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COUNSELLING PSYCHOLOGY AND CANCER

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Declaration

I grant powers of discretion to the Department of Psychology to allow this dissertation to be copied in whole or in part without any further reference to me. The permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.

SECTION A: INTRODUCTION TO THE PORTFOLIO

1. OVERVIEW

This doctoral portfolio which is comprised of three distinct sections has allowed me to consider the psychological dimension of cancer from a variety of perspectives. The different components which include a piece of qualitative research, a client study and a critical literature review, all relate to different aspects of my work as a counselling psychologist and have allowed me to develop my skills in all these respective areas. During the course of this introduction an overview of the three sections is provided. However before this I have offered an account of the personal and professional factors which motivated me to undertake this work.

2. PERSONAL AND PROFESSIONAL MOTIVATIONS

My interest in cancer first began whilst working as a research psychologist for the Cancer Research Campaign. During this time, my frequent contact with cancer patients led me realise that despite great advances in treatment, many patients and families still felt insufficiently supported and were left struggling to cope with the emotional burden associated with life-threatening illness. This experience led to my decision to train as a counselling psychologist. Throughout this training my interest in the psychological dimension of cancer remained and since qualifying I have worked in two large cancer treatment centres and at the current time I hold a full-time psychology post at St Christopher's Hospice in South London. These posts have all afforded me the opportunity to work therapeutically with those affected by cancer and also allowed me to develop close professional relationships with those responsible for delivering both medical and nursing care. These experiences have left me confident that psychology has an important role to play in the care of those affected by cancer. My decision to undertake this doctoral thesis is therefore a direct reflection of my ongoing interest in, and commitment to, this field of work.

Although a relatively new branch of applied psychology, counselling psychology now has the largest number of trainees of any of the applied psychologies (Walsh and Frankland, 2009). However despite this, the number of counselling psychologists working in the field of cancer and palliative care is very small. This is a potential source of concern, particularly as the message frequently conveyed in the psycho-oncology literature is that considering the enormous psychological burden of a cancer diagnosis, the number of psychologists available to provide specialist support is woefully inadequate (Hellbom *et al.*, 2001; Sharpe *et al.*, 2004; Lawrie *et al.*, 2004; Strong, 2004). Part of my motivation for undertaking this work was therefore to establish the role that counselling psychology can play in caring for those affected by cancer and raise awareness amongst counselling psychologists themselves of the existence of this growing area of clinical work.

Although counselling psychology is still an emerging speciality with some way to go before it can be considered truly established, one of the criticisms levelled against it has been its lack of contribution in terms of research (Jordan, 2009). This is certainly the case in the cancer literature. My own thorough review revealed that to date no psycho-oncology research had been undertaken by a counselling psychologist. Furthermore, no research existed investigating the role that psychologists play in caring for those affected by cancer. In light of this I was keen to conduct a piece of research which would go some way to raising the profile of psychologists and their work in the field of cancer. I also felt it important that with research being viewed as a core counselling psychology competency, a contribution to the literature was timely.

3. SECTION B: THE RESEARCH COMPONENT

The research section of the portfolio is comprised of a qualitative study which explores the understanding and expectations that clinical nurse specialists working in cancer and palliative care settings have of cancer psychologists. It also examines how these nurses go about assessing patients and/or carers for psychological distress. The study was conducted on account of there being no literature which had explored the relationship between psychologists and clinical nurse specialists. Neither was there a comprehensive account of how clinical nurse specialists went about assessing patients for psychological distress. The aim of the study was therefore to gain greater understanding in both these areas. It was anticipated that the results would be particularly valuable in terms of identifying whether additional education, training and support may be required. It was also hoped that the research findings would offer a positive contribution in terms of assisting psychologists taking up new psychology posts within cancer settings and help foster improved collaboration between different professional groups.

4. SECTION C: THE CLIENT STUDY COMPONENT

During this section I have presented a client case study which offers an account of the therapeutic work undertaken with a terminally ill patient. This is a reflexive exploration, highlighting both the successes and challenges encountered during the work. The client presented was a 36 year old woman, suffering with incurable uterine cancer whose prognosis at the time of referral was in the region of 3 months. There were a number of reasons for choosing to present this particular case. Firstly it represented my first attempt to use cognitive behavioural therapy with a terminally ill client. Secondly, although the work was emotionally very challenging it proved to be particularly significant in terms of my personal and professional development and learning.

5. SECTION D: THE CRITICAL LITERATURE REVIEW

This critical literature review offers a critique of some of the key research studies which have attempted to explore whether any relationship exists between psychological interventions and survival in cancer patients. Eleven randomised controlled trials conducted between 1982 and 2007 were selected for the review and each was considered for methodological rigour. The review offers a summary of the current understanding of the relationship between psychological interventions and survival times and also explores the challenges associated with this type of research. Finally in light of the existing evidence, future research ideas are suggested and explored.

6. PERSONAL STATEMENT

Undertaking this doctoral thesis has offered me the opportunity to focus in detail on a number of different aspects of the cancer experience. Producing such a piece of work, although challenging, has been of tremendous developmental benefit both from a personal and professional perspective. I feel I now have a more fundamental understanding of the psychological complexity of cancer which is underpinned by a sound awareness of the relevant literature. I also feel this work has allowed me to gain a broader perspective and has left me with a better understanding of the challenges faced by both patients and professionals. In turn, I feel I am now a more skilled and insightful clinician and am better able to contribute effectively within the context of the multi-disciplinary team. I have also developed a growing interest in the creation of initiatives designed to improve the psychological care of cancer patients both at local and national level.

With this work now completed, my focus has turned to the task of sharing the findings in a sensitive and productive fashion. I am in the process of arranging a presentation of the key findings to the study's participants thereby giving them the opportunity to decide whether they are happy for me to disseminate them to a wider audience. If agreeable, I would hope to achieve this through a combination of publications and conference presentations. I am equally committed to promoting the importance of psychological assessment in those with cancer and currently deliver assessment skills training to a range of professionals working in the field. Following the findings from this research, I hope to develop this aspect of my role and would like to consider the development of additional training for those undertaking assessments of this nature.

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SECTION B: RESEARCH

WHAT UNDERSTANDING AND EXPECTATIONS DO CANCER AND PALLIATIVE CARE CLINICAL NURSE SPECIALISTS HAVE OF CANCER PSYCHOLOGISTS AND HOW DO THESE NURSES ASSESS PATIENTS AND/OR CARERS FOR DISTRESS?

Abstract

Psychologists are increasingly being employed within cancer and palliative care settings in order to provide specialist psychological services for patients and families. Clinical nurse specialists working in these settings are considered largely responsible for assessing patients and carers for psychological distress. To date no research exists exploring the relationship between these two professional groups and only minimal research exists examining how nurses undertake psychological assessments. Considering the significant psychological distress experienced by those with cancer both these areas are worthy of investigation. This qualitative study investigates what understanding and expectations cancer and palliative care clinical nurse specialists have of cancer psychologists. It also investigates how these nurses assess patients and carers for distress. Ten clinical nurse specialists working in an acute NHS hospital were individually interviewed using a semi-structured interview format. The resulting data were systematically analysed using interpretative phenomenological analysis leading to the identification of twelve master themes. The findings suggest that despite a generally good understanding about the role played by psychologists, clinical nurse specialists would welcome greater openness and transparency. The findings also indicate that although clinical nurse specialists are undertaking psychological assessments no standardised process to do this is in place. These nurses also report a large emotional burden associated with their roles. On the basis of these findings a number of recommendations have been made. These include ideas for improving the understanding of the role played by psychology in cancer care, suggestions for formalising some aspects of clinical nurse specialist training, ways of creating a more standardised assessment process amongst clinical nurse specialists and finally strategies for reducing the emotional burden on these nurses.

CHAPTER 1

Introduction to the Research

During the course of this chapter, an overview of the relevant literature will be presented in an effort to illustrate how the research question was formulated and arrived at. The topics to be covered include: cancer, the psychological impact of diagnosis, management of psychological distress, the role of both clinical nurse specialists and psychologists within the field and finally the issue of psychological assessment in those with cancer. This review of the literature is followed by a rationale for why the current study was undertaken and includes a summary of the existing studies in the area, along with a professional justification for why the research was deemed to be relevant. The chapter concludes with a summary of the study's aims and objectives.

1.1 CANCER

The word cancer originates from the Latin for 'crab', and is a term used to describe up to 200 different diseases affecting organs or systems in the body. Egyptian papyrus dated between 3000-1500 BC is believed to be the earliest known reference to cancer in humans, although it is an illness which is believed to have existed since the evolution of complex life, with signs of the disease having been found in fossilised dinosaur bones (Cancer Research UK, 2009).

Cancer is essentially a disease of cells. These are the smallest building blocks in the human body, with each of us being comprised of approximately fifteen million, million cells (Tobias, 1995). For organs and tissues to function properly, cells must reproduce by dividing in a regular and orderly fashion; this ability is carefully controlled so that cell death and cell birth are roughly equal. In cancer, this normal function is disrupted and the balance lost, leading to an uncontrolled growth of cells. Other distinguishing features of cancerous cells include abnormalities of cell differentiation, meaning that cancer cells are less well differentiated than their non-malignant counterparts. They are also resistant to programmed cell death and have the potential to spread throughout the body; a process referred to as metastasising (Watson *et al.*, 2006).

Over time, if cells continue to divide uncontrollably a lump will form and depending on its location, may become detectable to the person e.g. in the case of breast cancer. In cases where the cancerous lump is not detectable, the person may instead begin to experience symptoms such as pain or internal blockages. If the cells are malignant (cancerous) in nature they may also begin to invade local tissues, or spread to nearby structures or even distant organs. These are referred to as secondary cancer growths or metastases and it is this process which makes cancer potentially life threatening, as metastatic cancer can affect multiple organs, leading to complex symptoms which are difficult to control or treat (William, 1986).

In terms of cancer incidence, the number of cases continues to rise and it is predicted that by 2030 more than 15.5 million new cases will be diagnosed every year, making it the world's leading cause of death. At the current time, approximately one in four people in the Western world will die from cancer. However the number of global cancer deaths is projected to increase by 45%, meaning that by 2030 it is estimated that 11.5 million people will die from cancer (World Health Organisation, 2008). The topics of cancer incidence, mortality, survival and treatment are all covered in more detail in Section D of this portfolio.

Thankfully, since the end of the nineteenth century, our understanding of and ability to treat cancer has improved quite dramatically. The discovery of x-rays and radium, along with advances in surgery, chemotherapy and hormone based therapies has led to more successful detection and treatment regimes, with the average ten-year cancer survival rate doubling over the past thirty years (Cancer Research UK, 2009). This is however not without its costs as many modern treatments, despite their improved outcomes remain aggressive and distressing, leaving patients coping with painful and unpleasant side effects. For many, the quality of life available to them within the context of cancer treatment remains both questionable and compromised (Watson, 1991; Brennan, 2004). So despite our increasing knowledge and ability to treat cancer, it remains a disease fraught with unpredictability making it psychologically enormously challenging to cope with.

1.2 PSYCHOSOCIAL ONCOLOGY

The past thirty years have heralded a growing trend towards total patient care. This in turn has led to the emergence of psychosocial oncology, a sub-speciality of oncology that aims to understand and alleviate the psychological, social and emotional impact of cancer on patients and their families (Watson, 1991; Lloyd-Williams, 2003a). Psychosocial oncology is now a well established, internationally recognised speciality in its own right and has been responsible for the generation of much research which has focused on investigating quality-of-life issues in those with cancer. The resulting findings have led to a much clearer understanding of the potentially devastating psychological and social impact that the disease can have and allowed for a greater openness about the emotional burden experienced by patients and their families (Brennan, 2004).

1.3 SUPPORTIVE CARE

The publication of the NHS Cancer Plan (2000) saw the introduction of the term 'supportive care', which in essence describes an approach which aims to ensure that those with cancer receive the most appropriate professional support, care and treatment in order to help both patients and families cope with cancer and its treatments at all stages of the disease. A number of key principles underpin the provision of good supportive care. These include; a focus on quality of life, a holistic approach, extending care to family members, respect for autonomy/choice and an emphasis on sensitive and open communication (Lloyd-Williams, 2003a).

1.4 PALLIATIVE CARE

Although the 1960s saw the emergence of the hospice movement in the UK and with it the establishment of palliative care, it was not until 1987 that the Royal College of Physicians formally recognised palliative care as a speciality within its own right. In 1990, The World Health Organisation (WHO) produced it first formal definition: "palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families" (WHO, 1990a, p.11).

Palliative care is essentially a patient-centred model of care which involves the use of various interventions, specifically aimed at ameliorating the physical, psychological social and spiritual problems experienced by those with incurable illness. The emphasis is very much on quality of life and on viewing patients within the broader context of their lives. Therefore consideration is given not only to patients' individual needs, but also to their cultural/spiritual beliefs, social circumstances and family relationships (Brennan, 2004). One of the key features of palliative care is its fundamental rejection of active euthanasia as an acceptable means of relieving suffering, meaning the provision of effective pain relief needs to be delivered in such a way as to ensure that death is neither hastened nor postponed (Lloyd-Williams, 2003).

1.5 PSYCHOLOGICAL REACTIONS TO CANCER

The diagnosis and treatment of cancer is now well recognised as having the potential to cause substantial levels of psychological distress (Farrington, 1994; The NHS Cancer Plan, 2000) and whether curable, chronic or terminal in nature, it is a disease which has the capacity to generate a series of emotional crises in those it affects (Vacc, 1989).

1.5.1 Emotional adjustment cycle

Successful adjustment to a crisis such as cancer involves a cycle of emotional responses which include an initial stage characterised by shock, feelings of disbelief, despair, denial, anger and emotional lability. Over time these emotions are gradually replaced by anxiety, irritability, sleep disturbance, ruminative thoughts, fears about the future and a general inability to concentrate on usual, everyday activities (Mermelstein and Lesko, 1992). It is estimated that with the necessary support from family, friends and health care professionals, approximately half of patients will successfully negotiate this cycle of emotions, leading to a state of adjustment and adaptation within a number of weeks (Kirsh and Passik, 2002).

1.5.2 Psychiatric/psychological morbidity

Unfortunately for others the process of adjustment is less successful. The National Institute for Clinical Excellence's (NICE) document, Improving Supportive and Palliative Care for Adults with Cancer (2004a) reports that at the time of diagnosis, 50% of patients will experience anxiety/depression severe enough to affect their quality of life and 10% will experience symptoms severe enough to warrant intervention by specialist psychological/psychiatric services in the year following diagnosis. At the point of disease recurrence, levels of anxiety and depression increase again to 50%, staying at this elevated level throughout the course of advanced disease. It is estimated that at this stage, between 10-15% of patients will experience distress severe enough to warrant specific psychological/psychiatric therapy (NICE, 2004a).

Numerous studies conducted during the past thirty years ratify these findings, with estimates that between 25-50% of cancer patients experience significant psychological problems (Maguire *et al.*, 1978; Massie and Holland, 1990; Hopwood and Stephens, 2000). In addition to this, at least 25% of patients meet the criteria for major depressive disorder or adjustment disorder with depressed mood (Sellick and Crooks, 1999), whilst one of the most widely quoted studies by Derogatis *et al.* (1983) indicates that the prevalence of psychiatric disorders as defined by DSM III criteria in newly diagnosed patients is 47%. Studies focusing on patients with advanced and terminal disease estimate the prevalence of mental health related difficulties to be between 20%-25% (Sellick and Crooks, 1999), with between 20% and 30% estimated to have a formal psychiatric disorder (Block, 2000). One in four patients with advanced disease are believed to experience severe depression (Lloyd-Williams, 2002b), whilst anxiety or other psychological problems affect between 10% and 15% of this patient group (Hotopf *et al.*, 2002).

Although anxiety and depression are the main psychological problems faced by cancer patients, these are by no means the only difficulties experienced. The literature identifies a range of additional problems including sexual/marital dysfunction (Dean, 1987; Bottomley, 1997), anticipatory nausea and vomiting associated with chemotherapy (Andrykowski, 1988; Watson *et al.*, 1992), neuropsychological problems (Bottomley, 1997), existential fears (Bolmsjo, 2000) and problems in social, employment and occupational functioning (Burton and Watson, 2000).

1.5.3 Psychological distress

Although much work has been done in order to establish the exact extent of psychological/psychiatric morbidity amongst those with cancer, more recently, there has been a tendency to move away from the use of more formal psychiatric terminology and/or diagnoses, and instead 'distress' is suggested as a more useful and less stigmatising term (Holland, 1997). In this context, The National

Comprehensive Cancer Network (NCCN) defines distress as "an unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that interferes with the ability to cope effectively with cancer and its treatment" (NCCN, 1999, p.115). In distinguishing psychiatric disorder from psychological distress, it is recommended that distress should be viewed as existing along a temporal continuum, with feelings of transient upset, worry, fear, sadness and vulnerability at one end, and persistent depression and/or anxiety at the other.

1.5.4 Suicide and euthanasia

White and Macleod (2002) report that the risk of suicide is significantly increased during the early stages of coping with a diagnosis of cancer, and Fox *et al.* (1982) suggest that the suicide rate amongst cancer patients is at least twice that of the general population. Within palliative care settings, suicidal thoughts are certainly not uncommon amongst patients, although it is suggested that for most, the verbalising of such thoughts does not reflect a serious intent, but instead acts as an outlet for emotional tension (Brietbart, 1995). That said, persistent suicidal ideation does occur in a small proportion of patients, particularly for those with advanced disease who are also managing additional complications such as poorly controlled pain, intense feelings of hopelessness, delirium and a loss of autonomy (Lloyd-Williams, 2003a). It is therefore not surprising that requests for euthanasia are fairly commonplace within palliative care settings (Seale and Addington-Hall, 1995). Whilst euthanasia is a topic which continues to generate ardent debate and presents complex moral challenges for modern medicine, at the current time the legal position in the UK is that euthanasia remains a criminal offence, so whilst patients may clearly state a desire for a hastened death, the legal prohibitions mean that all staff working in such settings have an obligation to refuse such requests (Webb, 2005). Instead, professionals are encouraged to try and gain an understanding as to why patients might be making such a request and offer the necessary support and interventions to help patients manage their difficulties more comfortably (Lloyd-Williams, 2003a).

1.6 RISK FACTORS

Although each patient's psychological reaction to a cancer diagnosis is a unique and largely unpredictable process, there are a number of risk factors, which are known to increase the likelihood of the development of psychological difficulties.

1.6.1 Age

A number of studies have identified that younger cancer patients (those aged under 45 years) tend to exhibit, overall, more anxiety and depression than their older counterparts (Levine *et al.*, 1978; Westbrook and Viney, 1983; Kathol *et al.*, 1990). Although the reasons for this are no doubt complex, Harrison and Maguire (1995) suggest that the prospect of death deprives younger patients of a greater part of their lives and is likely to leave them with feelings that their ambitions and goals are largely unfulfilled. In addition, Lloyd-Williams (2003a) suggests that younger patients are more likely to have worries about leaving dependants prematurely, thus contributing to the higher prevalence of depression in these patients.

1.6.2 Gender

It is now well documented that within the general population women have rates of major depressive disorder double those of men (Weissman *et al.*, 1996). It is therefore unsurprising that this finding translates across to the cancer population, with female cancer patients, both with early and late stage disease, experiencing more depressive symptoms, distress and anxiety than their male counterparts, (Stommel *et al.*, 1993; Bottomley, 1997). Although general population prevalence is likely to account for this gender difference, other factors are worth consideration. At the current time, the majority of psychosocial research has been conducted with women suffering from breast cancer, meaning our awareness of the psychological implications for female cancer patients is simply greater than for men. In addition, it is a generally held belief that emotional expression is more acceptable in women, meaning they may feel more confident than men to share their psychological concerns.

1.6.3 Cancer type and treatment

Certain types of cancer have been found to be more strongly associated with psychological distress beyond the level of expected reactive symptoms (Lloyd-Willams, 2003a). Gynaecological cancer, which is known to lead to an increased sense of social isolation, can result in higher rates of anxiety, whilst tumours which originate in, or metastasise to the central nervous system are linked with increased rates of depression (Brown and Paraskevas, 1982). Metabolic complications such as hypercalcaemia which are common features in those with breast or lung cancer are also associated with higher levels of depression (Shakin and Holland, 1988).

Studies have also found that various medications and anti-cancer treatments can precipitate the onset of depression (Sivesind and Baile, 2001). In particular corticosteroids, certain anti-biotics, radiotherapy and extensive surgery are all linked to symptoms of depression (Molassiotis *et al.,* 1996; Musselman *et al.*, 2000). Many chemotherapeutic agents are also believed to impact negatively on mood, with patients often reporting that chemotherapy treatment leaves them feeling anxious, depressed, and unable to concentrate or sleep. The hair loss and resulting body image issues associated with many chemotherapy regimes are also known to trigger feelings of depression, whilst hormone based therapies can impact negatively on libido, leaving patients feeling isolated, anxious and depressed (Riba, 2003).

1.6.4 Stage of disease

The risk of anxiety and/or depression is also known to increase at various key stages of disease (Minagawa *et al.*, 1996) including the point of recurrence (Cella *et al.*, 1990), advanced disease (Brietbart, 1995) and when disability and pain increases (Passik *et al.*, 1998). More recently, White and Macleod (2002) have identified a more extensive range of points along the disease trajectory where patients are more vulnerable to severe distress. These are the point of diagnosis, during treatment, ending treatment, after treatment, recurrence and terminal disease.

1.6.5 Pain and functional status

Increasingly, functional status and pain are both being viewed as significant contributors to the onset of depression and psychological distress. Those with advanced disease whose functional status is negatively affected due to complex symptoms have been found to be more likely to experience psychiatric difficulties, whilst patients with uncontrolled pain are at greater risk of depression (Kaasa *et al.*, 1993; Chochinov *et al.*, 1995; Glover *et al.*, 1995; Williamson and Schulz, 1995).

1.6.6 Prior psychiatric history

A well recognised risk factor in the onset of psychological morbidity in cancer patients is the existence of a psychiatric history, particularly depression. A number of studies have now shown that cancer patients suffering from depression are more likely to report prior depressive episodes from earlier periods in their lives (Hughes, 1985; Maunsell *et al.*, 1992), whilst Styra *et al.* (1993) found that patients who self-reported a psychiatric history had higher scores on both anxiety and depression.

1.6.7 Social support

Access to adequate social support, which includes the availability of support from family, friends and health care professionals, is now recognised as essential in helping patients adjustment psychologically to the challenges of a cancer diagnosis (Lloyd-Williams, 2003a; Brennan, 2004). Unfortunately out of a desire to protect loved ones from any additional burden, many patients hesitate to discuss their emotional concerns and therefore do not receive the support they require from those close to them, leaving them emotionally isolated and at greater risk of depression (Lloyd-Williams, 2003a). Research has also found that those who are unmarried, or who have limited social contact/networks are at greater risk of psychological distress (Pinder *et al.*, 1993; Tominage *et al.*, 1998; Grosfeld *et al.*, 2000)

1.7 IMPACT ON FAMILIES AND CARERS

Psychological problems do not only affect patients, and as family members commonly fill the role of primary care giver (Akechi *et al.*, 2006) it is perhaps not surprising that Burton and Watson (2000) report psychological distress to be as great or even greater for family members. Pitceathly and Maguire (2003) suggest that approximately 10-30% of family members experience some form of psychiatric morbidity, whilst Hinton (1995) found affective disorder to be more prevalent in carers than patients. Barraclough (2000) reports a concordance between patient and partner: if one of a couple is emotionally distressed the other is likely to suffer too. Communication difficulties between patients and family members are commonly observed (Bottomley, 1997; Brennan, 2004) and it is again perhaps unsurprising that cancer related stress has been consistently found to place great strain on close relationships (Given *et al.*, 1993; McCorkle *et al.*, 1993; Gilbar *et al.*, 1995; Harrison *et al.*, 1995; Northouse, 1995).

1.8 MANAGEMENT OF PSYCHOLOGICAL PROBLEMS

Given the growing awareness of the levels of psychological distress experienced by cancer patients, combined with the explicit aims of both supportive and palliative care to maximise quality of life, considerable effort has been made to identify the most effective psychological interventions for this patient group. This effort of course assumes that alleviating distress is desirable. However it is important to acknowledge that for those who believe euthanasia offers a more positive choice, such interventions may be viewed with some scepticism. In light of the UK's legal position regarding euthanasia and the subsequent obligations that professionals are under, it does however seem reasonable to assume that being able to at least offer patients the choice to access effective psychological interventions is a desirable goal.

1.8.1 Efficacy of psychological interventions

At the current time a variety of psychological interventions including individual psychotherapy, supportive/expressive group therapy, relaxation, hypnosis, psycho-education and cognitive behavioural therapy (CBT) are used with cancer patients in an attempt to ameliorate cancer related distress. This range of interventions is a clear reflection of the fact that just as distress varies, so too do the psychological needs of patients, meaning that whilst one patient may benefit from psycho-education, another may gain much more from expressive group therapy (Zabora and Loscalzo, 1996.)

The efficacy of such interventions in relation to a range of patients at different stages of disease have been assessed using studies ranging from clinical case reports and single case studies to large, well designed randomised control trials using standard quantitative instruments to measure outcomes: (Gordon *et al.*, 1980; Linn *et al.*, 1982; Burton and Parker, 1988; Watson *et al.*, 1988; Greer *et al.*, 1991; Greer *et al.*, 1992; Moorey *et al.*, 1994; Meyer and Mark, 1995; Marchioro *et al.*, 1996; Moorey *et al.*, 1998; Edelman *et al.*, 1999; Spiegel *et al.*, 1999; Esplen *et al.*, 1999; Shear and Maguire, 1999). This has led to the existence of a considerable body of evidence concerning the effectiveness of psychological interventions in people with cancer with their use being clearly linked to improvements in quality of life and psychological functioning (Boulton *et al.*, 2001). Consequently the use of such interventions are now clearly endorsed by NICE (2004a) resulting in a growing trend towards the development and implementation of counselling/psychology services within cancer settings.

Practical and emotional support has been positively related to good adjustment outcome (Funch and Marshall, 1984), whilst group interventions have been found to reduce psychological symptoms and improve coping responses and quality of life (Fawzy *et al.*, 1990; Johnson, 1992; Berglund *et al.*, 1994). More recently cognitive behavioural therapy (CBT) has been specifically established, and whether given in groups or individually has been found to be more effective than supportive/non-directive therapy, particularly for patients demonstrating severe psychological morbidity (White, 2001). There is also some evidence to suggest that patients with metastatic or more advanced disease benefit as much from CBT as those with early cancer (Moorey and Greer, 2002). A prospective randomised controlled trial, comparing CBT for cancer patients with no treatment found that at eight weeks following therapy, patients receiving CBT had significantly higher scores than control patients on 'fighting spirit' and significantly lower scores on helplessness, anxious preoccupation and fatalism. At four months the therapy group showed significantly lower scores on anxiety, psychological symptoms and distress (Greer *et al.*, 1992). In addition, Moorey *et al.* (1998) found CBT to produce a significantly greater change than non-directive supportive counselling on fighting spirit, helplessness, coping with cancer, anxiety and self-defined problems. (For a more detailed discussion about the use of CBT with this client group, please refer to the case study in section C of this portfolio).

The research in the field has also highlighted a number of additional benefits and found that patients receiving psychological interventions demonstrate improved adherence to medical treatment, less pain, fewer physical symptoms, less need for medical consultations and improved knowledge about their illness and treatments (Marchioro *et al.*, 1996; Moorey *et al.*, 1998; Barraclough, 2000; White and Macleod, 2002).

For patients with terminal disease, psychological interventions have been shown to alleviate anxiety and depression, enhance quality of life and ensure that patients and families are able to use their remaining time together more effectively; (Payne, 1998). Suggestions have also been made about the possible impact that such interventions can have on survival times, although it is acknowledged that further research in this area is required (Cooper and Watson, 1991). A detailed review of the literature examining the relationship between psychological interventions and survival is provided in section D of this portfolio.

1.9 MULTI-PROFESSIONAL WORKING

It is now generally acknowledged and accepted that effective patient care relies on a multi-professional approach (WHO, 1990b; Ajemian, 1993; National Council for Hospice and Specialist Palliative Care Services, 1995). Within cancer and palliative care settings, teams can now include a wide variety of professionals including doctors, clinical nurse specialists (CNSs), ward nurses, physiotherapists, speech and language therapists, occupational therapists, social workers, spiritual care workers, psychiatrists, welfare officers and psychologists. In theory, the multi-professional approach allows patients' needs to be addressed and considered by all disciplines and from different perspectives, thus providing comprehensive and seamless care (Brennan, 2004). Unfortunately professionals do not always find it easy to work collaboratively and multi-professionalism can be negatively affected by lack of time, poor communication, conflict, difficulties in defining roles, lack of understanding or respect for each other's roles and/or areas of expertise and difficulties in establishing professional boundaries (Craven, 2000). Such issues can easily lead to role conflict and ongoing tensions amongst team members.

1.10 CLINICAL NURSE SPECIALISTS

The first Clinical Nurse Specialists (CNSs) appeared in North America during the 1930s, however it was not until the early 1970s that the term was first officially adopted in the UK and the CNS role began to establish (Hunt, 1999). This was partly due to the publication of the Salmon Report (1966), which made recommendations for the creation of a new hierarchical management structure for nurses, thereby allowing new job titles above that of ward sister (Castledine, 2002). Other influences have included the reduction of doctors' hours during the 1990s, shortages of medical staff and a lack of clinically skilled nurses caused by experienced nurses having moved into management posts (Armstrong, 1999).

CNSs are essentially nurses who have developed extensive specialist knowledge about a specific area of medicine, and by combining their skills as clinical experts, researchers, consultants, teachers and change agents, aim to provide nursing care of the highest quality (Armstrong, 1999). Since the 1970s the role of the CNS has continued to evolve and there has been considerable expansion in the number of posts in the UK (Jack *et al.*, 2004). No longer restricted to institutional settings, CNSs can now be found working in the community and also in primary care settings (Castledine, 2002). As their numbers have grown, so too have the range of specialities in which they work and they are now found in over 600 different fields of practice (Hobbs and Murray, 1999).

The Calman-Hine report (1995) and its recommendations for the reorganisation of cancer services, along with the Department of Health's NHS Cancer Plan (2000), and Nurses Contribution to Cancer Care (2000b), have all contributed to the rapid appointment of many tumour site-specific and palliative care CNSs (Seymour *et al.*, 2002; Jack *et al.*, 2003). These specialist nurses have been encouraged to the take the lead in ensuring that the care of cancer patients is not only of the highest standard, but that interventions are based on sound evidence (Booth *et al.*, 2003). Consequently CNSs are now considered essential to the delivery of a comprehensive service to those affected by cancer and whilst there is considerable variation in the nature and content of each CNS role, all have a specific remit to provide supportive care to cancer patients and their families (Willard and Luker, 2005).

Changes in nursing education in the UK has meant that psychology is now included in the basic curriculum and many nurses now view psychological support as a key part of their role (Payne and Haines, 2002). This is compounded by an increasing tendency to dismantle traditional role boundaries, and encourage nurses to extend their roles and take more responsibility for the psychological assessment and care of patients (Wyatt, 1993; Strong, 2004). This is clearly illustrated in the NICE guidelines (2004a) which state that CNSs should be able to screen for psychological distress at key points in the patient pathway and are also well placed to be trained to deliver problem-solving interventions for those patients requiring them. The nature of the CNS role means they have considerably more contact with patients than many other professionals, leading to an expectation that they are best placed to detect symptoms of psychological distress: "the key to significantly improving the detection and management of anxiety and depression in this patient group lies in the use of the specialist nurses who have the relevant training and experience with the necessary communication skills" (Craven, 2000 p.504).

1.11 PSYCHOLOGISTS IN CANCER CARE

With the psychological implications of a cancer diagnosis now well documented, the appropriate management of psychological distress has become a pressing issue (Burton and Watson, 2000). Both the NHS Cancer Plan (2000) and NICE guidelines (2004a) have made explicit the need for the development of specialist psychological services, leading to an expectation that every cancer service should have access to psychology expertise. Increasingly, chartered clinical and counselling psychologists are being viewed as part of the multi-disciplinary team and are employed to provide specialist psychological care to those affected by cancer. Macmillan Cancer Support, a UK charity traditionally associated with nursing, has been particularly involved in the funding of such posts. In reality this means that Macmillan fund the initial cost of a psychologist for up to 3 years, after which time the employing NHS Trust takes over responsibility. There are now in excess of 30 Macmillan psychologists working in cancer centres throughout the UK and a steadily increasing number being employed directly by NHS Trusts and hospices. This rise in numbers is reflected both in the recent publication of the British Psychological Society document, The Role of Psychology in End of Life Care, (BPS, 2008) and in the increasing membership of the British Psychological Society's Special Interest Group in Oncology and Palliative Care (SIGOPAC), which is a formal SIG of the Division of Clinical Psychology.

Despite growing numbers of psychologists in oncology and palliative care settings, psychology remains for many an unknown and poorly understood profession, often making it difficult for psychologists to integrate into pre-existing teams of predominantly medical professionals (McWilliams, 2004). Some report facing hostility and a lack of understanding about their skills and role, whilst other have reported concerns about boundaries of knowledge and expertise in psychological care (Payne and Haines, 2002a). In particular, CNSs regard psychological input as falling within their professional role and negotiating the boundaries of their expertise potentially gives rise to difficulties in establishing satisfactory working relationships between them and psychologists (Payne and Haines, 2002a).

1.12 PSYCHOLOGICAL ASSESSMENT METHODS

An ongoing challenge for those working within oncology and palliative care settings is the task of differentiating a normal psychological response from the signs and symptoms of a psychiatric disorder/psychological distress (Carroll *et al.*, 1993). Despite considerable efforts to establish a definitive way of assessing cancer patients' psychological health, the debate remains open and ongoing (Hackett and Gaitan, 2007), with various methods being utilised in different settings.

1.12.1 The clinical interview

Burton and Watson (2000) suggest that the most effective means of identifying psychological morbidity in those affected by cancer is through the use of a full mental state interview. This is endorsed by Craven (2000), who states "it has long been recognised that a structured interview is the most effective way of identifying depression" (p.506). The advantage of such interviews is that they allow patients to tell their story, as well as offering a sense of flexibility, meaning that any physical symptoms the patient may be experiencing can be accommodated. Interviews are however time consuming and require staff to be sufficiently confident and adequately trained (Maguire *et al.*, 1999). Sadly, these factors mean that undertaking psychological interviews routinely with patients is not a realistic option, and instead there is a growing interest in the use of self-assessment tools.

1.12.2 Self-assessment tools

A number of standardised measures including the Hospital and Anxiety Scale (HADS), The Edinburgh Depression Scale, The Zung self-rating Depression Scale, General Health Questionnaire, Brief Symptom Inventory (BSI) and the Profile of Mood States (POMS) have been suggested as possible ways of identifying patients experiencing significant distress (Ibbotson *et al.*, 1994; Holtom and Barraclough, 2000; Zabora *et al.*, 2001a; Lloyd-Williams, 2003b; Lawrie *et al.*, 2004). Whilst such tools have advantages, in that they are relatively easy to administer and also offer patients some sense of anonymity (Zabora, 1998), questions have been asked about the reliability and validity characteristics of these measures when used in either a cancer or palliative care setting (Herschbach *et al.*, 2004; King *et al.*, 2005). There is also the practical issue of patients needing to be physically well enough to complete scales of this type, and for patients in palliative care settings this may not be realistic (Lloyd-Williams *et al.*, 2004).

In line with the recent shift towards conceptualising psychological difficulties in terms of 'distress' the National Comprehensive Cancer Network (NCCN) has recently developed the Distress Thermometer in an attempt to generate a simple and more suitable context-specific screening tool which allows patients to describe their level of distress on a 0-10 scale, and also identify the specific factors contributing to it (practical, family, emotional, physical, spiritual). To date, the thermometer's specificity and sensitivity has been demonstrated in a number of studies, (Ransom *et al.* 2006) and there are hopes this tool will prove effective in allowing for the differentiation between normal distress and that which requires specialist intervention. At the current time, the distress thermometer is undergoing extensive piloting throughout cancer and palliative care settings in the United Kingdom.

Overall, although there are ongoing concerns about whether these tools are sensitive or specific enough to effectively screen for mental health issues in a cancer population, it is argued that despite these limitations, they do at least have a place in helping to identify those who require further evaluation/assessment or who may benefit from referral onto specialist services (Payne, 1998; Barraclough, 2000).

1.12.3 Single-item screening methods

Single-item screening methods, which involve asking just one question offer an alternative and perhaps simpler approach to assessment. A study undertaken by Chochinov *et al.* (1997), involving 197 North American patients, found that the question, "Are you depressed?" had perfect sensitivity and specificity and achieved 100% positive predictive value in terms of diagnosing depression. Whilst this study has led many to endorse the use of this single screening question, research conducted by Lloyd-Williams *et al.* (2003a) found less sensitivity and specificity when the research was repeated with a UK sample. This brings into question whether there may be cultural differences with regard to the understanding of the term 'depression', and casts doubt over the suitability of this single question for widespread use across different cultures (Lawrie *et al.*, 2004).

1.13 ASSESSMENT CHALLENGES

Given the extent of psychological morbidity amongst this population, the proven efficacy of psychological interventions and the increasing presence of psychologists within cancer settings, it is estimated that as much as 80% of the psychological and psychiatric morbidity of patients with cancer goes unrecognised and untreated (Maguire, 1985). This means that only a minority of cancer patients and their families are gaining access to the psychological support they need, with Fallowfield *et al.* (2001) estimating that every year as many as 180,000 people diagnosed with cancer in the UK are not receiving the help they need. This finding is substantiated by a report recently published by Macmillan Cancer Support, which revealed that up to 58% of cancer patients and 61% of carers feel that their emotional needs are not being met (2006). Whilst in part this is likely to be due to lack of available services (Barraclough, 2000) there are a number of other factors, which makes the task of accurately identifying patients in need of psychological help challenging.

1.13.1 Physical symptoms

The physical element of malignant disease is in itself a complicating factor, as many types of cancer and associated treatments commonly produce symptoms that mimic those seen in psychological disorders (Payne, 1998; King *et al.*, 2005). The diagnosis of depression in physically healthy patients depends heavily on the presence of somatic symptoms including loss of appetite, reduced energy, insomnia, loss of sex drive and psychomotor retardation (Kirsh and Passik, 2002). For patients with cancer these symptoms are far less reliable as diagnostic criteria, as although they are often present, they are usually attributable to their physical illness (Lloyd-Williams *et al.*, 1999). Equally, the accurate identification of anxiety can be problematic as certain drug regimes, medical complications (including hypoxia or sepsis), poorly controlled pain and adverse drug reactions can all produce symptoms similar to those seen in anxiety (Kirsh and Passik, 2002).

1.13.2 Appropriate sadness

For patients coping with a terminal diagnosis, adjusting is likely to involve feelings of sadness, loss and grief (Payne, 1998). This means that whilst patients can appear to be suffering from a depressed mood, it may be that they are actually experiencing what has come to be known as 'appropriate sadness' (Lloyd-Willams and Payne, 2003). The depressive reactions to dying are clearly different to those involved in depressive illness, with the former being regarded as understandable and indicative of normality rather than psychopathology (Casey, 1994). This poses a great challenge for those working in palliative care settings, where trying to distinguish between appropriate sadness at the end of life and an identifiable depressive illness requiring intervention relies on time, experience and skill.

1.13.3 Diagnostic criteria

A further challenge lies in the fact there is ongoing controversy regarding appropriate diagnostic criteria, and at the current time no universally accepted criteria exist for diagnosing depression in those with advanced cancer (Valente and Saunders, 1997; Lloyd-Williams, 2003b). In a physically healthy population the commonly used criteria, Diagnostic and Statistical Manual IV (DSM IV) and the International Classification of Diseases (ICD-10) both diagnose depression if a patient has persistent low mood and at least four additional symptoms (that have been present for most of the day for the preceding fortnight). These additional symptoms include significant weight loss/gain, fatigue or loss of energy and insomnia or hypersomnia all of which are commonly found in those with advanced terminal illness (Lloyd-Williams and Payne, 2003).

1.13.4 Patient fears and concerns

It is now well documented that patients themselves are often reluctant to disclose their psychological distress. For some this stems from a fear of stigmatisation and a concern about being viewed as weak, abnormal or unable to cope (Valente *et al.*, 1994; Lloyd-Williams and Payne, 2003). Others report worrying about wasting health care professionals' time (Lawrie *et al.*, 2004), whilst Maguire (1985) identifies some nondisclosure as stemming from a desire by patients to protect their relatives, carers or even their medical team from the full extent of their worries. There are also a number of patients who simply feel unsure how psychological interventions could be of use to them so consequently choose not share their worries (Halteren *et al.*, 2004).

1.14 ASSESSMENT SKILLS AMONGST HEALTH PROFESSIONALS

In addition to the assessment challenges outlined above, the literature has also revealed that healthcare professionals working in cancer and palliative care settings often lack the necessary confidence and skills to undertake psychological assessments (Maguire, 1985; Brugha, 1993; Craven, 2000; NICE, 2004a). This has been cited as one of the main reasons why patients' psychological distress often goes unidentified and untreated. Clinical staff with a key role in the psychological assessment of cancer patients have been the focus of much research, showing that the skill deficit exists at all levels of the multi-professional team.

Studies show that oncologists (doctors specialising in the treatment of cancer) are neither skilled at discussing psychological problems nor at recognising anxiety or depression and instead display a marked and consistent tendency to underestimate psychological distress (Hardman *et al.*, 1989; Ford *et al.*, 1994; Passik *et al.*, 1998; Sollner *et al.*, 2001; Fallowfield *et al.*, 2001). Fallowfield *et al.* (2001) report that in fact, oncologists' ability to detect psychological morbidity in patients is often little better than due to chance and in terms of in-patient populations Katon and Sullivan (1990) report that doctors' recognition of depression is only 14-30%. With regard to nurses, although research is sparse, Heaven and Maguire (1997) report there is little evidence to suggest they are any more effective than doctors. In Hardman *et al's* (1989) study involving both oncologists and nurses, both groups recognised only 50% of the depressed patients on a medical oncology ward.

The reasons for this lack of recognition are numerous and appear to differ between professional groups. Doctors have been found to be reluctant to explore psychological issues in any detail and instead prefer to stay focused on physical issues (Hardman *et al.*, 1989; Ford *et al.*,1996; McDonald *et al.*, 1999). Whilst this is most likely to be due to time constraints, in some cases it may reflect a reluctance to explore issues which are perceived as being too sensitive in nature (Holland, 2000). Doctors have also been found to be more likely to view psychological symptoms as a normal and expected consequence of cancer and they also have a tendency to assume patients will report psychological symptoms spontaneously (McCabe, 1991).

The reasons for poor recognition amongst nurses are slightly different and appear to be related more to issues of confidence. There is now growing evidence that CNSs working in oncology and palliative care settings feel inadequately trained and subsequently lacking in the necessary skills to undertake assessments of patients' emotional distress (Strong, 2004; Lloyd-Willams and Payne, 2003). Valente and Saunders (1997) report that nurses are reluctant to ask patients about their emotional well-being for fear of upsetting them and/or making the situation worse, whilst

Maguire (1985) found that this reluctance was due to a fear that they (the nurses), would be expected to fix any psychological problems they identified. It has also been found that some CNSs hold negative stereotypes about depression and consider there to be a stigma attached to psychological problems thus making them feel less able to negotiate conversations with patients about psychological difficulties (Lloyd-Williams and Payne, 2003). Findings from the same study also found that like oncologists, CNSs had a tendency to make assumptions that psychological distress within this patient group was expected and therefore did not require treatment.

Regardless of the reasons why, what is clear is that due to the challenges inherent in assessing patients' psychological health, combined with the fact healthcare professionals lack the necessary skills to undertake such assessments, many patients and carers with psychological problems that could be ameliorated are not receiving the care they need (Fallowfield *et al.*, 2001). The consequences of untreated psychological morbidity are hard to quantify, but it is reported that in addition to the obvious psychological suffering and poor quality of life, these patients experience difficulties making treatment decisions, struggle to persevere with prescribed treatment regimes or put their affairs in order and are at increased risk of suicide (Bottomley, 1997; Valente and Saunders, 1997). The impact is also likely to be felt by family members, as patients suffering from unmanaged distress are more likely to withdraw socially, stop interacting in their normal way and disengage from family life (Payne, 1998). Inadequate assessment skills can also lead to inappropriate referrals, meaning patients are referred for specialist input when this is not actually required. Richards (1999) suggests that in a small number of cases this could result in additional harm to patients.

Accurate assessment is now very much on the government agenda and is recognised as being the major prerequisite in providing appropriate psychological treatment and an integral part of effective clinical management. The expectation is therefore that regular psychological assessments should be offered to this patient group at key points in their illness pathway, in order to assess their overall psychological functioning, as well as their ability to cope (NICE, 2004a). If good psychological care is to be provided it is therefore vital that healthcare professionals, particularly CNSs who tend to have higher levels of patient contact, are able to recognise psychological distress, explicitly assess patients' concerns, offer appropriate support and if necessary feel confident to refer onto specialist services (Payne and Haines, 2002b; NICE, 2004a). For care to be of the highest standard, a multi-professional approach is also essential and for this to be effective all team members need to have a clear understanding of one another's knowledge, skills and role (Colquhoun and Dougan, 1997).

1.15 RATIONALE FOR THE PRESENT STUDY

1.15.1 Summary of the literature

In terms of literature relating to CNSs, an extensive and systematic review was undertaken and revealed that although a large body of literature exists, the majority of this has focused on the role of CNSs, along with the historical context of their development and their ongoing developmental needs (Davies and Oberle, 1990; Hunt, 1999; Ibbotson, 1999; Armstrong, 1999; Bamford and Gibson, 2000; McCreaddie, 2001; Seymour *et al.*, 2002; Skilbeck *et al.*, 2002; Castledine, 2002; Clark *et al.*, 2002; Booth *et al.*, 2003; Jack *et al.*, 2003; Willard and Luker, 2005; Jones, 2006).

In terms of literature pertaining to the issue of psychological assessment, numerous studies have been conducted however the majority of these have focused either on the assessment skills of doctors or on the efficacy of various assessment tools, (Hardman *et al.*, 1989; Carroll *et al.*, 1993; Gotay and Stern, 1993; Ibbotson *et al.*, 1994; Chochinov *et al.*, 1997; Passik *et al.*, 1998; Payne *et al.*, 1999; Holtom and Barraclough, 2000; Fallowfield *et al.*, 2001; Meyer *et al.*, 2003; Herschbach *et al.*, 2004; Lawrie *et al.*, 2004; Sharpe *et al.*, 2004a; Lee *et al.*, 2005; Robinson and Crawford, 2005; Guo *et al.*, 2006; Roth *et al.*, 2006). Only three studies have explored the psychological assessment skills of nurses (Lloyd-Williams and Payne, 2002; Lloyd-Williams and Payne, 2003; Hackett and Gaitan, 2007), however these have only involved staff working in the context of palliative care, with one study relying solely on questionnaires for the collection of data.

In terms of literature on cancer psychologists, a further systematic review revealed a very sparse amount and to date there have been no research studies undertaken examining the role of psychologists working in oncology or palliative care. The small amount of existing literature is comprised of individual articles written by psychologists themselves (Payne and Haines, 2002a; McWilliams, 2004; Kalus, 2008). At the current time no studies have been conducted to examine the relationship between CNSs and cancer psychologists. The aim of this research is in part to address the gap in the literature.

1.15.2 Professional justification

As a Chartered Counselling Psychologist, I have now held posts in two UK cancer centres and am currently employed in a large London hospice. In all of these roles I have focussed on creating a comprehensive psychology service for patients and families, and have also worked towards establishing myself within the multi-professional team. In all cases, I have been the first psychology post-holder and therefore a new addition to the team, and have found myself working particularly closely with established teams of CNSs. These experiences have highlighted to me that many skilled cancer professionals have a very limited understanding of the role that psychologists play in cancer, feel under-confident in their abilities to use psychologists effectively and are unclear about where the boundaries of professional responsibility lie in relation to patient care. I have also observed a general lack of confidence, particularly amongst CNSs about their ability to assess patients for distress and offer appropriate support. The fact that psychological care is a major part of the CNS role, combined with the fact they tend to work closely with psychologists, makes them a particularly valuable and important group to research.

In light of these observations, I feel it would be beneficial to have a clearer understanding of the perceptions and expectations that CNSs have of psychologists in order to ensure that productive and collaborative relationships between the two professions can be more easily achieved. In turn, I hope this would lead to a greater mutual understanding about the respective roles, offer clarity about professional boundaries, encourage more open communication between the professions, and instil a greater sense of confidence about adopting a multi-disciplinary approach. A possible additional benefit of this understanding would be that the challenges faced by psychologists taking up newly created posts in cancer/palliative care settings, could be somewhat reduced, as they would have a clearer sense about what CNSs expect from them, and how their skills could be most effectively utilised. Considering the importance of accurate psychological assessment in those with cancer, I feel it would also be of great benefit to have a more detailed understanding about how CNSs undertake assessments and identify the sorts of skills and approaches they use.

The implications of this increased understanding are potentially numerous. In particular it would make it possible to identify whether there is a need to develop additional training workshops, designed specifically to increase their abilities in the area of psychological assessment. It may also help to identify whether there is a need for newly appointed psychologists to provide training to the wider multi-professional team about the scope of their role and ways of working. Finally, it could help to offer insight into the types of support and/or supervision that CNSs may feel are required, which in turn could be developed into a model of supervision and shared with those responsible for providing such services to NHS nurses.

1.16 Aims and objectives of the study

In summary the aim of this study is to gain a better understanding about the relationship between CNSs and cancer psychologists. It will aim to identify the perceptions and expectations that CNSs hold about psychologists and explore how they perceive the working relationship between the two professions. The objective of the research is to explore how CNSs undertake psychological assessments and identify what factors influence their decisions to refer onto specialist services.

In summary it is hoped that this research will help to identify:

- what perceptions and expectations CNSs have of cancer psychologists
- how CNSs envisage a working relationship with a psychologist
- how CNSs approach the task of assessing patients for distress
- whether there is a standardised assessment approach/process amongst CNSs
- whether CNSs feel they require any additional training/support
- whether CNSs feel they require any additional education about the role of psychologists

CHAPTER 2

Methodology and Design

2.1 JUSTIFICATION FOR THE APPROACH

As the main objectives of the study were to gain an understanding of the views and expectations held by clinical nurse specialists about psychologists and to develop a clearer understanding about how these nurses negotiate the issue of psychological assessment with patients and/or families, I felt an approach which would provide sufficient opportunity for the nurses to engage in open and detailed discussion would be the most appropriate. With very little known about the topics under investigation and no theory or hypothesis to test, I simply sought to understand the nurses' experience from their perspective. The exploratory nature of this research led to a decision that a qualitative approach utilising semi-structured interviews would be the most appropriate fit, as this would allow for discovery and investigation in an open-ended fashion (Henwood and Pidgeon, 1995; McLeod, 1996).

2.2 QUALITATIVE RESEARCH

Qualitative research first emerged during the early part of the 20th century, initially being utilised by sociologists and anthropologists to gain greater understanding about the intricacies of human group life. It was not until the late 1960s following the publication of The Social Construction of Reality (Berger and Luckmann, 1966) that social constructionism emerged as an alternative epistemological position to the already well established positivism. Since that time qualitative research has become increasingly popular, particularly within the social sciences and has provided a range of methodologies fundamentally different to those associated with quantitative research.

Bryman (2001) describes qualitative research as being concerned with emphasising words rather than quantification in the collection and analysis of data. It is defined as "a form of social enquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live" (Holloway, 1997 cited in Gittens, 2000, p.1) and aims to explore and understand the attitudes, feelings and behaviour of individuals and/or groups from an epistemological position described as being interpretivist. Being constructionist, it suggests that social properties are outcomes of interactions between individuals, rather than existing separately from them and it is primarily concerned with the generation of theory out of research. As Willig (2001) states, the emphasis lies with gaining an understanding of the meanings attributed to events by the research participants without the researcher using any preconceived variables or predictions. This is in direct contrast to quantitative research, which is placed in a narrow positivist paradigm and has a deductive view of the relationship between theory and research hence involving the collection of numerical data and the testing of theories rather than the generation of them. This makes quantitative methods less helpful when conducting in-depth exploration of areas where relatively little is known and does not lend itself as readily to the generation of new theory (Henwood and Pidgeon, 1995).

2.3 EMIC AND ETIC DISTINCTIONS

The terms "emic" and "etic" which were first coined by linguistic anthropologist, Kenneth Pike in 1954, are used to describe two perspectives that can be adopted in the study of a society's cultural system (Lett, 2008). According to Pike, the emic or 'insiders' perspective focuses on the "intrinsic cultural distinctions that are meaningful to the members of a given society" (Lett, 2008, p.1), meaning that only the native members of a culture are able to judge the validity of an emic description. In contrast, the etic or 'outsiders' perspective refers to the "extrinsic concepts and categories that have meaning for scientific observers" (Lett, 2008 p.1), meaning that scientists are the only judges of the validity of an etic description.

For a qualitative researcher to gain access to the emic perspective, in-depth exploration and a close engagement with the population under investigation is required. This must however be balanced against an ability to maintain sufficient distance so that first order concepts derived from the emic perspective can be used and developed into second order concepts, which are more abstract and theoretical (Holloway, 2005). Data are therefore not just based on the understanding and accounts of the participants, but transformed by the researcher through the process of analysis into something that goes beyond both (Holloway, 2005). The challenge therefore lies in ensuring that the process of re-presenting data remains grounded in, and reflective of, the participants' accounts and ideas.

Within the context of this research study, the benefit of adopting a qualitative approach would be that it would allow me, as researcher, access to the emic perspective. This in turn could be transformed into etic knowledge which could then be of potential benefit to a wider professional audience.

2.4 QUALITATIVE METHODOLOGY AND COUNSELLING PSYCHOLOGY

In addition to a qualitative approach providing an appropriate framework from which to achieve the research objectives, I also felt it to be an approach sharing many of the characteristics central to the theory and practice of counselling psychology.

The British Psychological Society's (BPS) Division of Counselling Psychology Professional Practice Guidelines describes one of the key roles of the counselling psychologist as being to "respect first person accounts as valid in their own terms; to elucidate, interpret and negotiate between perceptions and world views but not to assume the automatic superiority of any one way of experiencing, feeling, valuing and knowing" (BPS, 2002, p.1). In essence, counselling psychology is influenced by both human science research and the psychotherapeutic traditions and is underpinned by what Duffy (1990) describes as a humanistic value base, meaning individuals are viewed as such, with their feelings, meanings and subjective experiences all being considered as unique and valuable (Woolfe, 1996). It is these features which link counselling psychology closely to qualitative methodology as both share a value base which encourages individual meaning to be sought, understood and valued.

The process of undertaking qualitative research also mirrors aspects of the therapeutic work involved in counselling psychology as both rely on the development of relationships based on empathy, genuineness and acceptance (Mearns and McLeod, 1984). With the topic under investigation involving exploration not only of beliefs, but aspects of clinical practice, I felt the reflective and clinical skills I have developed through working with patients affected by cancer and terminal illness would be of particular benefit in ensuring the research interviews were undertaken in a suitably sensitive fashion. I also felt my experience would ensure theoretical sensitivity, that is, having a good understanding of the meaning and subtlety of data, thus allowing for the formulation of conceptually dense theory (Barker *et al.*, 2000).

Overall I felt the concern that a qualitative approach has for individual experience, and the processes central to it; namely exploration and understanding, make it particularly consistent with my own professional role as a chartered counselling psychologist working in the field of cancer and palliative care.

2.5 RATIONALE FOR USING INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

Interpretative Phenomenological Analysis (IPA) is just one of many qualitative methods that can be used to address research questions within the field of psychology; the alternatives include discourse analysis, conversation analysis, Grounded Theory and ethnography (Shaw, 2001). IPA's concern with the "individual's personal perception or account of an object or event" (Smith *et al.*, 1999, p.218) makes it a particularly good choice for researchers aiming to explore the experiences of individuals, as the analytical process provides the opportunity to gain "an in-depth understanding of both the idiosyncratic and culturally constructed aspects of a person's being in the world" (Shaw, 2001, p.49). With this knowledge I, along with my supervisor felt IPA to be particularly apt, in that it would allow me to achieve my aims of exploring the individual experiences of a number of clinical nurse specialists. In addition, with very little known about the topic under investigation and no hypotheses to test, I felt the exploratory nature of IPA would be particularly valuable in allowing any unanticipated phenomena to be revealed and for the findings to be both contemporary and a direct reflection of the nurses' experience (Shaw, 2001). The approach also offered me an opportunity to engage with the nurses in a way that I hoped would allow them the chance to describe their experiences, without concerns about being tested or judged. Finally, I felt there to be significant advantage in the fact IPA has a good capacity to investigate human experience within a cultural context, as it recognises the contextual factors which may influence the process involved in creating meaning (Shaw, 2001). This means that IPA is capable of highlighting those experiences unique to the individual, as well as those shared by a number of participants and therefore constructed "by external forces within a culture or sub-culture" (Shaw, 2001, p. 50). With the nursing team under investigation existing within a National Health Service culture, I felt it important to be able to consider the influence this may have had on their experiences and resulting construction of meaning.

Before going on to outline the features of IPA, I feel it important to clarify why I chose this approach over Grounded Theory as the two approaches share many features and similarities. In essence they are both data, rather than theory driven and share an aim to produce a cognitive representation of an individual or group's view of the world (Willig, 2001). They both involve a systematic process of analysis based around identifying themes, which ultimately leads to the reduction of data. They also both suggest that individual cases should be considered before integration of cases is considered. My decision to choose IPA over Grounded Theory was in part due to the fact IPA has its origins in the field of health psychology and has become recognised as a specific psychological research method with capacity to unpick the "nature or essence of phenomena" (Willig, 2001, p.69). This means IPA is particularly able to gain a detailed understanding of the quality of individual experiences. This somewhat different to Grounded Theory which has better capacity to identify and explain the social process which account for phenomena, therefore making it more suited for research in the field of sociology (Willig, 2001, p.69). Secondly, as identified by Willig (2001), with there now being various versions of Grounded Theory in existence, the process of choosing the most appropriate version for any given research study is potentially complex. With IPA being a relatively new approach, it is free from such complexities, and instead offers the chance for a greater level of creativity and freedom within the research process.

2.6 OVERVIEW OF INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA)

IPA is a fairly new qualitative methodological approach, developed during the mid 1990s by Jonathan Smith. It has been widely employed within the field of health psychology (Smith, 1996; Shaw, 2001; Reid *et al.*, 2005), and is being increasingly adopted by researchers from other areas of applied psychology; including clinical, counselling and social psychology. It is an approach primarily concerned with understanding individuals' experiences, and specifically aims to "explore in detail participants' personal lived experience and how participants make sense of that personal experience" (Smith, 2004, p.40). The approach is strongly influenced by phenomenology, a philosophical stance originating with Husserl's construction of a philosophical science of consciousness. At its core, phenomenology is concerned with the way humans gain knowledge of the world and has a particular interest in how the world is experienced by certain people in a certain context, rather than in abstract statements about the world in general (Willig, 2001). The analysis involved in IPA is therefore phenomenological in nature as it aims to "represent the participants view of the world" (Willig, 2001, p.67). It is partly this which makes IPA so appealing to psychological research, as it enables researchers to investigate the diversity and variability of human experience, (Willig, 2001). A further feature of IPA is its recognition of the researcher within the research process; relying not only on their ability to become immersed in the participant's world, but also in their capacity to make sense of the participant's experience. Smith *et al.* (1999) state that interpretations should be based on the researcher's own conceptions, beliefs, expectations and experiences, meaning the IPA researcher must be able to demonstrate reflexivity and explicitly present their own perspectives in order to illuminate the analysis (Willig, 2001). This characteristic links IPA closely with the interpretative or hermeneutic tradition with the interpretation process being viewed as a double hermeneutic - "as the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith and Osborn, 2008, p.53). Throughout the interpretative process the researcher is required to self-monitor, so as to prevent bias and the development of the "story of the researcher, rather than that of the participants" (Shaw, 2001, p.50).

Smith (2004) identifies three key characteristic features of IPA, the first being that it is idiographic. This is a term traditionally associated with the study of individual persons, although it is also used to "distinguish the study of specifics from the study of things in general" (Larkin *et al.*, 2006, p.103). In the case of IPA, both meanings are pertinent as many studies focus on "individuals as they deal with specific situations or events" (Larkin *et al.*, 2006, p.103). From a methodological perspective it demands a particular process with regard to analysis, in that only when the first case transcript has been completed in terms of examination does the researcher move on to case two and only when all cases have been examined can a cross-case analysis be attempted and integration achieved. This allows for insight into the group under investigation as well as the individuals comprising it. Secondly, IPA is inductive, meaning no hypotheses are developed from the existing literature. Instead a combination of the collection of expansive data with flexible techniques allows unanticipated topics or themes to emerge during analysis. Finally, Smith (2004) describes IPA as being interrogative, for despite its methodological differences from mainstream psychology, it still aims to contribute to psychology by ensuring that research results are not viewed in isolation, but instead considered in a broader context and therefore "interrogating or illuminating existing research" (Smith, 2004, p.43).

IPA is undertaken with a number of elementary assumptions in place. Firstly it views the individual as a "cognitive, linguistic, affective and physical being" (Smith and Osborn, 2008, p.54), recognising the existence of a complex connection between narratives, thinking and emotion, and whilst individuals may not be able to, or prepared to verbalise their thoughts and feelings, the researcher, through the process of analysis is still able to achieve meaningful interpretations of such conceptions (Smith *et al.*, 1997). With regard to language, IPA only recognises the representational validity of language, meaning it overlooks the possibility of language constructing reality. Finally, experience is viewed as a product of cognition and perception, meaning that objective reality is unobtainable. That said, although it is emphasised that different people perceive experiences differently, there is an acknowledgement that social interactions (symbolic interactionism) can affect subjectivity (Smith *et al.*, 1997).

2.7 SAMPLE

2.7.1 Purposive sampling

Non-probability sampling is commonly used in exploratory studies; the defining feature being that the choice of participants is not based on random selection. Purposive sampling is a form of non-probability sampling, in which the selection of the sample is based on the judgement of the researcher as to which subjects best fit the criteria of the study (Silverman, 2000). In this case, a sample of clinical nurse specialists (CNSs) including both tumour site-specific and palliative care nurses was required in order to ensure a fair representation of the population under investigation. The criteria for participant eligibility included CNSs currently employed by the NHS, working in the fields of oncology, haematology and/or palliative care. Participants also needed to be working in a setting where there was no cancer psychologist in post, in order to ensure that the data collected was not biased by such an influence, but instead based on their general beliefs and thoughts about the profession of psychology.

2.7.2 Recruitment

Through discussion with colleagues working in the field of cancer and palliative care, a team of cancer/palliative care CNSs working in one district general hospital was identified who had no psychologist in post, although a counsellor employed on a voluntary basis was available one day a fortnight to provide support for patients. Contact was made via email with the hospital's Matron for Outpatient Services and permission was sought to approach the CNSs with regard to recruitment to the study. With this permission secured and the necessary ethical approval granted, invitation letters (see appendix 1) were sent out to all members of the CNS team, along with a Participant Information Sheet (see appendix 2). This offered relevant background information, an outline about the purpose of the study and a clear statement that participation was entirely voluntary. My intention to record interviews and an explanation about confidentiality and anonymity were also covered. A reply slip (see appendix 3) was also included in this correspondence and the CNSs were invited to complete and return it if they were interested in taking part in the research. Stamped addressed envelopes were provided for their convenience and no specific time limit was given for replies. A total of fourteen invitation letters were sent out and of this ten CNSs replied stating they would like to take part in the study. The remaining four did not reply and it was therefore assumed they did not wish to take part. As replies were received, each CNS was contacted individually by email to arrange a date and time convenient for them to be interviewed.

2.7.3 Sample size

Although there is no set sample size suggested for qualitative studies, the large amount of data generated and the complexity involved in analysis suggests a necessary limit in terms of participant numbers. Reid *et al.* (2005) state that based on a review of the IPA literature, the mean number of participants involved in IPA studies is 15. However Smith *et al.* (1999) suggest 10 participants to be at the higher end of most recommendations for sample size, with many studies recruiting just 5 or 6 participants. Having approached a team of 14 CNSs, recruiting 10 therefore felt very satisfactory and I felt confident this would result in sufficient data from which to draw meaningful conclusions. I also felt that the sample size felt manageable in terms of the size of research project being undertaken.

2.7.4 Participant demographics

All the CNSs who took part in the study were female, with a mean age of 42. Details of their demography are shown in Table 1, along with their areas of speciality.

TABLE 1: Summary of Participants' Demographic Details

Age* (years)	**Sex**	**Experience as CNS** (years)	**Time since qualifying** (years)	**Specialism**	**Full or part time**
34	F	4	13	Palliative care	Full
36	F	5	14	Haematology/research	Full
37	F	4	17	Breast cancer	Part
39	F	4	15	Gynaecology	Full
43	F	16	22	Palliative care	Part
43	F	6	22	Lung cancer	Full
45	F	5	20	Colo-rectal cancer	Full
45	F	18	23	Haematology	Full
49	F	9	29	Breast cancer	Full
49	F	4	31	Palliative care	Part
Av=42		**Av=7.5**	**Av=20.6**		

* In order to preserve anonymity, only minimal age related data are shown

2.8 DATA COLLECTION

2.8.1 Interview schedule and rationale

One to one, semi-structured interviews were used to elicit the data. These are interviews "conducted on the basis of a loose structure consisting of open-ended questions that define the area to be explored" (Britten, 2000, p.12). Consequently this style of interviewing is guided, but not dictated by a pre-determined interview schedule, meaning questions do not necessarily follow a set order. Participants are encouraged to diverge, to pursue an idea or response in more detail and a sense of flexibility is essential for discovering the participant's own framework of meanings and allowing unexpected concepts to emerge (Britten, 2000). Prior to conducting the interviews, time was taken to construct a schedule of questions to ensure the main areas of interest were explored. This process also allowed me to consider how particularly sensitive questions/issues should be worded and managed and just as Smith and Osborn (2008) suggest, efforts were made to ensure the interview questions were open, neutral and free from jargon, thereby ensuring participants did not feel led or limited in their responses. The schedule combined general questions designed to elicit general views, along with slightly more specific questions used to obtain information on more specific issues. Although the question list was constructed in order to ensure the main areas of interest were covered, I was aware that some questions were rather factual in nature, meaning there was a risk they would result in rather superficial replies from participants, instead of encouraging more in depth exploration of their views and feelings. I therefore decided to construct a number of additional prompts which were framed in a more explicit way, and could be used in the event that the original question generated a short or tangential response (Smith and Osborn, 2008). The questions that I perceived to be potentially problematic in terms of generating vague or general responses, when more in-depth data were hoped for, were those for which additional prompts were created. Prior to conducting the interviews, I ensured maximum familiarity with the interview schedule partly to assist in rapport building with the participants, but also to ensure they felt comfortable and listened to, rather than simply on the receiving end of a list of questions.

2.8.2 Questions and possible prompts to be used during the semi-structured interviews

- As an experienced clinician in this field, can you tell me what you feel about psychologists working in the field of cancer/palliative care?
  Prompt: general views/concerns/ experience of/pros and cons /perceived relevance
- If a psychologist was working in your department, what would you expect of them? *Prompt: remit/skills/access/qualities/place in team*
- What sort of issues do you feel necessitate a referral to a psychologist?
  Prompt: case examples/specific symptoms/signs/clues
- Can you describe how you currently assess patients for psychological distress? *Prompt: process/skills/approach/language/avoidance*
- How do you feel about assessing for psychological distress?
  Prompt: fears/concerns/taboos/confidence level/emotional impact
- Can you tell me about any training you have had which has assisted you in carrying out such assessments?
- Is there any other training you feel would be beneficial?

2.8.3 Interview process

Each interview began with welcoming and thanking the participants for giving up their time and agreeing to take part in the research. Effort was made to put the participants at their ease by being friendly, relaxed and informal. A short discussion then ensued, reminding them about the purpose of the research study and asking if they had outstanding questions they would like answered. The issues of confidentiality and anonymity were then covered and participants were reminded that the interviews would be recorded. Throughout this introductory discussion participants were encouraged to raise any points of concern and were also reminded that they did not need to answer any questions they did not feel comfortable with and were free to withdraw from the research at any time, without needing to give an explanation. They were then shown how to switch off the recording device should they wish to and told they could turn it off at any time during the interview without needing permission from the researcher. They were then asked to read and complete a consent form, which I then also signed and dated in their presence (see appendix 4). Interviews then commenced and lasted between 45 and 80 minutes. These were recorded using an Olympus digital voice recorder (model WS-100).

At the end of the interviews participants were given a post-interview information sheet (see appendix 5) which included contact details for me and three other professionals whom the participants could contact should they require any further information about the research or felt in need of a post interview debrief or ongoing support. Permission was then sought from them for me to contact them by email, should I require any further clarification whilst analysing the data. They were then asked if they would like to receive an abstract of the results obtained, and were reminded they would be invited to a presentation of the findings once analysis was completed. Participants were again thanked for their time and for sharing their thoughts with me and asked if they had any outstanding questions.

