



## City Research Online

### City, University of London Institutional Repository

---

**Citation:** Anstey, K.M. (2003). The nurse's role in promoting the involvement of older patients and informal carers in the assessment of their individual continuing health and social care needs. (Unpublished Doctoral thesis, City University London)

This is the accepted 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/8407/>

**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](mailto:publications@city.ac.uk)

---

**The Nurse's Role in Promoting the Involvement of Older Patients  
and Informal Carers in the Assessment of their Individual  
Continuing Health and Social Care Needs**

**Katharine Mountfort Anstey**

**City University  
Library Information Services  
Whitechapel**

**Thesis submitted for the qualification of Doctor of Philosophy**

**City University  
School of Nursing and Midwifery**

**Submitted January 2003**

# TABLE OF CONTENTS

ACKNOWLEDGEMENT .....	6
DECLARATION.....	7
ABSTRACT.....	8
LIST OF ABBREVIATIONS.....	9
THE STRUCTURE OF THE THESIS.....	11
CHAPTER 1 .....	13
INTRODUCTION.....	13
INTRODUCTION .....	13
AIMS OF THE STUDY .....	13
DEFINITION OF TERMS .....	14
<i>Older People</i> .....	14
<i>Patient</i> .....	14
<i>Informal Carer</i> .....	15
<i>Assessment</i> .....	15
<i>Continuing Care</i> .....	16
THE DEVELOPMENT OF POLICY ON THE ASSESSMENT OF CONTINUING CARE NEEDS .....	17
<i>The History of Assessment of Continuing Care Needs</i> .....	17
<i>National Policy on Assessment at the Time the Field Work was Undertaken</i> .....	18
<i>Local Assessment Policy at the Time the Fieldwork was Undertaken</i> .....	19
<i>The Development of Continuing Care Assessments</i> .....	20
BACKGROUND TO THE STUDY .....	23
<i>Origins of the Proposal</i> .....	23
<i>Influences on the Proposal</i> .....	23
<i>Initial Expectations</i> .....	27
THE IMPORTANCE OF OLDER PEOPLE'S INVOLVEMENT IN CONTINUING CARE ASSESSMENTS.....	28
THE IMPORTANCE OF FACILITATING OLDER PEOPLE'S INVOLVEMENT IN CONTINUING CARE ASSESSMENTS .....	29
SUMMARY .....	30
CHAPTER 2 .....	31
PATIENT INVOLVEMENT: THE CONCEPT .....	31
INTRODUCTION .....	31
USE OF SYNONYMS.....	31
LEVEL OF INVOLVEMENT .....	32
<i>Individual Involvement</i> .....	32
<i>Collective Involvement</i> .....	32
APPROACHES TO DERIVING DEFINITIONS .....	33
<i>Adopting Pre-existing Definitions</i> .....	33
<i>Identifying Core Elements</i> .....	33
<i>Use of 'Degrees of Influence' as a Differentiator</i> .....	34
<i>Ordering Concepts</i> .....	35
TOWARDS CONCEPTUAL CLARITY .....	36
THE POLICY LITERATURE ON INVOLVEMENT .....	37
<i>Policy Relating to Involvement</i> .....	37
<i>Guidance on Involvement in Continuing Care Assessments</i> .....	40
SUMMARY .....	42

<b>CHAPTER 3</b> .....	<b>44</b>
<b>LITERATURE REVIEW</b> .....	<b>44</b>
INTRODUCTION .....	44
LITERATURE REVIEW METHODS .....	44
<i>Overall Approach</i> .....	44
<i>Search Strategy</i> .....	45
<i>Inclusion Criteria</i> .....	46
<i>Critiquing the Research</i> .....	48
FINDINGS.....	48
<i>Attitudes to Patient Involvement in Decision Making</i> .....	48
<i>Barriers to Older People's and Informal Carers' Involvement</i> .....	57
<i>Patient and Informal Carer Involvement in Continuing Care Assessments</i> .....	59
SUMMARY .....	67
<b>CHAPTER 4</b> .....	<b>68</b>
<b>METHODS</b> .....	<b>68</b>
INTRODUCTION .....	68
PHILOSOPHICAL UNDERSTANDING .....	68
METHODOLOGICAL DETAILS.....	71
<i>Methodological Approach</i> .....	71
<i>Selection of the Study Site and Negotiating Access</i> .....	72
<i>The Research Setting</i> .....	74
<i>Use of Multi Methods</i> .....	77
<i>Strand 1: The context of patient and informal carer involvement</i> .....	78
<i>Strand 2: Patients' and Informal Carers' Experience of Involvement - The Patient Tracking Data</i> .....	82
<i>Data Analysis</i> .....	89
<i>Issues of Validity and Reliability</i> .....	91
<i>Generalizability</i> .....	94
<i>Ethical Issues</i> .....	96
SUMMARY.....	98
INTRODUCTION TO THE FINDINGS .....	100
<b>CHAPTER 5</b> .....	<b>102</b>
<b>ASSESSMENT OF PATIENTS' CONTINUING CARE NEEDS</b> .....	<b>102</b>
INTRODUCTION .....	102
NURSES LIMITED ROLE IN ASSESSING CONTINUING CARE NEEDS .....	102
<i>Nurses not making use of their ideal position</i> .....	103
NURSES CLAIMS OF COLLABORATING EFFECTIVELY NOT BORNE OUT IN PRACTICE .....	110
NURSES' MARGINAL ROLE IN CONTINUING CARE ASSESSMENTS .....	116
SUMMARY.....	122
<b>CHAPTER 6</b> .....	<b>124</b>
<b>NURSES' ROLES IN INVOLVING PATIENTS AND INFORMAL CARERS IN CONTINUING CARE ASSESSMENTS</b> .....	<b>124</b>
INTRODUCTION .....	124
NURSES' LACK OF ACCESSIBILITY .....	124
NURSES NOT PICKING UP CUES.....	130
NURSES NOT SEEKING THE OPINIONS OF PATIENTS AND INFORMAL CARERS .....	134
NURSES' FOCUS ON DOCUMENTATION AND NOT PATIENTS OR INFORMAL CARERS.....	137
NURSES NOT KEEPING PATIENTS AND INFORMAL CARERS INFORMED .....	139
NURSES NOT FACILITATING THE INVOLVEMENT OF PATIENTS AND INFORMAL CARERS.....	143
SUMMARY.....	148

<b>CHAPTER 7</b> .....	<b>149</b>
<b>PLACING THE ISSUES IN CONTEXT</b> .....	<b>149</b>
INTRODUCTION .....	149
STRATEGIC ISSUES .....	149
<i>Policies Restricting Choice</i> .....	149
<i>Limited health and social care budgets</i> .....	152
<i>Restricted services available</i> .....	153
PATIENT AND INFORMAL CARER ISSUES .....	154
<i>Communication Difficulties</i> .....	154
<i>Cognitive ability</i> .....	156
<i>Keeping things private</i> .....	157
<i>Patient passivity</i> .....	159
PRACTICE ISSUES .....	160
<i>Medical domination in meetings</i> .....	160
<i>Nurses' lack of understanding of their role</i> .....	161
<i>Limited contribution in multidisciplinary meetings</i> .....	162
<i>Lack of reviews of multidisciplinary meetings</i> .....	164
<i>Lack of collaboration between professionals</i> .....	165
<i>Lack of time</i> .....	166
<i>Poor knowledge</i> .....	167
<i>Lack of support for autonomous practice</i> .....	168
<i>Low morale</i> .....	170
SUMMARY .....	171
<b>CHAPTER 8</b> .....	<b>172</b>
<b>THE WAY FORWARD: DEVELOPING EXPERTISE</b> .....	<b>172</b>
INTRODUCTION .....	172
STRENGTHS AND WEAKNESSES OF THE STUDY .....	172
SUMMARISING THE MAIN ISSUES FROM THE FINDINGS .....	175
PRE-REQUISITES FOR EFFECTIVE PRACTICE: FOCUSING ON 'THE SENSES' .....	178
<i>Sense of Purpose</i> .....	182
<i>Sense of Continuity</i> .....	185
<i>Sense of Security</i> .....	193
<i>Sense of Achievement</i> .....	199
<i>Sense of Significance</i> .....	203
<i>Sense of Belonging</i> .....	204
EXPLORING THE SEVENTH SENSE: THE NOTION OF EXPERTISE .....	208
CONCLUSION .....	214
RECOMMENDATIONS .....	216
 <b><u>APPENDICES</u></b>	
1. TRUST DISCHARGE PLANNING POLICY .....	217
2. ELIGIBILITY CRITERIA .....	225
3. DOMAINS OF THE SINGLE ASSESSMENT PROCESS .....	229
4. KEYWORDS USED IN THE LITERATURE SEARCH .....	231
5. MEDLINE SEARCH STRATEGY .....	232
6. CRITERIA FOR THE EVALUATION OF QUALITATIVE RESEARCH PAPERS DEVELOPED BY THE MEDICAL SOCIOLOGY GROUP .....	233

7. TOPIC GUIDE FOR GENERAL STAFF INTERVIEWS .....	236
8. GENERAL INTERVIEW WITH A D GRADE NURSE (N7).....	238
9. PATIENTS' HEALTH AND SOCIAL CIRCUMSTANCES .....	248
10. TOPIC GUIDES FOR PATIENT FOCUSED INTERVIEWS.....	253
11. EXAMPLE OF A PATIENT FOCUSED INTERVIEW .....	256
12. THE NUD.IST TREE.....	259
13. EXAMPLES OF CATEGORIES USED IN DATA ANALYSIS, THEIR DEFINITIONS AND UNITS OF TEXT THAT WERE ASSIGNED TO THEM .....	264
14. ASSESSMENT MATRICES .....	267
15. INFORMATION TO PATIENTS TO PARTICIPATE IN AN AUDIOTAPED INTERVIEW .....	274
16. INFORMATION FOR STAFF -TO BE DISPLAYED IN THE STAFF ROOM - [NAME] WARD	275
17. INFORMATION FOR PATIENTS .....	276
<b>BIBLIOGRAPHY .....</b>	<b>277</b>

## **ACKNOWLEDGEMENT**

I would like to thank my academic supervisors, Professor Julienne Meyer and Dr Angela Cotter for their invaluable advice and support throughout this study.

I am also indebted to the patients, informal carers and professionals who participated in this study and generously gave of their own time. Without their support, this research would not have been possible.

In addition, I would like to thank my partner, Mark Woodall, for his unwavering patience and understanding.

Finally, I am also grateful to the Joint Research Board of St Bartholomew's Hospital for the award of a doctoral studentship, which allowed me to undertake this research.



## **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.

## ABSTRACT

This thesis looks at the concept of involvement as it applies to older patients and their informal carers in the assessment of their own continuing care needs. In particular it is concerned with the nurse's role within the multidisciplinary team in facilitating the involvement of patients and informal carers in this process.

The study was conducted in a district general hospital in London. Patient involvement in continuing care assessments was explored by following the care of 20 individual patients and their informal carers throughout their hospital stay, and after discharge in the community. Observations of key decision making activities in respect of these patients were contrasted with interviews with multidisciplinary staff who had been involved in their care, to provide insights into assessment practice. Interviews with patients and informal carers gave an indicator of how involved they felt in their own assessments. In addition, interviews with 32 multidisciplinary staff provided more general data on professionals' perceptions of their own roles with regard to involving patients in assessments.

Analysis of the data revealed nurses were not being seen to be contributing to the assessment of patients' continuing care needs. Nurses' marginal position in continuing care assessments meant that it was particularly difficult for them to facilitate the involvement of patients and informal carers. What makes these findings all the more remarkable is the fact that nurses' continual presence on the ward was almost universally seen by the multidisciplinary team as offering them unrivalled opportunities to build a rapport with patients and thereby develop better understandings of their needs. Furthermore findings suggest that continuing care assessments and patient and informal carer involvement in this process may be affected by strategic and practice issues, as well as factors relating to patients and informal carers themselves.

One explanation for these findings may be offered by Nolan et al.'s (2002) 'senses' framework. The application of the framework to the data suggests that a lack of attention to, 'the fundamentals of care' may affect professional practice. In particular, applying the framework to this multidisciplinary context suggests that a lack of these 'fundamentals of care' in one discipline may also affect the practice of other members of the multidisciplinary team. Moreover, the findings indicate that the framework may be incomplete and that it may require modification by the addition of a 'sense of expertise'. It is intended that generalizations may be made at a theoretical level from this case study.

## **LIST OF ABBREVIATIONS**

A&E	Accident and Emergency (Department)
CSAG	Clinical Standards Advisory Group  The CSAG provides independent advice to Ministers on aspects of the NHS. The group's members are nominated by the medical, nursing and dental Royal Colleges and professions allied to medicine.
DoH	Department of Health  The Department of Health is the Government department responsible for the delivery of health and social care services within England.
GP	General Practitioner
HA	Health Authority  Until April 2002, health authorities managed the NHS locally, and were the key link between the Department of Health and the NHS. In April 2002, they were replaced by strategic health authorities.
HAS 2000	Health Advisory Service  HAS 2000 is a charity, under management responsibility of the Royal College of Psychiatrists, the RCN, the British Geriatrics Society and the Office for Public Management. It conducts systematic service reviews.
HO	House Officer
LA	Local Authority  Local authorities are public sector bodies governed by elected members, which are responsible for the provision of statutory services.
MDT	Multidisciplinary Team  A group of professionals from different disciplines, such as medicine, nursing, social work and occupational therapy who work together.
NHS	National Health Service
OT	Occupational Therapist
RCN	Royal College of Nursing

The RCN is a trade union that promotes understanding of the value and skills of nurses and provides personal and professional support for its members.

SHO

Senior House Officer

SNMAC

Standing Nursing and Midwifery Advisory Committee

SNMAC is a Statutory Body which advises Ministers on the provision of nursing and midwifery services. Members are appointed by Ministers following nominations by professional bodies.

SSD

Social Services Department

Social services departments are the local authority departments responsible for the provision of social services.

SSI

Social Services Inspectorate

The SSI is part of the Department of Health. It provides advice to ministers on issues relating to personal social services, assists local government in delivering social care services, runs a national inspection programme and monitors the implementation of government policy for the personal social services.

UKCC

United Kingdom Central Council for Nursing, Midwifery and Health Visiting

The UKCC's main roles were to maintain a register of UK nurses, midwives and health visitors and to handle professional misconduct complaints. In April 2002 the UKCC was replaced by the Nursing and Midwifery Council.

## THE STRUCTURE OF THE THESIS

The first chapter provides an introduction to the thesis. It sets out the aims of the study and defines key terms. The study is placed in context by outlining policy at the time of data collection as well as relating subsequent developments. The chapter goes on to explore the background to the study and how the particular research topic was selected. It concludes by discussing the importance of older patients' involvement in continuing care assessments.

Chapter two focuses more specifically on patient involvement. The chapter looks at dimensions of involvement, distinguishing collective involvement from involvement at an individual level. It then examines involvement at an individual level in more detail, discussing different ways of distinguishing between synonyms, as the concept of involvement is clarified. The chapter concludes by examining the policy literature on individual patient involvement.

Chapter three gives details of the literature review that was conducted at the beginning of the study. Initially the methods used to conduct the review, including the search strategy and inclusion criteria are set out. The remainder of the chapter focuses on the results of this review. The first part of the results deals with attitudes towards the involvement of patients and informal carers in decision making. It is argued that the studies conducted in this area are fragmented and that it is difficult to draw any firm conclusions from them. The second part of the results focuses on the involvement of patients and informal carers in continuing care assessments. Studies of assessments conducted in the community are reviewed as well as broader research on the process of discharge from hospital. It is noted that fewer hospital based studies of assessment have been conducted, and in particular the review indicates that there is almost no UK research focusing on the nurse's role, highlighting the need for work in this area.

The methodological details are set out in chapter four. The philosophical understanding, on which the methods are based, is outlined before describing the process of selecting and gaining access to the study site. The main body of the chapter is concerned with the methods and process of data collection. The two strands of data collection are outlined. These are namely the context of patient and informal carer involvement, and patient tracking data exploring patients' and informal carers' experiences of being involved in practice. The approaches to data analysis are described before the chapter sets out the measures used to demonstrate the validity and reliability of the results. The extent to which the findings are generalizable to other environments is discussed, and the chapter concludes by considering ethical issues involved.

The findings from the study are presented in chapters five, six and seven. Chapter five presents the findings of the study that detail how members of the multidisciplinary team conducted continuing care assessments. The chapter begins by looking at professionals' approaches to identifying information that is significant to continuing care assessments. In the next part of the chapter, nurses' claims to liaise effectively with their multidisciplinary colleagues are critically examined. Finally, evidence of the ways in which professionals see their own roles in multidisciplinary assessments is presented. These indicate that nurses are reluctant to identify themselves as having responsibilities in this area.

Chapter six presents the findings that show how members of the multidisciplinary team involved patients and informal carers in individual assessments of patients' continuing care needs. Initially, professionals' strategies for obtaining information from patients and informal carers are examined before considering their approaches to sharing information with them. The chapter concludes by highlighting professionals' perceptions of their own roles in involving patients and informal carers in continuing care assessments. Again it appears as though nurses do not see themselves as having a role in facilitating patients' and informal carers' involvement.

In chapter seven evidence about the factors affecting both continuing care assessments and the involvement of patients and informal carers in this process is presented. The data fall into three broad categories; strategic issues; patient and informal carer issues and operational issues.

Chapter eight discusses the findings of this study in relation to the existing literature. This is done within the context of Nolan et al.'s (2002) 'senses' framework, which may explain why nurses appeared to have a limited role in multidisciplinary continuing care assessments. Suggestions are made about how the framework could be developed, before drawing conclusions and making recommendations for research, education and practice.

# **CHAPTER 1**

## **INTRODUCTION**

### **INTRODUCTION**

This chapter begins by outlining the aims of the study and defining key terms that are used throughout the thesis. It then sets the study in context, describing the history of continuing care assessments; the policy that was in place at the time that the fieldwork was undertaken and subsequent developments. Next, the background to the project is set out, outlining how influences from a number of spheres combined to affect the choice of research topic and how pursuit of this research interest was made possible. The chapter goes on to explore the importance of ‘involvement’, which forms a central part of this thesis. It concludes by arguing that the involvement of older patients and informal carers in assessments of continuing care needs is vital on a number of grounds.

### **AIMS OF THE STUDY**

The study sets out to examine the nurse’s role in facilitating the involvement of older patients and informal carers in assessment of their individual continuing health and social needs. It has five specific aims:

1. To explore the nurse’s roles and responsibilities within the multidisciplinary team in the assessment of patients’ individual continuing health and social care needs.
2. To explore the nurse’s experience of involving older patients and informal carers in the assessment of their individual continuing health and social care needs.
3. To compare and contrast the experiences of nurses, doctors and social workers of involving older patients and informal carers in the assessment of their individual continuing health and social care needs.
4. To explore the experiences of older patients and informal carers of being involved in the assessment of their individual continuing health and social care needs.

5. To identify factors that facilitate or inhibit the involvement of older patients and informal carers in the assessment of their individual continuing health and social care needs.

### **DEFINITION OF TERMS**

In many reports and research papers terms are used, sometimes interchangeably, without any explanation of how they are understood by the authors. This suggests that the authors view their interpretation as unambiguous. However, Farrell and Gilbert (1995) in their review of patient involvement found little agreement on the use or definition of key terms such as, 'patient', 'user' and 'client'. This diversity of meanings highlights the importance of stating clearly at the outset how terms are to be used. The definition of key terms used within this thesis is given below.

#### **Older People**

It is important to recognise that older people are not a homogenous group (Gilleard and Higgs, 1998). As with other groups of people, the circumstances in which they live are individual. Whilst acknowledging the distinctive nature of individual situations, the Department of Health (2001a) describe three broad sub-groups of older people. 'People entering old age' are those who have completed their employment and who enjoy an active retirement. Those in the 'transitional phase' are people who are moving between activity and dependency. The Department of Health (ibid) states that people often reach this stage in their seventies or eighties. Meanwhile, 'frail older people' are those who are more vulnerable as a result of health problems or disabilities that limit their independence. Whilst this is not a precise typology, it gives an indication of the range of individuals who can collectively be thought of as being 'older people'.

It should be noted that the patients participating in this study were all aged between 74 and 101 years and were either already receiving, or were considering the use of, continuing care services. Thus this study focuses on the needs of the sub-group, 'frail older people'.

#### **Patient**

The term used to describe an individual in receipt of health or social care to some extent gives an indication of the nature of the relationship between that individual and the service provider or commissioner. There has been some debate as to whether such individuals are, 'clients', 'consumers', 'users', 'patients' or indeed 'citizens', (e.g. Barnes and Wistow, 1992; Saltman,



1994). Farrell and Gilbert (1996) argue that the choice of term such as 'client' or 'patient' will reflect the role in which they are cast by the system that they use. As this research was conducted in an NHS Trust, the term applied to individuals using this service will reflect their position within the organisation.

Stevenson and Parsloe (1993) in their review of empowerment in community care are dismissive of some terms, seeing them as inappropriate. They contend that, for health and social services users 'citizen' appears to be too politically idealistic. In turn 'consumer' is seen as having too many connotations of the market place. For these reasons these terms are not used within this thesis. Instead the term 'patient' is used. This term was chosen as it is widely used within hospital settings by both professionals, and by individuals to describe themselves during the time that they use these services. Moreover, Farrell and Gilbert (1996) argue that the term 'patient' is appropriate to users of health care services as it acknowledges the traditional structures within which care is delivered.

### **Informal Carer**

Twigg and Atkin (1994) identify that the concept of caring draws on a number of elements. Amongst these is the notion that caring encompasses a supportive element. Thus caring entails doing things for people that they cannot do for themselves. In addition, Twigg and Atkin argue that kinship obligation is another element of caring. They contend that informal caring almost always takes place within a context of kinship. The term, 'informal' is used to distinguish unpaid caring from that for which payment is received. Within this study, informal carers are taken to be people, usually family or friends, who voluntarily provide unpaid support within the context of a kinship relationship.

### **Assessment**

Throughout this thesis assessment is used in accordance with the definition given by the Department of Health (2002a). Thus assessment is used to refer to:

*"a process whereby the actual or potential needs of an individual are identified and their impact on independence, daily functioning and quality of life are evaluated, so that appropriate action can be planned."*

Department of Health (2002a: 12)

This definition is used in preference to that given by the Royal College of Nursing, who contend that assessment is:

*“the process of collecting information about the individual and from that information making decisions about their health status and the best ways of working with the individual towards improving and maintaining his or her health”*

*(Royal College of Nursing, 1990: 4)*

This definition has a narrower focus than that used by the Department of Health, encompassing only health and not social care needs. In concentrating exclusively on health needs, the Royal College of Nursing’s definition was felt to be less appropriate for this study.

### **Continuing Care**

Many authors writing about continuing care fail to define the subject of their paper. Where definitions are given, these are sometimes muddled or contradictory. For instance Age Concern (1996) attempt to make a somewhat artificial distinction between continuous NHS nursing care and continuous nursing care, although it is not clear how this furthers understanding. In addition, Le Touze (1997) talks in very general terms about continuing care as:

*“care for a disability or chronic condition which extends over a prolonged period, requiring continuous, periodic or intermittent care”*

*(Le Touze, 1997: 8)*

This description seems too general to be of real value. In the light of this confusion, the UKCC (1997) carried out a concept analysis. They identified common themes which included that continuing care was seen as being unrelated to notions of cure. In addition, they argued that the goal of continuing care is to maintain as high a quality of life as possible in the presence of chronic physical, cognitive and social disabilities which commonly deteriorate over time. Taking account of these common themes the UKCC suggested that continuing care may be defined as:

*“care which occurs in institutional and non-institutional settings, that may be accessed by any age group and aims to assist a person to reach and maintain their maximum potential for self-care whilst recognising that some people may require continuing care for life.”*

*(UKCC, 1997: 16)*

This is the definition of continuing care that is used within this thesis.

## THE DEVELOPMENT OF POLICY ON THE ASSESSMENT OF CONTINUING CARE NEEDS

### The History of Assessment of Continuing Care Needs

In the post-war years, whilst ill or frail people may have been cared for by the NHS, those requiring long term care received this in residential Local Authority homes (Royal Commission on Long Term Care, 1999). Local Authority homes had waiting lists and residents were subject to means tests. The Royal Commission on Long Term Care argues that two developments changed this situation. The first of these was the increasing use of social security benefits to fund care. From 1983 people qualifying for supplementary benefit were eligible to have their care in private and voluntary sector residential and nursing homes paid for by social security. The only access criterion to these homes was a financial one, as no test of care need was applied. The second development was that during the 1980s the NHS became increasingly cost conscious. The availability of social security benefits for residential placements provided a means by which the costs of caring for older people could be transferred from the NHS (ibid).

The consequence of these developments was a dramatic expansion in nursing and residential beds and an associated growth in the cost of this provision. Expenditure on nursing and residential care grew from £10m in 1979 to £2500m in 1993 (Wistow, 1995). Concern prompted the government to commission Sir Roy Griffiths to review health and social services. His report formed the basis of the 1990 NHS and Community Care Act (Griffiths, 1988). Significantly the Act transferred resources from the benefit system to local authorities. In this way, social services departments became designated as the lead agencies in the purchase of social care. Funding was no longer automatically provided for residential and nursing home care, as access became based on an assessment of need and subject to means testing. Indeed, the Department of Health stated that one of the key aims of their reform of community care was:

*“to make proper assessment of need and good case management the cornerstone of high quality care”*

(Department of Health, 1989: 5)

However, the community care reforms also highlighted the anomalous divide between health and social care, which served to make assessments of need problematic (Jacques and Ryan, 1997). Assessments became problematic because patients assessed as requiring social care were subject to means testing whilst similar care was available free at the point of delivery in the NHS. For instance, care provided by registered nurses in nursing homes was subject to means testing as it was commissioned by social services departments, whereas the same nursing care

provided in NHS continuing care units was seen as health care and therefore no means test applied. Similarly in the community, personal care tasks undertaken by care assistants funded by social services were usually means tested, whereas the same tasks undertaken by district nurses were seen as health care and free at the point of delivery.

Crucially the reforms failed to remove the incentive for the NHS to make economic savings by passing on responsibilities for care to social services (Royal Commission on Long Term Care, 1999). Boundary disputes were notably highlighted in the 'Leeds case' in which Leeds Health Authority sought to discharge a man with severe brain damage to private nursing home care when he no longer needed acute hospital treatment, thereby making him subject to means testing (Health Services Commissioner, 1994). The NHS was seen to have withdrawn too far from its responsibilities to provide continuing care (House of Commons Health Committee, 1996). This led to the requirement for health authorities to identify their own responsibilities for meeting continuing health care needs, and to set out clear assessment criteria upon which funding decisions would be made (Department of Health, 1995).

#### **National Policy on Assessment at the Time the Field Work was Undertaken**

The fieldwork took place between February 1998 and March 1999. At this time, health authorities had developed assessment criteria from the guidance issued by the Department of Health (1995). This guidance identified a range of situations in which the NHS was required to provide continuing care. These situations included providing continuing care for people:

*“- who have a rapidly degenerating or unstable condition which means that they will require specialist medical or nursing supervision.*

*- who require routinely the use of specialist health care equipment or treatments which require the supervision of specialist NHS staff.”*

(Department of Health, 1995: 15)

These guidelines gave rise to initial concerns at a strategic level. The Department of Health failed to clarify relative terms such as 'rapidly' 'specialist' and 'routinely', leaving health authorities individually to determine eligibility criteria at a local level. Subsequent analyses of health authorities' eligibility criteria, used to inform assessments revealed a number of concerns. The Department of Health (1996a) reported that a significant number of health authorities' eligibility criteria were couched in general terms which could impede open and consistent decision making. In addition, documents were criticised for failing to outline how the criteria were to be applied in practice (Department of Health, 1996b; Henwood, 1996).

Furthermore there were worries that the lack of national criteria may result in inequitable

provision between localities (Royal College of Nursing, 1995; Clinical Standards Advisory Group, 1998). However, as local documents began to be revised more attention was focused on practice at an operational level.

At an operational level, the guidance on eligibility from the Department of Health (1995), instructed that decisions about how patients' continuing care needs might best be met ...

*“should be taken following an appropriate multi-disciplinary assessment of the patient's needs.”*

(Department of Health, 1995: 8)

As such, all front line staff were required to become familiar with the new assessment procedures and eligibility criteria. However, reporting in October 1996, on the initial impact of the continuing care guidance the Department of Health (1996a) found many front line staff to be unaware or uncertain of the new arrangements. The document identified that a key issue was the level of clinical ownership of the criteria and stressed that this needed to be addressed promptly if more serious difficulties were to be avoided. In October 1997, the Department of Health (1997a) outlined that one of its key areas of focus was to work to improve the content and process of multidisciplinary assessments of older people.

Thus, the fieldwork was conducted at a time when initial confusion about eligibility criteria was being replaced by an increased emphasis on the multidisciplinary practice of continuing care assessments.

### **Local Assessment Policy at the Time the Fieldwork was Undertaken**

During the initial stages of the fieldwork in early 1998, a new discharge planning policy was introduced within the Trust. This policy highlighted that assessment was inextricably linked with discharge, instructing staff that no patient should be discharged without an assessment of their needs being undertaken.

The policy also stressed the multidisciplinary nature of the discharge process, stating:

*“Discharge planning is a multi-agency, multi-disciplinary activity in which all professions have a contribution to make.”*

(Appendix 1)

More specifically, the discharge planning policy identified individual roles for specific professionals. Nurses were designated as having responsibility for both organising and co-

ordinating patients' discharges. In particular they were seen as being responsible for communicating with other professionals and for organising community nursing services. Medical staff were identified as being responsible for liaising with the patient's GP where continued medical intervention after discharge was seen to be required. Social workers were identified as being responsible for organising services delivered by the Social Services Department, including arranging placement where nursing or residential care was required.

In cases where nursing home or residential care was a possibility, as well as where NHS funded continuing care was being considered, a continuing care panel reviewed the recommendations of the multidisciplinary team. The continuing care panel was made up of senior health and social services staff and met fortnightly to approve proposed placements and agree their respective funding responsibilities. Fuller details of individual professional roles are contained in the discharge planning policy in Appendix 1.

The local eligibility criteria for residential, nursing home and NHS funded continuing care are given in Appendix 2.

### **The Development of Continuing Care Assessments**

Subsequent development has taken place within the context of an agenda of modernisation. The NHS Modernisation Agency was established to facilitate the delivery of service improvements announced in the NHS Plan (Department of Health, 2000a). In the light of these changes professionals have been encouraged to develop new ways of thinking and to find better ways of working (Department of Health, 2002b). Wide ranging changes are anticipated in areas such as quality and workforce planning (Department of Health, 2002c). These are set alongside targeted service improvements, highlighted in a range of national service frameworks, including the National Service Framework for Older People (Department of Health, 2001a).

#### **Introduction of a single assessment process**

In the NHS Plan (Department of Health, 2000a), the government announced the establishment of a single assessment process to determine continuing care needs. This is intended to improve the co-ordination of assessments and reduce the possibility of duplication by different professionals.

Guidance on the introduction of the single assessment process outlines four types of assessment (Department of Health, 2002a). These are the contact assessment, overview assessment, in-

depth assessment and comprehensive old age assessment. These range in their degree of depth. The contact assessment is the most basic and is concerned with the collection of essential information in order to explore the presence of wider health or social care issues. The assessments increase in complexity through to the comprehensive old age assessment, which involves in-depth assessment of all or most of the domains of the single assessment process. (The domains are listed in Appendix 3).

The guidance envisages that contact, overview and specialist assessments may be conducted by any appropriate professional. However, it also acknowledges that for comprehensive assessments in particular, input from specialists such as psycho-geriatricians and speech and language therapists will be appropriate.

#### Requirement for a nursing assessment

In setting out the implications for nurses the further guidance states:

*“Nurses in all settings ... will contribute to all the four types of assessment, undertake many overview assessments, and play a key part in care co-ordination ... Nurses, themselves, will undertake many in-depth assessments as appropriate.”*

(Department of Health, 2002d: 1)

Nurses are therefore seen as being integral contributors to multidisciplinary assessments of patients' continuing care needs.

More particularly nurses are required to be involved in assessments in which patients are likely to have a need for continuing nursing care. This requirement was set out in the National Service Framework for Older People which stated:

*“Suitably trained registered nurses will be involved in any assessment process which has identified registered nursing needs, including the decision on the appropriate setting for the delivery of that nursing care.”*

(Department of Health, 2001a: 34)

Nurses' contributions have recently taken on an added significance given that these assessments now include assessments of the Registered Nursing Care Contribution for older people who are admitted to nursing homes. One of the recommendations of the Royal Commission on long term care that was accepted by the government was that the care provided by registered nurses in nursing homes should become free at the point of delivery. By making registered nursing care free in all settings this removed the anomaly of means testing applying to the care nursing home residents received by registered nurses, but not to the care provided by registered nurses

in hospital and community settings. Since October 2001, for older people in nursing homes, that element of their care that is given by registered nurses has been provided free of charge up to a maximum of £110 per week (Department of Health, 2001b).

The Department of Health outlined that assessments of the Registered Nursing Care Contribution should be undertaken by specialist nurses who had undertaken appropriate training:

*“The determination of the registered nursing contribution will always be undertaken by a designated registered nurse ... The nurses who are most likely to be designated will be highly experienced and will include, for example: nurse specialists; nurse consultants; district nurses; discharge liaison nurses; Community Psychiatric Nurses, and Community Learning Disability Nurses. ... it will be essential that the people concerned are nominated and trained to undertake the determination of registered nursing need.”*

(Department of Health, 2001c: 11)

However, it is clear from this guidance that ward based hospital nurses also have a potentially important role in this area:

*“Most admissions are made from hospital, and there is an opportunity for the nursing staff who know the patient well and have been most closely involved in their care to exercise their professional judgement about the individual’s on-going needs for registered nursing”*

(Department of Health, 2001c: 11)

Thus assessments by both specialist and non-specialist ward based nurses are now instrumental in determining what level of registered nursing input those older people discharged to nursing homes will need.

In the future more power will be devolved to front-line staff to adapt and improve services to meet local needs. The government in its document, *Shifting the Balance of Power* (Department of Health, 2001d) outlines that staff empowerment will be key to delivering the reforms set out in The NHS Plan (Department of Health, 2000a). It states:

*“A real shift in the balance of power will not occur unless staff are empowered to make the necessary change. ... Staff need to be involved in decisions which effect service delivery. Empowerment comes when staff own the policies and are able to bring about real change.”*

(Department of Health, 2001d: 24)

A number of strategies are identified to encourage staff empowerment. Strategies aimed at increasing nurses’ involvement include the establishment of local nursing networks to empower staff and develop practice, appointing senior nurses in key positions in health bodies and developing a network of advisors to support the Chief Nursing Officer (Department of Health,



2000b). This policy of devolved power suggests that efforts to improve services are likely to be broad ranging. These efforts to effect reform may well include assessments of patients' continuing care needs, although it remains unclear what discretion individual front line staff will have, and how they will be able to exercise this.

Having outlined the policy context the next section describes the origins of, and influences on, the proposal.

## **BACKGROUND TO THE STUDY**

### **Origins of the Proposal**

In October 1996, funding was secured by City University, St Bartholomew School of Nursing and Midwifery from the Joint Research Board at St Bartholomew's Hospital for a PhD Studentship. This studentship allowed the development a proposal of personal interest that was also highly topical in the national agenda.

### **Influences on the Proposal**

In the next part of this section I set the study in context by reflecting on personal experiences and the influences that these have had.

#### **Personal interest in social and political issues**

I have always been broadly interested in social and political issues. After leaving school, I trained as a nurse. During my training I was stimulated by the teaching and in particular the research topic set for my final examination. This required me to investigate, 'Sociological Influences on Health in the Twentieth Century'. Whilst being very broad, it introduced me to new areas of research literature such as the Black Report (Black et al., 1982), which encompassed themes of inequality, social justice and the distribution of resources.

Intrigued by what I had learnt, I was keen to pursue this interest and in 1992 I commenced an undergraduate degree in Social Policy at the University of York. Three years there allowed me to develop a broad overview of welfare systems and their operation and permitted me to pursue individual areas of interest in more depth. For my final year dissertation (Anstey, 1995), I elected to interview a number of older social service users about the extent to which they felt able to influence the services they received. I had been impressed by the 1989 White Paper,

'Caring for People: Community Care in the Next Decade and Beyond' which promised to introduce a philosophy of greater independence and autonomy for service users. It stated:

*"Promoting choice and independence underlies all the Government's proposals ... The government therefore believes that the key components of community care should be: services that respond flexibly and sensitively to the needs of individuals and their carers; services that allow a range of options for consumers"*

(Department of Health, 1989: 4-5)

The older people I interviewed attended a day centre and were more independent than many other older people in receipt of social services. I was interested to see how far the government's proposals had filtered down and to what extent these articulate older people felt able to exert choice over aspects of the service they received. My findings showed how little influence they had in practice.

Later, after graduating, I began working for a health authority where I encountered similar issues, but from a different perspective. Here, the focus was on meeting collective rather than individual needs. Predictions about levels of need in the community were used to inform decisions about how much of which service to purchase. However, the collective data masked a myriad of differing individual circumstances and did not address whether the purchased services met people's own perceived needs. I felt that this was a real omission and therefore, when the opportunity arose, I sought to build on my undergraduate work and explore issues around individual involvement in more depth.

### Demographic influence of an ageing population

At the time of writing the proposal, one of the key issues facing the government was, as it continues to be, that of providing long-term health and social care for an increasingly ageing population. Demographic pressures mean that continuing care remains high on the political agenda and that there is an immediacy to the issue.

Older people make up a significant and growing proportion of the population. The National Service Framework for Older People outlines that currently a fifth of the population is aged over 60 (Department of Health, 2001a). It predicts that, over the thirty year timeframe between 1995 and 2025, the number of people over the age of 80 will increase by almost a half and the number of people aged over 90 will double. Whilst many older people live active, healthy lives not all older people are functionally independent. Some of the growing number of older people are likely to have disabilities which will have an impact on their lifestyle. Among people aged

65 or over in 1991, 10% of those living at home found at least one personal care task very difficult or impossible, 20% found at least one domestic task very difficult or impossible and 13% found at least one locomotive task very difficult or impossible (Jarvis et al., 1996). This creates a challenge for the government as the projected increase in the numbers of older people indicates that there will be an increasing need for both health and social care.

This challenge is made greater by the fact that the number of women aged between 45-69, who have formed the traditional pool of informal carers, has decreased in proportion to the number of people aged over 70 (Tester, 1996). This decrease is from a ratio of more than 2:1 in 1960 to 1.5: 1 in 1990, and is projected to continue downwards (ibid). This suggests that there may be an increasing reliance on statutory provision. The situation is likely to be compounded, as the future supply of informal carers seems set to be further reduced by the simultaneous social and cultural changes taking place in family life (Henwood, 1992). These include people's increasing geographical mobility and the growing number of women in the labour market. These demographic pressures in combination add to the political importance of continuing care provision, and contributed to the focus on older people within the research proposal.

#### Political influences on patient involvement

The challenge of providing continuing care for current and growing numbers of older people has given rise to financial pressures for successive governments. In particular, the spiralling cost of government spending on residential and nursing home care during the 1980s and early 1990s prompted the imposition of a cap on social security spending in this area as the first priority of the community care reforms (Wistow, 1995). However, more recently as part of the modernisation of the NHS there appears to be a move away from economic stringency, with the New Labour government announcing significant increases in spending on the NHS and on services for older people in particular (Department of Health, 2000a). For example the government outlined that by 2004 an extra £1.4 billion would be provided annually, specifically for older people (ibid). Yet, despite these additional resources concerns to control spending are still evident. Contained within policy documents are reminders that resources are finite, services are not available on demand and that there are restrictions on their use. Consequently, not all services are available to all people; rather, in accordance with the principles set out in the NHS Plan, priority is to be given to those with the greatest clinical need. Access is further limited as, older people must meet specific local eligibility criteria to be able to utilise many continuing health and continuing social care services. Similarly, economic considerations were evident in the government's failure to implement the recommendation of the Royal Commission

for Long Term Care (1999) that all personal care should be free at the point of delivery. Instead, the government opted for a less expensive alternative by restricting its commitment to that of meeting registered nursing costs. Together these indicators highlight that despite increases in spending on services for older people, financial stringency remains an imperative.

Running alongside concerns for financial stringency are parallel aims to tailor care around the needs of individual patients and their informal carers. The government, in the consultative document, *Shaping the Future NHS* summarises that the objective of respecting the preferences of older people and their carers, is a key theme running through policy initiatives relating to the development of health and social care for older people (Department of Health, 2000c). More recently this objective has been more firmly established as a standard within the National Service Framework for Older People. This Standard being:

*“NHS and social care services treat older people as individuals and enable them to make choices about their own care ...”*

(Department of Health, 2001a: 23)

However, as the government admits, there are fundamental tensions between some of its objectives for the NHS ...

*“... particularly the balance between access, quality and cost.”*

(Department of Health, 2000c: 41)

What remains unclear is the extent to which the two objectives of facilitating individual choice and of pursuing economic stringency are compatible and how far in practice older people will be allowed to influence decisions about their own continuing care. This tension contributed to the focus on involvement within the research proposal.

### Professional influence of the nurse's role in promoting patient centred care

Over about the last thirty years there has been a shift in the philosophy underpinning the practice of nursing. Armstrong (1983) argues that this shift in philosophy has changed the nature of nursing. He maintains that, formerly, nursing constructed patients in biological terms. The role of the nurse was to monitor patients for signs of physiological change. Thus the patient was an objectified entity. He argues that the philosophical shift, expounded in the nursing literature, placed increasing emphasis on the importance of communication and patient psychology. In this way nursing has gradually become more focused on the subjective aspects

of the individual and ‘knowing’ the patient has become a central element of nurses’ work (May, 1995).

Besides supporting an increased understanding of patients, the new philosophical thinking, which has been called ‘The New Nursing’ has promoted a change in the relationship between nurses and patients (Salvage, 1992). Whereas, formerly, patients were expected to be passive and compliant, ‘New Nursing’ advocates a more equal relationship in which patients assume a greater role:

*“‘New nursing’ ideology advocates participatory models of practice based on the active engagement of the client.”*

(Allen, 2000: 148)

Allen argues that facilitating patient participation is now an intrinsic part of the nursing role. Indeed, the government, in its strategy for nursing and midwifery, *Making a Difference* recognises that nurses’ closer working relationships with patients could offer more opportunities to promote their health (Department of Health, 1999). In particular, ‘New Nursing’ affords nurses the opportunity of using a collaborative approach in combination with their subjective knowledge of patients, to produce individualised packages of care:

*“Nurses are now encouraged to develop close relationships with patients so that they can understand the meaning their illness has for them and to use this knowledge to jointly plan individually tailored programmes of care.”*

(Allen, 2000: 148)

This new perspective influenced the focus on the role of the nurse in facilitating the involvement of patients and informal carers within the research proposal.

Thus, in summary, the combination of personal, demographic, political and professional factors all influenced my selection of, *the nurse’s role in facilitating the involvement of patients and informal carers in assessments of their individual continuing care needs* as a topic for my PhD study.

### **Initial Expectations**

I was aware of research studies conducted in the 1980s (e.g. Arenth and Mamon, 1985 and Waters, 1987) that suggested that nurses failed to accurately assess the continuing care needs of patients after their discharge from hospital, (see chapter 3 for a detailed review of the research literature). With little evidence published in the field in the intervening period, it was unclear how effective nurses might have become in assessing patients’ continuing care needs. Given the

demographic context and the significant developments in health care policy, emphasising the importance of multidisciplinary assessment, particularly the requirement for health authorities to develop eligibility criteria for NHS funding continuing care (Department of Health, 1995), it seemed reasonable to expect that the practice of nurses (and other professionals) would have developed in response to these pressures, and that assessment would have assumed a high priority.

In a similar way, it is interesting to note that the study by Waters (1987) found that very few patients could recall being asked by a nurse how they felt about their ability to manage after their discharge from hospital. Since this time, the government has placed increasing emphasis on tailoring care to the needs of the individual (Department of Health 2000c; 2001a). Professionally, within nursing, growing emphasis has also been placed on 'knowing the patient' (Salvage 1992; Allen 2000). Thus, it may have been expected that for the nurses in this study, involving patients in continuing care assessments would have been particularly important. In this way, within their practice, they may have been expected to have become increasingly aware of the concerns of individual patients.

It is in this light, that the findings of this thesis are all the more remarkable, and are of importance to policy makers, managers and practitioners as well as having implications for patients and their informal carers.

Having described the background and context of the study the next section outlines the importance of involving older people in continuing care assessments.

### **THE IMPORTANCE OF OLDER PEOPLE'S INVOLVEMENT IN CONTINUING CARE ASSESSMENTS**

Arguments for older peoples involvement in their own continuing care assessments include moral and economic rationales. Moral arguments dictate that patients should be involved purely on humanitarian grounds. These arguments are supported by prevailing societal attitudes. Ashworth et al. (1992) contend that the case for involvement is strengthened by society's ethos of individual freedom and responsibility. Involvement has been strongly endorsed by a number of bodies including the World Health Organisation (1979) who state that patient involvement is a duty of health care providers. This view is supported by researchers including Guadagnoli and Ward (1998), who in their review of the literature on patient participation in decision-making conclude that involvement is justified solely in view of a patient's right to self-determination.

Moreover, as the outcomes of continuing care assessments may be particularly significant for older people, their involvement is especially important. In many cases assessments will have long term consequences. These can entail a change in lifestyle and they may dictate where older people spend the remainder of their lives (Audit Commission, 1997). This is especially true for institutional placements, where there may not be regular reassessments of older people's needs (Department of Health, 1996a). As a result, there is a risk that single continuing care assessments may define older people's needs for sustained periods of time.

In addition, the outcome of continuing care assessments can have considerable financial implications for older people, again making their involvement in the process imperative. Patients assessed as needing NHS funded continuing care receive this free at the point of delivery whereas those patients whose needs are judged as best being met by residential or nursing home care will be subject to means tests for all or part of the costs of this care. Patients may be required to sell their homes to meet these costs.

In this way, the involvement of patients in continuing care assessments is important because of the moral, lifestyle and economic consequences associated with the process.

### **THE IMPORTANCE OF FACILITATING OLDER PEOPLE'S INVOLVEMENT IN CONTINUING CARE ASSESSMENTS**

For older people in particular, it is important that their involvement is supported. Ashworth et al. (1992) argue that it is almost inevitable that health care organisations will replicate the inequalities of power and status that are found more widely in society. Older people are particularly disadvantaged in this respect. Many of them experience considerable social and economic inequality compared with the rest of the population (Hughes, 1995). For example, The Royal Commission on the Funding of Long Term Care (1999) reports that nearly two-thirds of those people aged over 70 are among the poorest 40% of the population. As a consequence, in practice this means that older people may struggle to make their voices heard. Moreover older people face added barriers in seeking to be recognised as individuals, which is critically important with regard to assessments of their own continuing care needs. Richards (1996) argues that the preoccupation with reducing the economic costs associated with older people has led to the presumption that they constitute a distinct group, to be considered separately from the rest of the population. She cites Fennell et al. (1988) saying that this

perception of homogeneity leads to the loss of older people's individuality and subjective experience. This highlights the need for their involvement to be supported.

Compounding social and economic disadvantages, older people are also often vulnerable at the time when continuing care assessments are undertaken. For example, moves into institutional care have been associated with loneliness and fear. Fears of falls, attacks or an inability to cope have been themes identified in many people's accounts of moving into institutional care (Department of Health, 1994a). Similarly grief or bereavement may also prompt such a move (Allen et al., 1992). Failure to support older people's involvement at this time could therefore result in inappropriate decisions being made. Thus it is vital that older people and their informal carers are supported during the assessment process.

## **SUMMARY**

This chapter has set out the aims of the study and defined key terms that are used within the thesis. The background to the selection of the research topic has been described. Personal interests, understanding of demographic pressures, political and professional influences all had a bearing on the choice of research topic.

The policy context has been outlined and it is argued that policy envisages nurses as having a role in continuing care assessments both at the time of the data collection and subsequently, with the introduction of the single assessment process. The chapter concludes by arguing that the involvement of older patients in continuing care assessments is important on moral, lifestyle and financial grounds. Moreover, facilitating older patients' involvement may be necessary in the light of social and economic disadvantages and because they may be particularly vulnerable at the time when assessments are conducted.

The next chapter looks at the concept of 'involvement' and the way that it is defined within the policy literature.



## CHAPTER 2

### PATIENT INVOLVEMENT: THE CONCEPT

#### INTRODUCTION

This chapter sets out to clarify some of the ambiguity associated with the term ‘involvement’. It explores how the term has been understood within the research literature, and the use of synonyms and levels of involvement are discussed. The next section examines approaches to deriving definitions of involvement. It is argued that consideration of individuals’ respective degrees of influence offers one way forward. Attempts to place concepts in order are reviewed before outlining the way that involvement is used within this study. The final part of the chapter considers how involvement is defined within the policy literature.

#### USE OF SYNONYMS

The term ‘involvement’ is used diversely, making definitional clarity very difficult. In addition, it has a lot of frequently employed synonyms. These include among others, similarly ill-defined concepts such as, ‘participation’, ‘consultation’ and ‘partnership’. Farrell and Gilbert (1996) contend that whilst there is widespread agreement about the need for clarity of terms, publications have used a variety of different definitions and conventions. Indeed Cahill (1998) in her review of the literature concluded that patient participation was one of nursing’s most amorphous concepts.

The situation is further complicated as terms are often used interchangeably (Farrell and Gilbert, 1996). This is exemplified in Brownlea’s definition, where one word has been replaced by another without shedding any further light on the meaning:

*“Participation means getting **involved** or being allowed to become **involved** in a decision-making process or the delivery of a service or the evaluation of a service, or even simply to become one of a number of people **consulted** on an issue or matter.”*

(emphasis added)  
(Brownlea, 1987: 605)

Part of the difficulty with obtaining clarity is that synonyms are used to describe different levels of involvement.

## **LEVEL OF INVOLVEMENT**

### **Individual Involvement**

Few authors have devoted attention to defining ‘individual’ and ‘collective’ levels of interaction, but in general it can be stated that individual involvement relates to the personal interactions between patients and professionals.

Farrell and Gilbert (1996) argue:

*‘Individual involvement is about individual patients and their encounters with individual clinicians during episodes of illness or care.’*

(Farrell and Gilbert, 1996: 3)

However there are important omissions within this statement. Firstly it fails to acknowledge the possibility of a third party or proxy intervening on an individual’s behalf. This is particularly relevant in relation to older people where it is not unusual for family, friends or other informal carers to participate alongside the patient in the care planning process (although their interests do not always coincide). Independent advocates may also participate in this process on behalf of patients. Secondly, Farrell and Gilbert’s statement is restricted to patients and does not extend to include informal carers who may have their own needs assessment in which they interact with professionals on an individual basis.

In addition, the statement omits to say that individual involvement is undertaken to affect the course of an individual’s care. Therefore, for the purposes of this study, individual involvement will be taken to relate to the interactions between a single patient or carer, or someone acting on their behalf, and a member of authority, in negotiations for the patient’s benefit.

### **Collective Involvement**

Collective involvement relates to the engagement of members of a community in debate about the provision of services. Farrell and Gilbert (1996) state that:

*“Collective involvement is about participation of groups or communities in health care planning and/ or service delivery.”*

(original emphasis)  
(Farrell and Gilbert, 1996: 3)

The statement excludes the possibility of individual involvement in activities designed to bring about changes in the way that services are provided. For the purposes of this study collective

involvement will be taken to relate to any activity undertaken by an individual or a group, for the benefit of a community rather than to produce individual gain. However, this study deals primarily with individual rather than collective involvement.

Having outlined that the individual level of involvement forms the focus of this study, this chapter goes on to look in more detail at what is meant by the term 'involvement' and how it and its synonyms have been defined in the academic literature.

## **APPROACHES TO DERIVING DEFINITIONS**

### **Adopting Pre-existing Definitions**

The adoption of pre-existing definitions from the literature is one of the strategies used by researchers to describe the concept of involvement and its synonyms. For example, Brearley (1990) uses Brownlea's definition of participation. Whilst this approach is useful in principle as it aids consistency, the choice of definition needs to be made with care. In this case it may have been more helpful if Brearley had delineated her terms of reference more precisely.

### **Identifying Core Elements**

Rather than taking a definition from the literature as Brearley did, Jewell (1994) adopted a different approach. She convened a focus group of nurses to explore the meanings that they attached to patient participation. However, whilst the study produced some interesting findings about what the nurses viewed as the essential elements of participation, the fact that only one focus group was conducted with four nurses means that no firm conclusions can be drawn from this piece of work.

Others have attempted to clarify terms by identifying common attributes in the way that 'involvement' or its synonyms are used. One approach to this has been to use a model such as Walker and Avant's (1988) method of theory construction, which has been employed to explore involvement at both an individual level (Cahill, 1996) and a collective level (Chadderton, 1995). Walker and Avant break down concept analysis into an eight stage process. The stages include determining defining attributes and developing model cases. They argue that defining attributes are those characteristics that appear over and over again when the concept is described. Walker and Avant make no provision in this process for differentiating the more refined descriptions in the literature from those that are less well developed. Moreover neither Cahill nor Chadderton describe the process by which they derived their defining attributes thus

rendering the results open to question. Indeed Cahill produces a very broad list of five defining attributes of participation including that a relationship must exist and that there must be engagement in selective intellectual and/ or physical activities during some of the phases of the health care process. Taken together, Cahill’s defining attributes could apply equally to a broad range of terms and this approach does not appear to offer benefits in terms of differentiating between synonyms. Whilst Walker and Avant’s model appears of limited use, those approaches that have used people’s perceived degree of influence as a means of discriminating between various terms of reference have been more successful.

**Use of ‘Degrees of Influence’ as a Differentiator**

At a collective level, researchers have used ideas about degrees of influence to develop conceptual understandings of involvement (Arnstein, 1969; Taylor et al., 1992). These understandings could be applied to negotiations between individuals. Arnstein constructed a ladder of citizenship to highlight the different levels of participation. Degrees of influence range from ‘manipulation’ on the lowest rung of the ladder through to ‘citizen control’ on the uppermost rung, where participants are seen to have the greatest degree of influence. This can be represented diagrammatically as:

**A Ladder of Citizen Participation**

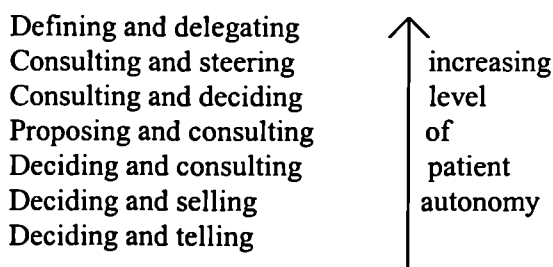
Citizen Control	<i>Degrees of citizen power</i>
Delegated power	
Partnership	
Placation	<i>Degrees of tokenism</i>
Consultation	
Informing	
Therapy	<i>Non- participation</i>
Manipulation	

(Arnstein, 1969: 217).

The author acknowledges that the model is an over-simplification of reality, and in many ways it can be seen as a product of its time. It has been criticised for unproblematically equating consultation with tokenism (Hamilton-Gurney, 1993), whilst others have argued with the order in which the hierarchical concepts are arranged (Burns, 1991).

Taylor et al. (1992), rather than seeking to order concepts, distinguish between six degrees of collective empowerment. These range from information being given about decisions that have already been made, at the lower end of the scale through to individuals having the authority to take decisions, at the upper end of the scale. However, Taylor et al's model does not cover the extremes of participation, that is, professionals making decisions but having no dialogue with individuals at all, at the lower end of the spectrum. At the upper end of the spectrum this would extend to individuals taking decisions without consulting professionals. Beattie (1991) gets round this problem by moving away from models reliant on discrete steps of involvement. Instead, he identifies a bi-polar continuum of approaches on an authoritative-negotiated dimension.

At an individual level, Gilbert (1995) argues that models from the literature on decision making can usefully be applied to the health care arena. She cites Woodcock and Francis' (1992) model of decision making styles which could be used to highlight the possible balances of power between patients and professionals. The model identifies seven distinct approaches that can be adopted by staff:



(Woodcock and Francis, 1992: 44)

This is helpful for looking at the degree of influence that patients have in decisions that relate to their own individual care. However, the problem remains of adequately differentiating between involvement and its synonyms.

### **Ordering Concepts**

Cahill (1996) devotes a section of her paper on the concept of participation to the definition of related cases, which she identifies as partnership and involvement/ collaboration. She arranges participation and its related concepts into a hierarchy with partnership at the apex and involvement/ collaboration at the base, drawing on nursing literature to justify this construction. Significantly no details are provided about how the literature was sampled. It appears as if this process was selective, at times relying heavily on single papers whose findings have been

adopted uncritically. This results in conclusions that seem debatable at best and, at times, illogical. For example she states:

*“Finally, since patient partnership is based on equality within a relationship (Quill 1983) the nurse must abnegate all power and control as opposed to only a degree of it. Froland et al (1981) confirm this by stating that within a partnership each partner needs to have equal control.”*

(Cahill, 1996: 567)

In this case, if the original assertion of equality within partnerships is accepted, this would indicate that the nurse retains an equal amount of power to that of the patient. However the next phrase contradicts the first, equating equality with complete patient autonomy, so that there are two incompatible arguments. The second sentence adds to the confusion by purporting to corroborate the statement on autonomy but ending up by supporting the original contention. Equally questionably, Cahill also claims that, involvement is a one-way process as the patient’s voice is mostly ignored and that patient participation is based on a contract between two people which may be verbal or written. Whilst Cahill’s attempt to order concepts is unsuccessful, Hamilton-Gurney’s comprehensive review is more productive.

### **TOWARDS CONCEPTUAL CLARITY**

More robust are Hamilton-Gurney’s (1993) descriptions of the concepts ‘participation’, ‘consultation’ and ‘involvement’, which are based on a comprehensive review of the literature. Hamilton-Gurney argues that the concepts are different from one another and that clarity of analysis can be obtained by ensuring that they are not used interchangeably. He uses people’s degree of influence to distinguish the terms, stating:

*“The fundamental distinction between these terms is the commitment to sharing the decision making”*

(Hamilton-Gurney, 1993:12)

For Hamilton-Gurney ‘consultation’ is indicative of an intention to obtain peoples’ views, without any given commitment to act on the results. He argues that it is up to those people consulted to make their case convincingly enough to influence outcomes.

In contrast, participation is a more dynamic activity drawing on the wider (dictionary) definition of the term as a ‘partnership’. Hamilton-Gurney maintains that participation demands joint or shared decision making between parties. He states that in cases where participation takes the form of activity, choice and potential influence then this may approach empowerment.

Finally, Hamilton-Gurney views involvement as the most general of the three concepts. He argues that it is a generic term covering all areas and levels of decision making from being present at meetings to playing a full participative role. Consequently no commitments about peoples' degree of influence are implied by the use of this term.

Throughout this study involvement is used as a generic term as outlined by Hamilton- Gurney to indicate a range of participative roles. Adopting a narrow definition would have unduly restricted the focus of the study and excluded clinical activities that inform the aims of the research. Chapters 6 and 7 give details of the ways in which involvement is understood and practised by staff in the clinical environment.

Having explored academic understandings of the concept, the next section examines the ways in which the topic of patient involvement is discussed in the policy literature.

## **THE POLICY LITERATURE ON INVOLVEMENT**

This section is divided into two parts. Initially policy relating to involvement is examined and the changing role of the patient is discussed. The second part of the section looks at guidance for professionals on how policy is to be implemented in practice.

### **Policy Relating to Involvement**

Patient involvement as a theme has gained greater prominence, particularly over the last two decades (Higgs, 1995). At the inception of the National Health Service, policy was aimed at creating social cohesion. Post-war reconstruction and the nationalisation of industries were directed at alleviating Beveridge's 'five giants': want, disease, ignorance, idleness and squalor (Beveridge, 1942). Gilleard and Higgs (1998) argue that a sense of social citizenship was engendered based on a benevolent relationship between the individual and the state. Individuals were loyal to the state, which in turn protected them in times of adversity. People's needs were regarded as identical and involvement played little part in this paternalistic relationship (Department of Health, 2000a). Gilleard and Higgs (op. cit.) contend that a sense of universalism was strengthened as everybody was in the same position. In the face of rationing and a lack of consumer goods, people's expectations were modest. They argue that this consensus began to fragment as people became more affluent and aspirational, with the politicians of the 1960s and early 1970s promising more choice and opportunity. However the economic crisis of the mid 1970s led to a re-evaluation of the role of welfare institutions resulting in a more managed approach to public services. Gilleard and Higgs maintain that it

was the election of the Thatcher government in 1979 which heralded the real shift in the relationship between the government and the citizen. People began to be encouraged to see themselves as consumers, choosing between a range of providers who competed for their custom.

Ideas of consumerism were exemplified in the reforms introduced in the 1990 National Health Service and Community Care Act (Great Britain, 1990). The establishment of quasi-markets was intended to stimulate competition and give an incentive for providers to be innovative in developing services to meet local needs.

At an individual level, personal choice was promoted. A philosophy of increasing patient autonomy lay behind the introduction of the community care policies:

*“The rationale for this reorganisation is the empowerment of users and carers. Instead of users and carers being subordinate to the wishes of service providers, the roles will be progressively readjusted. In this way, users and carers will be enabled to exercise the same power as consumers of other services”.*

(Department of Health/ Social Services Inspectorate, 1991: 9)

The election of the Labour government in May 1997, brought about a change in approach, although consumerist themes have continued to be visible. Whilst the internal market was abandoned, services were still intended to be shaped around the concerns of patients. The 1997 White Paper, *The New NHS: Modern Dependable* was unequivocal about this, arguing:

*“The needs of patients will be central to the new system. Abolishing the internal market will enable health professionals to focus on patients, making the NHS better every year.”*

(Department of Health, 1997b: 5)

It continues:

*“Rising public expectations should be channelled into shaping services to make them more responsive to the needs and preferences of the people who use them”.*

(Department of Health, 1997b: 7)

Moreover responsiveness was to be enhanced through the initiation of an annual patient survey. Subsequent policy documents have echoed this theme of increasingly tailoring statutory services. A year later the White Paper *Modernising Social Services* asserted:

*‘Everyone deserves to be treated as an individual, and to have the system geared to their needs, not vice versa’*

(Department of Health, 1998: 5).



The NHS Executive, in its guidance to health authorities and Trusts reminded agencies undertaking audits of continuing care assessments, of the importance of incorporating patients' wishes in these assessments:

*"The user is the central focus of assessment and agencies should reflect this in the style of their local reviews. Assessments must value the life choices that users have made and wish to make for themselves".*

(NHS Executive, 1998: Annex C)

More recently, the on-going development of services that respond to the needs of individual patients has emerged as one of the key themes of the NHS Plan (Department of Health, 2000a).

The Plan states:

*"Today, successful services thrive on their ability to respond to the individual needs of their customers. We live in a consumer age. Services have to be tailor-made not mass-produced, geared to the needs of users not the convenience of producers. The NHS has been too slow to change its ways of working to meet modern patient expectations for fast, convenient, 24 hour, personalised care".*

(Department of Health, 2000a: 26)

In addition, this theme is reiterated in the National Service Framework for Older People, with the second standard highlighting the importance of 'person-centred' care. This standard being:

*NHS and social care services treat older people as individuals and enable them to make choices about their own care. ...*

(Department of Health, 2001a: 23)

Although the language used in policy documents has changed over time, the current emphasis on the tailoring of services still requires older people to negotiate with professionals on an individual basis. However, the ability of older people to negotiate effectively, is circumscribed. Access to services is constrained by eligibility criteria, with patients being required to meet certain preconditions in order to be able to utilise provision. Whilst minimum service standards are set out for patients in, 'Your Guide to the NHS' (Department of Health, 2001e) once access has been obtained, patients frequently have been offered very little in the way of redress when shortfalls occur. Moreover, complaints have not always been adequately addressed, for example a national evaluation of the NHS complaints procedure found that many complainants expressed a high level of dissatisfaction with the procedure (Department of Health, 2001f). It remains to be seen whether recent initiatives such as the introduction of the National Care Standards Commission and Patient Advice and Liaison Services (PALS) in April 2002, can offer long term improvements for patients and informal carers, although these mark a recognition of the urgent need to support the interests of older people and their informal carers.

In the future, the government has indicated that older people should have a greater ability to tailor services to meet their own needs. The Department of Health has stated that local authorities will be obliged to offer older people access to direct payments, so that they have the opportunity to purchase services that best meet their individual needs (Department of Health, 2002e). However, concurrent developments suggest that, in practice, this choice could be limited. Plans to introduce 'cross-charging' mean that local authorities will be financially penalised for delays in patients' discharges incurred in the course of arranging care packages (Department of Health, 2002f). Given the current level of delayed discharges caused by difficulties arranging continuing care (Department of Health, 2002f), there is a danger that, despite additional funding, community resources may become stretched with older people being encouraged to accept inappropriate support. Moreover, it is unlikely that older people will fare significantly better than local authorities if they attempt to commission their own care with limited resources.

If patients are to be influential in negotiating tailored services they will need to be able to exert a degree of autonomy in defining their own needs. The next section examines the level of autonomy that it is envisaged that patients will be able to exert in practice when they are involved in making these decisions about their own needs. This will help indicate the extent to which the rhetoric of tailored care may become a practical reality for patients.

### **Guidance on Involvement in Continuing Care Assessments**

The first difficulty is to ascertain what level of involvement is being advocated in policy documents. Hamilton-Gurney (1993) argues that some ambiguity exists in the wording of some policy documents. Conceptual terms such as 'involvement' and 'consultation' are not only often not defined, but they are also used interchangeably. In other cases guidelines are vague or instructions seem contradictory.

For example a range of patient roles from active involvement to almost complete passivity are implied in the Hospital Discharge Workbook (Department of Health, 1994b). These can be arranged in a rough order to illustrate this point. The guidance envisages that patients will:

- Be given sufficient time and support to make important decisions
- Be taken seriously and listened to
- Receive a written and verbal explanation about what they can expect to happen during their hospital stay
- Experience no big surprises in what happens to them and that discharge happens according to plan



increasing  
patient  
passivity

These expectations all appear within the same paragraph of the guidance document, (Department of Health, 1994b: 4). It should be noted that patients can of course exercise different levels of autonomy at different points, however, the Department of Health's guidance indicates an extensive range of patient involvement in relation to a single episode of a patient's care. For both patients and staff, this very broad spectrum may add to the difficulties of knowing what is expected or required as they attempt to negotiate individual relationships.

The situation is further complicated by the large number of other recommendations and guidance documents dealing with the same issue that have been published by a range of institutions such as government agencies, voluntary organisations and professional bodies. These include standards for health and social care services for older people (Health Advisory Service (HAS 2000), 1999); older people's priorities for health and social care (Help the Aged, 2000); service standards for discharge care (Health Services Accreditation, 1996); a policy statement on the assessment of elderly people being considered for continuing care (British Geriatrics Society, Association of Directors of Social Services and the Royal College of Nursing, 1995a); a review of the hospital discharge arrangements for older people (Department of Health/ Social Services Inspectorate, 1998); recommendations from a review of care services for older people (Audit Commission, 1997); standards of care for older people (Standing Nursing and Midwifery Advisory Committee, 2001); the national service framework for older people (Department of Health, 2001a) and national minimum standards for care homes for older people (Department of Health, 2002g). This list is by no means exhaustive, but it does illustrate the plethora of instructions and guidance on needs assessment that has been issued in the last few years. Examples of advice given about patient involvement in these documents are highlighted below. The sometimes conflicting recommendations show how difficult it is for staff to know where boundaries lie and for patients to gain an understanding of what they are entitled to.

The Health Advisory Service identifies the standard that policies should be in place to ensure that older patients' rights are observed. The criteria associated with this standard are that:

*"There is a user empowerment strategy within the organisation.  
There is clear evidence of the strategy being implemented".*

(Health Advisory Service (HAS 2000), 1999: 22)

The Department of Health/ Social Services Inspectorate are more circumspect but recognise the subjective nature of involvement and the primacy of patients within the health and social services. They state that patients should receive assessments, care plans and services which respond to their needs, with one of the evaluative criteria being that:

*"Service users and their carers consider they are involved and consulted in all the care planning and discharge arrangements".*

(Department of Health/ Social Services Inspectorate, 1998: 56)

In contrast, the tone of some the Health Services Accreditation's standards are more paternalistic. For instance, they recommend:

*"It is good practice to contact elective patients before they attend their pre-admission clinic, explaining the importance of timely and appropriate discharge care arrangements and inviting their co-operation in the planning process".*

(Health Services Accreditation, 1996: 15)

Barnes and Walker (1996) attribute this confusion about the respective degrees of autonomy of patients and professionals to the lack of guidance on how involvement was to be effected. They argue that neither the 1990 NHS and Community Care Act nor any guidelines arising from it contained any concrete proposals for patient involvement or empowerment. In the absence of such proposals practice is determined at a local level in the individual relationships negotiated between patients and professionals.

