask any questions, and you will be given the opportunity to say whether or not you wish to be involved in the research. There is no obligation to take part.

Research Plan



Patient information phase 1 v1 6/16/2007

INFORMATION FOR PATIENTS ABOUT A RESEARCH STUDY

Title: A study to explore nurses' assessments of patients in the outpatient chemotherapy department

Researcher: Cathy Wilson MSc, BSc (Hons), RGN, Oncology Nursing Certificate, Diploma in Palliative Care
Nurse Researcher, [...] Hospital, and Honorary Nurse Researcher, [...] Hospital.

Introduction

You are being asked to take part in a research study. Before you decide, it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully, and discuss it with your family and your GP if you would like. Please ask if there is anything you do not understand, or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

The purpose of this study is to find out more about the way nurses identify your needs and make decisions about whether you might require additional help and support from other professionals. Generally, nurses find out this information by talking with you and asking questions, and encouraging you to share your worries and concerns. However, it may be that nurses would be more effective if they based their discussions with you on the answers to a questionnaire, which you fill in. We do not know if this will be better, or whether you would find this acceptable. We are asking you to take part in this research to help us find out some of the answers to this question.

We particularly want to hear your side of the story, as most research into how nurses' talk with patients has concentrated on the nurses' perspectives.

The information from this research will help us to continue to deliver the best possible care for patients, to plan training courses for nurses, and ensure that we provide appropriate support for them in their work.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What does the study involve?

The study involves you completing a questionnaire when you attend for your next course of chemotherapy. This will be given to you whilst you are sitting in the waiting room, before you are called through to the treatment area. Most patients find that the form takes less than 10 minutes to fill in. When it is time for your treatment, you will take the form with you, and give it to your nurse. She will then look at the form with you, and ask you about anything which you have indicated may be a concern or a problem to you. She will complete a checklist during your conversation, as a record of it.

Your chemotherapy will be given in the usual way, and your treatment is not affected by taking part in this research. However, during your time in the department, the conversations between you and your nurse will, with your approval, be tape recorded.

Patient information phase 2

and observed. This is not to judge you or the nurse, but to learn about what goes on during the administration of outpatient chemotherapy.

A week later, I should like to interview you, to play sections of the tape to you, so that you can explain to me what you thought, and what you understood about the conversation. This interview is to find out your opinion – there are no 'right' or 'wrong' answers, and neither you nor your nurse are being tested or judged.

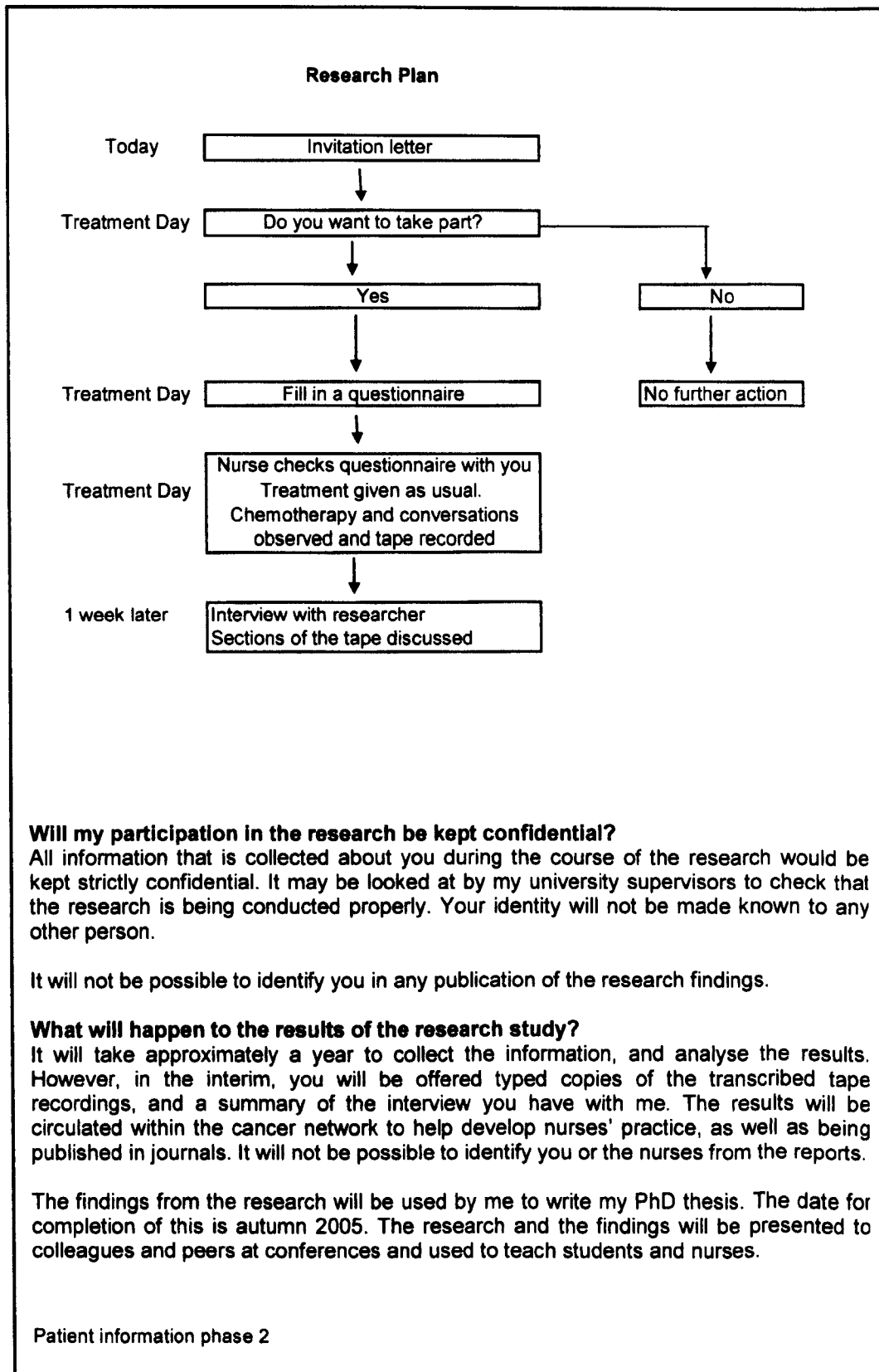
If you were willing to take part in this study, there would be no change in your chemotherapy or medical treatment. I would be collecting information about your experience in the chemotherapy department and observing the nurses as they give you your chemotherapy.

Your consultant and GP will be informed if you take part in this study.

If at any time, you identify a need for support or care that is not being dealt with, I will, with your permission, refer you to a relevant member of the health care team, so that any worries you have can hopefully be sorted out.

The flow chart overleaf summarises the plan of the research, and what will happen if you decide to take part in the study. When you arrive for your chemotherapy next week, you will be asked if you have received this information, given the opportunity to ask any questions. You will also be able to say whether or not you wish to be involved in the research. There is no obligation to take part.

Patient information phase 2



If you wish, a summary of the research will be sent to yourself or someone you nominate when the research is completed.

Who is organising and funding the research?

The study is organised by the [...] at [...] Hospital, [...]. My salary is being funded by Dr E.J. Maher, Consultant Oncologist at [...] Hospital and Medical Director of [...]. My university fees are being paid for by a scholarship from The Florence Nightingale Foundation. There is no sponsor of the research study, and no conflict of interests. You will not be paid for taking part in this research.

The research forms part of my studies for a PhD in nursing, and is being supervised by Professor R.M. Bryar and Dr. A. Lanceley at St. Bartholomew School of Nursing and Midwifery, City University, London.

Who has reviewed the study?

The Local Research Ethics Committee for [...] Hospitals has reviewed this study. This is an independent group of people with responsibility for advising on whether NHS research complies with recognised ethical standards.

The University Ethics Committee has also reviewed this research, to ensure it meets with their standards.

Contact for further information:

If you have any questions or concerns about this study, please contact me [...], telephone number [...].

Thank you.

Cathy Wilson
Nurse Researcher.

Patient information phase 2

INFORMATION ABOUT TAPE RECORDING INTERVIEWS

Title: A study to explore nurses' assessments of patients in the outpatient chemotherapy department

Researcher: Cathy Wilson MSc, BSc (Hons), RGN, Oncology Nursing Certificate, Diploma in Palliative Care
Nurse Researcher, [...] Hospital, and Honorary Nurse Researcher, [...] Hospital.

Introduction

You are being asked if you would like to continue your involvement in the above research study. You have already agreed to have your conversations with your nurse observed and recorded during the administration of your chemotherapy. Now you are being asked to consider whether I may interview you to find out more about your expectations and understandings of what you and your nurse discussed.

This information sheet is supplementary to the main information sheet sent to you on [date]. This information sheet refers to the next stage of the research, which is an interview with you, which I should like to tape record.

Before you decide whether you would like to continue to take part in the study, it is important for you to understand why I want to interview you and record our discussion, and what it will involve. Please take time to read the following information carefully, and discuss it with your family and your GP if you would like. Please ask if there is anything you do not understand, or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of this part of the study?

The purpose of this part of the research is to find out more about your views of your needs and expectations when attending for chemotherapy today.

So that I can accurately remember what you tell me, I should like to tape record the interview, which will then be transcribed onto paper. Everything you say will be anonymous and confidential. You are welcome to have a typed copy of the transcript if you so wish.

What is involved?

I will ask you if you would be willing to be interviewed. If you are, the date, time and place of our meeting will be at your convenience.

I expect that the interview will last up to 30 minutes, depending on how much there is to discuss.

During the interview, I will play sections of the tape made whilst you were having your chemotherapy. I will ask you to explain to me your interpretation of the conversation you had with your nurse when you came for your treatment, and what you feel about it.

It is not my intention to judge or criticise the nurses, the patients or make comments on the standards of care: I am interested in the meanings of the conversations, not their quality.

What if I change my mind?

The day before the interview, I will telephone you to make sure that the appointment is still convenient, and to check that you have not changed your mind. I can also answer any questions that may have arisen. If you decide that you wish to postpone the interview or cancel it completely, you will be able to say so.

If, during the interview you change your mind and wish to stop the tape recording, you can do so.

After the interview has finished, I will ask you whether you still agree for me to use the information you have given, and if you are happy about that, I will ask you to sign your name to this effect.

If you have changed your mind, you can say so, and the tape will be wiped without the information being transcribed.

What will happen to the tape?

The tape will be kept in a locked filing cabinet in my office, away from the chemotherapy unit until the end of the study. After the study has finished, the tapes will be destroyed. The tape will not have your name on it. Any names which you mention during the interview, for instance, yours, your family members, or health care professionals, will be identified in the transcript by initial only, and all the information will be strictly confidential.

I will abide by the regulations of the Data Protection Act 1998 when using or analysing the information given in the tape recorded interviews.

The tape may be listened to by me with my university supervisors: this is to help me with my studies, and to ensure that the transcripts and interpretations of the interviews are accurate.

Your legal rights are not affected by giving your consent to be interviewed in this study.

Your GP will be informed of the date of the interview and will be sent a copy of this information sheet.

What if I have a question?

If you have any questions or wish to discuss any aspect of the study with me, I can be contacted [...] on telephone number [...].

If, during the interview, you have a need for care or support which is not already being addressed, I will, with your permission, refer you to a relevant member of the health care team afterwards, so that it can hopefully be sorted out.

Thank you.

Cathy Wilson
Nurse Researcher.

Appendix 9 Nurses Interview Schedule

Nurse Interview Schedule

Follow-up interview nurse:

These questions were used as a guide, and were not strictly adhered to. There was a degree of flexibility in the interviews; some were more effective than others, with some nurses more able (and willing) to reflect on their practice than others.

- How well do you know this patient?
 - Can you tell me about his/her disease or the reasons for the chemotherapy?
 - What were you intending to achieve from the assessment?
 - Did you feel you had this information by the end?
 - What do you feel went well? or What did you feel you did well?
 - Was there anything that went less well during the conversation? Why?
 - What would you change, if anything?
 - Was this a long assessment/short assessment/about the usual length of an assessment?
 - What impressions did you have of the patient – at the beginning; during a particular section of the assessment (for example); at the end
 - What about this section (play back some of the assessment)? What did you think [patient] meant here? Can you tell me more about why you responded as you did? And/or What did you feel at this point? [After listening to it] Does it change what you think the patient meant/wanted?
 - Did you reach any conclusions about the patient's main concerns?
 - Did you take any actions as a result of the assessment? (e.g. liaise with palliative care services or GP; make a referral; find some information?)
 - Was there anything going on in the unit at the time of the assessment which might have affected your practice?
 - Anything in your circumstances (e.g. feeling unwell, tired, stressed) which might have had an impact?
 - What training have you had in the last year with regard to: assessment; communication skills; oncology issues; palliative care; symptom control; any other training?
1. Is there anything else you want to add?

The follow-up interviews for Phase 2 covered similar areas, but added the following issues:

- When (patient) raised (an issue), what did you feel? Why? (e.g. lack of knowledge; no service available; short of time – busy, did not want to discuss this issue; have discussed this before)
- What did you mean when you responded (play section) like this?
- Overall do you think the assessment tool added/changed your way of assessing patients?
- Were there any problems using the tool?
- Were there any good things about using the tool with this patient?
- What were the negative things about using the tool with this patient?
- Was the information raised by using the tool useful to you?
- Were there any things you had to do as a result of the assessment? (e.g. make a referral, find information)? Were you able to do these? (i.e. was the service available; the telephone answered? was time available; was the information readily obtainable? Did you know where to go for help?)

For your information

Research Study in progress today !

This involves tape recording certain conversations between patients & nurses.

Any information inadvertently recorded will not be kept. If you have any questions please speak to Cathy Wilson or one of the chemotherapy nurses.



(Name of hospital / Contact numbers)



IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Appendix 11 GP Letter

Dear Dr

Study to explore nurse assessment of cancer patients in the outpatient chemotherapy department

Re:

Your patient....., has consented to participate in a research study exploring nurse assessment in the outpatient chemotherapy department at [...] Hospital. This is a two-phase study. This phase (phase 1) is analysing current practice in the department.

This is a qualitative research study. The assessment interactions between the nurses in the chemotherapy unit andwere tape recorded and observed during her treatment. This is a collaborative study, acknowledging both the nurses' and patients' contribution to assessment, so a follow-up interview is scheduled to take place next week.....[date].

During this interview, parts of the tape recording of the assessment which took place whilstwas treated will be played, and s/he will be encouraged to share with me her understandings and perceptions of the encounter.

Should any issue arise during the interview which indicates a need for an intervention or assistance, I will, with the patient's permission, inform you.

The [...] NHS Trust Local Research Ethics Committee has reviewed and approved this study.

I am an oncology trained nurse, who has been working as a palliative care nurse specialist for the past seven years. This research will form part of my thesis for my PhD which is being supervised at St Bartholomew School of Nursing and Midwifery, City University, London.

If you wish to discuss your patient's involvement in the research, or require further information, please contact me in the Chemotherapy Department, [...] Hospital telephone.....

Yours sincerely,

Cathy Wilson (Mrs)
Nurse Researcher

GP phase 1 v1 Oct 2003

Dear Dr

Study to explore nurse assessment of cancer patients in the outpatient chemotherapy department

Re:

Your patient has consented to participate in a research study exploring nurse assessment in the outpatient chemotherapy department at [...] Hospital. This is a two-phase study. This phase (phase 2) is analysing the impact of using a quality of life tool to structure nurses' assessments.

This is a qualitative research study. The assessment interactions between the nurses in the chemotherapy unit and were tape recorded and observed during her treatment on day. This is a collaborative study, acknowledging both the nurses' and patients' contribution to assessment, so a follow-up interview has been arranged to take place on.....

During this interview, parts of the tape recording of the assessment which took place whilst was treated will be played, and she will be encouraged to share with me her understandings and perceptions of the encounter.

Should any issue arise during the interview which indicates a need for an intervention or assistance, I will, with her permission, inform you.

The [...] NHS Trust Local Research Ethics Committee has reviewed and approved this study.

I am an oncology trained nurse, who has been working as a palliative care nurse specialist for the past seven years. This research will form part of my thesis for my PhD which is being supervised at St Bartholomew School of Nursing and Midwifery, City University, London.

If you wish to discuss your patient's involvement in the research, or require further information, please contact me in the chemotherapy unit at [...] Hospital, telephone.....

Yours sincerely,

Cathy Wilson (Mrs)
Nurse Researcher

GP pt acceptance phase 2 v1

Specific Data set in Use	Procedural steps	Decision Rules	Analysis Operations		
Ph1 CSS1 Ph 1 CSS2	Use NVivo to bring up nodes: treatment, toxicity, symptom, problem	Patient volunteering it Nurse asking	Frequency √ per symptom	Theme building	Clustering Nausea + vomiting Temperature + coughs + colds Fatigue + tiredness
N-P Assessment transcripts	Count number of symptoms asked by nurse	Distinguish between symptoms and side effects where possible: e.g. nausea from tumour; constipation from anti-emetics	√	Replies: need to look at these and identify any patterns	Category: veins; sickness; infection; medication (have pts got enough tablets); appointments and system issues
Transcripts	Count number of symptoms mentioned by patient	Symptom = non-treatment related. Cough in lung cancer vs cough from chemo for e.g.	√		Symptoms
Transcripts	Count number of treatment effects asked by nurse		√		Veins: great emphasis on venous access
Transcripts	Count number of treatment effects mentioned by patient		√		Veins
Tape recordings Field notes	Time assessments Use stop watch	Include conversation before, during and after cannulation if same nurse	Timing: minutes and seconds Remove any conversation between other nurses and the patient or assessing nurse unless permission (L).		
Transcripts Assessments	Test CMO 1	Look for relaxed and friendly	Coding of relaxed and friendly and outcomes: trust, technical skills, know-how, knowledge competence emerging as important follow on from relaxed and friendly Noticed 'how are you type question': look in data for more of these. How is it answered? Socially or with problems? Unit philosophy: check Humour? When and what does it achieve? What do nurses advise? NB: field notes – seemed to ignore many issues – check for follow-up interviews		

Specific Data set in Use	Procedural steps	Decision Rules	Analysis Operations
Transcripts Follow-up interviews nurses	Transcribe tapes Listen to tapes, read field notes, prepare recordings, mark specific queries on transcript	Relaxed and friendly?	Approach to patients, aims for assessment, how achieved? If achieved? What do they think this achieves for patients, care? What does it achieve for nurses?
		Outcomes	Why not picking up on fatigue?
Follow-up interviews patients		Relaxed and friendly	Do patients identify this? Do patients find it constraining? Do patients like it? Did they know the nurse? Treated before by her? Similar type of assessment or different from the norm?
		Trust	What is trust? What does it mean to patients? What do nurses want? Does trust matter/make a difference? In what way? What is outcome of trust? Does trust come from relaxed and friendly?
Documentary analysis Nurse follow-up interviews	Identify and count Nurses opinions, keep record in diary of busy or short staffed Count number of patients treated per day, keep record and calculate mean over period of data collection	Issue of concern	What were patients main issues of concern on the day, divide into treatment and illness if possible. Keep mixed categories separate. Review with assessment transcripts Did patients feel they asked or raised what they wanted to? Did they feel they had to raise specific issues, importance to them? Perceived importance to nurse? Type issues documented
		Look at busy days, do these assessments differ in content and style?	Check with nurse at follow-up interview whether being busy was distracting or stressful Use stop watch and listen to assessment tapes and time them, minutes and seconds. Store in Excel file Were nurses pleased/satisfied with assessments? If not why not? What would they have changed? Keep note of sickness rate on units What is outcome of assessment from nurses' point of view? Patients' opinions of time and waiting, Appointment system

Specific Data set in Use	Procedural steps	Decision Rules	Analysis Operations
Patient interviews			Did patients sense nurse busy? Affected assessment? Feel constrained? What else constrains contribution? Helps contribution?
Assessments	Count and group categories of symptoms, issues discussed: who asked; who answered, how detailed?	Make distinction (if possible) between treatment-related side effect and illness symptom	Use patient interviews to check interpretation Symptoms: near metastases; medication; long-standing; not related to chemotherapy
Assessments	Technical theme Count and record instances of vein discussion: patient initiated vs nurse initiated		Include checking name and address: = safety Vein = safety too Think about patient anxiety underlying vein? Check in F/lp transcripts Nurse anxious during cannulation: look for humour afterwards: NB: Apologising and 'sorry'.
	Also use of chemo regime	Look for vesicant regimes	More care? More safety?
	Is technical focus shared by patients?	YES – and anxious	Field notes to supplement this.