2.8.4 Venue

All the interviews took place on site at the hospital where the CNSs worked. This was arranged to ensure maximum convenience for them. A private room was located in a building separate from their office space in order to foster a sense of comfort and privacy

2.9 RELIABILITY AND VALIDITY

Within qualitative research the issues of reliability and validity are deemed to be as important as in other approaches (Kirk and Miller, 1986; Miles and Huberman,1994 cited in Denscombe, 2003; Silverman, 2000). However the criteria by which such research is assessed differ from those used in quantitative research. Reliability, which is traditionally concerned with the neutrality of the research instrument, questions whether an instrument would produce the same results if used on a different occasion, whilst applied to the same object. Within the context of qualitative research, reliability becomes more a question of whether the same results and conclusions would be found if a different researcher undertakes the investigation. Although impossible to prove emphatically, reliability can be fostered by offering transparency in terms of the purpose and aims of research, how the research was undertaken and the reasoning behind key methodological decisions (Denscombe, 2003). The quality of recording and documenting data is central to this, as is clarity about how interpretations are made. Validity, which is sometimes referred to as trustworthiness or authenticity in the context of qualitative research (Holloway, 2005) relates to the issue of whether the researcher sees what he or she thinks they see (Kirk and Miller, 1986). The complexities of the relationship between the qualitative research process and the resultant findings have been the focus of much consideration and validity remains an issue of ongoing debate (Wolcott, 1990).

A number of strategies or 'checklists' are suggested as ways of addressing the issues of reliability and validity within qualitative research, and whilst these alone do not confer rigour, they have played an important role in conferring respectability on qualitative research and certainly contributed to the wider acceptance of such methods (Barbour, 2001). In the first instance and in accordance with the recommendations of both Arskey and Knight (1999) and Wolcott (1990), throughout the course of the study, I strove to enhance validity by being aware of good interviewing techniques, generating interview questions drawn from relevant literature, using prompts to encourage discussion, using a relevant sample, producing accurate notes, providing a transparent description of the research process and being truthful and accurate. I also employed a number of additional strategies to demonstrate credibility which are outlined as follows:

2.9.1 Respondent validation

Respondent validation, which is also referred to as a 'member check' or 'participant feedback', involves reporting findings back to participants thereby giving them the chance to confirm or challenge the account (Lincoln and Guba, 1985 cited in Holloway, 2005). I therefore decided to utilise this strategy in order to ensure congruence between my findings and the experiences and perspectives of the participants. During the analysis phase, contact via email was made with four of the participants whose words/phrases had left me with a sense of ambiguity. This type of checking was designed to ensure the validity of my interpretations and allowed for the corroboration or refining of my findings (Barbour, 2001).

2.9.2 Documentation

The accurate and detailed description of the audit trail is suggested as an important aspect of reliability and validity (Yardley, 2008). I therefore made efforts to ensure that every aspect of the research process was documented in a detailed and transparent fashion. A clear and thorough account of what was done, when and why is provided in Chapter 3, whilst raw data are presented in the appendices section. Every effort has been made to ensure that the themes can be traced back to the original data source and any decisions involved in the process of analysis are justified, illustrated and explained.

2.9.3 Independent judgement

Within qualitative research, independent judgement which is also known as multiple coding or verifying of themes, is a process by which independent researchers cross check coding strategies and interpretation of data. This process ensures that rather than being restricted to one perspective, the analysis makes sense to other people (Yardley, 2008). Whilst Pope and Mays (1995) identify the agreement rates between researchers as the significant criterion for assessing rigour, Barbour (2001) suggests it is actually more about the "content of disagreements and the insights that discussion can provide for refining coding frames" (p.1116). In order to maximise the reliability of my coding system, two independent judges (a liaison psychiatrist and a clinical psychologist both with experience of qualitative research) were invited to consider a list of sample themes, along with their identifiers, and then allocate them to the most appropriate master theme. I hoped that the combination of their experience, along with their objective positioning, would allow them to identify any overly idiosyncratic interpretations. This process provided a useful opportunity for discussion about the factors which had influenced my choices with regard to the analysis and both the independent judges were able to offer some constructive challenges and comments. In particular they raised concerns about my choice of theme titles, describing them as being overly factual and lacking in psychological depth. They also challenged my general approach to the analysis, and questioned whether I had shied away from pulling out the more psychological aspects of the findings. We discussed this issue in detail, and together considered the alternative interpretations that could have been made. This helped me to begin a reflective process, questioning what had influenced my approach and led me to make the choices I had (a more detailed account of these reflections is offered in Chapter 3, section 3.2). The input from the independent judges, combined with my own reflections on the matter, led me to return to my analysis and make a number of modifications. These are described in more detail in section 3.1.7 of Chapter 3.

2.10 REFLEXIVITY

Within the context of qualitative research, reflexivity is defined as "a confessional account of methodology or as examining one's own persona, possibly unconscious reactions. It can also mean exploring the dynamics of the researcher-researched relationship and how the research is constituted" (Finlay, 2002, cited in Holloway, 2005, p.278). It recognises that researchers are themselves part of the social world, using their own concepts to make sense of it, meaning interpretations made by a qualitative researcher are therefore affected and influenced by their experiences, norms and values. This means that any research findings can never be entirely objective (Denscombe, 2003). Reflexivity implies self-awareness, critical evaluation and recognition of the power relationships which may exist between researcher and participant and it strives to examine and uncover the researcher's place in the research process. According to Coffey (1999) the researcher's professional identity can effect participants' emotions and subsequent responses, whilst Richards and Emslie (2000) suggest that the professional background of the researcher can influence participants' perceptions of their status, and in turn influence their responses.

In line with a reflexive stance, throughout the interviewing process I strove to give due consideration to the impact my professional identity may have had on the CNSs, how my position as a stranger may have affected them, and the possible issues of professional hierarchy created by my role as a psychologist amongst nurses. I was very conscious of the impact my presence may have had on each participant and was aware of a strong possibility that their responses were open to being influenced by their individual perceptions of me, and my role/status. My concerns were not unfounded; by observing their body language, I detected that a number of them felt slightly nervous of me, and this combined with the fact I was asking them their views about psychologists, contributed to an increasing sense that a power imbalance could easily develop. A small number of the participants made explicit statements about viewing psychologists as being 'above them' in the professional hierarchy. Others were less direct, but conveyed similar messages by asking me for reassurance and/or validation about their knowledge level. Prior to, and throughout each interview I remained fully aware of these issues, keen to do anything to prevent a situation in which the participants viewed me as some sort of 'expert', meaning they may have begun to exert a pressure upon themselves to 'get it right', rather than feeling free to share their true thoughts and ideas.

I felt concerned by these issues and thought carefully about how best to manage them. I began with the issue of physical appearance, based on the fact I was aware that during the interviews the participants were likely to be wearing their uniforms, therefore reinforcing their status as nurses. I therefore took care to dress for each interview in such a way that was neutral and non-threatening, choosing simple, casual outfits and avoiding anything (clothes or accessories) that may have contributed to a perception of power or status. I endeavoured to present myself as approachable and non-judgemental and remained acutely aware of my verbal and non-verbal communication throughout all interactions. Finally, I took great care to emphasise early on in every interview their status as expert practitioners in their chosen speciality and reminded them that as a researcher, my interest lay in learning from them about their experiences, views and ideas.

Following each interview I chose to make notes in a reflexive journal, describing my own feelings and observations about the encounter. This not only helped me to reflect on how my reactions and feelings towards each participant may have influenced the research process, but also had a cathartic quality, encouraging me to be honest about my private thoughts and feelings. Through this process I identified, documented and reflected on the personal impact the interviews were having on me, which in turn helped me to judge how many interviews it was possible for me to undertake in any given timescale. This helped me to ensure I had the necessary energy to maintain high levels of awareness and sensitivity for each participant.

2.11 ETHICAL CONSIDERATIONS

Research of any type must be conducted in an ethical fashion, meaning it must respect the rights and dignity of participants, avoid causing harm and be underpinned by honesty and integrity. These guidelines are based on an assumption that there is no justification for researchers to, "pursue their interests at the expense of those they are studying" (Denscombe, 2003, p.135). These issues are compounded by the existence of data protection laws and human rights legislation, both essential in protecting the public from unscrupulous collection and use of data (Denscombe, 2003).

The British Psychological Society code of Conduct, Ethical Principles and Guidelines is an explicit code of conduct which incorporates the key points of legislation along with guidelines to ensure that any research undertaken is of a high moral and professional standing. In line with this code, there were a number of ethical points that required consideration.

2.11.1 Ethical approval

As the research participants were all employees of a NHS hospital, ethical approval was required from the Trust's Local Research Ethics Committee (LREC), as well as the Research and Development department. In line with City University's policy, a research proposal was submitted along with an ethics release form (see appendix 6 for a copy of the proposal). Approval was sought and received from the Research and Development department (see appendix 7) and City University (see appendix 8). However my first application to LREC was unsuccessful and the committee raised a number of concerns about the study (see appendix 9).

2.11.2 Ethical concerns

The first point of concern outlined by LREC related to the fact they felt the research interview posed a risk to the CNSs, in that it may have left them feeling professionally demoralised. They held concerns that after being interviewed, the CNSs may have begun to question their competence, which in turn could have a negative effect on patient care. This was compounded by the fact the Committee did not feel there was sufficient post-interview support in place nor any offer of training for those who felt that would be useful. The second point of concern related to the risk of coercion, as the Committee felt the CNSs could feel under pressure to take part in the research. They felt the risk of this was greater because it was not a study between peers, but rather a psychologist asking CNSs their views about psychologists. A number of other smaller issues were raised including concerns about the storing of information on computers, the lack of clarity about whether direct quotations would be used and concerns that my interview schedule included questions that were not sufficiently open-ended. Within this feedback the Committee made a number of helpful suggestions and informed me of my options with regard to pursuing ethical approval. These included making the recommended changes and re-submitting a second application to the same Committee, or alternatively appealing against their decision and seeking a second opinion on the original application from another Research Ethics Committee.

My initial response to the committee's rejection of my proposal involved a mixture of surprise and disappointment. I also interpreted their comments about the research interviews posing a possible risk to the CNSs on a particularly personal level and felt they were underestimating my awareness of the importance of sensitive interviewing. I also felt their decision reflected a rather paternalistic attitude towards the nurses which only added to my frustration. After a period of reflection and discussion with my supervisor, I realised that my reactions were all related to my own concerns and anxieties about my research timetable and the time pressures involved in undertaking this research. Once aware of this, I was able to see that the Committee's reasons for declining my application were all valid, considered, and most importantly, designed to ensure that no harm came to the CNSs. Realising this enabled me to engage with their feedback in a much more constructive way and feeling there was scope for improvements to my application, I decided to work on their recommended changes. A second application was therefore submitted to the same Committee and on the suggestion of my supervisor, I arranged to attend the LREC meeting, meaning I was able to present the changes made to the study and discuss any ongoing concerns the Committee members may have had in person. A week after attending this meeting, I received written confirmation that ethics approval for this research had been granted (see appendix 10).

2.11.3 Informed consent

In order for the premises of informed consent to be fulfilled, it is essential for participation to be voluntary and for participants to have sufficient information about the research to enable them to arrive at a reasoned judgement about whether they wish to take part (Denscombe, 2003). To ensure the participants were fully informed about this research study and procedure, they were all supplied with the necessary information prior to deciding whether to participate. Prior to commencing the interviews, sufficient time was allowed for discussion about the study and any outstanding questions were answered. All participants were then asked to complete a consent form which included a sub-section confirming they had read the information sheet and had had any outstanding questions answered satisfactorily.

In light of the ethics Committee's comments about the risk of coercion, I gave particularly careful consideration to the issue of voluntary participation. To minimise coercion risks, I made certain that both the information sheet and invitation letter clearly stated that participation was entirely voluntary and a decision to not take part would be totally respected and accepted without question and there would be no negative consequences for deciding to not take part. Secondly, a sub-section of the consent form stated the voluntary nature of participation and that participants were free to withdraw consent at any time in the research process. In addition, at the beginning of each interview I openly acknowledged the fact I was a psychologist asking them about psychologists, and in doing so, tried to reduce any discomfort about this dynamic. I reassured them there were no right or wrong answers and again emphasised that participation was entirely voluntary and they were under no obligation to answer any questions they were not comfortable with. Finally, in addition to these measures, I felt the fact that I was not known to any member of the team, and that no professional link existed between us meant pressure to participate would be negligible.

2.11.4 Anonymity and confidentiality

To ensure that all participants felt comfortable to speak openly and honesty, those taking part in the study had the right to anonymity. All research data (digital recordings and transcripts) were treated as confidential and kept securely locked in a filing cabinet, to which I was the sole key holder. Transcriptions were coded so as to maintain anonymity. Data in the form of anonymous transcripts were stored on my personal laptop, with back-up copies on an external hard drive. These were again stored securely in the aforementioned filing cabinet. The laptop was password protected throughout the process, and I was the only person with access. Participants were informed that all digital recordings would be erased after completion of the study, all written research data would be destroyed after completion of the thesis and that no identifying information relating to them would be published.

With regard to the writing up of this thesis, no references have been made to individual participant information at any stage in the process and any direct quotations have been used in such a way as to maintain anonymity. Any patient information that was discussed during interviews has been dealt with confidentially and no reference to individual patients has been made at any point.

2.11.5 Impact on participants

Taking into account the concerns raised by the ethics Committee about the possible impact on participants, plus my own responsibility for their well being, measures were put in place to manage any possible negative consequences of their involvement in the study. All participants were offered a post-interview de-brief and/or ongoing support with a cancer/palliative professional who had significant experience in the field but had no involvement in the project. Three such professionals were identified for this purpose in order to give participants a choice and their contact details were listed on the post-interview information sheet. Secondly, the participants were all made aware that I would be happy to provide a training session on any related topic, once the interviews were completed and I would also ensure that they were informed of any forthcoming related training events that they may wish to consider attending.

2.11.6 Ownership of results

Following the distribution of the initial individual invitation letters, a number of potential participants contacted me via email to register their interest in the research, but also to raise concerns about the ownership of results. Their main concern was that if the results showed them to be incompetent in any way, this could be used to undermine their professional position and job security. This was a sobering moment, as I realised how appropriate it had been for the ethics Committee to raise concerns about the negative impact this research could have on the CNSs, particularly in relation to feelings of competence. After careful thought about the nurses' concerns, I suggested the following as a possible solution: I agreed that the ownership of results would be shared between the participants and myself, and apart from those involved in reading my written thesis for purposes of academic assessment, the findings would only be shared with a wider audience if there was unanimous agreement amongst them. It was suggested that the key findings would be communicated to the participants by way of a presentation, in order for them to make this decision. During this presentation, care would be taken to ensure that both anonymity and confidentiality were maintained. An email explaining this issue about joint ownership was distributed to all the potential participants.

CHAPTER 3

Data Analysis

During this chapter a narrative account of the process of analysis is provided, for as Bryman (2001) suggests, a step by step account of what actually happened during the analysis phase and how any conclusions were arrived at is an important element of transparency. The analysis itself was conducted in accordance with the guidelines outlined by both Smith and Osborn (2008) and Willig (2001) and in order to maximise transparency, example sections from transcript number one are included throughout.

3.1 THE PROCESS OF ANALYSIS

3.1.1 Initial impressions

Data analysis began on an informal basis immediately after each interview. The interviews were scheduled in such a way as to ensure that following each one I had protected time in order to reflect on the interaction and note down my initial thoughts and feelings. These notes included observations regarding non-verbal communication, the general tone of the interview and the overall impression I was left with. Doing this immediately after each interview felt important in order to ensure accuracy and make sure my initial impressions did not become diluted over time or affected by subsequent interviews. I also aimed to listen to each interview within two days of it being conducted, giving me further opportunity for reflection and allowing me to gain an overall sense of the data collected. Whilst listening I again made informal notes, documenting issues such as participant tone, as well as noting down any questions that had been asked which appeared to create a particularly emotional response. Comparing these notes with those I had made immediately after each interview allowed me to reappraise any initial impressions that might have been more a reflection of my emotions rather than those of the participant. An example of the notes made immediately after the interview with participant one can be found in Table 2.

TABLE 2: Example of Notes Made Following Interview One

(For purposes of confidentiality, the letter S is used to represent the participant)

I feel surprisingly tired; it was harder than I thought it would be, mainly because S seemed nervous and in response I became overly anxious to create an environment in which she would feel comfortable to talk openly. On reflection, I am not actually sure whose nerves were greater – mine or hers. I think I detected some discomfort in her during the early part of interview. Her body language was rather closed and she seemed to respond to my early questions as though I was looking for particular answers. Was she worried about getting it wrong or being judged? Did I do enough to reassure her about the exploratory nature of the interview, or was I the one who was worried about getting it wrong and being judged? I recall her early verbal pace being pressured, suggesting she was anxious to get through the questions as quickly as possible. Or was that me, was I setting the pace and wanting to get through it all as quickly as possible? Whose anxiety am I describing? S appeared resistant to exploring/revealing her emotions, instead tending to focus on the factual aspect of my questions. Is this a reflection of my style of interviewing, did I do something to block or hinder, or does it reveal something about S feeling wary about emotional exposure? Could this be about her feeling it is too risky to explore emotions for fear of what may come out, or is it about my influence in the dynamic, or something else entirely? As the interview went on, something seemed to change; S appeared to relax, she began to laugh and started engaging with the more emotional aspect of her experience. I relaxed too but am unclear about who relaxed first, or what influenced this. Using the prompts seemed to help open the dialogue up and I felt the latter part of our interaction had a really different feel. There was a change in pace and a greater tolerance of silence. I wonder what led to this shift? Was it a particular question or comment? Towards the end, S made an explicit statement about how much she had enjoyed talking and alluded to the fact that this type of discussion was a new experience for her. I am wondering about this. Is this type of emotional exploration discouraged or just not prioritised amongst CNS's? I am struck by how S seemed genuinely surprised that I was actually interested in what she had to say – I wonder if this might be something I experience with other participants?

Points to consider when listening to interview

- Is my appraisal about the early part of the interview accurate?
- Consideration of whose anxiety/nerves are dominant
- If my perception that S initially resisted emotional exploration is correct, then what was the cause? Her anxieties or my interviewing style/nervousness?
- Did I do anything to block emotional dialogue?
- Did I set the pace and therefore dissuade S from talking in detail?
- Did particular questions appear to generate more anxiety in S?
- What was happening at the time the tone of the interview changed? Did I do something different, or was it in response to a particular question?

The final stage of this informal analysis occurred during the transcribing process, which I undertook on a semantic level, meaning all spoken words as well as silences, laughs and any other notable occurrences were included (Smith and Osborn, 2008). The advantage of having the interviews recorded digitally was that it was possible to slow the speed down, therefore improving transcribing accuracy and allowing me to listen carefully to sections of particular interest and/or complexity. This process again contributed to my overall sense of the collected data and allowed me to develop an increasing familiarity with each participant interview. All ten interviews were transcribed in this fashion. However due to issues of confidentiality only a section of transcript one has been included (see appendix 11). Copies of the full transcripts can be provided on request.

3.1.2 Preliminary observations

The first formal stage of IPA analysis is referred to as "a free textual analysis" (Smith and Osborn, 2008, p.67) meaning there are no specific rules for how it is conducted. I therefore began by re-familiarising myself with the initial notes I had made following interview one, and then re-listened to it digitally, before going on to read the full interview transcript through. This was done on a number of occasions in order to foster familiarity and intimacy with the content. Following Smith and Osborn's (2008) guidelines, I then began to make notes in the left hand margin of the transcript, commenting on any aspect of the text which struck me as particularly interesting or significant. These notes were fairly unfocused and included general observations, comments on the language used, potential connections, possible discrepancies, questions, general summary statements and preliminary interpretations. An example of this first stage of analysis follows in Table 3, with my initial informal notes shown in bold in the left hand margin of the transcript.

TABLE 3: Example of First Stage Analysis

(Transcript 1: lines 466-488)

Key R = Researcher, P1 = Participant One

	R: Ok, picking up on the point about what psychologists actually do. Do you have any ideas about that?
Nervousness/unsure?	**P1:** Laughs... ...I expect that they are taking from where I have
Taking it away?	left off and, but taking it and having the experience and the
Skill difference/training	training behind them to take that a step further, as in say

Going further/deeper	unearthing why, why someone is behaving why, why someone is
Focus on discovery	behaving like that..unwrapping it a bit more but then able to
Solving and planning	come up with some plan to move that patient on and I think
Unable to do/skill limit	that's where we are not trained, well we're not trained in that,
Area of competence	think we are experienced as the alarm bells and.. and yes we
Skill limit	can unpack things to a point, but then it's the unpacking and then
	moving forward and I don't think we have that, that's not.
Professional difference	we're not, we're not trained in that. They are more about
Problem solving	solutions, finding psychological ways to solve the problem
	R: Any ideas how they might do that?
Unsure/Nervous	**P1:** Um... it's sort of..um what do they do? Um......laughs.... I
Unknown/embarrassed	don't know.......I suppose I think what they do is offer um... I say
Thought focused	a plan, or a way of thinking, a new way of thinking for the
	person..um... instead of looking at it like this Mr Smith, why don't
Didactic/directive	you look at it like this, you know.. sort of that type of thing,
Doing to/rescuing	offering a pathway for them really, or changing their behaviour.
Rescuing	To get out of that situation they are in. So say I've seen a
	psychologist and I was extremely negative I would probably
Controlling/bossy	think the psychologist would say to me well let's look at it this
Leading	way, um and lead me into a more positive route, so... yeah,
Positive thinking	yeah, I think just looking at it a bit differently

3.1.3 Identification of themes

The second stage of analysis involved the identification of theme titles, meaning the process moves onto a higher level of abstraction. Again, following the guidelines offered by Smith and Osborn (2008), I returned to the beginning of transcript one, and this time using the right hand margin, began to document emerging theme titles which I felt captured the essence of the text. This process involved transforming my initial unfocused left margin notes into higher level, conceptual concise phrases, which in some cases involved the use of more technical psychological terminology. At this stage I viewed the entire transcript as data, and rather than focusing on any particular section or passage, simply worked through the entire transcript utilising this style of analysis. This process resulted in the generation of a fairly large number of themes, some of which were repeated a number of times throughout the transcript.

The challenge during this stage was in trying to ensure that the concepts I produced were sufficiently abstract, but also remained fully grounded in the text and therefore representative of the participant's original comments. An example of this second stage of analysis follows in Table 4, with the emergent themes shown in bold in the right hand margin of the transcript.

TABLE 4: Example of Second Stage Analysis

(Transcript 1: lines 466-488)

Key R = Researcher, P1 = Participant One

R: Ok, picking up on the point about what psychologists actually do. Do you have any ideas about that?	
P1: Laughs... ...I expect that they are taking from where I have	
left off and, but taking it and having the experience and the	
training behind them to take that a step further, as in say	**Training (psych)**
unearthing why, why someone is behaving why, why someone is	
behaving like that..unwrapping it a bit more but then able to	**Emotional exploration**
come up with some plan to move that patient on and I think	**Psychological movement**
that's where we are not trained, well we're not trained in that,	
think we are experienced as the alarm bells and.. and yes we	**Scope of role**
can unpack things to a point, but then it's the unpacking and then	
moving forward and I don't think we have that, that's not.	
we're not, we're not trained in that. They are more about	
solutions, finding psychological ways to solve the problem.	**Solution focused**
R: Any ideas how they might do that?	
P1: Um... it's sort of..um what do they do? Um......laughs.... I	
don't know.......I suppose I think what they do is offer um... I say	**Unknown**
a plan, or a way of thinking, a new way of thinking for the	
person..um... instead of looking at it like this Mr Smith, why don't	
you look at it like this, you know.. sort of that type of thing,	**Directive style**
offering a pathway for them really, or changing their behaviour.	
To get out of that situation they are in. So say I've seen a	**Psychological movement**
psychologist and I was extremely negative I would probably	
think the psychologist would say to me well let's look at it this	**Directive style**

way, um and lead me into a more positive route, so... yeah,
yeah, I think just looking at it a bit differently. **Effecting change**

3.1.4 Clustering of themes

Having generated a lengthy list of initial themes, the next stage of analysis involved the identification of connections between them, thus allowing a sense of structure to start developing. The first step in achieving this involved listing all the emergent themes from transcript one, chronologically on a piece of paper (Smith *et al.*, 1999). A small sample of these themes can be found in Table 5, although a full listing can be found in appendix 12.

TABLE 5: Sample of Initial Themes Generated from Transcript One
(Themes numbered according to the order they were found in the transcript)

1. Reflective practice
2. Informal peer supervision
3. Role-play
4. Confirmation of existing skills
5. Unknown acquisition
6. Unknown acquisition
7. Work/life boundaries
8. Feedback (clinical work)
9. Insufficient feedback
10. Feedback (learning aid)
11. Improved understanding
12. Learning restrictions
13. Unknown
14. Non-conformist
15. Stereotype vs reality
16. Risky knowledge
17. Scope of role
18. Causing harm
19. Idealised
20. Angel vs professional
21. Inaccurate perceptions
22. Discomfort
23. Non-comformist
24. Stereo-type vs reality
25. Behavioural expectations
26. Personal vs professional image
27. Perceptions of role
28. Challenging
29. Professional denial

Using this list, I then began looking for shared reference points, asking myself what relationships existed between them and considering whether any of the themes were actually saying the same thing but had been labelled with a different name. Through this examination, I found that some themes started to form natural clusters in that they shared a common meaning or feature, whilst others had what Smith and Osborn (2008) refer to as a 'magnet effect' thereby acting to draw other themes towards them. This process was iterative in nature, for whilst it involved me making interpretations about what the participant was saying, it also required very close monitoring of the text to ensure my interpretations were grounded in the data and truly reflective of what had been said. There was therefore an ongoing interaction between me and the transcript, with constant checking back to the source material (original transcript) to ensure that the clusters of themes were actually consistent with the participant's account. An example of clustered themes can be found in Table 6, although a full listing of theme clusters from transcript one can be found in appendix 13.

TABLE 6: A Sample of Theme Clusters from Transcript One

Beyond ability
Requiring specialist input
Limited time
Unable to help

Honesty
Openness

Stigma
Variations
Acceptability
Role of media
Unknown profession

Idealised
Angel vs professional
Inaccurate perceptions
Burden of association
Discomfort
Non-conformist
Stereotype vs reality
Behavourial expectations
Personal vs professional image
Perceptions of role
Challenging
Rejection of stereotype

3.1.5 Production of a summary table

The next stage involved trying to present the themes in a more organised and coherent fashion through the creation of a summary table (Willig, 2001). To achieve this, I considered the content of each cluster and then chose a descriptive label which was designed to capture something of the essence of the grouping. This label, otherwise known as the master theme, was then presented along with all the themes in that particular cluster. I then returned to the transcript and identified a brief but relevant quotation for each theme and listed this, along with a location reference (page and line number) thereby ensuring that each theme was suitably illustrated from the source material. The identifying of such quotations served two purposes: firstly on a practical level, it meant I felt confident that if necessary, relevant examples could be easily sourced at a later time, and secondly, the process helped me identify any themes which could be discarded, either because they were not well evidenced in the data or because they did not fit well into the structure of my emerging themes.

A section of transcript one's summary table is presented in Table 7, although the table in its entirety can be found in appendix 14.

TABLE 7: Section of Summary Table from Transcript One
(**Key**: 2.53 refers to page 2, line 53)

HOPES REGARDING PSYCHOLOGY ROLE

Clinical consultation	"talk through a patient"	2.53
Collaborative working	"working with"	2.59
Professional support	"support us"	2.66
Clinical supervision	"clinical supervision"	4.119
Feedback	"come back to me"	12.432
Clinical recommendations	"anything I could be doing"	13.451
Availability	"there and then"	3.92
Unknown	"inexperience of what a p does"	13.455

BEING A CLINICAL NURSE SPECIALIST

Knowing limits	"hand someone on"	2.57
Psychological assessment	"defining what's normal"	5.151
Offering time	"let people have time"	7.247
Emotional understanding	"understand whole process"	7.249
Managing difficult questions	"am I dying?"	8.257
Scope of role	"not trained in that"	13.474

WHAT PSYCHOLOGISTS DO

Psychological assessment	"assess the patient"	12.431
In-depth	"a step further"	13.467
Psychological movement	"move that patient on"	13.471
Solution focused	"about solutions"	13.475
Unknown	"I don't know"	14.480
Instigate change	"changing their behaviour"	14.484
Directive	"lead me"	14.486
Positive focus	"positive route"	14.487

3.1.6 Ongoing analysis

Once the summary table for transcript one was completed, I considered how best to proceed with the analysis of the nine other transcripts. Smith and Osborn (2003) and Willig (2001) both suggest that the researcher can either choose to use the summary table from the first transcript to inform analysis of any subsequent transcripts, meaning that the original themes can be added to and elaborated on, whilst new themes can also be identified, or alternatively, they can begin the process from scratch with each transcript and work through the various stages of analysis, meaning that for each participant, a summary table of themes is created. I decided to opt for the latter method, partly because Smith *et al.*, (1999) suggest that this system is particularly suitable for studies which involve a sample size of up to ten participants as this is "small enough to retain an overall mental picture of each of the individual cases and the location of the themes within them" (p.225). I was also mindful that although my sample was made up of CNSs, each of them specialised in a different area of cancer care meaning it was possible there would be differences to be found between them, and I wanted to ensure that my analysis allowed for me to give sufficient consideration to any differences. I therefore turned my attention to transcript two and began the process afresh. I worked through each transcript chronologically employing all the aforementioned stages, meaning that for every transcript there was the generation of an initial list of themes, (see appendices 15-23), followed by clustered themes (see appendix 24-32) and ultimately a summary table of themes (see appendices 33-41). Throughout this process, care was taken to recognise anything new and original that emerged as well as identifying repeating and familiar patterns, meaning that any differences existing between participants were both recognised and respected.

3.1.7 Integration of cases

Once all ten transcripts had undergone these various stages of analysis and a summary table of themes for each participant had been produced, the process of integration could begin. The aim of this was to combine the preliminary analyses from the ten participants into a consolidated summary of master themes which best represented the experiences of the group. Willig (2001) suggests this style of integration allows for a more generalised understanding of the phenomenon under investigation to be obtained, as well insight into the essence of the phenomenon, and means the overall findings are representative of the entire data set. The process of integration requires not only the prioritisation and reduction of data, but also the selection of the most significant themes. This selection process is not necessarily just based on the prevalence of particular themes within the data set, but also takes into account "the richness of the particular passages that highlight the themes" (Smith and Osborn, 2008, p.75)

My process of integration involved two distinct phases. Firstly, following input from my supervisor and the independent judges (see section 2.9.3, chapter 2), I engaged in a period of reflection, considering the decisions I had made in terms of the data analysis (these reflections are expanded on in section 3.2 of this chapter). As a result of this, I decided it was necessary to undertake a complete review of all the themes and re-consider the approach I had taken. A thorough examination commenced, allowing for a total re-appraisal of the data set and consequently I decided that some modifications were necessary as I realised the approach I had taken meant the data were presented in an overly factual fashion, meaning that many of the more psychological/emotional findings were eclipsed and potentially difficult to identify. I began this process by considering the titles I had given each master theme, and felt that many of them could be named more appropriately, thereby helping to illuminate the psychological focus and content. For example the master theme '**beliefs about psychologists'** was renamed '**feelings about psychology/psychologists',** the master theme **'being a clinical nurse specialist'** was renamed **'feeling competent as a CNS',** and the master theme **'difficulties and challenges of being a CNS'** was renamed '**sources of emotional discomfort/distress'**. I then went on to consider the titles of the sub-themes within each master theme and again found that many of them were somewhat factual and lacking in both abstraction and psychological depth. I also felt there were a number of themes which could be merged together without there being a loss of meaning. I therefore began another process which involved in some cases just the renaming of a sub-theme, and in others the merging together of many sub-themes along with the renaming of the new theme. For example within the master theme **'beliefs about the role'** the sub-theme 'unknown' was renamed 'secretive/mysterious' whilst the sub-themes 'secretive', 'unknown', 'confusion', 'negative' and 'threatening' found in the master theme **'feelings about psychology/psychologists'** were merged together into one new theme called 'fear/threat'. The entire process of data re-evaluation and change was again iterative, for whilst the renaming of themes involved the making of interpretations, I constantly returned back to the source material to ensure that my interpretations were fully grounded in the data and reflective of participant accounts.

This process of data consideration and re-evaluation continued until all the master themes from all ten summary tables had been reviewed and I felt happier that the resulting themes conveyed a greater sense of the psychological nature of the participants' experience. Further illustrations of the process of merging and renaming of themes are presented in Table 8. However for full details of the merging and renaming process of themes from all ten transcripts see appendices 42-51.

TABLE 8: Examples of Merged and Renamed Themes from Transcript One

(**Key:** new sub-theme titles are shown in brackets, italic type, whilst 2.53 refers to page 2, line 53)

HOPES AND EXPECTATIONS

Clinical consultation	*(clinical consultation)*	“talk through a patient”	2.53
Collaborative working	*(multi-disciplinary working)*	“working with”	2.59
Professional support	*(professional support)*	“support us”	2.66
Clinical supervision	*(professional support)*	“clinical supervision”	4.119
Feedback	*(communication/feedback)*	“come back to me”	12.432
Clinical recommendations	*(clinical consultation)*	“anything I could be doing”	13.451
Availability	*(availability)*	“there and then”	3.92
Unknown	*(unknowns)*	“inexperience of what a p does”	13.455

BELIEFS ABOUT THE ROLE

In-depth	*(emotional exploration)*	“a step further”	13.467
Psych movement	*(effecting psych change)*	“move that patient on”	13.471
Solution focused	*(structured approach)*	“about solutions”	13.475
Unknown	*(secretive/mysterious)*	“I don't know”	14.480
Instigate change	*(effecting psych change)*	“changing their behaviour”	14.484
Directive	*(structured approach)*	“lead me”	14.486
Positive focus	*(structured approach)*	“positive route”	14.487

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Knowing limits	*(having knowledge)*	“hand someone on”	2.57
Psych assessment	*(having knowledge)*	“defining what's normal”	5.151
Offering time	*(managing time)*	“let people have time”	7.247
Emotional understanding	*(offering support)*	“understand whole process”	7.249
Managing difficult questions	*(offering support)*	“am I dying?”	8.257
Scope of role	*(knowing limits)*	“not trained in that”	13.474

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

Emotional discomfort	*(working with death)*	“tolerating silence”	7.232
Depression vs realistic sadness	*(understanding)*	“such a fine line”	10. 351
Lack of understanding	*(understanding)*	“get it mixed up”	10.343
Lack of control/influence	*(team working)*	“not under our care”	14.513
Sudden endings	*(time pressure)*	“time stopped”	14.511
Insufficient feedback	*(team working)*	“not enough”	17.606
Managing unknowns	*(understanding)*	“I don't know”	19.670
Perceptions of role	*(expectations)*	“tough going”	20.727

Having made changes to the way in which the data were presented, I then embarked on the second phase of integration which involved the identification of the most significant themes and the production of a final table of master themes which best captured the quality of the participants' shared experience (Willig, 2001). Achieving this final stage of integration relied on a cyclical process, which again involved the close checking that higher-order and/or integrative themes were actually firmly grounded in the data. This process continued until full integration of themes was achieved, resulting in the identification of twelve master themes, which are presented in Table 9.

TABLE 9: Final Master Themes

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS
BELIEFS ABOUT THE ROLE
PERCEIVED QUALITIES
HOPES AND EXPECTATIONS
FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST
SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS
COPING WITH BEING A CLINICAL NURSE SPECIALIST
WAYS OF ASSESSING FOR DISTRESS
FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES
FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE
SIGNS OF DISTRESS
IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

A detailed summary table showing all master themes, their associated sub-themes, along with identifiers indicating where in each participant's transcript an illustration of the theme could be found was also created. A small section of this is presented in Table 10. However the full table can be found in appendix 52.

TABLE 10: A Sample of the Final Summary Table

(**Key** P1 = participant 1, whilst 2.53 refers to page 2, line 53)

HOPES AND EXPECTATIONS

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Clinical consultation	2.53	2.46	---	3.105	8.283	2.50	3.92	---	---	3.88
Professional support	2.66	3.78	5.181	4.133	3.89	3.78	---	13.455	4.125	2.58
Communication/feedback	12.432	15.535	17.615	---	8.284	13.456	---	12.405	13.451	11.396
Multi-disciplinary working	2.59	2.43	17.613	---	1.27	2.73	---	8.261	13.471	4.142
Availability	3.92	2.55	---	---	3.83	2.46	---	7.240	---	---
Professional position	---	13.454	5.163	---	3.76	2.54	11.389	11.377	6.187	5.152
Unknowns	13.455	13.457	---	---	---	3.92	3.85	---	16.575	12.407

BELIEFS ABOUT THE ROLE

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Secretive/mysterious	14.480	12.448	---	---	7.223	10.368	4.130	---	11.393	6.200
Effecting psychological change	13.471	5.173	---	---	5.181	10.352	2.39	---	11.402	3.106
Emotional exploration	13.467	---	4.114	11.403	---	---	---	9.306	1.36	---
Structured approach	14.484	5.171	4.122	13.446	6.196	10.365	5.150	8.280	---	6.204

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Knowing limits	13.474	5.176	3.105	1.12	1.17	---	1.19	2.51	7.246	6.207
Offering support	7.249	7.258	1.15	8.271	2.51	---	1.15	6.221	6.206	7.231
Managing time	7.247	1.25	16.590	8.281	---	7.235	---	---	13.462	4.126
Independent working	---	11.405	4.137	5.167	13.447	---	2.56	1.29	14.483	---
Having knowledge	2.57	9.329	4.128	---	---	---	12.428	1.30	1.28	6.205
Information sharing	---	---	8.279	---	10.349	---	11.391	1.20	---	---

3.2 REFLECTIONS ON THE ANALYSIS PROCESS

Input from the independent judges and my own supervisor led me to reflect on why it was that in analysing the data I had demonstrated a tendency to minimise the emotional/psychological content and highlight the more factual/practical findings. The time and consideration afforded to me by personal reflection helped me to identify a number of factors which I felt were likely to have contributed to this.

Looking back on the process of interviewing the CNSs, my main observation had been that a number of them had been resistant to exploring the emotional content of their experience, and although emotions were present, they were often hidden and subtle in nature. During many of the interviews, I had detected a sense that the participants perceived emotional discussion to be somehow risky and unsafe, meaning they tended to gravitate towards the more familiar and safe territory of factual/practical topics. Reflecting on this helped me to see that the approach I had taken with the data analysis was in fact a direct reflection of this; just as the CNSs had wanted to keep their emotions hidden, I had wanted to keep the emotional findings hidden behind the factual and practical content. There was however a tension in this realisation, for although I was anxious to avoid dismissing any emotional findings, I was equally keen to present the data in a true and accurate fashion, and with the CNSs tending towards factual dialogue, I needed to ensure this was captured. Overall however, I felt my anxiety to ensure accuracy had overpowered my ability to give equal consideration to the factual and emotional dimensions of the data.

I also reflected on the influence my own experiences may have had on the process of analysis and wondered whether the years I had spent working as a cancer psychologist may have left me defended against the emotional impact of such work, leaving me unwilling or maybe even unable to identify the emotions the participants were expressing. With emotional distancing well recognised as a self-protective strategy utilised by professionals working with those affected by life-threatening illness (Firestone, 1994 cited in Kalus, 2003), I was led to question whether my seeming reluctance to connect fully with the participants' emotions was an attempt to protect myself from my own emotions. Linked to the idea of emotions being perceived as 'risky', was also the possibility that I was in some way trying to protect the nurses and felt that by minimising the emotional content, I was reducing the chance of them feeling exposed. I was certainly aware of feeling anxious about how the findings would impact on them, and on reflection wondered if by presenting them in a more factual light, I was hoping to avoid causing any discomfort.

This process of reflection helped me enormously in identifying the factors which had influenced my original decisions with regard to data analysis. Having gained this insight, I felt able to return to the data set with a greater ability to recognise and consider the emotional content, thus ensuring the findings were a more accurate reflection of the participants' experiences.

CHAPTER 4

Findings and Discussion

4.1 OVERVIEW

During this section, each master theme identified during the process of analysis will be presented and discussed in terms of dimension and range, with quotations from the source material being used for purposes of elucidation. Quotes will be referenced to individual participants; for example, P1 denotes participant number one and for maximum transparency, the line number(s) from each transcript will also be included in the reference. The overall aim of this section is to translate the themes identified during the analysis phase into a narrative account, thereby providing a description of the nature and quality of the participants' experiences of the phenomena under investigation (Willig, 2001). During this section occasional reference is made to individual participants, for example the area of speciality in which they work may be posited as being relevant to a particular finding. However overall, individual interpretations have not been made as any individual analysis would be based on a total paucity of information, so although it may be tempting to consider factors such as years of experience or age, it was felt this would be meaningless as the range of reasons for any one finding extends far beyond the demographic information available.

Throughout this section, care will be taken to make clear the distinction between comments made by participants and my own interpretation of these comments. For convenience and ease of reading, the findings have been divided into three sections. However this division is artificial, as close relationships exist between all the themes. The first section is comprised of master themes, which include findings about the profession of psychology. Section two consists of those master themes which include findings about assessing for distress, and finally, findings about clinical nurse specialists comprise section three. Each master theme is followed by a discussion section, during which due consideration will be given to the themes in relation to other relevant literature. Possible areas for further research will also be identified and proposed throughout this chapter. Each section of findings concludes with consideration of the relevant reflective and reflexive issues. For purposes of transparency and in order to orientate the reader to the content of this chapter, all twelve master themes along with their sub-themes are presented in Table 11.

TABLE 11: Final Master Themes with Associated Sub-Themes

FEELINGS ABOUT PSYCHOLOGY/ PSYCHOLOGISTS
Open/positive
Acceptability
Fear/threat
Generational
Inaccessible

BELIEFS ABOUT THE ROLE
Structured approach
Emotional exploration
Effecting psychological change
Secretive/mysterious

PERCEIVED QUALITIES
Specialist training
Knowledge

HOPES AND EXPECTATIONS
Clinical consultation
Communication/feedback
Support
Multi-disciplinary working
Professional position
Availability
Unknowns

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST
Knowing limits
Offering support
Managing time
Having knowledge
Independent working
Information sharing

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS
Working with death/illness/loss
Expectations
Lack of support
Understanding
Time pressure
Team working

COPING WITH BEING A CNS
Colleague support
Boundaries

WAYS OF ASSESSING FOR DISTRESS
Intuition
Emotional discomfort
Feeling stuck
Style/approach
Communication skills
Time
Role of others

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES
Confidence
Awareness of language

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE
Experience
Reflective practice
Colleagues
Training

SIGNS OF DISTRESS
Depression
Anxiety
Adjustment/coping issues
Complex issues
Family/relationship issues
Treatment issues
Key point in pathway

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS
Understanding role
Skills/knowledge

SECTION ONE:
FINDINGS RELATING TO THE PROFESSION OF PSYCHOLOGY

4.2 MASTER THEME: FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

This first master theme is concerned with describing the participants' perceptions of, and feelings about psychologists and the profession of psychology in general. Their resulting accounts clustered around five sub-themes: 'open/positive', 'acceptability', 'fear/threat', 'generational' and 'inaccessible'. Each will be considered and explored in turn.

4.2.1 Sub-theme: Open/positive

Many of the participants spoke in very open and positive terms about psychology, conveying a sense of feeling that having a psychologist present in their clinical settings would be a useful and helpful addition both in terms of patient care and support for themselves.

"Overall I think it would definitely be good to have one. It could only be a good thing. It would be useful for patients and for me" (P9, 19-20).

These participants also went on to speak in equally positive terms about the way they felt the profession was perceived within the wider public context,

"I think psychology in general is very popular. It's in every magazine you pick up. It's certainly a lot more accessible and I don't think there is any embarrassment about it. It's very much part of our world now, todays world. People are much more aware of it and feel positive about it" (P3, 503-506).

4.2.2 Sub-theme: Acceptability

A number went on to state they felt the profession had over time gained favour and was now deemed to be more acceptable than it had been in the past. This was particularly felt to be the case when viewed in relation to psychiatry, with all of the participants feeling that psychology carried far less stigma. When comparing the two professions, psychology consistently emerged as having a more positive association, being described as less threatening and consequently more acceptable. Psychiatry was described as a profession which continued to be feared due to its strong associations with serious mental health problems. In contrast psychology was perceived to be less about mental illness and more about supporting patients through challenging life experiences. The following quotes capture the feelings of a number of the participants on this topic:

"Well the image you get with psychiatry is everyone lying flat out, drugged and out of it. It's the first thing that comes into mine, and probably most people's minds. I certainly think a psychologist is viewed differently. There is much less stigma attached and it's not so much about madness" (P1, 788-791).

"Having cancer does not send people mad, but it does mean they have a lot on their shoulders. I don't view their distress as mental health difficulties, it is different and in actual fact, it means their distress is more acceptable, more normal. It is just the same with psychologists in cancer and haematology settings, they definitely carry far less stigma than psychiatrists. They are acceptable and normal and not really about mental health, but about helping people cope with challenges" (P4, 468-474).

I was struck by the use of the words 'mad' and 'madness', and detected fear and defensiveness in both these statements. Although the participants did not label these emotions, I felt they were clearly illustrated by their seeming desire to normalise emotional distress and make clear the distinction between the sorts of emotional difficulties experienced by cancer patients, and those experienced by mental health patients. I sensed that behind their comments the participants were in some way looking for reassurance, and I wondered if they were hoping I might substantiate their views that psychology was not associated with mental illness. Overall, I was left feeling that the participants had revealed something of their own anxiety about the meaning they gave to mental health problems.

4.2.3 Sub-theme: Fear/threat

In contrast to these generally positive appraisals of psychology, a number of participants described the profession in much more negative terms describing it as a profession which carried negative connotations and was associated with fear and threat:

"I think there's still a label attached to seeing a psychologist. You are viewed as a failure, you're failing, you're mentally unbalanced and that's why you need a psychologist" (P1, 744-746).

"I think there is a patient and public perception of psychologists. People are scared of them because they analyse people and might go to places that are uncomfortable or that they are frightened of" (P8, 240-243).

I felt these comments perhaps offered insight into the participants' more personal beliefs about psychology, and revealed something of their own anxiety about what it meant to not cope or need psychological help. Behind these words I again detected unlabelled emotions, particularly fear and apprehension. I was left wondering how comfortable and confident they would feel about discussing psychological issues with patients.

Another participant described feeling threatened by psychology in a different way, revealing a much more professionally based anxiety:

"The idea of a psychologist here all the time makes me feel worried and I suppose a bit jealous because I enjoy looking after the psychological health of my patients. It's a central part of my role and why I do this job. It's the bit that is most satisfying. I suppose it is because there is overlap between the two professions, in fact an increasing amount of overlap and I suppose sometimes that is a happy condition, and sometimes it is not and causes friction. So I suppose I might be a bit jealous and wary of having someone come in and take something away from me, something that is important, it is not a comfortable thought (P10, 89-97).

This comment revealed a very real concern about the potential for loss of role and job satisfaction and conveyed a clear sense of the professional threat posed by psychologists. It also raised the issue of professional boundaries, along with the question of who is best qualified to do what. I was struck by the openness and honesty of this particular participant, but unfortunately felt unprepared for her comment and unsure how to manage it. Sadly, due to my own discomfort I failed to pursue the issue or feelings further.

4.2.4. Sub-theme: Generational

During these discussions, feelings about the role that generational difference played in the perceptions of psychology became apparent. A number of participants identified age as an important factor in determining attitude and reported feeling a strong sense that psychology was more keenly understood and embraced by those of a younger age.

"I think it's a generational thing really, it obviously depends who you are, but the older generation, I think feel that any type of talking therapy or analysing of feelings and what have you is not really useful or productive. I don't' think they welcome it and probably think it is a load of old clap trap. I think the younger generation are much more up for it and us in the middle are probably not quite certain one way or another" (P10, 371-375).

I felt this, along with other comments about age again revealed something of the participants' own feelings about psychology. I began to detect a sense of ambivalence and wondered if the reference to psychology being 'unwelcome and a load of old clap trap', was actually an expression of the participant's own feelings about the profession.

4.2.5 Sub-theme: Inaccessible

The final sub-theme to be considered is that of 'inaccessible' which relates to comments made by half of the participants about feeling that psychologists and psychology in general were largely an unknown quantity, poorly understood both by the public and professionals and a profession that they felt was largely inaccessible to them:

"I think psychology is all a bit of a myth in this country, because I think not many people have access to it, and there is just no way of knowing what it is really about, and so it is based on myths, and even with me, I've already said I don't really know anything about it" (P2, 441-444).

The tone used by this participant communicated a sense of acceptance and resignation that gaining insight and understanding about the world of psychology was an impossible task. I was left with a growing sense that the participants perceived the profession as wholly inaccessible and to a degree excluding.

4.3 DISCUSSION

These particular findings reveal the existence of a diverse range of feelings about the profession of psychology, with some participants conveying very positive associations, and others expressing more negative opinions based on perceptions of threat and inaccessibility. Although no specific literature exists examining perceptions of cancer psychologists, other related research has found that just as in this study, psychology is a profession which generates an array of opinions and feelings.
The more positive feelings described by some of the participants have also been identified by others. Farrell *et al.* (2005) conducted a study which explored teachers' perceptions of educational psychologists and found that overall, teachers reported feeling very positive about the role played by these psychologists, valued their work highly and felt keen that greater numbers of them were employed. LeCroy and Stinson's (2004) study about the public's perception of social work involved asking a random sample of 386 people their views about social work, along with a number of other helping professions including psychology. The results showed that out of all the helping professions, psychologists were the profession most frequently named as being 'very effective' in dealing with issues of addiction, child abuse, sexual abuse, marital/relationship problems and childhood behavioural problems. They were also cited as the profession that respondents would be most likely to seek help from, second only to medical doctors. In terms of the perceptions held about mental health professionals in general, Sydow and Reimer (1998) conducted a systematic content analysis of sixty studies on attitudes toward, and stereotypes of, psychotherapists, psychologists, psychiatrists and psychoanalysts. In their analysis of standardised questionnaire studies they found that the reputation of mental health professionals was in the main, evaluated highly by the public.

The participants' perception that psychology is a profession which has gained in acceptability, particularly when compared to psychiatry, is also reflected in the wider literature. The work conducted by Sydow and Reimer (1998) revealed that during the 1960s, psychology and psychiatry were viewed as interchangeable. However over time knowledge about psychology has gradually increased meaning that two distinct attitudes about the two professions have emerged. More recent research shows that psychology is primarily viewed as being related to counselling, research, diagnostics and work with children and just as in this study, is a profession associated with less serious mental health problems. In contrast, and again as identified in this study, psychiatrists have become synonymous with more serious mental health problems, and are perceived as using predominantly psychoanalysis, medication and electro-convulsive therapy (ECT) in their attempts to cure serious mental health disorders such as schizophrenia (Tallent and Reiss, 1959; Murray, 1962; Thumin and Zebelman, 1967; Folkins, *et al.*, 1981; Sharpley, 1986; Wood *et al.*, 1986; Walter, 1992 cited in Sydow and Reimer, 1998). Unfortunately, despite some positive evaluations of psychiatry, as illustrated by the data in this study, it is a profession which continues to be dogged by scepticism and negativity. Cinematic depictions of psychiatrists, which can affect both public opinion as well as patient/physician relationships, commonly show psychiatrists to be controlling, ineffective, dangerous and even brutal (Shortland, 1987; Dudley, 1994). Flores (2002) reports that in about one third of all films in which a psychiatrist is the main character, sexual intercourse with their patient(s) is a common feature. Films have also been found to consistently portray the non-psychotherapeutic treatment methods including ECT, psychoactive drugs and psychosurgery in a very negative style (Schneider, 1977 cited in Sydow and Reimer, 1998). Finally, from a linguistic perspective, slang appellations including head-shrink, shrink and nut-doctor continue to dominate and act to enforce the negative stereotype of psychiatry and psychiatrists (Walter, 1991).

The feelings of fear and threat described by some of the participants in this study are also well documented in other literature. The studies analysed by Sydow and Reimer (1998) in their systematic review revealed that fear of mental health professionals (including psychologists) was commonplace amongst the general population. Speculations about the cause of this fear have been offered by many. Davidson, (1964) hypothesised that it was simply a projection of the public's fear of mental illness, meaning that mental health workers became 'infected' with a negative image. However more recently other theories have been presented. One particularly persuasive argument is based on the fact that the main means of making a mental health diagnosis are through observation, listening and talking. Thus theoretically, the perception of psychologists is that they are always able to make mental health diagnoses, regardless of whether this is requested or not, thus leaving people feeling exposed, fearful and threatened and perhaps understandably defensive (Sydow and Reimer, 1998).

Whilst no literature exists examining the role that age plays in perceptions of psychology, the influence of age on psychological adjustment to cancer has been the focus of some research, and the subsequent findings may go some way to explain the generational differences perceived by the participants in this study. It has now been clearly demonstrated that significantly higher levels of psychological morbidity exist amongst younger cancer patients, with patients aged below 50 years experiencing the most distress, and those aged 70 years and over experiencing the least (Edlund and Sneed, 1989; Noyes *et al.*, 1990; Jarrett *et al.*, 1991 cited in Harrison and Maguire, 1995). This finding poses the question of whether the participants' perceived resistance of the older generation to psychology and psychological interventions is actually more a reflection of older patients just not having such a need for psychological input, rather than it being about them holding negative perceptions about the profession. Further research into this area would be valuable in order to establish whether age does influence perceptions about the value of psychological interventions, and if so whether this means older patients are coping with untreated distress due to fears about accessing specialist services.

4.4 MASTER THEME: BELIEFS ABOUT THE ROLE

This master theme is concerned with the participants' beliefs about what psychologists do clinically with patients. Their accounts clustered around four sub-themes: 'structured approach', 'emotional exploration', 'effecting psychological change' and 'secretive/mysterious'. The first two sub-themes to be considered, structured approach and emotional exploration, were identified by the participants as the therapeutic approaches they would most expect a psychologist to be adopting in their work with cancer and/or palliative care patients. These themes are therefore linked together by a belief that they represent more formalised and established methods of working psychologically.

4.4.1 Sub-theme: Structured approach

Of the ten participants, nine identified a structured problem-solving approach involving the use of specific interventions and strategies as the style they would most expect a psychologist to adopt with patients:

"I would expect them to work in a very structured way, and probably use all sorts of techniques and strategies to help people cope and feel better. They will have a clear plan in their mind about what they need to do in order to solve the problem" (P2, 171-174).

Most of the participants referred to a structured approach in very general terms, with limited ability to elaborate on what was actually involved in this type of therapeutic work. That said, two did describe having a clear expectation that a psychologist working with cancer patients should be predominantly using cognitive behavioural therapy,

"I would expect a psychologist to know all about, and use cognitive behavioural therapy and therefore use cognitive and behavioural techniques to improve or manage a situation". (P6, 364-367).

Whilst the use of interventions and strategies were the most commonly cited features of a structured approach, two participants identified time boundaries as being an important and distinguishing characteristic of this type of therapeutic work:

"I know it's structured work, so that means there will be a time limit. The sessions will probably be about 45 minutes, and they will only have something like 6 sessions. If it's structured it means there must be parameters in place" (P8, 280-282).

4.4.2 Sub-theme: Emotional exploration

In addition to structured interventions, half of the participants identified emotional exploration as a separate but important part of a psychologist's clinical remit and something they would expect to form part of their therapeutic work with patients. This hope was based on a view that emotional exploration was the most effective way of identifying the ultimate cause of a patient's distress. However the process of engaging in emotional dialogue with a patient was not described as being a distinct therapeutic approach in its own right:

"They would delve far more and explore the emotional side of things and find out what the patient is really struggling with, get to the root of the problem" (P9, 34-36).

4.4.3 Sub-theme: Effecting psychological change

'Effecting psychological change', the next sub-theme to be considered, refers to the expectations held by the participants about the possible impact that psychological interventions could have on patients. Half of them described feeling that through their use of specialist interventions, psychologists could effect some form of psychological change in patients, either in terms of behaviour or thoughts. Such change was perceived to be desirable because it was believed that in turn it would impact positively on a patient's capacity to cope and ultimately improve their quality of life. The following quotes capture thoughts expressed by many of the participants:

"A psychologist could help them change how they view it all, move them on and help them to think differently. That would help them cope better, it's about coping and getting their lives back, getting on with their lives is what it's about" (P7, 37-39).

"I'm hoping that behind the doors, psychologists get them to face the facts about the reality of their situation, help them to adjust and make changes, because they are going have to try and live with this, so I suppose bring them round to a state of thinking that it's alright to feel like this but you can live as well (P7, 141-145).

4.4.4 Sub-theme: Secretive/mysterious

Despite this range of fairly formed and concrete ideas about a psychologist's clinical role, the final sub-theme 'secretive/mysterious' reveals something rather different. During the interviews, ongoing discussion about the topic resulted in seven of the participants stating that although they had a superficial sense of what a psychologist did with patients, in truth their knowledge was actually very limited, leaving them feeling unclear, uninformed and with a perception that psychologists' clinical work was to a large degree hidden and shrouded in secrecy and mystery:

"I don't actually really know what psychologists do with patients when they see them, the truth is, it feels quite secretive, yeah, secretive, as though I shouldn't know" (P2, 445-447).

The tone used by this participant conveyed a strong sense of embarrassment, as though she felt she had been caught out and needed to confess to her lack of knowledge. I also sensed that behind this statement there lay feelings of exclusion and possibly even rejection. For other participants, the sense of secrecy and mystery seemed to generate different emotions:

"I don't really know what they do, I don't know how they help people, it's a bit of an unknown quantity to me. If I don't know that, then how can I be expected to use them properly? It's not possible, it's like wandering around in the dark" (P5, 228-231).

In this case feelings of frustration, anger and irritation were clearly present, and from the participant's body language and verbal tone it was clear these emotions were aimed directly me. Behind these more obvious emotions, I again detected feelings of exclusion and a sense that the participant felt psychologists purposefully withheld information that she needed in order to feel competent and confident in her own professional role.

4.5 DISCUSSION

The identification of structured interventions, (particularly CBT) to be the therapeutic approach the participants would most expect a psychologist to use is reflected by a substantial body of literature which endorses this style of working. The National Institute for Clinical Excellence (NICE) guidelines for treating depression recommend CBT as the treatment of choice for the management of mild to moderate depression (NICE, 2004b), whilst the guidelines for anxiety recommend CBT as the treatment of choice for generalised anxiety and panic disorder (NICE, 2004c). There is also evidence suggesting that CBT is beneficial in the treatment of eating disorders

(Hollon, 1998), chronic pain (Holtom and Barraclough, 2000) and insomnia (Montgomery and Dennis, 2004). This evidence, coupled with the practicalities of working within the NHS where therapies tend to be time limited, means CBT is often the model of choice and increasingly psychologists are expected to practice in a structured and time-limited fashion (McCleod, 1993).

With regard to cancer patients, there is also growing evidence that CBT is an effective way of managing psychological distress (Greer, et al., 1992; Moorey *et al.*, 1998; White, 2001; Moorey and Greer, 2002; Greer, 2002; Levesque *et al.*, 2004; NICE, 2004a; Tatrow and Montgomery, 2006). Clark *et al.* (2003) report that both group and individual psychological interventions, which are structured in nature, appear to be more effective at reducing levels of distress in those with cancer than interventions which are open-ended and without clear structure. Cognitive-behavioural interventions have also been found to reduce depressive symptoms in patients with advanced disease who are suffering from mild to moderate depression (Massie and Holland, 1990). Redd *et al.* (2001) undertook a review of the literature pertaining to psychological interventions in cancer patients and concluded that behavioural interventions were particularly effective for those experiencing treatment related distress. They found evidence that this style of therapy helped to control anticipatory nausea and vomiting (both in adults and children) and was effective in reducing anxiety associated with invasive medical procedures. Relaxation techniques and positive imagery were also found to have a positive effect on pain levels.

In light of this evidence base, the teaching of CBT techniques to non-mental health cancer professionals is increasingly being viewed as a legitimate and effective means of managing patients' distress. Mannix *et al.* (2006) trained 20 palliative care nurses in the use of CBT skills and consequently found they were able to challenge distorted thinking, encourage self-reflection and assist patients in changing behaviours which allowed them to gain a better sense of control. More recently Moorey *et al.* (2008) trained a team of palliative homecare CNSs to deliver basic CBT techniques as part of their everyday practice and found this impacted positively on levels of patient anxiety. Anderson *et al.* (2008) also demonstrated a positive effect and found that palliative care professionals trained in basic CBT skills could usefully apply these techniques to patients suffering from mild-moderate anxiety or depression. The question of how much supervision is required for these staff to maintain their skills is however far from clear and neither is it known whether these skills are maintained over time. The issue of sustainability is therefore a potentially important area in which further research is required.

In contrast, the emotional exploration identified by many of the participants as a way of working with cancer patients is much more akin to a person-centred model of counselling, which relies on the building of rapport through the use of the core conditions of empathy, genuineness and unconditional positive regard (Rogers, 1957 cited in Burton and Watson, 2000). The therapeutic relationship is central and as Kalus (2003) states, "the key is in the notion that everything one is hoping to achieve with a client happens within the interaction or relationship that one is trying to develop or maintain" (p.180). Supportive counselling which encourages emotional ventilation is certainly recognised as being useful in the context of cancer and/or palliative care (Burton and Watson, 2000; Barraclough, 2000; Carlson and Bultz, 2004). However at the current time, with the evidence base growing in favour of more structured models of work there appears to be a shift away from this more person-centred approach.

Despite this growing trend towards the delivery of structured approaches, a closer look at the literature reveals a distinct lack of clarity about which type of psychological therapy is in fact most effective. Marriott and Kellert (2009) compared cognitive analytic therapy with both person-centred and cognitive behavioural therapies and found all three approaches to be effective and equivalent, with little difference between the outcomes. Newell *et al's* (2002) systematic review of psychological therapies for cancer patients found that group therapy, education, CBT and unstructured counselling all showed potential benefits for many of the psychosocial outcomes explored. Not all studies have found CBT to be effective with cancer patients. Moynihan *et al.* (1998) conducted a randomised controlled trial evaluating CBT in patients with testicular cancer and found no difference in outcome between participants and non-participants, concluding that patients gained little benefit from this type of therapy. Finally, a satisfaction survey conducted by Kalus (2001) revealed that both the bereaved and those with cancer reported that being listened to, and being able to express thoughts and emotions in a safe environment was of particular value to them. This raises the question of whether the current evidence base which appears to favour CBT above all else is actually more a reflection of a desire by professionals to offer explanations about what works, rather than representative of what patients themselves want and find most helpful (Smail, 1996 cited in Kalus, 2003). It also brings into the frame the question about how best to conduct research in this field and although randomised control trials have until now been the design of preference, it may be that gaining a more detailed understanding about therapeutic interventions could be better achieved through the use of more qualitative methods (Bromley, 1986; Reason and Rowan, 1998 cited in Kalus, 2003).

The participants' expectations that intervention from a psychologist would result in some form of change is certainly in line with much of the psychotherapeutic literature. Facilitating change is considered to be an important and central aspect of most types of therapy (Feltham and Horton, 2000) and this is no different within the context of cancer and palliative care. Kalus (2003) identifies the therapeutic process as having the capacity to lead to two types of change. Firstly, the sort which occurs on a more fundamental level and can lead to greater self-awareness and insight, and secondly, change which occurs on a more behavioural level and can include helping patients find alternative ways of dealing with the difficulties associated with invasive medical procedures, treatment side-effects and phobias which can prevent treatment adherence. In terms of the overall impact of such changes, as identified by the participants in this study extensive evidence now exists to indicate that psychological interventions are often efficacious in decreasing distress and improving patients' coping abilities and quality of life (Carlson and Bultz, 2004).

Although the participants' perceptions of psychologists being mysterious and secretive is not found in any other literature, aspects of the finding do bear some similarities to a study conducted by Lewis and Bor (1998). They examined how counselling psychologists were perceived by senior managerial NHS clinical psychologists and found that the clinical psychologists felt very unclear about the skill-set, training and potential remit of counselling psychologists, leading to feelings of confusion. Similarly, in Farrell *et al.*'s (2005) study a significant discrepancy was found to exist between teachers' expectations of the role of educational psychologists and the role itself, leading in some cases to teachers expressing feelings of frustration and wariness about psychologists. Although not strongly evidenced in the literature, anecdotally psychology is a profession commonly associated with mystery and secrecy. Kalus (2003) offers a useful perspective on this, recognising that historically psychologists may have hidden "behind the mystique of being a blank screen, onto which the client can project their innermost thoughts and feelings" (p. 189). She goes on to suggest that reducing this sense of mystique is something from which the profession could potentially benefit.

4.6 MASTER THEME: PERCEIVED QUALITIES

Whilst sharing their beliefs about the role of psychologists, various ideas emerged relating to the specific qualities the participants perceived a psychologist working in the field of cancer and/or palliative care should possess. These ideas clustered around two sub-themes; 'specialist training' and 'knowledge'.

4.6.1 Sub-theme: Specialist training

Specialist training was identified by six of the participants as an essential and assumed quality to being a psychologist, and whilst there was a lack of clarity about what exactly this involved, there was a common and shared belief that whatever the training route for psychologists, it was challenging in nature and required a certain level of academic ability,

"I don't know exactly what training they have, but from the little I know, it is a long, training which is hard to stick with. I just think they are clever and clearly academic." (P7, 111-113).

"I think they have a first degree in anything, then go on to do a psychology degree or something sort of similar, then their clinicals at masters level and clinical practice so they have caseloads, and they do doctorates and whatever. I would expect them to have done that to work in the NHS" (P8, 357-360).

For one participant, the discussion about psychology training led her to reveal her feelings about the implications of this in terms of hierarchy and status:

"I would consider a psychologist to be far more clinical and able than myself. If I was looking at a job plan now, I would put a psychologist higher than what I am" (P7, 107 108).

The tone of this comment, combined with the participant's non-verbal communication, conveyed feelings of low self-esteem and poor confidence. I wondered if she was accustomed to perceiving others (not just psychologists) as superior to her and felt her comment revealed something about the hierarchical world in which she existed. I also sensed she felt resigned to a situation in which status was purely dependant on academic achievement rather than a reflection of experience or skill.

4.6.2 Sub-theme: Knowledge

In addition to specialist training, there was also a clear expectation from the participants that a psychologist should have an extensive range of knowledge in order to work in a cancer or palliative care setting. Whilst this included specific psychological knowledge, there was also an expectation that a psychologist would have medical knowledge. This was described by some as being an essential requirement in order to work effectively with this patient group. The following quotes capture the feelings of these participants:

"I think also that if a psychologist is working in a cancer setting, they need to know about the disease and its treatments – it is important. I suppose a diploma level at least" (P8, 360-362).

"You would need to understand the medical side, the treatments, the terminology, the ins and outs of cancer really. People say that getting recurrence is worse than the original diagnosis, so if a psychologist doesn't understand about recurrence then it would be pretty difficult for them to help anyone (P6, 384-387).

4.7 DISCUSSION

The participants' perceptions of psychologists having specialist level training are certainly in line with the training requirements for applied psychologists in the United Kingdom. At the current time, in order for psychologists (clinical and counselling) to obtain a practising certificate they must have completed an undergraduate degree in psychology, followed by a further three years of post-graduate academic/professional training, which combines clinical placements, research and training in a range of clinical skills and therapeutic approaches (Payne and Haines, 2002b; Kalus, 2003). With scientific method and enquiry underpinning their clinical practice, psychologists are often referred to as scientist-practitioners, meaning they are applied behavioural and social scientists with a clinical role. In addition to these practice-based skills, they are also trained in the organisational aspects of services, meaning they are well placed to offer support and consultancy whilst also being able to contribute to service development and education (Payne and Haines, 2002b). The academic style of the training, which includes research skills, methods and application is referred to by Kalus (2003) as being what distinguishes psychologists from both counsellors and psychotherapists, whilst Payne and Haines (2002b) state that "their distinctiveness stems from their training" (p.403). Although scarce, the little literature that does exist about cancer psychologists suggests that their level of training affords them expert status particularly in relation to the delivery of psychological interventions; "psychologists are the only NHS clinicians who receive systematic and regulated training in devising and providing tailored, structured and comprehensive psychological interventions. They are therefore uniquely qualified to take the lead in the widespread implementation of psychological therapies for people with cancer" (Clinical Psychology Workforce Planning Group, 2002, p.9).

Again in line with the participants' views about knowledge, the British Psychological Society's document, The Role of Psychology in End of Life Care (2008) makes clear recommendations about the sort of additional knowledge that psychologists working in palliative care should possess. In particular it is suggested that additional training in bereavement, grief, medical treatments/surgery, working with life limiting illness and pain management theory/techniques should be sought by any psychologist planning to take up a post in the field, particularly if they have no previous experience of the speciality.

4.8 MASTER THEME: HOPES AND EXPECTATIONS

During the course of the interviews, all the participants shared their hopes/ideas about what a psychologist would ideally provide for them. Their subsequent accounts clustered around seven sub-themes: 'clinical consultation', 'communication/feedback', 'support', 'multi-disciplinary working', 'professional position', 'availability' and 'unknowns'. The first three of these to be considered are clinical consultation, communication/feedback and support, which the participants identified as those things which would be of particular value in assisting them in their own work. These three sub-themes are therefore linked together by a belief that access to them would have a positive impact on the day-to-day experience of being a CNS.

4.8.1 Sub-theme: Clinical consultation

Many of the participants identified clinical consultation as particularly important and something they hoped would be offered by a psychologist. Six of them made reference to this very early during the interview process, describing it as something that would be valuable and beneficial in terms of aiding them in their own clinical practice. The following quote captures the hopes shared by these participants:

"I would hope .... hope they would be someone I could go to and talk through a patient or a family with and I'd hope they would then, give me ideas, perhaps come up with a plan with me, a plan of action" (P1, 52-54).

Implicit in this hope appeared to be an expectation that for clinical consultation to be of value, a psychologist would need to have both the necessary knowledge level as well as the ability to convey and share knowledge in such a way that would be applicable and of value to the CNSs in their various clinical settings,

"They would be a good source of knowledge, 'cos they don't always need to see the patients, we could pick their brains, they could tell us what we need to do, and we could then go off and apply it" (P4, 96-98).