The next chapter examines the research that has been conducted on involvement for patients.

## **SUMMARY**

This chapter has sought to clarify some of the ambiguity associated with the term 'involvement', which is central to this study, as the thesis is concerned with the ways in which older patients' involvement in continuing care assessments is facilitated. The review of the

policy literature indicates that services ought to be tailored to the needs of individual patients. However, conflicts within and between guidance documents on how involvement is to be effected means that in practice, patients' level of involvement is negotiated with individual practitioners at a local level. This study sets out to examine how conceptual ambiguities as well as those contained within guidance documents are being resolved in practice.

## **CHAPTER 3**

### **LITERATURE REVIEW**

#### **INTRODUCTION**

This chapter seeks to provide a comprehensive overview of the existing research based literature relating to the involvement of older people in their own continuing care assessments. It is only by doing this that the current level of understanding of the subject can be closely examined and gaps in the breadth and depth of knowledge identified. The chapter begins by setting out the methods by which the literature review was conducted. The remainder of the chapter is devoted to the findings of the literature review, which are presented in two sections.

The first section of the findings is concerned with an examination of patients', informal carers' and professionals' attitudes towards patient involvement. This area was included as attitudes towards involvement may have a considerable bearing on the degree of influence that each group is able to exert in practice.

The second section of the findings from the literature review focuses more specifically on the practice of patient and informal carer involvement, particularly in relation to continuing care assessments. Initially studies of patient and informal carer involvement in continuing care assessments that are conducted in the community are reviewed, as these may highlight good practice that could be applied in hospital settings. Next, studies examining patient and informal carer involvement in hospital based continuing care assessments are addressed. Many studies deal with continuing care assessments within wider research on discharge planning. These studies are reviewed separately from those where involvement in continuing care assessments is the primary focus. Finally, gaps in the literature are identified and the implications of these are outlined.

#### **LITERATURE REVIEW METHODS**

##### **Overall Approach**

The review was undertaken according to the approach adopted by Hart (1998). Hart emphasises that the literature review provides an overall framework for a study. This framework facilitates an understanding of the subject area, identifying key research and demonstrating the relevance of the current study. Hart argues that to develop such a framework a broad view of the topic

must be adopted. Therefore he states, it is necessary to be open to ideas, methods and arguments regardless of how or where they originated (Hart, 1998). In accordance with these principles, this review takes an eclectic approach and incorporates studies that have utilised a range of research methods, without privileging any particular approach e.g. randomised controlled trials, (Matthews, 2000).

### Search Strategy

Studies considered for inclusion in the literature review were identified from abstracts generated from electronic databases. Where appropriate this was supplemented with searches of specialist library catalogues e.g. Royal College of Nursing's library catalogue and the Cochrane library database. Articles were incorporated into the review if the inclusion criteria were met. In addition relevant citations in studies included in the review were followed up to minimise the risk of excluding relevant material.

### Electronic databases

A search strategy was developed for the electronic databases MEDLINE, CINAHL, British Nursing Index, BIDS, Age Info and the National Electronic Library for Health. In each case, the complete database was searched with no restrictions imposed in terms of the article's year of publication. The only limitation in this respect was the age of the individual database. So, for example articles published since 1985 were identified using the British Nursing Index. The database that included the earliest articles was Age Info. Age Info does not specify years for inclusion of articles, but searches revealed papers dating from the early 1960s.

The database search was conducted following the approach of Bekker et al. (1999). Bekker et al. suggest that database searches be conducted by identifying central keywords. In accordance with their method, the keywords were derived from the keywords as given in 15 studies considered of relevance to involvement in needs assessment. They go on to recommend the adaptation and broadening of keywords to minimise the chances of excluding studies (Bekker et al., 1999). In this way, keywords were modified according to the organisation of categories within each database, with the aid of each database's thesaurus. The modified keywords were then expanded to incorporate as many potentially significant studies as possible. (Expansion is a procedure whereby databases incorporate all related literature ordered in a 'tree hierarchy' below the expanded word). The keywords used in the searches of the databases are given in Appendix 4. The search strategy used for MEDLINE is given as an example in Appendix 5.

## **Inclusion Criteria**

The aims of this study focus on the involvement of older users and informal carers in the process of making decisions about their own care. Therefore, the literature review centres on the area of user and informal carer involvement.

What is particularly striking about this literature is that it contains two distinct parts and that there is dissonance between the elements of the literature. For clarity, these parts are presented separately in this chapter. The first part focuses on patient and informal carer involvement from a theoretical perspective, that is, what individuals say that they feel about the issue of patient and informal carer involvement. Although it is difficult to draw any firm conclusions because of methodological weaknesses in these studies, overall this literature appears to indicate that individuals are largely positive about patient and informal carer involvement. This contrasts with the second part of the literature review, which focuses on research examining the involvement of patients in practice and suggests that this apparent enthusiasm for involvement is not always evident in practice. This dissonance between stated, theoretical, attitudes towards patient involvement and the between patient involvement as it appears to be practised highlights the importance of the research on patient involvement as it is practised. Thus as the focus of the literature review narrowed and became concentrated on multidisciplinary roles in facilitating patient involvement, and more particularly the nurse's role, attention was centred on those studies that looked at the practice of patient involvement.

It should be stated that as the literature review progressed, it became more apparent what was already known about the topic and where the evidence base was less clear. Thus it was through an iterative process of examining the literature and identifying gaps in the body of knowledge, that the specific focus of the research emerged and the individual aims of the study were developed.

Thus, to be included in the review studies had to meet the inclusion criteria set out below. The rationale for each of the criteria is also given.



*1. To be included in the first part of the review the study must relate to attitudes to involvement in decision making.*

Studies relating to attitudes to the involvement of patients in the actual delivery of ‘hands-on-care’ were excluded from this review, as it is the process of decision making that is the focus of this research study.

*2. To be included in the second part of the review the study must address the involvement of patients or informal carers in assessments of continuing health and/ or social care needs at an individual level.*

Including studies of individual health and/ or social care assessments was essential as this is the focus of the study. Studies about patient involvement in collective assessments of need, such as participation in community consultations were excluded as they were not considered to be useful in informing assessment at an individual level.

*3. To be included in the second part of the review studies must also relate to the involvement of patients or informal carers in the assessment of patients’ needs.*

This is distinct from looking at the involvement of informal carers in the assessment of their own needs, although it is recognised that the assessment of informal carers’ needs is, in many cases an important element of the wider process of patient assessment.

In addition, all studies had to meet the following criteria:

*4. The study must relate to patients over 65 years of age.*

Research focusing exclusively on the needs of younger people, such as studies of maternity services were excluded from this review, as the focus lay with older people (and their informal carers, where appropriate).

*5. The study must relate to adults who are deemed capable of making informed decisions.*

There is an entire separate, related literature on proxy decision making for both children and cognitively impaired adults which is beyond the scope of this review. However, it is recognised that cognitively impaired adults are often excluded from research and that this is an area that may merit greater consideration in future research.

*6. The study must relate to assessments conducted in developed countries.*

The health care systems of less developed countries were considered to be too different for the findings to usefully inform the literature review. The definition of a developed country is to some extent subjective and judgements were made about research papers on an individual basis, although borderline cases were few in number.

*7. The study must be published in English.*

Time and resource constraints prevented translations of research papers being obtained.

### **Critiquing the Research**

91 studies were identified which met the review criteria. The overwhelming majority of these studies used qualitative research methods. The evaluation of these studies was informed by the review criteria developed by the Medical Sociology Group Section of the British Sociological Association (1996) (see Appendix 6). The Group's list of evaluative criteria for qualitative research contains twenty questions, covering the theory, methods, analysis, presentation and ethical aspects of the research. Each of the twenty questions has associated prompts to assist the reviewer to make judgements about the quality of each particular study.

## **FINDINGS**

The literature review is divided in two main sections. The first examines attitudes to the involvement of patients in decision making. The second moves on to explore studies of the practice of patient and informal carer involvement in continuing care assessments.

### **Attitudes to Patient Involvement in Decision Making**

Attitudes to the involvement of patients in decision making are explored in turn, from the perspectives of patients, informal carers and professionals before going on to examine the particular difficulties that older people may experience in seeking to become involved in the decision making process.

#### **Patients' attitudes to involvement in decision making**

Collectively studies of patients' attitudes to involvement in decision making are fragmented and difficult to collate to reach any general conclusions. It is argued that this is in part because they have used different approaches to measurement and have been conducted with different patient groups. The effects of patients' characteristics such as age and education on their attitude to

involvement is discussed, before arguing that sometimes additional difficulties are posed by researchers' narrow conceptual treatments of the term 'involvement'. This section concludes by suggesting that one of the principal problems with many of the studies is their focus on hypothetical situations rather than practice itself. Table 3-1 gives details of the studies on patients' attitudes to involvement in decision making included in this review.

### Difficulties comparing studies

Many studies examining patients' attitudes to involvement use survey methods. One of the reasons for the difficulty in drawing conclusions from these studies is that the surveys focus on patients' attitudes to different aspects of decision making. These include as well as the desire for participation in medical decision making (Strull et al., 1984), desire to participate in decisions about nursing care (Biley, 1992), desire for information (Blanchard et al., 1988), desire to participate in problem-solving (Deber et al., 1996) and patient preferences regarding 'locus of authority' (Beisecker and Beisecker, 1990).

In addition studies have used a variety of non-comparable instruments to measure the various aspects of attitudes to decision making, including the Beck Hopelessness Scale (Cassileth et al., 1980), Autonomy Preference Index (Ende et al., 1989), Health Opinion Survey (Pendleton and House, 1984) and tools specifically designed for individual studies (e.g. Strull et al., 1984).

The appropriateness of structured instruments as a mechanism for understanding attitudes to involvement has been questioned (Brooking, 1986; Meyer, 2001). Brooking designed an attitude measurement scale as part of her doctoral thesis but came to the conclusion that qualitative approaches may be more useful to explore issues identified by her survey. However Meyer, goes further questioning the validity of some of the structured instruments themselves. She queries whether survey questions always show enough understanding of the sophisticated nature of the concepts that they are investigating. This can be seen in Ende et al.'s (1989) Autonomy Preference Index. For example one statement reads:

"The important medical decisions should be made by your doctor, not by you."

Here patients are asked to record their responses on a five point Likert scale ranging from 'strongly disagree' to 'strongly agree'. The question gives no indication of how the subjective term 'important' is to be interpreted, and it will almost certainly mean different things to different people. Furthermore the question is stripped of any context thereby not allowing for

**TABLE 3-1**

**Studies examining patients' views of involvement in decision making**

<b>Year</b>	<b>Author</b>	<b>Method</b>	<b>Findings</b>
1980	Cassileth et al.	Questionnaire to 256 cancer patients	Patients generally wanted to take part in decision making. Those patients who were younger and better educated expressing the strongest desire.
1981	Faden et al.	Survey of 53 adult out-patients with seizure disorders plus 107 parents of children with seizures and 387 neurologists	83% of patients wanted to be given information about alternative medication. 56% of adult patients thought that the final treatment decision should be the patient's.
1981	Haug and Lavin	Survey of 466 members of the public and 86 doctors	Younger people expressed stronger consumerist attitudes than those in older age groups
1983	Lidz et al.	Observation and interviews with 101 cardiology and surgery patients	Patients preferred doctors to make decisions - typology of four reasons why patients still expressed a desire for information.
1984	Pendleton and House	Survey of 47 low income patients attending a diabetic out-patient clinic	Desire for participation is related to age, socio-economic status and level of health.
1984	Strull et al.	Questionnaire to 210 hypertensive out-patients and 50 professionals	41% of patients wanted more information compared with 1% who wanted less information. 47% patients wanted professionals to make decisions, whereas 19% wanted to share decision making equally.
1986	Brooking	Survey of 114 patients, 72 informal carers and 107 nurses	Patients reported little participation and wanted greater involvement in planning care.
1988	Blanchard et al.	Observation of 439 professional - patient interactions; survey of the 89 patients observed	69% of patients wanted to participate in decision making

Year	Author	Method	Findings
1989	Ende et al.	Questionnaire to 312 general practice patients	Patients presented with vignettes, expressed a greater desire for information than for involvement in decision making.
1989	Sutherland et al.	Survey of 52 cancer patients, including a Health Opinion Survey and Information Seeking Questionnaire	Many patients actively sought information, however 63% of patients thought the doctor should take primary responsibility for decision making, 27% felt decision making should be equally shared, and 10% of patients felt they should take the lead.
1990	Beisecker and Beisecker	Tape recording of 106 out-patient consultations; patients were also interviewed and filled in an opinion survey	Patients wanted information about a wide range of medical topics but engaged in few information seeking behaviours during their consultations with doctors.
1990	Waterworth and Luker	Interviews with a convenience sample of 12 patients	Patients were more concerned with pleasing the nurses than in being involved in decision making
1992	Biley	Interviews with 8 surgical patients	Patients not wanting involvement if they felt too ill, perceived that the decision was 'technical' or felt constrained by organisational issues.
1992	Degner and Sloan	Card sort technique used to explore the preferences of 436 oncology patients and 482 members of the general public	12% of patients preferred an active role in decision making about their medical treatment, 29% a collaborative role and 59% a passive role. Younger and more highly educated patients preferred more control over decision making.
1993	Gerteis et al.	Survey of 6455 patients discharged from hospital	98% of patients felt that treatment choices should be discussed.
1993	Thompson et al.	Survey of 459 member of a health maintenance organisation	Patients wanted more influence in decisions where values were perceived to be significant but wanted less involvement in decisions that required technical knowledge.
1994	Beisecker et al.	Survey of 67 oncologists, 94 oncology nurses and 288 patients	All groups stated that doctors should have the dominant role in decisions about breast cancer treatments.

<b>Year</b>	<b>Author</b>	<b>Method</b>	<b>Findings</b>
1994	Hack et al.	Survey of 35 women with breast cancer using card sorts, supplemented with interviews	23% women wanted an active role in decision making, 57% a collaborative role and 20% a passive role. Patients preferring an active role also wanted more information than passive patients.
1994	Tiemey et al.	Interviews with 326 older patients within 24 hours of admission, with 24 hours of discharge and at 2 weeks, 6 weeks, and 3 months post discharge. Interviews with 117 informal carers; survey of 8 ward managers	77% of patients said that they hadn't been consulted about their discharge but only 25% said that they would have liked more involvement in discharge planning.
1995	Robertson	4 focus groups of older people	Older people said that they would want access to their needs assessment form to review it and correct it if necessary.
1996	Beaver et al.	Survey of 150 women with breast cancer, using card sorts to ascertain their preferences for involvement	20% wanted an active role in their treatment and an additional 28% wanted to engage in joint decision making.
1996	Deber et al.	Survey of 285 angiogram patients	Patients wanted the doctor to identify the treatment options but wanted to be involved in decision making.
1996a	Jewell	Interviews with 5 patients at 3 points in their hospital admission	Patients felt they had a role in decision making but felt unable to initiate discussions with professionals.
1998	Caress et al.	Survey of 405 renal patients using a card sort technique to compare actual and preferred roles	46% of patients expressed a preference for a passive role and 36% preferred a collaborative role in decision making.
1998	Kerridge et al.	Survey of 152 patients and 511 professionals	80% of patients thought that their views should be taken into account when making decisions about CPR.
2000	Agard et al.	Interviews with 40 patients	Patients welcomed the opportunity to take part in decisions about CPR.

<b>Year</b>	<b>Author</b>	<b>Method</b>	<b>Findings</b>
2000	Arora and McHorney	Survey of 2,197 patients with chronic disease	A majority of patients preferred to delegate decision making to doctors, however, preferences varied by patient characteristics including age, education, medical condition and coping strategies.
2000	McKinstry	Video vignettes evaluated by 410 general practice patients	43% of patients under 60 preferred shared rather than directed decision making in general practice consultations. In contrast 27% of those over 60 favoured this approach. Preferences for decision making style also varied according to the presenting problem.
2001	Sainio et al.	Interviews with 34 oncology patients who were also given questionnaires.	The majority of patients were satisfied with their level of involvement in medical decisions but would have liked more information. (21% of patients were active participants, 26% gave active consent and 53% gave passive consent).
2002	Caress et al.	Interviews with 32 adult asthma patients. Card sort technique used to explore role preferences in decision making.	22% of patients favoured an active role in decision making, 34% a collaborative role and 44% a passive role. Role preferences were influenced by a number of factors including the severity of their condition.

the possibility that patients may have different feelings depending on the nature and circumstances of the particular situation. Here patients are left to substitute their own contexts. Finally, the possibility of shared decision making is excluded.

The Autonomy Preference Index also contains a section with three short vignettes asking patients their opinions about decision making in each given situation. However, the use of vignettes is also problematic. Asking respondents about hypothetical situations does not necessarily provide a reliable indicator of how people will act in practice. Respondents may be led to give false statements to conform with current trends in thinking or rely on guesswork (Meyer, 2001). This indicates that there is clearly a need for research that explores decision making in more depth.

A second difficulty comparing studies relates to the attitudes of different patient groups. Studies examining patient attitudes to involvement in decision making have produced a diverse array of findings. These range from 80% of patients wanting to participate in decision making (Hack et al., 1994) to 63% of patients expressing a preference for a passive role over an active or collaborative one (Sutherland et al., 1989). This may be due in part to differences in the patient groups surveyed. Although both the above studies were surveys conducted with cancer patients, Hack et al. attribute the discrepancy to specific differences in the groups of patients in the respective studies. Whereas Hack et al. surveyed only women with breast cancer, the patients in Sutherland et al.'s study had a variety of disease sites. Hack et al. report that studies have shown that some sub-groups of cancer patients e.g. women with reproductive cancer prefer more active decision making roles than patients who have other disease sites. This indicates that findings about attitudes to involvement in decision making may not be transferable across patient groups or even sub-groups, and points to the need to consider each decision making arena individually. Therefore, findings from, for example, a study of the attitudes of hypertensive out-patients to involvement in decision making may not inform staff seeking to understand the preferences of older people for involvement in decisions about their own continuing care. Such an understanding may only be developed from studying the actual preferences of older people faced with making these decisions. This highlights the urgent need for research to be conducted in this area if older people's wishes are to be more fully understood.

Although the preferences of patients may vary according to their clinical condition, making it difficult to compare studies and draw any firm conclusions, some broad general trends about attitudes to involvement are discernible from the literature.



### *Trends in the literature on attitudes to involvement*

Several studies indicate that there is a relationship between attitude and patient characteristics including education, personality and age.

A potential link between attitude to participation and level of education is reported in a number of studies (e.g. Cassileth et al., 1980; Pendleton and House, 1984; Arora and McHorney, 2000).

Cassileth et al. (1980) suggest that those patients who are better educated have the strongest desire for involvement in decision making. The study involved asking 256 cancer patients to complete an Information Styles Questionnaire and the Beck Hopelessness Scale. However all the patients were receiving treatment at a major urban medical centre, and it is possible that the setting may have encouraged preferences for involvement. In addition, patients who seek treatment in a large urban environment may differ from those who are treated in more rural settings. Cassileth et al. (1980) were not able to explore the reasons for people's preferences within their survey, highlighting a limitation of this method for examining attitudes.

Whilst the literature suggests that there may be a link between educational level and desire for involvement in decision making, it is important to question what motivates different groups to give different opinions. For example, less educated patients may not express as much desire for involvement because they may have less skill in processing information effectively. Hope (1996) argues that patients require a certain level of education in order to be able to make decisions about treatments. He defines education in this context as the background knowledge which is necessary for the patient to make good use of information. Hope contends that without such education patients' abilities to choose are limited and he calls for education to be provided alongside information. This highlights that attitudes to involvement may be more complex than they appear at first and it is possible that if less educated patients were provided with more background information they may display more positive attitudes to participating in decision making.

A number of research studies have also suggested that aspects of patients' personalities influence both their desire for involvement and their ability to achieve it in practice (McWilliam et al., 1994; Bekker et al., 1999; Arora and McHorney, 2000).

McWilliam et al. (1994) studied 21 patients and 139 carers with the aim of exploring the influence of personal characteristics on the maintenance of individual autonomy. They suggest that, in contrast to other patients, the autonomy of those patients with a positive 'mindset' was not threatened even when they were treated in a paternalistic manner. This indicates that the treatment of some patients can lead to threats to their autonomy. Indeed Davies et al. (1997) argue that there is a growing body of evidence which suggests that nurses can contribute to dependent behaviour in older people. This highlights the necessity for professionals to maintain high standards of practice and to treat all patients on an individual basis. In addition it suggests that dependent behaviours may be induced and are therefore not entirely a product of uninfluenced patient choice.

The relationship between age and attitude towards involvement in decision making also appears to be a recurring theme in the literature (Cassileth et al., 1980; Haug and Lavin, 1981; Pendleton and House, 1984; Arora and McHorney, 2000).

Pendleton and House (1984) administered a 16 item Health Opinion Survey to 47 low income adults attending an inner city diabetic out-patient clinic. The authors then compared the results with an earlier study in which the Health Opinion Survey was completed by a group of university undergraduates (Krantz et al., 1980). Pendleton and House suggest that age may affect preferences for involvement in health care. However they fail to explore how the wider socio-economic differences between the groups may also contribute to their different levels of desired involvement.

Again, as with education and personality, acceptance of the findings at face value may be misleading, and sociological explanations potentially offer greater insights. Older people's apparent lack of enthusiasm may be attributable to their being more accustomed to respecting, and not challenging, individuals in authority. This raises issues about the nature of involvement which are discussed in the next section.

### *Involvement as a concept in studies of patients' attitudes*

Some research suggests that rather than holding positive attitudes towards involvement in decision making, patients may feel that they are being pressured into compliance by professionals.

Waterworth and Luker (1990) selected a convenience sample of twelve patients and interviewed them about their attitude to being involved in decisions about their care. The authors claim to have used a grounded theory approach within the study, which produced one principal theme, namely that of 'toeing the line'. The authors use the term 'toeing the line' to indicate that the patients' main concern was with pleasing the nurses and this took precedence over the desire to become involved in decisions about their own care. This implies that patients' reticence to become involved may, in part be because they feel coerced by professionals. Acceptance of the findings is somewhat problematic due to the small sample size. A small sample makes saturation of categories more difficult to achieve, although interestingly the authors do not claim to have done this.

However, the study brings into question the understanding of 'participation' shown by both the patients interviewed and by the authors of the study, who suggest that patients may not want to be involved in decision making. Meyer (2001) states this is at odds with the true notion of patient participation, which would see the decision by a patient not to participate as a form of participation in and of itself. She adds that the question of coercion would not enter into an understanding of patient participation, which is concerned with enabling patients to make informed decisions which are independent of professionals' interests.

Another study that similarly adopts a narrow view of involvement was conducted by Biley (1992). Biley interviewed 8 patients and found that their desire for involvement was overtaken by other considerations such as a lack of information and organisational constraints including pressures to fit in with hospital routines. Biley regards patients' reticence to become involved because of these impediments as a rejection of the idea of contributing to, (or delegating) decision making. Again this highlights a misconception about the nature of involvement. Significantly, he fails to acknowledge that involvement is about supporting and empowering patients to make informed choices for themselves.

### *Patient involvement in practice*

One of the principal problems with the majority of studies conducted on patients' attitudes to involvement in decision making is the absence of observational data. The studies have tended to rely on survey or interview data. Whilst surveys can be useful for obtaining information about a population and interviews may give insights into individuals' motives (Robson, 1993), as previously mentioned, there can also be problems with these methods when used in isolation,

which mean that the studies' findings may not give a reliable indication of involvement as it occurs in practice.

Interestingly only 4 of the 30 studies examining patients' attitudes to involvement in decision making use any observational methods. However, it is arguable that observational methods have not always been employed to their full potential. For example, Beisecker and Beisecker (1990) derive counts of the number of information-seeking comments made by patients from their observational data. By using their observational data in an exclusively quantitative way, the researchers' rationale for the use of a qualitative approach to data collection becomes unclear. In addition the advantages that observational methods offer in the way of providing rich contextual data are lost.

In summary, it is argued that it is difficult to draw any firm conclusions about patients' attitudes to involvement in decision making. Studies examine different aspects of the concept making comparisons difficult. The situation is hampered by the use of different measurement instruments, some of which are of doubtful validity. It is also questionable whether reliance on structured instruments or interviews is the most appropriate methodology. These tend to elicit people's hypothetical responses which may or may not bear a resemblance to their actions in practice. Clearly there is a need for research that employs a more qualitative or a dual method approach (e.g. uses observation and interviews). Given the methodological problems and conceptual weaknesses inherent in many of the studies caution needs to be exercised in accepting the research findings. Thus, studies of involvement in practice settings may offer more insights.

The following section examines the research on the attitudes of informal carers to involvement in decisions about patient care.

### Informal carers' attitudes to involvement in decision making

#### Lack of research studies

Far fewer studies have been conducted examining the attitudes of informal carers to involvement in decision making (see table 3-2). Indeed Collier and Schirm (1992) comment that studies of nursing practice that have a family focus are scarce, adding that those that do exist are concentrated around the area of families with children. They cite Gonzalez et al. (1989) who contend that 'there is a near vacuum in the clinical literature describing interventions for

**TABLE 3-2**

**Studies examining informal carers' views of involvement in decision making**

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1984	Robinson and Thorne	No details given	Families expect to collaborate on decision making and experience frustration when information is withheld.
1986	Brooking	Survey of 114 patients, 72 informal carers and 107 nurses	Informal carers wanted more participation. Those who held the most positive attitudes tended to be middle class, well educated and knowledgeable about the patient's condition.
1990	Schwartz and Vogel	Survey of 142 nursing home staff and 144 informal carers	Informal carers want to share responsibilities for patient care (within a nursing home context).
1991	Williams and Fitton	Interviews with 193 informal carers	Informal carers reported that the lack of adequate information about the patient's condition exacerbated feelings of helplessness and despair.
1994	Jones and Lester	Postal survey of 960 patients and 865 informal carers	Informal carers particularly appreciate being informed about the patient's progress.
1994	Powell et al.	Semi-structured interviews with 40 patients and 26 informal carers	Informal carers value opportunities to discuss plans for the patient's care with health and social care professionals.
1994	Twigg and Atkin	Interviews with 90 informal carers	Informal carers reported 'not knowing what it was that they didn't know' and wanted a single accessible source of advice
1995	Dellasega and Mastrian	Interviews with 7 informal carers	Families were given advice by professionals about placement decisions, but felt inadequately supported and that they were left to make choices in isolation.
1996	Laitinen and Isola	Survey of 369 informal carers	Characteristics of professionals are important in promoting involvement. Informal carers want more discussions with and advice from hospital staff.

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1996	Rowles and High	Participant observation, semi-structured interviews focused around the care of 10 residents, event analysis	Family members perceived that they had been 'fully involved' in 50% of the decisions they identified, 'somewhat involved' in 15% and 'not at all involved' in 35% of these decisions.
1998	Henwood	Survey of 3,031 members of the Carers National Association	Informal carers don't feel that there is enough discussion about discharge, and aren't satisfied with their degree of involvement.
1998	Warner and Wexler	Survey of 1,985 informal carers, the majority of whom had 'intensive' caring responsibilities	68% of informal carers agreed that, in their experience, nobody asks the carer if they can cope before they send someone home from hospital.
2000	Lundh et al.	Interviews with 14 spouses who had been involved in care home placement	In many instances spouses felt that professionals dominated their partners' move to a care home. They experienced significant amounts of guilt associated with the placement.
2000	Ryan and Scullion	Interviews with 10 informal carers following the transfer of an older relative to a nursing home	Informal carers stated that they received inadequate support from health care professionals and often had no choice in the decision making process.

families coping with serious chronic illnesses'. More recently similar sentiments have been expressed by other researchers. Jones and Lester (1994) could find no evidence of any surveys having been conducted of carers' satisfaction with patients' hospital admissions. In addition, Laitinen and Isola (1996) highlight that the degree of family involvement in care of the elderly settings is particularly poorly documented.

In general those studies that have been conducted suffer from similar methodological weaknesses to those addressing patients' attitudes to involvement.

### Methodological approaches

Studies of informal carers' attitudes have relied heavily on the use of surveys and interviews. Questions about wishes and expectations are reliant on informal carers' best guesses about what they may reasonably want (Hanson, 1980). Respondents may also potentially be influenced by worries about a lack of anonymity and so give the answer that they anticipate that the researcher may prefer (Robson, 1993), or they may be reluctant to criticise professionals.

In some of the studies it is also difficult to judge the quality of the surveys as the questionnaires are not given and readers are required to take their rigour on trust. Jones and Lester (1994), for example describe the topics covered in their questionnaire and the types of questions asked, without providing readers with the questionnaire or excerpts from it. They state:

*"The shorter carers' questionnaire recorded positive and negative opinions about the hospital stay, involvement of the carer in discharge procedures and formal help received and carers' opinion of it. These topics were covered by both closed questions in order to record standard responses, and open-ended questions to collect in-depth information."*

(Jones and Lester, 1994: 92)

To date, only one study contains any significant degree of observation (Rowles and High, 1996). Rowles and High develop a typology of 8 decision types including 'physical environment' and 'daily living'. On a methodological note, the authors purport to derive quantitative statistics about degree of involvement from in-depth interviews, and it is unclear to what extent they engage in subjective judgements in the process of classifying the responses. In addition this research was conducted in the US and because of the different policy contexts, the findings are not necessarily transferable to a UK setting. This illustrates the need for multi-method research incorporating the views and behaviours of informal carers to be carried out in the UK.

As with the studies of patients' attitudes to involvement it is difficult to draw any conclusions from the research on informal carers' attitudes that has been conducted to date. This is in part because the research has focused on different aspects of informal carers' attitudes to involvement including; the roles of professionals in supporting informal carers (Henwood, 1998), involvement in decisions about nursing care (Laitinen and Isola, 1996; Rowles and High, 1996), involvement in discharge procedures (Jones and Lester, 1994).

Another contributory factor that makes drawing conclusions difficult is that the studies were conducted in a variety of health care environments including hospital wards, nursing homes and domiciliary settings, making the process of reaching meaningful comparisons additionally problematic.

It could be tentatively suggested that the studies as a whole indicate that informal carers welcome opportunities to be consulted when decisions are made concerning patients. However, on account of the methodological issues discussed above, this conclusion cannot be stated with any real degree of confidence, highlighting the need for contextually specific research addressing the issue of informal carers' involvement in the decision making process.

#### Professionals attitudes to the involvement of patients and informal carers in decision making

A review of the studies conducted on professionals attitudes to the involvement of patients and informal carers in decision making, (see table 3-3), yields similar issues to those identified in the previous sections on patients' and informal carers' attitudes. Not only is there a paucity of research on the topic, but many of the papers are reports of the results of surveys. The limitations of surveys in terms of their reliance on either hypothetical situations or people's recollection of events have already been discussed.

Again, drawing conclusions from the studies that have been conducted is problematic given the disparate groups of professionals who have been questioned and the different health and social care environments in which they practice. In addition, the policy contexts in which practice is conducted have changed in the 20 year timeframe over which the studies have been conducted.

Consideration of the findings of the studies in table 3-3 would suggest that in general professionals have positive attitudes towards the involvement of patients and informal carers in decision making, with the possible exception of studies that address decisions around medical



**TABLE 3-3**

**Studies examining professionals' views of the involvement of patients and informal carers in decision making**

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1981	Faden et al.	Survey of 53 adult out-patients with seizure disorders plus 107 parents of children with seizures and 387 neurologists	7% of adult neurologists believed that the patient should make the final decision about drug therapy, compared with 56% of adult patients who thought they should have the responsibility for decision making.
1986	Brooking	Survey of 114 patients, 72 informal carers and 107 nurses	Nurses expressed generally positive views about patient involvement. Those with the most positive attitudes tended to be older and more senior.
1986	Weiss	Dialogue groups of nurses, doctors and members of the public	Development of a typology of key norms governing the involvement of patients.
1992	Collier and Schirm	Interviews with 60 nurses; 200 patient records examined	Nurses cited benefits of family involvement, and were able to verbally describe more involvement than was documented in patient care records.
1994	Beisecker et al.	Survey of 67 oncologists, 94 oncology nurses and 288 patients	All groups stated that doctors should have the dominant role in decisions about breast cancer treatments.
1994	Jewell	1 focus group of nurses (n=4)	Nurses stress the importance of developing close relationships with patients and of the need to see and treat patients as individuals. They see their own role as empowering patients.
1996b	Jewell	2 focus groups with nurses (n=3 and 6).	Patient passivity viewed as patient related, with patients seen to adopt a 'traditional' role of nurse knows best or be passive as a function of their age.
1996	Myers and MacDonald	Interviews with 65 professionals - mainly social workers	Professionals saw their role as enabling patients to make choices, but in practice recognised that there were numerous barriers to involvement, some of which were related to the personal characteristics of the patients.

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1998	Kerridge et al.	Survey of 152 patients and 511 professionals	99% of professionals thought that patients views should be taken into account when making decisions about CPR.
2000	Obeid	Interviews with 12 health visitors	The majority of interviewees felt that they should act in a facilitative rather than directive way in their interactions with patients.
2001	Meyer	Action research approach Methods included semi-structured interviews, questionnaires and participant observation of 45 multidisciplinary professionals	Professionals expressed positive views towards the involvement of patients and informal carers but did not encourage involvement in practice. They were found to be suspicious of the motives of policies promoting the philosophy of lay participation.
2002	Rogers	Semi-structured interviews with 21 GPs	GPs' attitudes towards patient autonomy in the management of low back pain varied according to the nature of the issue in question. For example, the majority of GPs interviewed expressed controlling attitudes with regard to the use of analgesics but accepted patient autonomy in the use of complementary therapies.

treatments (Faden et al., 1981; Beisecker et al., 1994; Rogers 2002). For example, positive attitudes were indicated by Jewell (1994), who conducted a focus group with four nurses in a rehabilitation unit, exploring their perceptions of patient participation. Interestingly she reports that the nurses identified the need for both formal and informal approaches to facilitate involvement such as including patients in planning and evaluating care as well as through more informal interactions between nurses and patients. However the very small study size does not allow the results to be generalized, and the researcher's failure to describe the process of data analysis makes acceptance of the findings more difficult. Further research is needed to address these limitations to determine to what extent the findings are a reflection of practice and to what extent they mirror the prevailing rhetoric.

Meyer (2001) in an action research study, found that although professionals expressed positive views towards patient participation in care in theory, they did not actively promote patient participation in practice. Closer scrutiny of the data revealed that professionals were aware of the culture promoting lay involvement; however they were suspicious of the motives behind the introduction of such policies, viewing them as bureaucratic rather than as initiated for patients' benefit. Given the array of policies on the involvement of older people in continuing care assessments there is a need for research that not only examines the impact that this has had on professionals' attitudes but also examines how practice is affected.

Before going on to look at studies that have been conducted on the involvement of patients and informal carers in continuing care assessments, it is worth considering the particular difficulties that older people face in seeking to participate in the decision making process.

## **Barriers to Older People's and Informal Carers' Involvement**

### **Barriers for older people**

Potentially one of the biggest barriers to older people's involvement in decision making is physical communication difficulties. As Myers and McDonald (1996) highlight, participation in the process of care planning relies on the communicative skills of the patient. The patient has to be able to articulate their preferences by some means. This may be particularly problematic for those people who are hard of hearing or who have speech difficulties. These are issues that are likely disproportionately to affect older people as a group.

Communication difficulties affecting older people may also include language barriers. If patients do not get information in a form that they can understand then they can effectively be

marginalised from decision making processes. Language barriers may be a particular problem amongst minority communities. Tuffnell et al. (1994) report an illiteracy rate of 59% amongst non-white patients in Bradford. This is to say, that 59% of patients about whom the researchers gathered information were not able to read or write in any language. Tuffnell et al. conclude that providing information in other languages is useful but argue that far more attention also needs to be given to disseminating information in other forms such as via audio and video tapes.

In cases where older people's involvement is impeded the onus lies on professionals to ensure that older people contribute to the extent that they wish and are able to do so. However, research shows that this does not always happen in practice. Cotter et al. (1998) describe an action research study which found a number of practices that inhibited older people's involvement in their own assessments. Foremost amongst these were the reactions of hospital staff to older people themselves. Disabling and arguably ageist practices included the failure to accommodate older people's pre-existing disabilities which were overlooked in the focus on acute needs. Older people were further marginalised by their lack of information about both their own condition and treatment and also about the process of assessment itself. Of equal concern was the researchers' finding that the older people in their study felt ignored at times and that in particular there was a lack of attention to their emotional needs. This highlights the urgent need for older people's involvement in their own assessments to be facilitated.

### Barriers for informal carers

Informal carers may experience a different range of practical barriers to involvement including work responsibilities (Collier and Schirm, 1992) and inflexible visiting times (Laitinen and Isola, 1996). In addition many informal carers are older people themselves. Data from the 1995 General Household Survey shows that 13% of adults aged 65 and over are informal carers (Office for National Statistics, 1998). As older carers they are likely to experience similar barriers to involvement as older patients themselves and again, the onus rests on professionals to facilitate their participation.

The next section examines the research in continuing care assessments and discusses the approaches that have been used to explore older people's involvement in practice.

## **Patient and Informal Carer Involvement in Continuing Care Assessments**

As the topic of continuing care has climbed the political agenda, a growing number of studies have focused on, or incorporated, elements of the decision making processes involved in assessments of need. This section begins by describing the research on continuing care assessments conducted in the community, highlighting the fragmented nature of the process for patients and drawing lessons for hospital professionals. Next the broad research on discharge planning that touches on assessment is discussed before moving on to examine more specific studies addressing continuing care assessments.

### **Research on the involvement of patients and informal carers in continuing care assessments conducted in the community**

#### **Defining community assessments**

It is difficult to draw precise delineations around studies of assessments that have been conducted in the community. This is in part because some studies (e.g. Richards, 1996) have included examinations of assessments conducted in both community and hospital settings. In other cases (e.g. Audit Commission, 1997) the method is not described in sufficient detail to be able to judge precisely what investigations were undertaken making the drawing of boundaries more problematic. However, table 3-4 contains a list of studies that have in whole, or part explored patient and/ or informal carers involvement in continuing care assessments conducted within the community.

#### **Assessment as a part of a continuing process**

What is striking in many of the studies is the way in which assessment is viewed as a single episodic event (e.g. Ellis, 1993; Hudson, 1993). Even in studies which focus on the transition to residential care, which is frequently the culmination of a whole chain of events and decisions for older people and informal carers, there is a tendency to isolate the final assessment process, decontextualising it from the processes that led up to it, again giving the impression of assessment as an isolated event. For instance Johnson et al. (1994) identify that patients' state of health, immediately prior to entering a nursing home has an impact on the decision. Similarly the willingness of family to provide care is also cited as influential. However this merely provides a snapshot at one point in an individual's life, and with very minimal biographical details of the older people (age and gender - expressed collectively), it is difficult to form an understanding of how decisions were made and what they meant to the individuals concerned. On a methodological note the interviewees in Johnson et al.'s study had entered nursing homes

**TABLE 3-4**

**Studies examining the involvement of patients and informal carers in assessments of continuing care needs conducted in the community**

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1992	Allen et al.	Interviews with 203 older people, 146 informal carers, 51 social workers, 11 domiciliary care organisers and 43 heads of homes	Older people had little knowledge about available services and prior to moving into residential care had often coped with small care packages. Many older people delegated the decision to move into a residential home.
1993	Ellis	Observation of assessments, interviews with social workers, patients and informal carers	Lack of information prior to assessment made involvement more difficult. Patients and informal carers were confused about assessors' areas of responsibility and felt as though they had to fight for services.
1993	Hudson	Interviews with case managers, 26 older patients and 32 informal carers; 8 case studies; postal questionnaire of professionals.	Older people were reluctant to mention difficulties and defined needs in terms of their knowledge of available services. Case managers felt uncomfortable about raising expectations that could not be met.
1993	Hunter et al.	Retrospective interviews with 12 older people who had moved into long term care; retrospective interviews with 94 professionals involved in the older people's assessments	No professional group stood out as the patient's friend - personal style was more important.
1994	Johnson et al.	Interviews with 18 older people who had moved into a nursing home	Older people either described themselves or a 'powerful other' e.g. family member/ GP as the decision maker.

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1996	Myers and MacDonald	Interviews with 65 professionals - mainly social workers	Professionals described trying to empower older people through assisting them to identify their own needs but recognised that there were a number of factors that inhibited this in practice.
1996	Nolan et al.	Research drawing on 4 discrete independent studies	Development of an idealised typology identifying 4 types of admission to care homes are described with varying degrees of patient choice.
1996	Richards	Observation of 20 older patient's assessments, interviews with the patients, their informal carers, the assessor and referrer	Attention was focused primarily on the need for personal care, excluding other needs. Professionals experienced communication difficulties both with older people and between each other.
1997	Audit Commission	Fieldwork in 12 LAs, HAs and associated trusts	Older people and informal carers don't appear to have as much influence over their care as they could, limited information is available to them and care manager have restricted choices to offer.
1999	Hardy et al.	Interviews with 28 patients, 20 informal carers and 22 care managers	Development of a typology of choices available to patients. Finding that choice is very limited in practice and that people are fitted in to the services that currently exist.
2001	Abbott et al.	Interviews with 99 continuing health care patients and/or their informal carers	The majority of interviewees were unclear about how their needs had been assessed and how services had been arranged. Lack of information was a particular problem.

up to a year prior to being interviewed, casting doubt on the detail and reliability of their recollections.

One study that sought to explore the complexity of continuing care assessments conducted in the community was undertaken by Hunter et al. (1993). Hunter et al. explored the assessment process for 12 older people who had entered institutional care in the previous four to six weeks. They report that the older people in their study received between five and thirteen assessment visits from health and social service professionals, typically over an approximate two years period of decline. This highlights both the complex and fragmentary nature of the assessment process. In addition Hunter et al. point to the number and range of professionals involved, some of whom had long term contact with older people and others who tended to be involved only at times of crisis. Hunter et al.'s study provides a salutary reminder to hospital staff that assessment is part of an ongoing chain of events within an individual's life and needs to be viewed within that context.

Hunter et al. also pinpoint the fluctuating nature of older people's health, highlighting that a range of support services of varying intensity (including, for instance, intermediate care) will be required to meet the range of individual circumstances encountered.

#### *Assessment as a multidisciplinary activity*

Given the recent emphasis on the multidisciplinary nature of continuing care assessments (e.g. Department of Health, 2001a) it is interesting to note that several of the studies of community assessments focus on a single event conducted by one individual practitioner in isolation from the wider interprofessional team, (almost exclusively social workers). For example Richards' (1996) study is concerned solely with the practice of social workers, and does not gather evidence from the wider community of professionals involved in care and assessment of the older people concerned. Given the findings of Hunter et al.'s (1993) study it is highly probable that many of the older people in Richard's study would have come into contact with other professionals including doctors and nurses. These professionals may have had contact with the older people over a long period of time and therefore may have been able to provide insights into the broader context in which the particular assessment was conducted.

Although in some situations individual practitioners act as gatekeepers and make independent decisions about access to services, this is not always the case. Decisions, particularly those concerning moves to institutional care, are likely to involve staff from more than one



professional group. Research adopting a uniprofessional focus may underestimate the complexity of the assessment process and overlook fora in which older people and their informal carers may or may not have opportunities for involvement.

### Methodological concerns

The need for research that views continuing care assessments within the wider context of older people's lives and that reflects the multidisciplinary nature of the process has been highlighted. As well as problems with the focus of the research to date, there are also methodological weaknesses in many of the studies conducted on community assessments. In particular some of the studies have excluded informal carers (e.g. Johnson et al., 1994) potentially further marginalising the experiences of a group of people who are acknowledged to have received little attention in research terms (Office for National Statistics, 1998).

Again, as with many of the studies of individuals' attitudes to involvement, the researchers have tended to rely heavily on the use of interviews at the expense of observational data. The potential pitfalls of this approach have already been highlighted. Sadly some of the studies that have used observation give very few methodological details (Ellis, 1993; Audit Commission, 1997), rendering it almost impossible to discern exactly what was observed, the frequency of the observations or how events were recorded. Without adequate methodological details the findings of such studies must be treated with a degree of caution.

### Lessons for hospital staff

The limited number of studies conducted in the field, combined with the difficulties already discussed, make it problematic drawing any firm conclusions from the research. However this does not mean that there are no lessons to be learned from these research studies. In particular it is important for hospital staff to view continuing care as one episode in the longer story of older people's state of health and well-being and not as a one off event. Viewing assessment as part of an on-going sequence of events may help raise hospital staff's awareness of the wider network of professionals. Developing an awareness of those community staff who could contribute to assessments is especially important, as they may have knowledge of individuals built up over a number of months or years. Seeing assessment within a wider frame may also help place the assessment process within the context of older people's lives and contribute to decisions that are more in keeping with their own beliefs and practices. Such assessments would clearly be of greater value to them (McCormack, 1998).

The next section examines studies of hospital discharge that have included analysis of continuing care assessments.

### Research on discharge planning examining the involvement of patients and informal carers in continuing care assessments

#### *Breadth of the research*

A number of studies have been conducted which examine the process of discharging patients from hospital, some of which include scrutiny of the process of patient assessment (see table 3-5). However, although the amount of attention devoted to the topic of assessment varies, in all cases assessment is one of a broader range of issues around discharge which are covered within the studies. Research on discharge also includes care in hospital (Godfrey and Moore, 1996), transport home (Dalley and Denniss, 1997), liaison between professionals (Victor et al., 1993; McBride, 1995; Allen et al., 2002), strategic issues of joint working between agencies (Department of Health/ Social Services Inspectorate, 1998), patient outcomes (Armitage and Kavanagh, 1998) advocacy arrangements (Audit Commission, 1997), the quality of community services (The Equip team, 1997) and complaints procedures (Department of Health/ Social Services Inspectorate, 1998). Whilst these related aspects of patient discharge have a bearing on patients' overall experience they do not directly inform the process of assessment. The way that the topic of assessment is treated within these studies is now examined.

#### *Limited conceptual understandings*

Part of the difficulty associated with many of the studies of discharge is the lack of space devoted to assessment and in particular the involvement of patients and informal carers. Because assessment is often one of a number of areas being researched there may be a more limited scope for exploring involvement in sufficient detail to produce insightful findings. There is a danger of terms like 'discussion' and 'consultation' being used in a black and white fashion, with researchers reporting that patients either were, or were not variously involved in discussions or consulted. For example McBride (1995) reports that 37% of patients stated that needs had been discussed with a nurse. This offers a reductionist view, in that no indication is given about the nature or extent of the discussion, which could range from a simple closed question checking patients were all right, to a more detailed assessment of patients' home circumstances, and in any case 'discussion' may have varied from patient to patient. The lack of contextual detail means that it is impossible to be clear about the quality of these interactions,

**TABLE 3-5**

**Studies of discharge planning examining the involvement of patients and informal carers in continuing care assessments**

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1975	Roberts	Post-discharge interviews with 164 patients (including 6 interviews with proxies), analysis of medical and social work records, survey of 16 ward sisters	81% of patients stated that while in hospital no-one had asked them about whether they might need any help at home. The majority of ward sisters placed a relatively low priority on the importance of patients' well-being after discharge, relative to other aspects of care provision.
1979	Gay and Pitkeathley	Post-discharge interviews with 257 patients	Staff may collude in painting an over-optimistic picture about going home in order to ease the pressure on acute beds.
1982	Skeet	National survey supplemented by informal discussions with hospitals and community services	Ward staff sometimes assume that if an older person does not live alone then their care be continued adequately.
1987	Waters	Interviews with 32 patients after discharge and examination of their medical and nursing records	56% of patients recalled being asked about their ability to manage at home. Only 9% of patients recalled being asked about their ability to manage by a nurse.
1988	Abramson	Questionnaire to 57 social workers about patients' level of participation	Patients' level of health influenced their degree of participation. Social workers reported discussing either none or only one discharge planning option in 42% of cases.
1988	Coulton et al.	Survey of 314 older patients prior to their discharge from hospital	Identification of 6 factors influencing patient decision making including the perception of restricted choice.
1988	Victor and Vetter	Survey of 1930 older patients, 3 months after discharge from hospital	Two thirds of patients reported having discussions about their discharge whilst in hospital and 44% stated that these included their need for help at home.

Year	Author(s)	Method	Findings
1992	Neill and Williams	Interviews with 3 social workers in each of 71 LAs; monitoring of referrals for home helps in 4 LAs; 71 case studies comprising 132 interviews with patients, 60 with informal carers, 71 with home help organisers and 68 with home helps	Patients' negative memories of being in hospital were associated with feelings of helplessness, loss of autonomy and lacking information. 35% of patients said that no-one had talked to them about how they would manage at home.
1993	Jewell	Interviews with 4 patients, 2 informal carers and 26 hospital and community staff around the cases of 5 patients	Discharge planning took place informally and although staff felt they encouraged patient involvement, interviews with patients suggest they the patients and informal carers were marginal to decision making
1993	Victor et al.	Survey of 172 GPs, 35 community staff and 85 hospital staff (HOs, ward managers and ward clerks) within one HA; Interviews with 15 older patients, their informal carers, GP and ward manager	Patients and informal carers were peripheral to the process of discharge planning.
1994	Congdon	Interviews with 8 older patients with hip fractures, 8 family members and 8 nurses	Decisions were made by professionals excluding patients and family members from the process.
1994	Kadushin and Kuly's	Interviews with 80 social workers	Overall indications were that there were relatively low levels of patient involvement in discharge planning with social workers judging that 1 in 3 cognitively unimpaired patients was not involved in goal setting.
1994	Powell et al.	Semi-structured interviews with 40 patients and 26 informal carers	Few patients who were discharged home discussed any active involvement in the decision making process in contrast to those discharged to residential care.

Year	Author(s)	Method	Findings
1994	Tierney et al.	Interviews with 326 older patients within 24 hours of admission, within 24 hours of discharge and at 2 weeks, 6 weeks, and 3 months post discharge. Interviews with 117 informal carers; survey of 8 ward managers	Discharge arrangements appeared to be fragmented. There was not always a comprehensive assessment of patients needs and patients and informal carers often felt excluded from discharge planning.
1995a	DoH/ SSI	Inspection of 7 local authority SSDs including in each area - scrutiny of 8 assessments, interviews with patients, informal carers, practitioners and managers, documentary analysis	Most patients were satisfied with the help they received and the placement arrangements made. Carers seeking placements were often hampered by a lack of information.
1995b	DoH/ SSI	Inspection of 6 local authority SSDs including in each area - scrutiny of 8 assessments, questionnaire completed by 50 assessors, interviews with patients, informal carers, practitioners and managers, documentary analysis	Patients are disadvantaged when it comes to choosing a nursing or residential home and may need additional support. The range and quality of information available to assist in choosing a home is often inadequate. Patients do not always get information even where it does exist.
1995	McBride	Interviews with 60 patients, 26 informal carers, 27 community nurses and a review of 60 patient records	63% of patients and 81% of informal carers said that the patients needs had not been discussed prior to discharge.

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1996	Clark et al.	Observation of 60 home visits and interviews with 30 older patients at 1 and 3 months post-discharge, interviews with staff key to these patients; interviews with 20 patients discharged within the previous 18 months	The outcome of needs assessment depends upon the will of the individual professional, the determination of the patient as well as the availability of local services and social services budgets.
1996	Godfrey and Moore	Interviews with 28 patients and 23 informal carers; questionnaires to hospital and community professionals; policy audit	The process of assessment was inconsistent. Patients felt they had a limited degree of involvement, carers felt more marginal to the process and that the onus was on them to obtain information.
1996	Shepherd	Interviews with 100 older patients and 36 informal carers	Almost one third of carers reported having little or no information about discharge, service arrangements and contact numbers for health and social services.
1997	Audit Commission	Fieldwork in 12 LAs, HAs and associated trusts	Older people and informal carers don't appear to have as much influence over their care as they could, limited information is available to them and care manager have restricted choices to offer.
1997	Dalley and Denniss	Post-discharge interviews with 211 older patients	45% of patients said that staff had talked to them about how they would manage at home.
1997	The Equip team	Interviews with 14 patients assessed as needing home care but who were considered to be vulnerable	Most patients could recall speaking to staff about managing at home, but appeared to have been told that they needed help and that a referral had been made. Assessments were conducted post-discharge but service provision was limited.

Year	Author(s)	Method	Findings
1997	Social Services Inspectorate	Inspection of 4 hospital and community trusts including in each area - scrutiny of 8 assessments, interviews with 81 patients and informal carers and 266 professionals, documentary analysis	Many patients were satisfied with the services they received, although some informal carers felt that there was inadequate time to make informed decisions.
1998	Armitage and Kavanagh	Interviews with 29 patients	Few patients (14%) were able to recall, without prompting, discussions about what support services were available. However the researchers were aware that over 30% had been seen by a discharge planner.
1998	DoH/ SSI	Approximately 8 days fieldwork in each of 8 SSDs encompassing - tracking of 12 patients, interviews with the patients, informal carers and social workers, interviews with hospital and community staff, short observations of practice, documentary analysis	Nearly all patients felt involved in assessment and care planning, however patients weren't always involved early enough and care plans didn't always offer patients real choice.
2001	Procter et al.	Interviews with 30 patients in hospital and 2 weeks after discharge. Interviews with their informal carers and multidisciplinary professionals involved in their care	The assumption that informal carers could cope led to other sources of support for the patient not being explored.

Year	Author(s)	Method	Findings
2002	Allen et al.	Tracking 8 patients, who had suffered a stroke, for 6 months - interviews with patients, informal carers and key staff involved, observation of meetings and home visits, analysis of case notes	Families' disagreements with health and social services staff sometimes resulted in negative formulations of patients and their families, which hampered partnerships.



for instance whether information was provided about community services or the degree of choice that patients were able to exert. It is also unclear whether the needs that were 'discussed' were simple, complex or a combination of both. In addition, McBride's use of statistics is problematic in that without a clearer idea of what constitutes a discussion and whether a universal understanding was shared by all interviewees, responses cannot reliably be collated. Similarly Tierney et al. (1994) report that only 21% of patients said that they had been 'consulted' about discharge plans.

### Aspects of involvement

A few of the studies explore individual elements of patient involvement, although again in general the research suffers from being too broad in its approach and lacking sufficient depth. One element of involvement that is touched on is the area of information giving. However, what is striking about the area of information giving is the research's concentration on information as advice post-discharge rather than information supporting the process of decision making. Within the studies on discharge, references to information required by patients or informal carers to make decisions is rare. Godfrey and Moore (1996) describe informal carers' experience of feeling as though the onus was on them to find the relevant information, but this is an exception. More often researchers have enquired about specific aspects of advice that patients have been given on discharge including medication (Tierney et al., 1994; McBride, 1995; the Equip team, 1997), diet (Armitage and Kavanagh, 1998), and exercise (Powell et al., 1994). In addition the frequency with which patients and informal carers are supplied with written information such as discharge plans has also been the focus of attention (Dalley and Denniss, 1997; Department of Health/ Social Services Inspectorate, 1998).

A second aspect of involvement that is touched on in studies on discharge is the way that options are presented to patients. The studies do not explicitly make reference to the language used by professionals or the way in which control is exerted, although this is a recognised area of study within the nursing literature (Hewison, 1995; Draper, 1996). Instead the studies tend to report verbatim patients' experiences of their dealings with professionals to illustrate patients' degree of control e.g.:

*"One of the male nurses came up to me and hugged me and said 'I think you need a bit of help at home' and he told me what to do and everything."*

(The Equip team, 1997: 10)

Again as with the issue of information giving, there is a great deal more scope for researchers to have explored the issue of framing decision making and exerting control, which has only received superficial attention within the studies.

Finally it is worth making some methodological points before going on to discuss the research focusing on continuing care assessments.

### Methodology

Again many of the studies rely heavily on the use of interviews, several just interviewing patients, or patients and informal carers. One of the dangers of only obtaining patients' perspectives is the reliance on people's recollection of events. Armitage and Kavanagh (1998) report:

*"Despite the majority of respondents being unable to remember or being unsure of information given to them, it was known that nine had been seen by a Nurse Discharge Planner during their hospital stay but only two clearly remembered this."*

(Armitage and Kavanagh, 1998: 72)

Patients in Armitage and Kavanagh's study were also unsure at times of exactly which professional they had spoken to. This highlights the need for additional sources of confirmatory data. In addition, without clear indications of each professional's practice it is impossible to be sure about individual roles in supporting patient involvement.

In general the lack of depth of the studies restricts the claims that they are able to make. There is a notable lack of discussion on organisational or professional influences on the practice of assessment. Besides this, the role of particular groups of professionals in facilitating patient involvement is conspicuous by its absence.

### Research focusing on the involvement of patients and informal carers in continuing care assessments conducted in hospital

#### 'Richer' research studies

In contrast to the studies of discharge planning, in general, the research focusing on patient involvement in continuing care assessments (see table 3-6) is much richer and has a greater depth to it. The studies of assessment offer more detailed insights into the process and have more developed and sophisticated understandings of the practices occurring. For instance Dill (1995) uses her knowledge of the status of different professional groups to explain particular

**TABLE 3-6**

**Studies focusing on the involvement of patients and informal carers in continuing care assessments conducted in hospitals**

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1981	Evers	3 weeks observation in 8 care of the elderly wards; informal discussions with patients and professionals	Teams were medically led. Patients and informal carers were not included in assessments except where their views coincided with those of the multidisciplinary team.
1994	Baldock and Ungerson	Interviews with 32 stroke patients and their informal carers just after discharge and again at 3 and 6 months post-discharge. Health questionnaires given to patients and informal carers.	People found it difficult to choose their own community care. They often had difficulties understanding the assessment process, particularly in the early stages of their dependency.
1995	Dill	Observation of key decision events; interviews with key staff and patients	Professionals priorities predominate e.g. for an early discharge. Professionals may question patients' decision making capacity where patients views do not coincide with the views of the professionals themselves.
1995	Wells	Participant observation of decision making around 31 patients. Interviews with patients, informal carers and key professionals.	Decision making was focused around administrative concerns rather than those of patients or informal carers. Decisions were made early in patients' admissions in order to facilitate early discharge.
1996	Richards	Observation of 20 older patient's assessments, interviews with the patients, their informal carers, the assessor and referrer	Attention was focused primarily on the need for personal care, excluding other needs. Professionals experienced communication difficulties both with older people and between each other.

**TABLE 3-6**

**Studies focusing on the involvement of patients and informal carers in continuing care assessments conducted in hospitals**

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1981	Evers	3 weeks observation in 8 care of the elderly wards; informal discussions with patients and professionals	Teams were medically led. Patients and informal carers were not included in assessments except where their views coincided with those of the multidisciplinary team.
1994	Baldock and Ungerson	Interviews with 32 stroke patients and their informal carers just after discharge and again at 3 and 6 months post-discharge. Health questionnaires given to patients and informal carers.	People found it difficult to choose their own community care. They often had difficulties understanding the assessment process, particularly in the early stages of their dependency.
1995	Dill	Observation of key decision events; interviews with key staff and patients	Professionals priorities predominate e.g. for an early discharge. Professionals may question patients' decision making capacity where patients views do not coincide with the views of the professionals themselves.
1995	Wells	Participant observation of decision making around 31 patients. Interviews with patients, informal carers and key professionals.	Decision making was focused around administrative concerns rather than those of patients or informal carers. Decisions were made early in patients' admissions in order to facilitate early discharge.
1996	Richards	Observation of 20 older patient's assessments, interviews with the patients, their informal carers, the assessor and referrer	Attention was focused primarily on the need for personal care, excluding other needs. Professionals experienced communication difficulties both with older people and between each other.

<b>Year</b>	<b>Author(s)</b>	<b>Method</b>	<b>Findings</b>
1998	Cotter et al.	Action research study including interviews with 35 older patients and their informal carers in hospital and post-discharge in the community	Assessment was a fragmented process for older people, and without explanations particular exercises could be meaningless. Lack of information, such as about the timing of assessments may have impeded involvement.
1998	Opie	Observation and taping of 45 team reviews and 10 family meetings	Professionals adopted the role of experts, 'feeding back' to patients and informal carers and rarely actively solicited their views. Informal carers views could be given greater precedence than those of the patient.
1999	Reed and Morgan	Interviews with 20 older patients, 17 informal carers and focus groups with 23 professionals	Few older people had opportunities to discuss their move to a care home with nurses and there was a lack of clarity about whose role it was to initiate such discussions.

aspects of discharge planning. She shows how social workers make pre-emptive referrals sometimes regardless of patients' preferences in order to fit in with the restricted notice of discharge often given by doctors. This avoids delayed discharge with its associated organisational costs and is advantageous to social workers in that it helps them maintain good working relationships with colleagues.

In addition the studies focusing on assessment more often use a multi-method approach to data collection, allowing both the verification of interviewees responses and for participants to interpret observations of practice. As a group the studies are more robust and as such offer more useful pointers for practice development.

### *Different health care settings*

The small number of studies conducted in the field makes the drawing of any conclusions from the work problematic. The difficulties are compounded by the fact that several of the studies were conducted within different organisational contexts. A review of the findings (see table 3-6) would seem to indicate that older people and their informal carers struggle to become involved in assessments. However the situation is more complicated in that three of the eight studies were conducted abroad (Dill, 1995 (USA); Wells, 1995 (Canada); Opie, 1998 (New Zealand)). Findings from studies conducted within the different health care systems are not automatically transferable to a UK setting. Different health care policies and professional practices may influence the nature and degree of patient involvement. For this reason caution must be exercised about uncritically claiming that patients universally experience problems in being involved in their own continuing care assessments.

Even drawing common threads from the five studies conducted in the UK is far from easy. The data collected by Evers (1981) are over 20 years old and the policy context in which assessments are made has changed considerably. In addition, on a methodological note it is questionable whether 3 week periods of observation in each setting are long enough to yield reliable data that are not significantly affected by the presence of a researcher, and that allow adequate access to participants' beliefs and understandings (Fielding, 1993).

This highlights the need for research on patient involvement in continuing care assessments to be conducted in the UK and also the need for this research to take account of the rapidly changing policy context.

### Gaps in the literature

One of the noticeable features of the research studies is the lack of a central focus on the roles of multidisciplinary team members, particularly nurses, in supporting the involvement of patients and informal carers. Baldock and Ungerson (1994) in exploring assessment from a lay perspective report that patients were sometimes unsure of professional identities. Thus no conclusions can be drawn about individual roles. In contrast, Opie (1998) provides a general overview of the way individual members of two multidisciplinary teams approach the practice of family meetings without singling out any profession for particular attention. More focused observations are provided by Evers (1981) who discusses the impact of medical staff on decision making, and social work roles are highlighted in two other studies (Dill, 1995; Richards, 1996).

The only study specifically focusing on the role of nurses in supporting the involvement of patients and informal carers was conducted by Reed and Morgan (1999). Reed and Morgan interviewed 20 older patients and conducted focus groups with 23 members of staff to provide insights into older people's transition from hospital to nursing homes. They contrast the different priorities of doctors, nurses and social workers, and highlight the fragmented nature of assessment and the haphazard way in which patients are involved. Of concern is the fact that they report that nurses do not have a standardised approach for discussing the move to a care home with older patients, and that conversations tend to occur on an ad hoc basis. Moreover the nurses feel that they lack the knowledge to adequately support older people.

The fact that only one study focusing on the nurse's role in supporting older people's involvement in needs assessments has been conducted highlights the paucity of research in this area. Reed and Morgan's study focuses on one specific scenario, that of patients moving to nursing home care. It is unclear whether similar findings would occur in the context of other situations, for example patients receiving domiciliary care packages or moving into residential care. Research building on these findings would permit exploration of the extent to which nurses' interactions really do occur on an ad hoc basis.

Moreover given the current policy context with its emphasis on patient involvement and the requirement for all members of the multidisciplinary team, including nurses, to contribute to continuing care assessments, there is an urgent need for more research to be conducted in this area. Unless clearer understandings are developed about how involvement occurs and the role of individual team members in promoting and inhibiting it, then older people risk being

marginalised from decisions that are likely to have a considerable bearing on the remainder of their lives.

## **SUMMARY**

The literature review shows that it is difficult to draw any firm conclusions about patients', informal carers' or professionals' attitudes to involvement in decision making. Studies have examined different aspects of involvement and have used a variety of measurement instruments, making comparisons problematic. The difficulties of relying solely on the use of structured instruments and interviews has been outlined and it is argued that multi-method approaches to the study of involvement in practice settings may be more productive.

Those studies focusing specifically on the practice of patient and informal carer involvement in continuing care assessments were examined in three parts. Studies of assessments conducted in the community had the potential to offer lessons for hospital staff. However, much of the research focuses on isolated episodes in what were often complex chains of decision making. In contrast, studies of discharge planning were found to be very broad in nature and consequently their treatment of assessment was often superficial. Significantly, studies concerned specifically with patient and informal carer involvement in continuing care assessments were more sophisticated, offering more detailed understandings of practice. In spite of this, the literature review revealed conspicuous gaps in the literature, notably in relation to the nurse's role in facilitating patient and informal carer involvement. It is this gap that this study seeks to address.



## **CHAPTER 4**

### **METHODS**

#### **INTRODUCTION**

This chapter outlines the methodological approach taken, giving the rationale for the methodological decisions that have been made. The chapter begins by outlining the philosophical position taken before going on to describe the study site. In the main body of the chapter a detailed account of the research methods and data analysis techniques employed is provided. Issues of reliability and validity are addressed along with those of generalizability from case study research. Finally, ethical questions including those of informed consent and participant anonymity are discussed.

#### **PHILOSOPHICAL UNDERSTANDING**

Inherent in all research methodologies are underlying epistemological beliefs. These form the bases of understandings about the status of research findings. In essence epistemological positions are an attempt to explain how we know what we know (Crotty, 1998). The philosophical stance taken will have implications for the type of knowledge produced and the kinds of claims that can be made about research findings. It is therefore imperative that the approach taken be appropriate to the aims of the research. The following section outlines with reference to positivism, (the prevalent paradigm within scientific communities), why in this case a constructivist paradigm has been selected and concludes with a discussion of the process of theory development.

Guba and Lincoln (1994) state that positivist paradigms provide the backdrop against which other perspectives operate. This approach to scientific enquiry has dominated the field of health care research, and it is from criticisms of this paradigm that other schools of thought have emerged. Guba and Lincoln (1994) outline several difficulties with positivism, which they contend can be addressed by adopting a constructivist approach.

Firstly they argue that the positivist paradigm fails to account adequately for human intentions. They maintain that human behaviour cannot be fully understood without reference to the meanings invested in those actions, and that qualitative approaches derived from constructivism can help provide such insights. Social scientists have expressed frustration that the results they

have achieved using traditional scientific methods are unresponsive to the research problems that confront them (Erlandson et al., 1993). In response to the difficulties they encountered Erlandson et al. recommend the use of a constructivist approach, as a more appropriate technique for conducting research in human settings. Similarly Crabtree and Miller (1999) conclude that constructivism is the paradigm of choice if the researcher wants to understand individual participants' experiences of particular circumstances or events.

Secondly Guba and Lincoln contend that positivist approaches fail to give adequate attention to the context of the study. Traditional studies often focus on particular variables and are designed to exclude as many other extraneous variables as possible in order to isolate specific effects. This approach is not particularly well suited to research in social settings, given the difficulties of isolating specific variables. Moreover, it is argued that the findings from such studies can then only be applied to similarly manipulated environments (Guba and Lincoln, 1994). Crotty (1998) cites Husserl (1970), who argues that a scientific approach has the effect of distancing people from their everyday lived experiences. In contrast constructivism seeks to explore participants' experiences within the context of their own environments. It provides benefits in terms of rich contextual data that offer greater insights into individual participants' understandings. Criticisms about lack of empirical generalizability are addressed later in this chapter.

Finally, and perhaps most significantly Guba and Lincoln argue that the positivist approach of viewing 'facts' as unambiguous objective knowledge is flawed on two principal grounds. Firstly, they contend that the inter-dependence of theories and facts has become increasingly accepted, casting doubt on positivist objectivity. This being the case, facts become relative, and are only 'facts' within a given theoretical context. Secondly they argue that the positivist view of a researcher being able to access a single objective reality is flawed. Instead they support the idea that findings are created through interaction between the researcher and the subject(s) of the study as a far more plausible description of the inquiry process. This latter claim has resulted in the charge of relativism, and concerns that there is no basis on which to judge between interpretations as all are seen as valid understandings (Schwandt, 1997; Murphy et al., 1998). Hammersley (1992) rejects this criticism. He adopts a position which he calls 'subtle realism' in which phenomena are seen to exist independently although understanding is always mediated through the social world. Within this position perspective is inevitable, permitting multiple non-competing valid descriptions. However contradictory valid descriptions are not

possible (Murphy, 2001). Hammersley concludes by stating that truth should be interpreted as 'beliefs about whose validity we are reasonably confident'.