DECISION TRAIL

Decision trail	Thoughts	Developments	Outcome
October 2003	<p>The dance of assessment</p> <p>Misunderstandings working to get in step</p> <p>Causes nurses to get embarrassed and anxious</p> <p>Patients don't always clarify issue nurses sometimes move off subject before clarifying</p> <p>Out of step The bow The curtsy</p>	<p>Look for causes of misunderstanding</p> <p>Steroids Names Banter cricket, football, conversation, leisure activities Drugs Syringes Fatigue Symptoms</p>	<p>Abandoned not clearly defined Not enough examples of interest. Becoming hackneyed April 2004</p> <p>June 2004 Seen at The Southern important theme, so think again</p> <p>Aug 2006 Negotiation Work</p> <p>Barriers, facilitators</p>
June 2004 July 2004	<p>The knowledge of assessment</p> <p>Assessment Knowledge for practice</p>	<p>Patients give nurses information based on what they think nurses need to know Nurses elicit information to enable them to give chemo</p>	<p>Abandoned Aug 2005 Nurses did not have knowledge for assessment Phase 2</p> <p>Assessment more than knowledge - nurses wanting to relax patients and make them feel good</p>
Sept 2004	<p>Foucault surveillance</p> <p>Assessment and the nursing gaze</p>	<p>Had chat with KF Foucault might be relevant Power is with nurses regulate behaviour in chemo units control of interaction with nurses</p> <p>Patients hide symptoms they have power too Does patients power make a difference? Patients tell story to fit their perception of nurses role Patients normalising issues - or is this nurses? Both?</p>	<p>Abandoned January 2005 read a critique of Foucault and doesn't fit with research design can't acknowledge user's interpretations and fit with practice</p> <p>But although not power issue of control is important to retain and think about</p> <p>No it's patients minimising issues and nurses normalising them</p>

Decision trail	Thoughts	Developments	Outcome
Nov 2004	Emotional Labour	MPhil/PhD upgrade examiner suggested this is what it was Read Hochschild : not sure this fits Look at Lyth	Emotion work in social org theory Emotion work in BMT units; denial of death Anxiety about treatment and illness which is hidden, not expressed to the nurses or explored by the nurses: Working in the dark
May 2005	Menzies-Lyth defences	Discuss with AL and RB. Some mileage in this	Emotion work and Lyth's theory not really Hochschild: Jan 2006
Nov 2004 June 2005 Jan 2006	Assessment work Constraints of chemo unit What is achieved by assessment as task talk?	Dance of assessment: Negotiation work Purpose of visit: to have chemo. Happy friendly. Control with nurse Assessment: information work	August 2006: Accepted as generative mechanism in the setting: fits data and nurses' perceptions and role of assessment
May 2005	Strong: role formats	Can I identify clinical, chatty, factual formats? From data analysis: 4 clinical; 5chatty; 4 controlled; 8 mixed. Too many mixed groups, and few 'pure' groups – seems like I'm forcing the data to fit. Look for right to criticise: no Character work: yes- patients want to be seen to be good and heroic Rights to control over interaction: changes from Ph1 to Ph2 Power dimension swapped: useful idea Speaking role pre-allocated: mostly, but not always. More often at Southern Equal competence? no Criteria for control of frame: can't see one	June 2005 Abandoned as data did not fit the codes very well. Too many mixed groupings But control idea useful: checked with data and accepted this. Agenda: set jointly in this study Power and control of Ph2 went to patient: nurse didn't lie this – moves to re-gain control: identified in data and re-coded Fits with Southern better than Northern data
July 2005	Division of labour	Volunteers; nurse assessing; nurse giving chemo; HCA; nurse discharging; doctor. Mac nurse; GP	June 2006: Incorporate into social organisation

Decision trail	Thoughts	Developments	Outcome
June 2006	Keeping a lid on Pandora's Box Working in the dark	Emotional control in assessment Nurses see the lid on Pandora's box as good. Like being in dark makes feel safe	Aug 2006 Emotion work Keep with Social organisation theory Emotions and control defences?
July 2006	Goffman Face work, front-stage, back stage?	Patients conceal anxiety stigma? Fear of treatment stopping. Put makeup on, dress in smart clothes, make an effort Backstage - waiting areas - patients cry Front stage treatment rooms all bright and jolly Stage and acting notion Nurses hide how anxious they are, how upset they are Present jolly front and happy Nurses at The Southern hide behind screen	Abandoned useful and promising, but not enough data to support backstage work. Didn't really observe waiting areas so it's all a bit tentative Doesn't quite fit
August 2006	Social organisation of Assessment	Assessment as Information Work Safety, bureaucracy, emotion, temporal negotiation	Fits with data and theory about generative mechanism have been doing a lot of work with realist evaluation and this is I am sure congruent with social org theory Assessment as task talk
November 2006	Defences against anxiety Routinisation read Bloor and Routinisation of decision making in high turnover clinical setting yes this fits but as a defensive mechanism	Assessment as a defence 4 defences from Lyth but with caveats of efficiency (did the system leave the nurses this way to prevent them opening Pandora's box?) Don't have enough macro context data on this but sth for another time	Menzies Lyth's theory But resistance to change can't really support from data esp. at Northern as might have been change mechanisms and response to change itself rather than defence (although at Southern was more pronounced)

Appendix 13 Data from ART

ART Categories

Question numbers	Analysis code letter	Category
1, 2, 3, 4	A	Physical Functioning
6, 7, 27, 39, 44	B	Role Functioning
8	C	Breathlessness
9, 19	D	Pain
10, 11, 12, 18	E	Fatigue
13, 14, 15, 32, 33	F	Nausea, vomiting, appetite, eating
16, 17, 31	G	Excretory
20, 25	H	Cognitive Functioning
21, 22, 23, 24, 40, 41	I	Emotional Functioning
26, 27, 38, 39, 40, 42	J	Social Functioning
28, 43	K	Financial issues
34, 35, 39	L	Communication
36	M	Treatment
40, 45, 46	N	Existential

Question numbers, 39, 40 (see below) appear in more than one analysis category: social (J), role (B) and existential (N).

39: Your Relationships with Important People In Your Life (e.g. partner, children, family)

40: Worries or Concerns about Important People in Your Life

However, they were analysed once, depending on the patient's answer to the follow-up questions. The reason for the overlap is that sometimes the answer to these questions issue was concerned with social reasons, other times the answer related to role, or existential issues

Assessment Response Tool (ART) Categories

Group		Quest	Fel	Pat	Dis	Ros	Mur	Pau	Em	Am	Ju	EI	Fel	Pat	Dis	Ros	Mur	Pau	Em	Am	Ju	EI	VALID	TOTAL	
A	PF	1	3	4	2	4	4	1	3	4	3	4	1	1	-	1	1	-	1	1	1	1	10	8	
A	PF	2	3	4	2	4	4	1	4	4	2	4	1	1	-	1	1	-	1	1	-	1	10	7	
A	PF	3	1	4	1	2	4	1	2	3	1	3	-	1	-	-	1	-	-	1	-	1	10	4	8
A	PF	4	2	3	1	4	3	2	2	4	2	4	-	1	-	1	1	-	-	1	-	1	10	5	
A	PF	5	1	1	1	4	1	1	1	2	1	1	-	-	-	1	-	-	-	-	-	-	10	1	
A+B	PF/RF	37	1	1	1	4	1	2	1	2	1	2	-	-	-	1	-	-	-	-	-	-	10	1	
																							<u>60</u>	<u>26</u>	43%
B	RF	6	2	4	1	4	4	2	2	4	2	4	-	1	-	1	1	-	-	1	-	1	10	5	
B	RF	7	2	4	1	4	3	2	3	4	2	4	-	1	-	1	1	-	1	1	-	1	10	6	6
A+B	PF/RF	37	1	1	1	4	1	2	1	2	1	2	-	-	-	1	-	-	-	-	-	-	10	1	
B+J+L	RF/SF	39	1	1	1	1	1	1	1	2	1	1	-	-	-	-	-	-	-	-	-	-	10	-	
B	RF	44	2	Mis	Mis	1	Mis	1	Mis	4	Mis	Missing	-	-	-	-	-	-	-	1	-	-	5	1	
																							<u>45</u>	<u>13</u>	29%
C	DY	8	3	4	1	1	4	1	2	4	1	3	1	1	-	-	1	-	-	1	-	1	10	5	5
																							<u>10</u>	<u>5</u>	50%
D	PA	9	2	2	1	2	4	3	2	2	3	3	-	-	-	-	1	1	-	-	1	1	10	4	4
D	PA	19	1	2	1	2	3	3	2	2	3	3	-	-	-	-	1	1	-	-	1	1	10	4	
																							<u>20</u>	<u>8</u>	40%
E	FA	10	3	3	1	4	3	3	3	4	2	4	1	1	-	1	1	1	1	1	-	1	10	8	
E	FA	11	2	4	1	2	2	1	1	2	3	1	-	1	-	-	-	-	-	-	1	-	10	2	
E	FA	12	2	3	1	4	3	3	3	4	3	4	-	1	-	1	1	1	1	1	1	1	10	8	8
E	FA	18	3	3	1	4	3	3	2	4	4	3	1	1	-	1	1	-	1	1	1	1	10	8	
																							<u>40</u>	<u>26</u>	65%
F	NV	13	1	4	1	3	2	2	2	4	2	3	-	1	-	1	-	-	-	1	-	1	10	4	4
F	NV	14	1	3	2	4	2	3	1	4	1	2	-	1	-	1	-	1	-	-	-	-	10	4	
F	NV	15	1	2	1	4	1	1	1	4	1	2	-	-	-	1	-	-	-	1	-	-	10	2	
F	NV	32	1	2	1	4	2	2	1	2	1	1	-	-	-	1	-	-	-	-	-	-	10	1	
F	NV	33	4	1	1	1	1	2	1	4	1	1	1	-	-	-	-	-	-	1	-	-	10	2	
																							<u>50</u>	<u>13</u>	26%
G	EXC	16	1	3	1	3	2	1	1	4	1	2	-	1	-	1	-	-	-	1	-	-	10	3	3
G	EXC	17	1	1	1	1	1	2	1	1	2	1	-	-	-	-	-	-	-	-	-	-	10	-	
G	EXC	31	1	1	1	1	1	1	1	1	1	2	-	-	-	-	-	-	-	-	-	-	10	-	
																							<u>30</u>	<u>3</u>	10%

Group	Quest	Fel	Pat	Dia	Ros	Mur	Pau	Em	Am	Ju	EI	Fel	Pat	Dia	Ros	Mur	Pau	Em	Am	Ju	EI	VALID	TOTAL	
H	CF	20	1	3	1	3	2	1	1	2	1	2	-	1	-	-	-	-	-	-	-	10	2	2
H	CF	25	2	2	1	1	2	1	1	2	1	2	-	-	-	-	-	-	-	-	-	10	-	
			<hr/>																			20	2	10%
I	EF	21	2	2	1	Mis	3	3	2	2	2	1	-	-	-	1	1	-	-	-	-	9	2	
I	EF	22	3	4	3	2	3	3	2	3	2	4	1	1	1	-	1	1	-	1	-	10	7	7
I	EF	23	2	3	2	2	3	2	2	2	3	2	-	1	-	-	1	-	-	-	1	10	3	
I	EF	24	1	3	2	1	Mis	2	1	2	2	1	-	1	-	-	-	-	-	-	-	9	1	
I+J+N	EF/SF	40	4	3	1	4	2	2	1	2	2	4	1	1	-	1	-	-	-	-	-	10	4	
I	EF	41	1	3	1	1	1	1	1	4	1	3	-	1	-	-	-	-	-	1	-	10	3	
			<hr/>																			58	20	34%
J	SF	26	2	1	3	4	2	2	2	4	1	4	-	-	1	1	-	-	-	1	-	10	4	
J	SF	27	2	3	3	4	2	2	3	4	2	4	-	1	1	1	-	-	1	1	-	10	6	6
B+J+L	RF/SF/CM	39	1	1	1	1	1	1	1	2	1	1	-	-	-	-	-	-	-	-	-	10	-	
J	SF	38	1	1	1	1	1	1	1	1	1	1	-	-	-	-	-	-	-	-	-	10	-	
I+J+N	EF/SF/EX	40	4	3	1	4	2	2	1	2	2	4	1	1	-	1	-	-	-	-	-	10	4	
J	SF	42	3	Mis	Mis	1	Mis	1	Mis	Mis	1	Missing	1	-	-	-	-	-	-	-	-	4	1	
			<hr/>																			54	15	28%
K	FI	28	1	3	3	2	1	2	1	2	2	1	-	1	1	-	-	-	-	-	-	10	2	2
K	FI	43	1	1	1	2	2	2	1	1	2	1	-	-	-	-	-	-	-	-	-	10	-	
			<hr/>																			20	2	10%
L	CM	34	1	1	1	1	1	1	1	1	1	1	-	-	-	-	-	-	-	-	-	10	-	
L	CM	35	2	1	1	1	1	1	1	1	1	1	-	-	-	-	-	-	-	-	-	10	-	-
B+J+L	RF/SF/CM	39	1	1	1	1	1	1	1	2	1	1	-	-	-	-	-	-	-	-	-	10	-	
			<hr/>																			30	-	0%
M	TRT	36	2	1	1	3	1	1	1	1	1	1	-	-	-	1	-	-	-	-	-	10	1	1
			<hr/>																			10	1	10%
I+J+N	EF/SF/EX	40	4	3	1	4	2	2	1	2	2	4	1	1	-	1	-	-	-	-	-	10	4	
N	EXI	45	1	1	1	1	1	1	1	1	1	1	-	-	-	-	-	-	-	-	-	10	-	
N	EXI	46	4	2	3	4	1	4	1	4	2	4	1	-	1	1	-	1	-	1	-	10	6	6
			<hr/>																			30	10	33%
Global	QL	29	5	3	6	2	3	5	4	3	4	1	1	-	1	-	-	1	-	-	-	10	3	
Global	QL	30	6	4	6	2	3	5	4	2	4	5	1	-	1	-	-	1	-	-	-	10	4	4
			<hr/>																			20	7	35%

ART data for The Southern - (page 1 of 2)

Group	Quest	May	Faith	April	June	Daisy	Joy	Viol	John	Hope	May	Faith	April	June	Daisy	Joy	Viol	John	Hope	VALID
A	PF	1	4	1	2	4	2	2	3	1	2	1	-	-	1	-	-	1	-	9
A	PF	2	4	1	2	4	2	2	3	2	3	1	-	-	1	-	-	1	-	9
A	PF	3	4	1	2	4	1	1	4	1	2	1	-	-	1	-	-	1	-	9
A	PF	4	4	1	2	4	1	2	3	1	2	1	-	-	1	-	-	1	-	9
A	PF	5	3	1	1	2	1	1	1	1	1	1	-	-	-	-	-	-	-	9
A+B	PF/RF	37	3	1	1	3	1	2	1	1	1	1	-	-	1	-	-	-	-	9
<hr/>																				
54																				
B	RF	6	4	1	2	4	3	2	3	1	3	1	-	-	1	1	-	1	-	9
B	RF	7	4	1	2	4	2	2	2	2	3	1	-	-	1	-	-	-	1	9
A+B	PF/RF	37	3	1	1	3	1	2	1	1	1	1	-	-	1	-	-	-	-	9
B+J+L	RF/SF	39	1	1	1	4	2	2	1	1	1	-	-	-	-	-	-	-	-	9
B	RF	44	-	1	2	4	3	-	2	1	1	-	-	1	1	-	-	-	-	7
<hr/>																				
43																				
C	DY	8	1	1	2	4	2	1	-	1	2	-	-	1	-	-	-	-	-	8
<hr/>																				
8																				
D	PA	9	4	1	2	3	2	1	4	1	3	1	-	-	1	-	-	1	-	9
D	PA	19	4	1	2	3	1	1	3	1	3	1	-	-	1	-	-	1	-	9
<hr/>																				
18																				
E	FA	10	4	1	2	4	2	2	3	1	3	1	-	-	1	-	-	1	-	9
E	FA	11	1	2	2	2	2	2	2	2	2	-	-	-	-	-	-	-	-	9
E	FA	12	3	1	2	3	2	2	2	1	2	1	-	-	1	-	-	-	-	9
E	FA	18	3	1	2	4	2	3	3	2	3	1	-	-	1	1	1	1	1	9
<hr/>																				
36																				
F	NV	13	2	1	2	4	2	2	2	1	2	-	-	1	-	-	-	-	-	9
F	NV	14	1	1	1	1	1	3	2	1	1	-	-	-	-	1	-	-	-	9
F	NV	15	1	1	1	1	1	1	1	1	1	-	-	-	-	-	-	-	-	9
F	NV	32	2	1	2	4	1	2	1	1	2	-	-	1	-	-	-	-	-	9
F	NV	33	1	1	1	1	1	1	1	1	2	-	-	-	-	-	-	-	-	9
<hr/>																				
45																				
G	EXC	16	2	1	3	2	1	1	2	1	1	-	-	1	-	-	-	-	-	9
G	EXC	17	1	1	1	1	1	2	1	1	2	-	-	-	-	-	-	-	-	9
G	EXC	31	1	1	1	1	1	2	1	1	2	-	-	-	-	-	-	-	-	9
<hr/>																				
27																				

Group		Quest	May	Faith	April	June	Daisy	Joy	Viol	John	Hope	May	Faith	April	June	Daisy	Joy	Viol	John	Hope	VALID
H	CF	20	2	1	1	2	2	2	2	1	2	-	-	-	-	-	-	-	-	-	9
H	CF	25	1	1	1	3	1	2	1	1	2	-	-	-	1	-	-	-	-	-	9
																					<u>18</u>
I	EF	21	2	1	2	2	4	2	2	1	2	-	-	-	-	1	-	-	-	-	9
I	EF	22	2	2	3	2	3	2	2	1	2	-	-	1	-	1	-	-	-	-	9
I	EF	23	2	1	2	2	3	2	2	1	2	-	-	-	-	1	-	-	-	-	9
I	EF	24	1	2	2	2	3	2	2	1	2	-	-	-	-	1	-	-	-	-	9
I+J+N	EF/SF	40	1	2	1	3	2	2	3	1	1	-	-	-	1	-	-	1	-	-	9
I	EF	41	1	2	1	2	2	2	3	1	1	-	-	-	-	-	-	1	-	-	9
																					<u>54</u>
J	SF	26	3	1	1	4	1	2	1	1	2	1	-	-	1	-	-	-	-	-	9
J	SF	27	3	1	2	3	2	2	1	1	2	1	-	-	1	-	-	-	-	-	9
B+J+L	RF/SF/CM	39	1	1	1	4	2	2	1	1	1	-	-	-	1	-	-	-	-	-	9
J	SF	38	1	1	1	1	1	1	1	1	1	-	-	-	-	-	-	-	-	-	9
I+J+N	EF/SF/EX	40	1	2	1	3	2	2	3	1	1	-	-	-	1	-	-	1	-	-	9
J	SF	42	-	1	-	4	-	-	-	-	1	-	-	-	1	-	-	-	-	-	3
																					<u>48</u>
K	FI	28	2	2	3	3	3	2	2	1	1	-	-	1	1	1	-	-	-	-	9
K	FI	43	1	2	3	4	2	2	2	1	1	-	-	1	1	-	-	-	-	-	9
																					<u>18</u>
L	CM	34	1	1	2	1	1	1	1	1	1	-	-	-	-	-	-	-	-	-	9
L	CM	35	1	1	1	4	1	1	1	1	1	-	-	-	1	-	-	-	-	-	9
B+J+L	RF/SF/CM	39	1	1	1	4	2	2	1	1	1	-	-	-	1	-	-	-	-	-	9
																					<u>27</u>
M	TRT	36	1	1	2	3	1	1	4	1	1	-	-	-	1	-	-	1	-	-	9
																					<u>9</u>
I+J+N	EF/SF/EX	40	1	2	1	3	2	2	3	1	1	-	-	-	1	-	-	1	-	-	9
N	EXI	45	1	1	1	1	1	2	1	1	1	-	-	-	-	-	-	-	-	-	9
N	EXI	46	2	2	4	4	3	3	3	1	1	-	-	1	1	1	1	1	-	-	9
																					<u>27</u>
Global	QL	29	3	6	5	4	5	4	4	6	3	1	-	-	1	-	1	1	-	1	9
Global	QL	30	3	6	6	4	5	4	5	6	3	1	-	-	1	-	1	-	-	1	9
																					<u>18</u>

IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Appendix 14 Toxicity Proforma The Southern

Continuation sheet/ Inter-chemotherapy assessment

For nursing staff		Ongoing evaluation sheet (sign and date each entry).
Test required	Done	Medicine staff
<input checked="" type="checkbox"/> Biochemistry	<input checked="" type="checkbox"/>	<p>Fit for chemo See with CT Scan prior to next cycle Chen</p>
<input checked="" type="checkbox"/> Haematology	<input checked="" type="checkbox"/>	
<input type="checkbox"/> Clotting	<input type="checkbox"/>	
<input type="checkbox"/> Tumour markers	<input type="checkbox"/>	
<input type="checkbox"/> PK sample and time	<input type="checkbox"/>	
<input type="checkbox"/> QoL	<input type="checkbox"/>	
<input type="checkbox"/> Diary	<input type="checkbox"/>	
<input type="checkbox"/> X-ray/scan	<input type="checkbox"/>	
<input type="checkbox"/> ECG	<input type="checkbox"/>	
<input type="checkbox"/> Urinalysis	<input type="checkbox"/>	
Cannulation record		
No of attempts <u>2</u>		
Cannulated by <u> </u>		
Site <u> </u>		
Comments <u> </u>		
<u> </u>		
<u> </u>		
Current medication over last 4 weeks		
<u> </u>		
Date of next visit: <u>01/03/2005</u>		

C:\Documents and Settings\shelley\My Documents\LANChemotherapy sheet.doc

Appendix 15 Interim Phase Field Notes Extracts

Field Notes:

Interim Phase

The Northern

10th May 2004

Have decided to start teaching and supervising the questionnaire as I'll never get this project done. It was quite quiet to start with this morning so I was able to introduce the plan at the end of the 'report meeting', and Myra seemed keen to be the first 'stooge'. Brenda disappeared into the office (she has discovered 'drug reps' and has a steady stream of them arriving at the moment to tell her all sorts of things). Then she went to the ward for a long time to see a patient about starting chemo – the one who was referred urgently last week, but who was delayed because the nurses were short staffed. She was off the ward all morning (her grand daughter was admitted to the paediatric ward last night, and I think she is very worried about her and probably tired too).

More sickness on the unit today – F and J away again. I ended up doing all sorts of extras like answering the phone, making patients tea, and actually, doing some obs on D who was clearly neutropenic (?septic) – very ill, with BP 90/60, p120, temp 39, and was left in a corner for 3 hours with no-one noticing her. I really was quite concerned. D was also very sick, so helped clear that up, emptying the vomit bowls, and assisting her to the toilet.

Myra and I tried ART out on our first patient, who had no high scores! Interesting as she is young 27, was diagnosed at 28 weeks pregnant and has a 12 week old baby, and has bone and lung mets at diagnosis. I wonder if she just didn't want to discuss or disclose anything – or maybe I am too pessimistic by nature and she really didn't have any concerns at all!

Question for me to think about: Myra's listening skills are quite poor – little eye contact and she spent most of the time reading the questionnaire – should I correct this/feedback this observation? On reflection have decided to wait and see if this improves as she gains confidence with the questionnaire and is more familiar with it. Then I will ponder on this again.

Two patients said they were willing but had forgotten their glasses – this will be a problem if it is to be introduced routinely!

Myra only dealt with 3 patients today. I asked her what she thought and she said ART seemed OK.

11th May

Asked a patient if she would like to complete the questionnaire- S suggested this one. New patient - advanced head and neck cancer. 1st treatment - has been resisting chemo, and now she has very extensive neck node involvement - huge mass in her neck and face. Interestingly, she declined - felt too ill (she looked very poorly) - this has implications for introducing it - if patients feel too ill to complete it. This lady said she hadn't the energy. I was intrigued that no-one tried to find out *anything* from her at all before giving her the chemo - they just cannulated her and put up the infusion - very kindly - and left her to sleep. No questions were asked AT ALL. Nothing along the lines of support, palliative care, symptoms, nothing. I was shocked and still am. Didn't know whether to intervene or not. Her daughter was very tearful (it turns out she is a recovering drug addict - about 20 years old) sitting quietly by her side. Came to ask me if she could give her mother a pain killer (co-dydramol - brought in from home)- I checked with S, who had to make several phone calls to The Southern to check - seemed odd not to be able to say 'yes' as they were already prescribed. Another role issue - which didn't sit very comfortably with me. I am concerned in case this lady's tumour erodes a major blood vessel - didn't know whether I should voice that concern to anyone. I asked S and Myra if they thought patient was supported - they didn't know so I saw in the notes the head and neck nurse and hospice team were involved. She seemed so ill to me. The nurses were pleased that they had managed to get her treatment in without any waiting around, she was able to leave by 11.30. This for them was the key outcome - I feel it was important but it wouldn't have been my only priority. Am I too idealistic? But I must remember that this is not my area, and to avoid judging. Actually, knowing this appointment system is important here. good insight.

2 more patients declined to fill in the questionnaire - one patient said he didn't want to criticise the nurses (I reassured him this wasn't the aim) and the other said they weren't interested.

Another had forgotten her glasses! I feel so hopeless and discouraged and uncomfortable.

Finally, this afternoon a man agreed to fill one in, and it was very interesting. He was having his last 5FU - 24 weeks - and we identified he had appetite problems, and dreadful fatigue which he is very distressed by. Myra was at a loss to know what to say, so I stepped in and acknowledged the fatigue problem and tried to explore that a bit with him, looking at ways to achieve what he wanted to and giving permission not to do everything he would have done. I find fatigue a difficult one. I also suggested some food alternatives (snacks, drinks, the usual) and suggested we get some info from the information centre, which I did at the end of his treatment as Myra went off to do something else. I went through suggestions for eating and he seemed really pleased - said it was the first time anyone had asked him about this and he hadn't known it was normal. Mind you, as he said, he hoped his appetite would soon recover, and that he would feel less tired.

It was difficult getting the information out of the information lady - she keeps everything hidden away and photocopied me 2 sheets, when I know another one exists. She couldn't show the fatigue video as it is out on loan - I'm not sure the patient would have wanted to see it - perhaps this could be available to show on the TV/video player that is constantly on in the unit?

Spoke to Myra and explained what I had done and suggested. I think she is learning new stuff about symptom management.

Implications, implications!

12th May

Better success today. Was beginning to despair and lose my nerve! Am not sure ART is going to work in the unit – so much potentially will be uncovered, and am beginning to see what I am asking these nurses to do, but realise they have not the skills or knowledge to deal with it. Feel glad I didn't try a formal teaching programme – it would have been wrong to assume what to provide.

A sweet little 70 year old lady completed the questionnaire with me this morning, and Myra and I went through it together. (Pt is having weekly 5FU for Ca bowel – course 9 today). Myra is getting better at asking the follow up questions, although she is still not listening very well– her non-verbals are not positive – she was reading the questionnaire while the patient talked and didn't seem to be responding. I had to tell her what to fill in – she finds the responses difficult to summarise and the format confusing as the ART C is grouped into categories not question numbers – can I change this?.

This lady had dozens of issues: sore mouth (which she said she had had for 3 weeks); palmar plantar (I think that's how it's spelt – I am losing touch with non-breast ca. symptoms) (quite severe); depression (GP has prescribed Prozac), panic attacks, irritable with her husband – doesn't mean to be and doesn't want to be; severe fatigue (can't go out, won't go out – perhaps the depression exacerbating this); poor appetite; sexual issues; can't talk to her husband, daughter in USA; angina; gritty eyes which water – stops her from doing her knitting, which she is really upset about – loads of problems. The assessment took over 30 minutes and Brenda was really agitated as the work was building up. I also felt really stressed and Myra was tiring. Lots to acknowledge and try to sort. Went through the dietary stuff again, and fatigue; I wanted to offer/suggest counselling and complementary therapy- but no service available (implication); information lady even more limited this time – I can see a role for her coming into the unit to discuss in person with the patients. I asked for helpful hints on fatigue [network one] and she said her's was better – I didn't give it to the patient as it was on anaemia and blood counts. (I've kept it). Perhaps we should have thought about Hb, though, and it was interesting that the patient later said her GP was doing repeat TFTs on her as some last month (when antidepressants had been prescribed) were abnormal.

Myra called the doctor who came and gave her a prescription for her hands and eyes.

As she left, the patient apologised for having so many problems, and said it had been so nice to be able to talk – the first time she had talked and shared her worries since Christmas (diagnosis). She went out repeating to her husband how lovely it had been - despite, I think the fact that she was in the unit for 2 hours instead of 30 mins (had to wait a long time for the doctor to write a prescription). Her husband then rushed back into the waiting area where I was talking to the volunteers, as I watched Mrs H go down the corridor, and he thanked me for showing such an interest. How sweet.

Implications – service gaps; symptom knowledge; time taken; privacy (I felt embarrassed addressing her sexual issues in the unit, although I asked her if she wanted to talk about that in private, and she said no, the man next to her was, I think uncomfortable); doctors are not in unit - having to ask haematologists to come over and prescribe for oncology patients.

Unit quite busy today – 2 people still off sick and a poorly lady was wheeled down from the ward (this was the patient Brenda had been so long with on Monday trying to give chemo to but had failed as the lady had been too oedematous – had to have a femoral line put in on Tuesday, so treatment today). I was horrified. She had severe SVCO – she was blue, with a stridor, on continuous oxygen, sats were 67%, very frail – and they were going to treat her in a chair! Anyway, with a bit of a prompt from me re better in bed and a reminder about the femoral line, she was put in bed. I really didn't think she was well enough, but the nurses said she had been delayed for 10 days already. Half way through, the daughter came to ask if her mum could have some morphine as it was overdue. The bank HCA didn't know what to do, and gave a half-hearted reply, so the daughter turned to me and repeated the question. I had to step in to help this poor lady, so I asked S to phone the ward and eventually (well it felt like slow progress, but perhaps 15 minutes or so later) S went up to collect some morphine. I have been answering the phone etc today again, as they are short staffed and think I am beginning to merge the roles a bit too much sometimes – teaching with ART has increased my confidence and street cred' among the staff, and I feel more able to make suggestions – I must watch this

14th May

F back from sick leave today (actually she was in my lecture yesterday) so the unit slightly better staffed. The nurses spent lots of time this morning after the report looking through the Avon catalogue, which I found irritating – I wanted to talk about ART'

Sad news came through just as the first patient was coming in for cannulation – which was that the lady with SVCO treated on Wednesday had died in the night. I'm not surprised, but it's very sad.

I asked Brenda if she would be willing to try ART today, as on Monday the new sister starts, and I feel pressure to have introduced it to more than Myra before then. Brenda said yes. She suggested we tried her first patient of the morning, a man in his 50s who was having APD (for myeloma). I have to say that when I asked him, something was not quite right – but he said he was willing, so I left him the questionnaire and he filled it in very slowly. Brenda and I approached him after about 5 minutes, and he was crying quietly. Brenda quickly leant over him and asked 'what's wrong?'. He said he had been upset by some of the questions, he was not willing to discuss the answers to the questions about his family ('worries and concerns about those important to you', and 'intimate relationships') as these had upset him. He really began to break down. There was this horrified silence on the unit, everyone looked at me as if I had caused a dreadful thing – it was awful, and I felt so bad.

Brenda hurriedly took the questionnaire away, and said 'no, no, we won't do any of it, if it's upsetting you. Leave it. Leave it, it doesn't matter at all', and she asked him if he would like a drink. He wanted a glass of water, which she brought. He did seem rather cold towards me – I felt awful. I touched his arm (for comfort – for me perhaps more than him'), and he said he was 'fine'. Brenda stood up from bending over to put the water on the table and asked if she could speak to me in the office. I excused myself. In the office she said (angrily) 'That was awful. Just awful'. She then started to beg me to find a different questionnaire that 'wouldn't upset the patients' – and started to look through some files for the toxicity scales and performance status tables that are used in clinical trials sheets. I said I was very sorry about the man being upset, and what did she think it was. She said she didn't know but wondered if his wife had died recently. I apologised to her for the problem, and she said it wasn't my fault – she hadn't expected him to react like that, and now she was very worried about doing this research – 'we can't have the patients upset like that', and please could we not use ART with its personal questions – especially not the sexuality questions for patients who were elderly, she just felt that they were too personal and inappropriate.

I didn't say anything for a while. Initially, I felt the same as her and then I realised that I didn't own ART and that what I was trying to do was find out the impact of introducing it – and here was an impact which I hadn't foreseen, even though I have found patients upset discussing issues on it before – but that I had sat with and listened and talked through these things – and that's what we hadn't done in this case. Why? Was it fear of what we might uncover? Did Brenda lack the skills to 'go there'? Was it the culture and context of the unit that prohibited discussion of these issues?

So, I suggested that perhaps, next time, I could explain to patients that they don't have to answer anything they don't want to, or discuss anything they would rather not, and she was happier with this (?participation or power CJW!!).

When we came out of the office, S went straight to the patient and adjusted the speed of his infusion, and as she looked at the speed of the drip said 'are you all right now?' to which he replied 'yeah, fine'.

I felt the need to 'close' the incident, but didn't know how. I decided to wait a while, and was thinking about it all and writing a few notes as everyone else was busy cannulating and giving chemo, and I was the only one at the desk. Then after about 20 minutes, it just felt right to go to him to ask him if he wanted a drink. He asked for a cup of tea, which I went and made. As I put it down, I apologised if the questionnaire had caused him distress. I didn't sit down, but stood stooping, slightly to one side of him. I felt that to sit down would be intrusive and inappropriate so I stood up (what would Susie Wilkinson have made of that?!) He said it was OK; he had been to [Major City Hospital] the day before and had had bad news re his myeloma, and he just felt vulnerable and worried about the future. And he hadn't got over his wife – 'I suppose I just have to get over it, but it's hard' – I looked quizzically at him – I had no idea what he meant, and he said she was in a nursing home with Alzheimer's because he couldn't care for her. I said how I was sure it wasn't something he would necessarily 'get over', and how difficult for him, and how sorry I was. He said it was 'OK'. At that point the consultant came in to talk to him, and I moved away. I noticed he had a leg bag and was catheterised – the consultant later told me he has been on the waiting list for 9 months waiting for a TURP and has recently been prescribed anti-depressants, and that the news yesterday had been particularly bad – his transplant has to be postponed and he has to have radical therapy to control his disease first, and that she was pessimistic for him. Clearly the nurses have no idea what is going on for this poor man.

I have thought a lot about this incident since, and realise that this is the first time in 8 months that I have seen anyone upset on the unit, which raises questions for me about management of distress and acceptability of tears.

Also, the privacy issue – if this man was in the interview/counselling room, would it have been easier to 'manage/cope with/accept his distress? Was it that it was a public place?

I really don't think the nurses can cope with distress – it was abhorrent to them – the atmosphere and shock was terrible for about 15 minutes after the initial incident. Even the patients were shocked I think. It was almost odd atmosphere.

Brenda said she is very 'scared' and 'reluctant' to 'upset the patients' through ART.

I thought her follow-up to him of the standard 'are you all right' which I hear 25 times a day was very interesting.

And the thought that toxicity information would give the nurses the useful information without 'upsetting the patients' is an interesting thing too: do they think that these non-chemo issues are not of interest? Perhaps not for them. Is it just me, or is this important? It will be interesting to see what the patients say about this when phase 2 is up and running, since none of them in phase 1 thought the nurses needed to know anything other than which vein to use. (Well apart from Mrs E but that was after her husband had developed more symptoms).

Later Myra and I did another ART together on a young woman (well she's my age but looks 20) on her 2nd course of EC. She had one concern which I was able to help Myra tackle better (nausea – Myra was going to ignore again – I find she does that – asks and then doesn't follow through with suggestions or hints or anything) and a question over dexamethasone – Myra clearly doesn't understand that, so I explained it to the patient with Myra listening, as a 3-some I think Myra quite likes having me there – she seems more confident and outgoing – perhaps she knows I'm not tape recording her!

Afterwards, Myra was so pleased, and said how much she likes using ART, and how good it is. She was really enthusiastic. I decided to strike while the iron was hot, and ask her to do the feedback interview about Amar – she agreed! I had to wait hours, though, as Brenda was off with some more drug reps and visiting her grand-daughter, who is still in the paediatric ward. Anyway, have finally completed Phase 1 of the data collection – albeit if the final follow-up interview was limited by the time scale between the assessment and the feedback. I think I got some insight into the encounter.

Field Notes:

Interim Phase

The Southern

March 2nd 2005

Clearly, there is an issue of knowledge – nurses don't know what to assess – can't pick up cues if don't know significance of what hearing. Eg bladder, sleep; ?disease progression issues – patients mention them and then the nurse has to decide if important. Much of this decision seems to be related to whether the nurse knows what to suggest; confidence in knowledge and whether she has met the problem before and knows what to advise

Nurse A [Penny] spoke about confusion between role of assessor and role of advisor (in relation to AZ [Grace] and diarrhoea management) – what is the organisation's expectations for the nurse in chemo unit with regard to advising patients – some anxiety on Penny's part that she was stepping on doctor's toes.

Role of the chemo nurse from organisation's point of view is that of technician – not nurse-led; doctors see all patients and little autonomy for the nurses.

Questionnaire makes people listen and hear things they don't want to – raises anxiety.

Highlights gaps in knowledge; how to decide whether something is important or not; whether something is a need or not.

Eg the urine and sleep issue: how to deal with that -nurse not experienced to know what to advise; where to send patient.

Sexual issue came up – nurse very nervous about that.

Nurse expressing anxiety when handed the questionnaire – not sure what going to be asked or say.

Need:

- Signposting tool
- Preparation – communication skills: listening to distressing information – how to cope; personal cost
- Acknowledgement is OK, not all issues require intervention
- Education on symptoms
- Where to send people and how to advise
- Supervision
- Change in appointment system

Notes from first patient:

Charge nurse came up and asked us to leave the room – taking too long; blocking a chair – interrupted – saw significance of chemo more than assessment practice – that's OK

He was irritable – saw assessment as detracting from the work of the department

Nurse's reaction:

I was surprised I had not thought she would react like that. Feelings of incompetence, anxiety made her very tearful.

She said she was 'shocked' at how the questionnaire made her feel. Had not met these issues before, like breathlessness, and sleep problems – didn't know what to say, and what to do. Powerlessness – no control over what is being talked about.

She said she felt silly asking patient about those questions, thought it should be left to intuition and felt the questionnaire made her role more of a 'griller' than a professional nurse - and then she couldn't deal with the questions which raise huge feelings of insecurity. Takes her professionalism seriously; thought she was a good nurse, giving good care and high standards, and now thinking that this isn't the case. She said this is all very distressing.