4.8.2 Sub-theme: Communication/feedback

All but two of the participants identified 'communication/feedback' as something they would value receiving from a psychologist. One of the most commonly cited reasons for this was a desire to be kept informed about any clinical work a psychologist might undertake with their patients. Some participants also identified it as having an educational component, viewing it as a means of learning and developing their skills:

"I would like them to communicate with me about what they are doing, because it helps you get a broader sense of knowledge and understanding about individual patients they are working with, and equally some of the feedback you can utilise in your own practice, it maybe opens something that you weren't aware of, or hadn't considered. It's a form of ongoing education really, so that is why I would like it" (P8, 406-410).

In terms of the specific educational value of feedback, a number of the participants reported feeling that it would be particularly valuable in terms of gaining a better understanding about referral suitability, describing it as a potentially effective way of helping them evaluate and reflect on their own referral decisions,

"I would want to know whether the referral was felt to be a good one or not. Getting something back from the psychologist, written or verbal would really help me with that" (P10, 398-400).

I felt these comments conveyed a real sense of openness and a clear desire to work collaboratively with a psychologist. I also felt they illustrated an awareness of the differences between the two professions and a keenness to work in a multi-professional capacity in order to provide high quality patient care.

4.8.3 Sub-theme: Support

Support was identified by all but one of the participants as something they hoped a psychologist would provide for them. This was described in very different terms to that of clinical consultation, with the emphasis on 'being listened to', rather than receiving guidance or advice. The following quotations offer illustrations of this and capture the feelings of many of the participants:

"I would certainly hope a psychologist would offer some support, just to know there is somewhere safe to go, to talk, just to share stuff and offload a bit. We deal with some hard things in this job, to have someone listen would be amazing" (P4, 122-124).

"They don't need to have the answers. Just to be listened to. To have that opportunity would be very supportive in itself" (P9, 124-126).

The participants' comments about wanting support suggested that many felt heavily burdened with unprocessed emotions and although unspoken, I detected strong feelings of vulnerability, isolation and loneliness. However, despite them voicing a clear desire for support, many described feeling very unsure about how this could be most effectively offered and delivered. This added to my sense of their vulnerability and brought to mind the issue of safety and I began to wonder if their struggle to articulate what they needed on a practical level was more a reflection of feeling uncertain about what constituted adequate emotional safety.

A few suggestions were made by some of the participants, ranging from one to one support through to formalised group supervision. These were however always counterbalanced with comments about feeling unsure about how such formats might work in practice. The following quote is an illustration of this:

"Having some sort of support for us nurses would be great, but I have no idea how that works. I have no experience of it and wouldn't know where to start, either in terms of format or content. I don't know the first thing about it" (P5, 87-90).

A small number did describe having past experiences of receiving support and of those, group supervision was generally deemed to be the most useful. The reason for this lay in the fact that a group format allowed for experiences to be shared, thereby reducing feelings of isolation and providing reassurance and normalisation:

"I've had group supervision before and it's about being able to share stuff really, to know others worry about the same things and to know that actually you are doing ok.

Knowing you aren't the only one who finds things hard helps a lot. It's reassuring." (P4, 132-134).

The next three sub-themes to be discussed, those of 'multi-professional working', 'professional position' and 'availability' relate to the participants hopes about how a psychologist would function within the context of an organisation and what sort of approach they would adopt. These hopes were again linked to what the participants felt would be the most supportive in terms of enhancing their own working practice.

4.8.4 Sub-theme: Multi-disciplinary working

Many of the participants identified multi-disciplinary working as an approach they hoped a psychologist working in such a setting would adopt and actively promote. For some, the reason for this was bound up in feelings of it being the most efficient and effective way of delivering good care to patients,

"I would really hope that they would be joining in the life of the various teams, so you know, attendance at multi-disciplinary meetings and things. I would hope they would value that way of working as it benefits us and of course the patient. It's when you are discussing situations and sometimes it hasn't occurred to you that there is a different way of managing or going forward with a family or whatever, so a multi-team approach would be vital" (P10, 142-147).

Two described a very different reason for wanting a multi-professional approach, instead expressing hopes that a psychologist's presence and contribution at multi-disciplinary team meetings would be an effective way of challenging and ultimately changing what they perceived to be the ongoing dominance of the medical model:

"I think the whole approach needs to change, particularly our MDT meetings. Ours are so medically led, the doctors are really the main players, they dominate the meetings and so the whole focus is on diagnosis and treatment. I can feel intimidated by it and would think very carefully before saying anything that wasn't just about the medical issues. To have a psychologist there would be interesting – the doctors

would have to listen and take notice and I think ultimately it would make it easier for people like me to say a bit more" (P9, 471-477).

Behind these words I felt various emotions were being expressed. I detected frustration, fear and anxiety, along with a sense that the hierarchy within which the participant existed left her feeling silenced and without a platform from which she felt safe to express her views or thoughts.

4.8.5 Sub-theme: Professional position

Despite a clear desire for psychology to have a strong presence at a multi-professional level, there was much less clarity amongst the participants about where a psychologist would be best placed in terms of organisational structure. Three of them felt clear that the correct professional position for a psychologist should be within the CNS team itself:

"They should be part of our team, certainly they should, that would make the most sense and would work fine" (P3, 171-172).

Others did not share this view, instead suggesting that psychology and nursing should exist separately. This appeared to be underpinned by a belief that having strong boundaries in place would make engaging with a psychologist feel safer and less threatening:

"It would just feel safer if they were separate and removed and you didn't need to see them everyday. If they were part of the team, you wouldn't want to air your real true feelings to them. It's about maintaining your professionalism with your colleagues and not wanting to lose face with them" (P4, 166-170).

I was particularly struck by this comment as it conveyed a strong sense of vulnerability and a fear of being exposed. It led me to wonder if there was a common belief amongst the participants that any sort of emotional discussion was risky and indicative of a lack of professionalism. Throughout the course of the interviews, other participants began verbalising similar feelings about struggling to cope with the expectations that others placed on them. This led to the creation of a separate theme 'expectations', which is examined in more detail in section 4.27 of this chapter.

4.8.6 Sub-theme: Availability

Availability, the final sub-theme in this particular grouping, was raised by half of the participants to be something they hoped would be given due consideration by a psychologist. Whilst all recognised it would be unrealistic for a psychologist to be available on an immediate or emergency basis, knowing how and when they could be contacted was described as something that would be important for a successful working relationship:

"I don't think you need them all the time, and it's never going to be an emergency type service, but you would need to know how to get to talk to them and when the most appropriate time for that would be" (P2, 55-57).

4.8.7 Sub-theme: Unknowns

The final sub-theme to be considered is that of 'unknowns', which relates to numerous statements made by over half the participants about feeling their understanding of the profession of psychology was full of unknowns, leaving them very unsure about what a psychologist could realistically offer. The following statement captures this particularly clearly:

"You know, I have no idea what a psychologist does or doesn't do. I can't see how I would find out 'cos there aren't any around. I am not sure how they would work or what they could achieve. I have a few ideas but I'm really not sure how accurate they are. It makes me realise that if I don't know anything about them or what they do, I wouldn't be much good at utilising them or referring on" (P7, 86-90).

4.9 DISCUSSION

The hopes expressed by many of the participants that psychologists would be directly involved in providing clinical consultation is directly in line with the literature, as consultancy has long been recognised as a key role of psychologists. For those working in cancer and palliative care settings it is considered a particularly important part of their work (Payne and Haines, 2002b; BPS, 2008). Providing consultative services to the numerous health-care staff involved in delivering patient care is deemed to not only have a supportive element, but is also believed to be helpful in terms of engaging staff in ongoing education by offering evidence-based suggestions for how they may manage challenging situations and/or presentations (Payne and Haines, 2002b).

Effective communication between professionals is increasingly recognised as being essential to the delivery of high quality patient care and is also known to have a direct impact on the well being of healthcare staff. Firth-Cozens (2001a) reports that poor communication between staff can lead to higher levels of stress and low morale, whilst Jenkins *et al.* (2001) suggest that poor communication can create confusion about role boundaries, leaving team members feeling poorly understood and isolated. Conversely, Perry and Burgess (2002) suggest that teams in which communication is open and effective are more likely to be perceived as supportive by the staff working in them. The potential for negative impact on patients is also considerable and as Brennan (2004) reports, ineffective systems of staff communication can leave patients feeling confused and lacking in confidence, whilst the staff responsible for these patients may feel unable to provide adequate care due to a lack of necessary information.

Communicating about patients' mental health is equally important and as identified by the participants in this study, mental health professionals including psychologists have a responsibility to communicate with other team members, particularly referrers, about progress in order to ensure that patients receive appropriate levels of care (Burton and Watson, 2000; Brennan, 2004). Of course the challenge of this lies in conveying the necessary information without undermining confidentiality and it is therefore the responsibility of psychologists to ensure that information sharing is done in a sensitive, professional and appropriate fashion (Brennan, 2004).

The participants' hopes that a psychologist would offer them professional support are again supported by the more general expectations of the profession found in the wider literature. Payne and Haines (2002b) clearly state that psychologists have a central role in the provision of staff support and suggest that all specialist staff should have access to regular, confidential supervision. This is further endorsed by Brennan (2004) who suggests that staff working with cancer patients may well benefit from having access to clinical supervision in order to help them manage the emotional burden of their work and develop personal resources to manage their stresses. The purpose of clinical supervision is therefore to offer staff a safe and supportive environment in which they can reflect on their skills and consider issues such as workload, style of working and pressures. It can also be an opportunity for the sharing of concerns, helping staff to learn how to work within their personal limitations and provides a chance for staff to process their emotional reactions, whilst receiving validation, support and acknowledgement for their achievements (Perry and Burgess, 2002; Brennan, 2004).

Although clinical supervision has been on the nursing agenda for some time now, it is a subject linked with uncertainty and scepticism. In 1996 despite the UKCC, (the nursing regulatory body) recommending that "all practitioners should be able to reflect on practice with a skilled facilitator to develop personally and professionally, thus promoting ongoing learning" (Howatson-Jones, 2003, p.37) it was not made mandatory, and to date the professional bodies concerned with nursing have yet to establish formal guidelines for the delivery of supervision.

Some research has identified potential benefits associated with clinical supervision within nursing. These include the creation of quality services by improving standards of care through supported reflective practice and assisting staff in their personal and professional development by helping to improve practice skills, knowledge levels and stress management skills (Butterworth, 1992; Burrow, 1995; UKCC, 1996; Lowry, 1998; Clibbens, 1999; Driscoll, 2000 cited in Lilley *et al.*, 2007). With regard to models of supervision, a number of studies have identified group supervision for nurses as an effective means of helping them manage stress-related difficulties, identify strengths and providing opportunities for sharing, learning and offloading (Houston, 1985; Kunkler and Whittick, 1991; Gardner, 1995; cited in Jones, 1999). In terms of the specific benefits for cancer nurses, Hider *et al.* (2005) found that providing clinical supervision for breast care nurses impacted positively on their levels of job satisfaction, understanding about their roles and improved job efficiency and overall well-being.

Despite these clear advantages, there is a larger body of research which has as yet failed to show how clinical supervision is best conducted, delivered or how it actually benefits clinical practice (Jones, 2006). There are ongoing questions about what factors make for an effective supervisory relationship or which model of supervision is the most appropriate for nurses. Given that nursing is comprised of numerous specialities, it may be that a single theory of supervision for nursing may be unrealistic and restrictive (Jones, 2006). Whatever the answers, without clarity in these areas, nurses continue to view clinical supervision with confusion and scepticism (Butterworth and Faugier, 1992; Faugier and Butterworth, 1994 cited in Jones, 2001). A study conducted by Walsh *et al.* (2003) found that nurses feel fundamentally uncomfortable with the hierarchical connotations of the term, and in line with the findings of this study, Jones (2006) reports that ambiguity exists throughout nursing about how supervision should be conducted.

The participants' views about the importance of working in a multi-professional fashion certainly reflect the literature, which endorses this approach above all others (WHO, 1990b; Ajemian, 1993; National Council for Hospice and Specialist Palliative Care Services, 1995; Brennan, 2004). Multi-professionalism shows an increasing acknowledgement of the role and contribution of psychology and recent government initiatives have recommended that specialist psychological services have a fundamental place in providing high quality patient care (DOH, 2000a). Whilst the role of psychologists within such teams is a relatively new phenomenon, Payne and Haines (2002b) suggest that their skill set may be of great value in assisting multi-professional teams in their functioning. In particular, the knowledge that psychologists have of group work skills may help to develop team working and allow for the exploration of any interpersonal tensions. Their knowledge of the biomedical and social science paradigms of research also means they are able to assist multi-disciplinary research teams who are required to collaborate in order to consider complex research questions (Payne and Haines, 2002b).

Although multi-professionalism is the model of choice, this does not mean it is always easy to implement or function within. Throughout the course of the interviews a number of participants voiced negative feelings about the challenges of multi-professional working. This led to the creation of a separate sub-theme 'team working', which is examined in more detail in section 4.27 of this chapter.

Just as the participants in this study felt unclear about the most effective professional positioning for a cancer psychologist, the literature also demonstrates a lack of clarity about the issue. In the past, those responsible for providing psychological support to patients were usually voluntary counsellors who often worked in total professional isolation (Burton and Watson, 2000). Although today psychologists are thankfully more integrated, they are still not considered to be core members of the team (NICE, 2004a) meaning they continue to exist on the periphery and are rarely involved in the management structures of cancer services at either local and/or national level. One of the ongoing difficulties in terms of achieving greater integration is that many psychology posts are supported through charitable funding, meaning that although the NHS benefits from their expertise they cannot be regarded as an integral part of the NHS establishment (Clinical Psychology Workforce Planning Group, 2002).

The finding in this study that psychology is a poorly understood profession and to a large extent an unknown quantity is also present in other related literature. Fallowfield and Roberts *(1992)* undertook a study exploring cancer counselling in the UK and found that many counsellors working in oncology settings felt there was a lack of understanding about their role amongst their professional colleagues. Bottomley *(1997)* also reports that levels of understanding about psychological interventions amongst staff working in cancer and palliative care settings continues to be limited. One of the possible reasons for this is that there are still only very few psychologists working in these settings meaning opportunities for educating the wider team about the role are very limited (Hellbom *et al.*, 2001; Strong, 2004; Sharpe *et al.*, 2004b).

4.10 CRITICAL REFLECTION

My initial impressions about the participants' views about psychologists were that they seemed to represent a fairly functional and practical viewpoint about the profession. However, closer examination and further consideration of the transcripts led me to see that the responses were in fact far from this but actually included some powerful, yet subtle expressions of emotion. The understated nature of these emotions proved challenging and identifying them necessitated constant searching for the feelings hidden behind the words. In many ways this directly reflected my experience of interviewing the nurses, as on many occasions I had found it hard to encourage them to engage in emotional discussion. They had often appeared uncomfortable with elaborating on any emotional content and instead tended to gravitate towards the seeming comfort of factual, solution-focused conversation. Throughout the interviews I sensed a distinct lack of familiarity with emotional discourse and was left feeling this was something which in their professional world was possibly discouraged or at least not prioritised. I also wondered if the 'problem-solving' focus of their training and the task-orientated nature of nursing were in some way responsible for creating a tendency to view emotional expression as less valuable or perhaps less safe.

4.11 ISSUES OF REFLEXIVITY

Throughout the interviews I was acutely aware of the impact that my presence had on the participants and the possible power imbalance that existed between us. Prior to the interviews I had reflected carefully on the fact that asking the participants questions about psychology and psychologists had the potential to lead to a variety of feelings. Whilst I was concerned about leaving participants feeling professionally exposed or anxious about 'not knowing', I was also aware that my identity as a psychologist might have inhibited them from being open and honest. During the interviews the participants seeming comfort with articulating negative feelings about psychologists meant my fears about these issues settled slightly. That said, as some of them described feeling that psychology was an inaccessible profession, I experienced feelings of embarrassment as I realised that I had at times been guilty of denying nursing colleagues access to my professional world. This led to much post-interview reflection about the possible reasons for blocking other professionals out and actively preventing them from gaining a better understanding of the role.

Other aspects of the discussions were also hard to manage. When talking with the participants about psychologist's training and knowledge levels, I felt very aware that by focusing on the academic differences in our training, this might inadvertently elevate my status and risk compromising how safe participants then felt within the context of the interviews. In particular, I found the previously quoted comment made by one participant about perceiving psychologists as being "higher" than her, hard to manage.

When asking about the participants' beliefs regarding a psychologist's clinical work I was struck by the strength of emotion that accompanied their descriptions of psychologists being secretive/mysterious. The anger and irritation that I sensed from some generated substantial discomfort in me and I became immediately concerned about being perceived as withholding and unwilling to offer the clarity that some of them were explicit about lacking. I was also concerned that they may have felt exposed about not knowing what it was I did, and therefore fearful that I may make a negative judgment about them. I began to experience an internal tension, for whilst I wanted to explore their feelings further, I was also mindful that doing so was risky. My main concern was that pursuing these issues may have left some of the participants feeling undermined or worried about their lack of knowledge. Equally I did not want to risk a situation in which feelings of anger and frustration spiralled and became personal and destructive. So on a number of occasions, despite wanting to know more, I decided that pursuing was neither appropriate nor ethical.

The other particular point of tension occurred when asking the participants to articulate what they hoped a psychologist might be able to offer them. I felt I risked leaving them feeling acutely aware of their needs without being able to offer tangible solutions for meeting them. This issue became a reality when after completing an interview one participant who during the course of the interview had described a particularly challenging ongoing patient case stated how helpless she felt and asked me for advice, feedback and support.

I had given much consideration to these potential challenges prior to commencing the research and whilst managing them was possible, it involved sensitivity, awareness, respect and the maintaining of boundaries. I worked hard throughout all the interviews to convey a totally non-judgemental and accepting approach and also tried to offer appropriate support, reassurance and encouragement when necessary. I tried to ensure that the participants felt able to share their views without any fear of exposure or retaliation and utilised many of the skills I commonly use during therapeutic encounters in order to foster collaboration and equality. I purposefully resisted any disclosure, which could have risked elevating me to 'expert practitioner' thereby placing additional constraints on participants. In terms of direct requests for information or clarification about my role, I avoided engaging directly, fearing it would only add to an already complex dynamic. Instead I reminded them that following the interviews I would be providing training for them on any topic of their choice and would be more than happy to cover the issue of the psychologist's role during that.

At times during the interviews certain topics generated very powerful feelings in me. I felt particularly caught off guard by the views shared by some participants about the potential professional positioning of a psychologist within an organisation. Although not altogether surprised by the existence of a split between those who felt a need for separateness and clear professional boundaries, and those who had a desire for total professional integration, I was surprised by the power of the discomfort it triggered in me. I was forced to engage with the issues of professional isolation and detachment that I often experienced as a lone psychologist working in a cancer centre and it also brought to the fore the ongoing challenges I faced in trying to develop productive working relationships with other professionals, whilst maintaining the necessary boundaries. I quickly realised that by listening to the participants' views on the topic, my own internal tensions about both needing boundaries but wanting integration were being triggered. I managed these feelings by tapping into my skills as a counselling psychologist. I recognised their existence but did not allow them to undermine my concentration or neutrality. I worked hard to remain focused on the interview in question and ensured my personal feelings did not impact on my interaction with any of the participants.

SECTION TWO:
FINDINGS RELATING TO PSYCHOLOGICAL ASSESSMENT

4.12 MASTER THEME: WAYS OF ASSESSING FOR DISTRESS

This master theme is concerned with the ways in which the participants described approaching assessing patients for distress. Their resulting accounts clustered around seven sub-themes: 'emotional discomfort', 'intuition', 'feeling stuck', 'style/approach', 'communication skills', 'time' and 'role of others'. The first three sub-themes to be considered, those of 'emotional discomfort', 'intuition' and 'feeling stuck' are linked together because they all share the feature of involving the participants' own feelings.

4.12.1 Sub-theme: Emotional discomfort

Half of the participants reported using their own emotional experience to inform their assessments of patients. Feelings of emotional discomfort were described as particularly central and significant in identifying patients who were likely to need referring on for specialist intervention. The following quotes convey the feelings shared by the participants on this topic:

"I have had times when patients and relatives have left me feeling so helpless, so useless and I worry and get myself in a state. They can leave me feeling like, god I can't cope, I don't know how to help them, it is a bad feeling, really bad. In those cases I know I would refer on to someone more specialist if they existed. Those patients need a psychologist, not me" (P4, 183-188).

"I didn't know how to handle him, or his thoughts. I didn't understand his reaction, I'd not seen anything like that before, I just didn't understand the reaction, or know how to help him, so I knew I needed some help and I couldn't cope on my own. It was pretty hairy at the time" (P2, 159-163).

4.12.2 Sub-theme: Intuition

In addition to emotional discomfort, all but one of the participants identified intuition as playing an important role in the assessment process, with some describing it as the thing they relied on above all else to inform them about the psychological state of a patient. The following quote captures this particularly clearly:

"I would say it is a lot about intuition, it is a gut feeling. I think that on almost all occasions intuition plays a part as to whether you feel someone is suffering psychologically. It is hard to describe what that actually means, but nurses tend to have it, this ability to just know. So I rely a lot on my intuition 'cos it is rarely wrong" (P9, 308-312).

4.12.3 Sub-theme: Feeling stuck

'Feeling stuck', the final sub-theme in this grouping was recognised by half of the participants as an emotional experience which they recognised as a cue, often leading them to conclude that the patient/family member was experiencing levels of psychological distress that were likely to be beyond their scope of competence and would instead benefit from a specialist intervention. This experience is clearly illustrated by the following quotes:

"You have tried everything, spoken about feelings and yet things are not moving along, you end up going round in circles, and you don't know what else to say, you just know you aren't enough for them or their distress" (P6, 249-252).

"I can only recognise that what I have said to the patient isn't working, and they need something better, they need to go to someone more specialist, more skilled than me, they need more than I can give" (P7, 74-77).

The next three sub-themes to be considered – 'style/approach', 'communication skills' and 'time' - are findings which are linked together by the fact they all share the feature of being practical and tangible in nature.

4.12.4 Sub-theme: Style/approach

'Style/approach' refers to the various styles, approaches and methods the participants reported using when undertaking an assessment for distress. Almost half of them described adopting an approach which involved a process of open and unstructured emotional exploration designed to build rapport with patients and allow them to gain the necessary insight into their emotional state:

"What I do is ask the patient how they are feeling, it's a general chat really. I don't have a particular agenda, I just encourage them to talk about how they are feeling. I try to unpick things, and unravel it a bit, ask about the family, ask about how supported they feel. There needs to be trust which can take time to develop, so I just allow them to talk and I gently steer it towards emotions, without being too direct. Soon enough you get a sense of what is happening and whether there are problems" (P7, 215-221).

The remaining participants described using an approach that was much more structured in nature and included particular questions specifically designed to screen for symptoms of emotional distress, including depression and/or anxiety. The following illustrates this alternative approach:

"Overall I tend to be quite direct, I am looking for particular information really, so I use particular questions. The 'are you depressed?' question has been researched and I use that, I also ask about their sleep pattern and appetite and ability to experience pleasure, what they are doing on a day to day basis.... I will want to know if there is a history of mental health problems and whether they have seen a psychiatrist. So it's sort of a formula I go through" (P5, 196-202).

4.12.5 Sub-theme: Communication skills

The majority of the participants identified the use of advanced communication skills as being central to the assessment process and vital in order to identify psychological problems in their respective patient groups. This was irrespective of whether a structured or unstructured assessment approach was adopted:

"Well I use active listening, questioning – the "why", "how" open questions, sometimes some closed questions, summarising, paraphrasing – all those skills. The other thing is empathy, all that goes part and parcel with it, creating the right environment, the right positions. I am very aware of my body language and their body language, what they are telling me and whether there is any discrepancy between what they are saying and how they look" (P8, 155-160).

4.12.6 Sub-theme: Time

In addition to the use of these key communication skills, all but one of the participants identified time as playing a key part in the assessment process. The majority described this in terms of the importance of assessing patients over time, rather than making decisions about psychological distress after just one meeting. This is clearly illustrated in the following:

"I wouldn't make any decisions about a patient the first time that I see them, I would want to see them again and consider their presentation over time. I certainly wouldn't necessarily think, "oh they are clearly barking", so therefore I've got to refer them now, or they are clearly very distressed and never going to cope. The truth is they are going to feel a bit off kilter, they have lots to take on board and so I need to give them time and assess how things go over time" (P7, 291-296).

One participant described feeling very differently about this, reporting that she actually needed very little time to make an assessment, with only one encounter usually being necessary in order to know whether someone was emotionally distressed or not:

"You just know the first time, it doesn't take long to know, you pick it up immediately, just by how they present in that first meeting, what they say and how they look" (P1, 502-504).

The same participant also talked about the importance of the timing of assessments, recognising that moments of high emotion (just after bad news had been broken), were not conducive to conducting psychological assessments:

"You have to let people have time to think, that's why I don't see people straight away after receiving bad news. I see them the next day or a few days later because they have to have time to think, shout, scream and cry. They need time to let the shock settle slightly" (P1, 246-250).

4.12.7 Sub-theme: Role of others

The final sub-theme to be considered is that of 'role of others' which relates to ideas voiced by over half the participants about feeling that people other than themselves had some role and/or responsibility in assessing patients for distress. Four participants described feeling that patients themselves had some role in this, and that they (patients) had a responsibility to be both open about their feelings and sufficiently motivated to confront and ultimately change their psychological state:

"Patients who want help, who are prepared to do something about it, need to tell you they have a problem. There is a self-selection process that goes on, because it is only those who know they are depressed who will recognise it and to an extent we rely on them to do that "(P5, 207-211).

Two participants reported feeling that the task of assessing patients for distress was something which other members of the multi-professional team needed to take more responsibility for, making it more of a shared process:

"It shouldn't just be down to the nurse, it should also be the medics, the physios or even the receptionists, because if the patient comes to the desk in clinic and they are very angry or very agitated or something like that then it is a clue that they might be really struggling with the situation. It would help to know from other members of the team what they thought" (P9, 364-368).

4.13 DISCUSSION

This section of findings reveal the participants to be using a wide range of methods to assess patients for distress with a significant proportion describing their own emotional experience as playing a key role in the process. The role that staff emotions play in the assessment of patient distress has received little attention in the literature. One reason for this may be that great emphasis is placed on the importance of assessment being a patient centred process, with White and McCleod (2002) suggesting that assessment should be based entirely on detailed information obtained from the person themselves about their situation and emotional state. Further weight is given to this by the NHS National Cancer Action Team, whose report, Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer (2007) states that assessment should be "patient concerns-led" and identifies that "the patient is seen as being at the heart of assessment and care-planning" (p.8). With the focus being so clearly on the patient experience, it is perhaps unsurprising that the role that staff emotions may play has been somewhat overlooked. Brennan (2004) however recognises that despite it being a more advanced skill, there is potentially great scope for health care professionals to use their emotional reactions to patients as sources of important and additional information. However another point to consider is one raised by Kalus (2003) who identifies that for many staff, emotional discomfort stems from having to engage with the psychological aspect of dying and this discomfort, rather than being used as a basis for engaging further, leads staff to default to what she describes as the "emotional retreat", meaning they automatically refer patients on for specialist psychological input (p.179). Likewise Razavi *et al.* (2002) report that cancer nurses experience significant levels of emotional discomfort during discussions with patients about emotional concerns/distress, stemming from a combination of fear about talking openly about emotions and from a difficulty in dealing with their own emotions. This would suggest that for nurses to use emotional discomfort as an indicator of patient distress could be highly problematic.

The issue of intuition and the role it plays in assessment is also unclear and despite it being cited by all of the current study's participants as being the emotion they relied on above all else, very little is actually known about its true value and whether it is in any way an accurate measure of patient distress. Hackett and Gaitan (2007) recognise that historically assessing patients' needs relied in the main on health care professionals using intuition and subjective opinion. However Razavi and Delvaux (1997) state that personal intuition alone is insufficient for dealing with the complexity of the problems which often affect those with cancer. They instead suggest that those undertaking psycho-social assessments need to acquire an expertise in communication skills in order to effectively elicit the psycho-social needs and concerns of cancer patients and their families.

It is clear from the findings of this study that participants place a high value on the role their emotional experiences play in guiding them through patient assessments. This is not however a topic which has received adequate research attention, suggesting that further work in this area would be valuable in order to establish exactly what role these emotions play and whether they have a positive or detrimental effect on the accuracy of identifying patient distress.

In terms of assessment approach, the participants were totally split. Half described a preference for a structured approach, characterised by the use of specific screening-type questions, whilst the remainder preferred an unstructured emotion-based approach, focused on rapport building, information gathering and ongoing exploration of emotional needs. The question of which approach is most effective remains unanswered and the literature continues to present a confused picture and lack of agreement. Payne (1998) and Craven (2000) both suggest that the most effective form of assessment involves an assumption-free discussion with the patient, during which gentle questions should be asked about their emotional well-being. The National Cancer Action Team who in 2007 published detailed guidelines for the undertaking of patient assessments further endorses this, suggesting that assessments should be patient led and follow a conversational style which allows for detailed discussion about a variety of topics (background information, physical needs, social needs, psychological well-being and spiritual well-being). They also suggest that questions should be used in such a fashion as to ensure that patient's concerns are elicited thoroughly, yet sensitively. Despite these recommendations, with the growing tendency towards evidence-based practice and clinical governance there has been a significant shift in the way patient assessments are approached and increasingly assessment tools are being looked to as the most efficient way of detecting distress. This, combined with the potential benefits of saving both time and money only adds to their attraction (Clinical Psychology Workforce Planning Group, 2002). There is therefore rapidly growing interest in developing valid and reliable tools which can be administered by a range of professionals caring for cancer patients. Whilst numerous tools exist, there is currently no agreement about which is the most suitable for a cancer population (Hackett and Gaitan, 2007) and as Lawrie *et al.* (2004) warns, all tools have limitations meaning that over-reliance on any one particular tool may obscure certain psychological symptoms or signs of distress. The lack of clarity about which screening tools offers the greatest reliability and/or validity is a source of ongoing confusion which in turn is reported to impact negatively on the ability of health care professionals to make informed choices about which tool to use for which condition or patient (Muldoon *et al.*, 1998 cited in Hackett and Gaitan, 2007). This is clearly an area in which ongoing research is required in order to achieve clarity and definitive guidelines.

The importance of communication skills in patient assessment is now well recognised and just like the participants in this study, the literature considers these skills to be key to the delivery of effective supportive care (Craven, 2000; NICE, 2004a). Fallowfied *et al.* (2001) identify the use of good communication skills as the single most important aspect of psychological assessment with Carney *et al* (1999) reporting that doctors working in general practice who are proficient at recognising depression, ask more open questions about feelings and affect than their less proficient counterparts. Communication skills are not only important for healthcare professionals, for as a report published by the Audit Commission (1993) cited in Craven (2000) states, patients themselves care more about communication than any other aspect of care.

Effective communication involves far more than the delivery of information. Advanced skills including listening, empathic understanding, commitment, appropriate questioning, reflection, awareness of non-verbals, challenging, summarising, probing, clarification, checking, silence and appropriate reassurance are all considered essential if communication is to be successful (Renwick, 1992; Razavi and Delvaux, 1997; Craven, 2000; Buckman, 2000). Despite this knowledge, numerous studies have revealed that many professionals working in cancer settings either lack these skills or do not feel confident in their ability to communicate. Fallowfield *et al.* (1998) report that a group of 178 senior oncologists attending communication skills courses found that eliciting and dealing effectively with patients' emotional problems caused them considerable difficulty. Wilkinson (1991) undertook a survey of cancer nurses and found that although many of them did not lack communication skills, during conversations with cancer patients they employed blocking behaviours (closed questions, changing the topic and ignoring cues) as much as 50% of the time. As a result of these research findings, communication skills training is now very much on the agenda. For a more detailed discussion about this please see section 4.17 of this chapter.

The common view held by this study's participants about assessments needing to be conducted over time is totally in line with the existing literature. The importance of psychological assessments being ongoing in nature is stated explicitly both by NICE (2004a) and more recently the National Cancer Action Team (2007). That said, the one participant in this study who reported needing very little time to make an assessment raises a point that is perhaps worth pursuing. As a palliative care nurse specialist her comments lead to the question as to whether those working in this speciality (in which time is often limited) utilise a different assessment approach or are perhaps simply more skilled when it comes to making assessment decisions under time pressure. At the present time there does not appear to be any research which has compared the assessment approaches between tumour-site specific and palliative care nurses, meaning further research would be required in order to establish the existence any of differences.

The importance of timing is however further highlighted in the literature with suggestions that offering psychological interventions too early in the disease trajectory could compromise their effectiveness. Edgar *et al.* (1992) compared early and late CBT interventions in the first year after a cancer diagnosis in a sample of 205 patients and found that those who received CBT interventions seven months after their diagnosis experienced less depression, anxiety and worry when compared with those who received it during the first three months. This led them to suggest that giving psychological therapies too soon may interfere with the natural coping process, potentially removing patients' sense of control over their emotional recovery from the shock of diagnosis. Meanwhile Cain *et al.* (1986) cited in Edgar *et al.* (1992) demonstrated an equal improvement in psychosocial adjustment in both their control and intervention groups at three and four months. Both these studies point to the importance of giving patients sufficient time to process feelings of shock, thereby allowing psychological adjustment and coping strategies to occur and develop naturally. This reflects another finding from the current study, which identifies the importance of not conducting psychological assessments at times of high emotion and instead suggests waiting until the initial reaction has had time to settle.

With regard to the question about who is responsible for undertaking psychological assessments, a number of this study's participants stated feeling that CNSs should not bear the responsibility alone but that it should be shared by all members of the multi-disciplinary team. Craven (2000) concurs with this suggesting that placing all the responsibility onto CNSs is unreasonable and instead all team members should be involved. The National Cancer Action Team (2007) also agree stating "the responsibility for ensuring that assessment is undertaken lies with the health care team in whose care the patient happens to be" (p.11). In addition, Hackett and Gaitan's (2007) study examining the assessment of mental health issues by palliative care professionals found that multi-disciplinary team meetings were perceived as being a positive influence on the assessment process suggesting that input from the wider team should be encouraged.

The literature offers slightly more mixed opinions on the finding that patients themselves should take some responsibility in the assessment process. Whilst the National Cancer Action Team (2007) clearly recognise assessment as a patient centred process, they also state that the responsibility for undertaking such assessments lies solely with a 'clinical professional with an appropriate level of knowledge who has reached an agreed level of competence in key aspects of the assessment process' (p.11). This is further endorsed by NICE (2004a) who offer a four level model relating to psychological assessment and support and make clear recommendations about which staff should be undertaking what level of psychological assessment. They do however also suggest that this model should be "underpinned by a recognition that patients and carers can often assess their own emotional status" (p.77), and although this does not imply responsibility, it certainly recognises the importance of input from patients themselves.

4.14 MASTER THEME: FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

During discussions about assessing patients for distress the participants shared their thoughts about how approaching the topic of psychological issues with patients made them feel. Their subsequent accounts clustered around just two sub-themes: 'confidence' and 'awareness of language'.

4.14.1 Sub-theme: Confidence

Every participant in the study reported feeling that the idea of talking about psychological issues or introducing the idea of a referral to a psychologist with patients generated nothing but feelings of confidence. The following quotes captures the feelings of all the participants:

"I would feel pretty confident to have a conversation about a psychologist with any of my patients. It wouldn't phase me at all, I would feel fine about it" (P4, 456-457).

"I would never, never be afraid of saying to a patient, you know perhaps you need to talk more about this, perhaps a psychologist would be useful" (P7, 379-380).

4.14.2 Sub-theme: Awareness of language

All of the participants described feeling very aware about the importance of the language they chose when talking about psychological issues and there was great variation with regard to the terminology they would feel comfortable using. A few described feeling very happy to talk openly about psychology with patients as the following quote illustrates:

"I would just be open with them, and say 'there are things you are talking about that make me think you may benefit from seeing a I think a psychologist' – I would just say it, be up front" (P1, 763-766).

Others did not share this confidence and instead described feeling uncomfortable with the word psychologist and would avoid using it. The following quote illustrates this and also conveys a sense of fear about the possible ramifications of using the term openly with a patient:

"I wouldn't use the word psychologist, I would be concerned about saying it, I would talk more generally but not actually say the word" (P10, 358-359).

The majority of the participants however described a fairly flexible approach to their choice of language, reporting feeling that being aware and sensitive to each patient's individual needs were the most important things to consider when discussing topics which had the potential to cause anxiety or concern:

"It's all about how you introduce it. You need to be careful and respectful of using the word psychologist. That might frighten some people, so you need to normalise it and take it slowly and not just land the idea on them too quickly" (P5, 252-255).

4.15 DISCUSSION

Despite some concerns about the exact language used when discussing psychological issues, all the participants in this study reported feeling ultimately confident about discussing those issues with patients. This is directly opposed to findings in the existing literature. Recent studies conducted by Hackett and Gaitan (2007) and Lloyd-Willams and Payne (2003) both reported that nurses working in the field of palliative care felt under-confident about broaching the topic of mental health and concerned about the stigma associated with psychological illness. Lloyd-Williams and Payne (2003) also reported that nurses held negative stereotypes about depression, meaning they felt less able to negotiate conversations with patients about psychological difficulties. In addition, Barraclough (2000) states that the fact psychological issues continue to be associated with stigma and embarrassment means that many people, including cancer professionals, continue to feel under-confident about discussing issues of a psychological nature. The findings from this study therefore indicate something different and demonstrate a level of confidence amongst the CNSs that has not been previously reported. Whilst the reasons for this are not entirely clear and further research would be required in order to ascertain exactly what underpins this, the next master theme offers some indication as to what factors had contributed to this particular team's feelings of confidence.

4.16 MASTER THEME: FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

This master theme describes a range of factors which the participants identified as having contributed to and/or influenced their ability to assess patients for distress. Their subsequent accounts clustered around four sub-themes: 'experience', 'reflective practice', 'colleagues' and 'training'.

4.16.1 Sub-theme: Experience

The first sub-theme to be considered is that of 'experience', which was mentioned by all but one of the participants as having been particularly important in building their feelings of confidence and/or competence with regard to assessing patients for distress. For most this was described in terms of professional experience which came from having had the chance to work in a variety of clinical settings, allowing them to gather diverse clinical experience over a period of time:

"I couldn't do this job and make these assessments if I hadn't had all my years in medicine, because in medicine you get it all thrown at you and you learn to cope with lots of different situations and that builds your knowledge, confidence and skills. So yes, I very much felt I wouldn't have been able to do this if I hadn't have done that first" (P2, 572-577).

Two of the participants also identified life experience as playing an important role in contributing to their feelings of confidence/competence:

"I found that after becoming a parent, I saw things differently, the impact of things felt more real, I suppose you just have more life skills and you come from a more experienced position from which to consider others' emotions. I certainly feel more confident now that I know a bit more about life" (P8, 187-191).

4.16.2 Sub-theme: Reflective practice

Reflective practice was raised by a number of the participants as a style of working that had helped them build their confidence levels and feel more comfortable about assessing patients for distress. This is illustrated in the following:

"It's about reflecting back on what you have done and asking yourself if you could have done anything better. You would then take that learning onto the next one, so it's an ongoing process and over time I think you get more confident, you learn by constantly reflecting and evaluating and reflecting back on what you have done." (P3, 559-562).

4.16.3 Sub-theme: Colleagues

Another factor identified by the majority of the participants as being particularly influential in their practice was the role played by their colleagues. Many reported feeling that observing their colleagues, particularly doctors, was a valuable learning tool, both in terms of adopting good practice and avoiding bad practice. The opportunity to observe colleagues negotiating conversations with patients which had a psychological component left participants feeling more confident to approach the issue of psychological assessment themselves:

"I am with the doctors a lot of the time, so I watch them assess patients. It is really useful, especially watching them doing it badly, I mean it makes you do it better. It is also good seeing the good ones, it reminds you of certain phrases to use. I find that one of the most useful things" (P7, 498-501).

"Working alongside very experienced colleagues is as good a training as anything that you could read about in a book" (P10, 436-437).

4.16.4 Sub-theme: Training

The final sub-theme is that of 'training', which was mentioned by all of the participants as something they viewed as fundamental to their ability to assess patients for distress. Many types of training were mentioned as having contributed positively, including nursing training, additional academic based courses, experiential communication skills courses and other self-directed training on a variety of topics. Whatever the academic content, all the participants described feeling that training was an essential way of building their confidence to assess patients for distress:

"I feel lucky, I have had lots of relevant training, right from the beginning of nurse training, through to now. In a way it underpins everything, because without that education you wouldn't' know where to start. Without question I would say that training is what you need if you are going to assess people properly" (P3, 526-529).

4.17 DISCUSSION

It is clear from these findings that the participants' feelings of confidence and competence about assessing patients for distress had been influenced by a variety of factors, with a significant number citing experience as being particularly important. Although there is a dearth of research investigating the role that experience plays in assessment, a few studies do suggest that unlike in this study, experience does not contribute to enhanced competence. Fallowfield *et al.* (2001) found that senior oncologists misclassified a significantly greater number of distressed cancer patients than their less experienced junior colleagues. In addition, Cantwell and Ramirez (1997) and Helbom *et al.* (2001) both report that assessment skills do not reliably come from experience accumulated through working with a particular patient group.

The role that colleagues and reflective practice play in assessment competence is also unclear and despite the findings from the current study suggesting that both play an important role, there is very little in the wider literature to either support or challenge this. That said, Degner *et al's* (1991) study examining the nature of expert nursing practice within palliative care found that nurses rely greatly on their colleagues to provide both constructive criticism and positive feedback about the quality of their nursing care, suggesting that colleagues do play a central role in professional development. With regard to reflective practice, although this has long been recognised as a central feature of good nursing practice (Davies and Oberle, 1990), no literature has examined its place in the context of assessing cancer patients for distress.

In light of the fact the participants in this study felt such conviction about the role that experience, colleagues and reflective practice had in underpinning their competence levels, further research in this area may be of value in order to explore in more detail the exact role that these factors play in psychological assessment.

The role that training plays in improving assessment skills is now very well documented and just as indicated in this study, numerous others have shown that training and education programmes have the capacity to impact positively on the assessment competence of those working in oncology settings (Razavi, *et al.*, 1993; Roter *et al.*, 1995; Stewart, 1996; Fallowfield, *et al.*, 1998; Gerrity, *et al.*, 1999; Maguire, 1999; Baile, *et al.*, 1999; Fallowfield *et al.*, 2002a; Razavi, *et al.*, 2002; Fallowfield, *et al.*, 2003). In particular, communication skills training has been found to be particularly effective in improving assessment skills and as a result of the considerable evidence base it is now recommended that all health care professionals working with cancer patients should receive specialist communication skills training (NICE, 2004a).

A number of different training programmes have been evaluated and whilst content and design may vary, those leading to the most positive outcomes tend to include cognitive, behavioural, experiential and stress management components (Razavi and Delvaux, 1997). In addition, it is suggested that courses should be learner-centred and facilitated by professionals who understand the issues relevant to the clinical context and are able to provide participants with constructive feedback. Finally, courses which include a large amount of experiential work have been found to increase the chances of improvements being maintained over time (NICE, 2004a).

In terms of nurses, a number of studies have been conducted to evaluate the potential benefits of communication skills training. In 1998, Wilkinson *et al.* undertook a study to evaluate the impact of a 26 hour communication skills programme conducted over the course of 6 months on nurses working in palliative care. Post-course the results showed there to be an overall statistically significant improvement in assessment skills amongst the nurses and this was accompanied by significant improvements in their confidence levels. A follow-up study designed to evaluate the long-term effects of this training found that in the area of psychological assessment the nurses had maintained their skills and had also become more confident in the emotional areas of care (Wilkinson, *et al.* 1999). A more recent study conducted by Wilkinson *et al.* (2008) has indicated that a shorter communication skills training model for nurses, this time conducted over just three days, resulted in improvements both in communication skills and confidence levels. They also found that patients themselves felt more satisfied and demonstrated a more positive emotional state.

Despite these encouraging findings the research has also revealed that not all staff benefit from this type of training. In fact, it is estimated that for about 10% of staff, communication skills training will have no effect or may even result in worsened performance (Wilkinson, 1991; Wilkinson, *et al.,* 1998). In addition to this, other studies have found that unfortunately for those who do benefit, the skills gained through such training courses are often lost within 3-12 months, (Corner and Wilson-Barnett, 1992; Heaven and Maguire, 1996). This has led to recommendations that the availability of consolidation programs and ongoing support/supervision is essential if skills acquired through communication training are to be maintained over time (Razavi and Delvaux, 1997).

4.18 MASTER THEME: SIGNS OF DISTRESS

This master theme is concerned with describing a range of problems which the participants identified as indicators of psychological distress. Their subsequent accounts clustered around seven sub-themes: 'depression', 'anxiety', 'adjustment/coping issues', 'complex issues', 'relationship issues', 'treatment issues', and 'key point in pathway'. The participants identified these as the sorts of presentations they were particularly aware of looking out for in their respective patient groups, and they also described them as problems they would be likely to refer onto a psychologist should there be one in post.

4.18.1 Sub-theme: Depression

Although a number of emotional difficulties were identified, over half the participants cited depression as a presentation they were particularly mindful of looking out for and a problem that they felt required specialist intervention. This is illustrated by the following:

"She started talking about feeling she had a dark cloud hanging over her and that she didn't think she would see Christmas, she was so low and flat and became more and more withdrawn. It was a clear case of depression, clinical depression, and I just felt straightaway that she needed a bit more help really" (P4, 38-42).

4.18.2 Sub-theme: Anxiety

Anxiety was also identified as something that a number of the participants were aware of seeing in their patients. This was again considered to be a problem that was likely to warrant specialist input:

"He's always on the 'phone worried about different things, headaches, stomach ache, pain in his arm….. he checks his body all the time for lumps and signs of cancer, because he thinks it's spreading and he interprets every little ache as a sign of that and wants extra scans and blood tests, and the thing is that actually yes, I know he has a serious illness, but at the moment he is actually fairly well and it is the anxiety that is the main problem, so he really needs some help, because it is a terrible way to live, worrying all the time" (P9, 252-258).

4.18.3 Sub-theme: Adjustment/coping issues

Another emotional presentation mentioned by over half the participants was that of poor psychological adjustment. This tended to be described in terms of patients having problems coping with the impact of their illness as the following quote illustrates:

"The people who are having problems adjusting to the situation, who just can't take it on board and who are clearly not coping, they can't live their lives because of this

thing hanging over them, and they can't move anywhere, and their coping skills are just paralysed by it all" (P2, 146-149).

4.18.4 Sub-theme: Complex issues

Others described feeling that it was patients who appeared to have complex psychological difficulties who would benefit most from specialist support. Whilst 'complex' was defined by each participant slightly differently, the common feature was the existence of multiple problems, meaning that the cancer diagnosis was just one of a multitude of issues that the patient was trying to deal with:

"This is yet another event for them, on top of many events in their life and it makes the whole thing more complicated, because the diagnosis is likely to trigger unresolved stuff, things from the past, whatever those are, so the whole thing is deeper and more complicated, and not a straightforward illness reaction. You just feel there is more than one thing going on, it's as though something deep and dark is happening that I wouldn't want to, um.............necessarily touch on" (P10, 179-184).

4.18.5 Sub-theme: Family/relationship issues

A smaller group reported feeling that the indicators of psychological distress were relationship problems including sexual difficulties and fertility issues. These were spoken about as being directly related to a cancer diagnosis. Again, those who identified these problems, felt that specialist input from a psychologist would be beneficial:

"Fertility issues and relationship problems, sexual problems and things like that, they are big problems for some patients after a diagnosis, certainly marital problems are common, the illness can place such a strain on relationships and on family members. It's not just the patient who suffers you know. I would ideally refer those patients on for extra help" (P3, 358-362).

4.18.6 Sub-theme: Treatment issues

Others focused more on issues associated with cancer treatments, citing treatment adherence, side effects, phobias and the resulting impact on body image as the sorts of difficulties they felt were likely to cause the level of emotional distress that a psychologist could be of assistance with:

"For some people the thought of losing their hair is just the worst thing, some say they would rather not have treatment at all, would actually rather die than lose their hair and I know they have got 6 months of treatment ahead of them and they will lose their hair and are likely to feel pretty ill as well, so I would certainly like to refer those patients on, because otherwise probably won't have treatment they really need" (P3, 403-408).

4.18.7 Sub-theme: Key point in pathway

Finally, a few of the participants reported feeling that a decision to refer on to a psychologist would be guided more by the point their patient was at in terms of disease trajectory, rather than by emotional presentation. A number of stages were identified including the point at which curative treatment ended and the point of disease recurrence, however the most commonly cited was the time of original diagnosis:

"I would see a psychologist as being needed more at the time somebody is newly diagnosed, they would have the time, the luxury of time in terms of helping the patient to get used to the diagnosis and help them develop ways of thinking about treatment options or the time they have left, or whatever" (P10, 104-107).

4.19 DISCUSSION

These findings illustrate a clear awareness amongst the participants of the many different psychological problems that cancer patients are known to experience. The fact that half cited depression as the presentation they were most aware of watching out for is certainly reflective of the literature, as depression is now widely reported to be the most common psychological problem encountered by patients (Pasacreta and Massie, 1990; Wilson *et al.*, 2000). In essence, depression is a response to perceived loss and with the many losses that accompany a cancer diagnosis patients are particularly vulnerable to developing this psychological problem. Depression is characterised by persistently low mood, an inability to experience pleasure (anhedonia), a sense of hopelessness about the future and a range of somatic symptoms including insomnia, loss of appetite and fatigue (Kirsh and Passik, 2002). Numerous studies have attempted to quantify the extent of the problem and whilst most estimate that clinical depression affects approximately 25% of cancer patients, some studies suggest the rate to be nearer 50% (Derogatis *et al.*, 1983; Sellick and Crooks, 1999; Maguire, 2000; Zabora *et al.*, 2001b). Research has also found that the prevalence of depression rises as disease progresses (Maguire, 2000) and patients most at risk of developing it are those with advanced disease, a prior psychiatric history, poorly controlled pain and other life stressors or losses (Kathol *et al.*, 1990). The research also indicates that cancer is not the only medical illness known to precipitate depression, as those suffering from Parkinson's disease, dementia and stroke have all been found to be significantly more likely to suffer from depression than those in the general population (Kelly *et al.*, 2006).

Anxiety, as identified by three of the participants in this study is also known to be a psychological problem commonly experienced by cancer patients (Bottomley, 1997). In contrast to depression, anxiety is the response to a perceived threat and is characterised by a combination of psychological and somatic symptoms. These include feelings of worry, apprehension, restlessness and irritability, along with autonomic hyperactivity, shortness of breath, numbness and insomnia (Barraclough, 2000). Research suggests that anxiety-producing situations vary according to disease type and stage, meaning there are variations in the prevalence of anxiety within different populations of cancer patients (Bottomley, 1997). For example, those suffering from lung cancer are potentially more likely to worry about not being able to breathe, whilst those with head and neck cancer are perhaps more prone to worries about not being able to communicate or swallow. Certain cancer treatments are also associated with particularly high levels of anxiety, with chemotherapy known to lead to phobias and anticipatory vomiting (White and McCleod, 2002). It is therefore not surprising that the three participants in this study who cited anxiety as a particularly relevant presentation all worked in areas of cancer care (colo-rectal, breast and haematology) where active treatments (particularly chemotherapy) are commonly used.

Adjustment difficulties, mentioned by over half of the participants in the study, are known to affect up to 30% of patients (Massie and Holland 1989 cited in Barraclough, 2000). For some these difficulties will involve a combination of anxiety and/or depression but of a type which are considered appropriate as a reaction to physical illness, meaning they are not classified as mental disorders (Barraclough, 2000). For others their difficulties will be an indicator of adjustment disorder which is classified as a psychiatric diagnosis, again with a prevalence rate amongst cancer patients of about 30% (Derogatis *et al.*, 1983). Unfortunately the disorder lacks the precise features of other psychiatric illnesses, making diagnosis particularly challenging. It is however often associated with depressed mood, anxiety or disturbance of conduct and tends to be characterised by a group of maladaptive reactions such as total social withdrawal which occurs as a result of a triggering stressor (Fincannon, 1995). Those who develop adjustment disorder are also more likely to demonstrate rigid styles of thinking, leaving them vulnerable to becoming overly focused on utilising old style coping strategies to deal with their cancer-related problems. In turn this means that just as recognised by the participants in this study, an inability to cope is often a key feature of adjustment disorder (Kirsh and Passik, 2002).

Family and relationship issues as identified by a number of this study's participants are widely documented in the literature as being a potential source of distress for many affected by cancer. Difficulties of this nature tend to arise from communication barriers/failures, dependency issues, worries about children, relationship breakdown, role changes, mood disorders/distress in carers and sexual difficulties (Barraclough, 2000; Brennan, 2004). Psycho-sexual problems are particularly prevalent. Anderson and Lamb (1992) report that changes in sexual habits occur in as many as 90% of patients, whilst approximately 30% of women end treatment with some type of sexual dysfunction (Anderson *et al.*, 1989 cited in Brennan, 2004). Problems of this nature tend to be underpinned by a combination of both physical and psychological factors. Various treatments or the location of the cancer itself can lead to physical changes and permanent damage to those parts of the body involved in sexual activity. Goldstein *et al* (1984) report that only 10-20% of men treated with radiotherapy for prostate cancer regain normal erection response, whilst tamoxifen - a hormone drug commonly used in the treatment of breast cancer - has been found to cause loss of libido and ability to orgasm (Schover, 1998). Mutilating surgical procedures, radiation burns and chemotherapeutic agents are also well documented as exhibiting significant influences on sexual behaviour (Bottomley, 1997). Psychological factors are equally relevant, with body image difficulties caused by factors such as hair loss, mastectomy and weight gain, all being commonly reported as reasons for a loss of sexual confidence, interest and function (Barraclough, 2000; Brennan, 2004).

The fact that treatment itself was cited by half of the participants is again reflective of the wider literature which recognises that despite significant advances, treatment remains a significant source of distress for patients (Bottomley, 1997). Worden (1983) suggests that up to 60% of emotional distress experienced by patients can be attributed to medical and treatment variables, rather than the disease itself. Surgery, which is often the treatment of choice, particularly in early stage cancer frequently has distressing consequences including pain and disfigurement (August *et al.* 1994). Fear and anxiety are commonly reported in patients prior to surgical procedures and up to 5% are known to decline due to their excessive feelings of fear (Strain, 1985). Radiotherapy is another common treatment modality and is given to 40% of cancer patients (Brennan, 2004). Like surgery, it is associated with high levels of fear, anxiety and depression (Graydon, 1994) and whilst some of this may be linked to inaccurate and outdated beliefs, it is more likely that the nature of the treatment itself, along with numerous unpleasant side-effects are the cause of this distress. The use of plastic head/face masks necessary for immobilising patients with certain types of cancer can generate extreme anxiety and claustrophobia, whilst the physical side-effects, which can include fatigue, skin burns, nausea, sexual difficulties, diarrhoea and increased frequency of micturition are known to cause great distress (Brennan, 2004). Chemotherapy, along with hormone-based treatments are also known to be related to much psychological distress and although there is great variation between the different drug regimes, common side effects include hair loss, fatigue, nausea, vomiting, sore mouth, peripheral neuropathy, weight gain/loss, impaired immune function, cognitive changes and the development of food aversions (McCabe, 1991; Brennan, 2004). This combined with the fact that for many, chemotherapy carries with it a connotation of debilitation, suffering and ineffectiveness it is perhaps not surprising that for those undergoing such treatments anxiety, depression, irritability, insomnia and sexual problems are commonplace (McCabe, 1991; Bottomley, 1997).

Treatment related changes in physical appearance have the capacity to cause particularly high levels of distress. In Holland and Lesko's (1989) study of 144 patients undergoing chemotherapy, 84% reported hair loss as the most distressing aspect of their experience. McCabe (1991) suggests that such side effects act as a public manifestation of having cancer, thus making them particularly distressing. In addition to all of this, infertility resulting from cancer treatments (surgery, radiotherapy and chemotherapy) is also recognised in the literature as being a source of great distress to both men and women (Schover *et al.*, 1999). Unfortunately, this is an area in which many health care professionals feel under confident, meaning the topic is often overlooked and never discussed; (McCabe, 1991; Schover *et al.*, 1999; Barraclough, 2000).

The suggestion from a number of the participants that referral on to more specialist psychological services would for them be guided by patients having reached certain points in the pathway is to some extent supported in the literature. It is increasingly recognised that there are certain periods of time in the cancer trajectory when patients are at greater risk of emotional distress and at these times psychological assessment is certainly recommended (White and McCleod, 2002; NICE, 2004a; Madden, 2006). As identified by most of the participants, the point of diagnosis is a time of particular vulnerability for many patients, often causing a range of emotions including shock, anger, disbelief and distress, and although for most these emotions resolve without intervention, especially high levels of distress at this time are known to be predictive of later emotional difficulties (White and McCleod, 2002).

As previously discussed, the stage of active treatment which often involves unpleasant side-effects can be a potent cause of distress. However the point of ending treatment can be equally problematic as patients often feel abandoned and have to start engaging with the reality that their disease may return (White and McCleod, 2002). The period of time after completing treatment when patients are encouraged to 'get back to normal' is often a time of significant distress as coping with the uncertainty and the possibility of disease recurrence poses a very significant psychological challenge (Brennan, 2004). A study conducted by Polinksy (1994) in which 223 breast cancer survivors were surveyed to assess their physical, psychological and social functioning status revealed that almost 90% of the sample continued to experience thoughts about recurrence and nervousness about medical follow-up, eight years after their initial treatment. Polinksy (1994) therefore concluded that length of survivorship is not necessarily associated with the presence of fewer psychological concerns. Ongoing fears about recurrence are known to manifest as health anxiety, meaning that patients develop a tendency to misinterpret physical sensations as signs of their cancer having returned. Not only does this cause significant distress, but it also makes them more likely to engage in reassurance seeking behaviours (White and McCleod, 2002). The point of recurrence is also well documented to be a time of particular distress. Research indicates that recurrence is often experienced by patients as being more distressing than the original diagnosis, with those who believed their cancer had been cured being at increased risk of experiencing symptoms of post-traumatic stress disorder (Cella *et al.,* 1990). For many, recurrence brings with it a deep sense of hopelessness and a surge of existential concerns which can make communicating with loved ones particularly problematic (Weisman and Worden, 1985 cited in Brennan, 2004). The final point in the trajectory which has been identified as being particularly difficult for patients is the stage of terminal disease. During this period, patients often experience intense feelings of fear about the dying process and existential concerns also continue to dominate. For those with poorly controlled physical symptoms, depression is also not uncommon (White and McCleod, 2002).

4.20 MASTER THEME: IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

This master theme is concerned with a number of ideas generated by the participants about what they felt would enhance their ability to care for patients' psychological health. Their subsequent accounts clustered around just two sub-themes: 'understanding role' and 'skills/knowledge'.

4.20.1 Sub-theme: Understanding role

All of the participants felt that having a better understanding about the role of psychologists would be beneficial. This was partly because they wanted to feel clearer about what a psychologist could offer, but also because they believed an improved understanding would impact positively on their own management of psychological issues with patients. The majority felt that this could be best achieved through observational learning with most stating that observing a psychologist conducting a psychological assessment with a patient would be particularly valuable. The following quote captures the feeling of most of the participants:

"The truth is it would be good to know what a psychologist actually does because I don't honestly know. It would useful to sit in and observe one because that would really clarify things in my mind and help me to know whether a patient really needed their services or not. I also think that seeing a psychologist in action would get rid of the mystery a bit and would maybe even help me feel less anxious about broaching topics with patients. So to see it for real would make a huge difference" (P9, 574-579).

4.20.2 Sub-theme: Skills/knowledge

The second and final sub-theme is that of 'skills/knowledge', which was identified by the majority of participants as something they would like to improve. They all felt that having extra knowledge would impact positively on their ability to assess patients for distress. The topics which the nurses felt would be of most value to learn more about included: general psychology theory, mental-health, anti-depressants, cognitive behavioural therapy and assessment tools:

"I would like to learn about the different scales and assessment tools. That would be really helpful and something that would benefit patients. I think it's important that we are constantly learning and keeping our skills up to date, that is how we do the best by patients" (P1, 348-352).

"I think having the chance to learn and develop my skills would make me feel more confident about managing psychological issues. I need to learn about cognitive behavioural therapy, just to understand what everyone is going on about. I also need to have a better understanding about anti-depressants because at the moment I feel under confident in that" (P2, 595-599).

4.21 DISCUSSION

It is clear from this finding that all the participants felt that having a better understanding about the work of psychologists would be beneficial and desirable. Although other literature examining this issue is scant, the few existing studies demonstrate something similar. In Farrell *et al's* (2005) study of teachers' perceptions of educational psychologists, they found that many teachers felt that having a better understanding about the work of these psychologists would enable them to utilise the profession more effectively. The Department for Education and Skills (2004) have recommended that for purposes of clarity and understanding, educational psychologists should explain their role more carefully and establish a clear statement regarding roles and function. In addition, following their study examining the perceptions of counselling psychologists by clinical psychologists, Lewis and Bor (1998) suggest that more information and greater clarification about counselling psychology is required in order to help create a clearer and stronger professional identity.

The desire expressed by many of the participants for improved skills and knowledge is also reflected in the wider literature. Studies investigating areas of health other than cancer have identified a strong need for ongoing training, particularly in the area of mental health (Gray *et al.*, 1999; Lehman and Kelly, 1993). With regard to cancer, studies have found that health care professionals, including both doctors and nurses openly acknowledge that they have a need for continual professional development in order to improve their abilities to assess patients for distress (Faulkner *et al.*, 1991; Samaroo, 1996; Lloyd-Williams and Payne, 2002; Lawrie *et al.*, 2004; Hackett and Gaitan, 2007). In many of these studies, the health care professionals involved identified mental health as the area in which they felt most under-confident and poorly trained.

The reasons for this are likely to lie in the fact that nurses working in cancer and palliative care are not required to undergo any mental health training and the vast majority take up specialist posts without having any specialist mental health knowledge (Lloyd-Williams and Payne, 2002). In addition, with the ongoing emphasis being on the management of physical rather than psychological symptoms coupled with the shortage of both liaison psychiatrists and psychologists, the provision of teaching on mental health related topics in these health settings is relatively rare (Lawrie, *et al.*, 2004).

4.22 CRITICAL REFLECTION

The questions about how the nurses went about assessing patients for distress resulted in them moving away from emotional type discussion and towards more factual descriptions about their practice and skills. I was struck by how comfortable they seemed when talking in this way and sensed that this was the style of interaction that they felt most familiar and comfortable with. It was another reminder of the problem-solving focus that nursing seems to emphasise and encourage.

4.23 ISSUES OF REFLEXIVITY

Prior to the interviews, I had been mindful that asking the participants questions about how they assessed patients for distress had the potential to feel very threatening and/or exposing. In reality, this did not appear to be the case and instead all the participants offered detailed accounts of their assessment strategies. The fears I had about them thinking I may have been judging their competence began to settle slightly as they appeared to enjoy the opportunity to talk in detail about this aspect of their clinical practice. That said, although the participants described feeling ultimately confident about assessing for distress, I felt wary and unsure. The fact they spoke with such conviction about their confidence led me to wonder whether this was actually a true reflection of their experience or whether they were telling me what they thought I wanted to hear. This unsettled me and I found myself looking for signs that this confidence was actually designed to hide something more fragile. With time, this feeling in me settled slightly. I could not detect anything behind their words and felt concerned that I was seeking something that did not exist and was a reflection of my assumptions rather than anything else. During these interactions the professional differences between us seemed to disappear and I was able to relax and simply enjoy listening to their engaging descriptions about their work with patients.

SECTION THREE: FINDINGS RELATING TO CLINICAL NURSE SPECIALISTS

4.24 MASTER THEME: FEELING COMPETENT AS A CNS

Although specific questions about the CNS role were not on the interview schedule, during the course of discussion, all participants were keen to offer detailed descriptions about their role and remit. These were often described in terms of the skills which they believed were central to them feeling like effective and competent practitioners. Their accounts clustered around six sub-themes: 'knowing limits', 'offering support', 'managing time', 'having knowledge', 'independent working', and 'information sharing'.

4.24.1 Sub-theme: Knowing limits

The first theme to be considered, 'knowing limits', reflects comments made by all but one of the participants about the professional boundaries of the role and their perceived limits of competency. A number made reference to this very early in the interview process, suggesting that an ability to know their boundaries was perceived to be particularly important:

"I am not a counsellor, I am not a trained counsellor, you know I have got basic counselling skills training but I am not a counsellor and I know where to stop and I know when I need to hand over" (P8, 48-50).

"A psychologist is likely to have ways of helping that person to think differently or manage the thoughts differently and I don't have that knowledge, I am not trained in that or competent to even try. I know my limits" (P10, 206-208).

I was struck by the fact that in defining their role, many of the participants chose to start with those things which they felt they couldn't or shouldn't do. Behind these comments I sensed a degree of concern about being 'found out' for doing something wrong, or something they were not trained to do. This left me wondering if their statements were about wanting to reassure me that they were not over-stepping their boundary of competence in terms of psychological care.

4.24.2 Sub-theme: Offering support

In terms of what they did feel competent to deliver, all but one of the participants identified the offering of support as a key part of their role. This was described by most in the context of offering emotional support to patients and families:

"They (patients) use me as their support and I see that and know it is a key part of my job, so I try my hardest and if it is about getting them through treatment then I will do my utmost to offer all the emotional support they need to get through it" (P9, 207-209).

One participant spoke about support in slightly different terms, describing it instead as something she provided for junior nursing staff in an attempt to improve their confidence levels and help them feel more empowered to deal with patients' emotions:

"I say to people (junior nurses) it's alright, you don't need me, you can deal with this, I will come and deal with it if you really can't but just have a go, because you know the patient and I know you can do this. So I support them and hope it builds up their confidence" (P8, 229-232).

4.24.3 Sub-theme: Managing time

Another issue mentioned by many of the participants was that of 'managing time'. The majority described this in terms of trying to manage the demands of their role in such a way as to ensure they had sufficient time to offer their patients. Whilst simple in concept, this was often described as very challenging in practice due to the numerous other demands placed on them:

"I try to offer them ample time, that is part of my role, because I think there is nothing worse than a patient feeling under pressure and aware that I am limited for time. It would make them feel "oh god, I daren't burden her with anything I'm worried about", so I am constantly trying to protect patients from the pandemonium that is always going on behind the scenes and instead I try to present as calm and as though I have all the time in the world" (P6, 231-236).

Another dimension to 'managing time' mentioned by a number of the participants was the short time scales that many of their patients had in terms of life expectancy. This resulted in a constant awareness of trying to ensure that patient and family needs were prioritised and met within these limited time frames:

"There's a subtle, ongoing time pressure in this job. You can't wait until next week, because they may not be alive next week. You need to keep your eye on that and always remember that time is precious and you need to get on and do things" (P10, 119-121).

I sensed from these comments that effective time management, although an expected part of their role and something they were clearly competent in, was perceived by some as a source of ongoing stress. Throughout the course of the interviews, others began describing time as something they struggled to cope with, leading to the creation of a separate theme 'time pressure', which is examined in more detail in section 4.27 of this chapter.

4.24.4 Sub-theme: Having knowledge

Many of the participants identified 'having knowledge' as a particularly important and defining feature of their role and central to their experience of feeling competent. Knowledge about cancer, treatments, side effects, symptom management, pain control and referral processes were all identified as areas they felt they needed to be fully informed about. Maintaining this knowledge level was described by some as a particularly important and tangible sign of credibility and something they felt others were likely to judge them on:

"You need to be as informed about treatments as the surgeon and as your colleagues are because you have to be able to understand it, talk about it, answer every possible slant on a question because if you don't, if you don't know about it, and understand about it you lose all credibility you are lost really, because you have no credibility with that individual whom you are supposed to be saying I am here to help you and no credibility with your colleagues " (P8, 29-34).

4.24.5 Sub-theme: Independent working

In addition to adequate knowledge, a number identified the importance of being able to work in an independent, autonomous and flexible fashion. This was again described as an essential skill and central to their feelings of competence. The following quote illustrates this:

"I have got all this knowledge and all these skills and I need to work out what each person needs. Do I need to offer support or write a prescription? I need to work that out, I need to know how to work that out and what is the best course of action to take. It means I need to be open in how I think" (P5, 445-449).

4.24.6 Sub-theme: Information sharing

The final sub-theme is that of 'information sharing'. A number of participants identified the ability to share information in an effective and sensitive fashion as a key part of their role and yet another sign of them being competent practitioners:

"We have so much information to give them (patients), it can take over sometimes but you have to get it done, and done in such a way that is calm and at the right pace, so they don't feel overwhelmed. It is quite a skill to balance it all" (P5, 349-351).

Behind the sub-themes 'having knowledge', 'independent working' and 'information sharing', I detected feelings of pressure, along with anxiety and fear about the possibility of being viewed as incompetent by others. This raised thoughts for me about how safe and supported the participants felt in their working environments and whether the expectations placed on them were realistic and manageable. These issues are explored in more detail in section 4.27 of this chapter

4.25 DISCUSSION

This section of findings reveals a range of skills which the participants felt to be central to feelings of competence, with all but one of them citing awareness of professional limits/boundaries as particularly important. An extensive review of the literature reveals somewhat conflicting opinions about what constitutes the professional limit of the CNS role. This in part appears to be due to long standing problems with role definition, which Bamford and Gibson (2000) state is underpinned by ongoing issues of role ambiguity, individual interpretation, variation in educational preparation, title confusion, lack of authority and insufficient research into the role. Armstrong (1999) adds to this by stating that although the CNS role traditionally involves five main areas; clinical work, research, teaching, consultancy and effecting change, in reality each CNS interprets their role uniquely depending on their position, level of education, personal goals and expectations of others. With this in mind, it is unsurprising that there are no clear guidelines for where the limits of competence lie. Compounding this problem is a growing pressure on nurses to diversify, extend their roles and take on greater levels of responsibility (Craven, 2000; Willard and Luker, 2005). The growing trend towards holism has seen nurses being placed under increasing pressure to be solely responsible for the supportive and psychological care of patients and this has involved an expectation that they should be able to deliver counselling and other psycho-therapeutic interventions to patients (Wyatt, 1993). The overall lack of clarity and regulation regarding the CNS role is increasingly problematic and clearer guidelines as to what is expected from them is timely (Castledine, 2002).

