Psychosocial Support Within the Everday Work of Hospice Ward Nurses:

An Observational Study

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Declaration

I hereby declare that this thesis embodies the results of my own research and that I am the full author of this thesis, except where otherwise stated, and that it has been submitted only for the degree of PhD in the University of Stirling.

Signed:

Hazel Hill

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Abstract

Psychosocial support is said to be an inherent component of nursing care and a major focus of palliative care. Literature exists which outlines perceptions of the psychosocial needs of patients and how psychosocial support should be provided. However, there is a lack of empirical evidence on how psychosocial support is operationalised in practice. This study provides a valuable and substantial new contribution to the evidence on the psychosocial needs expressed by patients in a hospice ward and how nurses immediately respond to these needs within their everyday practice.

A study gathering data via observations with matched interviews of patients and nurses, organisational, documentary, and demographic variables, was conducted over an eight month period. Thirty-eight nurses (registered and auxiliary) and 47 patients were included in a maximum variation sampling strategy. Data was analysed using constant comparative qualitative techniques.

Patients expressed a wide variety of psychosocial needs, often only signalling them whilst receiving care for other reasons. Considering these needs in relation to Maslow's (1943) hierarchy of needs suggests that in-patients more commonly express prerequisites to physiological care and 'lower level' safety needs rather than the more thoroughly researched and espoused 'higher' level psychosocial needs. The nurses reacted to these psychosocial needs with a range of responses which indicated a diminishing level of immediate support: 'dealing', 'deferring', 'diverting' and 'ducking'. The majority of the nurses were observed using each of these responses at some point during data collection. A variety of the responses were used for each type and context of psychosocial need. These responses were influenced by the ward's workplace culture.

This study demonstrates a requirement for more thorough consideration of the true psychosocial needs of patients, which appear to vary dependent on the context of care. Consideration should be

given to workplace culture and its influence over psychosocial support, with nurses being supported to expand their response repertoire so that patients' psychosocial needs are acknowledged more. Increasing nurses' knowledge of the reality of psychosocial support through education and research will encourage formalisation of the place of psychosocial support in the planning, documentation and provision of care.

This study shows that ward nurses can offer psychosocial support as an inherent component of their everyday work. Findings derived from this research indicate that developing an understanding of how patients express psychosocial needs in practice, through a consideration of Maslow's (1943) hierarchy of needs, may increase recognition and support of psychosocial needs and enable nurses to respond more comprehensively.

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Chapter 1: Introduction

Psychosocial care has long been regarded as being fundamental to nursing care. This study explores how nurses in a hospice ward operationalise psychosocial care during their daily practice. This chapter sets a background to the study by outlining the concept of psychosocial care. I demonstrate how one aspect of psychosocial care marked in the literature is an expectation of nurses to offer psychosocial support as an inherent component of their care. I make the case for why the clinical setting of palliative care is ideal for exploring nurses' provision of psychosocial support. Understanding the psychosocial needs of palliative care patients is a useful starting point for this exploration. I, therefore, finish this chapter with an illustration of how psychosocial needs are described in existing palliative care literature.

1.1   Psychosocial care: a core aspect of nursing

Exploration of psychosocial care as an inherent component of daily nursing practice must start with a recognition of what is meant by 'psychosocial'. The term 'psychosocial' is associated with the concepts of 'holism' (Maslow 1943; Smuts 1927, Phillips 1977), Engel's 'biopsychosocial model' (Gross and Kinnison 2014, Malmgren 2005, Whitbourne 2001, Schwartz 1982) and 'integrated care' (Walker *et al.* 2007, Bendelow 2009). Regardless of which of these labels is used, the ultimate aim of these approaches is providing care which considers equally, and concurrently, the physical, psychological, social, and spiritual aspects of patients' illnesses. The idea of holistic care has been embraced by many healthcare professionals, but defining what psychosocial care actually is, has proved to be problematic.

Psychological elements are considered to be those relating to behaviours, thoughts, feelings, and emotions that lead people to behave in the way that they do (Gross and Kinnison 2014, Priest 2012,

Upton 2010, Bennett 2000). Social elements concern how individuals interact within their positions in society including the roles they have in groups to which they belong (Willis and Elmer 2007, Nettleton 2013, Bradby 2012, Barry 2012), such as family and on a ward. Both psychological and social elements have an impact on health, and vice versa, and are concerned with how patients and nurses relate to each other (Gross and Kinnison 2014, Priest 2012, Barry 2012). The elements of psychological and social care are often combined, so much so that psychosocial care is often considered as one main area of healthcare (Walker *et al.* 2007, Bennett 2000). The debate over whether the elements should be combined or discussed separately, or what term we use for their application, is not a focus of this thesis. Whenever the term 'psychosocial' is used, it should be considered as a vital aspect of healthcare and a major component of nurses' role. Because the term 'psychosocial' is used to refer to such a diverse range of practices, in section 1.3 I will define how I am using it in this study.

Nursing has been defined in a variety of ways, all of which indicate the importance and prevalence of psychosocial care. The World Health Organisation (1991) stated that the aim of nursing is:

> *"To help individuals, families and groups to … achieve their physical, mental and social wellbeing" (p3).*

In contrast, the International Council of Nurses (2013) have a classification system identifying what nurses do, which includes enhancing psychological well-being and facilitating social interaction as well as supporting individuals by giving social/psychological help. In addition, the Royal College of Nursing (RCN, 2003) defines nursing as having six characteristics: the "particular domain" characteristic indicates that nursing involves supporting the psychological and social aspects of people's lives. The Nursing & Midwifery Council (NMC) espouse the RCN's view,

rather than formulating a separate definition of nursing, but regularly refer to psychosocial aspects of care in their code of conduct (NMC 2008).

The importance of psychosocial support in nursing has been indicated since Florence Nightingale's first descriptions of nursing (Carroll 1992) and is repeated throughout redefinitions of nursing as a profession. For example, in 1960, Virginia Henderson defined nursing by identifying fourteen components of 'basic nursing care', five of which are psychosocial (Henderson 2004). The importance of meeting psychosocial needs is advocated by many, for example, LeMone *et al.* (2014), Potter *et al.* (2009) and Walsh and Crumbie (2007). Similarly, some models of nursing are based around attaining psychosocial needs, such as Orem's (2001) self-care model which views nursing's ultimate role to be maximising patient independence: a psychosocial need. Roper *et al.*'s (2000) much used *Elements of Nursing* model, focusses on patients achieving the 'Activities of Living', which are affected by, amongst other things, psychological and sociocultural influencing factors. Similarly, outcomes of nursing can be measured in terms of meeting psychosocial needs (Alligood 2014, Roy and Andrews 1999, Neuman 1995).

Psychosocial support is also a core part of nurse training (NMC 2010) with key texts defining nursing as above or from a health, caring or skills perspective. From a health perspective, psychological and social aspects are included as vital components of health (Potter *et al.* 2009; Craven and Hirnle 2009, Wigley and Wilson 2009). While caring-based textbooks advocate an approach based on patients' psychological needs and social circumstances (Watson 2012, Chambers and Ryder 2009, Walsh 2002), skills-based texts focus on developing skills, many of which are communication skills, in order to assess and manage psychosocial needs (Baillie 2009, Wilson and Foret 2009, Nettina 2001).

Throughout all the definitions and explanations of nursing discussed above, there is a common theme that stresses the importance of providing psychosocial care for patients' psychosocial needs as a component of basic nursing practice. However, they do not explain what psychosocial care is or how nurses should provide it. This study sets out to understand what role nurses play in meeting the psychosocial needs of patients by exploring how nurses operationalise psychosocial support, including liaising with colleagues and documenting care, vital processes that enhance care (Nursing & Midwifery Council 2009). To understand what is meant by 'psychosocial support', we should first consider nursing's role in psychosocial care.

1.2 Psychosocial Nursing

The inclusion of psychosocial care as part of nursing practice has been demonstrated in the previous section. Nursing textbooks offer guidance on psychosocial care by framing psychosocial needs in psychological and sociological theories (Roper *et al.* 2000; Lewis and Timby 1993), which, although useful, may not translate to the reality of nursing practice. From a review of the literature on psychosocial nursing there appear to be three main approaches directing nurses' delivery of psychosocial care: as a component of psychiatry, as nursing interventions, or by listing psychosocial needs.

A large proportion of the literature on psychosocial nursing classifies psychosocial care as part of the domain of psychiatric nursing. For example, a journal that, on first consideration, appears to be about psychosocial nursing, "The Journal of Psychosocial Nursing and Mental Health Services", focusses on psychiatric illness, with occasional articles on loss, bereavement, spirituality, and the use of specific therapies. An even more recently published textbook on psychosocial nursing (Roberts 2013) begins by discussing general concepts relevant to psychosocial support, such as communication skills, then follows the style of older textbooks (Barry 1996, Gorman *et al.* 1989,

Skodol Wilson and Kneisl 1988) and focusses on applying care to individuals with psychosocial morbidities, for example: anxiety disorders or depressive states. Another substantial proportion of psychosocial nursing literature focusses on nurses' use of specific interventions – such as relaxation techniques, visualisation and group therapy – with patients (Craven and Hirnle 2009, Holyrood *et al.* 2001, Edelman 2000). The other common approach to literature on psychosocial nursing describes patients' psychosocial needs (Moore *et al.* 2014b, Wolf 2004, Arantzamandi and Kearney 2004, Thomas *et al.* 2001) – for example, for control, dignity and privacy – and suggests ways of meeting these needs (Hansen *et al.* 2012, Kenny *et al.* 2007, Frazier *et al.* 2003, Dirksen 2000), such as providing social support and making informed decisions. The literature described above comes from nurse or patient perceptions of psychosocial care, anecdote or conjecture. There is a little empirical evidence written about how psychosocial nursing is carried out in practice.

Whether or not psychosocial care is a specialist domain or the application of specific interventions is not under investigation in this study. What is in question here is whether psychosocial nursing is a component of everyday nursing practice, as suggested in the definitions of nursing, and, if so, how do nurses provide it? If nurses state that a major component of their day-to-day role is the provision of psychosocial support, they must be able to demonstrate that this is the case and show how the concept is operationalised. This study explores what actually happens in an area of healthcare in which psychosocial care is said to be particularly important: palliative care.

1.3 Psychosocial Palliative Nursing

Palliative Care has been recognised as a medical speciality since 1987 (Doyle *et al.* 2004) and is defined as:

"An approach that improves quality of life of patients and their families facing

the problems associated with life-threatening illness, through the prevention and

relief of suffering [...] of pain and other problems, physical, psychosocial and

spiritual" (World Health Organisation 2003, n.p.).

Palliative care practitioners pride themselves in providing psychosocial care (Radbruch *et al.* 2010; NHS Quality Improvement Scotland 2004; Clinical Standards Board for Scotland 2002; Glickman 1997, The National Council for Palliative Care 2005). Palliative care nurses are expected to have high level of skills in providing psychosocial care and are expected to act as a role-model to generalist nurses (Becker and Gamlin 2010; Stratford 2003, Kissane and Yates 2003; Macnish 2002).

Similar to the literature associated with psychosocial nursing there is much written about the nature of psychosocial palliative care. The majority of general palliative care textbooks have sections dedicated to psychosocial palliative care (Woodhouse and Baldwin 2011, Kissane *et al.* 2010, Ferrell and Coyle 2001; Becker 2001), as do national palliative care guidelines (National Institute for Clinical Excellence 2011; National Care Standards Committee 2005; Clinical Standards Board for Scotland 2002). Other papers focus completely on psychosocial palliative care (Lloyd-Williams 2003; Hockley 2000; Craven 2000; Glickman 1997; Sheldon 1997) and guidelines exist for the psychosocial care of cancer patients, for example, the National Breast Cancer Centre and National Cancer Control Initiative (2003) which include information on how to meet the psychosocial needs of these patients when they reach the 'palliative' phase of their illness. However, the literature describing how care is provided to meet the psychosocial needs of the recipients of palliative care is restricted: either identifying potential psychosocial needs (Thomas *et al.* 2001) and suggesting perceived ways of meeting them (Hockley 2000, Ramirez *et al.* 1998); or focussing on specific

psychosocial problems, especially anxiety and depression, and interventions to control these, such as medication and counselling (Harding and Higginson 2003; Fisher 2002, Craven 2000; Lloyd-Williams *et al.* 1999). There is a gap in the literature: it remains unclear as to how psychosocial care is applied in the practice of palliative care (Scottish Partnership for Palliative Care 2011, Johnston *et al.* 2006).

Psychosocial palliative care is

> *"concerned with the psychological and emotional well-being of the patient and their family/carers, including issues of self-esteem, insight into and adaptation to the illness and its consequences, communication, social functioning and relationships"* (Glickman 1997, p3).

All practitioners in specialist palliative care have a responsibility to provide psychosocial care; however, the focus of this study is on nurses' psychosocial support, which can be described as:

> *"care which does not use formal psychological methods but enhances well-being, confidence and social functioning"* (Glickman 1997, p6).

The underlying principle is that patients should receive psychosocial support whenever they have a psychosocial need.

1.4   What are the psychosocial needs of palliative care patients?

I have demonstrated that both nursing and palliative care aim to provide psychosocial support, but it is unclear whether, and especially how, this happens. Since the inception of the idea that nurses should provide psychosocial care, there have been numerous proposals, by academics and clinicians alike, about what types of psychosocial needs patients have. An exploration of how

nurses provide psychosocial support would be difficult without an initial idea of what the psychosocial needs of patients receiving palliative care may be. Psychosocial needs are difficult to consider as singular entities. Different psychosocial needs interact and overlap with each other, and other types of needs, thus providing care for psychosocial needs is complex (Smuts 1927, Carter *et al.* 2004, Gross and Kinnison 2014, Walker *et al.* 2007). Existing research into psychosocial care has been carried out in many ways and has identified many psychosocial needs. However, I am primarily interested in the psychosocial needs of palliative care patients and how these are supported in specialist palliative care in-patient units by nurses. The first step in this process was to carry out a search to identify pertinent literature and produce an overview of existing evidence.

The following sections, in this and the subsequent chapter, draw upon literature identified by extensive searches of the CINAHL, MEDLINE, and PsychINFO electronic databases. The aim of the chapter is to describe the landscape of literature pertaining to palliative nursing care and the psychosocial needs of palliative care patients. Initial searches were undertaken between December 2003 and June 2005 for the previous 10 years. These searches were repeated again in May 2014 and again in June 2016, to check for more recent publications. In order to ensure identification of the full scope of research related to psychosocial palliative nursing, a number of key terms, using truncations, denoted here by '*', were searched in a variety of combinations. The term 'Nurs*' was combined with either 'Psycho*' or 'Soci*' and then in turn with each of the following terms: 'Hospice' 'Palliat*' 'Terminal' 'Dying' 'Death' and 'End of Life'. Many articles were identified that were not relevant to this study, so the following limits were set: Human, Adult (16+), English language and, where possible, Research; fields searched were Abstract, Title, Keyword, and Subject Heading. Checking articles' reference lists and using the 'cited by' facility in the databases generated additional research papers. In this study, I focus specifically on the psychosocial support

of palliative care patients from their own perspectives or the perspectives of their nurses. I have excluded research purely from informal carers' perspectives as they are skewed by their own psychosocial needs, but have included studies which consider informal carers alongside patients. Similarly, a number of studies reviewed had a variety of allied health professionals (AHPs) participating, as long as these included nurses they have been included in these sections.

This search of the literature identified that palliative care patients' psychosocial needs have been examined in research studies in a number of ways. Some studies identify psychosocial needs by enquiring about those that patients have or those they wish to have supported (Rydahl-Hansen 2005, Lawton 2000), while others explore specific psychosocial needs, such as hope (Herth 1990, Buckley and Herth 2004), control (Volker *et al.* 2004a, 2004b), quality of life (Cohen *et al.* 2001, Olthuis *et al.* 2006, Thompson *et al.* 2006, Sahlberg-Blom *et al.* 2001) and privacy (Street and Love 2005). Additionally, researchers extrapolate psychosocial needs by discussing patients' and/or nurses' views about their experiences of care (Bradley *et al.* 2010, Cotterell 2008, Costello 2006). Another approach is satisfaction or quality of care assessment (Adams 2005, Rogers *et al.* 2000, Wilkinson *et al.* 1999).

In the remainder of this chapter, and the following chapter, I discuss the evidence that summarises current views on nurses' support of the psychosocial needs of palliative care in-patients. Sources ~~come~~ from all of the above foci are summarised below and often both refer to the psychosocial needs and their support, or lack thereof. Twenty-one studies were of particular significance to my area of research: they either focussed specifically on psychosocial aspects of nursing care of palliative, or dying, in-patients or were seminal pieces of work identifying the role of palliative care nurses. These 21 studies, which are summarised in Table 1.1, may appear dated, however, this reflects the nature of current research into this area. Both the types of psychosocial needs of

palliative care patients and the support offered are covered in the majority of the 21 studies, therefore, this table provides information relevant to both Chapters One and Two.

A wide range of additional research on psychosocial care by nurses exists. Although not specific to my area of study (they may be concerned with emergency care for example), these sources contain some valuable ideas. These are not included within Table 1.1 as they do not concern palliative care, but may be referred to within this chapter, and the following chapter, to clarify current views on psychosocial nursing. Examples of these are studies focussing on: care of cancer patients, without differentiating palliative care patients; or palliative care provided in a generalist setting. When such studies elaborate on psychosocial support of specialist palliative care in-patients or their psychosocial needs they have been included in the following discussion.

Having reviewed the literature on palliative care patients' psychosocial needs, these appear to fall into four main areas: emotional expression, rights, coping, and identity. The remainder of this chapter, therefore, draws on the findings of the studies included in Table 1.1 and other relevant work, focussing on what are considered to be the psychosocial needs of palliative care patients. An initial overview of psychosocial needs follows and is succeeded by four subsections discussing the different categories of psychosocial need. This categorisation of psychosocial need was created by me during my reading for this study. I created a concept map (Figure 1.1) outlining what are considered, in the literature discussed below, to be the main psychosocial needs of palliative care patients. The placing of the needs, and links, in the map was dependent on how needs were described concurrently in the literature.

Table 1.1: Literature on nurses' support of palliative care in-patients' psychosocial needs

Authors	Aims and setting	Methodology	Sample	Key findings	Limitations
Booth *et al.* (1996)	To explore the impact of practical and psychological training for nurses on their use of blocking communication tactics in two English hospices.	Questionnaire, interview, survey on support, Recording of patient assessments	41 nurses	Nurses regularly used blocking tactics, because they: wished to protect patients and/or themselves; believed their blocking tactic to be helpful; or did not feel skilled enough to support the expressed needs. Support from managers was found to have the greatest influence over reducing blocking.	Assessment interviews were the only communication scenarios analysed. Potential impact of audio-recording.
Cannaerts *et al.* (2004)	To find out what palliative care actually is. Two hospices in Belgium.	Grounded theory: interviews; observations of care and team	8 patients, 9 relatives, 24 staff members	By controlling symptoms palliative care allows patients to focus on	Over-reliance on interview data. Exploring different episodes of care.

		meetings; care documents	(11 nurses)	'enjoying' life until death. Conditions in the hospice make this possible.	Comparison to hospital care.
Cohen *et al.* (2001)	To investigate whether quality of life (QoL) does improve following admission to one of five Canadian palliative care units.	Comparison of self-reported QoL scores on admission and 1 week later, interviews.	88 patients	Significant improvement in QoL in all domains, including psychological and social, after one week as a hospice inpatient.	Only those patients in better health conditions could participate. Comparison to previous state, rather than on expectations.
Copp (1999, 1997)	To develop theories of death and dying through an exploration of these experiences in patients and their nurses in an NHS hospice.	Participant observation, informal interviews	12 patients, 15 nurses	Patients' 'readiness' to die can be physically and psychosocially disparate. Hospice nurses plan care around trying to enable dying patients to accept their	Descriptions of actual care are not included. Important theory proposed but how to apply this to practice is missing.

				forthcoming deaths.	
Costello (2006, 2001)	To explore the care offered to and received by dying older people in three hospital wards in England	Participant observation and interviews	74 patients, 29 nurses, 8 doctors	Nurses focussed on physical aspects of care, often failing to recognise psychosocial support when they had offered it. Organisational constraints were blamed for the lack of psychosocial support, especially failure to discuss concerns around dying.	Data describing nurses' views on psychosocial support was reported to a much greater extent than patients' views. Hospital environment and ethos may cause substantial difference from palliative care settings.
Davies and Oberle (1990, 1992*)	Community pallaitive care in Canada	Grounded theory analyses of descriptions of care	One palliative care nurse's encounters with 10 patients	Developed a model of palliative care nursing consisting of: creating relationships; respecting and	Palliative care has evolved in the 25+ years since this study. Only one nurse's care was examined

				empowering patients; helping patients to maintain a sense of self-worth; and providing physical care.	and taken from her own perspective.
Devery *et al.* (1999)	To investigate the role of health outcomes in palliative care in Australia.	Interviews	77 patients, caregivers and healthcare professionals	Patients gained a sense of normality and well-being from honest, open, two-way communication with professionals, despite having to negotiate with staff in order to have their needs met.	Lack of distinction between who holds which views. Self-report.
Field (1989)	To explore the impact of the organisation on psychosocial aspects of nursing dying patients in hospital wards and the community in England.	Interviews and observation	47 nurse interviewed 13 patients observed	Psychosocial support is challenging in nursing due to: lack of experience; disparity with	Generalist care of the dying. Differing methodologies over clinical areas,

				medical colleagues; and organisational pressures	limited observation.
Haraldsdottir (2011)	To discover whether nurses spent time 'being with' patients in a city based Scottish hospice's wards.	Ethnomethodology: observation of care and meeting, informal conversations	All ward nurses observed, 6 in conversations	Nursing care was task-oriented, with organisational constraints inhibiting nurses from 'being with' patients.	Majority of data is the researcher's interpretation, risk of bias. Limited time periods of observation (9-12 or 2-6). Less participant observation.
Heaven and Maguire (1997 & 1998)	To discover whether nurses, in two English hospices, accurately elicit and document patient concerns.	Comparison of tape-recorded nurse-patient assessment interviews to researcher-patient interviews including written assessment tools.	87 patients, 42 nurses	Nurses recognised under half (42%) of patients' reported concerns and documented less (19%). A greater number of concerns were identified by the researcher. Nurses reported	Restricted aspect of patient-nurse interactions studied. Non-verbal cues missed (by use of tape-recorded assessment interviews).

				mostly physical concerns while those revealed by patients were more frequently psychosocial.	
Ingleton (1999)	Evaluation of one community palliative care service in England	Ethnography: survey, observation, interview, document analyses	70 patients For 52 days 9 patients, 8 carers	Availability of, and relationships with, the nurses, in combination with a friendly, open atmosphere, made the patients' and carers' experiences of care positive	Focus on patient interview data. Lack of objectivity. Researcher cared for participants.
James (1992) James and Field (1996)	To investigate the role of nurse in caring for the dying in an NHS hospice.	Ethnography: observation, conversations	Hospice staff	Nursing care in the hospice is a combination of practical tasks and emotional input, with a strong focus on the former. With organisational	Researcher and staff perspectives of care, not patients. Focus on sociological theory rather than nursing skill.

				constraints controlling both.	
Johnston (2002), Johnston and Smith (2006)	Understanding of what patients and nurses, in two hospices and two acute hospitals in Scotland, consider an expert palliative nurse to be.	Phenomenological interviewing	22 patients, 22 nurses	Expert palliative nurses connected with patients to form relationships with them. This allowed nurses to: maximise patient independence; meet patients' needs; create a safe, secure and relaxed atmosphere in the hospice.	Perception of what is desired of the expert nurse, lack of insight into reality of providing this care.
Kuuppelomaki (2003)	To identify how Finnish community nurses perceived the emotional support they offered to palliative patients.	Questionnaire	328 community nurses	Emotional support is a regular and integral part of nursing care. Mainly given in the form of listening to emotional concerns and	Self-report, retrospective and often on care not witnessed by respondent. Lack of patient comparison.

				fostering hope. Discussions around dying were limited. Documentation and liaison of emotional needs was limited.	
Lawton (2000)	To understand how individuals can maintain a sense of self, whilst physically deteriorating towards death, in day-care and affiliated in-patient unit in an English hospice.	Ethnography: participant observation, informal conversations	Day-care: 40 patients, 12 relatives. Whole hospice population: 280 pts, all staff, volunteers	Patients' deteriorate psychosocially and physically as they approach death. Psychosocial support may not be achievable for palliative patients. Identifies social needs. Questions realities of practice.	Sociological perspective. First encounter with dying people.
Li (2004, 2005)	To investigate the process of nurses and patients being 'nice' to	Grounded theory: partial-participant observation, tape-	28 nurses	Nurses consider patients to sit on a continuum of	"Incidental" nature of patient inclusion.

Li and Arber (2006)	each other in order to form relationships and provide psychosocial support, in three palliative care units in England.	recording nurse hand-overs. Discourse and conversation analyses.		'credible to troublesome' which is influenced by their health status and psychosocial attributes. When patients and nurses are nice to each other, their problems lessen, this can results in 'negative' emotions being suppressed.	Specific focus on the impact of talk and the concept of 'niceness'.
McNamara (2001)	To explore how patients in Australian hospice care (community and in-patient) achieve 'good death' and the impact of staff support on this.	Ethnographic observation, interviews, survey.	32 health professionals (22 nurses), 53 patients or carers.	Patients experience a 'good death' when their wishes are met. Most important factors in this are: maximising independence; having choice; acceptance of	Analysed against social theory instead of reality of nursing care.

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				and preparation for impending death; and quality of life.	
Skilbeck and Payne (2003)	To identify, through analyses of existing evidence, how clinical nurse specialists (CNS) support the emotional needs of palliative care patients with cancer. Participants in included studies were mainly UK based.	Systematic literature review	Undescribed.	Patients and carers feel emotional support is gained through physical care, information giving and technical knowledge, whereas nurses view it as a specific, separate, component of their role. Recommended research on whether emotional support is provided separate to, or in combination,	Clinical nurse specialists only. Cancer patients. Lack of detail on inclusion/exclusion criteria and studies included.

				with other aspects of care.	
Taylor *et al.* (2001)	Explore the expectations of patients, their families and staff relating to what constitutes valuable palliative nursing	Interviews Focus group	5 patients, 6 relatives, 15 nurses	Patients and family members felt sensitivity and empathy from nurses, was most important. Whereas the nurses focussed on the 'doing' aspects of their jobs.	Researcher role (nurse to patient, manager to nurses) may influence response.
Thomas *et al.* (2001) McIlmurray *et al.* (2001)	To explore the main psychosocial needs of cancer patients, and their carers, and how these are met in clinical practice across locations served by one cancer centre in England.	Cross-sectional survey, interviews and focus groups of patients and carers. Semi-structured interviews of health professionals.	402 cancer patients and their carers. 39 professionals: doctors, specialist nurses, dietician and care organisers/managers.	Psychosocial needs, in order of importance were related to: communication with professionals; information; support; identity; emotions and hope; and assistance with practical issues. Two significant changes when	Low response rate of palliative patients: 57 out of 380 (15%). Only patients with cancer and nurses in specialist roles. Self-report.

				patients 'become palliative': increased need for information about the future and having some control over what happens.	
Wilkinson (1991)	To explore nurses' use of blocking and facilitating communication skills with cancer patients in six hospital wards in England.	"Analytical relational survey": Questionnaire on nurses' anxiety and social support; Recording of patient admission assessment; Interview; observation of setting and organisation of care.	54 qualified nurses.	The majority of nurses used blocking tactics regularly which inhibited eliciting patients' true needs, especially psychological ones. Four types of nurses: facilitators, ignorers, informers and mixers. Ward environment, including	Admission assessments were the only communication scenarios analysed. Tape-recording of the patient assessments may have influenced the communications.

				preference for patient over task allocation and charge-nurse attitude to psychosocial care, was identified as the key predictor of which communication skills were used.	

Figure 1.1 Concept-map of palliative care patients' psychosocial needs

Coding
Requirements
Means to achieving
Personal qualities enabling achievement

Expression
Rights
Coping
Identity

Acceptance
Readiness
Coping
Understanding
Communication
Hope

Expression of Emotions, Thoughts & Feelings
Emotional Well-Being
Quality of Life

Psychosocial Needs of Patients

Relationships
Companionship

Dignity
Privacy
Safety & Security
Self-determining

Self-Concept
Self-Esteem

Respecting Rights
Autonomy
Control of Choices
Independence
Individuality
Social Functioning

Identity
Sense of Belonging
Role Recognition

A comprehensive overview of psychosocial needs experienced by patients with cancer, including those whose care had become palliative, was provided via a cross-sectional survey, by Thomas *et al.* (2001). Data from 402 responses were analysed to create a categorisation, in order of those considered most important, of psychosocial needs. These categories were summarised as: emotional well-being and hope; trust in communication with health professionals; dignity; information to aid understanding; social support and maintenance of relationships; identity, through independence, control and positive self-concept; and assistance with practical issues. Verification of the categorisation was gained through patient and carer focus groups and professional perception of supporting these needs was explored through interview (n=39). Although the sample was restricted to cancer patients and their carers, analyses for differences for palliative care patients were made throughout. Two significant changes in the psychosocial needs of palliative care patients were identified: an increased need for information about, and maintenance of control over, their futures. While these results do show a heightened psychosocial need for some palliative care patients, they must be reviewed with caution. The low response rate of this group of patients, 57 out of 380, may be attributable to the overzealous protection of palliative care patients (those felt not to be well enough to participate were excluded and, unlike the other groups, no reminders were sent). Further studies concur that the psychosocial needs suggested by Thomas *et al.* (2001) do exist (Taylor 1994, Lawton 2000, McNamara 2001, Johnston 2002), with other studies adding the importance of 'quality of life' and safety and security' (Copp 1999, McNamara 2001, Johnston 2002) for palliative care patients. The needs identified by all of these authors are discussed in greater depth below.

1.4.1 **Emotional expression**

The importance of **emotional expression** and a desire for **emotional wellbeing** occurs throughout psychosocial need literature (Law 2009, Rydahl-Hansen and Eriksen 2009, Skilbeck

and Payne 2003, Field 1989). A broad range of 'negative' emotions are described, for example: fears about the future (Fitzsimons et al. 2007) and of death (Copp 1997); feelings of depression over conditions and stress from hiding the fear from families (Chapple *et al.* 2006); and anger or sadness over care experiences (Wollin *et al.* 2006). 'Positive' emotions were also reported, though to a lesser extent, for example: patients feeling confident about the future because of confidence in their nurses (Conner *et al.* 2008); and joy or appreciation at care received (Kuuppelomaki 2003).

Skilbeck and Payne's (2003) systematic literature review exploring how clinical nurse specialists provide emotional support for palliative care patients supports the existence of emotional needs. A major finding was that the views of patients, carers and staff on what emotional support is differ greatly: patients and carers felt that support is gained through physical care, information giving and technical knowledge, whereas nurses stated that they provide emotional support as a specific, separate component of their role. Skilbeck and Payne (2003) also found that there is a common belief that emotional support, a confusing term, means the same to everyone; they found that this is not in fact the case. Though over a decade old these findings appear to have ongoing salience to contemporary practice. This confusion over the provision of emotional support within practice initiated a request for exploration into: what patients actually find supportive; whether emotional support is provided separate to, or in combination, with other aspects of care; and individuals' roles within interactions involving emotional issues.

Emotional needs interact with many other psychosocial needs, for example, Carter *et al.* (2011) found the variety of emotions encountered by men with end-stage prostate cancer impacted on their ability to cope with, and make choices about, life and their illness.

1.4.2 Rights

Respecting a patient's **right** to be **self-determining** were other commonly identified psychosocial needs (Roche-Fahy and Dowling 2009, Cannaerts *et al.* 2004, Csikai 2004). Giving patients control over choices and ensuring they have an active role in decision-making is a primary means to enabling self-determination (Pease and Finlay 2002, Volker *et al.* 2004a, Harstade and Andershed 2004, Kennedy 2005), though decision-making is often a joint process with HCPs (Bradley *et al.* 2010). Cannaerts *et al.* (2004) carried out a grounded theory study exploring the experiences of patients, relatives and staff working in two hospices in Belgium. Consensus was suggested across the participant groups: care enabled patients to 'enjoy' – a psychosocial concept - life as much as possible and this was facilitated through good symptom control and patient choice. Priority was given to physical needs, with psychosocial needs being attended to as a second priority, in line with Maslow's (1943, Frager *et al.* 1970) hierarchy of needs. The decisions patients participate in are many and vary from 'where care is given' (Street and Love 2005) and 'what care to accept' (Morgan 2001) to simple things such as 'when to get washed'. The type of decision appears not to matters, the most important thing to some patients is being allowed to 'take charge' of as much of their lives as possible (Carter *et al.* 2004), whilst other patients choose to relinquish their decision-making role (Sahlberg-Blom *et al.* 2000).

The ability to participate in decision-making can deteriorate alongside palliative care patients' physical conditions; when this occurs the scope for the psychosocial need of **autonomy** diminishes. The challenge of palliative care patients maintaining a sense of self – a psychosocial need in itself – was the subject matter of Lawton's (2000) ethnographic study of an English hospice. Observations were made of respite patients remaining 'social beings' while physically deteriorating, through continuing hobbies and the presence of memorabilia. Conversely, actively dying patients declined personal belongings and reminders of life or requested their removal. Lawton (2000) found that some patients appeared reluctant to discuss deeper issues,

choosing instead to 'live in the present' to avoid acceptance of impending death; some nurses supported such wishes, while others denied them. Disparity was observed between health care professional and patients' wishes and dying was often 'hidden' by moving patients into single rooms. These latter findings led to the suggestion that it may not be possible to meet a key ethos of palliative care and 'die with dignity' with Lawton requesting further exploration of whether palliative care can be what its aims to be. However, caution must be taken in accepting this claim as the study explores one hospice alone.

Wilson *et al* (2013) suggest a need to reconsider how autonomy is maintained for patients as they near the end of their lives: rather than being about decision-making, the focus of autonomy for these patients should be on ensuring care is carried in accordance to their current, or – in the case of patients who are no longer able to communicate – previously expressed, individual needs. The challenge is that patients' wishes often change as their condition deteriorates. Autonomy is viewed by a number of authors as being an important psychosocial need (Bergdahl *et al.* 2011, Johnston 2002, Csikai 2004).

The psychosocial need of **independence** as a right is often discussed in the literature (Seymour *et al.* 2003, Brereton *et al.* 2011, Johnston 2002). Being in receipt of palliative care in itself makes it likely that a patient will have deteriorating physical independence but this loss can be, at least partially, compensated for by meeting other psychosocial needs. Patients in Cotterell's (2008) study described independence in relation to physical tasks and other psychosocial needs: control of choices, self-determination, identity, self-esteem, relationships, emotional well-being, self-concept, and communication, while McClement *et al.* (2004) found that maintaining dignity could compensate for loss of independence.

To be treated with **dignity**, being considered as an 'individual of worth and value' (Royal College of Nursing 2008) rather than as a 'patient', is a regularly cited psychosocial need

(Beckstrand *et al.* 2006, Mok and Chiu 2004, Brereton *et al.* 2011, Gallagher 2012). One way of providing dignity is offering another psychosocial need: **privacy** (Casey *et al.* 2011, Roche-Fahy and Dowling 2009, Kirk 2003).

The psychosocial need of **individuality** is also commonly recognised (Spichiger 2008, Johnston and Smith 2006, James 1992). Individuality is about taking each patient's preferences into account (Bradley *et al.* 2010), and respecting them even when they are very different choices from the majority, such as a desire for isolation (Copp 1997). Alternatively, in McSteen and Peden-McAlpine's (2006) phenomenological study, one nurse described how she helped a patient meet his needs for individuality by helping him understand that what mattered to his significant others was who he was, not what job he had done.

The psychosocial needs of feeling **safe** (Harstade and Andershed 2004, Richardson 2002, Johnston and Smith 2006) and **secure** (Mok and Chiu 2004, Brannstrom *et al.* 2005, Johansson and Lindahl 2011) in both place of care and trusting those providing care, are considered to be important. These also include financial security (Seymour *et al.* 2003) despite some considering that financial support is a separate need (Adams 2005).

Fewer studies than expected were found that explicitly mentioned '**quality of life**' as a psychosocial need (Rydahl-Hansen 2005, Sahlberg-Blom *et al.* 2001, Wallerstedt and Andershed 2007). This may be because it is such an overarching aim of palliative care that it is not discussed, as Cannaerts *et al.* (2004) found the focus of care by all staff was on maximising patients' quality of life.

1.4.3 Coping

The many changes that occur to patients with palliative conditions result in distress if the psychosocial need of **coping** is not met (Canning *et al.* 2007, Rydahl-Hansen and Eriksen 2009, Copp 1999). Patients need to adjust, and cope with, lifestyle changes (Bradley *et al.* 2010,

Morgan 2001). A key aspect of coping is **acceptance** (Spichiger 2008, Canning *et al.* 2007, Parish *et al.* 2006). This includes accepting the deterioration of health that has resulted in a need for palliative care so patients can prepare for the future (Enes and de Vries 2004) and being **ready** for the outcome of death (Copp 1997, Costello 2006, Dale and Johnston 2011).

The challenge of meeting the latter psychosocial need was uncovered by Costello (2001) when he explored nursing dying older patients, by observing care then interviewing patients, nurses and doctors about what he had observed. Patients' requests, to nurses, to discuss their diagnoses and prognoses were denied by medical staffs' refusal for these discussions to take place. Similarly to McNamara (2001), nurses in Costello's (2001) study recognised the importance of psychosocial support: they labelled deaths as 'good' when they knew patients' psychosocial needs prior to them 'entering' the dying phase. However, contradictions were reported between what was said to happen and what actually happened: nurses talked about how important psychosocial support was but gave priority to physical care. And often, nurses were unable to recognise when they were providing psychosocial support: when nurses were interviewed about an observed assessment, which the researcher deemed to be psychosocial support, they were often oblivious to having carried out the assessment. It may be that Costello's (2001) variable level of participation in care during the observations may have restricted the researcher's opportunities to witness psychosocial care: by withdrawing to "a more passive observer role", he may have missed the chance of observing the psychosocial support that took place alongside the physical care of the patient. Similarly, in limiting the patients' interviews to informal conversations, he may have missed the opportunity to explore whether patients really wanted or needed psychosocial support. Minimising the views of patients puts into question the credibility of this study; Costello (2001) appears to be allowing his own preconceived ideas about patients' ability to understand psychosocial support to affect the data, thus skewing the results towards focussing on the views of nurses, a group to which he belongs.