She asked 'What is the value of this information' – it was not giving her any of the 'toxicity stuff' – so will need to ask that too and fill in the other form – time consuming. For me it all feels dreadful.

Preparation required in terms of symptom management for sure.

Nurse's comments: 'I was shocked', the questionnaire is shocking. Asked me to accompany her to the office where she burst into tears, and sobbed 'I can't hear those things'.

My feeling was that the patient raised very few difficult issues – interesting in my lack of perception here about how much the nurses hide and the patients hide. The nurse gave no hint that she was struggling at all. She admits that disease knowledge weak as well as symptom knowledge.

Thought that using the questionnaire meant she observed the patient less, concentrating on the paperwork and not looking at the patient, and also not looking for physical things so much – eg dry mouth (even though this is asked on the questionnaire) – seems that if the patient leads on these issues, the nurse doesn't feel as though she knows about it.

Powerlessness about not being able to help – acknowledging that it's OK to hear these things and not have to do something about them – need help with that.

Second patient:

Fewer issues so the nurse felt less anxious, but still found it hard, especially when the patient talked about sleep disturbance caused by going to the loo all night (?hormone bladder syndrome). Felt very inadequate and unsure of herself and raised uncomfortable feelings. Said it was better than yesterday because there were fewer issues, but felt very anxious all the time. To me, this indicates that my findings from The Northern, that assessment of toxicity was to confirm coping with treatment, not to look for problems, and not to intervene, and not to identify patient needs.

Clearly indicates that patients accept a lot of discomfort and disruption as normal.

Second patient raised sexual issues in a roundabout way at the end, she had given it a '0', but asked why it was there, and then with a catch in her voice began to talk about how she and her husband have withdrawn for each other since her mastectomy. We didn't really pursue this – wasn't sure whether she was asking for this or not; again, role confusion here.

Nurse A spoke afterwards and said she found that hard – wouldn't know where to start talking about this; had never done so, and wouldn't know where to send people for help.

Am thinking more and more about the need to develop a signposting tool for the assessment process. Think it is highlighting to A that assessment is more than ringing boxes and sending patients to the doctor.

4th April

SR (Kim) did a second assessment. Patient had scored high for pain (turned out to be secondary to Taxol) – but she never explored this at all; just 'hmed' and 'mmed', and then moved on. Unit very busy and short of staff; but I am left with the question, how can a nurse assess and not want to find out more? Was Kim just going through the motions for me, or was it a subconscious or unspoken thing to move the questionnaire along; she was quite neutral about it, and didn't find it valuable. Interestingly, although the questionnaire only picked up scores of 3 or 4, when asked in the toxicity questions, the patient raised sore mouth issues and bladder problems which she had given a score of 2 for. She looked like she had thrush to me – should I have intervened in this? Kim did not look in her mouth or make any attempt to do so; the doctor didn't either so it wasn't dealt with.

I noticed a patient sitting in the chair having chemo trying to bite back tears; struggling to contain emotion. Nurses busy with other patients and ignoring her struggle. Interesting. Again, do I bring this to their attention or leave it? Chose to leave it as she was about to finish (short infusion) and nurse didn't address it with her when she took bag down, but I'm not so comfortable about it.

Radio playing again – very loud; nurses waiting behind the screen in the preparation area. FG [Sue] off sick once more.

6th April

Had a quick chat in the unit waiting for patient to do an interview, and Nurse is struggling with essay on how to be therapeutic – this is a theme that has run and run with several nurses in the unit – writing an essay on this topic and not feeling it relevant, not seeing how they are therapeutic. Makes me wonder if we aren't manufacturing something unreal for them.

Nurses still looking for new jobs; don't feel they have one to get their teeth into; bored and finding it a drudgery.

IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Appendix 16 Patients' Professional Support

Phase 1				
Patient	Age	Diagnosis and site of metastases	ECOG score	Professional support available/accessed
Clive Died	80	Prostate Bone; abdominal and inguinal lymph nodes	3	Macmillan nurse (loose contact) District nurse: fortnightly
Charlie Died*	73	NHL relapsed	2	None
Amar Died*	44	Lung (advanced) Bone; skin	2	Macmillan nurse (regular contact)
Doreen Died*	53	Breast Bone; SCF nodes; ?lung	1	None
Edwina	53	Breast Bone; SCF nodes	1	District nurse (three- weekly visits to give injection)
Frances	50	Breast Contra-lateral breast; auxiliary nodes	1	Macmillan nurse (pt. had telephone number but had not met her)
George Died*	70	Lung	3	None
Hazel	58	Breast Mediastinal & auxiliary nodes	1	Macmillan nurse (loose contact)
Lesley	58	Breast Bone; liver	2	Macmillan nurse (loose contact)
Jim Died*	52	Lung Bone; adrenal glands; lymph nodes; skin	3	None

Patients who are marked as 'died' were known to have died by the end of 2004. Those patients who died within three months of the end of data collection are marked with an asterix

NB: Amar, Jim, and George all died within 6 weeks of the follow-up interview

The Northern - Phase 1

Phase 2				
Patient	Age	Diagnosis and site of metastases	ECOG score	Professional support available/accessed
Felicity Died*	55	Lung (advanced) Pleural effusion	2	Distict nurse, Macmillan nurse (regular contact)
Patricia Died*	50	Lung ?brain	3	Macmillan nurse (regular contact); District nurse
Diane Died*	40	Breast Liver, bone	2	None
Rose Died*	65	Stomach Local advanced spread	4	Macmillan nurse (loose contact); District nurse
Muriel Died	82	Myeloma (relapsed)	3	Macmillan nurse (regular contact). Day Hospice
Pauline Died*	46	?Head of pancreas	2	None
Emily	79	Breast SCF nodes, gross lymphoedma of arm	2	None
Amar Died*	44	Lung (progressive disease despite treatment) Bone; Skin	2	Macmillan nurse (Monthly contact)
Julia Died	60	Breast Bone; liver	2	Macmillan nurse (but no contact for 3 months as nurse on sick-leave)
Elizabeth Died*	53	Sacral tumour Muscle, liver	3	Macmillan nurse (Fortnightly) Distict nurse (daily) Carer (Twice daily)

Patients who are marked as 'died' were known to have died by the end of 2004. Those patients who died within three months of the end of data collection are marked with an asterix

NB: Felicity and Elizabeth died within 6 weeks of the follow-up interview

The Northern - Phase 2

Phase 1				
Patient	Age	Diagnosis and site of metastases	ECOG score	Professional support available/accessed
Barbara	57	Breast Skin; auxiliary lymph nodes	1	None
Patrick Died	59	Head of pancreas	3	None
Desmond	68	Bowel Abdominal lymph nodes	1	None
Dave Died	55	Bowel Sacral secondary	2	None
Edward* Died	82	Prostate Bone; lymph nodes (lymphoedema leg)	2	None
Grace* Died	68	Recurrent malignant melanoma	2	Macmillan nurse (loose contact – SOS by telephone if necessary)
Harriet	73	Breast Liver; bone	2	None
Ian* Died	49	Lung	2	None
Joanna	34	Breast Lung	2	None

Patients who were known to have died by the end of 2005 are labeled as 'died'. Those who died within three months of the follow-up interviews are marked with an asterisk.

NB: Edward and Charlie died within 6 weeks of the follow-up interview

The Southern - Phase 1

Phase 2				
Patient	Age	Diagnosis and site of metastases	ECOG score	Professional support available/accessed
April* Died	59	Lung	2	None
May	33	Breast Lung	2	None
June* Died	50	Breast Lung	4	Macmillan nurse (regular fortnightly contact); District nurse weekly
Joy	57	Ovary	2	Home care nurse from hospice visited monthly
Violet* Died	69	Ovary	3	None
Daisy	45	Breast Lung; ?liver	2	Macmillan nurse (support for husband)
Hope	38	Breast Lung; pleural effusion	3	None
John	69	Prostate	2	None
Faith* Died	48	Breast Bone; lung	2	None

Patients who were known to have died by the end of 2005 are labeled as 'died'. Those who died within three months of the follow-up interviews are marked with an asterix.

The Southern - Phase 2

Appendix 17 Theory of Planned Behaviour

Theory of Planned Behaviour



IMAGING SERVICES NORTH

Boston Spa, Wetherby

West Yorkshire, LS23 7BQ

www.bl.uk

BLANK PAGE IN ORIGINAL

Appendix 18 Nurse Information

INFORMATION FOR NURSES ABOUT A RESEARCH STUDY

Title:

A study to explore and evaluate the impact of introducing an assessment tool to structure nurses' assessment of patients' needs in the outpatient chemotherapy department.

Researcher:

Cathy Wilson MSc, BSc (Hons), RGN, Oncology Nursing Certificate, Diploma in Palliative Care
Nurse Researcher, [...]Hospital, and Honorary Nurse Researcher, [...] Hospital.

Introduction:

You are being invited to take part in a research study. Before you decide, it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your colleagues if you wish. Please ask if there is anything which is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Background:

In order to care for patients, nurses routinely ask questions and make judgements during conversations in order to assess patients' needs. Much of the research to date has indicated that cancer nurses are not very accurate when identifying patients' concerns, although this research has been carried out using quite restrictive methods, which have not enabled the nurses being studied to explain their practice. Nor have patients' perspectives been sought. The proposed study intends to involve you in the analysis of the data, and enable you to interpret your own assessments of patients.

Recently, NICE recommended that assessments of palliative cancer patients be structured using an assessment tool. The implications of this, from an organisational point of view need to be explored before such a change in practice is introduced across the cancer network. In addition, it is important to find out what nurses working in busy clinical areas think of structured assessment, and what effect this has on your work load, use of time, stress, and communications with patients and colleagues. This study will explore these issues with you.

What is the purpose of the study?

The purpose of the study is to explore nurses' assessments of patients with incurable cancer who are receiving outpatient palliative chemotherapy, and to evaluate the impact of introducing an assessment tool to structure assessments. The study is in three stages. There are two phases of data collection, with a period of training in between.

The aim of the first phase of data collection is to obtain insight and understandings of nurses' current assessment practice, by involving you and your patients in the interpretation of assessment meetings. This will be baseline information, so that any changes in practice arising from the introduction of the tool can be identified.

In the second phase of data collection, an assessment tool will be introduced into practice following some training and support. In this phase, the study is looking particularly at the effect of structured assessment on your perceptions of your work, on your understanding of patients' needs, and the organisational issues arising from the introduction of a tool. In addition, the study is trying to identify what kind of preparation might be required in other units to support a similar change in practice across the network, so the study is looking to obtain information about what kind of training is needed, and whether on-going support is necessary or desired.

Do I have to take part?

No. You are under no obligation to take part. It is up to you to decide whether or not to participate in this research. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your job or role in the department.

What is involved?

The study has three stages, and you will be involved in all three. Stage 1 is concerned with exploring current practice. Stage 2 is an interim phase during which I will teach you how to use the assessment tool. After this, Stage 3 will commence, and you will use the tool to assess patients before they receive their chemotherapy. In all other ways, you will continue to work as normal.

Not all the patients you care for will be involved in the study: only those who are eligible and consent to participating will be entered into the research. Eligible patients are those who are receiving palliative chemotherapy.

Stage 1

You will continue to care for patients and assess them as usual. When a patient participant arrives you will be asked to sign a consent form to agree to the tape recording of the conversations you have with that patient on that day only.

The conversations you have with the patient, and the administration of the chemotherapy will be observed by me. *I will not be judging your work, or the standard of your care.* I will be watching the non-verbal signals, and trying to understand how patients and nurses talk to each other.

At the end of the treatment, you will be asked if the tape recording may be used. We will then discuss your perceptions of the patient, the decisions and conclusions you reached about him/her, and whether you feel you need to take any action as a result of the assessment you carried out. This is because nurses work intuitively, and, this hidden knowledge can go unrecognised. This research wants to acknowledge such expertise, by helping you to make it explicit.

Approximately one week after the assessment, I will give you a transcript of the taped nurse-patient assessment meeting for you to read. Two days or so later (when convenient), we will meet to discuss the assessment. I may play sections of the tape to you, and ask you to tell me what you were thinking and feeling at the time, and what you understood by what the patient was saying. With your permission, this interview will also be tape recorded. This interview may take 30 minutes.

I will not be judging your work or set out to be critical. I am hoping that this research will be collaborative. Your involvement is crucial to the understandings and conclusions generated from the data. I will give you a copy of the transcript of this interview, and a summary of our discussion. The interview, the assessment tapes, transcripts and summary sheets are confidential, and will be shared only with you.

Stage 2:

The assessment tool (ART) will be introduced to you individually, and I will teach you how to use it. There will be opportunity to practise using it and I will support you, before Stage 3 of the study commences.

Stage 3:

The research aims are similar to Stage 1, except in Stage 3, the patients who consent to participate will be given a quality of life questionnaire (ART-A) to complete whilst they are in the waiting area before they come into the treatment room to be given their chemotherapy.

When they are called through to have their treatment, you will carry out an assessment based on their responses on the questionnaire, and you will complete your part of the assessment tool.

I will be observing this interaction, and the conversations that take place during the administration of the chemotherapy. As in stage 1, *my role is not to judge or criticise*, but to try and understand how the tool is helping or hindering you in your work.

As in Stage 1, I will ask you to share with me your thinking and the conclusions you reached about the patient. This conversation, with your permission, will be tape recorded.

The taped nurse-patient assessment meeting will be transcribed, and a copy given to you at least 2 days before we meet to discuss the assessment. This interview will follow a similar format to that of Stage 1, and with your consent will be tape recorded. A transcript of this interview and a summary of the discussion will be given to you, in confidence, for your information.

The flow-chart at the end of this information letter illustrates the design of the study and what is involved if you decide to take part in the research. There is no obligation to participate in the study.

The data collection process is expected to take no more than six months, although you will not be involved all the time. You will be asked to be involved for 2-3 patients in Stage 1, the training programme, and for 2-3 patients in Stage 3.

What do I have to do?

This study is exploring nurses' practice in its every day setting. To take part in the first part of the research, you will not need to do anything unusual or different from your normal work. The only difference the research makes is that your practice will be observed, and your conversations with two patients will be listened to, and tape recorded by the researcher. This is not to judge the quality

of your care, but to try and understand more about what you do in your day-to-day work.

The extra things which result from taking part in the study are to help interpret the conversations you have with patients, by listening to the tape recordings of your interactions with 2 patients, and sharing your thoughts and opinions about these with the researcher.

There will be a need to be trained in the use of the assessment tool. You will have the opportunity to practise using the tool before data collection recommences in Satge 3.

Following the training, Stage 3 of the study will commence. Patients will complete a questionnaire whilst waiting for their treatment, and you will use their answers and a printed check list to guide your assessment of them. Afterwards, you will be asked to reflect in private with the researcher on this method of assessment and what you discussed with the patient. This interview will be confidential, and will involve listening to and interpreting some of the tape recorded interactions which took place during your assessment of the patient.

Will my participation in the study be confidential?

Yes. All information about you, your work and our interviews will be kept in the strictest confidence. The tapes and transcripts may be listened to and looked at by my university supervisors, to check that the study is being carried out properly, and to guide me in my studies. However, the tapes and records will be anonymous, so that it will not be possible to identify you or the patients.

Who is organising and funding the research?

The study is organised by the [...] Team at [...] Hospital, [...]. My salary is being funded by Dr E.J. Maher, Consultant Oncologist at [...] Hospital and Medical Director of [...]. My university fees are being funded by a scholarship from The Florence Nightingale Foundation. However, there is no sponsor of the research study, and no conflict of interests. You will not be paid for taking part in this research.

The research forms part of my studies for a PhD in nursing, and is being supervised by Professor R.M. Bryar and Dr. A. Lanceley at St. Bartholomew School of Nursing and Midwifery, City University, London.

What will happen to the results of the research study?

It will take approximately a year to collect the information, and analyse the results. However, in the interim, you will be offered copies of the transcribed tape recordings, and a summary of the interviews you have with me. The results will be circulated within the cancer network to help develop nurses' practice, as well as being published in journals. It will not be possible to identify the research participants from the reports. I should like to write a paper in collaboration with you, regarding the findings of the research and the process of conducting it. You would be a co-author.

The findings from the research will be used by me to write my PhD thesis. The date for completion of this is autumn 2005. The research and the findings will be presented to colleagues and peers at conferences and used to teach students and nurses.

Who has reviewed the study?

The Local Research Ethics Committee for [...] NHS Trust has approved this study. This is an independent group of people with responsibility for advising on whether NHS research complies with recognised ethical standards.

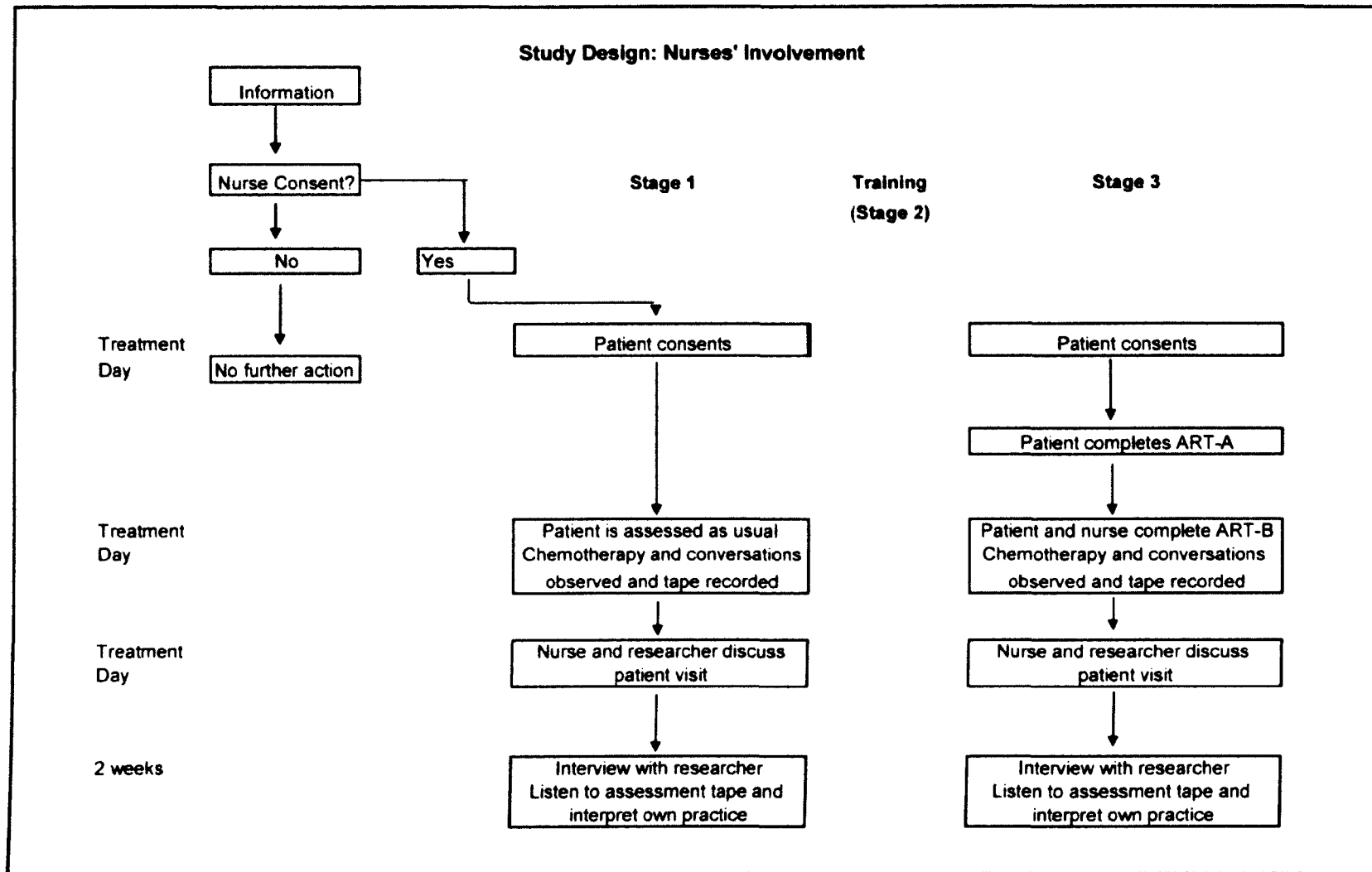
The University Ethics Committee has also reviewed this research, to ensure it meets with their standards.