That all said, the issue of boundaries has recently been highlighted by the NICE guidelines (2004a) and they have gone some way to establish clearer boundaries of professional competence in the area of psychological assessment of patients. They state that anyone involved in the delivery of emotional care to cancer patients should "be able to identify when they have reached the boundary of their competence and should refer the patient onto a more specialist service" (p.78). More specifically, they provide a four level model of care and make it clear that CNSs should only be practicing at level two. This involves screening for psychological distress and offering certain psychological techniques (problem solving) to help patients manage situational crises at key point in the cancer pathway.

The importance of offering emotional support, both to patients and more junior colleagues as identified by almost all the participants in this study is well documented in the wider literature. Despite the aforementioned problems with the exact definition of the CNS role, it appears from the literature that within cancer and palliative care settings, CNSs certainly have a specific remit to provide emotional support to patients and families (Willard and Luker, 2005). Jack *et al.* (2003) identified support as one of the main contributions made by CNSs to both patients and staff, whilst Bamford and Gibson (2000) found that CNSs felt that the offering of support was a particularly key and valued part of their role. Other studies have identified the empowering of more junior staff through the provision of support as an important aspect of the work of the CNS (Bullen, 1995; Armstrong, 1999; Castledine, 2002).

The emphasis placed by many in this study on the importance of being effective time managers is poorly represented in the wider literature. Only one article written by a CNS, offering a personal account of her role, was found which described the importance of being able to prioritise and manage time (Bullen, 1995). The lack of literature in this area is discussed in greater detail in section 4.27 of this chapter, along with recommendations for future research.

'Being knowledgeable', something that the majority of participants felt to be a requirement of their role, is present in other literature. Armstrong (1999) identifies that the very nature of the role being a 'specialist' one implies that post holders should demonstrate knowledge, skill and abilities at an advanced level. Other literature also reveals that CNSs themselves feel that having sound knowledge is essential for competent practice (Bullen, 1995; Bamford and Gibson, 2000; Jack *et al.*, 2003). What is less clear is what constitutes sufficient knowledge and as already established, educational variation amongst CNSs is not uncommon (Bamford and Gibson, 2000). There appears to be no agreement as to the educational requirements for CNSs; however Bamford and Gibson (2000) in their study of 25 specialist nurses found that many felt that a pre-existing educational pathway was something that would have prepared them much more fully for their roles. They also found that the nurses felt education alone was not sufficient to produce an expert practitioner, and that substantial clinical experience was equally important.

The ability to work independently and share information effectively were both cited by many of the participants as important aspects of work. This is another finding reflected in the wider literature. Autonomous working, accountability, responsibility and an ability to make high level decisions about treatments, admission and discharges have all been identified as key CNS competencies (Torn and McNichol, 1998; Bamford and Gibson, 2000; Clark *et al.* 2002). In addition to this Clark *et al.* (2002) state that the giving and receiving of information forms a considerable and important part of the CNS role.

4.26 MASTER THEME: SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

During the interviews, many of the participants spoke openly about the aspects of their jobs which caused them to experience a variety of negative emotions including worry, stress, anger and anxiety. Their subsequent accounts clustered around six sub-themes: 'working with illness/death/loss', 'expectations', 'lack of support', 'time pressure', 'understanding' and 'team working'.

4.26.1 Sub-theme: Working with illness, death and loss

Working with illness, death and loss was identified by all but one as a source of intense emotional discomfort. Some cited certain situations which they found particularly challenging in terms of emotional cost. These included dealing with young patients, those patients using denial as a coping strategy and patients who were no longer curable. For most however, the emotional burden was described as being more generalised in nature. The following quote captures the thoughts of one participant, and clearly conveys the intensity of her emotional discomfort:

"This job really takes it out of you. There is a big emotional cost and I know everyone has their different way of dealing with it, but the truth is that it takes something from you and if you're not careful you end up sucked dry and burnt out. I have seen it happen and I know I am not immune, I sometimes feel so full of misery, other people's misery that it paralyses me. It is the real downside to the job and you need to keep yourself safe and not let it get out of hand" (P8, 431-437).

4.26.2 Sub-theme: Expectations

Another source of discomfort described by many of the participants were the expectations placed on them both by others and by themselves. For some it was the public's expectations that caused most discomfort and these were described as being largely unrealistic and leading to feelings of pressure and burden:

"The public don't see you as a human being a lot of the time, they forget that we are just people who feel things and can only do so much. I find the expectations they have really extraordinary, it is really tough going sometimes" (P1, 725-728).

"We are seen as angels. We are not you know, we are professionals. So the public perception of what we do is not right. It's a constant bloody battle, because if people think we are angels, it makes breaking bad news pretty difficult to reconcile" (P1, 690-693).

Others reported feeling that the most problematic expectations, existed either within themselves or amongst their colleagues. One participant identified her immediate colleagues as the source of her discomfort due to the competitive expectations she felt they placed on her and each other:

"It's so competitive, it's all about who is the busiest, and you know, I can't keep up with it, I struggle 'cos there is also an unwritten rule that you mustn't show any signs of weakness. The whole thing is pretty awful really" (P7, 455-457).

Another reported feeling that the culture in which she worked had placed such excessive pressure on her to cope that she had consequently developed unrealistic expectations about her own potency and coping capacity:

"I think nurses are very reluctant to let their guard down. I am aware I feel like I am invincible, that I can take this, take anything and just grit my teeth and get on with it, when inside I am actually falling to bits, but I don't want anybody to know I am not coping, there are connotations of not being able to cope, so I keep this façade going, I feel I need to do that to survive" (P8, 481-485).

For another, the expectations which caused her most discomfort were self-generated and appeared to be driven by very personal motives:

"It's when patients haven't got long and I feel this terrible urgency and pressure to get it right for them, there isn't any time to mess about and I really feel it, the weight of responsibility to get it right. It's horrible but I can't help it, 'cos that could be my dad". (P2, 252-255).

I was moved and struck by the power of all these comments and felt the intensity of the vulnerability behind them. They were clear illustrations of the pressure the participants felt under and also offered insight into the feelings of loneliness and isolation that they were managing.

The next three sub-themes to be considered – 'lack of support', 'understanding' and 'time' - are linked together by a shared feature of being viewed by the participants as significantly lacking or in some cases totally absent.

4.26.3 Sub-theme: Lack of support

Over half the participants reported feeling there was totally insufficient or even non-existent professional support in place for them, leaving them feeling undervalued and at times overwhelmed. The following quote captures the thoughts and feelings of a number of the participants:

"As it is, there isn't any support, there is nowhere to go, there is absolutely no support at all for us. We are just left to cope and cope take on more and more. It isn't easy to maintain, everyone needs to feel they are valued and supported, and we just aren't." (P7, 442-445).

Behind this comment I detected strong feelings of anger and resentment, along with a sense that the participant felt let down and in some way abandoned by the organisation in which she was trying to function. I also sensed feelings of accepting that support was never going to be something which was prioritised or forthcoming.

One participant reported feeling it was more the lack of support available for patients which caused her difficulty and distress as she was often left managing their emotional distress on her own:

"Patients all want to know what is out there for them, what support there is, what counselling they can get, and I have to tell them there isn't anything. There is no specialist counselling services, nothing through the GP and I find it hard having to tell them that, and then I have to cope with their anger and frustration. It's a bit of a nightmare really" (P5, 267-271).

4.26.4 Sub-theme: Understanding

Lack of understanding was cited by many of the participants as leading to a variety of negative emotions. This was spoken about in a number of different ways. Some reported feeling that they themselves had a lack of understanding about certain issues/topics, meaning that decision making was challenging and left them worrying about whether they had done the right thing or not:

"To me the symptoms of dying and depression are the same and I find that really difficult. I suspect it is because I don't have a good enough understanding of depression to really know what is what, but it means I am unsure about whether anti-depressants are needed. I worry about that because you don't want to get that wrong, but sometimes it is just so hard to know" (P2, 297-302).

For others, the challenge was described more in terms of feeling that their role and the stresses associated with it were just not properly understood by others including: management, members of the multi-professional team, the public and even members of their own families. The following quotes capture the thoughts of a number of the participants and all convey feelings of isolation, frustration and loneliness:

"I don't think the management here have a clue about what we do, they don't understand our jobs at all, not being understood makes our lives much more difficult" (P7, 457-459).

"A lot of people think we do hands on nursing, that we actually give the physical care. They just don't understand the role at all, they don't have a clue what we do I think the main thing is that they think we only get involved in the last days of life, which is rubbish" (P2, 419-422).

"My family doesn't understand, they can't understand. It's not possible for them to and so I can't take it home, you can't talk it through over dinner like other jobs, so you just don't talk about it at all, and sometimes that can do my head in" (P9, 164-167).

4.26.5 Sub-theme: Time pressure

Time, or lack of it was cited by half of the participants as an ongoing challenge, which was felt to be a persistent source of pressure and concern. Some described the cause of the time pressure as being the progressive nature of their patients' illnesses, meaning they felt they were working against the clock and often literally running out of time:

"Sometimes we don't have time because people die too quickly and therefore there is no time to do that work or sort that problem out. I find that very hard when time just runs out and you know there are outstanding things" (P2, 201-204).

Others identified time pressure as stemming more from the numerous demands their roles placed on them, making it hard for them to deliver the necessary levels of emotional support to patients:

"I mean I don't have the time to offer that sort of support, there is so much else to do, I am always pushed for time and proper emotional support would take time that I don't have to give" (P7, 145-147).

A number described feeling that the organisation in which they worked did not prioritise or protect sufficient time for them to consider and process their own emotional needs. This appeared to be a source of considerable distress for the participants and generated feelings of frustration and anger:

"Thinking about it, we are not given any protected time to be supported or to offload, there is no consideration given to the fact we might sometimes need time for us, perhaps time to reflect or time to talk something through. That makes this job really hard, not feeling there is any protected time" (P7, 461-465).

4.26.6 Sub-theme: Team working

The final sub-theme to be considered is that of 'team working' which was raised by over half the participants as a source of difficulty and worry. For most this was described in terms of the practical challenges of communicating effectively with a large team and ensuring all members were kept up to date with the necessary information:

"There are so many people to keep in the loop, it is really hard to do it, plus things change so quickly, so actually it is not really possible, so it becomes a source of stress, and you are always worrying that you haven't handed things over" (P5, 298-301).

For others the issue was more about the lack of team working and the feelings of isolation and loneliness that stemmed from having to function as a lone practitioner without anyone to rely on for support or information:

"I am really isolated here, there are only two of us in the hospital and we work differently to other research nurses. It is a pretty huge job, I rarely see my other colleague, so not belonging to a team can be really isolating and lonely" (P4, 149-151).

4.27 DISCUSSION

This section of findings reveals a number of different factors which the participants cite as causing them emotional discomfort and distress, with half of them identifying working with death, illness and loss as particularly hard to cope with. This finding lends support to previous research which has shown there to be potentially serious psychological implications for health care professionals working in such environments (Payne, 2008). Research examining the impact of stress on staff has led to the identification of two concepts; burnout and compassion fatigue. The former refers to a state characterised by emotional exhaustion, depersonalisation and a loss of personal accomplishment and job satisfaction (Brennan, 2004), whilst the latter refers to a feeling of helplessness, confusion and exhaustion (Payne, 2008). These areas have received significant research attention leading to a greatly improved understanding of the psychological implications of caring for those affected by cancer. A study by Ramirez *et al.* (1995) found that amongst oncologists, rates of psychiatric morbidity and emotional burnout were almost as high as those found in patients, whilst Whippen and Canellos's (1991) study of 598 oncologists found that

56% of the sample reported a degree of professional burnout. A further study by Ramirez *et al.* (1996) found that out of a sample of 393 oncologists, 31% were suffering from emotional exhaustion, whilst 28% had above threshold scores on a psychiatric screening inventory. The impact on nurses is no less concerning and out of all the professions, research has found nurses to have the highest rate of suicide and psychiatric illness (Firth-Cozens, 1997 cited in Brennan, 2004). Those working in cancer settings have been found to experience particularly high rates of health anxiety, with specific fears about developing malignant disease (Escot *et al.,* 2001). Research also indicates that nurses are exceptionally vulnerable to the emotional impact of their work and are very affected by patient death, particularly when it is sudden or involves a young patient (Wilkinson, 1995). An American study involving 217 nurses working in palliative care settings, found that 78% were at moderate to high risk of compassion fatigue (Payne, 2008).

The issue of problematic expectations which were mentioned by many of the participants, has also been identified in other literature. A study conducted by Jarrett *et al.* (1999) sought to explore the expectations held by patients about palliative care teams and revealed that many patients and carers had rigid and inaccurate expectations about nurses and doctors. Of note, doctors were viewed as only being involved in medical interventions, whilst patients expected nurses to only deliver counselling and listen to their problems. More recently Seymour *et al.* (2002) undertook a study to examine the expectations held about Macmillan nurses and found that many of these nurses felt their managers held expectations about their roles which were totally at odds with their own expectations and also conflicted with the everyday demands made on them. These differing expectations were found to be an ongoing source of pressure and tension for the nurses, leading to problems of ambiguity and role conflict. The study also revealed that the public's expectations of Macmillan nurses were unrealistic and served only to add to the nurses' sense of worry, frustration and pressure.

Feeling unsupported - a problem identified by over half the participants in this study - is another finding well documented in other literature. Ibbotson (1999) reports that CNSs generally feel unsupported by both nurse managers and senior trust managers, whilst McCreaddie's (2001) study revealed that out of 20 CNSs, 18 reported feeling completely unsupported, having little or no contact with their line managers. In addition, these nurses described feeling an expectation that they should be able to work in an unsupported fashion and believed that seeking support would be interpreted as a sign they were not coping. A slightly more recent study conducted by Booth *et al.* (2003) which involved a particularly large sample (1048 cancer and palliative care specialist nurses) found that the majority of these nurses felt unsupported in their roles and 25% cited increased support as their most pressing need. The implications of this lack of support are considerable, not only in terms of the potentially negative consequences for professionals but also for patients, for as Vachon (1987) cited in Booth *et al.* (2003) states, "care givers who feel supported in their work provide a high level of care to patients and families" (p. 78).

The issues raised by half the participants in this study about feeling poorly understood by others and having inadequate levels of understanding about certain aspects of their clinical work are problems which others have also identified. In terms of clinical knowledge/understanding, Booth *et al.* (2003) report that from their sample of CNSs, many reported feeling a need to improve their levels of knowledge as well as their clinical skills. These nurses also stated a need for improved access to resources and educational support. In terms of feeling poorly understood by others, Ibbotson (1999) and Clark *et al.* (2002) in their respective studies both found that many CNSs felt their colleagues had poor levels of understanding about their roles, and consequently made inappropriate referrals to their services. Bamford and Gibson (2000) suggest that poor understanding of this nature is a major contributing factor in generating feelings of professional isolation.

Time pressure, which was mentioned by most of the participants as being a source of ongoing distress has received little attention in the literature. Only two other studies could be identified which highlighted the issue. In her study examining the role of the CNS, McCreaddie (2001) identified lack of time as a considerable source of frustration for nurses, whilst Booth *et al.* (2003) found that out of 1048 nurses, 62.6% cited lack of time combined with workload pressure as major source of difficulty. It is clear not only from this study, but from the two cited that time pressure is a significant problem for nurses. This coupled with the known risks of burnout and compassion fatigue is clearly something which requires consideration. Further work into this area would be valuable in order to identify the exact source of the problem (e.g. caseload size, organisational issues) and establish whether any changes could be considered in order to alleviate the burden of this pressure.

The challenges of team working as mentioned by many of the participants is something that is being increasingly recognised. There is a growing body of literature stating that whilst the multi-professional model of working is certainly beneficial to patients, it can actually be a source of considerable conflict and stress for those staff involved (Payne, 2008). The reasons for this are manifold and include professional allegiance, hierarchical behaviour, role ambiguity, inequality, differing perspectives, overlapping professional boundaries and poor communication (Ovretveit *et al.*, 1997; Hill, 1998; Payne, 2000; Firth-Cozens, 2001b). The issue of isolation is particularly well documented and much of the research into the CNS experience has identified it as a problem and source of distress (Bousfield, 1997; Torn and McNichol, 1998; McCreaddie, 2001; Corner and Bailey, 2001; Loftus and Weston, 2001; Richardson *et al.*, 2001; Clark *et al.*, 2002). Booth *et al.* (2003), who also identified isolation and professional loneliness as a source of distress for CNSs, recommend that these nurses require specific support and facilitation if they are to develop their full potential.

Whilst it is clear that these particular findings lend support to the existing literature, it also raises the question as to whether other members of multi-professional teams, particularly those who tend to be lone professionals (e.g. physiotherapists, occupational therapists) experience similar difficulties. Further research into this area would offer potentially valuable insight and provide possible solutions for how professionals working in such teams can ensure that their working environments and professional relationships are both sufficiently supportive and conducive to providing patient care from a multi-disciplinary perspective.

4.28 MASTER THEME: COPING WITH BEING A CLINICAL NURSE SPECIALIST

This master theme is concerned with the ideas generated by the participants about how they coped with the challenges of their role. Their accounts clustered around two sub-themes: 'colleague support' and 'boundaries'

4.28.1 Sub-theme: Colleague support

All but one of the participants cited their colleagues as playing a central role in providing the necessary support to help them manage the inherent stresses of their work. All described this support as being informal in nature and involving the sharing and offloading of emotions, concerns and difficulties:

"We are very supportive of each other, we can offload onto our colleagues, our team and at the end of most days and the beginning of every day we will talk about all the patients we have got on our caseload and talk about anything you think went wrong or went right and that is very useful" (P2, 387-390).

"When I see my CNS colleagues in the corridors we sort of let off steam a little bit sometimes, or we go for coffee and let off steam" (P6, 81-83).

"I am sort of like the more junior one and I feel very well supported with my colleagues and I feel we can discuss issues. It's good if you've got close work colleagues like that because they understand the specialist problems" (P3, 222-225).

4.28.2 Sub-theme: Boundaries

Half also described boundaries as playing a key role in helping them manage the stresses of their work. For most, this involved the use of time boundaries which were viewed as essential for maintaining psychological health and balance:

"You need to take care of yourself because it's a hard job and unless you have a strategy you end up burning out, so for me it's about saying it's 5pm, that's my lot, I'm out of here. That's what I do every day, 5pm and I am gone" (P1, 836-839).

However for one participant, the boundary that helped her to cope with the challenges of working in the field was the ultimate boundary offered by the death of her patients:

"The thing that makes it possible to do this work is the fact that people die. Perhaps that sounds selfish, it certainly doesn't mean I won't do everything to make sure things go well, but ultimately it's often the fact that they are going to die and the situation is going to end that makes it possible for me to stick with it and manage it" (P10, 279-282).

Behind the words of this participant I detected embarrassment and a sense of guilt. This was reinforced by her desire to reassure me that her ultimate need for patient death in no way compromised patient care. I was left wondering whether she had inadvertently verbalised something that perhaps many nurses thought, but felt unable to admit to.

4.29 DISCUSSION

The idea expressed by all but one of the participants that colleagues play a central part in helping them cope with the demands of their roles is directly in line with other literature. Baker (1987) identifies colleague support as essential for professional survival, whilst Ibbotson (1999) who undertook a qualitative study to examine the role of the CNS, found that out of a sample of 14 CNSs, 10 cited support from medical colleagues as being particularly valuable. A larger study, conducted by Bamford and Gibson (2000) identified colleague support as being crucial both in terms of helping CNSs develop their roles and in coping with the stresses inherent in their work. The style of support identified was predominantly informal in nature and lacked any formal structure, which again reflects the finding of the current study. The importance of support is further endorsed by Brennan (2004), who states that support amongst colleagues is essential for reducing feelings of stress and isolation.

The use of boundaries is well established both in concept and practice within the field of psychology. Within the nursing literature however, the importance of boundaries as a means of managing stress is far less evident, making the finding from this study somewhat unusual. Although some literature does exist, the majority of it advocates the use of boundaries in terms of nurses protecting their professional registration, rather than being viewed as a proactive measure for maintaining psychological health (Sheets, 2000; Jacobson, 2002; La Tonia, 2006, Holder and Schenthal, 2007). Whilst Brennan (2004) makes clear that for those working in cancer settings, the maintaining of clear boundaries, particularly between work and home life is an essential strategy for reducing stress, no other literature could be found which endorses this particular practice for nurses. This raises a number of questions. On a specific level, it would be useful to explore further what led this particular nursing team to adopt boundaries as a key coping strategy. Secondly the lack of literature in the area suggests that nurses may be being encouraged to work without the boundaries necessary for psychological safety, hence the high rates of compassion fatigue and burnout. It would therefore be of potential value to examine what underpins this tendency and discover whether the task orientated nature of the profession makes boundary setting particularly challenging. Clearly further research in this area would be useful in order to gain a better understanding of the issue and could perhaps lead to the identification of ways in which boundaries could become a more familiar concept within nursing practice.

4.30 CRITICAL REFLECTION AND ISSUES OF REFLEXIVITY

Although specific questions about the participants' roles and responsibilities were not included on the interview schedule, I was struck by how keen they all were to talk about these issues. As they began talking about their individual roles I sensed distinct feelings of stress and pressure however these emotions were again implied rather than stated openly, meaning that identifying them relied on searching carefully behind their words. I however felt clearer about the possible cause of this guardedness, as during the interviews their concerns about being judged as incompetent by others became clear. Despite the lack of verbalised emotion many of the interviews felt emotionally charged and I was therefore very careful in my handling of this. I maintained a supportive, open and non-judgemental approach and remained very mindful that participants were possibly feeling fearful about professional exposure.

As the discussions progressed, the participants' willingness to engage emotionally changed. Many began to verbalise more openly how they felt, labelling feelings of isolation, loneliness, frustration and worry. During these interactions I was aware that the dynamic between us had altered slightly. The participants appeared less guarded, and consequently I experienced a stronger emotional connection with them. My worries about a power imbalance between us no longer felt so acute and instead the interactions felt more equal and balanced. I felt the challenge now was to maintain an appropriately supportive and safe environment in which they could continue expressing emotions without allowing the interviews to become therapeutic encounters. I did this by continuing to listen in a supportive and non-judgemental fashion, whilst also maintaining clear boundaries and staying focused on the task at hand.

4.31 ADDITIONAL KEY REFLECTIONS

4.31.1 Critical reflection on my use of IPA

IPA is a qualitative methodology which offers a creative yet robust means of exploring, understanding and communicating the experiences and viewpoints of participants. My decision to employ IPA was in part guided by a conviction that it would allow me to fully explore the experiences of the participants and gain access to their thoughts, beliefs and feelings about the topics under investigation. Despite this aim I feel that due to some weaknesses in my application of the methodology this was not totally achieved.

One particularly important reflection is that throughout the research process I exhibited a tendency to neglect the quality of the participants' experience and instead concentrate on their thoughts and perceptions. This is clearly evident in the findings as the majority describe participant thoughts rather than feelings. This tendency extends beyond my findings and can even be found when examining the construction of questions in my interview schedule (see section 2.8.2). For example, in the first question: "As an experienced clinician in this field, can you tell me what you feel about psychologists working in the field of cancer/palliative care?" the use of the word 'what' encourages a focus on thoughts rather than feelings. Had I instead used the word 'how', the participants may have felt more inclined to engage in discussions about how they felt. Further consideration of the interview schedule reveals that only one question specifically asked the participants about their feelings thus immediately reducing the overall likelihood of eliciting 'feeling based' responses.

The reasons for my seeming inclination towards cognitions rather than feelings can possibly be traced back to the original challenges I had in gaining ethical approval for the study. From the outset the committee had concerns that the research risked leaving participants feeling demoralised and questioning their competence. Whilst these concerns were dealt with accordingly and ethical approval was granted it somehow left me with a sense that the nurses' feelings needed protecting, meaning that exploring them was somehow risky and to be avoided. This sense of 'feelings being risky' was further compounded by my experience of interviewing the participants. During these interactions there was a distinct lack of emotional discourse despite efforts to encourage otherwise. I observed an ongoing resistance amongst them to offer any insight into the quality of their experience and instead a preference to move towards factual, thought based dialogue. Throughout the interviews gaining access to the participants' emotional worlds felt fraught with difficulties and I experienced a powerful sense that doing so was unfamiliar and unsafe. Ultimately the combination of me feeling under some pressure to not cause distress coupled with their resistance to engage in emotional discourse resulted in data which were weighted in favour of cognitions and perceptions.

Within IPA the analytical process is divided into two distinct phases. In the first instance the researcher aims to place themselves alongside the participant in order to gain an understanding about their world and get as close to their views as is possible. The second phase involves a much more interpretative style of analysis, thus allowing the researcher to consider the data in a more speculative manner. This can involve posing questions about what it means for participants to have made particular statements or expressed certain feelings or concerns. It is this second stage of analysis which moves IPA from being simply a descriptive methodology to one which offers an interpretative account of what these descriptions mean for participants (Larkin *et al.* 2006). Reflecting on my own phases of analysis, I became aware of having demonstrated a rather conservative stance towards interpretation and a reluctance to offer any substantial account of what it may have meant for participants to have certain thoughts or concerns. This somewhat cautious attitude meant that whilst the analysis may have successfully summarised participant concerns, it had often failed to progress to a more interpretative level. This lack of additional focus meant that my attempts to provide a detailed exploration of and understanding about the participants' experience were somewhat compromised.

Although this reluctance was partly about inexperience, it was mainly due to feeling anxious about making inaccurate interpretations. This was underpinned by a sense of not feeling sure that I had the right to make interpretations about what the participants had said and tapped directly into some of the reflexive challenges that had been evident throughout the process. Having striven so hard to ensure that the participants had felt a sense of equality and were free of judgement or exposure, making interpretations felt uncomfortable, contradictory and incongruous. On reflection I realised that these concerns had stood in the way of allowing the full potential offered by IPA to be realised, meaning that the research was somewhat lacking at an interpretative level. These reflections allowed me to engage much more fully with the challenges involved in qualitative research, particularly with the difficulties of balancing representation against interpretation. I also felt more aware of the obligation that qualitative researchers have of making sense of data through the process of interpretation, meaning they must be willing to take responsibility for interpretations that participants may not necessarily feel comfortable with. These reflections mean that should I utilise IPA again, I would do so with greater confidence, embracing more fully the interpretative phase of analysis and therefore producing a richer account of the meaning of the insider's perspective.

4.31.2 Style of discourse and possible implications

Reflecting on the overall style of this thesis I became aware of having used two distinct types of discourse. The first and most prevalent of these is medical discourse which dominates both the introduction and discussion sections. This means that the style of language I chose to use is the sort more associated with a medical model of care which tends towards a disease orientated approach to patients, placing particular emphasis on diagnoses, causation and remediation. This tendency is clearly illustrated in my use of psychiatric terminology such as 'morbidity' and 'disorder' (see section 1.5.2). In stark contrast to this are sections of the thesis in which psychological discourse emerges. Whilst these sections appear less often they include language which is much more aligned to the world of counselling psychology and indicative of a holistic model of care. This style of discourse is particularly evident in section 2.4.

In light of this being a doctoral thesis in counselling psychology it raises the question as to why it is so dominated by medical discourse? Related to this comes other questions about my professional identity and why as a psychologist whose role is to engage with the emotional experience of clients, I should choose to present my work and therefore part of myself in such a medical fashion? Consideration of these questions offered a welcome opportunity to reflect on the potential challenges posed by language that psychologists working in medical settings face. In terms of my own experience I became aware that it was certainly the environment in which I worked that had led to this leaning towards medical rather than psychological discourse. Achieving acceptance and successful integration into a multi-disciplinary cancer team is a challenging and difficult process. I realised that one of my strategies had been to mirror the dominant style of discourse, which was in all cases medical. Engaging in this 'common language' seemed to offer my medical and nursing colleagues some level of reassurance and a sense that I was 'singing from the same hymn sheet'. This strategy had been reinforced by a past experience of seeing a psychologist who had chosen to always use psychological discourse within the context of multi-disciplinary cancer team meetings. This had resulted in suspicion, ridicule and ultimately marginalization. This experience left me with a clear sense that professional survival in such an environment relied on me being able to trade my psychological language for something much more medical in nature and whilst this has proved be a successful strategy in terms of allowing professional integration it has posed other challenges. At the most fundamental level I am a counselling psychologist who thinks in psychological terms and works psychologically with clients. This means that my natural discourse is psychological. This is always reflected in the way I think about my clients and the work I do with them. The challenge therefore lies in the need to translate this natural, internal and often silent psychological discourse into a more 'acceptable' medical discourse without losing meaning or compromising my professionalism. This requires a chameleon-like ability which at times can generate quite intense discomfort including feelings of professional disloyalty and a sense of doing a disservice to a profession, of which I am proud to belong.

In addition to the personal challenges posed by the use of two discourse styles, there are other implications to consider. Firstly it presents difficulties in relation to conducting psychological research. Undertaking any sort of qualitative research within an environment where quantitative methodologies and randomised controlled trials continue to dominate is difficult in itself. However doing so using psychological discourse risks total disengagement from a significant proportion of the multi-disciplinary team. This means that the only way to maintain interest and support for such projects is to present it using the 'common language'. This was certainly my experience and is further illustrated by the fact that much of the published psycho-oncology research tends towards very 'medicalised' language. This in turn poses further problems, for although medical discourse may in some way offer psychological research some form of pseudo-credibility, the long term consequences are that the true essence of psychology is never revealed, leading to false perceptions and an inaccurate understanding of the profession. This is an area in which future research may well be enormously valuable, as in the first instance it would allow for an exploration about the role of language within multi-professional teams. This in turn could improve our understanding about how professionals regard different types of discourse and whether certain types of language are viewed as less useful or less respectable than others.

The second area in which there are implications to consider is that of clinical practice. In my own experience it is in this domain where the tensions of moving between two styles of discourse can become most acute. This is best illustrated by the challenge of writing initial assessment reports to consultant physicians which are routinely copied to clients. Finding a language which reflects the client's experience of both me and the assessment process but is also 'medical enough' for the clinician is not easy. However, it can be in these moments of discomfort that my professional identity feels clearest, for despite a pressure to 'speak' the medical language the importance of staying true to myself and my client always feels more powerful and important.

My general reflection about this issue is that over time, as psychology becomes a more established profession within medical settings such as cancer services, the pressure to conform and use medical discourse will abate. For now though it still feels as though we as a profession are being 'tested out' and until we are more acceptable to our medical colleagues, limits remain about how open we can be with regard to our natural discourse. In the meantime the main challenge is to continue the process of professional integration perhaps through the adoption of a somewhat alien discourse, but in such a way that our core identity as psychologists remains strong and our awareness of our professionalism and commitment to our client group is never compromised.

4.31.3 Absence of findings relating to systemic and/or bereavement issues

A final key reflection about this research relates to the somewhat unexpected absence of findings about families/carers or systemic issues in general. Neither is there any mention of the bereavement needs of this group. This is particularly striking in view of the fact that the psychological difficulties experienced by family members are now well documented (see section 1.7), coupled with the fact that for some time both the supportive and palliative care literature have openly stated that the care of cancer patients must extend to family members. In the case of palliative care this includes bereavement support. It is therefore rather surprising that the data were devoid of any reference to these issues.

Whilst the reasons for this are not totally clear there are a number of ideas which I fee, merit exploration. Firstly as already discussed in section 4.26 of this chapter the participants identified a number of issues which they described as causing them emotional distress. Included in these were time pressure, lack of support and working with death and loss. Considering these, it is perhaps clearer as to why the needs of family members were not high on the CNS agenda. In particular, their constant battle against time would suggest a very practical reason why extending care to families would be unrealistic and unmanageable for them. On a more emotional level, the fact that the participants described the constant exposure to illness, death and loss as a source of difficulty for them, coupled with the lack of available support would perhaps suggest that not accommodating the needs of family members was in fact a coping strategy and way of protecting themselves from further psychological distress.

Another issue worth considering reflects my own experience of having regularly heard nurses expressing anxieties about managing the emotional needs of family members. Watching a loved one cope with a malignant illness can be enormously distressing for families and it is not uncommon for them to experience and voice feelings of frustration, hopelessness and anger. It is these emotions which nurses often claim to be the ones they dread being exposed to as they feel unequipped to deal with them. They also describe feeling fearful about being drawn into pre-existing family conflicts or worse still, being asked to collude with lies about a patient's diagnosis and/or prognosis. This all results in a tendency for nurses to avoid family members and instead keep patients at the centre of their focus of care. This is likely to be compounded by the fact there is considerable ambiguity about whose role it is to provide support for family members. I have again been witness to many conversations where nurses have stated that the provision of family/bereavement support does not fall within their remit or reflect their skill set.

There are a number of implications relating to the absence of systemic findings in this research. Firstly it is an indication that there is perhaps scope to develop training courses specifically designed to cover some of the systemic issues associated with cancer. Such a course could involve some basic systems and bereavement theory, common psychological reactions to cancer (adults and children), collusion, changes in family roles and skills for managing difficult emotions. This would hopefully go some way to empowering nurses and helping them feel more confident in offering support to families. There is also something in this finding which suggests that nurses may benefit from feeling clearer about what their role involves with regard to families and what level of support they are competent to provide. Without this clarity it is perhaps unsurprising that they err on the side of caution. Of course without further research such recommendations are based on speculation and anecdotal evidence. Obtaining a clearer understanding about how nurses view and feel about family and bereavement issues therefore feels timely. This could be achieved through further qualitative research which would allow insight to be gained into an area which has as yet been unexplored.

CHAPTER 5

SUMMARY AND CONCLUSIONS

5.1 OVERVIEW

This study was conducted with two specific aims in mind. Firstly it was hoped to gain an understanding about the beliefs and expectations that cancer and palliative care clinical nurse specialists have of cancer psychologists. Secondly it was hoped the research would lead to a better understanding about how these nurses go about assessing patients and/or carers for psychological distress. In order to achieve these aims a qualitative research paradigm was adopted, thus allowing the topics under investigation to be explored in detail. This study can claim originality on the basis of it being the first attempt to examine the relationship between psychologists and clinical nurse specialists working in cancer care. It is also the first piece of purely qualitative research to have examined the assessment processes utilised by both tumour site specific and palliative care clinical nurse specialists.

5.2 MAIN CONCLUSIONS

From this study's findings it is clear that the level of understanding amongst the team of CNSs about the potential contributions of psychologists within cancer care was high and largely reflective of the literature pertaining to the topic. All demonstrated a good sense of the work undertaken by psychologists and although this was often lacking in specific detail, there was clearly an understanding about the key features of the role, the level of training required and the multi-faceted nature of the work. The perceptions about the profession in general were less cohesive, revealing a combination of both positive and negative beliefs. This finding was again reflective of the wider literature. However, the most consistent and perhaps important finding was that whatever the CNSs' beliefs or thoughts about psychology and/or psychologists, these were underpinned by feelings of uncertainty, a conscious awareness of lacking knowledge and/or understanding and a sense of the profession being esoteric in nature.

In terms of assessing patients for psychological distress, the findings indicate that this is an area in which all the CNSs felt confident. There was however no evidence of a formal or consistent assessment process in place, with a variety of different skills and approaches being employed by the nurses. What is evident from the findings is that communication skills, time and the CNSs' own emotions played the most significant role in the assessment process. This offers further support to the idea that assessment rather than being a standardised process appears to rely instead on the individual skills of each nurse. This raises the serious question of whether there is an expectation on CNSs to make decisions about patients' psychological health regardless of whether they have the skills to do so. Certainly the lack of a consistent assessment strategy would suggest that patients are potentially vulnerable to a 'pot luck' approach rather than a consistent and reliable standard of psychological care.

Most of the CNSs attributed their confidence in, and abilities to, undertake psychological assessments to two factors: experience and training. That said, almost all stated feeling a need for additional training, particularly in the areas of mental health, bringing into question how robust their reported feelings of confidence are. As already discussed (see section 4.17) the role that experience plays in assessment competency is unclear and the findings from this study do not lend support to the small amount of existing literature which argues that experience is not related to competence. Conversely the importance of training is very well documented, meaning these findings add further weight to an already substantial body of literature.

From the findings it is also possible to conclude that the CNS role itself is one beset with difficulties and challenges. Whilst all identified their roles as involving a number of key competencies, these were not consistent across the sample, suggesting considerable variation between post holders. This indicates a degree of ambiguity about exactly what constitutes being a CNS. In addition, all reported significant emotional burden associated with their respective roles. Whilst the nature of the work accounted for some of this, the majority was related to organisational issues and included feeling poorly understood, insufficiently supported and having to cope with unrealistic expectations placed upon them. These findings therefore suggest that CNSs are expected to have an extensive range of skills and knowledge, function at a senior level and carry considerable responsibility for many aspects of their patients' care. However despite this they face organisational challenges, combined with a lack of clarity about their professional identity which combine to create quite a considerable source of emotional distress.

5.3 RECOMMENDATIONS

On the basis of this study's findings a number of recommendations have been identified. Before outlining these, it is important to note that various areas of possible further research which would build on the current findings have been identified and proposed at various stages during the discussion sections of this thesis (please see chapter 4 for details).

In response to the findings about psychologists a number of proposals are suggested. It is clear that although psychologists have an increasing presence in cancer settings, it continues to be a profession which is unfamiliar to many and at risk of being misunderstood and tainted with its history of myth and stigma. The onus is therefore very much on the profession itself to make the necessary changes in order to foster greater openness and transparency. In the first instance it is suggested that psychologists holding posts in cancer and/or palliative care settings should be responsible for educating their colleagues about their role, remit and professional boundaries. This could best be achieved through informal presentations, scheduled on a regular basis in order to accommodate the high turn over of staff commonly found in such settings. These presentations could include a range of topics including: what constitutes a training in psychology, the various roles of the psychologist working in cancer and the types of psychological therapy used in cancer settings. Secondly it is recommended that psychologists work towards achieving a greater openness about the clinical work they undertake with patients. Historically those providing psychological care have tended towards the keeping of separate patient notes, meaning that the wider team is often left unclear about the nature of the work being undertaken. It is therefore suggested that in addition to detailed assessment/discharge reports and verbal feedback, psychologists ensure that their clinical work is sensitively documented in the patient's multi-disciplinary notes so that everyone responsible for their care has access. This suggestion does not preclude the keeping of separate process notes; however it does challenge the notion that psychological care needs to remain separate, secretive and hidden. It is also recommended that psychologists ensure a regular presence at multi-disciplinary meetings and use such forums not only to promote the importance of psychological care but to provide colleagues with ongoing education about their role and work. This could best be achieved through the regular presenting of client case studies. Finally, as specifically identified by the participants in this study, it is suggested that psychologists are open to inviting colleagues to observe their work. It is of course understood that this is not always appropriate and would need the full agreement of the patient. However it is believed that observing at least an assessment session would be of enormous benefit to any staff who have little sense of what is involved in such work.

With regard to the issue of assessing patients for distress, a number of other recommendations have been identified. Firstly it is suggested that a more formalised approach to assessment is implemented so as to ensure patients are assessed in a standardised fashion. In light of the fact there is little agreement about which screening tool is the most effective, it is instead suggested that the organisation is responsible for deciding on its own assessment approach, thereby taking into account the skills and needs of the CNSs. This for example could involve using a short screening tools (e.g. HADS or the Distress Thermometer) and combining it with a list of more qualitative questions designed to gauge the thoughts and emotions of the patient. It is recognised that further work would be necessary in order to identify the most suitable assessment strategy for this particular team. Secondly in response to the findings about training, it is suggested that further education is provided for the CNS team. A training programme could be designed covering topics such as the psychological reactions to cancer, signs and symptoms of psychological morbidity, methods of assessing for distress, general mental health, psychological therapies and psychopharmacology. It is also suggested that CNSs have regular access to communication skills refresher courses in order to ensure they are able to maintain and develop their skills in this areas.

The final set of recommendations relate to the findings about the CNSs themselves. It is suggested that further consideration about the exact knowledge, skills and qualifications required by CNSs is long overdue. As it stands there are no agreed minimum requirements for such post holders, meaning that the scope for variation is enormous. Not only does this risk a lack of consistently in terms of patient care, but it leaves the profession without a clear sense of identity and struggling to find its place in the multi-disciplinary team. It is therefore suggested that a formal qualification for CNSs is developed, thus offering parity for post holders and a greater sense of clarity about the role. It is hoped that this would go some way in reducing the unrealistic expectations placed on these nurses and help to foster a greater sense of understanding amongst their colleagues. It is also suggested that such a qualification would afford these nurses the professional status which they clearly deserve.

Lastly, it is urgently recommended that the emotional needs of the CNSs are both recognised and catered for. It is suggested that supervision provided by an external supervisor is offered on a regular basis, along with protected time for informal peer supervision. The monitoring of caseloads is also recommended in order to ensure that staff do not become clinically overloaded and explicit encouragement should be given to staff to leave work on time so as to allow them to maintain a clear work/life balance. Finally, a mentoring system is suggested so that new CNSs can be guided and supported by those with greater experience. Again protected time should be made available for this system to work effectively thus allowing staff to meet with their mentor on a frequent basis.

5.4 LIMITATIONS

Although considerable care was taken both in the designing and conducting of this research, a number of methodological limitations exist which need to be borne in mind when interpreting the study's findings and associated recommendations.

Throughout this research process the issue of reflexivity proved to be a source of concern and a significant methodological challenge. Although impossible to quantify, my professional identity as a psychologist is likely to have impacted in some way on the participants. It is most likely that my presence influenced how they chose to discuss certain topics, thereby affecting aspects of their responses. Throughout all the interviews I was acutely aware of the risk of the questions leaving the participants feeling professionally exposed or in some way lacking. This in turn impacted on how far I felt able to pursue certain lines of questioning. Whilst enormous effort was made on my part to manage these difficulties and minimise their impact (see chapter 2, section 2.10), on reflection it may have been more appropriate for someone neutral to have conducted the interviews on my behalf. This may have gone some way to reduce the risks of perceived status and inequality, thus allowing the participants to be more open in their responses. However this solution in itself would pose other difficulties. Firstly there would be the challenge of actually finding somebody with the necessary skill set, knowledge, neutrality, theoretical sensitivity and time to undertake the interviews. Secondly, by not conducting the interviews myself I would have been unable to observe the non-verbal behaviours or pick up the subtle nuances that are only available through direct contact with participants. Consequently I would have risked losing important data and insight. Finally, even if I had managed to find a suitably neutral and competent interviewer, the participants would have been aware that ultimately I would need to listen to the digital recordings in order to transcribe and analyse the data. This would possibly have created as much concern for them as me conducting the interviews and would not have guaranteed that their responses were any less guarded. Although a possible solution to this would have been for someone else to transcribe the interviews in such a way as to protect participant anonymity this would have totally compromised the quality of my analysis, as listening to, and transcribing the interviews proved to be a crucial part of the analysis phase. A final possible solution to this particular problem could have been for focus groups to be have used rather than one to one interviews. This may have reduced the intensity of the impact of any reflexive issues and provided an environment in which the participants felt less threatened and more able to be open in their responses. Again, this would not have been without its difficulties. On a practical level it would have been very hard for a group of nurses to be released from their work settings. The one to one interview format meant that each participant was able to ask a colleague to hold their bleep for the duration of their interview. This would not have been a possibility if a group format had been used. Secondly, a focus group would have been as likely to have its own difficulties in terms of group dynamics. Such settings can prove intimidating for more junior staff and would certainly have made discussions about colleagues much more difficult to have had. Also, a group format would be more likely to suppress individual honesty. Overall, there is no doubt that the study carries with it weaknesses relating to issues of reflexivity. The alternatives outlined are however problematic in other ways. It is therefore hoped that my awareness of the difficulties and concerted efforts to mange them, combined with the fact I was not known to any of the participants goes some way to have minimised their overall impact.

Another limitation that requires highlighting is the fact that I was the only person involved in the process of the research. Despite efforts to maintain objectivity, at times I was aware that my beliefs and experiences were impacting on my analysis decisions. I occasionally found myself looking for data which did not really exist, or placing themes into clusters where they didn't really belong. Without fellow researchers to constantly challenge such decisions, it is acknowledged that complete objectivity cannot be guaranteed. However as already described in chapter 2, section 2.9, various methods were used to maximise the reliability, validity and credibility of this research. Input from the independent judges proved particularly valuable and this combined with my own levels of awareness about the risks of subjective interpretation, helped to ensure that the results of this study offer an accurate account of the participants' thoughts, feelings and experiences.

The final limitation necessitating brief discussion relates to the small sample size (10 participants) and fact that the findings are an outcome of both the participants' thoughts and my interpretations. Both these factors mean it is important that the study's findings are not generalised but instead viewed in a tentative fashion and limited to the particular participants involved.

5.5 FINAL SUMMARY

In summary, despite a number of limitations with this study's design, I feel confident that this research offers important and unique insight into the issues under investigation. It has helped to highlight a number of the challenges associated with introducing new professions such as psychology into existing multi-professional teams, and has also provided some clear ideas for how these can be managed and overcome. The complex processes involved in the psychological assessment of cancer patients have been revealed and again, productive ideas have been generated for how CNSs can build on their existing skills. I also hope that this study has gone some way to increase understanding about the role of the CNS, along with the numerous challenges they face. Overall, I feel confident and hopeful that this research has the potential to impact positively not only on professionals working in this field, but on the patients and families for whom they care.

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SECTION C: CLIENT WORK

AN EXPLORATION OF THE PROFESSIONAL AND PERSONAL CHALLENGES OF WORKING WITH A DYING CLIENT

1.0 PART A – INTRODUCTION AND THE START OF THERAPY

1.1 INTRODUCTION

During the course of this client study, I aim to outline the therapeutic work undertaken with a terminally ill cancer patient, whilst using a cognitive behavioural approach. I have attempted to provide a summary of the model, along with a transparent account of the rationale for why I chose to work in this way and have explored the therapeutic process, noting my reasons for making certain therapeutic decisions. Finally, I have aimed to evaluate my work, reflecting on my learning and self-development as a counselling psychologist.

My decision to present the case of Nokita[1] was influenced by a number of factors. Firstly, Nokita represented my first attempt to use a cognitive behavioural model with a client suffering from a terminal illness, and whilst it proved to be a personally challenging experience, it offered an important opportunity for me to learn, develop and ultimately re-evaluate my approach to working with this client group. I also feel this case offers an illustration of the balance between success, difficulty, process and change, therefore providing an opportunity to present and discuss how these various aspects were considered and managed. Finally, by presenting this case I hope to illustrate the huge personal challenge that I faced whilst working with Nokita, and also convey the sense of privilege that accompanied the encounters we shared, for working with her proved to be an enormously powerful and moving experience, and one which continues to influence my work both as a clinician and educator within the field of palliative care.

1.2 SUMMARY OF THEORETICAL ORIENTATION

The cognitive behavioural model suggests that, "emotional difficulties begin when the way we see events gets exaggerated beyond available evidence" (Wills and Sanders, 2000 p.11). This link between thought and emotion was proposed by Beck in 1963 when he identified distorted thinking in those with psychological disturbance (Feltham and Horton, 2000). Central to this theory is the 'schema'; a hypothetical cognitive structure which acts as a template, allowing us to "filter out unwanted information, attend to important aspects of the environment and relate new information to previous knowledge" (Kovacs and Beck, 1978 cited in Dryden 1998, p.257). Theory suggests that emotional disturbance results from maladaptive

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[1] All names and identifying features have been changed to preserve client anonymity

schemas, which are characteristically rigid, absolute and negatively biased, meaning that when unhealthy schemas are activated, incoming information is distorted, leading us to experience negative automatic thoughts (Feltham and Horton, 2000). The process of distorting information in a negative way often involves systematic logical errors or cognitive distortions. The most common of these were identified by Beck (1976) and include: all or nothing thinking, selective abstraction, arbitrary inference, overgeneralization, labelling and magnification/minimization.

Cognitive behavioural therapy (CBT) involves active, directive, time-limited interventions designed to modify maladaptive assumptions and works by helping clients to "recognise patterns of distorted thinking and dysfunctional behaviour by using systematic discussion and carefully structured behavioural assignments" (Hawton *et al.*, 1989 cited in Sage *et al.*, 2008, p.3). Whilst cognitive therapy has traditionally viewed the therapeutic relationship as "necessary but not sufficient for therapeutic change" (Beck *et al.*, 1979 cited in Wills and Sanders, 2000, p.55), there has been a recent shift towards recognising that the quality of the relationship is central, with it playing a significant role in the overall outcome and success of therapy. The relatively recent work of Safran and Segal (1990) has explored the issue of interpersonal processes within CBT and has consequently highlighted the importance of these within the therapeutic relationship, meaning that difficulties within this relationship can provide possible insight into the maladaptive cognitive interpersonal cycle. Collaboration is also viewed as central; meaning that client and therapist must work together as a team in order to achieve goals and ultimately psychological change (Padesky and Greenberger, 1995).

Adjuvant psychological therapy (APT) originally developed by Stirling Moorey and Steven Greer in 1989 is an adaptation of the cognitive theoretical framework first described by Beck in 1976. Designed specifically for a cancer population, APT aims to assist patients in their psychological adjustment to malignant illness, reduce psychiatric symptomatology and help promote control and mastery. In line with the traditional cognitive therapy viewpoint, Moorey and Greer (1989) suggest that it is the appraisals, interpretations and evaluations that individuals make about cancer that determine their emotional and behavioural reactions to it, meaning that those patients who view cancer predominantly in terms of loss, threat or violation are likely to experience depression, anxiety or anger respectively. In contrast, patients who view their disease in more positive terms and conceptualise it as a challenge, are more likely to demonstrate a coping style referred to as 'fighting spirit'; a style which has been found to correlate with lower levels of anxiety and depression (Watson *et al.*, 1988; Moorey and Greer, 2002).

Just as in traditional cognitive behavioural therapy, APT is directive in nature and concerned with the identification and modification of maladaptive cognitions, and utilises many of the well-established techniques; including guided discovery, Socratic questioning, de-catastrophising and alternative thinking. The therapeutic relationship is deemed important and building rapport with clients is viewed as fundamental to the success of therapy. The role of warmth, genuineness and empathy underpin this relationship, and allow client and therapist to develop a working alliance based on trust and mutual respect. Without such a relationship in place, the use of any problem solving techniques can prove futile and may lead the client to view the therapist as confrontational and lacking in understanding (Moorey and Greer, 2002). Collaborative empiricism, a termed originally coined by Beck, describes another important feature of APT, and refers to the type of relationship which exists between client and therapist. In essence, the partnership is one based on equality, and during the course of therapy develops on a reciprocal basis, meaning everything is shared openly, and hidden agendas or private therapist interpretations are avoided. Beck *et al.* (1976) suggest that in order to foster collaboration, it is, "useful to conceive of the patient-therapist relationship as a joint effort" (p.221).

APT is a model which emphasises the importance of emotional expression and recommends that such expression should be encouraged before the use of any problem solving approaches, "giving patients the opportunity to tell their story is often one of the most important aspects of therapy" (Moorey and Greer, 2002, p.78). However, whilst recognising that for many emotional ventilation will be cathartic, just as in more traditional cognitive therapy it is suggested that emotional expression alone is not deemed adequate to facilitate change, but instead needs to be combined with cognitive processing.

Although APT shares many features of CBT, it also has a few distinguishing features which set it apart. As it is usually occurring alongside demanding treatment regimes (e.g. chemotherapy, radiotherapy), APT needs to be a very flexible therapy, recognising the importance of accommodating the physical manifestations of both disease and treatments. In reality this means therapy sessions are often not possible to schedule on a weekly basis and cancellations due to illness are to be expected and managed accordingly. The second key feature of this type of therapy is that it works on the premise that assisting patients to achieve a 'fighting spirit' coping style is desirable and the ultimate aim of therapy (Moorey and Greer, 2002).

1.3 THE CONTEXT OF THE WORK

Nokita was seen in a health psychology unit, based in a district general hospital which employs clinical, counselling and assistant psychologists and provides placements for both clinical and counselling psychology students. The service receives referrals from senior members of the on-site based medical teams, as well as from local GPs, and has a remit to provide short-term therapy for patients experiencing psychological difficulties directly related to physical illness. As a member of this team, I received regular clinical supervision from the departmental manager, a consultant clinical psychologist with considerable experience in the use of CBT in the context of health psychology. I also attended monthly group cognitive behavioural supervision which was facilitated by a clinical psychologist and open to both psychologists and cognitive behavioural therapists.

1.4 THE REFERRAL

Nokita was referred by her consultant oncologist .The letter of referral informed me that she had been diagnosed with cancer of the uterus 5 years previously, following a long period of unexplained abdominal pain. Treatment had required her to undergo extensive surgery involving a total hysterectomy with bi-lateral salpingo-oophorectomy (removal of both ovaries). This was followed by a 6-month course of chemotherapy treatment which was administered intra-venously, every 3 weeks in an outpatient chemotherapy clinic. Two years after her initial diagnosis, Nokita experienced local disease recurrence in her pelvis, necessitating further surgery. Six weeks before my first meeting with Nokita she had begun to experience some shortness of breath and had very recently received the news that her cancer had metastasised (spread) to her lungs, meaning her disease was no longer considered to be curable. At the time of referral to the health psychology service, she was waiting to commence palliative chemotherapy. The consultant oncologist estimated that with chemotherapy, her prognosis was in the region of 3 months, although recognised this to be optimistic. He also informed me that Nokita had until now been "managing very well psychologically". However the recent news of disease progression had left her distressed and highly anxious, leaving him concerned that her psychological difficulties were now impacting negatively on her quality of life.

1.5 SUMMARY OF CLIENT'S BIOGRAPHICAL DETAILS

Nokita was 36 years old when starting psychological therapy. Originally from Japan she had been living in the UK for fourteen years, having moved to the UK after meeting Simon, a London based freelance journalist. They had been married for twelve years, had no children, but both gained enormous enjoyment from their two dogs. Nokita was a qualified interior designer, although had not worked for the past six weeks due to her illness. Simon's work afforded him much flexibility and at the time of assessment, he was spending much of his time working from home. Nokita's family all lived in Japan and whilst she had regular email and telephone contact with them, she had not seen any of her immediate family for over three years. Simon, an only child, had lost both his parents to cancer and had minimal contact with a great aunt who lived in Wales. Nokita described herself as very shy, and although had a few close friends, preferred spending time with Simon and the dogs. She had had no previous experience of counselling or contact with the mental health services and no history of either anxiety or depression.

1.6 CONVENING THE FIRST SESSION

My first session with Nokita took place in a therapy room within the health psychology unit and took the form of semi-structured assessment thereby allowing me to listen to Nokita's story, gather information about her goals and motivations and also build rapport with her (Milner and O'Byrne, 2003). I began the assessment by greeting her in a warm but professional fashion, introducing myself, and ensuring she was physically as comfortable as possible. I then went on to explain the issues of confidentiality, outlining the secure storage of client notes/paperwork and clarifying the fact that after our assessment I would be communicating with her consultant oncologist by means of an assessment report. I went on to talk openly with Nokita about the referral I had received from her oncologist, and asked her whether she felt the information provided by him was an accurate reflection of her experience. I chose not to share the prognostic estimation of 3 months, simply because I was unsure whether her oncologist had shared this exact information with her. Instead I chose to describe her disease as 'incurable'. This sharing of information was designed to generate a sense of openness from the very start of our relationship, and lay the foundations for a collaborative approach to Nokita's problems. Having done this, I then began to ask Nokita gentle questions about her cancer journey, her emotional experience and also asked her to identify why she had to come to see me.

1.7 THE PRESENTING PROBLEM

Nokita explained that the recent news of her disease progression had left her feeling "totally overwhelmed" and experiencing intense feelings of fear about the future. She described feeling anxious and acutely distressed on a very frequent basis and felt totally unable to cope with everyday life. She was spending much of her time crying and simply trying to manage extreme feelings of panic, which left her physically drained. Finally, she stated that she had no idea about how to regain any sense of hope and did not know how to live her life in the knowledge she was going to die: "I am so afraid of not living, that any life I have left is being ruined by emotions that I can't control".

1.8 INITIAL ASSESSMENT AND FORMULATION

Nokita presented for the assessment session looking very smart and well groomed. She wore a light pink checked suit (skirt and jacket) with black patent shoes and a matching handbag. I was immediately struck by her presentation and how much effort she had made, despite being in obvious physical discomfort. On entering the room, she appeared anxious and unsure. She sat on the edge of the chair, her posture formal and upright, her hands clasped tightly together, with her handbag upright on her lap. Nokita made little eye contact with me, instead choosing to look down at the floor; the occasional eye contact she offered was accompanied by a nervous, apologetic smile. She spoke in a polite, formal and quiet fashion, and early on, displayed a tendency to focus on the factual aspects of her disease, at one point producing a meticulously typed out list of all the details relating to her illness, thereby providing me with an exact account of all her investigations, medical results and treatments to date. The telling of the 'cancer story' is considered fundamental to the assessment, not only because it offers the client the containment of a chronological structure whilst they tell their story, but also because it provides a chance for the therapist to gather valuable information about thoughts, feelings, coping strategies, critical incidents and other relevant contextual information (White, 2001). Having listened carefully to Nokita's account, I began to move my questions towards the more emotional aspect of her experience. Very quickly her eyes welled with tears, and trying to fight them back, she turned her head away from me and apologised for her loss of control. I offered Nokita gentle reassurance that crying was alright and consequently she began to sob. Simultaneously, her body language changed; she turned her head back towards me, briefly making direct eye contact before allowing her upright posture to relax, leaving her sitting hunched over, looking down at the floor, with her head in her hands. For quite sometime, Nokita sat and wept. Gradually her sobbing subsided and she tentatively began describing some of her emotions. She spoke of feeling anxious and panicky, but most intense was her fear. She described fear of unimaginable magnitude, fear about dying, fear about being dead and fear of not knowing how to live whilst she was still alive. She described the fear as "unbearable, beyond words, nausea inducing, paralysing and the loneliest feeling in the world".

During the assessment, I had moments of struggling to contain my own emotions. I felt intense sadness as I listened to Nokita articulate her terrible reality and all her associated fears. As the session progressed, my sadness turned into helplessness and then fear, as I began to wonder if it would be possible to assist Nokita in any way. I feared being useless and letting her down at a time when she was clearly so afraid and vulnerable and also felt concerned about whether I would be able to contain my own emotions during the course of therapy. The assessment session left me exhausted and emotionally drained. However the following day I was relieved to find my own emotions settling, leaving me able to think more clearly about the assessment content and the best way to proceed therapeutically.

Reflecting on our session, I felt that Nokita was showing a number of reactions commonly seen in cancer patients facing terminal illness (Burton and Watson, 2000). Anxiety and emotional distress are well recognised as being features of a normal adjustment process in those adapting to the reality of advanced malignant disease (Barraclough, 2000). My initial sense was that under the circumstances her emotions were totally normal and based entirely on realistic thinking about loss and death, leaving very little scope for any type of cognitive restructuring. However, there was something about the intensity of her fear that led me to question my initial appraisal, for although Kubler-Ross (1997) highlights fear as a common and understandable component of dying, both Watson (1991) and Moorey and Greer (2002) suggest that by identifying the cognitive processes involved in the appraisal of death, overly negative beliefs can often by identified, explored and challenged, resulting in reduced emotional distress. I therefore began to wonder whether there was scope to explore the cognitive processes underlying Nokita's fear in more detail and started to conceptualise her problems using Moorey and Greer's (2002) adjuvant psychological therapy model for cancer patients.

My decision to use this approach was discussed in detail with my supervisor as I had concerns and reservations about whether such a model was appropriate for a client like Nokita. I felt worried that a structured approach would restrict her and not allow her to process her emotions sufficiently. My supervisor engaged with my doubts and worries and helped me to see that dying people can still have unhelpful thoughts, making APT potentially an appropriate choice. He also reminded me that the encouragement of emotional expression was central to model, meaning that Nokita would have opportunity to process her emotions. Reassured by this, I then turned my attention to the evidence base to explore whether a decision to proceed with a cognitive behavioural approach would be supported by any research.

CBT is now well evidenced within mental health care and is commonly used in the treatment of depression, anxiety, panic disorders, eating disorders and trauma (Whitfield and Williams 2003; NICE, 2004; Butler *et al.*, 2007). It has also successfully transferred into some areas of chronic illness, including pain management and chronic obstructive pulmonary disease (Kunik *et al.*, 2001; Adams, 2006). During the past 5 years, there has been a steady increase in the employment of CBT in cancer settings, with it being used to treat cancer-related depression, anxiety and insomnia (Quensel *et al.*, 2003; Savard *et al.*, 2005). There is also a growing trend to use it as a way of assisting patients in coping with challenging cancer treatments e.g. chemotherapy (Sherwood *et al.*, 2005; Doorenbos *et al.*, 2005). The majority of efficacy studies have involved patients with early stage disease, and have found CBT to be effective in reducing distress in women with breast cancer (Antoni *et al.*, 2001; Kissane *et al.*, 2003), in those with malignant melanoma (Trask *et al.*, 2003) and in patients with mixed sample cancers (Greer *et al.*, 1992; Moorey *et al.*, 1994). Despite the inherent difficulties of undertaking research with a palliative population, a few studies have found CBT to be effective in the treatment of depression, anxiety and fatigue in those with metastatic cancer (Moorey *et al.*, 1998; Levesque *et al.*, 2004; Savard *et al.*, 2006). CBT also been endorsed by the National Institute of Clinical Excellence (NICE) and their document 'Improving Supportive and Palliative Care for Adults with Cancer' (2004) suggests the model has a role in the psychological care of patients, particularly in reducing distress and assisting adjustment.

I also found that research had been done to compare CBT and non-directive counselling within a cancer context, with Moorey *et al.* (1998) finding that patients undergoing CBT experienced greater improvements in self-esteem, mood and coping skills. In addition, there is evidence that patients with advanced disease benefit as much from CBT as those with early cancer as it can help patients stay life-centred rather than becoming death-centred, (Moorey and Greer, 2002). A final and particularly relevant finding from the research relates to the issue of timing, as Moorey *et al.* (1998) found CBT to produce positive changes in patients, in a shorter period of time, than in those undergoing non-directive counselling.

Taking all these issues into account, I felt more confident that adopting a CBT approach would maximise the chances of Nokita's emotional distress being reduced, her coping mechanisms activated and her quality of life improved (Barraclough, 2000). I also felt that despite her advanced illness, she appeared to have sufficient motivation, concentration and energy levels to allow her to engage collaboratively and therefore benefit from the therapeutic relationship. Her potentially short prognosis was a major consideration, and I felt aware that the window of opportunity in terms psychological input was likely to be short. Knowing that CBT had been found to work more quickly than other non-directive counselling was certainly a major influencing factor in my decision to proceed with the model.

Within CBT, formulations are "the central driving force of the therapy process, a guide for understanding new material, the choice of strategies and the therapeutic relationship itself" (Wills and Sanders, 2000, p.28). Formulations therefore represent an understanding or explanation of the client's problem, allowing for the identification of both contributing and maintaining factors. Using the information gained during the assessment with Nokita, I began to develop a downward spiral formulation, this is a style of formulation which illustrates the domino effect of how one thing can lead to another, therefore providing insight into where in the chain of events interventions may be best targeted in order to effect change (Sage, 2008). I combined this with vicious cycle formulation in an attempt to demonstrate to Nokita how the interplay between thoughts, emotions, behaviours and physical sensations can work to perpetuate and reinforce certain problems (for Nokita's formulation see appendix 53). I kept in mind the importance of keeping the formulation simple: "an easy to remember formulation with the bare minimum of detail will be of the greatest use to the patient when trying to put changes into practice" (Sage, 2008). I shared the initial formulation with Nokita, as "sharing and discussing the conceptualisation with the client is an integral and important part of the therapy process" (Wills and Sanders, 2000, p.34). In line with collaborative working I was careful to emphasise to her that my ideas were not necessarily right and the formulation was a shared venture that we should view as a work in progress, meaning it could be changed and adapted by either of us at any time. Nokita's response to the formulation was positive. She described feeling "reassured" that I had obviously been listening carefully during the assessment session and she stated feeling that the formulation was a true representation of her current situation. During our discussion about the formulation, Nokita became very emotional, stating how hard it was to see the "truth in stark black and white". I felt embarrassed, suddenly aware that my efforts to produce a simple formulation had in fact reduced the enormity of her situation into a stark and emotionless diagrammatic illustration. I acknowledged this to Nokita, and apologised for any insensitivity. Her reaction surprised me - she smiled, offered me eye contact, and stated that although the formulation was hard to read, it helped her to feel there was a shared understanding between us, and in turn a sense that she was no longer alone.

1.9 NEGOTIATING A CONTRACT AND THERAPEUTIC AIMS

At the end of the assessment session, Nokita and I discussed a counselling contract. We agreed to meet weekly for six sessions, with flexibility to accommodate her forthcoming chemotherapy treatment and her unpredictable physical status. Nokita's therapeutic aims were to feel less emotionally distressed, thus allowing her to enjoy whatever of her life was left.

2.0 PART B – THE DEVELOPMENT OF THERAPY

2.1 THE THERAPEUTIC PLAN AND MAIN TECHNIQUES USED

My overall plan was to assist Nokita in identifying and exploring her thoughts, with the ultimate aim of teaching her how to challenge those which were unrealistic and overly negative. To achieve this, a trusting relationship was required, for Beck (1979) cited in Wills and Sanders (2000), states that for any techniques to work, "a good relationship has to be in place" (p.55). By incorporating some humanistic concepts (core conditions) I strove to develop a collaborative relationship by being "warm, open, empathic, concerned, respectful and non-judgemental" (Feltham and Horton, 2000, p.350). By utilising these skills, my plan was to ensure that throughout our therapeutic work together Nokita would feel able to express her emotions freely within a safe, secure and trusting relationship.

During the course of therapy I chose to use a combination of techniques, as suggested by Moorey and Greer (2002). These included thought diaries, Socratic questions (guided discovery) designed to help Nokita evaluate her thinking patterns, behavioural experiments to help her test out her negative beliefs, and some cognitive rehearsal. I chose to use homework tasks, but sparingly as I realised her energy was limited and time between sessions was precious.

2.2 KEY CONTENT ISSUES

My early work with Nokita focused on gaining a shared understanding of the key issues and I encouraged her to share her thoughts and I strove to listen, understand and validate her experience (Moorey and Greer, 2002). Of particular significance was her intense fear of dying, a fear based on her belief that it would inevitably involve being in a clinical environment, having to endure endless chemotherapy and suffering uncontrolled pain. She described cancer in terms of embarrassment and shame and also shared with me her belief that doctors were "superior" and that questioning them or asking them for help was "disrespectful".

2.3 THE THERAPEUTIC PROCESS

Initial sessions with Nokita were difficult and sad. She was anxious and tense, and cried for much of the time. She would sit, wringing her hands in an attempt to self-soothe and manage the intensity of her distress. Sensing her overwhelming fear, I tried to connect with her, wanting to reduce her sense of isolation. I worked to convey empathy, understanding and interest by using some basic counselling skills - I maintained good eye contact, utilised silence, kept still and calm, and used reflective comments when appropriate. She responded to this by trying to express her emotions but doing so was painful for her and each time she touched on the issue of dying, her tears returned. The enormity of the situation seemed to paralyse her, leaving her often unable to speak. Her presentation appeared hopeless; staring down at the floor and sitting in a hunched position. I felt increasingly desperate to connect with her and alleviate her obvious emotional suffering. With time, Nokita gradually became more able to verbalise her experience; I noticed her tears became less frequent, her body language and general demeanour less hopeless. She was able to hold eye-contact more comfortably and her hand wringing ceased.

2.4 DIFFICULTIES IN THE WORK AND HOW THESE WERE ADDRESSED

Nokita's thought diary effectively revealed the frequency and intensity of her dying related thoughts, and also showed the strength of her belief in these thoughts (for an exert of her diary see appendix 54). I became increasingly aware that these beliefs were based on experiences in Japan, where attitudes towards cancer, treatment and death were obviously very different from the UK. This meant her thoughts were only unrealistic/unhelpful when placed in a Western culture. I discussed this issue at length with my supervisor and explored way of challenging these thoughts whilst respecting her cultural background (d'Ardenne and Mahtani, 1990). He suggested that educating Nokita about the care of cancer patients in Britain would need to form part of our work together, therefore offering her access to an alternative cultural view. Consequently I focused on some educational work with Nokita around the issue of palliative care in an attempt to open up the possibility of a different reality; "the patient can be helped to take more control of the situation by being directed to sources of information" (Moorey and Greer, 2002). Whilst Nokita was empowered by her new knowledge, her thought diary continued to describe high levels of fear about dying in pain; a belief based on having witnessed her aunt die of cancer in Japan. I gently challenged Nokita's negative beliefs, using guided discovery and the Socratic method. Using questions like: "I just wonder what the evidence is to support the belief that you will die like your aunt?" and: "is there any other way of seeing the situation?", I tried to draw her attention to relevant information that could help her test the reality of her belief. Nokita found these questions difficult to engage with; her facial expressions and verbal tone conveyed fear and despair. Her reaction made me concerned about whether my challenging had been appropriate. I shared this with my supervisor who reassured me that the balance between challenging and supporting patients like Nokita is often a difficult one. He drew my attention to Moorey and Greer's (2002) suggestion that "a behavioural test can prove far more effective in changing negative attitudes than several sessions of discussion" (p.91). I therefore decided to change my approach slightly and following discussion with Nokita, we decided to plan a behavioural task which would allow her to test out her belief about dying. The task involved her meeting the Macmillan palliative care nurse and visiting the on-site hospice in order to witness first hand the delivery of terminal care in the UK. This experience had a powerful and dramatic effect on her. As we evaluated the experience together she said: "the hospice was amazing, the people were ill, but they seemed alright, no one was having chemotherapy or crying in pain". Nokita's fear was replaced with a sense of sad calm and she began talking with some urgency about wanting to "enjoy the remaining time left". With further guidance from my supervisor, I began working with Nokita to generate a list of goals which would maximise her pleasure (Philips and Smith, 1990). She identified her first goal as telling her oncologist she wanted to stop chemotherapy and be referred to the specialist palliative care team. To assist her in this, I suggested some cognitive rehearsal during our session, therefore allowing her to practice what she wanted to say to her oncologist. Despite some concerns about meeting with him, Nokita left our session with confidence and a sense of clarity.