Coping, acceptance and readiness are facilitated by patients **understanding** what is happening to them (Chapple *et al.* 2006, Spichiger 2008, Weber and Grohman 2004). Understanding was gained through seeking, and the receipt of, information (McIlfatrick 2006, Kennedy 2005, Herth 1990) with patients suffering "psychosocial distress" in its absence (McClement *et al.* 2004, p174).

Palliative care patients can have **hope** until their deaths though it changes from the desire to be well enough to continue to function in life, through a number of phases, until it focusses on being respected as an individual (Herth 1990). The importance of hope has been suggested in a number of studies (Duggleby and Berry 2005, Johnston and Smith 2006, Buckley and Herth 2004) though not as many as might be expected.

1.4.4 Identity

The other psychosocial needs identified in the literature relate to palliative care patients' **identities** (Bergdahl *et al.* 2011, Rowlands and Noble 2008, Weber and Grohman 2004, Sayers and de Vries 2008). Patients seek a sense of normality (Devery *et al.* 1999), while for others, it is about not being alone (Lawton 2000, Bradley *et al.* 2010) or maintaining integrity (Morgan 2001, Dale and Johnston 2011). Devery *et al.* (1999) combined the views of patients, caregivers (family or friends who supported the patient) and healthcare professionals in their study, looking at the best way to measure outcomes in palliative care. They found that the greatest value patients and caregivers gained from palliative care practitioners was their investment of time in honest, open, two-way communication about their situation, where all parties were talking on the same wavelength. These conversations gave patients a sense of normality and well-being, despite the fact that at times they had to negotiate with staff in order to have their needs met. Devery *et al.* (1999) concluded it was the relationship built between practitioners, patients, and their caregivers that enabled them to talk on the same wavelength.

Identity can be maintained by patients completing practical activities or ensuring financial security for themselves and their significant others (Conner *et al.* 2008) which, on some occasions, has been the only way patients express psychosocial needs. For example, in Carter *et al.*'s (2011) study on the supportive needs of advanced prostate cancer patients, participants made little explicit reference to psychosocial needs, however, their focussing on the physical aspects of living uncovered the importance of maintaining identity and relationships (Lawton 2000). Sharing experiences affirms identity (Rydahl-Hansen 2005, Taylor *et al.* 2008), strengthens self-concept and maintains relationships (Sahlberg-Blom *et al.* 2001).

Copp (1999) took a symbolic-interactionist approach to comparing nurses' and patients' experiences of care in a hospice in a bid to develop modern theories on death and dying. In doing so she discussed many aspects of nurses' psychosocial support. Dying patients needed to see themselves as 'living on' – for example, in the memories of others – so that their lives still had some worth. Similar to the findings of Lawton (2000), Copp's (1999) main proposition was that: individuals' often deteriorate physically at a difference pace than psychologically, socially and/or spiritually, when this disparity occurred patients were not 'ready to die'. Nurses were observed using communication skills to respect denial and/or patients' choices not to disclose psychosocial needs and putting time and effort into relationship-building. The suggestion is made that nurses devote much time to assessing patients' psychosocial states in order to plan care and facilitate an acceptance of impending death but how they do this and whether they are successful is not explored. Although descriptions are given of the patients' conditions and the input provided by the hospice, reference to actual care are missing in publications of this study.

Part of having an identity is still having **recognition of a role** in life (Spichiger 2008, McSteen and Peden-McAlpine 2006, Wollin *et al.* 2006). Patients desire to maintain their usual role (Lawton 2000, McClement *et al.* 2004), including employment (Bradley *et al.* 2010). When patients become unable to continue their roles as they did previously, they can adapt so as to

recreate their roles in order to still feel valued in life (Enes and de Vries 2004). At times, the psychosocial need of role recognition is met through a sense of belonging (Brannstrom *et al.* 2005), either as a family member or as part of a society, even that of the ward.

Having a **positive self-concept** is also a psychosocial need (Bergdahl *et al.* 2011, Brereton *et al.* 2011, Roche-Fahy and Dowling 2009, Buckley and Herth 2004). Self-concept is about redefining meaning and purpose in life (Duggleby and Berry 2005, Herth 1990, Copp 1997), coping with the toll of realising that ambitions in life cannot be met (Wollin *et al.* 2006, Haraldsdottir 2011), and through confidence (Conner *et al.* 2008, Richardson 2002) in still being valued by others as an individual (Seymour *et al.* 2003, Bradley *et al.* 2010, Lawton 2000).

Self-esteem is closely linked with self-concept but is the psychosocial need of viewing yourself in a positive light. It is explicitly identified in a few studies (Mok and Chiu 2004, Wollin *et al.* 2006, Sayers and de Vries 2008).

Having **relationships** (Dale and Johnston 2011, Duggleby and Berry 2005, Wollin *et al.* 2006) and sustaining them throughout a palliative illness (Beckstrand *et al.* 2006, James 1992, Johansson and Lindahl 2011) are both means to achieving many psychosocial needs and is a psychosocial need itself. McNamara's (2001), during her exploration of palliative care nurses attitudes to, and actions in the face of, patients' deaths, found it important that whilst patients are dying they maintain some form of social interactions (McNamara 2001). However, a mixture of reactions to what was on offer within these interactions was observed: although nurses offered psychosocial support on occasions, the issue of impending death was hidden behind the medicalisation of palliative care. Discussions around fear of death were avoided. Without relationships, patients stop having an influence on the lives of their significant others (Lawton 2000) and encounter a 'social death' (Glaser and Strauss 1965). This can be prevented

by continued social interactions with the other people patients encounter (Fitzsimons *et al.* 2007).

The **companionship** patients receive from other patients (Bradley *et al.* 2010, Rowlands and Noble 2008, Kirk 2003, Arantzamendi *et al.* 2012) and formal or informal carers (Oliver 2010) is considered by some to be a separate psychosocial need from relationships (Wollin *et al.* 2006, Rydahl-Hansen 2005, Canning *et al.* 2007). Without companionship patients face isolation (Lawton 2000, Fincham *et al.* 2005). Relationships and companionships are facilitated by another psychosocial need: **communication** (Chapple *et al.* 2006, Weber and Grohman 2004, Johnston and Smith 2006).

1.4.5 Psychosocial needs and their place within Maslow's hierarchy of needs

The literature on psychosocial needs discussed above is reminiscent of, though not explicitly referring to, Maslow's (1943) work on a hierarchy of needs. Maslow's work is, therefore, considered as a theoretical backdrop to this thesis. Maslow's hierarchy of need (Maslow 1943, Frager *et al.* 1970), although written with an aim of explaining what motivates humans, is respected as a model demonstrating the range of needs people have. In health psychology of nursing, it is still taught in undergraduate curricula and referred to by many authors (Walker 2009, Upton 2010, Priest 2012, Gross and Kinnison 2014). The theory asserts that people have different levels of needs, which become harder to obtain the 'higher up' the levels an individual attains. The basic needs are said to be 'physiological' and, usually, only once these are met does an individual seek gratification of the higher needs. Higher needs are, in order of progression: 'safety and security', 'love and belonging', 'self-esteem' and 'self-actualization'. Some of the types of needs identified in the literature above, are included in the naming of Maslow's levels: 'safety and security' are rights; and love and self-esteem are part of identity Maslow (1943). Even Maslow's initial diagrammatical model of his theory identify all of the other categories

of psychosocial needs, such as: acceptance in self-actualisation; individuality as part of self-esteem; and role recognition in safety and security (Maslow 1943). When Maslow's theory has been updated to match modern day society (Kenrick *et al.* 2010) these psychosocial needs continue to be considered within higher levels of need (Peterson and Park 2010). The only group of needs within the literature not clearly represented in Maslow's hierarchy are emotional expression, though some stronger emotions (fear, anxiety, and panic) are discussed in relation to safety and security needs. There are two possible reasons for the lack of Maslow's discussion of emotions. First, the lack of discussion of less strong or positive emotions is that Maslow's is a theory of motivation, while emotions are more responses to whether individuals gain what motivates them. Maslow indicated a need for further exploration and understanding on the overlaps between emotions and motivation. The second possible rationale for the paucity of Maslow's discussions on emotional expression may be linked to the abundance of physiological needs. So many emotions manifest themselves physically, such as happiness with a smile or sadness with tears, that Maslow may have considered emotions to be physiological. Emotional expression may have been one of the many physiological needs to which Maslow did not explicitly refer. Considering Maslow's (1943) theory was written to describe motivation, a major part of which appears to be psychosocial, within the human race, how then does Maslow's theory related to people who are unwell?

Maslow's theory connects many of the psychosocial needs discussed in palliative care literature together. Palliative care in-patients have physiological needs underpinning their admission, for example symptom management. Does the need to have these physiological needs met, therefore, preclude the desire for higher psychosocial needs? Maslow mentions three ideas that suggest this may not be the case. Firstly, he recognised that people do not always achieve gratification in one level of need before seeking higher level needs, Secondly, not everyone satisfies the levels of needs in order. For example: an individual may gratify their self-

actualisation needs, by being recognised for their talents, but in working to achieve this recognition has sacrificed personal relationship and missed gratification of love and belonging needs (Maslow 1943, Frager *et al.* 1970). Thirdly, there is recognition that previous deprivation of having a need met makes future deprivation more acceptable. This latter point suggests the possibility that patients who have progressed through previous illness, may now seek higher needs with an awareness that their physical needs cannot be gratified. An alternative view is that psychosocial needs may be some of the "prerequisites for the basic needs satisfactions" (Frager *et al.* 1970, p22) as they include: expression, communication, autonomy, and understanding. The points raised above through consideration of Maslow's theory leads to the question: how does being an in-patient, and having had an illness deteriorate, affect the needs which patients seek? Maslow's theory on hierarchies of need therefore offers a useful framework for considering the expression and response to psychosocial needs in palliative care in-patients.

1.4.6. Summary of Psychosocial Needs

The literature identified a number of psychosocial needs, which are interconnected. Figure 1.1 is a concept map of these psychosocial needs and my conceptualisation of their inter-connections. The psychosocial needs included in the map are taken from literature involving participants who represent the demographics of the current adult palliative care patient population. A higher proportion of the palliative care patients in the literature cited above had cancer; however, patients with a variety of life-limiting illnesses also participated in the studies. No discernible difference between patient groups was identified or noticed.

Knowing what patients' psychosocial needs are should enhance the provision of palliative care (Beckstrand *et al.* 2006). McIllmurray *et al.* (2001) suggest that if healthcare providers recognise and support the psychosocial needs of patients they can prevent the development of

psychosocial morbidity. There are, however, challenges. Not all psychosocial needs can be met for all patients, for example, Mok and Chiu (2004) reported an inability to meet patient's emotional psychosocial needs because of a need to respect patients' desires for privacy through not discussing them. Additionally, psychosocial needs are not always explicitly expressed (Canning *et al.* 2007), so nurses may not recognise them. The literature indicates disparity between what patients and AHPs see as important. For example: are physical needs prioritised above psychosocial needs or is meeting the former a means to meeting the latter when facing a shortened life span?

The discussion above demonstrates that psychosocial needs are overlapping and interconnected. Four groups of needs were identified and relate to: emotions and the expressions thereof; the right to be self-determining and treated as an individual; understanding and coping with illness and impending death, whilst maintaining hope; and retaining an identity whilst sustaining relationships. However, what the literature does not tell us is: whether these are the psychosocial needs of hospice in-patients; how these needs are expressed; or how nurses immediately react to them. A description of the needs encountered during my time in the field and how they are expressed occurs in Chapter Five, while Chapter Six explores how the nurses responded to them.

1.5   Conclusion

There is agreement that a component of nurses' roles is psychosocial care. The speciality of palliative care is an ideal setting in which to explore nurses' psychosocial support, as meeting patients' psychosocial needs is an explicit aim of palliative care. As documented above, there is an extensive body of literature which reports on the psychosocial needs of palliative care patients. The majority of the studies above, and those cited in the following chapter, also indicate that there are a variety of ways in which these psychosocial needs may be met;

however, there is a lack of evidence on what needs are expressed by hospice in-patients and how nurses actually respond to these in practice. The main aim of this study is to go beyond the points described in existing evidence and find out exactly what, if anything, nurses do in an attempt to immediately support the psychosocial of palliative care patients. This is an especially pertinent time for research into nurses' psychosocial support, in palliative care and all areas of nursing, as the importance of this aspect of care in being highlights in many policy documents (Francis 2013, NHS Improving Quality 2014, The Scottish Government 2015, Department of Health 2016)

In the following chapter I will discuss the current beliefs on how nurses support psychosocial needs, identifying some of the barriers to this aspect of care, and justifying the need for the research carried out in my study.

Chapter 2: An introduction to previous research on nurses' psychosocial support of palliative care in-patients

In Chapter One I identified that there is an expectation of nurses to provide psychosocial support as a component of their daily care of patients and this aspect of care is a key area of focus in palliative care. Outlining what existing literature proposes to be the psychosocial needs of palliative care patients, and relating this to Maslow's (1943) hierarchy of needs, raised a number of questions. The main questions in this thesis are what are the psychosocial needs of palliative care in-patients, how are these expressed and how do nurses immediately support them. In this chapter, I discuss the current views on how nurses support the psychosocial needs of palliative care in-patients.

There is an extensive range of literature, of a variety of methodologies and foci, which discuss aspects of nurses' psychosocial support: sometimes focussing on a specific aspect of psychosocial care; sometimes evaluating palliative care as a whole. All of these studies include descriptions of at least on of the types of psychosocial need, as discussed in chapter One.

This chapter is organised into four sections. Firstly, I consider the broad question of whether the providers and recipients of palliative care have an expectation for psychosocial support from nurses. The following sections explore in more depth the three most commonly referred to issues within the provision of psychosocial support by nurses: the nurse-patient relationship; the impact of the organisation and environment; and the concept of 'being there'. A number of the studies referred to in this chapter are included in my table of key studies which either focus specifically on psychosocial aspects of nursing care of palliative, or dying, in-patients or were seminal pieces of work identifying the role of palliative care nurses (Table 1.1).

2.1   Is psychosocial support a component of palliative nursing?

The demand for nurses to offer psychosocial support, outlined in Chapter One, comes from nursing and healthcare theorists and policy makers. Literature exists which addresses whether: patients have an expectation of nurses to offer psychosocial care and whether nurses see this as their role. Despite research reporting both significant others (SOs) (Fitzsimons *et al.* 2007) and patients (Lawton 2000) to be the main source of psychosocial support for palliative care in-patients, many studies show patients viewing nurses as holding the ideal position to support patients' psychosocial needs (Duggleby and Berry 2005, Herth 1990, Fitzsimons *et al.* 2007). Similarly a number of nurses consider psychosocial support to be a large component of their palliative care role (Kuuppelomaki 2003, Costello 2001, Wallerstedt and Andershed 2007), and patients value this support (Richardson 2002, Johnston 2002, Taylor *et al.* 2001).

Psychosocial support is a key thread running through Davies and Oberle's (1990, 1992) much respected definition of palliative nursing. The participating specialist palliative care nurse was described as someone who: 'valued patients' by supporting their emotions, 'connected' with patients on a personal level, encouraged independence through 'empowering' and facilitated maximum quality of life. The outcome of this grounded theory study was the creation of a model of nursing whereby patients are: given a feeling of continuing self-worth through emotional support; enabled to maintain maximum potential independence; respected as individuals; assisted with physical care; and involved in a personal relationship with their nurse. However, this study explores the perception of one nurse's care in a community setting, in Canada, a number of years ago. The changes in palliative care over the years and constraints of providing care in an organisational setting may make the reality of offering such extensive psychosocial support as a component of palliative nursing on a hospice ward very different. Other palliative care nurses agree in the importance of psychosocial support: in response to questionnaires, Finnish nurses (*n=328*) suggested emotional support for palliative care was a

large and integral component of their work (Kuuppelomaki 2003). Similarly, Johnston's (2002) phenomenological interviewing 22 nurses and 22 patients on what constitutes an expert palliative care nurse identified psychosocial support as a key attribute. The nurses reported providing psychosocial support through: providing comfort and emotional support; developing nurse-patient relationships; and 'being there' for, and spending time with, patients (Johnston 2002). In all of these studies nurses are describing their provision of psychosocial support, but it remains unclear whether this is what happens in practice or nurses perceptions of what they should be doing.

Patients (*n=5*) and carers' (*n=6*) perspectives on psychosocial support were compared to those of their nurses (*n=15*) by Taylor *et al.* (2001) who explored what constitutes valuable palliative nursing. Patients and carers felt the personal qualities of the nurses - their ability to form relationships and be sensitive, genuine and empathic - were most important; whereas the nurses focussed on the 'doing' aspects of their jobs. These findings are in opposition of previously discussed studies (Davies and Oberle's 1990, 1992, Johnston 2002, Kuuppelomaki 2003, Skilbeck and Payne 2003) which suggest nurse give priority to psychosocial care. The relationship between researcher and participant may have affected the results of this study: interviewers asking about care they themselves provide may make patients and relatives reluctant to provide disparaging example of care; and being the manager, or educator, of the nurses may make the nurses wish to impress that they are doing their jobs correctly rather than discussing their personal attributes. These opposing views strengthen the need for further research into the realities of psychosocial palliative nursing.

The actual practice of nursing care was explored in three studies which centred around data from tape-recordings of patient assessment interviews (Booth *et al.* 1996, Heaven and Maguire 1997 & 1998, Wilkinson 1991). Heaven and Maguire (1997 & 1998) carried out a broader study to identify the overall needs of palliative care patient in two English hospices. They compared

the recorded nurse assessments to interviews carried out by researchers which included the use of formal concern eliciting tools (concerns checklists, Hospital Anxiety and Depression Scale, and Speilberger Anxiety State Score). Nurses reported mostly physical concerns while those revealed by patients to researchers were more frequently psychosocial. The two most common concerns were psychosocial: loss of independence and being a burden. Nurses recognised under half (42%) of patients reported concerns and documented less (19%). This study highlights the challenge of nurses recognising psychosocial needs. This disregarding of psychosocial needs by nurses led Booth *et al.* (1996), in a linked study (using the same hospices), to investigate nurses (n=41) behaviours in blocking communication about psychosocial support. A number important points concerning in-hospice psychosocial nursing were identified. The majority of nurses were aware of their use of blocking of blocking tactics. Their use was justified by three intentions: to protect patients and/or nurses from emotional pain; because nurses believed the blocking action would be more beneficial to the patient; or from fear of causing the patients 'harm' by saying the wrong thing. Nurses' use of blocking tactics increased proportionately to patients' expressions of more emotional needs. These findings corroborated an earlier study by Wilkinson (1991) who explored facilitating tactics alongside blocking tactics. Blocking tactics could also be used by nurses to control the patient assessment and ensure they gain only the information they needed in the interaction. Wilkinson (1991) suggested the nurses fell into one of four categories of communicators: 'facilitators', 'ignorers', 'informers' or 'mixers'. Each of these in turn either: identified needs well; avoided patient needs, focussing instead on their own agendas; prioritised the giving of information and opinions; or used a variety of these styles. In these three studies, there is a possibility that blocking tactics were used more in these interactions in response to nurse anxiety over being tape-recorded. Despite this and although these studies are dated and nursing, especially its organisation, has changed greatly since these

times, the questions the findings raise remain today. What is interesting to explore is whether such tactics are used today in everyday practice.

The variability in nursing tactics to support or inhibit psychosocial needs has been recognised in studies using data collected from a more participant-observational stance. James' (1992) ethnographic study of all staff in a British hospice found variability in offers of psychosocial support. Nursing care of the dying appeared to a process of balancing organisational constraints with physical and emotional work; the balance of workload being unequal in favour of physical care. Some health care professionals suggested they would, on occasions, avoid psychosocial support and focus on tasks or aspects of care where an improvement would be clearly noticed. However, others considered focussing on tasks, or formal conversations, to be part of psychosocial support: effective interactions could enable physical activity and enhance feelings of well-being. Similar difference in the provision of psychosocial support in another hospice were identified in Lawton's (2000) study. Despite not focussing specifically on nursing, Lawton discusses many interactions where psychosocial needs were expressed: some nurses supported these needs, while others ignored them.

Variations in psychosocial support were also reported in Li's (2004, 2005) observational study on nurses exhibition of 'niceness'. Niceness was proposed to facilitate psychosocial support by enabling nurses to be 'genuine' with patients. 'Being genuine' is considered an attitude nurses can portray to provide psychosocial support by demonstrating respect and compassion for patients, making them feel welcome and important (Gallagher 2012, Johnston 2002, Seymour *et al.* 2003, Richardson 2002, McClement *et al.* 2004) Nurses in Li's study demonstrated 'niceness' to different degrees with different patients. Data was interpreted to suggest that nurses viewed patients as being on a continuum of troublesome to credible depending on their physical and emotional status (Li and Arber 2006). The nurses forgave those patients who were 'troublesome' as they attributed their reactions to their ill-health, but there is no indication of

nurses supporting the issues that lead to the 'troublesome' nature. The focus of the study discussed in these three papers appears to be more on the impact of emotion on the relationship between patient and nurse, rather than whether the emotional needs of patients are met. There is an underlying suggestion that the nurses' perceptions of the patients and their desire to be viewed in a favourable light may result in a suppression of psychosocial support. A lack of reporting of patient views was one limitation of this study. Nurses suggest being genuine is a vital characteristic required in order to communicate well with patients, respond to psychosocial needs and ultimately enhance nurse-patient relationships (Li 2004, Buckley and Herth 2004, Canning *et al.* 2007, Sayers and de Vries 2008). The importance of building nurse-patient relationships is often raised in literature on psychosocial support.

2.2 Nurse-patient relationships as a prerequisite of psychosocial support

The nurse-patient relationship is regularly referred to as a central tenet of palliative nurses' provision of psychosocial support. This section gives an overview of current thoughts on the relevance of the nurse-patient relationship in psychosocial support by drawing on existing evidence concerning in-patient palliative care. Many authors found nurses consider the creation of an effective, reciprocal, trusting, relationship with patients to be the gateway to effectively meeting patients' psychosocial needs (Johnston 2002, Walshe and Luker 2010, Arantzamendi *et al.* 2012, Li 2004). Patients are reported to agree that nurses' ability to form relationships is a key quality in defining valuable palliative nursing (Taylor *et al.* 2001, Adams 2005, Cohen *et al.* 2001). The interaction between these relationships and psychosocial support is considered to be two-way: forming the relationship facilitates the provision of psychosocial support and offering support for psychosocial needs enables creation of the relationship (Canning *et al.* 2007).

But what is this relationship and how is it thought to be created? Bergdahl *et al.* (2007) used semi-structured interviews of eight 'expert' palliative home-care nurses to attempt to answer these questions. Their result was a model in which nurses combine their ability to recognise the patient as a unique individual, with their intuitive and expert knowledge, and their desire to do the best for the patient. Nurses created relationships by communicating effectively, being empathic, and remaining open to patients' wishes (Bergdahl *et al.* 2007, Luker *et al.* 2000). Subsequent action research and observational studies support these ideas (Bergdahl *et al.* 2011, 2013). Once the relationship is formed, nurses can discover patients' preferences at an early stage of their illness in order to facilitate autonomy as their condition deteriorates (Wilson *et al.* 2013). This, in turn, is thought to increase the chance that deaths can be labelled as 'good' because the nurses know patients' psychosocial needs prior to them 'entering' the dying phase (Costello 2006). However, as concerns around dying were rarely discussed in Costello's study and documentation of psychosocial needs appears to be low (Wilkinson *et al.* 1991) this appears to be an unsupported claim. Other questions have arisen which challenge the importance of nurse-patient relationships in psychosocial support.

Firstly, it has been suggested that nurses face the dilemma of creating a close relationship in order to provide psychosocial support or keeping an emotional distance from patients to minimise their own distress (Kuuppelomaki 2003, Blomberg and Sahlberg-Blom 2007, Johansson and Lindahl 2011). Olthuis *et al.* (2006) advance these ideas by proposing that the relationships nurses form with patients fall somewhere on a continuum between "contact" and "connection" (p30): a nurse who uses effective communication skills connects with patients; whilst being task orientated, and failing to meet patients' psychosocial needs, allows only contact and is unethical care. It is proposed that nurses make contact with patients at a deeper level to achieve the goals of palliative care, utilising their experience and knowledge to communicate effectively with patients and maintain the balance between providing the best

care for each patient and meeting the rules of the organisation in which they work. However, whether, and how, this is actually achieved, is not discussed. One alternative view is that nurses develop a type of friendship with patients in order to provide psychosocial support (Nagington *et al.* 2013). These connections are differentiated from other friendships and are formed by carrying out physical tasks to help patients.

Additionally, nurse-patient relationships are regularly referred to as something that need to be developed, rather than an immediate connection. If developing nurse-patient relationships is so important for psychosocial support, does this mean patients' psychosocial needs cannot be met when relationships are not formed? Relationship-building can be restricted by attempts to meet the challenges of organising care (Luker *et al.* 2000, Newton and McVicar 2013) but it is necessary also to consider whether patients require this relationship. Patients report open communication creating an immediate personal connection with their palliative nurses: hospice nurses are able "to go deeply, quickly, sensitively into sensitive areas of patient lives" (Newton and McVicar 2013, p1669, Richardson 2002, Seymour *et al.* 2003, Devery *et al.* 1999).

Further studies have identified that developing a nurse-patient relationship may not be a prerequisite for psychosocial support. One such example was when Cohen *et al.* (2001) explored the effect of palliative care on patients' quality of life. Eighty-eight patients were interviewed about their quality of life and completed a combination of validated, reliable quality of life tools following admission to one of five Canadian palliative care units. The results suggest an overall improvement in quality of life, including psychological and social well-being. Nurses were reported as having both positive and negative impacts on psychosocial well-being, dependent on: whether the nurses were available when the patients needed them, and the nurses' behaviours and attitudes. The environment in the unit was also reported as being a major contributor to quality of life. These findings match those of Ingleton (1999) who combined survey, non-participant observation, and interview data to evaluate one specialist palliative care

service in the UK. Ingleton concluded the friendly, open atmosphere of the hospice gave the patients' and carers' a positive palliative care experience. However, in discussing her findings, Ingleton (1999) rarely refers to her observations, instead focussing on the patient and carer interviews; she never mentions the staff's views. Recognition is given that the positivity of these findings are likely to be skewed by gratitude for the service and the researcher's involvement with the team. Had the analysis of data included a comparison of what the researcher observed with what the interviewees said, as advocated in an ethnographic approach (Morse 1994), it could have produced some evidence relating to whether the nurses really were available and how the atmosphere was created. What would be useful to know is how nursing action helps to bring about the positive changes reported by both of these samples of patients. That it was not just a response to being removed from the difficult situation that necessitated admission. Additionally, it would be interesting to know whether the hospice environment truly affects psychosocial support as, subsequent studies, including observational ones, question whether 'psychosocial climates' do exist in hospices (Heaven and Maguire 1998, 1997, Haraldsdottir 2011).

2.3 Environmental and organisational influences on psychosocial support

It has been proposed that palliative care ward environments facilitate nurses' psychosocial support. These are described as having: patient allocation in force; charge-nurses as active role-models; nurses who are encouraged to be autonomous practitioners; and consideration given to psychosocial aspects of care during hand-overs (Wilkinson 1991, Cannaerts *et al.* 2004, Williams and Kristianson 2008).

Cannaerts *et al.* (2004) agree with Ingleton (1999), Cohen *et al.* (2001), and Johnston and Smith (2006) that palliative care patients' quality of life can improve on admission to a hospice. This improvement is attributed to the skills, team-working, and caring attitude of the staff: the higher

staff to patient ratios allowing nurses to more time to spend with patients, in an environment more conducive to living. However, these results appear skewed. Reports of this study focus on the interview data and appear – from all participant groups - to be a comparison to the care provided in acute hospital: all participants suggested that moving to the hospice resulted in an improvement of care. Some data excerpts include indications that psychosocial support was not consistently offered in the hospices, for example: patients indicating that nurses explored psychosocial needs but did not subsequently communicate the support offered amongst the team; or medication being prescribed for anxiety without discussions arounds its cause. James (1992) observed a different perspective of higher staffing numbers in hospices: the heavier workload necessitated the increased proportion of nurses, but as a substantial number of these worked part-time continuity of care was hindered and psychosocial support inhibited. Other studies indicated the value of continuity of care in improving psychosocial support (Beckstrand *et al.* 2005, 2009, Adams 2005). The allocation of the same nurses to look after the same patients on subsequent shifts, is considered to facilitate relationship development (Johansson and Lindahl 2011), decision-making (Sahlberg-Blom *et al.* 2000) and feelings of safety (Harstade and Andershed 2004).

Conversely, it can be argued that this psychosocial environment is partly created by the attitudes and characteristics of the nurses, not their individual presence, that facilitated psychosocial support. Presenting an attitude of being available, willing to spend time with patients, and flexible is espoused as the ideal approach for psychosocial support (Chapple *et al.* 2006, McIlfatrick 2006, Wollin *et al.* 2006, Canning *et al.* 2007). James (1992) observed nurses, especially auxiliaries, giving patients the feeling that nurses were always available for them by adapting their care according to patients' choices. However, nurses are not consistent in offering availability (Cohen *et al.* 2001) or flexibility in their work: Rydahl-Hansen and Eriksen's (2009) observations found that once hospice nurses had planned their shifts they were reluctant to alter

their plans: nurses failed to notice psychosocial needs as they attempted to complete a number of practical tasks.

The nurses in Kuuppelomaki's (2003) study identified environmental and organisational issues in relation to the provision of psychosocial support, reporting a number of challenges. They felt the increasing number of palliative care patients - due to the evolution of the speciality and its expansion for a much wider range of conditions - reduces their ability to offer psychosocial support because of a heavier workload. They also reported feeling pressure from their colleagues to complete their share of a shift's workload which hindered their willingness to offer psychosocial support. The range of practices and challenges observed in Kuuppelomaki's (2003) study were also identified in Field's (1989) participant-observation studies of palliative care nursing in general hospital wards and the community. Field found that the majority of nurses wanted to provide psychosocial support but were challenged in their attempts to do so by: their lack of experience and/or education; disparity with medical colleagues over what they should discuss with patients; and organisational pressures. Field (1989) identified palliative care nurses' lower level in the hierarchy of healthcare professions as a major barrier to nurses' provision of psychosocial support. Although this study is dated, and the role of nurses and palliative care has altered quite extensively, it still has value today. The issues reported by Field (1989) have been reflected in a variety of research over the proceeding twenty years, with some studies identifying the provision of effective psychosocial support for palliative care patients, others concluding that physical care and achieving workload takes priorities and a final group illustrating a variety of care. The question then remains over whether staffing levels and organisational challenges prohibit psychosocial support or is there an incorrect expectation of what psychosocial support nurses can offer in everyday hospice life?

2.4 Nurses' 'being there' as an expectation of psychosocial support

Is the debate over whether psychosocial support is really offered more to do with expectations of how it is offered? Studies that identify psychosocial support as missing illustrate palliative care nurses as focussing on tasks instead of, for example, sitting down with a patient and discussing their concerns (Beckstrand *et al.* 2009, Johnston and Smith 2006, Haraldsdottir 2011). When availability, as discussed above, is matched by nurses being willing to spend time with patients, psychosocial support is considered more effective (Richardson 2002, Morgan 2001, Johnston 2002, Seymour *et al.* 2003, Bradley *et al.* 2010). This is referred to as 'being there' and can mean nurses simply sitting with a patient. 'Being there' is especially valued, by nurses, when it prevents patients who are dying from being alone in a single-room (Beckstrand *et al.* 2006, Hopkinson *et al.* 2003, Kuuppelomaki 2003, Benner 1984, Rowlands and Noble 2008).

Haraldsdottir's (2011) ethnomethodological study of two wards in a Scottish city-based hospice, sought to explore the idea that nurses provide psychosocial support by 'being there' for patients. Analyses of observations of care and meetings, and informal conversations, concluded that nurses adhered to an organisation-led, task-oriented, routine of working and nurses were never observed spending time purely talking to or sitting with patients. Nursing time spent with patients carrying out physical care was not respected and often registered nurses were disturbed during care episodes. Completing tasks seemed to take priority over patients' needs. The psychosocial needs of patients were not considered in organisational aspects of care. This was justified by the suggestion that avoiding psychosocial needs is a useful coping mechanism: patients would cope better with the challenges of their disease, through avoidance; and nurses could manage their workload more effectively. On the occasions when nurses did respond to patients' psychosocial needs, they were observed changing the subject or making light of the psychosocial need. However, the absence of 'being there' as described above does

not equate to an absence of psychosocial support, it simple means the concept was not witnessed (Haraldsdottir 2011). Patients were not asked about their perception of, or desire for, nurses 'being there'. Two main concerns exist with the suggestion that a lack of 'being there' equates to a failure of ward nurses to provide psychosocial support.

Firstly, what are patients views about 'being there'? Patients in Johnston's (2002) study were reported as valuing nurses 'being there' but no exploration was made of what patients meant by this: was it spending time with patients or simply that the nurses were available? Johnston's (2002) study gives valuable insights into what patients and nurses perceive as important qualities in palliative care nurses. However, use of the phenomenological approach fails to illustrate the reality of how care is provided in practice and has the potential of researcher bias from preconceptions from her own palliative care nursing background. Taylor (1994), in her observational study, gives an alternative patient view to the concept of 'being there', suggesting it is emotional support and physical care provided simultaneously. This view reflects the way psychosocial support is described by patients in both Skilbeck and Payne (2003) and Cannaerts *et al.* (2004) studies as part of practical interactions and by other patients who request nurses combine psychosocial support with other aspects of care such as symptom control (Seymour *et al.* 2003, Buckley and Herth 2004). These findings suggest that perhaps 'being there' in the way patients, not nurses, desire may occur. The second concern about the concept of 'being there' relates back to the organisational issues of psychosocial support. Some palliative care nurses feel that being with patients in this way is 'not getting on with your work' (James 1992, Roche-Fahy and Dowling 2009).

The variation between the findings, and the age of the studies, discussed in this sections support the value of carrying out further observational studies of hospices. One of the questions that arises is: have the organisational constraints of hospices changed over the years so that nurses

can no longer find the time for the 'being there' ideal of psychosocial support? Or, in reality, is 'being there' a much sought after concept that has rarely existed for ward nurses?

2.5 Conclusion

The four sections above all raise valuable points that demand reconsideration of whether nurses can offer psychosocial support in a hospice ward, and, if so, how. As with the literature reviewed in Chapter One, Maslow's (1943) hierarchy of needs can aid this exploration of in-patient hospice nursing. When the studies above found that psychosocial support was provided, patients described higher levels of psychosocial needs being met by specialist nurses. The key facilitator for this support was proffered as the development of a nurse-patient relationship. When studies reported care by ward nurses, there was a more common suggestion that nurses avoided patients' psychosocial needs, focussing instead on completing their duties for the day.

Two main issues arise from the literature discussed in the previous chapter and above. Firstly, there seems to be relative agreement on the types of psychosocial needs palliative care patients have, which are illustrated in Figure 1.1. However, there is little understanding of whether and how these needs are expressed to nurses by palliative in-patients. Answering these questions is the first aim of this study. Secondly, the studies above present opposing views over a number of issues, including: the existence of a 'psychosocial climate'; whether physical or psychosocial care takes priority; and the importance of building nurse-patient relationships. This continuing debate suggests there may be a different way to consider how psychosocial support is truly offered. The extent to which psychosocial support is really offered by palliative care nurses remains unclear. Further studies are required to explore the reality of practice in specialist settings to understand how nurses can more fully meet patients' psychosocial needs. The first step in meeting patients' psychosocial needs is in recognising and acknowledging them; this study identifies whether and how nurses do this immediately after the needs are expressed.

A common limitation across the studies reviewed in this chapter is that they have relied on self-report data (Devery *et al.* 1999, Taylor *et al.* 2001, Johnston 2002, Kuupelomaki 2003). Caution must be taken in regards to self-report studies as research participants can be unwilling to voice criticism of their care (Nagington *et al.* 2013). What is indicated is the need for evidence generated from observation, which is divorced from the proclivities of individuals to misrepresent actions. A few studies have adopted an observational method (James 1992, Ingleton 1999, Lawton 2000, Haralsdottir 2011) which enrich the evidence base. However, they do not explore the minutiae of psychosocial needs of palliative care in-patients or how nurses respond to them. Nor do they match their interviews to the observations on the care provided (Skilbeck and Payne 2003, Mok and Choi 2004, Walshe and Luker 2010, Herber and Johnston 2013) thereby failing to provide an all-inclusive exploration of the reality of nursing care of patients. The literature reporting psychosocial needs and their support in palliative nursing has a paucity of theoretical frameworks. As noted in Chapter One, Maslow's hierarchy of need may be a useful theoretical lens with which to view the literature and explore nurse psychosocial support in hospice wards.

The first two chapters of my thesis have identified a need to develop a clearer understanding of the reality of palliative care nurses' provision of psychosocial support. My study contributes to this understanding by exploring, for the first time, whether and how palliative care in-patients in one ward express their psychosocial needs to nurses and how the nurses immediately respond. In the following chapters I discuss my study which explores the aims above. Chapters Three and Four discuss methodological considerations, while Chapters Five and Six present my findings. This thesis is concluded by a discussion comparing the literature to my findings (Chapter Seven).

Chapter 3: Methodological Considerations

My primary research question is:

- How do nurses immediately respond to palliative care in-patients' expressions of psychosocial need?

In answering the primary question, I also consider the secondary questions of:

- What psychosocial needs do palliative care in-patients express?

- How do palliative care in-patients express psychosocial need?

- In what way do nurses' immediate responses to psychosocial needs vary?

Answering these questions will offer a new understanding of the aspects of psychosocial nursing that can be provided within the constraints of a healthcare setting. This information will help to illustrate how psychosocial support is actually provided in nursing care.

In order to carry out as full an exploration of nurses' psychosocial support as possible participant observation was combined with interviews of the observed patients and nurses. Section 3.1 outlines the methodological considerations leading to the design of his study, while the remainder of this chapter discusses how the study maintained ethical principles. In Chapter Four I explain the procedures used to carry out this research into nurses' psychosocial support.

3.1 Selecting the methods

There is a common argument, especially in nursing research, that a researcher should choose their research methods from their epistemological viewpoint of the world and 'follow' a research paradigm (Guba and Lincoln 1994, Cormack 2000, Wolcott 1990, Morgan 1998). Commitment to paradigms came from the idea that individuals should have a belief that the world works in certain ways and, therefore, can only be studied in certain ways. It has been suggested that the first decision to be made around which paradigm to follow is whether to have faith in research approaches that use quantitative or qualitative data (Guba and Lincoln 1994).