It is this concern with perspective which makes constructivism, and in particular a subtle realist approach, especially suitable for research in social settings. The approach highlights the different understandings held by individuals. By focusing on subjective interpretations, it offers a way of accessing the richness and complexity of social environments (Murphy, 2001).

Finally, it is worth exploring the process of theory development, as this forms an important part of this thesis. Unlike in quantitative research, which is often focused around the deductive testing of a hypothesis, qualitative studies such as this one, may be exploratory in nature and produce a large volume of very rich detailed data. Instead of being used to test a hypothesis, findings are produced inductively through an intensive process of analysis that involves reading and re-reading and coding data into common themes (Dey, 1993). In this way, findings may therefore be seen as 'emerging' from the data.

Within this thesis these emergent findings suggested that, in contrast to other members of the multidisciplinary team, nurses may not accurately assess patients' continuing care needs or involve them in this process. The central question was why, contrary to initial expectations, this should be the case. No strong patterns were evident within the data which suggested why this should have occurred. Moreover the process of generating theories on the basis of single case studies has been heavily criticised as being unreliable (Hammersley et al., 2000).

During the course of this study, Nolan et al.'s (2002) senses framework was published. What was striking about the framework, which in essence seeks to describe 'the fundamentals of care', was its resonance with the then emerging findings of this study. Although it is evident from the date of the framework's publication, that this thesis did not set out to deductively empirically test this hypothesis, this is not in itself problematic. Experts in the field of case study method have stressed the importance of researchers building on each other's work (Hammersley et al., 2000) and have long stressed the importance of generating theory in case studies by using a constant comparative approach (e.g. Znaniecki, 1934). Moreover, the resonance between the framework and findings of the thesis means that the findings of the study are both detailed and relevant enough to be meaningfully applied to the framework. Significantly Nolan et al. (2001a) cite the work of others, particularly Redfern and Norman (1999), as providing empirical support for the senses framework, although these authors did not set out to provide such support and make no reference to the senses framework in their study. In addition, the fact that the findings

of this thesis have been generated in a different context from those in which the framework was developed is also advantageous. Rigorous testing of theories dictates that they be applied in a broad range of environments (Yin, 1994). In applying the framework within a different context, this study may have identified a weakness in the senses framework. Importantly, the central contribution of this thesis to the body of knowledge is the finding that the senses framework does not appear to adequately account for the findings of this study and that the framework may need to be modified to incorporate a seventh sense in order to adequately account for the 'fundamentals of care'.

Thus, in summary, it was decided, given the synergy between the emergent findings and the opportunity provided by the publication of the senses framework that the findings from the study, which were developed inductively would be considered in relation to the framework thereby providing a comparison between the inductive findings and deductive theory.

Having set out the philosophical underpinnings of this research, the next section outlines the approach taken along with the methods of data collection and analysis.

## **METHODOLOGICAL DETAILS**

### **Methodological Approach**

The aims of the study which focus on professionals', patients' and informal carers' experiences of patient involvement in continuing care assessments are mainly exploratory. Bryar (2000) states that case study research is concerned with providing a description of individual or multiple cases. In addition, Hammersley and Gomm (2000: 4) argue that a case study's 'main concern may be with understanding the case itself'. Thus the aims of this study lend themselves towards using a case study approach. In contrast, experimental methods seek to evaluate interventions whilst the principal aim of surveys is to make empirical generalizations from samples to populations. In this way the aims of these approaches make them less suitable to this research study.

In addition, although in principle exploratory questions can be answered using survey or experimental strategies, these approaches have a limited ability to incorporate contextual detail (Yin, 1994). Experimental methods seek to manipulate environments to isolate the effects of specific variables. This is neither technically possible nor desirable on ethical grounds in many social settings. Instead a case study approach facilitates research of 'naturally occurring cases'

(Hammersley and Gomm, 2000: 4). In this study 'the contextually situated perspectives of individual participants are crucial in developing an understanding of the ways in which continuing care assessments are conducted. Manipulation of the research setting within an experimental design could have altered the social environment and thus modified participants' experiences. It is thus unsuited to the aims of this study of exploring individuals' contextually situated perspectives. Moreover, with both surveys and experimental approaches, the quantification of data is a priority. By placing an emphasis on quantification the richness and detail that may be present in qualitative data may be lost. In conclusion, Yin (1994) advises researchers to use a case study approach when the contextual detail of the situation is highly pertinent to the study.

In summary, a case study approach was chosen as its aims were compatible with those of this study. It facilitates research of naturally occurring cases, allowing the collection of the rich contextual data that is necessary to explore individuals' experiences of patient involvement in continuing care assessments.

Yin (1994: 22) argues, 'the definition of the unit of analysis (and therefore of the case) is related to the way the initial research questions have been defined'. Within this study, the principle decision was whether the individual patients, or the multidisciplinary ward teams should form the unit of analysis, or 'case'. Whilst one of the aims of the study is to explore patients' experiences of involvement, the central focus of the thesis is on the roles of multidisciplinary team members in facilitating involvement and thus in this instance it was decided that the team should constitute the 'case'. However, that is not to dismiss the importance of patients and their informal carers, as their experiences are integral to this thesis and play a significant part in developing an understanding of the roles of multidisciplinary team members in facilitating patient involvement.

### **Selection of the Study Site and Negotiating Access**

In order to develop an understanding of the roles of individual professionals in continuing care assessments, it was important to select a site where multidisciplinary teamwork was well developed. By conducting the research in a location where best practice could be expected, exemplars from this environment could potentially be transferred to general wards where the majority of older adults are admitted as patients. Moreover, the government's increasing emphasis on multidisciplinary practice (Department of Health, 1994b, 1995) indicates that all professionals will increasingly be encouraged to work in this way. Evidence from the literature

indicated that multidisciplinary teams were most established and effective on care of the elderly wards and were weaker on general medical and surgical units (Department of Health, 1996a; Audit Commission, 1997). Therefore it was decided to select an elderly care setting.

Stipulations imposed by the research funders limited the number of data collection sites available to five local Trusts covering eight hospitals, all of which were in London. Three hospitals were rejected as potential locations for the study because they were specialist tertiary centres and had no care of the elderly provision. Through contacts with nurse managers, informal visits were arranged with the remaining hospitals. Initial background information was obtained from the nurse managers, discharge planning staff and clinical tutors. This included details about ward sizes, lengths of patient stay and dependency levels. This was set alongside local administrative and managerial issues. Having identified the most suitable Trust for the location of the study, the next step was to identify an appropriate ward or wards for the research.

It was anticipated that the continuing care assessments of twenty patients would be observed. It was felt that if the study were conducted on only one ward, individual multidisciplinary staff may be repeatedly involved in the assessments of these twenty patients. Therefore, to obtain a reasonable spread of professionals and avoid too narrow a focus on the practice of individual members of staff, two care of the elderly wards were selected. Data collection took place on one ward at a time because of the time intensive nature of the research.

The particular wards included in the study were selected for several reasons. As the focus of the study was on decision making around patients' discharge, it was thought important to select sites where patients' lengths of stay were long enough to allow planning to take place, but not so long that observation of the process would be infrequent. Estimates by staff of three to four discharges per week on both wards and an average length of stay of about a fortnight were considered suitable. The wards also had the advantage of accommodating patients with a wide range of dependencies, thereby allowing for observation of decision making in relation to both simple and complex packages of care. In addition the majority of patients came directly to the wards from the accident and emergency department and were rarely transferred from other parts of the hospital. This was important as nurses conducted patient assessments on admission from the accident and emergency department, (and also with elective admissions), whereas this information would have already been asked of patients who were moved between wards. These initial assessments would include questions about patients' health and social circumstances,

affording the opportunity to observe the preliminary identification of patients' continuing care needs.

The first stage in negotiating access involved sending a copy of the research proposal to the consultants responsible for the medical care of the patients on the wards identified. Permission to conduct the study was also sought from the nursing staff. A first meeting was arranged with the ward sisters to discuss the research and allow any concerns to be raised. Subsequently a second meeting was arranged with the other nursing staff to allow an opportunity for individual worries to be addressed. Once consent had been obtained from both the medical and nursing staff, an application was made to the ethics committee of the local health authority to conduct the research. Ethical approval was sought by completing the committee's application form for research studies. This application form contained sections on; the general description of the research proposal, recruitment of subjects, and discomfort and potential hazards. In addition it sought information on how informed consent would be obtained and, how confidentiality would be maintained. Ethical approval was granted after clarifying for the committee that an information sheet about the study would be sent to the nurse bank and that, when interviewed in the community, patients and informal carers would be given local health and social service telephone numbers in case the interviews raised queries about the care they received. Formal ethical approval to begin data collection was granted by the committee in November 1997. Ethical issues that relate particularly to this study are discussed in detail later in this chapter (see page 96).

Data collection began on Ward 1 in February 1998 and lasted 8 months and was followed by a 6 month data collection on Ward 2.

## **The Research Setting**

### **The community**

The study was undertaken at a district general hospital in London. The hospital is located in a large and diverse multicultural community. However at present, people from minority communities make up a smaller proportion of the elderly population compared with younger age groups. Thirteen percent of elderly people belong to one of these communities, the largest of which are made up of South Asian and Caribbean people (Borough Community Care Plan, 1996 -1999). In addition, the Borough Community Care Plan shows that the area suffers from high levels of social deprivation. It reports that in 1995 the Borough's unemployment rate was double that of Greater London as whole. Correspondingly, average income levels were lower

than in neighbouring areas. In 1993, 55% of gross annual household incomes in the Borough were below £10,000 compared with 40% of household incomes across the capital. Residents also suffered high levels of ill health. A 1990 survey asking people in the Borough about their own state of health found that people reported high levels of asthma, diabetes, hypertension and mental illness, with almost half the sample stating that they experienced at least one symptom related to stress or mental ill health.

In addition, many houses in the Borough were found to be in need of renovation. The situation for older people was of particular concern with one in three pensioner households lacking central heating at the time of the 1991 census.

### The hospital

The site where the study took place is the smaller hospital of a two hospital acute Trust. A dozen wards were located on this site, including general medical, dermatology and care of the elderly wards. The building was constructed in 1870 and parts of it were in a very poor state of repair. Maintenance work was ongoing although it was planned eventually to relocate several wards into the larger Trust hospital site. The general shabbiness of the environment was immediately apparent. Fieldnotes from the first day of observation record:

*“The ward looked grubby despite the presence of a cleaner. A window behind one of the beds had ivy growing in through it, and judging by the small cobwebs, had not been shut for quite some time.”*

[Fn060298 72-75]

Ward 2, was in a better state of repair. It was located immediately above Ward 1, so that they had the same floor plans. Both wards had 20 beds, and were divided up into bays containing groups of 3, 3, 4 and 8 beds respectively; in addition each ward had 2 single siderooms. Both were mixed sex wards although as far as possible bays were always segregated to separate males from females.

### The staff

Table 4-1 shows the nursing staff working on Ward 1.

During the period of data collection two nurses left and none joined the ward.



**Table 4-1**

Nursing Staff	Grade	Gender	Ethnicity
Ward sister/ Charge Nurse (2)	G (1) F (1)	F (1) M (1)	Caribbean (1) White - British (1)
Staff nurses (7)	E (5) D (2)	F (6) M (1)	African (2) Asian - Philippine (1) Caribbean (1) Chinese (1) White - British (1) White - Irish (1)
Enrolled nurse (1)	C (1)	F (1)	Caribbean (1)
Non registered nurse (8)	B (1) A (7)	F (7) M (1)	African (2) Caribbean (1) Indian (2) White - British (3)
Student nurse (0)			
Total	18	3M 15F	

(The ethnic groupings used in the table are the same as those used in the 2001 census).

It is important to note that, although a large number of the nursing staff (on both wards) were from minority communities, all but one of them had undertaken their nursing training in the United Kingdom.

All patients on Ward 1 were under the care of one consultant physician. On a day to day basis their medical care was provided by a senior house officer (SHO). In contrast to other staff, SHOs worked in rotation, being attached to the ward for periods of approximately 2 months as part of their ongoing training. In addition Ward 1 had a designated social worker and shared a physiotherapist with Ward 2. Occupational therapists worked across the hospital, having individual allocated geographical areas for which they conducted all the requested home visits. However occupational therapists also had designated link wards for which they attended multidisciplinary meetings.

Table 4-2 shows the nursing staff working on Ward 2. During the research period no nurses either left or joined the ward. The patients on Ward 2 were split between the care of two consultant physicians. Each consultant conducted one ward round during the week. However, on ward rounds, each consultant reviewed all the patients on the ward, regardless of the consultant under which they had been admitted. As with ward 1, medical care was provided by an SHO, with SHOs rotating at approximately two monthly intervals. Similarly Ward 2 had a designated social worker and a shared physiotherapist. The organisation of the occupational therapy department changed early in the data collection on Ward 2, so that wards had

designated occupational therapists who carried out home visits for their patients as well as attending multidisciplinary meetings.

**Table 4-2**

Nursing Staff	Grade	Gender	Ethnicity
Ward sisters (3)	G (1) F (2)	F (3)	African (1) Caribbean (2)
Staff nurses (10)	E (5) D (5)	F (8) M (2)	African (3) Asian - Philippine (1) Caribbean (4) Indian (2)
Non registered nurse (9)	B (2) A (7)	F (8) M (1)	African (2) Caribbean (3) Indian (1) White - British (3)
Student nurse (0)			
Total	22	3M 19F	

Having described the contextual background to the study, the following section goes on to detail the research methods employed and the rationale for their use.

### **Use of Multi Methods**

A multi method approach was taken to data collection.

The data are made up of two main strands. The first strand explores the context of patient and informal carer involvement. This strand of the data collection facilitates an increased understanding of the background against which continuing care assessment and patient involvement takes place and allows for the identification of unique features of the health care setting. It consists of general observations of the way that continuing care assessments were conducted and the factors that impinged on the degree of patient and informal carer involvement. These observations were supplemented by general interviews which used a semi-structured approach to ascertain professionals' detailed views on their approach to continuing care assessments and the involvement of patients and informal carers. In addition, local documentary evidence obtained at Borough and Trust levels served both to further enhance the understanding of patient and informal carer involvement.

The second strand explores in detail, the experiences of members of the multidisciplinary team in assessing individual patients' continuing care needs and facilitating patient involvement and

patients' and informal carers' experiences of being involved in this process. It consists of observation of key events in relation to the continuing care assessments of twenty patients who were tracked through their hospital stay. These observations were supplemented by semi-structured interviews with professionals, patients and informal carers about how patients and informal carers had been involved in identifying their own continuing care needs. In addition, documentary evidence in the form of medical records gave added insights into patient involvement in the assessment process.

The rationale for these methodological choices is discussed below. These two aspects of the data collection occurred concurrently, but for explanatory purposes they will be described separately.

### **Strand 1: The context of patient and informal carer involvement**

The aims of the study meant that it was important to look at the context of patient and informal carer involvement. This is because there may have been particular features of the setting which could have influenced professionals' roles in continuing care assessments or affected their experiences of this process. In addition there may have been aspects of the setting which could have had an impact on the degree of influence that patients and informal carers were able to exert or that facilitated or inhibited the involvement process.

Three main methods were used to collect this strand of the data; observation, general interviews and documentary evidence.

#### **Observational data**

Observational data were important in informing the aims of the study. Fieldnotes from observations shed light on the way that professionals viewed patient involvement and the assessment of individual needs. More particularly, they included records of informal conversations with multidisciplinary staff. Staff, especially nurses, would often talk candidly during breaks and before the start of shifts. At these times they would discuss their opinions on a variety of topics, talk about the pressures they felt or highlight difficulties they were experiencing. Such discussions could provide insights into their attitudes towards patient involvement and the ways in which they approached continuing care assessments. In addition, fieldnotes from observations of ward rounds and of debates in multidisciplinary meetings about the discharge of patients who were not being tracked in the study, could reveal important details about the way that patients and informal carers had been involved in the assessment process. Factors that may have both facilitated and inhibited involvement were also able to be explored.

The means by which the fieldnotes were obtained is explored in more depth below.

The most pressing issue when entering the field was to clarify my role as the researcher. In particular it was important to be clear about the extent to which I would be a 'detached observer' and how much I would be involved in the routine of the ward. A typology of four field roles was identified by Gold (1958) (cited in Hammersley and Atkinson (1995)). Gold calls these roles the complete participant, the participant as observer, the observer as participant and the complete observer. The complete participant role is a covert one, with the researcher hiding their purposes from other people in the research setting. This role has significant ethical implications and is infrequently used. In contrast, the complete observer does not interact with those people who are being observed, and as a consequence Gold argues, the risks of misunderstanding behaviour are increased. More commonly used are the participant as observer and observer as participant roles. The participant as observer role requires the researcher to adopt or create a role within the group, but the observation is overt and allows questions to be asked of the group members. Similarly the observer as participant is known to the group but does not participate in activities. These roles are not mutually exclusive, and researchers may make different choices about their degree of participation at different times (Schatzman and Strauss, 1973).

I initially decided to go into the ward in a participant as observer role. I worked shifts alongside the ward staff as an auxiliary nurse. This had two main advantages. Firstly it allowed for a rapport to be built with the ward staff, and for them to get used to the presence of an outsider on the unit. Secondly it provided a period of time to become familiar with the ward routines. During this time I was able to identify the occasions when needs assessments took place and select key events whose observation were likely to provide the most useful insights. By being supernumerary to the staffing levels I was also able to leave the ward to attend relevant meetings such as the hospital discharge planning group. However, I found the role of participant as observer to be increasingly constraining. During ward rounds and at other times patients would ask for assistance and because I wore a staff uniform I found it impossible to refuse their requests and so I was being drawn away from my real purpose of observing others on the ward. Therefore before commencing the data collection, I decided that I would switch to become more of an observer as participant. I decided that I would no longer wear a uniform or work alongside the staff but would focus my time on the ward around the key events that I had previously identified through experience. By this stage I also felt less self-conscious and was comfortable being on the ward solely as a researcher, without an identified participatory role.

The ward staff also adapted and on many occasions quite naturally introduced me to patients and visitors as 'our research nurse'. In this way I perhaps unconsciously created a new role for myself on the ward. Although I sometimes still helped staff with tasks such as making drinks for patients, the majority of my time on the ward was focused around events relating to patients' needs assessments.

Fieldnotes were the means through which observations were recorded. As details could be very quickly forgotten, writing was a way of retaining information. As it was not possible to record events in their entirety, particular aspects needed to be selected. Spradley (1980) identified nine dimensions of social situations which were used as a guide to focusing observations and formulating more detailed lines of inquiry (Burgess, 1984). Spradley urges observers to pay attention to; space - the physical layouts, the actors involved, the activities occurring, the actions of individuals and the physical objects in the setting. In addition he suggests researchers should take note of events that take place, time sequences and the goals and feelings of individuals. Sometimes it was possible openly to take brief notes of events, for example during multidisciplinary meetings, as most members of staff also wrote during these and it was seen as a natural or even expected activity. At other times taking notes was less appropriate, and may have caused anxiety. On the whole I followed the general rule of not jotting conspicuously (Lofland and Lofland, 1995), but instead wrote short phrases to assist recall when writing up full fieldnotes. Full, anonymised fieldnotes were typed onto a laptop computer as soon as possible after they were taken which was usually the same day.

During the study fieldnotes were made on a daily basis in relation to continuing care assessments and the involvement of patients and informal carers. These notes were not taken at set regular intervals, rather jotted phrases were written opportunistically as and when events of interest occurred. The ethical implications of making fieldnotes from these observations are discussed at the end of the chapter.

### General interviews

General interviews were conducted with all consenting qualified multidisciplinary staff on Wards 1 and 2 with the exception of those staff who worked solely at night. These staff were excluded because they had minimal involvement in multidisciplinary assessments. In addition, one nurse chose not to be interviewed and another was off sick on his last day of work, during which he had agreed to be interviewed. In total 32 general interviews were conducted with multidisciplinary staff.

The interviews provided an arena to explore general rather than specific issues relating to the involvement of patients in assessments. It was intended that these data would provide an increased understanding of the background against which continuing care assessment and patient involvement takes place. Within these interviews staff were encouraged to reflect on their own roles and those of other members of the multidisciplinary team in assessing patients and facilitating their involvement. They were also encouraged to consider those factors that both promoted and inhibited patient involvement. In this way, insights were obtained about the context within which patient involvement took place. The interviews were conducted using a topic guide (see Appendix 7) that was constructed to address these specific areas and thus inform the aims of this study.

The format and structure of the topic guide was informed by reference to the literature in the field, and in particular by those studies that had examined the involvement of patients and informal carers in continuing care assessments. Studies that had examined involvement and that also contained interview topic guides (e.g. Powell et al., 1994) were especially useful starting points. In addition, the advice of academic experts was used to inform the development process. Thus, in summary, the topic guide used in this study was constructed by reference to the academic literature, other topic guides and following the advice of academic experts, including Dr Charlotte MacDonald and Dr Sally Richards who helpfully commented on an earlier version of the topic guide. These individuals were approached because they had recently used interviews in research examining patient involvement in continuing care assessments (Myers and MacDonald 1996; Richards 1996) and were able to draw on their experience of working in this field.

The topic guide contained a list of open questions that were used as probes to encourage interviewees to contribute their own ideas about the subjects under discussion. The questions were not intended to be asked in a rigid sequence, but instead cues were taken from the interviewees who were encouraged to follow their own train of thought. In this way, the topic guide acted more as a checklist of areas that it was important to cover in the interview.

All interviews were tape recorded with interviewees' permission and typically lasted between 45 minutes and 1 hour. They were conducted in work time, often at weekends or in the evenings when the wards were quieter as it was easier for staff to find this amount of free time. An example of a transcript from a general interview is given in Appendix 8.

### Local Documentary Evidence

Local documents provide evidence of the way in which patient involvement was approached at both a local and regional level. Documents shed light on the roles and responsibilities that managers anticipated that staff would adopt in assessing individual needs and the priority that was attached to patient involvement at this level. These documents therefore provide a framework within which local practice can be interpreted.

Information was collected systematically at a Borough level and included a copy of the local community care plan, and an independent review of the local eligibility criteria. A meeting with the member of health authority staff responsible for continuing care helped ensure that all relevant local documents were obtained. At a Trust level a copy of the newly revised hospital discharge policy was obtained, as was a copy of a previous audit of patient discharge. In addition, minutes of the meetings of the hospital's discharge planning group were also retained.

Further information was collected more opportunistically at ward level. Informal conversations with staff would occasionally reveal that the results of a ward audit were expected or that a memo had arrived giving details of a staff training session.

### **Strand 2: Patients' and Informal Carers' Experience of Involvement - The Patient Tracking Data**

#### Sampling and inclusion criteria

A purposive sample of twenty patients was selected and followed throughout hospital admission and for 2-4 weeks post-discharge in the community. A sample size of twenty was decided upon as this was the maximum amount of data that was able to be collected and analysed within the given time and resource constraints. For practical purposes a maximum of three patients were followed at any one time. Once one patient had been discharged the next admission to the ward was considered for inclusion in the study. It was important to include a broad range of patients to avoid producing a partial account of the study environment (Burgess, 1984). Care was taken to ensure a representative sample in respect of their age, gender, ethnic backgrounds and dependency levels. A table summarising their health and social circumstances along with details relating to their hospital admission, can be found in Appendix 9. Patients were excluded from the study if they had a diagnosis of acute or chronic confusion, or dementia, as their ability accurately to recall events may have been impaired. Older people admitted with a terminal illness were also excluded for ethical reasons. Finally, it was

considered that valuable assessment data would not have been obtainable for patients who were transferred from other wards and so these patients were also ineligible for inclusion in the study. On two occasions, patients' inclusion in the study was discontinued because these patients were transferred to other non care of the elderly wards, and were therefore outside the inclusion criteria of the study. These patients were replaced, and are not included in the sample of twenty patients whose care was tracked.

It was also decided to remove from the study any patient for whom no decision was made about their health and social care needs after discharge from hospital. One patient initially included in the study was subsequently found to have a large aneurysm, and sadly died in hospital before any plans were made about post-discharge care. There were no significant socio-demographic differences between the three patients initially included in, and later removed from the study and the final group of twenty patients whose care was followed.

It was decided to follow patients for a period of 2-4 weeks post-discharge in the light of the experience of other researchers who had interviewed patients in the community about their hospital discharge. The Equip team (1997) highlight the need to strike a balance between allowing people to settle at home but not leaving it so long that they forget the details of their discharge experience. The home care staff in their study were critical of a 4-6 week follow-up period, arguing that this was too long. However, other researchers have found a 2-4 follow-up period to work well in practice (Powell et al., 1994).

Having given a rationale for the sample selection and inclusion criteria, the next section provides details of the research methods used to collect the patient tracking data.

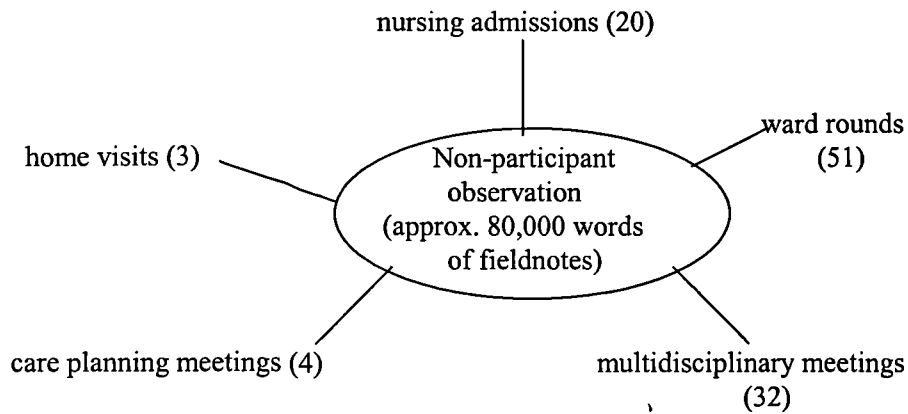
### Patient Tracking: Data Collection

Three main methods were used to collect the patient tracking data; observation, semi-structured interviews and documentary evidence in the form of patients' notes.

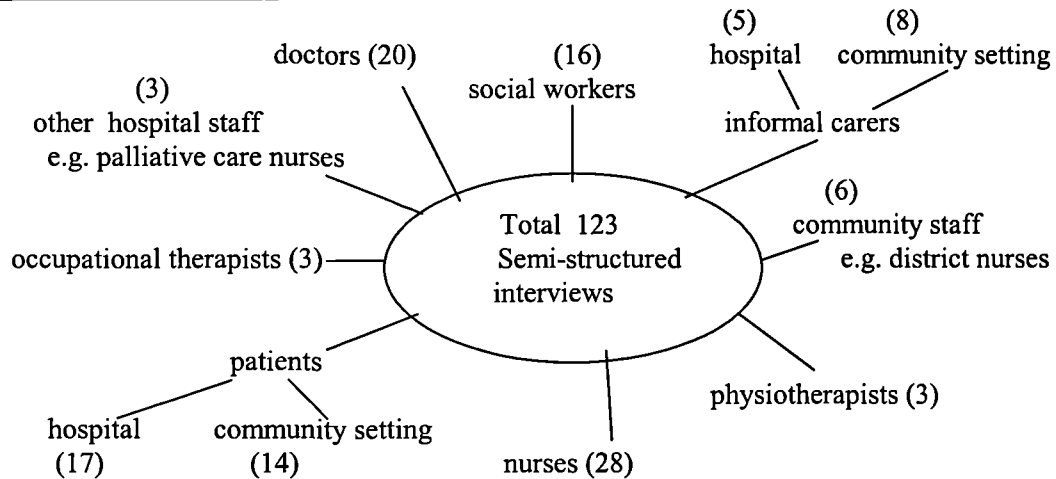
The patient tracking data can summarised diagrammatically:



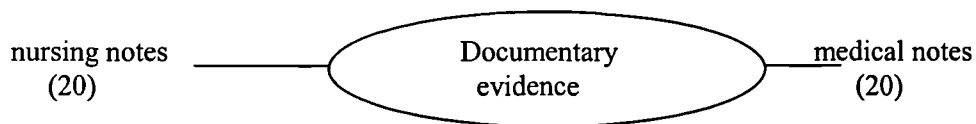
Observation



Semi-structured interviews



Documentary evidence



Focused observations

Focused observations of continuing care assessments were important in informing the aims of the study. Observations indicated how, in practice, individual members of the multidisciplinary team approached continuing care assessments and highlighted their roles in facilitating the

involvement of patients and their informal carers. Moreover, these observations focused around the twenty patients being tracked provided insights into the role that patients played in this process and factors that affected their involvement.

During the initial period of participant observation, whilst working as an auxiliary nurse on the ward, key points in patients' needs assessments were identified and became the focus of ward observations. These were ward rounds, multidisciplinary meetings, care planning meetings, home visits and nursing admissions. An audio tape recording was made of each patient's nursing admission and fieldnotes were written about each of the other ward events, which are described briefly below. (The routines were the same on Wards 1 and 2).

Nursing admissions were conducted when patients arrived on the ward. This was perhaps the one time when nurses systematically assessed patients, and thus this afforded an ideal opportunity to observe both how needs were assessed and the role that patients and informal carers (who were often present at admission) played in identifying the patient's continuing care needs. Basic biographical information was collected alongside assessments of patients' health and social circumstances. The nursing assessment form was based on Roper's model of nursing (Roper et al., 1983). The form was divided in two halves, with one side listing the activities of daily living, giving nurses prompts or cues in relation to each activity (see e.g. page 106). The other side was blank allowing nurses space to write their corresponding evaluation.

Consultant led ward rounds took place two mornings per week. The ward rounds were when patients' state of health was assessed and, if appropriate, provisional plans were made for their discharge. Observation of ward rounds elucidated the role of individual members of the multidisciplinary team in identifying patients' continuing health and social care needs and the ways in which they involved patients in this process. The consultant was accompanied by an SHO and staff nurse and sometimes also by medical students or other team members e.g. a physiotherapist. The staff, led by the consultant, started at one end of the ward and reviewed each patient in turn. Typically the staff would have a short discussion around the notes trolley about the patient's medical condition before the consultant would go over and ask the patient about their clinical progress.

Multidisciplinary meetings were held on Tuesday lunchtimes, following a ward round. At the meetings information was fed back from the ward round, allowing patients' discharges to be

planned. It was through observing the process of planning patients' discharges that the roles and responsibilities individual team members adopted became more apparent. The meetings were attended by the staff who had been on the ward round and in addition by a social worker, physiotherapist, occupational therapist, community liaison nurse, a member of the hospital discharge team, and a member of staff from Age Concern.

Care planning meetings were held in cases where patients' discharges were felt to be complex or where moves to institutional care were being considered. They allowed for a more detailed discussion of individual needs than was possible in the multidisciplinary meetings. The other significant difference was that, in contrast to the multidisciplinary meetings, care planning meetings were attended by the patient and informal carers. The meetings were led by a social worker and were usually also attended by a nurse, SHO, and often by a physiotherapist and an occupational therapist.

Decisions about whether a home visit was required were made by the consultant. Home visits were conducted by an occupational therapist where there was some doubt about patients' ability to continue to manage independently at home. Informal carers were usually present on these occasions. The occupational therapists assessed patients' ability to move safely around their home and to carry out basic tasks such as those required to meet their nutritional and hygiene needs. Care planning meetings were often held a few days after a home visit to decide what level of support patients required.

In addition to observing key events, I was able to interview patients informally during the fieldwork. In this way I built up a rapport with patients and their informal carers. Day to day contact meant that I developed a clearer understanding of their continuing care needs and the ways in which they were involved in the assessment of these needs.

However, it was inevitable that the focus on selected ward activities did not give the entire story. Discussions between staff concerning patients also took place informally in corridors or during telephone conversations. Informal carers also sometimes visited social workers in their offices. It was impossible to observe all these interactions, and it would have been futile to try to do so. Being a lone researcher also compounded the difficulties and meant that occasionally choices had to be made between relevant activities that were occurring simultaneously. Given greater resources it would have been interesting to observe SHOs' initial assessments of patients to see what needs they identified. However this was impractical as assessments were often conducted in A&E and made before it was known if the patient would be admitted to the

ward. Patients also arrived in the A&E department at unpredictable times of day and night. Similarly it would have been interesting to observe social workers' assessments of patients, but again these took place at unpredictable times, and it would have been difficult to be sure of observing all of these. The implications of this are discussed in the findings chapters.

### Semi-structured interviews

Semi-structured interviews were conducted with key multidisciplinary staff, patients and informal carers, both in hospital and after discharge in the community. The interviews allowed respondents to focus on the continuing care needs of the individual patient in question and the extent of patients' involvement in the assessment process. Information from these sources could then be triangulated with a view to comparing and contrasting different perspectives.

79 semi-structured interviews were conducted with multidisciplinary staff who had been involved in the care of the twenty patients being tracked. Specifically, these interviews revealed the extent of different professional groups' knowledge about the individual patient's state of health and their social circumstances, and allowed them to reflect on their own role in the patient's continuing care assessment. In addition, they allowed exploration of professionals' perceptions of the degree to which they had involved patients and their informal carers in the process identifying their own continuing care needs. In thinking about patients' and informal carers' experience of involvement, professionals were also encouraged to identify factors that may have facilitated or inhibited this process. Thus, as with the general interviews, the semi structured interviews were designed specifically to inform the aims of the study (see page 13). The semi-structured interviews were also conducted using a topic guide (see Appendix 10), which was constructed in the same way as that used in the general interviews, with reference to the research literature and academic experts in the field.

The interviews were conducted with all key staff involved with each of the 20 patients as soon as possible after the patient's discharge so that the details of events were not forgotten. Where possible, the patient's named nurse (specified nurse, allocated to individual patients to coordinate their care during their hospital stay) was interviewed. However, it should be noted that patients often did not have an identified named nurse. In cases where there was no named nurse, interviews were conducted with the nurse or nurses who most closely approximated to this role, in respect of each patient in the study. In addition to the nurses, interviews in relation to each patient were also conducted with other multidisciplinary staff, where they had had an input into the decision making about the patient's continuing care services. This included

SHOs, social workers and occupational therapists as well as physiotherapists and palliative care nurses. The duration of interviews varied but on average they lasted about 15 minutes.

Patients were also interviewed before their discharge from hospital to explore their experience of being involved in assessments and the way that this had been facilitated by members of the multidisciplinary team. Patients were interviewed again 2-4 weeks later, in the community to see how, in practice, their continuing care needs were being met. In addition, informal carers were interviewed in the community with patients' permission. Where informal carers had had significant inputs into decision making in the hospital setting, for example, where care planning meetings had been held, informal carers were also interviewed in hospital. An interpreter was used in an interview with one patient who was unable to speak English. Written information about the study was also provided for this interviewee in her own language. Interviews with patients and informal carers were conducted using a topic guide (see Appendix 10).

All interviews were tape recorded with interviewees' permission. One nurse agreed to be interviewed but asked not to be tape recorded and so notes were taken and written up from her interviews. An example of a transcript from a semi-structured interview is given in Appendix 11.

Some key staff were interviewed in relation to more than one patient's care. Their familiarity with the interviewing process coupled with a generally positive response from other staff helped lessen any initial anxiety they may have had.

#### Documentary evidence

Documentary evidence was also collected to support the data from the semi-structured interviews and observations of practice. This evidence comprised copies of patients' medical and nursing records. These records provided written evidence of discussions with patients and informal carers. In addition, they showed the continuing care needs that had been identified and outlined how plans to meet these needs had progressed. Referral forms to multidisciplinary colleagues based in the community revealed needs that professionals considered patients would require assistance to meet. Moreover, information passed onto community professionals gave insights into the knowledge of hospital staff and the starting point from which staff located in community operated.

Having examined the methods of data collection the next section discusses the techniques used to analyse the data sets.

### **Data Analysis**

Unlike quantitative data analysis which is characterised by widely accepted statistical procedures, there are many strategies for qualitative analysis. For example Tesch (1990) identifies twenty-six distinct approaches to analysing qualitative data. Coffey and Atkinson (1996) state that the level of disagreement is such that there is not even consensus about what the term 'analysis' means let alone agreement on the specific strategies that should be employed. Researchers have variously focused on the content of documents (Kracauer, 1993), biography (Gearing and Dant, 1990; Smith, 1994) and linguistic approaches (Mishler, 1984). In fact any number of strategies could be used to analyse any given data set and each would produce a different interpretation (Dey, 1993). Given that there is no, 'one true' analysis waiting to be discovered, Dey argues that the onus shifts onto the researcher to be open and explicit about their choice of approach.

For me the key issue when approaching the data was to remember what I was looking for. I found it helpful to revisit the aims of the study and in this way I was able to identify a number of themes that it would be advantageous to search for in the data. For example, when analysing data from the first strand of the data collection, using NUD.IST, key 'branches' of the tree were used to create categories that directly related to the aims of the study. These branches included the assessment roles of members of the multidisciplinary team, their experience of involving patients and informal carers, as well as factors that were felt to facilitate and inhibit involvement (see Appendix 12). Similarly, when looking at the second strand of data that was collected, matrices were created that explored individual roles in both the continuing care assessment itself and in involving patients and informal carers in this process. In this way, the aims of the study formed a framework for the analysis of the data. However, the identification of these themes did not produce a rigid set of categories, rather they became a starting point and were modified and added to as the analysis progressed. The analysis of each of the strands of the data collection is explored in more detail below.

#### **Strand 1: The context of patient and informal carer involvement**

The tapes of all the general fieldnotes and general interviews were transcribed onto NUD.IST (version 4), a software analysis package for qualitative data. The package was chosen because

of the ease of coding and because it allowed searches to be performed on categories and hypotheses to be tested.

A preliminary framework of categories was created before applying any codes to the data. The categories were arranged hierarchically in a 'tree' structure, (see Appendix 12 for the final tree structure). A provisional definition was written for each of the categories created. Dey (1993) asserts that the writing of definitions is important both as record of how each category is viewed conceptually and also as a way of ensuring that each category is applied in a consistent way. Therefore, before units of text were assigned to a category, the current definition of that category was re-read to check that the units of text fitted. Where units of text were felt to 'belong' to a particular category but fell outside the definition then a decision was made about whether to amend the definition. Amending a definition necessitated the re-examination of all text units that had previously been assigned to that category. Where definitions were not amended, new categories were sometimes created. In both cases transcripts that had already been coded were re-examined for text units that required re-coding in the light of the new or revised categories. Applying coding was thus a time intensive process.

Some researchers have recommended the use of inter rater reliability checks to aid the process of category clarification (e.g. Goodwin and Goodwin, 1984), although this has not been universally accepted (Morse, 1994). Morse argues that the use of additional raters actually violates the process of induction because it is only the investigator that has access to the complete bank of data gained from conducting the research. In this case resource constraints prevented the use inter rater reliability checks. However anonymised extracts of data containing examples where coding was felt to be borderline were taken to a meeting of a qualitative research support group (Anstey et al., 2000). The group consisted mainly of doctoral students and helpfully offered new insights into how the data might be viewed. In all 80 categories were created, some of which became more central to the analysis than others. Examples of the categories created, their definitions and units of text that were assigned to them are given in Appendix 13.

When all the interview transcripts and fieldnotes had been coded, NUD.IST was used to ask questions of the data. For example it was possible to separate out what the doctors said from what the nurses said on a range of issues and see if there were any emergent patterns. Similarly the nurses' responses could be separated by the grade of nurse. The results of these searches were able to be saved and then to be used in additional searches.

In addition, documents obtained during the study were read for insights into the roles that professionals ought to play in continuing care assessments or the way that patients and informal carers should be involved in this process.

### Strand 2: Patients' and Informal Carers' Experience of Involvement - The Patient Tracking Data

As with the first strand of the data, I felt that it was important to be explicit about the way that the analysis was conducted. This concern with the need for analytic clarity is echoed by Miles and Huberman (1994). Miles and Huberman advocate the use of matrices to support a systematic process of data reduction, data display and conclusion drawing and verification. Matrices offer the advantage of allowing large amounts of information from different sources, that relate to specific events, to be viewed together, which makes them ideal to accommodate patient tracking data. This form of data display would not have been possible using NUD.IST. The initial phase of data analysis was concerned with data reduction.

The data reduction phase consisted of selecting and abstracting text from both the fieldnotes and the interview sections of the patient tracking data. There were two main foci around which this phase of the analysis was orientated. These were the assessment of patients' continuing care needs and the extent of their, and their informal carers' involvement in the assessment process. For each of the twenty patients in the study two tables were drawn. The first table related to the assessment of each patient's continuing care needs. As each need was identified a new row of the table was created. In addition a separate column was used for each interviewee and included multidisciplinary staff, patients and informal carers. In this way it was relatively easy to compare what respondents had said about any given need. Miles and Huberman (1994) argue that this type of data display facilitates conclusion drawing and is therefore preferable in this respect to narrative which is bulky and poorly structured. The second table created for each patient related to the extent to which each professional had facilitated their, and their informal carers' involvement. These were set alongside patients' and informal carers' perceptions of their own involvement. Factors that facilitated and inhibited the involvement of individual patients and carers were also noted. An example of the tables created for an individual patient can be found in Appendix 14.

### Issues of Validity and Reliability

All scientific research strives to demonstrate the authenticity of results, often through discussions concerned with validity and reliability. Instruments are valid to the extent that they



measure the concept they intended to measure and reliable to the extent that they are consistent from one measurement to the next (Gilbert, 1993). Although measures of validity and reliability have been widely used to critique quantitative studies, some researchers have questioned their applicability to qualitative studies (Hammersley, 1992; Altheide and Johnson, 1994). Murphy et al. (1998) argue that the significant differences between quantitative and qualitative research in terms of the problems they address and the methods employed mean that different approaches are required to establish the degrees of error and the relevance of studies within each tradition. They contend that validity and relevance are the more appropriate for evaluating qualitative research. They identify four practices that enhance the validity of qualitative research; detailed descriptions of the processes of data collection and analysis, reflexivity, attention to negative cases and fair dealing. The next section examines the ways in which these practices, along with the second criteria of relevance have been addressed in this study.

#### Detailed descriptions of the processes of data collection and analysis

Murphy et al. (1998) argue that giving an adequate account of the circumstances and methods of data collection is an important part of establishing the credibility of a study. The account needs to be detailed enough for readers to be able to form judgements about the evidence upon which the research findings are based. Jorgensen (1989) supports this approach and offers specific advice about what should be included in a research report. He instructs researchers to:

*“Discuss research methods and strategies. Talk about the setting, gaining entry, and procedures for establishing rapport and sustaining relations. Describe strategies and procedures related to the participant role, data collection, analysis, and theorizing.”*  
(Jorgensen, 1989: 122)

This guidance has been followed in the writing of this chapter and it is intended that sufficient detail has been included for readers to be able to make judgements about the adequacy of the data collection.

Similarly the quality of data analysis is dependent upon the nature and adequacy of the interpretive processes used and it is incumbent upon the researcher to describe the strategies used in sufficient detail. This includes defining the categories adopted in the data analysis (Dey, 1993). Again, these instructions about providing detailed reports of strategies used have been followed in this study.

### Reflexivity

Reflexivity refers to an awareness of the ways in which the presence of the researcher has influenced the data collection and how the data analysis has been shaped by individual assumptions (Murphy et al., 1998). It is therefore important that researchers are explicit about their personal and theoretical biases. The personal and professional interests that I brought to the study and which have inevitably shaped my own perspective have been described in the first chapter of the thesis, setting out the background to the study.

Data will also be shaped by the match between the personal characteristics of the researcher such as their gender and their ethnicity and those of the group that they are studying (Burgess, 1984). In this study it may have been expected that because I am white and the majority of the nurses on the study wards were from minority communities that I could have been viewed as an outsider. However within the study wards the majority of the patients were white and the staff in the other professional groups were from diverse ethnic backgrounds. The hospital, like the local area, was a very mixed multi-cultural community, and I never felt that my ethnic background posed any particular problems or raised any barriers. In contrast I feel that my professional background as a nurse had a bigger impact on the data. As I initially worked alongside the nurses I came to be identified by the multidisciplinary team as a member of this particular group. Occasionally during interviews with members of other professional groups I observed a slight hesitancy when talking about the nurses and a reluctance to be seen to be too critical of them. More telling was the use of the collective 'you' by interviewees, albeit infrequently, that identified me as a member of the nursing staff. This needs to be borne in mind when reading the research findings.

### Attention to negative cases

Silverman (1998) argues that the presentation of negative or, as he calls them, deviant cases, enhances the credibility of the findings of qualitative research. Attention to deviant cases helps ensure that alternative plausible interpretations of the data are considered. Failure to search for contradictory evidence can result in the production of explanations that support the researcher's own prior ideological position (Silverman, 1993). In this way, not only may analyses be inadequate, but researchers may miss the opportunity to develop more sophisticated understandings of their data, that are more inclusive and do not selectively ignore sections of text. Deviant cases are presented in the findings chapters of this thesis.

### Fair dealing

Dingwall (1992) has called for 'fair-dealing' in research, stating that this entails an undertaking to represent study participants even-handedly. This approach runs counter to philosophical perspectives such as Marxism and feminism, which are characterised by a commitment to a particular section of society. However such commitments risk privileging one account at the expense of another and so distorting the data. As a way of minimising such effects Dingwall (ibid) has called for researchers to incorporate the viewpoints of as many people as possible within the bounds of the inquiry. The approach taken in this study of interviewing and observing both patients, informal carers and all multidisciplinary staff seeks to do this and to be explicit about whose views are being represented at each point.

### Relevance

Murphy et al. (1998) argue that one of the central questions that needs to be asked of any piece of research is, what does it add to what we already know? They maintain that for research to be relevant it must in some way contribute to the existing body of knowledge. Key to ideas of knowledge accumulation is the issue of generalizability, i.e. the extent to which the research findings are applicable beyond the individual study environment(s). Indeed, Sharp (1998) maintains that the value of any piece of research is determined by the extent to which the findings can be generalized.

### Generalizability

Murphy et al. (1998) argue that there are three potential means by which qualitative research may be generalized beyond the setting in which it was conducted. These means are transferability, empirical generalization and theoretical generalization.

Transferability represents the extent to which the findings of an individual study may be applied to similar contexts. To facilitate transferability the researcher must provide readers with a sufficiently 'thick' description to allow an informed judgement to be made about the degree of similarity between the study site and the location to which the findings are to be applied (Guba and Lincoln, 1989). Lincoln and Guba (2000) state that this description should specify everything that a reader may need to know in order to understand the findings. Significantly, Guba (1981) argues that if the description demonstrates an essential similarity between two contexts, then it is reasonable to assume that the tentative findings in the first context are also

likely to hold in the second context. Within this study it intended that the case has been described in sufficiently rich contextual detail to allow readers to judge the relevance of the findings to their own practice.

With respect to empirical and theoretical generalization, Sharp (1998) states that these types of generalization have often been confused. He argues that empirical and theoretical generalizations allow different types of conclusions to be drawn from studies. Empirical generalization is concerned with showing that a particular characteristic of a sample is typical of a population. Whilst relationships between variables may be identified by this means, empirical generalization does not say anything about the reasons for a correlation existing, or whether the correlation is a causal one. Sharp argues that these types of question can only be answered with reference to explanatory theory. In contrast theoretical generalizations are made on the basis of identifying general principles concerning the study phenomenon and seek to offer explanations for observed relationships.

In general qualitative studies lend themselves to theoretical rather than empirical generalization. Empirical generalizations in qualitative studies are problematic as there is often incomplete knowledge of populations which restricts the use of the random sampling needed to make statistical inferences. In addition random sampling is frequently an inappropriate methodology for case studies (Yin, 1994). The alternative strategy of repeating a study in a number of settings Sharp argues, undermines the whole purpose of generalizing. Furthermore the discovery of additional confirming cases does not alter the possibility that the next case will give conflicting results.

By contrast, Sharp argues that qualitative studies can offer benefits to health services research through the generation of theoretical explanations. Sharp maintains that one test of the adequacy of a theoretical explanation will be the extent to which it is not contradicted by some empirically generalizable observation. However, Sharp also highlights that atypical cases have an important role in theory generation, as the absence of particular phenomena may be as significant as their presence. Sharp argues that there has been a long tradition of generalizing from atypical cases in bio-medicine where historically pathological forms have been used to inform normal physiological functioning.

In conclusion, Sharp contends that once the distinction between theoretical and empirical generalization has been understood then it can be recognised that valid generalizations can be produced from case studies. In line with this argument, the findings presented in this study are

intended to be theoretically rather than empirically generalizable. In addition it is hoped that by providing rich context detail, others will feel able to judge the relevance of these findings to their own practice.

## **Ethical Issues**

### **Informed consent**

Perhaps the most important ethical issue, and one that was returned to throughout the study was that of informed consent. Some patients were unfamiliar with hospital routines and almost all were in a particularly vulnerable position when they first arrived at hospital, often having suffered a traumatic event such as a fall. As I was interested in their initial assessments, it was important that patients differentiated me from the hospital staff and their procedures and did not feel that the presence of a researcher was just another routine part of going into hospital. To minimise the pressure on patients, rather than approaching them directly, a nurse would explain that there was a researcher on the ward who was interested in patient assessments, and who would like to observe some of their care while they were on the ward. If the patient was happy with this, I would speak to them and any accompanying relatives about what I was interested in and what participation in the study would entail. It was stressed they could withdraw from the study at any time and that this would not affect their hospital care. In fact the process of obtaining informed consent was one of continued re-negotiation. It was not assumed that because a patient had participated in an earlier part of the study they would want to continue participating. In fact, although all patients initially approached agreed to be involved in the study, one patient chose not to continue participating in the study after he had been discharged from hospital.

Consent to conduct all the interviews was obtained by providing participants with a verbal explanation and a written information sheet to take away. The information sheet had office and home telephone numbers on it, so that any queries which people had not thought of at the time could be addressed later (see Appendix 15). Along with the information sheet was a written checklist for interviewees to confirm that they had been fully informed and a space for their signature at the bottom. I was concerned about the effect on participation rates of asking older people to sign pieces of paper. Researchers had previously found that older people could be particularly reluctant to sign forms (Reed and Payton, 1996). In the light of this, permission was obtained from the chair of the ethics committee for observation and interviews to proceed on the basis of verbal consent. I had initially intended to tape record the process of obtaining consent, although this was not required by the ethics committee, but in practice I found it too

uncomfortable to switch the tape recorder on to record a conversation, part of which was, ironically, to discuss the use of a tape recorder. This seemed presumptive and unnatural and so tape recording started after patients' verbal consent had been obtained.

For staff the issue of informed consent was more complicated in some respects. A significant part of the data collection involved observation of ward events, and it was not possible to observe some staff and exclude others from observations. It was therefore important that staff were aware that observation formed a part of the research and that they were reminded of this as they grew accustomed to the presence of a researcher on the ward. Observation was highlighted during the initial meeting with ward staff before the start of the study and in addition a poster, (see Appendix 16), was pinned to the notice board in the ward office reminding staff that their actions could be observed. Letters were also sent to the heads of the social work, physiotherapy and occupational therapy departments so that they were able to inform all relevant staff. In addition the nurse bank was informed so that any bank staff who may come to work on the ward would be informed, although in practice there was very minimal use of bank or agency staff.

Although it was not possible to exclude individual staff from observations of multidisciplinary or group activities, it was possible to exclude them from observation of individual tasks. For example, when patients were admitted to the ward, consent was obtained from both the patient and the admitting nurse to observe the assessment process. Two nurses on Ward 1 chose not to be observed admitting patients.

#### Anonymity and confidentiality

During the process of obtaining consent from participants, they were informed that their anonymity would be protected and that all information would remain confidential.

Data stored on computer, i.e. fieldnotes and transcripts of interviews were numbered and anonymised to protect individual identities. Similarly, to protect confidentiality, written information about participants and interview tapes were stored in a locked cupboard.

In addition, external presentations of findings have not identified the study site and individual participants have been referred to by their role and a number i.e. N7 indicating nurse number seven, thereby preventing individual identification. Feeding back findings to the study participants was more problematic. Care was taken not to identify particular staff, for example

if a quote attributed to the ward sister had been presented, this would have meant that all other staff would have immediately known who had said what. This meant that at a local level far greater attention had to be given to disguising identities and protecting personal privacy.

### Unmet needs

As the study was concerned with the identification of patients' continuing care needs, it seemed probable that when I spoke to people after discharge in the community that some would mention needs that had not been addressed in hospital. I did not feel as a researcher that I could just record these needs and then walk away. I had prepared a list of telephone numbers to give to the patients in the community (see Appendix 17), so that they would then be able to contact the relevant agency. However in practice I found patients to be well supplied with contact numbers. The hospital social services department gave patients contact numbers on discharge and community nurses left folders which also contained contact numbers. What appeared to be more problematic for patients was knowing what to do when 'the system' did not respond. For example one man had had a referral made for bath rails on a previous admission a few months before and was concerned about the delay as they had still not been fitted. In this instance, with his permission, I phoned the occupational therapy department and discovered that they had an incorrect phone number for him and so had not been able to arrange a visit. The patient's bath rails were fitted a couple of weeks later. Regular contact with multidisciplinary staff through attending weekly meetings meant that I built up a rapport with them, and they accepted these 'referrals' from me although fortunately these were rare events.

What was more difficult to deal with were patients who had needs for which no service existed. These included patients who wanted overnight domiciliary carers and those who were simply concerned that their gardens were becoming over-grown. I felt fairly impotent in such situations, but in practice I was forced to accept that there was little that I could do except refer them back to their GP or the social services department.

### SUMMARY

This chapter has set out the methodological approach taken to the data collection. The two strands of the data collection have been outlined, these being namely, the context of patient and informal carer involvement and patients' and informal carers' experience of involvement. Significantly other studies in the field have not observed the everyday experiences of patients

of being involved in continuing care assessments by multidisciplinary professionals, especially by nurses. Issues of validity and reliability have been addressed along with that of generalizability. It has been outlined that the findings of this study are intended to be generalizable at a theoretical rather an empirical level.



## **INTRODUCTION TO THE FINDINGS**

The large volume of data collected within this study meant that a fundamental decision had to be taken about how this should both be organised and presented. The principal choice appeared to be between that of preserving the narratives of patients and their informal carers by presenting these sequentially as twenty individual stories (see e.g. Richards' (1996) thesis) and that of drawing out common themes that recurred within the individual continuing care assessments. Significantly, examining the data revealed that there were key issues that came across very strongly about the way professionals conducted assessments and involved patients in this process. Thus, rather than locating these key issues within the detail of twenty stories, the decision was taken to present the findings around these central themes. In doing this, it is recognised that the patient narratives have to a certain extent been fragmented. However, crucially the common themes relating to individual assessments and patient involvement in this process are brought to the fore.

The findings are presented in three chapters. Chapter 5 presents the findings of the study that show how members of the multidisciplinary team conducted continuing care assessments. In chapter 6, professionals' roles are examined in more detail, focusing specifically on how members of the multidisciplinary team involved patients and informal carers in these assessments of patients' continuing care needs. These chapters indicate that there could be problems with the assessment process. In chapter 7 evidence on the factors affecting both continuing care assessments and the involvement of patients and informal carers is presented.

The findings relate principally to the practice of nurses, doctors and social workers. This is because these were the professionals who were consistently involved in the care of the patients in this study. Other professionals were involved, but on fewer occasions. Both nurses and doctors were involved with all 20 patients in the study, social workers with 17 patients, physiotherapists with 4 patients and occupational therapists with 3 patients. However, where the practice of physiotherapists, occupational therapists or other team members such as community liaison nurses was felt to be significant, it has been included. Moreover, all members of the multidisciplinary team took part in general interviews. These interviews provide a range of insights into assessment practice on the two wards.

Finally, one limitation of the study should be mentioned. It was not possible to observe either doctors' initial assessments or social workers' assessments of patients because of the

unpredictable timing of these events. However, information was obtained about these events by interviewing patients, their informal carers and the professionals involved.

## **CHAPTER 5**

### **ASSESSMENT OF PATIENTS' CONTINUING CARE NEEDS**

#### **INTRODUCTION**

This chapter presents the findings of the study that detail how members of the multidisciplinary team, (principally doctors, nurses and social workers) conducted continuing care assessments. The chapter draws on the general interviews that were conducted with the multidisciplinary staff involved. These interviews explored their perceptions of the ways in which assessments were carried out and offer insights into the meanings they attached to their practice. These perceptions are contrasted with the evidence obtained from tracking 20 patients through their hospital stay. Observational data and interviews with these patients, their informal carers and with key staff involved in their care help to reveal the extent to which professionals' perceptions of their conduct are borne out in practice.

The chapter begins by looking at professionals' approaches to identifying information that is significant to continuing care assessments. It is argued that despite nurses having greater opportunities than other professionals to assess patients, they sometimes fail to recognise information that is pertinent to this process. In the next part of the chapter, nurses' claims to liaise effectively with their multidisciplinary colleagues are critically examined. The potential consequences of a lack of collaboration are highlighted. Finally, evidence on the ways in which professionals see their own roles in multidisciplinary assessments is presented.

#### **NURSES' LIMITED ROLE IN ASSESSING CONTINUING CARE NEEDS**

There has long been a requirement for all multidisciplinary professionals to be familiar with assessment processes and to contribute to the assessment of patients' continuing care needs. In 1994, the Hospital Discharge Workbook prompted stakeholders to consider:

*“Are the procedures for community care assessments ... understood by all front-line staff?”*

*Are there opportunities for different disciplines to make an input into cases which do not require full assessment?”*

(Department of Health 1994b: 10)

More recently the need for professional competence in conducting continuing care assessments has been accentuated with the introduction of the single assessment process. Policy identifies that this process should be able to be conducted by any multidisciplinary professional.

*“A fuller assessment will consist of the exploration of a set of standardised domains of need ... This can be carried out by front-line health and social care staff such as community nurses, social workers, occupational therapists or physiotherapists.”*

(Department of Health, 2001a: 31)

All multidisciplinary professionals therefore need to be able to recognise information pertinent to continuing care needs. Claims for professional competence are made by a number of academics and professional bodies. For instance, writing in the nursing literature Jacques and Ryan (1997) state:

*“Nursing assessment ... is the process of collecting information on which to make judgements about the needs of the person receiving care... The effective registered nurse will understand that this information is constantly being collected while the quality of that information will be dependent on the relationship developed between nurse, patient and family or friends.”*

(Jacques and Ryan, 1997: 23)

#### **Nurses not making use of their ideal position**

In the general interviews with members of the multidisciplinary team, many of them commented that nurses had advantages over other disciplines with regards to assessing patients. The majority of staff felt that as nurses spent more time with patients they had more opportunities to assess them than other members of the team. It was thought that by spending more time with patients, nurses had more chances both to assess physiological needs and to obtain information from patients by building a rapport with them. In this way, members of the multidisciplinary team considered that nurses may potentially be privy to information that was not readily accessible to other professional groups. For example a senior house officer stated that in his view nurses may have a greater knowledge of patients' physiological functioning:

*SHO: “ ... I mean the nurses provide the care on the wards and so they probably have the best idea of what continuing care is required ... I mean I spend less time with the patients than they do and I'm usually focused much more on the medical side of things than on the day to day, on their day to day level of functioning, you know ... I'm also trying to pay attention to what they are managing to achieve for themselves on the ward, but I don't know first hand”*

[Genisho4 357-367]

Nurses shared this view, and a G grade nurse highlighted the potential advantages that he felt were derived from the profession's continual presence on the ward:

*Nurse: "...she [the nurse] is with him more often than anybody else, the social worker doesn't see the patient as often as the nurse for instance, even the doctor that's on the ward all the time doesn't see the patient, doesn't do things for the patient, doesn't talk with the patients, so it's the nurse that gets all that kind of information"*

*KA: "Right"*

*Nurse: " And all that erm, everything else because he might say while washing him, he might start chatting about his home situation or he might say you know, he's worried because he has got a disabled wife at home, or, or his dog or his cat or something is at home and things like that, they open up to nurses more than they open up to the other disciplines"*

[Geninn6 370-382]

However, when in the general interviews nurses were pressed for details about how they themselves actually conducted assessments and the sources of information that they made use of, a more limited picture emerged. All of the nurses made reference to the documentation that they completed when patients were initially admitted to the ward, and described working through this. For example an E grade nurse explained:

*Nurse: " There's a kardex and there are pages of questions, you have to go by the, you know name, next of kin, what, what job, what job you used to do in the past, your next of kin, your, in what sort of, what sort of accommodation you live, meals on wheels, services, we have got a sort of format, you know, the questions will guide you"*

[Geninn13 257-262]

Moreover there was little sense of assessment continuing beyond the initial questions that were asked when patients were admitted to the ward. Nurses did not talk about making use of the advantages of their position that they had identified earlier in the interviews. In contrast their comments focused almost exclusively around working through the documentation. Some nurses made reference to the fact that information that was not specifically asked for on the assessment forms may not be obtained. For example a D grade nurse highlighted:

*Nurse: " ... I would go through everything that's on the form and, like, I would actually ask the relatives and everything but I know even though I might think to myself I've been really thorough, I know sometimes there's things I've missed. Like I said to you, outside toilet, no bathroom erm, who does your shopping for you, they might say erm, 'home help comes in and does it' not saying erm, she might just come in once a week, now who does the shopping for the other 6 days? You know, things like that, it actually escapes you ... I know there's times when I have missed something ... and those things are the ones that can cause a lot of hassle later"*

[Geninn7 334-344]

In addition, there was the realisation that information obtained at assessment would not necessarily be amended or updated during a patient's admission. An F grade nurse admitted:

*Nurse: "Assessment's supposed to be an on-going process ... I think sometimes it doesn't happen and you, you get a one off assessment when they come into a hospital and then it's not necessarily changed"*

[Geninn12 179-183]

Thus there was a recognition by nurses that their assessments were orientated around the assessment documentation and that this initial patient evaluation may be the only time when they systematically assessed patients' needs.

Observation of nurses' assessments of patients on admission indicated that these assessments were based very rigidly around the assessment forms. Patients were often asked for information in the order that the questions were laid out in the nursing documentation. Whilst this may have simplified and hastened the process for nurses, it did not always suggest that a comprehensive and coherent picture of the patient was being assembled, as the conversation tended to jump from topic to topic with little logical flow. For example, patient 11, a 74 year old man, was asked:

*Nurse: "That's all right, first of all can I say welcome to [name] ward, and my name's [name] and I'm one of the nurses that will be like looking after you on the ward, now we have to ask you a few questions when you first come onto the ward, now can you tell me what your religion is?"*

*Patient: "It's C of E"*

*Nurse: "And do you want the vicar to know that you're in hospital?"*

*Patient: "Well I believe in God but I've never, er, er can do, but er you know what I mean"*

*Nurse: "All right, no OK then right, er what did you used to do when you was a young man?"*

*Patient: "A pipe fitter, right until I was up to sixty five"*

*Nurse: "Now while you're in here on admission we have to do a nasal swab on you"*

*Patient: "Yeah she just done one"*

*Nurse: "Oh she just done one right, to make sure you're not carrying any like little germs or anything"*

*Patient: "She's gone"*

*Nurse: "Right, do you know why you're in hospital?"*

*Patient: "I do yes because I'm er paralysed in my legs ..."*

[Pt11 adm 4-25]

This created the impression that the task of completing assessment forms may have taken precedence over developing an in-depth picture of patients and their individual needs.

In addition, nursing handovers rarely contained information that was significant for continuing care assessments. Nursing handovers took place out on the ward, rather than in an office. A nurse going off duty would walk around the ward with nurses from the shift coming on duty, stopping at the end of each bed to discuss that patient. The discussions took place between the

nursing staff and patients were rarely included. What was noticeable in these conversations was that they tended to take the form of narrating the events that had occurred during the previous shift. For example, fieldnotes record what a nurse who had worked the night shift told the nurses coming on duty about one patient:

*“The nurse stated that Mr [name] had come in with ?MI, ?UTI and reduced mobility. He had been incontinent plus plus overnight and had not used the bottle but had sat on the edge of his bed and weed on the floor. She added that he had a high white blood cell count and had been started on Trimethoprim and that he was confused and pulled out his venflon at 6.30 this morning. The doctor had been phoned and she was coming to re-site it. The nurse concluded that the patient was a nice man - to which the patient replied ‘Thank-you very much’.”*

[Fn130598 5-10]

Thus during nursing handovers there was little discussion of assessments of patients’ continuing care needs. Moreover, nursing documentation rarely contained information that was significant for continuing care assessments. Given nurses’ focus on completing assessment documentation, it appeared from examining these records as if this task could take precedence over the identification of patients’ needs. This became more apparent when, during the course of the study the documentation used by nurses was redesigned. The new documentation included a needs assessment form based around Roper et al.’s twelve activities of living which include; maintaining a safe environment, breathing, communicating, eating and drinking, eliminating, personal cleansing and dressing, controlling body temperature, mobilising, working and playing, expressing sexuality, sleeping and dying (Roper et al., 1983). Each activity had associated cues to prompt nurses, thereby aiming to minimise the risk of omissions. For example, under the activity ‘elimination’ there were the following prompts:

<u>Elimination</u>	<u>Comments</u>
Continent	(State frequency and/ or any problems - Cystitis)
Incontinent of urine/ faeces/ both	
Continent if prompted	
Catheterised	
Altered bowel habits	
Constipated	
Diarrhoea	Urinalysis on admission:      MSU taken    YES/ NO
	Catheter size:                      Date inserted/ last changed:

[Patient Assessment Form]

However, in practice, nurses often circled or ticked prompts without adding any additional information. Eight patients in the study were admitted using the redesigned forms containing the prompts. Overall, 53% of all the assessment areas on the forms, which included ‘breathing’,

'mobility' and 'pain', contained no worded evaluations. Furthermore 40% of the evaluations which were given consisted of statements of only one or two words in length (n = 120).

The difficulty with this was that as a consequence, there was not enough detail contained within them for somebody other than the assessor to use them to form reliable judgements about a patient's needs. One of the community liaison nurses expressed her frustration at trying to use these assessment documents. She stated:

*Liaison nurse: "... often erm, if you ask a member of the nursing staff for an assessment, they'll say well here it is, and they'll give you the kardex, which tells you lots about how well they slept and whether their catheter was draining all right, but it doesn't actually give you any depth or you know breadth of information that you are going to need to make a case to a funder to fund something out of the ordinary or over and above the contracts, erm, you know, you. I mean it's hard work even to get them to give you something like a Waterlow score, erm, because they see assessment as the admission process"*

[Geninln1 175-184]

Thus, it appeared as though nurses were not making the most of the opportunities they had to assess patients by virtue of their greater contact time. Rather, by concentrating on the documents themselves they were sometimes failing to recognise information that could have been significant to the assessment of patients' continuing care needs.

In contrast to nurses who, in the general interviews talked about completing assessment documentation, doctors discussed using forms as a starting point to stimulate their thinking to cover areas that may not have been directly mentioned. A senior house officer commented:

*SHO: "... well, I think certainly both the doctors and the nursing staff have sort of boxes to fill in with regard to what's available at home and what they're getting at the moment and, and that. As I say with care of the elderly it is much, you know, it does prompt a lot more questions about, 'well is this going to be enough, is this person going to get back to that condition,' but erm, and I know that mentally I, I sort of think, 'well, I reckon this person will be in for seven days'"*

[Geninsho3 174-181]

In the general interviews with the doctors, the sense of a broader purpose to their assessments came across, in that they were able to explain why they collected information and indicate how this information would be used.

Observation of ward rounds indicated that doctors' interests went beyond completing assessment forms. During discussions with patients on ward rounds, it was evident that doctors were conscious that there were times when they did not have all the information that they



needed in order to make decisions about patients' continuing care needs. On these occasions, doctors sought to address these gaps in their knowledge by asking for the details that they required. For example, when considering the discharge of a 91 year old man, one consultant noted that:

*"... she understood that he [the patient] was better and that they were planning for home tomorrow. She asked whether there would be someone at home. The patient replied that his son would be at home. The consultant checked that this meant that the patient wouldn't have to get things ready himself and the patient confirmed that his son would do that for him. The consultant summarised that the scan they had of his leg wasn't good, but they they didn't think that the blood clot in his leg could be very big. She asked if he would come and see them in clinic and the patient agreed that he would."*

[Pt22fn 209-218]

Thus there was a sense that doctors recognised that they did not always have all the information they required from their initial assessments but that they addressed these omissions at a later date.