Working with Nokita generated many painful emotions for me, which at times felt difficult to manage. As our sessions progressed, I began experiencing feelings of helplessness, sadness and anger. Seeing Nokita experience such distress often left me feeling vulnerable and tearful. Discussing these feelings in supervision was invaluable and being able to offload in a safe and supportive environment helped me manage their intensity. These discussions also allowed me to gain a better understanding about which emotions were mine and which were Nokita's.

2.5 CHANGES IN THE THERAPEUTIC PROCESS OVER TIME

With time, Nokita became more able to articulate her thoughts and emotions and consequently we began to achieve a shared understanding, allowing the collaborative element of our relationship to flourish. I sensed a connection and trust between us that allowed us to move onto the cognitive content of her problems, and once we began to utilise the various techniques, I noticed a distinct change in her presentation. Her body language conveyed a sense of determination, different from her previously hopeless presentation and her focus was no longer solely on dying, but began to incorporate the quality of her existing life.

3.0 PART C – THE CONCLUSION OF THE THERAPY AND THE REVIEW

3.1 THE THERAPEUTIC ENDING AND EVALUATION OF THE WORK

The ending of my work with Nokita was abrupt and unplanned. Her physical health deteriorated rapidly and she was unable to attend our final session. Three weeks after our last meeting I received a letter from Nokita's husband, Simon:

An exert from Simon's letter

> "I write to tell you that sadly Nokita died last week. I thought you might like to know that due to wonderful care from her Macmillan nurse and the hospice, her pain was really well controlled and she died calmly, at home, with me and the two dogs lying next to her. You may be amazed to hear that ten days before she died I took Nokita to Brighton, where we had a special day. We sat on the beach, watching the ocean, eating chips. Thank you for helping to make this possible."

Reading this letter was enormously painful but helped me to reflect on my work with Nokita and despite great sadness at her death, I felt a sense of satisfaction that through our work together she had been able to achieve some of her goals. In particular I felt that my awareness of the importance of the therapeutic relationship allowed Nokita to feel safe enough to offload her emotions, thus allowing her to explore alternatives, and ultimately challenge her own beliefs. Of particular value was the behavioural experiment, as it seemed to be the turning point which allowed her to experience first hand the difference between Japanese and British care of terminally ill patients, thus helping her accept the possibility of alternatives.

3.2 LEARNING ABOUT PSYCHOTHERAPEUTIC PRACTICE AND THEORY

Despite my initial reservations, I learnt that CBT can be an appropriate and effective way of working with those facing terminal illness. However it needs to be used in a flexible and creative way, accommodating the high levels of emotion and limitations placed on clients by physical deterioration. The usual structure associated with this model is not necessarily possible, but the underlying theory is applicable and useful. I learnt that the model can maximise quality of life, allowing people to remain life-centred for as long as possible.

The therapeutic relationship is of paramount importance when identifying and challenging unrealistic beliefs with dying clients as I felt it was really through the creation of a relationship based on trust, safety and containment that allowed Nokita to begin exploring and ultimately changing her problematic thoughts. It is also necessary to find the right balance between the interpersonal and technical elements of the model, thereby facilitating both emotional expression and change. Finding this balance felt difficult for me, and something which remains an ongoing challenge in my work.

3.3 LEARNING ABOUT MYSELF AS A THERAPIST

Working with Nokita had a profound impact on me both personally and professionally. Her deterioration was incredibly difficult to watch, tapping into my own feelings and fears about mortality. Ultimately, I realise I had felt scared of challenging someone who was dying and felt fundamentally frightened of exploring death in such detail. I somehow feared that talking about dying would make a terrible situation even worse.

My supervisor provided me with enormous support, which in turn helped me manage my discomfort. I therefore learnt that regular, supportive supervision when working with such clients is essential and the key to coping with the challenges inherent in such work. It is also fundamental for development and improvement as a therapist and the cornerstone to safe and ethical practice.

The abrupt ending of my work with Nokita was another difficulty. Without closure, I was left with questions, concerns and fantasies about what had happened to her and what her death had really been like. Part of me felt angry that I had been denied an ending and had not been given a chance to say goodbye and thank Nokita for what she had taught me. I therefore learnt about the importance of endings and the frustration of not having one. Again, supervision helped me to deal with these feelings and encouraged me to use the letter from Nokita's husband to create my own ending and sense of closure.

Finally, I learnt that despite the difficulty of watching a client dying, I have the capacity to do it and am able to tolerate extreme levels of distress, without allowing my own feelings to hamper or obstruct the therapeutic process. I have learnt I am more resilient and robust than I had thought and have the ability to use supervision in such a way as to sustain me as a therapist. As a result of my work with Nokita, I have continued to use CBT with terminally ill clients and am now doing so in the context of a hospice. Despite the ongoing struggles with sadness and loss that come with working with those affected by terminal illness, my confidence continues to grow slowly, and finding the balance between the use of technical and interpersonal skills feels slightly less daunting.

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SECTION D: CRITICAL LITERATURE REVIEW

AN EXAMINATION OF THE RELATIONSHIP BETWEEN PSYCHOLOGICAL INTERVENTIONS AND SURVIVAL IN CANCER PATIENTS

Keywords: cancer, survival, prognosis, psychological therapy, intervention

1. INTRODUCTION

According to figures released by Cancer Research UK (2009), it is estimated that one in three people living in the United Kingdom will develop some form of cancer during their lifetime. This translates into approximately 289,000 new cases and 150,000 deaths every year. Cancer has outstripped heart attack and other cardiovascular disorders as the UK's leading cause of death and despite a 10% fall in the overall cancer death rate during the past ten years, it still accounts for one in four of all deaths.

During the past twenty years, with a growing understanding of the psychological dimension of the disease, the timely delivery of psychological interventions are increasingly being viewed as fundamental to patient care. In addition to improving quality of life, questions have been raised about whether such interventions may impact on disease progression and overall survival, and although controversial, this suggestion has led to a number of research studies which have attempted to investigate the existence of a possible link.

2. RATIONALE FOR THE REVIEW

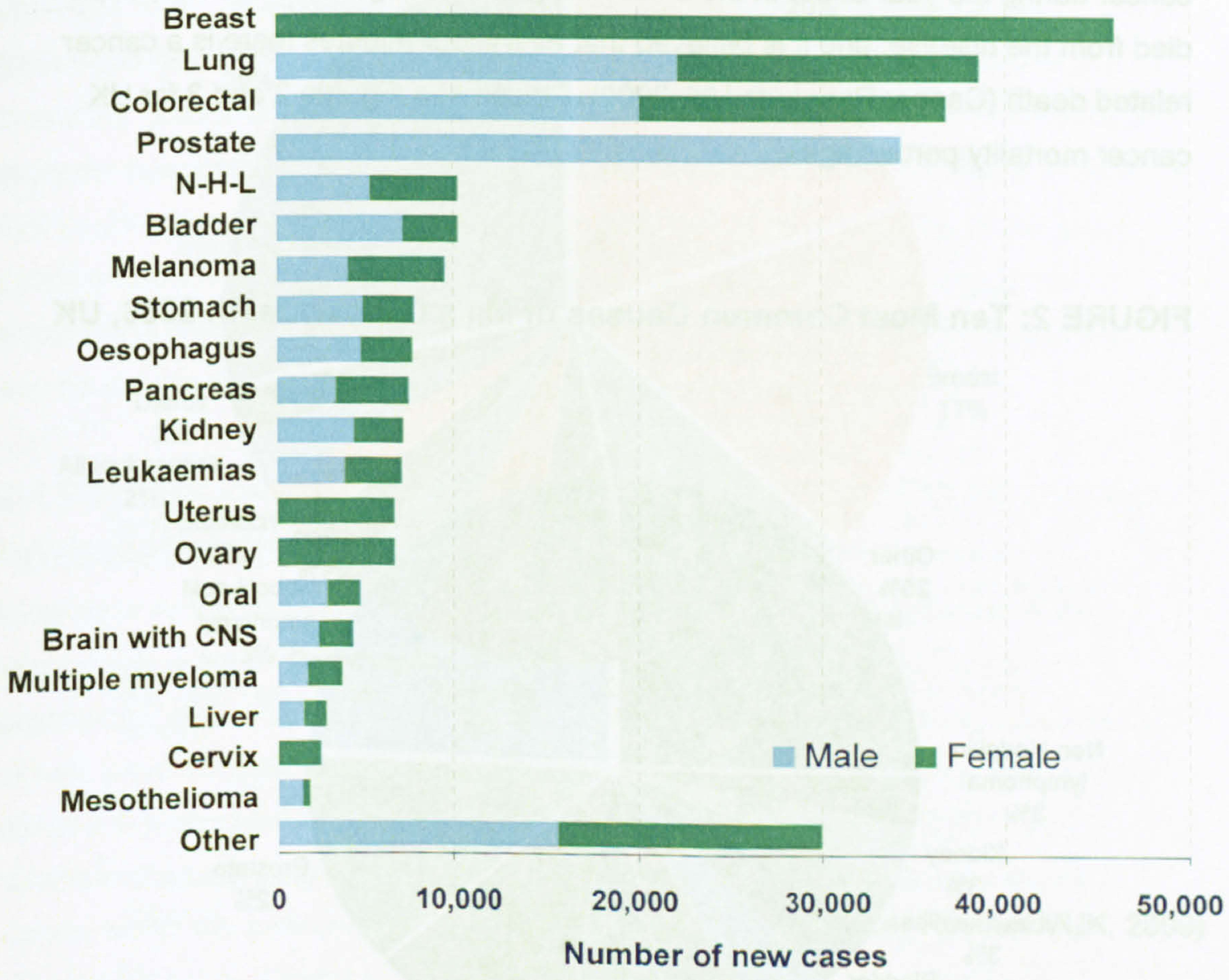
2.1 INCIDENCE AND MORTALITY RATES

Since 1975, cancer incidence in the UK is estimated to have increased by 25%, although for the past decade rates have remained relatively stable. On a global scale the situation is bleaker with rates continuing to rise at an alarming pace. The World Health Organisation (1996) cited in Brennan (2004) report that in 1990, 8 million people worldwide were diagnosed with cancer. However by 2020 this is estimated to rise to in excess of 15 million new cases every year.

In the UK, lung, breast, bowel and prostate cancer are the most common types, accounting for over half of all new cancers diagnosed every year. For a more detailed overview of cancer incidence please see Figure 1.

FIGURE 1:

The Twenty Most Commonly Diagnosed Cancers During 2005 (UK)

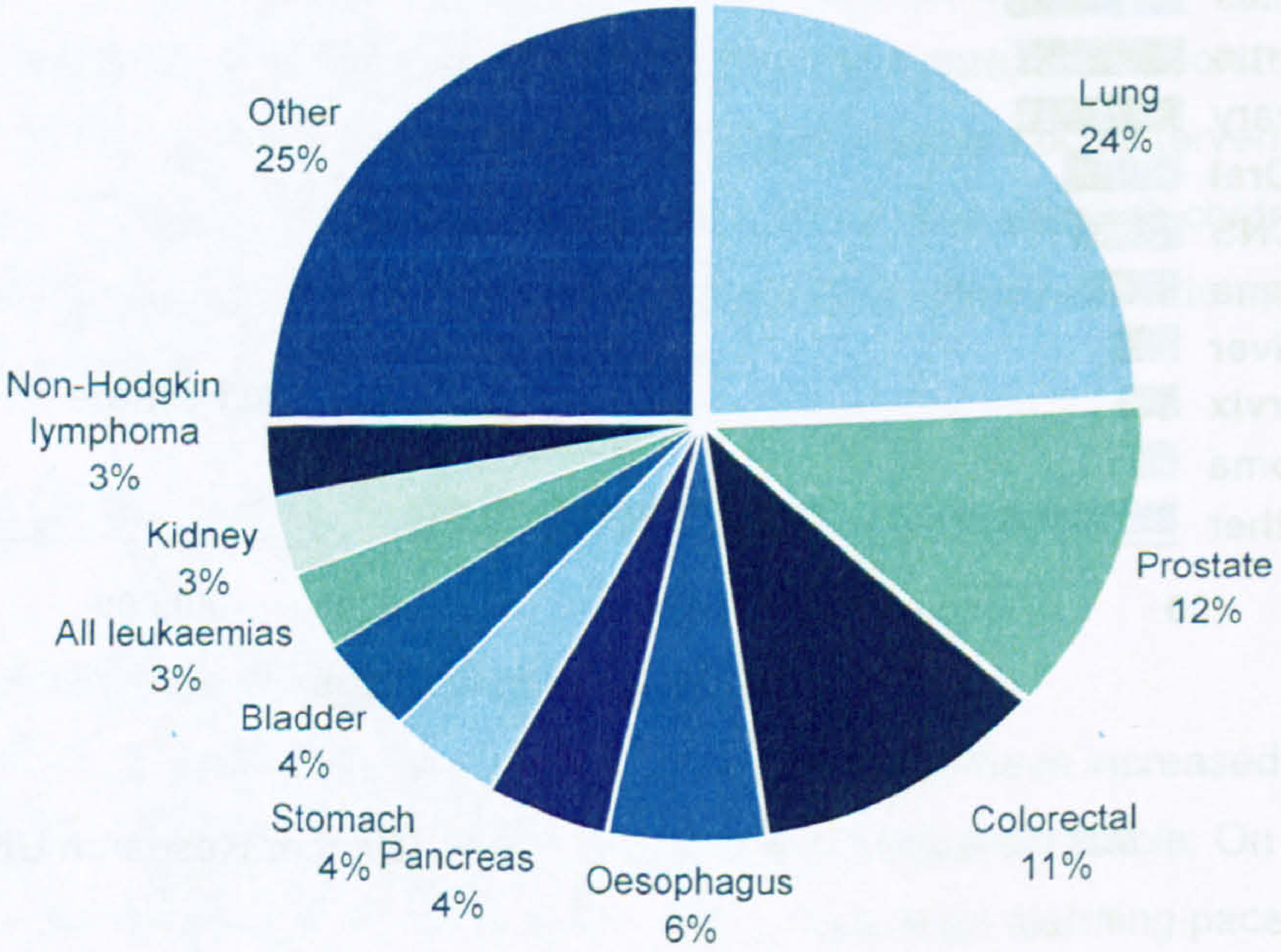


(Cancer Research UK, 2009)

The reasons for this increasing incidence are multi-faceted. There is no question that improved life expectancy is a major contributing factor, and as 60% of all cancers are diagnosed in those aged 65 years and over, it is likely that with time, cancer will become an even greater problem (Watson *et al.*, 2001). Lifestyle is also recognised to be hugely significant with smoking, obesity, poor diet and excessive exposure to UV radiation all being clearly identified as potential cancer causing behaviours. The links between behaviour and cancer are now so well evidenced, it is estimated that up to as many as half of all cancers could be avoided if lifestyle changes were made. In addition to age and lifestyle factors, it is estimated that 10% of cancers are caused by inherited factors, whilst a small number of infectious agents, particularly viruses, are known to have a role in causing certain types of cancer (Cancer Research UK, 2009).

With regard to mortality, it is estimated that worldwide 7.8 million people died from cancer during the year 2000. In the United Kingdom during 2006 154,162 people died from the disease, and it is believed that every four minutes there is a cancer related death (Cancer Research UK, 2009). Please see Figures 2 and 3 for UK cancer mortality percentages.

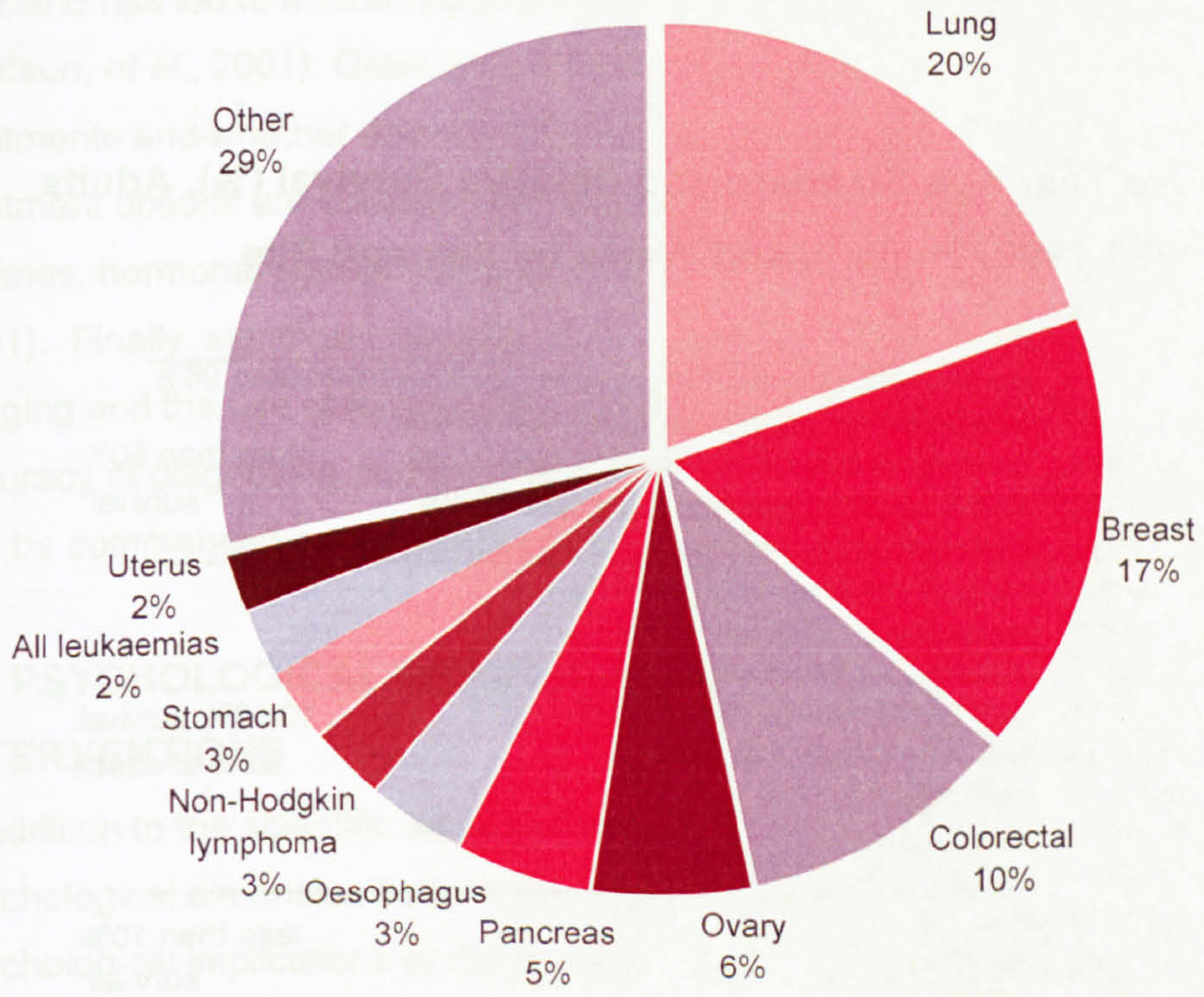
FIGURE 2: Ten Most Common Causes of Male Cancer Death 2006, UK



All malignant neoplasms - 80,541

(Cancer Research UK, 2009)

FIGURE 3: Ten Most Common Causes of Female Cancer Death 2006, UK



All malignant neoplasms - 73,621

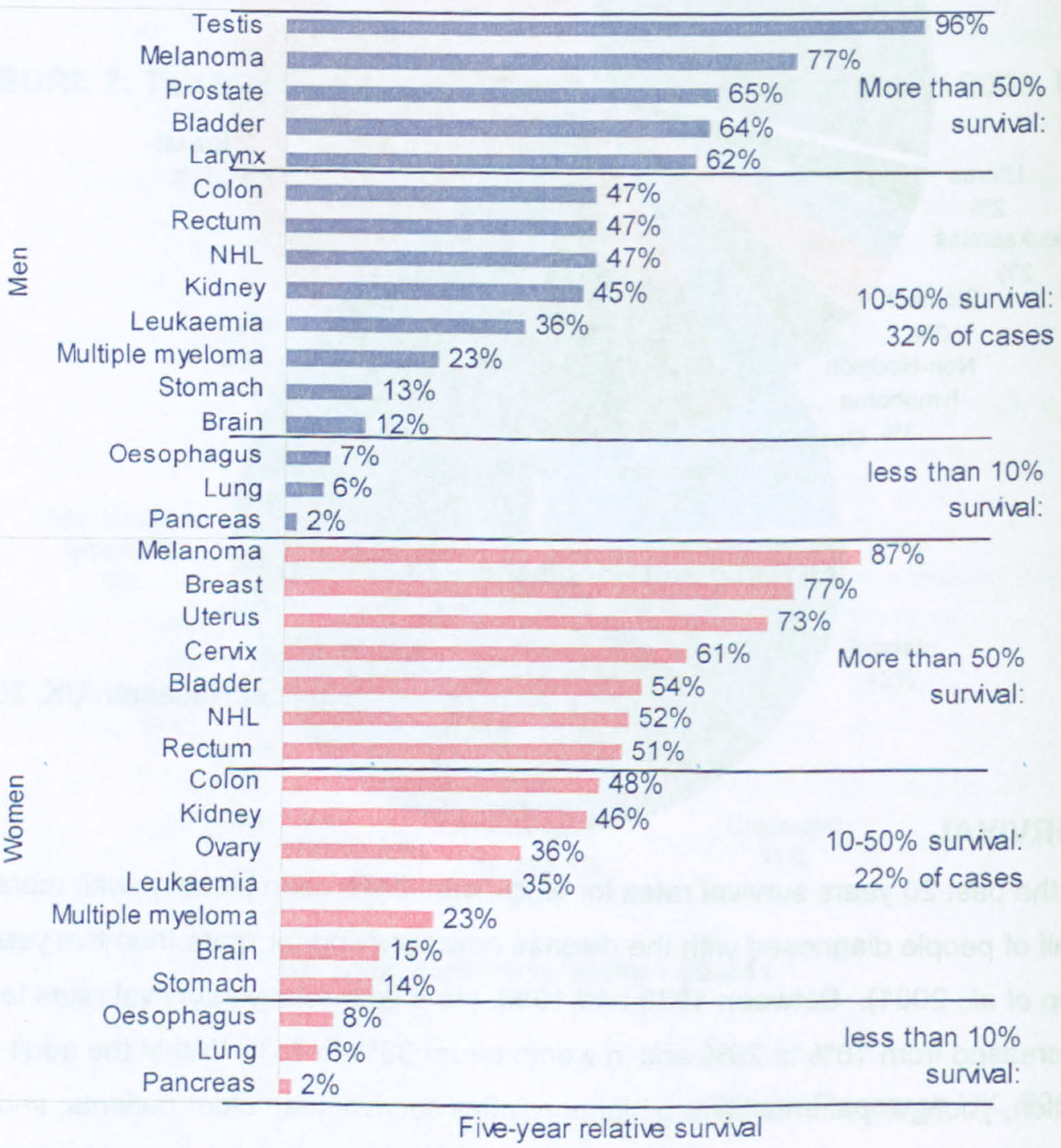
(Cancer Research UK, 2009)

2.2 SURVIVAL

During the past 20 years survival rates for all cancers have risen steadily, with more than half of people diagnosed with the disease now surviving for more than five years (Watson *et al.*, 2001). Between 1970 and 1990, the 5 year relative survival rates for men increased from 18% to 29% and in women from 33% to 43%. Within the adult population, younger patients have a higher relative survival than older patients, and for most types of cancer women have a small survival advantage over men (Watson *et al.*, 2001). In terms of children, more than seven out of ten cases of paediatric cancer are now successfully treated.

Although cancer survival statistics are of very limited value in terms of predicting an individual prognosis they do offer useful information about the numbers of patients who have survived a certain type of cancer for a specific amount of time. Statistics can also offer more specific information with disease free survival rates describing the number of people who achieve remission (i.e. no signs of cancer present), whilst progression-free survival rates pertain to the number of people whose disease is present but stable. For the UK's 5 year relative survival rates for adults please see Figure 4.

FIGURE 4: Five Year Age Standardised Relative Survival (%), Adults Diagnosed 1996-1999, England and Wales by Sex and Site



(Cancer Research UK, 2009)

2.3 FACTORS AFFECTING SURVIVAL

Improvements in survival are due to a combination of factors which are all underpinned by substantial improvements in our understanding of the disease. Secondary prevention which has involved the development of extensive screening, testing and surveillance programmes has impacted significantly on the detection of both pre-malignant and early malignant disease. Translated into real terms, the breast screening programme in the UK is believed to prevent up to 1,250 deaths per year and has led to a 25% reduction in mortality in women aged over 50 years (Watson, *et al.*, 2001). Great advances have also been made in anti-cancer treatments and whether disease is considered curative or palliative in nature, the treatment options are considerable and include surgical interventions, chemotherapy regimes, hormonal agents, biological therapies and radiotherapy (Watson, *et al.*, 2001). Finally, significant developments in histological assessments, radiological imaging and the use of tumour markers have also meant improvements in the accuracy of diagnosing and staging disease, meaning that appropriate treatments can be commenced earlier, thereby making them more effective.

2.4 PSYCHOLOGICAL REACTIONS TO CANCER AND PSYCHOLOGICAL INTERVENTIONS

In addition to the scientific advances made in the field, a growing interest in the psychological dimension has led to a much improved understanding of the psychological implications of the disease. Research has revealed a high prevalence of both psychological distress and psychiatric illness amongst patients, with most studies detecting distress in the 35-45% range (Carlson and Bultz, 2004). An additional finding has been the identification of five common adjustment styles to cancer which are believed to be determined by the individual's appraisal of the disease (Greer and Watson, 1987). These styles are fighting spirit, avoidance/denial, fatalism, helplessness/hopelessness and anxious preoccupation (see appendix 55 for a summary of these styles). Further research has gone on to suggest that individual attitude to cancer is associated with overall psychological adjustment, with 'fighting spirit' being shown to correlate with lower levels of anxiety and depression (Watson *et al.*, 1988, 1990). Equally, patients demonstrating a helpless/hopeless or anxiously preoccupied adjustment style are more likely to suffer with ongoing depression or anxiety (Osborne *et al.*, 1999).

In light of the prevalence of psychological distress, there has been a proliferation of research examining various interventions designed to help patients cope with the psychological challenges. Most reviews have concluded that psychosocial interventions can be efficacious in decreasing distress and improving quality of life (Carlson and Bultz, 2004) and in terms of impact on adjustment style, some studies have illustrated that therapy (particularly CBT) can help patients to adopt a fighting spirit approach (Geer *et al.,* 1992; Moorey *et al.*, 1998). A number of other studies in this field have also highlighted a possible survival advantage in those receiving interventions (Cooper and Waston, 1991; Barraclough, 2000; Boulton *et al.*, 2001; White and McCleod, 2002). This is a suggestion which has provoked much debate and the controversial nature of the claim has resulted in the development of a separate and specialist research area called psycho-neuroimmunology.

2.5 PSYCHO-NEUROIMMUNOLOGY

Whilst many biological and life style factors are known to influence both the onset and course of cancer, some believe that psychological factors could also be involved (Cooper and Watson, 1991; Spiegel, 2001). Psycho-neuroimmunology, an area of specialist research, is the study of the interaction between psychological processes and the immune/nervous systems, meaning it aims to explore the link between phenomena of the mind (thoughts, emotions, mental images) and the body's defences against disease (Barraclough, 2000).

Whilst it is known that the immunological and hormonal systems work together to provide protection against cancer, it has been suggested that a number of psychological variables may be responsible for impairing immune function and therefore contributing to disease onset and progression (Watson, 1991). These include a cancer prone personality (Type C personality), stress, adverse life circumstances and levels of social support. Sephton *et al's* (2000) finding that a loss of normal diurnal variation in cortisol levels was a predictor of early death in patients with breast cancer offers some support to the existence of a link between psychosocial stress and tumour progression being mediated by endocrinologic or immunologic mechanisms. Other studies have examined the role that emotional state plays in cancer relapse and/or survival, with findings showing higher rates of recurrence-free survival in patients exhibiting 'fighting spirit' (Greer *et al.,* 1990), positive expectations (Roud, 1986), joy (Levy *et al.,* 1988) and denial (Greer *et al.,* 1990).

With the existing research showing that psychological interventions can influence individual adjustment styles, the question of whether psychological variables can be manipulated in order to alter the course of the disease is pressing. Whilst initially such an effect may seem implausible, consideration must be given to the fact there are two components which can influence cancer progression: tumour characteristics and host resistance. The former is largely determined by genetic damage, whilst the latter involves the host's ability to respond to tumour invasion, and includes behavioural elements, adherence to medical treatment and the endocrine, immune and autonomic nervous systems. It is therefore not entirely implausible that participation in psychological therapy could impact positively on survival time (Cooper and Watson, 1991).

3. REVIEWING THE LITERATURE

A number of studies now exist which provide some insight into the important question of whether psychological interventions can impact on survival time for cancer patients. The following review offers an examination of these, and considers the findings and limitations of each. As will be seen, these studies vary hugely in their ambition, the type of cancer suffered from and the type of psychological intervention assessed for effect. An additional challenge for the consistent interpretation of the findings is the set of limitations of comparison and rigour which longitudinal and real-life based investigations of this type pose. A summary of the studies to be discussed during the course of this review can be found in Table 12 below and even a cursory look at this shows the existence of many differences which in themselves pose significant challenges to meaningful or conclusive interpretation of the studies' findings. (NB, only randomised controlled trials have been selected for this review).

TABLE 12: Summary of Research Studies Under Review

Authors	Effect of treatment on survival?	Cancer type	Point at which survival time measured	Intervention type	Total patient sample	Design weakness?
Linn *et al.*, (1982)	No	Mixed	1 year	Psychotherapy	120	Yes
Spiegel *et al.*, (1989)	Yes	Breast	10 years	Expressive group	68	Yes
Richardson *et al.*, (1990)	Yes	Lymphoma/Leukaemia	2 and 5 years	Educational programme	94	No
Fawzy *et al.*, (1993)	Yes	Melanoma	5 years	CBT	68	No
Illnyckyj *et al.*, (1994)	No	Mixed	1 year	Group therapy	127	Yes
Ratcliffe *et al.*, (1995)	Yes	Lymphoma	5 years	Psychotherapy	63	Yes
Cunningham *et al.*, (1998)	No	Breast	4, 8 and 14 months	Expressive group	66	Yes
Edelman *et al.*, (1999)	No	Breast	5 years	CBT	124	Yes
Kuchler *et al.*, (1999)	Yes	Gastro-intestinal	2 years	Psychotherapy	271	Yes
Goodwin *et al.*, (2001)	No	Breast	1 year	Expressive group	235	Yes
Kissane *et al.*, (2007)	No	Breast	2 years	Expressive group	227	No

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Kissane *et al.*, (2007)	No	Breast	2 years	Expressive group	227	No

3.1 A LANDMARK STUDY: SPIEGEL *ET AL.* (1989)

Spiegel *et al's* (1989) study was not designed to examine the issue of survival per se, but instead to explore the effect of group therapy on quality of life and mood disturbance. Despite this aim, because of its findings it has come to be acknowledged as a landmark study in the field of psycho-oncology research and has also sparked significant debate amongst both researchers and practitioners alike. The study involved eighty-six women with metastatic breast cancer who were randomised into either a treatment (n=50) or control group (n=36), with those in the treatment group receiving weekly supportive/expressive group therapy for at least one year. The therapy sessions, facilitated by either a social worker or psychiatrist, were designed to create a supportive environment in which patients could share worries, improve their relationships and focus on the issue of meaning and purpose. It was also hoped that the group therapy format would encourage the creation of connections between participants, thereby reducing feelings of isolation and loneliness. In terms of measures, the women were asked to complete a set of psychological questionnaires prior to randomisation. The measures chosen were locus of control, self-esteem, mood, coping style and phobias. These questionnaires were then distributed every 4 months throughout the duration of the study.

As previously mentioned the study's original aim was not to examine the issue of survival. However ten years after its completion, Spiegel *et al.* (1989) re-visited their results, with the explicit aim of confuting the argument that psychological state and disease progression are in some way connected. Despite their conviction, what they discovered was that although during the time of treatment no difference in survival time was found, in the twenty months after the beginning of the study a divergence in survival began to emerge, with those in the treatment group living on average 18.9 months longer than those in the control. Possible explanations for the survival difference were explored thoroughly by testing 26 different variables including age, initial disease staging, number of days of radiotherapy treatment, type of surgery, intervention from first diagnosis to death and degree of metastatic spread. However none of these factors explained the difference in duration of survival, leading Spiegel *et al.* (1989) to reluctantly conclude that the difference was due to the group therapy intervention.

The conclusions of this study generated intense debate and could be argued to have influenced the arena of psychological interventions offered to cancer patients in a seminal fashion. Despite some reluctance in the scientific and practitioner community to accept the findings, examination of the study's methodology failed to reveal any serious flaws, with it instead being felt to meet "the customary requirements for scientific evidence" (Moorey and Greer, 2002 p.42). Since then, questions about the study's rigour have consistently been raised, and alternative explanations for the findings suggested. This in itself perhaps further underlines both the potential significance of the conclusions drawn but also the reluctance of the scientific community to welcome them as reliable. Coyne *et al.* (2007) for example raise issues about participant attendance at therapy sessions, highlighting that 44% of those randomised to the treatment group never in fact attended, whilst 30% died during the intervention stage. They also suggest that due to the fact the study was originally designed to test for quality of life and **not** a survival effect the sample size was small, meaning the findings could simply be due to chance or randomisation problems. Fox (1998) offers a different suggestion, claiming that the anomaly actually lies in the unexpected early deaths of patients in the control group. Other alternative explanations include the possibility that those in the treatment group were simply highly motivated and therefore took extra steps to ensure increased survival and that they may have been more compliant with medical treatment and encouraged one another in terms of healthy living practices. Moreover, pre-existing differences between the intervention and control groups with respect to psychosocial variables (coping styles and social support) may have caused the observed effects. However, it must be remembered that as the study was randomised both of these options are unlikely.

So, as can be seen Spiegel *et al's* (1989) study has caused long running and multi-faceted debate and interest. To this day, this interest remains unabated, and most notably has hence triggered at least 3 specific attempts at replication.

3.2 REPLICATION ATTEMPTS

The first of the replication attempts was published by Cunningham *et al.* (1998) and was a specific attempt to repeat Spiegel *et al's* (1989) study. It involved examining the effects of a psychosocial intervention on quality of life, mood and survival time in women with metastatic breast cancer. This was the same cancer type as studied by Spiegel *et al.* (1989) and involved a similar number of patients: a total of 66 women were recruited and randomised to either a treatment group (n=30) or control (n=36). The intervention was provided by a registered psychologist and included weekly supportive-expressive group therapy lasting for 35 weeks. In addition, patients in the treatment group received a 20 week course of cognitive behavioural therapy (including homework assignments) and an intensive two-day workshop focusing on coping skills. Immediately it could be argued that this is a deviation from Spiegel *et al's* (1989) original work and hence not a pure replication. However this difference in itself highlights the near impossibility of reproducing identical circumstances in trials of this nature. At the most prosaic level, it is impossible to reproduce every element of a therapeutic patient centred intervention which by its very nature is based upon the relationship and meaning attributed to the interaction between patient and therapist, both of whom are individuals in their own right. That aside though, those in the control group received written material covering the content of the coping skills workshop, which included a workbook and audiotapes with relaxation/mental imagery instructions. Again, as with Spiegel *et al.* (1989), a variety of psychological dimensions were measured at baseline and then in this case at 4, 8 and 14 months. These included quality of life, mood, social support, mental adjustment to cancer, defensive repression, social desirability and rational versus emotional defensive styles. Although these dimensions were not identical to Spiegel *et al.* (1989), the key outcome variable under investigation was survival, and these data were analysed five years after the commencement of the study. Again, it should be noted that this time measurement represents a divergence from Spiegel *et al's* 10 years.

Analysis of the results showed the intervention had no demonstrable effect on either survival or any of the psychological factors, except for an increase in levels of anxious preoccupation and a decrease in helplessness in the treatment group. In light of Spiegel *et al's* (1989) previous findings, these results proved disappointing, at least to practitioners who did not question the validity of the original study. A challenge to their optimism though is that this study had been specifically designed to assess survival as its main variable, and the stratification procedure used during randomisation had ensured that the two groups were balanced on the most important prognostic factors: age and metastatic site. The groups were also well balanced in demographic and disease-related factors. Despite these methodological strengths, other aspects of the study were less robust with Cunningham *et al.* (1998) themselves conceding that the null result could have been a reflection of the small sample size. In other words one of the weaknesses levelled against Spiegel *et al.* (1989) could also be cited here as a factor causing an inconclusive outcome.

From a methodological point of view, the other and perhaps most significant problematic issue relates to the fact the control group itself received a considerable degree of intervention which could be argued was very close in nature to the treatment itself, (i.e. workbook and relaxation audio tapes). In addition to this, 28% of the control were also found to have attended outside support groups. Clearly as mentioned above, as such studies deal with real issues and (literally) life and death matters, patients cannot ethically be contained within any control group that would prohibit such additional support being sought. Nonetheless, from a scientific perspective such potential contamination of the control group not only weakens the study's validity, meaning that it cannot be concluded that the group intervention was ineffective but the overall size of any effect might have been lessened, therefore decreasing the statistical power of the study. Finally, it is possible that the findings relating to survival may be premature due to an inadequate follow-up period. Despite the attempt to replicate Spiegel *et al.* (1989) this study drew its conclusions after only 5 years, and other studies suggest that survival analysis at 10 years or longer may be necessary before any firm conclusions can be drawn about the impact of the intervention on survival.

So it could be argued the position is no clearer after this attempt at specific replication, and despite the ambition of the researchers, it has to be recognised that in longitudinal patient-centred studies of this nature, there are always going to be the unplanned-for features and variables that may distort results. In such a sensitive area, perhaps this in itself makes direct replication of findings unlikely?

The second replication attempt to be discussed is that of Goodwin *et al. (*2001) which will perhaps provide more insight. Their work involved examining the effect of supportive-expressive group therapy on survival in women with metastatic breast cancer, and this study immediately avoided the criticism of small sample size by dint of involving 235 patients. Everyone in the study had an estimated prognosis of 3 months or more, and were randomised to either a control group (n=77) or treatment group (n=158). Those in the treatment group were invited to attend weekly therapy for at least one year. This therapy was based on a pre-written manual and was delivered by a combination of psychologists, psychiatrists, social workers and clinical nurse specialists. As with Cunningham *et al.* (1998), both the treatment and control group received written educational materials along with standard medical care. Mood, pain, suffering, social support, medical status and demographics were assessed at baseline and every 4 months for one year. This in itself could be argued as surprising given the intent of the study at replication, inasmuch as discussed above, Spiegel *et al's* (1989) beneficial survival effects were reported after an elapsed time of 10 years, and this difference could again be a major contributory reason for an outcome difference between the two studies.

Whilst the study did not show any survival advantage, those who participated in the group therapy did show significantly less distress and pain than those in the control. The authors therefore concluded that the intervention was effective in terms of improving quality of life, if not quantity. There are however again a number of issues that bring into question the overall quality and reliability of the study, despite the large sample size. Firstly, attendance at the group therapy sessions only averaged 66.7%. Reasons for this included ill-health, treatment appointments and inability to travel, and 30 women dropped out of the group therapy altogether after an average time of 3.5 months. Eight of the women did not attend any therapy sessions at all. Secondly, after randomisation, 13 members of the intervention group and 8 members of the control group were found to have attended support groups outside the study and despite randomisation, the intervention group were found to have major differences from the control group. These differences included:

1) A significant age discrepancy at initial diagnosis
2) More distress at baseline
3) More positive lymph nodes
4) The receipt of more adjuvant chemotherapy

However despite issues of non-compliance and the above possible contamination of results, an intention-to-treat approach was used for all the analysis. So again, despite many attempts to adhere as closely as possible to the circumstances of Spiegel *et al's* (1989) original work, this study had significant areas of variance from the original and so the results it presents are not conclusive or unambiguous.

The final replication study to be considered is that of Kissane *et al.* (2007). This was a multi-site randomised controlled trial which aimed to examine the impact of supportive-expressive group therapy on survival in women with advanced breast cancer. Again avoiding the critique of small sample size, 227 women with an estimated prognosis of one year or more were randomised to either a control (n=80) or treatment group (n=147). To reduce the risk of demoralization occurring in the control group, members of both groups received three relaxation classes. Those in the treatment group were additionally invited to attend a weekly session of group therapy which aimed to improve relationships, create a network of support and assist participants in developing new coping skills. Attendance for at least one year was encouraged. At baseline and every 6 months for 2 years, participants were asked to undergo a structured psychiatric interview and also complete various psychosocial questionnaires measuring quality of life, social functioning and mental adjustment. Demographic and clinical data were assessed at baseline.

With regard to findings, whilst the authors identified a positive impact on psychosocial wellbeing and clinical depression in those receiving group therapy, again no survival advantage was found. The fact that this study identified survival as the a priori endpoint, combined with the fact it is deemed to be very well designed (Coyne *et al.,* 2007), make the results particularly important. The study has a number of strengths, including the large sample size, the avoidance of common sources of confirmatory biases and the completeness of the reporting style. Kissane *et al.* (2007) are also totally transparent about the challenges faced during the study including the difficulties in recruitment, the delivery of such intensive psychological treatment to patients with advanced disease and the analytic difficulties posed by the inevitability of missing data. Despite all this however, as the elapsed time for assessing potential effects on survival was limited to 2 years, again it is totally conceivable that any relationship had yet to emerge.

So, on the face of it these four studies leave us with an unclear and complex picture, and do not shed convincing or unequivocal light on the major question in hand. The first set of findings by Spiegel *et al.* (1989) have never been successfully replicated, but many of the studies that appear to negate their original conclusions are arguably contaminated or flawed, or open to another set of interpretations. Perhaps more evidence can usefully be gained by an examination of the one other recently published study that whilst not setting out to be an explicit replication of Spiegel *et al's* (1989) work, does look at the effects of psychological treatments on survival rates amongst breast cancer patients.

3.3 A NON-REPLICATION STUDY: EDELMAN *ET AL.* (1999)

This study aimed to examine the effect of cognitive behavioural therapy (CBT) on survival in those with advanced disease but did not set out to explicitly replicate the original Spiegel work. One hundred and twenty four patients with metastatic breast cancer were randomised to either a control (n=62) or treatment group (n=62). Treatment comprised 8 weekly sessions, and included thought monitoring, cognitive restructuring, use of coping statements, effective communication, goal setting and relaxation. Each session involved an element of education, along with the setting and discussion of homework tasks. In addition, 3 post-therapy follow up sessions were provided to assist patients in maintaining any newly acquired skills. Mood, self-esteem and medical status were assessed at baseline, 3 months and 6 months, and survival analysis was carried out after an elapsed time of 2 and 5 years. The findings however showed no survival advantage for those in the intervention group, and although there was some improvement in both mood and self-esteem immediately following intervention, by 6 months this had dissipated.

Again, there are a number of possible reasons for these results. The first is that out of 62 patients randomised to the treatment group, 19 were classified as 'dropouts' due to death, illness, ineligibility to participate or failure to complete post-therapy questionnaires. Thus whilst the survival analysis included all randomly assigned patients on an intention-to-treat basis, almost one third of the intervention group did not commence or did not complete therapy. This may have had a distorting effect on the findings as such dramatic non-compliance of this nature significantly weakens validity (see Cunningham *et al.*, 1998). In addition, some members of the control group were found to have participated in non-study related support groups using psychological techniques, and this raises the possibility of contamination. Finally, survival analysis was conducted 5 years after commencement of the study and 2 years after the last group intervention, meaning the timing of analysis may have obscured a late effect of therapy, although this is balanced against the fact that over time it would have become more difficult to attribute survival effects to the intervention.

So, taking all these above (5) studies in total, it could be that one would begin to conclude that despite the original thoughts of Spiegel *et al.* (1989) there is no reliable or replicable relationship between psychological interventions and survival. However, such a tentative conclusion can only be drawn from studies which focused solely on patients with breast cancer, and thus it is possible that there are specific psychological dimensions associated with this variant of the disease that make it less susceptible to psychological "treatment". Also, alongside this possibility, it must be remembered that with the plethora of design and measurement issues associated with the above studies, that perhaps only more reliable or consistent results can be drawn from studies that are acknowledged to be more robust? I shall therefore now go on to look at two further studies which do not suffer from so many of the design weaknesses cited above and examine whether any firmer conclusions can be drawn than thus far.

3.4 STUDIES WITH FEWER CONTAMINATION DIFFICULTIES

The first of these studies was published by Fawzy *et al.* (1993). Unlike the above five studies which had a focus on breast cancer, they examined the impact of a structured short-term group intervention on coping and distress in patients with either stage I or II malignant melanoma. Again, sample size was relatively small (68), and patients were randomised to a treatment group (n=38) or a control group (n=28). The treatment intervention involved a highly structured cognitive behavioural approach delivered to small groups of participants (between 7 and 10 per group). Sessions were run weekly for 6 weeks, and included sessions on stress awareness/management, education, emotional expression and coping skills. Outcome measures included both immune and psychological responses up to 6 months after the treatment intervention, as well as survival at 5 years post study. Both groups received the same medical treatment.

The survival data which were analysed 6 years later revealed that ten patients from the control group had died compared to only three from the treatment group. This was a statistically significant difference in survival times. In addition, 6 months after the end of the psychological intervention, patients from the treatment group were found to have higher levels of natural killer cell activity. This is particularly interesting as it could suggest for the first time the physiological mechanism that is triggered by psychological therapy which then in turn aids survival. Does therapy lead to some form of physiological effect on an aspect of immune function? Furthermore, two other factors were also found to be predictors of survival irrespective of group randomisation – namely higher distress levels and strong coping skills at baseline. Fawzy *et al.* (1993) concluded that in light of the fact both the control and treatment groups had been well-matched groups that had been randomly assigned, the results suggested the group psychological intervention was likely to have played some role in the differential survival outcomes.

Whilst these results appear promising and potentially profound in terms of effect causality, there are a number of alternative explanations which require consideration. It is possible that the intervention may simply have resulted in improved health habits (diet, sun protection, exercise) and more effective coping, resulting in greater treatment compliance, positive mental attitude and improved doctor/patient relationships. In addition, just as in the case of Spiegel *et al.* (1989), this study was not specifically designed to investigate long-term survival outcome, meaning the small number of patients involved in the follow up severely limits the validity of any generalisations. So whilst the intervention appears to have benefited some patients, it is impossible to know specifically which aspect was of benefit to which patient. Instead, the results would tend to suggest that further research using a larger number of subjects would provide more insight and understanding. Such studies are of course very difficult to organise or control.

The second study which has arguably a still stronger research methodology was that published by Richardson *et al.* (1990). This study involved 94 patients and investigated whether a psychological intervention designed specifically to encourage treatment adherence would impact on patient survival times. The patients (suffering from either lymphoma or leukaemia), were randomised to either a control group (n=25), or one of three intervention groups (n=69). These three groups involved:

1) An educational programme and a home visit (n=22)
2) The same educational programme and a shaping group (n=23) or
3) An educational programme, home visit and shaping group (n=24).

The educational programme involved a nurse-led presentation which focused on cancer and its treatments, followed by questions and discussion. The shaping group involved a nurse working with patients so they could learn to take responsibility for self-medication. The home visit occurred within 1 week of a patient's discharge from hospital and involved at least one family member to help support the patient in their self-care. Those in the control group received routine medical care from the same staff providing treatment to the intervention groups.

Psychological factors of depression, locus of control and coping were measured both at baseline and 6 months later, and survival data were assessed after 2 to 5 years. The results showed that whilst the psychological measures did not correlate with increased survival times, assignment to any of the treatment groups did result in longer survival times, with the interventions remaining significant even after treatment effects on adherence were controlled for.

The authors proposed a number of possible explanations for their findings. It may have been that the participants in the intervention groups simply gained knowledge about positive health behaviours that in turn may have enhanced survival. These would include such things as eating an improved diet, keeping hospital appointments and presenting with treatment side-effects sooner. They may also have learnt additional skills, which led to an increased sense of control, thus reducing feelings of fear and anxiety. In addition to these suggestions, the other point to consider is that of a possible placebo effect, as this has been found to exist in other treatment adherence studies (Pizzo *et al.,* 1983; Epstein *et al.*, 1984). Overall, as with all the above studies, although the exact nature of the relationship between the intervention and survival times remains unclear, these findings certainly appear to demonstrate a positive effect on patient adherence behaviour and ultimately on survival time. Perhaps then the answer to this important debate does lie in "cleaner" studies with more consistent measures, and may in fact also be related to cancer type? Further evidence investigating these relationships are presented below, from four final studies. They are clustered in this section as their design and interpretation seem more flawed than the two cited above, and as will be seen, together they again give less than unequivocal results.

3.5 ADDITIONAL STUDIES

Kuchler *et al.* (1999) conducted a randomised controlled trial in order to examine what impact the provision of psychotherapeutic support would have on the survival of a sample of patients suffering from gastro-intestinal cancer. A total of 271 patients were recruited, stratified by gender and then randomised to either a control (n=135) or treatment group (n=136). Clearly this is a large group of patients, and suggests that the findings from the study auger well for a more authoritative position on the subject under debate. Whilst patients in both groups received standard medical care, those in the treatment group received additional psychotherapeutic support, which was delivered by a therapist trained in behavioural and analytical psychotherapy. During hospital admissions, patients in the treatment group met every 2 days with the therapist, who delivered interventions which focused on reducing helplessness/hopelessness/anxiety and building hope, confidence and so called "fighting spirit". The intervention also aimed to improve post-operative coping.
The findings showed that at the end of a 2 year follow-up period, those in the treatment group had statistically significant longer survival times. Of the original 136 randomised to the treatment group, 69 were alive, compared to only 45 of the 135 in

the control group. In addition, female patients from the treatment group appeared to have an added survival advantage, as 66% of the women in the intervention were alive, compared to only 41% of the men. In the control group 39% of the women and 29% of the men had survived. This difference (the first of its kind that has been identified) raises interesting questions about male/female differences in likely benefit from therapy, though why such differences emerge here and not elsewhere in the literature is unclear.

In light of these findings, Kuchler *et al.* (1999) concluded the existence of a positive link between the delivery of psychotherapeutic support and survival. They suggested the reason for this was that the psychological intervention had been delivered to patients on an individual basis and at an early point in the disease trajectory, thereby reducing stress levels, which in turn improved immune function and therefore impacted on overall survival. In terms of the gender difference, they suggested a simple explanation, stating that the women in the study had received more psychological support than their male counterparts, both in terms of frequency and duration of sessions.

Whilst Kuchler *et al.* (1999) state that these results clearly demonstrate that a formal programme of psychotherapeutic support has a survival benefit for gastrointestinal cancer patients, the exact nature of this relationship again remains elusive. In terms of the variables investigated in this study, there were no statistically significant differences between the two groups, thus giving no reason to suspect problems with the randomisation. However a major limitation is that during the post-operative period, 10 participants from the treatment group requested a transfer to the control group, as they no longer wanted to receive psychotherapeutic support and 34 participants from the control group transferred to the treatment group, because they did want support. The authors also employed an 'intent to treat' analysis, meaning that participants remained in their originally assigned groups for the analysis. In reality this means that 34 patients in the control actually received the intervention and this may have diminished the differences between the groups in terms of outcome and the effect of the intervention.

A second study which again suggests a positive relationship was conducted by Ratcliffe *et al.* (1995). This aimed to examine what effect hypnosis and relaxation training would have on patients undergoing chemotherapy treatment for either Hodgkins or non-Hodgkins lymphoma. A total of 63 patients were recruited and assigned to either a control (n=27) or intervention group (n=36). Those in the intervention group received relaxation training (with or without hypnosis), whilst those in the control underwent standard anti-emetic review. Personality, anxiety and depression scales were administered to patients for a 5 year follow up period. The findings revealed that the hypnosis intervention significantly reduced treatment-related anxiety, whilst relaxation training reduced nausea. In addition, Ratcliffe *et al.* (1995) found that those receiving an intervention had a 33% (p=0.06) reduction in the risk of dying by the end of the study. It is recognised that this result in itself is marginally outside the levels customarily accepted as statistically significant, and therefore technically could be argued to be only a non-significant trend. However, given the "noise" associated with potential psychological efficacy effects, a result of this magnitude should not be overlooked.

Again, although these results appear encouraging, the study still suffers from a number of arguable limitations which necessitate consideration. Firstly, although it is stated that hypnosis and/or relaxation was delivered to those patients in the treatment group, no further information about the nature or content of either intervention is provided. Secondly, the authors do not indicate whether this is a randomised study and it is not known how patients were allocated to each group. Thirdly, the incidence of chemotherapy side effects in these patients was reported to be small, resulting in minimal compliance with either relaxation or hypnosis. In addition the interventions were not introduced until after the third cycle of chemotherapy, meaning they were actually used very little. This combination of issues has to bring into question not only the overall validity of study, but the relevance of the interventions in terms of survival.

The penultimate study to be considered was conducted by Linn *et al.* (1982). It aimed to examine the effects of supportive psychotherapy on physical functioning, quality of life and survival time in 120 male cancer patients. Whilst the patients recruited had a range of cancers, all had metastatic disease, which was considered to be end-stage, with a prognosis in the region of 3 to 12 months. The participants were randomised to either the treatment group (n=62) or control (n=58). Those in the treatment group underwent counselling which was aimed to help them find meaning in their lives, share their feelings and make plans for those who would be left after their death. The intervention also encouraged patients to adopt a realistic view of their prognosis, whilst simultaneously helping them to maintain a sense of hope and optimism. Functional status, depression, self-esteem, life satisfaction, alienation and locus of control were measured at baseline and at five additional points during the duration of the study, which was 1 year.

The findings revealed that whilst all the psychological areas improved for those in the treatment group when compared to the control, there was no overall difference in survival or functional status between the two groups. So although Linn *et al's* (1982) initial hypothesis that if quality of life were improved then physical functioning would also improve, leading to increased survival times, was not upheld, the supportive psychotherapy intervention was found to enhance quality of survival. The study did however again suffer from a number of limitations. Firstly, the fact these results were based on the work of just one counsellor, combined with the fact only male patients with certain types of cancer were included in the study, severely limits any possible generalisations. This is particularly true when we compare the male/female difference hypothesised to exist by Ratcliffe *at al.* (1995) above. Finally, as all patients in the study had end-stage disease there is the possibility that if the disease process is far advanced, psychological interventions of any kind are unlikely to have any effect on survival. This does not however answer the question of whether interventions at an earlier stage may have.

Finally, Illnyckyj *et al's* (1994) randomised prospective study of 127 cancer patients with various types of disease aimed to examine the possible psychological benefit of group therapy. The participants who were stratified based on gender, performance status and disease status were randomised to either a control (n=31) or one of three intervention groups. These three groups involved:

1) A professionally led group (n=31)
2) A professionally led group for 3 months, followed by 3 months as a peer-led group (n=30), or
3) An entirely peer-led group (n=35).

An additional 21 patients joined the study at a later date and were assigned to the purely peer-led group for the final 3 months of the intervention. In terms of frequency, the groups met for 1 hour on a weekly basis for a total of 6 months. Participants were asked to complete depression, anxiety and locus of control measures prior to randomisation and again at regular intervals throughout the study.

No survival benefit was found to exist in any of the treatment groups. This was regardless of whether the analysis included the data from the 21 additional recruits or not. There are a few possible explanations for why this study failed to generate a survival benefit, as well as study limitations, which necessitate comment. Firstly, it is known that tumour site-specific support groups increase the sharing of common dilemmas, leaving patients more likely to find resolution through the group process (Illnyckyj, 1994). This means that the diverse range of cancers found in this study's sample may have impacted negatively on the value of the interventions. Secondly, there is a total lack of information concerning the nature of the group therapy provided for those in the peer-led groups. The only guideline offered was that they could use the allotted time in any way they wished. Finally the intervention in this study only lasted for 6 months, which may as has been seen in many other studies discussed here have been insufficient in terms of impacting on survival.

4. CONCLUSIONS

The role that psychological interventions play in cancer survival remains unclear and the existing evidence is conflicting and divided. Studies investigating the relationship have yielded mixed results. Some report survival benefits, however replication has not been achieved in others, despite similar effects appearing on non-replication studies. With nothing conclusively demonstrated, the question as to whether psychological interventions can increase quantity of life has to remain open.

The reasons for these inconsistencies are no doubt complex and may forever be not completely known or understood. However some differences can be attributed to the numerous methodological problems associated with this area of research. One of the main limitations of some of the studies showing a survival advantage is that they were originally designed to examine the effect of interventions on psychological functioning in cancer patients and **not** survival. Consequently, many of the sample sizes used were inadequate in terms of demonstrating a convincing survival effect. There are also problems with regard to the randomisation process, as in some studies the stratification procedures used did not necessarily ensure balance on two important prognostic factors: age and metastatic site. In addition, sometimes more patients were randomised to the treatment group than to the control (see Shrock, 1999 for a further discussion of problems thus arising). The measuring of immunological variables as used by Fawzy *et al.* (1993) is also potentially problematic, for variables of this nature are highly delicate and measurements can easily be affected by other factors including diet, time of day and general lifestyle. All of these are notoriously difficult to control for. It must also be recognised that the cancer process itself is influenced by many factors acting in combination and taking all these relevant variables into account in a study's design is hugely challenging if not impossible. It is therefore perhaps the complexity of cancer itself and a patient's response to it, which makes research in this area far from straightforward (Cooper and Watson, 1991). Consideration must also be given to the fact that the course of human cancers are usually measurable in years rather than months; and so for any valid results to be obtained, clinical follow-up studies perhaps need to be continued for at least 10 years. This raises the more pragmatic issue of funding, as money is usually only given for studies of shorter duration (Barraclough, 2000).

The lack of replication between the existing studies and the inconsistency of findings may also be due to a number of major differences between the studies themselves. Some studies chose to focus on one cancer type (e.g. breast cancer), whilst in others recruitment was open to patients with any type of cancer. This led to some samples involving a multitude of diagnoses. The stage of disease at recruitment also varied between studies, with some focusing on end-stage patients and others only recruiting those with early-stage cancer. It is possible that intervening behavioural factors including treatment compliance, physical exercise, diet, smoking and alcohol intake may have been responsible for the reported associations between psychosocial factors and progression of the disease, and unfortunately many of the studies failed to account for, or control for these. In most cases too there were major differences in the psychological interventions themselves, making them difficult, if not impossible to compare. The interventions varied with respect to duration, content, and format (individual vs group) as well as therapist education/experience levels. Perhaps a final point to consider is that of the context in which Spiegel *et al's* (1989) original study took place. Twenty years ago, cancer treatments were substantially less effective and access to emotional support; almost non-existent. Today, with more advanced cancer detection and treatment, combined with much better access to psychological support, the positive effect of a formal psychosocial intervention on survival time as was found in some of the earlier studies, becomes arguably much more difficult to replicate (Spiegel, 2001).

What is clear is that a growing number of studies, with survival as the a priori endpoint have failed to demonstrate a significant difference in median survival time for psychotherapeutic intervention versus control group for any cancer patient sample (Cunningham *et al.*, 1998; Edelman *et al.*, 1999; Goodwin *et al.*, 2001; Kissane *et al.*,

2007) meaning that overall the literature is now slightly weighed in favour of there being no survival advantage. The overall balance in terms of effect versus no effect between studies can be clearly seen from Table 12 above. So whilst the overall debate continues, in the meantime, what the literature has helped to do is further highlight the positive impact that psychological interventions may have for some in terms of reducing distress, improving quality of life and countering isolation (Coyne *et al.*, 2007).

5. FUTURE RESEARCH IDEAS

With a current lack of definitive studies and without a sufficient number of long-term outcome studies offering themselves as reliable indicators of the efficacy of psychological interventions in slowing down the course of cancer, there remains a considerable opportunity and need to increase our understanding in this area. Opinions about the direction of appropriate future research however appear as split as the existing evidence base. Some feel that rigorous replication studies are required in order to allow for a final judgement to be made about the value of Spiegel *et al's* (1989) original work, whilst others feel that further study of the immune, endocrine and other biological mechanisms is necessary in order to improve understanding about how interventions may impact on these and ultimately disease progression (Mulder, 1992). Gellert (1993) suggests that future research should examine the role that additional variables such as diet, compliance, exercise, social support and health habits may have in the progression of cancer. Patient characteristics are another complex area requiring attention, as it could be that demographic variables (age, race, culture, gender, socio-economic status and education) could influence the efficacy of an intervention (Mulder, 1992). Type and stage of cancer may also be crucial and just as tumours themselves differ, so too can the associated psychosocial issues. Psychological responses can vary between disease types and it may be that different diseases require different kinds of psychological interventions. For example, patients with primary breast cancer may benefit more from a short-term intervention, whereas patients with metastatic disease may need longer-term supportive expressive group therapy (Mulder, 1992).

If the future is to involve pursuing such research avenues, in line with the design of preference, randomised controlled trials are suggested as the best way of undertaking such investigations, for by assigning patients to treatment or no-treatment control groups, maximum information can be obtained (Illnyckyj, 1994). However, randomised trials have their own limitations and since we know that psychological interventions impact positively on the quality of life in cancer patients, it may now be considered unethical to assign patients to a no-treatment group (Mulder, 1992). With large numbers of patients being needed to ensure that treatment and control groups are similar in all respects, the aforementioned ethical concerns would make recruitment problematic, as patients may not want to risk being assigned to a control. Another difficulty identified by Moorey and Greer (2002), is that the results from such trials are based totally on comparisons between groups and therefore do not offer insight into whether individual patients will benefit from a particular intervention. Cunningham (1998) has suggested that one way of uncovering the influence that psychological change has on cancer progression would be to establish single case studies, in which individuals are followed for years, and changes in their psychological functioning are compared with the extent to which these patients outlive their predicted survival according to medical prognostic features. However, a weakness with this design is that, unlike randomised trials, valid and widespread generalisations cannot be made. So at the current time, despite its limitations, randomisation remains the most effective and bias-free methodology and continues to be the design of choice for such investigations (Moorey and Greer, 2002).

Others feel less convinced that any further research into the question of whether psychotherapy promotes survival is warranted and instead feel that the existing evidence is sufficient for the conclusion to be drawn that the two factors are not related (Coyne, 2007). Amongst this fraternity, there is a growing sense that psychosocial research should now re-focus on issues such as improving treatment adherence, assisting patients in coping with unpleasant treatment side-effects and reducing emotional distress (Coyne, 2007). Spiegel (2001) suggests that an additional and useful direction for future research would be to focus on identifying those cancer patients that are most likely to need and respond to emotional support. So in summary, whilst this field of investigation remains full of uncertainty and ongoing debate, it is hoped that the studies presented in the course of this review have at least helped to clarify the current understanding about the relationship between psychological interventions and survival, as well as identify those areas in which future research may be beneficial.

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APPENDICES

Northampton General Hospital NHS
NHS Trust

APPENDIX 1

Cliftonville
Northampton
NN1 5BD

Direct Dial:
Direct Fax:
Switchboard: (01604) 634700

Dear ....(CNS name)

I am writing to invite you to take part in a research study which I am undertaking as part of my Doctorate in Counselling Psychology.

Please find enclosed a Participant Information Sheet which is designed to give you an overview of the study, as well as a clear understanding of what would be involved should you decide to take part. Participation is entirely voluntary so please ensure you read this information carefully before making your decision about whether you would like to take part.

If you have any further questions, would like to discuss any aspect of this study or clarify any points raised then please do not hesitate to contact me directly either by telephone (01604 523735) or email (philippa.jones@ngh.nhs.uk).

If you decide that you would like to take part in this study then please return the enclosed Reply Slip using the stamped addressed envelope provided. I will then contact you directly, to arrange a convenient time for an interview.

Thank you for taking the time to read this information.

With best wishes

Yours sincerely

Philippa Jones
Macmillan Psychologist

Encs.

APPENDIX 2

PARTICIPANT INFORMATION SHEET

What understanding and expectations do cancer and palliative care Clinical Nurse Specialists have of cancer Psychologists and how do these nurses assess patients and/or carers for psychological distress?

Principal Investigator: **Philippa Jones**

You may contact: Philippa Jones, Macmillan Psychologist,
Department of Clinical Health Psychology,
Northampton General Hospital NHS Trust
Cliftonville,
Northampton, NN1 5BD

Telephone number: 01604 523735

You are being invited to take part in a research study. Before you decide whether you would like to take part it is important for you to understand why the research is being done and what it will involve. This information leaflet is designed to explain a little more about the research, so please take some time to read it carefully. I hope it will help to answer any questions you may have but if there are any outstanding questions or concerns please feel free to contact me on the above telephone number. Taking part is entirely voluntarily so please take as much time as you need to decide whether you wish to take part or not.

Thank you for taking time to read this information sheet.

Purpose of the study

The aim of this qualitative study is to gain a better understanding about the relationship between Clinical Nurse Specialists (CNSs) and cancer Psychologists. The study will aim to identify the perceptions and expectations that CNSs have of Psychologists and explore how they perceive the working relationship between the two professions. The objectives of the research is to gain a better understanding about how CNSs carry out psychological assessments, establish whether they feel adequately trained to carry out such assessments and identify what factors influence their referral decisions. Finally the research will aim to ascertain whether there is any difference in the way site-specific and palliative care CNSs conduct psychological assessments. It is important to note that there are no right or wrong answers and the research is an exploration of your views and **not** an assessment of your skills.

Why have I been chosen?

You have been chosen for this study because you are a Clinical Nurse Specialist who works with cancer patients.

Do I have to take part?
Participation in this study is **entirely voluntary** and if you decide not to take part, this will be totally respected and accepted without question. There will be no negative consequences for deciding not to take part. If you do decide to take part please complete the enclosed Reply Slip and return it in the stamped addressed envelope provided.

What do I have to do?
You will be invited to participate in a one-to-one, recorded interview with Philippa Jones. These interviews will explore the expectations that you have of Psychologists within the area of cancer care and also explore how you assess patients for distress. Interviews will be held at a time and place that is convenient to you and will last no longer than one hour. You will be asked to sign a consent form, prior to the interview commencing.

Will my taking part in this study be kept confidential?
All information collected during the course of this study will be kept strictly confidential and all participants taking part will have the right to anonymity to ensure they feel able to speak openly. Written transcriptions of the recorded interviews will be coded so as to maintain anonymity and no references will be made to any individual participant at any stage in the research process or within the written thesis. Furthermore, all tapes used in the interviews will be kept in a locked cabinet to ensure your confidentiality and anonymity is maintained at all times. All tapes will be destroyed following completion of the study. Should this research lead to any type of publication anonymity will be maintained and no identifying information relating to participants will be published.

What will happen to the results of the study?
The outcome of this research will be shared with the CNS team involved by way of a short presentation of the key findings. They will also be offered a written summary of the key findings. A copy of the presentation and written summary will also be provided to the NHS Trust Research & Development office for their information. In order for the NHS Trust involved to be able to benefit from the research findings a contract of terms is suggested.

Who has reviewed this study?
The study has been reviewed by Dr Jacqui Farrants, City University, London and has been approved by the Leicestershire, Northamptonshire & Rutland Local Research Ethics Committee.

For additional information please feel free to contact:
Philippa Jones, Macmillan Psychologist
Contact details above

Thank you for reading this information leaflet.
If you would like to take part in the study, please complete the enclosed reply slip and return it to me in the stamped addressed envelope provided.

APPENDIX 3

REPLY SLIP

What understanding and expectations do cancer and palliative care Clinical Nurse Specialists have of cancer Psychologists and how do these nurses assess patients and/or carers for psychological distress?

Yes, I would like to take part in the above named research study.

Name..

Contact telephone and/or email...

Date....................................

Please return to: Philippa Jones (using stamped addressed envelope provided)

APPENDIX 4

CONSENT FORM

What understanding and expectations do cancer and palliative care Clinical Nurse Specialists have of cancer Psychologists and how do these nurses assess patients and/or carers for psychological distress?

Name of Researcher / Principal Investigator: **Philippa Jones**

	Initials
1. I confirm that I have read and understood the information sheet (version 3.0, dated 2nd January 2007) and I have had all my questions answered to my satisfaction.	
2. I understand that I may refuse to answer any of the questions without giving reason.	
3. I understand that my participation is entirely voluntary and that I am free to withdraw my consent at any time, by contacting Philippa Jones on 01604 523735 and have my interview tape destroyed.	
4. I agree to take part in the above study.	

---------------------------------- ---------------------------------- --------------

Name Signature Date

---------------------------------- ---------------------------------- --------------

Investigator's name Signature Date

APPENDIX 5

POST-INTERVIEW INFORMATION

Thank you very much for taking part in this interview and supporting this piece of research. In due course I will be arranging to present the findings to those who took part – this will be done at a time and place convenient to you and the other participants. I would also be very happy to provide written summaries of the findings to anyone who would like one.