A crude idea being that quantitative studies explore objective topics, in controlled situations, producing numeric data which undergo quantitative analyses (Cormack 2000, Polit and Beck 2010), while qualitative data should be used when attempting to understand the subjective experiences of individuals (Tong *et al.* 2007, Cormack 2000, Polit and Beck 2010, Leinenger 1994).

An alternative view, and the one I follow, is that the design of a research study should be determined by the best way to answer the research questions (Silverman 1998, Strauss and Corbin 1990). This pragmatic view of research encourages researchers to choose their methods in accordance to the best way to explore their subject matter within their area of study (Creswell 2014). Taking this stance is supported by Morgan (1998) and Pawson and Tilley (1997) who agree that data can be used in combination without breaking paradigmatic beliefs, as long as careful attention is paid to the process of designing the research study.

Silverman (2013) and Hammersley and Atkinson (1995) both support the combination of data in order to strengthen research findings, while Robson (2002) argues that the methodological choice is not between quantitative and qualitative but instead should be about "fixed" versus "flexible". This flexibility refers not only to the types of data collected, but also to the data and analyses used and to adjusting the study design to focus exploration on the emerging results (Corbin and Strauss 2008).

There is a risk that having a flexible approach to research jeopardises the rigour of a study (Gibbs 2007, Robson 2002, Guba and Lincoln 1994). However, I maintain rigour by:

1. clearly demonstrating how and why this study was completed;
2. ensuring my conclusions are backed up by appropriate data'; and

3. sharing data excerpts – with participants, my supervisors and readers of this study –

    and questioning my results, through comparisons and analyses of negative or

    opposing cases (Glaser and Strauss 1967, Tong *et al.* 2007).

In this study I am exploring how palliative in-patients express psychosocial needs and what their nurses do to support them. In the previous chapter I demonstrated that nurses' descriptions of what they do are not necessarily representative of their actions, and there can be a vast difference between what a person says happens and what actually happens (Bridges *et al.* 2013, Robson 2002; Silverman 1998; Rose *et al.* 1995). Therefore, to explore nursing practice it is necessary to observe the practice of nursing. However, if I just watch nurses' actions I may not get an understanding of: whether nurses provide psychosocial support in accordance with the patient's wishes; what influences nurses' actions; or why nurses' responses vary. To find the answer to all of these questions, a number of approaches must be taken and a variety of data types collected. However, care must be taken to ensure the methods enable thorough, rigorous answering of the research questions (Morgan 1998, Creswell and Plano-Clark 2007, Robson 2002, Corbin and Strauss 2008, Teddlie and Tashakkori 2009), I did this by considering two important methodological points. Firstly, I carefully considered which approaches to data collection and analyses to take in order to answer my research questions. Then I considered how and when to collect each dataset and how they should be combined.

3.1.1   The selected data collection and analyses approaches

The best means to ensuring rigour is to follow the existing principles for high quality research studies in each of the chosen data collection techniques (Creswell 2014). Many of the aspects discussed throughout this chapter follow the analytical principles of specific research methodologies and approaches. The majority of the methodological principles used in this study come from either Grounded Theory (GT) or ethnography.

3.1.1.1   Grounded Theory

Grounded theory (GT) is an approach to research that is used to systematically explore data in order to develop new theories (Gray 2014, Charmaz 1990, Strauss and Corbin 1990, Glaser and Strauss 1967). The aim of GT is to construct theories through constant comparison of, mainly qualitative, data in order to identify similarities and differences between the concepts under exploration. Theories produced in GT should be explicitly evident in the data that are analysed and presented in the study's findings. Many of the concepts and principles of GT are utilised in my study and these will be referred to throughout this methods chapter. However, there are four main aspects that differentiate this study from GT.

Two factors differentiating my study from GT are related to the use of existing literature and what my study aims to create. The main aim of GT is to create a "substantive" or "formal" theory that "emerges" from the data on a topic that is currently unknown (Glaser and Strauss 1967). Therefore, there would be little if any existing literature on the topic. In GT, literature is more commonly used after concepts are discovered during data collection; any literature used in GT before data collection usually works as a "beginning foothold": a summary of concepts to help guide a study. The literature defining psychosocial needs was used in my study as such a tool, however, in GT, these footholds are considered irrelevant once data are obtained, whereas the psychosocial needs I identified from existing literature provided variables which were analysed during my study. Similarly, my analyses follow the GT approach in that they explore rather than evaluate the evidence (Glaser and Strauss 1967) but my aim was that the data act as an instrument for reflecting on practice and future research rather than creating a "substantive" theory. The main reasons for me not attempting to create a substantive theory are linked to funding constraints and can be considered alongside the two other factors differentiating my study from GT.

GT advocates a "theoretical" approach to sampling, whereby initial findings indicate which subsequent samples to use to explore the concepts emerging from analyses of collected data (Glaser and Strauss 1967, Corbin and Strauss 1990). In GT, new data are sought out by involving different participants from different settings to corroborate or disprove findings. In my study I followed the GT technique of analysing data concurrently to the collection of new data. I also focussed my areas of exploration on the concepts that were emerging from the data. However, I did not select my sample of nurses according to these emerging concepts. My sample, the nurses working day-duty on the ward, was identified at the beginning of the study. Which nurses participated was chosen by convenience sampling, guided by which nurses would be available to maximise the amount of data per case I could collect. Theoretical sampling contributes to the decision of when data collection is complete, which, in many qualitative studies, is when "saturation" – nothing new emerges from the data (Leinenger 1994, Glaser and Strauss 1967) – is reached. I did not have the resources to carry on until saturation. I did, however, obtain enough evidence to illustrate the reality of psychosocial support in this hospice ward. My findings are of value in future practice and research.

A final point is required in relation to GT's use of quantitative data and how I applied it in this study. Although GT is commonly referred to as qualitative research (Creswell 2014, Cormack 2000), GT in its original form saw value in quantitative analyses by presenting percentages to discuss associations between variables (Glaser and Strauss 1967, Strauss and Corbin 1990). The inclusion of numerical findings in my study make the results clearer to the reader and support the qualitative data which were collected following many of the principles of the ethnographic approach to research.

3.1.1.2 Ethnography

Original definitions of ethnography consider it to be an in-depth written description of a culture, taking into account a number of aspects including: the individuals within the culture and how

they interact; their norms and habits; and the way the environment around them is shaped (Creswell 2014, Silverman 2011, Atkinson *et al.* 2001, Muecke 1994). Data were collected by researchers entering the site of research and observing what occurred. The term, ethnography, has subsequently been re-interpreted over the years so that some see it as an alternative name for observational fieldwork (Lofland *et al.* 2006, Bryman 2012).

As the main aim of this study was to explore whether psychosocial support is an inherent component of hospice ward nurses' daily work, it was vital that the research focussed on nurses' actual care. Self-report studies can only provide perceptions of care provided, therefore, observation was the method adopted to discover what was occurring in practice (Walshe *et al.* 2011, Lofland *et al.* 2006, Wolcott 1990, Silverman 1998). Many of the procedural challenges faced by ethnographic researchers concern their use of observation as a data collection technique. The use of observation, as the central mode of data collection in this study, indicates the value of ethnography in guiding many of the methodological decisions I made.

Similarly, my exploration of the influence of aspects of the ward culture on nurses' psychosocial support could indicate my study is 'ethnographic' (Polit and Beck 2010, Atkinson *et al.* 2001). However, I recognise that my study is not a pure ethnography as it focusses on the minutiae of nurses' psychosocial support rather than creating a thorough account of the ward and the culture in which the nurses work (Bryman 2012, Silverman 2011, Polit and Beck 2010).

3.1.2 Summary of methodological considerations

The methodological background to this study uses a number of techniques from ethnography and approached data collection and analyses from a grounded theory perspective. Regardless of which label is placed on the methodology of this study, data are combined to provide answers to my research question. A combination of observation, interview, and documentary evidence was used to explore how nurses responded to patients' psychosocial needs. What is important

to understand is how these data are combined, which is explained in depth in Chapter Four. Before carrying out the research, especially with an observational component, it is also important to consider the ethics of a study.

3.2 Ethical Considerations

Research involving palliative care patients has been challenged as being inappropriate because it is disrupting the short time left to the patient (Ross and Cornbleet 2003; Seymour and Ingleton 2005, Calman and Hanks 1998). However, I adopted the approach that by taking due care and attention to the rights of all individuals involved, palliative care research can be both rigorous and ethical. My experience with research committees and more recent literature (Rodin 2013, Hughes 2006, Murray and Sheikh 2006) supports this idea.

The care that patients received was not changed by this study. The ward nurses remained responsible for the care given to the patient. The time I spent becoming familiar with the workings of the ward, combined with my palliative nursing experience, allowed me to assist with care as part of the nursing team. There was still a risk that having a researcher present could change the interactions, so I kept a reflexive diary (excerpt in appendix 1) to record my feelings about this. These factors helped to maintain ethical integrity throughout the study. Additional ethical issues are described below using Beauchamp's key principles of ethics (Beauchamp and Childress 2001, Murphy and Dingwall 2001).

3.2.1 Consent

In any research study it is ethically important to consider the issue of consent to participate. If a decision has been made in observational studies that individual participant consent is required, it is vital that the researcher ensures at each stage that participants are happy to continue their involvement in a study (Silverman 2013, Seymour *et al.* 2005, Lawton 2001). The process of verbal and written consenting of participants is described in section 4.1.3.

Continued consent was verified verbally during each stage of data collection. No participant who gave written consent to participate in the study withdrew their consent as the study progressed. However, some patients' conditions deteriorated during data collection to the extent that they had to be withdrawn from the study.

3.2.2 Non-maleficence and beneficence

The issues of not doing harm to, and aiming to help, research participants can be considered simultaneously. The most potentially damaging, or helpful, aspect of this study was interviewing. Revisiting psychosocial needs, or the response given, had the potential to upset patients or nurses – in the latter case, because they may recognise deficiencies in the care they provided. A sensitive, reflective, counselling-skills approach to the questioning was used to minimise the risk of introducing new, potentially upsetting issues. In some cases this approach helped participants to see value in what was observed. My extensive experience as a palliative care nurse enabled me to recognise if anything that was being discussed was distressing an interviewee. I was able to deal with any distress appropriately, either by myself, or by arranging for someone else to help the interviewee.

3.2.3 Autonomy/self-determination

The overt nature of the research gave all potential participants ample opportunity to choose whether or not they wished to participate: I wore a different uniform from all other staff, as a reminder of my different role. The study was well advertised by presentations, posters, and information sheets to everyone in the ward. Autonomy, the right to choose (in this case whether to participate), was further ensured by: obtaining consent in writing from each participant; re-confirming consent at each phase of data collection; and reminding participants that they could withdraw consent at any time, even temporarily. Repeatedly checking the participants' continuing consent to participate also protected their privacy. Privacy was further protected by

minimising feelings of voyeurism or exploitation, through my active participant observer role in patient care.

Participants in this study were free to do and say whatever they wished without being judged by me. It was also important to protect research participants' rights to share their views without being judged; I have done so by ensuring that confidentiality and anonymity are maintained throughout. Every participant has a pseudonym which only I can recognise. Due care has been taken to hide any identifiable characteristics which might allow internal recognition by hospice staff. For example, when a patient says something that makes nurses, or their colleagues, potentially recognisable, the distinguishing characteristic has been removed. Likewise, all efforts have been made to disguise the identity of the hospice in presentations about this study.

Using a 'realistic' (Pawson and Tilley 1997) and reflective style of interviewing respected participants' right to self-definition: sharing observations with the participants gave them the opportunity to clarify, or correct, my ideas about what happened, thus increasing the validity of the data. This process of self-definition for the nurses was enhanced by the collaborative approach to the research, whereby the nurses were given opportunity to comment on the analyses of the data (Bailey *et al*.2002, Murphy and Dingwall 2001).

3.2.3.1   Distinguishing Between Patient and Participant

The ethical right of self-determination is also protected by considering the changing roles of participants in observational research. Because I am an experienced, registered, palliative care nurse, who had spent time on the ward familiarising myself with the ways of the ward, I was able to provide the same care for patients as any of the nurses on the ward. Interactions between myself and patients only changed when I was interviewing them. This change was facilitated by moving from the patients' usual ward environment, to a private room, and the presence of a tape-recorder. The ethical dilemma of patients not being acutely aware that they are currently

being recorded for research purposes was overcome by a commitment to ensure that their care was not compromised. Patients were given the opportunity to withdraw their observational data from the study when they were approached for interview. This offer was never accepted.

3.2.4   Justice

All potential participants were treated equally. All nurses were given the opportunity to consent to participate, and the off-duty rota determined whom I would observe. Participation was offered to all eligible patients who had the potential to be involved in the study. All other patients and people in the ward were informed of my role whenever I had contact with them. Everyone who consented was made aware that their participation would depend on whether a psychosocial need arose during my observations. I was very strict in only retaining data on individuals who had consented to participate in the study, and I repeatedly checked that the consent continued.

3.2.5   Ethical Approval

This study had ethics committee approval from Stirling University Nursing & Midwifery Departmental Research Ethics Committee (date of approval: 2nd August, 2004) and from the Local Research Ethics Committee (date of approval 30th June, 2004, appendix 2). The independent status of the hospice meant that the local Research & Development Office did not need to approve the study, however, they were advised of the study and agreed that it could go ahead.

3.2.6   Summary of Ethical Considerations

Much consideration was given to ethical issues throughout this study. The anonymity of all participants has been carefully maintained throughout and once written consent had been gained, consent was continuously verbally verified. Patients received the same care from me in my researcher role as they received from the other nurses. All participants were given the

opportunity to voice their opinions about psychosocial support, without judgement. Throughout this thesis data excerpts and discussions refer back to these rigorously upheld ethical principles.

3.3 Summary of methodological and ethical considerations

This study takes a combines methodological stances to explore the realities of nursing practice. Combining and adhering to the relevant principles from GT and ethnography safe-guarded accurate collection and analyses of data on nurses' psychosocial support of palliative care patients. In addition, abiding by the ethical values throughout provides answers to the research questions which are true to both the process of research and the rights of all individuals concerned.

The following chapter illustrates how the data were collected and analysed, following the principles discussed above, in order to develop our understanding of the psychosocial needs expressed by palliative care in-patients and whether they are immediately supported by nurses.

Chapter 4: Data Collection and Analyses

As outlined in the previous chapter, an exploration of the reality of how nurses respond to patients' psychosocial needs in practice is very complex. My study combines many processes of data collection and analysis, which I explain in this chapter.

4.1 Data Collection

A variety of data were collected during this study, which are diagrammatically illustrated in Figure 4.1.

Figure 4.1 Diagrammatic illustration of interaction of datasets
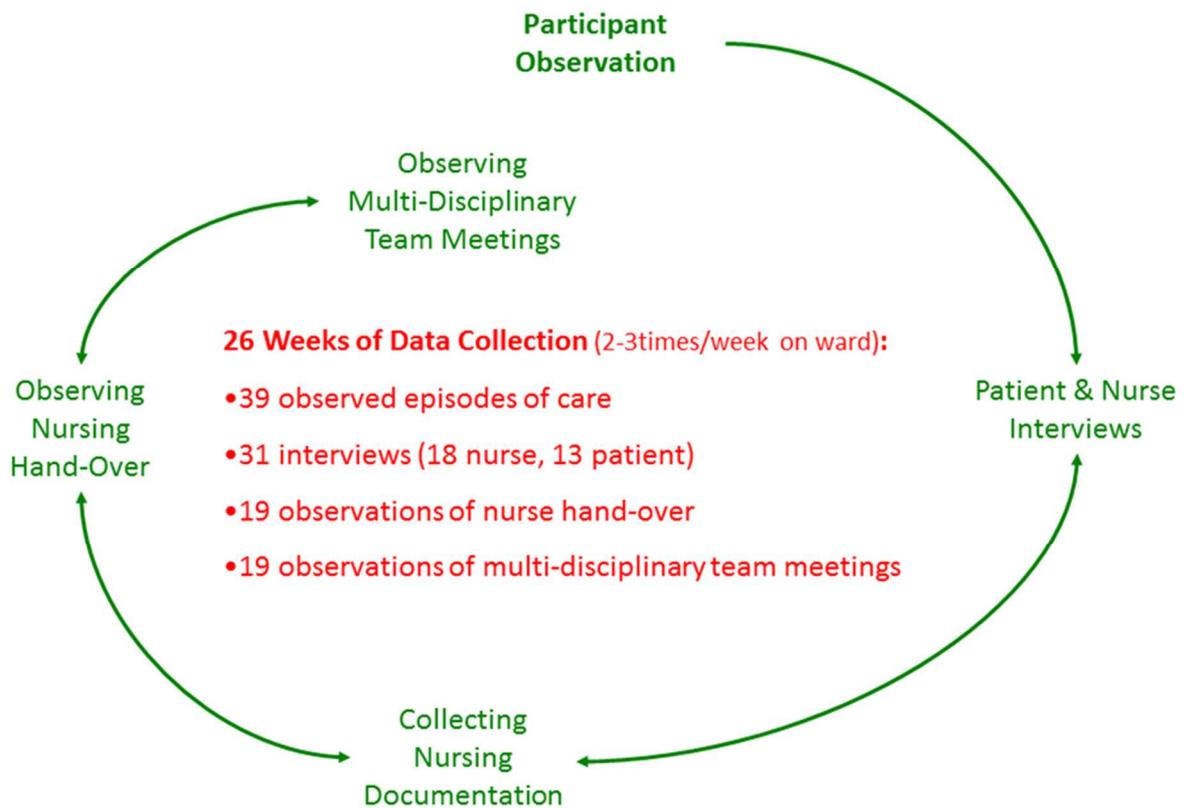
Lofland *et al.* (2006) suggest that all of these types of data can be collected under the umbrella of participant observation. However, it is important to outline the rationale behind the collection of each dataset individually.

4.1.1 Observation

Observational research has provided various insights into palliative care (Copp 1999, Heaven and Maguire 1998, Heaven and Maguire 1997, Ingleton 1999, Lawton 2000) and into nursing practice (Costello 2001, Johnson and Webb 1995, Penrod *et al.* 1999, Wiman and Wikblad 2004). Observation was chosen as the main method of data collection for this study as it allowed me to see exactly how nurses immediately responded when patients expressed psychosocial needs, instead of eliciting nurses' perceptions of their psychosocial support.

Observation is a difficult method of data collection which must be carefully considered before it is undertaken. There are a number of decisions concerning observational data collection that must be made before commencing data collection (Lofland *et al.* 2006, Bryman 2012). These include considering the practicalities of the observer role and maintaining access to the study site/s. Before commencing data collection, an observational researcher must give careful consideration to: the degree of involvement they have within the setting; whether the participants will be aware of their presence; and how to identify when they are observing the focus of their research. Consideration must also be given to how the researcher will gain access to the site and participants, and how they will leave the site.

4.1.1.1   Continuum of observation

When observation is used to collect data, the level of researcher involvement can affect the field of study. It is therefore important to clearly identify where on the continuum of complete-observer to complete-participant a researcher stands (Bryman 2012, Walshe *et al.* 2011, Cormack 2000, Gold 1957). Psychosocial needs can be very sensitive areas for patients to discuss, and may be expressed during other more intimate episodes of care. A patient may be inhibited with a stranger watching them. For this reason it was more appropriate for me to take a participative role during my observations. My extensive experience as a palliative care nurse

made this a natural position for me to take. However, my experience put me at risk of leading care. To minimise this risk and allow me to keep a focus on collecting data, I refrained from adopting the complete participant role. From the beginning of the study, I outlined tasks I would not undertake, such as: participating in decisions on planning patients' care; taking the lead in care when working with auxiliary nurses (AuxNs); or documenting patients' care. I would only carry out duties that involved me assisting the consenting nurse I was shadowing that day or help a patient in need if no other nurse was available. So for example, if a patient wished to use the toilet and the other nurses were busy I would assist with the patient's toileting. In an attempt to remind people of my researcher role, I wore a different uniform from any other member of staff.

Taking all of these factors into account led me to adopt an almost complete participant-observer stance for this study.

4.1.1.2 Overt versus Covert Observation

A participant observer must also consider whether their participants should be aware of their presence, in other words, whether they undertake overt or covert observation, and what impact this may have on their study. In participant observation it is possible to record the actions of participants without their knowledge. A researcher can enter their site under the guise of a real member of that area. I could have been introduced to the ward as a new member of the nursing team, thereby carrying out covert observation. The argument for covert research is that what is observed is what would really happen in that situation: the presence of a researcher has not influenced the behaviour of the individuals involved. The main argument against covert observation is that it is unethical to deceive people in this way (Gray 2014, Lofland *et al.* 2006, Robson 2002). However, in this study it would also have restricted my access to some aspects of the study, most notably the behaviours of the AuxNs who would have looked to me, as a registered nurse (RGN), to take the lead in psychosocial support. Additionally, although I had

never been a member of the ward team, the ward staff knew me due to a previous role in the hospice's education department.

Overt research, when all participants are aware of the researcher's presence and role, was the stance adopted for this study, not just because the staff knew me – I could have carried the study elsewhere if this were the only reason – but also to overcome any ethical difficulties that may have been perceived (see section 3.2). The major challenge of overt observation is that participants may behave differently in the presence of the researcher. Researcher impact is reduced through continuous awareness of your impact on the field (Hammersley and Atkinson 1995, Robson 2002, Rock 2001) and use of a reflexive research approach (Woolgar 1988, Finlay 2002, Shaw 2010).

4.1.1.3   Observer Impact

An argument can be made that by carrying out participant observation a researcher is getting as close to their data as possible and, therefore, getting the most accurate account of what is happening (Lofland *et al.* 2006, Rock 2001, Coffey 1999). One aspect of this is that the researcher may see things that may be so intuitive to a participant that they would not mention it on interviewing. There is a risk that my personal background of having worked as a staff nurse on a ward in more than one hospice may reduce this benefit. This risk is reduced by the fact that I have never held that role in the research site but also by staying 'true' to the data and making them visible to the reader.

In order to gain accurate data, observers must consider the 'naturalisation versus going native' debate (Coffey 1999, Glaser and Strauss 1967). Great effort was applied during this study to maintain an effective stance in this issue. As advocated by Rock (2001), during the preparatory phase of this study, I spent much time – a minimum of one day a week – working on the ward, developing a relationship with the nurses. This reciprocal arrangement enabled me to work

effectively within the setting, encouraging nurses and patients to act as naturally as possible in my presence (Seymour and Ingleton 2005, Coffey 1999, Hammersley and Atkinson 1995, Robson 2002, Rock 2001). This encouraged the nurses to see me as one of them and trust that what they would tell me would remain confidential. Patients would consider me as one of the nurses. All of this work allowed me extensive access to the reality of practice, but ran the risk of me becoming so immersed in the field that I would be unable to observe events objectively, and obtain accurate data. I prevented this naturalisation from becoming too native by the boundaries I had over things I would not do, such as admitting patients; and also, by remaining independent with my times of entering and leaving the ward. This did prove challenging but was managed by keeping a reflective diary (excerpt in appendix 1), wherein I included notes on when my presence appeared to influence what was happening (Coffey 1999), and by following Copp's (1999) idea of receiving personal support. These aspects were considered in the analyses of the data.

4.1.1.4   Clarifying the topic of observation

An observational researcher does not simply enter a site and begin collecting data. Before beginning data collection, observers should have identified research questions they wish to answer and have perceived a means to finding the answers. There are a variety of options for this and the researcher must decide what approach to take in pre-defining what observational data to collect. A continuum of pre-defining foci for observation exists (Miles and Huberman 1994). At one end sits observational schedules, where the range of things to be observed is pre-defined and the researcher uses the schedule to code what is observed. At the other end, the researcher adopts a more exploratory approach, and remains open to episodes and situations which cannot be pre-coded (Bell 2010, Glaser and Strauss 1967, Miles and Huberman 1994). My approach fell more towards the exploratory approach. I designed a concept map of potential psychosocial needs of palliative care patients (Figure 1.1, section 1.4), from the literature

discussed earlier in this thesis, which was used as a "beginning foothold" (Glaser and Strauss 1967). In the initial stages of data collection this map was the only observation instrument I used. When a patient expressed a psychosocial need from the map, psychosocial support was in demand, and data collection was prompted.

Minimal usage of observational tools allowed my mind to stay open to recognise all ways in which the nurses responded to psychosocial needs (Bryman 2012, Miles and Huberman 1994). As data collection progressed, the concurrent data analyses provided me with clearer prompts on which to focus future observations (Robson 2002). An issue linked to the use of observational tools is how to record observations.

4.1.1.5   Recording Observational Data

A major challenge in observational research is recording what actually happened rather than the researcher's perception of activity (Gray 2014, Denscombe 2010). The key factor in this is recording observations as close in time, as possible, to their occurrence (Lofland *et al.* 2006, Robson 2002). The best method for this is to record actions as they occur. However, in my study it was not appropriate to do this. Not only because I was participating in the care but because this would have been unnatural and awareness of me taking notes may have altered the behaviour of both patient and nurse. I recorded my observations into a digital voice recorder whenever I left the participants' company, writing them up as soon as possible after the episode of care.

4.1.1.6   My participant observer role

Prior to commencing data collection I had clearly identified, and shared with my potential participants, what my role would be. I would be carrying out almost complete participant observation as a nurse on the ward; my restrictions from this role were based around not participating in RGNs' organisational duties. I would be supernumerary to the staff, defining

my own times on the ward to allow time for documenting field-notes and interviewing. The time given by me in providing nursing care compensated for the time (10-45 minutes) the nurses would be away from the ward for interviews. My researcher role would be overt throughout and my transition, during times of observation, from nurse to researcher would be triggered by patients expressing a psychosocial need from my mind-map (Figure 1.1, section 1.4). Once observational options are clarified, the researcher has to gain access to the research site.

4.1.1.7   Gaining access to the research site

Gaining access to a research site is a challenge faced by many observational researchers (Lofland *et al.* 2006). Gaining initial access to my research site was not a challenge as the study was initially funded by the participating hospice. However, this did not guarantee participant engagement and, in actuality, could have hindered it. When managers employ a researcher to explore their premises, suspicion and fear can arise amongst staff (Bryman 2012). They may fear negative consequences from the research, either for themselves, their colleagues or the workplace as a whole. They may worry about: an increase in workload as a result of the findings; being identified as someone who management will disapprove of; or loss of jobs. The participant observer has to work hard to overcome such potential issues (Lofland *et al.* 2006).

One means to encouraging participation is to give the participants a sense of ownership over the research (Walshe *et al.* 2011, Robson 2002). A collaborative approach was used throughout this study, both with potential nurse participants and all staff in the hospice. Collaboration occurred informally, as described above, but also formally throughout presentations and the distribution of written materials.

From the outset of the study, I met regularly with members of the management team and attended regular nursing study days. In these meetings I shared my current position within the research process, asking for comments and ideas. I took notes during these meetings and

included, where appropriate, feedback in the study's design, data bank, and the analyses. From the outset the management were keen to contribute to these discussions, but most of the nurses required encouragement before they did likewise. By the end of the study the majority of the nurses were very forthcoming with ideas. On three occasions throughout the study I also met with the full multidisciplinary team (MDT): in the first meeting we discussed the study plans, in the second my primary findings, and, in our final meeting, I gave a formal presentation of an overview of the study and the findings, at that time. Since completing the study, these findings have not changed but are more detailed.

Posters were distributed throughout the hospice outlining the initial study plans and inviting questions. These were updated when data collection was commencing. Individual letters were sent to each nurse with information sheets and consent forms. Update letters were sent to all nurses, not just those who had consented to participate, once the pilot phase of the study was completed. The update letters offered participation to those nurses who had initially declined and clarified the study to new members of nursing staff.

Informal one-to-one or small group discussions also impacted on the nurses' ownership of the study. Many of the nurses were keen to participate in the study from the outset, while others were initially reluctant but later went on to participate. This change in mind was not always a result of my endeavours. For example, on one occasion, prior to data collection commencing, when the ward was quieter, a group of AuxNs started to discuss the study with me. One AuxN's interest in the study encouraged another to approach me later and ask, 'Can I still be involved?'

Another important aspect in getting individuals to agree to participate in a study like this is to gain their trust. As mentioned earlier, I worked very hard to gain acceptance as a credible, if temporary, member of the team by the nurses, patients and others working in the ward and hospice. Great care was taken throughout data collection to maintain this trust.

4.1.1.8   Getting Along with Participants

As part of the reciprocal relationship between a fieldworker and the 'inhabitants' of the field, I carried out a large number of tasks carried out by the nurses, partly to enable them to feel comfortable, and therefore, act normally in my presence. This work also reduced the risk of alienating the nurses: I hoped that by them seeing how I was prepared to fully carry out their roles, they would be more willing to participate in the research.

I pre-empted the risk of alienating the nurses (Lofland *et al.* 2006) by discussing, with them and their managers, those tasks I feared would inhibit my researcher role, prior to commencing the study. For example, rather than risk the nurses feeling I was not 'pulling my weight' by refusing to take part in the medication round, I made it explicit early in my time on the ward that I would not be administering medications.

It was not always easy to stick to these 'rules'. During data collection, I kept a reflective diary in which I identified areas in which I crossed these limits of my 'duties'. Through reflection and discussions – with nurse managers or my research supervisors – I developed ways of stopping myself 'breaking the rules' again, without jeopardising the study. Eventually, I learnt to openly decline requests to carry out duties exceeding my research role: such as refusing when I was asked to carry out, and document, a patient's admission interview.

I found maintaining these boundaries more challenging when the patients were asking for assistance. My nurse identity 'forbade' me to allow a patient to call for a nurse and not respond if unanswered by another. Any detraction from my researcher role this may have caused was balanced by the additional interactions with patients, which gave me better access to them as potential participants.

Differentiating between roles may also be considered an issue when participants are being interviewed in the same settings as they are being observed. This was not an issue for the nurses

as they were able to withdraw from their nursing role by going to another room and informing their manager they were undertaking an interview. The challenge of patients' inability to change their roles was covered in section 3.2.3.1.

The issues of overlapping roles in observational research also become an issue when the decision is made to withdraw from the field.

4.1.1.9   Exiting the site

Lofland *et al.* (2006) suggest it can be a challenge in observational studies to determine a time to withdraw from the research site. For me the time to exit the site was determined by having enough data to provide substantial answers to my research questions and also by the need to allow sufficient time to compile my findings.

When I felt I had reached an appropriate time to withdraw from the hospice ward I shared and discussed my findings with the nurse participants. The lack of argument against my findings served as a way of member checking that an appropriate time to exit the field had arrived (Bailey *et al.* 2002). For over a year after the end of data collection, I had a continued presence in the hospice. I worked in an office in the education department whilst carrying out analyses and initial write-ups. I saw the nurses regularly during breaks and occasionally at education sessions.

4.1.1.10   Summary of Observational Data Collection

An overt, almost complete, participant observer stance was taken to explore the psychosocial needs expressed by the hospice ward's patients and how nurses immediately responded to them. I worked with a consenting nurse from the beginning of a shift until the end of an episode of care when a patient expressed a psychosocial need. I had a summary of psychosocial needs, the key concept I was studying, to act as my only guide to trigger data collection. I was otherwise open to whatever actions the participants made in the request for, and offering of, psychosocial

support. These observations were recorded as soon after the episode of care as possible and guided the additional data to be collected, namely patient and nurse interviews and documentation. I had gained access to the site and developed an appropriately trusting reciprocal relationship with the participants. However, additional considerations were required. Although the observational data are central to this study, it was equally important to understand how the other datasets (interviews and documentation) would combine with it.

4.1.2 Sampling

Random sampling of the nurses or patients in this study was not considered feasible. However, as this is an exploratory study, rather than one which claims to provide results which represent the population (Bryman 2012, Lofland *et al.* 2006), what took priority was obtaining evidence of psychosocial support with the greatest variety of people, times and contexts (Rock 2001; Hammersley and Atkinson 1995). Therefore, convenience sampling, the use of the consenting participants who are most "accessible" to the researcher (Bryman 2012, p201, Robson 2002, Teddlie and Yu 2007), was used.

I determined which nurse to observe from the off-duty rota: primarily on the basis of whether they were on duty over the next couple of days, which would increase the chances of getting time for an interview. As the study progressed, I chose the nurse in order to observe the maximum variety in relation to their role, responsibility, contracted hours, and which shift they were working. Initially I would work with whichever patients the nurse had been allocated for that day, only collecting data on those who had consented to participate. Similarly, during later data collection, I tried to collect data on patients with different diagnoses, admission reasons, and levels of previous contact with the hospice. For the later patient sample, once I had identified the nurse I was observing and she had been allocated her patients, we discussed which patients I would work with and how I would manage this – sometimes by carrying out other

research tasks, such as copying patient documentation at the nurses' station so that I was available to the nurse when she was ready to work with identified patients.

The variations were identified using sampling frameworks (Appendix 3) to ensure maximum variation sampling (Patton 1990, Sandelowski 1995, Coyne 1997) and encouraged the greatest diversity of data, to provide the most thorough picture of the nurses' psychosocial support (Lofland *et al.* 2006, Miles and Huberman 1994).

4.1.3　Consent process

Patients were not formally approached about participating in the study until they had been in the hospice for 24 hours. However, I did introduce myself and explain my different role to all patients as soon as possible after their admission. Introducing myself served to reduce potential apprehension about my different appearance and encouraged willingness to participate. At this point, some patients indicated their preference to participate or not.

My initial plan was to approach all eligible patients – those well enough to be interviewed about their care and cognitively intact – to offer participation in the study. The recruitment process for patients was to give interested patients further verbal and written information on the study (see information sheet, Appendix 4). Patients were encouraged to consider and discuss participating with their significant others. After a minimum of one day, I would return to ask for written consent (Appendix 5). This process took longer than anticipated and was altered after the pilot phase of the study. As the study progressed I identified, by consideration of sampling matrices and the duty rota, those patients I was more likely to be working with, and gave them information sheets. Further information sheets were handed out during the data collection episodes as other potential participants were identified.

Although patients were never approached on the day of their admission, I did record observational data right from our first meeting, destroying the data if they did not consent to participate or sharing it with them and gaining their permission to use the data if they did.

Forty-seven patients (67.5% of those eligible and approached for consent) gave written consent to participate in the study. All of these patients participated within the study, to varying extents, as will be explained further in this thesis as described in the introduction to Chapter Five. Patient involvement was determined by which nurse was working with them.

Potential nurse participants were the RGNs and AuxNs who worked on the hospice ward, either on a permanent contract or working from the hospice's nurse bank, including those who worked night duty (some rotated between day and night duty). Information sheets outlining the research (Appendix 6) and consent forms (Appendix 7) were sent to all of these nurses (n=63), and 67% consented to participate. As the study progressed, I found it difficult to gain interviewing access to the night nurses; as this greatly increased the chances of having a higher proportion of incomplete cases, these nurses were excluded from the study. This meant that 88% of the day-duty nursing staff in the ward consented to participate in the study. Thirty-eight (23 RGNs and 15 AuxNs) of the 42 nurses (24 RGNs, 18 AuxNs) who consented to participate in the study were observed during data collection.

4.1.4 Interviewing

The main aim of interviewing in this study was to enhance the observational data: to verify my accounts of the care, and to provide more information on its impact. Where possible, both nurses and patients were interviewed. Nurses were asked about how they responded, and why, and whether they were satisfied with their reactions to the expressed psychosocial needs. With patients I explored whether they felt their psychosocial needs had been met and what they thought about the actions the nurses took in relation to psychosocial support. Similar to

observational data, certain choices must be made before interviewing, mainly who participates in the interviews and how are they completed.

4.1.4.1 Interview Participants

As the aim of this study is to explore the conditions of nurses' provision of psychosocial support it was important to, try to, interview both patients and nurses about the same episode of care – which I refer to as "paired interviews". The patients provided data discussing whether they received the psychosocial support they sought and how they felt about their care. Patients could only conjecture on why the nurses acted in the way they did. The nurses could clarify why they provided care in the way they did and could explain the various constraints affecting the care they provide. However, neither patients nor nurses were likely to understand all of the factors affecting psychosocial support. It was my role to elicit and synthesise these factors and then formulate questions which patients and nurses understand and provide useful answers (Lofland *et al.* 2006, Miles and Huberman 1994).

The different people involved in interviews on observations, participant/s and researcher/s, provide different views on data which should be compared to elicit valuable findings (Bryman 2012, Nelson and McGillion 2004, Heyl 2001; Pawson and Tilley 1997). In this study, patients, nurses, and I all brought different perspectives of the same episodes of care, which were analysed in combination (see section 4.2). Interviewing participants explicitly about recorded observations strengthens the rigour of research, by reducing researcher bias and misinterpretation (Bryman 2012, Heyl 2001).

Nurse and patient interviews were managed using the same techniques and will be described simultaneously.

4.1.4.1.1   Paired Interviews

My initial plan was to interview patients first from each pair, as they were likely to give most clarification as to whether their psychosocial needs were met and indicate reasons as to why, or why not, this happened. Additional questions from the patients' interview data could then be included in the nurse interview schedules. This allowed exploration of what I observed happening and what the patient perceived as important in regards psychosocial support. Unfortunately, it was not always practical to interview the patient first.

One of the challenges was to conduct the interviews soon enough after the observed interaction for both patients and nurses to remember it clearly (Lofland *et al.* 2006). Writing up the observational data and designing each interview schedule (see section 4.1.4.2.1) around this data took time. I would return to the ward as soon as practically possible after this, but patients and nurses were not always available to be interviewed; they both had other priorities. Early in the study I learnt that if patients were not available, but nurses were, I should grasp the opportunity to get a nurse interview or run the risk of failing to get either. In the instances that nurses were interviewed first, they often provided further, or alternative, questions for patients.

If an interview could not be completed within two days of the episode of care, the interview did not take place. In such circumstances, the remaining data for that case were included in the study. I observed 19 episodes of care where I was unsuccessful at having formal interviews with either patient or nurse.

Thirteen patient interviews were completed. Reasons for not gaining patient interview included: their conditions having deteriorated, having to prioritise treatments, and being discharged home. Eighteen (47%) of the nurses participated in interviews about their responses to psychosocial needs.

Some participants were observed on more than one occasion but only one interview per participant was requested. If informal discussions occurred around observations recorded subsequent to an interview, these statements were recorded and included within the data. This happened during nine of the twenty case occasions (45%).

4.1.4.2   Interviewing Practicalities

For an interviewer to produce high quality evidence to answer the research questions they must ensure they have the correct approach to interviewing. Consideration must be given to whether an interviewing schedule is required, and, if so, what type and how the interviewer will interact with the interviewees.