Data from the patient focused interviews confirms the observations of practice. When interviewing doctors about the twenty patients, whose care was tracked throughout their hospital stay, they sometimes highlighted the fact that additional information was needed in order to be confident in making assessments of patients' continuing care needs. Furthermore they were aware that arrangements had been made to ascertain this information. For example, a senior house officer said in relation to an 85 year old man:

*SHO: "... there's a home visit, to sort of see what the home situation is like and how much he really is managing, and how much is the family worrying too much, and how much is him being too stubborn to accept care when he actually does need it"*

[Pt10idrh 73-76]

In this way, doctors showed that they were aware that particular pieces of information were significant to the assessment of patients' needs and that they were active in seeking these pertinent details.

Social workers also held similar views towards assessment as doctors in that, in the general interviews, they too spoke about assessment as an on-going process of collating information about a patient. They indicated that only once, 'all the pieces of the jigsaw' were in place did they feel that they had satisfactorily completed a patient's continuing care assessment. For instance one social worker commented:

*KA: "When would you say that people are assessed?"*

*Social worker: "Hmm? when will I say that people are assessed, I would say that you couldn't pinpoint any particular moment, it's an ongoing process from the time they come on the ward."*

*KA: "Right."*

*Social worker: "To begin with they are assessed by, by nursing staff, well medical staff and nursing staff, erm, and the social worker's involvement is gradual. You could say the assessment begins from the first ward meeting perhaps, the first ward meeting after the patient has been admitted because you gain the information so that's the beginning of the assessment"*

*KA: "Yeah"*

*Social worker: "You could say it commences from the time the nurse rings you in your office and says Mrs. Smith and bla bla bla, you've got information and you could also say assessment, part of the assessment is the OT home visit ... because the report comes to you. I would say it is an ongoing process up to the date of discharge... and if the patient is happy and the family is happy and the other members of the team feel this is adequate support then I consider it complete."*

[Geninsw1 149-174]

During the care planning meetings social workers seemed anxious to collate information from all members of the multidisciplinary team in order to build up a comprehensive picture of patients and their individual continuing care needs. This is difficult to illustrate in a short extract, but the following example shows a social worker inviting the opinion of a community nurse and also recognising the importance of obtaining a medical perspective. This care planning meeting was held to determine the appropriate discharge arrangements for an 82 year old woman:

*"The social worker asked about what help the patient was getting before she came in to hospital. The community nurse replied that she was getting morning and evening carers, and although she had been able to take her tablets when they were put out for her, recently she had had to have someone to come in to give her these, as she had been forgetting to take them. In addition she had developed ulcers on her legs and had had the fall that had led to her previous admission to hospital. The patient's daughter added that she had been sent home from hospital on her own, and was not able to get out of bed, the daughter said that she and her sister could not leave their mother. The social worker said that was bad, and asked that they wait for the SHO."*

[Pt12fn 218-227]

So, in contrast to other members of the multidisciplinary team, nurses seemed to be failing to take advantage of their unique position within the team with regard to having unrivalled opportunities to access information from patients and informal carers. Observational data suggests that they were not exploiting these opportunities to identify information pertinent to patients' continuing care assessments. The following section looks at how nurses shared the information that they did have with their multidisciplinary colleagues.

## NURSES CLAIMS OF COLLABORATING EFFECTIVELY NOT BORNE OUT IN PRACTICE

Good practice guidance has consistently highlighted that continuing care assessments ought to be multidisciplinary in nature. For example, principles jointly outlined by the British Geriatrics Society, the Association of Directors of Social Services and the Royal College of Nursing on the discharge of older people from hospital state:

*“Multi-disciplinary assessment should be carried out at the earliest opportunity... Adequate numbers of appropriately trained staff are required ... these staff should be skilled and knowledgeable in assessing the specific needs of older people and dedicated to ensuring efficient, appropriate discharge from hospital.”*

(BGS, ADSS and RCN, 1995b: 2)

However, crucially, good practice guidance also stresses the need for effective liaison between members of the multidisciplinary team. For instance, the Health Advisory Service 2000's ‘Standards for Health and Social Care for Older People’, highlights that within organisations there ought to be:

*“evidence of good communication within and between all levels of staff”*

(Health Advisory Service (HAS 2000), 1999: 23)

The consequences of the failure of multidisciplinary professionals to work together were spelt out in the ‘Hospital Discharge Workbook’. It stated:

*“Many different individuals, professional groups, private and voluntary organisations are involved in hospital discharge... Communication and co-ordination between the various stakeholders is essential. It is only through such processes that the best quality care will be provided, and problems of both overlap and omission of responsibilities will be resolved.”*

(Department of Health, 1994b: 3)

It is therefore important that multidisciplinary professionals involved in continuing care assessments collaborate effectively with each other.

In the general interviews, nurses recognised that collaborating with multidisciplinary colleagues was an essential part of their role. For example, a D grade nurse remarked:

*Nurse: “I suppose because nurses are involved with the patients more than anybody else, they spend the longest time with them, then they need to be the person who’s sort of able to observe them and pass information on to other members of the team”*

[Geninn2 317-320]

Moreover, all but one of the nurses stated that this was a role that they actually fulfilled and that in practice they did pass on information about patients to other members of the

multidisciplinary team. Nurses identified a number of fora in which these collaborative discussions took place. This included updating doctors about patients on ward rounds, as a D grade nurse highlighted:

*Nurse: "...when the doctor comes to do his round before he, before the consultant makes a date for the discharge of the patient the, the consultant would ask me, 'What can the patient do for herself? What is she.. ? Is she eating and drinking all right? Is she able to wash and dress herself? Is she be able to walk to and from the toilet?' You know, this is what will happen before the decision has been made for the patient to be discharged at home"*

[Geninn9 193-199]

Nurses also stated that they provided information about patients in multidisciplinary meetings when all members of the multidisciplinary team were present. For example, an F grade nurse outlined:

*Nurse: "We have a multidisciplinary meeting every week after the ward round erm, so we then discuss the patient and their needs and what their social circumstances are at home, so if there are any concerns I would raise them then, so we could discuss them"*

[Geninn12 363-367]

In this way nurses identified both that they should be collaborating with their multidisciplinary colleagues and that they were actually doing this in practice.

In the general interviews, professionals stated that in order to conduct their continuing care assessments, they were reliant on nurses to provide them with essential details about patients. For example a consultant admitted:

*Consultant: "... certainly I rely very much upon what the nursing staff say someone's capabilities are, so it's sort of, because it's the nursing staff who know whether people are able to, what their activities of daily living are"*

*KA: "Yeah"*

*Consultant: "So I think it's, you take into account what was happening before they came in, what's happened during their stay and what the nursing staff feel somebody's capabilities are"*

[Genicon1 223-231]

This was a view that was widely held by members of the multidisciplinary team, who almost universally indicated the importance of nurses in respect to assessments of patients' continuing care needs, as nurses were the professionals who were likely to have the greatest knowledge of patients. Professionals found it difficult to overstate how important they considered that this information was to them as they sought to draw accurate conclusions about patients' needs. For example, a social worker argued:

*Social worker: "... nurses are probably the first people to really communicate with the patient and it's vital that they report back any information that they get from the patient. I think, I think their role is a key role actually, they will get to know the patient better than anybody else, more so than the doctors or the social workers because they have more time from a practical point of view on the ward and yeah, I think their role is vital"*  
[Geninsw1 387-394]

In this way, professionals highlighted the importance of the nurse's role within the multidisciplinary team.

Although multidisciplinary professionals were unequivocal in identifying nurses as being key to continuing care assessments, they also expressed considerable frustration that, in practice, it was difficult to obtain vital information from them. The main forum for multidisciplinary discussions were the weekly multidisciplinary meetings, attended by all professional disciplines. Nurses were noticeably reticent to contribute on these occasions, as a member of the hospital discharge team reported:

*Discharge team member: "Yeah, I think, you know, from those meetings [weekly multidisciplinary meetings] I'm always disappointed in the nursing, oh nursing side, because the nurse seems to take the role of the administrator and will read out the names but actually not participate, and they're the people that know the people better, and I always think, 'why aren't you saying?' You know. I don't understand, they have got more knowledge about the clients or see their relatives at 9 o'clock at night, or whatever; and they never [emphasis] say anything"*  
[Geninhdt 22-29]

Clearly the perceptions of nurses and those of other members of the multidisciplinary team are at odds with each other. However, analysis of observational data collected in the course of tracking patients through their hospital stay allows more light to be shed on these claims.

The perception expressed by members of the multidisciplinary team that nurses were not collaborating was confirmed in practice. During the course of the study 51 patient reviews during ward rounds were observed along with 32 discussions in multidisciplinary meetings and 4 care planning meetings, that specifically related to the twenty individual patients whose care was being followed. Nurses made no contribution in 15 (29%) of the 51 ward round reviews. They responded to questions or prompts in 28 (55%) of the reviews and in only 16 (31%) of the reviews made unprompted contributions, which included functional information about patients as well as administrative details. Nurses' presence in multidisciplinary meetings was even less evident as they made no contribution during 23 (72%) of the 32 discussions relating to the patients being tracked. They responded to questions or prompts in 8 (25%) of the discussions and made unprompted contributions on just 3 (9%) occasions. Although nurses were more

vocal in the care planning meetings, on most occasions when multidisciplinary discussions took place on the ward, they only provided information if they were specifically asked for it.

These figures are more striking when compared with the contributions of other members of the multidisciplinary team. In contrast to nurses, social workers made unprompted contributions in 10 (33%) of the 30 discussions at which they were present, relating to the patients being tracked. They responded to questions or prompts in 6 (20%) of the discussions and made no contributions on 14 (46%) occasions on which they were present. The comparisons are set out in table 5.1.

Table 5.1

Comparison of multidisciplinary professionals' contributions to discussions of individual patients in multidisciplinary meetings.

	Unprompted contribution (%)	Responded to question or prompt (%)	No contribution (%)
Nurse	9	25	72
Social worker	33	20	46
Occupational therapist	14	14	69
Physiotherapist	27	18	59

(Figures may add up to more than 100% as professionals could make both prompted and unprompted contributions within discussions).

Doctors have not been included in this table as they chaired the multidisciplinary meetings and gave summaries of patients' conditions and so could always be said to make contributions without prompts from other professionals.

A typical multidisciplinary discussion relating to an individual patient (see below) indicates how the discussion was led by medical staff. Other professionals played smaller parts but the nurse's presence is not evident from the conversation.

*"Multidisciplinary meeting attended by: Consultant, SHO, two medical students, physiotherapist, occupational therapist, E grade nurse, social worker, community liaison nurse, and worker from Age Concern.*

*The SHO said that the patient had fallen and hit his ribs, but did not have any fractures, and although he had developed a chest infection this had resolved. She added that he was mobilising and wandering around the ward with, or without his frame. They were waiting for a home visit, but she was aware the patient had not wanted social services input in the past.*

*The consultant stated that a lady came in to make the patient's bed, because he fell if he made his bed. He told the social worker that he imagined that he would go home next week.*

*The occupational therapist said that she had spoken to the patient's daughter, who was concerned about the stairs.*

*The consultant concluded that they would aim for home around Wednesday."*

[Pt10fn 242-252]

Thus in practice nurses' claims of collaborating effectively with other members of the multidisciplinary team were not borne out. Most of their contributions in both ward rounds and multidisciplinary meetings were as a direct result of queries from other members of the multidisciplinary team. Moreover, they contributed in fewer of the meetings they attended than doctors, social workers, physiotherapists and occupational therapists.

The failure of professionals, particularly nurses, to collaborate could have adverse consequences for patients. Nurses' knowledge of patients' continuing care needs could be relevant to other professionals. For example, nurses sometimes obtained information that was applicable to assessments of patients' continuing social care needs. For instance, after the discharge of a 77 year old woman, a nurse commented:

*Nurse: "... it is more loneliness and companionship than, than actually doing anything for somebody, because the home help comes and does her cleaning and she can do everything herself, she can care for herself and it's just more loneliness than anything else, because at the end of the day she closes the door and it's only her and her alone"*

[Pt17inn1 288-251]

In this case the social worker was unaware of the patient's loneliness and the patient was discharged without this continuing care need being addressed. Lack of multidisciplinary communication meant that in this case this significant piece of information was not shared. If this information had been passed on to the social worker, she could have explored the possibility of the patient attending a day centre or asked her about receiving a volunteer visitor. Thus, although nurses obtained information that could be important to patients' assessments, failure to recognise its significance or to share it with multidisciplinary colleagues meant that there was a risk that patients could be negatively affected.

A second example reinforces the potentially adverse consequences of multidisciplinary professionals failing to discuss patients' continuing care needs. In this case during her admission to the ward an 85 year old housebound woman identified two specific concerns to the admitting nurse ...

*Nurse: "What's your hearing like, is it all right?"*

*Patient: "Very bad now, it's got very bad"*

*Nurse: "But you don't have a hearing aid or anything?"*

*[Patient shakes head]*

*Patient: "When I go out [get discharged] I need to see to a hearing aid"*

...

*Nurse: "Are they your own teeth? Open your mouth, have you got any up top?"*

*Patient: "No, no"*

*Nurse: "Just those at the bottom?"*

*Patient: "I want to get some when I go home ..."*

*Nurse: "You don't have a set now for the top?"*

*Patient: "No"*

*Nurse: "No, so it's just those few at the bottom?"*

[Pt25adm 75-93]

In this case, these needs for a hearing aid and a top set of dentures were not discussed in any multidisciplinary forum, and the patient was discharged without any further progress having been made to resolve the issues. The patient was not asked during the admission, when these problems were identified, if she knew how to go about acquiring the hearing aid and dentures that she required. In addition, when she was interviewed in her warden controlled flat one month after discharge these issues remained unresolved. Had there been more communication between professionals it is possible that the patient could have been referred to a dentist who was able to see her at home, or transport arranged for her to visit a local practitioner. Similar arrangements could have been made with respect to her hearing aid. Airing of these problems in a multidisciplinary forum would also have allowed doctors to consider whether any underlying medical causes needed to be investigated and whether the patient was at risk from a potentially inadequate nutritional intake. Had social workers been aware of the patients' poor hearing they could have also considered the patients' wider needs such whether a flashing door bell, telephone or fire alarm would have been of benefit to her.

Again the lack of multidisciplinary discussion meant that valuable information was not shared within the multidisciplinary team with potentially adverse consequences for patients and their informal carers.

Finally, it was also evident from the study that a failure to collaborate more widely with other multidisciplinary professionals who were based in the community could have similar implications.

A lack of communication between hospital and community nurses meant that there was a risk that services would not always adequately meet patients' needs. One of the community liaison nurses illustrated the potential pitfalls of this approach:



*Liaison nurse: "... I had a patient that was going home from one of the wards here last week that was referred to the district nurse because they needed catheter care. The fact that the patient had a metastatic adenocarcinoma wasn't mentioned, neither was the fact mentioned that they actually had bony metastases and cord compression, because they [nurses] see district nursing in terms of providing catheter care"*

[Geninln1 508-514]

Therefore, although professionals felt a sense of frustration at nurses' failure to collaborate with them, the consequences for patients and informal carers could be more significant.

### **NURSES' MARGINAL ROLE IN CONTINUING CARE ASSESSMENTS**

As highlighted in the previous policy sections in this chapter, there has long been a requirement for assessments of patients' continuing care needs to be multidisciplinary in nature. For example, the NHS Health Advisory Service, in their report on the assessment of older people unequivocally state that a multidisciplinary assessment:

*"requires accurate **medical diagnosis, formal therapy and nursing assessments, and the assessment of their [patients'] social needs.**"*

(The NHS Health Advisory Service, 1997: 37) (emphasis added)

In this way, all professionals have a role in assessing patients' continuing care needs.

As highlighted in the previous section, nurses' apparent failure to recognise information significant for their assessments could be a source of irritation to other members of the multidisciplinary team. In particular, one of the community liaison nurses, when discussing nurses' limited vision, suggested that they may work in this way because of a failure to see the assessment of patients' continuing care needs as integral to their role. She commented:

*Liaison nurse: "... there seems to be this thing that as soon as they [patients] get to the point of discharge they magically become social services' responsibility and unqualified, unregulated carers can go in and deliver care that they, as qualified nurses, have been delivering for the last however long, and they don't seem to see that there's something funny in that, or that there's something wrong in that. That's just how the system works, and it's just like, so when you're in hospital you need nursing care and when you go home you can have social care and that's fine, you know, it's .. and there's never any kind of erm, oh, [exasperated] they never, they never question that, they don't say, well hang on a minute"*

[Geninln1 288-299]

The liaison nurse's feelings that nurses may be dissociating themselves from assessments were borne out in the general interviews with the nurses themselves. In these interviews, which focused on continuing care assessments, under half of the nurses talked about themselves as

having a role in identifying patients' needs. Even in the interviews where nurses mentioned the identification of continuing care needs as part of their role, these references took the form of brief allusions which were somewhat hesitant in nature. For example, one nurse identified three other professionals before nurses when considering which professionals assessed patients' continuing health care needs:

*KA: "Who's involved in assessing continuing health care needs?"*

*Nurse: "The OT, the social worker, the doctor and the you know, maybe the nurse as well because I mean if she says 'I feel that this man needs, blah, blah, blah when he goes', and then somebody else can look at it and say, 'yeah, yeah probably that might be a good idea', or even if it's just a suggestion that, 'I think when he goes home it might be nice that he goes to a day centre for twice a week because it'll get him to interact with different people', or whatever, so I think the nurse is involved as well in that"*

[Geninn6 305-313]

Moreover, one nurse completely dissociated herself from identifying patients' needs stating that it was unnecessary for nurses to be involved with this, as there were other professionals who fulfilled that role:

*Nurse: "... I wouldn't want to be involved [in assessments] I don't think I am involved, apart from providing the information of the patient's ability er, or lack of ability"*

*KA: "Right, right"*

*Nurse: "Yeah because I, I think it will erm, you know, it, it's an unnecessary task, an unnecessary role ... obviously that there's another you know, there's another sort of bag of professionals there who should know what they are supposed to do, and basically I don't want to be involved, yeah"*

[geninn3 735-760]

Further evidence that, in practice nurses did not see continuing care assessment as part of their role comes from the way that they sought to answer questions about how they actually went about conducting assessments. Nurses often struggled with this, finding it difficult to produce a response. Such responses, when they were given, lend further weight to the theory that continuing care assessments were not something with which the nurses were familiar, or saw as inherent to their position. For example, an E grade nurse commented:

*KA: "How do you assess continuing health care needs?"*

*Nurse: [pulls a face] "Er, how do I assess it?"*

*KA: "Yeah"*

*Nurse: "Erm, [long pause] .... yeah well like I said before, we just refer them back to the district nurse or increase the services from the district nurse"*

*KA: "Hmm"*

*Nurse: "Or the health visitor"*

[geninn4 290-315]

At times nurses seemed to suggest that they did not assess patients' continuing care needs at all. On occasion, nurses described their actions in terms of a uniform practice applied to all patients, indicating that they did not assess individual needs. For instance in discussing referrals to community health services, some nurses also talked about making blanket referrals of all, or certain categories of patient. For example a D grade nurse stated:

*Nurse: "... we refer every patient from here to the district nurse or the health visitor"*  
[Geninn8 182-183]

In fact, some nurses suggested that they passed on the task of assessing patients' continuing care needs to community based professionals. So, rather than identifying needs they left community professionals to make their own patient evaluations. For example one nurse stated:

*Nurse: "... they might need district nurses to go in to assess them erm, with their medication or a dressing if they've got ulcers or such like, or if not we refer them to the health visitor who goes in for about 10 days or so after their discharge and they'll assess them and then follow them up as need be"*  
[Geninn4 243-248]

Only one nurse reported actually identifying specific support services to meet a recognised need. This was a G grade nurse, the most senior member of the nursing staff on the ward. He stated:

*Nurse: "Well it's the nurses would assess them before they tell the social worker what they need, because we on the ward would, would automatically see what they require, or what they need when they go home, so we will tell the social worker that she will need a bath attendant for instance, or she would need the carer erm, the home carer going in every morning to make sure she has washed and dressed and things like that"*  
[Geninn6 543-549]

However, this was an isolated claim and overall in the general interviews nurses were reluctant to associate themselves with having a responsibility for identifying patients' continuing care needs.

Analysis of the patient tracking data indicates that in practice nurses sometimes had a limited awareness of patients' continuing care needs. Their lack of awareness appeared to stem in part from an apparent failure to collect and evaluate relevant information about patients and their home circumstances. Two examples are given that illustrate this point. Again, these have been constructed from fieldnotes from the patients who were tracked through their hospital admission.

Firstly, a 101 year old man was admitted following a transient ischaemic attack or mini-stroke, he quickly recovered to his pre-morbid state of health and was able to be discharged home.

When interviewed the key nurse involved in his care commented:

*Nurse: "... he came in the afternoon, the next morning, when the nurse tried to give him a wash he wasn't happy about it, he wanted to do it himself, he didn't need really any help, he said he could do it himself, minimal help with his back probably, but he's been mobile, doing everything for himself"*

[pt24inn1 56-59]

However the patient's referral to the community nursing service stated that the patient was unable to manage stairs. This should have triggered alarm bells, as it was recorded in the patient's nursing notes that he had stairs at home. Although the information about his toilet location was missing, both his toilet and bathroom were in fact located upstairs. Given that the patient lived alone and his only other community services on discharge were daily meals on wheels, the nurse ought to have been concerned about this patient's ability to manage at home.

Secondly, a 79 year old woman was admitted to the ward with shortness of breath. This patient had congestive cardiac failure and her breathing difficulties were a chronic problem. In this admission her condition was exacerbated by a chest infection. In the nursing kardex it was noted that the patient was able to walk independently on the ward. However neither of the two ward nurses interviewed had identified that the patient's main problem was that she was living alone in a second floor council flat and, as she was unable to manage the stairs, she was effectively housebound as there was no lift. In fact, when interviewed, one nurse stated that the patient was living in ground floor warden controlled accommodation, the other was unsure if she lived in a house or a flat. (The nursing admission documents record that the patient had stairs to climb, although no response was marked against the prompt, 'is living on the first floor or higher?').

This highlights that although nurses may have been able to care for patients appropriately within the confines of the ward, without ensuring that they had detailed knowledge of patients' home circumstances it was very difficult for them to make accurate assessments of individual continuing care needs.

What was more revealing was that when interviewed about the needs of individual patients for whom they had cared, nurses reported deferring decisions to other professionals, principally social workers. Nurses outlined that it was these other professionals who made decisions about continuing care needs and as such they distanced themselves from the process. For example, in

an interview concerning a 79 year old woman who had recently been discharged following an admission to treat her shortness of breath, one nurse stated:

*KA: "So is she going to get any services on discharge?"*

*Nurse: "As far as I know, [name - social worker] spoke to her and there was no services arranged, as far as I know, but I don't know what was discussed between her and [name - social worker] because [name - social worker] has been off for a few days, so I haven't seen her, so I don't know what happened"*

[pt16inn2 158-162]

Similarly when describing how a decision to transfer a patient to NHS funded continuing care was made, a nurse dissociated herself from the process and indicated that this had been the province of the medical staff:

*Nurse: "Right now, I don't think we had a care planning meeting on her, what's been happening, the doctor wanted to discuss what's going to happen in the future yeah, about her condition, and you know, whether the family can cope with her at home, so the doctor had a word with the son .... you know they have got a criteria about who goes to [name - NHS funded continuing care] really"*

*KA: "What's that"*

*Nurse: "They got, they've got sort of a list of criteria they have to go through about who goes to [name - NHS funded continuing care]."*

*KA: "Right"*

*Nurse: "You know, and if they need nursing care they go to [name - NHS funded continuing care] you know, instead of going home sort of thing, or to, or to a home, it's mainly doctors with family involved or with the palliative care in her case you know .... I'm, I haven't really discussed anything at all"*

[Pt06inn2 29-76]

Further evidence of nurses dissociating themselves from assessing individual continuing care needs was obtained from the referral forms sent by ward nurses to community health staff. In the section headed, 'reason for referral' many of the forms contained the phrase 'for assessment'. This indicates that ward nurses themselves had not identified a specific continuing care need that they considered could be met by the person to whom they were making the referral.

Thus observational and interview data obtained from tracking twenty patients through their hospital stay indicates that, in practice, nurses often did not see the identification of patients' continuing care needs as part of their role.

When questioned about doctors' role, multidisciplinary professionals, almost without exception, agreed that doctors had an important part to play in identifying patients' continuing care needs. For example, a community liaison nurse outlined the centrality of the medical staff:

*KA: "Are you involved in assessing continuing care needs?"*

*Liaison nurse: "I wouldn't say as much as maybe the consultant would be, obviously they have, I would say more total charge of it"*

[Geninln2 172-174]

Doctors too saw themselves as taking an active part in the assessment of patients' continuing care needs. For example, during a general interview, a senior house officer described in essence how she went about assessing whether patients could manage after their discharge from hospital:

*Doctor: "Well generally if they're had an acute illness from which they've recovered well ...then the basic question is on my part basically just to try and check that they have got some social services in place that seem appropriate and that neither the patient nor the relatives feel that there is a problem at home, and then we send them home"*

[Genisho4 222-229]

This perception of doctors as being integral to assessments of patients' continuing care needs contrasts with the hesitance with which nurses were identified as having a role in this area.

The perception that doctors were actively involved in identifying, not just continuing health care needs, but also continuing social care needs was borne out in practice. Despite spending far less time than nurses on the ward and having fewer opportunities to talk to each individual patient, data indicated that doctors actively looked for indicators that an individual may struggle after discharge in the community. For example, one doctor talked about her satisfaction with the discharge of a 76 year old man, as in spite of her probing and observation, she had not discovered any potentially unmet continuing health or social care needs:

*KA: "And how was that decision made that he didn't need any additional services?"*

*SHO: "I normally, we do it on the basis of what they had before and what they're like now, and I think if he didn't have things before, and certainly functionally he was, he was actually pain free when he left although he'd only just had a few days of treatment, I think we have to assume well, this is somebody that has coped before and should cope now because there's no other reason not to ...*

*....  
when we said 'would he like to go home now?' they [the family] were all very much in favour, so I think, I think again, if they'd have said, 'no, no, no he can't possibly', we would have had so say, 'right, something's up, so' but they didn't*

*...  
with the family member, that's sort of on the sort of condition the patient is in when they arrive, are they, do they look like they've been well fed and kept clean and things, is their skin good, is their sort of nutritional status good? I mean those sort of things would give us a better indicator of whether the family are actually coping"*

[pt09indr 24-67]

The actions of doctors in assessing patients' continuing care needs provides a contrast to nurses' activities in this area which were often more notable by their absence.

In common with doctors, social workers were also seen as having a role in identifying patients' continuing care needs. Again, despite spending limited amounts of time on the ward, and being based in a somewhat remote office within the hospital, in many ways their role was seen to be pivotal. Many professionals saw social workers as the professionals who collated information about patients from the rest of the multidisciplinary team. It was by liaising with patients and synthesising this information that social workers were seen to form decisions about patients' continuing care needs. As one of the consultants and a social worker confirmed:

*Consultant: "... I think social workers talking to both patients and relatives erm, in conjunction with what everybody has told them will identify what, what someone's needs are, so it's sort of, it really depends on how dependent someone seems to be on the ward"*

[Genincon1 232-235]

*Social worker: "What's my role, it's all part of the, the general, the comprehensive assessment that I carry out, erm, again it's, it's speaking to the patient obviously, the family, erm, the nurses, everyone involved, the OTs, erm, it's all part of the general comprehensive assessment and my role is, is to speak to everyone involved, get all the information I can, and co-ordinate it all."*

[Geninsw1 260-265]

In practice, social workers played a key role in gathering and processing information in order to form judgements about whether patients would be able to cope in the community. For example, one of the patients in the study was an 85 year old man who had been admitted following a fall at home. In the interview with the social worker after the patient's discharge, she discussed collecting information from a number of sources and thereby forming the opinion that this constituted a continuing care need which necessitated the provision of additional support.

*Social worker: "[The patient's] mobility seems to be worse and the home visit indicated that it has decreased since he came in, um the family are also saying that since he came in he's lost his confidence as regards to mobilising and I think before he came in it was gradually going down anyway so he now definitely needs an increase in services"*

[pt10iswh 26-30]

## **SUMMARY**

Findings presented in this chapter suggest that nurses may not be taking advantage of their unrivalled opportunities to assess patients' continuing care needs. The data indicates that they may not always recognise information that is significant to the identification of these needs. In addition their claims of collaborating with multidisciplinary colleagues were not borne out in practice. Interestingly, nurses made few claims about their own roles in continuing care

assessments and observations of practice suggest that they dissociated themselves from this process.

Having examined professionals' roles in assessing patients' continuing care needs, the next chapter looks at the ways in which these professionals integrate the involvement of patients and informal carers into their assessment practice.



## CHAPTER 6

# NURSES' ROLES IN INVOLVING PATIENTS AND INFORMAL CARERS IN CONTINUING CARE ASSESSMENTS

### INTRODUCTION

During the general interviews, professionals were asked about their own roles and those of their colleagues in involving patients and informal carers in assessments of patients' continuing care needs. In this chapter, the understandings obtained from the general interviews are set alongside good practice recommendations from the professional and academic literature. Evidence from tracking 20 patients through their hospital stay and from interviewing them, their informal carers and key staff involved in their care highlights the extent to which professionals were fulfilling the involvement roles that they had described. These roles include strategies for obtaining information from patients and informal carers as well as approaches to sharing information with them. The chapter presents the findings relating to nurses, doctors and social workers in turn. It concludes by contrasting professionals' perceptions of their roles in involving patients and informal carers with observations of their practice.

### NURSES' LACK OF ACCESSIBILITY

Policy literature pertinent to multidisciplinary practice strongly supports the development of open and trusting relationships between professionals and informal carers in relation to conducting continuing care assessments. Guidance for practitioners carrying out assessments, issued jointly by the Department of Health and the Social Services Inspectorate recommends:

*"The practitioner has to establish a relationship of trust with potential users and carers; the more personal the needs, the more important is that trust. .. The tasks of **listening, observing and understanding** place great demands on staff... The practitioner has not only to hear what is being said but to relate to the feeling with which it is being conveyed. Assessment involves considerable skill in inter-personal relations."*

(original emphasis)

(Department of Health/ Social Services Inspectorate, 1991: 52)

Moreover, this sentiment is reinforced by recommendations contained in the literature of individual disciplinary groups. For example, Jacques and Ryan (1997) outline a number of principles of continuing care assessment developed by the RCN Steering Committee for Mental Health and Older People. Amongst these guidelines is the recommendation that assessment should:

*“Be based on a relationship built upon trust and mutual respect”*

(Jacques and Ryan, 1997: 23)

In the general interviews, nurses recognised that particular skills were associated with being accessible and with creating the conditions in which patients and informal carers felt confident enough to approach them with any concerns. These included being perceived as sympathetic and unthreatening by patients. In addition, nurses stressed the need for patients to feel that their concerns would not be dismissed. Significantly they contended that these were skills which they, as a professional group possessed. For example a community liaison nurse outlined:

*Community Liaison Nurse: “... I think nursing, the one thing it does do, is train you to listen very well to what people are saying to you often, and therefore nurses have the skills to do that, they have the skills to listen, and therefore take on board what people are saying, erm, and not dismiss it. I think there’s much less of, a hierarchical thing, and patients and relatives are much less likely to be passive with a nurse than they are with say a doctor in a white coat, because the cultural thing is different so, yeah, I think they’re in a very good position to involve them”*

[Geninln1 331-339]

In the general interviews nurses indicated not only that they had the requisite skills but also that they considered that making themselves available to patients and informal carers was an important part of their role. For instance, a D grade nurse highlighted the significance that being accessible to patients had for her. She stated:

*Nurse: “I think it’s, we either, I think nurses either create barriers between ourselves and the patient and relatives, or we actually make us, you know, or we provide that accessibility for involvement. ... That primarily means being open to listen and to be, you know, to show that one you know, is concerned about what is being said and that, you know, what is being said is, is useful erm, and that it’s you know, it’s taken note of, you know, whether it’s the patient or, or the relatives”*

*KA: “So it’s mainly about valuing what people have to say?”*

*Nurse: “Yeah, yeah I think so, I think that, that’s part of our you know, it is part and parcel of our profession because we are caring for people, and and you can’t care for people if you don’t care”*

[Geninn3 797-819]

Moreover, nurses also indicated that making themselves available to patients was something which they actually did in the course of their practice, as a G grade nurse remarked:

*Nurse: “I think they [nurses] just have to sit and chat with them [patients] and say look you know you’re going home soon ...she [the nurse] will just sit and chat with him and say you know, what would you like us to set up for you”*

[Geninn6 765-774]

In this way nurses identified both that they were aware of the importance of being accessible to patients and informal carers and that this was something that they actually did in practice.

In the general interviews with members of the multidisciplinary team there was a sense that nurses perhaps had a better knowledge or understanding of patients than other disciplinary groups. This understanding was almost universally attributed to their having a greater amount of contact time with patients. For example a senior house officer stated:

*SHO: "... I suppose they [nurses] know the patients better than we do because they're sort of you know, constantly with the patients, so I think it's important to get input from nurses"*

[Genisho1 206-209]

Interestingly none of the members of the multidisciplinary team attributed nurses' greater knowledge of patients to them displaying more sympathy for, or empathy with patients. Neither was there any mention of nurses being less intimidating than other professional groups. In fact no sense of nurses making themselves especially accessible to patients and informal carers was discernible in these interviews.

However, members of the multidisciplinary team did not explicitly say that nurses avoided contact with patients. Rather they talked about nurses building up physiological knowledge of patients as opposed to developing their understanding of patients' and informal carers' perspectives.

Only one member of the multidisciplinary team highlighted that in the course of their work, nurses made time to talk to patients. What was significant about this observation was that this member of the team perceived that it was the unregistered nurses who spent more time doing this. She commented:

*SHO: "... I think they [nursing staff] are the ones sort of socialise as it were more with the patients ... more the sort of auxiliary nursing staff are more the ones that sort of sit and chat to them and, you know, and they're there all the time"*

[Genisho3 331-335]

Thus although members of the multidisciplinary team did not say that nurses avoided patient contact, neither did they indicate that nurses made themselves particularly accessible.

It was in the interviews with patients and informal carers that they were best able to express how they interacted with professionals and identify the factors that assisted this interaction. In

addition patients and informal carers talked about barriers that they felt impeded communication.

In many of the interviews patients and informal carers expressed a sense of gratitude to the nurses for the care that they had received whilst they were in hospital. For example, an 85 year old woman stated:

*Patient: "... the nurses have got all my tablets and that, they have really been very, very good, I must say that."*

[Pt25ipth 322-323]

However, in a significant minority of interviews, patients and informal carers expressed considerable dissatisfaction about the communication that they had had with nursing staff. For example, the son of an 87 year old patient, after her discharge, said in an interview that he had concerns about his mother's continued ability to manage in the community but had been put off raising the issue:

*KA: "Were there nurses around that you could have asked, or doctors?"*

*Son: "There was, but there was a, there was someone on the ward who was shouting out for a nurse to come to their assistance for about 15 minutes or so"*

*KA: "Right"*

*Son: "And nobody came, so, erm, I didn't bother you know, if they couldn't come to him. when he was shouting out"*

[pt08isoc 78-82]

The relative of another patient in the study, talked about his relationship with the nursing staff being damaged because of their negative attitude towards the care of his mother-in-law. He stated:

*Son-in-law: "There always seems to be a big problem, I don't know why, I mean I've been quite annoyed at times because of this negative attitude .... we're just asking for a commode and you know, it seems as if we're asking for the moon, you know, it seems, they always seem most negative, I can't understand that ... my wife's mother is a person who they should know by now, after what, 8th of December, [interview - 7th January]. She wouldn't be saying she needed something and couldn't walk in there if she could"*

[pt26infh 208-219]

Nurses' perceptions of their approach could therefore be at odds with the negative experiences sometimes reported by patients and informal carers.

One of the concerns that some doctors expressed in the general interviews was that they felt time pressured and that they couldn't spend as long with patients as they wanted to. For example a consultant remarked:

*Consultant: "... you're very conscious that you'd like to spend a certain amount of time with each patient and spend as long as you'd like, but as a doctor I actually feel that I don't have long enough, I never have long enough, as much as I would like to spend"*

[Genincon2 15-19]

Doctors were aware that limited amounts of time restricted their accessibility to patients and informal carers, but they were conscious of the need to try to compensate for this and to speak to patients and informal carers when opportunities arose. For example, one senior house officer talked about how he interacted with informal carers:

*SHO: "... as a doctor you just try, and if you see a relative and you've, you know, you've got a couple of minutes and there's something you think would benefit if you spoke to them then you grab them and speak to them, it's not a fixed practice but you know you just try and pop your face in and say hello"*

[Geninsho4 183-188]

Thus doctors indicated that although their opportunities to speak to patients and informal carers were limited, this was something that they considered that it was important for them to do.

Despite the time constraints imposed on them, in practice patients and informal carers reported largely positive relationships with doctors, in which they stated that they felt listened to and supported. For example, one informal carer reported:

*Informal carer: "No, I think the doctors are excellent - I really do. You can see how pushed they are, but I think the doctor and mother have sort of a rapport. ... I have to say, I think the doctor's been terrific, he is obviously working his socks off, poor lad. As I say [name - doctor] has been terrific, you know, he's always had time, and you can see that time is not, but yeah he's been excellent.... He has a good patient-doctor relationship."*

[pt26infh 359-398]

In fact only one patient or informal carer reported a negative relationship with a doctor. In this instance, the daughter of an 85 year old man expressed frustration that she felt that the onus was always on her to seek information from medical staff.

Overall, even given restricted opportunities to involve patients, unlike nurses, doctors came across as being more proactive in seeking to build a rapport with both patients and informal carers. Similarly social workers also worked to make themselves accessible.

In the general interviews, social workers discussed very similar issues to the doctors. Again time was of the essence for them, which led them to feel rushed. For example one social worker talked about how frustrating this could be:

*Social worker: "I find myself spending, if I'm lucky, 10 or 15 minutes initially, talking to the patient, but the rest of my time is involved in paperwork and telephone calls, but mostly paperwork so I, I don't get enough time to build up a relationship"*

[Geninsw1 345-348]

However, their emphasis was on making the most of opportunities to discuss issues with patients and informal carers. Social workers placed particular stress on always trying to meet not just patients but also informal carers before a continuing care assessment was conducted. Again, the same social worker mentioned the potential usefulness of an introductory meeting for informal carers:

*Social worker: "... initially I suppose meeting families on the wards erm, just perhaps not, not just to do an assessment but to say hello and to know who you, you know, who you are actually looking at and who you are meeting prior to any assessment"*

[Geninsw1 125-129]

In this way social workers highlighted that although their opportunities to speak to patients and informal carers were restricted, it was something that they considered was essential to their assessments.

In practice the patient tracking data revealed that social workers tried to ensure that both patients and informal carers had opportunities to speak to them and to raise any concerns that they may have. For example, one social worker outlined how she had been trying to speak to a patient's daughter to see how she felt about her mother's discharge.

*Social worker: "I haven't spoken to any of the family, I did try [name - daughter], but didn't get her, but hopefully I'll be able to get her at about 4 o'clock after my meeting, just to double check that all is well and the daughter has no concerns"*

[pt05insw 32-25]

Good practice guidelines on continuing care assessments place a lot of emphasis on establishing trusting relationships between professionals and patients and their informal carers. Although nurses spent the most time on the ward with patients and thought they were accessible, the experience of patients and informal carers sometimes contradicted this view. In contrast both doctors and social workers felt time pressured but appeared more conscious of the need to be proactive in involving patients and informal carers in discussions about their own continuing care needs.

## NURSES NOT PICKING UP CUES

It has long been recognised that patients and informal carers have information that is crucial to assessments of their own continuing care needs. Part of the assessment process involves asking patients for key details about their own health and social care in order that accurate decisions about continuing care needs can be made. The Department of Health highlights the value of information from patients, outlining that they and informal carers should:

*“be given appropriate opportunities to share ... information at all stages of their admission and hospital episode”*

(Department of Health, 1994b: 4)

Over time there has been a growing recognition within the policy literature that patients and informal carers are experts on their own health and social circumstances. Consequently it is increasingly seen as appropriate that this expertise should be central to continuing care assessments. Good practice guidance has stressed that it is imperative that professionals make use of this valuable information resource. For example, Nolan and Caldock argue that a good assessor will:

*“- listen to and value the user’s and carer’s expertise”*

(Nolan and Caldock, 1996: 83)

Thus professionals need to be able to recognise information from patients and informal carers that is significant to an assessment of patients’ continuing care needs.

In the general interviews the majority of nurses stated that patients were a key source of information when it came to conducting assessments of their continuing care needs. For example an F grade nurse illustrated that information from patients about how they managed on a day to day basis in the community was significant to assessments of their continuing social care needs:

*KA: “Right, when are continuing social care needs assessed?”*

*Nurse: “Again, that’s an ongoing thing from when a patient comes into a hospital, a lot of information about the social circumstances are picked up in the assessment, we, we’ve now got additional areas on the kardex to ask what sort of accommodation they live in, what services they have and how they manage so some problems might be picked up when they come into a hospital, other times it’s um, yeah it’s an ongoing thing, we get people coming in, when we talk to patients we’re, we often talk to them about how they manage at home or you know, who does the shopping”*

[Geninn12 342-351]

Similarly the majority of nurses also stressed that informal carers could be valuable sources of information about patients. For instance, a D grade nurse highlighted that informal carers could be particularly helpful when patients were admitted to the ward:

*Nurse: "... because the patients are so, so dependent, they really do need somebody else, yeah, even for interviewing, [admission] you want to take an interview, a good interview, very often you need the next person, yeah"*

*KA: "The next person?"*

*Nurse: "Very often you need someone else like a relative or a friend or a neighbour or even sometimes a care worker or, we do need someone else half the time, it all helps"*

[Geninn8 96-103]

No nurse said that they dismissed information from patients or informal carers as being irrelevant to assessments of patients' continuing care needs. ›

However, observation of nurses' assessments of patients indicated that nurses had a tendency to focus on the sequential completion of assessment documentation. They were inclined to focus on one area of the documentation at a time. As a consequence if patients brought up issues at times when nurses were not explicitly concentrating on those areas, it could appear as if patients' concerns lacked any particular significance for them. Significantly, there was also a risk that these issues could be ignored and needs go unrecorded. For example, during the admission of an 87 year old woman, the admitting nurse seemed unconcerned about the patient's repeated allusions to her urinary frequency:

*Nurse: "Okay. Are you taking any medication presently?"*

*Patient: "Erm, where is it, that's me calcium, I have that in the morning, one in the morning"*

*Nurse: "Ah ha"*

*Patient: "And this is my water pills, which mean that I'm running all day, wetting meself. Oh they've all fallen out, fallen out"*

*[pause]*

*Nurse: "Yeah. Oh dear."*

.....

*Nurse: "And what time do you get up in the morning?"*

*Patient: "6"*

*Nurse: "6. Do you get up at nights to use the toilet?"*

*Patient: "Oh yes, I keep running with these tablets"*

*Nurse: "Okay, what are your bowels like, have you got any problem with your bowels?"*

*Patient: "Not really no"*

*Nurse: "No problem. And what your urine is like. Do you go, often go to do a wee or ?"*

*Patient: "Oh yes, I'm running better than the next"*

*Nurse: "And how often do you bath?"*

[Pt08adm 178-184; 209-217]



Interestingly, the documentation from this assessment, recorded 'regular bowel movements' under the heading 'elimination', and no mention was made of any urinary frequency or incontinence.

In this case, had the nurse had a broader focus, it is possible that she may have prompted the patient to expand on her statements about her urinary frequency and to explore the extent to which this limited her independence. Although nurses claimed to see patients as valuable sources of information about their own health and social circumstances, observation indicated that nurses did not always recognise information from patients and informal carers that was significant to assessments of patients' continuing care needs.

Like nurses, doctors too stated that that they viewed patients and informal carers as valuable sources of knowledge about their own health and social circumstances. They indicated that patients and informal carers provided information that was fundamental to making decisions about patients' needs. This information covered a broad range of topics, as one senior house officer outlined:

*SHO: "... first thing that we do is we ask them about their presenting complaint, why they've come in, what their main problem is at the moment ...and then we go through their past medical history, what kind of diseases they have had in the past, especially chronic problems that are going to affect them in the future ... then their social set up, who they live with, what they are able to do, do they smoke, how much alcohol they have, how much home help, or you know meals on wheels, things like that. So, we look into the social set up and that's very important especially in elderly people"*

....

*"If I can, I get my history from the patient first, because they're the ones who can tell you what the problem is, but, if that's not possible, then whoever is looking after them or the relatives"*

[Genisho1 46-59; 79-82]

Thus, in the general interviews doctors highlighted how important patients were in providing them with information that was central to an assessment of their continuing care needs. In addition, there was a recognition that informal carers could act as valuable additional or surrogate sources of knowledge.

Whilst doctors' admission assessments were not observed, other observational data suggest that doctors were able to pick up on cues from patients. These cues could indicate wider continuing care needs that required the intervention of health professionals or social services support. For example, fieldnotes demonstrate how a consultant identified a continuing care need for an 89 year old woman. This woman had previously been discharged from another ward in the same

hospital and had been readmitted 4 days later. The fieldnotes relate to a ward round that took place 4 days after her readmission.

*“The consultant mentioned to the patient that she might be well enough to go home next week. In response the patient said that she had gone home on Thursday with envelopes, and explained that the ambulance had come for her, and she had not known that it was coming. The consultant indicated that this story was bit confused and wondered if the patient might be a bit deaf. When asked the patient said that she had got a hearing aid but that she could not put it in herself because of her arthritis.”*

[Pt15fn 245-260]

The information from the patient about her arthritis led the consultant to instruct the nurses that, on discharge, the patient would need somebody to go in every day to put her hearing aid in for her.

In this way, observational data suggests that doctors may recognise information from patients that is significant to assessments of their continuing care needs.

Social workers too had no doubt that information from patients and informal carers was essential in order to be able to conduct accurate assessments of patients' continuing care needs. For example, one social worker commented:

*Social worker: “... you can't actually set up a care package or assess the needs without starting with the patient, if the patient is unable to speak or is too ill for whatever reason you might start with the family and nurses or whoever is involved in the care, but eventually you're going to have to speak to the patient anyway before you carry out any sort of assessment.”*

[Geninsw1 28-33]

Again, social workers' admission assessments were not observed, but other observational data suggest that social workers were able to pick up on cues from patients. For example, during an interview with a 74 year old man on his discharge from hospital he highlighted that he thought that his wife was struggling to help him with the stairs:

*Patient: “Well I suppose it [help] would have been handy for the wife because she, I could see she was getting a bit down because though she's doing all this, trying to get me upstairs and ... and that it's getting her down but at the same time she didn't want to show it but I knew what it was.”*

[Pt11ipth 133-114]

When interviewed, the social worker involved in this patients' care outlined that this was a need that she had recognised and acted upon before rails were directly requested by the patient:

*Social worker: "... I've done that, I've referred for an OT assessment so I went in the ward to tell him today and, actually before I started to speak to him he started to tell me you know there is one thing, [laughter]"*

[Pt11iswh 24-26]

In summary, although all professionals claimed to recognise the importance of information from patients and informal carers, observational data indicates that nurses do not always pick up on cues from patients that are relevant to assessment of their continuing care needs.

### **NURSES NOT SEEKING THE OPINIONS OF PATIENTS AND INFORMAL CARERS**

Obtaining the perspectives of patients and informal carers is an established principle of continuing care assessments. In 1994, the Hospital Discharge Workbook instructed practitioners to ensure that patients' and informal carers' views were sought before patients returned to the community. It asks professionals to check:

*"Are care plans agreed with patients and carers, and are there opportunities for them to disagree and sufficient time for alternative and acceptable arrangements to be made?"*

(Department of Health, 1994b: 11)

Similar recommendations about the need for professionals to consider the views of patients and informal carers are set out in other good practice guidance on continuing care assessments including the Health Advisory Service (HAS 2000) (1999) and the National Service Framework (Department of Health 2001a).

These themes are also echoed in guidance to individual disciplines from academics and professional organisations. For instance, Jacques and Ryan (1997) state that assessment should:

*"Involve fully the service user and seek to enhance the lifestyle preferred by that person."*

(Jacques and Ryan, 1997: 23)

Therefore if professionals are to comply with good practice guidance, they need to ensure that they seek the views of patients and informal carers.

In the general interviews some nurses stated that they involved patients and informal carers by asking them about their situation and how they felt about their discharge from hospital. For example an F grade nurse outlined:

*Nurse: "And I mean we talk to them as well, you know if, once they are over their acute illness we'll often say to them, 'well, you know, how do you see your discharge, what do you want to do, when you're ready for discharge and that'"*

[Geninn12 270-273]

Interestingly there was a subtle difference in the way that other multidisciplinary professionals viewed how nurses learnt about patients' wishes. The other members of the multidisciplinary team also thought that nurses knew how patients felt but they described nurses' acquisition of information as a passive process. They stated that nurses came across or picked up details, or that families would approach nurses with their concerns, as opposed to reporting that nurses actively asked patients about how they felt about their discharge. For example a physiotherapist commented:

*Physiotherapist: "... often the patients will tell the nurses their problems or what they want more than they will someone who just comes and sees them for half an hour"*  
[Geniphy3 471-473]

Similarly the hospital discharge nurse remarked:

*Discharge nurse: "... they [nurses] will have the knowledge of how that patient feels about going home, because half the time a patient will talk to a nurse but might, might say a different thing to a doctor because they don't want to upset the doctor but they might tell the nurse exactly how they feel"*  
[Genindn 219-223]

Thus the perceptions of some nurses differed from those of other members of the multidisciplinary team who felt that, rather than asking patients their views, nurses passively relied on coming across information.

Observation of the 20 patients whose admission was tracked, and interviews with the key professionals involved in their care, as well as patients and informal carers, showed that nurses rarely actively sought information about how patients and informal carers felt about their discharge from hospital. It was only on admission that patients were regularly asked by nurses if they had any worries, or concerns about their care, but at this stage patients appeared to be more preoccupied with adjusting to the ward. Until their medical condition had stabilised it was too early to begin predicting continuing care needs with any degree of accuracy. Only twice during the 28 interviews (focused around the patients whose care was tracked) nurses stated that they had asked patients about what they wanted on their discharge from hospital. More commonly in these interviews nurses said that they had not asked patients what their wishes were or that they did not know what patients wanted.

What was more revealing was that in many interviews nurses reported patients' and informal carers' wishes at second hand. In this way nurses relayed that another member of the multidisciplinary team (usually a social worker) had seen the patient and they described the

patient's wishes in terms of the reported outcome of these discussions. For example, after the discharge of a 77 year old woman who went home with no increase in services, one nurse stated:

*Nurse: "She doesn't need an increase in services, the social worker has been to see her and she is happy with what she has got .... she will still continue having the home help, the social worker decided you know, asked, talked to her and asked her if she needed, and if she was happy with the care she was getting, and she said yes, she didn't need an increase because of her friend"*

[pt17inn1 198-222]

Nurses' failure systematically to ensure that they were aware of the wishes of patients and informal carers may have added to their difficulty in facilitating their involvement in continuing care assessments.

In the general interviews one of the ways in which doctors stated that they facilitated the involvement of patients and informal carers in assessments was to ask them what their views were about the support that they would require after their discharge from hospital. For example, one consultant talked about the way that he practised:

*Consultant: "... we talk to patients on the ward rounds and ask them what their wishes are, and then erm, if someone has complex care needs then a care planning meeting is held"*

[Genincon1 78-80]

Observational data suggest that, in practice doctors often took the opportunity to explore with patients how they felt about coping in the community and what kinds of support they wanted after their discharge from hospital. For example, during one ward round a consultant discussed the plans for an 82 year woman's continuing care with her. Fieldnotes show:

*"The consultant approached the patient and asked her how she was. The patient replied that she was not too bad, and not too good. The consultant stated that he had had a chat to the doctor, and again asked the patient how she thought that she was managing. The patient stated that she wanted to move into a care home. After getting confirmation from the patient that this was a decision that she had made herself, the consultant agreed to arrange a meeting with the social worker."*

[pt12fn 103-110]

In contrast to the nurses, doctors appeared to be more active in seeking the views of patients and informal carers.

Like doctors, social workers also saw obtaining the perspectives of patients and informal carers as a central part of their role. In the general interviews, a social worker explained at some

length how she was careful to set aside her own views and that it was more important to listen to exactly what it was that the patient themselves wanted. He stated:

*Social worker: "Well, you see, oh, you introduce yourself obviously, and say, 'I've come to find out what do you think you would like me to do for you when you go home', that's the way I always put my case across to the elderly lady, you know, 'I understand you live by yourself' and 'are you coping all right by yourself?' That's the way the question comes, if she says 'oh no I can't get into the bath any more, I have nobody to assist me and my family lives far away, and I've been doing it by myself but now I don't think I could do it any more' or they will say that um, 'my neighbour is helping with the shopping, I don't know whether she might be able to carry on' then you know that you need to look into that area and you ask her, 'anything else again you think you need?' You don't tell, you don't bring your own ideas into her, she must tell you exactly what she thinks she needs, you see because what I might think she needs might not be what she would like to have, that would help her to be happy in her home, so she must really tell us"*

[Geninsw3 480-495]

In practice, the patient tracking data shows that social workers were thorough in ensuring that they knew how patients felt about their discharge and that they were satisfied with the plans that had been drawn up to meet their continuing care needs. Whilst social workers took account of the views of informal carers, these were not taken to be a substitute for the views of patients themselves and it was considered vital that patients express for themselves their preferred options about continuing care support. For example, in one care planning meeting, the views of informal carers had been influential in the discussion which led to the proposal that a residential placement may be appropriate. However the social worker was insistent that the patient state how she felt about this course of action. Fieldnotes from the meeting record:

*"The social worker said that they wanted to know her [the patient's] views of where she would like to be. The son-in-law stressed that it had to come from her and the patient clarified that he meant that she should not be forced. At this point the social worker told the patient that she was not supposed to be told what to do. In response the patient indicated that she wanted to be with them, indicating her daughter and son-in-law. The social worker pointed out that she would be in a place like a hospital and not live with them, and asked if she would be happy with this and that if it was okay, they could look for a home near where they lived. The patient said that she was happy."*

[Pt26fn 616-626]

In this way, both doctors and social workers appeared more proactive and rigorous than nurses in seeking the views of patients and informal carers.

### **NURSES' FOCUS ON DOCUMENTATION AND NOT PATIENTS OR INFORMAL CARERS**

Policy documents and good practice guidance outline that patients and informal carers must not be marginal to the assessment of their own continuing care needs. Rather they are key

individuals and ought to be central to the assessment process. For instance, the British Geriatrics Society, the Association of Directors of Social Services and the Royal College of Nursing, in their joint statement on the discharge of older people from hospital to community care recommend:

*“Discharge planning systems need to be sensitive to the global needs of older people and should place the patient, family and carers at the centre.”*

(BGS, ADSS and RCN, 1995b: 2)

Professionals therefore need to remain aware of the key position of patients and informal carers throughout the assessment of their continuing care needs.

In the general interviews nurses talked about involving patients and informal carers in continuing care assessments. All nurses stated that patients and informal carers should be involved. Moreover they claimed that patients and informal carers were key to assessments, and as such they should be central to decision making. For example, a D grade nurse stated:

*Nurse: “I think they [patients] should have the overall say in what happens about their care providing of course they are mentally able to do so”*

[Geninn2 356-357]

There was also a recognition that patients should be central to assessments on humanitarian grounds, that they had to live with the consequences and that therefore it was only reasonable that they had a significant input. One nurse speculated on how he might feel in their position:

*KA: “Is it important the degree to which patients are involved?”*

*Nurse: “Yeah it is because it’s themselves, it’s them as an individual they need to say, because looking at it like now from me if the, if the tables were turned, I wouldn’t like, I would like to be so much more involved and have a lot of say”*

[Geninn6 456-460]

In this way nurses stated that they considered that it was very important that patients were central to assessments of their own needs. At times nurses’ focus on completing assessment documentation was such that patients could seem almost peripheral to the process. In these cases there appeared to be little commitment to developing a partnership with them. For example, fieldnotes from the admission of a 91 year old man show how one nurse approached his assessment. The patient had been brought to the ward accompanied only by a porter:

*“[Name - nurse] had got a few patient details scribbled on a paper towel, and looked down at these when he came over to the patient initially, to verify these. The auxiliary nurses were concerned about the property and started to look at the contents of the property bags without asking permission or explaining their actions.*

...[the patient went out to the toilet] .....

*The patient came back, and the nurse started the admission, he began with the ADL sheet, and started circling boxes, and got as far as the section on nutrition before he asked the patient any questions, the first one being whether he had diabetes. The nurse had got the notes from A&E, where the patient had spent 2 nights, which had come up with the patient, but at best he had only had a cursory glance at these, as initially he was using the notes from his paper towel.....*

*Towards the end of the admission, [name - ward sister] came and sat down by the nurse at the end of the bed, and had a read through the notes. When the nurse appeared to have finished asking questions, the patient walked out to the toilet again, [name - nurse] continued with the forms. I happened to notice the patient heading out of the ward and told the nurse, who managed to re-direct him in time.*

*[Name - nurse] had a pile of forms to fill in; after the main assessment he did the Waterlow score chart, and then wrote an initial problem onto a care plan, without comment or explanation, the patient sitting silently throughout watching the task, as the nurse was writing the paperwork on his lap, the writing would not have been discernible to the patient. Then there was the social work referral form, then the discharge planning form and finally the ethnic monitoring form, which were completed. After this form, the patient needed to go to the toilet again ... ”*

[Pt22fn 20-60]

Nurses' focus on completing documentation meant that patients could appear to be marginalised. In such situations nurses' practice sometimes failed to match their intentions with respect to maintaining the centrality of patients.

### **NURSES NOT KEEPING PATIENTS AND INFORMAL CARERS INFORMED**

The policy literature on continuing care assessments is fairly unequivocal in its opinion that patients and informal carers be kept informed throughout their own continuing care assessments. For instance, the Health Advisory Service HAS 2000 (1999) recommends:

*“Information about the full range of options for their [users and carers] care is provided and explained.”*

(HAS 2000, (1999): 9)

Moreover, it follows that if professionals are to keep patients and informal carers involved then they themselves must be fully conversant with assessment procedures. Without up to date knowledge they will be unable to comply with good practice guidance.

The Department of Health and Social Services Inspectorate (Department of Health/ Social Services Inspectorate, 1998), in their review of the hospital discharge arrangements for older people go further, arguing that the accuracy of the assessments themselves is influenced by



professionals' knowledge of eligibility criteria and the type of services that can be offered. In their report they contend:

*"Health staff need to be well informed not just to make appropriate referrals, but also to convey accurately treatment and outcome expectations to patients."*

(Department of Health/ Social Services Inspectorate, 1998: 27)

It is therefore imperative that professionals ensure that they are well informed and that they share this knowledge with patients and informal carers.

In the general interviews some of the nursing staff stated that they facilitated patient involvement in continuing care assessments by providing patients with information. This information included details of ward routines and procedures. For example an E grade nurse outlined:

*Nurse: "...we just try to involve the relatives in assessment, try to explain as at admission, as they come into the ward"*

*KA: "Yeah"*

*Nurse: "We explain to them what's going to happen, like visiting hours, consultant rounds, social workers being involved etcetera"*

[Geninn4 13-18]

However, none of the nurses claimed to provide patients or informal carers with information beyond such very basic factual details. In the general interviews there was no sense of nurses engaging in deeper discussions about, for instance, what services were available locally, or how patients and informal carers could go about finding out about local residential homes or sheltered accommodation. In the general interviews no other professional group identified that nurses had a role in providing patients or informal carers with information. Importantly, some nurses themselves felt that sometimes they lacked the necessary knowledge to be able to inform patients and informal carers about community services. For example one nurse described finding out that one particular service had changed:

*Nurse: "... now I didn't even know, I thought meals on wheels was hot dinners until I found out now they do freezer meals... like I said, I, I just thought meals on wheels that was it, but now they don't really do them like that any more now, it's just frozen stuff and the home help comes in but she might just be giving them a sandwich but she does not always wash them, you know, it's just little silly things that you have to keep clued up on because you don't know"*

[Geninn7 614-636]

Without adequate up to date knowledge of what resources are available and the procedures that are in place to access those resources, nurses are not in a position to be able to support the involvement of patients and informal carers.

Perhaps unsurprisingly, given nurses' modest claims in the general interviews, the patient tracking data revealed only isolated incidents of nurses providing patients and informal carers with information. Most of these instances occurred on admission, with nurses telling patients about the ward routine. With respect to the 20 patients being followed, observational and interview data revealed only two occasions on which nurses gave patients or informal carers information or advice about continuing care support. In one case the ward sister told informal carers about the nature of care provided by a hospice. In the second instance, when interviewed after the patient's discharge, the admitting nurse stated that she had given the patient details about home care:

*Nurse: "I admitted her and she felt that she was able to manage, and I even said to her, you don't have to pay for the home help, in case she needs a home help to dust, but she says that she doesn't need it because her daughter does it for her"*

[pt16inn1 307-310]

In this case the nurse reports giving one isolated piece of information about one particular service. What may have been more beneficial would have been to wait until the patient's condition had stabilised and then outline the range of support available and the implications of each alternative. Out of context this information is free-floating and is of questionable usefulness to the patient.

Given nurses greater accessibility, their limited role in informing patients and informal carers about continuing care support suggests that there is potential for them to expand their role in this area.

In the general interviews, doctors spoke a lot more about how they went about collecting information but made only isolated statements about providing patients and informal carers with information about their continuing care needs. One reference to informing patients was made by a senior house officer who stated:

*SHO: "... we [doctors] ask them [patients] what they think they want and what they can do and you know, give them, sort of make them aware of what's available"*

[Geninsho3 206-208]

Given the requirements for patients and informal carers to be kept informed about their own continuing care assessments, it is curious that doctors were not more forthcoming about their own roles in this area.

However, in practice the patient tracking data shows that doctors did provide patients with information both about their continuing health care needs and also about options for support services available. Doctors regularly gave patients information about their own medical condition, much of which was relevant to their continued treatment in the community. For example, a consultant on a ward round reviewed a 77 year old woman who had been admitted with shortness of breath. Fieldnotes record the patient was instructed about managing her continuing health care needs.

*“The consultant told the patient that it sounded like she had an infection that had been difficult to get rid of, and said that they would give her Frumil [a diuretic] to get rid of the excess fluid in her lungs. He said that her not taking the Frumil [at home] may be the reason why she was not getting better and advised her that continuing to take her diuretics would help her breathing.”*

[Pt18fn 72-79]

In addition doctors also provided patients with information about the services which may be available to them in the community. The options did not always coincide with the level of support that patients felt that they needed but learning about the available support helped patients to be more realistic about the services to which they were likely to be entitled. For example, after observing a 78 year old man walk, a consultant brought up the topic of continuing care for the patient. Fieldnotes from the ward round record:

*“The consultant told the patient they would get him and his son to have a chat with the social worker. The patient replied that he thought he would be better off in here [hospital]. The consultant informed him that he couldn't stay here as the ward was for ill people. The patient seemed reluctant to agree but said that his son should be here soon. Reinforcing his message, the consultant repeated that he could not stay in hospital, he said that he was not being funny but that it simply was not an option ... adding that he thought that the patient needed some help. The patient agreed and the consultant summarised that the patient had never had help - and that as a maximum he could have help in the morning, and someone coming in with meals, and that that was really the only option open at the moment”*

[pt28fn 133-146]

The response was not the one that the patient wanted but the patient did come away with more idea about how much continuing care support he may be eligible to receive.

Although doctors did not make any real claims about their role in providing patients with information, in practice the patient tracking data shows how they helped to keep patients informed about their own individual continuing care.

Unlike nurses, social workers did consider themselves to have a role in informing patients about the procedures of assessment and the support services that were available to them. Social

workers in particular were proud of the candid way in which they involved patients and informal carers. For example in the general interviews, one social worker stated:

*Social worker: "... we operate an open system here ... we are honest with the families and I explain everything to them"*

[Geninsw2 64-66]

In practice it was evident that patients and informal carers did receive information about the support that was available along with supplementary details such as start up arrangements and waiting times. For example, in one care planning meeting in which an 85 year old man was present along with his son and daughter and members of the multidisciplinary team, the social worker outlined a number of community services that she thought may be of interest to the patient. Fieldnotes record:

*"The social worker asked the family if their father would be interested in going to a day centre. The patient's daughter replied that he had been to [name], which she was told was a day hospital and not a day centre and that they did social activities at the day centre. The social worker added that there was a waiting list, she did not know how long it was but suggested that it may be a couple of months, but said that she could make a referral. The patient's son repeated this information for his father, who agreed that this would be nice in the summer months. The social worker continued, saying that she could also make a referral to Age Concern for a visiting service. The patient's son stated that the company would be appreciated"*

[pt10fn 557-566]

Only one patient or informal carer felt that social workers had not informed them about the range of potential support services, and that instead there was an assumption that they would continue to cope. In this case, an informal carer highlighted the lack of discussion about her father-in-law's housework, saying:

*Daughter-in-law: "I suppose that was naturally assumed that the son would pick that up"*

[pt28idac 262-263]

However, overall observational data indicate that social workers kept patients and informal carers informed about their own continuing care assessments.

### **NURSES NOT FACILITATING THE INVOLVEMENT OF PATIENTS AND INFORMAL CARERS**

Guidance on the introduction of the single assessment process outlines that assessments can be undertaken by a front-line professional. All such front-line professionals must therefore be familiar with guidance on how these assessments ought to be conducted.

Included within the guidance from the Department of Health (2002h) is the instruction that:

*“They [older people] should expect assessments of their need to begin with their perspective, and for their views to be kept to the fore throughout the assessment and subsequent stages of care planning and service delivery.”*

(Department of Health, 2002h:1)

Similar instructions have for some time been contained within good practice guidance issued by professional bodies. For example, the UKCC (1997) in reviewing nurses’ contribution to continuing care tells nurses:

*“Integral to discharge planning should be assessment of need from the perspective of patients and carers”*

(UKCC, 1997: 23)

Therefore all professionals, including nurses have a role in involving patients and informal carers in assessments of their continuing care needs.

In the general interviews some professionals stated that as part of their role, nurses should encourage patients and informal carers to become involved in the assessments of their continuing care needs. For example the discharge nurse stated how she thought ward nurses ought to practice:

*Discharge nurse: “... it’s up to her [the nurse] to say what she, the patient feels and to encourage the patient to be involved, a lot of patients will just tend to let the team decide for them, but, and say, ‘oh well, whatever’s best’”*

[Genindn 274-277]

Some professionals felt that the nurse’s role went beyond encouragement and that nurses also had a part to play in speaking on patients’ behalf and representing their interests. For example a physiotherapist discussed how vulnerable patients could feel at times:

*Physiotherapist: “... they [nurses] are much better qualified to act as the patient’s advocate. Not every patient needs somebody to speak up for them, but I would say that most of the patients that I have met need somebody to stand there and say no to a doctor”*

*KA: “Hmm”*

*Physio: “Or to bring something up, because doctors are scary people”*

[Geninph1 470-476]

Whilst professionals outlined the role that they considered that nurses ought to be fulfilling, it was difficult to find professionals who considered that nurses actually practised in this way.

Although one of the ward nurses argued that the nursing team did actually support patients and informal carers, this point of view was an exception. The nurse said:

*Nurse: "We encourage the relatives or the next of kin you know, just to take part in the future plans"*

[Geninn11 14-15]

More often in the general interviews, professionals were sceptical about nurses having a role in facilitating the involvement of patients and informal carers. For example, a senior house officer commented:

*KA: "Would you say that the nurses have a specific role in involving patients in assessments?"*

*SHO: "No I don't think they do, I don't think they do have a specific role, no, not that I've noticed I have to say ... I think it's probably a deficiency in that they know an awful lot about the patient's needs but on the whole I'm not sure how much of this is actually communicated back to the patient, I don't think the patient is often asked a lot about what they might want"*

[Genisho2 205-215]

In summary, there was a feeling that nurses ought to have a role in facilitating patient involvement, but that this was a role that they had yet to fulfil.