In the meantime, if you have any questions or issues regarding this research which you would like to discuss further, please feel free to contact me:

Philippa Jones

Work:	01604 523737
Mobile:	07952 332031
Email:	pnutjones@hotmail.com

In the event that after this interview you feel you would benefit from talking through any issues which arose the following staff would be very happy to provide a one to one debrief and/or ongoing support, so please feel free to contact them:

Philippa Jones (details above)	Macmillan Psychologist
Carolynn Ginns	Matron Outpatient Services, KGH
Telephone:	01536 492408 Blp 808
Email:	carolyn.ginns@kgh.nhs.uk

mailto:carolyn.gins@kgh.nhs.uk

Linda Pirie	Psychotherapist, KGH
Email:	linda.pirie@kgh.nhs.uk
Addy Hackett	Consultant Psychologist, Cynthia Spencer Hospice
Telephone:	01604 678089
Email:	addy.hackett@northants.nhs.uk

MANY THANKS AGAIN FOR TAKING PART IN THIS RESEARCH

PHILIPPA JONES

APPENDIX 6

DOCTOR OF PSYCHOLOGY – POST CHARTERED RESEARCH PROPOSAL

Title

What understanding and expectations do cancer and palliative care clinical nurse specialists have of cancer psychologists and how do these nurses assess patients and/or carers for psychological distress?

Name, Course, Supervisor

Philippa Jones
Doctor of Psychology, City University, London
Supervisor (provisional) – Dr Jacqui Farrants

Summary of Project

This will be a qualitative research study investigating the perceptions and expectations that a team of NHS clinical nurse specialists working in the fields of cancer and palliative care have of cancer psychologists. In addition, the ways in which they assess patients and/or carers for psychological distress will be explored, as will the factors which influence their decisions to refer on to specialist psychology services. In order to explore these issues individual, in-depth, semi-structured interviews will be carried out.

Justification of Project

The psychological implications of a cancer diagnosis are now well documented and the management of psychological distress is fast becoming recognised as an essential part of patient care (Burton & Watson 2000). The NHS Cancer Plan (2000) and The National Institute for Clinical Excellence's Guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004) have both made explicit the need for good quality psychological care for cancer patients and their families. Increasingly, chartered clinical and counselling psychologists are being viewed as part of the multi-disciplinary team and are contributing to the care of people with cancer. There is now an expectation, fully endorsed by the NICE guidelines (2004) that every cancer service should have access to psychology expertise. In response, Macmillan Cancer Support, a UK charity traditionally associated with nursing has recently begun to fund Macmillan Psychology posts. This means Macmillan fund the initial cost of a psychologist for up to 3 years, after which time the employing NHS Trust takes over responsibility. There are now approximately 25 Macmillan Psychologists working in cancer centres throughout the UK. There also exists a Special Interest Group in Oncology and Palliative Care (SIGOPAC) which is a formal SIG of the Division of Clinical Psychology of the British Psychological Society which has a growing membership.

Despite this increasing presence of psychology within cancer, many patients and carers are still not gaining access to much needed support. Macmillan Cancer Support recently reported that up to 58% of cancer patients and 61% of carers feel that their emotional needs are not being met (2006). It is suggested that this may be due to many of the healthcare professionals involved in caring for cancer patients including: ward nurses, clinical nurse specialists and oncologists lacking the necessary skills to assess psychological issues and also underestimating the effectiveness of psychological interventions (Bottomley 1997). As a direct consequence patients and/or carers with psychological problems that could potentially be ameliorated are not receiving the care they need.

Northampton General Hospital is a large acute NHS Trust serving a population of approximately 580,000. It is also a cancer treatment centre and provides the facilities for patients receiving either chemotherapy and/or radiotherapy. The oncology service comprises a 24-bedded in-patient ward, an outpatient chemotherapy unit, a large radiotherapy treatment centre and a Macmillan cancer support and information centre. The service is staffed by a combination of Consultant Oncologists/Haematologists, cancer trained nurses, radiographers and a team of tumour site-specific and palliative care clinical nurse specialists. In 2005 the cancer centre secured funding from Macmillan Cancer Support to establish a new, full time psychology post, which I took up in September 2005.

Since commencing in this role I have focused on establishing a comprehensive psychology service for patients and/or carers and have also worked towards establishing myself within the multi-disciplinary team. This process has highlighted that many skilled cancer professionals have a limited understanding of the role that psychologists play in cancer care, feel under-confident in their abilities to use psychologists effectively and are unclear about where the boundaries of professional responsibility lie in relation to psychological care.

I feel it would be of enormous benefit to have a clearer understanding of the perceptions and expectations that clinical nurse specialists have of psychologists in the field of cancer. In addition, gaining insight into the ways in which they carry out psychological assessments would ensure that appropriate psychological support is always being offered to those who need it. The fact that psychological care is a major part of the clinical nurse specialist's role, combined with the fact that they work closely with psychologists, makes them a particularly valuable group to research.

Brief Review of the Literature

At the current time there appears to be no existing research which has investigated the relationship between clinical nurse specialists and cancer psychologists. Whilst this is probably due to the relatively recent emergence of such posts, there does exist a body of literature which I feel illustrates the relevance of the proposed study. A brief review of this is summarised below.

During the past 20 years the psychological dimension of cancer has become a sub-speciality of oncology and many recent government policy initiatives have recommended that specialist psychological services have a fundamental place in providing high quality patient care (Payne & Haines 2002). This is clearly illustrated by the growing numbers of psychologists working in both oncology and palliative care.

White and Macleod (2002) report that depression, anxiety, fear, panic and distress are commonly found in patients affected by cancer. It is estimated that at the time of diagnosis 50% of patients will experience anxiety and/or depression severe enough to affect their quality of life. Out of this group, one in ten patients will experience psychological symptoms severe enough to warrant specialist interventions. The risk of suicide is increased in the early stages of coping with cancer and severe distress is likely to occur at specific points in the disease trajectory including; diagnosis, during treatment, ending treatment, after treatment, recurrence and terminal disease (White and Macleod, 2002).

Numerous studies have now addressed the efficacy of psychological interventions in relation to a range of patients at various stages of disease and there is now strong evidence that psychological interventions significantly reduce psychological morbidity and lead to improved quality of life (Boulton *et al.* 2001). These interventions have also been shown to result in improved adherence to medical treatment, less pain, fewer physical symptoms, less need for medical consultations, improved knowledge regarding cancer and longer survival times (Cooper & Watson, 1991; Greer 1995; Marchioro *et al.* 1996; Moorey *et al.* 1998 cited in Boulton *et al.* 2001; Barraclough, 2000; White and Macleod, 2002). For palliative patients, interventions have been shown to alleviate anxiety and depression, enhance quality of life and ensure that patients and families are able to use their remaining time together effectively (Payne, 1998).

Despite an ever-growing evidence base, psychology remains for many an unknown profession making it difficult for psychologists to integrate into pre-existing cancer teams of health care professionals, predominantly made up of nurses and doctors (McWilliams, 2004). Some report facing hostility and a lack of understanding about their skills, whilst others have reported concern about boundaries of knowledge and expertise in psychological care (Payne and Haines, 2002). Clinical nurse specialists in particular regard psychological input as falling within their professional role and negotiating the boundaries of their expertise potentially gives rise to difficulties in establishing satisfactory working relationship between them and psychologists (Payne and Haines, 2002).

Clinical nurse specialists (CNSs) are nurses who have developed extensive specialist knowledge about a specific area of medicine and by combining their skills as clinical experts, researchers, consultants, teachers and change agents they aim to provide high quality nursing care, (Armstrong, 1999). Since the 1970's the number of CNSs has steadily grown, as have the range of specialities in which they work and they are now found in over 600 different fields of practice (Jack *et al.* 2004).

The Calman-Hine report (1995) and its recommendations for reorganising cancer services led to the rapid appointment of many tumour site-specific and palliative care CNSs (Seymour, 2002). They are now considered essential to the delivery of a comprehensive service to those affected by cancer, and whilst there is considerable variation in the nature and content of each CNS role, all have a specific remit to provide supportive care to patients and families (Willard and Luker, 2005). Changes in nursing education in the UK has meant that psychology is now included in the basic curriculum and many nurses view psychological support as a key part of their role (Payne and Haines, 2002). This is emphasised in the NICE guidelines (2004) which state that CNSs should "be able to screen for psychological distress at key points in the patient pathway and for patients experiencing significant distress a referral for specialist psychological support/intervention should be offered". The guidelines also suggest that CNSs could be trained to deliver problem-solving interventions for those patients requiring them. Despite such recommendations, research shows that many CNSs still feel inadequately trained to detect distress and many fail to refer patients to psychologists because of concerns about the stigma of psychological illness. It has also been found that many share the general negative stereotypes about depression and often make assumptions that psychological distress within this patient group is expected, normal and therefore requires no treatment (Lloyd-Williams and Payne, 2002).

If good psychological care is to be provided, it is vital that health care professionals such as CNSs are able to recognise psychological distress, explicitly assess patients' concerns, offer appropriate support and if necessary refer on to those with specialist expertise (Payne and Haines, 2002). This may only be achieved through the provision of specialist education and training which in turn could also ensure there are clearer distinctions between the boundaries of expertise of the various professionals providing psychological care and more clarity regarding referrals to specialist services.

Aims and Objectives of this Study

The aim of this qualitative study is to gain a better understanding about the relationship between clinical nurse specialists and cancer psychologists. It will aim to identify the perceptions and expectations that CNSs hold about psychologists and explore how they perceive the working relationship between the two professions. The objective of the research is to establish whether CNSs feel adequately trained to carry out psychological assessments and identify what factors influence their referral decisions.

In summary it is hoped that this research will help to identify:

- what perceptions and expectations CNSs have of cancer psychologists
- how CNSs envisage a working relationship with a psychologist
- whether there is a an established, standardised assessment approach/process amongst CNSs
- whether there is the need for the implementation of a standardised assessment tool for CNSs working in the fields of oncology and palliative care
- whether any additional training is required for CNSs making assessments
- whether additional training/education is required to ensure that CNS teams are better prepared to accommodate the different professional perspective held by psychologists

Research Design

This qualitative research study will involve a team of 10 clinical nurse specialists working within cancer and palliative care. This number of participants is manageable for the size of the project and will provide sufficient data to allow for meaningful conclusions to be drawn. They will be based in an NHS Trust where there is as yet no cancer psychologist in post. In depth, semi-structured interviews will be conducted on a one-to-one basis. These interviews will last no longer than one hour and will be tape-recorded.

Recruitment

Once an appropriate team of CNSs has been identified, letters will be sent to each individual inviting them to take part in the study. The letter will outline the aims of the study, the intention to tape-record interviews and an explanation about issues of confidentiality and anonymity (see ethical considerations section). Participants will be asked to state their willingness to take part by means of a reply sheet. Stamped addressed envelopes will be included so they can reply directly to me. This will be done to ensure an adequate sample size is achieved.

Data Collection

Each recruited CNS will be interviewed at a time/place convenient to him/her. Each interview will begin with a reminder about the issues of confidentiality and anonymity and an explanation about the arrangements for debriefing and ongoing support post-interview. They will also be reminded that the interview will be tape-recorded. All participants will be asked to sign a consent form agreeing to this. After the interview each participant will be thanked for his or her time and input. Permission will be sought from each participant for me to contact them should I require any further clarification whilst analysing the data (respondent validation). They will each be asked if they would like an abstract of the results obtained.

The interviews will be semi-structured in nature, guided by a prompt list to ensure that the main issues are covered.

Prompt List

Possible questions to be included on the prompt list:

- Can you tell me what you feel about psychologists working in the field of cancer?
- If a psychologist was working in your department what would you expect from them?
- What do feel are the main differences between CNSs and psychologists?
- What sort of issues do you feel would necessitate a referral onto psychology?
- Can you describe how you currently assess patients for psychological distress?

- How do you feel about assessing for psychological distress?
- Can you tell me about any training you have had, which has assisted you in carrying out such assessments?
- Do you feel adequately prepared and supported to undertake these assessments?
- Is there any other training you feel would be beneficial?

Data Analysis

The tape recordings will be transcribed and the data coded and analysed using interpretative phenomenological analysis (IPA). By utilising this approach, I hope to gain insight into the thoughts and feelings CNSs have about psychologists and patient assessment. I have chosen this method as it is primarily concerned with understanding individuals' experiences and specifically aims to "explore in detail participants' personal lived experience and how participants make sense of that personal experience" (Smith, 2004). I therefore feel it would allow me to achieve my aims of exploring the individual experiences of a number of clinical nurse specialists. In addition, with very little known about the topic under investigation and no hypotheses to test, I feel the exploratory nature of IPA would be particularly valuable in allowing any unanticipated phenomena to be revealed and for the findings to be both contemporary and a direct reflection of the nurses' experience (Shaw, 2001). As a counselling psychologist with experience of working in this area, I feel I would be theoretically sensitive, having a good understanding of the meaning and subtlety of the data thus allowing me to formulate conceptually dense theory (Barker *et al.* 2000). Finally, IPA involves a systematic method of analysis which would offer me a more structured framework when interpreting my data. This is in contrast to some other qualitative methods which rely upon the application of more general principles which can make application and interpretation more problematic.

Ethical Considerations

The British Psychological Society code of Conduct, Ethical Principles and Guidelines states that investigators must consider the ethical implications and psychological consequences for participants taking part in research. In line with this code there are a number of ethical points to consider.

- **NHS Ethics Approval** - as it is proposed to use NHS employees as participants in this study, ethical approval will be required from the appropriate NHS Trust's Ethics

Committee. In this case approval will be sought from the Leicestershire, Northampton and Rutland Research Ethics Committee.

- **Informed Consent** - participants will need to be fully informed about the research procedures. All participants will be supplied with a written Participant Information Sheet and direct contact with myself (via telephone or email) will also be suggested for any participant who would like to discuss any aspect of the study in more detail. In each case a consent form will be signed prior to interview.

- **Impact on Participants** – it is acknowledged that participation in this study could leave nurses feeling somewhat demoralised and questioning of their own competence. Whilst it is hoped that sensitive interviewing will avoid this scenario, the following suggestions hope to address this risk:
  - **i.** All participants will be offered a post-interview de-briefing session with a professional who has significant experience in the field of cancer and palliative care, none of whom have any involvement in the project.
  - **ii.** Three people have been identified for this purpose. It is hoped that by identifying three people for this purpose, participants will have a choice of who they de-brief with:

    Carolyn Ginns – Matron of Outpatient Services, Kettering General Hospital

    Linda Pirie – Voluntary Psychotherapist, Kettering General Hospital

    Addy Hackett – Consultant Clinical Psychologist, Cynthia Spencer Hospice, Northampton (as Addy does not work at Kettering General Hospital, participants also have the option to de-brief with someone external to their own hospital).
  - **iii.** On-going support will also be available from the three aforementioned staff for all participants.
  - **iv.** Following the interview stage of the research study, I would be happy to provide a training session on any topic(s) that the participants would feel to be beneficial. This would be done at a time convenient to them.
  - **v.** A number of network based training events focusing on the issue of assessing patients for distress are currently being discussed. Once finalised, I would ensure that details of such courses were distributed to the team.

vi. Whilst it is possible that this research may identify gaps in CNSs knowledge and/or skills, it is hoped that ultimately it will ensure that staff will receive the necessary training and support in order for them to feel empowered and confident when dealing with the psychological aspect of patient care.

vii. The issue of debriefing, ongoing support and training will be discussed with each participant at the beginning of each interview. Contact details for Carolynn Ginns, Linda Pirie and Addy Hackett will also be distributed at this stage.

- **Risk of Coercion** – it is acknowledged that as a psychologist asking CNSs about psychologists, there is a risk of coercion, meaning staff members may feel under pressure to participate. The following points hope to address this issue:
  i. Every effort will be made to make it **very** clear to potential participants that participation is entirely voluntary and there would be no negative consequences from deciding to not take part. The invitation letter, information sheet and consent form all emphasise this point.
  ii. At the beginning of each interview I will again stress that taking part is entirely voluntary and participants may choose to stop the interview or withdraw from the study at any time. It will be emphasised that a decision to withdraw participation would be accepted unconditionally and respectfully.
  iii. I hope the fact I am not known to any of these staff members and am external to Kettering General Hospital will reduce any pressure they may feel to participate.
  iv. Although every effort will be made to address the risk of coercion, it will be acknowledged as a limitation of the study and discussed in the final written thesis.

- **Confidentiality and Anonymity**
  i. All participants taking part in this study will have the right to anonymity to ensure they feel able to speak openly. All research data (tapes and transcripts) will be treated as confidential and locked in a filing cabinet to which I am the only key holder. Transcriptions will be coded so as to maintain anonymity. Participants will be informed that the tapes will be

destroyed after completion of the study. During writing up, any details, which could lead to the identification of any individual will be omitted.

ii. Data in the form of anonymous transcripts will be stored on two computers (my work computer at NGH and my work laptop which is kept at home). My laptop will be used for the writing up of my thesis, with back-up copies being stored on my work computer at NGH. Both computers are password protected and I am the only person with access to these passwords.

iii. Direct quotations will be included in the final thesis, however they will be used in such a way as to maintain anonymity.

iv. Any patient information which is discussed during the interviews will be dealt with confidentially and no reference to individual patients will be made at **any** point in the research process or within the final thesis.

- **Dissemination of the Research Findings** – the outcome of the research will be communicated to the participants by way of a presentation. During these presentations care will be taken to ensure anonymity and confidentiality is maintained for the participants.

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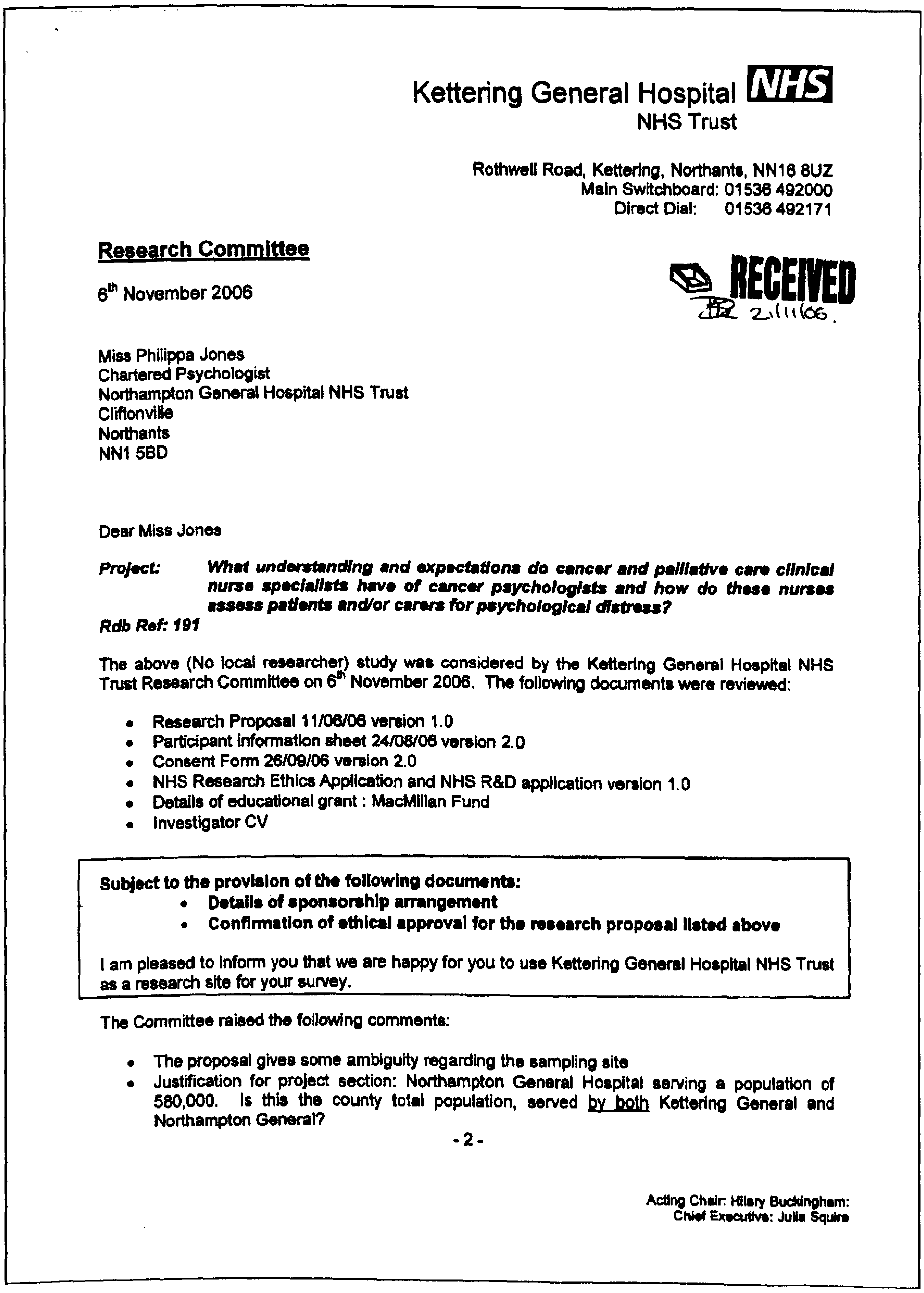
APPENDIX 7



Kettering General Hospital NHS
NHS Trust

Rothwell Road, Kettering, Northants, NN16 8UZ
Main Switchboard: 01536 492000
Direct Dial: 01536 492171

Research Committee

RECEIVED
21/11/06.

6th November 2006

Miss Philippa Jones
Chartered Psychologist
Northampton General Hospital NHS Trust
Cliftonville
Northants
NN1 5BD

Dear Miss Jones

Project: ***What understanding and expectations do cancer and palliative care clinical nurse specialists have of cancer psychologists and how do these nurses assess patients and/or carers for psychological distress?***
Rdb Ref: 191

The above (No local researcher) study was considered by the Kettering General Hospital NHS Trust Research Committee on 6th November 2006. The following documents were reviewed:

- Research Proposal 11/08/06 version 1.0
- Participant information sheet 24/08/06 version 2.0
- Consent Form 26/09/06 version 2.0
- NHS Research Ethics Application and NHS R&D application version 1.0
- Details of educational grant : MacMillan Fund
- Investigator CV

Subject to the provision of the following documents:

- **Details of sponsorship arrangement**
- **Confirmation of ethical approval for the research proposal listed above**

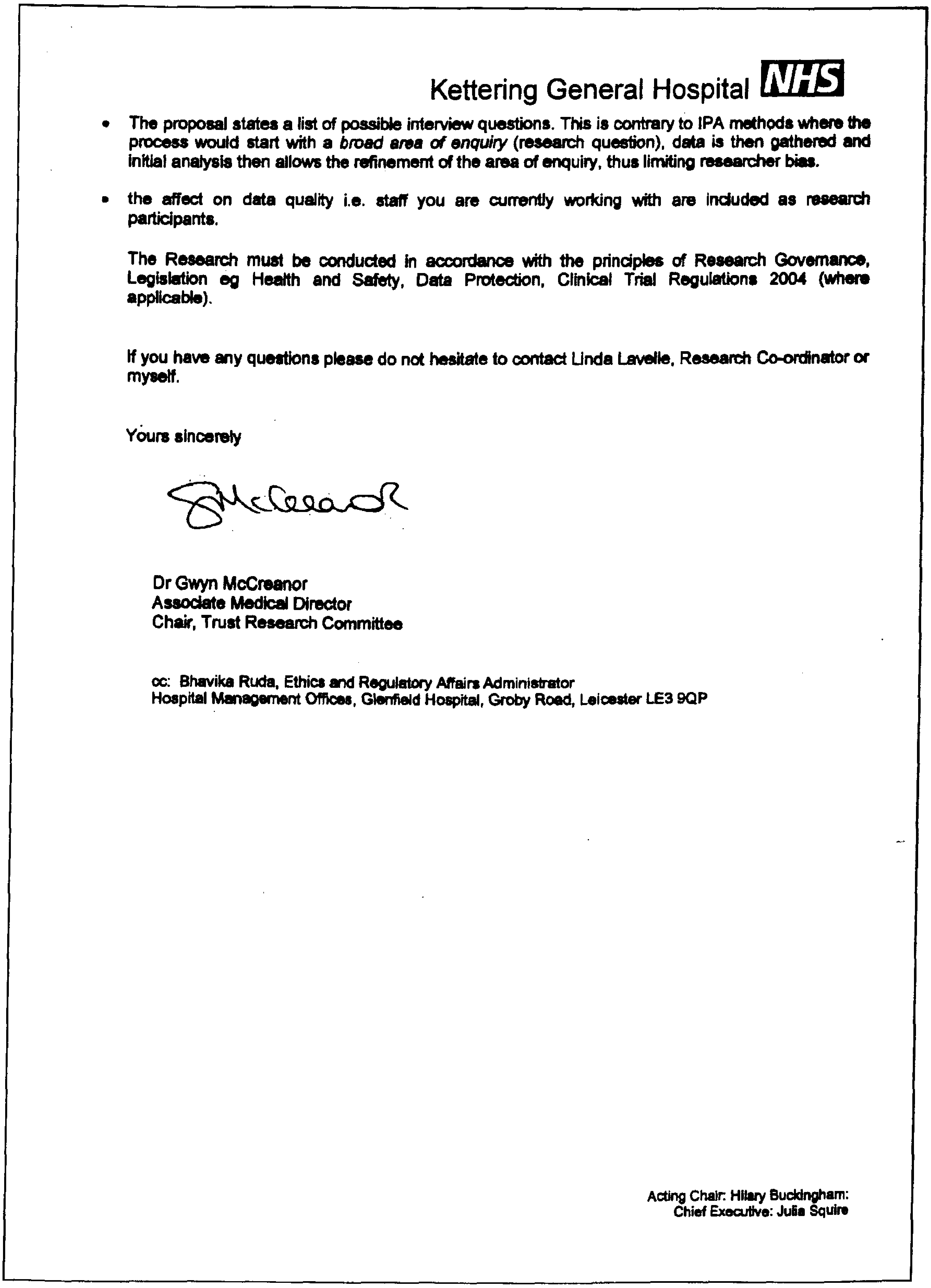
I am pleased to inform you that we are happy for you to use Kettering General Hospital NHS Trust as a research site for your survey.

The Committee raised the following comments:

- The proposal gives some ambiguity regarding the sampling site
- Justification for project section: Northampton General Hospital serving a population of 580,000. Is this the county total population, served by both Kettering General and Northampton General?

-2-

Acting Chair: Hilary Buckingham:
Chief Executive: Julia Squire



Kettering General Hospital NHS

- The proposal states a list of possible interview questions. This is contrary to IPA methods where the process would start with a *broad area of enquiry* (research question), data is then gathered and initial analysis then allows the refinement of the area of enquiry, thus limiting researcher bias.
- the affect on data quality i.e. staff you are currently working with are included as research participants.

The Research must be conducted in accordance with the principles of Research Governance, Legislation eg Health and Safety, Data Protection, Clinical Trial Regulations 2004 (where applicable).

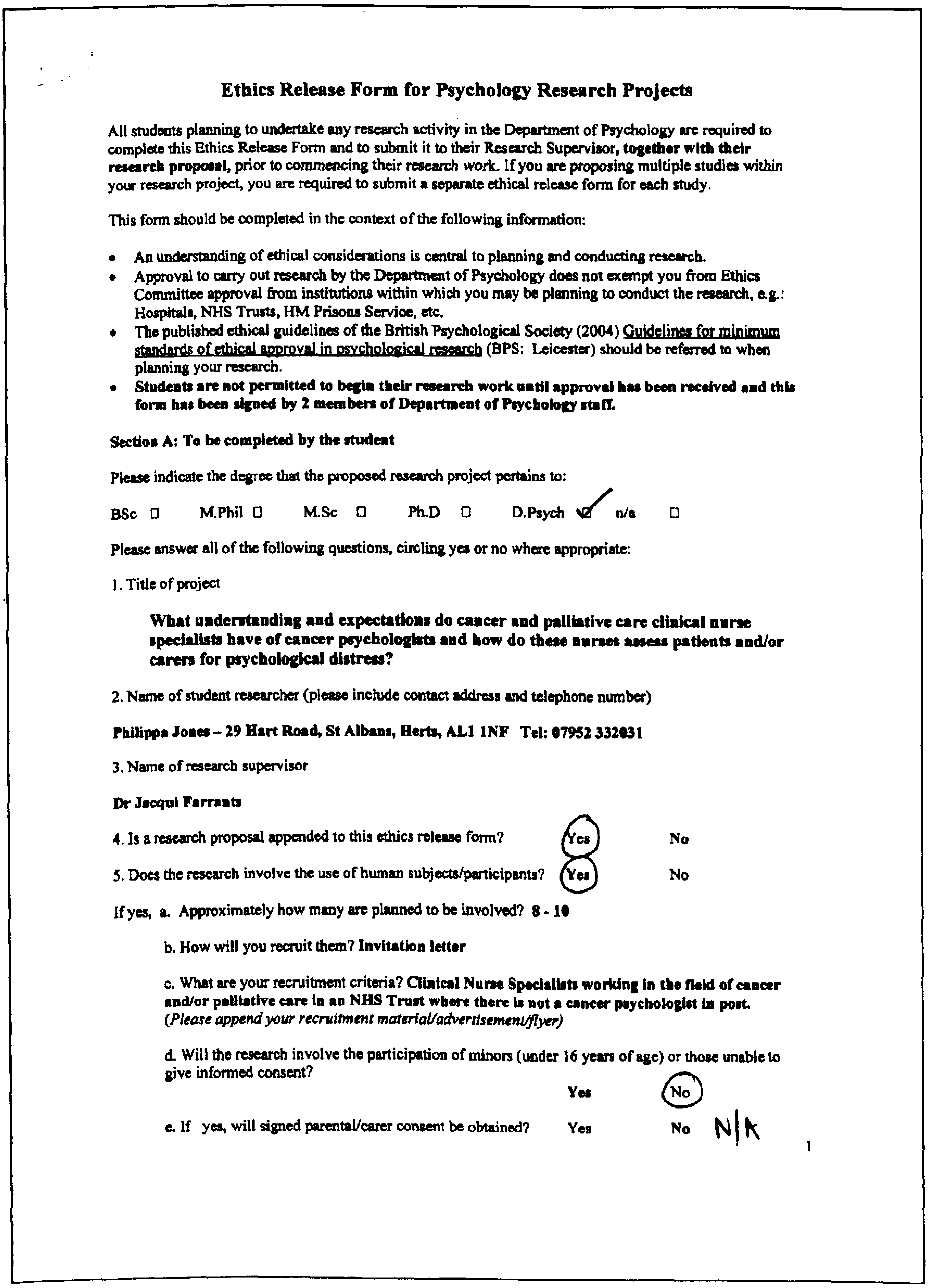
If you have any questions please do not hesitate to contact Linda Lavelle, Research Co-ordinator or myself.

Yours sincerely

Dr Gwyn McCreanor
Associate Medical Director
Chair, Trust Research Committee

cc: Bhavika Ruda, Ethics and Regulatory Affairs Administrator
Hospital Management Offices, Glenfield Hospital, Groby Road, Leicester LE3 9QP

APPENDIX 8



Ethics Release Form for Psychology Research Projects

All students planning to undertake any research activity in the Department of Psychology are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department of Psychology does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2004) Guidelines for minimum standards of ethical approval in psychological research (BPS: Leicester) should be referred to when planning your research.
- **Students are not permitted to begin their research work until approval has been received and this form has been signed by 2 members of Department of Psychology staff.**

Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

BSc ☐ M.Phil ☐ M.Sc ☐ Ph.D ☐ D.Psych ☑ n/a ☐

Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project

What understanding and expectations do cancer and palliative care clinical nurse specialists have of cancer psychologists and how do these nurses assess patients and/or carers for psychological distress?

2. Name of student researcher (please include contact address and telephone number)

Philippa Jones – 29 Hart Road, St Albans, Herts, AL1 1NF Tel: 07952 332031

3. Name of research supervisor

Dr Jacqui Farrants

4. Is a research proposal appended to this ethics release form? [✓ Yes] No

5. Does the research involve the use of human subjects/participants? [✓ Yes] No

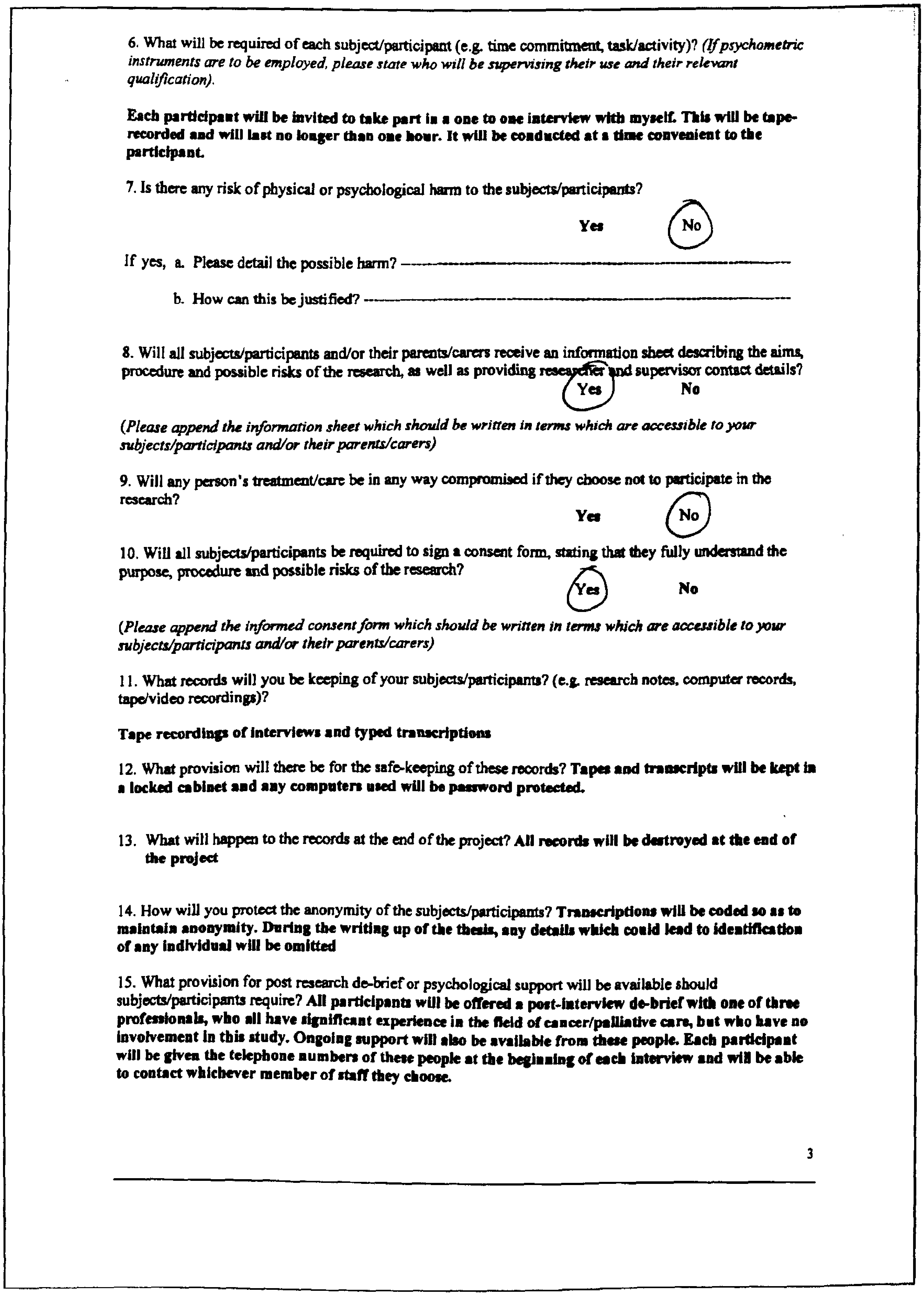
If yes, a. Approximately how many are planned to be involved? **8 - 10**

b. How will you recruit them? **Invitation letter**

c. What are your recruitment criteria? **Clinical Nurse Specialists working in the field of cancer and/or palliative care in an NHS Trust where there is not a cancer psychologist in post.**
(Please append your recruitment material/advertisement/flyer)

d. Will the research involve the participation of minors (under 16 years of age) or those unable to give informed consent?
Yes [✓ No]

e. If yes, will signed parental/carer consent be obtained? Yes No N/A



6. What will be required of each subject/participant (e.g. time commitment, task/activity)? *(If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).*

Each participant will be invited to take part in a one to one interview with myself. This will be tape-recorded and will last no longer than one hour. It will be conducted at a time convenient to the participant.

7. Is there any risk of physical or psychological harm to the subjects/participants?

Yes [✓ No]

If yes, a. Please detail the possible harm? ——————————————

b. How can this be justified? ——————————————

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

[✓ **Yes**] **No**

(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

9. Will any person's treatment/care be in any way compromised if they choose not to participate in the research?

Yes [✓ No]

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

[✓ Yes] **No**

(Please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

Tape recordings of interviews and typed transcriptions

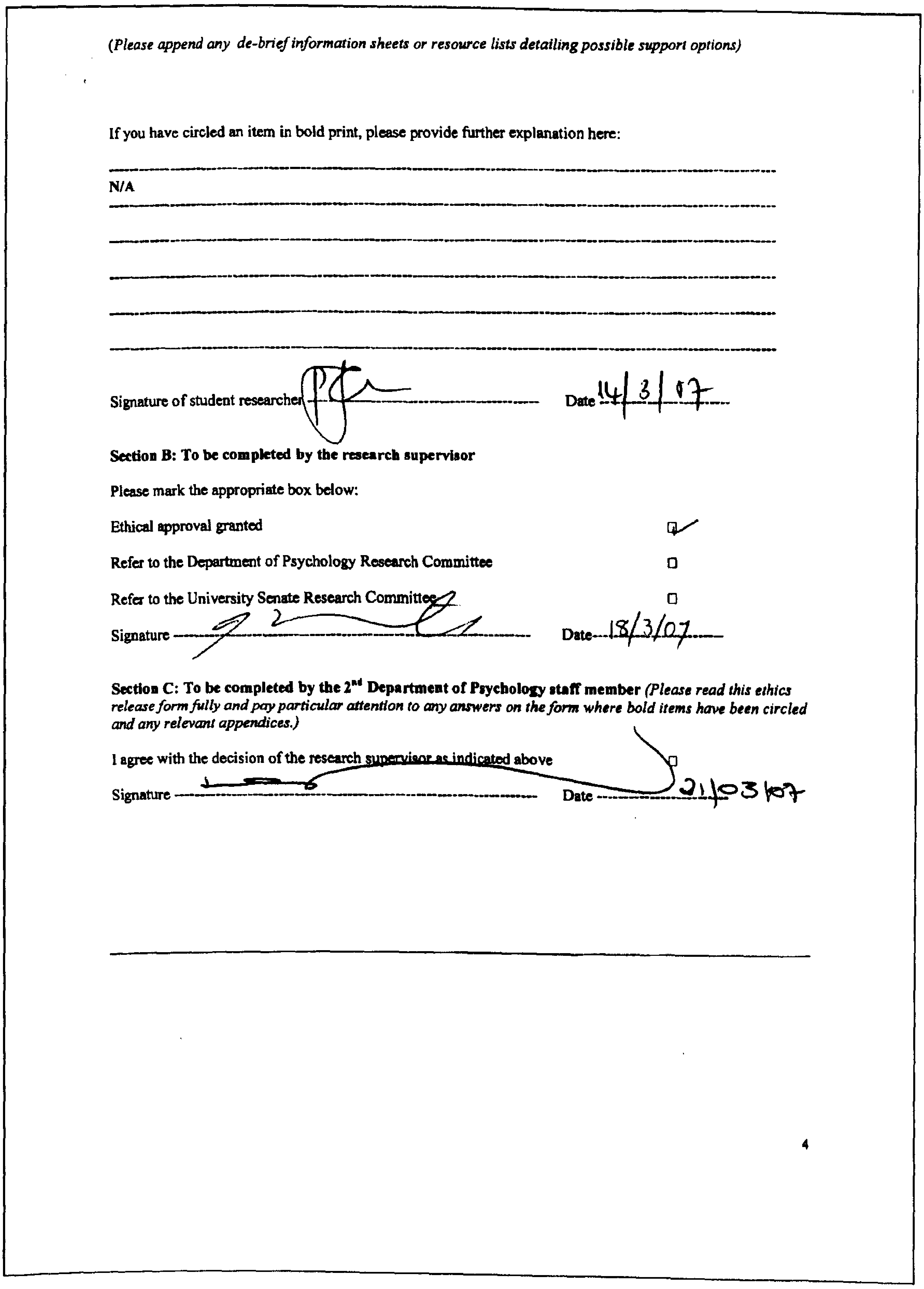
12. What provision will there be for the safe-keeping of these records? **Tapes and transcripts will be kept in a locked cabinet and any computers used will be password protected.**

13. What will happen to the records at the end of the project? **All records will be destroyed at the end of the project**

14. How will you protect the anonymity of the subjects/participants? **Transcriptions will be coded so as to maintain anonymity. During the writing up of the thesis, any details which could lead to identification of any individual will be omitted**

15. What provision for post research de-brief or psychological support will be available should subjects/participants require? **All participants will be offered a post-interview de-brief with one of three professionals, who all have significant experience in the field of cancer/palliative care, but who have no involvement in this study. Ongoing support will also be available from these people. Each participant will be given the telephone numbers of these people at the beginning of each interview and will be able to contact whichever member of staff they choose.**

3



(Please append any de-brief information sheets or resource lists detailing possible support options)

If you have circled an item in bold print, please provide further explanation here:

N/A

Signature of student researcher Date 14/3/07

Section B: To be completed by the research supervisor

Please mark the appropriate box below:

Ethical approval granted ☑

Refer to the Department of Psychology Research Committee ☐

Refer to the University Senate Research Committee ☐

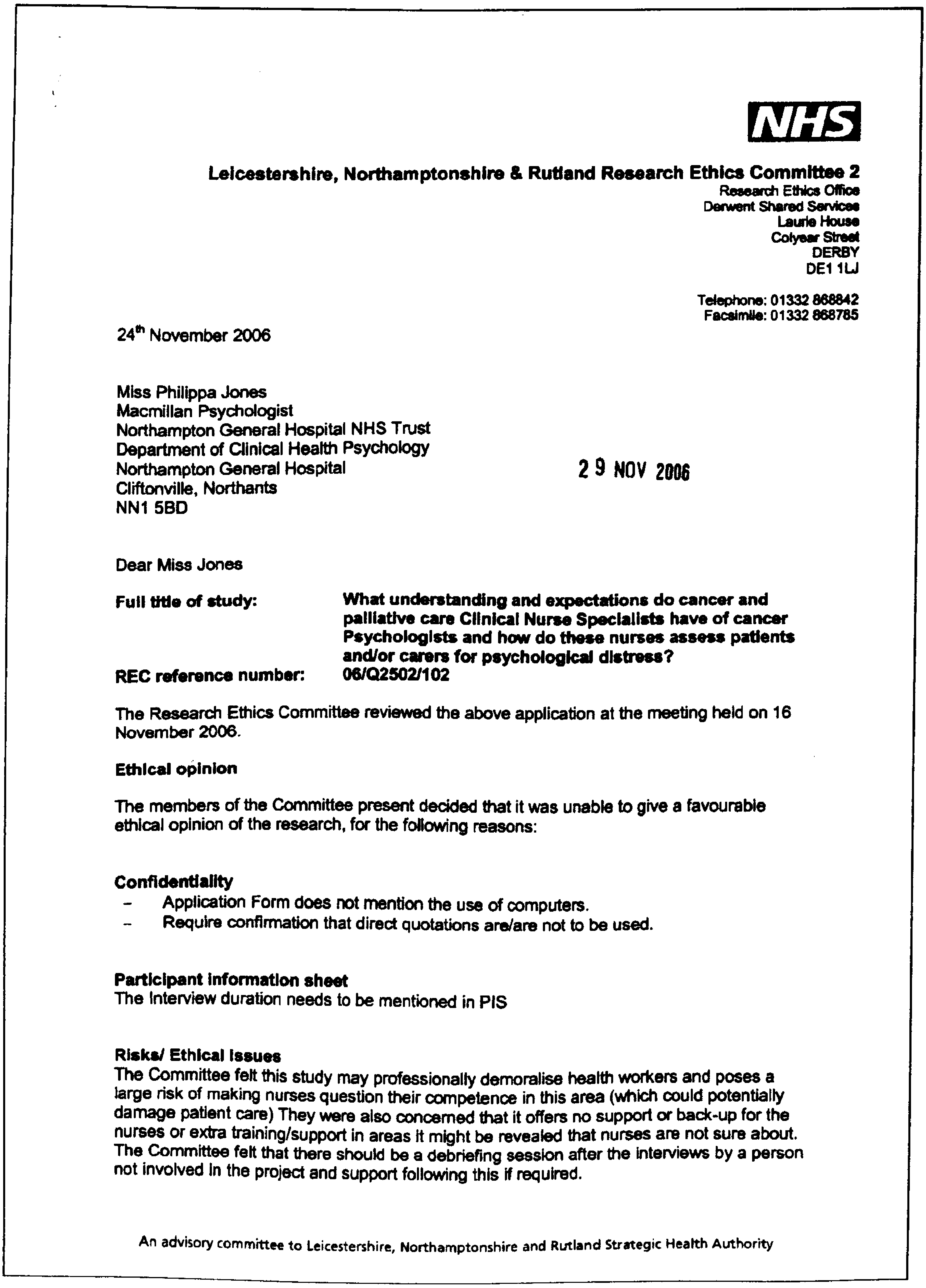
Signature Date 18/3/07

Section C: To be completed by the 2nd Department of Psychology staff member *(Please read this ethics release form fully and pay particular attention to any answers on the form where bold items have been circled and any relevant appendices.)*

I agree with the decision of the research supervisor as indicated above ☐

Signature Date 21/03/07

APPENDIX 9



NHS

Leicestershire, Northamptonshire & Rutland Research Ethics Committee 2
Research Ethics Office
Derwent Shared Services
Laurie House
Colyear Street
DERBY
DE1 1LJ

Telephone: 01332 868842
Facsimile: 01332 868785

24th November 2006

Miss Philippa Jones
Macmillan Psychologist
Northampton General Hospital NHS Trust
Department of Clinical Health Psychology
Northampton General Hospital
Cliftonville, Northants
NN1 5BD

29 NOV 2006

Dear Miss Jones

Full title of study: **What understanding and expectations do cancer and palliative care Clinical Nurse Specialists have of cancer Psychologists and how do these nurses assess patients and/or carers for psychological distress?**

REC reference number: **06/Q2502/102**

The Research Ethics Committee reviewed the above application at the meeting held on 16 November 2006.

Ethical opinion

The members of the Committee present decided that it was unable to give a favourable ethical opinion of the research, for the following reasons:

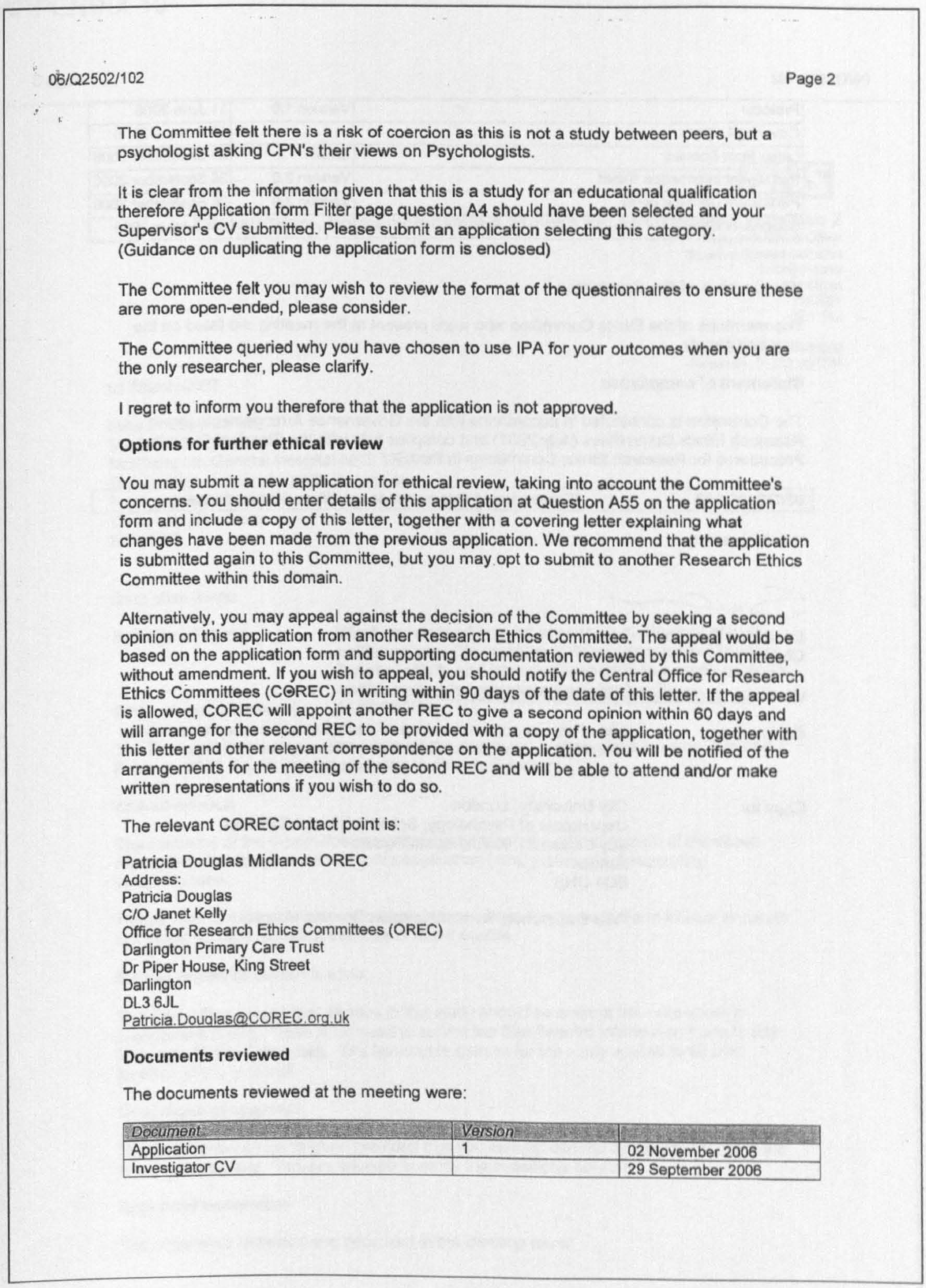
Confidentiality

- Application Form does not mention the use of computers.
- Require confirmation that direct quotations are/are not to be used.

Participant information sheet
The interview duration needs to be mentioned in PIS

Risks/ Ethical Issues
The Committee felt this study may professionally demoralise health workers and poses a large risk of making nurses question their competence in this area (which could potentially damage patient care) They were also concerned that it offers no support or back-up for the nurses or extra training/support in areas it might be revealed that nurses are not sure about. The Committee felt that there should be a debriefing session after the interviews by a person not involved in the project and support following this if required.

An advisory committee to Leicestershire, Northamptonshire and Rutland Strategic Health Authority



The Committee felt there is a risk of coercion as this is not a study between peers, but a psychologist asking CPN's their views on Psychologists.

It is clear from the information given that this is a study for an educational qualification therefore Application form Filter page question A4 should have been selected and your Supervisor's CV submitted. Please submit an application selecting this category. (Guidance on duplicating the application form is enclosed)

The Committee felt you may wish to review the format of the questionnaires to ensure these are more open-ended, please consider.

The Committee queried why you have chosen to use IPA for your outcomes when you are the only researcher, please clarify.

I regret to inform you therefore that the application is not approved.

Options for further ethical review

You may submit a new application for ethical review, taking into account the Committee's concerns. You should enter details of this application at Question A55 on the application form and include a copy of this letter, together with a covering letter explaining what changes have been made from the previous application. We recommend that the application is submitted again to this Committee, but you may opt to submit to another Research Ethics Committee within this domain.

Alternatively, you may appeal against the decision of the Committee by seeking a second opinion on this application from another Research Ethics Committee. The appeal would be based on the application form and supporting documentation reviewed by this Committee, without amendment. If you wish to appeal, you should notify the Central Office for Research Ethics Committees (COREC) in writing within 90 days of the date of this letter. If the appeal is allowed, COREC will appoint another REC to give a second opinion within 60 days and will arrange for the second REC to be provided with a copy of the application, together with this letter and other relevant correspondence on the application. You will be notified of the arrangements for the meeting of the second REC and will be able to attend and/or make written representations if you wish to do so.

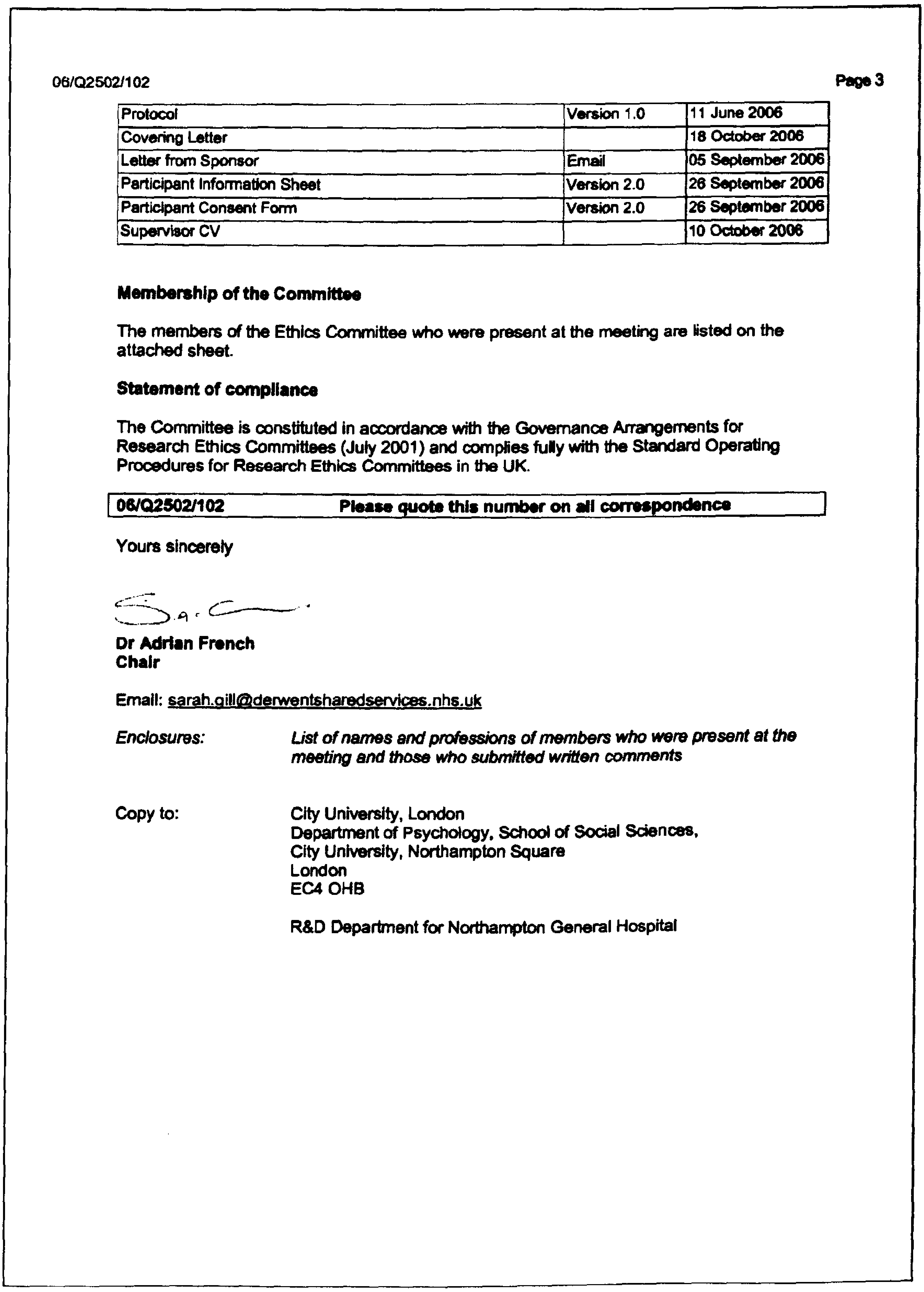
The relevant COREC contact point is:

Patricia Douglas Midlands OREC
Address:
Patricia Douglas
C/O Janet Kelly
Office for Research Ethics Committees (OREC)
Darlington Primary Care Trust
Dr Piper House, King Street
Darlington
DL3 6JL
Patricia.Douglas@COREC.org.uk

Documents reviewed

The documents reviewed at the meeting were:

Document	*Version*	
Application	1	02 November 2006
Investigator CV		29 September 2006



Protocol	Version 1.0	11 June 2006
Covering Letter		18 October 2006
Letter from Sponsor	Email	05 September 2006
Participant Information Sheet	Version 2.0	26 September 2006
Participant Consent Form	Version 2.0	26 September 2006
Supervisor CV		10 October 2006

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q2502/102 **Please quote this number on all correspondence**

Yours sincerely

Dr Adrian French
Chair

Email: sarah.gill@derwentsharedservices.nhs.uk

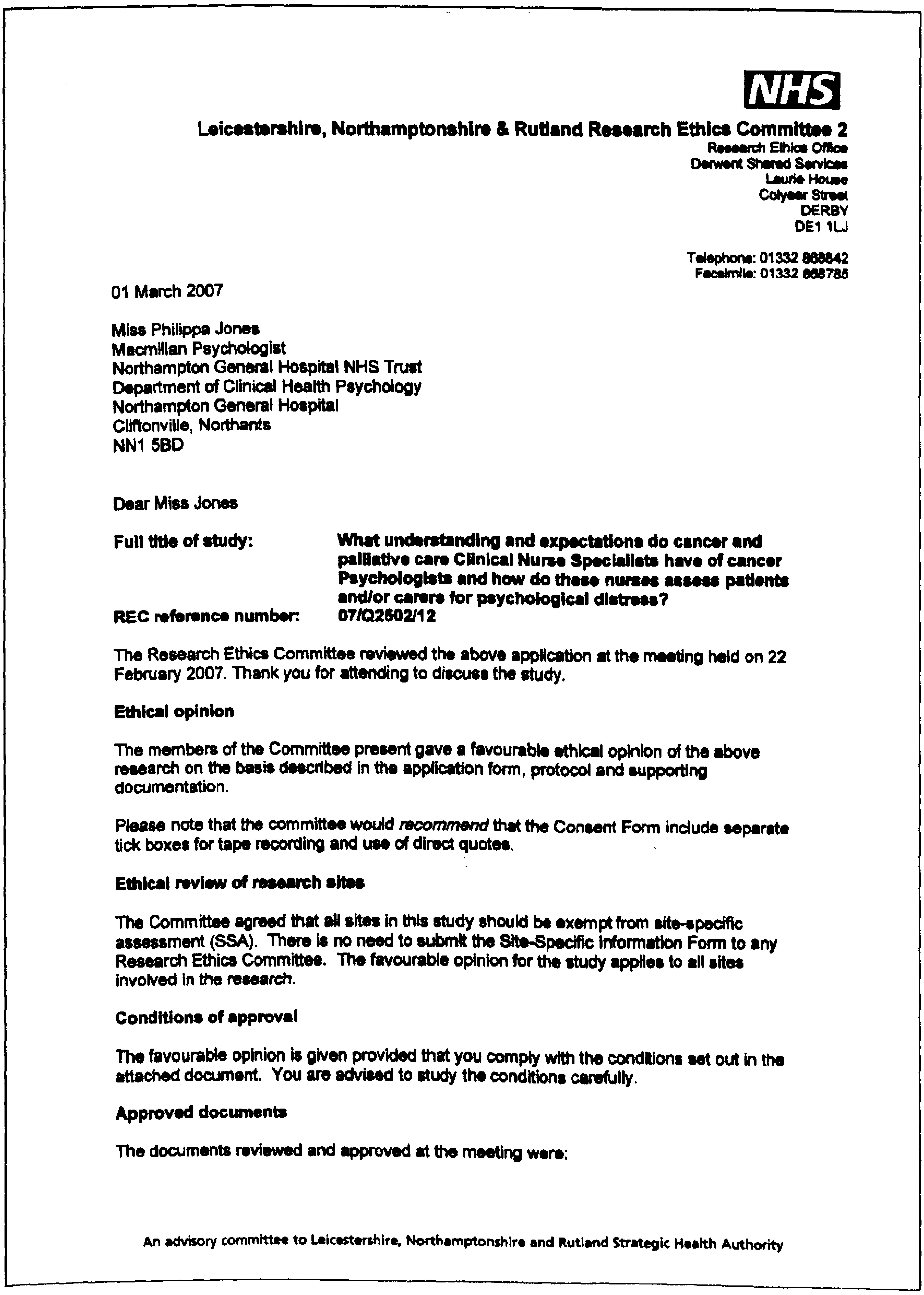
Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

Copy to:

City University, London
Department of Psychology, School of Social Sciences,
City University, Northampton Square
London
EC4 OHB

R&D Department for Northampton General Hospital

APPENDIX 10



NHS

Leicestershire, Northamptonshire & Rutland Research Ethics Committee 2
Research Ethics Office
Derwent Shared Services
Laurie House
Colyear Street
DERBY
DE1 1LJ

Telephone: 01332 868842
Facsimile: 01332 868785

01 March 2007

Miss Philippa Jones
Macmillan Psychologist
Northampton General Hospital NHS Trust
Department of Clinical Health Psychology
Northampton General Hospital
Cliftonville, Northants
NN1 5BD

Dear Miss Jones

Full title of study: **What understanding and expectations do cancer and palliative care Clinical Nurse Specialists have of cancer Psychologists and how do these nurses assess patients and/or carers for psychological distress?**
REC reference number: **07/Q2502/12**

The Research Ethics Committee reviewed the above application at the meeting held on 22 February 2007. Thank you for attending to discuss the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

Please note that the committee would *recommend* that the Consent Form include separate tick boxes for tape recording and use of direct quotes.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

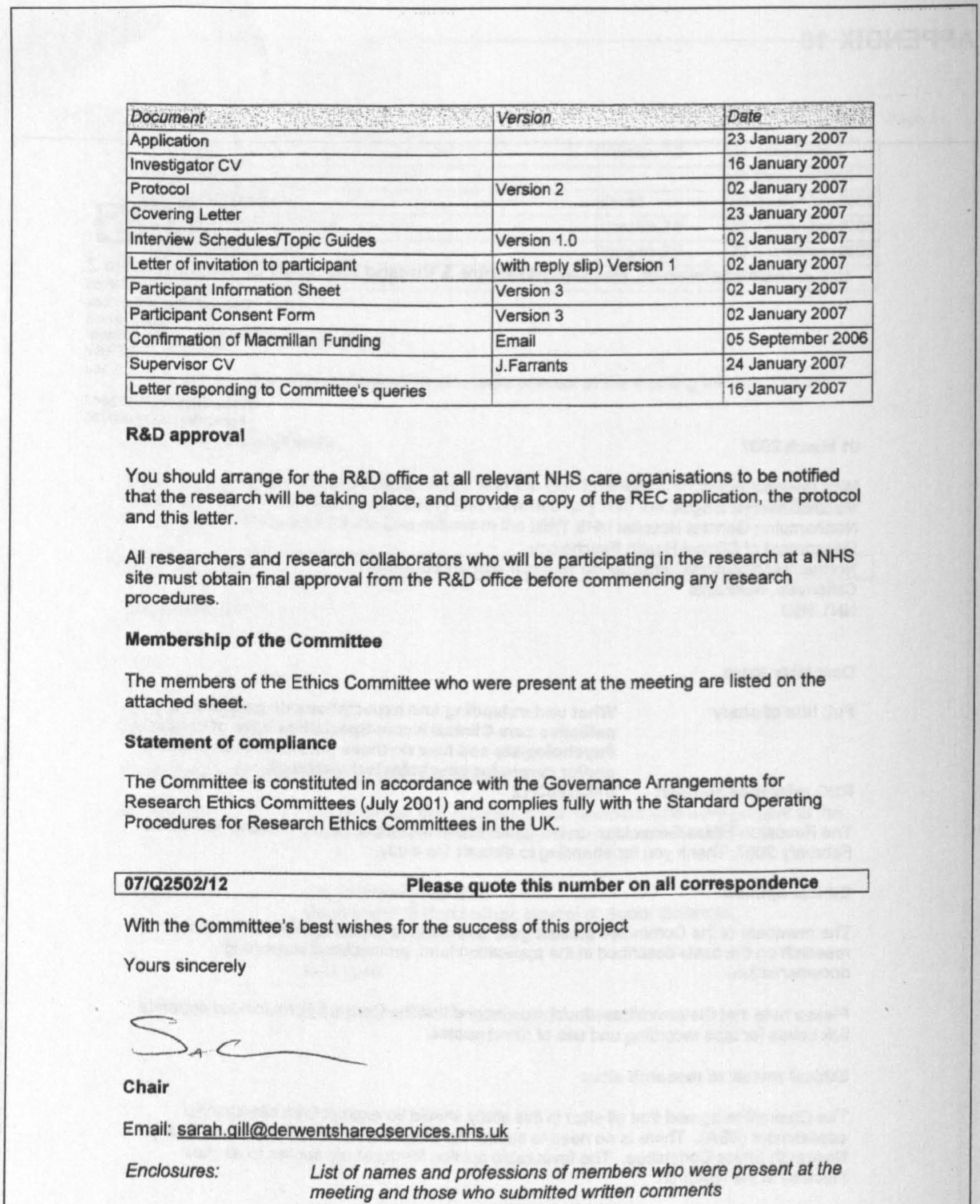
Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

An advisory committee to Leicestershire, Northamptonshire and Rutland Strategic Health Authority



Document	*Version*	*Date*
Application		23 January 2007
Investigator CV		16 January 2007
Protocol	Version 2	02 January 2007
Covering Letter		23 January 2007
Interview Schedules/Topic Guides	Version 1.0	02 January 2007
Letter of invitation to participant	(with reply slip) Version 1	02 January 2007
Participant Information Sheet	Version 3	02 January 2007
Participant Consent Form	Version 3	02 January 2007
Confirmation of Macmillan Funding	Email	05 September 2006
Supervisor CV	J.Farrants	24 January 2007
Letter responding to Committee's queries		16 January 2007

R&D approval

You should arrange for the R&D office at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain final approval from the R&D office before commencing any research procedures.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q2502/12	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

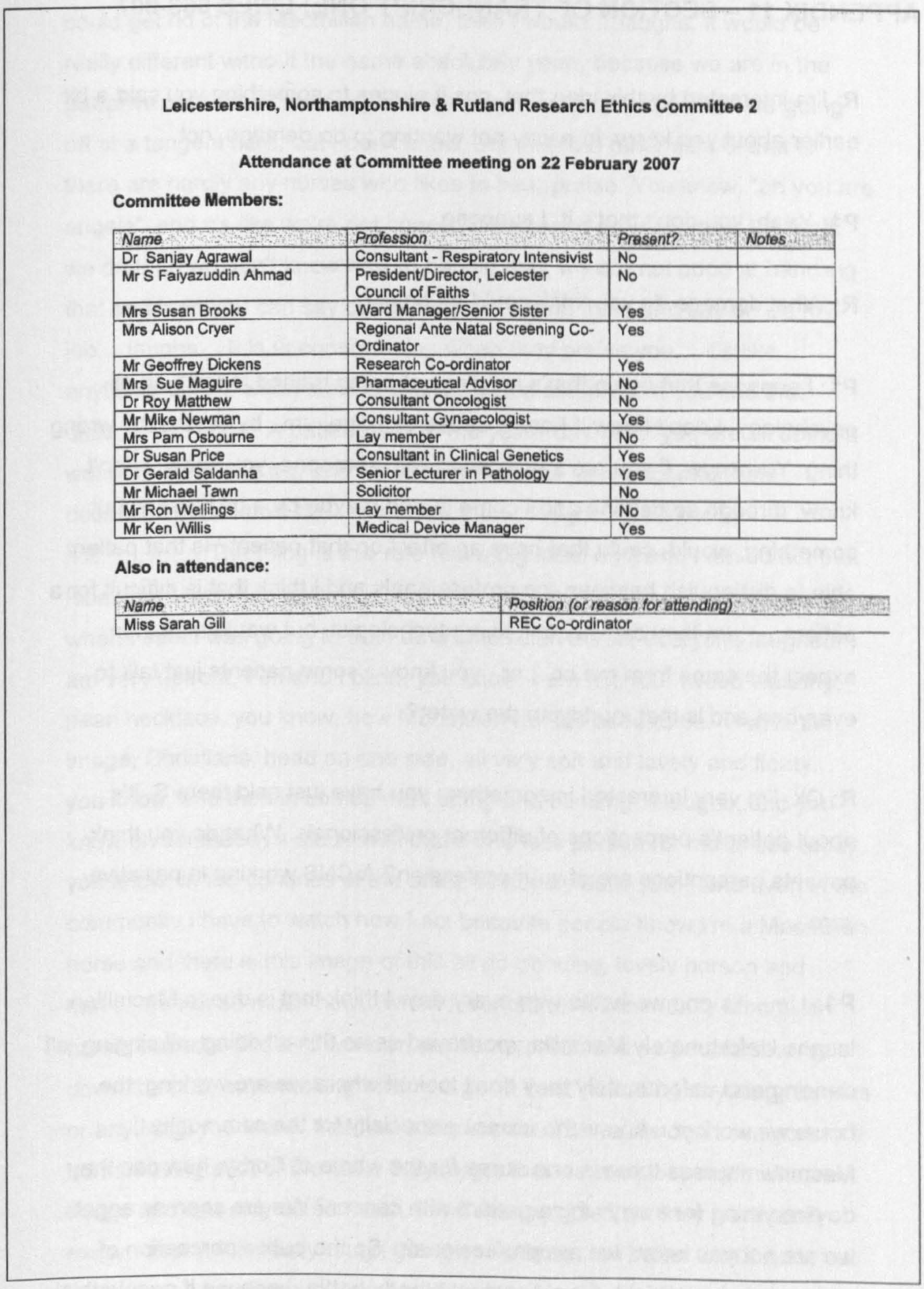
Yours sincerely

Chair

Email: sarah.gill@derwentsharedservices.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
Standard approval condition (SL-AC2)

Copy to: *City University, London*



Leicestershire, Northamptonshire & Rutland Research Ethics Committee 2

Attendance at Committee meeting on 22 February 2007

Committee Members:

Name	*Profession*	*Present?*	*Notes*
Dr Sanjay Agrawal	Consultant - Respiratory Intensivist	No	
Mr S Faiyazuddin Ahmad	President/Director, Leicester Council of Faiths	No	
Mrs Susan Brooks	Ward Manager/Senior Sister	Yes	
Mrs Alison Cryer	Regional Ante Natal Screening Co-Ordinator	Yes	
Mr Geoffrey Dickens	Research Co-ordinator	Yes	
Mrs Sue Maguire	Pharmaceutical Advisor	No	
Dr Roy Matthew	Consultant Oncologist	No	
Mr Mike Newman	Consultant Gynaecologist	Yes	
Mrs Pam Osbourne	Lay member	No	
Dr Susan Price	Consultant in Clinical Genetics	Yes	
Dr Gerald Saldanha	Senior Lecturer in Pathology	Yes	
Mr Michael Tawn	Solicitor	No	
Mr Ron Wellings	Lay member	No	
Mr Ken Willis	Medical Device Manager	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Sarah Gill	REC Co-ordinator

APPENDIX 11 – SECTION OF TRANSCRIPT ONE: LINES 663-807

R: I'm interested by this idea that, cos it eludes to something you said a bit earlier about you know, in a way not wanting to do damage, not...