4.1.4.2.1   Interview Schedules

In order to gain appropriate answers to the research questions it is important to have an effective interviewing schedule (Robson 2002, Silverman 2013). Pawson and Tilley (1997) advocate combining both structured and unstructured interviewing methods as a means of eliciting a complete explanation of the process under investigation. As the purpose of the interviews was to identify why nurses respond to psychosocial needs in the way that they do, and what both nurses and patients think about these responses, it was important that the interview questions were based around the observed care. Therefore, semi-structured interviews were used for this study. Initially, interviews were designed around what had been observed by a process of identifying the relevant aspects of the observation; planning question topics from this around which to structure the interview; and, for paired interviews, including issues that arose in the first interview.

Each interview started with an introduction about what I was trying to achieve, and how the data would be used; this allowed for a collaborative approach to the study (Heyl 2001). Responder validation (Moore 2014 *et al.*, Silverman 2013, Lofland *et al.* 2006) was gained by

sharing my observations with the interviewee and asking their opinion on my reflection. The nurse interviews finished with some standard questions on how they felt they acquired their skills and their experience. Questions from the schedule were asked in an open style.

4.1.4.2.1.1   Open Interviewing Style

A factor equally important for successful interviewing is the style of communication between researcher and participant. I kept the interviews conversational in manner to allow participants to feel comfortable enough to talk, while probing enough to show I was interested in what was being said. Although I had a script of questions to ask in each interview, I did not follow it in order or word for word. As a topic arose, I asked a similarly pertinent question to that on my schedule. As interviews were concluding, I checked that all questions had been covered. These techniques are considered to stimulate the most fruitful answers in ethnographic interviewing (Lofland *et al.* 2006).

I also signalled interest by writing notes (Rubin and Rubin 1995). Questions must be open enough to allow the interviewee to describe their experience, but must be focussed enough to provide data on the specific research topic (Rubin and Rubin 1995); therefore, the majority of questions were open, and usually included a probe concerning some aspect of the observed behaviour. For example:

> *Hazel: "Yesterday when I came in and May was giving you a wash, you were*
>
> *talking about things from your past and I was wondering how does it make*
>
> *you feel when these conversations come up about the past?"*

Topics that arose from responses were followed up by reflecting them back in order to encourage clarification; reflecting the answer back also showed the interviewee that they were being truly listened to. Active listening encourages participants to be open and honest, thereby producing richer data (Heyl 2001). The process of reminding interviewees of their actions or

comments, and asking them to explain or clarify them, is known as 'conceptual refinement' (Pawson and Tilley 1997).

Conceptual refinement was one of two methods used in this study that Pawson and Tilley (1997) advocate for focussing questions in order to obtain answers pertinent to the research topic. The other method used was the 'teacher-learner' approach (Pawson and Tilley 1997), where I explained what I was exploring, and asked participants for their views. These strategies were used more often as the data collection progressed and the concurrent analyses made the key topics more apparent, so that more focussed questions were used to specifically explore the concepts of interest.

4.1.4.2.2   Using the Interview Data

Interviews were tape-recorded and transcribed by me. Doing the transcriptions myself aided in the design of subsequent interviews, and permitted analyses of the data to begin before the interview series was complete (Heyl 2001). Similar to the observational data, analyses of the interview data occurred alongside the data collection phase of the study, thus allowing refinement of the concepts and exploration to provide more robust answers to the research questions (Glaser and Strauss 1967).

4.1.5   Procedure of observations and interviews

Semi-structured interviews, of patients and nurses, were individually designed around the observation, and associated interview, in order to elicit further information on the nurses' responses to the patients' expressions of psychosocial needs (Heyl 2001, Pawson and Tilley 1997, Rubin and Rubin 1995). The interviews were carried out as soon after the observed care as possible and had a flexible style in order to obtain high quality data.

The core observational and interview data were collected in the following way:

- I identified a nurse to observe from the off-duty rota, in relation to whether she was on-duty over the following two-to-three days, and her role, responsibility and level of experience (see section 4.1.2).

- I then worked with that nurse, assisting her with the nursing care of patients, whilst observing the care she provided.

- If a patient, who had consented to participate in the study, expressed a psychosocial need (as outlined in the concept map, Figure 1.1, section 1.4) then that episode of care became a potential case.

- I would then make a mental note of the interaction between nurse and patient, whilst continuing to assist with the nursing care.

- Immediately after completion of the episode of care, or at any point that it was natural to leave the patient during the care, I recorded my observations on a digital voice recorder.

- I exited the field of study once all aspects of care concerning that psychosocial interaction had been completed.

- The recorded observations were transferred to written data and further notes were made on my observations, as soon as possible after the interaction had occurred.

- An initial analysis of the observation data was undertaken and used to design separate interview schedules for both patient and nurse interviews (both schedules were designed at this point as I was unable to predict whether I would be able to interview the patient or nurse first).

- Either the patient or nurse, depending on who was available, was then interviewed.

- The tape-recording of the first interview was listened to and the interview notes considered. My analyses of these was then related to the unused interview schedule. The latter interview schedule was adjusted to incorporate responses from the first interview (whilst maintaining confidentiality).

- The second interview was then completed.

- No further interviews were carried out in relation to that case.

Interviews produced mainly qualitative, and some quantitative, data which were analysed concurrent to collecting the other data types.

4.1.6   Observation of Meetings

Throughout the eight months of data collection, nursing handover and multidisciplinary team meetings (MDTM) were also observed, when possible, to record nurses' discussions around consenting patients' psychosocial needs. During these meetings I wrote notes on any discussions relating to psychosocial support of participating patients. These observations were valuable for a number of reasons.

When I attended handovers at the beginning of shifts they could identify patients who were likely to express psychosocial needs. This contributed to sampling. The handovers following observed care provided valuable perspectives of the support the nurses provided: especially, further details of the nurses' perceptions of what happened during the interactions. The post-observation hand-overs also provided data on liaison about psychosocial needs.

Although an RGN always led the hand-overs, AuxNs were present. All nurses at hand-overs contributed to discussions around psychosocial support. Only RGNs attended the MDTM.

A valuable component of observing meetings was the interactions between the nurses, and members of the MDTM (although only the nurses' views were used in the study), when

different views were expressed regarding patients' psychosocial needs. Additionally, the presence of a nurse at a meeting contributed directly to their categorisation within some of the variables analysed for the study: for example, when nurses considered they had developed a degree of familiarity about a patient from the knowledge they had learnt in the meetings. If the meetings occurred before participant interviews, they provided further evidence for questions, especially if what was discussed was different from what was observed. The documentary evidence collected had a similar role in the study.

4.1.7   Documentation Collection

Nursing documentation, written by nurses who had consented to participate in the study, and concerning psychosocial needs, was collected from each participating patient's notes. Documentation cannot be considered as evidence of how care is provided (Atkinson and Coffey 1997, Silverman 2011), but it can be compared to what has been observed, and to what has been reported in interviews. In this way, it is possible to determine whether documentation corresponds with what has occurred. Analysis of documentation allows additional insight into nurses' perceptions of the psychosocial support provided. Nursing documentation also provided data which identified categorisation within variables. For example, when nurses suggested that familiarity was gained through having been previously aware of a patient's psychosocial needs, documentation provided concrete evidence that a psychosocial need had been previously identified.

A semi-structured approach was taken to collecting documentation. Aspects of the nursing notes relating specifically to psychosocial issues – that is, those under the heading, "psychological assessment, perception & understanding of illness" – and anything documented under these headings was copied. Additionally, all participating patients' nursing notes were browsed and anything relating to psychosocial needs copied. This was often done while waiting

to carry out an interview, thus, sometimes, adding another dimension to the interview questions. Nursing documents also provided demographic data on patients.

4.1.8   Demographic Data

Demographic data were collected on all participants and used to explore possible effects of participant characteristics, such as: age, care need, and length of stay of patients; and years of experience, role, and working hours of nurses. Patients' demographic data were gained from nursing documentation, therefore, the full sample of 47 patients are represented in patient demographic analyses. The demographic data on nurses were collected in interviews when they occurred (n=18). The remaining twenty nurses were sent a questionnaire requesting this information; thirteen (65%) were returned. Most nursing demographics analyses occurred using the full sample (n=38) of nurses, with the exception of information on years of experience (n=31, 81.6% return) and education (n=32, 84.2% return). Demographic data were one example of quantitative data that were used to corroborate the findings of the qualitative data; organisational data were another.

4.1.9   Organisational Data

As concurrent analyses identified organisational aspects of care as having potential influence over the nurses' responses to patients' psychosocial needs, it became evident that records of the duty rota and patient allocation would play an important role in this study. Duty rotas are kept by the hospice as managerial records, so were easy to collect.

Patient allocation (described in section 4.4.1.2.1) for an early shift was recorded on a sheet on the ward, which was usually destroyed the following day. Once patient allocation emerged as an important concept, I collected these sheets. Although I had not recorded this data at the beginning of my observations, I could work out most of the patient allocations from my recordings. Because of the smaller numbers of nurses working on a late shift, I was able to

determine more often which nurse worked with which patient from my observational notes and the duty rota.

4.1.10 Data Collection Methods Summary

The study is centred on observational data, which were collected when a consenting patient expressed a psychosocial need to an observed consenting nurse. Interviews of patients and/or nurses about the observed psychosocial need and the nurse's response were subsequently completed. The observations of care and interview datasets were strengthened by data from observations of meetings relating to the participating patients' psychosocial needs, demographic and organisational records. The different types of data were combined in varying ways to form collections of data to enhance analyses.

4.1.11 Terms Defining Collections of Data

Due to the constraints of patient care it was not always possible to collect each type of data. The variety of types of data collection that were used within this study were collated and analysed in different ways. I have applied different terminology to the various clusters of data obtained throughout the study; these are: 'episodes of care', 'cases', interactions', and 'encounters'. These terms are defined below.

4.1.11.1 Episodes of Care

An episode of care relates to each day that I was on the ward and witnessed at least one patient expressing at least one psychosocial need. In one episode of care I could participate in a number of patients' care or only one patient's care. I tried to work specifically with only one nurse during an episode of care but the requirements of the patients, and the ward's team approach to care, often resulted in me assisting other nurses on occasions throughout one episode of care. I have data from 39 episodes of care (during the eight months of data collection; there were times when I was on the ward and I did not observe any patients expressing psychosocial needs).

4.1.11.2   Cases

Cases are when an observation of one patient's care is supported by other pieces of data. Ideally, a case would include:

- Interviews of both patient and main nurse providing that patient's care at the time the psychosocial need was expressed;

- Documentation of the psychosocial needs and any psychosocial support offered; and

- Observations of meetings that included discussion of psychosocial aspects of the patient's care.

However, as explained above, it was difficult to obtain all of these pieces of data for each observed expression of psychosocial need. If only one piece of data, additional to the observational data, was collected, I could still create a case. By the end of data collection I had 24 cases to analyse; 21 of these included interviews, 13 with interviews of both patient and nurse.

Cases could occur over more than one episode of care. On occasions I would observe a patient expressing a psychosocial need on one shift and would observe a nurse facing the same psychosocial needs on subsequent shifts; both pieces of observational data were then collated in the same case. Likewise, one case could involve more than one nurse, either when the patient required assistance of more than two nurses, or when another nurse became involved in an episode of care.

Although my initial aim was only to include a patient once throughout data collection, I did witness patients expressing different psychosocial needs on different occasions. These observations were included in my data, with consent from the patient, but the patient was not interviewed again. I have cases relating to two patients twice; the remaining twenty cases involve separate patients.

4.1.11.3   Interactions

Interactions are when an observation of one patient's care is not supported by other pieces of data. This happened because of difficulties carrying out timeous interviews (see section 4.1.3 above) and a lack of documentation or discussions by nurses on the observed psychosocial needs. Twenty-six interactions involving potential psychosocial support were observed.

4.1.11.4   Encounters

Every case and interaction contained a number of interesting concepts and variables which could be explored in order to answer the research questions. A more thorough analysis of the nurses' psychosocial support could be provided by dividing the cases and interactions further. Therefore, encounters, one nurse's response to one phrase expressed by one patient, were created. Encounters could contain just my observations or a combination of data types. Two-hundred-and-twenty-seven encounters were identified.

4.1.11.5   Distribution of Data Collections

One hundred and eighty-five of the encounters came from the 24 cases; the number of encounters per case ranged from two to 33. The remaining 42 encounters came from the 26 interactions; the number of encounter per interaction ranged from one to four.

Forty-seven patients participated in the study. They were involved in a range of encounters: one patient was the focus of 33 encounters, whereas 15 patients were involved in only one encounter. Thirty-eight nurses were involved in encounters, ranging from one nurse who was involved in 17 encounters to three nurses who were only involved in one encounter each.

4.1.11.6   Summary of Terms Defining Data Collection

The different terms for collating data – 'episodes of care, cases, interactions, and encounters' – are used throughout this thesis to discuss the observed responses to psychosocial needs and to

analyse data. Gaining a wide enough variety of data to answer my research questions required careful sampling of participants.

4.1.12 Pilot

A pilot was carried out, amongst other reasons, to test whether planned data collection techniques provided appropriate, rigorous data to answer the research questions (Bryman 2012, Teddlie and Tashakkori 2009). It is often advocated that the pilot should be performed with a different sample and the data kept separate from the main study. However, studies following a "flexible design can incorporate piloting within the study itself" (Rock 2001, p383).

In this study, the first two months of data collection were considered the pilot stage. A break from data collection was taken at this point to consider adjustments that were required. The seven cases that had been collected underwent intense analyses, which were shared with my supervisors for corroboration. The depth of data and potential answers to the research questions uncovered at this point, and the lack of problems with my methods, reinforced continuation of the study as designed and allowed for inclusion of the 'pilot' cases in the main study.

The final question relating to data collection was when it could cease.

4.1.13 Stopping Data Collection

After eight months of concurrent data collection and analyses, clear, substantial and supportable claims could be drawn from the collected data. This was a good point at which to cease data collection. The sample size was large enough to meet Teddlie and Tashakkori's (2009) various criteria for ceasing data collection in qualitative studies:

- My 24 cases met their upper criteria of 24 from case study research;
- Having completed 30 interviews from one hospice ward culture, I achieved their lower limit for ethnographic studies; and

- Fell within their range of 20 to 50 interviews in grounded theory.

4.1.14 Summary of Data Collection

This study used convenience sampling, of both patients and nurses, to collect observational and qualitative data. Data collection centred on almost complete participant observation, which was, where possible, complemented by matched, paired, interviews; observations of meetings; and nursing documentation about the participating patients' psychosocial needs. The concurrent analyses indicated further areas of useful data so participants' demographics and organisational data were also collected. The bank of data was then collated into cases, interactions, and encounters to undergo further analyses in order to explore how the nurses responded to patients' psychosocial needs.

4.2 Analysis

A large variety of data were collected throughout this study, analysing this data demanded a number of techniques. Following the practices of many qualitative, exploratory methodologies (Silverman 2013, Lofland *et al.* 2007, Miles and Huberman 1994, Glaser and Strauss 1967), analyses began early in this study and were carried out concurrently to data collection. A variety of analysis techniques contributed to: the creation of the first interview schedule while formalising the observation field-notes, through producing the paired interview schedules, past the decision to cease data collection, until the findings chapters of this thesis were finalised.

All analyses were shared with my research supervisors in order to maximise rigour. A discussion around the selection and use of each of these analyses follows.

4.2.1 Qualitative Analysis

In order to examine the qualitative data thoroughly, different types of analyses were used. As the combination of data types – rather than observations alone in the interactions – allowed for

more substantial claims (Teddlie and Tashakkori 2009, Robson 2002), the initial focus of the qualitative analyses was on the cases. Each case was analysed independently to identify variables and processes (which I refer to collectively as 'concepts') involved in psychosocial nursing (within-case analysis (Paterson 2010, Miles and Huberman 1984)). The cases were then analysed in relation to each other, to look for similarities and differences (between-case analysis (Burns 2010, Miles and Huberman 1984)). The interactions were included in the final 'stage' of qualitative analyses when the concepts arising from the cases underwent comparative analyses. These are explained below in order of occurrence.

All of the qualitative data were entered into an NVivo electronic qualitative analysis software project. This allowed coding of each case to identify emerging concepts (appendix 8a), comparison of the concepts between cases in the form of memos (appendix 8b), and diagrammatic representation of the concepts that emerged in the study (appendix 8c). The use of electronic packages aids managing large quantities of data but the responsibility for analyses remains with the researcher (Silverman 2011, Gibbs 2002, Hammersley and Atkinson 1995).

4.2.1.1 Within-Case Analysis

A 'descriptive analysis approach' (Miles and Huberman 1994) was taken. Each case was analysed during the data collection process, in order to develop interview schedules and identify issues for further exploration. As I typed up fieldnotes, I made reflective comments on sections of data that concerned psychosocial needs or nurses' responses to these and made notes in the interview schedules. Each individual interview was created around these notes. As the study progressed, concepts that emerged recurrently were also added to an interview schedule template, so that each subsequent interview explored these concepts as well as anything new that arose from the observations.

Each individual case was searched for evidence relating to the research questions. Transcribing the interviews myself began this process (Silverman 2011, Lofland *et al.* 2006). As I transcribed interviews I made reflections on what had been said. As each interview write-up was completed I re-read the interview and identified further concepts. Once cases had been completed, all the data for each case were re-read in a search for additional concepts and to link concepts within the case.

Each emerging piece of relevant evidence was given a code identifying it as a significant concept (Glaser and Strauss 1967, Boyle 1994, Miles and Huberman 1994). For example, when nurses related their ability to deal with patients' psychosocial needs to whether they knew this patient, I labelled this 'familiarity'. Segments of data could be assigned more than one code. When I found further evidence in a case referring to a concept it was assigned the same code. Using NVivo I could then create documents collating each piece of evidence, under the appropriate code, to build up a picture of that aspect of the nurse's response to each patient's observed psychosocial need within each case. This comparison of words, or phrases, in a case to another part of the same case checks data and allows clarification (Glaser and Strauss 1967, Corbin and Strauss 2008, Creswell 2014).

4.2.1.2   Between-Case Analysis

The NVivo software enables printing of all segments of data relating to each code in one document and the creation of diagrams illustrating the relationships between codes. Doing this allowed me to explore occurrences of the same concepts in different cases to consider similarities and difference in the realisation of concepts between cases (Silverman 2011, Morse 1994). For example, when a nursing behaviour, such as how nurses responded to patient's expression of a psychosocial need, was identified in one case, I could check all other cases for similar behaviours. When similar behaviour occurred, I could consider the factors involved and explore whether the factors had the same or different outcome in the other cases.

When a regular pattern of concepts emerged, I was more alert to observing for future occurrence of these concepts. These frequently occurring concepts then became the focus for further data collection and analyses. The similarities and difference were compared to identify possible associations between concepts.

When patterns of concepts were less frequent, further exploration of them in this study was discounted. This process of funnelling data into categories is time consuming (Glaser and Strauss 1967, Silverman 2011) but allows for rigorous in-depth exploration of the key concepts in order to answer the research questions (Hammersley and Atkinson 1995). Funnelling also enables identification of dichotomous variables for comparative analyses (Glaser and Strauss 1967).

4.2.1.3   Comparative Analysis

More focussed analyses of all of the qualitative data, including interactions and encounters, occurred following the comparative approach advocated by Glaser and Strauss (1967) and Ragin (1987, 1994). This approach to analysis is particularly suitable for a small number of cases. The aim of this analysis is to determine whether there are specific factors which lead to specific outcomes – for example, what influences each nurse to behave in the way they do. This style of analysis is a process of recognising which factors are involved in which outcomes; and ruling out factors that have a different outcome under the same circumstances. This is done by forming pairs of variables (factors) that may affect each other within each case. All pairs of variables are then compared to the same pairs of variables in all of the other cases; if one pair of variables has an opposite outcome in a different case then these variables have been shown not to be related. These analyses identified associations for investigation in future studies, and indicated similarities and differences within this study's data.

4.2.1.4   Summary of Qualitative Analyses

The qualitative data in the study's 24 cases were analysed by identifying and coding the emerging concepts associated with nurses' responses to patients' psychosocial needs. A process of constant comparison and consideration of similar and different cases, with all of the qualitative data, enabled a narrowing down of concepts. Narrowing concepts allowed exploration of the key issues with potential associations to the nurses' provision of psychosocial support.

Many of the variables identified in the qualitative analyses could be categorised, for example, the different ways nurses responded to patients' psychosocial needs. Once a variable can be categorised, it can be counted and, therefore, undergo numerical analyses. These categorical variables, and many of the demographic variables, were analysed using one or more of the quantitative techniques described below.

4.2.2   Management of quantitative variables

Four main SPSS databases were created to manage the quantitative variables containing

1. A row per encounter,

2. A row per nurse,

3. A row per patients,

4. A row for one, randomly selected, encounter per nurse-patient interaction (this file was created to exclude impact of any individuals' characteristics or pairs' 'relationship style'. For example, including data for all five encounters between one nurse and patient, when there are only two encounters for another nurse-patient pair would skew the results in favour of the first paring).

Quantitative demographic and organisational data and, where possible, concepts translated from the qualitative analyses, were added to the appropriate databases as variables. Exploratory analyses were undertaken to indicate whether there might be associations between possible dependent variables – nurse response to psychosocial need or nurse response style – and a number of independent variables, for example: the type of need, nursing experience, and patient care aim.

The lack of probability sampling, uncertain statistical representativeness of the samples and small sample sizes raised the question as to the appropriateness and value of inferential statistics. However, this does not discount the value of exploring quantitative data to support the qualitative findings in a hypothesis-generating as opposed to hypothesis-testing context. Simple descriptive analyses were therefore used to summarise relevant variables and cross-tabulations carried out to explore possible associations where appropriate.

4.2.3 Summary of Analysis

This study employed a variety of methods of qualitative data analyses to explore how patients expressed psychosocial needs and how nurses' immediately responded to them. Constant comparative descriptive analyses of the qualitative data allowed identification and analyses of the key concepts associated with psychosocial needs and their support.

4.3 Summary of Data Collection and Analyses

In this study observational, interview, documentary and demographic data were collated to build a picture of the psychosocial support nurses offer in response to the psychosocial needs expressed by palliative care patients in one hospice ward. A range of data was combined, where possible, into cases, and analysed to explore ward based palliative care nurses' provision of psychosocial support and the psychosocial needs they encountered. Before the findings of this

study are presented in Chapters Five and Six, it is important for the reader to be aware of a few aspects concerning the ward in which the study took place.

4.4 Study Context

The purpose of this study is not to describe the workings of the hospice ward, but some aspects of this need to be explained in order to understand key aspects of this thesis. Before discussing the findings of this study it is important to introduce some aspects pertaining to the research site and the individuals working there.

4.4.1 Research Site

This study site was a 24-bedded ward in a specialist palliative care unit (henceforth referred to as 'hospice'), caring for patients from both urban and rural areas of Scotland. Patients admitted to the ward had active, progressive, non-curative diseases (90% had a malignancy; the majority of the remaining 10% had a neurological illness).

When patients were admitted to the ward they were considered to have one of five care aims: symptom control, assessment, rehabilitation, respite, or terminal care. These care aims are closely linked to the extent of a patient's illness, their likelihood to be discharged from the hospice and the focus of care provided by all practitioners in the ward:

- 'Symptom control' patients were admitted to make their symptoms less distressing; they were expected to be in the hospice for approximately two weeks before being discharged home.

- 'Assessment' admissions were very similar to 'symptom control' admissions. These patients were admitted to identify and alleviate their main problems, the aim was to achieve this in two weeks at which point the patient would return home.

- 'Rehabilitation' patients were admitted to help them gain as full independence as possible and to develop new ways of functioning with their illness. Length of admission was variable depending on how long it took them to develop maximum functioning.

- 'Respite' patients came into the hospice to provide a break from their normal routine giving them, and/or their significant others, rest. Length of admission was for a predetermined time period, usually one to two weeks.

- 'Terminal care' patients were admitted to the hospice to die. The main focus of their care was comfort up to and during death; their length of admission was variable, death often appeared to be close – expected within a few weeks – but could still be a number of weeks away.

Patients can have multiple admissions to the hospice, for varying time periods (shortest during data collection two days, longest 71 days), with the care focus changing both during and between visits.

The ward consists of shared bays and single rooms. The nurses followed a 'team' approach to care, with two teams split geographically across the ward: each team cared for the same number of patients, in both bays and single-rooms.

The majority of nursing shifts were split across early, late, and night shifts, with most staff rotating throughout the shifts. A few members of staff only worked either day or night duty. A small number of nurses worked twilight shifts, where they came on shift at 5pm and stayed until 11pm, after night duty had commenced.

As is common in most ward environments, the workloads varied across the shifts. Early shifts involved the 'heaviest' workload and most 'intimate' patient care. On 'earlies' there was an expectation for all patients to be assisted to wash and change their clothing. Most activities, such as bowel care, wound dressing changes, and ward rounds (when the nurses accompanied

the doctors to review the patients), took place on 'earlies'. In the cross-over period, between early and late shifts, much of the RGNs' time was taken up with medications and documentation. The AuxNs spent this time settling patients for a 'rest period' and ensuring the ward environment was conducive to the patients' needs. On a late shift, after meals were served and before the night-duty started, there was an expectation that the majority of patients would be offered a 'light' wash and assisted to prepare for bed. On night shift, care was provided to patients on an 'as required' basis as most patients were sleeping. The staff-to-patient ratios per shift reflected this workload with, on average, nine nurses (five RGNs and four AuxNs) on an early shift, five nurses (three RGNs and two AuxNs) on a late shift, and four nurses (two RGNs and two AuxNs) on a night shift.

At the beginning of each nursing shift the team leader from the previous shift would give the team coming on duty a hand-over. Each patient was discussed in turn, mentioning their age, gender, diagnosis, reason for admission, their current care priorities and any outstanding actions required. Any nurse was able to contribute to these meetings but the majority of conversation came from the nurse on the earlier shift.

Once a week the nurse in-charge of each team would attend the multi-disciplinary team meeting (MDTM), where the at least one representative from each professional discipline working in the hospice would contribute to a discussion on each patient's condition, progress and care needs.

At the time of the study, nursing documentation concerning patients' psychosocial needs was only made by RGNs.

4.4.1.1   The Hospice Staff

Although this study explores the actions of nurses in the ward, other members of the hospice staff were present during some psychosocial support episodes and are mentioned in some data

excerpts. To maintain anonymity, the term 'colleague' is used to identify other members of staff. 'Colleague' can refer to other ward nurses who did not consent to participate in the study. In these instances there is no reference made to their input in the interaction, thereby respecting their wish not to participate, but a comment is made to their being present as it is necessary to accurately describe the interaction. Alternatively, 'colleague' can refer to another member of hospice staff who is not a nurse on the ward, for example: a home care specialist nurse, an allied health professional, or a member of the domestic staff. What role the colleague has in the hospice in not divulged as this could affect the anonymity of the individual: there were some sole practitioners working in the Hospice.

4.4.1.2   The Nurses

The term 'nurse' is used to refer to: RGNs and AuxNs; nurses who were permanently employed by the hospice and those who worked from the hospice's nurse bank; and nurses who work on day and night duty (some nurses rotated between these shifts). A total of 72 nurses worked on the ward. At the time of data collection all nursing staff working on the ward were female, therefore the term 'she' is used throughout this thesis when referring to the nurses.

As mentioned above, the nurses worked in two teams. The majority of nurses participating in the study 'belong' to a specific team, the aim being that nurses work in their 'own' team. Shift patterns were planned with an aim of equal representation from each team on each shift, so that each team of patients were cared for by their 'own' nurses. There were some exceptions to this practice:

- the ward manager alternated weekly between teams;

- nurses working twilight shifts (5pm – 11pm) cared for a third of the patients from each team;

- bank nurses worked in whichever team required their input, though they were always allocated a team per shift; and

- at times, due to patient numbers or staffing issues, it was necessary for nurses to work in the 'other' team.

4.4.1.2.1   Patient Allocation

The principle of team allocation was applied to patients, as well as nurses, but not to the same extent. When a patient was admitted to the ward their team of allocation was dependent on where there were available beds, suitable to that patient's condition. This was the case even when patients had previously been ward in-patients.

Patients were informed which team was caring for them and the team to which a nurse was allocated was clearly identified to patients by a colour coding system. There was a preference that patients were in the same team throughout their admission. There were, however, because of the geographical nature of team-allocation, times when patients were swapped teams (this only happened once to participating patients during my observations). This happens, for example, when a decision is made to move a patient from a bay to a single-room: if single-rooms are only available in the other half of the ward the patient is moved to that room and, thereafter, comes under the care of the other team.

Although the hospice had a team approach to ward nursing, further divisions of which nurse was caring for which patient per shift occurred. On a late shift it was, generally, a case of each team caring for 'their own' patients. However, on an early shift further patient allocation occurred. At the beginning of each shift, nurses were allocated the specific patients whose care they were to focus on for that shift. This usually involved the nurses working in pairs (either one RGN with one AuxN or two RGNs, depending on staffing ratios). In most circumstances, each pair was allocated a maximum of four patients per shift.

Chapter 5: Findings: observed psychosocial needs

In Chapters One and Two I identified a range of psychosocial needs that palliative care patients are thought to have (Figure 1.1) and that there is an expectation on nurses to provide psychosocial support as an inherent component of their practice. However, there is a lack of empirical evidence demonstrating the psychosocial needs expressed by patients when they are in a hospice ward or of how ward nurses support them during everyday in practice. By observing nursing practice, interviewing the observed nurses and patients, recording both verbal and written reports concerning psychosocial support, and collating other related data (see section 4.1) I have provided new evidence on two main issues. Firstly, whether the psychosocial needs suggested in the literature really exist whilst individuals are hospice in-patients and, secondly if so, how these are expressed. These questions are considered in this chapter. Secondly, in Chapter Six, I explore how the nurses in my field of study reacted when patients expressed psychosocial needs during their everyday practice. In both of these chapters factors influencing the nurses' provision of psychosocial support are uncovered.

The findings of this study come from a number of data sources collected over an eight-month period (the different terms for the data collected are outlined in section 4.1.11):

- 39 observed episodes of care, of which:

    - 20 became cases with interviews about the observed care:

        - 11 cases included interviewing both the nurse and patient;

        - 7 cases included interviewing only the nurse; and

        - 2 cases included interviewing only the patient.

- 26 interactions (observations not followed by formal interview),

- 19 observations of nurse-handovers,

- 19 observations of the multidisciplinary team meetings (MDTMs),

- Copies of nursing documentation on the psychosocial aspects of the care of 47 patients.

- Demographic details on:

  - 38 nurses, and

  - 47 patients.

- The duty rota for 35 weeks and nurse-patient allocation charts for 18 weeks.

Two-hundred-and-twenty-seven encounters (one nurse's response to one expression of psychosocial need/s) emerged from these data sets and were used as the main variable for quantitative analyses.

The psychosocial support provided by nurses on the ward under investigation was multifaceted. Patients expressed a wide variety of psychosocial needs for many different reasons and nurses responded to these needs in a range of ways. In order to understand how nurses operationalise psychosocial support it is worthwhile exploring what psychosocial needs were observed and the context of care in which they were expressed.

5.1 Categorisation of psychosocial needs

This chapter presents, for the first time, empirical data outlining categorisations of psychosocial needs that are expressed by patients during their stay in a hospice ward. The focus of this chapter is to report and categorise the psychosocial needs observed. Patients were rarely observed interacting with nurses with the explicit aim of expressing psychosocial needs. Patients mostly expressed psychosocial needs when interacting with nurses for other reasons. The contexts of care (henceforth referred to as 'contexts') in which psychosocial needs were expressed emerged as an important concept during this study. Since such codification has never been reported

before, the first novel contribution to understanding psychosocial support this study offers is, therefore, the categorisations of observed psychosocial needs according to both their type and the context of care in which they were expressed.

A variety of psychosocial needs could be expressed under a number of contexts within one episode of care. In the following example, Diana, an auxiliary nurse (AuxN), supports a patient, Grace, with three psychosocial needs: independence, control over choices, and self-concept. This occurs whilst assisting Grace with two things she wanted to achieve ('contexts'): washing and eliminating.

Fieldnotes

> *Diana and I were assisting Grace with her personal hygiene. Before starting to wash Grace, Diana asked, 'Would you like to wash your own face?' She replied, "Yes", but then told us her arm was sore. Diana said, "Would you like me to do it for you?" and she said, "Yes". Diana washed Grace's face but then offered her the facecloth. Throughout the care, whenever Grace seemed to be struggling, Diana asked, "Would you like me to do that for you?" When it came to changing her stoma bag Diana continued to hand Grace the equipment that was needed, Diana allowed and encouraged Grace to do as much as she could herself. When we had finished, Grace said, "It was good to get to* [change my stoma bag]. *I'm getting more used to it now."*

The complexities created by this simultaneous expression of different type of needs within different contexts of care create a challenge for analysing data, to overcome this challenge categorisation of type and context of psychosocial need were created as they emerged from the data. The following two sections discuss these categorisation in turn.

5.1.1 Type of psychosocial needs

The types of psychosocial needs discussed in section 1.4 and collated in my concept map (Figure 1.1), were all expressed at some point within the 227 observed encounters. More than one psychosocial need could be expressed at a time. During the observations, 51 nurse-patient psychosocial interactions were recorded. Of these nine (17.6%) considered only one type of need, all but one of these were brief interactions. Even when encounters alone are considered, 151 of the 227 (66.5%) could be categorised as more than one, and up to as many as four, types of psychosocial need.

From both existing literature concerning psychosocial care (as cited in Chapters 1 and 2) and the data collected throughout this study, it is clear that psychosocial needs are interrelated and overlapping. To aid analyses within this study I have categorised psychosocial needs into four groups, as demonstrated by the coloured patches in the concept map (Figure 1.1): expression, rights, coping and identity. Table 5.1 identifies the frequency of expression of each category of type of psychosocial need.

Table 5.1 Frequency of expression of types of psychosocial need

	Expression	Rights	Coping	Identity	Total
RGNs	60	125	34	25	244
AuxNs	12	39	7	25	83
Total	73	165	42	50	330

The following sections discuss these categories in turn.

5.1.1.1 Expression

'Expression' psychosocial needs concern the emotions, thoughts and feelings palliative care patients have and how they express them. There are a vast range of these from elation to despair and the desire for quality of life. The aim of psychosocial support for these types of needs are

to maximise emotional well-being and avoid clinical conditions such as anxiety states or depression, which can be common in palliative care (Delgado-Guay 2009). Seventy-three 'expression' psychosocial needs were observed. Psychosocial needs in the expression category were observed being openly conveyed, subtly hinted at and withheld from nurses – the latter category being uncovered by another nurse or during my interviews.

Nurse-patient interactions, on occasions, took place with the specific purpose of allowing patients and/or family members to express emotions, as happened when Annie, an RGN who had been caring for Carrie over the past three days, met with Carrie and her husband:

Fieldnotes

> *A patient, Carrie, was expressing to Annie her worries about her son's difficulties coping with Carrie's illness and life in general but did not want to involve other members of the team. Following their talk Annie they left Carrie to have a cry with her husband. When the husband came out of the room he asked Annie if he could speak to her. He asked for a hug and broke down crying... Annie was tearful when she handed over about this interaction and seemed to feel she was letting Carrie down by not looking after her tomorrow.*

Whilst discussing this episode of care Annie told me that '*Carrie **now** trusts the hospice staffs' judgement but needs help making decisions*'. By using of the word 'now' Annie is suggesting Carrie has built this trust since her admission. It is clear from this interaction that both Carrie and her husband trust Annie and have gained some emotional release. It also appears that Annie has concerned that she will no longer be available to continue this emotional support.

The idea that continuity of care impacts on psychosocial support also arose in an interaction when Millie (RGN) was caring for Davina, a patient she had never met before. During Millie's interview she stated that she "*she needed to get to know a patient through providing continuity*

of care in order to offer psychosocial support". However, her actions contradicted this perception when she described the conversation I had observed her having with Davina, a patient in the 'other' team, involving a subtle 'expression' psychosocial need.

Nurse Interview

> Millie *"It was good on Sunday though, because Davina gave off a lot of cues about how she was feeling and we actually had a really long chat about how she felt. It was really good and I felt that she was able to tell me more, and, because I didn't really know her that well … she seemed to want to talk. … we discussed about how her husband died five years ago… we went through all the things, her shock, she was quite upset. I think it was good for her, because she got a lot of things off her chest and she's also feeling vulnerable at the moment …we'd had that time for her to vent a lot of her fears, and she did tell me a lot of her fears, and we were able to discuss them, and I think we helped her, 'cause she'd actually witnessed, a wee lady, a few days previously, was dying in that room. She'd told me that she could hear [her] 'moaning and groaning' and was quite distressed, and how much it had upset her… so we went through all that and she said to me, 'Is that what happens when you start to die?' So, I thought that was a very big cue, so we went through all that. She seemed really … pleased that we could discuss that. I felt that we had put her mind to rest, which was good. And I feel, although she's poorly, she does seem to be more at ease with herself, somehow. I think she got a lot of her questions answered that day and she obviously had these ideas in her mind, that when you get terminally ill you don't talk about it."*

In this interaction Millie picked up on Davina's cues that something was wrong and encouraged her to express a number of emotions, including: fear, shock, and upset. When asked about her ability to deal with Davina's psychosocial needs on this first interaction with her, Millie related this to having time because the ward was quiet:

Nurse Interview

> *Millie: "I don't know, sometimes I think some situations work out better than others, I don't know whether it's to do with the timing ... on Sunday I felt it was good, I felt quite satisfied that and I suppose the time 'cause we were a bit quieter."*

Interactions could also be categorised under 'expression' when no feeling was actually expressed but a nurse took action to prevent or alleviate a negative emotion to which a patient was susceptible. This happened when an auxiliary nurse, Maisie, and I were working for the first time with Bruce:

Fieldnotes

> *When Maisie and I were helping Bruce back into bed, he appeared quite nervous. We knocked a bottle off the locker, it made a loud noise as it hit the floor and Bruce appeared to get a bit panicked. Rhona (RGN) came in behind the curtains, saying, 'Oh, I thought they'd dropped you there.' She stayed and assisted us with Bruce's transfer. After he was settled into bed we were all talking about the move and he said, 'I'm okay, because my aunty Rhona is here.'*

Patient Interview

> Hazel: *"What I'm thinking about is, whether the nurses get continuity with patients, so they get to work with the same patients more, so they know the patients more, and can look after them."*
>
> Bruce: *"Aye, to a certain extent, there's certain nurses and you get used to the same nurses being on every day to help me. If a stranger comes you feel a bit more vulnerable"*
>
> Hazel *"Would [changing teams] make a difference to you?"*
>
> Bruce *"I'm not against the other team because they come in every now and then to help but I know they're all ... basically everybody's the same. Like I would get on with the nurses in the other team just the same, so it's not a big concern."*

Rhona was in-charge of the team that day and was aware of Bruce's anxiety about nurses working with him for the first time. Rhona came in to assist at the first possible opportunity; she did this with an aim of reducing Bruce's anxiety and make him feel safer. This interaction illustrates the challenges of both identifying and categorising psychosocial needs. Patients may hide their feelings for a number of reasons making them difficult for nurses to recognise. In Bruce's case, he tried to hide his anxiety about Maisie and I, both new nurses to him, providing his care. Although Bruce is saying he is happy to receive care from any nurse, he is more comfortable when the nurse has worked with him before. While categorising feeling safe is difficult as it both an emotion and a 'right' for vulnerable people who put their lives in others, in this case nurses, hands.