In practice it was difficult to find evidence of nurses supporting the involvement of patients and informal carers. There were occasions on which informal carers did approach nurses with concerns about how patients would manage in the community. However nurses did not always appear to welcome these concerns. They gave the impression that they did not want to take on the responsibility for addressing the issues that were raised. One of the ways in which they avoided committing themselves was to tell informal carers about other people who they could talk to. For example, fieldnotes recall a discussion between the researcher and the son of a 78 year old patient. The son related how he had tried to get his concerns addressed:

*"The son said that they would have to get his father some help at home - he said that he had spoken to the sister yesterday and had been told that 'they' came round on Tuesday mornings and Fridays, although he did not know what time. I said that the ward round usually lasted from 11am-1pm. The son said that he couldn't get to the ward before about 1.30pm as he would have to arrange cover at work. He did not know who the 'they' were and asked if it was an almoner or somebody like that, that came round. He said that the best thing to do may be to make an appointment to see someone - I don't think he knew how to go about this."*

[pt28fn 177-185]

In this way nurses sometimes even absolved themselves of the task of liaising with multidisciplinary team members on informal carers' behalf, with the result that informal carers were left feeling somewhat bewildered.

On occasions nurses appeared to pass on informal carers' anxieties. However again there was little evidence that nurses were interested in taking responsibility for addressing informal carers' concerns. For example, during a ward round an F grade nurse informed the medical team that the family of an 89 year old woman were concerned about her continued ability to cope. It became evident that the nurse only had a very superficial knowledge of the concerns, suggesting that a very limited exploration of the issues from the informal carers' perspective had taken place. Fieldnotes from the ward round record:

*"The consultant suggested discharge on Tuesday. The nurse interjected that the patient was not coping at home. The consultant questioned in what way she was not coping as she lived in a warden controlled flat. The nurse replied that the patient had come in with a chest infection and the family were concerned about her managing at home. The consultant stated that a chest infection was different to not coping, adding that there may be possible concerns about her eating at home, but that if the family were concerned then they needed to speak to the family"*

[pt15fn 230-238]

In this case, a doctor subsequently phoned the patient's daughter and discovered several issues including that the patient's home carers had been coming too late and there were problems with a day centre. It is difficult to see why nurses could not have obtained this information when they became aware of the family's worries; and set about resolving some of the problems.

Moreover, nurses also seemed to be reluctant to take action when they were aware that patients were not involved in decisions about their own continuing care. For example an 86 year old Punjabi woman was admitted to the ward with abdominal pain. It was later discovered that the patient had metastatic disease in her liver. During the course of her admission discussions took place with the patient's family about the most appropriate continuing care for the patient. However, the patient was marginal to this process as a key nurse in the patient's care admitted in a subsequent interview:

*Nurse: "No, I don't think she's aware what's happening"*

*KA: "Right"*

*Nurse: "Probably she probably knows that she's not going to get better in her own way, in her own language, but whether she knows what is that problem medically, I don't think, but probably the son told her, I don't know whether he wants her to know that"*

[pt06inn1 312-316]

In this case part of the problem was, that the unlike the rest of her family, the patient spoke no English. Communication was therefore very difficult. Despite the patient being alert and orientated for a large part of her admission, there was no evidence of nurses attempting to involve her in her own needs assessment. Moreover, they did not use the resources that were available to them such as the hospital interpreting service.

In summary, although nurses described a number of strategies for involving patients and informal carers in continuing care assessments, in practice the evidence shows that they were not following good practice guidelines and that they made few attempts to facilitate the involvement of patients and informal carers.

In the general interviews, some doctors stated that one way they supported the involvement of patients was by ensuring that they listened to their point of view. They outlined that there was a real danger that informal carers could state their case more forcefully than patients and that consequently the perspectives of patients themselves could be overlooked. For example one consultant warned:

*Consultant: "... you may have somebody who so much wants to protect a parent, and it's particularly child and parent that we find, or spouse, that they so much want to protect a loved one or not worry them, they'll speak for them and you almost have to say you know, especially in clinic I'll say to people, let me hear it from the horse's mouth and then I'll ask you know, your son, daughter, husband, wife because I know they want to tell me"*

[Genincon2 450-457]

In practice, a senior house officer talked about her empathy with a 101 year old man who did not want any services on discharge. The patient's son had concerns about his father. However the doctor suspected that the son may have been acting in an over-protective way. She talked about the importance of helping the patient to retain his independence and ensuring that his views were not completely marginalised. In the interview with her just after the patient's discharge she stated:

*SHO: "... The problem on going home, his son, as quite a lot of people do think you know, now somebody's in hospital we'll have to make sure that they get all the services they can do erm, and erm, was saying you know, he needs this, this, this and this and of course he didn't want this, he didn't want any of it at all, and I quite often think, 'well you know, they were coping well on their own before and he went out every day for his own shopping', erm, you know, and I think things like that keep, keep them going, so, but we compromised"*

[Pt24indr 180-186]

In contrast to nurses, doctors appeared to support patients rather than ignoring or passing on their concerns to other professionals.

In the general interviews social workers stated that they saw themselves as supporting the involvement of patients and informal carers by ensuring that they spoke to them and obtained their opinions on patients' individual continuing care needs. In addition social workers also



talked about the importance of offering patients choice and making sure that patients were happy with the packages of continuing care that were arranged. For example, one social worker argued:

*Social worker: "... once you've met the family and you've discussed with the clients involved ... then we all sit together .. because she [the patient] has the right of her own choice, we can't, they cannot force what they want on her, so she needs to be involved about what she would like to have"*

[Genisw3 417-423]

Interviews with social workers in relation to the continuing care assessments of the twenty patients whose care was tracked showed that social workers did discuss care arrangements with patients and their informal carers. For example a 76 year old man was admitted to the ward with acute abdominal pain. This was quickly resolved and he was able to be discharged three days later. The social worker reported checking with the patient and his informal carers that he was satisfied with his current continuing care support and that there was nothing else that he needed:

*Social worker: "When I came to assess him just to find out about social problems, how he's going to cope when he goes back home because it's very important and the family too were present you see, to see how they are coping with him with his condition at home, erm, and through that assessment he'll be able to tell what his needs will be and he's requiring from us, that might be important to him you see... when I came to assess him I asked 'what support do you need from us?'"*

[Pt09insw 160-175]

Again, social work practice appeared to be more closely allied to that of the doctors, with social workers recognising the importance of the involvement of patients and informal carers in continuing care assessments.

## **SUMMARY**

The previous chapter showed nurses' lack of involvement in continuing care assessments. Looking in more detail, this chapter has identified that nurses do not appear to be facilitating the involvement of patients and informal carers. In contrast to both doctors and social workers, nurses did not seem to make themselves accessible to patients and informal carers. In addition, nurses did not appear to pick up cues, seek the opinions of patients and informal carers or keep patients and informal carers informed about their continuing care assessments.

## **CHAPTER 7**

### **PLACING THE ISSUES IN CONTEXT**

#### **INTRODUCTION**

During the general interviews professionals were asked about issues that they felt affected the conduct of continuing care assessments. They were also asked about issues that they felt affected the involvement of patients and informal carers in this process. Data analysis revealed that there was a large degree of overlap between the issues highlighted in response to both questions. In view of this, the findings from these two areas of the data collection are presented together, with differences being identified where they occur. The findings fall broadly into three categories; strategic issues, patient and informal carer issues and practice issues. In each case, data from the general interviews are set alongside observations from fieldnotes and patient tracking data.

#### **STRATEGIC ISSUES**

Strategic issues refer largely to policy and resourcing factors that affect the way that professionals work. These issues include government regulations and legal boundaries within which staff must practice. They are often determined at senior levels, with little direct input from front line professionals.

In nearly all cases professionals indicated that strategic issues affected the manner or degree to which patients and informal carers could be involved in continuing care assessments. There were almost no references to strategic issues affecting the way that professionals actually conducted assessments.

#### **Policies Restricting Choice**

One of the most frequently cited strategic issues mentioned by professionals in the general interviews as affecting continuing care assessments was that of policy restrictions. For instance, professionals highlighted that patients had to fulfil certain clinical conditions, (eligibility criteria) determined by the health authority and local social services department, in order to receive particular services. For example, an E grade nurse outlined which patients could not receive nursing home care:

*Nurse: "There are criteria ... if you can walk, if you can wash and dress yourself, you're not a candidate for a nursing home, you'll most probably go to a residential home"*

*KA: "Right, are those, is that the only criteria?"*

*Nurse: "With infection, people with MRSA, they [nursing homes] won't take you, even if you have drips, if you are on a nasogastric tube, or gastrostomy feed or whatever feed the doctor put you on, they won't take you, probably you will go to [name - NHS funded continuing care], I mean there's a lot of things ..."*

[Geninn13 315-328]

In turn, the requirement to fulfil eligibility criteria limited the degree of choice available to patients and informal carers when considering what continuing care support would best meet patients' individual needs. For example, a social worker highlighted the potential for conflict when informal carers did not understand how eligibility criteria could be applied:

*Social worker: "... the public tend to understand that if I get my mother or father in the nursing home, he's going to receive better care, but it is not what you choose for your mother if the person doesn't fit that criteria, because nursing homes costs about £150 more than residential. So if somebody is more or less feeding himself, is not incontinent, and the family says that they want that person in a residential or nursing home, he's not going to get it"*

[Geninsw2 263-270]

In this way, professionals indicated that unless patients were judged to have met the eligibility criteria for a particular service, then access would be restricted.

During the course of tracking the twenty patients and their informal carers through their hospital stay, it was apparent that a failure to fulfil eligibility criteria could deny patients access to certain services, thereby limiting their options and affecting their involvement in continuing care assessments. In practice, conflict sometimes occurred when patients and informal carers felt that they needed services for which they were not eligible. For example, in an interview with a social worker after the discharge of a 101 year old man, the social worker highlighted why the patient was initially refused meals on wheels in spite of family concerns that he should have them:

*Social worker: "... he [the patient] is walking, he doesn't need anybody to wash him or put clothes on him ... the son was a bit upset, and spoke to me, I said, 'yes, what did you want for him?' He said that he used to do his shopping for him and he [the patient] used to manage to prepare his meals but he wouldn't be able to stand on his feet firmly now to prepare a meal, whether he could have meals on wheels? Now the new criteria is that unless you are receiving help for personal care, you cannot get meals on wheels, because if you are able to get up and wash yourself, you should be able to warm a frozen meal, which you can arrange to buy yourself"*

[Pt24iswh 08-16]

Thus, in practice, if patients were not seen to fulfil the eligibility criteria for a particular service then provision could be refused. However, in this case, after family protests, an exception was made in view of the patient's age, but the example illustrates how eligibility criteria could restrict choice for patients and informal carers.

Another issue affecting choice mentioned by professionals concerned the policy of determining appropriate continuing care support. They outlined that continuing care policies could determine which services would be available to patients. For instance, professionals indicated that patients who had not previously had domiciliary support were required to try to cope at home with a care package, before institutional care would be considered. This again limited the options for older people in need of continuing care support. For example, a physiotherapist outlined the procedure for patients to obtain institutional continuing care:

*Physiotherapist: "... if the person hasn't had any services, I mean the doctors aren't going to say to the social worker, ' yeah, sure you can try out a residential home ', because they must try them with the services first"*

*KA: "Hmm"*

*Physiotherapist: "If they're going to be funded by the social services"*

[Geninph2 91-96]

In this way, professionals indicated that continuing care policies could limit the options available to older people.

In practice, it was evident that professionals were reluctant to recommend patients for institutional care, without evidence that they could not manage at home with a care package. For example, during one care planning meeting, it emerged that the patient and informal carer favoured institutional care, but this was not an option that the professionals present were keen to endorse:

*"The social worker summarised that the patient could receive an evening service and a morning call. The patient indicated his reluctance to leave hospital but the social worker replied that they could consider residential care after this and that he should manage within one room at home. The occupational therapist outlined that they needed a trial before going to a residential home to show that he couldn't manage. The patient's son was clearly anxious and asked for confirmation that a discharge home would indeed be just a trial."*

[Pt28fn 947-965]

In this case, professionals sought to persuade the patient and informal carer to accept a package of domiciliary care by referring to policy that patients should try to cope at home, before admission to residential care would be considered. This effectively reduced the range of options available to this patient and his informal carer.

### **Limited health and social care budgets**

In addition to the constraints imposed by eligibility criteria and continuing care policies, professionals also indicated that there were other limitations to what services could be offered to patients imposed by health and social services budgets. Services could only be provided if there were the funds available to do so. In the general interviews this came across as a concern when asking patients about the social services that they felt that they needed. For instance a liaison nurse commented:

*Liaison nurse: "I think, I mean if you are asking someone about what their care needs are or what they want to have happen, there are very real parameters around what actually is available in the current funding, I mean it's always economic isn't it"*

[Geninln1 44-47]

Moreover, there was a realisation that services that patients might want may not be provided by the social services department. For instance fieldnotes from a general interview with a member of Age Concern who attended the weekly multidisciplinary meetings revealed:

*"He said that one of the gaps was bathing, as there were so many people who could not get in and out of the bath, adding that a bathing service would be useful. He also said that there had been a restriction in the activities of home helps, and that they used to wash curtains, and periodically clean the upstairs of houses when people were restricted to the downstairs, but now the whole range of activities was very restricted"*

[Geniagec 126-132]

The professionals thus highlighted the difficulty that patients wanting help with activities such as bathing may experience in accessing appropriate support through the social services department.

As a consequence of the lack of particular continuing care services professionals indicated that they were aware that there were some needs which patients had which they were unable to meet. For example, an occupational therapist stated:

*Occupational therapist: "... I think that blatant needs are somehow met, but things like emotional needs, perhaps, yeah, you know, may not be met but they may not be met in any hospital system just because simply there's, there's not the resources to do that sort of thing"*

[Geninot2 571-575]

In this way professionals highlighted that budgetary constraints and the consequent absence of continuing care services to meet particular needs could limit the options available to older people and their informal carers.

Budgetary constraints were evident in practice, in assessments of patients' continuing care needs. At times it was apparent that services which patients wanted either had prohibitively long waiting lists or did not exist at all. For example, during a 78 year old man's care planning meeting it became apparent that what he was most concerned about was being left alone overnight. However, in this borough no night nursing or night home care service existed. The meeting had been discussing the possibility of discharge home with a care package:

*"The social worker said that the district nurse could come in every day for medication. At this point the patient reiterated that he didn't want to be on his own at night. The social worker highlighted that there was an evening service. In response to the son's enquiries the social worker and occupational therapist clarified that this was from 6pm until 9.30 or 10pm and then carers would come in again at 7 in the morning."*

...  
*"The son was still unhappy about his father being left overnight. The social worker explained that if the family wanted a sleep-in, it was expensive, but the borough of [name] did not provide this. The son confirmed that they could not afford this themselves."*

[Pt28fn 862-74; 897-99]

In this case the patient was discharged home without any night visiting, as the service was not available in the borough and the family could not afford private provision. In this way budgetary constraints could affect the services that could be offered to older people.

### **Restricted services available**

Even where continuing care services were available, professionals highlighted that their use could be limited. There were sometimes ceilings on the amount of particular support services available to any individual patient. For example, a community liaison nurse highlighted that there were limits to the size of domiciliary care packages:

*Community liaison nurse: "... I feel as though they could, patients probably could stay at home for a longer period if they could put in more care but they can't seem to, they don't have the means to do that, and that's when they have to go in to a residential or nursing home which is a shame for some patients really"*

[Geninln2 444-449]

More specifically, for those patients who were discharged with domiciliary care packages, a D grade nurse indicated that these individuals could receive a set maximum number of daily visits by home carers:

*Nurse: "... the total support that is available is sort of visits 3 times a day"*

*KA: "Right"*

*Nurse: "And I think that's the maximum they would get"*

[Geninn2 485-488]

Thus, in the general interviews, professionals indicated that they were aware of maximum amounts of provision, which again could affect the involvement of patients and informal carers in continuing care assessments.

In practice, as highlighted in the general interviews, there could be limits on the amount of particular services that could be offered to older people. For example, one of the patients in the study, an 85 year old man was keen to return home. The multidisciplinary team felt that his discharge was risky and were anxious that he should get as much support as possible. However, within the discussions during the care planning meeting there was a recognition that services, particularly home care visits, were limited:

*“The son said that maybe they were being too optimistic, but that they were asking for a try at home, and that if he couldn’t manage then they would look at the alternatives. The social worker replied that that was what they were trying to plan and summarised that he would have a morning carer, meals on wheels, an evening carer and an afternoon call if she could get that. She said that she would ask for it, but there was no guarantee about it. She went on to ask at what time the patient would like his home care visits”*

[Pt10fn 504-512]

In this way, the options available to patients and informal carers were restricted by the size of the care packages that could be offered to individual patients by the local social services department.

Thus, interviews with professionals and observations of practice suggest that a number of strategic issues may affect the involvement of patients and informal carers in the assessment of their own continuing care needs.

## **PATIENT AND INFORMAL CARER ISSUES**

### **Communication Difficulties**

During the general interviews with professionals, they highlighted that both continuing care assessments, and the involvement of patients and informal carers, could be affected by issues relating to the behaviour or attributes of patients and informal carers. More specifically, professionals stated that one key issue was the ability of patients to communicate with them. In particular, difficulties could arise with patients who were unable to take in information because of problems with their hearing or eyesight. For example, a D grade nurse outlined how, these could limit patients’ contributions and how, in practice, she worked around these when conducting assessments:

*Nurse: "Very often you need someone else like a relative or a friend or a neighbour or even sometimes a care worker or, we do need someone else half the time, it all helps"*

*KA: "Why"*

*Nurse: "Because well, it's, very often they're deaf.. if they can understand all that is happening and they can't hear it, they can't communicate it. They have eyesight problems sometimes ..."*

[Geninn8 101-108]

In addition to issues with patients taking in information, professionals indicated that there were also issues with patients being able to communicate their thoughts to professionals. Such issues included difficulties posed by patients being too ill or breathless to speak. Again, this could affect the process of assessing patients' needs, as, for example, one D grade nurse stated:

*Nurse: "... I would take the details as per the admission procedure, the forms, kardex and anything else that I want to know, I would ask the patient then. That is if the patient is not too breathless or not too ill, otherwise I would get the information from possibly the casualty forms, that maybe someone has actually brought the patient in and they have answered some questions regarding the patient, so I would, I would have some information from them."*

[Geninn3 12-19]

Moreover some professionals highlighted the difficulties faced by older people who were unable to speak English. Patients from minority communities could be particularly disadvantaged in this respect. For instance a senior house officer stated:

*SHO: "they [patients] might not be able to speak English and you might not have a translator, in which case you sort of ask the relatives, but most patients like that usually come in with relatives. Obviously if they come on their own then it's a bit of a problem"*

[Genisho1 74-78]

Thus, professionals stated that communication difficulties could impede continuing care assessments and patient involvement.

The communication difficulties outlined by professionals in the general interviews were evident in practice. In interviews with professionals focused around these patients' continuing care needs, it became apparent that communication barriers could impede the assessment of patients' needs and restrict patients' involvement in the assessment process. For example, a palliative care nurse described her attempt to assess an 86 year old Punjabi woman and her concerns about the patient's level of involvement in a decision about her potential discharge to an NHS funded continuing care bed:

*Palliative care nurse (PCN) : "... I came over to see her on Monday, at the time I came to see her she was actually sleeping, and because of, she can't speak English and there was nobody to interpret, it wasn't possible for me to actually communicate with her, and*



*there weren't any family members around, but I talked to [name], the SHO, and other nurses about how she was"*

....

*PCN: "... my feelings with [name - patient] is that she seems to have been a bit left out of this decision making process really"*

*KA: "In what way"*

*PCN: "In that as far as I know she hasn't actually been informed of her diagnosis yet in that you know, I don't know how much the family have talked to her about what she wants, or whether she's been given you know, the opportunity to say what she would like"*

*KA: "Right"*

*PCN: "And that's something that doesn't sit very easily with me, because our philosophy is that you know, the patient has the right to make decisions and informed decisions"*

*KA: "Right"*

*PCN: "And you know, I don't like the idea of people being put in places where, you know, where they haven't made that decision themselves"*

[Pt06ipch 11-15; 67-79]

In this instance, without the use of an interpreter, the hospital staff were completely reliant on the family to communicate with the patient on their behalf. This, as the palliative care nurse highlighted, restricted their ability to assess and involve the patient.

### **Cognitive ability**

Another issue highlighted by the majority of professionals as affecting assessments, was patients' ability to understand what was being discussed. Professionals indicated that patients who were confused or who had diagnoses of dementia played more limited roles in the assessment process. For example, a G grade nurse stated:

*Nurse: "... most of our patients cannot participate in their, in their you know, be involved in sort of their care or their needs or whatever, so we just have to decide and do it for them, because if they are sort of just you know, confused or disorientated or got dementia or whatever"*

[Geninn6 110-114]

However, many professionals also stressed that cognitive impairment did not mean that patients should be denied choice, rather that patients should be involved as far as possible. For instance a senior house officer reflected:

*SHO: "... I think even people with quite severe cognitive impairment, I'd like to think I'd give them choice even if you take it into consideration with a lot of other factors, it gives them an idea of what's going on"*

[Genisho3 610-614]

Thus, professionals indicated that despite attempts to involve them, patients with cognitive impairments were likely to play more limited roles in assessments.

In practice, observational data indicate that patients with cognitive impairments could have a restricted role in the assessment process. Although patients with a diagnosis of confusion or dementia were excluded from this study, fieldnotes indicate how cognitively impaired patients on the study ward had limited roles. For example fieldnotes from a care planning meeting show how a man with a diagnosis of confusion was peripheral to the decision making process. The care planning meeting took place in the day room on the ward and was attended by a social worker, nurse and the patient's daughter and two sons. The patient was unable to get to the day room because of restricted mobility due to recent surgery.

*"It was agreed that [name - patient] was unable to care for himself, as he was at risk, i.e. leaving the gas on; putting an electric kettle on the gas etc. If left to care for himself, the family thought that he would go to bed and stay there. The family felt that they would be unable to cope with him, and would prefer a placement near them. They had seen a home that may be appropriate ... The social worker questioned whether he would meet NHS continuing care eligibility criteria. It was agreed that the social worker would contact the hospital's placement officer. The social worker and nurse concluded that [name - patient] was likely to need nursing as opposed to residential care. The social worker explained that the family would have to complete a financial assessment form, which would be reviewed by an independent person, then his case would be presented to the long stay panel..."*

...

*"The social worker explained that to fulfil statutory duties, the patient really ought to be included in the discussion, and his views sought. A discussion followed at the patient's bedside, with the daughter initially taking the lead, and asking her father whether he would like to come and live near but not with them, which he agreed he would, but he did not appear to fully appreciate the distinction between living near and living with. The social worker asked [name - patient] a series of questions about what he was able to do for himself. It was agreed that the family should start to look for a suitable nursing home placement."*

[FnJa0599 47-63; 75-87]

In this instance, the patient was only consulted after a decision about placement had been reached with his family and it was presented to him without allowing for consideration of alternative options, illustrating how patients with cognitive impairments could be marginalised from decision making.

### **Keeping things private**

Aside from issues of communication and comprehension, professionals also felt that some patients consciously restricted their interactions with them. Professionals indicated that they were aware that asking patients a lot of questions could be perceived as intrusive. They

reported that patients could be reluctant to divulge this information, some of it personal, to people with whom they were unfamiliar. For example, one nurse outlined:

*Nurse: "... remember that we're coming from a different generation, they don't open up to everything that you ask them, and they're very private, you know, and what we're really doing is intruding as well, so sometimes they don't want to answer every question that you ask them and they'll answer in the way that what they want to answer it, and you just, yeah, that's how things get missed"*

[Geninn7 363-369]

Interestingly, some professionals interpreted this withholding of information by patients as an attempt to hold on to their independence. They described how some patients were reluctant to admit to having difficulties coping and to accept services. For example one social worker stated:

*Social worker: "... we don't know the patients as much as the families or carers know them, there's always a long history behind some people, until you get such information, you are not going to make an accurate assessment because somebody can put on a front here, that things are okay, they're very well, he or she wants to go home but if you speak to other people who know before they will tell you that very often he get depressed, he doesn't want to do anything for himself, neglects himself ..."*

[Geninsw2 13-22]

Thus there was a recognition by professionals that patients may consciously withhold information to prevent intrusion into their lives or as a means of trying to retain their independence.

In practice, as highlighted in the general interviews, the patient tracking data indicated that patients could withhold information from professionals in order to protect their privacy. As a consequence some professionals felt that they had a limited knowledge of some patients. For example, in an interview about the continuing care assessment of a 77 year old woman, who had been very reluctant to be admitted to hospital, a senior house officer remarked:

*SHO: "I mean the main concern with letting somebody like her home is making sure that she is well enough in terms of her chest and that you know, she probably is quite hypoxic usually, and, but making sure that this is no worse than it should be and that she is managing the things that she says she can manage, but with somebody like her it is going to be very difficult because she doesn't let you really approach and chat about things and she, because she's so determined to get home, if we say, 'oh are you sure you can manage it?', she'll say, 'yes, yes, yes'"*

[Pt18idrh 366-374]

In this way, as highlighted in the general interviews, patient tracking data indicates some patients could be more difficult to assess because of their reluctance to share information.

### Patient passivity

Finally, particularly in relation to involving patients and informal carers, professionals stated that in some instances where choices were offered, patients were reluctant to indicate a preference, as they saw professionals as having more knowledge than themselves and as being the experts in their field. This reluctance to express an opinion could result in patients not getting support that best met their individual needs or in professionals acting as proxy decision makers. For example, a senior house officer highlighted the difficulty:

*SHO: "Well I'm sure that some of them [patients and informal carers] feel intimidated by the hospital environment and feel that, that they don't know best, that we know more than they do and I suppose that puts them off becoming involved"*

[Genisho4 191-194]

In addition, professionals indicated that patient involvement could be restricted by over zealous family or informal carers. Professionals stated that sometimes families or informal carers could be so anxious about a patient that there was a danger that their views may predominate. In this way, patients may be rendered passive and their involvement could be restricted. For example, a consultant outlined the potential problem:

*Consultant: "... I think often because people's relatives perceive, for example, things like residential home care as being safe, they will be trying to persuade their elderly relative that that's where they should be going even if that isn't really what the elderly person wants to do and I think a lot of the time we don't stand up for the elderly people themselves enough and I think it's very important that all of the members of the multidisciplinary team take into account that person's wishes first"*

[Genicon1 28-36]

Thus, professionals indicated that there was a danger that patients may not feel able to contribute to their own continuing care assessments.

In practice, patient tracking data indicated that, as outlined in the general interviews, patients' involvement in continuing care assessment could be limited as a result of their passivity. On occasions patients sat back as the assessment process went on around them. For example, at times during the care planning meeting for an 85 year old man, the only person who did not contribute to the discussion about his continuing care support was the patient himself:

*"The social work manager reading from the occupational therapy report stated that the patient couldn't manage upstairs or the kitchen or the living room downstairs, so he would be confined to 1 room. The ward social worker indicated that this was the discharge plan. The patient's daughter then summarised that her father had improved in hospital, but had had 2 falls and had now relapsed and lost confidence. But he had benefited from the physiotherapy. The ward social worker invited the nurse to comment*

*on this, and the nurse outlined that the patient was at risk of falling, but that he could take bigger steps when reminded to do so. The discussion then moved on to consider what adaptations the patient might need at home. The ward social worker indicated that everything would need to be in 1 room to minimise the risk, and that he would need a commode, she also enquired about whether the patient would wear a Piper alarm. The patient's son retorted that he would and that they would chain him to it if necessary ..."*  
[Pt10fn 459-489]

This illustrates that the concerns expressed by professionals in the general interviews about patient passivity were sometimes borne out in practice.

Thus, interview and observational data suggest that a range of issues relating to the behaviour or attributes of patients and informal carers could affect continuing care assessments and the involvement of patients and informal carers. These issues included communication and comprehension difficulties, as well as patients' reluctance to contribute either because they sought to protect their privacy or because they saw professionals as 'experts'.

## **PRACTICE ISSUES**

Findings from the general interviews and patient tracking data indicate that there were a number of issues relating to the way that members of the multidisciplinary team worked, both individually and collectively, which had an impact on the way that continuing care assessments were conducted. These issues relate to the way multidisciplinary meetings were conducted as well as to joint working outside meetings. In addition, a number of extraneous issues, which affected the way professionals practised were identified.

### **Medical domination in meetings**

During the general interviews, some professionals indicated that they thought that doctors dominated the weekly multidisciplinary meetings. They felt that this domination made it difficult for other members of the team to contribute to discussions about patients' continuing care needs. In this way there was a danger that decision making may not reflect all multidisciplinary perspectives. For example, a physiotherapist commented:

*Physiotherapist: "... the consultant shouldn't be doing all the talking, we should be doing more really"*

*KA: "Why do you think it is that the consultants do the talking"*

*Physiotherapist: "'Cos we, we don't, it's our, you know, they listen to me when I open my mouth, but if the nurse doesn't say anything, they're not going to, they'll just keep talking ... it's easier for them just to tell us what to do and say, 'home on Wednesday with this and this and this' and that's it. I think we just let them get away a little there, I know they listen when I speak up, to me, so, it's very rare that they actually ask you, but then if*

*you don't speak up and they just move on to the next patient, I think it's our fault always, we let them get away with it"*

[Geninph2 516-541]

In practice, fieldnotes from multidisciplinary meetings show that doctors always opened the discussions about individual patients. In this way they set the agenda for multidisciplinary debate. At times doctors could monopolise the proceedings. For example, discussions about the progress of an 85 year old woman were led by the consultant:

*"The consultant began by stating that this was a bright little lady, and that the nurses had done miracles on a circular lesion, and that they were getting improvements doing things that the district nurses were not doing. He said that they should let the ward nurses talk directly to the district nurse rather than going through the community liaison nurse. The G grade nurse replied that he had spoken directly to the district nurse. In response the consultant concluded that the patient could go home on Thursday, that she was a bright lady who had had an uncomplicated UTI"*

[Pt25fn 100-106]

However, other professionals often did contribute to multidisciplinary debate, although as highlighted in chapter 5, nurses made fewer contributions than social workers and other professionals allied to medicine.

In this way, there was a risk that unless professionals made a conscious effort to contribute in multidisciplinary meetings, decision making about patients' continuing care needs could be medically led.

### **Nurses' lack of understanding of their role**

In the general interviews with professionals, some indicated that they felt that nurses were unsure of their roles within the multidisciplinary team. There was a feeling that this uncertainty could be unproductive, and led to nurses trying to clarify their position. For example, a community liaison nurse argued:

*Community liaison nurse: "... I think nurses are very unclear then about what their role is and, so therefore they're, you know it's more important for them to take on that care management role, to try and co-ordinate what everybody else is doing and make sure that what everybody else is doing is informed by their nursing assessment of need is, which also links to what clients and carers are saying the need is, it's, again it's cultural change, but it's about finding some kind of realistic role for nurses on the ward, they, I don't, I think they're kind of sloshing about a bit trying to find themselves a role and 'cos they're not quite clear what it is, and I think that's why or where a lot of the problems arise from and they're not quite sure whose responsibility it is and they're not quite sure that they have the permission to do this anyway"*

[Geninln1 401-414]

Other professionals outlined that this lack of understanding by nurses about their role could have a detrimental effect on the assessment of patients' needs. For example, fieldnotes taken at the end of the general interview with a physiotherapist, after the tape recorder had been switched off, reveal:

*"After the interview with [name] she said that she thought that nurses weren't contributing because they didn't understand the relevance of their role or their purpose. By way of an example, she said that in a recent team meeting, there was a patient with very low blood sugars, and that she had been the one to mention it. When she had said this, the nurses had joined in and said, 'oh yes, the blood sugar was 3'. [Name] said that if she had not brought the issue up, the meeting would have moved on to the next patient. She said that this was an example of where nurses ought to be contributing."*

[Fnmr2699 5-12]

These findings from the general interviews highlight that a failure by nurses to understand their role could have potentially adverse consequences for the assessment of patients' continuing care needs.

In practice, in line with the physiotherapist's argument, the patient tracking data contains instances of nursing needs being discussed in meetings without nurses contributing to the discussion. For instance, during a multidisciplinary meeting the outcome of a patient's care planning meeting was reviewed by the team:

*"The senior house officer summarised that the patient had an adenocarcinoma of gastric origin, that she'd had a chest drain put in. He added that she had had a care planning meeting and he understood she was going for residential care. The social worker confirmed this. The senior house officer wondered if, in fact in view of her likely deterioration, she might need nursing home care and if that need might not be too far away. The social worker commented that the home chosen was dual registered. The consultant indicated that this was excellent, as it would be a pity for the patient to go to a home and have to move straight away."*

[Pt26fn 682-692]

In this case, although the discussion revolved around the patient's potential need for continuing nursing care, the E grade nurse present at the meeting made no comment about the appropriateness of the proposed placement.

Thus, the patient tracking data suggests that nurses may not fully understand their role, and that as a consequence, patients' continuing care assessments may be impaired.

### **Limited contribution in multidisciplinary meetings**

When asked in the general interviews about nurses' contributions to multidisciplinary decision making, several professionals indicated that they felt nurses were not assertive in these

meetings. There was a concern that, if nurses were passive, decisions may be made with incomplete information or that a limited range of options may be considered. Thus, there was a feeling that nurses ought to be more forthright in their opinions. For example the hospital's discharge nurse observed:

*Discharge nurse: "... nurses tend to just go with what everybody else says, but I want them to be more, basically outstanding and say, 'yes, I'm happy for this patient to go home' or, 'no, I'm not happy with your decision'"*

[Genindn 209-212]

Moreover, professionals indicated that when nurses were assertive in multidisciplinary meetings their contributions were not always sufficiently analytical. As a consequence there was a sense that nurses could have a restricted influence on decision making. For instance a community liaison nurse commented:

*Liaison nurse : "... if nurses are going to contribute, they have to be able to take the information from the care plan, take out the key points of their observations, their assessments, their, their understanding of what this patient actually needs in terms of care, and be able to kind of summarise that down into a report that can be given, in, or fed into the multidisciplinary planning process, and it just doesn't happen. They will give again very factual information that they have read from a kardex, which is about whether they slept well or whether they are walking with one person or two people, which I suppose is relevant, but you know, there's got to be more insightful stuff or otherwise it, it's not very relevant and easily gets dismissed, and I'm sure that's why we've got to the stage we've got, because the information that they have been feeding in hasn't been thought through and hasn't been focused on a professional opinion around what this person needs, it's been dismissed out of hand, and people have got so used to it being dismissed out of hand that they don't volunteer it now"*

[Geninln1 245-262]

In this way professionals suggested that there was a danger that multidisciplinary continuing care assessments may be limited because of a particular failure on nurses' part to contribute considered professional opinions.

In practice, whilst nurses did make contributions to multidisciplinary meetings that were recognised as being significant, there were also some occasions within the patient tracking data in which their responses could appear ill thought out. In these instances their influence was limited and decisions about patients' continuing care needs were made without the full involvement of all members of the multidisciplinary team. For example, during the care planning meeting for an 94 year old woman the senior house officer had just concluded that, in his opinion the patient needed nursing home care. The social worker then asked the nurse for her opinion:



*“The nurse replied that the patient could do everything for herself, she was walking with a zimmer frame without support, she was eating independently, and when she was short of breath, she stopped to rest”*

[Pt26fn 554-556]

In this instance the nurse outlined some of the patient’s functional abilities, without using these to form an opinion, as requested, about the most appropriate form of continuing care for the patient.

In this way, multidisciplinary assessments could be restricted because of the limited contribution of nurses.

### **Lack of reviews of multidisciplinary meetings**

In the general interviews conducted with multidisciplinary staff, the issue of reviewing the practice of multidisciplinary meetings was raised. There was a concern that reviews were not undertaken and therefore opportunities to seek to improve practice were missed. As a result of these missed opportunities, there was a feeling that the conduct of multidisciplinary meetings became routine in nature. For example, a social worker outlined how reviews had promoted good practice in his previous employment and the effect their absence had on team working:

*Social worker: “... what I did in the past is in [name - town], there was what we call community care meetings, sometimes we had lunch, it was in the canteen, on each ward we asked the sister, the nurses to come, the occupational therapist to come, sometimes the team leader went, two social workers, we went there and then talked about what was the critical thing that was eating everybody, so every three months we met, but there is nothing like that, just a meeting that is conveyed just to discuss with others, the sister, is it functioning properly or not, I’ve never seen anything here like that, so we carry on, we plod through the system”*

[Geninsw2 240-249]

In this way, assessments could be limited because of a failure to review the way that multidisciplinary meetings were conducted and to ask professionals how practice could be made more effective.

During the fourteen month period of data collection, I was never aware of any reviews being undertaken of the way multidisciplinary meetings were conducted. No fieldnotes, or formal or informal discussions with staff ever indicated that any reviews had taken place or were planned in the future. In addition I was not aware of any documentation suggesting that the conduct of meetings ought to be reviewed. Thus, there was a risk that assessments could be limited because of a failure to develop multidisciplinary practice further.

### Lack of collaboration between professionals

When questioned in the general interviews about the way that they worked together, some professionals indicated that disciplines had their own areas of expertise and that individuals could be protective of what they saw as their own professional territory. In this way assessments could be impeded because of a lack of collaboration between staff. For example, a D grade nurse highlighted how multidisciplinary professionals tended to practice individually rather than collaboratively:

*Nurse: "... I still walk a patient that's had a stroke but I wouldn't get too much into the physio bit, because to me I would be treading on the physio's toes"*

*KA: "Right"*

*Nurse: "And I might get her all upset, same with the speech therapist I would observe and do everything that they said, sit the patient up 90 degree and everything, but I would never take it on myself to go and get too involved in it because I don't want to upset anybody, I might be capable of doing whatever, but I just wouldn't, I just wouldn't do it"*

*KA: "Yeah"*

*Nurse: "You know, because I just did it yesterday and I got into a whole load of trouble [laughter] so I just, this is what I'm saying, you know you don't, there's a fine line and you just better not cross it because you'll get people upset and, and that's the way I'm, no that one is a very hard question, but I stick to my, to what I, I think is nursing and let them stick to their bit"*

[Geninn7 479-495]

Thus, a fear of upsetting colleagues could impede individual practice and therefore affect the assessment of patients' needs.

In practice, fieldnotes indicated that although professionals occasionally collaborated, such as social workers going on home visits with occupational therapists, there were several instances when occupational boundaries were apparent. For example, an F grade nurse related how she noticed that a patient was struggling to get washed and dressed and referred her to the occupational therapists for assessment:

*"I asked the nurse why she was having an assessment by the occupational therapist. She said that it was because she was not very good at it. .... She said that she had made the referral, because the OT could give hints, such as putting in the affected limb first when dressing, and implied that OTs had greater expertise in this area than nurses".*

[Fnja2098 115-123]

In this case the nurse evidently saw the assessment of patients' washing and dressing skill as the province of occupational therapy.

Thus, in practice, the presence of occupational boundaries may have made some professionals hesitant about conducting aspects of assessments of which they were capable, with the ensuing risk of greater fragmentation and delay for patients and a lack of professional development for staff.

### Lack of time

The issue most frequently cited by professionals as affecting the way in which they both conducted continuing care assessments and involved patients and informal carers was that of time. Professionals in all disciplines commented that a lack of time impeded their ability to conduct assessments as comprehensively as they would have wished to do. For example, a nurse highlighted how limited time could impede patient and informal carer involvement:

*Nurse: "... we haven't got much time to actually sit down like we used to and, I don't know give more, be able to communicate more with the relatives then this is why you know, there's a sort of breakdown really with the information you know"*

[Geninn7 141-144]

Moreover there was a feeling that time pressures were accentuated by low staffing levels. Several professionals commented that they felt that there were not enough staff working in their areas for them to be able to practice in the way that they wished. They stated that the effect of this was that patient involvement was restricted. For example, a senior house officer reflected:

*KA: "Are there things that inhibit involvement?"*

*SHO: "I think lack of time does, I think that's quite a valid factor, lack of time and a lot of patients does inhibit patient involvement because there simply is not the staff to, to ask patients what is required and, I said it's more tell them rather than ask them and I, I think that's a real problem but it is an age old problem, lack of time, lack of staff"*

[Genisho2 333-339]

Thus, professionals indicated that time pressures impeded their assessments and in particular, their ability to involve patients and informal carers in the assessment process.

In practice, it was evident that at times staff were especially busy and that the pressure that this caused may have affected the way that assessments were conducted. For example fieldnotes indicate that during the nursing admission of an 85 year old man, who was hard of hearing, the patient was effectively excluded from this initial assessment:

*"The ward was busy, with a lot of activity going on, when the patient arrived from the receiving room. ... The agency nurse had the basic data collection sheet, and collected this information from the patient's daughter, whilst an auxiliary nurse did the observations and name band. He also took a nasal swab for MRSA screening with no*

*prior explanation for the patient, who recoiled. It had also been established from my struggles with consent that the patient was very hard of hearing. The patient had a thermometer in his mouth when the initial information giving was going on, so could not have contributed even if he had been able to hear, there was also loud background TV noise. ...”*

[Pt10fn 12-20]

In this instance, it is possible that time pressures may have contributed to the agency nurse not attempting to involve the patient in her assessment. In this case obtaining information from the patient’s daughter may have been a more expedient way of completing the task.

Thus, it is possible that a lack of time, as highlighted by professionals, may have impeded their assessments and especially the involvement of patients in this process.

### **Poor knowledge**

Another area highlighted by professionals that they saw as affecting the way that they participated in multidisciplinary assessments, and involved patients, was their degree of knowledge. Several professionals stated that they felt that they lack knowledge about the process of assessment and about the continuing care services that may be available to patients on discharge from hospital. This lack of knowledge could lead professionals to withdraw from multidisciplinary discussions as they did not see themselves as being sufficiently informed. For example, a D grade nurse described how decisions about continuing care services were made:

*Nurse: “... it really does depend on what vacancies, and very often it is said the patient is more suited to that home as opposed to that home and because I haven’t done much work on the district, I haven’t worked in this area and I haven’t worked recently, I don’t really, you know what I mean, I don’t question it, you know what I mean I just concentrate on writing what I’ve got to write as a nurse in the book”*

[Geninn8 371-377]

In this way, professionals indicated that on occasions when they perceived that they did not have sufficient knowledge, they could withdraw from multidisciplinary decision making.

In practice, it was sometimes evident during the interviews with staff focused around the twenty patients who were tracked, that they sometimes dissociated themselves from decision making. At times staff described decisions as being made by other people, and they were vague about the criteria on which these decisions were based. For instance a D grade nurse outlined how a decision to transfer an 82 year old woman to nursing home care had been taken by others, hinting that she was unaware of the application of specific eligibility criteria in this decision:

*KA: "How the was the decision made for her to go there [nursing home]"*

*Nurse: "Well they had a care planning meeting and the daughter felt that she wasn't able to cope at home any more, so they had a care planning meeting with the district nurse, the physio, the OT, social worker the doctor, everybody and they decided that she wasn't able to manage at home any more, but even if they had given her a full package, with everything she wasn't able to manage so the next move was to consider her for nursing home because she needed nursing input"*

*KA: "What kind of nursing input specifically did she need"*

*Nurse: "For washing and dressing, and for doing her dressing and for transferring from bed to chair"*

....

*Nurse: "It's more the decision of the family and the doctors, the nurses can only say, but we don't really have a say where she goes"*

[Pt12inn2 128-137; 163-164]

In this way, professionals may not get involved in multidisciplinary decisions about patients' continuing care in instances where they feel that they have insufficient knowledge. There is an associated risk, that decisions that ought to be multidisciplinary in nature may be made by individual professionals or by a limited number of staff.

#### **Lack of support for autonomous practice**

In the general interviews, some professionals commented that nurses' role in multidisciplinary assessments was affected by their degree of autonomy. Significantly, no interviewee mentioned autonomy as having an effect on the role of members of any other discipline. However, there was a feeling that nurses were not encouraged to behave autonomously and that consequently they found it difficult to express individual opinions. Moreover, one professional indicated that she thought that this may have been accentuated by nursing's traditional role in relation to medicine. She stated:

*Physiotherapist: "I don't think they [nurses] were ever trained to understand, to think in a certain way, yes, about this planning and about as you say, but some of them are excellent you know, they've grasped everything [pause] but I think maybe the nurses have had a different role as well, that they wait for the doctors to tell them what to do with the drugs and etcetera, or the drip, or the dressings or whatever, but I would, the physios have never worked that way, so we tend to run around and do our own thing and be our own boss and not follow what the doctor says [laughter], and make up our mind what to do, I think it's a totally different concept isn't it really, different training"*

[Geninph2 351-361]

Moreover, other professionals thought that it was not just nurses' training that had an effect on their autonomy, but also the amount of managerial support available after qualification.

Without support for autonomy, it was felt that nurses could have a more marginal role in multidisciplinary decision making. For example, a consultant highlighted a perceived shortfall in managerial support and the effect it could have in terms of nurses' practice:

*Consultant: "I mean there was, there was a tradition of, you know, nurses doing as the senior nurses said, but no-one actually being interested in development or education, I mean this is still a Trust wide problem, as far as I know no senior nurse manager takes any interest in their ward staff and they never meet them unless there's a problem, they come up here when there's a crisis and I don't think that the best and modern ideas in nursing are ever going to filter through unless you actually have someone that's prepared to do that ... at the end of the day if you don't actually have senior nurses who actually know their wards and know their staff and actually be, so that they don't just come in whenever there's a crisis ... what use is that for actually promoting people to be autonomous"*

....

*"I don't think there's a tradition of being autonomous here and thinking for yourself, I still felt when I came here just over a year ago and would turn round to say to them [nurses], 'well what do you think, have I got this right or am I talking rubbish?', and I will do that quite often during the ward round, you know, some of them would just look to me thinking, 'is she trying', I could just see it going through their heads you know, 'is she trying to catch me out?'"*

[Genicon2 340-357; 317-324]

In this way, professionals highlighted that they felt that a lack of support for autonomy could impede nurses' involvement in multidisciplinary continuing care assessments.

In practice, it was evident that support for nurses had recently been reduced. At the beginning of the data collection, during a discussion with a nurse manager, she revealed the extent of the cuts. Fieldnotes indicate:

*"The manager mentioned that all the 'H' grades had recently been abolished to produce financial savings, with the staff either being redeployed or made redundant. As the manager spent some of her time off site, this meant that ward sisters sometimes had no on-site senior manager."*

[Fufe1998 85-88]

Moreover nurse managers were often spoken of in unfavourable terms by ward staff, who saw them as an obstacle, creating work rather than supporting them. For instance, the comment made by one of the ward nurses was typical:

*"[Name] was resentful of them [managers], and said that he wished that they would stop bothering him, he said that the bigger their title, the less they did adding that he could sit at the end of the bed and chat to patients and fill in forms, suggesting that he saw this work as not legitimate."*

[Fufe1098 106-109]

The findings therefore suggest that a lack of support for autonomy may impede nurses' contribution to multidisciplinary continuing care assessments.

## Low morale

A further factor mentioned by some professionals as affecting practice was that of morale. It was felt that low morale could negatively affect professional practice. Again, as with the lack of support for autonomy, low morale was only mentioned in relation to nurses. For example, a community liaison nurse outlined that in her opinion, this, in conjunction with other factors, was bound to have an impact on nurses' role within the multidisciplinary team. She stated:

*Community liaison nurse: "... where there's low morale, there's little support, and little vision about what it is we're trying to do, there's you know, it feeds, it doesn't feed down into kind of assertive, knowledgeable practitioners, who, who feel able and willing to give of their opinion, their professional opinion"*

[Geninln1 417-421]

An additional factor that could have contributed, particularly to nurses' low morale, was the threat of ward closures:

*Consultant "... there are things that make a danger, I think instability is a big one and actually when everybody's jobs were under threat last winter I mean you know, you can't start sort of planning as to what kind of care you'd like if you don't actually know the ward's going to be there"*

[Genicon2 596-600]

Thus there was a sense in which low morale was perceived as a threat to the operation of the multidisciplinary team.

In practice, from fieldnotes it was evident that, at times, nurses felt demoralised. For instance when discussing the 50th anniversary of the NHS with a D grade nurse, she responded by stating that:

*"it was going down the pan"*

[Fnfe0598 59]

Moreover there was a sense that low morale could affect the way that nurses practised. Nurses talked about 'nothing ever changing' and of an acceptance of 'the system'. Even when nurses had ideas about potential improvements they stated that they felt impotent to initiate change. For example, a D grade nurse commented:

*Nurse: "... it's just the way that the things are, they can be put in a different way, but, that's that, what else can I say, I think there's a lot, there's a lot of changes that would be better, especially in care of the elderly but like I said, it's, I, I feel as though I don't have the strength or that to say anything to anyone because they don't listen"*

[Geninn7 179-185]

In this way, low morale and instability could affect multidisciplinary practice.

Findings from the general interviews and evidence from fieldnotes and the patient tracking data indicate that there were a number of practice issues, including those relating to multidisciplinary meetings and interprofessional collaboration, as well as various extraneous factors that were seen to have an impact on the way continuing care assessments were conducted.

### **SUMMARY**

The previous findings chapters showed nurses' marginal position in continuing care assessments and highlighted how they failed to facilitate the involvement of patients and informal carers in this process. This chapter summarises some of the contextual issues which need to be considered when reviewing the nurse's role within the multidisciplinary team in involving patients and informal carers in continuing care assessments. These issues naturally emerged in the course of the study and will be taken into account when discussing the theoretical perspective as to why nurses are not fulfilling their role. These issues include strategic issues (policies restricting choice, limited health and social care budgets and restricted services available), patient and informal carers issues (communication difficulties, cognitive ability, keeping things private and patient passivity) and practice issues (medical dominance in meetings, lack of understanding of the nurse's role, limited contribution in multidisciplinary meetings, lack of reviews of multidisciplinary meetings, lack of multidisciplinary collaboration, lack of time, poor knowledge, lack of support for autonomous practice and low morale).



## **CHAPTER 8**

### **THE WAY FORWARD: DEVELOPING EXPERTISE**

#### **INTRODUCTION**

This chapter discusses the findings that were presented in chapters 5, 6 and 7. The discussion centres around the finding that nurses appeared to have limited involvement, both in continuing care assessments, and in promoting the involvement of patients and informal carers in this process. The chapter begins by discussing the strengths and weaknesses of the study before going on to outline the senses framework (Nolan et al., 2002) that may help to explain why the nurse's role appeared to be so limited. The findings of the study are discussed within the context of this framework. The extent to which the data fit Nolan et al.'s framework is reviewed and suggestions made as to how the framework could be further developed. Finally, conclusions are drawn and recommendations made for research, education and practice.

#### **STRENGTHS AND WEAKNESSES OF THE STUDY**

One of the most remarkable features of the field of continuing care assessments is how rapidly the policy has changed over recent years. Developments which are particularly worthy of note include documents outlining the NHS' responsibilities for meeting patients' continuing health care needs (Department of Health, 1995); the development of eligibility criteria by health authorities; the introduction of a Single Assessment Process (Department of Health, 2002a) and the requirement for nurses to assess the Registered Nursing Care Contribution for patients entering nursing home care (Department of Health, 2001a). This rapidly changing policy context provides the opportunity to highlight how practitioners are adapting and the challenges that remain. This is significant in an area which has a politically high profile and in which there is a dearth of studies, and none that have explored, in as great a depth as this one, multidisciplinary roles in assessing patients with a range of continuing care needs.

This exploration was facilitated by the choice of methodological approach. As, the aims of the study were to explore individual experiences of continuing care assessments and of involving patients in this process, the development of an understanding of these experiences necessitated the examination of assessments in rich contextual detail. The use of a case study approach allows the exploration of such a 'naturally occurring case', in a way that would not have been

possible using an experimental or survey design which both place a high priority on the quantification of data. Thus in employing a case study approach the perspectives of individuals were able to be explored in the degree of detail, which was vital to obtain an understanding of the assessment process. Although Yin (1994) highlights that case studies have been criticised for both a lack of rigour and for the potential difficulties that may be encountered in applying the findings to other settings, these issues have been addressed in this thesis. The issue of rigour was addressed in chapter 4, with in-depth descriptions being given of the measures taken to establish the validity and relevance of the study. The potential problem of generalizability was also discussed in chapter 4, and is summarised at the end of this section on strengths and weaknesses of the thesis. Thus, the use of a case study approach facilitated the exploration of the nurse's role in involving patients in continuing care assessments.

An additional strength of this study is that by adopting a multidisciplinary focus, insights into the broad context in which assessment is conducted could be obtained. Moreover, by following patients through their hospital stay and after discharge into the community, this study reflects the ongoing nature of continuing care assessment, rather than seeing it as a single event. This is particularly important as continuing care assessments are frequently fragmentary and may be conducted over several weeks or months by numerous professionals (Hunter et al., 1993). By focusing on assessment as an ongoing, multidisciplinary process this study adopts a holistic rather than partial view of the assessment process.

One of the notable features of the research in this field is how few studies make use of observational methods. Instead, researchers have tended to rely on the use of questionnaires or interviews. These have the associated drawback that participants wishing to present themselves in a favourable light may relate what they feel ought to occur rather than what actually happens in practice (Robson, 1993). In this study observation provided a means of overcoming this potential problem of 'social desirability response bias' by allowing access to practice as it occurred. In this way it was possible to observe the everyday practice of professionals as they conducted continuing care assessments and involved patients and informal carers in this process. However, there were also disadvantages with using this approach, one of these being that, as a lone researcher, there is a limit to what can be observed. In particular, observation of concurrently occurring events, or those which took place at unpredictable times, proved problematic. Whilst it was not possible to observe all events of potential relevance, the use of interviews and documentary evidence in conjunction with observational methods facilitated the development of detailed insights into the study environment.

Participant observation was facilitated by my background as a nurse. The initial period of working alongside staff as a participant observer was important in identifying key decision making points in the assessment of patients' continuing care needs. However, it was whilst working alongside nurses that I came to be identified by the multidisciplinary team as a member of this particular group. Occasionally, during interviews with team members I observed a reluctance to be seen to be too critical of nurses. Thus at times professionals may have described nurses' practice in a more favourable way, than if they had not been aware of my professional background. This makes the finding that nurses were marginal to continuing care assessments particularly remarkable.

As a result of the insights obtained, it has been possible to suggest why nurses may not have been central to multidisciplinary assessments. Previous studies conducted in the field have presented research findings without offering theoretical explanations that may account for the reported results. Without the development of such theoretical understandings it is particularly difficult for researchers to make recommendations for education or practice with any real degree of confidence. In this way, this study facilitates the development of more robust recommendations that seek to enhance the quality of care received by older people.

Findings from this study are presented in rich contextual detail in order that the reader can judge the relevance of them to their own practice situation (transferability). However, care should be taken not to dismiss the findings of this case study on the basis of them being context bound. Many of the findings are supported in the literature, which suggests that they were generated from a context that was by no means unique. Furthermore, the findings are likely to have wider implications beyond the "care for older people" context. For instance, the research was conducted in a care of the elderly unit where multidisciplinary teamwork is thought to be more highly developed (Department of Health, 1996a; Audit Commission, 1997) and yet the practice of multidisciplinary continuing care assessments was found to be poor. This potentially raises the question of the effectiveness of multidisciplinary continuing care assessments in other areas where multidisciplinary teamwork is thought to be less well developed (e.g. on general medical and surgical units). Although findings should be approached with caution, they should certainly not be ignored. Indeed it could be argued that this study adds to the body of theoretical knowledge, not only by providing empirical data to support Nolan et al's (2002) senses framework, but also, by generating a new theoretical perspective through the addition of a new sense (expertise) to this framework. In so doing, it moves beyond the weakness identified in many field studies of lacking a theoretical perspective (Bengston et al., 1997).

## **SUMMARISING THE MAIN ISSUES FROM THE FINDINGS**

The findings of this study indicate that nurses and other members of the multidisciplinary team may not perceive the assessment of patients' continuing care needs to be integral to the nurse's role. In the general interviews members of the multidisciplinary team expressed concerns about what they saw as nurses' limited views of their own role in assessments. In these interviews, nurses' uncertain and hesitant responses to questions about how they conducted assessments tended to confirm these views. These findings are remarkable given the significant policy changes that were taking place in assessment at the time that the fieldwork was undertaken and the political importance of the subject. As key front line staff, policy makers saw nurses as being important contributors to multidisciplinary assessments of patients' continuing care needs (Department of Health, 1995). Yet, these findings concur with those of other studies e.g. Lowenstein and Hoff (1994) in suggesting that this may not be how nurses see themselves. Observational data indicated that the identification of continuing care needs was not of particular importance to nurses. Instead, observations revealed that nurses seemed overly concerned with the sequential completion of assessment documentation. Moreover, when asked, in the patient focused interviews, about how decisions were made about the continuing care needs of individual patients with which they had been involved, nurses often stated that these decisions had been made by other multidisciplinary professionals such as doctors or social workers. In stating that they had deferred decision making to others, nurses were clearly dissociating themselves from this process. Thus these findings support the work of authors including Roberts (1975), Arenth and Mamon (1985) and Waters (1987). The studies by Arenth and Mamon and Waters both found that that nurses do not accurately identify patients' continuing care needs, whilst in interviews with 16 ward sisters, Roberts reports that they placed a relatively low priority on the importance of patients' well-being after discharge. The lack of change over this time period is especially notable and highlights the need to understand why nurses practice appears not to have developed despite political and professional pressures.

For policy makers these findings must be of concern. They suggest that if nurses fail to contribute to multidisciplinary continuing care assessments then they may experience even greater difficulties with the single assessment process. The single assessment process marks a move away from serial assessment by several multidisciplinary professionals, with the intention that patients are asked fundamental questions about their circumstances just once. Thus it becomes imperative that when nurses assess patients using this process that they are able to identify effectively patients' continuing care needs.

The findings from this study also suggest that, although members of the multidisciplinary team may perceive nurses as having a role in involving patients and informal carers in continuing care assessments, as yet nurses do not appear to do this. It is interesting to note that, whilst in the general interviews some nurses indicated that they sought patients' and informal carers' opinions, other members of the multidisciplinary team saw nurses' acquisition of knowledge as a passive process, with patients often initiating discussions. In addition, observational and interview data from tracking the twenty patients supports the suggestion that nurses fail to involve patients and informal carers. Nurses only stated twice during patient focused interviews that they had asked patients about what they wanted on their discharge from hospital. Again, it is notable that nurses' apparent failure to seek the views of patients and informal carers has long been identified in the literature. For example, Skeet (1970) reports that nurses ask few patients about how they would manage on returning home from hospital. Similarly Bowling and Betts (1984) found that limited consultation with patients impaired the assessment of the individual needs. It is therefore surprising that this study's findings suggest that nurses' practice may have changed very little in the intervening period, in spite of substantial policy shifts. For example, the government in its policy document, 'Better Services for Vulnerable People Maintaining the Momentum' (Department of Health, 1998) emphasises that assessments ought to value older people's priorities. It states:

*"Assessments must value the life choices that users have made and wish to make for themselves."*

(Department of Health 1998: Annex C)

This study's findings suggest that, in the light of their lack of knowledge of individual patients, nurses are likely to find it difficult to ensure that assessment outcomes are consistent with older people's life choices.

Moreover, nurses made no claims to provide patients with information beyond factual details about ward routines. This was borne out by observational and patient focused interview data which revealed only very isolated incidents of nurses providing patients and informal carers with information or advice about continuing care support. Yet, policy recognises that in order for older people to make appropriate choices about their own continuing care, information ought to be routinely available to them (Department of Health, 1996a). Thus it appears as though nurses have some way to go before their practice matches policy objectives. This has potentially significant consequences for older people and the degree of influence that they and their informal carers are able to exert over the assessment process.

The findings of this study also suggest that there may be barriers to continuing care assessments and the involvement of patients and informal carers in this process. These barriers appeared to fall into three broad categories, namely; strategic issues, patient and informal carer issues and practice issues.

Strategic issues refer to policy and resourcing factors including government regulations and legal boundaries which restrict professional practice. In the general interviews professionals identified a range of strategic issues which they thought affected the degree of patient involvement in continuing care assessments. The issues raised included assessment procedures, the application of eligibility criteria and the range and amount of continuing care provision that was locally available. Observation suggests that all of these issues may indeed have had a bearing on patients' and informal carers' involvement.

Study data also suggest that the practice of continuing care assessments and the involvement of older people could be inhibited by patient and informal carer issues. These attributes included communication difficulties, cognitive impairments and a reluctance to share information due to concerns to protect personal privacy. In addition some patients and informal carers appeared to view professionals as the experts and therefore did not perceive themselves as having a legitimate input into the assessment process.

Finally, the findings indicated that a number of practice issues seemed to affect continuing care assessments and patient and informal carer involvement. These practice issues included factors relating to the conduct of multidisciplinary meetings, the degree of collaboration between professionals and other factors such as morale and time pressures.

Whilst the professionals in this study may have had a limited ability to overcome strategic barriers, such as the availability of local services, that influenced continuing care assessments, this was not the case in relation to some other factors affecting assessments. This is particularly true when considering the barriers presented by the attributes of patients and informal carers themselves, such as communication difficulties. The findings of this study indicate that whilst professionals may have been aware of the possible negative affects of these attributes, they did not always take action to compensate for these effects and to support older people's involvement. Unless professionals do take action, including making more use of interpreting services and encouraging patients and informal carers to take a greater role in decision making, there is a danger that some older people will continue to play marginal roles in decision making

about their own continuing care needs. These findings suggest that there is still be some work to do before the government's aspiration that, 'NHS and social care services treat older people as individuals and enable them to make choices about their own care' (Department of Health 2001: 23), can be deemed to have been met.

The next section discusses the application of a theoretical framework that may account for these findings, and in particular for the differences in the roles of individual disciplines in the assessment of patients' continuing care needs. It may also help explain why nurses' practice appears to have changed so little over the past 20 years in spite of significant political and professional developments.

### **PRE-REQUISITES FOR EFFECTIVE PRACTICE: FOCUSING ON 'THE SENSES'**

The theory that resonates most strongly with the findings of this thesis and appears to further understandings about why nurses seemed to have a marginal position within multidisciplinary continuing care assessments is that of Nolan et al.'s (2002) senses framework. More particularly, and relating directly to the aims of the study, the framework may further understanding of why, in contrast to doctors and social workers, nurses had little role in both the assessment process and in involving patients and informal carers. If the issues within the framework which suggest why nurses' practice may have been inhibited are addressed, then older people's involvement may be facilitated. The key recommendations listed at the end of this chapter highlight the main areas where change may be required if improvements to continuing care assessments are to be brought about. These changes may significantly improve the experience of assessment for both patients and their informal carers.

The senses framework was developed in response to a concern about the lack of a therapeutic rationale for work with older people in long term care settings. They argue that too little attention has been devoted to what older people themselves see as constituting a good quality of life (Nolan et al., 2001a). Indeed, Nolan (2000) makes the case for 'person-centred' care, which recognises individual perspectives and requires that service providers reflect older people's aspirations. Nolan et al. (2001a: 16) state that, whilst they recognise the importance of structural aspects of ageing, the senses framework represents a deliberate attempt to incorporate, 'the subjective and perceptual nature of the important determinants of care'. Moreover, they argue that there is now enough agreement on what constitutes a 'good life' in older age from a subjective standpoint for the senses framework to provide a degree of analytic generalizability. Thus the framework may help inform service developments across a range of

care environments. However, they also argue that high quality care is unlikely to be both achievable and sustainable unless staff enjoy and value their work. Thus they suggest, that to be useful, it was important that their framework incorporated the perceptions of staff and proposed ways in which work with older people could be accorded greater status and value. Taken together, the senses that make up the framework outline the subjective perceptions which appear to underpin the delivery and receipt of good quality care (Davies et al., 1999). In this way the senses framework is intended to both improve the care received by older people themselves and to provide a direction for staff. Succinctly, Nolan et al. (2002: 14) describe the framework as an attempt to identify, 'an epistemology of practice' or in layman's terms 'the fundamentals of care'.

Drawing on the work of Kitwood (1997), Nolan et al. (2002), conclude that practice with older people may best be developed by moving towards relationship-centred care. Nolan et al. (2001b) argue that, as relationships are crucial in determining most people's quality of life, more attention should be devoted to relationships within health care. This includes the relationships that practitioners form with patients, informal carers, communities and each other. Davies and Nolan (2003) state that the senses framework provides a logical framework for implementing this emerging philosophy of relationship-centred care. By focusing on the subjective elements of care, good practice may be facilitated and effective relationships developed.

The framework comprises six 'senses', namely; a sense of security, a sense of continuity, a sense of belonging, a sense of purpose, a sense of achievement and a sense of significance. Each sense contains sub-sections which give definitions of the sense in relation to older people, staff and family carers. In this way, the definitions vary according to the group concerned. Each of the six senses and their sub-sections are outlined in the discussion of the framework in relation to the findings of this study.

Nolan first presented his work on the senses in 1997, (Nolan, 1997). Since 1997, the senses framework has been developed from Nolan's initial construction in two studies. These studies are the 'Dignity on the Ward' report (Davies et al., 1999) and the AGEIN project (Nolan et al., 2002), which explored how effective education was at preparing practitioners to meet the needs of older people and their informal carers. In addition it has informed a pilot project exploring the development of a teaching nursing home (Davies et al., 2002). The initial phase of the AGEIN project involved a comprehensive literature review in six key areas, which added support for the senses framework, these key areas being; acute/ rehabilitative care, primary



care, continuing care, older people with mental health problems, older people with learning disabilities and palliative care and older people. This review identified an emerging consensus within the theoretical literature that to improve quality of life in older age more attention needs to be paid to the individual values and perceptions of older people themselves. This consensus supports the senses framework's focus on the subjective elements of ageing. In addition Nolan et al., (2001a) argue that the senses framework is supported by data from some empirical studies. The authors cite in particular the work of Redfern and Norman (1999). Whilst Redfern and Norman do not explicitly use the senses framework, their findings that a therapeutic ward atmosphere, therapeutic relationships in patient care and attention to emotional needs were seen by both patients and nurses to be indicators of high quality care are consistent with the key principles identified in Davies et al.'s (1999) study in which the framework was empirically tested. In addition to being empirically tested by Davies et al., the senses framework has also been empirically tested by Nolan et al. (2002) in their exploration of the effectiveness of educational preparation to meet the needs of older people and their carers. In both studies modifications were made to the framework in the light of the findings. It is important to point out that whilst the authors state that they believe that the major dimensions of the senses framework are robust and reflect important parameters of good care, they also state that the framework may not necessarily include all potential subjective components (Nolan et al., 2001a), and that there remains much to explore (Nolan et al., 2002). This indicates the need for further empirical research that uses the framework. This study makes an important contribution to understanding in this area.

Despite Nolan et al.'s (2002) caution, the findings of this study appear to support their contention that the presence of the senses may enhance care and that in their absence care may be deficient, as will be shown. Thus the promotion of effective practice by facilitating the development of 'the senses' within professionals, is one of the key recommendations of the thesis, which are listed at the end of this chapter.

In particular, the lack of a sense of purpose and the lack of a clear understanding of what was expected of them appeared to impair nurses' ability to conduct continuing care assessments. Changes in this area are also listed in the recommendations. This fit between the findings of this thesis and the senses framework provides additional empirical support for the framework. This is significant as Nolan et al. (2002) stated that further investigation of the framework was required. Thus the additional empirical evidence from this study gives added support to the robustness of the framework. Moreover, the fact that, within this study, the framework has been applied in new context (i.e. the examination of continuing care assessments within the

multidisciplinary team) suggests that it may have a wider applicability beyond those investigated by Davies et al. (1999) and Nolan et al. (2002), and that it may be relevant to a broader range of practices and care environments.

In addition, it is significant that the senses framework has not been used to focus on the practice of the multidisciplinary team. The two previous studies, whilst drawing on multidisciplinary perspectives, have used the framework as a basis to explore how to promote high quality care for older people (Davies et al., 1999), and to look at the educational needs of practitioners working with older people (Nolan et al., 2002). Importantly in this thesis the senses framework is applied to the key practitioners involved in patients' continuing care assessments (nurses, doctors and social workers). In this way it is possible to identify differences between the disciplines and to highlight where change may be needed within the team. Moreover, by applying the framework to the practice of multidisciplinary professionals it is possible to examine how one discipline's lack of 'senses' may affect the rest of the team. Professionals' need for a greater awareness of the ways in which their practice has an influence on other members of the team is also recommended.

In applying the findings of this study to the senses framework, it became apparent that there was a body of data that did not fit and which remained outside the framework. On reviewing the remaining data it appeared as though it may be important in understanding the practice of professionals. The fact that this could not be accommodated within the senses framework suggests that the framework may be incomplete. Thus, by applying the findings of this study to Nolan et al.'s framework, a possible seventh 'sense', may have been identified, this being a sense of expertise. However, it should be stated that further empirical research is required to establish the robustness of this 'seventh sense'.