P1: Yeah, you don't that's it, I suppose...

R: What damage do you think could be done?

P1: I suppose that again that's my, me not being trained in the field of psychology. I don't know if I could cause damage..um.. by saying the wrong thing. You know, if you are say working with someone, you know, I don't know, through something and I come in and maybe be a bit blasé about something, would, could that have an effect on that patient? Is that patient able to distinguish between the professionals and I think that is difficult for a patient.. ...um they can say talk to a psychologist, but would they then expect the same from me or....or.. you know.. some patients just talk to everyone and is that muddying the water?

R: Ok, I'm very interested in something you have just said there S, it's about patient's perceptions of different professionals. What do you think patients perceptions are of your profession? A CNS working in palliative care..

P1: Um.. it's one we battle with every day. I think that is due to Macmillan... laughs Unfortunately Macmillan portrayed us as this all doing, all singing, all dancing and unfortunately they don't look at where we are working, the hours we work you know, the areas.. especially for the community Macmillan nurses there is one nurse for the whole of Corby, how can they do everything for every single patient with cancer? We are seen as angels, we are not you know, we are professionals. So the public perception of what we do is not right. It's a constant bloody battle, because if people think we are angels, it makes breaking bad news pretty difficult to reconcile. You see we have to do that, we, we are harsh with some patients I suppose with things... it does destroy that image they've got I suppose. In some ways it's like we have been set up, Macmillan's like the stone we drag around, if I could get rid of the Macmillan name, then I would….laughs, It would be really different without the name absolutely yeah, because we are in the palliative care team, we are palliative care nurses…. I know we are going off at a tangent here, but I don't know, but then the other side of that is there are hardly any nurses who likes to hear praise..You know, "oh you are angels"..and it's like we're not angels. If someone praises us for the work we do then we don't know how to handle that, we are not good at handling that and then you can say completely the wrong thing and say oh it's my job… laughs… It is uncomfortable.. when they praise you… it's like anything, isn't it, when someone gives you a compliment you find that difficult, you know. A patient said to me yesterday um.. "you are all doing a wonderful job" and it's, and it's very, makes me very uncomfortable, because I don't know how to answer that… laughs…You know, still…………..The thing is this role has a big label on it and I am so not that label, the Macmillan palliative care label, angels…Because, you know, when I said I was going to train as a Macmillan nurse, everyone laughed. I am very upfront, I eff and I blind, you know, I am not your tweed wearing, pearl necklace, you know, how Macmillan nurses used to be. That is the image; Christians, head on one side, all very soft and lovely and floaty… you know, and then in comes me.. effing and blinding….laughs..and you know,oh somebody's died –well that's one less person for me to see today, you know, in the confines of the office obviously but….Um.. and even in the community I have to watch how I act because people know I'm a Macmillan nurse and there is this image of this all do gooding, lovely person and that's.. it's not so much now…when I worked as a community Macmillan nurse, I used to live and work on the same patch and so people saw me down the pub, say smoking having a good time, not doing anything raucous or anything, you know, that had a big impact. The public don't see you as a human being a lot of the time, they forget that we are just people who feel things and can only do so much. I find the expectations they have really extraordinary, it is really tough going sometimes. I'm better with it now, but in the past it has been to the point I have denied my profession, a lot of nurses deny their profession in the social scene, because your meant to be, your perceived as this good person, this angel, angelic.. whose lovely to every one, you know, never has a cross word and your not….laughs… I'm the one with road rage going down the road you know, and I think god if they, if I then see them in the hospital... so there is... It's just sometimes not very easy being this role

R: I just wonder if you have any sense of what perception patients might have of a psychologist? Do you know what patients might think?

P1: Um...I think... I think.. um...the label of someone seeing a psychologist again is.. I think the psychologist has a label attached to it, like a psychiatrist, anything to do with mental health. I think it, it's .. your not a coper and although I think in my generation, that is slowly, slowly changing, um.. I think there's still a label attached to seeing a psychologist, you are viewed as a failure, your failing, your mentally unbalanced and that's why you need a psychologist. Your going onto anti-depressants oh no, that.. you know.. anti-depressants still have, they do still have horrible label attached to them, although they can be so useful. It is a stigma, mental health is a stigma, saying that I think in the younger generation it's different, because everyone is growing up with everyone going on anti-depressants say, it is slightly different, but I think it's like...yeah those are my thoughts.

R: So bearing that in mind, if you were having a conversation with a patient and you were perhaps wanting to discuss a referral to this psychologist, how would you negotiate that?

P1: Ok, I am extremely honest with my patients and I say everything quite black and white to them, so I would honestly say.. um....I'm not going to say the right words now... but.....um...I would acknowledge what they were saying you know, and I think I would you know.. I can't say it word right now but it would be along the lines of 'how would you feel about me referring you to my psychologist who I work with' um.. .and it would be, I would just be open with them, and say 'there are things you are talking about that make me think you may benefit from seeing a I think a psychologist' – I would just say it, be up front

R: Would you have any concerns about what that might do, if you are aware of this possibility of stigma?

P1: I would ask them if they had any questions about that, absolutely, and try and try and dispel those because it's like when we use the word morphine, my next question to them is have they got any questions about that and they are always worried that they are going to get addicted to it and so you need to dispel those myths, so it would be the same with psychologists...um... but I think it all depends on the age of the person.

R: Ok, would there be any people um...that you can think of, not individuals but general presentation that you would think oh.. I'm not going to even suggest it because there is something about them?

P1: Um......... no I wouldn't actually because I just see you as another speciality... um... no I wouldn't, but ask me if I would say that with a psychiatrist

R: Is that different?

P1: Well the image you get with psychiatry is everyone lying flat out, drugged and out of it. It's the first thing that comes into mine, and probably most people's minds. I certainly think a psychologist is viewed differently, there is much less stigma attached and it's not so much about madness, perhaps because the way the media have portrayed psychiatrists, it's actually probably just that the media hasn't shown any pictures of a psychologist.

R: Ok, but you are clearly saying that psychology carries with it some stigma, perhaps

P1: Yes I do yes

R: And psychiatry even more?

P1: Yes, it's like with the Macmillan nurse every person in the public will have a picture of that, everyone in the public will have a picture of a psychiatrist, you know like "one flew over the cuckoos nest " etc.. etc.. but say a psychologist or say a palliative care nurse, they are not, they are unsure, they are not sure who, cos they will say what is that to us? You, psychologists are more of an unknown, as is a palliative care nurse

APPENDIX 12

TRANSCRIPT ONE: INITIAL THEMES

(Themes numbered according to the order they were found in the transcript)

1. Beyond ability
2. Requiring specialist input
3. Distinct profession
4. Behavioural problems
5. Clinical consultation
6. Knowing limits
7. Collaborative working
8. Professional support
9. Team support
10. Personal support
11. Needing immediate solutions
12. Protected access
13. Clinical supervision
14. Specialist knowledge
15. Behavioural knowledge
16. Group facilitation skills
17. Supervision skills
18. Fine line
19. Psychological assessment
20. Anticipating problems
21. Unknown acquisition
22. Experience
23. Personality
24. Empathic understanding
25. Non-judgemental
26. Professional perspective
27. Recognising projection
28. Empathic understanding
29. Fearlessness
30. Confidence acquired over time
31. Confidence
32. Emotional discomfort
33. Human instinct vs professional responsibility
34. Emotional processing time
35. Death talk
36. Listening skills
37. Ongoing learning
38. Communication blocks
39. Communication skills
40. Intuitive sense
41. Challenge of depression vs realistic sadness
42. Absence of psychological connection
43. Reality of situation
44. Realistic sadness
45. Lack of understanding/knowledge (colleagues)
46. Limited time
47. Identifying depression
48. Screening tools
49. Fine line
50. Realistic sadness
51. Greater challenge
52. Burden of death
53. Intuition
54. Sense of discrepancy
55. Physical manifestation
56. Rejecting quality of life
57. Discomfort
58. Giving up on life
59. Unable to help
60. Individual psychological assessment
61. Feedback
62. 1:1 working
63. Causing harm
64. Clinical recommendations
65. Lack of knowledge
66. Observation
67. Training (psych)
68. Emotional exploration
69. Psychological movement
70. Scope of role
71. Solution focused
72. Unknown
73. Directive style
74. Facilitate change
75. Directive style
76. Positive thinking
77. Instinctive process
78. Information gathering
79. Initial impressions
80. Lack of control/influence
81. Sudden endings
82. Reflective practice
83. Experiential learning
84. Mentorship
85. Observational learning
86. Ongoing learning process
87. Reflective practice

88. Informal peer supervision
89. Role-play
90. Confirmation of existing skills
91. Unknown acquisition
92. Unknown acquisition
93. Work/life boundaries
94. Feedback (clinical work)
95. Insufficient feedback
96. Feedback (learning aid)
97. Improved understanding
98. Learning restrictions
99. Unknown
100. Risky knowledge
101. Scope of role
102. Causing harm
103. Idealised
104. Angel vs professional
105. Inaccurate perceptions
106. Burden of association
107. Discomfort
108. Non-conformist
109. Stereotype vs reality
110. Behavioural expectations
111. Personal vs professional image
112. Perceptions of role
113. Challenging
114. Professional denial
115. Rejection of stereotype
116. Stigma
117. Variations
118. Honesty
119. Clarification
120. Acceptability
121. Role of media
122. Unknown profession
123. Unknown acquisition
124. Intuition
125. Time boundaries
126. Time boundaries
127. Family influence

APPENDIX 13

TRANSCRIPT ONE: CLUSTERED THEMES

Beyond ability
Requiring specialist input
Limited time
Unable to help

Distinct profession
Supervision skills
Behavioural knowledge
Group facilitation skills
Supervision skills
Training
Unknown

Clinical consultation
Collaborative working
Professional support
Team support
Personal support
Clinical supervision
Feedback
1:1 working
Clinical recommendations
Needing immediate solutions
Protected access
Feedback (clinical work)
Unknown

Individual psychological assessment
Emotional exploration
Psychological movement
Solution focused
Directive style
Facilitate change
Directive style
Positive thinking
Unknown

Knowing limits
Psychological assessment
Anticipating problems
Offering time
Understanding emotional process
Managing difficult questions
Scope of role
Scope of role
Fearlessness
Confidence acquired over time
Confidence
Clarification/education

Idealised
Angel vs professional
Inaccurate perceptions
Burden of association
Discomfort
Non-conformist
Stereotype vs reality
Behavourial expectations
Personal vs professional image
Perceptions of role
Challenging
Rejection of stereotype

Stigma
Variations
Acceptability
Role of media
Unknown profession

Unknown acquisition
Experience
Personality
Ongoing learning
Reflective practice
Experiential learning
Mentorship
Observational learning
Ongoing learning process
Reflective practice
Informal peer supervision
Unknown acquisition
Unknown acquisition
Role-play
Validation of existing skills
Unknown acquisition
Intuition

Empathic understanding
Non-judgemental
Professional perspective
Recognising projection
Empathic understanding
Listening skills
Awareness of communication blocks
Communication skills
Intuitive sense
Intuition
Instinctive process
Information gathering
Initial impressions
Sense of discrepancy
Physical manifestation
Discomfort

Emotional discomfort
Human instinct vs professional responsibility
Challenge of depression vs realistic sadness
Emotional burden (pts)
Realistic sadness
Lack of understanding/knowledge (colleagues)
Identifying depression
Fine line
Realistic sadness
Palliative status
Burden of death
Lack of control/influence
Sudden endings
Insufficient feedback
Fine line
Learning restrictions
Causing harm
Causing harm
Risky knowledge

Screening tools
Observation
Improved understanding
Feedback

Behavioural problems
Absence of psychological connection
Rejecting quality of life
Giving up on life
Work/life boundaries
Professional denial
Time boundaries
Time boundaries
Family influence

Honesty
Openness

APPENDIX 14

TRANSCRIPT ONE: SUMMARY TABLE

(**Key** 2.53 refers to page 2, line 53)

HOPES REGARDING PSYCHOLOGY ROLE

Clinical consultation	"talk through a patient"	2.53
Collaborative working	"working with"	2.59
Professional support	"support us"	2.66
Clinical supervision	"clinical supervision"	4.119
Feedback	"come back to me"	12.432
Clinical recommendations	"anything I could be doing"	13.451
Availability	"there and then"	3.92
Unknown	"inexperience of what a p does"	13.455

WHAT PSYCHOLOGISTS DO

Psychological assessment	"assess the patient"	12.431
Emotional exploration	"a step further"	13.467
Psychological movement	"move that patient on"	13.471
Solution focused	"about solutions"	13.475
Unknown	"I don't know"	14.480
Facilitate change	"changing their behaviour"	14.484
Directive style	"lead me"	14.486
Positive thinking	"positive route"	14.487

PERCEIVED QUALITIES OF PSYCHOLOGISTS

Superior skills	"something extra"	4.123
Specialist knowledge	"understand people's behaviour"	4.128
Training	"having the training"	13.467
Unknown	"no idea"	25.920

BELIEFS ABOUT PSYCHOLOGISTS

Negative	"has a label attached"	21.741
Variations	"younger generation"	21.749
Acceptability	"less of a stigma"	22.790
Undefined	"hasn't shown pictures"	22.791
Unknown	"they are not sure"	22.805

BEING A CLINICAL NURSE SPECIALIST

Knowing limits	"hand someone on"	2.57
Psychological assessment	"defining what's normal"	5.151
Offering time	"let people have time"	7.247
Emotional understanding	"understand whole process"	7.249
Managing difficult questions	"am I dying?"	8.257
Scope of role	"not trained in that"	13.474

BELIEFS ABOUT CNSS

Idealised	"seen as angels"	19.690
Inaccurate	"not right"	19. 691
	"don't see you as human"	20.726
Stereotype vs reality	"I am not that label"	20.711

ASSESSING PATIENTS FOR DISTRESS

Empathic understanding	"where they are coming from"	5.176
Emotional exploration	"unwrap it"	5.179
Communication skills	"it's communication skills"	8.281
Intuition	"gut feeling"	11.394
Physical manifestation	"what they are doing"	11.401
Sense of discrepancy	"doesn't add up"	12.408
Discomfort	"wasn't happy"	12.420
Instinctive	"second nature"	14.496
Information gathering	"pick up clues"	14.496
Initial impressions	"first time"	14.502

FACTORS CONTRIBUTING TO CONFIDENCE/COMPETENCE

Experience	"from experience"	5.158
Personal ability	"I'm very astute"	5.174
Reflective practice	"learning from mistakes"	15.537
Experiential learning	"learn on the job"	15.526
Mentorship	"asking my mentors"	15.528
Observational learning	"I wouldn't do that"	15.535
Ongoing process	"continuously learning"	15.535
Peer support	"talk it through"	15.544
Training	"a refresher course"	16.557

APPROACHING PSYCHOLOGICAL ISSUES WITH PATIENTS

758 Honesty	"extremely honest"	21.757
763 Openness	"just be open"	21.763
774 Clarification	"dispel those myths"	22.774

DIFFICULTIES AND CHALLENGES OF BEING A CNS

Emotional discomfort	"tolerating silence"	7.232
Human instinct vs professional responsibility	"want to jump in"	7.241
Depression vs realistic sadness	"such a fine line"	10. 351
Lack of understanding (colleagues)	"get it mixed up"	10.343
Lack of control/influence	"not under our care"	14.513
Sudden endings	"time stopped"	14.511
Insufficient feedback	"not enough"	17.606
Managing unknowns	"I don't know"	19.670
Perceptions of role	"tough going"	20.727

IMPROVING PSYCHOLOGICAL CARE FOR PATIENTS

Screening tools	"depression scales"	10.348
Observation	"see how they work"	13.456
Understanding	"present a patient"	17.625
Feedback	"having feedback"	17.610

PRESENTATIONS AND SYMPTOMS

Absence of psychological connection	"can't get through"	9.321
Loss of motivation	"choosing not to"	12. 417

COPING WITH BEING A CNS

Work/life boundaries	"cut off point"	17. 596
Time boundaries	"5pm and I'm out"	23.838

APPENDIX 15

TRANSCRIPT TWO: INITIAL THEMES

(Themes numbered according to the order they were found in the transcript)

1. Time
2. Facilitate expression
3. Manage complex issues
4. Need support
5. Aid understanding
6. Scope of use
7. MDT contribution
8. Clinical consultation
9. Accessibility
10. Collaborative working
11. Complex issues
12. Clinical recommendations
13. Clinical supervision
14. Separate
15. Impartial
16. Clinical supervision
17. Clinical supervision
18. Impartial
19. Impartial
20. Trustworthy
21. Adjustment issues
22. Unable to help
23. Adjustment issues
24. Patient motivation
25. Not coping
26. Emotional discomfort
27. Beyond abilities
28. Insufficient knowledge
29. CBT
30. Improved coping
31. Structured interventions
32. Scope of role
33. Unknown
34. Confidence
35. Communication style
36. Limited time
37. Confidence
38. Screening questions
39. Risk assessment
40. Semi-structured assessment
41. Emotional exploration
42. Offering choice
43. Wider input
44. Comparison over time
45. Limited time
46. Limited time
47. Time pressure
48. Responsibility
49. Limited time
50. Systemic support
51. Timing
52. Capacity
53. Overload
54. Offering choice
55. Gate keeping
56. Depression vs dying
57. Physical deterioration
58. Depression vs dying
59. Realistic sadness
60. Inappropriate prescribing
61. Personal expectations
62. Undetected distress
63. Inappropriate prescribing
64. Gate keeping
65. Symptom management
66. Pt collaboration
67. Doing
68. Doing
69. Direct question
70. Patient insight
71. Direct question
72. Organisational agenda
73. Screening tools
74. Scope of role
75. Risk assessment
76. Insufficient understanding
77. Lack of support
78. Team debrief
79. Work/life boundary
80. Peer support
81. MDT discussion
82. Joint assessment
83. Professional autonomy
84. Joint assessment
85. Joint assessment
86. Terminal care
87. Inaccurate
88. Inaccurate
89. Terminal care
90. Helpful
91. Unrealistic
92. Unrealistic
93. Unrealistic
94. Secretive

95. Limited access
96. Unknown
97. Unknown
98. Secretive
99. Separate
100. Limited numbers
101. Limited exposure
102. Unknown
103. Increasing contact
104. Limited numbers
105. Unknown
106. Coping
107. Drug free
108. Talking therapy
109. Drug free
110. Understanding
111. Feedback
112. Education
113. Understanding
114. Observation
115. Training
116. Professional transparency
117. Positive
118. Change over time
119. Coping
120. Drug free
121. Acceptability
122. Acceptability
123. Confidence
124. Acceptability
125. Feedback
126. Feedback
127. Training
128. Training
129. Training
130. Training
131. Experience
132. Unknown acquisition
133. Experience
134. Negotiation
135. Education
136. Education
137. Education

APPENDIX 16

TRANSCRIPT THREE: INITIALTHEMES

(Themes numbered according to the order they were found in the transcript)

1. Scope of role
2. Initial support
3. Boundaries of role
4. Requiring specialist input
5. Information giving
6. Scope of role
7. Diverse knowledge
8. Treatment focus
9. Workload
10. Past issues
11. Body image issues
12. Require more
13. Longer term support
14. Boundaries of role
15. Boundaries of role
16. Intuition
17. Experience
18. Experience
19. Initial impression
20. Experience
21. Screening tools vs instinct
22. Instinct
23. Screening tools
24. Experience
25. Broad focus
26. Specific focus
27. Coordination
28. Scope of role
29. Going no further
30. Need more
31. Techniques
32. Scope of role
33. Emotional exploration
34. Broad focus
35. Emotional exploration
36. Techniques
37. Specialist knowledge
38. Specialist knowledge
39. Broad focus
40. Multiple issues
41. Scope of use
42. Offering choices
43. Team member
44. Scope of use
45. Ongoing
46. Team member
47. Staff support
48. Formality
49. Psychological assessment
50. Rapport building
51. Colleague support
52. Isolation
53. Colleague support
54. Team debrief
55. Staff support
56. Offload
57. Staff support
58. Peer support
59. Staff support
60. Negative
61. Managing perception
62. Emotional containment
63. Check understanding
64. Psychological assessment
65. Information giving
66. Psychological assessment
67. Ongoing
68. Communication skills
69. Intuition
70. Continuity
71. Rapport building
72. Communication skills
73. Accessibility
74. Rapport building
75. Giving time
76. Child abuse
77. Ongoing
78. Critical point in pathway
79. Ongoing
80. Giving time
81. Fertility issues
82. Relationship issues
83. Finding solutions
84. Giving time
85. Not coping
86. Offering choices
87. Specialist counselling
88. Going no further
89. Going no further
90. Going no further
91. Depression
92. Treatment issues

93. Offering choices
94. Relationship issues
95. Limited time
96. Broad focus
97. Scope of role
98. Individual
99. Confidence
100. Ongoing input
101. Critical point in pathway
102. Critical point in pathway
103. Critical point in pathway
104. Treatment issues
105. Critical point in pathway
106. Individual
107. Generational
108. Positive
109. Generational
110. Generational
111. Confidence
112. Training
113. Education
114. Training
115. Experience
116. Training
117. BBN
118. Observational learning
119. Experiential learning
120. Reflective practice
121. Observational learning
122. Observational learning
123. Ongoing learning
124. Experience
125. Ongoing input
126. Ongoing input
127. Feedback
128. Medical focus
129. Feedback
130. MDT contribution
131. Feedback
132. Observation
133. Patient request

APPENDIX 17

TRANSCRIPT FOUR: INITIAL THEMES

(Themes numbered according to the order they were found in the transcript)

1. Scope of role
2. Ongoing input
3. Scope of role
4. Critical point in pathway
5. Treatment issues
6. Relatives
7. Critical point in pathway
8. Depression
9. Withdrawn
10. Sudden diagnosis
11. Beyond ability
12. Unable to do more
13. Require more
14. Treatment adherence
15. Managing treatment
16. Side effects
17. Total pain
18. Clinical consultation
19. Professional support
20. Supporting children
21. Clinical consultation
22. Professional support
23. Clinical supervision
24. Clinical supervision
25. Clinical supervision
26. Clinical supervision
27. Isolation
28. Broad remit
29. Isolation
30. Colleague support
31. Lack of support
32. Colleague support
33. Separate
34. Loss of control (families)
35. Systemic support
36. Emotional discomfort
37. Emotional discomfort
38. Relief
39. Emotional discomfort
40. Managing denial
41. Managing denial
42. Unable to do more
43. Not coping
44. Unable to do more
45. Stopped helping
46. Communication skills
47. Listening
48. Emotional containment
49. Emotional containment
50. Expectations
51. Offering time
52. Communication skills
53. Discrepancy
54. Communication skills
55. Intuition
56. Time
57. Intuition
58. Avoidance
59. Protection
60. Transparency
61. Confidence
62. Collusion
63. Transparency
64. Experience (time)
65. Observational learning
66. Peers
67. Clinical supervision
68. In-depth
69. Boundaries of role
70. Objective view
71. Complexity
72. Objective view
73. Active
74. Unclear boundaries
75. Boundaried
76. Techniques
77. Boundaries of role
78. Beyond ability
79. Experience
80. Training
81. Experience (time)
82. Non medical
83. Referring on
84. Confidence
85. Unable to do more
86. Referring on
87. Not coping
88. Stopped helping
89. Confidence
90. Communication skills
91. Acceptability
92. Acceptability
93. Acceptability
94. Acceptability

95. Training
96. Training
97. Training
98. Experience
99. Experience
100. Time
101. Observation
102. Observation
103. Feedback
104. Feedback
105. Feedback
106. Screening tools
107. Screening tools
108. Screening tools

APPENDIX 18

TRANSCRIPT FIVE: INITIAL THEMES

(Themes numbered according to the order they were found in the transcript)

1. Past experience
2. Coping
3. Scope of role
4. Helpful
5. Education
6. Joint working
7. Budgetary restrictions
8. Clinical supervision
9. Clinical supervision
10. Reflective practice
11. Broad remit
12. Emotional support
13. Emotional support
14. Need more
15. CBT trained
16. Psychological models
17. Medical knowledge
18. Informing colleagues
19. Medical knowledge
20. Team member
21. Availability
22. Professional support
23. Professional support
24. Accessibility
25. Peer support
26. Unknown
27. Professional support
28. Boundaries
29. Lone worker
30. Team member
31. Education
32. Unique issues
33. Accepting
34. Key point in pathway
35. Not coping
36. Adjustment problems
37. Improved coping
38. Patient insight
39. Patient insight
40. Frequency of contact
41. Limited time
42. Require more
43. Structured interventions
44. Single screening question
45. Patient insight
46. Patient motivation
47. Motivation
48. Self-selection
49. Communication style
50. Unknown
51. Adjustment
52. Unknown
53. Unknown
54. Confidence
55. Confidence
56. Communication style
57. Communication style
58. Acceptability
59. Unknown
60. Patient request
61. Limited resources
62. Insufficient feedback
63. Feedback
64. Clinical recommendations
65. Feedback
66. Insufficient feedback
67. Team communication
68. Team communication
69. Referring on
70. Team communication
71. Team communication
72. Team communication
73. Scope of role
74. Education
75. Education
76. Patient centred
77. Education
78. Limited time
79. Limited time
80. Flexibility
81. Limited time
82. Information giving
83. Intuition
84. Patient insight
85. Communication skills
86. Time
87. Time
88. Individual
89. Patient responsibility
90. Patient responsibility
91. Ongoing process
92. Experience

93. Reflective practice
94. Peer support
95. Patient feedback
96. Patient feedback
97. Patient feedback
98. Patient expectations
99. Limited choice
100. Limited choice
101. Limited choice
102. Patient centred
103. Multi-skilled
104. Screening tools
105. Screening tools
106. Screening tools
107. Screening tools
108. Screening tools
109. Screening tools
110. Single screening question
111. Screening tools
112. Training
113. Training
114. Training
115. Training
116. Peers
117. Reflective practice
118. Peers
119. Reflective practice
120. Reflective practice
121. Failing
122. Failing
123. Professional support
124. Understanding
125. Observation
126. Understanding
127. Professional transparency
128. Education
129. Understanding
130. Lone worker
131. Specialist knowledge
132. Distinct profession
133. Team working
134. Peer resistance

APPENDIX 19

TRANSCRIPT SIX: INITIAL THEMES

(Themes numbered according to the order they were found in the transcript)

1. Emotional discomfort
2. Non-cancer issues
3. Family conflict
4. Family conflict
5. Unable to help
6. Require specialist input
7. Accessibility
8. Clinical consultation
9. Availability
10. Clinical consultation
11. Clinical consultation
12. Team member
13. Availability
14. Availability
15. Availability
16. MDT contribution
17. MDT contribution
18. Staff support
19. Colleague support
20. Offloading
21. Colleague support
22. Offloading
23. Managerial support
24. Unknown
25. Behavioural problems
26. Treatment adherence
27. Younger patients
28. Younger patients
29. Fertility issues
30. Family conflict
31. Fertility issues
32. Pain
33. Pain
34. Emotional discomfort
35. Boundaries of role
36. Extreme distress
37. Time
38. Time
39. Emotional exploration
40. Communication skills
41. Validation
42. Validation
43. Offering time
44. Offering time
45. Intuition
46. Discomfort
47. Boundaries of role
48. Going no further
49. Emotional discomfort
50. Methodological
51. Time
52. Individual
53. Clarification
54. Openness
55. Confidence
56. Individual
57. Confusion
58. Negative
59. Validation
60. Loss of control
61. Fear inducing
62. Stigma
63. Fear inducing
64. Unknown
65. Techniques
66. Improved coping
67. Specialist knowledge
68. Specialist knowledge
69. Broad experience
70. Structured interventions
71. Unknown
72. Training
73. Medical knowledge
74. Medical knowledge
75. Medical knowledge
76. Training
77. Training
78. Training
79. Training
80. Training
81. Training
82. Experience
83. Observation
84. Observation
85. Observation
86. Feedback

APPENDIX 20

TRANSCRIPT SEVEN: INITIAL THEMES

(Themes numbered according to the order they were found in the transcript)

1. Professional autonomy
2. Broad remit
3. Support
4. Scope of role
5. Scope of role
6. Scope of role
7. Positive
8. Negative
9. Managing uncertainty
10. Not coping
11. Coping mechanisms
12. Expert
13. Observational learning
14. Improved coping
15. Positive
16. Broad remit
17. Broad remit
18. Psychological focus
19. Training
20. Explore past experiences
21. Coping mechanisms
22. Coping mechanisms
23. Going no further
24. Require more
25. Unknown
26. Clinical consultation
27. Clinical consultation
28. Not coping
29. Limited time
30. Not coping
31. Intellectual
32. Intellectual
33. Unknown
34. Age
35. Younger patients
36. Not coping
37. Younger patients
38. Anxious preoccupation
39. Acceptance
40. Acceptance
41. Acceptance
42. Limited time
43. Brief intervention
44. Brief intervention
45. Normalisation
46. Impressive
47. Positive
48. Language
49. Acceptability
50. Reassurance
51. Reassurance
52. Acceptability
53. Unknown
54. Unrealistic expectations
55. Unknown
56. Unknown
57. Training
58. Emotional exploration
59. Available support
60. Anxious preoccupation
61. Anxiety
62. Requesting medication
63. Persistent anxiety
64. Frequent contact
65. Not coping
66. Not coping
67. Frequent contact
68. Living with uncertainty
69. Living with uncertainty
70. Living with uncertainty
71. Living with uncertainty
72. Information seeking
73. Information seeking
74. Information seeking
75. Unknown
76. Time
77. Time
78. Relationship
79. Comparison over time
80. Available support
81. Not coping
82. Comparison over time
83. Denial
84. Confidence
85. Honest
86. Palliative patients
87. Instinct
88. Palliative patients
89. Palliative patients
90. Incurable at diagnosis
91. Sign posting
92. Scope of role

93. Confident
94. Separate
95. Safe
96. Separate
97. Confidence
98. Team member
99. Separate
100. Breaking bad news
101. Breaking bad news
102. Insufficient feedback
103. Insufficient feedback
104. Insufficient feedback
105. Insufficient feedback
106. Negotiating confidentiality
107. Holding confidence
108. Lack of support
109. Job insecurity
110. Job insecurity
111. Job insecurity
112. Competitiveness
113. Competitiveness
114. Pressure
115. Lack of understanding
116. Lack of understanding
117. Lack of time
118. Lack of support
119. Peer support
120. Experience
121. Experience
122. Patient feedback
123. Self-directed learning
124. Communication skills training
125. Communication skills training
126. Communication skills training
127. Observational learning
128. Observational learning
129. Observational learning
130. Observational learning
131. Education
132. Observation
133. Observation
134. Language
135. Language

APPENDIX 21

TRANSCRIPT EIGHT: INITIAL THEMES

(Themes numbered according to the order they were found in the transcript)

1. Positive
2. Manage complex issues
3. Emotional discomfort
4. Beyond ability
5. Information giving
6. Support
7. Scope of role
8. Emotional support
9. Broad remit
10. Knowledgeable
11. Knowledgeable
12. Knowledgeable
13. Expectations
14. Instinct
15. Going no further
16. Scope of role
17. Scope of role
18. Patient request
19. Formalised
20. Anxiety
21. Anxiety
22. Anxiety
23. Loss of control
24. Emotional support
25. Going no further
26. Going no further
27. Depression
28. Suicidal thoughts
29. Require specialist input
30. Mental health history
31. Recent bereavement
32. Mental health history
33. Co-ordination
34. Psychological reaction
35. Adjustment process
36. Adjustment process
37. Adjustment process
38. Instinct
39. Instinct
40. Experience
41. Verbal cues
42. Suicidal thoughts
43. Assessment questions
44. Depression
45. Body image issues
46. Communication skills
47. Communication skills
48. Communication skills
49. Discrepancy
50. Communication skills
51. Communication skills
52. Professional experience
53. Professional experience
54. Knowledge
55. Education
56. Professional experience
57. Life experience
58. Life experience
59. Life experience
60. Knowledge
61. Knowledge
62. Knowledgeable
63. Education
64. Education
65. Educating
66. Educating
67. Educating
68. Accessible
69. Threatening
70. Threatening
71. Negative
72. Negative
73. Accessible
74. Accessible
75. Accessible
76. Fear of judgment
77. Collaborative working
78. MDT contribution
79. Accessible
80. Structured
81. Time limited
82. Boundaries
83. Persuasion
84. Persuasion
85. Relaxation techniques
86. Emotional exploration
87. Communication style
88. Negative
89. Confidence
90. Reflective learning
91. Ongoing process
92. Communication style
93. Training
94. Training

95. Medical knowledge
96. Medical knowledge
97. Medical knowledge
98. Academic
99. Medical knowledge
100. Separate
101. Separate
102. Separate
103. Separate
104. Separate
105. Medical knowledge
106. Collaborative working
107. Feedback
108. Feedback
109. Feedback
110. Clinical supervision
111. Budgetary restrictions
112. Prioritisation of budget
113. Prioritisation of budget
114. Clinical supervision
115. Peer support
116. Peer support
117. Informal support
118. Lack of time
119. Emotional burden
120. Individual
121. Burn out
122. Clinical supervision
123. Clinical supervision
124. Clinical supervision
125. Peer support
126. Clinical supervision
127. Fear of judgment
128. Fear of judgment
129. Fear of judgement
130. Unrealistic expectations
131. Unrealistic expectations
132. Fear of judgment
133. Crying
134. Crying
135. Managing emotions
136. Time out
137. Pressure
138. Pressure
139. Individual
140. Crying
141. Peer support
142. Peer support
143. Training
144. Training
145. Training
146. Self directed learning
147. Training
148. Training
149. Training
150. Role play
151. Observation
152. Separate
153. Observational learning
154. Observational learning
155. Screening tools
156. Screening tools
157. Screening tools
158. Experience

APPENDIX 22

TRANSCRIPT NINE: INITIAL THEMES

(Themes numbered according to the order they were found in the transcript)

1. Insufficient numbers
2. Positive
3. Scope of role
4. Expert
5. Scope of role
6. Knowing limits
7. Referring on
8. In-depth
9. In-depth
10. Uncertainty (roles)
11. Training
12. Medical knowledge
13. Not coping
14. Safe environment
15. Lack of time
16. Beyond ability
17. Referring on
18. Negative
19. Helpful
20. Unknown
21. Negative
22. Negative
23. Intelligence based
24. Confidence
25. Psychological assessment
26. Treatment issues
27. Needle phobia
28. Psychological assessment
29. Communication style
30. Normalising
31. Normalising
32. Positive
33. Positive
34. Staff support
35. Clinical supervision
36. Clinical supervision
37. Clinical supervision
38. Clinical supervision
39. Lack of support
40. Family support
41. Boundaries
42. Boundaries
43. Boundaries
44. Clinical supervision
45. Lack of support
46. Clinical supervision
47. Limit of understanding
48. Peer support
49. Clinical supervision
50. Clinical supervision
51. Flexible
52. Trustworthy
53. Trustworthy
54. Holding confidence
55. Trustworthy
56. Flexible
57. Accessibility
58. Boundaries
59. Frequency of contact
60. Adjustment issues
61. Boundaries of role
62. Scope of role
63. Limited resources
64. Support
65. Support
66. Requires more
67. Complex history
68. Body language
69. Scope of role
70. Anxiety
71. Anxiety
72. Anxiety
73. Emotional support
74. Patient insight
75. Communication skills
76. Limited time
77. Beyond ability
78. Beyond ability
79. Frustration
80. Time
81. Patient beliefs
82. Patient beliefs
83. Patient beliefs
84. Patient beliefs
85. Not coping
86. Unknown
87. Instinct
88. Instinct
89. Instinct
90. Instinct
91. Unknown
92. Quality of relationship
93. Confidential
94. Treatment issues

95. In-depth
96. Assessment tools
97. Assessment tools
98. Psychological assessment
99. Shared responsibility
100. Frequency of contact
101. Support
102. Unknown
103. Emotional exploration
104. Improved coping
105. Instigate change
106. Unresolved issues
107. Feedback
108. Trustworthy
109. Feedback
110. Feedback
111. Feedback
112. Feedback
113. Feedback
114. Ongoing input
115. Ongoing input
116. Feedback
117. Ongoing input
118. MDT contribution
119. Medical model
120. Psychological dimension
121. Medical model
122. Medical model
123. Training
124. Training
125. Training
126. Training
127. Training
128. Role play
129. Training
130. Training
131. Training
132. Observation
133. Unknown
134. Observation
135. Observation
136. Boundaries of role
137. Expert
138. Unknown

APPENDIX 23

TRANSCRIPT TEN: INITIAL THEMES

(Themes numbered according to the order they were found in the transcript)

1. Positive
2. Non-medical
3. Clinical consultation
4. Clinical consultation
5. Clinical supervision
6. Clinical supervision
7. Uncertain
8. Objective view
9. Medical focus
10. Solution focused
11. Aid understanding
12. Aid understanding
13. Lack of time
14. Aid understanding
15. Professional relationships
16. Clinical supervision
17. Clinical supervision
18. Positive
19. Unknown
20. Unknown
21. Unknown
22. Objective view
23. Objective view
24. Threatening
25. Emotional support
26. Limited scope
27. Clinical consultation
28. Threatening
29. Threatening
30. Threatening
31. Newly diagnosed
32. Adjustment
33. End of life care
34. Managing limited time
35. Managing limited time
36. Managing limited time
37. Managing limited time
38. Access to psychologist
39. Limited scope
40. Limited scope
41. Limited scope
42. MDT contribution
43. MDT contribution
44. MDT contribution
45. Separate
46. Separate
47. Limited scope
48. Newly diagnosed
49. Adjustment issues
50. Complex issues
51. Past issues
52. Complex issues
53. Info gathering
54. Info gathering
55. Instinct
56. Unknown
57. Structured
58. Understanding
59. Instigate change
60. Structured
61. Symptom control
62. Instigate change
63. Scope of role
64. Instigate change
65. Respect choices
66. Respect choices
67. Respect choices
68. Time
69. Time
70. Communication skills
71. Communication skills
72. Respect choices
73. Respect choices
74. Systemic support
75. Systemic support
76. Systemic support
77. Limited scope
78. Clinical consultation
79. Death of patient
80. Death of patient
81. Chronic illness
82. Chronic illness
83. Death of patient
84. Death of patient
85. Boundaries
86. Boundaries
87. Boundaries
88. Death of patient
89. Listening
90. Listening
91. Assess tools
92. Listening
93. Communication skills
94. Patient insight

95. Patient insight
96. Patient insight
97. Assess tools
98. Assess tools
99. Assess tools
100. Normalising distress
101. Normalising distress
102. Anti-depressants
103. Staff resistance
104. Staff resistance
105. Staff resistance
106. Depression
107. Capacity for pleasure
108. Ongoing sadness
109. Staff resistance
110. Over prescribing
111. Acceptability
112. Language
113. Language
114. Acceptability
115. Language
116. Generational
117. Generational
118. Generational
119. Undervalued
120. Undervalued
121. Undervalued
122. Undervalued
123. Feedback
124. Feedback
125. Unknown
126. Unknown
127. Unknown
128. Unknown
129. Feedback
130. Personal motivation
131. Personal motivation
132. Education
133. Experience
134. Experience
135. Observational learning
136. Experiential learning
137. Observational learning
138. Observational learning
139. Education
140. Education
141. Experiential learning
142. Observation
143. External placement
144. External placement
145. Observation
146. Observation

APPENDIX 24

TRANSCRIPT TWO: CLUSTERED THEMES

Time
Facilitate expression
Manage complex issues
Scope of role
Offering choice
Systemic support
Offering choice
Gate keeping
Gate keeping
Symptom management
Collaborative working
Scope of role
Professional autonomy
Negotiation

Need support
Unable to help
Beyond abilities
Insufficient knowledge
Insufficient understanding

Aid understanding
Scope of use
MDT contribution
Clinical consultation
Accessibility
Collaborative working
Separate
Clinical recommendations
Clinical supervision
Impartial
Clinical supervision
Clinical supervision
Separate
Unknown
Feedback
Feedback

Complex issues
Adjustment issues
Adjustment issues

Impartial
Impartial
Trustworthy
Unknown

Patient motivation
Not coping
Emotional discomfort
Screening questions
Risk assessment
Semi-structured assessment
Emotional exploration
Wider input
Comparison over time
Capacity
Personal expectations
Direct question
Patient insight
Direct question
Screening tools
Risk assessment
MDT discussion
Joint assessment
Joint assessment
Joint assessment

CBT
Improved coping
Structured interventions
Coping
Drug free
Talking therapy
Drug free
Coping
Drug free
Unknown
Unknown

Limited time
Limited time
Limited time
Time pressure
Responsibility
Limited time
Depression vs dying
Physical deterioration
Depression vs dying
Realistic sadness
Lack of support
Organisational agenda
Screening tools
Timing

Doing
Doing
Team debrief
Work/life boundary
MDT discussion

Terminal care
Inaccurate
Inaccurate
Terminal care
Unrealistic

Helpful
Unrealistic
Unrealistic
Secretive
Limited access
Unknown
Unknown
Secretive
Limited numbers
Positive
Change over time
Acceptability
Acceptability
Acceptability

Understanding
Feedback
Education
Understanding
Observation
Training
Professional transparency
Education
Education
Education

Training
Training
Training
Training
Experience
Unknown acquisition
Experience

Communication style
Confidence
Confidence
Confidence

Overload
Inappropriate prescribing
Undetected distress
Inappropriate prescribing
Limited exposure
Increasing contact
Limited numbers

APPENDIX 25

TRANSCRIPT THREE: CLUSTERED THEMES

Scope of role
Initial support
Information giving
Scope of role
Broad focus
Treatment focus
Broad focus
Coordination
Scope of role
Scope of role
Broad focus
Specialist knowledge
Specialist knowledge
Broad focus
Offering choices
Psychological assessment
Emotional containment
Check understanding
Psychological assessment
Information giving
Psychological assessment
Continuity
Accessibility
Finding solutions
Offering choices
Offering choices
Broad focus
Scope of role
Ongoing input
Treatment issues
Breaking bad news
Ongoing input
Ongoing input

Boundaries of role
Requiring specialist input
Boundaries of role
Boundaries of role
Limited time

Past issues
Body image issues
Multiple issues
Child abuse
Critical point in pathway
Fertility issues
Relationship issues
Not coping
Depression
Treatment issues
Relationship issues
Critical point in pathway
Critical point in pathway
Critical point in pathway
Critical point in pathway

Require more
Intuition
Initial impression
Screening tools vs instinct
Instinct
Going no further
Require more
Ongoing
Rapport building
Ongoing
Communication skills
Intuition
Rapport building
Communication skills
Rapport building
Giving time
Ongoing
Ongoing
Giving time
Giving time
Going no further
Going no further
Going no further
Patient request

Longer term support
Emotional support
Techniques
Emotional exploration
Emotional exploration
Techniques
Specialist counselling

Experience
Experience
Experience
Experience
Training
Education
Training
Experience
Training
Observational learning
Experiential learning
Reflective practice
Observational learning
Observational learning
Ongoing learning
Experience

Scope of use
Team member
Scope of use
Team member
Staff support
Staff support
Staff support
Feedback
Feedback
MDT contribution
Feedback

Colleague support
Colleague support
Offloading
Offload
Peer support
Staff support

Workload
Isolation
Managing perception

Negative

Individual
Confidence

Individual
Generational
Positive
Generational
Generational
Confidence

Observation

Screening tools
Screening tools
Formality
Medical focus

APPENDIX 26

TRANSCRIPT FOUR: CLUSTERED THEMES

Scope of role
Ongoing input
Scope of role
Broad remit
Systemic support
Emotional containment
Emotional containment
Offering time
Transparency
Transparency
Experience based
Experience (time)
Listening

Active
Flexible

Critical point in pathway
Treatment issues
Relatives
Critical point in pathway
Depression
Withdrawn
Treatment adherence
Side effects
Total pain
Loss of control (families)
Not coping
Sudden diagnosis
Not coping

Beyond ability
Unable to do more
Unable to do more
Unable to do more
Stopped helping
Boundaries of role
Boundaries of role
Beyond ability
Unable to do more
Stopped helping

Require more
Emotional discomfort
Emotional discomfort
Emotional discomfort
Communication skills
Communication skills
Discrepancy
Communication skills
Intuition
Intuition
Time

Managing treatment
In-depth
Objective view
Objective view
Techniques

Supporting children
Clinical supervision
Isolation
Isolation
Lack of support
Managing denial
Managing denial
Expectations
Collusion
Screening tools
Screening tools
Screening tools

Colleague support
Colleague support
Referring on
Referring on

Clinical consultation
Professional support
Clinical consultation
Professional support
Clinical supervision
Clinical supervision
Clinical supervision
Separate

Boundaried
Acceptability
Helpful

Non-medical
Training
Complex skills

Experience (time)
Observational learning
Peers
Clinical supervision
Training
Training
Training
Experience
Experience
Time

Confidence
Confidence
Communication skills
Acceptability
Acceptability
Acceptability
Changed over time

Observation
Observation
Feedback
Feedback
Feedback

Protection
Confidence

APPENDIX 27

TRANSCRIPT FIVE: CLUSTERED THEMES

Education
Joint working
Team member
Availability
Professional support
Professional support
Accessibility
Team member
Education
Feedback
Clinical recommendations
Education

Improved coping
Structured interventions
Unknown
Unknown
Unknown

Helpful
Acceptability
Unknown

CBT trained
Psychological models
Medical knowledge
Medical knowledge
Unknown
Specialist knowledge
Distinct profession

Scope of role
Broad remit
Emotional support
Emotional support
Informing colleagues
Team communication
Team communication
Team communication
Scope of role
Patient centred
Flexibility
Information giving
Patient centred
Multi-skilled

Patient insight
Patient insight
Frequency of contact
Require more
Single screening question
Patient insight
Patient motivation
Motivation
Self-selection
Communication style
Patient request
Intuition
Patient insight
Communication skills
Time
Time
Individual
Patient responsibility
Patient responsibility
Single screening question

Ongoing process
Experience
Reflective practice
Peer support
Patient feedback
Patient feedback
Patient feedback
Training
Training
Training
Training
Peers
Reflective practice
Peers
Reflective practice
Reflective practice

Limited time
Need more

Budgetary restrictions
Lone worker
Limited resources
Insufficient feedback
Insufficient feedback
Team communication
Team communication
Limited time
Limited time
Limited time
Patient expectations
Screening tools
Screening tools
Screening tools
Screening tools
Screening tools
Screening tools
Screening tools
Failing
Failing
Lone worker
Team working
Peer resistance

Understanding
Feedback
Education
Education
Professional support
Understanding
Observation
Understanding
Professional transparency
Education
Understanding

Coping
Key point in pathway
Not coping
Adjustment problems
Adjustment

Clinical supervision
Clinical supervision
Reflective practice
Peer support
Professional support
Individual
Boundaries
Referring on

Confidence
Confidence
Communication style
Communication style

Past experience
Unique issues
Accepting
Limited choice
Limited choice
Limited choice

APPENDIX 28

TRANSCRIPT SIX: CLUSTERED THEMES

Emotional discomfort
Emotional discomfort
Time
Time
Emotional exploration
Communication skills
Validation
Validation
Offering time
Offering time
Intuition
Discomfort
Going no further
Emotional discomfort
Methodological

Non-cancer issues
Family conflict
Family conflict
Behavioural problems
Treatment adherence
Fertility issues
Family conflict
Fertility issues
Pain
Pain
Extreme distress

Unable to help
Require specialist input
Boundaries of role
Boundaries of role

Younger patients
Younger patients

Accessibility
Clinical consultation
Availability
Clinical consultation
Clinical consultation
Team member
Availability
Availability
Availability
MDT contribution
MDT contribution
Staff support
Unknown
Feedback

Colleague support
Offloading
Colleague support
Offloading
Managerial support

Time
Training
Training
Training
Training
Training
Training
Experience

Individual
Clarification
Openness
Confidence
Individual
Validation

Confusion
Negative
Unknown

Loss of control
Fear inducing
Stigma
Fear inducing

Techniques
Improved coping
Structured interventions
Unknown

Specialist knowledge
Specialist knowledge
Broad experience
Training
Medical knowledge
Medical knowledge
Medical knowledge

Observation
Observation
Observation

APPENDIX 29

TRANSCRIPT SEVEN: CLUSTERED THEMES

Professional autonomy
Broad remit
Support
Scope of role
Scope of role
Scope of role
Negative
Broad remit
Broad remit
Explore past experiences
Sign posting
Scope of role
Breaking bad news
Breaking bad news
Holding confidence

Positive
Expert
Positive
Impressive
Positive
Acceptability
Acceptability
Unknown
Unknown

Managing uncertainty
Not coping
Not coping
Not coping
Younger patients
Not coping
Younger patients
Anxious preoccupation
Anxious preoccupation
Anxiety
Requesting medication
Persistent anxiety
Frequent contact
Not coping
Not coping
Frequent contact
Living with uncertainty
Living with uncertainty
Living with uncertainty
Living with uncertainty
Information seeking
Information seeking
Information seeking
Not coping
Denial

Coping mechanisms
Improved coping
Psychological focus
Coping mechanisms
Coping mechanisms
Unknown
Acceptance
Acceptance
Acceptance
Brief intervention
Brief intervention
Normalisation

Unknown
Clinical consultation
Clinical consultation
Team member
Separate
Negotiating confidentiality

Training
Training
Experience
Experience
Patient feedback
Self-directed learning
Communication skills training
Communication skills training
Communication skills training
Observational learning
Observational learning
Observational learning
Observational learning

Going no further
Require more
Age
Unknown
Emotional exploration
Available support
Unknown
Time
Time
Relationship
Comparison over time
Available support
Comparison over time
Instinct

Limited time
Limited time

Intellectual
Intellectual
Separate
Safe
Separate

Language
Reassurance
Reassurance
Confidence
Honest
Confident
Confidence
Language
Language

Unrealistic expectations

Palliative patients
Palliative patients
Palliative patients
Incurable at diagnosis
Insufficient feedback
Insufficient feedback
Insufficient feedback
Insufficient feedback
Lack of support
Job insecurity
Job insecurity
Job insecurity
Competitiveness
Competitiveness
Pressure
Lack of understanding
Lack of understanding
Lack of time
Lack of support

Peer support

Education
Observation
Observation

Observational learning

APPENDIX 30

TRANSCRIPT EIGHT: CLUSTERED THEMES

Positive
Formalised
Threatening
Threatening
Negative
Negative
Negative

Manage complex issues
Information giving
Support
Scope of role
Emotional support
Broad remit
Knowledgeable
Knowledgeable
Scope of role
Scope of role
Emotional support
Coordination
Educating
Educating
Educating

Emotional discomfort
Instinct
Going no further
Patient request
Going no further
Going no further
Instinct
Instinct
Experience
Verbal cues
Assessment questions
Communication skills
Communication skills
Communication skills
Discrepancy
Communication skills
Communication skills

Beyond ability
Require specialist input

Knowledgeable
Knowledgeable
Unrealistic expectations
Unrealistic expectations

Expectations
Fear of judgment
Clinical supervision
Budgetary restrictions
Clinical supervision
Lack of time
Emotional burden
Burn out
Fear of judgement
Fear of judgement
Fear of judgement
Fear of judgement
Managing emotions
Pressure
Pressure
Role play
Screening tools
Screening tools
Screening tools

Anxiety
Anxiety
Anxiety
Loss of control
Depression
Suicidal thoughts
Mental health history
Recent bereavement
Suicidal thoughts
Depression
Body image issues

Psychological reaction
Adjustment process
Adjustment process
Adjustment process
Prioritisation of budget
Prioritisation of budget
Assessment tools

Professional experience
Professional experience
Knowledge
Education
Professional experience
Life experience
Life experience
Life experience
Knowledge
Knowledge
Reflective learning
Ongoing process
Training
Training
Training
Self directed learning
Training
Training
Training
Observational learning
Observational learning

Education
Education
Accessible
Accessible
Accessible
Accessible
Collaborative working
MDT contribution
Accessible
Separate
Separate
Separate
Separate
Collaborative working
Feedback
Clinical supervision

Structured
Time limited
Boundaries
Relaxation techniques
Emotional exploration

Persuasion
Persuasion
Communication style
Confidence
Communication style

Training
Training
Medical knowledge
Medical knowledge
Medical knowledge
Academic
Medical knowledge
Separate
Medical knowledge
Separate
Feedback
Feedback

Peer support
Peer support
Informal support
Individual
Clinical supervision
Clinical supervision
Peer support
Clinical supervision
Crying
Crying
Time out
Individual
Crying
Peer support
Peer support
Observation
Experience

APPENDIX 31

TRANSCRIPT NINE: CLUSTERED THEMES

Lack of support
Lack of support
Limit of understanding
Limited resources
Assessment process
Patient beliefs
Patient beliefs
Patient beliefs
Patient beliefs
Psychological assessment
Medical model
Medical model
Medical model
Unknown

Insufficient numbers
Positive
Expert
Negative
Helpful
Negative
Negative
Intelligence based
Positive
Positive
Expert

Scope of role
Scope of role
Knowing limits
Referring on
Uncertainty (roles)
Referring on
Psychological assessment
Psychological assessment
Holding confidence
Accessibility
Support
Support
Scope of role
Emotional support
Instinct
Instinct
Instinct
Support
Ongoing input
Ongoing input
Ongoing input
Psychological dimension
In-depth
In-depth
Safe environment
Confidential
In-depth
Unknown
Emotional exploration
Improved coping
Instigate change
Unresolved issues

Training
Medical knowledge
Trustworthy
Trustworthy
Trustworthy
Trustworthy

Lack of time
Beyond ability
Boundaries of role
Limited time
Beyond ability
Beyond ability
Boundaries of role

Unknown
Staff support
Clinical supervision
Clinical supervision
Clinical supervision
Clinical supervision
Flexible
Flexible
Feedback
Feedback
Feedback
Feedback
Feedback
MDT contribution
Unknown

Confidence
Communication style
Normalising
Normalising

Not coping
Treatment issues
Needle phobia
Frequency of contact
Adjustment issues
Boundaries of role
Complex history
Anxiety
Anxiety
Anxiety
Not coping
Treatment issues
Frequency of contact

Clinical supervision
Family support
Boundaries
Boundaries
Boundaries
Clinical supervision
Peer support
Clinical supervision
Clinical supervision
Boundaries

Requires more
Communication skills
Patient insight
Communication skills
Time
Unknown
Instinct
Unknown
Shared responsibility

Quality of relationship

Assessment tools
Assessment tools
Feedback
Feedback
Observation
Observation
Observation

Training
Training
Training
Training
Training
Role play
Training
Training
Training

APPENDIX 32

TRANSCRIPT TEN: CLUSTERED THEMES

Positive
Positive
Threatening
Threatening
Threatening
Threatening
Acceptability
Acceptability
Generational
Generational
Generational
Undervalued

Non-medical
Objective view
Unknown
Unknown
Unknown
Objective view
Objective view

Clinical consultation
Clinical consultation
Uncertain
Aid understanding
Aid understanding
Aid understanding
Clinical supervision
Clinical supervision
Limited scope
Clinical consultation
Limited scope
Limited scope
Limited scope
MDT contribution
MDT contribution
MDT contribution
Separate
Separate
Limited scope
Limited scope
Clinical consultation
Feedback
Feedback
Unknown
Unknown
Feedback

Clinical supervision
Clinical supervision
Access to psychologist
Death of patient
Death of patient
Death of patient
Death of patient
Boundaries
Boundaries
Boundaries
Death of patient
Assess tools

Medical focus
Solution focused
Emotional support
End of life care
Managing limited time
Managing limited time
Managing limited time
Managing limited time
Symptom control
Scope of role
Respect choices
Respect choices
Respect choices
Respect choices
Respect choices
Systemic support
Systemic support
Systemic support
Listening
Listening
Listening

Lack of time

Multi professional working
Chronic illness
Chronic illness
Assess tools
Assess tools
Normalising distress
Normalising distress
Staff resistance
Staff resistance
Staff resistance
Staff resistance
Over prescribing

Newly diagnosed
Newly diagnosed
Adjustment issues
Complex issues
Past issues
Complex issues
Depression
Capacity for pleasure
Ongoing sadness

Adjustment
Unknown
Structured
Understanding
Instigate change
Structured
Instigate change
Instigate change
Unknown
Unknown

Info gathering
Info gathering
Instinct
Communication skills
Communication skills
Communication skills
Patient insight
Patient insight
Patient insight

Time
Time
Personal motivation
Personal motivation
Education
Experience
Experience
Observational learning
Experiential learning
Observational learning
Observational learning
Education
Education
Experiential learning

Assess tools
Observation
External placement
External placement
Observation
Observation

Language
Language
Language

Undervalued Undervalued Undervalued	Anti-depressants

APPENDIX 33

TRANSCRIPT TWO: SUMMARY TABLE

(**Key** 1.30 refers to page 1, line 30)

HOPES REGARDING PSYCHOLOGY ROLE

Aid understanding	"make some sense"	1.30
MDT contribution	"add anything"	2.43
Clinical consultation	"talk to them"	2.46
Accessibility	"need to know"	2.55
Collaborative working	"two way thing"	2.67
Clinical recommendations	"try and do this"	2.71
Clinical supervision	"clinical supervision"	3.78
Separate	"not part of the team"	13.454
Unknown	"don't really know"	13.457
Feedback	Information... passed on"	15.535

WHAT PSYCHOLOGISTS DO

Improved coping	"help people to cope"	5.173
Structured interventions	"CBT"	5.171
Unknown	"don't....know"	12.448

BELIEFS ABOUT PSYCHOLOGISTS

Helpful	"help them"	12.432
Secretive	"feels secretive"	12.449
Unknown	"bit of a myth"	12.444
Positive	"it is positive"	14.500
Acceptability	"more stigma with psych"	14.520

BEING A CLINICAL NURSE SPECIALIST

Time	"have the time"	1.25
Scope of role	"we are not psychologists"	5.176
Systemic support	"families"	7.258
Gate keeping	"gate keep"	8.283
Symptom management	"neuropathic pain"	9.329
Professional autonomy	"own devices"	11.405
Negotiation	"negotiation job"	16.590

BELIEFS ABOUT CNSs

Terminal care	"last days of life"	12.419
Inaccurate	"don't understand"	12.424
Unrealistic	"sort everything out"	12.438

FACTORS CONTRIBUTING TO CONFIDENCE/COMPETENCE

Training	"ACST course"	15.549
Experience	"experience"	16.583

ASSESSING PATIENTS FOR DISTRESS

Patient motivation	"wanted to talk"	4.151
Not coping	"I couldn't cope"	5.158
Emotional discomfort	"freaked me out"	5.159
Screening questions	"HADS questions"	6.221
Emotional exploration	"open it up"	6.225
Wider input	"bring in other people"	7.234
Comparison over time	"same as they were before"	7.238
Capacity	"need to be able"	8.270
Personal expectations	"I'd feel like that"	9.310
Patient insight	"patients themselves"	10.352
Single question	"are you depressed"	10.354
Joint assessment	"see someone together"	11.406

DIFFICULTIES AND CHALLENGES OF BEING A CNS

Limited time	"don't have time"	6.203
Time pressure	"quickly"	7.247
Responsibility	"get it right"	7.254
Depression vs dying	"quite difficult"	8.300
Realistic sadness	"normal"	9.309
Lack of support	"no one to help you"	11.387
Screening tools	"pushed into it"	10.364
Timing	"time has run out"	7.262

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Understanding	"knew a bit more"	13.476
Feedback	"nice to know"	13.481
Observation	"shadowing"	14.491
Professional transparency	"more open"	14.494
Education	"need to learn"	16.598

PRESENTATIONS AND SYMPTOMS

Complex issues	"complex issues"	2.69
Adjustment issues	"couldn't process that"	4.148

COPING WITH BEING A CNS

Team debrief	"we will talk"	11.391
Work/life boundary	"leave it"	11.393
MDT discussion	"we can talk"	11.399

APPROACHING PSYCHOLOGICAL ISSUES WITH PATIENTS

Communication style	"the way"	6.200
Confidence	"quite comfortable"	6.194

APPENDIX 34

TRANSCRIPT THREE: SUMMARY TABLE

(**Key** 5.163 refers to page 5, line 163)

HOPES REGARDING PSYCHOLOGY ROLE

Team member	"part of the team"	5.163
Staff support	"support for staff"	5.181
Information sharing	"telling them"	17.613
Feedback	"feedback to us"	17.615

WHAT PSYCHOLOGISTS DO

Techniques	"mind maps"	4.122
Emotional exploration	"exploring"	4.144

BELIEFS ABOUT PSYCHOLOGISTS

Generational	"older people"	14.501
Positive	"very popular"	14.504

BEING A CLINICAL NURSE SPECIALIST

Support	"initial support"	1.15
Coordination	"liasing"	3.97
Scope of role	"not trained in that"	3.105
Treatment focus	"specialist knowledge"	4.128
Broad remit	"cover the whole aspect"	4.137
Check understanding	"have they understood"	8.274
Information giving	"going over things"	8.279
Breaking bad news	"give results"	15.553
Ongoing input	"all the way through"	16.590

ASSESSING PATIENTS FOR DISTRESS

Intuition	"pick up a sense"	2.65
Initial impression	"initial meeting"	2.73
Screening tool	"got their place"	3.79
Going no further	"gone as far..."	3.102
Communication skills	"communication skills"	9.303
Rapport	"build the relationship"	9.311
Ongoing	"ongoing assessment"	9.333
Giving time	"give people the time"	9.339
Patient request	"can you refer me?"	17.636

FACTORS CONTRIBUTING TO CONFIDENCE/COMPETENCE

Experience	"experience is really central"	3.87
Training	"nurse training"	14.526
Education	"taught"	14.527
Observational learning	"watching people"	15.557
Experiential learning	"just doing it"	15.559
Reflective practice	"reflecting back"	15.559

DIFFICULTIES AND CHALLENGES OF BEING A CNS

Workload	"a lot of work"	2.38

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Observation	"see what you do"	17.622

PRESENTATIONS AND SYMPTOMS

Past issues	"issues from the past"	2.45
Body image issues	"body image"	2.47
Multiple issues	"a lot of issues"	4.142
Fertility issues	"pregnancy"	10.356
Relationship issues	"marital problems"	10.361
Not coping	"not coping"	11.382
Depression	"depressive symptoms"	11.396
Treatment adherence	"not have treatment"	11.404
Critical point in pathway	"treatment is finished"	13.476

COPING WITH BEING A CNS

Colleague support	"it helps me"	6.224
Offloading	"we offload"	7.237
Peer support	"collective support"	7.243

APPROACHING PSYCHOLOGICAL ISSUES WITH PATIENTS

Individual	"that patient"	12.434
Confidence	"wouldn't have a problem"	12.438

APPENDIX 35

TRANSCRIPT FOUR: SUMMARY TABLE

(**Key** 3.105 refers to page 3, line 105)

HOPES REGARDING PSYCHOLOGY ROLE

Clinical consultation	"source of advice"	3.105
Professional support	"support to the CNS"	3.107
Clinical supervision	"offer supervision"	4.133

WHAT PSYCHOLOGISTS DO

In-depth	"root of the problem"	11.403
Techniques	"visualisation, hypnotherapy"	13.446

PERCEIVED QUALITIES OF PSYCHOLOGISTS

Training	"trained for that purpose"	13.459
Complex skills	"more complex"	12.416

BELIEFS ABOUT PSYCHOLOGISTS

Acceptability	"carry less stigma"	15.521
Helpful	"helped enormously"	6.209

BEING A CLINICAL NURSE SPECIALIST

Scope of role	"can't do everything"	1.12
Ongoing input	"no end"	1.14
Broad remit	"pretty huge job"	5.167
Systemic support	"wives, husbands...."	6.201
Emotional containment	"having a presence"	8.271
Offering time	"giving the time"	8.281

ASSESSING PATIENTS FOR DISTRESS

Emotional discomfort	"being so helpless"	6.203
Stopped helping	"not helping her anymore"	7.253
Communication skills	"listening skills"	8.260
Discrepancy	"lying in bed"	8.295
Intuition	"gut instinct"	9.327
Time	"over time"	9.326

FACTORS CONTRIBUTING TO CONFIDENCE/COMPETENCE

Observational learning	"watching colleagues"	11.385
Peers	"working with colleagues"	11.386
Training	"role-play"	15.548
Professional experience	"what you learn on the wards"	16.550
Personal experience	"life experience"	16.564
Time	"comes with time"	16.564

APPROACHING PSYCHOLOGICAL ISSUES WITH PATIENTS

Confidence	"feel pretty confident"	14.504
Communication skills	"way we put it across"	14.514

DIFFICULTIES AND CHALLENGES OF BEING A CNS

Supporting children	"really difficult"	4.117
Isolation	"only 2 in the hospital"	5.164
Lack of support	"nobody to go to"	5.173
Managing denial	"difficult to deal with"	7.226
Listening	"listening can be really hard"	8.264
Expectations	"have to be seen to be doing"	8.272
Collusion	"still not know it's cancer"	10.358

IMPROVING PSYCHOLOGICAL CARE FOR PATIENTS

Clinical supervision	"a way to learn & reflect"	11.390
Observation	"useful to be able to see it"	16.583
Feedback	"which referrals were right"	17.595

PRESENTATIONS AND SYMPTOMS

Critical point in pathway	"coping with diagnosis"	1.27
Treatment issues	"side effects"	1.28
Carers	"relatives"	1.30
Depression	"dark cloud "	2.41
Treatment adherence	"staying motivated"	3.84
Total pain	"complete mental anguish"	3.95
Loss of control (families)	"completely out of control"	6.197
Not coping	"they are not coping"	7.247
Sudden diagnosis	"3 days later...."	2.53

COPING WITH BEING A CNS

Colleague support	"go to them"	5.170
Referring on	"weight off your shoulders"	14.487

MISCELLANEOUS

Protection	"shelter patients"	10.342
Confidence	“more confident in yourself”	10.352

APPENDIX 36

TRANSCRIPT FIVE: SUMMARY TABLE

(**Key** 1.27 refers to page 1, line 27)

HOPES REGARDING PSYCHOLOGY ROLE

Joint working	"worked together"	1.27
Team member	"part of the team"	3.76
Availability	"seen fairly promptly"	3.83
Professional support	"clinical support"	3.89
Accessibility	"at the end of the phone"	3.110
Feedback	"being kept in the loop "	8.284
Clinical recommendations	"any way that I can be involved"	8.283

WHAT PSYCHOLOGISTS DO

Improved coping	"coping better"	5.181
Structured interventions	"structured coping mechanisms"	6.196
Unknown	"I don't know much"	7.223

PERCEIVED QUALITIES OF PSYCHOLOGISTS

Training	"cbt training"	2.58
Medical knowledge	"illness and treatment"	2.66
Specialist knowledge	"a different level"	16.577

BELIELFS ABOUT PSYCHOLOGISTS

Helpful	"useful for the patients"	1.20
Acceptability	"psychiatrist is a different matter"	7.256
Unknown	"public don't have any perception"	8.260

BEING A CLINICAL NURSE SPECIALIST

Scope of role	"I am not a counsellor"	1.17
Broad remit	"mine is a very general training"	2.47
Emotional support	"emotional support"	2.51
Communicating	"give that background"	2.69
Flexibility	"very flexible"	10.343
Information giving	"so much information to give"	10.349
Multi-skilled	"all those skills"	13.447

ASSESSING PATIENTS FOR PSYCHOLOGICAL DISTRESS

Patient insight	"they tell you"	6.188
Single screening question	"asking the question"	6.197
Patient motivation	"prepared to do something"	6.204
Self-selection	"they self-select"	6.210
Communication style	"the way you put it"	6.211
Patient request	"I want to be referred"	8.264
Intuition	"it is intuition"	10.357
Communication skills	"listening, watching & silence"	11.370
Time	"take it slowly"	11.374
Individual	"tailor it to the person"	11.376
Patient responsibility	"they have to take responsibility"	11.384