5.1.1.2 'Rights'

The psychosocial needs labelled as 'rights' were labelled as such because they concerned what relates to the ethical principles of rights: maximising the patient's individual freedom, keeping them safe, and showing respect for them as a person (Thompson *et al.* 2006). These psychosocial needs included, amongst others, the need for: self-determination and dignity, with the key aims of safety and security and maximising quality of life. 165 (50%) of all psychosocial needs expressed were rights related, by far the largest number per category expressed. Examples are discussed below where patients' choices are considered, being both respected and avoided and how this impacts on independence, privacy, dignity, and individuality.

Often the nurse-patient interactions involved some aspect of self-determination, where the patients were involved in making choices over what would happen. The outcomes of these interactions often affected patients' other psychosocial needs, as occurred when Ralph was re-admitted for assessment of his mobility because his condition had deteriorated. The nurses were familiar with Ralph and aware of how he normally transferred from the bed to his wheelchair because of his numerous prior admissions to the ward. However, it was unknown whether Ralph would still be able to transfer his usual way and assessing this was important:

Fieldnotes

> *Beatrice asked Ralph how he 'liked to do things?' but as she was asking she lifted up the Banana board [a mobility aid]. Ralph said, "Oh, here we go again! People always do this before I tell them."*
>
> *Once Ralph was up in the wheelchair he asked for his foot-rests. Beatrice tried to put these on for him. I could see Ralph not only trying to do this himself but that it was easier for him to do this and for Beatrice to lift his legs, as he was requesting.*

Beatrice's familiarity with Ralph resulted in her automatic insertion of the banana board and wheelchair foot-rests. On previous occasions this would have made Ralph's transfer faster. However, on this occasion it impeded Ralph from discovering if he could transfer independently:

Patient Interview

> *Hazel: "I wanted to ask you about when Beatrice was getting you up the other day and I was wondering about independence and how we work with patients' independence."*

> *Ralph: "One of the reasons for my admission was to find out how independent I am still, because the changes in my balance and … obviously there's been a deterioration in my condition … I'd got to the point where I was unsure of my own abilities and I was looking for assessment to check out, It's to find my centre again if you like, to find my balance, to know where the limits are, where the boundaries are, and what I can and can't do…the global effect is that I know I'm safe and there's people around me."*

When nurses know a patient well they learn how patients prefer to do things; this can lead to the nurses doing things for patients without asking them. This 'natural process' of care can be helpful but the assumptions that nurses make can prevent patients from doing something they need to do, as in this example. Being familiar with Ralph's preferences and automatically doing things for him, Beatrice did not, at that time, support Ralph's psychosocial needs – independence and understanding of his changing condition – instead she focussed on the physical aspects of his transfer. When asked about this interaction Beatrice explained her actions in relation to her workload and how nervous she can get if she takes 'too long' with her work:

> *Beatrice (RGN): "Because that's a horrible feeling if you've got a patient or maybe two patients that do take a long time, and, well my tummy just goes round … if you look out and everyone else seems to be getting on fine with their patients and you're just still on the same one."*

The inter-related nature of 'rights' psychosocial needs was demonstrated in other interactions where nurses were concerned with realising their daily workload. There were occasions when patients did not want physical care at the time it suited the nurses. In meeting these patients' psychosocial needs of control over choices, the nurses could leave themselves with 'nothing to do'. Both RGNs and auxiliary nurses were observed in similar situations of being 'held back' from getting their work done by supporting patients' psychosocial needs. Both groups of nurses expressed feeling frustration at 'not being able to get on with their tasks' but regularly, though not always, kept these feelings hidden from patients:

Fieldnotes

> *When Andy was in the bath, Rhona (RGN) asked him if he 'wanted to stay in longer?' He did, so we went away, leaving him with the buzzer. However, it did appear that Rhona was in a hurry to get Andy washed and this became more apparent later when after he'd buzzed for us to get him out of the bath, he started telling us a story. When he buzzed Julie (AuxN) joined us but the story-telling delayed us from getting Andy out of the bath. Rhona was very patient with him, took her time with him and did not show any signs that she was frustrated and wanted to get on with things. Julie, however, was pulling faces as if to say 'Oh come on, hurry up' but Andy did not appear to notice this*

Rhona respected Andy's choice to stay in the bath, gave him privacy and dignity by leaving him, and offered the security that we were available when he needed us by giving him the buzzer. Julie, however, was less happy respecting Andy's choice and offering him companionship.

Nurse Interview

> Hazel: "You can see [nurses are] actually desperate to get on with [care] and I just wondered … we don't show it to the patients. The patients don't pick up on that and I was just wanting to check out how you'd felt about that conversation."

> Rhona: "I would hate to, and I'm aware of it myself sometimes, I would hate to show anybody that I wasn't listening to them or that their story wasn't worth their time … it's [not] the end of the world if you take five minutes to listen to somebody, is it?"

Although Rhona is not explicitly admitting that there are times when she does not listen to patients, her comment "*I'm aware of it myself sometimes*" suggests that she has observed this practice and perhaps carried it out herself. Rhona did, however, on this occasion respect Andy's individuality by respecting his choices and listened to him.

Often while patients are in hospices their lives become very limited in what they can do and the little things such as making choices and being treated as an individual are what gives them quality of life. This was demonstrated in one interaction when Amelia (RGN) gave Janie a bath despite her having one the previous day:

> *Janie had requested a bath, which Amelia, agreed to give. Amelia discussed with me the issue of Janie wanting a bath every day and how this might be disapproved of by other members of staff in the ward. Amelia explained the benefits of a bath for Janie and added to her justification of this that she was fairly independent and workload-wise they could manage this.*

The 'rights' psychosocial needs appear to be easiest for nurses to respond to within constraints of their workload. The contexts within which this group of needs were expressed were often the least intrusive or problematic areas as the issues around which the needs were focussed were often the reason why the professional was interacting with the patient. Exploring the 'rights' psychosocial needs often regularly occurred at the same time that patients were facing their ability to cope with their current situations.

5.1.1.3 'Coping'

The psychosocial needs categorised as 'coping' related to patients gaining understanding and acceptance of their condition and approaching death whilst maintaining hope. Although coping needs were observed 42 times, one of the interactions exemplifies the full range of coping needs: Stuart, a patient newly diagnosed with Motor Neurone Disease, who had recently been admitted to the hospice for rehabilitation, had a need for information to help him understand, accept and cope with his illness whilst giving him hope for the future.

Patient Interview

> *Stuart: "somebody should be saying to you 'oh, you're going along well' or 'we'll need to work stronger on this side'… or "you're deteriorating, you'll need to work harder". But they just come in and do for you. The nurse comes in and does her job automatically and you're wondering how you're getting along, you're sore, you're stiff, you know and*

you don't know if …this is gonna be it. And it would be fine for somebody to say "well

the right leg's no as strong as the left, you'll need to work a lot more on that. You'll

need to do this and you'll need to do that". Another thing to report to reassure a patient,

that this is not the end that you're still fighting on. That'd be a great thing. You know

don't leave them sitting wondering. It would be a good thing."

[…]

Hazel: "Would you like me to ask somebody to come to talk to you about that?"

Stuart: "Well no really, it should be a daily thing, you know. Somebody coming to talk

to you every so often is alright. The physio and the nurses are the people working with

you every day and they've got a better result than what one person sitting reading the

notes and then coming and talking to you."

Hazel: "That's a very important thing so, yeah, and had your experience been of that

happening, of one person reading the notes and then coming and telling you things

rather than people telling you things as they're going along."

Stuart: "Well you get that feeling that's what's happening. That they're consulting the

notes, you know, instead of talking to the nurses finding out how you're going, talking

to the physio, [that's better] *than seeing what someone else is writing down and coming*

and repeating it."

At the end of Stuart's interview he told me that he wanted the nurses to talk to him about how

he was progressing day to day instead of plans for how to manage when he gets home. He gave

me permission to tell the nurses this. I told Camille, the registered nurse I was observing, about

Stuart's coping preferences and documented them in his nursing notes.

When we were washing Stuart, two other members of staff – who were not ward nurses but had

been asked to assess Stuart's understanding of his illness – came into the room:

Fieldnotes

> *Half way through bed-bathing Stuart (when he was lying naked, covered only*
>
> *in a sheet, and was half shaven) two other health professionals came into the*
>
> *room. As they came in Camille had stepped back from the bed into the corner*
>
> *the room; she stayed there throughout their conversation. One of them asked*
>
> *some poignant questions about how much Stuart knew about his illness and*
>
> *tried to talk about what might happen to him. Stuart said, "but that's in the*
>
> *future and I'm not ready to talk about that yet". At which point the staff*
>
> *member looked across at Camille, as if to offer her the chance to participate*
>
> *in the conversation; Camille said and did nothing.*

The other staff member gave Camille an opportunity to support Stuart's wishes and current desires for understanding, however, on this occasion she failed to support Stuart's psychosocial needs. Camille had looked after Stuart on many occasions before I observed them together. She felt she knew Stuart well and was aware that Stuart did not wish to discuss his illness and prognosis:

Nurse interview

> *Camille: "Doctors had spoken to his family yesterday, just to see how aware*
>
> *they were about the progression of his illness, and prognosis, and apparently*
>
> *they were much more up to speed than we had anticipated, but they said*
>
> *they're "not discussing it, because Stuart doesn't want to discuss it"'*

When Camille (RGN) was discussing why she did not then support Stuart's psychosocial needs she blamed this on being in-charge of the team:

Nurse Interview

> *Camille: "I felt I just couldn't carry things forward…it was difficult being in-charge and then having patients as well because then you're pulled in two different directions."*

Camille proceeded to suggest that she managed to offer Stuart more psychosocial support the following day (the day of our interview) because she was no longer in-charge:

Nurse Interview

> *Hazel: "You said at the beginning 'that it was difficult yesterday because you kept getting disrupted because you were in charge.' You weren't in-charge today?"*

> *Camille: "No, so that was much better and we spent a long time in there with [Stuart]… I just thought that he was too low today to take that conversation any further."*

However, Camille she still did not discuss his current state. Despite Stuart requesting 'an update on his current state', and me advising Camille that he had repeated this request during our interview, she continued to try to discuss plans for home. She related Stuart's lack of response to her attempts at psychosocial support to the deterioration in his physical condition.

Nurse Interview

> *Camille: "I thought afterward, after I'd said it* [Camille had responded with, 'no, you shouldn't stop eating' when Stuart expressed concern that it was the food he was eating that was causing his condition to deteriorate] *'that I should have taken it further on, why, and take littler things'. But then you get distracted. 'Cause you're working round him and working with a partner and*

then sometimes perhaps you should stop and pick up where you are, stop

doing what you're doing and take the conversation on from there."

"He just hasn't got the energy levels from day to day, and even when we were

doing his passive exercises today he said, 'that arm's not as strong as it was

last week, my other arm's fine and my legs are all right,' and he moved his

legs. So I just thought that he was too low today to take that conversation any

further. I just felt he would just have been in tears because you can just look

at him and he's so unhappy."

Camille did not deal with Stuart's desire to know how his condition was progressing in this description; thus indicating that her lack of dealing cannot be purely due to being in-charge of the team. The impact of being-in-charge on a nurse's ability to provide psychosocial support commonly arose: Camille was not the only nurse to give being in-charge as a reason for not dealing with patients' psychosocial needs, though other nurses demonstrated psychosocial support whilst being-in-charge.

5.1.1.4 'Identity'

The psychosocial needs falling within the 'identity' category relate to issues concerning social functioning and communication. This includes, sustaining and creating relationships and the feelings associated with these, such as love and compassion; maintaining a role in life; and having a positive self-concept. Fifty of the psychosocial needs observed were categorised in 'identity'. An influential need within the identity category is that of relationships, as it interacts with all other identity needs. An explanation of the interactions of these follows, with data excerpts concerning pre-existing relationships, and new relationships with fellow patients, and nurses. This section finishes with an observation concerning self-concept.

One of the few interactions observed where the main focus of care was psychosocial support centred on 'identity' needs: Chrissie (RGN) admitted Helen to the ward one afternoon. The following morning I observed the nursing report. The nurse from the night shift was unable to report anything about Helen other than her demographic details and that 'she had a settled night', as Helen's admission documents were incomplete. When the night nurse left, the team discussed their plans for the day. Chrissie explained that she had 'spent a lot of time with Helen yesterday discussing some complex psychosocial problems which Helen may, or may not, wish to continue discussing today'. Chrissie requested to look after Helen this morning.

When we came out of report, Chrissie told me about what Helen had been saying: about difficulties with her families, how difficult it was to cope with her increasing dependence, and her fears of dying:

Fieldnotes

> *Chrissie and I went over to speak to Helen. Chrissie sat down on the bed beside Helen and had a chat with her about how things had gone overnight and how we would take things over the rest of the day. At the end of the conversation Chrissie offered Helen a move to a single room.*

> *When we moved the last of Helen's belongings into the single room, Chrissie sat down on the bed and asked Helen how she was feeling, she stayed there and had a long conversation (at least 45 minutes). I did not feel it was appropriate for me to stand over this conversation, so withdrew to the corridor. Chrissie reported her conversation during the hand-over.*

Handing Over

Chrissie: 'Helen's worried sick about her son, how he's going to cope and his needs for the future. She's in for respite which her husband needs too, he clams up about the future; can we facilitate his openness? She's isolated in thoughts and feelings, finds it nice to be able to speak to people and they listen. Her situation at home is despairing, if things weren't as they are she could cope with her pain at home. I worry about how she's going to be. Three siblings have died, but Mum is still alive, it will be a difficult bereavement for her. We moved her from the Bay because control is important, she came in for a rest, peace and quiet. She needs time just to be. In some ways she wishes her son would die before her, but knows this isn't going to happen, this was a hard thing for her to say but she sees the huge pressure that her husband is going to have coping with this but he doesn't want to open up at all. Nieces and nephews are close. She finds religion supportive.'

When I asked Chrissie about her interactions with Helen and how she uncovered Helen's psychosocial issues she described their first conversation:

Nurse Interview

> *Chrissie: "I never asked her any questions about her admission; it was really all about the reasons why she came in, her anxieties, and her fears for other peoples' futures. It's almost as if she's been ready to talk. I think it would have happened anyway but yesterday she was talking [about] her son, and things like that, I actually can really empathise with her and I was actually able to share that with her. You could see her opening and becoming so comfortable with telling me that."*

This first interaction between Chrissie and Helen, where Helen's admission documentation was not completed, demonstrates how a nurse can approach a patient with one aim, but be flexible and explore psychosocial needs instead. The following day Chrissie specifically requested to work with Helen so she could continue to discuss Helen's relationship, love and identity needs. The needs for relationships, especially companionship was also observed in relation to the formation of relationships between patients:

Fieldnotes

> *Andy moved from a side-room to a bay. Rhona (RGN) told the consultant that the beds had been moved, saying "we're doing it for the psychology of Bruce* [the patient in the opposite bed] *too."*

> *Rhona talking to Andy, when he was in the bath, said 'yeah, I thought it would be quite good for you and it would be good company, for Bruce across the way to have you in the room', adding 'you know, in time you'll see that it'll be of good benefit to you', and he said 'yes, I was quite surprised that we started to talk to each other'. Andy also said 'it'll be best for Bruce as he now has someone else to talk to, but also someone else to keep an eye on the other patient in the room* [who is quite unwell and agitated].*'*

Patient Interviews

> *Andy: "at the end of the day having gentlemen in the room is of no benefit for me. The only thing that I could see is that if that old guy became incapacitated and he couldn't ring his bell, I could ring my bell for him, but also just recently, Bruce rang his bell for him and the woman came in and*

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said "yes, what can we do for you Bruce?" and he said "it's not me it's [that other patient]*" 'cause the chap was just, really not quite compos-mentis"*

Bruce: "there's more going on in here, I'm not just sitting staring at four walls trying to think of things to amuse myself, and if I see something with another patient I tell the nurses, I don't think they think I'm interfering, but if I can point out what the problem is, I'd rather help somebody if I could."

Nurse Interview

Rhona: "we've all got to the stage where we're all very fond of Bruce and aware of his plight, and I think, to try and make things easier for him, not at the disadvantage of other patients, but I think if you can see someone that would interact with him and help him … help each other, but who's to say we're right, it could all backfire, that's the thing. But that's the rationale behind it … and because it's a hospice, and patients are more likely to be in here longer, you really do have to think of who you're putting where and if people will gel and be good for one another, or if one patient is seeing too much death and dying. Bruce's a very observant man, if maybe he wasn't the type of person he was it would be easier for him."

In the example above Andy was moved from a single room to a bay, partly with the reasoning that it would be good for both him and Bruce: to give each other companionship. Rhona identifies that the nurses try to take into account patients' personalities and the need to continue having relationships when considering where a patient resides in the hospice. However, the comments from both Andy and Bruce suggest this so not so much of a priority for them, it appears from the interviews that the sharing of rooms gives patients a different form of identity:

a role in caring for others. Having such a role helps to give the patients an identity and purpose in life by feeling they are doing something to help others

Another aspect of relationship that was said to be of great importance during the study were those between nurses and patients – 37 out of the 38 nurses commented on the need for familiarity with patients in order to provide psychosocial support - though there were times when this was not evident as a nursing priority:

Fieldnotes

> *The ward has been very quiet this afternoon. At the period of time when the nurses haven't got anything physical to do they have been hanging around the nurses' station. There are a lot of patients who have got neurological illnesses in the ward at the moment, including the new admission who is quite frightened about her admission, who are just lying in bed looking into space. This applies more to the auxiliaries than the trained nurses although Alexa (RGN) has been standing around doing not a lot as well.*

Nurse Interview

> *Maisie: "if you're on a day shift and you get that lull in between I find it quite annoying, I don't like hanging about."*
>
> *Hazel: "What kind of things would you normally do, to fill that"*
>
> *Maisie: "well, you'd go and see if there was any clean laundry to be given out to the patients; any dirty laundry to be put in bags and tied up; if there's anything needing done in the sluice, likes of shelves filled up; just things like that; medicine pots needing done."*

> *Hazel: "Would you ever in these times [when the ward's quiet], go and chat to patients?"*

> *Maisie: "Yes, if they were patients that you actually knew, and you could chat with them, then, yes, if they didn't have any visitors."*

> *Hazel: "So, it does make a difference whether you know them already."*

> *Maisie: "Yeah, or, you can go in, if their relatives are there, and you've got to know their relatives, at the same time, 'Cause that lets the relatives get to know you, as well."*

Nurse talking to patients and/or their relatives can support patients identity needs in a number of ways, through the process of communication patients can: share experiences, recognise their continuing position in societies, have companionship which may develop into a relationship, and share compassion. However, Maisie suggests she is only able to go and chat with patients, and relatives, once she knows them but this in itself is a quandary as one way of getting to know a patient is to talk with them. Nurses asked the patients about themselves to try and build up relationships but also to assess patients' abilities and encourage independence:

Fieldnotes

> *When it was time for Sam to go for his shower Margo asked him whether he 'wanted a wheelchair to get through to the shower room?' even though it states in his care-plan that he needs a wheelchair.*

Patient Interview

> *Sam: "It could make you feel nice, because I got asked one day if I wanted a shower and I'd never had a shower there, it was the bath and it was quite good that you got on the shower in the wee cubicle, and it's handy, it's quite*

tidy, so, you can go in there, and get your shower, and you cannae always do it yourself and this is why they're doing it for you, so they're going to give you a good wash. And if you get your choice what you want, either you get it as a shower, or you'll sit yourself at the sink and give yourself a wash. No, I've nae qualms that way, everything's getting done for me."

Hazel: "So, you're saying that, you get some things done for you and there's some things you can do for yourself."

Sam: "There is certain things I will do for yourself, aye."

Hazel: "And, do you think we let you do that, encourage you to do that, or we maybe take over from you?"

Sam: "I think sometimes it's up to yourself, what you want to do. If I want to try and do it for myself I'll try and do it for myself ...it's up to yourself whether you want to do it or not...It's not as if they're saying "well, you cannae do this and you cannae do that", they're encouraging you to do things."

The above data identifies how Margo is encouraging Sam's independence but also showing a subtle respect for and encouragement of positive self-concept by helping Sam to be aware of his abilities and aiming to maximise his self-esteem by encouraging him to do all he can.

As with the other categories of type of psychosocial need, the identity needs interact with each other and the other needs of patients psychosocial, physical or spiritual. Ultimately 'identity' needs affect social functioning and communication of patients.

5.1.1.5 Summary of Type of Psychosocial Needs

The data excerpts in this section identify the variety of types of psychosocial needs expressed throughout my observations. These needs have been categorised into four categories:

expression, rights, coping and identity. However, it is clear that there is much overlap with different types of need often being expressed during individual interactions. Psychosocial needs were usually expressed when the nurses were interacting with patients for other reasons. The psychosocial needs were often implied rather that clearly stated, making them difficult for the nurses to identify, act upon, record, or report to their colleagues. This provides a major challenge for nurses trying to offer psychosocial support. Throughout data collection patients were rarely observed clearly expressing psychosocial needs as standalone entities: I did not observe a patient asking a nurse if they could talk about something and then express a psychosocial need. The psychosocial needs that were expressed were usually presented within another context of care.

5.1.2 The contexts of care in which psychosocial needs were expressed

The contexts in which psychosocial needs were expressed were collated into four groups: practical issues of daily life; needs related to a patient's disease and its treatment; how patients spend time within the societies to which they belong; and issues surrounding where care should be provided. The frequency of each category of context of psychosocial need is outlined in Table 5.2.

Table 5.2 Frequency of expression of contexts of psychosocial needs

	Practical	Disease	Societal	Place of Care	Total
RGNs	54	47	45	60	206
AuxNs	37	8	17	2	64
Total	93	56	62	63	274

The following subsections describe the different contexts in which psychosocial needs were expressed, providing examples to illustrate these contexts in practice. The examples included in this chapter demonstrate a variety of ways the nurses respond to patients' expressions of

psychosocial needs, how the nurses responded to the psychosocial needs is discussed in depth in Chapter Six.

5.1.2.1 Practical issues of daily life

The psychosocial needs expressed by patients during this study have been categorised as 'practical issues of daily life' when they are related to physical actions of everyday life: they are activities that most human beings carry out daily. Ninety-three of the 227 encounters involved practical issues. These psychosocial needs were expressed on 54 occasions to registered nurses (RGNs) and on 37 occasions to AuxNs (in two encounters the nurses involved were unrecorded) and were usually related to choice, independence, safety, dignity, or individuality. Four subgroups of practical issues were identified: washing and dressing, mobility, elimination, and eating and drinking. These are discussed in turn below.

Forty-six encounters involving washing and dressing – psychosocial needs expressed in relation to mouth-care was also included in this category – were observed. This group of needs regularly included issues concerning choices over when and how patients would wash and dress, and who would assist with this, for example:

Fieldnotes

> *Alexa (RGN) 'We'll get you into the bath later', to a patient who was admitted yesterday.*
>
> *He replied, 'Not those young ones,' [meaning me and the volunteer]. Alexa respected his choice and got one of the older AuxNs to assist him.*

And issues related to maximising independence:

Fieldnotes

> *Cecilia (AuxN) explained to me, 'Kevin wants to dress himself, so I let him but I make the bed for him whilst he's doing this, so that I can keep an eye on him.'*

> *When it was time for Kevin to dress I put his clothes within reaching distance (pre-empting Cecilia's action). Kevin managed to dress himself independently, but struggled with his belt. Cecilia allowed him to struggle for a short while, before offering to help and having helped with the buckle stepped back until Kevin struggled again.*

Often during these encounters, the psychosocial needs of safety, dignity, privacy and individuality were also expressed.

Thirty-seven of the encounters concerned mobility, these included: whether patients were independent with mobilising; which mobility aids were required and how these should be used, if patients were not independent; and whether patients needed to mobilise at all. For example:

Fieldnotes

> *Louise buzzed and asked for a hand to sit up the bed, I asked her whether she 'needed up the bed or just forward?' She wanted up the bed. As I couldn't do this alone, I asked Joan (RGN), who was nearby, 'for a hand'. I got the sliding sheets out, but Joan just went in stating, 'Och no, you're far enough up for that. Sit forward and we'll put these pillows behind you.'*

Again the psychosocial needs involved in 'mobility' encounters focussed strongly around choice, independence and safety; additionally, the expression of feelings, and needs around self-concept were simultaneously encountered.

Twenty-one encounters involving elimination were observed during which patients sought control over choices and dignity. This included giving patients a choice over what bowel care they received, when, and control over the positioning of urinary bags for catheters:

Fieldnotes

> *Maisie (AuxN) was setting up Claire's urinary drainage bag for the evening: she explained what hospice staff usually do with overnight bags (this was Claire's first admission to the hospice), and attached it, leaving it lying on the bed, according to usual hospice practice. Claire said, 'I normally still have it attached to my leg overnight,' she seemed quite concerned about the change, so Maisie left the bag attached to Claire's leg.*

Seven of the encounters involved eating and drinking. They concerned issues around timing and choice of foodstuffs, as well as offering assistance with feeding, and being aware of patient's preferences about eating and drinking, for example:

Fieldnotes

> *As Julie (AuxN) started to get the bed ready to sit Rita forward for her breakfast, Daisy (AuxN) came in and said, 'Oh, are you just staying in your bed for breakfast this morning?'*
>
> *Julie said to Daisy, 'Och, it's just easiest.'*
>
> *Daisy said, 'You normally get up for breakfast, don't you?' to Rita, who replied, "Yeah."*
>
> *Julie then asked Rita, 'Would you prefer to get up?' Rita replied, 'Yeah, I would,' so we got her up.*

This example demonstrates how patients' individuality can be respected if nurses consider patients' wishes, instead of enforcing the quickest or easiest way of getting the job done. This example also involved Rita's preferences about mobility and was analysed in relation to both the contexts of 'eating and drinking' and 'mobility' and demonstrates how practical issues can interact with each other and result in the same type of psychosocial needs.

Psychosocial needs are often expressed around practical issues because of changes caused by patients' advancing diseases or as side-effects of treatments, which define the next category of context of need.

5.1.2.2 Impact of disease and its treatment

Fifty-six of the encounters involved issues directly related to a patient's disease and medical management of this. There were a variety of different ways in which patients expressed needs concerning their disease. These needs were substantially more likely to be expressed to RGNs (n=47, 83.9% of these encounters). Disease encounters concerned two main issues: medications and disease progression.

Thirteen needs concerned medications and were mainly related to patient choice: usually choice of which medications to take, but also choosing to delay taking medications at the time of normal drug rounds:

Fieldnotes

> *A patient, Frances, told Marianne (RGN), 'I want to rest now and have my breakfast later. I'll take my medicines after my breakfast' [Frances' normal routine at home]. Marianne struggled with this, explaining to me that she really should do the drug round but could see why Frances would want to wait for her medicine. Marianne complied with Frances' request.*

Marianne had struggled over whether to allow Frances' choices or to carry out the ward's normal routine of giving medications at a set time. She told me later that the decision was made easier because Frances' care aim was respite and because Marianne felt able to advocate for her, by discussing the delayed medications with a doctor and documenting the delay.

Another patient was observed declining analgesia as she felt she deserved her pain because "her lifestyle had caused her illness":

Fieldnotes

Olivia blamed herself for contracting cancer because she smoked, this led her to believe that she should suffer pain as punishment. Chrissie (RGN) negotiated this with Olivia, giving her information in an attempt to counteract her beliefs. Chrissie talked to Olivia about her feelings about smoking and her disease. They discussed: how Olivia was trying to stop smoking; that smoking had not necessarily caused Olivia's bowel cancer; and how, regardless of what had caused her cancer, suffering now would not take it away. Olivia remained insistent on not taking pain relief and Chrissie ultimately accepted this choice. By the following day Olivia had reconsidered her beliefs and accepted the recommended medication.

In this example, Olivia was observed expressing strong emotions around the impact of her lifestyle on her disease. This interaction demonstrates how discussions about what appears to be a simple thing like aiding patients' understanding about medications – with an aim of getting patients to comply with pharmacological therapy – can unveil deep emotional concerns – such as guilt and blame from deserving ill-health because of poor lifestyle choices earlier in life and their negative impact in well-being. By allowing Olivia to express these feelings and respecting

her choice not to take the medications without judgement, Chrissie supported Olivia's psychosocial needs, for example: self-determination and understanding. Similar expressions of psychosocial needs occurred often during encounters related to a patient's disease, its treatment and progression.

Disease progression encounters (n=43) concerned a wide gamut of psychosocial needs, in a variety of combinations, especially: expression, acceptance, understanding, dignity, identity, coping, and respecting rights. Patients had worries about their condition deteriorating and their approaching deaths. Some sought information around diseases, their symptoms, and whether to accept further treatment, though few made these desires explicit. Others made it clear they did not wish to discuss their disease, its management or its progression. Included within this category was the recognition, by nurses, of how patients' moods were affected when they had to adjust to their progressing illnesses:

Fieldnotes

> *One patient, Kate, was unhappy. She felt: unable to get on in life, her condition had not improved at all, she was being a burden on her family, and that constantly talking about how bad she felt was unfair on her family. Iris (AuxN) sat down with her, saying, 'Think back to your admission and see how things are now.'*

> *With prompts from Iris, Kate hesitantly suggested how her mobility had slightly improved and how she was adapting to doing things differently. Iris went on to say, 'People with cancer need to take time to accept it to be able to get on with living. It's about finding out what helps you. You've talked to your family and told me about what they said. It seems your family feel the same way as you.' This seemed to give Kate some comfort and she*

acknowledged that talking to her family did help in some ways, saying, 'Well,

I had to tell my husband.'

Often the psychosocial support offered by nurses regarding disease and treatment involved the nurses talking informally with patients. When patients initiated informal conversations it was often with the purpose of maintaining interactions within the ward society, another category of context of need.

5.1.2.3 Patients' interactions within society

Sixty-two of the encounters were related to patients' desires for interaction with other members of the societies to which they belong (included in this category is the idea that the ward is a society). These psychosocial needs were expressed to both RGNs and AuxNs (RGN=45, AuxN=17), and concerned patients' informal conversations, social relationships, and how patients occupied their spare time.

Psychosocial needs were expressed during 17 encounters when nurses and patients were having informal conversations, for example, reminiscing, having humorous conversations, and/or talking about everyday matters. Discussions were observed both when patients shared personal information or thoughts, and when nurse gave details about themselves.

Both patients and nurses initiated reminiscence in order to get to know each other and, once they were known to each other, to maintain rapport:

Fieldnotes

> *May (AuxN) did seem to have a rapport with the patient, Teresa. When I went*
>
> *in to join them Teresa was recounting a story to May about a day-trip she*
>
> *had as a child.*

> *Hazel: "Yesterday when I came in May was giving you a wash and you were*
>
> *talking about things from your past ... How does it make you feel when these*
>
> *conversations come up about the past and things?"*
>
> *Teresa: "Well I brought it up because of the weather, that's how it started ...*
>
> *So, that's why that all came about, it just reminded me about things. That was*
>
> *nice ... Well, they [the nurses] all have their different personalities ... some*
>
> *of them are really quite jocular and just like you to be happy and have jokes*
>
> *all the time and they like to involve you."*

Sharing stories about the past and seeing how each other reacted enabled patients and nurses to connect with each other. Reminiscing encouraged patients' emotional expressions and gave them a sense of identity. Teresa's comments include a commonly observed concept: both patients and nurses enquired about each other's pasts as a way of identify their personalities. Assessing personalities helped participants interact more effectively with each other:

Fieldnotes

> *As soon as we started the bed-bath Sybil (AuxN, who had never met Polly*
>
> *before) asked Polly where she came from.*
>
> *Sybil told her that in a previous job she had worked in that town and asked*
>
> *about places she remembered. Polly was able to update Sybil on how the*
>
> *town had changed. Sybil then went on to ask Polly about her family.*

Nurses would encourage patients to reminisce as a way of assessing them. Telling stories about things that had happened in the past enabled the identification of patients' psychosocial backgrounds. Exploring backgrounds encouraged patients to discuss, among other things:

significant relationships in their lives; things that affected them emotionally, and how they gained a sense of identity. Nurses used reminiscence and gentle probing questions to lead up to more difficult conversations:

Fieldnotes

> *Ava (RGN) told me at the beginning of the morning, 'I find it difficult with Cameron, I've tried to have some deeper conversations with him but it feels like I'm only really scratching the surface.'*

> *When we were working with Cameron, Ava asked about his family and they talked about holidays he had been on. Ava told him, 'I'm just trying to get a baseline, because I don't know you.' She then asked about his recent bereavement.*

Informal conversations occurred during care, through the patient and nurse chatting about shared experiences. This helped patients to have a sense of belonging in the hospice and a relationship with their nurses. Beatrice (RGN) told me about an example of this when I was interviewing her about her care of Ralph:

Nurse interview

> *"*[Ralph and I] *were talking* [about] *his last admission, we were out in the back garden and had photographs taken* [by] *his daughter. We were talking about that photograph."*

Ralph's inclusion of Beatrice in photographs, and his memories of this experience, demonstrates that he includes Beatrice as someone who has a place in his life. Having relationships, both sustaining existing ones with significant others and creating new ones with fellow patients or allied health professionals (AHPs), is a psychosocial need itself.

Twenty-three encounters involved patients expressing psychosocial needs specifically around their relationships with their significant others and other patients. For example, the nurses were concerned that Elma's quiet nature was due to her struggle to grieve for her son and that this was causing strain on her other family relationships. The nurses felt it may be valuable for Elma to have the opportunity to release emotions concerning this:

Fieldnotes

> *Gabrielle (RGN) and I were bed-bathing Elma. Gabrielle asked Elma about her family. She began by asking about Elma's daughter-in-law, who comes in to visit, then mentioned her son, leading up to asking Elma, 'Do you and your daughter-in-law talk about your son much?'*

Relationships were also formed between patients, either through the patients' own exploits or stimulated by nurses. This could provide psychosocial support, through companionship, or create additional psychosocial needs. For example, Rhona (RGN) felt that moving Andy into a bay from a single-room would provide support to both Andy and Bruce, a patient in the shared-room:

Fieldnotes

> *Rhona talking to Andy about his move into the bay: 'I thought it would be quite good for you and it would be good company for Bruce to have you in the bay.'*

Nurse Interview

> *Hazel: "I'm very interested about the issues of moving beds, especially, in relation to all the discussions that have gone on around Bruce and how he's finding things in Bay2."*

> *Rhona: "I was keen to move someone into that space who had a wee bit of*
>
> *spark about him … Andy and Bruce would have been good for each other."*

Rhona thought that moving Andy would provide companionship for both him and Bruce. She also hoped the move would help them both to understand that being in the hospice did not mean they were about to die.

However, the relationships patients developed with each other were often short-lived, exposing hidden psychosocial needs or even creating new ones. For example, when patients died, other patients grieved for them and questioned their own mortality. This was observed when Amelia (RGN) offered support to Janie:

Fieldnotes

> *Janie had been upset yesterday by the death of another patient in her room.*

The relationships patients developed with other patients often served as a useful way of occupying spare time in the ward. Psychosocial needs were expressed in relation to other ways of filling time.

The time patients spend in hospices is very busy: there is a lot of assessment and management of symptoms by a variety of AHPs; there is time spent when families and friends are visiting; and, as a result of a weaker physical condition, there is the extended time required to carry out daily practices and a greater need for rest periods throughout the day. Despite this there are occasions when patients in hospices have nothing to do with their time; their reactions to this can range from mere acceptance to feeling bored. Twenty-five of the encounters related to ways patients could occupy their spare time. Examples of this can be very obvious – such as a patient's desire to continue attending day-care while being an in-patient – or very subtle, for example, when a patient decides not to follow a ward norm. The latter happened when Polly declined the offer of having a rest after lunch – a practice that is encouraged of all patients

because of the fatigue suffered by palliative care patients. Polly explained her reasons for this during our interview:

Patient Interview

> *Polly: "I've had enough of the bed while I'm getting done, and I've had a change out of the chair for a length of time, so I don't see why I should lie in my bed. I mean you're really only doing the same thing lying in your bed."*

At times patients expressed their psychosocial needs around managing their time, such as Sam, who expressed his boredom. At other times, hospice staff would identify a psychosocial need and offer a solution, such as suggesting that patients might like to go on an excursion.

I have shown how a patient's choice, or ability, to interact with others in the societies to which they belong, including the society of the ward, is one of the ways patients express psychosocial needs. This is done through informal conversations, formation and maintenance of relationships, and occupying time in a variety of ways. A factor which may impact on this, as shown above in the example of Andy moving rooms, is the location of care provision. The impact of place of care provision on patients' psychosocial needs warrants this being considered as a separate group of contexts of psychosocial need.

5.1.2.4 Place of care provision

Sixty-three of the encounters involved issues concerning the place of care provision. Patients' views on where care is provided also incites psychosocial needs. Place of care has links to all categories of need observed during this study but are most strongly linked with societal contexts of psychosocial need. Psychosocial needs were classified in this category when they were centred on receiving care in a different place, the change of care setting may be long-term or temporary and pre-empted by patients or staff.

Psychosocial needs concerning the place of care arise throughout a patient's time in the hospice: from the moment of their admission, when patients need assistance with 'settling in'; during their time in the ward, when nurses determine a need to move the patients' place of care in the ward or when patients want to leave the hospice to 'visit their home, one last time'; to times when discharge from the hospice were under consideration.