In the next section the findings of this thesis are discussed in relation to each of the six senses in Nolan et al.'s framework, before considering the evidence for the existence of a seventh sense. In their study, Nolan et al. (2002) noted a temporal ordering of the senses, with some being more prominent in the early stages of students' study, only to be superseded in importance later on. Similarly in this study some senses appeared to be more prominent than others. Thus the senses are discussed in their order of significance, this order being; sense of purpose, sense of continuity, sense of security, sense of achievement, sense of significance and sense of belonging.

In this thesis the framework is applied solely to the practice of professionals in conducting continuing care assessments. It has not been applied to older people themselves or their informal carers as 'the senses' need to be addressed in relation to professionals as a fundamental pre-requisite. It is argued that unless professionals have a sense of purpose, continuity, security, achievement, significance and belonging, they are unlikely to be in a position to develop these senses in others.

### **Sense of Purpose**

Nolan et al. (2002) highlight that, for staff, it is important that they have a sense of direction and goals to which they can aspire, if they are to achieve and sustain a sense of purpose (see table 6-1).

### **Table 6-1**

#### **A Sense of Purpose - To Have Direction**

<p><b>For older people</b></p> <p>To have the opportunity to do something that is meaningful and stimulating.</p> <p>To pursue personal goals and challenges.</p> <p>To be able to exercise choice.</p> <p><b>For staff</b></p> <p>To have a clear rationale and direction for the care that you give.</p> <p>To be able to pursue personal career goals and aspirations.</p> <p><b>For family carers</b></p> <p>To ensure the dignity and individuality of the person they care for.</p> <p>To ensure that the person they care for receives the best possible care.</p> <p>To be able to achieve a balance between caregiving and other important parts of their life.</p>
--

Nolan et al., (2002) identify two factors that may be central to the development a sense of purpose for staff, these being; having a clear rationale and direction for the care they give and having the opportunity to pursue personal career goals and aspirations. These factors are considered in turn in relation to the findings of this study.

Documentary evidence highlights how the purpose of continuing care assessments was defined at a local level. The discharge planning policy at hospital Trust where the study was undertaken states:

*“Discharge planning is a multi-agency, multi-disciplinary activity in which all professions have a contribution to make. The outcome of a properly planned discharge is that the patient can function appropriately in his/ her home immediately after discharge with no deterioration to their quality of life.”*

(Trust discharge planning policy: 2)

It is interesting to note that the policy does not elaborate on what constitutes ‘quality of life’ or how this complex indicator may be measured. The policy’s reference to patients being able to function appropriately in their own homes is suggestive of a biomedical emphasis on physical functioning. However, it is unclear whether the term ‘function’ is also intended to include more subjective elements such as the maintenance of personal relationships, which were highlighted as being important by Nolan et al. (2001a). The policy is also unclear about whose definition of quality of life should be used, and whether this should be a professional’s view or if there is provision for patients to outline what is significant to them. The situation is no clearer at a national level. Whilst the Social Services Inspectorate state that the purpose of assessment is, ‘to understand an individual’s needs’ (SSI, 1991: 47), ‘need’ implies an ultimate end state such as good health or happiness (Lightfoot, 1995), which is not elaborated. This highlights the requirement for greater clarity in local and national policy documents about the aims of continuing care assessments. This requirement is listed in the recommendations at end of this chapter.

In view of this, it is particularly interesting to see how the professionals in this study interpreted the ambiguity about the purpose of assessment contained within the policy documents. When questioned in the general interviews about their knowledge of discharge policies, the most common response was that professionals stated that they knew that there was a hospital discharge policy but were unaware of its contents. When they did talk about the purpose of assessments they gave a variety of rationales including:

*Nurse: “... when I do an assessment it is primarily one for the ease of nursing itself, for the ease of my care, so for example if a patient can walk, then it will save me carting the patient around”*

[Geninn3 93-95]

*Social worker: “... they [patients] are prone to, to risk, so you want to explore a little bit about how you could help them, that’s what assessment is all about”*

[Geninsw3 85-87]

*SHO: "... I suppose the ultimate aim is to stop them [patients] bouncing back in again"*  
[Genisho3 300-301]

Interestingly although most professionals talked about the purpose of assessment in terms of providing benefits for patients, this was not always the case for nurses. Whilst the quote cited was the most stark example, nurses sometimes gave professional advantages as their main motivating factor. This finding is supported by Penhale (1997) who found that whilst doctors operated from a curative perspective and social workers from a concern for patient self-determination, both groups were focused on different aspects of patients' welfare. Whilst no professional was able to cite the purpose of assessment as set out in the Trust policy document, explanations in terms of patient benefits came closest. Indeed observational findings suggest that when patients were admitted to the ward, nurses appeared at times to be more preoccupied with completing admission documentation than with identifying either objective or subjective factors relevant to individuals' quality of life.

Nurses may struggle to make effective contributions to team decisions about continuing care needs if they conduct assessments for substantially different purposes to those of their multidisciplinary colleagues. Moreover if nurses do not make effective contributions they are unlikely to be well placed to promote the involvement of patients and informal carers. The findings highlight the urgent need for greater clarity within policy documents at all levels and for policy to be more widely disseminated so that all professionals may work towards a shared understanding.

Nolan et al. (2002) also highlight the need for professionals to be able to pursue personal career goals and aspirations in order to attain a sense of purpose. Within this study evidence from the general interviews indicates that there appeared to have been a lack of interest within the hospital Trust in the development and education of nurses. Whilst this situation was acknowledged by professionals as having existed for some time, there was a feeling that it had yet to be addressed. For instance a consultant remarked:

*Consultant: "I mean there was, there was a tradition of, you know, nurses doing as the senior nurses said, but no-one actually being interested in development or education, I mean this is still a Trust wide problem"*

[Genicon2 340-343]

The problem of a lack of training opportunities and a failure to develop nurses and maximise their potential has long been recognised (Mackay, 1989). The findings from this thesis appear to indicate that these shortcomings may still exist. Significantly, nurses were the only

professional group singled out by any discipline as in need of professional development. No professional from any other discipline indicated that there were any barriers to their own development, or that they felt impeded in the pursuit of career goals. This suggests that, within the multidisciplinary team, nurses may have experienced special difficulties in pursuing personal career goals and aspirations.

These data lend further support to Nolan et al.'s senses framework. In addition, they suggest that within the multidisciplinary team, nurses in particular appear to lack the conditions necessary to foster a sense of purpose. If nurses lack an understanding about the purpose of continuing care assessments, which the data suggest may be the case, this indicates a very serious and fundamental misapprehension. Without such basic understandings it is difficult to comprehend how nurses can fulfil the central roles within multidisciplinary continuing care assessments that are envisaged for them by policy makers. These roles, including those set out in the single assessment process, require individual practitioners to conduct holistic assessments of patients' continuing care needs. In this way, nurses may no longer be able to defer decisions about these needs to their multidisciplinary colleagues.

### **Sense of Continuity**

The framework outlines that, for staff, a positive experience of working with older people in environments where there are clear expectations is important in fostering a sense of continuity (see table 6-2).

### **Table 6-2**

#### **A Sense of Continuity - Linking the Past, Present and Future**

##### **For older people**

To have their personal biography acknowledged and used as a basis for planning and delivering individualised care.

To receive consistent care delivered by known people within an established relationship.

To receive seamless care at key transition points such as hospital discharge and admission to care.

**For staff**

Positive experience of work with older people, exposure to good role models and standards of care.

To work as part of a stable team.

To work in an environment where there are consistent expectations and standards of care which are clearly communicated.

**For family carers**

To be able to maintain shared pleasures and interests with the person they care for.

To be able to ensure consistent standards of care, whether delivered by themselves or others.

To be actively involved in care across care environments when desired/ appropriate.

The framework identifies three factors that may be crucial to the development a sense of continuity for staff, these being; positive experience of work with older people and exposure to good role models and standards of care, working as part of a stable team, and working in an environment where there are clear expectations and standards of care. Each of these three factors is discussed in relation to the findings of this study.

The first factor indicates that, for staff, positive experiences of working with older people with exposure to good role models and standards of care may be key to the promotion of a sense of continuity. Findings from this study appear to indicate that for nurses the identification of colleagues who could act as role models with respect to the conduct of continuing care assessments could be problematic. An important attribute of role models is that they are individuals from whom others can learn (Sloan, 1999). Yet within this study's data there were no instances of nurses stating that they had either asked for, or been given, advice from colleagues on assessing patients' need. Of concern, some senior nurses indicated that continuing care assessment was an instinctive skill and therefore did not need to be learnt. As such this suggests that they considered role models to be unnecessary. For instance a G grade nurse talking about continuing care assessments stated:

*Nurse: "... nobody has to train you, I feel that if you have got a little bit of common sense, and you're working with people all the time, you automatically pick those things up [continuing care needs]"*

[Geninn6 726-728]

This mirrors concerns identified by Salvage (1985) that for many people, including some nurses, the ability to nurse is an intuitive skill and something that individuals are born with. If this line of argument is followed, nurses therefore need little education.

In practice, evidence from the patient tracking data suggests that nurses did not automatically identify patients' continuing care needs, and that their practice may not have been effective in this area. In interviews focused around patients' care, nurses frequently described continuing care needs as having been assessed by other members of the multidisciplinary team. For instance, in an interview with the same G grade nurse focused on the assessment of a 91 year old man's continuing care needs, the nurse appeared to dissociate himself from this process:

*"[name - patient] has been coping on his own before he came to us, [name - social worker] came to see him yesterday and have a chat with him, but I don't know if he accepted any services from her"*

[Pt22inn1 67-69]

These findings suggest that for nurses, exposure to good standards of care and the identification of individuals who are role models for continuing care assessments, may be problematic.

The data suggest that it may not have been only the nurses in this study who lacked role models. During the discussion with one social worker after an interview, she stated that she did not bring problems to her monthly supervision with the senior social worker as it was not useful, preferring to deal with the issues herself. This sentiment is in contrast to that expressed by the SHOs in the study who appeared appreciative of the advice offered by the consultants.

*SHO: "... our training comes from experience you know, you go on ward rounds with your consultants and the consultants do give you quite a lot of guidance"*

[Genisho5 318-320]

It is interesting to note that policy (Department of Health, 1993; UKCC 1996) recommends that practitioners have access to individuals who are in a position to develop their clinical practice. However, Cote and Leclere (2000) note that teaching through being a role model requires a precise understanding of what is being modelled and what trainees are intended to learn. This would appear to be a barrier for some nurses in this study who were in a position to act as role models, in that they seemed to lack understanding of the skills required to assess continuing care needs. Therefore they did not seem to be well placed to teach these skills to others. This finding is despite an increasing focus on leadership within nursing (e.g. RCN, 1996, 2001; Department of Health, 1999), and in particular on facilitating individual development. The RCN (2001) state that the role of leaders is to help others excel. It is reasonable to expect that



this may entail an element of role modelling. In contrast, Basco and Reigart (2001) found the adoption of role models to be widespread amongst junior doctors. Thus role models may be under-utilised in nursing and this may affect nurses' ability to develop a sense of continuity.

A second factor identified by Nolan et al. as being important for the development of continuity is that staff work as members of a stable team. As outlined in the chapter 4, the nursing team on both wards was stable, with a total of two nurses leaving and none joining during the study period. There is no reason to believe that this is atypical of this type of setting. Similarly both wards had designated social workers, occupational therapists and physiotherapists who did not change during the study period. Notably there was a lack of stability in relation to the SHOs who worked in rotation, being attached to the ward for periods of approximately 2 months as part of their ongoing training. SHOs indicated that they learnt about continuing care assessments during their placements and that, before they acquired this knowledge, they delegated to social workers, as one SHO at the end of her placement reflected:

*SHO: "... unless you do care of the elderly, you're not, it's only because I've done care of the elderly that I'm aware of discharge now, and about, and about planning for discharge ... Certainly in any other medical job, you're not really taught, you know it's always a bit, oh well, ahh, oh now we hand it over to the social worker and they'll sort that bit out. And I think it's only as a care of the elderly doctor that you're actually playing an active part in getting people home"*

[Genisho3 509-517]

Thus the data suggest that until SHOs became familiar with continuing care assessments, social workers may have been affected by their rotation. In this way, a lack of stable personnel in one discipline may have implications for the development of a sense of continuity for other members of the multidisciplinary team.

Paradoxically, it was suggested that some staff turnover could be important to generate new ideas and challenge existing ways of working.

*Consultant: "... that's what I meant also about newer ideas and different styles of working, I mean you know they've got to come from somewhere, and it's not enough for them just to come from a consultant once a week, if they come from more senior nurses, if they come from new blood of new nurses coming, which we don't really have, I don't think we have students do we? ... We don't have students, who are very good for making you think and challenge always, we don't have them. There used to be on wards, you'd often get perhaps a new staff nurse coming for you know, maybe three or four years as a D grade then they'd perhaps move on somewhere else to their E grade job but that doesn't happen here, so you don't get new ideas, perhaps people who've worked at a good ward at another hospital or another unit coming round, you don't tend to get that"*

[Genicon2 549-563]

This suggests that, in fact, the stability of the nursing team, may have stifled creativity and impeded the way that nurses practised. Thus stability may not always be beneficial for a team, if this means that it fails to develop. A balance therefore needs to be struck between a stable team and one with frequently changing members, and the senses framework should perhaps be amended to reflect this.

The final factor identified by Nolan et al. as being important for the promotion of a sense of continuity is that staff work in an environment where there are consistent expectations and standards of care which are clearly communicated. The findings of this study suggest the nurses did not have a clear understanding of what was expected of them. Policy issued before the field work was undertaken identified that there could be problems with multidisciplinary continuing care assessments and recommended that arrangements be strengthened for ensuring nursing input (Department of Health, 1996a). However, findings from this study indicate that nurses did not seem to perceive the assessment of patients' continuing care needs to be integral to their role. Their hesitant inclusion of themselves in the list of professionals who were involved in assessing continuing care needs indicates that they did not see themselves as being key practitioners in this area. For example, a D grade nurse only included nurses as being one of the professionals involved in assessing patients' continuing health care needs as an afterthought:

*KA: "Which professionals would be involved in assessing what health care needs people would have when they're discharged from hospital?"*

*Nurse: "[pause] I'd say that the social workers, erm, definitely like the OTs and [pause], the district nurses or health visitors and even us ourselves, because at the end of day sometimes they go home and something might happen and they might come back to us"*

[Geninn7 257-263]

Moreover, their uncertain and hesitant responses to questions about how they conducted continuing care assessments suggest that this was not a process that was familiar to them. Again the impact of policy expectations not being understood appeared to be felt by other members of the multidisciplinary team. For instance in chapter 7, the concerns of a physiotherapist about nurses' lack of contributions in multidisciplinary meetings were outlined alongside the worry that she felt that she had to compensate for these omissions. In particular she gave the example of a case where the nurse had not alerted the team to a patient's low blood sugar and that she had been the one to do this. No professional indicated that any other members of the multidisciplinary team had a problem understanding their role. In contrast other members to the team were often explicit about their own roles in the assessment of patients' continuing care needs. For example a doctor and social worker respectively stated:

*SHO: "... from a medical point of view the consultant and the rest of the medical team decide when this patient will be ready to go home ..."*

*...  
"in terms of whether they need follow up, it's normally done on whether I clinically feel it is or whether they, they have given me enough signs to think, they're not going to be happy unless they do see me [laughter] which is often the case"*

[genisho1 179-180; 323-327]

*Social worker: "... we assess social care needs, then make referrals, because once she [the patient] is discharged from the hospital, she'll be going into the community. We make all the referrals for home care, for shopping, you know, for Age Concern, for day care centres, if they need a piper alarm ..."*

[Geninsw3 355-359]

These findings mirror those of McClelland and Sands (1993). McClelland and Sands spent one year observing multidisciplinary decision making in a child evaluation centre. They found that when one member of the multidisciplinary team was absent, members of other related disciplines sought to fill their role. When 'missing' members were shown videotape of team meetings, they felt that there were areas where their expertise could have added to the decision making process. The findings of this thesis suggest that it may not only be when team members are absent, but also when they are present but lack understanding of their roles that members of related disciplines seek to fill the gap. Thus, it would appear critical that if patients are to benefit from all multidisciplinary perspectives, that all team members understand what is expected of them and how they can contribute to continuing care assessments. The development of such understandings is listed in the key recommendations.

Nurses' uncertainty about their own roles within the multidisciplinary team has been noted in the research literature (O'Hare, 1992; McCormack and Wright, 1999). More particularly Johnson (1989) suggests that the value of discharge planning is not always recognised by nurses in an acute setting. This is a finding supported by Lowenstein and Hoff (1994) who, in a survey of 225 nurses found that 63% stated that they thought social workers were primarily responsible for discharge planning.

It is interesting to note that these findings are not new. Research conducted over 15 years ago highlights hospital nurses' failure to accurately assess the post discharge needs of their patients (Arenth and Mamon, 1985; Waters, 1987). Policy on the practice of assessment has changed appreciably over this period. Perhaps most notably assessment was key to the community care reforms under which access to nursing and residential care became dependent on evaluations of individual need. Given this significant policy change one might expect nursing practice to have developed in this area. This study's findings that there appears to have been little

implementation of policy in practice, and that nurses do not seem to have clear understandings of what is expected of them, has potentially far reaching implications for the other members of the multidisciplinary team who may have to fill the gap left by nurses.

In addition it is important for the development of a sense of continuity that staff have a clear understanding of their role in involving patients and informal carers in continuing care assessments. This is particularly significant given the increasing prominence of patient and informal carer involvement in the policy literature in recent years. Findings from this study indicate that some nurses felt that they talked to patients and informal carers about their situation and how they felt about their discharge from hospital. For example, an F grade nurse claimed:

*Nurse: "... we always talk to people about if they're going to be happy, well, not necessarily if they going to be happy, but we always talk to them about their discharge, I mean we can't, can't just discharge a patient without first discussing their discharge"*

[Geninn12 424-428]

However, other members of the multidisciplinary team were more circumspect about nurses' role in involving patients and informal carers. They indicated that they felt that nurses relied on patients and informal carers to initiate discussions, rather than ensuring that they systematically asked patients and informal carers about their wishes.

These perceptions were borne out by observational data which indicated that, in practice, assumptions could be made about patients' wishes. For example, when discussing the discharge of an 89 year old woman, a G grade nurse stated:

*KA: "Was she happy with the way things were set up when she left?"*

*Nurse: "She was, she seemed to be, she seemed to be happy with that, because that's what she was getting before she came in, so she seemed as if that was okay"*

[Pt15inn1 173-175]

In this case, it appeared as though the nurse had not asked the patient about her continuing care needs, and the services that would best meet these needs, but had assumed that the patient was content with the services she had been receiving before her admission. Nurses' failure to involve patients and informal carers could have implications for other members of the multidisciplinary team. For instance, in this case, this patient's daughter had concerns about her mother's ability to cope at home with her existing social services. As highlighted in chapter 6, the daughter had raised concerns with nurses, who had not explored the family's concerns.

Field notes from a ward round show:

*“The consultant suggested discharge on Tuesday. The nurse interjected that the patient was not coping at home. The consultant questioned in what way she was not coping as she lived in a warden controlled flat. The nurse replied that the patient had come in with a chest infection and the family were concerned about her managing at home. The consultant stated that a chest infection was different to not coping, adding that there may be possible concerns about her eating at home, but that if the family were concerned then they needed to speak to the family”*

[pt15fn 230-238]

In this case an SHO telephoned the patient’s daughter and identified a range of concerns, including that the patient’s home carers had been coming too late and problems with a day centre. Thus, nurses’ failure to identify family concerns meant the doctors ultimately took on this role. In this way, nurses’ apparent failure to understand what was expected of them in relation to involving patients and informal carers in continuing care assessments, meant that, in practice, other members of the team could be required to fill this gap.

In contrast, other members of the team appeared to have clearer understandings of their own role in involving patients and informal carers. For example, a doctor and social worker respectively commented:

*SHO: “... it’s about patients being, A able to highlight areas where they’re having difficulties and, and B being made aware of the choices available or the services available, which could fulfil those needs. And likewise with the carers that they, they’ll you know that both patient and carer are given an opportunity to ... given a choice about which of the services that they want to use”*

[Genisho3 623-631]

*Social worker: “... although we may not be about to satisfy every need, it is just good practice to know exactly what the patient is feeling, and how you can address it, so we involve them in the process, to know what it is the patient is feeling and how he or she thinks that can be resolved. It may be we are unable meet their need but it is always advisable to record them on paper, ‘this is an unmet need’, so they are part of the process, and we should always involve them if we are going to do a great job”*

[Geninsw2 26-32]

Interestingly, in contrast to other studies, nurses in this study were more cautious about claiming that they had a key role in facilitating patient and informal carers involvement. Although some nurses in this study claimed to seek patients’ views about their discharge, unlike the participants in Armitage’s (1981) study, they were more reticent about claiming to act as informants for patients and informal carers. In addition, whilst Busby and Gilchrist (1992) and Jewell (1994) report nurses’ seeing themselves as being patients’ advocates, this was not supported in this study. One potential explanation for this difference is that as none of these studies contained significant amounts of observation, nurses may have felt freer to express an

idealised opinion of how they might like to practice. It is possible that as this thesis involved substantial periods of observation, nurses may have been more hesitant about making such claims.

However, this study's findings are supported by other research examining nurses' practice. Waters (1987) found that only 9% of the patients in her study recalled being asked by nurses about their ability to cope at home. More recently, Reed and Morgan (1999) explored lay experiences of moving into a care home. They found that nurses rarely initiated discussions with patients about their move to a care home, stating that they saw this as falling within other professionals' remit. The findings of this study suggest that it may not only be in relation to moves to nursing homes that nurses rarely facilitate patient involvement. This study indicates that nurses may also have a limited role in involving patients discharged with domiciliary care packages, as well as those moving to residential care or NHS funded continuing care.

Nurses' marginal role in involving patients and informal carers in continuing care assessments has potentially significant implications for patients and informal carers, whose views may not be fully represented as a consequence. In addition, there are implications for other members of the multidisciplinary team, such as doctors and social workers, who may have to fill this gap.

This discussion provides empirical evidence to support the senses framework. In addition it highlights that nurses' ability to develop and maintain a sense of continuity may have been affected by their failure to understand their role in continuing care assessments and in involving patients and informal carers in this process, as well as by their lack of exposure to good role models and standards of care. Other professionals appeared to be better placed to maintain a sense of continuity, although social workers may also have been affected by a lack of role models.

### **Sense of Security**

Nolan et al. (2002) highlight that, for staff, it is important that they feel free from physical threat and censure, have secure conditions of employment, have the demands of their work recognised and work within a supportive, challenging culture, if they are to achieve and sustain a sense of security (see table 6-3).

Nolan et al., (2002) identify four factors that may be central to the development a sense of purpose for staff, these being; having the physical and emotional demands of their work acknowledged and minimised, working in a supportive, enabling but challenging environment, free from rebuke and censure, having secure conditions of employment and being able to raise and discuss concerns in an open and honest manner. These factors are considered in turn in relation to the findings of this study.

**Table 6-3**

**A Sense of Security - To Feel Safe**

**For older people**

To receive competent, sensitive and consistent care in a supportive environment enabling them to feel safe and free from threat, harm, pain or discomfort.

To acknowledge and reduce unnecessary risk while encouraging informed risk taking.

**For staff**

To have the physical and emotional demands of work acknowledged and minimised.

To work in a supportive, enabling but challenging environment, free from rebuke and censure.

To have secure conditions of employment

To be able to raise and discuss concerns in an open and honest manner.

**For family carers**

To feel able to say 'no' to care if they want to.

To have their own needs recognised and acknowledged.

To feel they have the knowledge and skills to provide good care without detriment to their health.

To have appropriate sensitive and timely support.

To recognise the existence of differing viewpoints within caring relationships.

The first factor relates to the need for staff to have the physical and emotional demands of their work acknowledged and minimised. Nurses sometimes made reference to the physical demands of their work, such as the D grade nurse who, as highlighted on page 183, stated that she conducted assessments because it would save her ‘carting’ patients around. However, these were relatively isolated references. In this study emotional aspects of care appeared to be more significant for participants than physical demands. Interviews and field notes suggest that nursing staff felt demoralised. For example, in an interview an E grade nurse outlined how she felt:

*Nurse: “we get a lot of, erm, you know, we get a lot of aggravation, no matter what we do, we’re still not right you know, still get complaints about things so”*

*KA: “Yeah”*

*Nurse: “It’s just the job I suppose”*

[Geninn3 24-28]

Fieldnotes revealed other instances that suggest that nurses felt that their emotional needs were not addressed.

*“A page from one of the tabloid newspapers, with anecdotes bemoaning the stressful conditions that nurses had to work under, had been stuck to the wall at the front of the ward in a prominent position, underneath the welcome notices to the ward.”*

[Fnjy2998 9-11]

Nurses’ apparent lack of morale was remarked on during the study by a number of other members of the multidisciplinary team. For example, early in the study, a nurse specialist indicated what she felt this study would find and why:

*“The Nurse Specialist told me that she thought nurses here would have a minimal role in discharge planning and that the doctors would decide and the nurses ‘do’. She said that she thought that the reasons for this were political - that nurses were unsupported, there was low morale and a lack of professional development.”*

[Fnma0298 21-24]

Doctors and social workers both expressed frustration with aspects of their work, in particular with a lack of time, and with feeling rushed:

*Social worker: “... it’s because of our workload that we don’t, we just don’t get time, it would be lovely to sit by each bed for half an hour each day, but it’s totally impossible”*

[Genisw1 353-355]

*SHO: “... you’re very busy and you wish that could spend a bit longer with each patient”*

[Genisho5 238-239]

However, they did not appear to have the same sense of demoralisation as that shown by nurses. Significantly, low morale was only mentioned by team members in relation to nurses, this was



not a factor identified as affecting any other disciplinary group, again suggesting that nurses may have been particularly affected.

The potential effects of low morale and instability were highlighted in chapter 7 by the community liaison nurse who commented:

*Liaison nurse: "... where there's low morale, there's little support and little vision about what it is we're trying to do, there's you know, it doesn't feed down into the kind of assertive knowledgeable practitioners, who feel able and willing to give of their opinion, their professional opinion"*

[Geninln1 417-421]

This interviewee's opinion is supported by the Royal College of Nursing (1984) who found low morale to be associated with declining standards. This suggests that if nurses are demoralised, other members of the multidisciplinary team may have to compensate for nurses' reduced standards of practice. In this way, a lack of attention to the emotional needs of one professional group, in this case nurses, may have an effect on other disciplines, if as a consequence they are less able to contribute to team goals.

Secondly, Nolan et al. contend that, to foster a sense of security, staff need to work in a supportive, enabling, but challenging environment, free from rebuke and censure. Field notes show that in this study nurses of all grades reported feeling unsupported, for example, they highlight the sentiments of a D grade nurse:

*"She said that nurses get the blame for everything. She talked about the difficulty of sometimes having a lot to do without the appropriate support and said that for example, today other nurses had gone off duty and had left her a nurse-to-nurse form to do for a patient she did not know who was being discharged"*

[Fnmr1799 12-15]

Field notes show that a G grade nurse experienced similar feelings:

*"[Name] was angry because yesterday he had been summoned to see a nurse manager, who instead of praising his efforts had asked him why he had not informed the hospital administrator about a particular incident. [Name] said that he had not had any orientation prior to becoming a bleep holder and did not realise that he had been required to do this, in addition he said that he had been pressured to write a statement for the coroner in about 10 minutes."*

[Fnja1398 17-23]

In addition nurses appeared to have concerns about being rebuked. These concerns were evident to some members of the multidisciplinary team. For example a consultant reported:

*Consultant: "...when I came here just over a year ago and would turn round to say to them [nurses], "Well, what do you think, have I got this right or am I talking rubbish?" and I will do that quite often during the ward round, you know. Some of them would just look to me thinking, 'Is she trying?' I could just see it going through their heads you know, 'Is she trying to catch me out?'"*

[Genicon2 319-324]

Social workers also stated that they felt isolated at times with one social worker highlighting a particular concern that managers were unsupportive when complaints were made by patients' families. Interestingly, no participant identified lack of support as being an issue affecting doctors.

One implication of a lack of support and a fear of rebuke is that professionals, and in this study especially nurses, may be hesitant to give their opinions. Thus it is possible that assessments of patients' continuing care needs may not reflect all multidisciplinary perspectives. A second potential implication is the effect on professionals' practice. Baron (1988) conducted three studies in different settings on the effect of destructive criticism. Unsurprisingly, he found that individuals who received destructive criticism of their work set lower goals and reported lower self-efficacy. Thus the practice of nurses, and to a lesser extent social workers, may be adversely affected by critical feedback and they may have greater difficulty in maintaining a sense of security.

The third factor identified by Nolan et al. as helping to create a sense of security is that staff have secure conditions of employment. This was a particular issue during this study as wards 1 and 2 were threatened with closure. This appeared to particularly affect nurses as they were the only professionals permanently based on these units. Field notes reveal that on one occasion when these threats seemed particularly acute the nurses working night shifts were unsure whether they would find the ward padlocked and if they would be relocated to other parts of the hospital. Moreover, threats of closure appeared to have been poorly managed as one consultant remarked:

*Consultant: "... the one thing I have done is had a go at senior nursing, but that's why, because that's how they manage people, that's no way to do it. The idea of sitting down every member of staff, and it wouldn't take that long to actually say, 'Look you know, problems with funding for the Trust as a whole, problems with funding coming from the health authority, God knows what's going to happen to wards, all the wards could be changing, under threat, let's take this opportunity to sort of look at you, look where you are in your career, look where you might want to go if things happen, and you know, we'll try and keep you posted' ... I get warning of what's happening generally, and very often the first the nurses hear of it is from us, it's not from their managers at all. But there's very much a sort of hierarchical way of managing them which is, has never really, never really been dismantled, erm, and particularly the way wards have been*

*closed or threatened with closure I think has been very badly managed. I mean it could have been managed in a similar way erm, with people saying, 'Look you know, hang on in there, we don't know what's going to happen, but we will be here', and again if you have senior nurses and people that keep coming up then I think you have confidence that you know, the rug isn't just going to be pulled out under your feet one day"*

[Genicon2 606-629]

Job insecurity has been shown to have adverse effects. In the Whitehall study of civil servants Ferrie et al. (2002) found that loss of job security had adverse effects on self-reported health and minor psychiatric morbidity, which were not completely reversed by the removal of the threat. This suggests that there may have been health effects for the nurses in this study which could have had implications for their practice.

The final factor identified by Nolan et al. as being important for the development of a sense of security is that staff are able to raise and discuss concerns in an open and honest manner.

In this study, it appeared as though members of the multidisciplinary team could also have difficulties openly discussing concerns about patients' continuing care needs. Within this study professionals stated that the consultant could dominate multidisciplinary meetings and that they did not often ask for other opinions, as a physiotherapist highlighted:

*Physiotherapist: "...it's very rare that they actually ask you, but then if you don't speak up and they just move on to the next patient, I think it's our fault"*

[Geninph2 538-540]

These findings are supported in the literature with Meyer (1993) reporting that senior medical staff dominated multidisciplinary discussions and that nurses and professionals allied to medicine were reluctant to contribute. Significantly a social worker highlighted that this lack of openness could have drawbacks, one being that he felt that he did not get sufficient information from other professionals. This suggests that if professionals are discouraged from contributing, assessments may not reflect all multidisciplinary perspectives.

Taken together these findings provide empirical evidence to support the senses framework. Moreover they suggest that nurses may have had particular difficulties in creating a sense of security, but that there could also have been problems for other individuals including social workers. Again it is interesting to note a 'ripple effect' in that weakness in one area of the team may have had implications for the practice of individuals in other disciplines.

## Sense of Achievement

The framework outlines that, for staff, the ability to provide good care, to feel satisfied with one's efforts, to contribute towards therapeutic goals as appropriate and to use skills and abilities to the full in addition to being able to pursue career aspirations may be important in fostering a sense of achievement (see table 6-4).

**Table 6-4**

### **A Sense of Achievement - To Feel You're Getting Somewhere**

#### **For older people**

To feel satisfied with their efforts.

To feel that they are making progress towards meaningful and valued goals.

To feel that they are making a recognised and valued contribution.

#### **For staff**

To feel that you are able to give the best possible care.

To be able to use your skills and abilities to the full.

To have your contribution acknowledged and valued.

To meet personal career goals and aspirations.

#### **For family carers**

To know that they are providing/ have provided the best possible care.

To develop new skills and abilities.

To be able to meet competing demands successfully.

To have their caregiving abilities and expertise acknowledged and valued.

The framework identifies four factors that may be crucial to the development a sense of achievement for staff, these being; to feel that they are able to give the best possible care; to be able to use their skills and abilities to the full; to have their contribution acknowledged and valued and to meet personal career goals and aspirations. Each of these three factors is discussed in relation to the findings of this study.

Firstly, Nolan et al. contend that the development of a sense of achievement may be facilitated by staff feeling that they are able to give the best possible care. In the interviews with staff the most commonly cited barrier to both the assessment of patients' continuing care needs and the involvement of patients in this process was that of lack of time. Lack of time was cited by all members of the multidisciplinary team as inhibiting the way that they practised. For example a D grade nurse reported:

*Nurse: "... to be honest you don't get time .. I do try my best but you can't always get through things because there, there's a lot of things I know that with the discharge planning that you have know, but like I said, I go through the orange form there, the discharge planning form and hope that everything's done"*

[Geninn7 566-571]

Maynard (1987) suggests that nursing establishments have been more determined by rhetoric, historical accident and well intentioned guesswork than by scientific evaluation of the needs of the individual patient. Moreover, there have been doubts about the accuracy of some workload prediction tools in use. Carr-Hill and Jenkins-Clarke (1995) report large discrepancies between the predictions of the nursing workload management systems 'Criteria for Care', 'EXCELCARE', 'FIP' and 'SENS'. However, within this study there was no evidence that members of any discipline attempted to match staffing levels to the needs of patients. This highlights the need for further work in this area.

In addition, it is possible that professionals' perceptions that they lacked sufficient time to conduct continuing care assessments may have been exacerbated by shortages of resources and by working in a very poor physical environment. Shortages of basic items such as linen were a frequent occurrence on both study wards. Meyer (2001) found practising in a poor work environment to increase professionals' dissatisfaction and reduce their morale. In this way a lack of time may have inhibited the development of a sense of achievement within the multidisciplinary team.

The ability to use personal skills and abilities to the full is also cited by Nolan et al. as being potentially important for the development of a sense of achievement. However, for nurses it appeared as though rather than needing the opportunity to use their assessment skills, that there may have been a more pressing need for these skills to be developed. Data suggest that assessments could be a paperwork exercise and not used as the basis for the assessment of patients' continuing care needs. For example a community liaison nurse described nurses' approach to assessments:

*Liaison nurse: "... it's very kind of question and answer, erm, tick box, fill it in, often isn't done properly, often isn't done at all, erm, so, so it's limited really, and the other thing is, they never pass that information on, so it's kind of, it's a task to be done and filed away, so it's not used and you know, it's not used in care planning"*

[Geninln1 234-249]

Moreover, there were indications that nurses avoided assessing patients continuing care needs, and that this was a task which they deferred to other members of the multidisciplinary team. For instance a D grade nurse outlined:

*Nurse: "... we refer every patient from here to the district nurse or the health visitor"*

*KA: "Right"*

*Nurse: "And maybe that's for assessment, yeah, so, very often you either find that the district nurse will refer or discharge a patient"*

[Geninn8 182-187]

This indicates that nurses may have had a uniform approach towards patients, with community professionals asked to identify continuing care needs. This finding is supported by Waters (1987) who, on examining referral forms from ward nurses to district nurses, found that these frequently requested assessments. In addition, the statement by this D grade nurse suggests that not all referrals may have been appropriate, if community professionals, including district nurses, often made other referrals or discharged patients from their own care. In this way, nurses may have had opportunities to assess patients needs, but they appeared to pass these opportunities to conduct assessments to other members of the multidisciplinary team.

The third factors identified by Nolan et al. as being important to the development of this sense is that professionals have their contribution valued and acknowledged. Significantly nurses' apparent reluctance to conduct continuing care assessments is in marked contrast to the feelings of other professionals about the value of nurses' contributions. Other members of the team talked about relying on information from nurses in order to perform their own roles. For instance a social worker outlined how it was useful when talking to informal carers:

*Social worker: "... you'll be able to involve the family, to say, "Look, I've been on the ward to assess your mum, the nurses have said she can't do her personal care and stuff any more, they are doing it, she's not eating, you have to prompt her to eat, and she can't walk by herself to the toilet, she has to be assisted", those are three major areas that are very very important"*

[Geninsw3 158-163]

Thus professionals emphasised how valuable nurses' contributions could be, and expressed their frustration and disappointment when nurses were not forthcoming in multidisciplinary meetings. For example, a physiotherapist highlighted:

*Physiotherapist: "I think there could probably be, a lot bigger role for nursing ... I think at the moment what happens is, erm, whoever's doing the meeting will sit there and read out the names and then write down whatever the consultant says, and that's mostly, for most people that's, that's the amount of input that nurses have"*

[Geninph1 489-496]

Thus it appeared as though members of the multidisciplinary team appreciated and valued the nurse's role. Similarly the contributions of both doctors and social workers were acknowledged as being important:

*Social worker: "... at multidisciplinary meetings, using the ward ideally, the consultant will say briefly what is the medical condition, how the far the treatment is going ... the social worker is listening to all this information"*

[Geninsw2 138-146]

*Nurse: "... the social worker assesses the patient and finds out from the patient and the relatives, what their needs are, what more they need to do to increase, to improve health at home, safety at home, and work from there, and then the social worker comes back to us and says well look this patient needs further input from the district nurse maybe or whatever"*

[Geninn4 337-342]

Thus the development of a sense of achievement appeared to be supported within all disciplines through the acknowledgement of their respective contributions.

Meeting personal career goals and aspirations is the final factor identified by Nolan et al. as being important to the development of a sense of achievement. Field notes indicate that nurses may have struggled to do this:

*[Name] told me that he had been an E grade for a year and before that had been a D grade for about 4 years. He said that initially, when he joined as a D grade, he had been told that there were no E grade vacancies on the ward, and yet whilst he had been there, despite his experience, people had been brought in from outside to fill E grade posts.*

[Fnfe1098 34-38]

In addition, a G grade nurse suggested that a lack of career progress may be a contributory factor in some nurses' decisions to leave the hospital:

*"[Name - G grade] complained that he was short of trained staff, and that he could understand why people left as they were badly graded, and singled out one D grade nurse as a particular example."*

[Fnfe1098 67-69]

Little data was obtained during this study about the extent to which other professionals, including doctors and social workers, felt that they had met personal career goals. However,

unlike in the case of nurses, nobody suggested that there were any particular problems, or that these professionals had had their aspirations thwarted.

This evidence lends weight to the robustness of the senses framework. In addition, it highlights that nurses may have had some difficulties in developing a sense of achievement as they perceived that there were some obstacles, including lack of time that impaired their ability to give the best possible care. Furthermore difficulties meeting career goals could also have had an effect. However, this discussion has also highlighted the need for nurses to develop their skills in conducting continuing care assessments, if they are to maximise the opportunities available to them.

### **Sense of Significance**

Nolan et al. identify just one factor as being important for the development of a sense of significance. They argue that it is important for staff to feel that gerontological practice is valued and important and that they and their work 'matter' (see table 6-5).

#### **Table 6-5**

##### **A Sense of Significance - To 'Matter'**

###### **For older people**

To feel that they are recognised and valued as a person.

To feel that their actions and existence are important.

To feel that they 'matter'.

###### **For staff**

To feel that gerontological practice is valued and important, that you and your work 'matter'.

###### **For family carers**

To feel that they are recognised and valued as a person.

To feel that their actions and existence are important.

To feel that they 'matter'.



It is interesting to note that in the general interviews whilst the majority of professionals talked about difficult issues and problems areas, there was not the same air of futility and hopelessness that came across in some of the interviews with the nurses. For instance some professionals highlighted that there were limits to their powers and that this could at times prove irritating:

*Social worker: "...there are a number of cases where people went home, everybody's screaming that you sent this person home, the telephone is ringing here and there but there isn't much I personally, I can do, I don't discharge, it's the consultant who discharges, we put in the personal care package available"*

[Geninsw2 483-487]

However, nurses appeared to have a greater sense of frustration. They stated that they felt that people did not listen to them. Importantly whilst nurses identified a number of measures that they felt could improve nursing practice they added they had not pursued these ideas as this would have been fruitless as nothing would have happened. In this way one nurse complained:

*"I think there's a lot, there's a lot of changes that would be better, especially in care of the elderly but like I said, it's, it's, I, I feel as though I don't have the strength or that to say anything to anyone because they don't listen"*

....

*"there's so many questions and things that need to be answered and so many things to be changed that I, I'd be what 2000 years old before you've got it, it's true"*

[Geninn7 181-185; 678-680]

The application of the senses framework would suggest that both nurse managers and the multidisciplinary team may need to pay more attention to valuing nurses and fostering a sense of significance within them.

### **Sense of Belonging**

The senses framework outlines that, for staff, feeling part of a team, or community of practitioners, with a recognised and valued contribution is important for the development of a sense of belonging (see table 6-6).

Nolan et al. (2002) identify three factors that may be central to the development a sense of belonging for staff, these being; feeling part of a team with a recognised and valued contribution; having a sense of professional/ work 'identity', and having a 'say' in the way in which things are done. These factors are discussed in relation to the findings of this study.

**Table 6-6**

**A Sense of Belonging - To Have a 'Place' and Feel Part of Something**

**For older people**

Having a place or personal space

To be able to maintain and form meaningful, valued and reciprocal relationships.

To feel part of a community or group if desired.

To be an equal partner in a caring relationship.

**For staff**

To feel part of a team with a recognised and valued contribution.

To have a sense of professional/ work 'identity'.

To have a 'say' in the way in which things are done.

**For family carers**

To be able to maintain/ form meaningful, valued and reciprocal relationships.

To have someone to turn to if they need to talk things over.

To feel that they are not 'in this alone'.

To feel an active and equal partner in caregiving.

The first factor indicates that, for staff, feeling part of a team with a recognised and valued contribution may be important to the promotion of a sense of belonging. Whilst the need for staff to have their contribution recognised and valued has been considered in the discussion of a sense of achievement, the data from this study shed light on the extent to which professionals felt part of a team. When questioned in the general interviews as to which professionals were involved in making decisions about patients' continuing care needs, nurses sometimes omitted themselves or added themselves as an afterthought. For example, a D grade nurse outlined which team members he felt were involved:

*Nurse: "... every member of the staff has a role, for example the OT has a role, for example the physiotherapist has a role, and the district nurses have their role, quite a big role, and then GP has a role and district nurse, yeah and also and the social worker especially has a role, just arranging the services required"*

[Geninn11 222-225]

Thus nurses did not appear to have a strong perception of themselves as integral members of a multidisciplinary team. This is in contrast to both doctors and social workers who clearly saw themselves as having a central role in the assessment of patients' continuing care needs. Moreover, observation of multidisciplinary meetings suggested that nurses may indeed have a marginal role. Nurses were not seen to make any contribution during 23 of the 32 formal multidisciplinary team discussions relating to the twenty patients who were tracked through their hospital stay. Moreover, nurses made unprompted contributions on just 3 occasions. They made proportionally fewer unprompted contributions than doctors, social workers, occupational therapists and physiotherapists.

These findings that nurses may not have felt part of a team with a recognised contribution are supported in the literature. In a study of the role of the nurse in rehabilitation wards for elderly people, Waters and Luker (1996) report that nurses saw rehabilitation as something done by other members of the team such as physiotherapists and occupational therapists, rather than seeing it as part of their own role. Similarly they also found that many team members found it hard to define the nurse's role in rehabilitation. The findings of this study suggests that actually there may be a range of multidisciplinary contexts in which nurses could be failing to fulfil their potential.

Thus nurses failure to feel part of a team with a recognised and valued contribution may mean they experience greater difficulties than other members of the multidisciplinary team in developing a sense of belonging.

A second factor that is potentially important to the development of a sense of belonging is the need to have a sense of professional/ work 'identity'. In this study professionals in all disciplines appeared to have a well developed sense of professional identify and to have strong ideas about their work identity. These ideas appeared to make them hesitant to work in flexible or collaborative ways. Interviewees spoke about sticking to individual areas of practice and being wary of getting involved in any activity that they considered may be the province of another discipline. They indicated that they were cautious about upsetting others and

highlighted the difficulties new team members may encounter. For example, fieldnotes from the end of a multidisciplinary meeting revealed:

*“The nurse said that the sister from the discharge lounge was new, and that she did not know what her role was. She added that she had overheard this new sister stating that she just wanted to stay in the background for the moment. The nurse commented that she did not know whose toes the sister would be treading on, and reinforced this by walking on tip toes.”*

[Fufe2299 5-9]

Similarly, an occupational therapist also outlined that there were concerns within his team that the work by some members of the hospital discharge team may in fact overlap with occupational therapy. These findings fit with other research in the field. Dill (1995) reports a lack of collaboration between professionals in a study of discharge planning conducted in the USA. She also found professionals to operate within their own domains of practice, with discharge planners arranging services and doctors deciding the date of a patient’s discharge. Due to the short notice discharge planners received, Dill notes that patients could be discharged without home care services being in place. Nolan (1995: 306) also notes what he terms, ‘professional reductionism’, that is, ‘the tendency to restrict the legitimate area of focus of attention to an area consistent with a given professional paradigm’. Thus in practising defensively to protect what they perceived as their own territories, professionals may have encouraged multidisciplinary colleagues to behave cautiously so as to avoid confrontations. Whilst professional identity may have fostered a sense of belonging it may also have been detrimental to the promotion of a team identity.

The last factor identified as being important for the development of a sense of belonging is for staff to have a ‘say’ in the way in which things are done. Within this study it appeared as though the multidisciplinary team did not have a say in the way that continuing care assessments were conducted. The multidisciplinary team within this study did not appear to engage in any reviews of the way that it operated in practice. However, as highlighted in chapter 7, this failure to review the way that the team operated could be a source of frustration, as one social worker lamented:

*Social worker: “... there is nothing like that, just a meeting that is conveyed just to discuss with others, the sister, is it [the team] functioning properly or not, I’ve never seen anything here like that, so we carry on, we plod through the system”*

[Geninsw2 246-249]

Although the importance of carrying out reviews of the way teams operate is widely stated in the teamwork literature, (Parker, 1990; Woodcock and Francis, 1994; Owen, 1996), this did not

appear to have happened in this case. This failure to conduct reviews meant that in practice the roles of individual members within the team were not evaluated. In addition, the operation of the team as a collective unit was not subject to scrutiny. The lack of reviews may have particularly affected some members of the team, including social workers, who felt that they had something to contribute to this issue.

Thus, whilst nurses may have been especially disadvantaged by not feeling part of a team, the lack of opportunities for professionals to have a 'say' in how assessments were conducted may have affected the ability of all team members to develop and sustain a sense of belonging. However the picture is mixed, with all disciplines appearing to have a well developed sense of 'identity' which, conversely, may have facilitated the development of a sense of belonging.

From this discussion, it can be seen that this study provides empirical evidence to support the senses framework. The application of the senses framework suggests that nurses may lack the majority of the characteristics needed in order to provide the 'fundamentals of care' with respect to the assessment of patients continuing care needs. Nurses' lack of the senses contained within the framework may account for their marginal position in multidisciplinary continuing care assessments. The situation for other professionals is more mixed with doctors seeming to largely meet the needs identified as important for the development of the senses. However the senses framework allows for the identification of areas within the team that may need attention such as social workers' perceived lack of role models and lack of support. It is also significant that the application of the framework to the practice of the multidisciplinary team demonstrates how the lack of 'senses' in one discipline may affect the practice of other members of the multidisciplinary team.

The next section looks at how well the data from this study fit the senses framework and suggests how the framework may be amended.

### **EXPLORING THE SEVENTH SENSE: THE NOTION OF EXPERTISE**

It appears as though the senses framework is highly applicable to this study and that it may be of real value in highlighting how a lack of senses in individual disciplines can have significant effects on other members of the multidisciplinary team. Interestingly although the data collected during the study fit with the senses framework, there seemed to be one significant theme from the data that fell outside the framework. This theme that appears to be unaccounted for is that of expertise.

If it is to sit within the senses framework then the theme of expertise must fit with the framework's philosophy. In introducing the senses framework Nolan et al. (2001a) identify that it is intended to focus on subjective elements and draw attention to quality of life issues. Nolan et al. argue that this is not to deny the importance of structural elements but rather to provide a direction for staff. Thus, whilst there is clearly a need for staff to develop technical abilities as part of the assessment process, following Nolan et al.'s focus on the subjective elements of care, the findings of this study suggest that it may also be important for staff to develop a sense of expertise and feel that they are proficient in assessing patients' continuing care needs. Moreover, a sense of expertise need not be restricted to staff expertise but could be broadened to reflect patient and informal carers' perspectives. Such a sense of expertise may then include for example the need for patients and family carers to have their detailed understandings of their own situations acknowledged and valued. A table outlining this additional sense is given in table 6-7 below.

**Table 6-7**

**A Sense of Expertise - To feel proficient**

<p><b>For older people</b></p> <p>To receive sufficient and appropriate education and training to remain as independent as possible.</p> <p>To be recognised and acknowledged as being experts about themselves and their own situation.</p> <p><b>For staff</b></p> <p>To receive sufficient and appropriate education to feel able to provide skilled care.</p> <p>To have regular opportunities to update their knowledge and skills.</p> <p>To be recognised and acknowledged as having professional expertise.</p> <p><b>For family carers</b></p> <p>To receive sufficient and appropriate education and training to feel able to provide skilled care.</p> <p>To be recognised and acknowledged as being experts about the person that they care for.</p>
--

This study suggests that there may be three factors that could be important for the development of a sense of expertise for staff.

Firstly, the findings of this study suggest that, for staff, the receipt of sufficient and appropriate education to feel able to provide skilled care may be important for the development of a sense of expertise. One of the most striking findings of this study was how little training the nurses could recall having had on how to assess continuing care needs. For instance D and E grade nurses respectively admitted:

*Nurse: ... nobody's really gone into any depth about assessing a patient, I think somehow you know, it comes with skill, you know, with practice*

[Geninn2 145-146]

*KA: "Have you had training in assessing needs?"*

*Nurse: "Just the usual"*

*KA: "The usual being?"*

*Nurse: "Erm, [long pause]"*

*KA: "Are thinking of like the general training?"*

*Nurse: "I don't know erm, what should I say? Having no training, just observance and things like that"*

[Geninn4 570-576]

This possible lack of training is worrying given that the assessment of older people's needs is a fundamental nursing skill (SNMAC, 2001). In spite of the fundamental nature of this skill many educational programmes have been found to provide inadequate grounding for the care of older people (UKCC, 1997). More particularly, Bergen (1996) identified that community nurses had specific educational needs in regard to assessing patients' needs in the light of policy changes introduced in the 1990 NHS and Community Care Act. Gaps in their education included a lack of teaching of theoretical concepts such as 'need'. The findings from this study suggest that it may not just be community nurses who have educational needs with regard to assessing patients' needs. It appears as though ward based nurses may also have training requirements.

Significantly, it seemed as if nurses' lack of education may have had a bearing on the way that they saw themselves. Whilst nurses stated that they used Roper, Logan and Tierney's (1983) model to collect information about patients', nurses' hesitant responses to questions about how they actually identified patients' continuing care needs suggests that this was not a practice with which they felt comfortable. For example an E grade nurse stated:

*KA: "How do you assess continuing health care needs?"*

*Nurse: "[pulls a face] Er, how do I assess it?"*

*KA: "Yeah"*

*Nurse: "Erm, [long pause] .... yeah well like I said before, we just refer them back to the district nurse or increase the services from the district nurse"*

*KA: "Hmm"*

*Nurse: "Or the health visitor"*

[geninn4 290-315]

It is suggested that a lack of education may have affected nurses' perceptions of their own ability to provide skilled care and consequently it may also have affected their ability to develop a sense of expertise. Thus, if professionals, and particularly nurses, are to assess patient's needs effectively, it appears as though more attention needs to be devoted to teaching them the appropriate skills, in order that they then recognise themselves as being skilled practitioners. This key recommendation is listed at the end of this chapter.

The findings also indicate that nurses may have had little training on involving patients and informal carers in assessments. For example, a D grade nurse outlined:

*KA: "Right. Have you had any training on involving patients and their families in assessments?"*

*Nurse: "No, no never"*

[Geninn9 515-516]

This contrasts with the experience of social workers who highlighted the position of patient involvement in their training on assessing individuals' needs.

*KA: "What kind of training have you had on assessing patients needs?"*

*Social worker: "Erm, the basic training that social workers will have is in their first year they have five months, field work training ..., your final year you have six er, months training on the job, and have to be assessed by the supervisor, pass the same to get as you did before. And to get through ... you have to listen, you have to listen to the patient"*

[Geninsw2 388-402]

Significantly, the involvement of patients is also identified by SNMAC (2001) as being a fundamental nursing skill and yet nurses within this study did not always appear to be confident in involving patients and informal carers in the identification of their continuing care needs. Rather nurses seemed to lack understanding of what constitutes involvement, outlining that this could be limited to seeking patients' responses to the questions they were asked when they were admitted. For example one nurse stated:

*Nurse: "I'll say like you know, 'Do you manage to get into a bath, or do you, can you wash yourself down every day?' I mean I'm, I'm assessing let me see,*



*I'm assessing this man's needs for his personal hygiene for instance, 'Can you walk? How far can you walk? Do you use a stick? Do you use any aids?' So I'm assessing his mobility, and then if I ask him about questions about his home social situation, I'm, I'm assessing that, so that I can then get the social worker more involved so it's, that's the way we involve our clients anyway"*

[Geninn6 196-204]

This suggests that nurses were unused to allowing patients greater degrees of influence, for instance in identifying their own continuing care needs. Significantly, Meyer (2001) found that the health care professionals in her study did not have adequate communication skills to understand problems from a patient perspective. This lends weight to this study's finding and associated recommendation, that additional education may be needed in this area to enable professionals to feel proficient in involving patients and informal carers in the identification of their continuing care needs.

Secondly, the findings suggest that having regular opportunities to update their knowledge and skills may facilitate the development of a sense of expertise. Of concern, is the finding that nurses highlighted that they had not had opportunities to develop their knowledge and skills in relation to continuing care assessments. For example, a D grade nurse stated:

*Nurse: "... when I say discharge training they, they sort of talk about it in your training, you know"*

*KA: "Right"*

*Nurse: "You plan towards a discharge ... but that I think is the end of the training basically, you weren't told how to go about this, or, how to assess someone's needs when they go out into the community"*

*KA: "Right. Have you had any updates since your training?"*

*Nurse: "No, not on that side"*

[Geninn2 152-164]

As highlighted earlier in this chapter, this view was supported by a consultant who outlined that nurses may lack opportunities for continuing education and training:

*Consultant: "I mean there was, there was a tradition of, you know, nurses doing as the senior nurses said, but no-one actually being interested in development or education, I mean this is still a Trust wide problem"*

[Genicon2 340-343]

This finding is remarkable because of the increasing focus within professional bodies on professional development (e.g. RCN, 1998) and also because of the rapidly changing policy context that requires practitioners to be aware of, and apply policy. For example, the

Department of Health (1996a) instructs that all professionals must have knowledge of the eligibility criteria that patients are required to meet in order to be able to access services.

In addition, nurses indicated that they had not had any recent training specifically on involving on patients or informal carers in assessments. In addition only one nurse stated that she had had any updates since her training focusing on patients' perspectives, having attended a one day customer care course. With the increasing emphasis on tailoring care to the needs of individuals (e.g. Department of Health, 1997b), it is surprising that nurses did not identify professional development as occurring in such a significant and high profile area. Without opportunities to update their knowledge and skills, it unlikely that staff will be able to develop sense of themselves as being expert practitioners. Thus, it is recommended that all professionals' expertise is reviewed and individual development plans established.

Furthermore given the lack of development in the practice of assessment over the past 15 years despite significant policy shifts, it is unclear whether nurses' practice in particular will change in response to the introduction of the single assessment process and the registered nursing care contribution. It is recommended that further research be conducted to assess the extent and nature of any change.

Finally, being recognised and acknowledged as having professional expertise may also be important in engendering a feeling of proficiency. In this study, doctors' and social workers' expertise appeared to be recognised by their multidisciplinary colleagues. For example, a consultant highlighted the importance of proficient social workers:

*Consultant: "... we always appreciate our social worker when a not very good locum comes to do his job, it happened last week [laughter] which is when you realise, because I know [name - consultant] spent about 2 or 3 hours trying to sort out all the things he's either made worse or, or got wrong"*

[Genicon2 149-153]

In addition, perceived proficiency in involving patients and informal carers in continuing care assessments also appeared to be valued, as an SHO highlighted:

*KA: "Do you think other staff have a role in relation to involving patients?"*  
*SHO: "I think the social workers are very good, I have to say the social workers are excellent and I think that they feel that it is a big part of their role and they generally ask the patient what it is they want and what they would be happy with, so yes I think they do"*

[Genisho2 225-231]

However, the same sentiments were not expressed about nurses. At times members of the multidisciplinary team expressed their frustration with nurses for seemingly lacking expertise. For example, a member of the hospital discharge team stated:

*They [nurses] must see people, relatives and that in the evenings, that others wouldn't see 9 to 5, they're the only people that work different hours and, and yet you don't hear them saying, well I spoke to the son, and they're very anxious about them coming, you know that's the kind of [pause] and I don't know why that is, I don't know.*

[Genihdt 144-148]

In this way, it appeared as though nurses were not always viewed as being proficient in involving patients and informal carers in continuing care assessments or identifying their individual needs. It is suggested that if professionals are not regarded as experts by other members of the multidisciplinary team, then their ability to develop a sense of their own expertise may be impaired.

Thus, a lack of a sense of expertise may have been a significant factor in nurses' marginal position within multidisciplinary continuing care assessments and therefore may warrant inclusion within the senses framework.

## CONCLUSION

Despite policy indicating that nurses have an important role in the assessment of patients' continuing care needs, and other professionals within this study highlighting how much they valued nurses' contribution, nurses still had a marginal position within multidisciplinary continuing care assessments. They appeared to defer assessments of need to other members of the team and failed to involve patients and informal carers in the assessment process. In this way the role of the nurse with the multidisciplinary team may be being eroded.

The application of Nolan et al.'s framework suggests that nurses' lack of these senses may account for their marginal position within multidisciplinary assessments. If nurses had a sense of purpose, continuity, security, achievement, significance and belonging then they may be better placed to assess patients' continuing care needs and involve them and their informal carers in this process. However, the findings of this study suggest that nurses may also have lacked a sense of expertise, and this may be pivotal to their ability to participate in

multidisciplinary assessments. Unless nurses are supported in developing a sense of expertise in assessing needs and involving patients and informal carers, then they may continue to have a peripheral role within multidisciplinary continuing care assessments.

## **KEY RECOMMENDATIONS**

Although a large number of recommendations could be made from the outcomes of this study, there were some situations where the need for action appeared particularly pressing. For ease of reference, this section contains a bullet point list of the key recommendations for policy makers, practitioners, researchers and those working in education.

### **For Policy**

- That there is greater clarity in local and national policy documents about the aims of continuing care assessments

### **For Education**

- That nurses are supported in understanding what is expected of them, and how they can contribute to assessments of patients' continuing care needs
- That more attention is devoted to teaching professionals, particularly nurses, how to assess patients' continuing care needs
- That greater attention is devoted to training on how to work with patients and informal carers and how to incorporate their perspectives into professional practice

### **For Practice**

- That team members are aware of the impact that their practice can have on other multidisciplinary professionals
- That attention is paid to ensuring that practitioners possess 'the senses' in order that they are able to practice effectively
- That, in particular, the expertise of practitioners is evaluated and that individual development plans are established

### **For Research**

- That more empirical work is conducted to establish the analytic generalizability of the senses framework
- That this empirical work seeks to establish the robustness of the seventh sense of expertise

That research is conducted to investigate the nature and extent of any change in nurses' assessment practice in response to substantial policy developments including the single assessment process and registered nursing care contribution.

## **APPENDIX 1**

### **TRUST DISCHARGE PLANNING POLICY**

#### **1. POLICY STATEMENT**

It is the Trust's belief that:

- 1.1 The assessment process for all patients in regard to their discharge planning, social and health care needs should begin at or before admission. No patient should be discharged without an assessment of their needs being undertaken.
- 1.2 Communication and consultation with the patient and their relatives and carers is of primary importance, regardless of their length of stay. Due account must be taken of the patient's and carer's needs in the discharge planning arrangements (Charter 1992, Community Care Act 1990).
- 1.3 The Named Nurse/ Midwife is responsible for co-ordinating the discharge plan.
- 1.4 Discharge planning is a multi-agency, multi-disciplinary activity in which all professions have a contribution to make.
- 1.5 The outcome of a properly planned discharge is that the patient can function appropriately in his/ her home immediately after discharge with no deterioration in their quality of life. This requires that:
  - i) The patient be well informed about their illness and continuing care arrangements.
  - ii) The patient has the appropriate arrangements waiting for them on return home.
  - iii) The patient receives the appropriate services on return home.
- 1.6 For patients unable to return home, the appropriate arrangements have for alternative accommodation taking into account, where possible, the preferences of the patient and his/ her carers.
- 1.7 When these arrangements involve residential or nursing home placements, assessments will have been undertaken either in accordance with [Borough] Social Services' or the Health Authority's Community Care Eligibility Criteria (introduced in April 1996). Local Community Care Panels will approve placements and determine funding responsibility.

#### **2. GOOD PRACTICE GUIDELINES**

- 2.1 The Trust regards the discharge planning process as a collective activity with the different professional disciplines making their own key contributions. It acknowledges that whilst not all patients in an acute unit require lengthy and individually focused discharge plans, communication and consultation with the patient and their relatives and carers remains of prime importance regardless of their length of stay. Multi-disciplinary involvement as soon as possible after admission is seen as the key to successful discharge planning. Early

referral to Physiotherapy, Occupational Therapy, Community Nursing, Social Work, General Practitioners and other disciplines (see attached appendices for criteria) will ensure proper consideration of patient's medical, personal, functional and social circumstances alongside family support and local services. Communication between the disciplines is essential and will very often take place in 'ward meetings' ideally attended by a senior member of the medical team as delegated by the Consultant concerned. The following are some common points of good practice irrespective of the client group:

- a) The patient's rights as expressed in the Patients' Charter are addressed i.e. that before discharge from hospital a decision should be made about any continuing care or social care needs the patient has. That the hospital will make arrangements with agencies such as Community Nursing Services, Local Authority Social Services, before the patient is discharged; and that the patient and their carers will be consulted and informed at all stages of the planning discharge process.
- b) That the wishes of the patient and their carers should be considered. Whenever possible, due notice of discharge to be given to patient and carers to allow preparatory arrangements to be made.
- c) Early referral to all disciplines involved in the assessment of home circumstances for discharge planning is a priority.
- d) Known carers at home have all relevant information, and their questions answered.
- e) Contact with Primary Care Services; fax to GP where possible; in advance of discharge.
- f) The timing of discharge takes account of the delivery time of the patient's services. Therefore Friday and week-end discharges for some patients requiring services are usually not appropriate.
- g) The successful organisation of transport.
- h) Medication to take home has clear instructions.

### **3. OPERATIONAL GUIDELINES**

- 3.1 Due account should be taken of the patient's and carer's wishes. Appendix 2 lists patient groups who may require particular attention.
- 3.2 The decision to discharge should involve the minimum of stress. The patient and carer should be offered a clear explanation of their illness. Full and clear information should be given regarding continuing care arrangements, endeavouring to maintain their quality of life and activities of daily living.
- 3.3 Without agreed support at home vulnerable patients requiring multiple community services to be in place before discharge, should not normally be discharged on Fridays, Bank Holidays or week-ends.

#### **PRE-ADMISSION**

- 3.4 Every opportunity should be taken to commence discharge planning before the patient is admitted through communication of relevant information from the patient's relatives, GP,

Social Services and other relevant agencies to the hospital, and co-ordination of discharge information in pre-admission clinics. The psychological needs of the patient should also be communicated as early as possible. 60% of patients should have a planned discharge date from the date of admission recorded in their medical/ nursing records.

#### CO-ORDINATION

- 3.5 The Senior Sister/ Charge Nurse in charge of each ward/ clinical area has key responsibility for ensuring that plans are in place for all patients within the ward.
- 3.6 Each discharge should be organised and co-ordinated by a named member of staff (i.e. **the Named Nurse/ Midwife**), who should be responsible for ensuring plans are effectively completed and communicated to all concerned. **Nurses are responsible for organising services by Community Nursing**, in collaboration with the Community Liaison Nurse. **A Discharge Co-ordinator** will trouble shoot delayed/ problems in liaison with ward staff.
- 3.7 Referrals to other members of the **multi-disciplinary team** (e.g. Physiotherapists, Occupational Therapists, Dieticians, Nurse Specialists) should be made as soon as possible after admission, particularly where discharge planning needs have been identified. They can be made by the Senior Sister/ Charge Nurse or Named Nurse/ Midwife.
- 3.8 Services required to support the patient in discharge from hospital must be identified during the hospitalisation and confirmation of their availability be received before discharge. **Social Workers are responsible for organising services delivered by Social Services.** (In cases where community nursing is required in a residential or nursing home setting, social workers arrange the accommodation and will liaise with current key professionals involved to secure from [name] Health Authority the mix of continuing health care needed).
- 3.9 If **new procedures or equipment** are involved in the nursing care of the patient following discharge, the Community Nurse should be invited to visit the ward to see the patient and have the care directly explained.
- 3.10 Where **medical intervention** will be needed following discharge, **medical staff** will provide written information which will be sent with the patient with formal confirmation to follow within 14 working days. Ward staff should fax discharge details to the GP where urgent follow up is required.
- 3.11 Where possible medical staff should prescribe TTAs 24 hours prior to discharge. Nurses should order seven days supply of dietary supplements for patients requiring them, on the ward order form, prior to discharge.
- 3.12 The nurse liaises with the **Pharmacist** as soon as the need for medication to take home is identified in order that the patient may be assessed for self medication and their education needs. The nurse should check the patient's TTAs correspond with their prescription before leaving the ward.
- 3.13 Where patients are to be discharged with **artificial methods of nutrition** at least one week's notice must be given to the Nutrition Team or Dietician in order to cover the situation regarding arrangements for home tube feeding for patients discharged from both sites.



- 3.14 Nursing staff must ensure appropriate **transport** is booked 48 hours prior to discharge. Transport requests should take into account the needs related to the discharge accommodation (e.g. 2 man transport will be necessary if the patient is going to high rise apartment blocks). Double check patients' correct address; clothing and keys where appropriate.
- 3.15 In cases of **Child Protection** discharge planning will inevitably take account of all the legal procedures under the Children Act 1989. The Child Protection Team **must** be involved at all stages.
- 3.16 In cases where patients are detained under **Sections of the Mental Health Act 1983** special attention should be given to meeting the legal requirements before discharge. The Mental Health Administrator and Hospital Social Services must be involved at all stages.
- 3.17 The patient should be assessed immediately prior to discharge by the nursing staff (and/ or doctors) to ensure the patient remains fit for discharge.

### **SELF-DISCHARGES**

- 3.18 When a patient discharges themselves against medical advice it may not be possible to adhere to these guidelines. However, the GP should be advised by the medical team by fax of what has occurred, the Trust's procedure for self-discharge followed, and the outcome of the admission recorded accordingly.

### **PROCEDURE AT WARD LEVEL**

- 4.1 The Named Nurse screens the patient at admission for their nursing/ midwifery and social care needs, taking into account the requirements this might impose for discharge planning.
- 4.2 Patients highlighted in Appendix 1 may need to be **referred to the Social Work Department within 1 working day of admission**. A referral form must be completed even though a telephone referral has been made.
- 4.3 Patients requiring nursing services should be referred to **Community Nursing at the earliest opportunity** (minimum 48 hours prior to discharge. A referral form must be sent even though a telephone call has been made). Please refer to [Borough] Community Services Trust information Pack about Community Nursing Services and Guide to Making A Referral.
- 4.4 The discharge plan documentation in the patient's nursing records should note the **activities and involvement of all members of the multi-disciplinary team**, including Social Work, Occupational Therapy, Physiotherapy, Speech Therapy, Dietetics, Pharmacy and Nurse Specialists.
- 4.5 The nurse liaises with the Pharmacist as soon as the need for medication to take home is identified in order that the patient may be assessed for their ability to cope with their medication. Three working days before discharge, the nurse should liaise with the ward Dietician regarding the need for the patient to take home dietary supplements so that a letter may be sent to the General Practitioner.