FACTORS CONTRIBUTING TO CONFIDENCE/COMPETENCE

Ongoing process	"I'm still learning"	11.396
Experience	"a lot of experience"	11.400
Training	"role-play is very valuable"	14.497
Peer support	"biggest learning tool"	14.513
Reflective practice	"constantly reviewing & reflecting"	15.517

DIFFICULTIES AND CHALLENGES OF BEING A CNS

Budgetary restrictions	"never on the budget"	1.32
Limited resources	"very little out there"	8.270
Insufficient feedback	"don't get any feedback"	8.272
Team communication	"so many people to keep in the loop"	9.299
Limited time	"don't have much time"	10.348
Patient expectations	"patient's expect to be seen tmw"	12.417
Screening tools	"it's clinical governance"	13.476
Failing	"when you get it wrong it's awful"	15.519
Team working	"working as a team is not easy"	16.588
Peer resistance	"people see barriers"	17.598

IMPROVING PSYCHOLOGICAL CARE FOR PATIENTS

Understanding	"I need more clarity"	7.231
Feedback	"learn from that as well"	8.287
Professional support	"ongoing clinical support"	15.529
Observation	"possibly observing"	15.540
Education	"educating the whole team"	15.549

PRESENTATIONS AND SYMPTOMS

Key point in pathway	"shocked at diagnosis"	5.169
Not coping	"just aren't coping"	5.174
Adjustment problems	"hasn't been able to go out"	5.178

COPING WITH BEING A CNS

Clinical supervision	"helping to deal with all the issues"	1.36
Peer support	"other people come up with ways…"	4.113
Boundaries	"I very much compartmentalise"	4.121
Referring on	"comforting to know"	9.307

APPROACHING PSYCHOLOGICAL ISSUES WITH PATIENTS

Confidence	"I broach a lot of topics"	7.239
Communication style	"it's how you introduce it"	7.252

MISCELLANEOUS

Unique issues	"lung patients are different"	5.160
Accepting	"more laissez-faire"	5.162
Limited choice	"don't have much choice"	12.427

APPENDIX 37

TRANSCRIPT SIX: SUMMARY TABLE

(**Key** 2.49 refers to page 2, line 49)

HOPE REGARDING PSYCHOLOGY ROLE

Accessibility	"being able to access them"	2.49
Clinical consultation	"tap into their knowledge"	2.50
Team member	"part of the mdt"	2.54
Availability	"available on a Thursday…"	2.59
MDT contribution	"contribute their views"	2.73
Professional support	"staff support"	3.78
Unknown	"not sure about the details"	3.92
Feedback	"helpful to know"	13.456

WHAT PSYCHOLOGISTS DO

Techniques	"giving people techniques"	10.351
Improved coping	"helping people to cope"	10.352
Structured interventions	"cbt"	10.365
Unknown	"bit out of my understanding"	10.368

PERCEIVED QUALITIES OF PSYCHOLOGISTS

Specialist knowledge	"greater understanding"	10.354
Training	"degree plus 3 years"	11.372
Medical knowledge	"understand disease process"	11.380

BELIEFS ABOUT PSYCHOLOGISTS

Confusion	"patients get confused"	9.314
Negative	"so think I am mad"	9.317
Unknown	"more of an unknown"	10.345

BEING A CLINICAL NURSE SPECIALIST

Offering time	"I make myself available"	7.235

ASSESSING PATIENTS FOR DISTRESS

Time	"need to give it some time"	6.208
Emotional exploration	"unravel this"	6.216
Communication skills	"open questions"	6.220
Intuition	"it's intuition"	7.247
Emotional discomfort	"start feeling oh my goodness"	7.247
Going no further	"not moving along"	7.251
Methodological	"methodological way of going thru"	8.260

FACTORS CONTRIBUTING TO CONFIDENCE/COMPETENCE

Time	"it has only come with time"	8.268
Training	"all came up in my training"	12.418
Experience	"I think practice"	12.431

DIFFICULTIES AND CHALLENGES OF BEING A CNS

Younger patients	"the young ones"	4.111

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Observation	"seeing how others work"	13.442

PRESENTATIONS AND SYMPTOMS

Non-cancer issues	"the other problems"	1.16
Family conflict	"bullied by this daughter"	1.23
Behavioural problems	"behaviour issues"	3.105
Treatment adherence	"making it difficult to treat"	3.106
Fertility issues	"won't be able to have kids"	4.145
Extreme distress	"very serious distress"	6.206

COPING WITH BEING A CNS

Colleague support	"I see my CNS colleagues"	3.81
Offloading	"let off steam a little"	3.82
Managerial support	"go to my line manager"	3.83

APPROACHING PSYCHOLOGICAL ISSUES WITH PATIENTS

Openness	"quite open"	8.289
Confidence	"no problems"	9.299
Individual	"look at each patient"	9.306
Reassurance	"takes a long time"	9.319

MISCELLANEOUS

Loss of control	“choices taken away”	10.333
Stigma	“think of madness”	10.336
Fear inducing	“something that is feared”	10.336

APPENDIX 38

TRANSCRIPT SEVEN: SUMMARY TABLE

(**Key** 3.85 refers to page 3, line 85)

HOPES REGARDING PSYCHOLOGY ROLE

Unknown	"I have no idea really"	3.85
Clinical consultation	"go to them and say I have this problem"	3.92
Team member	"intrinsic part of the team"	11.388
Separate	"also be separate"	11.389

WHAT PSYCHOLOGISTS DO

Improved coping	"get them to cope with it"	2.39
Psychological focus	"focus far more on the psychological"	2.59
Coping mechanisms	"give out different mechanisms for coping"	3.74
Unknown	"I don't know"	4.130
Acceptance	"face the fact"	4.141
Brief intervention	"need six weeks"	5.150

PECEIVED QUALITIES OF PSYCHOLOGISTS

Intellectual	"they are clever"	4.110

BELIEFS ABOUT PSYCHOLOGISTS

Positive	"it's good that they are there"	1.20
Expert	"an expert"	1.34
Impressive	"looks clever & has got a good title"	5.156
Acceptability	"they are not psychiatrists"	5.168
Unknown	"I don't know"	6.193

BEING A CLINICAL NURSE SPECIALIST

Professional autonomy	"get on with it"	1.13
Support	"give them lots of support"	1.15
Scope of role	"aren't even qualified to give the support"	1.19
Broad remit	"we have to focus on so much"	2.56
Sign posting	"I am really the sign-post"	10.344
Breaking bad news	"gives them all this bad news"	11.391
Holding confidence	"I don't share what patients say to me"	12.428

BELIFS ABOUT CNS

Unrealistic expectations	"drs think we can deal with everything"	6.193

ASSESSING PATIENTS FOR DISTRESS

Going no further	"what I have said is not working"	3.75
Emotional exploration	"ask them how they are feeling"	6.218
Time	"I would want to see them again"	8.292
Relationship	"my relationship with them"	9.297
Comparison over time	"haven't changed from the day I met them"	9.304
Instinct	"based on instinct really"	9.325

FACTORS CONTRIBUTING TO CONFIDENCE/COMPETENCE

Nurse training	"we covered an awful lot"	2.66
Experience	"learnt through experience"	14.482
Self-directed learning	"a lot of reading & learning"	14.483
ACST	"that was brilliant"	14.485
Observational learning	"especially watching them doing it badly"	14.499

APPROACHING PSYCHOLOGICAL ISSUES WITH PATIENTS

Reassurance	"they are quite comforted"	5.169
Confidence	"I would never be afraid of saying"	11.379
Language	"I don't tell pts they are going for counselling"	16.567

DIFFICULTIES AND CHALLENGES OF BEING A CNS

Palliative patients	"I am not skilled there at all"	9.329
Incurable at diagnosis	"I would seek help and advice"	10.335
Insufficient feedback	"we are never informed of deaths"	12.420
Lack of support	"we don't have any support at all"	13.445
Job insecurity	"CNSs are a position that's under threat"	13.447
Competitiveness	"great deal more competition in the group"	13.454
Pressure	"we aren't allowed to show weakness"	13.458
Lack of understanding	"management don't understand what we do"	13.459
Lack of time	"we are not given any protected time"	13.462

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Training	"I could do with a study day"	6.216
Education	"I want to do a masters module"	15.521
Observation	"useful to see an assessment being done"	15.540

PRESENTATIONS AND SYMPTOMS

Not coping	"people that can't cope"	3.98
Anxiety	"become extraordinarily anxious"	7.227
Requesting medication	"contemplating anti-depressants"	7.233
Frequent contact	"ring me up all the time"	7.246
Uncertainty	"managing the uncertainty"	8.273
Information seeking	"wanted to know statistics all the time"	8.278

COPING WITH BEING A CNS

Colleague support	"you can find other people in the group"	13.466

MISCELLANEOUS

Observational learning	"I've learnt through listening"	1.35

APPENDIX 39

TRANSCRIPT EIGHT: SUMMARY TABLE

(**Key** 7.240 refers to page 7, line 240)

HOPES REGARDING PSYCHOLOGY ROLE

Accessible	"not in an ivory tower"	7.240
Collaborative working	"it's about partnership"	8.261
MDT contribution	"go to the mdt meetings"	8.266
Separate	"independent from the team"	11.377
Feedback	"about what they are doing"	12.405
Clinical supervision	"well placed to offer some cs"	13.455

WHAT PSYCHOLOGISTS DO

Structured	"it's structured"	8.280
Time limited	"got 45 minutes"	8.281
Boundaries	"it's about setting parameters"	8.283
Relaxation techniques	"help you relax"	9.305
Emotional exploration	"exploring some of these feelings"	9.306

PERCEIVED QUALITIES OF PSYCHOLOGISTS

Training	"psychology degree or something"	10.356
Medical knowledge	"know about disease & treatments"	10.360
Academic	"fairly academic"	10.363

BELIEFS ABOUT PSYCHOLOGISTS

Positive	"can only be good for patients"	1.12
Threatening	"scared of them"	7.241
Negative	"there is a stigma"	7.245

BEING A CLINICAL NURSE SPECIALIST

Information giving	"cancer information"	1.20
Emotional support	"manage a lot of emotional distress"	1.29
Broad remit	"lots of other things too"	1.29
Knowledgeable	"need to be as informed"	1.30
Scope of role	"I am not a counsellor"	2.51
Co-ordination	"liasing with other HCP's"	3.88
Empowering staff	"it's about encouraging them"	6.221

BELIEFS ABOUT CNSs

Unrealistic expectations	"feel we are invincible"	14.483

ASSESSING PATIENTS FOR DISTRESS

Emotional discomfort	"struggling with this patient"	1.18
Instinct	"it's gut feeling"	2.46
Going no further	"going nowhere"	2.46
Patient request	"some want to see a counsellor"	2.51
Assessment questions	"the right questions"	4.140
Communication skills	"all those skills"	5.157
Discrepancy	"looking to see if it matches up"	5.164

FACTORS CONTRIBUTING TO CONFIDENCE/COMPETENCE

Professional experience	"comes with age & experience"	5.170
Education	"education, without a doubt"	5.180
Life experience	"more life experience"	6.190
Reflective learning	"learn for the next one"	9.327
Ongoing process	"ongoing learning"	9.328
Training	"diploma in cancer nursing"	15.528
Self directed learning	"only through my own direction"	15.546
Observational learning	"picking up those phrases"	16.583

APPROACHING PSYCHOLOGICAL ISSUES WITH PATIENTS

Persuasion	"I have to sell that referral"	8.292
Communication style	"you have to do it sensitively"	10.336

DIFFICULTIES AND CHALLENGES OFBEING A CNS

Expectations	"you will know all this stuff"	2.38
Budgetary restrictions	"won't put their money down"	12.415
Lack of time	"there is no protected time"	12.432
Emotional burden	"emotional burden that you take on"	12.433
Burn out	"you can just get burnt out"	12.436
Fear of judgment	"may be deemed less skilled"	13.477
Managing emotions	"no sluice to hide in"	14.499
Pressure	"sense of pressure"	14.502

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Feedback	"it's ongoing education really"	12.410
Observation	"watching a psych assess a pt"	16.575

PRESENTATIONS AND SYMPTOMS

Depression	“real depression”	2.72
Suicidal thoughts	“suicidal tendencies”	2.72
Mental health history	“history of depression”	3.81
Recent major life events	“recent bereavement”	3.83
Body image issues	“body image”	4.144
Anxiety	“signs of anxiety”	5.165

COPING WITH BEING A CNS

Peer support	“my colleagues”	12.430
Informal support	“had a little chat”	12.432
Clinical supervision	“helps people feel valued”	12.439

MISCELLANEOUS

Adjustment process	“response that is well documented”	3.109
Prioritisation of budget	“find the money for something”	12.416

APPENDIX 40

TRANSCRIPT NINE: SUMMARY TABLE

(**Key** 4.125 refers to page 4, line 125)

HOPES OF PSYCHOLOGY ROLE

Staff support	"supporting the staff"	4.125
Clinical supervision	"support as a team"	4.129
Flexible	"position in the team could be flexible"	6.187
Feedback	"good to have feedback"	13.451
MDT contribution	"MDT meetings"	13.471
Unknown	"I don't honestly know"	16.575

WHAT PSYCHOLOGISTS DO

In-depth	"delve far more"	1.36
Unknown	"I don't know"	11.392
Emotional exploration	"unpick things"	11.393
Improved coping	"coping strategies"	11.402
Instigate change	"if anything can be changed"	11.404

PERCEIVED QUALITIES OF PSYCHOLOGISTS

Training	"background in psychology"	2.45
Medical knowledge	"some sort of medical knowledge"	2.47

BELIEFS ABOUT PSYCHOLOGISTS

Positive	"good to have them"	1.20
Expert	"have that expertise"	1.27
Negative	"you think they are mad"	2.61
Helpful	"how useful it has been"	2.64

BEING A CLINICAL NURSE SPECIALIST

Knowing limits	"we should all know our limits"	1.28
Referring on	"refer them on"	1.29
Holding confidence	"I would never spread that"	5.185
Support	"use me as their support"	6.206
Scope of role	"I am not psychiatrically trained"	7.246
Ongoing input	"from diagnosis through to death"	13.462
MDT contribution	"something to contribute"	14.483

ASSESSING PATIENTS FOR DISTRESS

Patient insight	"he said..."	8.271
Communication skills	"listening skills"	8.281
Time	"after a couple of months"	8.294
Instinct	"gut feeling"	9.308
Shared responsibility	"shouldn't just be down to the nurse"	10.364

FACTORS CONTRIBUTING TO CONFIDENCE/COMPETENCE

Training	"in my training"	15.549
Role play	"really learnt from it"	16.555
Training	"3 day communication skills course"	16.558

APPROACHING PSYCHOLOGICAL ISSUES WITH PATIENTS

Confidence	"I would have no problem"	3.90
Communication style	"put it in a way"	3.107
Normalising	"you need to normalise it"	3.110

DIFFICULTIES AND CHALLENGES OF BEING A CNS

Lack of support	"nurses don't get support"	4.140
Limit of understanding	"they don't understand"	5.164
Limited resources	"very little out there to refer to"	6.204
Patient beliefs	"he should be coping"	9.298
Psych assessment	"sure there are patients I am missing"	10.359
Medical model	"medically led"	14.490
Managing unknown	"if you don't know..."	16.582

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Assessment tools	"could use it in my practice"	10.354
Feedback	"help me to decide about future referrals"	13.443
Observation	"good to see what a psych does"	16.574

PRESENTATIONS AND SYMPTOMS

Not coping	"really struggling"	2.55
Treatment issues	"struggling with chemotherapy"	3.93
Needle phobia	"needle phobia"	3.95
Adjustment issues	"struggling to come to terms"	6.202
Complex history	"has a lot of background"	7.225
Anxiety	"he's on the phone, he has got pain"	7.251
Frequency of contact	"excessive phone calls"	11.381

COPING WITH BEING A CNS

Clinical supervision	“felt very supported”	4.138
Boundaries	“it is very separate”	4.144
Peer support	“I use colleagues”	5.165

APPENDIX 41

TRANSCRIPT TEN: SUMMARY TABLE

(**Key** 1.35 refers to page 1, line 35)

HOPES REGARDING PSYCHOLOGY ROLE

Aid understanding	"your not likely to change it"	1.35
Clinical supervision	"how we manage this situation"	2.58
Clinical consultation	"talk about this situation"	3.88
MDT contribution	"attendance at MD meetings"	4.142
Separate	"not part of management structure"	5.152
Feedback	"want to know"	11.396
Uncertain	"not certain"	12.407

WHAT PSYCHOLOGISTS DO

Adjustment	"somebody has to get used to"	3.106
Unknown	"my lack of knowledge"	6.200
Instigate change	"change the way their mind reacts"	6.203
Structured	"much more structured"	6.204

PERCEIVED QUALITIES OF PSYCHOLOIGISTS

Non-medical	"not medically minded"	1.14
Unknown	"I am not really sure"	2.67

BELIEFS ABOUT PSYCHOLOGISTS

Positive	"really useful"	1.13
Threatening	"I might be a bit jealous"	3.90
	"this is part of what I do"	3.92
Acceptability	"more acceptable than psychiatry"	10.356
Generational	"generational thing really"	11.369
Undervalued	"not prestigious or valued"	11.388

BEING A CLINICAL NURSE SPECIALIST

Emotional support	"emotions are very intense"	3.84
Managing limited time	"dealing with short time scales"	4.126
Symptom control	"analgesic ladders"	6.205
Scope of role	"I don't have that knowledge"	6.207
Respect choices	"respectful of people's coping style"	7.231
Systemic support	"families"	7.231

ASSESSING PATIENTS FOR DISTRESS

Info gathering	"you get clues"	6.187
Instinct	"it is a gut feeling"	6.193
Communication skills	"hold up a mirror"	7.222
Patient insight	"they will usually tell you"	9.300

FACTORS CONTRIBUTING TO CONFIDENCE/COMPETENCE

Time	"over the years"	6.220
Personal motivation	"I wanted to try & learn"	12.418
Education	"care of the dying course"	12.421
	"palliative care degrees"	13.449
Experience	"hospice experience"	12.425
Experiential learning	"do it yourself in practice"	12.431
Observational learning	"seen it done by someone else"	12.433

DIFFICULTIES AND CHALLENGES OF BEING A CNS

Multi professional working	"how we related"	2.47
Normalising distress	"you're going to be sad"	9.316
Staff resistance	"hard to get people to realise"	9.324
Over prescribing	"throwing citalapram at every pt"	10.346

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Assess tools	"gives permission to talk"	9.308
External placement	"a month in another hospital"	13.464
Observation	"learn so much by just seeing"	13.467

PRESENTATIONS AND SYMPTOMS

Key point	"newly diagnosed"	3.105
Adjustment issues	"completely paralysed"	5.177
Past issues	"happened previously"	5.180
Complex issues	"something deep & dark happening"	5.182
Depression	"completely black sky"	9.324

COPING WITH BEING A CNS

Clinical supervision	"managing the chaos"	1.20
Death of patient	"person is going to die"	8.271
Boundaries	"it is never a personal relationship"	8.281

APPROACHING PSYCHOLOGICAL ISSUES WITH PATIENTS

Language	“may not put it in the words”	10.357

MISCELLANEOUS

Anti-depressants	“pharmacological management”	9.317

APPENDIX 42

TRANSCRIPT ONE: MERGED & RENAMED THEMES

(**Key:** new theme titles are shown in brackets and italic type, whilst 21.741 refers to page 21, line 741)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

Negative	*(fear/threat)*	"has a label attached"	21.741
Variations	*(generational)*	"younger generation"	21.749
Acceptability	*(acceptability)*	"less of a stigma"	22.790
Undefined	*(inaccessible)*	"hasn't shown pictures"	22.791
Unknown	*(inaccessible)*	"they are not sure"	22.805

BELIEFS ABOUT THE ROLE

Emotional exploration	*(emotional exploration)*	"a step further"	13.467
Psych movement	*(effecting psych change)*	"move that patient on"	13.471
Solution focused	*(structured approach)*	"about solutions"	13.475
Unknown	*(secretive/mysterious)*	"I don't know"	14.480
Facilitate change	*(effecting psych change)*	"changing their behaviour"	14.484
Directive	*(structured approach)*	"lead me"	14.486
Positive thinking	*(structured approach)*	"positive route"	14.487

HOPES AND EXPECTATIONS

Clinical consultation	*(clinical consultation)*	"talk through a patient"	2.53
Collaborative working	*(multi-disciplinary working)*	"working with"	2.59
Professional support	*(support)*	"support us"	2.66
Clinical supervision	*(support)*	"clinical supervision"	4.119
Feedback	*(communication/feedback)*	"come back to me"	12.432
Clinical recommendations	*(clinical consultation)*	"anything I could be doing"	13.451
Availability	*(availability)*	"there and then"	3.92
Unknown	*(unknowns)*	"inexperience of what a p does"	13.455

PERCEIVED QUALITIES

Superior skills	*(knowledge)*	"something extra"	4.123
Specialist knowledge	*(knowledge)*	"understand people's behaviour"	4.128
Training	*(specialist training)*	"having the training"	13.467
Unknown	*(specialist training)*	"no idea what training"	25.920

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Knowing limits	*(knowing limits)*	"hand someone on"	2.57
Psych assessment	*(having knowledge)*	"defining what's normal"	5.151
Offering time	*(managing time)*	"let people have time"	7.247
Emotional understanding	*(offering support)*	"understand whole process"	7.249
Managing difficult qstns	*(offering support)*	"am I dying?"	8.257
Scope of role	*(knowing limits)*	"not trained in that"	13.474

DIFFICULTIES AND CHALLENGES OF BEING A CNS

Emotional discomfort	*(working with death)*	"tolerating silence"	7.232
Human instinct vs professional responsibility		"want to jump in"	7.241
Depression vs realistic sadness	*(understanding)*	"such a fine line"	10. 351
Lack of understanding	*(understanding)*	"get it mixed up"	10.343
Lack of control/influence	*(team working)*	"not under our care"	14.513
Sudden endings	*(time pressure)*	"time stopped"	14.511
Insufficient feedback	*(team working)*	"not enough"	17.606
Managing unknowns	*(understanding)*	"I don't know"	19.670
Perceptions of role	*(expectations)*	"tough going"	20.727

COPING WITH BEING A CNS

Work/life boundaries	*(boundaries)*	"cut off point"	17. 596
Time boundaries	*(boundaries)*	"5pm and I'm out"	23.838

WAYS OF ASSESSING FOR DISTRESS

Empathic understanding	*(style/approach)*	"where they are coming from"	5.176
Emotional exploration	*(style/approach)*	"unwrap it"	5.179
Communication skills	*(communication skills)*	"it's communication skills"	8.281
Intuition	*(intuition)*	"gut feeling"	11.394
Physical manifestation	*(style/approach)*	"what they are doing"	11.401
Sense of discrepancy	*(style/approach)*	"doesn't add up"	12.408
Discomfort	*(emotional discomfort)*	"wasn't happy"	12.420
Instinctive	*(style/approach)*	"second nature"	14.496
Information gathering	*(style/approach)*	"pick up clues"	14.496
Initial impressions	*(time)*	"first time"	14.502

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

Honesty	*(confidence)*	"extremely honest"	21.757
Openness	*(awareness of language)*	"just be open"	21.763
Clarification	*(awareness of language)*	"dispel those myths"	22.774

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

Experience	*(experience)*	"from experience"	5.158
Personal ability	*(experience)*	"I'm very astute"	5.174
Reflective practice	*(reflective practice)*	"learning from mistakes"	15.537
Experiential learning	*(experience)*	"learn on the job"	15.526
Mentorship	*(colleagues)*	"asking my mentors"	15.528
Observational learning	*(colleagues)*	"I wouldn't do that"	15.535
Ongoing process	*(reflective practice)*	"continuously learning"	15.535
Peer support	*(colleagues)*	"talk it through"	15.544
Training	*(training)*	"a refresher course"	16.557

PRESENTATION OF SYMPTOMS

Absence of psychological connection	*(depression)*	"can't get through"	9.321
Loss of motivation	*(depression)*	"choosing not to"	12. 417

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Screening tools	*(skills/knowledge)*	"depression scales"	10.348
Observation	*(understanding role)*	"see how they work"	13.456
Understanding	*(understanding role)*	"present a patient"	17.625

APPENDIX 43

TRANSCRIPT TWO: MERGED & RENAMED THEMES

(**Key:** new theme titles are shown in brackets and italic type, whilst 12.432 refers to page 12, line 432)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

Helpful	*(open/positive)*	"help them"	12.432
Secretive	*(fear/threat)*	"feels secretive"	12.449
Unknown	*(fear/threat)*	"bit of a myth"	12.444
Positive	*(open/positive)*	"it is positive"	14.500
Acceptability	*(acceptability)*	"more stigma with psych"	14.520

BELIEFS ABOUT THE ROLE

Improved coping	*(effecting psych change)*	"help people to cope"	5.173
Structured interventions	*(structured approach)*	"CBT"	5.171
Unknown	*(secretive/mysterious)*	"don't....know"	12.448

HOPES AND EXPECTATIONS

Aid understanding	*(multi-disciplinary working)*	"make some sense"	1.30
MDT contribution	*(multi-disciplinary working)*	"add anything"	2.43
Clinical consultation	*(clinical consultation)*	"talk to them"	2.46
Accessibility	*(availability)*	"need to know"	2.55
Collaborative working	*(multi-disciplinary working)*	"two way thing"	2.67
Clinical recommendations	*(clinical consultation)*	"try and do this"	2.71
Clinical supervision	*(support)*	"clinical supervision"	3.78
Separate	*(professional position)*	"not part of the team"	13.454
Unknown	*(unknowns)*	"don't really know"	13.457
Feedback	*(communication/feedback)*	"information... passed on"	15.535

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Time	*(managing time)*	"have the time"	1.25
Scope of role	*(knowing limits)*	"we are not psychologists"	5.176
Systemic support	*(offering support)*	"families"	7.258
Gate keeping	*(having knowledge)*	"gate keep"	8.283
Symptom management	*(having knowledge)*	"neuropathic pain"	9.329
Professional autonomy	*(independent working)*	"own devices"	11.405
Negotiation	*(independent working)*	"negotiation job"	16.590

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

Limited time	*(time pressure)*	"don't have time"	6.203
Time pressure	*(time pressure)*	"quickly"	7.247
Responsibility	*(expectations)*	"get it right"	7.254
Depression vs dying	*(understanding)*	"quite difficult"	8.300
Realistic sadness	*(understanding)*	"normal"	9.309
Lack of support	*(lack of support)*	"no one to help you"	11.387
Screening tools	*(expectations)*	"pushed into it"	10.364
Timing	*(time pressure)*	"time has run out"	7.262

COPING WITH BEING A CNS

Team debrief	*(colleague support)*	"we will talk"	11.391
Work/life boundary	*(boundaries)*	"leave it"	11.393
MDT discussion	*(colleague support)*	"we can talk"	11.399

WAYS OF ASSESSING FOR DISTRESS

Patient motivation	*(role of others)*	"wanted to talk"	4.151
Not coping	*(emotional discomfort)*	"I couldn't cope"	5.158
Emotional discomfort	*(emotional discomfort)*	"freaked me out"	5.159
Screening questions	*(style/approach)*	"HADS questions"	6.221
Emotional exploration	*(style/approach)*	"open it up"	6.225
Wider input	*(role of others)*	"bring in other people"	7.234
Comparison over time	*(time)*	"same as they were before"	7.238
Capacity	*(role of others)*	"need to be able"	8.270
Patient insight	*(role of others)*	"patients themselves"	10.352
Single question	*(style/approach)*	"are you depressed"	10.354
Joint assessment	*(role of others)*	"see someone together"	11.406

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

Communication style	*(awareness of language)*	"the way"	6.200
Confidence	*(confidence)*	"quite comfortable"	6.194

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

Training	*(training)*	"ACST course"	15.549
Experience	*(experience)*	"experience"	16.583

SIGNS OF DISTRESS

Complex issues	*(complex issues)*	"complex issues"	2.69
Adjustment issues	*(adjustment/coping issues)*	"couldn't process that"	4.148

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Understanding	*(understanding role)*	"knew a bit more"	13.476
Observation	*(understanding role)*	"shadowing"	14.491
Professional transparency	*(understanding role)*	"more open"	14.494
Education	*(skills/knowledge)*	"need to learn"	16.598

APPENDIX 44

TRANSCRIPT THREE: MERGED & RENAMED THEMES

(**Key:** new theme titles are shown in brackets and italic type, whilst 14.501 refers to page 14, line 501)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

Generational	*(generational)*	"older people"	14.501
Positive	*(open/positive)*	"very popular"	14.504

BELIEFS ABOUT THE ROLE

Techniques	*(structured approach)*	"mind maps"	4.122
Emotional exploration	*(emotional exploration)*	"exploring"	4.144

HOPES AND EXPECTATIONS

Team member	*(professional position)*	"part of the team"	5.163
Staff support	*(professional support)*	"support for staff"	5.181
Information sharing	*(multi-disciplinary working)*	"telling them"	17.613
Feedback	*(communication/feedback)*	"feedback to us"	17.615

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Support	*(offering support)*	"initial support"	1.15
Coordination	*(independent working)*	"liaising"	3.97
Scope of role	*(knowing limits)*	"not trained in that"	3.105
Treatment focus	*(having knowledge)*	"specialist knowledge"	4.128
Broad remit	*(independent working)*	"cover the whole aspect"	4.137
Check understanding	*(information sharing)*	"have they understood"	8.274
Information giving	*(information sharing)*	"going over things"	8.279
Breaking bad news	(information sharing)	"give results"	15.553
Ongoing input	*(managing time)*	"all the way through"	16.590

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

Workload	*(expectations)*	"a lot of work"	2.38

COPING WITH BEING A CNS

Colleague support	*(colleague support)*	"it helps me"	6.224
Offloading	*(colleague support)*	"we offload"	7.237
Peer support	*(colleague support)*	"collective support"	7.243

WAYS OF ASSESSING FOR DISTRESS

Intuition	*(intuition)*	"pick up a sense"	2.65
Initial impression	*(time)*	"initial meeting"	2.73
Screening tools	*(style/approach)*	"got their place"	3.79
Going no further	*(feeling stuck)*	"gone as far..."	3.102
Communication skills	*(communication skills)*	"communication skills"	9.303
Rapport	*(style/approach)*	"build the relationship"	9.311
Ongoing	*(time)*	"ongoing assessment"	9.333
Giving time	*(time)*	"give people the time"	9.339
Patient request	*(role of others)*	"can you refer me?"	17.636

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

Individual	*(awareness of language)*	"that patient"	12.434
Confidence	*(confidence)*	"wouldn't have a problem"	12.438

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

Experience	*(experience)*	"experience is really central"	3.87
Training	*(training)*	"nurse training"	14.526
Education	*(training)*	"taught"	14.527
Observational learning	*(colleagues)*	"watching people"	15.557
Experiential learning	*(experience)*	"just doing it"	15.559
Reflective practice	*(reflective practice)*	"reflecting back"	15.559

SIGNS OF DISTRESS

Past issues	*(complex issues)*	"issues from the past"	2.45
Body image issues	*(treatment issues)*	"body image"	2.47
Multiple issues	*(complex issues)*	"a lot of issues"	4.142
Fertility issues	*(treatment issues)*	"pregnancy"	10.356
Relationship issues	*(family/relationship)*	"marital problems"	10.361
Not coping	*(adjustment/coping)*	"not coping"	11.382
Depression	*(depression)*	"depressive symptoms"	11.396
Treatment adherence	*(treatment issues)*	"not have treatment"	11.404
Critical point in pathway	*(key point in pathway)*	"treatment is finished"	13.476

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Observation	*(understanding role)*	"see what you do"	17.622

APPENDIX 45

TRANSCRIPT FOUR: MERGED & RENAMED THEMES

(**Key:** new theme titles are shown in brackets and italic type, whilst 15.521 refers to page 15, line 521)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

Acceptability	*(acceptability)*	“carry less stigma”	15.521
Helpful	*(open/positive)*	“helped enormously”	6.209

BELIEFS ABOUT THE ROLE

In-depth	*(emotional exploration)*	“root of the problem”	11.403
Techniques	*(structured approach)*	“visualisation, hypnotherap	13.446

PERCEIVED QUALITIES

Training	*(specialist training)*	“trained for that purpose”	13.459
Complex skills	*(knowledge)*	“more complex”	12.416

HOPES AND EXPECTATIONS

Clinical consultation	*(clinical consultation)*	“source of advice”	3.105
Professional support	*(support)*	“support to the CNS”	3.107
Clinical supervision	*(support)*	“offer supervision”	4.133

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Scope of role	*(knowing limits)*	“can’t do everything”	1.12
Ongoing input	*(managing time)*	“no end”	1.14
Broad remit	*(independent working)*	“pretty huge job”	5.167
Systemic support	*(offering support)*	“wives, husbands....”	6.201
Emotional containment	*(offering support)*	“having a presence”	8.271
Offering time	*(managing time)*	“giving the time”	8.281

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

Supporting children	*(lack of support)*	“really difficult”	4.117
Isolation	*(team working)*	“only 2 in the hospital”	5.164
Lack of support	*(lack of support)*	“nobody to go to”	5.173
Managing denial	*(working with death)*	“difficult to deal with”	7.226
Listening	*(working with death)*	“listening can be really hard”	8.264
Expectations	*(expectations)*	“have to be seen to be doing”	8.272
Collusion	*(working with death)*	“still not know it’s cancer”	10.358

COPING WITH BEING A CNS

Colleague support	*(colleague support)*	"go to them"	5.170
Referring on	*(colleague support)*	"weight off your shoulders"	14.487

WAYS OF ASSESSING FOR DISTRESS

Emotional discomfort	*(emotional discomfort)*	"being so helpless"	6.203
Stopped helping	*(feeling stuck)*	"not helping her anymore"	7.253
Communication skills	*(communication skills)*	"listening skills"	8.260
Discrepancy	*(style/approach)*	"lying in bed"	8.295
Intuition	*(intuition)*	"gut instinct"	9.327
Time	*(time)*	"over time"	9.326

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

Confidence	*(confidence)*	"feel pretty confident"	14.504
Communication skills	*(awareness of language)*	"way we put it across"	14.514

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

Observational learning	*(colleagues)*	"watching colleagues"	11.385
Peers	*(colleagues)*	"working with colleagues"	11.386
Training	*(training)*	"role-play"	15.548
Professional experience	*(experience)*	"what you learn on the wards"	16.550
Personal experience	*(experience)*	"life experience"	16.564
Time	*(experience)*	"comes with time"	16.564

SIGNS OF DISTRESS

Critical point in pathway	*(key point in pathway)*	"coping with diagnosis"	1.27
Treatment issues	*(treatment issues)*	"side effects"	1.28
Carers	*(family/relationships)*	"relatives"	1.30
Depression	*(depression)*	"dark cloud "	2.41
Treatment adherence	*(treatment issues)*	"staying motivated"	3.84
Total pain	*(complex issues)*	"complete mental anguish"	3.95
Loss of control	*(family/relationship)*	"completely out of control"	6.197
Not coping	*(adjustment/coping)*	"they are not coping"	7.247
Sudden diagnosis	*(key point in pathway)*	"3 days later...."	2.53

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Clinical supervision	*(skills/knowledge)*	"a way to learn & reflect"	11.390
Observation	*(understanding role)*	"useful to be able to see it"	16.583

APPENDIX 46

TRANSCRIPT FIVE: MERGED & RENAMED THEMES

(Key: new theme titles are shown in brackets and italic type, whilst 1.20 refers to page 1, line 20)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

Helpful	*(open/positive)*	"useful for the patients"	1.20
Acceptability	*(acceptability)*	"psychiatrist is a different matter"	7.256
Unknown	*(inaccessible)*	"public don't have any perception"	8.260

BELIEFS ABOUT THE ROLE

Improved coping	*(effecting psych change)*	"coping better"	5.181
Structured interventions	*(structured approach)*	"structured coping mechanisms"	6.196
Unknown	*(secretive/mysterious)*	"I don't know much"	7.223

PERCEIVED QUALITIES

Training	*(specialist training)*	"cbt training"	2.58
Medical knowledge	*(knowledge)*	"illness and treatment"	2.66
Specialist knowledge	*(knowledge)*	"a different level"	16.577

HOPES AND EXPECTATIONS

Joint working	*(multi-disciplinary workin*	"worked together"	1.27
Team member	*(professional position)*	"part of the team"	3.76
Availability	*(availability)*	"seen fairly promptly"	3.83
Professional support	*(professional support)*	"clinical support"	3.89
Accessibility	*(availability)*	"at the end of the phone"	3.110
Feedback	*(communication/ feedback)*	"being kept in the loop "	8.284
Clinical recommendations	*(clinical consultation)*	"any way that I can be involved"	8.283

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Scope of role	*(knowing limits)*	"I am not a counsellor"	1.17
Broad remit	*(independent working)*	"mine is a very general training"	2.47
Emotional support	*(offering support)*	"emotional support"	2.51
Communicating	*(information sharing)*	"give that background"	2.69
Flexibility	*(independent working)*	"very flexible"	10.343
Information giving	*(information sharing)*	"so much information to give"	10.349
Multi-skilled	*(independent working)*	"all those skills"	13.447

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

Budgetary restrictions	*(lack of support)*	"never on the budget"	1.32
Limited resources	*(lack of support)*	"very little out there"	8.270
Insufficient feedback	*(team working)*	"don't get any feedback"	8.272
Team communication	*(team working)*	"so many people to keep in the loop"	9.299
Limited time	*(time pressure)*	"don't have much time"	10.348
Patient expectations	(expectations)	"patient's expect to be seen tmw"	12.417
Screening tools	(expectations)	"it's clinical governance.."	13.476
Failing	(expectations)	"when you get it wrong it's awful"	15.519
Team working	*(team working)*	"working as a team is not easy"	16.588
Peer resistance	*(team working)*	"people see barriers"	17.598

COPING WITH BEING A CNS

Clinical supervision	*(colleague support)*	"helping to deal with all the issues"	1.36
Peer support	*(colleague support)*	"other people come up with ways..."	4.113
Boundaries	*(boundaries)*	"I very much compartmentalise"	4.121
Referring on	*(colleague support)*	"comforting to know"	9.307

WAYS OF ASSESSING FOR DISTRESS

Patient insight	*(role of others)*	"they tell you"	6.188
Single screening question	*(style/approach)*	"asking the question"	6.197
Patient motivation	*(role of others)*	"prepared to do something"	6.204
Self-selection	*(role of others)*	"they self-select"	6.210
Communication style	*(communication skills)*	"the way you put it"	6.211
Patient request	*(role of others)*	"I want to be referred"	8.264
Intuition	*(intuition)*	"it is intuition"	10.357
Communication skills	*(communication skills)*	"listening, watching & silence"	11.370
Time	*(time)*	"take it slowly"	11.374
Individual	*(style/approach)*	"tailor it to the person"	11.376
Patient responsibility	*(role of others)*	"they have to take responsibility"	11.384

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

Confidence	*(confidence)*	"I broach a lot of topics"	7.239
Communication style	*(awareness of language)*	"it's how you introduce it"	7.252

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

Ongoing process	*(reflective practice)*	"I'm still learning"	11.396
Experience	*(experience)*	"a lot of experience"	11.400
Training	*(training)*	"role-play is very valuable"	14.497
Peer support	*(colleagues)*	"biggest learning tool"	14.513
Reflective practice	*(reflective practice)*	"constantly reviewing & reflecting"	15.517

SIGNS OF DISTRESS

Key point in pathway	*(key point in pathway)*	"shocked at diagnosis"	5.169
Not coping	*(adjustment/coping)*	"just aren't coping"	5.174
Adjustment problems	*(adjustment/coping)*	"hasn't been able to go out'	5.178

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Understanding	*(understanding role)*	"I need more clarity"	7.231
Professional support	*(skills/knowledge)*	"ongoing clinical support"	15.529
Observation	*(understanding role)*	"possibly observing"	15.540
Education	*(understanding role)*	"educating the whole team"	15.549

APPENDIX 47

TRANSCRIPT SIX: MERGED & RENAMED THEMES

(**Key:** new theme titles are shown in brackets and italic type, whilst 9.314 refers to page 9, line 314)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

Confusion	*(threat/fear)*	"patients get confused"	9.314
Negative	*(threat/fear)*	"so think I am mad"	9.317
Unknown	*(inaccessible)*	"more of an unknown"	10.345

BELIEFS ABOUT ROLE

Techniques	*(structure approach)*	"giving people techniques"	10.351
Improved coping	*(effecting psych change)*	"helping people to cope"	10.352
Structured interventions	*(structured approach)*	"cbt"	10.365
Unknown	*(secretive/mysterious)*	"bit out of my understanding"	10.368

PERCEIVED QUALITIES

Specialist knowledge	*(knowledge)*	"greater understanding"	10.354
Training	*(specialist training)*	"degree plus 3 years"	11.372
Medical knowledge	*(knowledge)*	"understand disease process"	11.380

HOPES AND EXPECTATIONS

Accessibility	*(availability)*	"being able to access them"	2.49
Clinical consultation	*(clinical consultation)*	"tap into their knowledge"	2.50
Team member	*(professional position)*	"part of the mdt"	2.54
Availability	*(availability)*	"available on a Thursday.."	2.59
MDT contribution	*(multi-disciplinary working)*	"contribute their views"	2.73
Professional support	*(professional support)*	"staff support"	3.78
Unknown	*(unknowns)*	"not sure about the details"	3.92
Feedback	*(communication/feedback)*	"helpful to know"	13.456

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Offering time	*(offering time)*	"I make myself available"	7.235

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

Younger patients	*(working with death)*	"the young ones"	4.111

COPING WITH BEING A CNS

Colleague support	*(colleague support)*	“I see my CNS colleagues”	3.81
Offloading	*(colleague support)*	“let off steam a little”	3.82
Managerial support	*(colleague support)*	“go to my line manager”	3.83

WAYS OF ASSESSING FOR DISTRESS

Time	*(time)*	“need to give it some time”	6.208
Emotional exploration	*(style/approach)*	“unravel this”	6.216
Communication skills	*(communication skills)*	“open questions”	6.220
Intuition	*(intuition)*	“it’s intuition”	7.247
Emotional discomfort	*(emotional discomfort)*	“start feeling oh my goodness”	7.247
Going no further	*(feeling stuck)*	“not moving along”	7.251
Methodological	*(style/approach)*	“methodological way of going thru”	8.260
Time	*(time)*	“it has only come with time”	8.268

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

Openness	*(awareness of language)*	“quite open”	8.289
Confidence	*(confidence)*	“no problems”	9.299
Reassurance	*(awareness of language)*	“takes a long time”	9.319

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

Training	*(training)*	“all came up in my training”	12.418
Experience	*(experience)*	“I think practice”	12.431

SIGNS OF DISTRESS

Non-cancer issues	*(complex issues)*	“the other problems”	1.16
Family conflict	*(family/relationship)*	“bullied by this daughter”	1.23
Behavioural problems	*(treatment issues)*	“behaviour issues”	3.105
Treatment adherence	*(treatment issues)*	“making it difficult to treat”	3.106
Fertility issues	*(treatment issues)*	“won’t be able to have kids’	4.145
Extreme distress	*(complex issues)*	“very serious distress”	6.206

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Observation	*(understanding role)*	“seeing how others work”	13.442

APPENDIX 48

TRANSCRIPT SEVEN: MERGED & RENAMED THEME

(Key: new theme titles are shown in brackets and italic type, whilst 1.20 refers to page 1, line 20)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

Positive	*(open/positive)*	"it's good that they are there"	1.20
Expert	*(open/positive)*	"an expert"	1.34
Impressive	*(open/positive)*	"looks clever & has got a good title"	5.156
Acceptability	*(acceptability)*	"they are not psychiatrists"	5.168
Unknown	*(inaccessible)*	"I don't know"	6.193

BELIEFS ABOUT THE ROLE

Improved coping	*(effecting psych change)*	"get them to cope with it"	2.39
Psychological focus	*(effecting psych change)*	"focus far more on the psychological"	2.59
Coping mechanisms	*(structured approach)*	"different mechanisms for coping"	3.74
Unknown	*(secretive/mysterious)*	"I don't know"	4.130
Acceptance	*(effecting psych change)*	"face the fact"	4.141
Brief intervention	*(structured approach)*	"need six weeks"	5.150

PERCEIVED QUALITIES

Intellectual	*(knowledge)*	"they are clever"	4.110

HOPES AND EXPECTATIONS

Unknown	*(unknowns)*	"I have no idea really"	3.85
Clinical consultation	*(clinical consultation)*	"go to them and say I have this problem"	3.92
Team member	*(professional position)*	"intrinsic part of the team"	11.388
Separate	*(professional position)*	"also be separate"	11.389

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Professional autonomy	*(independent working)*	"get on with it"	1.13
Support	*(offering support)*	"give them lots of support"	1.15
Scope of role	*(knowing limits)*	"aren't even qualified to give the support"	1.19
Broad remit	*(independent working)*	"we have to focus on so much"	2.56
Sign posting	(independent working)	"I am really the sign-post"	10.344
Breaking bad news	*(information sharing)*	"gives them all this bad news"	11.391
Holding confidence	*(having knowledge)*	"I don't share what patients say to me"	12.428

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

Palliative patients	*(working with death)*	"I am not skilled there at all"	9.329
Incurable at diagnosis	*(working with death)*	"I would seek help and advice"	10.335
Insufficient feedback	*(team working)*	"we are never informed of deaths"	12.420
Lack of support	*(lack of support)*	"we don't have any support at all"	13.445
Job insecurity	*(lack of support)*	"CNSs are a position that's under threat"	13.447
Competitiveness	*(team working)*	"great deal more competition in the group"	13.454
Pressure	*(expectations)*	"we aren't allowed to show weakness"	13.458
Lack of understanding	*(understanding)*	"management don't understand what we do"	13.459
Lack of time	*(time pressure)*	"we are not given any protected time"	13.462

COPING WITH BEING A CNS

Colleague support	*(colleague support)*	"other people in the group"	13.466

WAYS OF ASSESSING FOR DISTRESS

Going no further	*(feeling stuck)*	"what I have said is not working"	3.75
Emotional exploration	*(style/approach)*	"ask them how they are feeling"	6.218
Time	*(time)*	"I would want to see them again"	8.292
Relationship	*(style/approach)*	"my relationship with them"	9.297
Comparison over time	*(time)*	"haven't changed from the day I met them"	9.304
Instinct	*(intuition)*	"based on instinct really"	9.325

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

Reassurance	*(awareness of language)*	"they are quite comforted"	5.169
Confidence	*(confidence)*	"I would never be afraid of saying"	11.379
Language	*(awareness of language)*	"I don't tell pts they are going for counselling"	16.567

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

Nurse training	*(training)*	"we covered an awful lot"	2.66
Experience	*(experience)*	"learnt through experience"	14.482
Self-directed learning	*(training)*	"a lot of reading & learning"	14.483
ACST	*(training)*	"that was brilliant"	14.485
Observational learning	*(colleagues)*	"especially watching them doing it badly"	14.499

SIGNS OF DISTRESS

Not coping	*(adjustment/coping)*	"people that can't cope"	3.98
Anxiety	*(anxiety)*	"become extraordinarily anxious"	7.227
Requesting medication	*(depression)*	"contemplating anti-depressants"	7.233
Frequent contact	*(anxiety)*	"ring me up all the time"	7.246
Uncertainty	*(anxiety)*	"managing the uncertainty"	8.273
Information seeking	*(anxiety)*	"wanted to know statistics all the time"	8.278

IMPROVING PSYCHOLOGICAL CARE FOR PATIENTS

Training	*(understanding role)*	"I could do with a study day"	6.216
Education	*(skills/knowledge)*	"I want to do a masters module"	15.521
Observation	*(understanding role)*	"useful to see an assessment being done"	15.540

APPENDIX 49

TRANSCRIPT EIGHT: MERGED & RENAMED THEMES

(Key: new theme titles are shown in brackets and italic type, whilst 1.12 refers to page 1, line 12)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

Positive	*(open/positive)*	"can only be good for patients"	1.12
Threatening	*(fear/threat)*	"scared of them"	7.241
Negative	*(fear/threat)*	"there is a stigma"	7.245

BELIEFS ABOUT THE ROLE

Structured	*(structured approach)*	"it's structured"	8.280
Time limited	*(structured approach)*	"got 45 minutes"	8.281
Boundaries	*(structured approach)*	"it's about setting parameters"	8.283
Relaxation techniques	*(structured approach)*	"help you relax"	9.305
Emotional exploration	*(emotional exploration)*	"exploring some of these feelings"	9.306

PERCEIVED QUALITIES

Training	*(specialist training)*	"psychology degree or something"	10.356
Medical knowledge	*(knowledge)*	"know about disease & treatments"	10.360
Academic	*(knowledge)*	"fairly academic"	10.363

HOPES AND EXPECTATIONS

Accessible	*(availability)*	"not in an ivory tower"	7.240
Collaborative working	*(multi-disciplinary working)*	"it's about partnership"	8.261
MDT contribution	*(multi-disciplinary working)*	"go to the mdt meetings"	8.266
Separate	*(professional position)*	"independent from the team"	11.377
Feedback	*(communication/feedback)*	"about what they are doing"	12.405
Clinical supervision	*(professional support)*	"well placed to offer some clinical supervision"	13.455

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Information giving	*(information sharing)*	“cancer information”	1.20
Emotional support	*(offering support)*	“manage a lot of emotional distress”	1.29
Broad remit	*(independent working)*	“lots of other things too”	1.29
Knowledgeable	*(having knowledge)*	“need to be as informed”	1.30
Scope of role	*(knowing limits)*	“I am not a counsellor”	2.51
Co-ordination	*(independent working)*	“liaising with other HCP's”	3.88
Empowering staff	*(offering support)*	“it's about encouraging them”	6.221

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

Expectations	*(expectations)*	“you will know all this stuff”	2.38
Budgetary restrictions	*(lack of support)*	“won't put their money down”	12.415
Lack of time	*(time pressure)*	“there is no protected time”	12.432
Emotional burden	*(working with death)*	“emotional burden that you take on”	12.433
Burn out	*(working with death)*	“you can just get burnt out”	12.436
Fear of judgment	*(expectations)*	“may be deemed less skilled”	13.477
Managing emotions	*(expectations)*	“no sluice to hide in”	14.499
Pressure	*(expectations)*	“sense of pressure”	14.502
Unrealistic expectations	*(expectations)*	“feel we are invincible”	14.483

COPING WITH BEING A CNS

Peer support	*(colleague support)*	“my colleagues”	12.430
Informal support	*(colleague support)*	“had a little chat”	12.432
Clinical supervision	*(colleague support)*	“helps people feel valued”	12.439

WAYS OF ASSESSING FOR DISTRESS

Emotional discomfort	*(emotional discomfort)*	“struggling with this patient’	1.18
Instinct	*(intuition)*	“it's gut feeling”	2.46
Going no further	*(feeling stuck)*	“going nowhere”	2.46
Patient request	*(role of others)*	“some want to see a counsellor”	2.51
Assessment questions	*(style/approach)*	“the right questions”	4.140
Communication skills	*(communication skills)*	“all those skills”	5.157
Discrepancy	*(style/approach)*	“looking to see if it matches up”	5.164

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

Persuasion	*(awareness of language)*	“I have to sell that referral”	8.292
Communication style	*(awareness of language)*	“you have to do it sensitively”	10.336

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

Professional experience	*(experience)*	"comes with age & experience"	5.170
Education	*(training)*	"education, without a doubt"	5.180
Life experience	*(experience)*	"more life experience"	6.190
Reflective learning	*(reflective practice)*	"learn for the next one"	9.327
Ongoing process	*(reflective practice)*	"ongoing learning"	9.328
Training	*(training)*	"diploma in cancer nursing"	15.528
Self directed learning	*(training)*	"only through my own direction"	15.546
Observational learning	*(colleagues)*	"picking up those phrases"	16.583

SIGNS OF DISTRESS

Depression	*(depression)*	"real depression"	2.72
Suicidal thoughts	*(depression)*	"suicidal tendencies"	2.72
Mental health history	*(complex issues)*	"history of depression"	3.81
Recent major life events	*(complex issues)*	"recent bereavement"	3.83
Body image issues	*(treatment issues)*	"body image"	4.144
Anxiety	*(anxiety)*	"signs of anxiety"	5.16

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Observation	*(understanding role)*	"watching a psychologist assess a patient"	16.575

APPENDIX 50

TRANSCRIPT NINE: MERGED & RENAMED THEMES

Key: new theme titles are shown in brackets and italic type, whilst 1.20 refers to page 1, line 20)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

Positive	*(open/positive)*	“good to have them”	1.20
Expert	*(open/positive)*	“have that expertise”	1.27
Negative	*(fear/threat)*	“you think they are mad”	2.61
Helpful	*(open/positive)*	“how useful it has been”	2.64

BELIEFS ABOUT THE ROLE

In-depth	*(emotional exploration)*	“delve far more”	1.36
Unknown	*(secretive/mysterious)*	“I don’t know”	11.392
Emotional exploration	*(emotional exploration)*	“unpick things”	11.393
Improved coping	*(effecting psych change)*	“coping strategies”	11.402
Instigate change	*(effecting psych change)*	“if anything can be changed”	11.404

PERCEIVED QUALITIES

Training	*(specialist training)*	“background in psychology’	2.45
Medical knowledge	*(knowledge)*	“some sort of medical knowledge”	2.47

HOPES AND EXPECTATIONS

Staff support	*(professional support)*	“supporting the staff”	4.125
Clinical supervision	*(professional support)*	“support as a team”	4.129
Flexible	*(professional position)*	“position in the team could be flexible”	6.187
Feedback	*(communication/feedback)*	“good to have feedback”	13.451
MDT contribution	*(multi-disciplinary working)*	“MDT meetings”	13.471
Unknown	*(unknowns)*	“I don’t honestly know”	16.575

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Knowing limits	*(having knowledge)*	“we should all know our limits”	1.28
Referring on	*(having knowledge)*	“refer them on”	1.29
Holding confidence	*(having knowledge)*	“I would never spread that”	5.185
Support	*(offering support)*	“use me as their support”	6.206
Scope of role	*(knowing limits)*	“I am not psychiatrically trained”	7.246
Ongoing input	*(managing time)*	“from diagnosis through to death”	13.462
MDT contribution	*(independent working)*	“something to contribute”	14.483

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

Lack of support	*(lack of support)*	"nurses don't get support"	4.140
Limit of understanding	*(understanding)*	"they don't understand"	5.164
Limited resources	*(lack of support)*	"very little out there to refer to"	6.204
Patient beliefs	*(expectations)*	"he should be coping"	9.298
Psych assessment	*(understanding)*	"sure there are patients I am missing"	10.359
Medical model	*(team working)*	"medically led"	14.490
Managing unknown	*(understanding)*	"if you don't know..."	16.582

COPING WITH BEING A CNS

Clinical supervision	*(colleague support)*	"felt very supported"	4.138
Boundaries	*(boundaries)*	"it is very separate"	4.144
Peer support	*(colleague support)*	"I use colleagues"	5.165

WAYS OF ASSESSING FOR DISTRESS

Patient insight	*(role of others)*	"he said..."	8.271
Communication skills	*(communication skills)*	"listening skills"	8.281
Time	*(time)*	"after a couple of months"	8.294
Instinct	*(intuition)*	"gut feeling"	9.308
Shared responsibility	*(role of others)*	"shouldn't just be down to the nurse"	10.364

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

Confidence	*(confidence)*	"I would have no problem"	3.90
Communication style	*(awareness of language)*	"put it in a way"	3.107
Normalising	*(awareness of language)*	"you need to normalise it"	3.110

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

Training	*(training)*	"in my training"	15.549
Role play	*(training)*	"really learnt from it"	16.555
Training	*(training)*	"3 day communication skills course"	16.558

SIGNS OF DISTRESS

Not coping	*(adjustment/coping)*	"really struggling"	2.55
Treatment issues	*(treatment issues)*	"struggling with chemotherapy"	3.93
Needle phobia	*(treatment issues)*	"needle phobia"	3.95
Adjustment issues	*(adjustment/coping)*	"struggling to come to terms"	6.202
Complex history	*(complex issues)*	"has a lot of background"	7.225
Anxiety	*(anxiety)*	"he's on the phone, he has got pain"	7.251
Frequency of contact	*(anxiety)*	"excessive phone calls"	11.381

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Assessment tools	*(skills/knowledge)*	“could use it in my practice’	10.354
Observation	(*understanding role)*	“good to see what a psych does”	16.574

APPENDIX 51

TRANSCRIPT TEN: MERGED & RENAMED THEMES

(**Key:** new theme titles are shown in brackets and italic type, whilst 1.13 refers to page 1,line 13)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

Positive	*(open/positive)*	“really useful”	1.13
Threatening	*(fear/threat)*	“I might be a bit jealous”	3.90
Acceptability	*(acceptability)*	“more acceptable”	10.356
Generational	*(generational)*	“generational thing really”	11.369
Undervalued	*(fear/threat)*	“not prestigious or valued”	11.388

BELIEFS ABOUT THE ROLE

Adjustment	*(effecting psych change)*	“somebody has to get used to”	3.106
Unknown	*(secretive/mysterious)*	“my lack of knowledge”	6.200
Instigate change	*(effecting psych change)*	“change the way their mind reacts”	6.203
Structured	*(structured approach)*	“much more structured”	6.204

PERCEIVED QUALITIES

Non-medical	*(knowledge)*	“not medically minded”	1.14

HOPES AND EXPECTATIONS

Aid understanding	*(clinical consultation)*	“your not likely to change it’	1.35
Clinical supervision	*(professional support)*	“how we manage this situation”	2.58
Clinical consultation	*(clinical consultation)*	“talk about this situation”	3.88
MDT contribution	*(multi-disciplinary working)*	“attendance at MD meetings”	4.142
Separate	*(professional position)*	“not part of management structure”	5.152
Feedback	*(communication/feedback)*	“want to know”	11.396
Uncertain	*(unknowns)*	“not certain”	12.407

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

Emotional support	*(offering support)*	“emotions are very intense”	3.84
Managing limited time	*(managing time)*	“dealing with short time scales”	4.126
Symptom control	*(having knowledge)*	“analgesic ladders”	6.205
Scope of role	*(knowing limits)*	“I don’t have that knowledge”	6.207
Systemic support	*(offering support)*	“families”	7.231

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

Multi professional working	*(team working)*	"how we related"	2.47
Normalising distress	*(understanding)*	"you're going to be sad"	9.316
Staff resistance	*(understanding)*	"hard to get people to realise"	9.324
Over prescribing	*(understanding)*	"throwing citalapram at every pt"	10.346

COPING WITH BEING A CNS

Clinical supervision	*(colleague support)*	"managing the chaos"	1.20
Death of patient	*(boundaries)*	"person is going to die"	8.271
Boundaries	*(boundaries)*	"it is never a personal relationship"	8.281

WAYS OF ASSESSING FOR DISTRESS

Info gathering	*(style/approach)*	"you get clues"	6.187
Instinct	*(intuition)*	"it is a gut feeling"	6.193
Communication skills	*(communication skills)*	"hold up a mirror"	7.222
Patient insight	*(role of others)*	"they will usually tell you"	9.300

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

Language	*(awareness of language)*	"may not put it in the words"	10.357

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

Time	*(experience)*	"over the years"	6.220
Personal motivation	*(training)*	"I wanted to try & learn"	12.418
Education	*(training)*	"care of the dying course'	12.421
	(training)	"palliative care degrees"	13.449
Experience	*(experience)*	"hospice experience"	12.425
Experiential learning	*(experience)*	"do it yourself in practice"	12.431
Observational learning	*(colleagues)*	"seen it done by someone else"	12.433

PRESENTATION AND SYMPTOMS

Key point	*(key point in pathway)*	"newly diagnosed"	3.105
Adjustment issues	*(adjustment/coping)*	"completely paralysed"	5.177
Past issues	*(complex issues)*	"happened previously"	5.180
Complex issues	*(complex issues)*	"something deep & dark happening"	5.182
Depression	*(depression)*	"completely black sky"	9.324

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

Assess tools	*(skills/knowledge)*	"gives permission to talk"	9.308
External placement	*(skills/knowledge)*	"a month in another hospital"	13.464
Observation	*(understanding role)*	"learn so much by just seeing"	13.467

APPENDIX 52

FINAL SUMMARY TABLE
MASTER THEMES, SUB-THEMES AND IDENTIFIERS ACROSS ALL PARTICIPANTS

(Key P1 = participant number 1, whilst 14.500 refers to page 14, line 500)

FEELINGS ABOUT PSYCHOLOGY/PSYCHOLOGISTS

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Open/positive	---	14.500	14.504	6.209	1.20	---	1.20	1.12	1.20	1.13
Acceptability	22.790	14.520	---	15.521	7.256	---	5.168	---	---	10.356
Fear/threat	21.741	---	---	---	---	9.317	---	7.241	2.61	3.90
Generational	21.749	---	14.501	---	---	---	---	---	---	11.369
Inaccessible	22.805	12.444	---	---	8.260	10.345	6.193	---	---	---

BELIEFS ABOUT THE ROLE

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Structured approach	14.486	5.171	4.122	13.446	6.196	10.365	5.150	8.280	---	6.204
Emotional exploration	13.467	---	4.114	11.403	---	---	---	9.306	1.36	---
Effecting psychological change	13.471	5.173	---	---	5.181	10.352	2.39	---	11.402	3.106
Secretive/ Mysterious	14.480	12.448	---	---	7.223	10.368	4.130	---	11.393	6.200

PERCEIVED QUALITIES

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Specialist training	13.467	---	---	13.459	2.58	11.372	---	10.356	2.45	---
Knowledge	4.128	---	---	12.416	16.577	10.354	4.110	10.360	2.47	1.14

HOPES AND EXPECTATIONS

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Clinical consultation	2.53	2.46	---	3.105	8.283	2.50	3.92	---	---	3.88
Communication /feedback	12.432	15.535	17.615	---	8.284	13.456	---	12.405	13.451	11.396
Support	2.66	3.78	5.181	4.133	3.89	3.78	---	13.455	4.125	2.58
Multi-disciplinary working	2.59	2.43	17.613	---	1.27	2.73	---	8.261	13.471	4.142
Professional position	---	13.454	5.163	---	3.76	2.54	11.389	11.377	6.187	5.152
Availability	3.92	2.55	---	---	3.83	2.46	---	7.240	---	---
Unknowns	13.455	13.457	---	---	---	3.92	3.85	---	16.575	12.407

FEELING COMPETENT AS A CLINICAL NURSE SPECIALIST

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Knowing limits	13.474	5.176	3.105	1.12	1.17	---	1.19	2.51	7.246	6.207
Offering support	7.249	7.258	1.15	8.271	2.51	---	1.15	6.221	6.206	7.231
Managing time	7.247	1.25	16.590	8.281	---	7.235	---	---	13.462	4.126
Having knowledge	2.57	9.329	4.128	---	---	---	12.428	1.30	1.28	6.205
Independent working	---	11.405	4.137	5.167	13.447	---	2.56	1.29	14.483	---
Information sharing	---	---	8.279	---	10.349	---	11.391	1.20	---	---

SOURCES OF EMOTIONAL DISCOMFORT/DISTRESS

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Working with death/illness/loss	7.232	---	---	7.226	---	4.111	9.329	12.433	---	---
Expectations	20.727	7.254	2.38	8.272	12.417	---	13.458	14.483	9.298	---
Lack of support	---	11.387	---	5.173	8.270	---	13.445	12.415	4.140	---
Understanding	10.351	8.300	---	---	---	---	13.459	---	5.164	9.316
Time pressure	14.511	6.203	11.416	---	10.348	---	4.144	12.432	2.59	1.36
Team working	14.513	---	---	5.164	9.299	---	13.454	---	14.490	2.47

COPING WITH BEING A CNS

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Colleague support	---	11.391	6.224	5.170	4.113	3.81	13.466	12.430	4.138	1.20
Boundaries	17.596	11.393	---	---	4.121	---	---	---	4.144	8.281

WAYS OF ASSESSING FOR DISTRESS

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Intuition	11.394	---	2.65	9.327	10.357	7.247	9.325	2.46	9.308	6.195
Emotional discomfort	12.420	5.158	---	6.203	---	7.247	---	1.18	---	---
Feeling stuck	1.20	1.29	3.102	7.250	2.52	7.251	3.76	2.46	6.220	---
Style/approach	5.176	6.221	9.311	8.295	6.197	6.216	6.218	4.140	---	6.187
Communication skills	8.281	---	9.303	8.260	11.370	6.220	---	5.157	8.281	7.222
Time	14.502	7.238	9.339	9.326	11.374	6.208	8.292	---	8.294	---
Role of others	---	7.234	17.636	---	6.188	---	---	2.51	10.364	9.300

FEELINGS ABOUT APPROACHING PSYCHOLOGICAL ISSUES

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Confidence	21.757	6.194	12.438	14.504	7.239	9.299	11.379	---	3.90	---
Awareness of language	21.763	6.200	12.434	14.514	7.252	8.289	16.567	8.292	3.107	10.357

FACTORS CONTRIBUTING TO FEELINGS OF CONFIDENCE/COMPETENCE

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Experience	5.158	16.583	3.87	16.560	11.400	12.431	14.482	5.170	---	12.425
Reflective practice	15.537	---	15.559	---	15.517	---	---	9.327	---	---
Colleagues	15.535	---	15.557	11.385	14.513	---	14.499	16.583	---	12.433
Training	16.557	15.549	14.526	15.548	14.497	12.418	14.485	15.528	15.549	12.421

SIGNS OF DISTRESS

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Depression	12.417	---	11.396	2.41	---	--	7.233	2.72	---	9.324
Anxiety	---	---	---	---	---	---	7.227	5.165	7.251	---
Adjustment/coping issues	---	4.148	11.382	7.247	5.178	---	3.98	---	6.202	5.177
Complex issues	---	2.69	2.45	3.95	---	1.16	---	3.81	7.225	5.180
Family/relationship issues	---	---	10.361	1.30	---	4.145	---	---	---	---
Treatment issues	---	---	11.404	1.28	---	3.106	---	4.144	3.93	---
Key point in pathway	---	---	13.476	1.27	5.169	---	---	---	---	3.105

IMPROVING PSYCHOLOGICAL CARE OF PATIENTS

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Understanding role	13.456	13.476	17.622	16.583	7.231	13.442	6.216	16.575	16.574	13.467
Skills/knowledge	10.348	16.598	---	11.390	15.529	---	15.521	---	10.354	9.308

APPENDIX 53

NOKITA'S CBT FORMULATION

Early experiences
Witnessed aunt dying of cancer in Japan

↓

Formulation of dysfunctional assumptions
All people dying of cancer die like my aunt

↓

Core belief
Dying of cancer is terrifying and unmanageable

↓

Critical incident
Diagnosis of metastatic cancer (incurable cancer)

↓

Activation of assumptions

↓

Negative automatic thoughts
I will die in terrible pain
I will die alone
I will die in a clinical environment having toxic chemotherapy
I will not cope with dying
My life is over now

↗ ↘

<u>Physical sensations</u>
Pain
Nausea
Tiredness

<u>Emotions</u>
Fear
Anxiety
Panic
Sadness
Worry

↖ ↙

<u>Behaviours</u>
Avoiding talking about situation with husband and doctors
General withdrawal from others
Increased time at home, lying on bed
Active 'remembering' of aunt's death

Adapted from Beck (1976)

APPENDIX 54

AN EXERT FROM NOKITA'S DIARY OF EMOTIONS AND THOUGHTS

SITUATION	EMOTION HOW DO YOU FEEL? (RATE 0-100%)	THOUGHT WHAT WENT THROUGH YOUR MIND? (RATE BELIEF 0-100%)
Lying on my bed, trying to rest	Frightened **100%** Panicky **90%**	Think I am getting worse. They will take me into hospital soon and I will only see Simon occasionally because of infection risk. I will be alone in a room and no one will talk to me **100%**
Middle of the night, downstairs with the dogs	Frightened **100%** Sad **100%**	The pain is getting worse. It will be intolerable soon **100%** I won't see the dogs for much longer **100%**
Lying on the sofa, too tired to move	Terrified **100%** Anxious **100%**	I will look like my Aunt soon. When the chemo starts I will be so sick and I will lose my hair again **100%** The end is going to be terrible. I won't manage the pain **100%**
Lying on the sofa, watching Simon at his computer	Sad **100%** Frightened **100%**	I will have to say goodbye to Simon soon. He won't be able to visit me towards the end **100%**
In bed, not able to sleep because of the pain	Frightened **100%** Panicky **80%**	The pain is becoming unbearable. I am not coping with it. People will think I am weak **100%**

APPENDIX 55

PSYCHOLOGICAL ADJUSTMENT STYLES IN CANCER

Adjustment Style	Definition	Typical Statements
Fighting Spirit	The patient views cancer as a challenge and has a positive attitude towards outcome. They exert control by taking an active role.	*"I see my illness as a challenge"* *"I try to carry on as I always have"*
Avoidance/ Denial	The patient denies the impact of the disease. Threat is minimised, control is irrelevant and the prognosis is seen as good.	*"They just took my breast off as precaution"* *"It isn't serious at all"*
Fatalism	The patient has an attitude of passive acceptance. The cancer represents a minor threat and no control can be exerted over the situation. Active strategies towards fighting the cancer are absent.	*"It's all in the hands of the doctors/fate/God"* *"I've had a good life, what is left is just bonus"*
Helplessness/ Hopelessness	The patient is overwhelmed & engulfed by the enormity of the threat of cancer. The diagnosis is viewed as a major threat, loss or defeat. A negative outcome is assumed and control is lost. There are no active strategies utilised. The patient just gives up.	*"What's the point in going on?"* *"There is nothing I can do"*
Anxious Preoccupation	The patient is anxious and demonstrates compulsive searching for reassurance. Worries about the cancer returning are relentless and any physical symptoms are assumed to be signs of disease.	*"I can't cope not knowing what the future holds"* *"I am so worried about it coming back"*

Greer and Watson (1987)