Contact for further information:

If you have any questions or concerns about this study, please contact me in the chemotherapy unit, or by email: [...] or telephone: [...] (home) or at [work]: [...].

Thank you.

Cathy Wilson
Nurse Researcher



Appendix 19 Nurse Invitation Letter

Date

Dear

I am writing to ask you if you would consider taking part in my research study to explore nurses' assessment practice, and to identify the impact of using quality of life questionnaire to structure assessments of patients receiving palliative chemotherapy.

As you know, I am hoping that this study will be a collaborative project with you all, with the aim of developing a greater understanding of nurses' assessment practice in the outpatient chemotherapy department, as well as identifying the necessary preparatory steps which will be required if the Network is to implement the NICE guidance on the use of assessment tools.

I enclose a booklet which explains the study in detail, and sets out what will be required from you. You are under no obligation to participate. However, I hope that you will feel able to do so – your opinion and feed back about the question of using an assessment tool in your practice would be valuable. I know this research might seem threatening or daunting, but please be reassured that it will not be a critical analysis of your work. Rather, it is 'real world' research, rooted in the busy day-to-day life of the department. Moreover, you will have the opportunity to explain (in confidence) what you were thinking and feeling when talking with the patients or using the questionnaire, so no-one will be judging your work or your skills.

Please read the enclosed leaflet, and make your decision as you wish. If you would like to talk it over, or ask anything, please feel free to speak to me during the day either at [...] or at [...] (telephone number at the top of the letter) or ring me at home in the evenings (number).

Many thanks,

Cathy Wilson

IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Appendix 20 Consent Forms

PATIENT CONSENT FORM

Title of Project:

A research study to explore nurses' assessments of patients in the outpatient chemotherapy department

Name of Researcher:

Cathy Wilson MSc, BSc(Hons), RGN, Oncology Nursing Certificate, Diploma in Palliative Care
Nurse Researcher, [...] Hospital

Please initial box

1. I confirm that I have read and understand the information sheet dated
(version) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time,
without giving any reason, without my medical care or legal rights being affected.

3. I understand that sections of any of my medical notes may be looked at by responsible
individuals from St Bartholomew School of Nursing and Midwifery, City University, London
or from regulatory authorities where it is relevant to my taking part in research.
I give permission for these individuals to have access to my records.

4. I agree to the tape recording of my conversations with the nurse whilst I am attending
the chemotherapy unit today.

5. I agree to take part in the above study.

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

Patient Identification Number for this study:

SDS0210M

P.I.S. (February 2001)

After the tape recording:

I agree to the use of this tape for the purposes of the research as they have been explained to me.

I understand that the tape will be stored in a locked cupboard in accordance with the Data Protection Act for up to two years, and that my name will not appear on any transcript made from it.

I understand that the tape may be listened to by Cathy Wilson's academic supervisors at City University.

I will be offered a copy of the transcript of the tape for my records.

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

Patient Identification Number for this study:

SDS0210M

P.I.S. (February 2001)

PATIENT CONSENT FORM

TAPE RECORDING OF INTERVIEWS

Title of Project:

A research study to explore nurses' assessments of patients in the outpatient chemotherapy department

Name of Researcher:

Cathy Wilson MSc, BSc(Hons), RGN, Oncology Nursing Certificate, Diploma in Palliative Care Nurse Researcher, [...] Hospital; Honorary Nurse Researcher, [...] Hospital

Please initial box

1. I confirm that I have read and understand the information sheet dated
(version) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time,
without giving any reason, without my medical care or legal rights being affected.

3. I agree to the tape recording of my interview with Cathy Wilson
today.

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

Patient Identification Number for this study:

SDS0210M

P.I.S. (February 2001)

After the tape recording:

I agree to the use of this tape for the purposes of the research as they have been explained to me.

I understand that the tape will be stored in a locked cupboard in accordance with the Data Protection Act for up to two years, and that my name will not appear on any transcript made from it.

I understand that the tape may be listened to by Cathy Wilson's academic supervisors at City University.

I will be offered a copy of the transcript of the tape for my records

_____ Name of Patient	_____ Date	_____ Signature
_____ Name of Person taking consent (if different from researcher)	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

Patient Identification Number for this study:

SDS0210M P I S. (February 2001)

CONSENT FORM (Nurse)

Title of Project:

A research study to explore nurses' assessments of patients in the outpatient chemotherapy department

Name of Researcher:

Cathy Wilson MSc, BSc(Hons), RGN, Oncology Nursing Certificate, Diploma in Palliative Care
Nurse Researcher, [...] Hospital; Honorary Nurse Researcher, [...] Hospital

Please initial box

1. I confirm that I have read and understand the information sheet dated
(version) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time,
without giving any reason, without my professional or legal rights being affected.
3. I agree to the tape recording of my conversations with the patient (name).....
whilst administering chemotherapy to him/her today.
5. I agree to take part in the above study.

Name of Nurse

Date

Signature

Researcher

Date

Signature

Nurse Identification Number for this study:

Copy: 1 for nurse; 1 for researcher

Nurse consent form version 1 Feb 2004

Nurse Consent Form

NURSE CONSENT FORM

TAPE RECORDING OF INTERVIEWS

Title of Project:

A research study to explore nurses' assessments of patients in the outpatient chemotherapy department

Name of Researcher:

Cathy Wilson MSc, BSc(Hons), RGN, Oncology Nursing Certificate, Diploma in Palliative Care
Nurse Researcher, [...] Hospital, and Honorary Nurse Researcher, [...] Hospital

Please initial box

1. I confirm that I have read and understand the information sheet dated
(version) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time,
without giving any reason, without my professional or legal rights being affected.

3. I agree to the tape recording of my interview with Cathy Wilson
today.

Name of Nurse

Date

Signature

Researcher

Date

Signature

1 copy for nurse; 1 copy for researcher.

Nurse Identification Number for this study:

Nurse tape consent March 2004 SDS0210M

P I S (February 2001)

After the tape recording:

I agree to the use of this tape for the purposes of the research as they have been explained to me.

I understand that the tape will be stored in a locked cupboard in accordance with the Data Protection Act for up to two years, and that my name will not appear on any transcript made from it.

I understand that the tape may be listened to by Cathy Wilson's academic supervisors at City University.

I will be offered a copy of the transcript of the tape for my records.

Name of Nurse

Date

Signature

Researcher

Date

Signature

1 copy for nurse; 1 copy for researcher;

Nurse Identification Number for this study:

Nurse tape consent March 2004 SDS0210M

P.I.S. (February 2001)



IMAGING SERVICES NORTH

Boston Spa, Wetherby
West Yorkshire, LS23 7BQ
www.bl.uk

BLANK PAGE IN ORIGINAL

Appendix 21 Examples of Transcripts

Nurse Sue and Ian - Phase 1 - The Southern

- P: Hi
- N: How are you
- P: We've to be on our best behaviour today
- N: Yes I know. (Laughs) Taped and recorded aren't we. How's things
- P: Not too bad
- N: Not too bad? The last time you saw us you weren't feeling too bright so
- P: No um
- N: Have things picked up a little bit since then.
- P: No I mean I was very de- was it the Friday after
- Wife: Last Friday
- P: But I went a bit too mad I walked all the way to [town] to the [shopping centre] and then I walked all the way home and did some gardening and then the next day I suffered
- N: You were totally wiped out were you the next day? Oh yeah
- P: And this week I haven't been that great. Haven't been that great, no
- N: You haven't been that great, no? You've just been -
- P: No
- N: In what way?
- P: Tired achy
- Wife: Joints
- N: Yeah? OK sure. Have you just been resting up since last week?
- P: Yeah
- N: Yeah?
- P: Yes I have. I try and get out and have a walk as much as I can but
- N: That's a good
[idea =
- P: =[But on Friday I did too much
[walking =
- N: = [Gentle exercise, not too strenuous
- P: So I took some Co-Proxamaol, I do take Co-Proxamol just to make you feel a bit better and I think it probably hid the fact that I shouldn't have been doing it but anyway
- N: Yes, yes. But you did it and now you know -
- P: Not to
- N: Not to, not so strenuous, as much as that day,
- P: Sure
- N: Ah bless. Any other problems? Nausea, vomiting?
- P: No
- N: No? Any soreness of your mouth, or tongue, any mouth ulcers?
- P: No

Nurse Sue and Ian - Phase 1 - The Southern (continued)

- N: Any diarrhoea, constipation?
- P: No it hasn't been bad has it (to wife) this time. I was constipated before but I think it's because I'm not taking so many CoProxamol because they are inclined to bind you up I
[think=
- N: = [Yeah they can do
- P: but no, it's not been too bad
- N: It's manageable. yeah?
- P: Yeah
- N: Right. Any coughs, colds, sore throats?
- Wife: Yes a little cough
- P: A little cough
- N: Right
- P: Niggly little cough that's all, its' nothing
- N: (Laughs – wife making gestures) Taking anything for it?
- P: No no no
- Wife: Cigarettes
- P: Yeah, a cigarette. When I have a cigarette. I mean I'll be honest I've virtually packed up but I still need the one or two a day I'm struggling with being able to pack it up completely so I probably has a little bit to do with it that I'm still having the one or two a day
- N: What help has been provided for you?
- P: I'm on patches but I'm also investigating something else that friends of mine have been on and um its proved to be pretty good so I'm probably going to try to go on that and give it a try
- N: Mmm. How many were you smoking a day?
- P: 40
- Wife: 5
- P: Too many
- N: 40?
- Wife: 45
- N: 40, 45 any increase? (laughs)
- P: (to wife) I didn't realise you was counting them
- Nurse (Laughs) OK
- Wife: He's doing well he really is
- P: You tell that lady that but you don't tell me that. (Nurse laughs). You keep having a go at me for it. Anyway I know its not good for me. The only concern I've got is this one vein and I think it's probably standard, but it's really quite hard and that's where I had it put in once and because I was getting pain where they put it in there once and this will probably go as well I suggest will it?
- N: I'm sure it will

Nurse Sue and Ian - Phase 1 - The Southern (continued)

- P: It's a bit hard that vein you know
- N: I'll keep away from that one today shall I? Would you like me to use the other side?
- P: No no. Down here's been fine, it's just when it was put in there
- N: Sure. OK. It's a just a bit of phlebitis. Unfortunately the drugs that we give can aggravate the vein
sometimes]=
- P: = [Oh I see
[OK =
- N: = [But it should hopefully settle down in a few days. All right? Can I have your date of birth please?
- P: Yeah XXX
- N: (Checks address)
- P: yes that's right
- N: I'm just going to pop your wristband on. OK. I'm just going to put a needle in your arm and take some blood from you. Can your jumper go up any higher?
- P: Sure. You want to put the band on. (Nurse taps vein). Naughty boy, me I'm a naughty boy!
- N: Mm
- P: Look at how that came up just by tapping it. Look at the way that vein it's come up just by tapping it
- N: Magic touch you see
- P: Yeah
- N: Sharp scratch coming now....
- 4min 48sec

IAN & CW FOLLOW-UP (Wife present and contributes; her initial is S)

CW: So do you mind just going back to the beginning for me, just to get this into context, getting diagnosed, when was that?

P: End of November, wasn't it?

WIFE: Yes, beginning of December.

P: I went to the GP with a cough. Initially he just put me on some antibiotics, and that was on the Thursday, because I had quite a severe pain in the right side of my chest and he put me on antibiotics, this was on the Thursday, and on the Monday I started coughing up blood.

CW: Right.

P: And S said "You ought to go to the doctor's". So I went straight back to the doctor's. He in turn sent me for an X-ray at [Hospital] and by that evening on the Monday I knew that there was a shadow there, basically.

WIFE: We rang him, because he said to us "If he coughs up more blood than he was coughing we must go to the A and E" and he started coughing a little bit more but not to the extent that I thought it would be too much, but I thought "No, I'm not going to leave it" and we know him very well, he's very concerned, he's a very good doctor, and I just explained to him "We're just concerned, tell me if I don't, we don't have to, but if you think we should we'll go" and that was it. And he said "Oh, I was going to phone Ian to tell him he's got a shadow on his lung".

P: And then from then on obviously he made an appointment to go and see Dr P, wasn't it, Doctor P?

CW: At [hospital X]?

P: No, that was at [Hospital Y] wasn't it? Yes. And then I went for different scans, CT scan.

WIFE: All sorts of things, a bronchoscopy, everything that.

P: Oh that's right, they took a sample biopsy, that's it.

WIFE: And TB you were being tested for.

P: Oh that's right, yes.

WIFE: Which he was really hoping he had.

P: To a certain extent, yes. But, of course, the day we went to see Dr P the person that was doing the TB tests came to us and said "You'll be pleased to know you haven't got TB". So of course when I was told that "No we're not" because it meant the other, that I'd got the cancer. From then on we went to see Dr P and he, of course, told us that there's cancer in the lung and it was inoperable, I think it was ten centimetres big, a big lump, and that they would treat it aggressively with chemotherapy basically. Which basically has now started and ongoing at The Southern.

CW: And has the pain gone?

P: Oh yes. Yes.

WIFE: And the cough.

P: Yes it has, really. The cough I've got now is, it's a catarrh cough rather than anything else, you know, it's not, and it's mainly in the morning anyway. So that would indicate that that tumour's responded I think. I hope so. They did give me a form to have an X-ray done but it was meant to be done the second or third one but I wasn't aware of that at the time and I took it with me the following time which was just after the first one, wasn't it?

WIFE: No they give it to you in the second one.

IAN & CW FOLLOW-UP (continued)

- P: Well, the start of the second one, but it was too early, obviously. It was, she did say "It might have diminished a little bit" but really couldn't, I don't think she could see, not enough to say. So now I've got to have one before I start the fourth which is not this week it's next week. Before I go and have that I've got to go and have it then. Then they'll obviously have a look at it, see how it's going and how much, or if, it's reduced then I'll know as to where to go after this fourth lot of chemo, whether it's going to be radiotherapy or some more chemo. So we're not sure. Living in limbo really.
- WIFE: At the outset didn't they say to you that it's likely to be three and check?
- P: They just said four.
- CW: Right.
- WIFE: Look at it after that.
- P: Yes.
- WIFE: And they assess it.
- P: So that's basically it up to now really.
- CW: And do you have a lung nurse or a palliative, a Macmillan nurse, or any nurse supporting you?
- P: No nothing. We did have a lung nurse see us first of all from [Hospital] wasn't it?
- WIFE: Yes.
- CW: Oh did you?
- P: Well no, when we were told, and then she said that she would keep in touch, if we wanted to. But she didn't hit my spot.
- WIFE: No, she didn't.
- CW: Because of?
- P: She was slightly condescending.
- WIFE: Not speaking like us.
- P: And we have spoken to some others and they've been fine but there was something about this one unfortunately that you couldn't get on with her. And she had a terrible voice. I don't know.
- WIFE: Every time she spoke to me I was in floods of tears. I don't know why.
- P: And that's not the purpose of them, is it?
- WIFE: She doesn't talk to me because I'm going to cry. I don't want her, that's not like me.
- P: We don't want to think about it really. So anyway, I have, I will make a point of going down to [support centre] and go to some of these group things. I think, not having been to one yet I don't know but I'm sure they will be beneficial, I would think so anyway because everyone, I mean, we find comfort although I'm going for the treatment we find comfort going to the centre on the Friday for treatment. Do you find other people recognise that?
- CW: Yes. A lot of other people say that because they feel very supported, they're seeing familiar faces and if there's something they're worried about they know that they can bring that up.

IAN & CW FOLLOW-UP (continued)

P: Just knowing that somebody's there checking on you is nice. I'm a bit worried about what happens when the treatment stops. So although life is dominated by treatment and by appointments and Friday schedules and that's a negative side, when it stops suddenly there's none and it will be "Oh my God, the future's endless". It makes me feel panicky.

WIFE: Unsupported perhaps.

CW: Unsupported and lost.

P: OK.

WIFE: And we've made friends with [other patient and wife] which is nice and we call each other. He's either going through whilst Ian isn't going through, what Ian is going through now, so we compare.

P: Well we actually phoned up last night because Saturday and Sunday is the first time it's laid me right up where I had to go to bed and sleep most of the time. Well, [he] had been experiencing that long before I had so we rang up yesterday just to say "Now I know how you feel" do you know what I mean?

CW: "Have joined your club".

P: But then he was saying after his last lot which was not this week, the week before, he said after four days he was coming out of it and he was feeling better. So that's reassuring, at least I knew that Saturday and Sunday was a horrible day but at least I know it's going to get easier as the week comes on. So we support each other that way a little bit, you know?

CW: Yes, and that's clearly very important to you.

P: Yes. I probably keep in touch. Probably will, yes. I will say this, this last Friday, and I don't think it was because of you taping me the Friday before, and I can't remember her name, the nurse.

CW: Sue.

P: Was it? Sue was it?

CW: Yes.

P: She was very supportive. I was a bit apprehensive Friday, I don't know why. I told her so, that I was nervous when I went in there, and I honestly can't put my finger on it.

WIFE: This last one.

P: And she said "Is it because of the needle?"

P: I said, "No, no, it's nothing like that" I couldn't put my finger on it or anything, I just felt a bit apprehensive on Friday. And she sat and talked to me and about my smoking and she really put me at ease and she spent a bit of time with me, and I said to her "I'm feeling guilty because you're taking time with me and I know what it's like waiting outside to go in" but I did find comfort from it, I really did and I believe this is what you're trying to establish that there's a bit more rapport with the patients, not just stick a needle in and whatever.

CW: Yes.

P: So, having experienced it on Friday I recognised that, that it was a comfort for me. And I haven't quite packed up smoking and it has been an issue for [wife] and I but I think she's, she's not come round but she's accepting that at the moment I still need these one, two or three a day. Not happy with it but accepting it. And Sue said the same, the doctors say the same "You've done well".

IAN & CW FOLLOW-UP (continued)

- WIFE: I said the same "You've done well but try".
- P: But I think I need to be stronger before I can.
- WIFE: I don't mind him doing one, two or three but not four or five.
- P: I know.
- CW: But when you think, even five compared with 45 is a huge drop.
- WIFE: Oh it is, but he can't, you see, if people say that to him he can't think "Oh I've done very well" he thinks "Oh well, they said I could do five, I'll do ten".
- CW: Yes, I know.
- P: It could be a slippery slope, it could be a slippery slope I do recognise that, yes. But she was also, I mean, all the doctors I've spoken to they all think I've done pretty well.
- WIFE: I do, and the family do, but it's just that.
- P: I said "If my wife was here listening to this now she'd say I wish she hadn't said that to him".
- WIFE: Because I know how he works, nobody knows him better than I do.
- P: Yes, I think you have to, you can only do so much emotionally and mentally, if emotionally and mentally you're actually getting through the treatment then it may be an extra fag is what I have to have. That's all I'm saying at the moment.
- CW: OK. Can I play you this bit about when you said you felt a bit tired? [play section]. Was there anything else?
- WIFE: It's his depression as well.
- CW: Was that what you were hinting at when you said you'd been less well
- P: Yes. It's been bad. You see I have a long history of depression and it's been really bad. Panic attacks and sleeplessness. In the end I rang Dr O [psychiatrist] and he said come and see me and so I have two emergency appointments last week, he's put me on some new tablets so we'll see. But it's all been getting too much. Getting on top of me like.
- CW: Yes, I think you're doing marvellously well considering what you've got going on.
- P: Thank you Cathy.
- CW: No, I do. I mean it. Very well
- P: You see you wonder how it's going to go, and the psychiatrist said don't think like that. A day at a time.
- CW: And what about S, does she – do you think she knows how you felt last week, and the reason?
- P: No. I wouldn't want to tell her either. She's not there for that. I'm not sure Dr X knows, although Dr [psychiatrist] might have told her. But it doesn't matter they – what you're trying to establish is did it work, and yes, there it worked for me on Friday, definitely, it was reassuring and it was comforting.
- CW: Do you mean with S doing the assessment and putting the needle in?