## MONITORING

5.1 The [Borough] Healthcare Discharge Monitoring Committee is responsible for monitoring primarily local arrangements for discharge first made under joint agreements between Local Authorities and Health Authorities as a requirement of the NHS and Community Care Act 1990, which was implemented in 1993.

5.2 The Committees Terms of Reference are clearly divided between Strategic and Operation and are printed below for reference.

### 5.3 A Strategic

i) To examine the existing [Borough] Discharge Planning Policy documents with a view to producing an updated and revised Policy to cover all patients for whose acute care the Trust is responsible.

#### **N.B. Not just those who reside within the boundaries of [name] Health Authority.**

ii) Responsibility for the Policy and discharge planning monitoring within the Trust to reside with all General Managers. The Director of Nursing and Patient Care will receive regular reports from service groups in regard to the policies implementation, and any required policy changes needing Trust Board approval shall be made via the Director of Nursing and Patient Care.

iii) To review the new policy annually with a view to advising the constituent responsible Authorities on amendments/ revisions necessary to the Joint Agreement between Local Authorities and the Health Authority as required by the NHS and Community Care legislation and the more recent Continuing Health Care regulations.

### 5.4 B Operational

iv) The committee should meet not less than 5 times each year and should produce an Annual Report by the end of May each year.

v) In general terms within the parameters of the current Joint Agreements the Committee should receive reports on the monitoring of:

Good practice

Delayed Discharges

Failed Discharges

Complaints

Statistical returns on discharge planning and care management from the social services department.

Continuing Care ... both NHS and social services placements.

vi) The Committee should note comments from any of the contributing professional disciplines about any adverse factors inhibiting performance in pursuit of implementing the policy.

vii) The Committee should report on such instances appropriately, in writing, making recommendations to resolve the problems.

viii) The Committee should act as the key vehicle in response to any Regional Office or Social Services Inspectorate inspection; or request for information from the responsible agencies.

ix) The Committee shall select its own Chairperson and may co-opt particular persons for specific time limited purposes.

## 5.5 Committee Membership

<b>[Borough] Healthcare Nurse</b>	4 representatives	e.g. Doctor, Senior
<b>[Borough] Community Trust</b>	3 representatives	e.g. Community nurse, Manager etc..
<b>[Name] Health Authority</b>	1 representative	e.g. Health Commissioner
<b>[Borough] GP Forum/ Multifund</b>	1 representative	
<b>[Borough] Social Services Dept.</b>	2 representatives	e.g. Hospital social worker manager, Area Officer

This provides a working membership of 11 with the Trust ensuring and providing appropriate secretarial support.

## 5.6 Monitoring of Discharge Practice

5.6.1 As recommended H[89]5 and LAC[89]7 the monitoring of the discharge planning process is a joint activity involving both health and local authority representatives.

5.6.2 A monitoring group meets monthly to review discharge practice across the Trust.

5.6.3 Monitoring will include indicators outlined in the [name] Health Authority General Quality Specification, including:

- a) Readmissions
- b) Length of time ad admission to refer for community care assessment
- c) Length of time between referral and implementation of discharge for
  - i) complex assessment
  - ii) different conditions
- d) Proportion of discharge plans produced and number requiring multi-disciplinary meetings
- e) Median length of stay for key patients groupings
- f) Follow-up surveys of patients after discharge
- g) Patients remaining in hospital after medically fit for discharge
- h) Day of the week people discharged

5.6.4 There will also be regular review of:

- a) Discharges which have been identified as having gone wrong in some way as identified by Community staff, patients or carers

- b) Complaints
- c) Discharge plan audits

### Appendix 1: Hospital Social Work

#### **Explanatory notes Re: The Social Worker's role in discharge planning.**

Social Workers have knowledge of health and social care services which can be mobilised to assist patients and carers. They give practical advice and information concerning welfare right specific to health-related issues and access to other financial assistance. They liaise with community agencies to meet social needs, including housing, domiciliary services, employment, day care and residential care. Social Workers have skills in counselling to assist patients, relatives and carers, in coping with the effects of stress of illness, disability, grief and bereavement.

Since 1974, hospital based social workers have been employed by Local Authorities hence those working within the Trust are staff of [Borough] Social Services Department. All their work is enshrined in statute and they primarily deal with adults, children and families who are at risk. Statutory responsibilities include child protection/ prevention of abuse and registration of children with disabilities under 1989 Children's Act; assessment under the Mental Health Act, 1983; assessment for provision of residential (Part III) accommodation; plus other duties under various Acts, including the NHS and Community Care Act, 1990.

Not all patients admitted to hospital will need help upon discharge from hospital. However, in order to ensure that people who do need help and not missed, a screening tool will be used to identify them. Upon admission, the admitting nurse will use a checklist, i.e. featured as Section 3 in the Policy, to identify those patients who will need to be referred to Social Workers for an assessment. This referral will be made within 24 hours of admission. The Social Workers will complete initial assessments devised by the Local Authority irrespective of residence. When comprehensive assessments are indicated on patients living beyond the locality, Area Social Workers or Care Managers of the home Authority will undertake them, usually at the invitation of the Hospital Social Worker.

There are initial and complex assessments. For patients who are judged to have complex needs, a community care assessment will be required from the multi-disciplinary team. A Care Planning Meeting may then be called involving purchasers if services from one or more of the Local Authority, Health Authority and Community Health Services NHS Trust. Social Workers will make decisions about the provision of social care in line with agreed priorities determined by the Social Services Department.

There is a statutory requirement for Social Services to commence Planning and Strategy Meetings and Case Conferences for **all children who have been or are likely to be, subject of a Child Protection investigation**. These meetings will be multi-disciplinary and will take place before a child is discharged from hospital. They will involve agencies outside the hospital such as the Police, School Representatives, if appropriate, Social Services and Child Protection Officers. These meetings are convened under the Procedures of the Area Child Protection Committees of the statutory Authorities concerned.

## **Appendix 2: Patient Groups who may require particular attention**

Patients living alone who are elderly (i.e. 70 years and over), frail or with an elderly or disabled carer. Attention should be paid to those patients demonstrating any form of mental deterioration, (e.g. dementia) combined with their physical illness.

Patients and their families for whom the illness is a major crisis in their lives.

e.g. a) where there will be significant continuing disability  
b) with a chronic condition or terminal illness

Patients in the early stages of recovery, or who are discharged quickly.

Patients suffering from psychiatric disorders.

Patients with learning difficulties.

Babies and children where evidence of family difficulty has been identified.

Babies and children in need of protection.

Mothers with newly born babies having a history of substance abuse.

Patients who have been in hospital for an extended period irrespective of age, i.e. in excess of the standard length of stay for the particular care group.

Patients with a serious housing which impacts on their health; the homeless or those unable to return to their previous home.

Patients whose home circumstances have revealed obvious conflicts and differences between themselves, their families and friends which would be exacerbated by their return home.

Patients diagnosed as having inflicted deliberate self harm.

Patients and carers who experience communication problems, particularly those whose first language is not English.

Patients who are at risk of abuse.

Patients who are to be discharged to a distant address.

Patients already in receipt of Social/ Community Services.

Patients on multiple and complex medication.

## **APPENDIX 2**

### **LOCAL ELIGIBILITY CRITERIA**

#### **Eligibility Criteria for Residential Care**

These criteria apply to service users who are elderly, disabled, or who experience physical or mental ill-health or learning difficulties.

1. Service users will be eligible for residential care if they either:

a) Need constant supervision or the constant availability of help due to their physical condition, mental health or learning difficulty and are unable to be left alone as this would cause severe risk to themselves or others.

OR

b) Need help with most aspects of daily living, including going to the toilet, due to their physical condition, mental health or learning disability.

OR

c) Have temporarily lost the ability to live independently following hospital admission, bereavement or other life event or be planning to live independently in the community for the first time and need help and support in establishing the patterns of everyday life.

2. Residential care must be the most appropriate response to the needs of the service user, community options having been exhausted or assessed as inadequate, given the current eligibility criteria for the provision of domiciliary care and carers' needs, ability and willingness to cope.

3. All options must have been discussed with the service user and, where appropriate, their carer and the service user must be in agreement with a placement in residential care.

4. The service user must understand that a charge will be made for accommodation in residential care based on an assessment of their financial position. The nearest relative or carer may be consulted if this is the service user's wish or if the service user is not able to understand the implications of financial assessment.

5. Service users should be able to feed themselves and wash and dress with assistance from staff.

6. Service users should be able to walk with the aid of a walking frame or stick with the assistance of one member of staff, or if wheelchair bound, be able to transfer independently or with the assistance of one person.

7. Service users with urinary incontinence e.g. 'accidents' because they cannot get to the lavatory through mobility or other problems, will be accepted for residential care. However, more serious cases of incontinence will need to be investigated by the Health Authority or other appropriate agency to determine possible cause and the support which may be required.

8. Service users who use catheters or colostomy bags will be accepted for residential care providing the catheter or colostomy can be managed with the help of care staff under the guidance of the Community Nursing Service.

9. Service users who are disorientated or confused can be accommodated providing this does not prevent them from having a degree of participation in the normal lifestyle of the home and does not frequently disrupt the lifestyle of the others. In some cases it may be necessary to seek specialist accommodation which is more able to respond to the needs and wishes of the particular service user.

10. Partners of service users admitted to residential care, where the couple do not wish to be separated, will be considered for placement even if they are not eligible on the above criteria.

11. The process of moving into residential accommodation often results in increased confusion and disorientation which may be temporary. It is important to ensure the widest possible communication and support between carers and family members and statutory and voluntary agencies when assessing an applicant who suffers from any form of mental health or behavioural difficulties.

### **Eligibility Criteria for Nursing Home Care**

These criteria apply to service users who are elderly, disabled, have learning difficulties or who are experiencing physical or mental ill-health.

Service users will be eligible for nursing home care if they either:

a) Need constant supervision or the constant availability of help due to their physical condition, mental health or learning difficulty and are unable to be left alone as this would cause severe risk to themselves or others

OR

b) Need help with most aspects of daily living, including going to the toilet, due to their physical condition, mental health or learning difficulty

AND

c) They require skilled nursing care beyond the capacity of the community nursing service.

This may include the following:

1. Administration of medication by injection
2. Dressing an open or closed wound where skilled nursing techniques are required.
3. Assisted feeding requiring nursing skills
4. Nursing care of the type given to bed-fast or predominantly bed-fast service users
5. Continuous and constant attention as a result of incontinence

6. Intensive rehabilitative measures following surgery or debilitating disease which is likely to continue for more than a very short period
7. Management of complex prosthesis or appliance, including administration of oxygen. However, if portable nebulisers are supplied a residential home placement would be appropriate
8. Service users suffering from illness which requires long term terminal nursing care
9. Service users who exhibit aggressive or violent behaviour likely to be harmful to other residents or staff
10. Service users who are confined permanently to bed
11. Service users who, after full medical assessment, are deemed to have uncontrollable or high incontinence levels
12. Service users who need the assistance of two staff for mobility and/ or transfers
13. Service users with a progressive, deteriorating condition which does not require ongoing medical supervision/ treatment 24 hours a day, but where the prognosis is that the condition will be terminal within a few weeks or months
14. There will be occasion where, because of the speed of a progressive medical condition, a patient should be placed in a nursing home immediately, although their level of dependency is not at the usual level required at the time of assessment

Care in a nursing home must be the most appropriate response to the needs of the service user, community options having been exhausted or assessed as inadequate, given the current eligibility criteria for the provision of domiciliary care and carers' needs, ability and willingness to cope.

All options must have been fully discussed with the service user, and where appropriate, their carer and the service user must be in agreement with a placement in residential care.

The service user must understand that a charge will be made for accommodation in residential care based on an assessment of their financial position. The nearest relative or carers may be consulted if this is the service user's wish or if the service user is not able to understand the implications of financial assessment.

Partners of service users admitted to nursing home care, where the couple do not wish to be separated, will be considered for placement, even if they are not eligible on the able criteria.

### **Eligibility Criteria for In-patient NHS Continuing Care**

People needing in patient continuing care must satisfy one or more of the following five basic criteria:

1. They will need ongoing comprehensive nursing care
2. They need accessible medical expertise



3. They need the routine use of highly complex specialist equipment where it is unreasonable to expect a private or voluntary nursing home to either possess or have the necessary expert staff to operate
4. They need a secure environment where specialist supervision is essential to prevent self harm or injury to others
5. They need terminal care. People who have completed acute treatment in hospital and whose prognosis suggests they may die within the near future i.e. within 6 months. In such instances individuals' clinical needs would be matched against the Authority's criteria for NHS terminal care provision

In order for consistency of practice comprehensive nursing criteria is met when any four of the following five care components are satisfied:

- i) Feeding - The presence of a nurse/ carer is required at least 75% of the time taken to feed the patient
- ii) Mobility - A completely dependent person - unable to walk; stand unaided; requires positioning in both chair and bed
- iii) Nurse attention - Two to four hourly, or more frequently: re intake - output; medications; dressing; catheter management; care of drainage tubes; diabetic monitoring; surveillance of very confused patients
- iv) Communication - Person has marked difficulty comprehending simple instructions and/ or difficulty in communicating their needs. E.g. someone with profound deafness, CVA induced speech loss, of those having MS, Parkinson's or Alzheimer's disease affected comprehension
- v) Involuntary elimination - Complete loss of control of the excretion of urine and faeces

People fulfilling the criteria will usually match four of the five listed components.

- vi) Major intervention - Applies only in exceptional circumstances e.g. an actively aggressive, suicidal, or disturbed person having to be specialised at all times

These eligibility criteria will need to be read in conjunction with admission criteria for specific facilities providing continuing in patient care for elderly people with mental health problems. Similarly the eligibility criteria for palliative care services may also overlap with the in-patient criteria and examining both may be helpful.

There may be local circumstances where the equivalent to in-patient continuing care will be purchased/ provided for people who wish to be cared for at home. Such people would also need to meet the eligibility criteria and live in home circumstances in which the necessary care can be provided safely.

It is necessary to consider the overall cost of individual arrangements and they would not normally exceed the cost of in-patient care, since they must be compatible with the authority's contractual arrangements with its providers.

## APPENDIX 3

### DOMAINS OF THE SINGLE ASSESSMENT PROCESS

#### User's perspective

- Needs and issues in the users' own words
- Users' expectations, strengths, abilities and motivation

#### Clinical background

- History of medical conditions and diagnoses
- History of falls
- Medication use and ability to self-medicate

#### Disease prevention

- History of blood pressure monitoring
- Nutrition, diet and fluids
- Vaccination history
- Drinking and smoking history
- Exercise pattern
- History of cervical screening and breast screening

#### Personal care and physical well-being

- Personal hygiene, including washing, bathing, toileting and grooming
- Dressing
- Pain
- Oral health
- Foot-care
- Tissue viability
- Mobility
- Continence and other aspects of elimination
- Sleeping patterns

#### Senses

- Sight
- Hearing
- Communication

#### Mental health

- Cognition and dementia, including orientation and memory
- Mental health including depression, reaction to loss, and emotional difficulties

#### Relationships

- Social contacts, relationships, and involvement in leisure, hobbies, work and learning
- Carer support and strength of caring arrangements, including the carer's perspective

#### Safety

- Abuse and neglect
- Other aspects of personal safety
- Public safety

Immediate environment and resources

- Care of the home and managing daily tasks such as food preparation, cleaning and shopping
- Housing - location, access, amenities and heating
- Level and management of finances
- Access to local facilities and services

## **APPENDIX 4**

### **KEYWORDS USED IN THE LITERATURE SEARCH**

#### **Involvement terms**

Involvement  
Participation  
Partnership  
Consultation  
Choice  
Empowerment  
Collaboration  
Decision making  
Autonomy

**PLUS**

#### **Assessment terms**

Needs assessment  
Nursing assessment  
Continuing care  
Care planning  
Discharge planning  
Continuity of care  
Multidisciplinary roles

**PLUS**

#### **Ageing terms**

Ageing  
Elderly  
Older people  
Older patients  
Informal carers  
Family

## APPENDIX 5

### MEDLINE SEARCH STRATEGY

exp patient participation  
exp consumer participation  
exp consumer involvement  
exp choice behavior  
exp cooperative behavior  
exp decision making  
exp freedom  
partnership\*  
consult\*  
empower\*  
#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10  
exp geriatric assessment  
exp nursing assessment  
exp needs assessment  
exp continuity of patient care  
exp patient discharge  
exp patient care planning  
#12 or #13 or #14 or #15 or #16 or #17  
exp frail elderly  
exp aged  
exp family  
exp caregivers  
#19 or #20 or #21 or #22  
#11 and #18 and #23  
limit LA=english

## APPENDIX 6

### CRITERIA FOR THE EVALUATION OF QUALITATIVE RESEARCH PAPERS DEVELOPED BY THE MEDICAL SOCIOLOGY GROUP

*1. Are the methods of the research appropriate to the nature of the question being asked?*

- i.e. does the research seek to understand processes or structures, or illuminate subjective experiences or meanings?
- Are the categories or groups being examined of a type which cannot be preselected, or the possible outcomes cannot be specified in advance?
- Could a quantitative approach have addressed the issue better?

*2. Is the connection to an existing body of knowledge or theory clear?*

- i.e. is there adequate reference to the literature?
- Does the work cohere with, or critically address, existing theory?

#### *METHODS*

*3. Are there clear accounts of the criteria used for the selection of subjects for study, and of the data collection and analysis?*

*4. Is the selection of cases or participants theoretically justified?*

- The unit of research may be people, or events, institutions, samples of natural behaviour, conversations, written material, etc.: in any case, while random sampling may not be appropriate, is it nevertheless clear what population the sample refers to?
- Especially in samples of time, or ethnographic studies, how were they chosen?
- Is consideration given to whether the units chosen were unusual in some important way?

*5. Does the sensitivity of the methods match the needs of the research questions?*

- Does the method accept the implications of an approach which respects the perceptions of those being studied?
- To what extent are any definitions or agendas taken for granted, rather than being critically examined or left open?
- Are the limitations of any structured interview method considered?

*6. Has the relationship between fieldworkers and subjects been considered, and is there evidence that the research was presented and explained to its subjects?*

- If more than one worker was involved has comparability been considered?
- Is there evidence about how the subjects perceived the research?
- Is there evidence about how any group processes were conducted?

*7. Was the data-collection and record keeping systematic?*

- e.g. were careful records kept?
- Is the evidence available for independent examination?
- Were full records or transcripts of conversations used if appropriate?

*ANALYSIS*

*8. Is reference made to accepted procedures for analysis?*

- Is it clear how the analysis is done? (Detailed repetition of how to perform standard procedures ought not to be expected).
- Has its reliability been considered, ideally by independent repetition?

*9. How systematic is the analysis?*

- What steps were taken to guard against selectivity in the use of data?
- In research with individuals, is it clear there has not been selection of some cases and ignoring of less interesting ones? In group research, are all categories of opinion taken into account?

*10. Is there adequate discussion of how themes, concepts and categories were derived from the data?*

- It is sometimes inevitable that externally-given or predetermined descriptive categories are used, but have they been examined for their real meaning or any possible ambiguities?

*11. Is there adequate discussion of the evidence both for and against the researcher's arguments?*

- Is negative data given? Has there been any search for cases which might refute conclusions?

*12. Have measures been taken to test the validity of the findings?*

- For instance, have methods such as feeding them back to the respondents, triangulation, or procedures such as grounded theory been used?

*13. Have any steps been taken to see whether the analysis would be comprehensible to the participants, if this is possible and relevant?*

- Has the meaning of their accounts been explored with respondents? Have apparent anomalies and contradictions been discussed with them, rather than assumptions being made?

*PRESENTATION*

*14. Is the research clearly contextualised?*

- Is all the relevant information about the setting and the subjects supplied?
- Are the variables which are being studied integrated in their social context, rather than being abstracted and decontextualised?

*15. Are the data presented systematically?*

- Are quotations, fieldnotes etc. identified in a way which enables the reader to judge the range of evidence being used?

*16. Is a clear distinction made between the data and its interpretation?*

- Do the conclusions follow from the data? (It should be noted that the phases of the research - data collection, analysis, discussion - are not usually separate and papers do not necessarily follow the quantitative pattern of methods, results, discussion.)

*17. Is sufficient of the original evidence presented to satisfy the reader of the relationship between the evidence and the conclusions?*

- Though the presentation of discursive data is always going to require more space than numerical data, is the paper as concise as possible?

*18. Is the author's own position stated?*

- Is the researcher's perspective described?
- Has the researcher examined their own role, possible bias, and influence on the research?

*19. Are the results credible and appropriate?*

- Do they address the research question(s)?
- Are they plausible and coherent?
- Are they important, either theoretically or practically, or trivial?

## *ETHICS*

*20. Have ethical issues been adequately considered?*

- Is the issue of confidentiality (often particularly difficult in qualitative work) been adequately dealt with?
- Have the consequences of the research - including establishing relationships with the subjects, raising expectations, changing behaviour etc. - been considered?



## APPENDIX 7

### TOPIC GUIDE FOR GENERAL STAFF INTERVIEWS

Thinking about the care on \_\_\_\_\_ ward:

How do you feel about patients and informal carers being involved in assessments?

What are the advantages from the perspective of:

- patients?
- informal carers?
- staff?

What are the disadvantages from the perspective of:

- patients?
- informal carers?
- staff?

What factors help you involve patients and informal carers?

What factors inhibit you?

Who is involved in assessing the continuing health care needs of older people in hospital?

When are their needs assessed?

Are you involved?

To what extent do you think that you should be involved?

How do you assess patients' continuing health care needs?

Are patients/ informal carers involved in your continuing health care assessments?

how?

is this level of involvement satisfactory/ appropriate?

Who is involved in assessing the continuing social care needs of older people in hospital?

When are their needs assessed?

Are you involved?

To what extent do you think that you should be involved?

How do you assess patients' continuing social care needs?

Are patients/ informal carers involved in your continuing social care assessments?

how?

is this level of involvement satisfactory/ appropriate?

What is the nurse's role in involving patients in the assessment of their continuing care needs?

What are the other multidisciplinary team roles?

Are there any gaps/ overlaps in the assessment of patients' continuing care needs?

What do policies say about:

-the conduct of continuing care assessments?

-the involvement of patients and informal carers in continuing care assessments?

national policies

professional policies

hospital policies

What training have you had in:  
assessing needs?  
involving patients and informal carers in your practice?

Have you at any time consciously changed the way you conduct continuing care assessments?

To sum up:

What does the involvement of patients and informal carers in assessments, mean to you?

## APPENDIX 8

### GENERAL INTERVIEW WITH A D GRADE NURSE (N7)

2nd March 1999

**KA:** What I'm mainly interested in really is how assessments are, are made, of what kind of needs people have when they're discharged from hospital and way that patients and their families are involved

**Nurse:** Okay

**KA:** Okay

**Nurse:** Yeah, uh ha

**KA:** Erm, so to start with, how do you feel about patients and their families being involved in assessments of needs?

**Nurse:** I think that's very good, that's a very good thing

**KA:** Yeah

**Nurse:** And erm, yeah, I think that's very good because in that way they know, we know what care the person, patient, needs we know what the relatives need and it makes for a very happy atmosphere as far as I am concerned when they're involved, yeah

**KA:** Are there advantages from their point of view of being involved?

**Nurse:** Well number one they can tell us what services they feel that their, their relative might need, and er we can get involved, like the social work as well, the speech therapist if needed, erm, dietician because they're very important as well and physio, that's another person that's, and also OT, it's just everybody can really get involved and what they also like is if the doctor also comes in, gets involved with them as well, you know, tells what's going on and they can let off steam and you know, it's just everything, everybody involved and it makes it better for the patient, makes it better for the relatives and nursing as well, because I feel that they see that they're being looked after properly as well, you know, and that's it, erm, so, yeah, yeah, it's a good thing

**KA:** Yeah. Are there any disadvantages of patients and families being involved in assessments?

**Nurse:** Sometimes, they can tell you stories, and it's not always a true picture that's coming out, and then you have to be a bit objective in the way in which you're listening to what they're saying because it's just like the, what 2 days ago, this lady told me she was feeling suicidal

**KA:** Right

**Nurse:** Because of all the care that she had to give her, her mum and I knew the lady was in sheltered accommodation but she said she still had to go in and do quite a lot, now I felt the lady was so tearful and looked really ill that she might do it, so I referred it to the social worker but the lady didn't, she has never rung back so obviously she was not as suicidal as, you know, as I thought, so you know, those are the sort of things that you have to look out for but in, in you know, it was, oh it was quite distressing to see her, it was, and then just to find out now that you know, she was probably playing a little sort of game with me because there's more, a lot of family wrangling that's been going on, so

**KA:** Right

**Nurse:** That was that, yeah

**KA:** Right

**Nurse:** Erm, what else can I really say about that, erm, I think that's one of the main disadvantages is getting the whole picture, the whole truth of really what family life is really like, because sometimes like I said it can get distorted and you know, sitting round there feeling really sympathetic to this person, and you know, it's not half as bad as you thought, but on the whole, like I said, I, I do like them getting involved, yeah

**KA:** Yeah. How, how do you tell what's distortion?

**Nurse:** Well that's it, it was, it was very hard for me to really work that one out and it wasn't until when I said I'll get the social workers and got myself into quite a lot of hot water that I realised the lady's not half as bad because she's never rung back, she has not rung back at all and that the way that, now we're talking like the next day, when this, the social worker said that you know, she would try and help that this lady didn't ring back and believe you me, she had tears were flowing, she said she was heading for a nervous breakdown, she hasn't eaten properly and I don't know whether she put some blackening around her eyes because they were really dark, like she hadn't slept for ages, but like I said, you know, or probably she just didn't want them to know too much of her business, I don't know but she, she never rung back

**KA:** Right

**Nurse:** So, I, it's very hard, it's really hard I, I couldn't really answer that truthfully because you can't, you don't know, you don't know, at the time you just erm ...

[interruption in office]

**KA:** Are there any ways in which you're aware of helping patients and families become involved in assessments?

**Nurse:** Erm, I think from the time when they're first admitted that you realise who, you know, when you're taking the, all the information about them, but then again you have to make sure that you also really do talk to the relatives because I find when you first admit the patient sometimes everybody's happy and mum or dad is in hospital they're happy until we hear about this discharge it's then we suddenly hear about you know, they've 16 stairs to climb or they live at the top floor in a flat and erm they can't, there's no lift and they can't get out they, you know, and these are the things that yeah, you should get when you admitting them but these are some of the things they sort of hold back until the day of discharge or a few days before the discharge and then, as you know, sometimes everybody's temper's very frayed by then, so, yeah, it, it's like I said everything's got it's good points if everybody comes out and says the truth and say really what's going on and not leave it to the last minute when you know, poor social worker's got to be running up and down to get everything, and they're upset with us for not, sending their their mum or dad home too early you know, those are the things, yeah, everything should be really done from admission but like I said, it's not, not always

**KA:** Are there ways in which it could be?

**Nurse:** [pause]

**KA:** Or, or are there reasons why it isn't?

**Nurse:** Erm, like I, because when the, the relative's coming in or the patient's coming in, the relative is relieved because number one they might have fallen over how many times and all they're thinking about at the time is, they're in hospital that's a burden off me, now we might be so busy that we don't, we, we get all the information but like I said it's just got, 'do you own your own house, do you live in a council place' all right it's fair enough having that 'do you have stairs to climb' 'yeah' it's all there on the form but it doesn't really say how many, you might just be writing 'yes' 'no' and then when you go back again to find out, they've got 20 stairs to climb, you haven't asked that question and nobody said that because, you know every side is sort of relieved that mum's in hospital and you're just trying to get the admission done properly, as far as you're concerned it's done properly because you've wrote, 'yes' or 'no' to what the, the question is on the form

**KA:** Hmm

**Nurse:** See you know, it's very rare, sometimes I remember that I must ask how many stairs, do they have a lift to go to the flat and things like that erm, do they go to day hospital, you might write 'yes' on the form, but how many days, you know, just, just little silly things like that and then it causes a lot of problems when their discharge is coming if, if it's not done properly, and I have to be honest it's not all the time I remember to do it, and if I've 3 or 4 admissions coming in, as you know, sometimes they all come in together, you might do the first one absolutely perfect and put everything down there, and then by the fourth one you're just writing the, 'yes' and 'no' on the form and then that's it, isn't it, so, it, it, it's hard getting it

right that's the problem you know, and as we haven't got much time to actually sit down like we used to and, I don't know give more, be able to communicate more with the relatives then this is why you know, there's a sort of breakdown really with the information you know, and I don't like the way that the kardex format is anyway I think it's, it needs to, it could be a bit more detailed in certain areas and less detailed in, in other areas you know, but

**KA:** Are, are you thinking of particular areas?

**Nurse:** Like I said erm, where's it's got your own house, and things like that

**KA:** Yeah

**Nurse:** Then, I, I'm not interested in, well I shouldn't say I'm not interested, if it's their own house or, or what, all I, if they live in a house that should be important, if they live in a flat, erm, and then put how many stairs, you know, because you do forget, you do forget those things and erm, it's got the meals on wheels, the district nurses, home help all, all those are the things yeah, that's, that's all important but you know, how many days do your relatives come in, you know, just little silly things because it's all right erm, putting down do you have home help seven over seven but sometimes the home help's coming seven over seven and the relative is coming seven over seven as well, you know, it's just a lot of things I'd have to really get the form and then have a good look and see where I would change it, I'd change a lot of things really

**KA:** Yeah

**Nurse:** And then like having 3 main people for erm you know, if anything happened it's a good idea but believe you me, when you're taking the erm admission and the relatives are all sitting there that's another thing that gets their back up as well, when you're asking, which one of you do you want to put down, 'well put me first, put that one second and put that one third' now you know, I don't know when we just had one and you just put down the one and then you go, 'if I can't get this' but when it's all there and they can see it you know, one two and three, it upsets them

**KA:** Yeah

**Nurse:** And I've seen it because when I admitted this lady you know, she said 'no, I am put', I was going to going to put her name down and the brother jumped in and said 'no, I'm first' you know, it's just the way that the things are put, they can be put in a different way, but, that's that, and erm, what else can I say, I think there's a lot, there's a lot of changes that would be better, especially in care of the elderly but like I said, it's, it's, I, I feel as though I don't have the strength or that say anything to anyone because they don't listen, you know, because the visiting hours as well, I mean we used to have them 10 till, till 8; to have it 2 till 8, now what I'm saying, is this might sound really awful but, they're just, everybody just comes in at any hour of the day and that's you know, there's a lot of things, there's so many things [unclear - 153], there's so many things now, that you know, it's not there, it's just not the same, I'd like to make everything to stay the same but there's thing's I'd like to improve

**KA:** So how does the change in visiting hours have an impact?

**Nurse:** Well I think sometimes it makes, they, they were used to their coming in in the morning and staying until whatever time, now they're coming in in the afternoon and spending less and what I've found out with many of the relatives, why they want to come at 10 in the morning was because they were using, use, they use less electricity and, that's the truth, and they don't have to put on their heating for nearly the whole day you know, and all these little silly things that you wouldn't believe, it's when you're actually sitting there and listening to them you know, but it's, it's makes it difficult for, for you as well as a nurse because they're erm, how can I put it, they're not as friendly as they were once when they used to be able to come in at you know, so everything's changed

**KA:** Hmm. Are you aware of any factors that maybe prevent patients or families becoming involved in assessments?

**Nurse:** No, no I couldn't really, the only time that that is happening is if a relative has been really far away and I mean doesn't live in this country and we've had to rely on like next door neighbours and things like that, but most of the time, and even saying that, we had a lady whose

daughter lived in America and she actually came over and spent a few months and got involved in the care, which was you know, so, no, like I said, the main problem is if you don't get everything right on the admission, so that if the discharge comes, and like I said their, their living accommodation or, or, is not up to scratch like, people have outside toilet, we take it for granted, right, that everybody has an indoor toilet and I've been on the community and I saw for myself a good fifty percent probably even more than that in the elderly, they don't have toilets indoors, it's way down the back garden, you know, and those are the things that, it's not on the form, you don't think of it, you know, because the form says have you got a toilet upstairs or downstairs, somebody might just go, 'no we haven't got a toilet upstairs or' and you think well you've probably got one downstairs, you know, not thinking that's it's right outside in the back garden, you know, and, that, that's another thing that gets people very upset when you're ready to send them home, you don't know and, yeah, yeah, those silly things, those things that we take for granted sometimes, we have to remember that they, they have, you know, they haven't got those, I was very shocked when I went round the community, I didn't even know so many people had outside toilets, you know, didn't even have a bathroom, never mind a toilet and then they were with this, in this kitchen sink you know, and I have never seen anything like it, honestly, and those sort of things you have to think about, but then when it, the majority of us have always been ward based and that's, that's another problem, we're ward based, we don't go out into the community, so we've got our circles, and we're, well relatively well off compared to some of these erm, patients and you would never, like I said in a million years, think that these sort of things happen, no central heating, no double glazing, no toilet inside, no bathroom, I mean it's just something that, just unheard of now isn't it, so, so sometimes you can see why the relatives get really upset

[interruption in office]

**KA:** Erm, I've got a short series of questions which relate to people's health care needs when they're discharged from hospital

**Nurse:** Yeah, okay

**KA:** And one, the same kind of questions related to their social care needs

**Nurse:** Yeah

**KA:** But, I'm a bit worried about the batteries in this, so I think I might change it

**Nurse:** Change it, oh, okay

[pause]

**KA:** Erm, who, which professionals er, would be involved in assessing what health care needs people would have when they're discharged from hospital?

**Nurse:** [pause] I'd say er, that the social workers, erm, definitely like the OTs and [pause], the district nurses or health visitors and even us ourselves, because at the end of day sometimes they go home and something might happen and they might come back to us as well, so in all, really, it's still the same sort of team and if they're diabetic the, the diabetic nurse, you know

**KA:** I'm thinking particularly about decisions that are made in hospital erm, you know, decisions about the kind of health care support people require in preparation for them going home, so it's decisions that are made here, erm, to organise ...

**Nurse:** On the ward like

**KA:** Yeah, to organise support for people at home

**Nurse:** Nurses, nurses definitely nurses then, doctors play a small part as well but definitely I think that falls on the nurses, yeah, because if we don't tell the other groups of people as well, it isn't going to get done, so, yeah, that's definitely 100 percent I think that's the nurses, yeah

**KA:** And when are, when are these decisions made about the kind of health care support people will require at home?

**Nurse:** Now realistically or it should be when the patient comes in, but it's usually, as I've noticed now a few days before the patient is leaving the ward which is not very good, it's not very good, because really as you, like I said, as you go through the assessment of the patient erm, the admission, you should be getting certain people involved anyway, from the beginning,

so by the time they're discharged you know you can get everything moving, but it can't always work like that

**KA:** Yeah

**Nurse:** And another thing what's, why I don't think it can work satisfactorily, a person might come in and you might be thinking 'well they'll only be in for a week' something else happens, and then you know, they'll be in for another week and so on and so on, so it's not always you know, very good to plan ahead in that sense, I know you should, but sometimes I have to admit I'm one of those who don't like to plan too far ahead in case anything happens, because I've done it before and then everything has to be cancelled and you know, that, that's another thing that upsets people as well you know, because everything you have to be careful how you, especially with care of the babies and, care of the elderly I think are two very important group of people where people's how can I put it, emotions, you have to be careful how you do things because er, they can get very distressed and upset with they way you do things, so, that, that's, but it should be right, right the way through like I said, from the beginning of their admission

**KA:** And how are decisions made about the kind of health care support that people will require when they're discharged?

**Nurse:** Well when you're going, when you're assessing and you're going through it, now if they had erm, like they have got ulcers and things, you know that, the might not be healed by the time the person goes home

**KA:** Right

**Nurse:** So you know you're going to get the district nurse, if they're diabetic and they are on insulin you know you have to involve the diabetic nurse and she'll have to be involved practically from admission, so that she can get involved with them and they get to know her as well, and the same with the people who are erm, suffering from really bad chest infection or COA, is it COPD, that, that you get the respiratory nurse and all these people like you to get them involved from, from admission really, so that they, they get to know their client and their client gets to know them as well, so, yeah, all the different sets of people that you have to involve them and not leave it because this is, this is where we do get ourselves in trouble because sometimes when a person, they're diabetic, the day before, you're ringing up the diabetic nurse to say oh such and such is diabetic, they're on how many units of insulin, can you go in and see them, she doesn't know them, they don't know her and there's like not that rapport and you know, it has happened quite a few times but because, I'm not making excuses, but because you're so rushed, these things that I can say to you quite rationally here and think, 'yeah, that's how it's done', it sometimes it, it's just not done, yeah

**KA:** How do you erm, make sure that you haven't missed areas?

**Nurse:** Hmm, now, that is a difficult, that's a very difficult question, hmm, well, [pause] I couldn't really answer that one truthfully because I would go through everything that's on the form and like I would actually ask the relatives and everything but I know even though I might think to myself I've been really thorough, I know sometimes there's things I've missed, like I said to you, outside toilet, no bathroom erm, who does your shopping for you, they might say erm, 'home help comes in and does it' not saying erm, she might just come in once a week, now who does the shopping for the other 6 days, you know, things like that, it actually escapes you and that's why I said I couldn't answer that one truthfully because I know there's times when I have missed sometimes

**KA:** Are there areas that you think are missing in relation to health care needs?

**Nurse:** Hmm, in what way, like erm?

**KA:** I mean areas like shopping and, and er you know, stairs. Not stairs maybe, but, but shopping certainly is more a social care need

**Nurse:** Yeah, yeah, we do miss it, I have to be, because like I said, you, you have got something in front of you, you answer it, and they say, 'yes home help does my shopping' you just put home help, and sometimes you might not think, well how many days a week, you just put down 'home help' and then you find out that you know, they only come once a week or, and you think 'well' afterwards 'well who's doing it', then you find out she's got an elderly relative

or elderly neighbour, who can't get about as much as she used to, and those things get missed, and those things are the ones that can cause a lot of hassle later you know

**KA:** Do you think that patients contribute enough to assessments of their health care needs?

**Nurse:** Not all the time, but then they're, remember that we're coming from a different generation, they don't open up to everything that you ask them, and they're very private, you know, and what we're really doing is intruding as well, so sometimes they don't want to answer every question that you ask them and they'll answer in the way that what they want to answer it, and you just, yeah, that's how things get missed as well, yeah, because erm, yeah, that, that is a major factor as well, because they don't, they just will not, I mean there are gentlemen, the gentleman died yesterday and erm his sister says she's been trying all these years to get him to get a home help, and they needed it, but he refused to open the door, and she said that they were actually very well off, but he just didn't want to spend the money, now you see all these sort of things, you, you're thinking, or I'm thinking well, why, you know, but there, he didn't feel that he wanted anybody coming into his house and basically doing the cleaning and probably telling him what to do as well, you know, so that's, yeah, you, you know, those points you don't always get the truth, truthful picture of really what is going on, because you, you hear relatives go, she can't do this, she'll tell you that she can do it, but she can't do it, and then until you really see them walking about, you'll find that they can't do it, they really can't so the things that they say that they can do, you know, well, yeah

**KA:** In relation to social care needs, which group, which hospital professionals are involved in erm, determining what social care needs a patient will have on discharge?

**Nurse:** I think now what was I going to say, would, would I be wrong in saying like, like the district nurses?

**KA:** I, I'm thinking of again I'm thinking of erm, the decisions that are made in hospital in preparation for somebody going home and thinking about the kind of social support that they will require

**Nurse:** Well, that can, well that will definitely involve nurses erm, social worker erm and the doctors, because we can't forget them as well, erm, it depends on their, their illness and things as well, to the different groups of people that might be helping them because if somebody had a stroke say, and their speech is erm quite impaired, now you'll probably get physio, because they can go to the day hospital and still get physio and speech therapist because they could still come to the hospital and so, it, it depends on their illness and you know, is there a group of people that are going to really advise them, yeah

**KA:** And, and when are decisions made about the kind of social support that people will need?

**Nurse:** Now again that should be done early on, right, I have to be honest but it should be done earlier on but we know that it is not [laughter] that's probably happening after discharge right, because of the way things are, it, it's wrong, I'm not saying that it's right, but it is definitely 90% on this ward, everything is after, you know, and it's not because we're not caring or everything, that is just the way it happens to work out, you know, somebody's supposed to have an OGD here, now they've sent her home so she's going to have the OGD as an out-patient, but really and truly she should have had it done, done here you know, and it's like with the, you know when they had the eye hospital upstairs, a lot of people were supposed to go up there, but now, now they're going to end up trooping half way across the city of London aren't they, to go and get their, it's just, it's just how the, the make up of it is, the hospital at the moment you know, things should be done far erm advanced but it never is, hmm

**KA:** Yeah. What kind of erm, what kind of role do nurses have within a team decision about patients' needs when they're discharged?

**Nurse:** I think we get quite erm, we have quite a good decision, I personally say that because erm, sometimes when we're doing the rounds and things, a doctor might ask a certain thing, we might not, we might not always agree, but they do listen and sometimes we can meet halfway, and you know, get things done and, we don't all end up tearing each other's hair out, but, yeah, yeah, that's not, that one's not too bad, usually and depending on the [unclear - 348] or the hospital's situation, and that we're usually okay



**KA:** Are there particular areas where nurses would contribute to a team decision, are there particular aspects of er, patient care that, that you would think of as, as nurses' having particular expertise?

**Nurse:** Hmm, god, it's getting harder though these questions, do you mean like erm, like somebody when they have to go to the [name - rehabilitation] unit and things like that, no?

**KA:** Yeah, I'm thinking in terms of you know, a team making a decision about the kind of help that a, a patient will need when they're discharged, you might say well you know, a physio knows about mobility or you know, the occupational therapist has done a home visit and they would talk about those particular areas, as a nurse you know, are there, are there particular things that you would contribute or you would say you know, this is what I would?

**Nurse:** I might think it, but to be honest I don't always follow it through in that way, I think I'm more likely to talk to the doctors about certain things than I would go up to a physio and go you know ... [trails off]

**KA:** Are there particular aspects of patient care that you would, that you would speak to doctors about, or?

**Nurse:** Yeah, if I felt that erm, oh if I think a patient could do better in a certain other unit or I felt they could do better down in the stroke unit or something like that, I would say, whether they listen is another thing, but I, I would go up and say you know, while, while we're doing the rounds I would say that so and so and that, and most of the time they do listen, and think about it and depending on, they might move them or they might say 'no, leave it' they, they need to stay here a bit longer and can talk their way, but other team are, I, I, because it's not really my, I shouldn't say domain really, erm, I should say we all speak but I don't want to get onto their territory

**KA:** Right, what, what would you see as your territory?

**Nurse:** More than nursing aspects, you know

**KA:** Being?

**Nurse:** [pause]

**KA:** What, what, what's kind of contained within the 'nursing aspects'?

**Nurse:** My, to me like er, oh, how can I put this now, like the temperatures, the, the observations and you know, anything that happens to be personal care to the patient

**KA:** Right

**Nurse:** Erm, gosh, I don't know how to put this, erm, because nursing is quite, is quite broad you know, I don't know how to really phrase it but anything that I think is nursing, I mean I would still, if a person had a, a stroke, I'd know that the pillow goes, how to set the, the table so that it's over the, it's over the you know, the side that's not affected or whatever, so you know, all, all things like that, but to actually, and I still walk a patient that's had a stroke but I wouldn't get too much into the physio bit, because to me I would be treading on the physio's toes

**KA:** Right

**Nurse:** And I might get her all upset, same with the speech therapist I would observe and do everything that they said, sit the patient up 90 degree and everything, but I would never take it on myself to go and get too involved in it because I don't want to upset anybody, I might be capable of doing whatever, but I just wouldn't, I just wouldn't do it

**KA:** Yeah

**Nurse:** You know, because I just did it yesterday and I got into a whole load of trouble [laughter] so I just, this is what I'm saying, you know you don't, there's a fine line and you just better not cross it because you'll get people upset and, and that's the way I'm, no that one is a very hard question, but I stick to my, to what I, I think is nursing and let them stick to their bit, yeah

**KA:** Right. Do you think that nurses have a particular role in helping patients contribute to assessments?

**Nurse:** [pause] Yeah, they do, er, [pause], well by talking and erm, getting as much information from them, you, you are helping them in that way you know, and they are helping

you as well to find out about themselves but I like I said, you have to do things very carefully with the elderly because we, you know, you have to always remember that they're quite a few generations you know, above us and we shouldn't, they are very private, very, very private people and you have to be very careful how you do the questions to them, yeah definitely, because you know, our mum and dad, we, we can probably say things to them we couldn't say to our grandparents and these are like being like our grandparents we're looking after, you have to, those things you have to be careful just how you you know, but yeah, yeah

**KA:** Do you think the nurse's role in involving patients in assessment is different from the way or different from other, other members of the team's role in involving patients, do nurses have a special role in that respect?

**Nurse:** Oh yeah, yeah, because I think they see us first

**KA:** Right

**Nurse:** Usually, and erm, nurses have always been thought of as, well we've been out on a pedestal like, isn't it, so erm, I think in that way they see us more, well they just see us as a bit more special than God, don't let me get this [unclear - 429], right erm, because we're the first people they see and definitely they think nurses, well you know, like Florence as they say isn't it, so, yeah

**KA:** Yeah

**Nurse:** Because that's a lot of them that's what they say when they come in you know, you know, you're like little angels and things like that so yeah, yeah, they do see us rather in a more special way than the other, well the other team and that

**KA:** Yeah. Are you aware of any hospital policies or professional guidelines on the discharge of people from hospital?

**Nurse:** Well I did read one that they wrote, but erm to be quite honest with you I don't always look them up you know, I know that you know, we're supposed to do certain things and er, and that but, I have to be quite honest, I don't always, I don't always do, read on these things, all I know is I go through that orange form and make sure that everything on there is done properly, as, to the best that I, I can and then hopefully I'd have done a proper assessment in the beginning and nothing comes back later you know, but, but even saying that you know, like when we have the care planning meeting, now, we've had patients like who have been in their 90s, I know that they couldn't go home and I've said so, you know, and, and everything else but the patient has wanted to go home, and they cannot cope and everything, that's why I said is everything sort of contradicts itself at sometimes you know because you're sitting there, you know that the person can't, they're going through all this discharge planning just like how they say you should do it, knowing full well that the person might be coming back, so sometimes you don't know how, well I don't know how you really get round that, even by knowing all the different procedures for the discharge planning

**KA:** Yeah

**Nurse:** Because as, as I said, we, we have to treat the person as an individual and sometimes, it sounds cruel, but sometimes they have to find out for themselves that they can't manage to, yeah, I should, I do know some of them but I can't even, to be honest I learned them and then because I don't always use them they don't you know, I'm terrible, I'm terrible I know, I might read up some today so that the next time you ask me that I know [laughter]

**KA:** What kind of training have you had on assessing people's needs?

**Nurse:** [pause] None, I, I've, no I shouldn't say that, I think the sisters have gone through some, in fact yeah, there was a sister here that went, quite a lot of budget went to, a lot with us, and, and the discharge planning thing, I have to be honest there, and [name F grade]'s done quite a bit, I haven't really done much with [name - senior sister] because as you know she's just come up here, but [name - F grade] and er [name - previous senior sister], yeah, I did, we did do a lot and er, quite a few assessment policies have come up here but to be honest you don't get time to really go through them you know, I do try my best but you can't always get through things because there, there's a lot of things I know that with the discharge planning that

you have know, but like I said, I go through the orange form there, the discharge planning form and hope that everything's done, because it's quite detailed really and erm, you know, that's it  
**KA:** [pause] Erm, are there areas of patients' needs that you think don't get assessed by anybody, are there any gaps in the team's assessment?

**Nurse:** [pause] Erm, I think sometimes when people's got next of kin that live abroad and you might like put down neighbours and things like that, and they might not want to be the next of kin but we've put them in the situation that they take on responsibility sometimes when they're not really wanting to take, there's you know, that, because those sort of things that I, I never thought until the other day until somebody rang me and said she doesn't want to be to next of kin, we've just put her down as the next of kin, you know, the lady said she was the next of kin, the patient, she not, her next of kin lives in Australia, and the next door neighbour says she doesn't want it, the responsibility, you know, it's just little things like that you know, and you, you, because you're just doing things, you're just doing it, you're not always thinking about these things you know, and when they've gone home then it's too late, I, I don't know it's very hard for me to explain but it's just little, little things like that that can make a you know, big difference to, to the patient in the end, because this poor lady she might be knocking on that neighbour's door and she's not going to open it, she said she's is not going to open it to let her in, now she has been put down as next of kin and she's totally refused to be next of kin now, so what do you do then, I mean I've referred it to the social worker but they're going to have to find somebody else to be you know, next of kin, it's just little, little silly things that you just take for granted those are the ones like causes the problem in the end you know, but that was, that was a, a big one in the discharge planning that wasn't sorted out just took, took the patient's word for it, never really, because I've never seen the neighbour come up and then erm, that was it, and she's got an 87 year old gentleman to look after, so she doesn't want the burden of a neighbour and looking after this 87 year old, so, like I said the forms need, we need to look at the form and see where we can change words so that you can pick up a bit more on things but, like I say I can't, we've changed the forms so many times I don't think it's going to change again for another 10 years, because it's took so long to change it this time you know, so

**KA:** Is there anything else you can think of in relation to discharge?

**Nurse:** Erm, [pause] all the different services sometimes, now I didn't even know, I thought meals on wheels was hot dinners until I found out now they do freezer ...

[reply cut by end of tape]

[New tape]

**Nurse:** ... So they might not have used a microwave and erm, and I've never seen anybody really show them how to use it so you know, it's just little silly things, very silly little things that you would not think about sending them home and you know

**KA:** How do you find out about community services?

**Nurse:** Well usually we ring up [name - social worker] and [phone rings] he will get back to us and he tells us all the services and things what's going to happen and whether they're getting frozen meals and all this

[Interviewee answers phone]

**Nurse:** Yeah, because he usually tells us so that all the different things that are going to happen and erm, like I said, I, I just meals on wheels that was it, but now they don't really do them like that any more now, it's just frozen stuff and home help comes in but she might just be giving them a sandwich but she does not always wash them, you know, it's just little silly things that you have to keep clued up on because you don't know and erm, district nurse does not do any thing apart from what we call nursing care you know, but I think it's like a more American because they don't wash do they, so that's, that's it yeah, I don't know, it's just so many things that I, you sit down and you think about it and it's changed, what happens in the ward here is not what happens in the community

**KA:** Are there ways of, of sharing this experience, because there are obviously things that you have learned?

**Nurse:** But that's because I've actually had to go out in the community now because I was doing the conversion course I saw a lot, like I said to you, I, I could not believe the amount of people in the [name] borough who did not have bathrooms you know to me it was just something that was secondary now it's made me more aware [phone rings] that when we're discharging people sometimes that they might not have all these facilities you know [tape stopped and restarted] the only reason why I found, found out about life in the community or else I, I'm ward based and that was it you know, a person gets better, you give them what you call services and you send them out and that's the end of it but you haven't actually seen the home environment they're in, all right an OT might go in, they see certain thing, they put rails in, rails there, higher the toilet seat, bring the bed down but there's a lot of other things that go on as well you know, yeah, it really opened my eyes, that was a very good experience, that's why I said I wouldn't go in the community now, because it's just, it's not what I expected, you know, it was nice, the nurses and district nurses are very nice but whole situation I have to be quite honest is not, I just don't think I could come through some of those doors you know, it's just, it was just awful, because one lady was washing with water that was as black as that bag, and no central heating, the stairs carpet was all frayed, now I wonder if she will tumble some day you know, it's just lots of things that you would never be aware of unless you've gone out in the community and how we're going to join together I just, I don't know you know, I mean we have the care planning meeting for certain we really know at risk patients and then we can join together there but you know, there's a lot of people that we don't really erm see either do we you know, unless they're down like, I, I don't know what the answer is to that really because you can't have a care planning meeting for everybody and you can't give all this service to everybody because we're you know, haven't got that much money to really do all these things, so, there's so many, there's so many questions and things that need to, to be answered and so many things to be changed that I, I'd be what 2000 years old before you've got it, it's true, it's true, it's because I've seen one set of nursing to another set of nursing and then seen the like the dressings, we do dressings differently to the community and that makes a big difference because they will kill me for saying it but, the district nurse never do the dressings the way that we do the dressings on the ward and that's why many of them come back in with the ulcers, you know, it's just a big, a big gap that needs to be, because you, I don't know if you've ever seen that yellow paste

**KA:** No

**Nurse:** They put this big slab of yellow paste and put this brown bandage which I don't think I've ever really seen from the year dot, and then the ulcers break down, you know ...

[Interruption - Interviewee fetched by auxiliary nurse for the consultant round - end of interview]

## APPENDIX 9

### PATIENTS' HEALTH AND SOCIAL CIRCUMSTANCES

<b>Pt no.</b>	<b>Age</b>	<b>Gender</b>	<b>Ethnicity</b>	<b>Housing on admission</b>	<b>Family/ informal carers</b>
5	84	F	White/UK	lives alone council flat	2 dau.s, cousin, friend provide informal care
6	86	F	Punjabi	living with son and 4- g/child	son/ g/children
8	87	F	White/UK	lives alone W/C	1 son locally - helps 1 son - Canada
9	76	M	Tamil	lives with wife W/C	wife, 2 sons, 1 dau living locally who help
10	85	M	White/ UK	lives alone own house	son/ dau - both abt 1hr away
11	74	M	White/ UK	lives with wife in own maisonette	wife, dau
12	82	F	White/ UK	lives alone own house	2 dau.s - (London and Essex)
13	83	F	White/UK	with son council flat	other son - Kent g/dau - local
15	89	F	White/ UK	lives alone W/C	dau - Devon, sister - Essex; neighrs at W/C help
16	79	F	White/ UK	lives alone council flat	dau & g/son - local v.supportive neighrs
17	77	F	White/UK	with partner W/C	partner, son 2 dau.s - little contact
18	77	F	White/UK	lives alone in house private rented	sister helps
22	91	M	White/UK	lives alone council flat	son, sister-in-law & neighbrs help
23	84	F	White/UK	lives alone W/C	dau-in-law

<b>Pt no.</b>	<b>Age</b>	<b>Gender</b>	<b>Ethnicity</b>	<b>Housing on admission</b>	<b>Family/ informal carers</b>
24	101	M	White/UK	lives alone in own house	son and 2 g/sons (son caring for own wife)
25	85	F	White/UK	lives alone W/C	son & g/dau help
26	94	F	White/UK	lives alone private rented house	2 dau.s and son-in-law 1 NE London, 1 Lanc.
27	89	F	Anglo-Indian	lives alone in own house	4 sons, 1 dau (India) & g/children; (1 son very supportive)
28	78	M	White/UK	lives alone council flat	son and dau-in-law help
30	82	M	White/UK	lives alone own flat	adopted son wife has dementia - in institutional care

Abbreviations are listed at the end of this appendix

## APPENDIX 9

### Admission details

Pt no.	Diagnosis	Length of stay (days)	Services on admission	Services on discharge	Change in services	Other
5	Gastro-enteritis	6	HH fortnightly - h/work HV every 3/12	HH fortnightly/ HV assmt bath rails/ kitchen aids	assmt for aids - comm OT	refused bathing service (would have had to change HHs)
6	Abdominal pain	19	nurse 3 times a week for w&d	decision for terminal care (NHS funded cc) [RIP]		
8	?DVT	6	day centre x2/weekly HV 3/12; HH weekly - bath, shopping, laundry fortnightly cleaning	same	none	
9	Abdominal pain/ Chest infection/ Falls	3 27	HH x3/ week DN monthly daily check - made bed HH for h/work	HH/DN aids incl. commode, Piper alarm, day	assmt for aids by comm OT (res.r referral) aids incl. commode, Piper alarm, day centre,	info. given abt asian elders outreach service pt discharged 3/52 ago - this adm new medical problem
11	Post spinal surgery	15	none am + pm carers, weekly shopping/ bathing, MOW 7/7, HH - h/work; DN for medication	rails/ bath seat	rails/ bath seat	
12	Fall	21		residential home	move to residential home	pt discharged from the same ward 1 month previously died 2 weeks after discharge
13	Back pain	11	none	none	rails (res.r referral)	

Pt no.	Diagnosis	Length of stay	Services on admission	Services on discharge	Change in services	Other
15	SOB, acopia chest infection	9	day centre x3/week HH - h/work, shopping,	same plus hospital discharge team	hospital discharge team	pt discharged 4 days previously pt readmitted two and a half weeks after this discharge
16	SOB	21	HV	HV, rails	rails	
17	High blood sugar	7	HH am - h/work and breakfast; DN daily	same	none	[known as a regular]
18	SOB		none	same	none	
22	SOB	6	HH - h/work, HV 3/12	same	none	
23	SOB	6	none	same	none	
24	TIA	6	none	MOW, HH weekly - shopping, Piper alarm, shopping, Piper alarm,	comm nurses picking up additional needs - eg dentist/	
25	Abdominal pain	6	HH - shopping, cleaning DN x3/wk	same	none	
26	SOB	38	HH x2/ week - shopping cleaning, laundry	r/h - then hospice, finally stayed on ward [RIP]		
27	SOB/ LVF	8	HH am - cleaning and some shopping	same	none	pt moved to a residential home 1 week after discharge
28	SOB/ urinary retention	67	none	tds calls - HH, hospital discharge team	discharge team self - discharge	due to go to respite pre-wc on day of adm pt re-admitted 1week after discharge
30	Falls	20	none	daily am call, hospital discharge team, piper alarm, rails, DN	daily am call, hospital discharge team, piper alarm, rails, DN	



Abbreviations (for both tables)

3/12.	three monthly
3/52.	three weeks
7/7.	daily
abt	about
adm	admission
assmt	assessment
bd	twice daily
cc	continuing care
comm	community
dau	daughter
DN	district nurse
DVT	deep vein thrombosis
g/child(ren)	grandchild(ren)
h/work	housework
HH	home help
HV	health visitor
info.	information
LVF	left ventricular failure
MOW	meals on wheels
neigbrs	neighbours
OT	occupational therapist
pt	patient
r/h	residential home
SOB	shortness of breath
tds	thrice daily
TIA	trans-ischaemic attack
W/C	warden controlled accommodation
w&d	washing and dressing

## APPENDIX 10

### TOPIC GUIDES FOR PATIENT FOCUSED INTERVIEWS

#### **Topic Guide for Multidisciplinary Staff**

Why did the patient come into hospital? (medical/ social reasons)

What are their social circumstances?  
housing/ formal/ informal support

How were they managing before they came into hospital in terms of:  
washing and dressing  
cooking  
shopping  
cleaning  
collecting pension/ prescriptions?

Was there anything that it was difficult for them to manage?

How have they been managing on the ward?

Has anything changed this admission - in terms of their dependency?

Have any continuing care needs been identified?  
What  
When  
How  
By who  
What was your role in this process  
What was the role of nursing staff  
Were the patient/ informal carers involved - how  
- by who

Have you got any concerns about how the patient will manage on discharge?

What contact have you had with the patient?  
(Check - is it known what the patient's wishes are)

Have you had any contact with informal carers - what?

Have you had any contact with community staff - who?  
- in relation to what?

Is there anything else you would like to add?

## Topic Guide for Patients

How were you managing before you came into hospital in terms of:

- washing and dressing
- cooking
- shopping
- cleaning
- collecting pension/ prescriptions?

Did anyone help you?

- formal/ informal support

Was there anything that it was difficult for you to manage?

Why did you come into hospital?

How have you been managing on the ward?

Is there anything that is harder to manage since your admission?

Has anyone asked you about the care you might need at home?

Who

When

What was discussed

Were you given any information about:

- how decisions about your care would be made

- what care you would get

- written/ verbal

Were your family/ friends involved

Were the nursing staff involved

Do you feel that the staff listened to you?

Do you think that you had a big enough say in the care that you would get when you went home?

Have you got any concerns about how you will manage on discharge?

Is there anything else you would like to add?

## Topic Guide for Informal Carers

How was the patient managing before admission to hospital?

Were you involved in their care - how?

What prompted their admission to hospital?

What contact did you have with hospital staff?

is this amount/ type of contact that you wanted?

were you involved in planning the help that would be needed at home?

do you think that you had a big enough say?

were the ward nurses involved - how?

did you receive any information about:

how decisions about the patient's care would be made?

what care they would get?

written/ verbal

How is the person managing after discharge with regard to:

washing and dressing - including getting in and out of the bath

cooking

shopping

cleaning

collecting pension/ prescriptions?

What support is being provided?

formal/ informal

what are these people doing (including interviewee)

Has there been anything that has been difficult to manage - for you/ the patient?

is there any help that would have been useful

is there any help that is unwanted

Have you had any contact with community health/ social care staff?

who

have they assessed the patient's needs/ your needs

Is there anything else you would like to add?

## APPENDIX 11

### EXAMPLE OF A PATIENT FOCUSED INTERVIEW

#### INTERVIEW WITH AN SHO RE: PATIENT 9

15th May 1998

**KA:** So, why did he come into hospital?

**SHO:** Um Mr [Name] had um abdominal pain which was um actually quite vague and I don't think the sort of vagueness of his symptoms were because of his English, because his English was actually quite good um er, our initial assessment was whether he was constipated um, but we also noted that he had had a previous history of gastric ulcers so um it was, that was something that we wanted to make sure to exclude and certainly when his blood results came back and showed that he was anaemic um our most, um the obvious option was to check um, check his stomach er which we did, and which proved to be positive for an ulcer and for H pylori which was treated so and certainly once once um those issues had been addressed and we'd found the source of A, the pain and B, the anaemia um then he was ready to go.

**KA:** Right, what were his social circumstances?

**SHO:** Um as far as I knew he lived with his wife and had good family support and that he didn't have any services um but he was usually self caring ...

**KA:** Right

**SHO:** ... and independent.

**KA:** How was he managing at home before he came in?

**SHO:** Um I don't remember very much about um how how well he managed, I mean I certainly don't remember the home situation being an issue at the time um, but I think its often difficult with Asian patients um because I think the assumption is normally made that the family look after them and if in some ways I wonder if they don't get as good a deal because we say, 'fine, the family looks after them', or, 'the family is there' um and a lot of the times they, they don't want any outside services but I wonder if we actually addressed it more closely whether they would um ...want more social services than we think they would

**KA:** Yeah

**SHO:** But with him I don't remember home being an issue....really.

**KA:** Was he getting any services on discharge?

**SHO:** Um he, no, he had a district nurse that went in monthly because he'd had previously CVA, and as far as I know she was checking blood pressure and things er but other than that no, nothing I mean obviously other than an follow up out patient appointment with us

**KA:** Right

**SHO:** Um

**KA:** And how was that decision made that, that he didn't need any additional services?

**SHO:** Um I think norm, normally we do it on the basis of what they had before and what they're like now and I think um if he didn't have things before and certainly functionally he was um, he was actually pretty much pain free when he left although he'd only just had a few days of treatment um, I think we have to assume well this is somebody that has coped before and should cope now because, because there's no other reason not to um and that, um we had improved his pain and found the cause of the pain for the future so um, in that way I think, I er, I don't think it was really appropriate to have sort of been sort of trying to find problems that may not even have been there anyway.

**KA:** Right.

**SHO:** Yeah

**KA:** So it's kind of looking at what people had before they came in?

**SHO:** Yes, and and I mean always think well if they, what did they have and can um can we get them back to their pre morbid state which I think we did, I mean this was not a major, its not like he had another stroke, and he came in in pain and we improved his pain and for that reason I think we have to assume well he's back to his pre-morbid state, he'd been mobilising on the ward, he'd been eating and drinking then therefore it's not at issue, if something had happened that meant that he was functioning not as good or mentally not as good as had been then obviously there are issues that need to be, the home situation needs to be looked at

**KA:** Mmm

**SHO:** But with him, his was quite in some ways sort of perfect hospital er stay, comes in, has a pain, do the test really quickly, find the cause, send him home, I mean that's what you want, high, I mean a nice high turnover, get them out, not quickly but, you know [laughter].

**KA:** Were there other members of the team that were involved in making decisions about er the services that he might need after discharge?

**SHO:** Er no, no, because he wasn't referred to social worker I don't think was he? No, so it was, it was us and the nursing staff

**KA:** Mmm

**SHO:** And the rest of the family as well, his son mainly.

**KA:** What kind of family involvement was there?

**SHO:** The family were, we did speak to them quite a lot because um ..... I mean they were interested in what had been happening and ..... I suppose there was a sort of, there was a language issue although I don't think it was a big language issue so they they were around and in fact when the mention of home was, when we said would you like to go home now, they were all very much in favour, so I think, I think again if they'd have said, 'no, no, no he can't possibly' we would have had to say right this, something needs, something's up, so that would have delayed it as well

**KA:** Right

**SHO:** But they didn't, so.

**KA:** So what stage are the family involved then in, in planning for home?

**SHO:** Um with him it was quite late but that's because things happened quite fast I mean, we got the test, we got the result within two days or something so .....and I mean normally, most people I say at quite, and when I explain to to the relative what's the matter with the patient I will say I think roughly this is going to take however many weeks or we'd like to hope that she'll be showing some signs of improvement then and whatever but with him it was, it was later purely because of the speed of the, of the, of the admission and the tests and things.

**KA:** So what kind of thing, what kind of issues would you be looking at from the family perspective?

**SHO:** Um, um well this um ... their level of, their level of input um how often they go in, how far away they live, how much they're actually doing in terms of um personal care for their parents or er, er for, for the family member

**KA:** Mmm

**SHO:** Um, whether they have jobs um, how they feel about having, going in, whether, I mean I think that's a lot of Asian families feel it is part of their duty and don't question it whereas there are, and obviously there are other families who don't think it is, reasonably so, um, so I think, I think it's sort of looking at their level of input and how they feel about their level of input

**KA:** Mmm

**SHO:** And, and whether they, whether we then feel that they're coping I mean and then um with the family member and that's sort of on the sort of condition the patient is in when they arrive, are they, do they look like they've been well fed and kept clean and things I mean its, is their skin good, is their sort of nutritional status good I mean those sort of things would make, give us a better indicator of whether the family are actually coping, with um.

**KA:** So with Mr [Name] were there particular issues you looked at in relation to the family?

**SHO:** Um no, probably not actually um, ... no, I suppose I mean when his wife arrived, she, she, she spoke less English but I think in general they were all, er they were all well dressed and and although that seems um ... er sort of presumptuous shall we say, but it, they they, and she was mobile and she didn't look like she was disabled and um and, and, the keenness to take him back was I suppose, I mean you have to sort of look on the subtle pointers this way [laughs] sometimes if you're

**KA:** Yeah

**SHO:** But er things like that. As I say because it was a short admission they were they weren't as involved as they would have been and I don't think that's just because they were a family that probably would have looked after each other anyway.

**KA:** Right, so what kind of contact did you have with them?

**SHO:** Um most days actually I spoke to them um, usually in relation to what was going on and what we'd found and what we were going to do um ... say a brief discussion on most days.

**KA:** And what kind of support did Mr [Name] want at home?

**SHO:** Um,

**KA:** If any

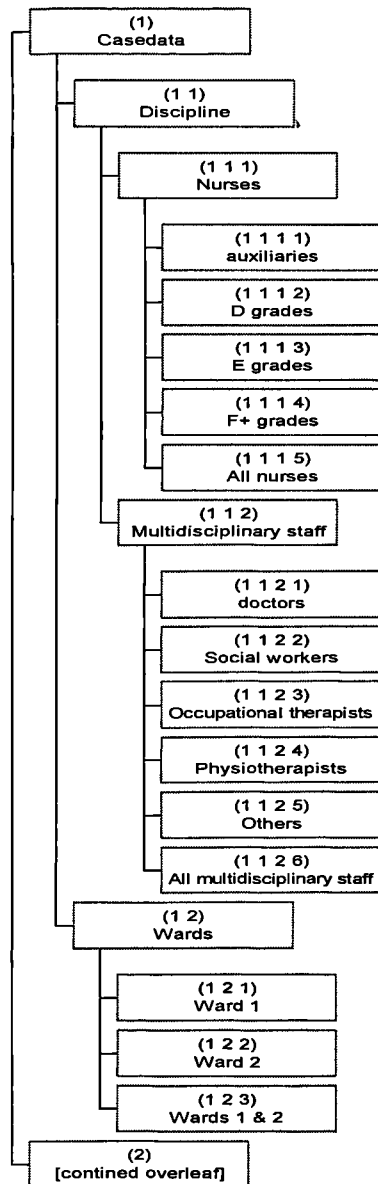
**SHO:** I don't think he um, he didn't he didn't mention anything and certainly when we did our initial assessments he hadn't brought up any issues, so no, I don't think he requested any [pause] okay?