Hospices – when people are familiar with the concept, but have not visited them – have a reputation of being somewhere frightening, relieving this emotion requires effort: patients need support, often psychosocial, to 'settle into' the ward. Both RGNs and AuxNs were involved in settling patients into the ward:

Fieldnotes

> *Helen was admitted to the ward yesterday, she is nervous about the routine and how things work on the ward. Chrissie (RGN) sat down on the bed beside her and had a long chat with her about ward routines and how things would progress over the rest of the day.*

Fieldnotes

> *Fleur (AuxN) was showing a relative of a new admission around the Hospice. When she came back, she told Marguerite, who is in-charge of the team today, 'Well, it helps them to feel a bit more comfortable leaving their relatives here.'*

Helping patients to settle into the ward enabled the nurses to identify some patients' individual idiosyncrasies; by doing this they were able to support patients' psychosocial needs:

> *When Iris (AuxN) and I were washing Maude, she began to cry; 'I know how some people were to me when I came in. Don't tell anyone I'm saying this.'*
>
> *Maude felt that the nurses 'found her frustrating because she was very particular about how she wanted things done and was always buzzing for things.'*
>
> *Iris responded, 'I won't [tell anyone] if you don't want me to, but maybe you or I could talk to Sister, she's very discreet.' Iris did not try to reassure Maude about her thoughts.*

Some of the nurses had described finding Maude easier to cope with once they recognised, and were to 'used to' Maude's 'demanding manner', which can be interpreted as her way of coping with the unknown environment of the ward.

The actual whereabouts of a patient in the ward can also arouse psychosocial needs, especially when this was changed. This hospice's norm was to admit new patients to a bay, if possible, unless a patient's admission referral specifically indicates a need for a single-room. When patients' conditions deteriorate they are usually transferred to a single-room – this is perceived, by the majority of the ward staff, to be more suitable for all patients and visitors. However, it can be considered as concealing death (Lawton 2000). Transferring frailer patients to single-rooms may require swapping another patient into a bay. The transfer of patients often has psychosocial repercussions. In the following observation a patient, Georgina, was frightened and lonely when she found herself in a single-room:

> *Georgina had been admitted to a bay. When her condition deteriorated and she had a low conscious level, she had been transferred to a single-room. Her condition improved and she insisted on being transferred back to the bay. Subsequently, as her condition deteriorated she was adamant that she did not want to go back to a single-room.*

This issue of who has control over whether the move happens arose in many of the observed room-moving encounters. As well as identifying organisational issues that affect psychosocial support, this example brings into question whether nurses shift the focus of psychosocial support from dying patients, once they are unconscious, to their significant others and other patients.

Transferring patients was also witnessed with an aim to helping with identity and relationships – as in the example with Andy, above (section 5.1.2.3). It also can be used to provide dignity and privacy, as shown in the following documentation data:

Documentation

> *"[Flora] would benefit from single room due to odour from fistula. Discussed benefits of this with patient who would like to speak to her daughters about this … Patient and her daughters were asked if she would like to move to a single room, but patient stated she would prefer to stay in [the bay] for the time being."* Annie

Despite the AuxNs usually carrying out the task of transferring patients between rooms, they were never observed participating in conversations with patients concerning moving rooms.

Patients also expressed psychosocial needs around leaving the hospice, either temporarily or permanently. People who are nearing the end of their lives, understandably, have things they wish to achieve before their death; for patients in the hospice this could include the wish 'to visit their home for one last time'. Again, discussions around these psychosocial needs were only observed with RGNs, though it was always AuxNs who accompanied patients during their visits.

Visiting patients' homes not only allowed dealing with the need for control over choices but was a catalyst for expressing many other needs, such as: release of emotions through the opportunity to say 'goodbye', preparing for death, and revisiting relationships and aspects from the past. As in the following example, this also enabled maintenance of a role in life. A patient, Eliza, was always the person in her partnership who arranged legal issues. Part of the reason she wanted to visit her home was to access documents she required to complete legal arrangements. This helped with her relationship with her husband, removing an additional burden from him – having to deal with something he is unfamiliar with – and allowing them both to focus more on their feelings. As described in both nurse liaison and documentation:

Handing-Over

> *Lily (RGN): "*[Eliza] *wants to visit her home, she wants to make* [a memory
>
> box to leave for her husband to help him remember their special times
>
> together] *and to get things so she can arrange her funeral."*

Documentation

> *"It seems it had been easier to attend to the practical side of her illness*
>
> *(funeral and financial arrangements) than to discuss in any depth their* [Eliza
>
> and her husband's] *feelings/fears re Eliza's illness progression."* Ava

Visiting home also gave patients acceptance and understanding about the impracticalities of being discharged. This happened when Flora's regular requests to go home were facilitated after a long period of discussions – with her, her family and a variety of hospice AHPs – and training her family in practical techniques to support Flora. After Flora's visit home it was documented in her nursing notes that Flora:

Documentation

> *"Enjoyed* [her] *time at home though* [was] *a little irritable on return."* Ellen

When Flora was asked her feelings about the visit home, she admitted she was trying to come to terms with the idea that she could no longer be at home. Flora had been asking to go home for seven weeks, her physical condition was such that the care team in the hospice felt this visit would be challenging for all concerned. Flora made the requests to go home to both the staff on the ward and to her family. Inability to meet these requests was causing strain on Flora's relationships with her children. The main aims of arranging for Flora to get home for the day were to be supportive of her need for control over choices and to improve her relationships with her children. Although the visit did this, it also enabled Flora to accept that she could not return home. This acceptance resulted in a loss of hope for the future and the irritability was an emotional reaction. Two days later, Flora's understanding of the impracticalities of being at home were reported at the multi-disciplinary team meeting as a positive experience:

MDTM

> Evie (RGN): *"Condition is deteriorating. The nurses saw she had a need to visit her home, which was quickly arranged and carried out, it had a very positive effect on Flora."*

Despite Flora living for a number of weeks after her visit home, she never requested to go home again. Flora's visit gave her the acceptance that visiting home was not in her best interest.

Other patients were able to go home from the hospice. The discharge procedures could stimulate expression of a variety of psychosocial needs. Encounters were observed concerning the timing of discharge, how agreement over this timing was made, and whether the patient was suitably equipped to manage at home. Different levels of patient involvement in decisions about discharge were observed. Decisions over date of discharge were usually made in the MDTM. One afternoon, following an MDTM, two patients in the same bay told me that they were going home:

Fieldnotes

> *Wendy: 'I'm going home next week; they came and asked me 'which day would I like to go?'*
>
> *Teresa: 'I've been told I'm going home on Friday, they just came and told me that's when I'm going. I didn't get a choice.'*

These opinions matched what I observed during the MDTM. During this episode of observation two very similar situations were managed very differently: Wendy was given the choice of when to go home, whereas Teresa was not allowed to determine her discharge date. There are a number of reasons for the nurses' differing approaches to supporting the same psychosocial needs, such as: patients' prior willingness to be involved in decisions; and demands made from further up the hospice hierarchy, as happened in this episode of care. Regardless of the different approaches to discussing discharge dates, the results of these conversations were the expression of further psychosocial needs: concerns about coping and being safe and secure at home for both ladies; anger, worry and the reconsideration of relationship problems for Teresa; and joy, and hope for the future for Wendy.

Decisions over discharge date could also be prolonged, even when a planned discharge date had been agreed before patients' admissions, as was the procedure with respite patients.

> *Maria (RGN) approached Vera, 'I'd like to talk to you about going home. It's just I was thinking after you having had such difficult time at the weekend it might be a good idea for you to stay a bit longer, maybe for another week.' Vera did not seem very happy about this, 'Oh, next week seems an awful long time away, too long,' so Maria said, 'What about over the weekend until Monday?' Vera: 'No, no it just seems that's too long.'*

During the MDTM it was reported that 'Vera's husband wants her to stay longer' and I was left to inform them of Vera and Maria's conversation. The MDT decided that Friday was an inappropriate day for discharge, despite no change in Vera's care needs, and agreed that Vera should stay until next week.

In this example, discussion around Vera's discharge home affected a number of her psychosocial needs, including: independence, her right to self-determination, acceptance, and emotional expression.

Other encounters observed concerning discharge from the hospice were: conflicting opinions over whether a patient should be enabled to meet their wish to be discharged to die at home – when death was expected imminently – and one patient's concerns about being transferred to hospital. Expressing psychosocial needs within these contexts concerned not only whether patients were allowed control over choices, but enabled the expression of thoughts, emotions and feelings.

5.1.2.5 Summary of Contexts of Psychosocial Needs

The first section of this chapter identified that the psychosocial needs were always expressed in relation to another context of care. The contexts of care have been categorised as practical aspects of daily life; disease progression and management; maintaining a social persona; and

the location of care. These contexts of care provide an illustration of how patients express psychosocial needs during their interactions with ward nurses. Identifying these contexts allows us to see more clearly when a need is expressed and should facilitate nurses' psychosocial support of previously unnoticed needs.

5.1.3 Summary of categorisation of needs

The categorisations of psychosocial needs I have presented in this chapter demonstrate that patients do express a wide variety of psychosocial needs for a variety of different reasons and in different contexts. Psychosocial needs, related to expression, rights, coping and identity, were expressed in many episodes of care and in relation to a number of issues such as: physical aspects of daily life; disease progression and management; maintaining a social persona; and the location of care. The different categories of needs were often expressed during one episode of care which could be carried out in a number of contexts. This interrelated nature of types and contexts of psychosocial needs can make psychosocial support more challenging for nurses.

Some of the psychosocial needs were explicitly expressed, some were uncovered by the nurses through activity or discussions, and, at times, neither participant appeared aware of the need. Often nurses, or even patients, only recognised a psychosocial need had been expressed when it was discussed during interview. Conversely, there were times when the nurses, with the best of intentions, perceived psychosocial needs to exist when they did not. The psychosocial support nurses offered during these encounters are equally important in this study as it is important to understand not only how nurses should provide psychosocial support but also how they can get it wrong. The findings in this chapter help to reduce the challenge of recognising when psychosocial support is required by clarifying the complicated, often hidden, nature of the psychosocial needs expressed by hospice in-patients. Similarly the findings suggest that the psychosocial needs ward nurses should be supporting are not the 'higher' needs in Maslow's hierarchy, which are discussed in most existing literature of psychosocial palliative nursing, but

basic physiological needs and some 'simpler' safety needs, accompanied by Maslow's prerequisites. This will be fleshed out in more detail in the discussion chapter.

These categorisations of psychosocial need support existing literature on types of psychosocial need and demonstrate for the first time how the previously proposed psychosocial needs (section 1.4) are exhibited in practice. Being aware of how psychosocial needs are exhibited in reality helps to identify the actual psychosocial needs of in-patients in a hospice setting. This facilitates greater recognition of the work nurses do in providing psychosocial support and provides a useful tool for research in this area. For my study, categorising the needs into types and contexts also allowed for further analyses of the data.

The following chapter refers to both types and contexts of psychosocial needs, in order to discuss a pattern of nurses' responses to patients' expressions of psychosocial needs. I demonstrate the different ways the nurses immediately responded to the variety of expressed psychosocial needs and identify some of the aspects of care that appear to influence the nurses provision of psychosocial support.

Chapter 6: Nurses' immediate responses to patients' psychosocial needs

In the previous chapter I presented data on how the patients in one hospice ward were observed expressing the variety of types of psychosocial needs identified in existing literature. These needs were not clearly expressed as standalone entities but often subtly, and always in combination with other needs within a variety contexts of care. This chapter explores the other main questions of this study: how do nurses immediately respond to these psychosocial needs and whether there was any difference in response according to the type, and/or context, of psychosocial need.

6.1   Nurses' Immediate Responses to Patients' Psychosocial Needs

Each of the 227 observed encounters were classified according to how the nurses immediately reacted to the patients' expressions of psychosocial needs. During data collection, and concurrent analyses, a pattern of immediate nurse response to psychosocial needs emerged: regardless of whether psychosocial needs were explicitly expressed or implied, the way the nurses immediately responded to the patient's actual need, at the time it was expressed, could be categorised in one of four ways. This chapter explores each of the following four categories, which are summarised below, in detail:

1. Dealing: The nurse recognised that a psychosocial need was being expressed and attempted to deal with that need, at that time, in accordance with the patient's wishes.

2. Deferring: The nurse recognised a need had been expressed, but postponed dealing with it. She informed the patients that she planned to either deal with the psychosocial need later herself, or ask another member of staff to deal with it instead.

3. Diverting: The nurse recognised that something should be done; but rather than responding to the psychosocial need expressed (implicitly or explicitly) by the patient,

she did something else. Typically, this would be something she thought would be beneficial to the patient, rather than what the patient had requested.

4. Ducking: The nurse did not acknowledge the patient's expressed psychosocial need at all: she carried on with what she was doing as if the need had not been expressed, or as if the overture had not been made.

I refer to these four categories collectively as 'the 4Ds'.

An important factor when considering 'the 4Ds' is that: by labelling the categories in this manner I am not commenting on the appropriateness of the nurses' actions; for each type of response there can be perfectly valid reasons for nurses responding the way they do. If a patient is distressed because of grief and pain it is understandable that a nurse will try to divert the patient away from their grief and initially offer pain-killers (as described by Newton and McVicar 2013). If a nurse does not feel she has the skills to deal with a patient's family problems, it is appropriate that she defers to the social worker. If a nurse does not recognise a patient's hint that they are 'worried they are dying', they will be unable to respond and will, unknowingly, 'duck' that need. There may be occasions when it is inappropriate for nurses to deal with patients' psychosocial issues, such as when there is an emergency on the ward. Splitting the encounters into response categories does not, therefore, act as a judgement on whether the nurses' actions were appropriate. Separating encounters allows additional analyses and, therefore, understanding of why the nurses respond in the way they do when psychosocial support is sought. Each of the response categories will now be discussed.

6.1.1 Dealing

When encounters were assigned to the 'dealing' category the nurse was either observed dealing with a patient's psychosocial need or had described the provision of psychosocial support in documentation or liaison. One-hundred-and-four 'dealing' encounters were witnessed during

this study. Allocating encounters to the dealing group was, in the majority of cases, straightforward: when a need was expressed and immediately dealt with, it was allocated to this group. As in the example below:

Fieldnotes

Flora, whose condition is deteriorating and is continuously incontinent of urine, buzzed. She told Ava, a registered nurse (RGN), 'I need to use the toilet'. Ava tried to persuade Flora that the incontinence pads she is sitting on are there to catch the urine, thereby allowing her to save her energy, so there is no need for her to get up to use the commode. Flora insisted on getting up. We brought her the commode which she struggled to get onto, even with our assistance, and was incontinent over the floor and very exhausted after. At the end of this episode of care Flora said "I'll no be doing that again!"

Documentation

Ava: "Requesting to sit on commode, rationale for present use of inco pads given, but request upheld. Did not feel comfortable on the toilet and would not choose this route again, however appreciated opportunity to attempt this."

Ava's experience, and Flora's care plans, suggested that Flora should not get out of bed for the toilet, because mobilising was difficult due to physical weakness. Ava tried to encourage Flora to use the incontinence pad she was lying on. However, Ava soon recognised Flora's need for dignity, independence, and choice to get up for the toilet. In recognising and immediately dealing with these psychosocial needs Ava also supported an understanding need of Flora's as Flora then accepted she could no longer get up for the toilet. Ava reported these needs, the support offered and outcome in Flora's nursing documentation.

However, nurses also demonstrated dealing when patients did not explicitly express a psychosocial need. This occurred in three ways: recognising implied psychosocial needs, adapting nursing practice, and responding to previously expressed psychosocial needs.

6.1.1.1   Recognising implied psychosocial needs

Firstly, nurses were observed detecting psychosocial needs: something occurred during the encounter that made the nurse believe the patient had a psychosocial need, the nurse offered psychosocial support which was accepted by the patient. One example of this happened when a patient, Wendy, was to attend the local hospital for an X-ray. Wendy asked if she could spend some time at the shops after her appointment. This was the first time she had tried shopping since her condition had deteriorated. As Ellen (RGN) and I were helping Wendy to get ready for her trip out of the hospice, she started to talk about going to the shops:

Fieldnotes

> *Wendy was talking excitedly about going to the shops after her X-ray, 'but I'm not sure how long I'll be, I do get very weak all of a sudden and if that happens I'll just need to come back.' She appeared despondent about this. Ellen suggested, 'Why don't you take a wheelchair with you? You don't have to use it, but it would be there as a safety-net and if you do get too weak your husband can push you round in it. That way you won't have to come home until you are ready.' Wendy was quiet, then after a short while replied, 'Hmm, I'm not keen on taking a wheelchair.' Ellen said, 'Okay, but if you change your mind before you go, just say.'*
>
> *When Wendy was about to leave for the hospital I observed Ellen talking to Wendy and her husband in the corridor. As Ellen walked away from this*

conversation I caught up with her and she told me, 'Wendy just came up to me and said, 'Can I take a wheelchair after all?'

Patient Interview

Hazel: "Sometimes [nurses] persuade you to do things, such as when you went out the other day taking the wheelchair with you. Did you feel okay about us doing that to you?"

Wendy: "Yes, I did. I wouldn't have asked for a wheelchair, but I was glad of the opportunity of having one, knowing that for several months previously I would have died to have had a wheelchair to sit in … it was quite good to know that I had the opportunity to use it, I didn't need it, but the opportunity was there for me."

Nurse Interview

Hazel: "When Wendy was going out for her X-ray, you were having a conversation with her about the wheelchair, she was initially, 'Och, no I'll not bother,' and then she agreed, but I missed the bit of the agreement; do you know if there was something specific that changed her mind?"

Ellen: "Well, I'd said to her, "You can take it with you, you don't need to use it, it means if you get tired you can take a seat," and maybe she thought, 'Oh well, it might, it'll enable me to do a bit more,' you know, 'I'll be able to shop for longer,' or whatever… so I think she came round to thinking, 'Well, I don't need to use it but it's there if I need it,' so it's a bit of compromise."

Ellen's suggestion to use the wheelchair, and the way it was put to Wendy, had various positive impacts on Wendy's psychosocial well-being: Wendy had control over whether to take the

chair; taking the chair gave her a sense of security; the time she had at the shops gave her a chance to be herself, doing something she enjoyed; and the time with her husband allowed them to have a 'normal' interaction. Thus Ellen's intuitive actions dealt with Wendy's psychosocial needs despite Ellen never having explicitly expressed these needs.

6.1.1.2   Adapting nursing practice

Secondly, 'dealing' encounters occurred when psychosocial support was provided by the nurses adapting their behaviour, and/or actions, to provide care in a way that was preferred by, but not essential for, a patient. Care would still be effective without this change of practice, but by the nurse adapting her style of care a patient could meet a number of psychosocial needs, such as: being more accepting of what was happening; feeling that patients' preferences were being respected; or having a social function through sharing experiences. In these situations the nurses altered their normal behaviour in order to interact more effectively with patients and support psychosocial needs: the nurses knew the way that patients preferred to interact and adjusted their own behaviours to match this. The effort nurses made to do this was observed when Beatrice (RGN) was working with Ralph. Ralph's regular joking and sarcasm is very different from Beatrice's quiet and reserved personality:

Fieldnotes

> *At the beginning of the shift, when I had indicated that I wanted to observe Ralph today, I was warned by Fleur (auxiliary nurse (AuxN)) that 'Ralph's humour can sometimes be a bit risky.' She was laughing when she said this, adding 'I can cope with it, but other people sometimes get a bit shocked.'*
>
> *Later in the day Beatrice was helping Ralph to get out of bed…he asked her, 'What did you get up to this morning?' She had been shopping and he was joking with her, 'I bet you were at the off-licence buying lots of beer, you're*

obviously the kind of person that drinks lots of beer.' Beatrice replied, laughing, 'Beer, never … it's lots of wine for me.' The conversation continued on in this light-hearted manner, with Ralph telling us about his old drinking habits.

Nurse Interview

Hazel: "Did you think there were any other differences with [Ralph] *than before?"*

Beatrice: "I found him easier to work with, there was a time a way back, it wasn't that he was difficult, he's just so much more relaxed now and it's probably easier for him. I think he could have been quite cocky at one time. It was lovely to see him, before you came into the room, [he would say] *'Hello, my old pal'."*

Beatrice found working with Ralph had become easier and, although she suggested this was because he has changed, it also appeared that she now accepted and responded to his sense of humour. Through conversations they were now able to have, Ralph was able to maintain a sense of identity during the challenging times of his illness.

Other ways nurses changed their behaviour to interact with individual patients in order to offer psychosocial support related to the transfer of information. Some patients liked to be told about everything the nurse was doing for them, whereas other patients preferred the nurse to 'just do things'. Alternatively, some patients had preferences about how nurses knew about what was happening with them. Some patients expected the nurses to know how to work with them and what their needs were, whereas, other patients preferred to tell nurses about their condition. When nurses matched these patients' preferences, encounters were classified as 'dealing', as the nurses were respecting the patients' rights.

6.1.1.3 Responding to a previously expressed need

Thirdly, the 'dealing' could be with a need that had previously been expressed, but not yet managed, for example, when Ann (RGN) eventually found out that Bruce did not want to move to a single-room. Bruce had been in a bay on the ward for 52 days, during which time many other patients were admitted to the bay. A large proportion of these patients then died. A lot of the ward staff were concerned that witnessing so many deaths was having a negative effect on Bruce. The solution, regularly suggested for this concern, was to move Bruce to a single-room. However, the nurses were finding offering the change of rooms to Bruce difficult. When another patient was moved from Bruce's bay into a single-room the nurses in his team discussed the effect of this on Bruce and the perceived urgency to move Bruce before there were no spare single-rooms available:

Fieldnotes

> *Ann - who had hinted to Bruce this morning about moving to the single-room – said, 'I'll talk to Bruce about it.'*

> *Ann told Bruce, 'There's still another side-room available, but it's up to you.' Bruce was not sure whether to go, saying, 'I would quite like to be able to play my music when I like without having to worry about other people, but I quite enjoy the company.' He seemed very hesitant to move to the single-room. After a short pause Ann suggested to him, 'But you're quite happy here, aren't you?' and he said, 'Yeah, so I'll stay here, today.'*

> *After this conversation Ann told me, 'it was important that Bruce had the opportunity to make that choice'.*

Patient Interview

> *Hazel: "I've noticed that you've been having quite a lot of conversations…about moving to the side-rooms and things, and I was wondering how you feel about these conversations?"*

> *Bruce: "I don't mind them, I know they're, on the whole, looking after my best interests, but if I don't know what's best for myself. And I don't want the latest [idea] about going to a single-room."*

Nurse Interview

> *Hazel: "I've noticed [there have been a lot of] discussions about Bruce and whether he would like a side-room, or not. I wondered if you could share what your thoughts are about that."*

> *Ann: "I think, we're seeing it from Bruce's side, but we're also seeing it from the nurses' side and we think Bruce would benefit mentally from not seeing so many people becoming poorer. He is also getting to know many of the patients, and the relatives, in [that room], and becoming friends, and then they get poorer, and he sees them get moved to the side-room, quite often, and then he hears that they die. So maybe his thoughts of side-room is: if he 'gets moved to a side-room then that's what's going to happen to him'. So, maybe it's an underlying fear that he's got and maybe he's worried that we know something that he doesn't. So, we offer him the side-room, because we see a different side: we see Bruce as not sleeping; being very anxious because other patients are restless and at risk of getting out of bed, so he's on guard with his buzzer, and also his relatives are on guard and, really, it's not their responsibilities to be the watch-dogs of the room. So, [we] feel that if he had*

a side-room he could enjoy his family, he doesn't need to be worried and concerned, and have all his homely things around the room, because [it is] very unlikely that he will get home. But it's how to get that across to Bruce, without frightening him, and that's why I wondered, if we just showed him the room, saying, 'you know, this is your room', but Bruce … I think, just too frightened to make a decision, so I think he decided to stay where he is, because he feels secure and that's him maintaining control. I think he just is frightened that, maybe, we're not telling him something, but we don't really know, I mean mentally it would be too soon to move him to a side-room, on sort a psychological illness side, but psychologically on the well side it would be a good move, maybe."

Ann's consideration of Bruce's moving to a single room identifies a number of potential psychosocial needs, including: fear of dying, loss of relationships, anxiety, and the need for safety. These needs were not discussed with Bruce during my observations. However, this example does demonstrate Ann dealing with a need that had previously been deferred by both her and others: giving Bruce the choice of whether to move rooms. Ann put aside what she, and other members of the hospice staff, felt would be best for Bruce. Ann focussed on what Bruce wanted, thereby meeting a number of his psychosocial needs, for example: autonomy and a sense of belonging.

6.1.1.4   Summary of 'Dealing'

'Dealing' occurred when nurses managed needs as they were expressed, when nurses detected needs, and when nurses met already known needs by either altering their normal behaviour or returning to deal with a previously expressed need. The common factor in all of the 'dealing' encounters is that nurses immediately support patients' psychosocial needs.

6.1.2 Deferring

Responses that involved 'deferring' are, similarly, self-explanatory: nurses delayed dealing with the need so that it could be dealt with at a later time, either by themselves or someone else. Twenty-seven 'deferring' encounters were witnessed during this study. Some psychosocial needs may have been responded to both by deferring, initially, and dealing, later, thus creating two separate encounters; as was observed in the previous example: Ann felt the discussion with Bruce, about whether to move rooms, was too difficult to conclude during his morning episode of care. She, therefore, waited until the afternoon, when she went back to Bruce with the specific aim of discussing the move to a side-room.

For an encounter to be classified as 'deferring', the nurse had to indicate to the patient that they had recognised the psychosocial need, suggesting that it would be dealt with later. This happened when Bruce's need for information about his disease progression was deferred at a later date by Evie (RGN). When Evie and I were bed-bathing Bruce, he asked her about some X-rays which had been taken four weeks previously. The X-rays had shown extensive advancement of Bruce's disease; all of the staff in the hospice, including Evie, knew about this and Bruce had been told the results of his X-rays as soon as they were known (I do not know whether Bruce had forgotten about these results or whether he had asked for any other reason – he had already taken part in one interview for the study and I did not re-interview him).

Fieldnotes

> *Bruce said, 'There is one thing nobody's ever told me: what the results of those X-rays were that I had four weeks ago.' Evie paused for a wee while, then replied, 'Oh, that's right, we must chase that up. Try not to worry about that just now.'*

Later on, when I was talking to her, she said, 'I did mention Bruce's query about his X-rays to the doctor and she told me that 'wasn't the case, I went through his images with him, but I'll go back and discuss them with him again.' Evie added, 'Yes, I should have realised that he wasn't right [I knew he had been told his results at the time]*'; she made no further comments about why Bruce might, therefore, have told her he 'hadn't received the results'. She has no plans to check whether Bruce gets the information he is looking for as 'the doctor is dealing with it'.*

Nurse Interview

Hazel: "There was one of the things with Bruce yesterday, he'd 'not got the results of his X-rays' and you spoke to doctor about it later on, has that [conversation] *gone any further at all?"*

Evie: "[One of the doctors] *was going to speak to him about that because when he said that to me I seemed to recall that he had actually been given that information, but I couldn't say definitively, and that was why I wanted to go away and find out. So I went and spoke to* [the doctor] *and she explained to me that she had quite clearly gone through everything with him … but all the way along one of the things that I've picked up a lot, from the multi-disciplinary, that Bruce is only wanting to go so far…so I think we have to respect that, because you can only go so far, if people don't really want to hear what you have to* [say] *then you've really got to, they'll let you in when they need to … It just came out, but what I would do now, in future conversations with Bruce I'd ask him about conversations he'd had with [the doctor] and what did he take from that, and what does he remember of it, so*

then I can try and explain it a bit further with him and I can probably do that

a bit further now. I mean it's not that I don't know Bruce because I've always

went in and said "hello" ... but because I'm doing the direct patient

care...that's where you get so much of your information."

Evie's response to Bruce's desire for information was representative of most of the deferring responses, she indicated that she heard Bruce's need and attempted to placate him: 'try not to worry about that just now'. Placation was a common response when nurses felt they required more information before a patient's psychosocial need was dealt with. What classifies Evie's response as a 'deferring', rather than 'ducking', response is that immediately following Bruce's episode of care, she reported his concern to a doctor.

Deferring encounters left the nurse with two options: offering to get another member of staff to deal with the psychosocial need or dealing with it later themselves. The nurses were observed deferring psychosocial needs to other nurses or other allied healthcare professionals (AHPs) working within the hospice. Deferral to other AHPs happened because the nurse felt the other AHP had better skills or knowledge to deal with that situation.

The alternative was for the nurse to return to the patient themselves at a later time to offer support. One reason for doing this was nurses felt they needed to be more familiar with the patients to deal with their psychosocial needs: nurses regularly 'deferred' until they felt more capable of dealing with the need themselves because 'it is more appropriate to provide psychosocial support when you know the patient better'. Evie referred to this idea during the interview, suggesting that in the future she would be able to deal with Bruce's requests for difficult information as she 'now knows him better'. Another explanations for being able to provide the required support later was the nurse had more time to spend with the patient or had new information related to the psychosocial need:

Doris was admitted to the hospice for symptom control, however, it has been noticed, since her admission, that she is very confused; despite Doris' attempts to hide this. The nurses are becomingly increasingly concerned that Doris has early onset Dementia and feel it is important to assess this before she goes home. Chrissie (RGN) told me that she 'wants to find out whether Doris is aware of her confusion, before starting the formal assessment of her mental state'. She was unable to do this when I was working with her, so I asked her about this during the interview.

Nurse Interview

Hazel: "Did you ever get a chance to catch up with Doris at all?"

Chrissie: "No, yesterday was really quite superficial. I've been in doing a bit of her care today. There is not much of an opening there to get any deeper than surface level with her, without getting her down ... I've acknowledged that would take some time. She's got social worker and her daughter coming in this afternoon and I think maybe then would be the time...I would love to take her out of the situation and maybe get her in somewhere, a quieter environment ... today in the bath she was talking about certain things and word stumbling and things [so I asked] *'do you feel you're just maybe not as sharp as what you used to be?' and 'do you feel a bit confused?'. And she was acknowledging so and even when she was getting dressed, I don't know if we were putting her off by being there because we gave her someone to talk to, so I'm not sure maybe I'll have to challenge her. But I'm concerned about*

her going home, how she'll be overnight. She's got up and down all night,

cleaning lockers and I just wonder … is she actually safe to be at home."

By trying to explore with Doris whether she felt confused, Chrissie was attempting to keep Doris safe but found this was beyond her abilities alone. Chrissie chose to defer dealing with this complex psychosocial issue until she had the support of the social worker and Doris' daughter and focussed on assisting with Doris' wash during the observed interaction. Chrissie hoped, by doing this, to reduce Doris' fears and provide her with companionship.

Psychosocial needs were also deferred when another AHP was involved in the episode of care. When other AHPs were working with a patient alongside a ward nurse, the nurse always gave the AHPs control over what care should be provided. If a patient expressed a psychosocial need, and the other AHP did not pick up on this, the nurse was inhibited from dealing with the patient's requirement, but could return to deal with it later:

Fieldnotes

> *Marianne (RGN), another AHP, and I were helping Eliza with her morning*
> *hygiene routine. When we were getting Eliza back off the commode the AHP*
> *explained what to do first of all and then Marianne said, 'Well, maybe when*
> *we're doing that we can get you all washed down below, so that saves having*
> *to move you' (movement causes Eliza's nausea to come on which is her*
> *biggest symptom). Eliza agreed to this.*

> *Once Eliza was back in bed. Marianne stood at one side of the bed and AHP*
> *at the other. Marianne tried to talk to Eliza about her concerns about her*
> *mobility, in an attempt to reassure her. Eliza replied, 'Well, my condition has*
> *changed' indicating her deteriorating condition. This looked like a good*

opportunity for a psychosocial conversation. But the AHP started talking about Eliza's mobility, so that opportunity was lost.

Later that morning, Marianne was crouching beside Eliza's bed obviously in deep conversation. When they had finished the conversation I asked Marianne about it. She told me, she had 'gone back to discuss Eliza's earlier concerns about her deteriorating condition. I didn't deal with at the time because [the other AHP] had different things to discuss'.

6.1.2.1 Summary of 'Deferring'

Nurses 'deferred' psychosocial support either because they felt: they did not know enough about the patient and/or their psychosocial need; there was a more important care priority at that time; or it was another staff member's role to deal with the need. At other times, deferring occurred when another member of staff redirected the conversation. When 'deferring' occurred, nurses always showed patients they had recognised their needs and indicated that the required psychosocial support would be offered later. In doing this nurses attempted to reassure patients their needs were valid and facilitate understanding of the need to balance individualised and organisational aspects of in-patient care.

6.1.3 Diverting

When nurses used a 'diverting' response, the support they offered did not correspond with meeting the expressed psychosocial need: the nurses' actions were aimed at meeting another need, which was not necessarily psychosocial. Twenty-two 'diverting' encounters were observed during this study. There were four ways the nurses 'diverted' patients' psychosocial needs: focussing on only one of a number of needs; offering practical solutions; acting upon different care aims; and altering patients' usual routines.

6.1.3.1   Multiple Needs

Patients often had multiple needs. One way nurses 'diverted' was by only dealing with part of a patient's requirements, rather than addressing the patient's full range of needs. It was common, in these circumstances, for a nurse to focus on patients' physical needs and, often unwittingly, omit psychosocial needs. This type of 'diverting' occurred when Millie (RGN) and I were bed-bathing Flora:

Fieldnotes

> *While we were washing Flora she said, 'I used to suffer from the cold, but now I'm always warm. It's part of being ill.' Millie said nothing and carried on washing Flora.*
>
> *A short time later Flora said, 'It's about time I'm not here anymore.' Millie did not say anything for a while, then responded, 'Things are much worse for you now?' Flora agreed. Millie explained to Flora how her symptoms could be managed as her condition deteriorates, telling her, 'We'll be able to keep you comfortable right up until the end.'*

In this example, Millie's initial verbal response gave Flora the chance to direct the flow of the conversation. However, Flora just agreed with Millie's comment thereby leaving Millie to choose what to discuss. Millie focussed on the possibility that Flora's concerns were about how they would manage her deteriorating physical state as death approaches. Millie's response may have addressed Flora's psychosocial need for understanding. However, Flora was expressing a number of psychosocial needs including: worries about the future and difficulties coping with her deteriorating condition. Millie diverted the conversation away from these needs, rather than checking with Flora what her concerns were and allowing Flora to prioritise which to support.

When asked about her responses to Flora's comments Millie suggested it was because she did not know Flora that she felt unable to recognise Flora's deeper concerns:

Nurse interview

> *Millie (RGN): "She was quite blasé about it … a bit tongue in cheek, although I'm sure there was a lot in it. But, in the way she was saying it, there was a bit of joking, but again that's when you don't know if that's their personality. Whereas, when you get to know them you know, maybe, that some of them will joke about dying, but they are joking in a way, although they are serious they're laughing about it …"*

However, Millie did admit she had recognised that Flora was really expressing concerns about her impending death and that she had passed these on to Rose, another RGN who regularly cared for Flora:

Nurse interviews

> *Millie (RGN): "I always feel you're probably better off not saying anything than saying something that's wrong or that's going to cause distress…I did say to Rose "will we try and follow up some of the things she was saying?'"*

6.1.3.2   Practical solutions

The second type of 'diversion' was to offer an easily achievable practical solution to one issue, rather than exploring and managing the more complex but actual psychosocial need. For example, Eliza was a young lady who was used to being busy. Throughout her stay in the hospice she was always finding different ways to occupy her time, for example: visiting her home, going out for trips in the car, and sorting out her affairs for when she died. As her condition deteriorated, she continued to express a desire to find ways of occupying her time.

Discovering alternative ways of spending free time was achievable by discussing how Eliza felt and negotiating less physically taxing ways of occupying her time: such as, bringing art and craft facilities, used by the hospice's day-care patients, to Eliza's room. However, instead of doing this, Marguerite (RGN) offered what she thought would be a quick solution to Eliza's problem and Lily (RGN) facilitated this offer:

Documentation

> "[Eliza's] *fed up with 4 walls, missing getting out of the room,* [query] *consider change of environment, move to* [another room] *would mean she could have patio doors open."* Marguerite

> "[Eliza] *agreed to move to* [the other room] *and very pleased with brightness and open aspect."* Lily

In these excerpts of documentation Marguerite and Lily both recognised that Eliza was unhappy with her current situation, however, their solution to this problem only had a temporary effect: Eliza's boredom returned later that day and the move of rooms did not help her to accept her changing condition.

The third and fourth way nurses 'diverted' psychosocial needs were related to the patients and nurses having different care priorities.

6.1.3.3 Differing care aims

Differences in care priorities arose when patients expected one thing from their care but the nurse's care aim was something else. This happened, in the example introduced in section 5.1.1.3, when Stuart was focussing on improving his current mobility but the nurses were considering how he would mobilise when he got home. Since his admission, Stuart's main concern had been about his deteriorating mobility. The general consensus amongst all AHPs

was that Stuart's mobility would not improve and, at best, Stuart would be able to get around in a wheelchair. Stuart had not come to terms with the fact that he would not regain full independence with his mobility. In an attempt to facilitate Stuart's acceptance, the nurses had asked another AHP who would also be involved with Stuart's care on discharge, to come and talk to him about his mobility:

Fieldnotes

> *When Stuart, the AHP, and Camille were talking, Stuart mentioned 'when I'm up walking'. Camille and the AHP looked at each other, then steered the conversation to talking about how Stuart would manage at home. Stuart said, 'But that's in the future and I'm not ready to talk about that yet.'*

Patient Interview

> *Stuart: "What else they can say about how you're doing, you know a progression report, yeah. It's as though they're not clued up on it. If you say, 'are your muscles getting stronger?' they just don't answer it."*

Stuart then went on to discuss how he wanted progress reports about how he is getting on day-to-day, instead of the plans for how to manage when he gets home. On discussing this, he wants 'to set shorter term goals'.

Nurse Interview

> *Hazel: "I wondered yesterday when* [Stuart] *was talking to* [the AHP] *and he said … 'but that's in the future, I'm not ready to talk about that yet,' and he was talking about getting home."*

> *Camille: "I think, I don't know, today he's much lower in mood and saying he feels his arms are weaker … So I think now he's more coming round to*

this is how things are going to be. But last week, and the week before when

he was admitted, I think really he thought he was going to be up on his feet,

walking out of here ... So he came with that expectation, so that's a further

disappointment but he's not going to be up and about."

Documentation

"Saying to [the AHP] *about not wanting to talk about getting walking again*

because that was too far in the future." Camille

Although the nurses and Stuart were concerned about his mobility, their different foci of care, and time, were preventing them from supporting Stuart to accept his changing condition. This incongruence between short and long-term goals of care meant Stuart's current psychosocial needs were not being dealt with.

6.1.3.4   Patients' usual routines

The fourth way diverting occurred was when nurses wanted to provide care in a way that was different from patients' normal routines. These differences in care provision occurred for a variety of reasons: ranging from preferences about the order in which a patient carries out their daily routine; to issues of safety, whereby nursing regulations demand that nurses provide care in a specific way despite patient preference. This type of 'diverting' was witnessed when I was assisting Marianne (RGN) with Frances' personal care. This was the first time Marianne had worked with Frances since she admitted her to the ward. Frances was unable to walk or weight-bear and needed to be hoisted whenever she changed where she was sitting. The morning I was observing Frances she requested a bath. Bathing an immobile patient safely, in the ward, requires many transfers using a hoist. These hoisted transfers are hard work for both patient and nurse. Transfers are made easier by skilful insertion of the hoist sling, which can be carried out

in a number of ways, and considering patients' psychosocial needs, such as gaining their acceptance, maintaining their safety, and respecting their choices.