IAN & CW FOLLOW-UP (continued)

P: Yes, yes. I'm not sure, having said that, and I don't want to, I'm not sure some of them would be as good as her at doing it.

CW: I think that's right.

P: And it's horses for courses to a certain extent. You know, not everyone can do the same, some people are better.

WIFE: She is older.

CW: She is, yes.

WIFE: She's more understanding.

P: She has. She is confident and gentle at the same time. She knows what she's doing. There's one or two in there that make me go "Oh". So I don't think you're going to get it across the board because everybody's a different animal and probably come across slightly different to how she does. I can only speak as I've found and I found her a comfort and reassuring.

CW: Yes.

P: Yes, I did. But as I said I felt guilty for taking her time. Making her slow down and spend time.

CW: And what was her response?

P: "No, no, yes, I know". I recognise what it's like waiting outside to go in, you know? And everyone wants to get it done and get out but then again, as I said, I really appreciated the time she spent with me. I think she was very warm, I think she's a lovely person. Usually it's just basic questions about the chemotherapy really, just about bowels and sore mouth and infections, coughs, colds, nothing really else, and you sort of say 'yes', if you've been a bit tired.

CW: Yes I noticed that you didn't develop that. Was there a reason for that?

P: In all the other things that you feel when you're having chemo, you don't share to her, she just wants to know that chemotherapy information and that you might tell your doctor the other bits, although I wouldn't always tell the doctor the other bits either.

WIFE: Yes, you do, you tell the doctor. Because I say to you "Did you tell the nurse?" and you say "No, I told the doctor". Tingly feet.

P: Oh yes, sorry.

WIFE: A rash, he keeps for the doctor. He doesn't think to waste the nurse's time, that's what it is, you see?

P: Well, I think the doctor is more the person to actually talk to about that sort of thing. Not the nurses, no.

CW: So, do you think the nurses know, what, what is your expectation of what the nurse would want to know?

P: "How have you basically been the last week, or since the last treatment, any changes in whatever?" I mean, she'll ask me if there was any changes, well then I'd probably say "Yes, I've got tingly feet" or whatever. If she asked the questions I would respond. But I probably wouldn't forfeit that information without being asked for it, probably.

WIFE: But I would, I would tell them. I think women are different anyway, men wouldn't, "She didn't ask me so why should I tell her?"

P: No, that's not how I feel about it. She asked me what she needs to know and I'll tell her so that I'm not holding her up."

IAN & CW FOLLOW-UP (continued)

CW: You're very conscious of your appointment time?

P: Yes. But, if you are intending for them to ask those questions well then I'd be happy to answer them, that wouldn't be a problem but no, I just felt the tingly feet and some of the other things was for the doctor to know rather than her, for the reasons I just said, wasted time taken up by. But if she had asked the questions I would respond. But I probably wouldn't forfeit that information without being asked for it, probably. It's like "she's asked me what she needs to know and I'll tell her so that I'm not holding her up

CW: Yes, and also perhaps because the doctor's the one prescribing the treatment and therefore if there's anything to be prescribed they will do it.

P: I mean, I do think sometimes those leaflets that they hand out there, I mean, we're conscious we don't like to waste people's time or this, that and the other, and I don't know how it manifests itself at The Southern but, to me, if you read those leaflets you could be phoning up every five minutes.

WIFE: You would.

P: And I don't know whether that is the case there, whether people do keep phoning up or whatever but sometimes the slightest thing if you read it in there they say "Well, ring up and tell them".

CW: Have you ever rung up, by the way?

P: No, no. But the tingly feet, you know? I mean, I had that all last week,

CW: Did you mention it when you went on Friday?

P: Yes.

CW: And what did they say to you?

P: I mentioned it to the doctor and she said she might reduce the dose because she said was it just tingly or was there a bit of pain, well there was a slight bit of pain in the top of the big toes but other than that, no, nothing excruciating or nothing like that but that's what she said. And when she said reduce the dose I thought "Oh dear, I wish I hadn't said anything" because that could lengthen or delay it. And if I thought I'm not going to finish it on the next one I wouldn't say anything, I don't deny that at all.

WIFE: But the tingly feet, you know?

P: I mean, I had that all last week, didn't I, basically? But my suspicion is that you don't tell an awful lot in case they reduce the treatment or stop the treatment. I wouldn't deny that at all. Because I mean, it's not cut and dried that this lot's going to be the end of my chemotherapy, I might have to have some more, but at the moment I'm hanging on to that it's going to be the last one, but whether it will.

WIFE: I would though, I'd tell her, because it's dangerous, you're putting yourself at risk having the tingly feet because she wouldn't say to reduce the dosage if there wasn't some slight risk.

P: She said something about the nerves, didn't she?

WIFE: Yes, you see you don't want to kill your nerves altogether.

P: No, I recognise what you're saying darling but there is the factor there.

CW: I think you do have a fear that if "I say this they might think oh, we'll stop early or cut it down".

P: Yes, prolong it.

IAN & CW FOLLOW-UP (continued)

P: It's prolonging it that I'm worried about, but I know they're doing all this for the right reasons but when you feel like you do with this chemo and there's always someone worse than you, there always is, but it doesn't comfort yourself, you feel you're having the worst feelings ever. Yes, so I don't want to prolong it any longer than I have to. So yes, that's the case that I don't want to prolong it any longer than I have to, but obviously I want to get it sorted.

CW: And, so in terms of your support at home, obviously your wife, and -?

P: Not many friends. Do you know what, you think you have lots but it's at times like this you find out who the real ones are. That's what I say. All right S will say to me "Sometimes you've got to make the effort, Ian" but then a lot of them are aware that I've got this at the moment and I've heard from other people "They're going to phone up, they're going to phone up" but they haven't.

WIFE: Men can't handle this like women can.

P: We have got lots of friends but, when it comes down to it, there's probably only three to half a dozen that you can actually say are in regular contact.

WIFE: Regular contact, yes.

P: And it has, I've got a bit disappointed about it and am a bit low on it sometimes.

CW: Perhaps a bit angry?

P: Yes.

WIFE: See my friends phone up.

CW: That's a woman thing, isn't it?

WIFE: Yes, because they know Ian as well, and family they do phone.

P: But yes, it can be a bit hard. It's very lonely. This is it, you see I was at [Company] for 15 years and even Dave has only just came round the other day.

WIFE: But Dee came round.

P: People don't know what to say, do they? Like Dee came round but Dave couldn't.

WIFE: Dave couldn't face it. But what I did, in his birthday card I put in it "Ian would love to see you, Dave, just pop in" and I think that clinched it and he came round.

P: But apart from that, no. And financially we were going to find out. S's on disability anyway because she's had a severe back problem for a lot of years and, of course, I have been with this depression and whatever before all this started. So, yes, I am on Incapacity Benefit but we're just going to go up there and see what else, probably not, I mean I have got a small pension from [company] as well so that probably boosts my income. But we just thought we'd go up there anyway and just, somebody suggested we should so we thought we'd go up there.

WIFE: A friend, wasn't it? F, our ex-next door neighbour. Oh she's been very good.

P: She's a psychiatrist actually and she's been really quite supportive, hasn't she? But yes, she suggested that we should do it. We're not beggars but at the same time we've paid our taxes.

WIFE: That's right. Paid taxes and national insurance but we're the quiet ones that "Oh well, you're ill and that's it".

P: I mean, we might even be entitled to free prescriptions or whatever, which isn't a lot but it adds up, you know? When you're not earning a living.

IAN & CW FOLLOW-UP (continued)

WIFE: You know, and it was F who said that last week and so we happened to make an appointment.

P: And, apparently, this is going to be the last opportunity for a while because apparently the lady that normally does it there has got her own problems and so I don't know if it's her we're seeing or someone else today.

WIFE: No, someone else is coming in.

P: But that's going to be the last for a while there apparently. You're aware of that, are you Cathy?

CW: I am, I am. I know the lady who's on this long-term sick and they actually did bring in a social worker, Macmillan paid for a social worker but she hasn't lasted very long so she's left. There is a gap. I think that actually it's something that.

WIFE: Should be addressed.

P: It is a gap. It's important. It's not necessarily high science but it might be something that the nurses could instigate, you know have some forms, or somebody to help cos it's all very expensive you know.

WIFE: Yes, somebody you could just go to.

P: I don't think so, Macmillan nurse maybe, but certainly not the people who are giving you the treatment, no.

CW: No?

P: They're too busy. I think you ought to go and see someone they should tell you "OK, this is the procedure, you go to the chemotherapy and then they make an appointment to see somebody in the Benefits office, these are all the things that you have to do". But I certainly wouldn't want the nurses at [the Southern] who do the treatment to get involved in that, no.

WIFE: They have too much to do.

CW: So you really want them to just concentrate on giving you your treatment, that's where you see their expertise?

P: Well yes. And, as we've already discussed, asking you the right questions and whatever but don't get involved in that side of it, no. I think that's above and beyond the call of duty. I do, no, that's honestly how I feel. I don't they should be getting involved in it.

WIFE: Because they are busy.

CW: Oh, I know.

WIFE: Very, very busy.

P: And they've had some sickness there as well this last, for a while, so they've been a bit short as well. No, I wouldn't want it to be them.

CW: What about your GP? You say he's a good GP, do you still see him?

P: Well, I've been there this morning, that's where I've been today to get some more patches, smoking patches and some more anti-constipation medicine I have my bouts of it and I was diagnosed, not diagnosed, So, where were we?

IAN & CW FOLLOW-UP (continued)

CW: You went to the GP, he's in the loop?

P: Oh yes, yes he is. And he is very supportive. We stayed with him, when we lived in [town], when we moved up here we stayed with the same GP fortunately because I think he lives near here and it enables us to still use him. So we were still able to use him. Yes, he's been very supportive, he even rang up a couple of weeks ago just to see how I was getting on.

WIFE: Yes, and "I'll come in one day but I can't tell you when".

CW: Oh that's good.

WIFE: "Well yes, whenever just knock on the door, Ian will be here".

CW: And you don't have a district nurse or any nurse visiting?

P: No, no. Not had the need.

WIFE: I find it would be too much for me to cope with, it's like final, do you know what I mean?

P: I don't want that at the moment.

CW: Some people refer patients very early on to district nurse, sort of at diagnosis, and the district nurse comes in once and then maybe every few weeks rings.

P: Oh I see, yes.

WIFE: Yes, but no nurse.

P: Somehow we could, I could handle the, although it was a blow when he told us, when he told me he said "We'll appoint a Macmillan nurse" I turned round and said "What do we want her for?" that's the first thing I said. Because you associate it with death

WIFE: That's right.

P: Exactly, you can do.

CW: And that's not how they are but that's how they're perceived.

P: Yes.

CW: Historically that's how they were.

WIFE: Exactly, that's what the public's perception is of a Macmillan nurse.

P: The doctor gave us the bad news and leaves the nurse to pick up the pieces. The doctor gives the bad news so that he can go on to another patient.

WIFE: That's exactly how we felt it was.

P: Oh yes.

WIFE: Exactly how I felt it was "OK, I've told you the news she can look after you now".

P: The couple who were in with [Doctor] before us, I mean, she came out in tears as well, didn't she?

WIFE: She was in tears, yes.

IAN & CW FOLLOW-UP (continued)

P: So these poor Macmillan nurses have got to pick up the pieces after the doctor's told the bad news. I don't know how that could be addressed either.

CW: No, I don't know.

P: I don't think it could be, really.

WIFE: This is it, you've just heard the diagnosis and you don't want to know about her.

CW: It's very difficult because everybody reacts to a diagnosis in their own way

P: As you say everybody deals with it in different ways, yes.

CW: But professionals will try very hard to help you.

P: They kept asking me if I had any questions

WIFE: You can't think of any.

CW: That's right, they come later, don't they?

P: But the consultant's been very good. We've seen her every time except once, only once, but other than that, so that's six times we've been there and we've seen her five out of the six.

WIFE: It's really very, very good. And she's very good. She's a lovely person. She's so easy to talk to.

CW: Yes, she's very normal, isn't she? She's lovely.

WIFE: Yes, but she is nice. But for us to see her all the time more or less, except once, I think that's really good. And I think the chemo unit is quite nice there anyway. It's not like an National Health Service clinic.

P: That's something we have thought, though, isn't it, a little bit of background music in the waiting room or something. Like if you're having the chemo and you're sitting there waiting, especially waiting to go for your bloods, because it's so quiet.

CW: It's too quiet, is it?

P: It can be.

WIFE: There's some quite nice characters, you get quite friendly with some of them in the waiting areas.

CW: That's good isn't it, you run your own support group while you're waiting?

P: Sure, yes.

WIFE: Yes, we do, because we're asking everything, some people they don't mind.

CW: No, absolutely, I think patients and relatives learn an awful lot from each other, don't you?

P: You gauge how you're getting on by looking round "I'm worse than him but I'm better than her"? A lot of that goes on.

WIFE: There was one who was very, very pale, wasn't he?

P: What, on Friday, yes, yes he didn't look well at all did he?

WIFE: No, an elderly gentleman but oh, he did look pale. And I said to Ian "I feel sorry for him he looks so pale". And then that other poor chap who is younger than us, every time he has chemo of course he's sick before he can get to the door. So they're trying him out with some more tablets, you know?

IAN & CW FOLLOW-UP (continued)

P: As I say there's always someone worse off than you. There is. At the time you don't think so, but there is.

WIFE: When you're suffering you don't think anybody else is worse, you can't think that way can you?

CW: And actually if you can see that, you know that you're actually doing all right. You know what I mean?

P: Oh yes, sure. Have you finished now?

CW: Yes thank you. Was there anything else you wanted to add

P: No that's all. Thank you Cathy

CW AND SUE FOLLOW-UP re IAN

CW: In general terms with your assessment, what sort of information are you wanting?

N: Well I suppose obviously whatever, I just want them to answer as truthfully as possible and, if they have got a problem with nausea, sometimes people think that "Oh well, I'm having chemotherapy so I should just put up with it". And what I'm really trying to tease out of them is "How bad has it been, is it something that you are coping with and are managing and you've got your tablets and you're taking them?" A lot of patients we'll say to them "If you have nausea, vomiting, take your tablets" you'll be amazed the amount of people that come back through and say "I don't know what these are for, I was given them but do I take them if I'm feeling sick?" "Well, yes, that's the reason they're there, they're not there to sit in a box on a shelf in the bathroom cabinet". So, really, it's just to identify and maybe just reinforce because I do appreciate that this is a difficult time and people aren't going to remember everything that's said, of course they're not, so really it's just for me to reinforce really that "Yes, if you are feeling nauseated, if you are vomiting, that's the time you take your tablets. If you're not, and even if you are taking the tablets and you're still nauseated and you're still vomiting then maybe we should be looking for something else because quite clearly that tablet isn't working for you". So, just to let them know that there is alternatives. So, I find, especially with the elderly patients they're very "Doctor knows best" they come from that sort of era and like I said it's very much "I'll put up and shut up". And really I don't think in this day and age that they have to put up and shut up, nobody does, irrespective of what age group they are. And I just find that, especially, definitely the older generation, it's like "I've had my life so this has happened".

CW: That's right, they tolerate much, much more, don't they?

N: They do, absolutely, they're so compliant as well, so compliant, they really are. Not all of them, obviously, but I'd say the majority of them and I think that must very much go with their era, the way they were brought up, definitely, rightly or wrongly. So really, yes, it is just to try and tease out of them because something they might think isn't a big issue I might think otherwise. Especially if they're having copious amounts of diarrhoea and going to the toilet every couple of minutes, but not taking the tablets appropriately. Not taking them at all. So really, again, it's important that you flag these things up because you'll be amazed what you do actually get out of people once you start probing.

CW: Now with Mr. B?

N: Yes. Yes.

CW: With this bit, [plays 'naughty boy'] at the end

N: Did I really say "magic touch"?

CW: [laughs] Yes.

N: Corny! But he's very suggestive here, well that bit, I hadn't noticed that at the time. Golly gosh. Oh my God. Yes, perhaps there was a little bit of, I don't think he meant it like that, that's out of context but there was definitely some flirtation.

CW: How well do you know Mr. B, have you treated him before?

N: Only once before that. He's not terribly well known to me, no, but again I had, a nice gentleman, I felt like I had a rapport with him immediately and he's since opened up to me quite a bit after this interview as well. This week I saw him and he said that, actually having this tape recorded and him thinking a bit more about it, and it made him - this week when he came he felt really bad but he thinks that actually having done this enabled him to see me in a different way. So, yes, he had said that. Mind you I must say this week he didn't have his wife with him, she was out in the waiting room and he was able to open up. She very much, there's a bit of difficulty there in the relationship.

CW AND SUE FOLLOW-UP re IAN (continued)

CW: Mm.

N: Definitely. And it's all to do with the fags. Am I allowed to say that?

CW: Yes, I've got the section [plays section]

N: So yes, he hasn't given up smoking and he says to her he has a couple a day and he fully admitted to me he has more. And I think, basically, the bottom line is that he doesn't want to give up smoking, he really doesn't. And she is angry with him. It came across there didn't it

CW: It did – and did you pick that up at the time?

N: Yes I did sense something between them. She was tense.

CW: What did you think about the cigarette exchange?

N: In what way?

CW: Well, what's your view on patients like him giving up smoking?

N: Well, half of me says it's too late anyway. I was desperate to say to him actually "Why are you bothering?" really. Because his prognosis is very short, isn't it, really? He looks poorly. So yes, why put yourself through the agony really, yes, sure. The other half of me, I mean, it's like well we are pumping you full of chemotherapy so you have got to try and do your bit as well, I feel. But I know it's hard and I did say to him "Don't be too hard on yourself" I don't know if he was telling me the exact amount that he smoked, because he came in saying he felt very jittery and very nervous.

CW: Yes he did

N: And I said to him "Oh, is that because you haven't had your nicotine fix?" and he said "No, I have, I have, I've had at least a couple today" and he clearly states in the notes that he's given up smoking. One of the doctors has actually, Doctor D I think, said it's documented and I said "Well he clearly hasn't because he fully admitted to me" but he enjoys a, it's a lifetime but the wife is not happy. I think it is causing a lot of tension.

CW: Yes

N: Definitely. She's probably thinking "I want him around for a few more years" Do you think he knows, does he know his prognosis is as bad as it is?

CW: I don't know. He hasn't really indicated that to me, did he indicate that to you?

N: No, he didn't. It's ever so hard, he's probably been doing it since he was 16 or something. But I worked out the tension between them. Definitely, yes, I picked up on that straightaway. She chipped in, didn't she? And then there's this little bit between them and I said "40?" and she said "45", I said "40, 45, any increase?" and so he was looking very uncomfortable at that point, and I tried to defuse that with a little light heartedness

CW: So I think you've used humour there deliberately?

N: Yes, I mean, I do try to definitely, obviously if I see there's a situation because I kind of felt, yes, I mean, dare I say it, I was kind of taking his side really, I felt. And I was trying to be, I was trying to stick up for him really in some ways because I could see she was trying to get at him. So yes, it was just trying to defuse the situation really.

CW: With him, and patients like him who have probably a poor prognosis, how much do you know about if they have, say, Macmillan nurses or anything? Do you have anything documented that you can easily identify?

N: No, no we don't, it's just a matter of rifling through the notes, really. No, I think our documentation so far as that's concerned is very, very poor.