**KA:** Yeah. Thank-you.

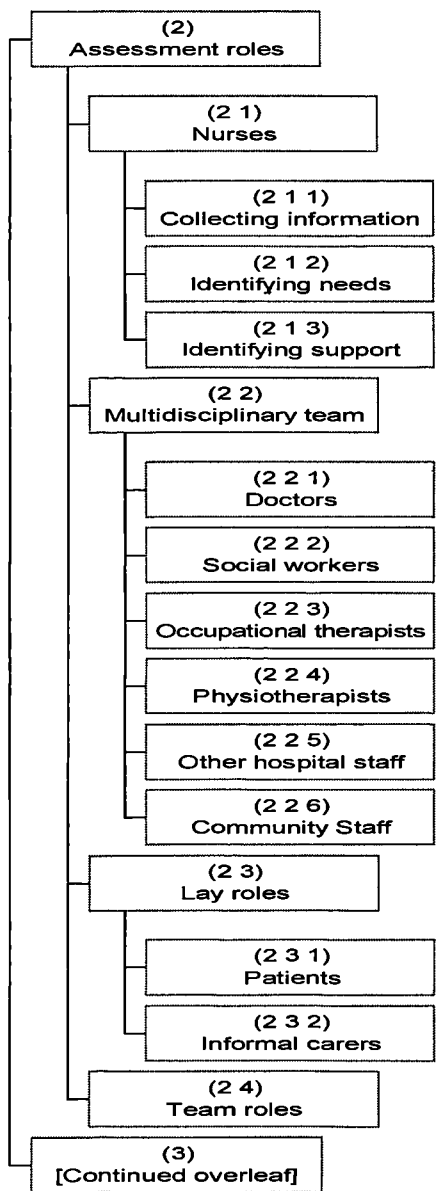
[End of interview]

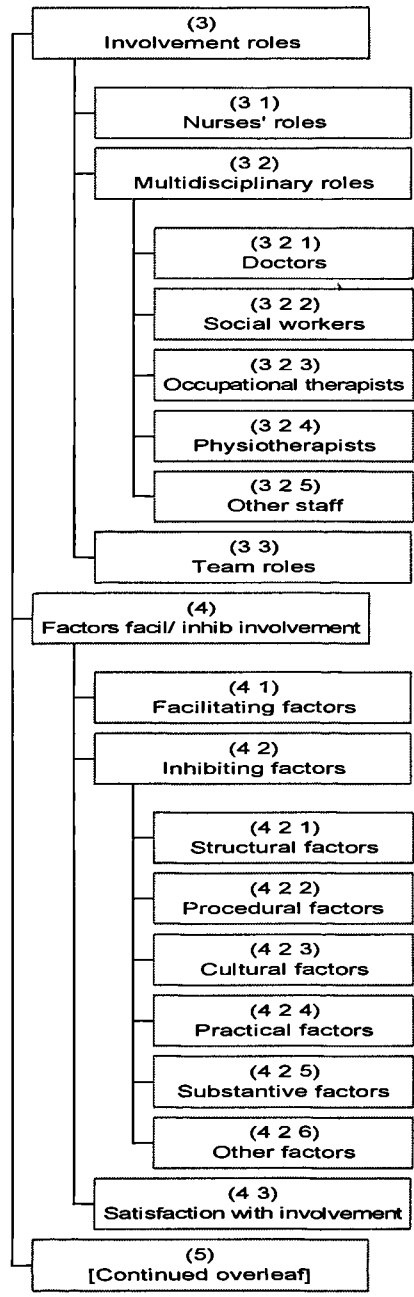
## APPENDIX 12

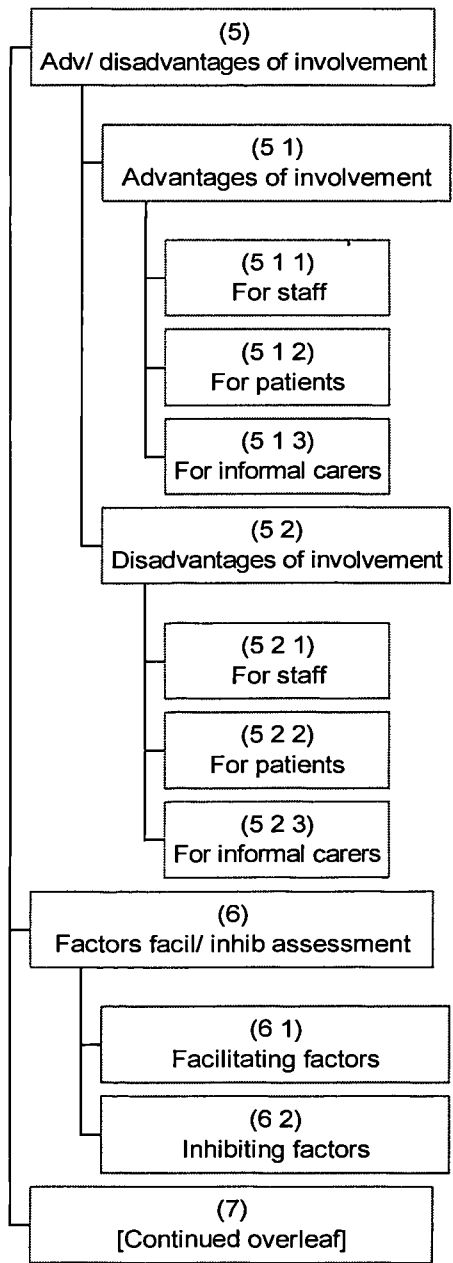
### THE NUD.IST TREE

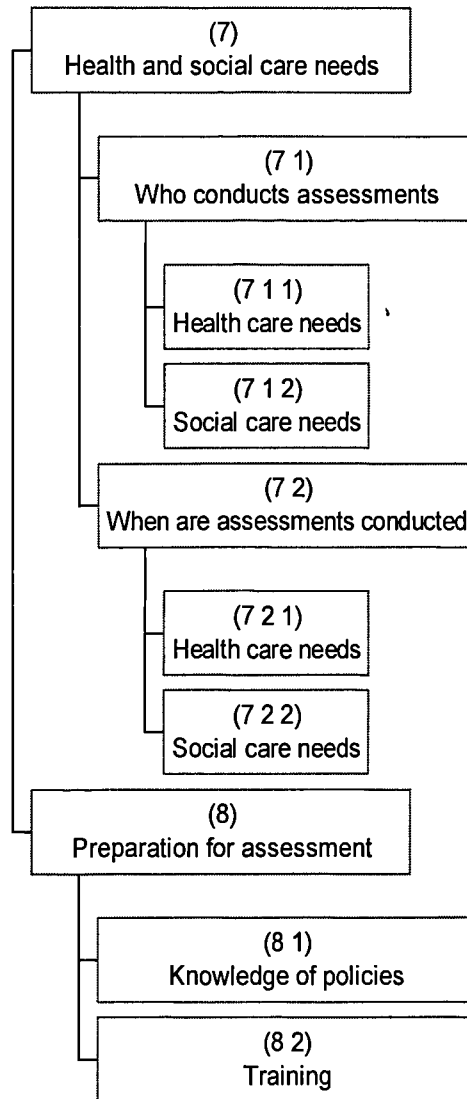












Additional Free Nodes:

F1 Purpose of assessment

F2 Attitude to involvement

F3 Feelings of being empowered

F4 The concept of involvement

## APPENDIX 13

### EXAMPLES OF CATEGORIES USED IN DATA ANALYSIS, THEIR DEFINITIONS AND UNITS OF TEXT THAT WERE ASSIGNED TO THEM

<b>Node</b>	<b>Title</b>	<b>Definition</b>
[2 1 3]	Assessment roles/ nurses/ identifying support	Use to code the nurse's role in identifying or setting up continuing care services including administrative tasks associated with discharge.

#### **Examples of units of text coded at this node:**

Nurse: '...we refer every patient from here to the district nurse or the health visitor

KA: Right

Nurse: And maybe that's for assessment, yeah, so, very often you either find that the district nurse will refer or discharge a patient and vice versa you know, because if they've got anything immediate like I mean diabetes or tracings or anything like that, that's the district nurse but if they've got nothing you send them out fit knowing that because of the age they're going to relapse, yeah, for whatever reason, you refer them to the health visitor and they're responsible for their needs, health care needs in the community'

[Geninn8 128-193]

Nurse: '... it's only when the patient goes home and needs a nursing input that's when we involve ourselves with the district nurse, most contact at home is the social worker, the physio, the OT, but it's only when the patient is ready to go home and needs a nursing input, that's when you get in touch with the district nurse'

[Geninn9 504-508]

Social worker : '... sometimes the demarcation lines are blurred, nurses are talking different things to the visitors, family visitors on the ward, and they come back to you, they have their own prescription of what they are going to get, that is not available, so you have a struggle like that'

[Geninsw2 230-234]

<b>Node</b>	<b>Title</b>	<b>Definition</b>
[3 3]	Involvement roles/ team	Use code to show where MDT ought to, or actually, promote the input of, or actively seek information from patients/ informal carers - include instances of patients /informal carers being provided with information.

#### **Examples of units of text coded at this node:**

Consultant: '... I think a lot of the time we don't stand up for the elderly people themselves enough and I think it's very important that all of the members of the

multidisciplinary team take into account that person's wishes first'

[Genicon1 32-36]

Nurse: '... looking at it like now from me if the tables were turned, I wouldn't like, I would like to be so much more involved and have a lot of say, but I know they [patients] don't get enough of that, they don't because as nurses and doctors and social workers and that, we barge in, we know what we're going to do, we know what's best for the patient, he hasn't told me that he wants this, and he needs that and he needs that you know

KA: Why is it do you think that nurses, or not just nurses but professionals do that

Nurse: I think it's probably that we've always done it and I mean we think we know best, we've got that attitude about 'yeah the man needs that' of course he needs it, because he can't cope, he can't do this, he needs it, we don't go and ask him, or we don't say, 'how do feel about that Mr so and so' you know, so I think that is, that is a fault that we all have'

[Geninn6 458-472]

Physiotherapist: '... I think the most, the biggest way that patients are involved is by, with the use of care planning meetings, where everybody is present, all the carers, the family, and everybody from the ward is present, the patient then, with certain exceptions, but usually what happens is the patient is responsible for making the decision, where do I want to go'

[Geninph1 404-410]

<b>Node</b>	<b>Title</b>	<b>Definition</b>
[4 2 6]	Involvement facilitating - inhibiting factors/ inhibiting factors/ other	Use code for factors inhibiting involvement that are not covered by above codes [4 2 1] - [4 2 5].

#### **Examples of units of text coded at this node:**

I noticed that there were patient information booklets in clear plastic folders pinned to the board behind every bed. The booklets had been hand assembled and were photocopies of a laser printed original. They did not have a date on them, but were obviously old. There was information about the profile of the ward, and how to recognise staff by their uniform (out-of date), as well as information about how to make complaints and suggestions. The booklet erroneously said that the ward consultant was [name] and that the ward rounds took place on Tuesdays and Thursdays.

[Fnfe1298 42-49]

Nurse: 'Sometimes it is difficult as well isn't it if they [families] are working, yeah, but at least like on their free time they could at least go there, at least every day, or in the morning if they're working in the afternoon, the evening, but the only disadvantage is if they live far and if they have children'

[Geninn10 36-40]

Issues - uncertainty about when care planning meetings are appropriate - on the ward round the consultant asked if a care planning meeting had been set up for [patient name]. The nurse replied that someone from [name - nursing home] was supposed to come and see her but she did

not know if anything had been set up. In the multidisciplinary meeting after the ward round the consultant outlined that a care planning meeting would be needed as he didn't think the patient's residential home could cope, adding that he thought that she was a candidate for [name - NHS continuing care]. The social worker asked about [name - nursing home], but the consultant said really [name - NHS continuing care] was more appropriate. The social worker questioned the need for a care planning meeting. However the consultant indicated that he thought that everyone should have one of these. In response the social worker stated said that the family were in agreement and that there was a community social worker so a care planning meeting wouldn't take place until the 25th. The consultant relented saying he supposed that if everyone was in agreement then that was as good as a meeting.

[Fnfe1798 20-34]

<b>Node</b>	<b>Title</b>	<b>Definition</b>
[F 1]	Free nodes/ purpose	Use code to indicate where people talk about the reasons for assessment, and why it is undertaken

**Examples of units of text coded at this node:**

Nurse: 'When I do an assessment it is primarily one for the ease of nursing itself, for the ease of my care, so for example if a patient can walk, then it will save me carting the patient around and also an assessment so as to, you know, to ascertain, the state the patient, the state of health of the patient, whether health is stable, improving or deteriorating, then I need to do something about it'

[Geninn3 93-99]

Social worker: '... living by themselves, on their own, they [patients] are prone to risk, so you want to explore a little bit about how you could help them, that's what assessment is all about'

[Geninsw3 85-87]

SHO: 'I mean I suppose the ultimate aim is to stop them bouncing back in again, so you have to sort of look at the sort of things that would cause them to bounce back in again and how are they going to be assessed and prevented'

[Genisho3 300-303]

## APPENDIX 14 Assessment Matrix

Patient 25	Nurses	Doctor
medical condition	n6 int - flu like symptoms - unwell, nausea admitted in case she had a viral infection	sho5 w/r 8/12 - adm with epigastric pain which had resolved within 12 hours sho5 int - adm, feeling unwell, feverish feeling better on arrival at hospital - blood cultures suggested UTI notes - Ca uterus; pulmonary oedema
nausea & vomiting	adm - pt feeling sick	nausea noted on proforma
mobility	n6 w/r 8/12 - pt up and about	proforma - recent fall noted sho5 int - pt mobile around the ward
ulcer	n6 w/r 8/12 - pt has ulcer from a fall 6/52 ago - sloughy wound, dressing mentioned - had contacted d/n about date dressing due - unsure what dressing had been used - but ulcer improving in ho. - talked to d/n pre-discharge.	sho5 w/r 8/12 - said that the dressing was green the previous day cons2 w/r 8/12 - wondering if d/n had been using the right dressing
?DVT		sho5 w/r 8/12 - queried dvt as pt's leg hard and swollen// cons2 w/r 8/12 - maintain fragmin in ho. - inform GP
communication	n6 adm - said that she thought that the pt was managing well re:hearing	
eating & drinking	n6 adm - identified that pt was missing a top set of teeth	proforma - pt independent
social services	n6 w/r 8/12 - pt lives in wc n6 int - pt fully self-caring, dn 3 times a week for dressing; lots of friends who visit/ unaware if pt has been seen by sw	sho5 w/r 8/12 - independent lady living in wc flat sho5 int - unable to remember pt's social support ?goes to day centre proforma - d/n 3 times a week
shopping	n6 int - age concern do majority - pt goes out to shop and does little bits	proforma - home care every 2 weeks
cleaning	n6 int - HH fortnightly	proforma - home care every 2 weeks
washing & dressing	n6 int - pt is independent	proforma - pt independent
cooking	n6 int - pt is independent	
pension	n6 int - pt is independent	
laundry		
other	spoke to niece when she phoned spoke to warden to inform of discharge date	



## APPENDIX 14 Assessment Matrix

Patient 25	Social worker	O/T	Physio	Other ho.
medical condition	sw2 int - pt admitted feeling unwell	[Not involved]	[Not involved]	[No other hospital staff involved]
nausea & vomiting				
mobility	sw2 int - pt was mobile around the ward without aids			
ulcer				
?DVT				
communication				
eating & drinking				
social services	sw2 int - lives alone in LA flat, but does almost everything for herself			
shopping	sw2 int - she can do her own shopping if she wants to - but already getting help - checked had enough food on discharge - prob. wouldn't get shopping if new referral			
cleaning	sw2 int - pt getting help			
washing & dressing	sw2 int - pt independent			
cooking	sw2 int - pt doesn't need anyone to prepare a meal for her			
pension				
laundry				
other				

## APPENDIX 14 Assessment Matrix

Patient 25	Community staff	Patient	Family
medical condition		w/r 8/12 - pt said she was fine ho int - said that the hospital had told her she had flu o/a; Hx Ca uterus, CVA adm - said that her pain had gone, but that she had had the shivers	[Not interviewed]
nausea & vomiting	warden - pt gets very travel sick	vomiting on arrival to the ward	
mobility		adm - pt said her walking was fine and that she didn't fall	
ulcer		w/r 8/12 - leg dressed 3 times a week in the community	
?DVT		w/r 8/12 - swelling began on falling 6/52 ago	
communication		ho int - wears glasses adm - said her hearing was very bad - does not have a hearing aid home int - thought that she might need a hearing aid - somebody from the surgery to visit	
eating & drinking	warden - pt not eating well on d. - worried about a poss. heart murmur - better after clinic appt.	n6 adm - pt said she wanted to get some dentures when she went home	
social services	warden - said ward had checked pt's SS with her - did not ask how pt was coping// phones each resident daily	w/r 8/12 - pt said she lived in wc since 1987 f/n - has HH; has not been able to go out since her fall - supportive son, visits at weekend - phones every day// has a 'woman' who comes to cut her nails	
shopping	warden: shopping done by private carer arranged free through social services	adm - pt saying doesn't go out bec of her leg f/n - age concern do her shopping; used to do her own shopping home int - pt had been to M&S that morning	
cleaning	warden - pt has a private cleaner	ho int - has HH for cleaning, fortnightly - does not do the dusting (leaves it bec it's easy for pt) additional help from private carer	
washing & dressing		ho int - grand-daughter helps with the bath adm - pt said she had a shower at home home int - has rails in bathroom	
cooking		ho int - likes to do her own cooking home int - said she was cooking for self	
pension		ho int - collected by age concern - pay rent	
laundry		ho int - does own	
other			

## APPENDIX 14 Involvement Matrix

Patient 25	Nurses	Doctors
medical	n6 adm - asked about previous. adms	cons2 w/r 8/12 - asked pt how she was
nausea & vomiting		noted on proforma so pt likely to have been asked about this
mobility	n6 adm - asked pt what was wrong with her leg and who was looking after it; asked about her mobility and if she fell	pt prob. asked as info. on proforma
ulcer	n6 adm - checked d/n arrangements re:leg	cons2 w/r 8/12 - info. that would take a while to heal
?DVT		cons2 w/r 8/12 - asked pt when the swelling had begun// pt asked cons2 if swelling would go down (yes)
communication	n6 adm - asked about her glasses and about her hearing	
eating & drinking	n6 adm - asked if she had her own teeth, and if she managed to chew alright	
social services	n6 adm - pt asked if she lived on her own; pt asked who did all her cooking, shopping, housework int -niece didn't raise concerns on phone when rang to ask about pt, so assume she's happy	n6 pt probably asked as info. given on medical proforma sho5 int - no concerns raised by family, so dr hasn't got any concerns
shopping	n6 adm - checked if pt able to do own shopping (bad leg - see mobil.)	pt probably asked as info. given on medical proforma
cleaning	asked at adm (see above)	pt probably asked as info. given on medical proforma
washing & dressing	n6 adm - asked pt if she could get into a bath, and if she could manage herself	pt probably asked as info. given on medical proforma
cooking		
pension		
laundry		
other	n6 adm - pt asked if she was worried about being in ho.	
d. date	n6 adm - thought pt would not be in ho. too long	

## APPENDIX 14 Involvement Matrix

Patient 25	Social worker	O/T	Physio	Other ho.
medical		[Not involved]	[Not involved]	[No other hospital staff involved]
nausea & vomiting				
mobility				
ulcer				
?DVT				
communication				
eating & drinking				
social services	sw2 int - pt happy to return home with current package			
shopping	sw2 int - checked she had enough food in the fridge on discharge			
cleaning	pt prob. asked as sw aware of support pt receiving			
washing & dressing	?pt asked or sw got info. from prof.s			
cooking				
pension				
laundry				
other				
d. date				

## APPENDIX 14 Involvement Matrix

Patient 25	comm.	patient's/ family's perspective
medical		
nausea & vomiting		
mobility		home int - wanting be able to get up and go to the supermarket again where all the staff knew her as she was the first person in every morning
ulcer		w/r 8/12 - pt worried by leg which was bleeding and swollen home int - said that they did her leg a lot of good in ho.
?DVT		pt - wanting swelling to go down
communication		pt thinking that she might need a hearing aid
eating & drinking		pt wanting some dentures
social services		ho int - worried that she has not been able to go out since fall; no extra help wanted or needed - other people need it more; said she had not been asked in ho. if she wanted extra help home int - said that she had been managing alright
shopping		pt would like to be able to get back to doing own shopping wanting to cont. with help until then
cleaning		pt says getting additional. support from private cleaner
washing & dressing		likes to shower - had shower installed at her own expense
cooking		ho int - likes to do her own cooking
pension		
laundry		
other		said that she didn't know how it was decided that she had enough support
d. date		pt wanting to know o/a how long she would be in ho./ medical notes 5/12 - pt wants to go home

## APPENDIX 14

### List of abbreviations used in the tables

6/52	6 weeks
8/12	8th December
adm	admission
appt	appointment
bec	because
cons2	consultant 2
CVA	cerebral vascular accident (stroke)
d.	discharge
dr	doctor
dvt	deep vein thrombosis
f/n	fieldnotes
HH	home help
ho	hospital
Hx	history of
info	information
int	interview
LA	local authority
med	medical
n	nurse
n6	nurse 6
o/a	on admission
O/T	occupational therapist
Physio	physiotherapist
prob.	probably
prof.s	professionals
pt	patient
res.r	researcher
sho5	senior house officer 5
SS	social services
sw	social worker
UTI	urinary tract infection
wc	warden controlled accommodation
w/r	ward round

## APPENDIX 15

### INFORMATION TO PATIENTS TO PARTICIPATE IN AN AUDIOTAPED INTERVIEW

I invite you to take part in a research study which I think may be important. The information which follows tells you about it. Try to make sure you know what will happen to you if you decide to take part. Whether or not you do take part is entirely your choice. Please ask any questions you want to about the research and I will try my best to answer them.

You have been invited to take part in this study because you have recently been an in-patient on [name] ward at [name] hospital and you currently live within the boundaries of [name] health authority. Evidence shows that patients have different experiences of being in hospital, and that plans for care that is needed after leaving hospital are made in different ways.

The study focuses on your experiences whilst you were an in-patient on [name] ward. To do this I shall invite you to take part in an interview which will be taped, during which I will ask you about your care in hospital, and the role that nurses played. The interview will last about 30 minutes and will not have your name recorded to protect your right to confidentiality and anonymity. The transcript will be coded and stored in a locked cupboard in the research office of the School of Nursing. I will be the only person to listen to the recording, and findings from this study will not use your name. The interview will provide a confidential forum in which I hope you will feel free to discuss your experiences. The interview will be tape recorded in order that I do not lose the essence of what you say. None of the hospital staff will have access to the tape, and I will not discuss any part of the interview with them. It can take place at a location of your choice, and you are free to stop at any point. The research is part of my PhD study, which is being supervised by Dr Julianne Meyer and Dr Angela Cotter at City University. The findings from this study will only be used for the purposes of research.

You don't have to join this study. you are free to decide not to be in this study or to drop out at any time. If you decide not to be in the study, or to drop out, this will not put at risk your ordinary medical care.

If you have any worries, you will always be able to contact me to discuss your concerns.

Name: Katharine Anstey  
Address: Room 318,  
St Bartholomew School of Nursing and Midwifery,  
City University,  
20 Bartholomew Close,  
West Smithfield,  
London EC1A 7QN

Telephone: 0171-505-5792 (Work)  
0181-675-6524 (Home)

## APPENDIX 16

### INFORMATION FOR STAFF - TO BE DISPLAYED IN THE STAFF ROOM - [NAME] WARD

#### **The nurse's role in promoting the involvement of older patients and informal carers in the assessment of their individual continuing health and social care needs**

Previous research suggests that there are different understandings about the role of the nurse within multidisciplinary assessments, in particular with respect to involving older users. The research approach is being taken to develop a broader picture than currently exists of the nurse's role in relation to the identification of continuing health and social care needs.

Part of the study involves observation of the ward environment. It is not possible to exclude individual staff from an observational study. You should be aware that notes of ward activity may be made during this time.

Your name will not be recorded at any stage to protect your right to confidentiality and anonymity. I will not be involved in appraising standards, and my supervisor and myself will be the only persons to have access to the observations. Findings from this study will not disclose your identity. They will be used for the purposes of research only.

If you get worried, or have any questions about any aspect of the study, you will always be able to contact me to discuss your concerns and/ or get help.

Name: Katharine Anstey  
Address: Room 318,  
St Bartholomew School of Nursing and Midwifery  
City University  
20 Bartholomew Close  
West Smithfield  
London EC1A 7QN

Telephone: 0171-505-5792 (Work)  
0181-675-6524 (Home)



## **APPENDIX 17**

### **INFORMATION FOR PATIENTS**

If you have any questions about the social care you are getting, you can contact your Social Services Department. Social care can include help with washing, dressing, shopping and cleaning.

The telephone number is:

[name] health authority - [telephone number]

If you have any questions about the health care that you are getting, you should contact your General Practitioner. Health care can include care from a doctor, nurse, physiotherapist, occupational therapist or dietician. If you are not registered with a General Practitioner, lists of local General Practitioners can be obtained from libraries or from Community Health Councils.

The telephone number of your Community Health Council is: [telephone number]

If you have a question about the care you are getting from a district nurse, you can contact a central help point, their number is [telephone number].

If family or friends looking after you would like advice or support about the help they are giving they could contact the Carers National Association on the telephone number below.

Carersline 0171 490 8898

## **BIBLIOGRAPHY**

- Abbott, S., Johnson, L. and Lewis, H. (2001) Participation in Arranging Continuing Health Care Packages: Experiences and aspirations of service users. *Journal of Nursing Management* 9: 79-85.
- Abramson, J. (1988) Participation of Elderly Patients in Discharge Planning: Is Self-Determination a Reality? *Social Work* 33: 443-448.
- Agard, A., Hermeren, G. and Herlitz, J. (2000) Should cardiopulmonary resuscitation be performed on patients with heart failure? The role of the patient in the decision-making process. *Journal of Internal Medicine* 248: 4, 279-286.
- Age Concern (1996) *Not at my Age*. London: Age Concern.
- Allen, D. (1997) 'Sorry nurse I didn't want to tell you your job': Negotiating care in hospital wards. *Paper presented at the British Sociological Association's annual Medical Sociology conference*. York.
- Allen, D. (2000) *The Changing Shape of Nursing Practice*. London: Routledge.
- Allen, D., Lyne, P. and Griffiths, L. (2002) Studying complex caring interfaces: key issues arising from a study of multi-agency rehabilitative care for people who have suffered a stroke. *Journal of Clinical Nursing* 11: 3, 297-305.
- Allen, I., Hogg, D. and Peace, S. (1992) *Elderly People: Choice participation and satisfaction*. London: Policy Studies Institute.
- Altheide, D. and Johnson, J. (1994) Criteria for Assessing Interpretive Validity in Qualitative Research In: Denzin N. and Lincoln Y. (Eds) *Handbook of Qualitative Research*, Thousand Oaks CA: Sage.
- Anstey, K. (1995) *An examination of the extent to which the objective set out in the 1990 National Health Service and Community Care legislation of enabling social service users to determine service priorities has been realised: A case study based on research of an East Kent community*. Unpublished undergraduate dissertation. University of York.
- Anstey, K., O'Flynn, N. and Barry, C. (2000) *Learning from each other: lessons from an inter-professional qualitative research group*. Paper presented at the Qualitative Research in Health and Social Care Conference, Bournemouth, 26th October.
- Arenth, L. and Mamon, J. (1985) Determining Patient Needs After Discharge. *Nursing Management* 16: 9, 20-24.
- Armitage, S. (1981) Negotiating the discharge of medical patients. *Journal of Advanced Nursing* 6: 385-389.
- Armitage, S. and Kavanagh, K. (1998) Consumer-orientated outcomes in discharge planning: a pilot study. *Journal of Clinical Nursing* 7: 67-74.

- Armstrong, D. (1983) The Fabrication of Nurse-Patient Relationships. *Social Science and Medicine* 17: 8, 457-460.
- Arnstein, S. (1969) A ladder of citizen participation. *Journal of the American Institute of Planners* 35: 4, 216-224.
- Arora, N. and McHorney, C. (2000) Patient Preferences for Medical Decision Making: Who really wants to participate? *Medical Care* 38: 3, 335-341.
- Ashworth, P., Longmate, M. and Morrison, P. (1992) Patient Participation: Its Meaning and Significance in the Context of Caring. *Journal of Advanced Nursing* 17: 1430-1439.
- Audit Commission (1997) *The Coming of Age: Improving care services for older people*. London: Audit Commission.
- Baldock, J. and Ungerson, C. (1994) *Becoming Consumers of Community Care: Households within the mixed economy of welfare*. York: Joseph Rowntree Foundation.
- Baron, R. (1988) Negative Effects of Destructive Criticism: Impact on Conflict, Self-Efficacy, and Task Performance. *Journal of Applied Psychology* 73: 2, 199-207.
- Barnes, M. and Walker, A. (1996) Consumerism versus empowerment: a principled approach to the involvement of older service users. *Policy and Politics* 24: 4, 375-393.
- Barnes, M. and Wistow, G. (1992) *Researching User Involvement*. Leeds: Nuffield Institute for Health Studies.
- Basco, W. and Reigart, J. (2001) When do medical students identify career-influencing physician role models? *Academic Medicine* 76: 4, 380-382.
- Beattie, A. (1991) Knowledge and Control in Health Promotion: A test case for social policy and social theory. In Gabe, J., Calnan, M. and Bury, M. (Eds) *The Sociology of the Health Service*. London: Routledge.
- Beaver, K., Luker, K., Owens, R., Leinster, S., Degner, L. and Sloan, J. (1996) Treatment Decision-making in Women Newly Diagnosed with Breast Cancer. *Cancer Nursing* 19: 8-19.
- Beisecker, A. and Beisecker, T. (1990) Patient Information-Seeking Behaviors when Communicating with Doctors. *Medical Care* 28: 19-28.
- Beisecker, A., Helmig, L., Graham, D. and Moore, W. (1994) Attitudes of Oncologists, Oncology Nurses, and Patients from a Women's Clinic Regarding Medical Decision Making for Older and Younger Breast Cancer Patients. *The Gerontologist* 34: 4, 505-512.
- Bekker, H., Thornton, J., Airey, C., Connelly, J., Hewison, J., Robinson, M., et al. (1999) Informed decision making: an annotated bibliography and systematic review. *Health Technology Assessment* 3 (1).
- Bengston, V., Burgess, E. and Parrat, T. (1997) Theory, explanation and a third generation of theoretical development in social gerontology. *Journal of Gerontology (Social Series)* 52: 2, 572-88.

- Bergen A., Cowley, S., Young, K. and Kavanagh, A. (1996) *An investigation into the changing educational needs of community nurses with regard to needs assessment and quality of care in the context of the NHS and Community Care Act 1990*. London: ENB.
- Beveridge, W. (1942) *Social Insurance and Allied Services*. London: HMSO.
- Biley, F. (1992) Some determinants that effect patient participation in decision-making about nursing care. *Journal of Advanced Nursing* 17: 414-421.
- Black, D., Morris, J., Smith, C. and Townsend, P. (1982) *Inequalities in Health: The Black Report*. Harmondsworth: Penguin.
- Blanchard, C., Labrecque, M., Ruckdeschel, J. and Blanchard, E. (1988) Information and decision-making preferences of hospitalized adult cancer patients. *Social Science and Medicine* 27: 11, 1139-1145.
- Borough Community Care Plan - For reason of anonymity this document cannot be referenced.
- Bowling, A. and Betts, G. (1984) Communications on Discharge. *Nursing Times* 80: 32, 31-32.
- Brearley, S. (1990) *Patient Participation: The literature*. London: Scutari Press.
- British Geriatrics Society, Association of Directors of Social Services and Royal College of Nursing (1995a) *The Assessment of Frail Elderly People Being Considered for or in Receipt of Continuing Care*. Wolverhampton: Wolverhampton Council.
- British Geriatrics Society, the Association of Directors of Social Services and the Royal College of Nursing (1995b) *The Discharge of Elderly Persons from Hospital for Community Care*. Wolverhampton: Wolverhampton Council.
- Brooking, J. (1986) *Patient and Family Participation in Nursing Care: The development of a nursing process measuring scale*. Unpublished PhD thesis. University of London.
- Brownlea, A. (1987) Participation: Myths, Realities and Prognosis. *Social Science and Medicine* 25: 6, 605-614.
- Bryar, R. (2000) An examination of case study research. *Nurse Researcher* 7: 2, 57-79.
- Burgess, R. (1984) *In the Field: An introduction to field research*. New York: Routledge.
- Burns, D. (1991) Ladders of participation. *Going Local* 18: 14-15.
- Busby, A. and Gilchrist, B. (1992) The role of the nurse in the medical ward round. *Journal of Advanced Nursing* 17: 339-346.
- Cahill, J. (1996) Patient participation: a concept analysis. *Journal of Advanced Nursing* 24: 561-571.
- Cahill, J. (1998) Patient participation: a review of the literature. *Journal of Clinical Nursing* 7: 119-128.

- Caress, A., Luker, K. and Ackrill, P. (1998) Patient-sensitive Treatment Decision-making? Preferences and perceptions in a sample of renal patients. *NT Research* 3: 5, 364-372.
- Caress, A., Luker, K., Woodcock, A. and Beaver, K. (2002) A qualitative exploration of treatment decision-making role preference in adult asthma patients. *Health Expectations* 5: 3, 223-325.
- Carr-Hill, R. and Jenkins-Clarke S. (1995) The chimera of nursing workload management systems. *Health Informatics* 1: 22-25.
- Cassileth, B., Zupkis, R., Sutton-Smith, K. and March, V. (1980) Information and Participation Preferences Among Cancer Patients. *Annals of Internal Medicine* 92: 832-836.
- Chadderton, H. (1995) An analysis of the concept of participation within the context of health care planning. *Journal of Nursing Management* 3: 221-228.
- Chang, B. (1980) Evaluation of health care professionals in facilitating self-care: review of the literature and a conceptual model. *Advanced Nursing Science* 3: 1, 43-58.
- Clark, H., Dyer, S. and Hartman, L. (1996) *Going Home: Older People leaving hospital*. Bristol: Policy Press.
- Clinical Standards Advisory Group (1998) *Community Health Care for Elderly People*. London: The Stationery Office.
- Coffey, A. and Atkinson, P. (1996) *Making Sense of Qualitative Data: complimentary research strategies*. Thousand Oaks CA: Sage.
- Collier, J. and Schirm, V. (1992) Family-focused nursing care of hospitalized elderly. *International Journal of Nursing Studies* 29: 1, 49-57.
- Congdon, J. (1994) Managing the Incongruities: The hospital discharge experience for elderly patients, their families and nurses. *Applied Nursing Research* 7: 3, 125-131.
- Cote, L. and Leclere, H. (2000) How clinical teachers perceive the doctor-patient relationship and themselves as role models. *Academic Medicine* 75: 11, 1117-1124.
- Cotter, A., Meyer, J. and Roberts, S. (1998) Humanity or bureaucracy? The transition from hospital to long-term continuing institutional care. *NT Research* 3: 4, 247-256.
- Coulton, C.J., Dunkle, R.E., Chow, J.C., Haug, M. and Vielhaber, D.P. (1988) Dimensions of Post-Hospital Care Decision-Making: A Factor Analytic Study. *The Gerontologist* 28: 2, 218-223.
- Crabtree, B. and Miller, W. (1999) *Doing Qualitative Research*. 2nd edn. Thousand Oaks CA: Sage.
- Crotty, M. (1998) *The Foundations of Social Research*. London: Sage.
- Dalley, G. and Denniss, M. (1997) *Patient Satisfaction: the discharge of older people from hospital - a survey*. London: Centre for Policy on Ageing.

- Davies, S., Laker, S. and Ellis, L. (1997) Promoting autonomy and independence for older people within nursing practice: a literature review. *Journal of Advanced Nursing* 26: 408-417.
- Davies, S., Nolan, M., Brown, J. and Wilson, F. (1999) *Dignity on the Ward: Promoting Excellence in Care*. London: Help the Aged.
- Davies, S., Powell, A. and Aveyard, B. (2002) Developing Continuing Care: Towards a teaching nursing home. *British Journal of Nursing* 11: 20, 1320-1328.
- Davies, S. and Nolan, M. (2003) A relationship-centred approach to working with older people and their families. In: *Nursing Practice and Health Care*. London: Arnold. (forthcoming).
- Deber, R., Kraetschmer, N. and Irvine, J. (1996) What Role do Patients Wish in Treatment Decision Making? *Archives of Internal Medicine* 156: 1414-1420.
- Degner, L. and Sloan, J. (1992) Decision Making During Serious Illness: What role do patients really want to play? *Journal of Clinical Epidemiology* 45: 9, 941-950.
- Dellasega, C. and Mastrian, K. (1995) The Process and Consequences of Institutionalizing an Elder. *Western Journal of Nursing Research* 17: 2 , 123-40.
- Department of Health (1989) *Caring for People: Community Care in the Next Decade and Beyond*. [CM 849] London: HMSO.
- Department of Health (1993) *A Vision for the Future - the Nursing, Midwifery and Health Visiting Contribution to Health and Health Care*. London: HMSO.
- Department of Health (1994a) *The F Factor: Reasons Why Some Older People Choose Residential Care*. London: Department of Health.
- Department of Health (1994b) *Hospital Discharge Workbook*. London: HMSO.
- Department of Health (1995) *NHS Responsibilities for Meeting Continuing Health Care Needs*. [HSG(95)8] London: Department of Health.
- Department of Health (1996a) *Progress in Practice: Initial Evaluation of the Impact of the Continuing Care Guidance*. [EL96(89)] London: Department of Health.
- Department of Health (1996b) *NHS Responsibilities for Meeting Continuing Health Care Needs - Current Progress and Future Priorities*. [EL(96)8] London: Department of Health.
- Department of Health (1997a) *Better Services for Vulnerable People*. [EL(97)62] London: Department of Health.
- Department of Health (1997b) *The New NHS: Modern Dependable*. London: The Stationery Office.
- Department of Health (1998) *Modernising Social Services*. London: The Stationery Office.

- Department of Health (1999) *Making a Difference: Strengthening the Nursing, Midwifery and Health Visiting Contribution to Healthcare*. London: Department of Health.
- Department of Health (2000a) *The NHS Plan*. London: The Stationery Office.
- Department of Health (2000b) *Shifting the Balance of Power: The Next Steps*. London: Department of Health.
- Department of Health (2000c) *Shaping the Future NHS: Long Term Planning for Hospitals and Related Services. Consultation document on the findings of the National Beds Inquiry - supporting analysis*. London: Department of Health.
- Department of Health (2001a) *National Service Framework for Older People*. [LAC 2001/12, (HSC) 2001/007] London: Department of Health.
- Department of Health (2001b) *Understanding and Applying the Registered Nursing Care Contribution (RNCC Tool)*. London: Department of Health.
- Department of Health (2001c) *NHS Funded Nursing Care: Practice Guide and Workbook*. London: Department of Health.
- Department of Health (2001d) *Shifting the Balance of Power: Securing delivery*. London: Department of Health.
- Department of Health (2001e) *Your Guide to the NHS*. London: Department of Health.
- Department of Health (2001f) *NHS Complaints Procedure: National Evaluation*. London: Department of Health.
- Department of Health (2002a) *The Single Assessment Process: Guidance for Local Implementation*. London: Department of Health.
- Department of Health (2002b) *Clinical governance defined*. London: Department of Health.  
Webpage address: [http://www.modern.nhs.uk/scripts/default.asp?site\\_id=18&id=3956](http://www.modern.nhs.uk/scripts/default.asp?site_id=18&id=3956)
- Department of Health (2002c) *Priorities - The NHS Plan*. London: Department of Health.  
Webpage address: <http://www.nhs.uk/thenhsexplained/priorities.asp>
- Department of Health (2002d) *The Single Assessment Process - Key Implications for Nurses*. London: Department of Health.
- Department of Health (2002e) *Government response to the Health Select Committee third report of the session 2001-02 on delayed discharges*. London: Department of Health.
- Department of Health (2002f) *More Older People are able to Leave Hospital on Time*. [Press release: reference 2002/0278] London; Department of Health.
- Department of Health (2002g) *Care Homes for Older People: National minimum standards*. London: The Stationery Office.
- Department of Health (2002h) *The Single Assessment Process - Key Implications for Older People*. London: Department of Health.

- Department of Health/ Social Services Inspectorate (1991) *Care Management and Assessment: Practitioners' Guide*. London: HMSO.
- Department of Health/ Social Services Inspectorate (1995a) *Moving On: Report of the National Inspection of Social Services Department Arrangements for the Discharge of Older People from Hospital to Residential or Nursing Home Care*. London: Department of Health.
- Department of Health/ Social Services Inspectorate (1995b) *Moving On: A further year. Inspection of Social Services Departments Arrangements for the Discharge of Older People from Hospital to Residential or Nursing Home Care*. London: Department of Health.
- Department of Health/ Social Services Inspectorate (1998) *Getting Better? Inspection of Hospital Discharge (Care Management) Arrangements for Older People*. London: Department of Health.
- Dey, I. (1993) *Qualitative Data Analysis: a user-friendly guide for social scientists*. New York: Routledge.
- Dill, A.E. (1995) The ethics of discharge planning for older adults: An ethnographic analysis. *Social Science and Medicine* 41: 9, 1289-1299.
- Dingwall, R. (1992) Don't mind him - he's from Barcelona: qualitative methods in health studies. In: Daly J., McDonald I. and Wilks E. (Eds) *Researching Health Care*. London: Tavistock/ Routledge.
- Draper, P. (1996) Compromise, massive encouragement and forcing: a discussion of the mechanisms used to limit the choices available to the older adult in hospital. *Journal of Clinical Nursing* 5: 325-331.
- Ellis, K. (1993) *Squaring the circle: User and carer participation in needs assessment*. Joseph Rowntree Foundation.
- Ende, J., Kazis, L., Ash, A. and Moskowitz, M. (1989) Measuring Patients' Desire for Autonomy: Decision making and information seeking preferences among medical patients. *Journal of General Internal Medicine* 4: 23-30.
- Equip Team (1997) *It's nice to be home... Patients' experience of being discharged from hospital*. Sheffield: Towards Co-ordinated Practice.
- Erlandson, D., Harris, E., Skipper, B. and Allen, S. (1993) *Doing Naturalistic Inquiry*. London: Sage.
- Evers, H. (1981) Multidisciplinary teams in geriatric wards: myth or reality? *Journal of Advanced Nursing* 6: 205-214.
- Faden, R., Becker, C., Lewis, C., Freeman, J. and Faden, A. (1981) Disclosure of Information to Patients in Medical Care. *Medical Care* 29: 7, 718-733.
- Farrell, C. and Gilbert, H. (1996) *Health Care Partnerships*. London: King's Fund.



- Fennell, G., Phillipson, C. and Evers, H. (1988) *The Sociology of Old Age*. Milton Keynes: Open University Press.
- Ferrie, J., Shipley, M., Stansfeld, S. and Marmot M. (2002) Effects of chronic job insecurity and change in job security on self reported health, minor psychiatric morbidity, physiological measures, and health related behaviours in British civil servants: the Whitehall II study. *Journal of Epidemiology and Community Health* 56: 6, 450-454.
- Fielding, N. (1993) Ethnography. In Gilbert N. (Ed) *Researching Social Life*. London: Sage.
- Froland, C., Pancoast, D., Chapman, N. and Kimboko, P. (1981) *Helping Networks and Human Services*. London: Sage.
- Gay, P. and Pitkeathley, J. (1979) *When I Went Home ... a study of patients discharged from hospital*. London: King Edward's Hospital Fund for London.
- Gearing, B. and Dant, T. (1990) Doing Biographical Research. In: Peace (Ed) *Researching Social Gerontology: concepts, methods and issues*. London: Sage.
- Gerteis, M., Edgman-Levitan, S., Daley, J. and Delbanco, T. (Eds) (1993) *Through the Patient's Eyes*. San Francisco: Jossey Bass Publishers.
- Gilbert, H. (1995) *Redressing the Balance: a brief survey of literature on patient empowerment*. London: King's Fund.
- Gilbert, N. (1993) Research, theory and method. In: Gilbert N. (Ed) *Researching Social Life*. London: Sage.
- Gilleard, C. and Higgs, P. (1998) Old people as users and consumers of healthcare: a third age rhetoric for a fourth age reality? *Ageing and Society*; 18: 235-248.
- Godfrey, M. and Moore, J. (1996) *Hospital Discharge: User, Carer and Professional Perspectives*. Leeds: Nuffield Institute for Health.
- Gold, R. (1958) Roles in sociological fieldwork. *Social Forces*; 36: 217-223.
- Gonzalez, S., Steinglass, P. and Reiss, D. (1989) Putting illness in its place: discussion groups for families with chronic medical illnesses. *Family Process* 28: 69-87.
- Goodwin, L. and Goodwin, H. (1984) Qualitative vs. Quantitative or Qualitative and Quantitative Research. *Nurse Researcher*; 33: 378-380.
- Great Britain (1990) *National Health Service and Community Care Act 1990*. London: HMSO.
- Griffiths, R. (1988) *Community Care: Agenda for Action: A report to the Secretary of State for Social Services by Sir Roy Griffiths*. London: HMSO.
- Guadagnoli, E. and Ward, P. (1998) Patient Participation in Decision-making. *Social Science and Medicine*; 47: 3, 329-339.
- Guba, E. (1981) Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication Technology Journal* 29: 75-91.

- Guba, E. and Lincoln, Y. (1989) *Fourth Generation Evaluation*. Newbury Park, CA: Sage.
- Guba, E. and Lincoln, Y. (1994) Competing Paradigms in Qualitative Research. In: Denzin, N. and Lincoln, Y. (Eds) *Handbook of Qualitative Research*. Thousand Oaks CA: Sage.
- Hack, T., Degner, L. and Dyck, D. (1994) Relationship Between Preferences for Decisional Control and Illness Information Among Women with Breast Cancer: A quantitative and qualitative analysis. *Social Science and Medicine* 39: 279-289.
- Hamilton-Gurney, B. (1993) *Public Participation in Health Care Decision Making*. Health Services Research Group, University of Cambridge.
- Hammersley, M. (1992) *What's Wrong with Ethnography?* London: Routledge.
- Hammersley, M. and Atkinson, P. (1995) *Ethnography: Principles in practice*. London: Routledge.
- Hammersley, M. and Gomm, R. (2000) Introduction. In: Gomm, R., Hammersley, M. and Foster, P. (Eds) *Case Study Method*. London: Sage.
- Hammersley, M. and Gomm, R. and Foster, P. (2000) Case Study and Theory. In: Gomm, R., Hammersley, M. and Foster, P. (Eds) *Case Study Method*. London: Sage.
- Hanson, D. (1980) Relationship Between Methods and Judges in Attitude Behavior Research. *Psychology* 17: 11-13.
- Hardy, B., Young, R. and Wistow, G. (1999) Dimensions of Choice in the Assessment and Care Management Process: The views of older people, carers and care managers. *Health and Social Care in the Community* 7: 6, 483-491.
- Hart, C. (1998) *Doing a Literature Review*. London: Sage.
- Haug, M. and Lavin, B. (1981) Practitioner or Patient - Who's in Charge? *Journal of Health and Social Behavior*. 22: 212-219.
- Health Advisory Service (HAS 2000) (1999) *Standards for Health and Social Care Services for Older People*. Brighton: Pavilion Publishing.
- Health Services Accreditation (1996) *Service Standards for Discharge Care*. Sussex: Health Services Accreditation.
- Health Services Commissioner (1994) *Failure to Provide Long-term NHS Care for a Brain-damaged Patient*. Report of the Health Service Commissioner, HC 197. London: HMSO.
- Help the Aged (2000) *Our Future Health: Older people's priorities for health and social care*; London: Help the Aged.
- Henwood, M. (1992) *Through a Glass Darkly: Community Care and Elderly People*. London: King's Fund Institute.
- Henwood, M. (1996) *Continuing Health Care: Analysis of a Sample of Final Documents*. Leeds: Nuffield Institute for Health.

- Henwood, M. (1998) *Ignored and invisible? Carers' experience of the NHS*. London: Carers National Association.
- Hewison, A. (1995) Nurses' power in interactions with patients. *Journal of Advanced Nursing* 21: 75-82.
- Higgs, P. (1995) Citizenship and Old Age: The End of the Road? *Ageing and Society*; 15: 535-550.
- Hope, A. (1996) *Evidence-Based Patient Choice*. London: King's Fund.
- House of Commons Health Committee (1996) *Long-Term Care: Future Provision and Funding*. Third Report, Session 1995-1996, HC 59-1, HMSO.
- Hudson, H. (1993) Needs-led assessment: nice idea shame about the reality? *Health and Social Care in the Community* 1: 115-123.
- Hughes, B. (1995) *Older People and Community Care: Critical Theory and Practice*. Buckingham: Open University Press.
- Hunter, S., Brace, S. and Buckley, G. (1993) The Inter-disciplinary Assessment of Older People at Entry into Long-term Institutional Care: Lessons for the New Community Care Arrangements. *Research, Policy and Planning* 11: 1/2, 2-9.
- Husserl, E. (1970) *The Crisis of European Sciences and Transcendental Phenomenology*. Evanston: North-western University Press.
- Jacques, I. and Ryan, A. (1997) Assessment and Continuing Care. *Elderly Care*; 9: 6, 20-23.
- Jarvis, C., Hancock, R., Askham, J. and Tinker, A. (1996) *Getting Around After 60: A Profile of Britain's Older Population*. London: HMSO.
- Jewell, S. (1993) Discovery of the Discharge Process: A study of patient discharge from a care unit for elderly people. *Journal of Advanced Nursing* 18: 1288-1296.
- Jewell, S. (1994) Patient Participation: what does it mean to nurses? *Journal of Advanced Nursing*; 19: 433-438.
- Jewell, S. (1996a) Elderly patients' participation in discharge decision making: 2. *British Journal of Nursing* 5: 17, 1065-1071.
- Jewell, S. (1996b) Elderly patients' participation in discharge decision making: 1. *British Journal of Nursing* 5: 15, 914-915 and-929-932.
- Johnson, J. (1989) Where's discharge planning on your list? *Geriatric Nursing* 10: 148-149.
- Johnson, R., Schwiebert, V. and Rosenmann, P. (1994) Factors Influencing Nursing Home Placement Decisions. *Clinical Nursing Research* 3: 3, 269-281.
- Jones, D. and Lester, C. (1994) Hospital Care and Discharge: Patients' and Carers' Opinions. *Age and Ageing* 23: 91-96.

- Jorgensen, D. (1989) *Participant Observation: a methodology for human studies*. Newbury Park CA: Sage.
- Kadushin, G. and Kulys, R. (1994) Patient and Family Involvement in Discharge Planning. *Journal of Gerontological Social Work* 22: 3/4, 171-199.
- Kerridge, I., Pearson, S., Rolfe, I. and Lowe, M. (1998) Decision Making in CPR: Attitudes of hospital patients and healthcare professionals. *Medical Journal of Australia* 169: 3, 128-131.
- Kitwood, T. (1997) *Dementia Reconsidered: The person comes first*. Buckingham: Open University Press.
- Kracauer, S. (1993) The challenge to qualitative content analysis. *Public Opinion Quarterly*; 16: 631-642.
- Krantz, D., Baum, A. and Wideman, M. (1980) Assessment of preferences for self-treatment and information in health care. *Journal of Personal Social Psychology* 39: 977.
- Laitinen, P. and Isola, A. (1996) Promoting participation of informal caregivers in the hospital care of the elderly patient: informal caregivers; perceptions. *Journal of Advanced Nursing* 23: 942-947.
- Le Touze, S. (1997) *A Critical Review of the Literature on Continuing Care*. Canterbury: Centre for Health Services Studies.
- Lightfoot, J. (1995) Identifying needs and setting priorities: issues of theory, policy and practice. *Health and Social Care in the Community* 3: 2, 105-114.
- Lincoln, Y. and Guba, E. (1985) *Naturalistic Inquiry*. Beverly Hills CA: Sage.
- Lincoln, Y. and Guba, E. (2000) The Only Generalization is: There is no generalization. In: Gomm, R., Hammersley, M. and Foster, P. (Eds) *Case Study Method*. London: Sage.
- Litz, C., Meisel, A., Osterweis, M., Holden, J., Marx, J. and Munetz, M. (1983) Barriers to informed consent. *Annals of Internal Medicine* 99: 539-543.
- Lofland, J. and Lofland, L. (1995) *Analysing Social Settings: a guide to qualitative observation and analysis*. 3rd edn. Belmont CA: Wadsworth.
- Lowenstein, A. and Hoff, P. (1994) Discharge Planning: A study of nursing staff involvement. *Journal of Nursing Administration* 24: 4, 45-50.
- Lundh, U., Sandberg, J. and Nolan, M. (2000) 'I don't have any other choice': spouses' experiences of placing a partner in a care home for older people in Sweden. *Journal of Advanced Nursing* 32: 5, 1178-1186.
- McBride, R.C. (1995) An audit of current discharge planning arrangements and their effectiveness on elderly care wards and community nursing services together with aspects of client satisfaction. *Journal of Nursing Management* 3: 19-24.
- McClelland, M. and Sands, R. (1993) The Missing Voice in Interdisciplinary Communication. *Qualitative Health Research* 3: 1, 74-90.

- McCormack, B. (1998) *An Exploration of the Theoretical Framework Underpinning the Autonomy of Older People in Hospital and its Relationship to Professional Nursing Practice*. Unpublished DPhil Thesis. Oxford: University of Oxford.
- McCormack, B. and Wright, J. (1999) Achieving dignified care for older people through practice development: A systematic approach. *NT Research* 4: 5, 340-352.
- Mackay, L. (1989) *Nursing a Problem*. Milton Keynes: Open University Press.
- McKinstry, B. (2000) Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. *British Medical Journal* 321: 867-871.
- McWilliam, C., Belle Brown, J., Carmichael, J. and Lehman, J. (1994) A new perspective on threatened autonomy in elderly persons: the disempowering process. *Social Science and Medicine* 38: 327-338.
- Matthews, J. (2000) *An Introduction to Randomised Controlled Clinical Trials*. London: Arnold.
- May, C. (1995) Patient Autonomy and the Politics of Professional Relationships. *Journal of Advanced Nursing* 21: 83-87.
- Maynard A. (1987) What Nursing Shortage? *Health Service Journal* 97: 5071, 1170.
- Medical Sociology Group (1996) *Criteria for the Evaluation of Qualitative Research Papers*. Medical Sociology Group.
- Meyer, J. (1993) Lay participation in care: a challenge for multidisciplinary teamwork. *Journal of Interprofessional Care* 7: 1, 57-66.
- Meyer, J. (2001) *Lay Participation in Care in a Hospital Setting: An action research study*. Portsmouth: Nursing Praxis International.
- Miles, M. and Huberman, A. (1994) *Qualitative Data Analysis: an expanded sourcebook*. 2nd edn. Thousand Oaks CA: Sage.
- Mishler, E. (1984) *The Discourse of Medicine: dialectics of medical interviews*. Norwood NJ: Ablex.
- Morse, J. (1994) Designing Funded Qualitative Research. In Denzin, N. and Lincoln Y. (Eds) *Handbook of Qualitative Research*. Thousand Oaks CA: Sage.
- Murphy, E. (2001) Micro-level Qualitative research. In: Fulop, N., Allen, P., Clarke A. and Black N. (Eds) *Studying the Organisation and Delivery of Health Services*. London: Routledge.
- Murphy, E., Dingwall, R., Greatbatch, D., Parker, S. and Watson, P. (1998) Qualitative research methods in health technology assessment: a review of the literature. *Health Technology Assessment*; 2: 6.

- Myers, F. and MacDonald, C. (1996) Power to the people? Involving users and carers in needs assessment and care planning -views from the practitioner. *Health and Social Care in the Community* 4: 2, 86-95.
- Neill, J. and Williams, J. (1992) *Leaving Hospital: Elderly people and their discharge to community care*. London: HMSO.
- NHS Executive (South Thames) (1998) *Better Services for Vulnerable People, Maintaining the Momentum*. London: NHS Executive.
- NHS Health Advisory Service (1997) *Services for People who are Elderly - Addressing the Balance: The multidisciplinary assessment of elderly people and the delivery of high quality continuing care*. London: The Stationery Office.
- Nolan, M. (1995) Towards an ethos of interdisciplinary care. *British Medical Journal* 311: 305-307.
- Nolan, M. (1997) *Health and Social Care: What the Future Holds for Nursing*. Keynote address at the Third Royal College of Nursing Older Person European Conference, Harrogate, 5th November.
- Nolan, M. (2000) Towards person-centred care for older people. In Warnes, A., Warren, L. and Nolan, M. (Eds) *Care Services for Later Life*. London: Jessica Kingsley Publishers.
- Nolan, M. and Caldock, K. (1996) Assessment: Identifying the barriers to good practice. *Health and Social Care in the Community*; 4: 2, 77-85.
- Nolan, M., Walker, G., Nolan, J., Williams, S., Poland, F., Curran, M. and Kent, B.C. (1996) Entry to care: positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing* 24: 265-274.
- Nolan, M., Davies, S. and Grant, G. (2001a) Quality of Life, Quality of Care. In: Nolan, M., Davies, S. and Grant, G. (Eds) *Working with Older People and their Families*. Buckingham: Open University Press.
- Nolan, M., Keady, J. and Aveyard, B. (2001b) Relationship-centred care is the next logical step. *British Journal of Nursing* 10: 12, 757.
- Nolan M., Davies, S., Brown, J., Keady, J. and Nolan, J. (2002) *Longitudinal Study of the Effectiveness of Educational Preparation to Meet the Needs of Older People and Carers*. London: ENB.
- Obeid, A. (2000) Perceptions of User Participation in Health Care. *Journal of Community Nursing* 14: 7, 32-36.
- Office for National Statistics (1998) *Informal Carers*. London: The Stationery Office.
- O'Hare, P. (1992) Comparing Two Models of Discharge Planning Rounds in Acute Care. *Applied Nursing Research* 5: 2, 66-73.
- Opie, A. (1998) 'Nobody's Asked Me for My View': Users' Empowerment by Multidisciplinary Health Teams. *Qualitative Health Research* 8: 2, 188-206.

- Owen, H. (1996) *Creating Top Flight Teams*. London: Kogan Page.
- Parker, G. (1990) *Team Players and Teamwork*. San Fransisco: Jossey-Bass.
- Pendleton, L. and House, W. (1984) Preferences for Treatment Approaches in Medical Care. *Medical Care* 22: 7, 644-646.
- Penhale, B. (1997) Towards Effective Discharge Planning. *Health Care in Later Life* 2: 1, 46-55.
- Powell, J., Lovelock, R., Bray, J. and Philp, I. (1994) Quality Issues in Discharge from Hospital - The Views of Older People and their Carers. *Social Services Research* 1: 42-55.
- Proctor, S., Wilcockson, J., Pearson, P. and Allgar V. (2001) Going Home from Hospital: The carer/ patient dyad. *Journal of Advanced Nursing* 35: 2, 206-217.
- Quill, T. (1983) Partnerships in care: a contractual approach. *Annals of Internal Medicine*; 98:4, 228-235.
- Redfern, S. and Norman, I. (1999) Quality of Nursing Care Perceived by Patients and their Nurses: An Application of the Clinical Incident Technique: Parts 1 and 2. *Journal of Clinical Nursing* 8: 407-421.
- Reed, J. and Morgan, D. (1999) Discharging older people from hospital to care homes: implications for nursing. *Journal of Advanced Nursing* 29: 4, 819-825.
- Reed, J. and Payton, V. (1996) Past the age of consent? A discussion of some of the ethical issues arising in a study involving older people. *Health Care in Later Life*; 1: 51-61.
- Richards, S. (1996) *Defining and Assessing Need: An ethnographic study of the community care needs assessment of older people* Unpublished PhD thesis, University of Southampton.
- Richardson, A. (1983) *Participation: Concepts in Social Policy One*, London: Routledge and Kegan Paul.
- Roberts, I. (1975) *Discharged from Hospital* London: RCN.
- Robertson, S. (1995) *'Fed and Watered': The views of older people on need, assessment and care management*. Edinburgh: Age Concern Scotland.
- Robinson, C. and Thorne, S. (1984) Strengthening Family Interference. *Journal of Advanced Nursing*; 9: 6, 597-602.
- Robson, C. (1993) *Real World Research* Oxford: Blackwell.
- Rogers, W. (2002) Whose autonomy? Which choice? A study of GPs' attitudes towards patient autonomy in the management of low back pain. *Family Practice* 19: 2, 140-145.
- Roper, N., Logan, W. and Tierney, A. (1983) *Using a Model for Nursing*. Edinburgh: Churchill Livingstone.

- Rowles, G. and High, D. (1996) Individualizing Care: Family roles in nursing home decision making. *Journal of Gerontological Nursing* 22: 3, 20-25.
- Royal College of Nursing (1984) *Nurse Alert*. London: RCN.
- Royal College of Nursing (1990) *Guidelines for Assessment of Elderly People*. London: RCN.
- Royal College of Nursing (1995) *Evidence to the Health Committee Inquiry into Long Term Care*. London: RCN.
- Royal College of Nursing (1996) *Developing Leaders: A guide to good practice*. London: RCN.
- Royal College of Nursing (1998) *CPD matters: the Royal College of Nursing and continuing professional development: all you need to know*. London: RCN.
- Royal College of Nursing (2001) *Inspired to Care: The RCN clinical leadership programme*. London: RCN.
- Royal Commission on Long Term Care (1999) *With Respect to Old Age*. London: The Stationery Office.
- Ryan, A. and Scullion, H. (2000) Nursing home placement: an exploration of the experiences of family carers. *Journal of Advanced Nursing* 32: 5, 1187-1195.
- Sainio, C., Lauri, S. and Eriksson E. (2001) Cancer patients' views and experiences of participation in care and decision making. *Nursing Ethics* 8: 2, 97-113.
- Saltman, R. (1994) Patient Choice and Patient Empowerment. *International Journal of Health Services* 24: 2, 201-229.
- Salvage, J. (1985) *The Politics of Nursing*. London: Heinemann.
- Salvage, J. (1992) The New Nursing: Empowering Patients or Empowering Nurses? In: Robinson, J., Gray, A. and Elkan, R. (Eds) *Policy Issues in Nursing*. Milton Keynes: Open University Press.
- Schatzman, L. and Strauss, A. (1973) *Field research: strategies for a natural sociology*. Englewood Cliffs NJ: Prentice-Hall.
- Schwandt, T. (1997) *Qualitative Inquiry: A dictionary of terms*. Thousand Oaks CA: Sage.
- Schwartz, A. and Vogel, M. (1990) Nursing Home Staff and Residents' Families Role Expectations. *The Gerontologist* 30: 1, 49-53.
- Sharp, K. (1998) The case for case studies in nursing research: the problem of generalization. *Journal of Advanced Nursing*; 27: 785-789.
- Sharp, R. (1982) Self-Contained Ethnography or a Science of Phenomenal Forms and Inner Relations. *Boston University Journal of Education* 164: 1, 48-63.
- Shepherd, A. (1996) Home from Hospital - the Experiences of Older People and Carers of Discharge to Community Care. *Research, Policy and Planning* 14: 2, 4-12.



- Silverman, D. (1993) *Interpreting Qualitative Data*. London: Sage.
- Silverman, D. (1998) The Quality of Qualitative Health Research: the open ended interview and its alternatives. *Social Sciences in Health*; 4: 104-118.
- Skeet, M. (1982) *Home from Hospital: Providing continuing care for elderly people*. London: King's Fund Centre.
- Skeet, M. (1970) *Home from Hospital*. London. Dan Mason Nursing Research Committee of the National Florence Nightingale Memorial Committee of Great Britain and Northern Ireland.
- Sloan, G. (1999) Good Characteristics of a Clinical Supervisor: A community mental health nurse perspective. *Journal of Advanced Nursing*. 30: 3, 713-722.
- Smith, L. (1994) Biographical Method. In: Denzin N. and Lincoln Y. (Eds) *Handbook of Qualitative Research*. Thousand Oaks CA: Sage.
- Social Services Inspectorate (1991) *Care Management and Assessment: Practitioners' Guide*. London: HMSO.
- Social Services Inspectorate (1997) *From Hospital to Home*. Belfast: SSI.
- Spradley, J. (1980) *Participant Observation*. New York: Holt, Rinehart and Winston.
- Standing Nursing and Midwifery Advisory Committee (2001) *Caring for Older People: A Nursing Priority*. London: Department of Health.
- Stevenson, O. and Parsloe, P. (1993) *Community Care and Empowerment*. York: Joseph Rowntree Foundation.
- Strull, W., Lo, B. and Charles, G. (1984) Do Patients Want to Participate in Medical Decision Making? *Journal of the American Medical Association* 252: 21, 2990-2994.
- Sutherland, H., Llewellyn-Thomas, H., Lockwood, G., Tritchler, D. and Till, J. (1989) Cancer Patients: Their desire for information and participation in treatment decisions. *Journal of the Royal Society of Medicine* 82: 260-263.
- Taylor, M., Hoyes, L., Lart, R. and Means, R. (1992) *User empowerment in community care: unravelling the issues*. Bristol: School for Advanced Urban Studies.
- Tesch, R. (1990) *Qualitative Research: analysis types and software tools*. London: Falmer.
- Tester, S. (1996) *Community Care for Older People*. London: Macmillan.
- Thompson, S., Pitts, J. and Schwankovsky, L. (1993) Preference for Involvement in Medical Decision-making: Situational and demographic influences. *Patient Education and Counseling* 22: 133-140.
- Tierney, A., Worth, A., Closs, S.J., King, C. and Macmillan, M. (1994) Older patient's experiences of discharge from hospital. *Nursing Times* 90: 21, 36-39.

- Tuffnell, D., Nuttall, K., Raistrick, J. and Jackson, T. (1994) Use of translated written material to communicate with non-English speaking patients. *British Medical Journal* 309: 992.
- Twigg, J. and Atkin, K. (1994) *Carers Perceived: Policy and practice in informal care*. Buckingham: Open University Press.
- United Kingdom Central Council (1996) *Position Statement on Clinical Supervision for Nursing and Health Visiting*. London: UKCC.
- United Kingdom Central Council (1997) *The Nursing and Health Visiting Contribution to Continuing Care for Older People*. London: UKCC.
- Victor, C. and Vetter, N. (1988) Preparing the Elderly for Discharge from Hospital: A neglected aspect of patient care? *Age and Ageing* 17: 155-163.
- Victor, C., Young, E., Hudson, M. and Wallace, P. (1993) Whose Responsibility is it Anyway? Hospital admission and discharge of older people in an inner-London District Health Authority. *Journal of Advanced Nursing* 18: 1297-1304.
- Walker, L. and Avant, K. (1988) *Strategies for Theory Construction in Nursing*. Norwalk: Appleton and Lange.
- Warner, L. and Wexler, S. (1998) *Eight Hours a Day and Taken for Granted?* London: The Princess Royal Trust for Carers.
- Waters, K. (1987) Discharge Planning: An exploratory study of the process of discharge planning on geriatric wards. *Journal of Advanced Nursing* 12: 71-83.
- Waters, K. and Luker, K. (1996) Staff perspectives on the role of the nurse in rehabilitation wards for elderly people. *Journal of Clinical Nursing* 5: 105-114.
- Waterworth, S. and Luker, K. (1990) Reluctant collaborators: do patients want to be involved in decisions concerning care? *Journal of Advanced Nursing* 15: 971-976.
- Webb, C., Addison, C., Holman, H., Saklaki, B. and Wagner, A. (1990) Self medication for elderly patients. *Nursing Times*; 86: 16, 46-49.
- Weiss, S. (1986) Consensual Norms Regarding Patient Involvement. *Social Science and Medicine* 22: 4, 489-496.
- Wells, D. (1995) The Importance of Critical Theory to Nursing : A Description Using Research Concerning Discharge Decision-Making. *Canadian Journal of Nursing Research* 27: 2, 45-58.
- Williams, E. and Fitton, F. (1991) Survey of carers of elderly patients discharged from hospital. *British Journal of General Practice* 41: 105-108.
- Wistow, G. (1995) Aspirations and Realities: Community Care at the Crossroads. *Health and Social Care in the Community*; 3: 4, 227-240.
- Woodcock, M. and Francis, D. (1992) *Change*. Aldershot: Gower.
- Woodcock, M. and Francis, D. (1994) *Teambuilding Strategy*. Aldershot: Gower.

World Health Organisation (1979) *Formulating Strategies for Health for All by the Year 2000*. Geneva: WHO.

Yin, R. (1994) *Case Study Research: design and methods*. London: Sage.