Fieldnotes

> *As Marianne was transferring Frances for the first time she asked, 'How do you like the sling for the hoist put in?' Frances replied, 'I like it slipped down from the back, but they seem to prefer to put it in here by rolling me.' Marianne described the pros and cons of putting the sling in either way, finishing by saying, 'We'll just do it by rolling today, and see how that does,' which we did. In doing this Marianne choose her own, not Frances', preferred method of sling insertion. It took us a long time to get the sling in a position that felt both comfortable and safe to Frances. When we were getting Frances into the hoist for the last time Marianne suggested, 'Let's try going down your back with the sling,' we all found that much easier.*

In this example we can see that Marianne eventually accepted Frances' preference. However, this encounter was classified as 'diverting' as Marianne initially ignored Frances' preference because she felt Frances was reassured that Marianne's method of sling insertion would be easy and safe. The outcome of the diversion was frustration for both Frances and Marianne, which was resolved by giving Frances her choice.

6.1.3.5   Summary of 'Diverting'

Nurses 'diverted' psychosocial support by focussing on physical care and practical solutions or by setting their own, rather than the patients', parameters to care. During all of the 'diverting' encounters the nurses responded to patients' needs. However, the support they provided did not deal with the patients' immediate psychosocial needs.

6.1.4 Ducking

'Ducking' responses were when a patient had a psychosocial need which the nurse did not attempt to support. In these circumstances no recognition was made by the nurse of the existence of the patient's psychosocial need at the time it was expressed. Seventy-four 'ducking' encounters were observed during this study. Ducking occurred under five conditions: when nurses did not recognise psychosocial needs had been expressed; when the nurses' current state of mind clouded her ability to respond; when nurses failed to engage with patients; when nurses did not want to disrupt the shift's planned work; or when the nurses felt not responding to psychosocial needs was in the patient's best interest.

6.1.4.1 Failure to recognise implied psychosocial needs

Firstly, there were times when nurses simply did not recognise patients were expressing psychosocial needs. This most commonly occurred when patients hinted concerns about their disease progression. For example:

Fieldnotes

> *After Nina (AuxN) and I finished assisting Eve to wash and dress, Nina supported Eve whilst she transferred into the arm-chair. Eve found this transfer difficult and had to rest during it. Both Eve and Nina's moods were light-hearted and jovial throughout Eve's care, even during the difficult transfer. However, when she was settled into the chair Eve's mood changed and she sombrely said, 'You know, I was up and walking when I first came in here and now I can't.' Nina made no response to this.*
>
> *Eve confirmed, during her interview, that she was hinting that her disease was advancing and causing her mobility to deteriorate (exact quote is not*

available due to a tape-recording failure); she had been looking to Nina to confirm this idea. Nina told me she had not realised Eve was voicing worries about her condition. Nina related her inability to recognise Eve's psychosocial needs to her lack of education concerning what psychosocial needs are. Nina felt she has "never had any training in psychosocial care". (I only observed patients expressing psychosocial needs to Nina on two occasions; she dealt with the other psychosocial need.)

For the remaining four groups of 'ducking' responses the nurses were aware that psychosocial needs had been expressed. On occasions the nurses told me later they 'had noticed a patient's psychosocial need but chose not to respond'.

6.1.4.2 Nurses' current frame of mind

Secondly, when a nurse possesses the knowledge and skills to carry out psychosocial support it is possible she may, temporarily, lose her ability to respond to these needs. Annie (RGN), who was observed dealing with some very complex psychosocial needs, commented about this during her interview:

Nurse interview

> *Annie: "There* [have] *been times when people have given me cues and I've been aware that I've not picked up on* [them]*, maybe because of the way I've been feeling at the time myself."*

Whether a nurse's mood does affect whether she provides psychosocial support is difficult to assess. It may, similarly to the idea of familiarity (appendix 9), be a nurses perception because her mood is low she has missed patients' psychosocial needs. However, there were a number of occasions when, for different reasons, the nurses recognised psychosocial needs and did not acknowledge them to patients.

6.1.4.3   Lack of engagement with patients

Thirdly, the nurses 'ducked' when they failed to engage with patients, on a personal level, when they were providing their care. This could be because the nurse was focussing on the tasks of care rather than the requirements of the individual patient, or because the patient's psychosocial need clashed with the only way the nurse could see of carrying out her duties thus denying patient choice. The latter happened throughout the day whenever Sybil (AuxN) and I had to transfer Polly to and from her chair. This was the first time Sybil had nursed Polly and the example below describes what happened during Sybil's first time transferring Polly:

Fieldnotes

> *Polly has limited mobility because of her disease. When she is at home she uses a stand-aid to transfer, however, the hospice does not have a stand-aid so a hoist must be used to transfer Polly. Sybil knew from Polly's daily care-record, which she had read before starting Polly's care that she was to be transferred using a hoist.*

> *When we had finished washing and dressing Polly in the morning it was time to hoist her out of her bed. Sybil said, 'I'll go and get the hoist,' Polly grimaced, Sybil did not respond to this and left to get the hoist. When we were alone, Polly told me, 'I hate the hoist, it's really scary.' When Sybil came back in with the hoist Polly said, 'Oh, here we go.' Sybil did not pick up on this comment, which appeared to be Polly expressing quite strongly that she wasn't happy with the hoist, nor did she explain to Polly what we were going to do.*

> *When we lifted Polly, Sybil asked, 'How is that?' Polly replied, 'Terrible.' Sybil said nothing and carried on with the transfer, Polly appeared frightened*

in the hoist. When we got her into the chair, she didn't look at all comfortable, but insisted we 'leave her'.

Patient Interview

Hazel: "I did notice today that it was really hard for you, when you were in the hoist … And then as soon as Sybil came in, behind the curtain with the hoist you went, something like, 'Oh, here we go,' and I could really sense how you were feeling about that. You were really quite frightened about the hoist."

Polly: "I just really don't like the enclosure it has on me, and I feel as if I'm pressed in, and that if I did fall there's nothing I could do to stop myself, I'd just need to let myself go. It's not in my control at all."

Hazel: "When we had you up in the hoist, Sybil asked you 'how you were feeling there?' and you did say that you were feeling 'terrible' and I just wondered, if there was any way we could have managed that differently, that might have made it better for you?"

Polly: "I don't think so. I'd still feel the same about the hoist, nothing you would say would make it any better, or any different, from what I already felt. You couldn't convince me that I was going to be alright … I get to know that I can trust [the nurses] *when I've had them before. I feel quite safe, just letting them go ahead and doing what they want to do, but, sometimes, when it's a new person, and they don't really tell me what they're going to do, I get quite annoyed, because it's not always the best way."*

Nurse Interview

> *Hazel: "With Polly yesterday, when you had her in the hoist, how did you feel about how she was?"*

> *Sybil: "Well she wasn't comfortable. She was frightened, but I didn't know how else we were actually going to get her off the bed and onto the chair. So, I think it's a case of having to try and reassure people that they're safe, and that they're actually secure, and that they're not going to fall out."*

Although Sybil could not have made Polly happy with the use of the hoist, she recognises that by telling Polly what she was doing throughout the lift she could have made her more accepting and less frightened of its use. Later in the interview Sybil mentioned she:

> *"would have needed to have got the physio ... to keep myself right and to keep* [Polly] *right, I just really didn't know what to do ...Maybe you've been told you've only got three-quarters of an hour to get a thing done, therefore, you can't stand with* [patients] *any longer than* [the time it takes to complete the task]. *So, therefore, you've got to go in and do it and not put up with them."*

The dilemma of having no immediately available alternative means of safely moving Polly blocked Sybil from meeting a number of Polly's psychosocial needs, including: expressing emotions, acceptance, safety, and security. Sybil ducked these needs and prioritised completing her physical work.

6.1.4.4   Disruption of planned work

The fourth type of 'ducking' is when patients' psychosocial needs disrupt the nurse's plans for the shift. Every nurse has a number of duties they need to complete each shift; I refer to this as

'getting the work done'. When the nurses focussed on 'getting their work done' rather than the patient's individual needs, they failed to provide the patient with the care they required. This usually happened because nurses felt there was pressure on them that 'they must complete a set of duties during their shift'. If a patient has an unexpected psychosocial need this gave the nurse an extra duty to manage which could disrupt their plans for the day. In order to prevent this disruption, nurses ignored patients' psychosocial needs. This happened whether it was the nurses themselves that were distracted by the need, or if the nurse they were working with that day had been distracted, as occurred when I was working with Julie (AuxN). We had assisted Teresa with a shower and to return to her bedside, where the doctor attended to her:

Fieldnotes

> *When the doctor left, I went behind the screens to put Teresa's Lidocaine patch on. Teresa was very upset. I sat down in the chair beside Teresa's bed and had a long chat with her. Teresa told me all about: her fears for the future, especially that she 'wouldn't be able to cope at home'; how difficult she'd found her illness; her family difficulties; and why she had such a lack of support. Teresa cried throughout this conversation and was visibly distressed.*

> *During this conversation Julie came in and out three times to put things in Teresa's locker, tidy things away, and leave the hairdryer.*

> *At another point later in the conversation Rhona, the nurse-in-charge of the team this morning, shouted, 'Hazel, we're away for tea, here's the keys'. Her hand appeared under the curtains with the keys.*

> *Later Julie said, 'I didn't want to disturb you to say we were away for our tea, 'cause I could see you were in something deep.'*

It is interesting that Julie found it acceptable to interrupt an in-depth conversation in order to tidy up after Teresa's shower – tidying is the last phase in washing a patient and can give nurses a sense of 'that duty being complete, now I can move on to the next thing' – but not to actually disturb the conversation, leaving the more senior nurse to do this. Both Julie and Rhona's disruptions were noticed by Teresa; however, because she was so upset, and I did not allow the disruptions to distract me, we managed to resume the conversation after each interruption. On other occasions, disruptions like these, or patients' awareness that their psychosocial needs were holding the nurse back from her work, could inhibit patients from requesting psychosocial support.

6.1.4.5   Paternalism

The final reason the nurses gave for 'ducking' was paternalism: the nurse did not respond because they thought this would be too upsetting for a patient, or they felt they knew what was best for the patient. One example of this occurred during the episode of care discussed in section 5.1.2.4.4, when the final decision was made about when Vera was to be discharged. Vera had been admitted to the ward for one week's respite; she had taken unwell shortly after her admission but was back to her normal state of health by the time of the multi-disciplinary team meeting (MDTM). The suggestion was made that Vera's respite should be extended for both her and her husband's sake. However, I had observed Maria (RGN) discussing this with both of them – together and separately – and they both wished Vera to return home on the Friday; the originally planned day of discharge. Maria informed the other nurses of Vera's wishes during the morning hand-over. The general consensus remained that Vera's admission should be prolonged; Maria reluctantly agreed with this. I helped Maria give Vera her personal care on the morning of the MDTM and attended the meeting once Vera's care was completed:

Fieldnotes

Maria told me, 'I'm going to have another chat with Vera and try to persuade her to stay in a bit longer. But I want to make sure we have plenty time to do this.' Maria planned her morning's care to allow time to spend with Vera to discuss her discharge date. Despite Maria's attempts to negotiate that Vera should stay in the Hospice longer, Vera was very insistent and still said, 'I'd like to go on Friday'.

Patient Interview

Hazel: "I noticed through yesterday morning, and the night before, that Maria had a chat with you about how you felt about when you were going home and I wondered how much of a say [you felt] *you had in that conversation?"*

Vera: "Well, I didn't really have much of a say and, as usual, I had agreed to come in for a week, and, of course, it gets pushed forwards and it's been stated two or three times that, 'Well, you're the boss,' but you're never the boss. If you come in [to] *stay until they think you're fit to go out, well that's an agreement, but I never ever do that. I don't want to do that because, most of the time, I don't feel I should be in here."*

Nurse Interview

Maria: "Maybe I see it differently from the other girls on the ward … I sometimes see scenarios which would appear to be bad and people do cope well at home, but when we think of Vera maybe she'll manage that bit better, because that's what she used to."

"Keen for discharge - case to be reviewed at MDTM tomorrow." Marianne

Vera had made it clear that she wanted to go home on Friday and her husband agreed with this; Maria had checked that Vera's husband really felt this way when she spoke to him alone. Despite Vera's clarity of choice the team decided it would be in her best interests to stay in the hospice longer and Vera's choice was denied. The outcome of this was: a frustrated and mistrusting patient; a husband who agreed with a foregone conclusion; and a nurse who found it easier to, and then had no choice but to obey the paternalism from the ward hierarchy and duck the patient's psychosocial needs.

6.1.4.6   Summary of 'Ducking'

The nurses 'ducked' some psychosocial needs when they did not recognise them. When psychosocial needs were noticed, they were not dealt with because the nurse felt it would not be in the best interests of all of the patients they were caring for that day. Nurses felt if they had offered psychosocial support it would either have been distressing for the individual patient or it would have made it difficult for the nurse to provide all of 'her' patients with all of the care they required during that shift. The common factor in all of the 'ducking' encounters was that the nurses and patients did not share an acknowledgement that a psychosocial need existed.

6.1.5   Summary of Nurse Responses

Throughout the eight months of data collection, 227 encounters involving different psychosocial needs, expressed for different reasons, were observed. The encounters were categorised into four groups according to how the nurses immediately responded to the patients' psychosocial needs. For each group the response to the psychosocial need varied:

- when a patient's actual need was dealt with, the response was categorised as 'dealing';

- when patients were told their need would be dealt with later, the response was categorised as 'deferring';

- when an alternative need was dealt with, the response was categorised as 'diverting'; and

- when a patient's need was not acknowledged, the response was categorised as 'ducking'.

The identification of these '4Ds' provides a new way of considering nurses provision of psychosocial support. During this study a number of different factors were identified which had the potential to influence the nurses' responses:

- the psychosocial need itself;

- organisational aspects of nursing;

- the characteristics of the individuals participating; and

- familiarity between the participants.

This thesis focuses on the first of these factors with an exploration of whether the type, or context, of psychosocial need was associated with the nurses' immediate responses (reference to the other factors occurs throughout the thesis and for the latter two in Hill *et al.* (2014, appendix 9) and Hill *et al.* (2015, appendix 10).

6.2 Are nurses' immediate responses to psychosocial needs related to the type or context of need?

A question that was explored in this study was whether the way nurses immediately responded to patients' expressions of psychosocial need was influenced by the type of psychosocial need itself or the context in which it had been expressed? The results of these explorations are

provided, in turn, below, following a clarification of the final number of types and contexts of psychosocial needs that were observed.

As discussed in Chapter Five, patients observed during this study expressed different types of psychosocial needs within different contexts. These needs, and their contexts, arose in a variety of combinations, with more than one type (ranging from one to eight needs) and/or more than one context (range 1-9) being expressed in most episodes of care (n=39). The complex nature of the way psychosocial needs were expressed to the nurses meant that more than one psychosocial need could also be expressed during one encounter, within more than one context of care. For example, when Jane (AuxN) was assisting George with his personal hygiene, he requested a bath but was scared about transferring safely. This meant in one encounter George expressed three psychosocial needs: emotional expression, control of choices, and safety; under two contexts: 'washing and dressing' and 'mobility'. Hence the number of needs (330) and contexts (274) presented in this section are different from each other and greater than the number of encounters (227).

The nurses were observed using different responses during most episodes of care, ranging from one to all four Ds.

6.2.1 Type of psychosocial need

During analyses, the psychosocial needs observed in this study were categorised into four groups: rights, identity, coping, and expression (see Chapter Five). Table 6.1 shows the distribution of responses (4Ds) within each category of psychosocial need for all nurses and separately by role.

As Table 6.1 illustrates, overall, the nurses 'dealt' with around 44% of needs, and 'ducked' around 30%, while deferring and diverting rates sat around 15% and 10%, respectively. The patterns of responses to psychosocial needs relating to rights and coping, regardless of roles,

displayed similar proportions to the overall sample. When identity psychosocial needs were expressed, nurses tended to either 'deal' with them or not; deferring or diverting was the response in only three of these needs and never by AuxNs. While RGNs' responses to identity psychosocial needs were divided almost equally between dealing or not, the AuxNs immediately dealt with a much higher (76%) proportion. For 'expression' psychosocial needs, the rate of dealing overall dropped to 32.9%, with AuxNs 'ducking' two-thirds and RGNs 'deferring' (23.3%) or 'diverting' (15%) psychosocial needs more often.

These findings suggest there is little, if any, association between the type of psychosocial need and how the nurses respond to it. One difference that occurs is related to the AuxNs' lower use of the 'deferring' and 'diverting' responses. The other difference is the AuxNs' lower dealing rate in 'expression' psychosocial needs. One reason for this may simply be a result of convenience sampling as only twelve 'expression' psychosocial needs were expressed to AuxNs. Alternatively, AuxNs felt they could not deal with 'expression' psychosocial needs when they 'did not know the patient'. The difference in responses according to nursing role was also identified in analyses of the distribution of the 4Ds according to context of psychosocial needs.

Table 6.1 Distribution of 4Ds according to type of psychosocial need and stratified by role

All nurses	Rights		Identity		Coping		Expression		Total per response
	Yes		**Yes**		**Yes**		**Yes**		
Ducking	45 (27.3%)		18 (36%)		13 (31%)		25 (34.2%)		101 (30.6%)
Deferring	25 (15.2%)		1 (2%)		8 (19%)		15 (20.5%)		49 (14.8%)
Diverting	20 (12.1%)		2 (4%)		3 (7.1%)		9 (12.3%)		34 (10.3%)
Dealing	75 (45.5%)		29 (58%)		18 (42.9%)		24 (32.9%)		146 (44.2%)
Total	165		50		42		73		330
RGNs	Rights		Identity		Coping		Expression		
	Yes		Yes		Yes		Yes		
Ducking	32 (25.6%)		12 (48%)		9 (26.5%)		16 (26.7%)		69 (28.3%)
Deferring	24 (19.2%)		1 (4%)		8 (23.5%)		14 (23.3%)		47 (19.3%)
Diverting	18 (14.4%)		2 (8%)		3 (8.8%)		9 (15%)		32 (13.1%)
Dealing	51 (40.8%)		10 (40%)		14 (41.2%)		21 (35%)		96 (39.3%)
Total	125		25		34		60		244
AuxNs	Rights		Identity		Coping		Expression		
	Yes		Yes		Yes		Yes		
Ducking	12 (30.8%)		6 (24%)		3 (42.9%)		8 (66.7%)		29 (34.9%)
Deferring	1 (2.6%)		0 (0%)		0 (0%)		1 (8.3%)		2 (2.4%)
Diverting	2 (5.1%)		0 (0%)		0 (0%)		0 (0%)		2 (2.4%)
Dealing	24 (61.5%)		19 (76%)		4 (57.1%)		3 (25%)		50 (60.2%)
Total	39		25		7		12		83

6.2.2   Contexts of psychosocial need

The contexts of psychosocial needs expressed by patients were also categorised into four groups: practical, disease, societal, and place of care (see Chapter Five). Table 6.2 shows the distribution of responses for 'contexts of psychosocial need'.

A similar overall distribution of contexts of need was found: 46% were immediately dealt with, 11.3% deferred, 10.9% diverted, and 31.7% ducked. When the needs were expressed in relation to practical aspects of care the distribution remained similar. The only difference in disease psychosocial needs was that AuxNs were more likely to 'duck' them. Nurses dealt with 'societal' psychosocial needs more than any of the other contexts of need, regardless of their role, though the RGNs continued to offer 'deferring' and 'diverting' responses. The proportion of 'deferring' and 'diverting' responses increased when 'dealing' dropped for 'place of care' psychosocial needs, with 'deferring' becoming increasingly prominent when only the RGNs are considered.

Table 6.2 Distribution of 4Ds according to context of psychosocial need and stratified by role

All nurses	Practical		Disease		Societal		Place of Care		Total per response
	Yes		Yes		Yes		Yes		
Ducking	30 (32.3%)		21 (37.5%)		15 (24.2%)		21 (33.3%)		87 (31.7%)
Deferring	8 (8.6%)		5 (8.9%)		4 (6.5%)		14 (22.2%)		31 (11.3%)
Diverting	10 (10.8%)		6 (10.7%)		5 (8.1%)		9 (14.3%)		30 (10.9%)
Dealing	45 (48.4%)		24 (42.9%)		38 (61.3%)		19 (30.2%)		126 (46%)
Total	93		56		62		63		274
RGNs									
	Practical		Disease		Societal		Place of Care		
	Yes		Yes		Yes		Yes		
Ducking	13 (24.1%)		15 (31.9%)		11 (24.4%)		20 (33.3%)		59 (28.6%)
Deferring	7 (13%)		5 (10.6%)		4 (8.9%)		14 (23.3%)		30 (14.6%)
Diverting	8 (14.8%)		5 (10.6%)		5 (11.1%)		9 (15%)		27 (13.1%)
Dealing	26 (48.1%)		22 (46.8%)		25 (55.6%)		17 (28.3%)		90 (43.7%)
Total	54		47		45		60		206
AuxNs									
	Practical		Disease		Societal		Place of Care		
	Yes		Yes		Yes		Yes		
Ducking	15 (40.5%)		5 (62.5%)		4 (23.5%)		0 (0%)		24 (37.5%)
Deferring	1 (2.7%)		0 (0%)		0 (0%)		0 (0%)		1 (1.6%)
Diverting	2 (5.4%)		1 (12.5%)		0 (0%)		0 (0%)		3 (4.7%)
Dealing	19 (51.4%)		2 (25%)		13 (76.5%)		2 (100%)		36 (56.2%)
Total	37		8		17		2		64

Again there is little association between the context of psychosocial need and nurse response. The lower number of psychosocial needs expressed to AuxNs about disease may reflect their reason for a higher rate of 'ducking'. AuxNs are not educated on disease processes or medications, so there is less expectation by patients that AuxNs would address such concerns, though patients may express disease needs to AuxNs in search of their 'lay' but experienced view. The difference in 'societal' responses is most likely what defines the needs as 'societal' – specifically, informal conversing and relationships (see section 5.1.2.3) – and, as above, the nurses' reliance on getting to know the patient. The nurses' reliance on having a relationship with their patients led them to not only deal with, but actively seek out, patients' societal psychosocial needs. 'Place of care' psychosocial needs are not so easily met by the nurses alone, many of these decisions are multidisciplinary – as in section 5.1.2.4 when the final decision to delay Vera's discharge was made during the MDTM – therefore, an increase in 'deferral' of these needs, as found, is what would be expected.

6.2.3   Summary of category of psychosocial need

The multifaceted nature of psychosocial needs resulted in different numbers of types and contexts of psychosocial needs from encounters, however, the distribution of responses overall was similar. The variations found in proportions of response across the context and type of psychosocial need categories appear to be due to factors related to nursing roles – the AuxNs limited use of 'deferring' or 'diverting', the differences in education, or boundaries of who makes certain decisions.

6.3   The Individuals Involved in the Encounter

A simple hypothesis that could be presented is that the nurses did not offer psychosocial support because they did not have the required skills to meet psychosocial needs, as suggested in previous studies (Law 2009, Phillips *et al.* 2006, Johnston 2002); this is not true for this sample

of nurses at least. All of the participating nurses demonstrated that they possessed some of the skills necessary for the provision of psychosocial support: 31 of the 38 nurses were observed offering patients psychosocial support; of the remaining seven, five of the nurses explained during interviews, or informal conversation, how they could have responded in a more supportive way to patients' psychosocial needs; and the last two demonstrated they could, at least, recognise patients' psychosocial needs.

Thirty-eight nurses and forty-seven patients participated in this study. The variability and sporadic nature of who was involved in which encounter (as explained in section 4.1.11.4) made testing for the effect of specific nurses interacting with specific patients impossible.

6.4 Conclusion of nurses' immediate responses to patients' psychosocial needs

This chapter demonstrates and explores the varying ways the nurses on one hospice ward immediately responded to patients' psychosocial needs. The nurses' responses were categorised into four groups in accordance to whether the actual need expressed was supported: the needs were 'dealt with, deferred, diverted or ducked'. An exploration as to whether the nurses' responses varied according to the type, or context, of psychosocial need found there was little association between the type or context of psychosocial need and whether the nurses immediately offered psychosocial support. One difference that was identified was in auxiliary nurses' use of 'deferring, and 'diverting' responses.

This study did not explore whether patients' psychosocial needs were ultimately met. What was identified was that almost half of both the types (44.2%) and contexts (46%) of needs were immediately dealt with by nurses. No judgement was, or can now be, made about whether the remaining psychosocial needs could have been immediately supported. There are times when it is not feasible to support patients' psychosocial needs for a number of reasons, however, ignoring that a need has been expressed is unlikely to be helpful for a patient. This novel

observation and categorisation of 'deferring' and 'diverting' responses provides nurses with a more suitable alternative when they cannot deal with patients' psychosocial needs.

Chapter 7: Discussion: Developing understanding of nursing support of palliative care in-patients' psychosocial needs

There has long been an idea that nurses provide psychosocial support as a component of their practice and a substantial amount of research has been undertaken in a bid to understand what this entails. However, previous publications come mainly from self-report studies of patients, carers, and/or nurses' perceptions of experiences or preferences. A greater understanding of the realities of psychosocial support in practice was needed. This thesis offers a substantial contribution to nursing knowledge by exploring how psychosocial needs are expressed by ward in-patients and how nurses' immediately respond to them. The field of study was a clinical area which prides itself in the inclusion of psychosocial care: a specialist palliative care ward.

The primary and subsidiary questions for this study were:

- How do nurses immediately respond to palliative care in-patients' expressions of psychosocial need?
    - What psychosocial needs do palliative care in-patients express?
    - How do palliative care in-patients express psychosocial need?
    - In what way do nurses' immediate responses to psychosocial needs vary?

These research questions were answered by combining data sources. Observations produced data on the psychosocial needs expressed and how nurses immediately responded. Observations were corroborated, when possible, by interviews of both patients and nurses. Datasets were strengthened by recording inclusion of psychosocial needs in ward hand-overs, multidisciplinary meetings, and nursing documentation.

In the first findings chapter of this thesis (Chapter Five) I have discussed the psychosocial needs expressed by patients during the study, categorising and analysing them according to the type

of psychosocial need and the context in which they were expressed. In Chapter Six I have shown how the nurses responded in four ways – 'dealing, deferring, diverting and ducking' – and that the nurses' use of these responses varied. I begin this final chapter by discussing these key findings, in relation to existing literature, and demonstrating their value for psychosocial nursing practice, education and research. These findings are then discussed in relation to Maslow's (1943) hierarchy of needs theory. This thesis is completed with a critique of the study's limitations, a discussion on reflexivity within the study, and clarification of the key recommendations.

7.1 Discussion of findings

In this section I discuss the key findings of this study and how they relate to existing literature. This study shows that nurses can offer psychosocial support as an inherent component of their practice but do not consistently respond to patients' psychosocial needs. Two key finding arose from analyses of this study's data. Firstly, all types of psychosocial needs described in existing evidence were expressed by in-patients on this hospice ward. However, their expression was complex: they were rarely expressed as standalone entities and were always expressed in relation to other contexts of care. Secondly, the nurses immediately responded to patients' psychosocial needs with a range of responses, categorised as either 'dealing', 'deferring', 'diverting' or 'ducking'. These findings are discussed in detail in the following sections.

7.1.1 The types and context of expressed psychosocial needs

Providing psychosocial support is challenging; the data indicate that these challenges can stem from how the psychosocial needs are expressed. In this section I discuss how the nature of psychosocial needs impacts on the nurses' ability to respond in a supportive way, finishing with a comment on the influence of the categories of psychosocial needs expressed in this study.

Psychosocial needs are identified in the literature as interacting components of a whole person (Smuts 1927, Maslow 1943, Engel in Malmgren 2005, Walker *et al.* 2007, Kenrick *et al.* 2010). My findings support the idea that psychosocial needs are not easily separated from other needs and that different psychosocial needs interact and overlap with each other, reflecting the complex nature of holistic care of patients (Carter *et al.* 2004, Gross and Kinnison 2014).

Explaining and exploring psychosocial needs as separate from other needs detracts from the notion that they are part of a 'holistic' person. The psychosocial needs currently identified in the literature (Figure 1.1) are from mostly self-report (Rowlands and Noble 2008, Sayers and de Vries 2008, Bradley *et al.* 2010, Brereton *et al.* 2011) and some observational studies (Field 1989, James 1992, Copp 1999, Lawton 2000, McNamara 2001, Haraldsdottir 2011). The needs in the literature (emotional, rights, coping and identity) were expressed during this study: the ward patients expressed a wide range of related needs. No additional types of psychosocial needs were identified. However, these psychosocial needs were rarely expressed as separate entities and were often concealed within other aspects of care, thus making them difficult for nurses to identify.

The contexts of care in which psychosocial needs were expressed emerged as an important concept during this study. Current palliative care literature does not explicitly discuss how psychosocial needs are integrated with other aspects of care - tending instead to discuss psychosocial support as a separate entity - but closer inspection of some studies (Moore *et al.* 2014a, Herber and Johnston 2013, Cotterell 2008) does show palliative care patients expressing psychosocial needs in relation to the context of their care. Developing a categorisation of contexts of care (section 5.1.2) in which psychosocial needs were expressed, provides a new classification of psychosocial needs which demonstrates how they are exhibited by palliative care in-patients. Since such codification has never been reported before, the first novel contribution to understanding psychosocial support this study offers is, therefore, the

categorisations of observed psychosocial needs according to both their type and the context of care in which they were expressed. The impact of the care setting on the psychosocial needs expressed suggests a need to redefine what the existing psychosocial needs of patients are across clinical settings.

The expression of psychosocial needs in combination with other needs creates a number of potential barriers to offering ideal psychosocial support: Can nurses recognise all of the needs? How should nurses prioritise which need to deal with first? And how can nurses manage potentially conflicting needs? The following paragraphs consider these questions.

One reason psychosocial needs are not dealt with is because nurses do not recognise that a psychosocial need has been expressed (Costello 2001 and 2006, Uitterhoeve *et al.* 2009, Sayers and de Vries 2008). Psychosocial needs are not necessarily obvious; often patients only hint, with verbal or non-verbal signals, to a psychosocial need's existence (Begdahl *et al.* 2007). Psychosocial needs were regularly expressed subtly during this study; nurses were observed both dealing with subtle psychosocial needs and failing to recognise them. The subtlety of psychosocial needs is two-fold: it can mean psychosocial needs are not met but, equally as often, it means when psychosocial support is offered the nurses do not recognise they have just met patients' psychosocial needs (Dovidio *et al.* 2006). Because of the simplicity of the psychosocial need, and/or its expression amongst other needs, nurses themselves can fail to recognise when they have offered psychosocial support and credit is not afforded when nurses **are** meeting this component of their role. An enhanced understanding of how psychosocial needs are expressed, as described in Chapter Five, helps to remove the camouflage around psychosocial needs and enables nurses to see more clearly when psychosocial support is in demand and offered.

Current ideology is that care should be patient-centred (Department of Health 2012, Manley *et al.* 2011, NHS Scotland 2008); therefore, patients should be involved in prioritising which

needs are addressed first. Patients actively prioritising their needs was not observed in this study. When psychosocial needs were not all dealt with, it was the nurse who chose which needs to deal with, rather than asking patients what was most important to them. Similarly, some psychosocial needs were encountered that patients had not expressed. Nurses envisaged some psychosocial needs: on occasions the nurses had made a correct judgement and the patient admitted to the existence of the underlying psychosocial needs; while on other occasions the patients denied the presence of the psychosocial need. Clarifying the existence of these 'hidden' psychosocial needs is equally as important as checking with patients which psychosocial need is currently most important to them.

Previous studies have identified the problem of certain psychosocial needs potentially conflicting with other psychosocial needs (Arantzamendi *et al.* 2012, Olthuis *et al.* 2006, Mok and Chiu 2004, Seymour *et al.* 2003, Lawton 2000). For example, conflicts are proposed to occur when patients maintain hope by avoiding understanding how their disease is likely to progress (Chapple *et al.* 2006, Mok and Chiu 2004). A major aim of palliative care in its infancy was to eradicate the practice of hiding impending death from patients, with much focus placed on 'open awareness' (Glaser and Strauss 1965, Field 1989, Saunders 2006). However, in more recent years, the idea of 'denial as coping' (Chapple *et al.* 2006, Copp and Field 2002, Copp 1999) has been recognised. These ideas are not dichotomous options but are either ends of a continuum. In this study, patients were observed with preferences across this continuum. Nurses were observed both supporting patients to gain the level of understanding they desired and trying to either enforce, or block, patient understanding according to what the nurse felt was best for the patient. Patients were also observed expressing different genres of needs that could be considered 'conflicting'; for example, Flora's wish to visit her home conflicted with her deteriorating health which made leaving the hospice physically challenging (section 5.1.2.4). However, I propose what is happening, in both of the examples above, is not a conflict of needs

but a form of paternalism where nurses, instead of patients, are prioritising which need is more important.

Nurses are challenged with recognising the complex psychosocial needs which patients often express simultaneously to, and hidden amongst, other needs. Clarification of which psychosocial needs truly exist, and are most important to patients, relies on nurses acknowledging psychosocial needs. Nurses should have confidence that patients choose to express psychosocial needs to them because patients trust nurses to offer the psychosocial support they require. Faced with these challenges it is understandable to see why nurses resort to a range of responses to psychosocial needs.

7.1.2 Use of the 4D responses

Commonly, when authors discuss psychosocial support the implication is usually given that psychosocial needs are either met or not (Bradley *et al.* 2010, Cotterell 2008) and nurses are consistent in the way they reply (Ellington *et al.* 2012). Previous studies look at whether patients' and/or nurses' expectations about psychosocial support have been met (Adams 2005, Rogers *et al.* 2000), while this study focussed on how nurses immediately respond to psychosocial needs. This study has shown responding to psychosocial needs is not as clear cut or simple as dealing with psychosocial needs or not, and nor do many patients expect it to be. I have identified that nurses exhibit a range of immediate responses to psychosocial needs: 'dealing, deferring, diverting and ducking'. Although the framework of the 4Ds emerged from the data in this study, the range of responses are not used by only my sample of nurses. The 4Ds can be recognised in data excerpts in other studies, for example, Rydahl-Hansen and Eriksen's (2009) paper on psychosocial nursing, though they have not been conceptualised or analysed as such.

Previous observational studies of palliative care have reported a range views on nurses' provision of aspects of psychosocial support. James (1992) reported nurses could be flexible, accessible and willing to spend time sitting with patients, thus supporting the findings of some self-report studies (Seymour *et al.* 2003, Brannstom *et al.* 2005, Johannsson and Lindahl 2011). While Haraldsdottir (2011) and Li (2004) reported a lack of this 'open approach to nursing' which is said by many to be the conduit for psychosocial support (Bridges *et al.* 2013, Canning *et al.* 2007, Chapple *et al.* 2006). Other studies (McNamara 2001, Lawton 2000, Copp 1999) described a variety of actions from the nurses which could facilitate or hinder meeting patients' psychosocial needs. The findings of the final group of authors are most akin to my findings: at times the nurses responded to psychosocial needs with the open approach above, while at other times nurses focussed on tasks. Nurses were observed, at times, changing their actions and/or behaviours to suit patient preferences, thus showing flexibility. On occasions nurses spent time sitting with patients, both to discuss psychosocial needs or simply to 'be there'. On other occasions, when patients appeared to be asking for the nurses' time, the nurse focussed on practical tasks. However, the idea that focussing on tasks is not providing psychosocial support should be questioned: it is evident from both categorisations of needs that when nurses are doing the practical tasks of their work, they can also be meeting basic psychosocial needs.

Regardless of whether nurses wish to offer the 'open approach' advocated (Bridges *et al.* 2013, Canning *et al.* 2007, Chapple *et al.* 2006), the reality is they cannot always immediately deal with psychosocial needs, for example, when an emergency situation occurs. Some patients recognise and accept that their psychosocial needs cannot always be dealt with. In instances when patients' psychosocial needs cannot be immediately dealt with, 'deferring', rather than 'diverting' or 'ducking' responses, may encourage more patients to understand why their psychosocial needs cannot be currently dealt with. 'Deferral' responses enable patients to understand their psychosocial needs have been heard, which can reaffirm self-concept and

install hope and/or trust that their psychosocial needs will be dealt with later (Dean and Street 2014, Griffiths *et al.* 2010). If another allied health professional (AHP) is to follow up on the psychosocial need, effective deferral relies on effective liaison, and/or documentation (Tomey 2009, Cotterell 2008, Dowding and Barr 2002) and teamwork, so that the offer of psychosocial support is carried through. Lawton (2000) observed little discussion around psychosocial needs during nurse liaison. Similarly, the nurses in this study dedicated a substantially smaller proportion of their working time to documentation and liaison on psychosocial needs, either amongst their profession or to the multidisciplinary team. Previous research in palliative care has identified a dearth of inclusion of psychosocial needs in the formal planning of nursing (Wallerstedt and Andershed 2007, Parish *et al.* 2006, Fincham *et al.* 2005). Similarly, there was little reference to psychosocial support during organisational or care planning in this study.

The framework of the 4Ds, especially the recognition of 'deferring' and 'diverting' responses suggests nursing may have progressed in its support of patients' psychosocial needs. Wilkinson (1991) identified four types of nurses - facilitators, ignorers, informers and mixers - who were categorised according to their use of facilitating and blocking communication tactics; the idea being that specific nurses had a preference for a specific communication technique. The nurses in my study had a much more variable use of responses. All of the facilitating and blocking communication tactics used in Wilkinson's (1991) study were observed during this study, with the same effects and for similar reasons; when psychosocial needs were avoided it was to enable nurses to remain in control of and to complete their tasks for the day. However, the nurses in my study exhibited more 'dealing' responses and were less likely to block patients' psychosocial needs. The use of 'deferring' and 'diverting' when nurses were unable to deal with some psychosocial needs demonstrates new communication tactics which can show patients their needs have been heard and may be dealt with later. Encouraging use of these tactics is another key recommendation of this study.