CW AND SUE FOLLOW-UP re IAN (continued)

CW: But part of me wonders if it's necessary for you to know if they've got a Mac nurse or a lung nurse or any nurse, a specific specialist nurse. One of the things that I'm puzzling over at that assessment is where you all see yourselves in the support loop, if you like, and where you see yourself, where you want to see yourselves, do you see what I mean?

N: Yes.

CW: So, with patients like him, clearly there's no obvious place for you to look at to see who else is involved, does it matter, would you want to know if he had?

N: Yes, without directly asking him.

CW: Yes.

N: Yes, definitely, I think that sort of information's really important. Just to know what level of support they are having up there. And with them coming up so regularly therefore, if they did have that support out there, we wouldn't get any feedback from these nurses anyway really, so no difference really. Do you see? But if there was a problem I would hope they would notify to us if there's a problem definitely. Definitely, pick up the phone. But no, we don't necessarily have any liaison unless they absolutely think it's appropriate. Like I had one Macmillan nurse ring me once, this is a long time ago now, about a patient, this patient used to come in on a weekly basis, perfectly nice, quite a gentleman, come in and have his treatment, absolutely no problem, go home and he was virtually battering his wife when he got home. Yes, yes, you never would have known it, never would have known it. Because he'd come in and do the assessment and everything was fine, standing in the garden, but yes, he was causing major, major problems at home. So he clearly wasn't coping but none of us picked up on that at all, it took the Macmillan nurse to ring us up. And obviously then we had to flag it up with the doctors and I think in the end he ended up going to some counselling. This is a long time ago so he would have finished his treatment but just thought then how sad it was that I hadn't detected it but then what do you do if somebody comes in and says everything's fine, without probing, which I don't necessarily do, yes if probing was called for, if I felt there was a need, but as I say he didn't give anything away. But quite clearly the wife had been in touch with the Macmillan nurse who then got in touch with us and that's how, you know? Well if a lot of people are in pain, if they're genuinely not coping out there, the Macmillan nurse will raise it with us and say "Please can you make sure they're seen in clinic" and then obviously we will alert the clinic nurses onto that. So, yes, I'd quite like to know, definitely, I think it's really important.

CW: OK. In this assessment he tells you, he opens up quite a bit and tells you how life has been and he describes it [plays section] he ended it with how awfully hard it was. Was there anything, as he was talking, that either raised anxiety for you or you thought "Oh yes, I did that really well" or "This is going well"? Was there anything you wanted to say about the assessment?

N: Only that, having not really met this gentleman before he was still able to tell me how he wasn't coping that well with chemotherapy and he was finding it all very difficult. I felt that he actually was holding back quite a bit here because A) he was being taped, B) his wife was there and C) you were there as well. So, this was a very neat interview.

CW: In what way?

N: Not knowing him, and that's only the second time I've met him he clearly had got quite a lot he wanted to say, he wasn't saying it here, no, definitely not. Definitely not. Because again I felt, because several times -he might have been a little bit more relaxed if she, his wife - I got the feeling particularly because she was there, yes. Definitely. Because as I said, he hinted that he wasn't coping, finding it very hard, And even though he did mention, can I just read that bit about the smoking?

CW: Yes.

CW AND SUE FOLLOW-UP re IAN (continued)

- N: We got round to, "niggling little cough" right, "wife making gestures" "taking anything for it?"
- CW: You said "Are you taking anything for it?" "No, no, no" she said "cigarettes". [plays section agin]
- N: She said that and then he got a bit, he said "Tell that lady but you don't tell me that". So it was quite a tense, there was quite some tension between them. Oh there was, I picked up on that straightaway. "You keep having a go at me anyway, I know it's for my own good, yes, the only concern I've got is that, this one vein" I think it's probably standard but he's quite hard, "that's why I had it" oh OK.
- CW: So he changed the subject, he moved it off and went on to something else, which was I think him moving it away.
- N: Yes, that's interesting, isn't it? Definitely. I was just thinking "God, I hope I didn't bring up the cigarettes" I couldn't remember if it was me or him or her. I said "Any coughs?" and she said "A little cough". Yes, but I meant cough in terms of having a cold.
- CW: Infection.
- N: Exactly, they interpreted it as meaning a smokers' cough. Right that's how we got on the subject. Oh God, we were on a different wavelength. Oh God. I didn't realise that at the time. So it's very, very dear to her, isn't it? And in a way she is the problem there, isn't she and it's difficult to know what to do about that, isn't it? Because she is the one almost crying out for some help, isn't she?
- CW: Yes, true.
- N: Well, she doesn't want to lose her husband, does she?
- CW: No.
- N: Exactly. She sees smoking, lung cancer, of course I can see where she's coming from on that one, definitely. Yes, they could probably both do with some counselling. Wow. What a lot of issues.
- CW: Were you aware of anything in his past medical history that might have affected him, other illnesses or past crises or coping?
- N: No, and I've checked his notes since, knowing I was seeing you today, and there's nothing in them, so I don't think I missed anything [laughs]
- CW: You're learning!! [laughs]
- N: It's interesting, isn't it? Nothing in the notes, so presumably nothing to tell. Although – but -and again I think that flags up this issue, we don't get a lot of background stuff on patients. We're not privy to information really.
- CW: No.
- N: And I don't know how we could overcome that. No, it could be a complete psychopath walked through the door, I wouldn't know anything at all, only what's in the notes. And really when I pick up the notes my main interest is what chemo are they having and where's their cancer. Yes, if I happen to pick up something else along the way then that's a bonus.
- CW: But part of me's saying "Does it matter?" Does it matter that you don't know much about patients' history?

CW AND SUE FOLLOW-UP re IAN (continued)

N: Yes, well maybe. I don't know. You can't assess what you don't know can you? I can only assess what's relevant for me to make things safe here whilst he's in the chemo suite. But when patients say things if there were other reasons I might give different advice. Having background information kind of puts a different slant on it

CW: It does, doesn't it, in terms of what you might advise and what you might say to him?

N: Absolutely, yes.

CW: Quite interesting, isn't it?

N: Yes, definitely. But it's not going to make me treat him any differently. Assessment is kind of like a jigsaw puzzle really and then if I think there's a piece missing I have to decide whether to fish for it or whether to leave it alone. Because I don't know him from Adam really, I don't know what he's been like for the rest of his life. No. He's a lovely man. Such a nice gentleman, isn't he?

CW: Yes. And I think he felt that warmth coming from you towards him.

N: Oh, bless him. Do you think I did it wrong, missed something then? He just said "I'm very nervous and very jittery today" and I naturally assumed rightly, or wrongly, that that was because he was a bit down on his nicotine levels, he hadn't had his prop.

CW: Well, I'm only trying to find out what you interpreted at the time, and what with hindsight you think, not saying what's right or wrong.

N: You see there are patients, and I think he's one who think they don't need to tell me everything. Maybe there's stuff I don't need to know. I think patients have a perception of what you need to know, that we down here need to know.

CW: Tell me more, this is interesting [laughs]

N: Exactly, unless the patient offers that information themselves. We're not in the loop of these things, because although we're very key people for these patients, they're coming regularly, and yet we don't get told that. Because we are very very key to the patients, we are the regular people who see them and look after them, but perhaps the system is pushing us out. We're very much out on a limb down here.

CW: Aren't you?

N: Yes, oh yes. That was something that was flagged up when I worked on the ward because again you get so much more knowledge of the patient, I don't know, there's just something about seeing them and seeing their families, because that's how you, whereas here it's very, yes, isn't it?

CW: Yes, it's just sort of like here you get a glimpse of what's going on, don't you?

N: Exactly. But that's it, that is it and it depends what they choose to tell you at that point of contact because after that they're lost then in the system, they go off and see the doctor and they come back and yes, you might have a chance to talk again but it's very rare that I will actually sit there, unless they particularly want to talk about their cancer, I try not to be honest with you, whether that's right or wrong I don't know.

CW: Because?

CW AND SUE FOLLOW-UP re IAN (continued)

- N: If I'm absolutely honest it's because I probably don't want to. I'm sick to death of the subject, to be absolutely honest. Perhaps I shouldn't say that. Unless, of course, I feel that there is a need. If somebody asked me something about their cancer or about treatment, of course I'll answer it and I'll answer it as truthfully as I possibly can but otherwise I don't necessarily bring up the subject, I really don't. I don't know whether they want to. That's probably part of it as well. Do you want to sit there and talk about cancer all the time? And the answer is no. So I sort of think, sometimes I think they're probably a bit bombarded by it as well. And probably sick to death of it. And I just really don't want to revisit it.
- CW: Do you think, you said you don't really want to, but part of me says "OK, is that because, it's protecting yourself, isn't it?" Is it?
- N: Partly yes, sometimes. Yes, I don't like being in awkward situations and sometimes I am and yes, it's kind of, maybe there is a partly.
- CW: Because?
- N: Because it's difficult, isn't it to do that? You're you know, opening up a can of worms and it's like "Where do I take this?" you know, "how long have I got, if I start stirring things" you know, "I've got another 20 patients in the waiting room I've got to get through". So I think there's just something about that room it doesn't lend itself to people opening up. If somebody wanted to really have a very frank discussion then I'd rather do that in a private, in what we call the quiet room. Because tears and tantrums don't go down so well in such an open environment.
- CW: But there are none, are there? I've been down there quite a few times but I haven't seen one tear yet.
- N: No, there's not that many tears.
- CW: But I think the patients get the message too.
- N: I think so. Some patients will cry, definitely, and I say to them "Shall we go and sit somewhere more private?" "Oh no, it's OK" and all of a sudden they dry up. It's like "No, no, don't make a fuss". But that works OK down there because we have to get through the patients and the patients hate making others wait too. They feel a responsibility to the others in the waiting room.
- CW: Yes, I think that's true.
- N: And then there's us and me as a nurse. Like I mean "Trish" had a very difficult patient this morning and her way of approaching it all, coming round and mentioning it to us was "I hate to say this but this Mrs whatever her name is" she said "she's going to be a right pain in the arse!" So that was Trish getting it out of her system like Trish does.
- CW: And was that difficult in terms of obstreperous and demanding? Or as difficult in terms of lots of issues here?
- N: Well, yes, I think she was just a bit, you know how you get these very precious patients who find it all very difficult to cope with and this patient was talking about some mountain of rocks that she was trying to climb up and hadn't quite managed to get over it, and Trish was like "What?" Yes, I think precious is definitely the word here. I mean, rightly or wrongly that's somehow how you do deal with it, yes. I mean, I might come round and say "Oh God that was a really, really awful pre-chemo talk" I did have a very difficult pre-chemo talk this morning in terms of the gentleman was perfectly nice and so were his family but for one reason or another they kept on, they wouldn't let me finish what I was trying to say, I don't mind audience participation but "Try and let me finish first" you know because otherwise, I was getting out of synch, yes, and they kept chirping in. And the patient just kept asking me questions but wouldn't let me finish, wouldn't let me answer, in the end I just got a little bit exasperated with him and I wasn't losing my patience but I could feel inside I was thinking "Oh, if you'd just shut up" and I suppose I could have said "Could you just let me" but I didn't want to because it comes across as a bit rude doesn't it, then? And asking me some very, I don't suppose they were silly to him, but they were silly questions, what I felt were silly, maybe that's a bit naughty of me to say that.

CW AND SUE FOLLOW-UP re IAN (continued)

CW: No I know what you mean, to you they were minor, were they?

N: Well, just like they were, if he'd just thought about what he was saying he probably could have answered them himself. Anyway. I did give them plenty of time but I was very exasperated when I came out and I did say to the others "Oh God, that was really hard going" and I remember saying "Why do people ask you questions and they're not allowing you to finish them?" and I was giving a full chemotherapy talk so I probably would have covered it, and I always say at the end of it "If I haven't explained myself properly, if it's something you're not clear about have you got any questions" of course. And then I sort of see that as their time and they weren't following my format. It was quite hard going when you've got three individual people all chirping in, you know? But we've done it and he's had his treatment and he's gone off and hopefully he's going to be OK. So yes, it tends to be moans really, as opposed to support. But we just say it, we don't even think about saying, I heard a patient yesterday of only 40 had died leaving five children.

CW: Oh dear.

N: Yes, she only came in for Hickman Line, she arrested on ward X and she's dead, and I was like "Oh my God" I was completely floored by that, that's something I've thought about since. But again, it's like "Well, where do I take that?" I can't take that to anybody at all. Yes, of course I'm saddened by it, because I knew this lady quite a lot, bless her heart, because she knew I could cannulate her she came in, she had no veins whatsoever, they were just dreadful which is the reason why I had to go for the Hickman Line. I mean, bless her heart, I don't think her prognosis was terribly good and she was a recurrence of breast cancer, it came back again. But it was just, I think the way the news was delivered as well was quite harsh, because I was told by the pharmacist downstairs and he was just very matter of fact about it.

CW: He didn't realise you knew the patient as a person?

N: And I just expected, as I say, "By the way she's come in and had her Hickman Line and she's on ward X" and she just went "Oh yes, she arrested and died this morning". I was like "Oh my God" it was like somebody had punched me in the head. And I just couldn't believe it. But there you go.

CW: And are you told when your regular patients die?

N: No, it's only if you pick it up on the computer. Very occasionally a very nice doctor in clinic might say "Oh by the way I thought you might like to know Mrs So-and-So hasn't done quite so well as we would have liked". Sometimes the receptionists know, they'll put it on the sheet of signing paper, put RIP next to it. But even so that's not a very nice way of finding out because you'll be looking down the sheet and you'll be like "Oh my God" and then well just say "Oh, So-and-So's died" and a couple of us will go "Oh blimey, really?" That's it, onto the next one. It's hard and it's harsh but what do you do?

CW: I don't know.

N: Exactly. We've got clinical supervision but they don't work for me at all.

CW: Who gives it to you?

N: Well, when I was G grade I had it from P who's wonderful, don't get me wrong, I love her to bits but it just doesn't, group therapy doesn't work for me, I don't like necessarily opening up in front of a group of people.

CW: Do you get it now on the chemo suite?

N: Should do, but I haven't been to one single session yet. I haven't got a clue who does it. It's very ad hoc. As an F grade it's like you go if you're able to.

CW AND SUE FOLLOW-UP re IAN (continued)

- CW: And do the other nurses go? Is it available for the others?
- N: Yes, I think so. I don't really know. I haven't seen anybody go yet, but no. No definitely not. But I always say the best therapy is down the pub with a gin and tonic, that works for me. But isn't this just all part of just being a nurse, it's our make-up, we can move on, we have to.
- CW: Do you feel downstairs the pressure of the appointments and the pressure of the waiting room?
- N: Yes, very much so. I always say "Don't make any eye contact" you don't, you scuttle to the toilet, you scuttle back, you scuttle to lunch and you can feel the eyes boring into you. Somebody once said to [previous sister] "You've had 40 minutes for the eyes" when you're only allowed 30 and she wasn't impressed by that at all, but you do, you're constantly getting bombarded with "When's my chemo, I've been here since whenever". Even though we say to them it's an all day job, be prepared to be here all day, I've even done a poster.
- CW: I know you have.
- N: There's even booklets that we hand out "if you get out earlier that's a bonus, if you don't" but they still won't let it go. And always, always I hear on a daily basis "Oh I bet you've forgotten me" "God if I hear that one more time I'm going to wring your neck!" I'd love to turn round and say "Yes, we're in the habit of forgetting people, we walk away or we go home and leave people sitting in the waiting room all night". But yes, it does grate on you. There you go, that's what I hate about it is the pettiness downstairs. I mean, I've been away now for eight months and I've gone back, nothing has changed.
- CW: It's the patient, after patient, after patient, do you think that's what it is?
- N: Yes.
- CW: Is that what you mean by repetitiveness?
- N: Oh everything, everything, even what the patients say to you. Always, it's always the same, it's just like it never changes and I think "God, get me out of here" it's like an asylum sometimes. But anyway, sorry, we're moving off the subject a bit here, but yes, it does get to you, after eight years it does get to you. Definitely.
- CW: And yet it doesn't come across in your work.
- N: That's the main thing. If it's a conveyor belt it must never come across like that to the patient, they must never know any of those things. Perhaps it's a sign coming out that it's time to go.
- CW: Really?
- N: Sometimes I do avoid patients and I think "God, is that a tell-tale sign that you've had enough?"
- CW: It depends if it happens all the time, if it's a bad day then it's a bad day isn't it? You have to admit there are days you just don't want to, aren't there?
- N: God, yes, I wonder if I do that too much actually. [laughs] [Nurse is asked to come back to the unit to help as work building up].
- CW: I've got you panicking now. But that's perhaps not for the tape, we'll pick up on that later over coffee if you want to. I think I've asked just about everything, and time is up, was there anything else you wanted to say?
- N: No not at all. Thanks Cathy. That was really helpful. Hope it was for you too.
- CW: Yes, thanks ever so much.

Brenda & Amar - Phase 2 - The Northern

- N: [Nurse A's] offering to make you a drink if you fancied one?
- P: No, no. I'm OK thank you. What's all this with drinks being offered today?
- N: That's because we've had some days where we haven't been able to offer at all because we've been so busy and short-staffed, so today we can do it. So, how are you feeling?
- P: I'm feeling OK.
- N: Yes? That was a bit of a scare last time. [Patient had a reaction to chemo; almost a respiratory arrest]
- P: It was, I really was feeling scared but I've got over it now.
- N: It didn't quite make our day. But you're all right now?
- P: Yes, I'm all right, as well as to be expected.
- N: Lovely. I'm just going to go through here with you because of what you've marked off. I tend to sort of look at them in categories as you've rung them, so just tend to look at the things that you really feel are a bit of a problem. And the thing to look at first is really things like doing strenuous activities, long walks, things like that, and you have put that they're quite a bit of a problem.
- P: Yes, they're a problem, you know? The problem is the surgery that took place did help quite a bit, but before when I was diagnosed I could barely walk ten yards, now I can walk bit more, any more than that is becoming very difficult.
- N: Is there any way you think we could help you in any of this?
- P: I don't know which way, you know? I've got the Macmillan Nurses coming to visit me and they also ask that question. But there's absolutely nothing I can think of. I can walk a few more yards.
- N: So it has actually improved?
- P: It has improved, you know, but not significantly. I couldn't walk from my house to town like I could do before um, I've got to catch a bus or drive there.
- N: And the daily activities and things, if you ever want to do anything you can't do that as well?
- P: Yes, no they are the same thing. Like washing-up a couple of cups and a plate I can wash up, anything more than that and I'm struggling after a while. Like walking upstairs is OK, I can do two or three and then I'm knackered. I'm lucky because where I'm staying there's a toilet downstairs. So I can go to the toilet without having to go up and down stairs. Having to go up and down is quite difficult.
- N: Again I mean there's nothing we can do?
- P: No not really. I don't think there's anything much that can be done. I've learned to expect that and learned to manage the illness
- N: Yes sort of try to put yourself back in control
- P: Yes it's become a routine now I know what I can do and what I can't do. I've adjusted myself to cope with that

Brenda & Amar - Phase 2 - The Northern

- N: You're saying that you're limited in pursuing hobbies and leisure time activities, that's gone?
- P: That's gone. Yes, it has to be gone.
- N: What were your hobbies?
- P: I used to play a lot of sports. Cricket, football, golf, table-tennis, you name any sport, I used to do a lot of that. I used to go and visit friends, to go out socially, friends would come round, visit people, talk to people, mixing quite well, now I've none of that
- N: Are you managing to get people to come to you? Or do you not feel up to any visits?
- P: No. I've not had a good time, because of the way I look, the way I am, I'm quite different from what I was. I get very nervous about people to visit me now. I'm not so keen for people to see me in this condition. So I'm a bit stressed with that.
- N: And obviously shortness of breath is a problem that you have?
- P: Yes.
- N: And needing to rest, sitting in the chair you just, do you find you sort of tend to pace your day so that you work out bits of day when you can do something?
- P: Yes, I do that. I know the periods of the day when I'm OK, when I'm stronger, yes. And I get really tired, I don't do anything when I feel like that.
- N: You work your way round. Now, you seem to be having quite a lot of problems as far as eating and appetite?
- P: That's a really big problem. Something that would be better about diet really would be good.
- N: How do you think we could help you? I mean, what sort of things?
- P: Well, I've been given some medication to make me eat and drink healthily, and it's a bit better. But then, it tells you that, I had a problem last week with the chemo, the previous week, I was vomiting quite a lot. By taking the medication it was constipating me so I had medication for that. It helped and that's when I had the chemo.
- N: Are you just taking that as you need it? Or are you taking anything regularly?
- P: I'm taking it regularly, three times a day. Yes, because if I do any less suddenly, if I didn't take Movicol for four days, it doesn't work and then
- N: Are you under a dietician?
- P: Yes, I am under a dietician and she suggested something three weeks ago.
- N: Oh right.
- P: I do take but I don't think it's helping me.

Brenda & Amar - Phase 2 - The Northern

- N: How do you tend to eat? I mean, are you just keeping to sort of a set three meals a day? Or, do you think if you tried to bring it up to say six meals, and very small things, or nutritious drinks, do you think that might help?
- P: I do have a set three meals a day. I don't have anything between meals like a snack. In the morning I have a glass of water, and lunchtime I eat something.
- N: What about if you had a nutritious drink instead of your meal, do you think that might help?
- P: It might help, yes.
- N: Because I mean -
- P: What the dietician suggested was to take a drink with every meal. But if I miss breakfast, lunch or dinner then I don't take one of those drinks.
- N: Right, well you can get other drinks as well which are meals which are quite nice, which you could perhaps discuss with the Macmillan Nurse who comes, or District Nurse.
- P: I've tried Fortisip, things like that. I don't like them.
- N: You don't like them?
- P: No, this drink is better but I don't know if it's doing any good or not but I drink it anyway. But my pattern is still the same, I still lack appetite, struggling to eat, struggle to eat anything.
- N: Just wondering if, perhaps, you brought more meals or more snacks, whether because sometimes if you don't eat you don't feel like eating. Whereas, if you could have something small, several times a day, that could stimulate your appetite to perhaps eat more, perhaps get more in. It might be worth thinking about.
- P: Yes, sure.
- N: Let me just check. And swallowing things again.
- P: Yes, all that's a problem, still is a problem even with the medication. I am struggling to swallow some things, drinks for example.
- N: Do you like soups and things?
- P: Yes, that's fine. I can drink soup. I do, yes.
- N: Do you find if you have something like a small sort of slightly fizzy drink or something, would that help with the swallowing, sometimes you have to clear it before you drink something? I mean, they're all things you can try, they may work, they may not. We have got a Handy Hints Guide actually which I'll go and find for you as well. Which actually, the stuff I'm doing is based on that. So I'll find that before you go and go through that with you.
- P: That would be a great help, yes.
- N: And, see where else we are. You've already actually brought up this one, haven't you, worries about your appearance? I mean we've only ever seen you, this is normal to us.
- P: Yes, I know, that's right, yes. It's become normal to my family as well but it's not normal to friends.

Brenda & Amar - Phase 2 - The Northern

- N: Have you lost a lot of weight then?
- P: I used to be 79 kilos, now I am 65.
- N: That's a huge amount.
- P: My clothes, you can see, my clothes.
- N: Just hanging.
- P: Hanging on me.
- N: And that's obviously giving you a loss of confidence, isn't it, meeting people and going out?
- P: Yes.
- N: So we need to get this eating going, don't we?
- P: Yes, definitely.
- N: I'll definitely go and have a look for that leaflet. And you've obviously marked up worries about the future. I imagine that's quite a big worry?
- P: Yes, it is.
- N: Do you find with the Macmillan Nurses, I know they're very good at helping for pain relief, do you find that you're able to talk to them about things like this? You and the family, really.
- P: Yes, to be perfectly honest she encourages me to talk about the plan but I struggle to talk, but that's the nature of me, I think it runs in my family, we don't talk to strangers about us.
- N: Yes, private things.
- P: You know, private things, things that you worry about affecting my general health I can, but I can't talk to a Macmillan Nurse about other things, that's the way we do things in the family, that's not the way I am. And I've never done it.
- N: Is there anybody else that you feel you're going to talk to?
- P: My sister-in-law is always telling me to talk but if this is your nature it's very difficult to change the way you are.
- N: There's no religious person that would help you like that?
- P: [Angrily] They're even worse. They're judgemental.
- N: Right, OK. I'm just trying to think of where you perhaps, because I know if you're dealing with somebody everyday coming to the house, maybe it's hard to talk to them. I was trying to think of somebody else who you could feel involved with, who you could speak to?
- P: No, there's absolutely no way I could talk to a religious person, they're the worst. So I am, I do know that I need to talk, I do know.
- N: You feel you want to?

Brenda & Amar - Phase 2 - The Northern

P: It's just not coming out. The Macmillan Nurse is with me all the time and my sister is with me every minute.

N: How efficient. I mean, if you didn't want to talk about it, that's fine, leave it. But if you feel deep inside you want to but can't then I think that is a problem that you perhaps need to find someone that you can feel comfortable with. It's how you feel.

Sister-in-law: I feel that he wants to but can't. And I try to talk to him.

P: [Firmly] I'm inclined to say there is nothing I want to talk about.

N: Fine. If you ever do and there's anything we can do that's all right, we'll keep that one open, and if you can come up with any brilliant ideas. So that's that side of it. Put the needle in. You thought this was just delaying the horrible moment. OK, I'm just going to wash my hands. This one [vein] should be all right.

P: Oh OK.

N: Have you come worrying about, thinking about what happened last time?

P: Yes, of course.

N: Yes, I mean, we have got quite a few people who are on this, I mean everybody reacts differently but so far I've never seen anybody have any bad reactions to this one, all right? So I will say that, because I know if it was me sitting in that chair I'd be, "Oh no!"

P: Yes, really. The doctor, Doctor X asked me whether I wanted to try the drug I had before. He was convinced it would be OK. I started on a very low dose and he said "I can put you back on it, if you want" and I said "No, please!"

N: Oh, you were quite poorly that day.

P: Yes, very.

Rel: What are the side effects of this one then, the same as the other one?

N: Has nobody gone through it with you?

P: Not really.

N: Let me go and get a sheet.

P: Yes.

Rel: How long is it going to be?

P: No, just I want to know how long this drug takes.

Brenda & Amar - Phase 2 - The Northern

N: Right, how we go about it, it's very similar to the other one that you had. Start with just pump that bit of saline, just to start off and then I'll put up the chemotherapy. And that should take about half an hour and then just push another flush through and that's it.

P: Yes, and for this one, every week for three weeks?

N: Every week for three weeks and you have one week off. All right? Side effects are very similar to all these that you've had. Temporary reduction of bone marrow which is where the blood cell count drops, that can happen.

P: Does it drop any more than any of them?

N: It shouldn't actually drop any more than the previous ones. I mean obviously we're not 100% sure because everybody will react to it differently, but just like the other one, we will test your blood before each treatment and make sure that that's all right. So when you leave today we'll give you a blood card for next, the day before the next one. With this one the nausea is quite mild. We do, when I put up the, when I set up that one, I'll give you two injections now which are for anti-sickness. One is for anti-sickness, one is a steroid. All right? And then I'll be giving you, or if you've got enough, I'll give you the metoclopramide to take for the next three days.

P: Yes my metoclopramide, when I was actually started the GP went through the different types, one is cyclizine, is it?

N: Cyclizine.

P: Cyclizine, and then another one is similar.

N: Domperidone. Domperidone?

P: Domperidone, yes. So I'm taking those two.

N: Right. And have you got a good supply of those?

P: I've got a good supply of those.

N: Right, do you want to carry on taking those and not take metoclopramide, then?

P: Yes, I will carry on with them.

N: And then what I'll do today when Doctor X goes I'll get him just to change it on your chart so that each time you come we'll give you more of those drugs and not the metoclopramide.

P: Right, yes.

N: OK. Now, occasionally this can give you a bit of an itchy rash. I've never seen this happen myself but it is what the manufacturers say just to warn you about. If you do find that is happening then remind me to give you one of the numbers. I don't want you to just go away, anything you're worried about just give us a ring. Sometimes people can feel a bit fluey as well from it, you should be all right but let us know if you do feel a bit like that. Again, I haven't seen that happen but it's something that they do say to warn you about. Hair sometimes can thin a bit but it's not usually lost with this treatment, so that's a good sign. Tiredness, I'm afraid, that's an effect. And that's really it. Obviously, like anything else, if you feel any stinging or burning around where the needle is let us know. And I'll give you that to take home. All right? I'll just go and wash my hands, remind me to look for that Handy Hints leaflet as well. [Nurse gets up and moves to the next chair]

Rel: So it's three weeks and then one week off.

Brenda & Amar - Phase 2 - The Northern

N: [Nurse getting intravenous pump and pulling it round to the side of the patient] Always worried about pulling you over with these things. Right I can see one there, I can see one there. Shall I get you to take your watch off and have a look at this, are you left or right-handed?

P: Right-handed.

N: So I'll have a look at this one, see how it comes up. Twist that round. You still like this as much as you ever did.

P: Yes.

N: If you want to put that in the palm of your hand then just give a couple of quite strong squeezes on there. The one I was looking at has gone, oh there it is. I've gone for the longest one I could find. They look good but when you look at them they've all got little bendy bits coming into them.

P: Yes.

N: Is that all right? Hold nice and still then for me. Right, oh is that hurting?

P: It's OK.

N: Are you sure? If it hurts too much tell me and then I'll stop. That's hurting, I'm coming out. Which is hurting? You have to tell me when I'm looking down there I'm not looking at your face. No good giving you something that's going to hurt. I am sorry. Don't be brave, if something hurts, tell me. You have to press on there for me. Relax that hand a bit, that's it. Do you want me to go to the other hand and give that one a rest?

P: Yes.

N: Sorry about that.

P: That's all right.

Rel: You mustn't be sorry.

N: You wouldn't like it if I wasn't sorry would you, it would be a bit heartless. Just switch that over to the other hand. Put it in the palm of your hand. Your veins are a bit fragile today. You know, as I'm going in, they're popping. I'm sorry. Relax. Don't like having more than two goes, because I feel you get to hate me and I don't like your veins.

P: I won't hate you.

N: You might. There are still plenty of places to go. That one's just popped. I have actually got it in both.

P: Did that go in?

N: It's gone in, yes. I was just a little concerned because it took a little bit of getting in. How does that feel?

P: All right, great!

Brenda & Amar - Phase 2 - The Northern

N: Bit of sarcasm there, I feel. Did it hurt?
P: No.
N: It seems fine. I was a little concerned because it didn't go straight in. You all right?
P: Yes.
N: Still speaking to me?
P: Oh yes, I'll always speak to you.
N: That's all right then. Got one already and then they're just getting some more off, so they're just little handy hints.
P: Oh right then.
N: OK so this one's the anti-sickness, actually I can see that, it's just underneath but it is there. Maybe this one will be better. OK?
P: Yes.
N: I just want to check again that you're on the telephone?
P: Yes.
N: That's your chemo note, if you feel anything untoward, fingers burning, anything like that you must let me know.
P: Sure.
N: That goes through in half an hour. Is that feeling all right?
P: Yes.
N: Now is your arm comfortable?
P: Very comfortable.
N: Sure? You are on heated pad, is that all right? Will you shout if I offer you another drink?
P: Actually I'll have water.
N: Can I get you a drink?
Rel: No.
N: Are you sure?
W: Yes. Thank you.

Assessment transcript - Phase 2 (page 8 of 8)

Amar & CW follow-up - Phase 2

- CW: Thank you for agreeing to do this. I know you're not feeling well, so I will try not to overtire you. Please though do say if you want to stop. Firstly, can I ask you a general question about the questionnaire? What did you think about the questionnaire as it was?
- P: I think it was hitting the right sort of things.
- CW: Were there things that upset you in any way?
- P: Not really. Not really, it just hit the right note. Everything that was, I felt, was asked there. It was very good. And then when she came along and asked whether she could do anything to help I felt very good, I felt very comfortable that somebody's actually looking at the right things. Something put down is better.
- CW: Better than?
- P: Better than just asking me. That's not so helpful
- N: Do you think there were too many questions?
- P: Well, as I was going through, I felt it was getting a bit too long, you know, but when I looked at the questions I thought they were good questions, the right ones. It didn't feel as long then.
- CW: Right, but when you first looked at it you thought it was a bit too long?
- P: When I first looked at it I thought "Oh my God!" And as I was filling it in I thought "No, all of these are good" and as you go through it and look at the questions. One of the things that might be good is to put it into a more booklet form, which might be nicer. I used to work in IT and I could do that. It would be easier to fill in and nicer to see.
- CW: That's a good idea. I will bear that in mind. And did you feel, because we can compare that slightly, can't we, with the other type of assessment [Amar took part in both of the data collection phases of the study], did you feel that it was different?
- P: Yes, definitely, definitely. Doing that way left it that it was a bit more your, following your concerns rather than having to wait for the nurse to go through the others
- CW: If you were to fill in one of these each time you came would that be too much?
- P: It probably would be too much. But it doesn't matter to me, the way I felt today I just needed these things sorted out, whether there's a questionnaire or not, it prompted the nurse to ask questions that I was going to ask. I don't know, I wouldn't mind, I would do it every time because your situation changes on a weekly basis and you might have a different need every week. Like I was saying it's very difficult for me to remember to talk about these things, and if that thing prompts the nurse to ask back it's very good.
- CW: That's really helpful. Were there any surprises in the questions in there?
- P: Not really, no. But if there had been, I'd not have answered them do you know?
- CW: Yes.
- P: Because actually you didn't have to answer the questions you don't want to.
- CW: And you mentioned to me earlier, before I put the tape on that you felt that going through it with nurse made it easier to discuss?
- P: Right, very good.

Amar & CW follow-up - Phase 2 (continued)

CW: What else made it helpful?

P: It's all very helpful. It's very good. It's very helpful. I guess it's being able to tell it like it is, to get someone to listen to me and hear how it is.

CW: Mmm. Yes. Is there anything else you wanted to say about it?

P: No. I was just thinking about what you said, every week, I would do it because I do come in several times a week and I've thought about certain questions then, but not had a chance to talk about them, and then later in the evening or such like I remember, and then next time I come other issues takes that one away and I forget what it was. This reminded me about a couple of things, so these kind of things – these questions – are helpful.

CW: I wonder, did you feel it was quite a long chat compared, say, with the last one that you had, wasn't it?

P: Yes.

CW: Did you feel it was too long before the chemo got started?

P: It was long, I can say so, but I didn't feel it was too long.

CW: And, when you said [play back section of tape re. Macmillan nurse] about not wanting to talk – yet here we were encouraging you to talk – what did you feel?

P: (Laughs) Well, I know! That's the strange thing – it was different. Different, it wasn't like I was being asked questions, but just being asked to say what things were like for me

CW: And that's better – a better way?

P: Yes. Much. It doesn't feel like it's being forced on you.

CW: And what about when Brenda suggested something you perhaps didn't want [plays section re. religion] did that upset you?

P: No not really. She meant it well. She was trying to find ways of helping me, so it didn't upset me, but it made me angry, the thing makes me angry, that religious people are like that

CW: Do you mean –

P: I mean that religious people are judgemental, and not - oh I don't know. I'm not sure what I think. How much more do you want to ask me?

CW: Nothing really, if you've finished. That's been really helpful. Is there anything else you wish to add?

P: No, that's all. I've finished.

CW and Brenda FOLLOW UP re Amar

- CW: Now today it's Amar. Do you remember?
- N: Yes, poor chap. He's so ill isn't he? He's not going to do I don't think
- CW: No I think you're right. Looking at the assessment do you have any comments?
- N: Just the same as always Cathy. Generally it was fine. I feel he was very nervous because last time he'd had this near respiratory arrest and so this time he was really scared even though it was different treatment and so I was thinking if I were him I'd want to get on with it not go through all these things beforehand. So I don't know if he felt that but that's what I wondered and so that made me doubt myself as I was going through. We just don't know if we're causing harm doing it like this and so it stalled me a bit
- CW: Yes, I see. So would you have preferred to do the assessment afterwards? And got his treatment going?
- N: Yes, of course. See these assessments they're not relevant are they? Not what I need to know. I need to know whether he's had a cough or infections and so on, whether I can go ahead with the treatment, but not this sort of stuff and so I think the chat just delays things and makes the patient more nervous 'cos everything's on hold while they talk about these things.
- CW: OK. I understand that
- N: Sorry do I sound rude
- CW: Not at all, this is as you know nothing that I own, I'm just seeing how it would or wouldn't work, so this is what I want for you to be honest as to how you feel
- N: OK that's good
- CW: Now looking at the transcript, when he's talking about constipation, what were you thinking?
- N: Well he's constantly constipated. Nothing new there. I should think his Mac nurse is sorting that
- CW: Do you speak to her about it
- N: No but I could do, but she's very experienced and involved and I'm sure she's dealing with it
- CW: OK No what about the eating things
- N: Well that was worthwhile, I have to admit. I like this side of the assessments, being able to give advice and things. That's really satisfying and I think I helped him. Afterwards I thought that was a nice thing to do. That is one good thing about this questionnaire isn't it [laughs]
- CW [laughs] I'm glad it's not all bad Brenda [laughs loudly]
- N: No it's fine. It just doesn't fit here. I don't think patients want us to stir up a wasps' nest before their treatment, it's not fair. He had enough on his plate as it was.
- CW And is that how you see it, stirring up a wasps' nest
- N: Absolutely. Don't you?
- CW: Not sure
- N: Well I do, maybe because you're palliative more than me but I think it's dangerous and a bit cruel almost, you know to go through things like the future when really patients want to come here and have a break. They want to come and have their treatment and be treated with warmth and for us to leave things alone. The Mac nurses will be doing all those other things.
- CW: OK. Got that. It's really helpful to understand. Thank you

CW and Brenda FOLLOW UP re Amar (continued)

- N: No offence of course
- CW: None taken. Swallowing? What was all that about?
- N: Don't know really I wasn't sure but I made a decision not to go there, I thought it would all take too long and I didn't know what that was all about. He's seeing the Mac nurse and the dietician so I guess subconsciously or maybe just quickly that it would be OK to leave that. But I did give him some advice like the fizzy drink, so I did address it.
- CW: Oh yes, I was just wondering as I looked through. Don't worry.
- N: [laughs]. Actually I think he was pleased with the fizzy drink idea. I thought it was a good one. I learned that on my course [N59]. I was very pleased with that. Gave me a lot of satisfaction that did. [laughs]
- CW: So looking at the transcript what would you say you did well
- N: I think it was the advice about the food and things, and that gave him confidence and some reassurance because he's lost so much weight.
- CW: OK. Anything you thought was not so good
- N: Well the bit about religious things I touched a nerve there and that really upset me. I wouldn't have done that for anything, and I'm sorry. You see that's it with this questionnaire thing, you don't know what you're going to uncover and what offence might be caused. It's sort of dangerous and can have unpleasant consequences. I did worry about him afterwards, whether I'd upset him.
- CW: Yes it's something I noticed, too, so I'm sorry it did that. Do you feel OK now?
- N: Yes what can you do? You move on. But it does make you more guarded I think. At least the old way we didn't have to worry about that there was none of that sort of thing – well not none but less of it.
- CW: Yes I think that's perhaps right, but some of that will be perhaps because you were in control sort of over the things that were talked about whereas here it's on the paper
- N: Yes that's right and that's what makes this so difficult
- CW: OK
- N: And all those things made me wonder if that's why he was sarcastic to me later on, whether he was having a little go back at me?
- CW: Don't know maybe.
- N: Well that's that. All finished now?
- CW: Yes, unless there's anything else you want to add.
- N: No, that's all
- CW: Many thanks
- N: No problem