'Emotional' psychosocial needs were the only category of psychosocial need where the proportion of 'dealing' (32.9%) reduced in comparison to overall 'dealing' (44.2%). Two factors were observed which may attribute to this reduced dealing with emotional psychosocial needs. Firstly, some nurses, as observed in this study (for example, Camille with Stuart, section 5.1.1.3) consider expression of emotions as being 'painful' for patients, they do not wish to upset patients, so avoid emotions with an aim to 'protect' patients (Wilkinson 1991, Booth *et al.* 1996). However, expression of emotions is considered cathartic (Eriksson 1997, Morse 2001). Secondly, the nurses' hesitancy in dealing with difficult emotions verifies findings of previous studies into nurses' palliative psychosocial support: nurses have been found lacking in confidence to deal with difficult, especially emotional, issues (Phillips *et al.* 2006, Law 2009, Herber and Johnston 2013, Clarke and Cooper 2001). It is especially important to enhance dealing with emotional needs as Heaven and Maguire (1997) identified patients' hesitancy to disclose emotional concerns to nurses. Consequently, when emotions are disclosed they should be interpreted as especially important, and nurses should facilitate discussion around them. One explanation for reduced dealing with emotional expression appears to be directly related to the 'disease' category of psychosocial need. Patients displayed emotions relating to the progression of their diseases, they looked to the nurses for support with these needs. However, some nurses, especially auxiliary nurses (AuxNs), were reluctant to offer support as they thought patients were looking for specific information on their diseases, beyond their knowledge. But patients were actually seeking the nurses' views and support in relation to what they had encountered previously. Similar patient faith in palliative care nurses as a result of their professional expertise and experience has been reported elsewhere (Conner *et al.* 2008, Rowlands and Noble 2008). The lower provision of dealing responses by AuxNs in the 'disease' psychosocial needs can be related to the education they received: AuxNs are not given education on disease

processes or medications. However, patients do at times relate these psychosocial needs to AuxNs when they believe their experience equips them with the required information.

Field (1989) identified palliative care nurses' lower level in the hierarchy of healthcare professions as a barrier to nurses' provision of psychosocial support. Although modern nursing has evolved in many ways, this group of nurses' behaviours were similar to those described in other studies (Bridges *et al.* 2013, Allen 2007, Carter *et al.* 2004) when they remained less confident in adopting an equal professional standing alongside their healthcare counterparts. The constraints of professional hierarchy were observed in this study. Multidisciplinary working was highly visible in the hospice and can be attributed to the high use of 'deferring' and 'diverting' in the 'place of care' psychosocial needs. A joint multidisciplinary decision is often required for addressing 'place of care' psychosocial needs, during which the nurses usually adopted the role of messenger. However, nurses were, at times, observed assuming the more participative role of patient advocate, though not always successfully. Similarly, in all interactions when AHPs or nurse specialists were present, the nurse failed to deal with patients' psychosocial needs while allowing their colleague to control the episode of care. Nurses' lack of 'dealing' responses in the presence of 'more senior' colleagues and the small amount of liaison they offered about psychosocial needs in multidisciplinary discussions suggests the ward nurses may be inhibited by their 'more senior' colleagues. The inequality of nurses' contribution to multidisciplinary work could be related to three issues: firstly, nurses lack confidence in providing psychosocial support (Walshe and Luker 2010, Kuupelomaki 2003); secondly, nurses may feel the limited time AHPs have with each ward patient makes the AHP's time more valuable, therefore the AHP should prioritise care; or thirdly, the nurse may simply feel other AHPs have better skills or knowledge to provide appropriate psychosocial support.

Great value can be taken from the use of 'deferring', and to a lesser extent 'diverting', responses when nurses have to choose between providing psychosocial support or completing their duties

for the day. When faced with some psychosocial needs nurses must weigh up the value of helping patients with these needs against the cost of not completing their workload. The nurses in this study, similar to in other studies (Bridges *et al.* 2013, Williams 1998) were observed considering the dilemma of following ward routines and completing practical tasks or meeting patients' psychosocial needs. Nurses in this study chose both sides of this quandary: some nurses risked not achieving their daily tasks in order to respect patients' psychosocial needs; while others appeared to follow Haraldsottir's (2011) findings by prioritising organisational constraints and neglecting psychosocial support. However, using 'deferral' responses allowed nurses to carry on their work as planned, but offered patients hope that their psychosocial needs might be dealt with later. In these instances patients understood that their psychosocial needs could not be a priority.

'Deferral' responses were given when the nurses aimed to return to deal with the need themselves. They justified not dealing immediately because of a lack of time but offered to return themselves because they were "familiar" with the patients. The importance of familiarity with patients and, therefore, the importance of the nurse-patient relationship has been questioned by the findings of this study. Nurses *dealt* with some psychosocial needs of patients with whom they were *not* familiar, and *failed to deal* with some psychosocial needs of patients with whom they *were* familiar (see Hill *et al.* 2014, appendix 9 for further discussion). This study identifies that, in reality, connecting with patients, rather than taking time to develop a nurse-patient relationship, is the condition required to offer psychosocial support (Nolan 2011, Csikai 2004, Richardson 2002, Luker *et al.* 2000, Devery *et al.* 1999). The way the nurses in this study connected with patients is linked to the higher proportions of 'dealing' responses to 'societal' psychosocial needs. The chatting observed between nurses and patients served to make connections and offer psychosocial support for a number of psychosocial needs,

especially: understanding and identity (also reported by Hansen *et al.* 2012), relationships and companionship.

Various perceptions on the provision of psychosocial support by palliative care nurses have been provided in previous research. None of which are refuted by this study, they simply do not provide complete answers to the specific questions addressed in my study: they either explore the work of specialist nurses (Davies and Oberle 1990, 1992, Johnston 2002) or focus on alternative and/or broader aspects of palliative or cancer care (Wilkinson 1991, Cohen *et al.* 2001, Cannaerts *et al.* 2004). At times the nurses in the hospice ward I observed altered their plans for the day in order to offer psychosocial support to patients' psychosocial needs. On other occasions nurses failed to acknowledge psychosocial needs and carried on with completing their tasks for the shift. One of the key issues this study adds to the literature is that it was not simply a case of nurses dealing with or avoiding ('ducking') psychosocial needs. There were occasions when the constraints of their jobs meant nurses could not immediately deal with patients' psychosocial needs. In these instances, 'deferring' and to a lesser extent 'diverting' responses to psychosocial needs can offer patients a later opportunity for psychosocial support, often by another member of hospice staff. The patients often accepted these responses which support the findings of previous studies (Seymour *et al.* 2003, Skilbeck and Payne 2003, Buckley and Herth 2004, Cannaerts *et al.* 2004) where patients did not expect psychosocial support from their ward nurses. The majority of nurses used a variety of 4D response to psychosocial needs.

7.1.3   Summary of findings

I have demonstrated that the psychosocial needs expressed by this sample of palliative care in-patients were complex. Multiple needs of different genres were expressed during most episodes of care. These needs interacted holistically so that psychosocial needs often became hidden amongst the context of care in which they were expressed. Nurses, therefore face a challenge

in recognising psychosocial needs, acknowledging them, and allowing the patients to prioritise what needs – psychosocial or otherwise – to support first.

When support for psychosocial needs is in demand, nurses' responses are not simply a choice between dealing or not. A range of responses were observed which resulted in diminishing amounts of psychosocial support being offered by nurses to patients: 'dealing', 'deferring', 'diverting', and 'ducking'. 'Deferral' responses gave nurses a means to offering patients psychosocial support when they were unable to provide it themselves, at the moment it was request. The inconsistency of individual nurses' use of the range of the 4Ds suggests work on increasing their response repertoires could result in an increase in nurses' immediately supportive responses to patients' psychosocial needs.

7.2   A candidate theoretical framework

As described in Chapter One, Maslow's (1943) hierarchy of needs model (figure 7.1) was created as an explanation of human motivation. It appears to offer a candidate theoretical framework from which to view the expression and response to psychosocial needs within in-patient palliative care nursing. The theory suggests that humans have different, hierarchical, levels of needs, from physiological to self-actualisation. The central tenet is that in most individuals the lower needs must be satisfied before they seek gratification of the higher needs – there are exceptions to these ideas, such as some individuals being willing to sacrifice 'lower' needs in order to gain 'higher' one (an artist foregoing relationships in a bid to perfect their work, thus reaching self-actualisation). Maslow's theory resonates with my study as the psychosocial needs identified in the literature - with the exception of emotional expression, which is discussed later - are referred to, by Maslow, as 'higher' level needs. Maslow's original diagrammatic representation of his theory names a number of the psychosocial needs included in my concept map (Figure 1.1), which were identified from the nursing literature. Psychosocial needs, and others discussed within Maslow's writing, are often taught as 'higher' needs to

undergraduate nursing students (Frager *et al.* 1970, Gross and Kinnison 2014, Priest 2012, Barry 2012), as discussed in Chapter One. It is important that nurses learn about 'higher' needs as they face them regularly in many areas of practice, including specialist palliative care roles. However, consideration of the findings of this study via a closer inspection of Maslow's theory (Frager *et al.* 1970) indicates ward nurses may be facing a different reality than that extolled in nurse education. Instead of expressing 'higher' level standalone psychosocial needs, ward patients may actually be expressing psychosocial needs as prerequisites to 'basic' physiological needs.

Figure 7.1 Maslow's (1943) hierarchy of needs
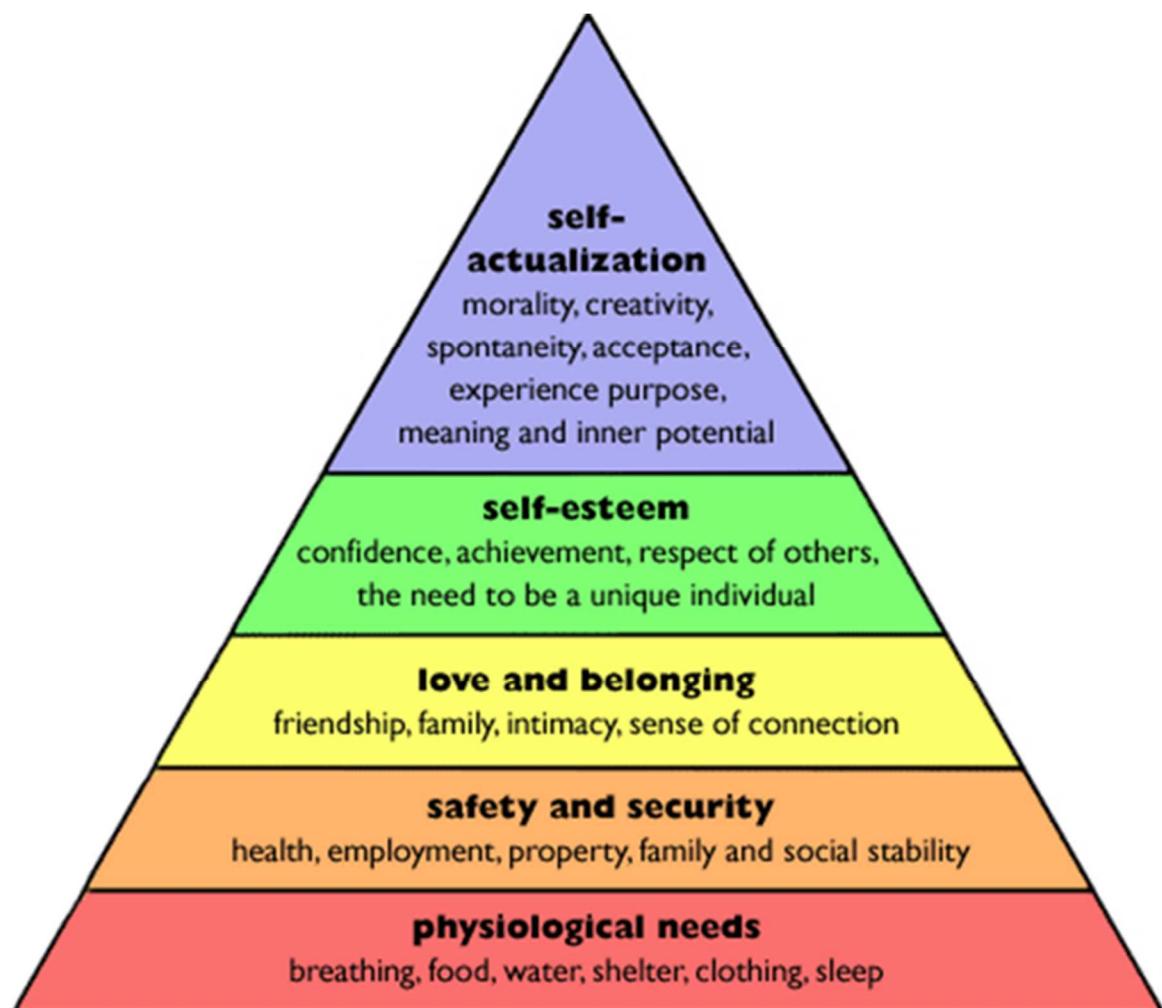
There are two elements, other than the hierarchy itself, which should be considered in Maslow's theory in relation to in-patient psychosocial support: firstly the prerequisites to 'lower' needs

and, secondly, his views on emotional expression. Maslow (1943) suggests there are "prerequisites for the basic needs satisfactions" (Frager *et al.* 1970, p22) - which include: emotional support, dignity, choice, understanding and social functioning. The prerequisites must be met in order for individuals to achieve gratification of the basic, 'physiological needs'. These prerequisites are included in the psychosocial needs identified in the palliative care literature (Figure 1.1). It would appear then that nurses face psychosocial needs throughout every level of motivation on Maslow's hierarchy: there are psychosocial prerequisites that must be met for gratification of 'lower' level needs and there are standalone 'higher' level psychosocial needs. Therefore, the question occurs as to whether the psychosocial needs in-patients have are 'higher' level needs or prerequisites for gratification of 'lower' level needs. The exception of emotional expression from obvious 'higher' level needs, excludes emotions from this dichotomy. Whether emotional needs (identified as a core psychosocial need in the literature outlined in Chapter One) fit with Maslow's theory is a moot point. Maslow identifies that emotions are either a component of a need or a need in its own right; the latter of which is unconscious, often uncontrollable, unmotivated, and effortless (Frager *et al.* 1970) and outwith the confines of Maslow's theory. Consequently, emotional needs may require exploration in relation to the purpose with which they were expressed (the contexts of needs). These questions suggest there may be a difference between the types of psychosocial needs a ward nurse encounters to a specialist nurse or a nurse in a different setting, ergo the difference between the findings of this study to those discussed in Chapters One and Two may be related to this distinction. Making a distinction between 'lower' level psychosocial needs, which are actually prerequisites to gratification of lower needs, and those that are 'higher' level should allow ward nurses to recognise patients' needs and, therefore, offer more psychosocial support.

The position of needs expressed by this study's patient participants on Maslow's hierarchy can be seen by considering the contexts of care. The '**practical aspects of daily life**' and '**impact**

of disease and its treatment' contexts of care are by definition physiological in Maslow's (1943) hierarchy. They concern physiological aspects of living: physical functioning of the body and the changes to the body because of a disease or its treatment. However, what is under consideration in this study is psychosocial needs not motivation, Maslow's focus. Maslow recognises his lack of discussion around some aspects of psychosocial support – for example, emotional expression as above – but does suggest "an act is psychologically important if it contributes directly to the satisfaction of basic needs" (np), Therefore, psychosocial needs expressed within 'practical' and 'disease' contexts of care (n=149) can be considered on the basic level of the hierarchy of needs (Maslow 1943) as they contribute towards gratification of physiological needs. The '**patients' interactions within society**' needs observed in this study – with the exception of those relating to problems with existing relationships which were supported with separate nursing time, see below – can be located within the **prerequisites of basic needs**: they relate to patients being free to express themselves, communicate with others and perceive a position within the ward group. It was rare to see '**place of care provision**' needs that could be considered within Maslow's physiological level, though the discussion over where Flora should be cared for in the ward resulted from a change in her physical condition. The majority of 'place of care' needs appear within Maslow's next level of need (**'safety and security'**). They were observed being achieved through the presence of people or things known to provide comfort to patients. Or, in Teresa's case, were placated when they referred to concerns about managing at home. Therefore, the vast majority of psychosocial needs observed being expressed during this study fell into Maslow's two lower levels of the hierarchy of need.

However, nurses' education and literature, as outlined in Chapters One and Two, suggest psychosocial needs are 'higher' needs. The dearth of studies documenting how palliative care nurses meet psychosocial needs may be because nurses are meeting 'lower' level needs and not recognising the psychosocial prerequisites amongst these. This challenge in recognising

psychosocial support contributes to the lack of verbal and/or written reporting of these needs. When patients are asked what needs are important to them it appears in-patients are looking for support with the lower needs (Seymour *et al.* 2003, Skilbeck and Payne 2003, Buckley and Herth 2004, Cannaerts *et al.* 2004). From the data in my study it would appear that in-patients look to ward nurses to meet the prerequisites of physiological needs, rather than higher levels of needs. Concurrently ward nurses have the organisational challenges of providing equitable care to a group of patients in the ward, thus inhibiting the opportunity for 'being there' (James 1992, Haraldsdottir 2006, Roche-Fahy and Dowling 2009) which requires time that is not available to nurses in a busy ward. This is not to say that ward nurses are unable to support 'higher' psychosocial needs – indeed supporting of these was occasionally observed during my fieldwork - but that they often do not have time to do it within the other constraints of their daily duties. Additionally, it may be the case that support for some 'higher' level of needs should be deferred to other members of the team. These points illustrate the disparity between what nurses expect of themselves, what patients expect, and what can be offered within the organisational constraints of a ward setting; and therefore, the challenge of providing and identifying psychosocial support.

Psychosocial needs were usually expressed when the nurses were interacting with patients for other reasons, the contexts of care. As explained above the psychosocial needs expressed during this study mostly fell within Maslow's (1943) physiological needs level, and some within safety and security needs or as a prerequisite to either of these. Some psychosocial needs were observed that could be classified as 'belonging' in a higher level of Maslow's hierarchy. On the few occasions when 'higher' level (not physiological or safety) needs were expressed four outcomes were observed. One, the psychosocial needs were 'ducked' (as with Camille (registered nurse (RGN)) and Stuart). Two, the psychosocial needs did not really belong to the patients but were imagined to exist by the nurses, as in the idea that Bruce and Andy would get

support from a patient-patient relationship (section 5.1.1.4). Three, the nurses changed their plans for their shift, sat down with patients to discuss their psychosocial needs (such as the two examples with relationships needs, Annie (RGN) and Carrie (section 5.1.1.1), and Chrissie (RGN) and Helen (section 5.1.1.4)). Or finally, the nurses 'deferred' the psychosocial needs. When nurses deferred the needs with the aim of going back later themselves, they suggested they were doing this because they were familiar with the patients. These nurses exhibited an awareness that they can support 'higher' needs but need more time to do this, they also gave an indication of the role of nurse-patient relationships in meeting Maslow's 'love and belonging' needs and, in some cases, this was suggested to be the means by which nurse supported patients to accept forthcoming death (Costello 2006).

Maslow's (1943) theory has much potential for guiding the provision and identification of nurses' psychosocial support. However, consideration must be given to the patient's current health status and place of care and the organisational constraints over the nurses' interactions with patients. My study suggests that ward patients seek support from their nurses with Maslow's 'lower' levels of needs, namely the "physiological" and "safety and security" needs. Nurses need to be aware of this in order to recognise when psychosocial support is in demand and how to respond.

7.3 Limitations

Existing literature reports patient and nurse opinions on the psychosocial needs of palliative care patients and how these psychosocial needs are met. This study sought to observe what psychosocial needs were expressed in a hospice ward and how nurses supported them. Observational research has many challenges, but if the attention outlined below is paid to these, rigorous results are achieved.

As data were collected by one researcher, it was only possible to accurately record nurses' *immediate* responses to patients' psychosocial needs, during limited time-periods. The focus, aim and design of this study took cognisance of the limited length of time for data collection. I do not attempt to illustrate whether psychosocial support is *successful.* Rather the aim of the thesis is to give a comprehensive picture of what psychosocial needs were expressed and how this sample of nurses responded to them. This is a novel contribution to the evidence base.

As a participant observer role was taken, a major concern is the impact of the observer on nurse and/or patient action. As discussed in section 4.1.1.3, great care was taken to prevent this. The ten months spent naturalising myself into the ward, the covert recording of observations, and lack of corrections to my recording of incidents from participants suggest I was successful at minimising researcher impact.

Researcher bias is a particularly high risk in observational studies. However, various steps were taken to minimise this risk, including: using interviews to verify what had been observed; sharing records of data with participants; and supporting qualitative data with quantitative analyses to substantiate the findings. Similarly, as I am a registered palliative care specialist nurse who was initially employed by the participating hospice to carry out this study, there is a risk I may wish to paint a positive picture of what I observed. I was true to the research process throughout and feel this thesis is testament to that: I have reported a range of responses and challenges that do not simply report the virtues of the care offered by the nurses on the ward.

My links to the setting of the study could also raise questions about the nurses letting me see the messy complexities of care. The nurses knew of me through my previous employment by the Hospice to facilitate a project educating care home nurses on palliative care. During this previous post I had occasional contact when educating nurses in the Hospice. There may be concerns that the nurses would have felt threatened by me because of my previous senior role in the Hospice, and that this could affect the care I observed or make nurses reluctant to discuss

care. This did not appear to happen. The nurses seemed very open with me – sharing very personal information and criticisms of the hospice – as I was with them – sharing my anxieties of returning to working in a ward after five years' absence. The collaborative approach adopted before, during, and after data collection gave the nurses ownership of the study – they contributed to planning the study and discussions on all of the key findings – enhancing their trust in me, which was reflected in the high consent rate.

The methods chosen to answer my research questions further bolstered against the potential observational limitations. Combining a wealth of different data sets, sharing observation recordings with participants, and focussing interviews around the observed care ensured greater rigour in this study. The different types of data presented in this thesis may appear disproportionate: there is substantially more observation and interview data than liaison data, either verbal or written. The proportions displayed in the thesis do, however, reflect the data collected across the study, through no fault of the researcher. Documentation was in fact the easiest to collect, however, there was a dearth of reporting and documentation of psychosocial needs, even of those that were dealt with.

It could be argued that the sample size was relatively small. However, the sample size is appropriate for either ethnographic or grounded theory exploratory studies which aim to identify areas for future research (Teddlie and Tashakkori 2009). The sample is substantial enough to examine patterns in the data which might suggest the presence or absence of associations. These associations challenge some of the conventional wisdom in the field and pose new and more detailed questions about the nature of psychosocial needs and how they are supported in this specialist setting. Throughout the findings chapters, data are clearly presented, allowing the reader to verify my findings for themselves.

Data were collected for this study between September 2004 and May 2005, therefore the data are old. However, this is a novel study. It was the first study to explore nurses' provision of

psychosocial support in practice, using observational data to explore the minutiae of how nurses immediately respond to psychosocial support. A unique view of psychosocial nursing has been provided and there is little evidence of practices having changed since the data collection occurred. Frequent and recent searches of research databases confirm that this study has not been replicated in palliative care.

Maslow's (1943) hierarchy of needs theory has been used as a theoretical framework in which to locate this study. This theory is not a perfect fit. For example, Maslow admits himself that a limitation of his study, and those drawing on it, is a lack of consideration of the importance of expression of emotions; one of the main categories of psychosocial need. And little consideration is given to death or dying, however the only reference made to this topic does support my suggestions: people in near death accidents revert back to focussing in basic physiological needs and "lose faith in their abilities" (Frager *et al.* 1970). Equally important is the fact that palliative care patients psychosocial needs are rarely about heading toward self-actualisation, but about core needs.

This is a study of one hospice, and the findings are, therefore, not generalisable to other specialist palliative care institutions (or to other healthcare settings). Indeed, they are not definitive, even in the context of this one hospice, as the sample is relatively small. However, the purpose of this study was not to provide definitive answers. This study sought to explore the conditions and constraints surrounding the nurses in this hospice ward's provision of psychosocial support. The aim of adding to the current patchy understanding of nurses' support of psychosocial needs and identifying future areas for research has been achieved.

7.4 Reflexivity within this study

Reflexivity is a process that is considered to be a vital component of any research using qualitative data (Creswell 2014, Gray 2014, Bryman 2012, Seale 1999, Maxwell 1996). A

number of stances can be taken to reflexivity (Woolgar 1988, Marcus 1994, Finlay 2002): from simple reflection ('benign introspection'), where a researcher describes some of their thoughts; to a set of complex processes ('constitutive reflexivity'), including the sharing of psychoanalyses and the reinterpretation of participants words in comparison to other participants and the researchers' beliefs. There is, however, a fine balance between too little or too much reflexivity: a fear of spending so much time on reflexivity that the quality of research suffers (Finlay 2002, Hammersley & Atkinson 1995). If reflexive stances are considered as being on a continuum (Woolgar 1988), the one I took within this study would be nearer the 'constitutive reflexivity' end but without such 'deep' analyses of my own ideas as psychoanalyses. The reflexivity actions in my study were focussed on four main issues: researcher bias; the overall approach of the study; the impact of researcher presence on the research setting; and the methodology used, including the interpretation of findings.

When I began this study I did have preconceived ideas about palliative psychosocial nursing. In an attempt to minimise the impact of these on data collection I reflected on, and recorded, my biases, the context of the study, and my place in the research field, before starting data collection (Creswell 2014, Robson 2002; Maxwell 1996; Rose *et al.* 1995). The value of comparing researcher's ideas to existing literature in reflexivity is one way of recognising biases. One of my examples of this is demonstrated below in the notes that I took whilst reading Lawton's (2000) study:

> *Lawton (2000) asks 'how can patients "live until they die" when they "bodily degenerate ('rot and die away')". The difficulty is people do 'rot away' physically and this is shocking for everyone involved, especially if they're seeing this for the first time (as Lawton was). But I can't agree that bodily deterioration makes you no longer yourself. At least while patients remain conscious they are living and life is maintained through things like: respecting as individuals, relationships, meeting hopes and wishes*

of those close to them. Lawton's views are down to her naivety with illness…or maybe
I just don't want to face up to this reality. Maybe my beliefs are because I've worked in
palliative care so long.

Looking back on my initial reflections I can see that this study has altered my perceptions of psychosocial support in hospice wards, which suggests I succeeded in putting aside some of my biases.

The overall approach of the study required much reflexivity. The study's funding protocol outlined that I was to observe ward nurses provision of psychosocial support, I was not to study other health care professionals or nurses working in the other areas of the hospice. This protocol created challenges for me of methodological constraints:

- Being allowed to only study nurses working in the ward, I was prevented from utilising an aspect use of the grounded theory approach: theoretical sampling. Being unable to include participants from elsewhere, even within the hospice, prohibited my opportunity to compare the types and contexts of psychosocial needs between, even, in-patient and day care patients. Comparison of such groups in Lawton's (2000) study, a true ethnography, provided some interesting insights into hospice care, which are missing from this study.

- I had to exclude evidence on the impact of multidisciplinary working, a potentially valuable resource in psychosocial support, which inhibited follow-up of observed psychosocial needs and gave the limitations of exploring only immediate response to needs.

- The post I was given was a research practitioner role. The initial plans being that this role had a care improvement component. This put risks to my relationships with the nurse participants as it was initially construed as a semi-managerial role. I worked

hard to persuade the nurses I would not be 'reporting back' on their individual working.

- My previous relationship with nurses, as an occasional provider of education, had a potential to impact on data offered as the nurses may have thought I was 'testing their abilities'. This challenge was overcome in the same way as the previous point.

I kept a reflective diary throughout the study: from starting my post as a research nurse, until all data analyses were concluded and the study written up (see appendix 1 for an excerpt) and reflected on data whilst transcribing it and creating interview schedules (appendix 8a). I shared these reflections with my research supervisors and we formulated solutions to any problems. Great care was taken to critically reflect upon and document any impact I had during data collection (Pleschberger 2011, Guba and Lincoln 1994, Gray 2014). My observation and interview transcripts are interspersed with reflections on my action and how they appeared to influence participants. For example, I recorded the rare occasions when nurses' eye-contact would drift from the patient to look at me: the nurse's eye-movements suggested she was checking whether I was watching her, therefore, I was impacting on her actions. These reflections were taken into account by comparing the nurses' actions at other times during within-case analyses.

From an early time in the field I recognised my anxieties about my positioning within the field – a common problem in observational research (Gray 2014) – which I recorded in my reflexive diary. In a bid to be accepted in the field I lacked confidence in saying "no" to requests for me to carry out duties outwith the boundaries I had set. I felt myself getting too 'close' to the field. Sharing these feelings with my managers resulted in an arrangement for 'supervision counselling' – a technique used in a very similar study by Copp (1999) – where I met with a senior member of hospice staff and had the opportunity to de-bunk my concerns and find techniques for drawing back from ward life.

The other area where reflexivity is important is in ensuring I was not letting my own ideas cloud my interpretation of the findings. One method of doing this was my repeatedly going back and forth between data and thoughts (Woolgar 1988). This was strengthened by my own transcriptions of all data, sharing this data with the participants, and creation of individual interview schedules for each interview which reflected my thoughts. Similarly, presenting un-edited data in this thesis validates my findings (Gray 2014, Bryman 2012). These reflective processes have been referred to in appropriate sections of the methodology/methods chapters.

7.5 Recommendations

The findings from this study are intertwined in their relevance for practice, education and research. Their application in practice should be explored by future research and the findings of research and practice recommendations supported through education. For the purpose of discussion, the recommendations – some of which may be already be in practice in some areas – are considered under separate headings but are applicable across all areas.

7.5.1 Practice

Nurses should identify which psychosocial needs are expressed, within which contexts of care, by their patient groups. This will allow for easier recognition of all psychosocial needs, whether they are expressed as sole entities or hidden amongst multiple needs. The expected psychosocial needs of each group of patients should take into account whether they are 'higher' level needs or prerequisites for 'lower' level needs (Maslow 1943). A list of perceived current psychosocial needs could be created by care teams and adjusted through reflection on care. My categorisation of contexts of psychosocial needs could be used as an example and/or starting point for identifying psychosocial needs, especially in in-patient palliative care settings.

The organisational constraints of care settings should be considered, in line with the needs as above, to evaluate what psychosocial support can be provided and by whom. Nurses should be

encouraged to expand their response repertoire when psychosocial needs are expressed. They should use more 'dealing' responses, but if they cannot then 'deferring' responses, when psychosocial need expression is recognised and arrangements for alternative support made, are the best alternative. This would benefit patients, individual nurses and the organisation as a whole: patients would have more psychosocial needs acknowledged; nurses would feel less guilt at failing in this aspect of care, as more psychosocial support would ultimately be offered; and a more psychosocially supportive culture would exist.

This change in attitude to nurse-patient relationships should occur alongside the changing attitude towards a more patient - rather than task - centred approach to care. The increased recognition of type of psychosocial needs expressed by nurses' patient groups should be formalised by their written and verbal reporting. Daily nursing records should reflect the psychosocial support offered and more thorough completion of admission, initial assessment, and care plan to reflect psychosocial needs should occur. Nurses should make cognisance of these needs during hand-overs and formally include patients' psychosocial needs in the organisational planning of nursing (Roche-Fahy and Dowling 2009, Costello 2006). Doing so will create a greater cycle of recognition of psychosocial needs and offering of psychosocial support.

All of the practice recommendations above should be supported by reconsideration of where to focus nurses' training and education in psychosocial care.

7.5.2 Training and education

Nurses should be taught about psychosocial needs and support from a more clinically oriented perspective – including scenarios from practice – rather than the traditional method of focussing on psychological and sociological theories. Greater exploration and dissemination of the reality

of how psychosocial needs are exhibited in practice should be carried out with the nurses during education sessions.

Maslow's (1943) hierarchy of need theory can be taught with particular emphasis on nursing in practice in different clinical settings. Current training on the support of 'higher' needs should continue, as they remain of vital importance throughout nursing. However, much more education on what the basic needs are and how these are psychosocial is needed. Ideally teaching about these basic psychosocial needs should be included within nurse education settings on aetiology, management, etc., of specific conditions, as well as a general overview of psychosocial needs and their support.

Greater care could be taken in education when explaining the importance of the nurse-patient relationship. The idea of a continuum of interaction between nurse and patient, with initial connection at one end and a relationship created over a period of time at the other, should be discussed. The latter end is valuable but the former a necessity for psychosocial support. It should be made clear to nursing students and practicing nurses that familiarity is not necessary to provide psychosocial care.

Education for AuxNs should include all of the above and work on expanding their response repertoire, especially the value of 'deferring' responses. Similarly, an AuxN training course should encourage AuxNs to share their knowledge from experience when patients ask about their diseases. AuxNs should be advised that they are asked these questions because the patients trust them and value their responses.

The influence of workplace culture on psychosocial care should also be shared and discussed during education sessions. Balancing organisational issues alongside the psychosocial needs of patients is an, often unseen, challenge for nurses. Enabling nurses to identify and respond to

these challenges can enhance the provision of psychosocial support in palliative care settings and elsewhere.

Ideally, education and practice recommendations should be combined to strengthen their impact. Consequently, the impact of these adaptations on practice and education could be explored through research.

7.5.3 Future research

A wide variety of research studies could be developed in light of this study's findings. The future research I consider to be most desirable for nursing are introduced below.

Further observational studies are required to build up a greater picture of how patients express psychosocial needs and how nurses respond to them in practice. Similar observational studies – participant, audio, or visual recording – to this study would compare practice in similar – including night duty – and differing clinical settings. Alternatively, the findings of this study could use an interactional analysis system (Ellington *et al.* 2012, Roter 2010, Sheldon *et al.* 2009, Gray 2014, Bryman 2012) to carry out structured observation of which psychosocial needs patients express. A schedule of potential needs, contexts and supporting techniques (the 4Ds) could be predefined for an observer to record as they happen. The observer would begin the shift observing hand-over and patient allocation, thereby collecting organisational data. They would then move to a bay, where they listen in to a number of interactions with the schedule thus allowing rapid recording of which psychosocial needs are expressed when and how the nurse responds. The result would be a higher sample of patients and psychosocial needs which could then be compared to more data on participant characteristics and organisational issues.

Another key study would be to identify nurses who exhibit a high dealer rate and carry out an action research study of the impact of a reflective, role-modelling. 'Dealing' nurses could be

identified by discussions with unit managers and the nurses. A brief period of participant observation could verify whether the suggested nurse offers psychosocial support in practice. These nurses could then be paired with less confident nurses. Baseline recordings of the 'learner' nurses' psychosocial abilities could be taken via interview, de-brief sessions recorded and subsequent interviews used to identify advancing skills. Participant observation of the 'learner' nurse could also provide data about the psychosocial support they offer before and after working with the role-model.

To investigate outcomes of psychosocial support observations of the same patient for longer periods of time, or involving more researchers, could identify whether psychosocial needs are met to patients' satisfaction. This would be especially beneficial to explore deferred psychosocial needs. Similarly, observing pairs of patients and nurses to allow comparison over a number of interactions will develop an understanding of interactional processes and the impact of familiarity.

7.6 In conclusion

This study builds on a wealth of evidence reporting how nurses support the psychosocial needs of palliative care patients. A pragmatist approach, centred on participant-observations, gives new insight into the realities of the psychosocial needs expressed by hospice in-patients and how nurses immediately respond to them within the constraints of nursing practice. This thesis reports that the nurses regularly, but not consistently, offered supportive responses to patients' psychosocial needs. This study demonstrates for the first time how nurses supportively use 'deferring' responses when the constraints of their jobs prevent their immediate 'dealing' with psychosocial needs. A novel explanation of the complexities of psychosocial needs and how they are addressed within the reality of nursing practice is provided. Nurses – practitioners, educators, and researchers – need to reconsider what is meant by psychosocial support and take

greater cognisance of the context in which psychosocial needs are expressed in order to enhance this important, achievable aspect of nursing care.

A number of the challenges faced by nurses in recognising, acknowledging and supporting palliative care patients' psychosocial needs were explored. It appears to have been accepted – both in existing literature and this study – that nurses should pay more attention to patients' psychosocial needs and adjust their planned interventions in response to these psychosocial needs. However, this 'open' approach to care does not always happen. If nurses increase their response repertoire to use more 'deferring', when they are unable to immediately deal with patients' psychosocial needs, patients should receive more psychosocial support. Similarly, identifying the psychosocial needs of patient groups and how these are expressed in individual care settings can increase nurses' provision of psychosocial support.

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Appendices

Appendix 1: Excerpt from reflexive diary

11th January 2005:

Came onto the ward, unfortunately the people I have been allocated to work with are the new staff nurse and 2 auxiliaries who have not returned their consent forms. I eventually plucked up the courage to ask both of the auxiliaries, one thought she had done it *- I must check up that I haven't got it wrong and allocate pseudonym … need to recheck others missing and chase up* – the other said she'd found her consent form and info sheet in her locker. Both are quite happy to be involved in research. *Why do I still not have confidence in this? I was nervous about asking them if they wanted to because I don't want them to feel that I'm pushing it on them.* I clearly stated they could do it or not whatever they liked. *Consent reassured.* So that's OK, I'll work with whichever of them is working with the 2 consented patients'. Both seem quite alert this morning though I haven't had a chance to speak to them as they're having breakfast.

As soon as I came onto the wards they were playing musical beds. It will be interesting to see how the patients feel about this and I may ask about this in interviews today. *Are they given choice about moving and, if so, how much? What are the reasons for moving patients? Are they hiding dying like Lawton suggested or is it to meet organisational need a la Haraldsdottir.*

Team 1 is quieter this morning and this is causing people to be anxious to kind of get on with work and I did ask Margo about this and she said "yes, it's such a waste of time just waiting". *But they're respecting patients' wishes by waiting. Must ask about this in interview and discuss with [supervisors], seems like a dilemma between getting their work done and providing psychosocial support. Keeps recurring. Emerging concept? Create node.* We were waiting for the nurse in charge of the team to allocate patient care. It was a bit awkward because she's not so familiar with the study, however I just said 'you should allocate the patients' as if I'm not here and we'll sort me out from there'. We decided which patient I would work with first of all and ==Margo went over to him and asked what he'd like to do, giving him the choice of a shower and everything. She's away to set that up, but he was still speaking to her as she walked away.== *No longer putting him first, she's gone into work mode, lack of communication, respect.* ==He was concerned about getting his nebuliser.== *I sorted that out for him.*

Margo and I were about to get Sam in the shower when Ellen asked if she could take another patient to the shower and that was fine because Sam was getting his nebuliser. However, this seemed to knock Margo off - *lack of flexibility, so much for open approach* - and she is now parading around the ward tidying things up and completely avoiding the two other patients who both looked uncomfortable after breakfast. She didn't appear to think about going to ask them if she could make them comfortable. So I did, *cannot get out of my being a nurse*.

However, ==she did ask Sam about whether he wanted a wheelchair to go through to the shower room== *seems to be meeting some psychosocial needs – choice, self-concept, acceptance - but not others. It does say in his care-plan that he needs a wheelchair but I'm wondering why she asked him? If she was doing that out of having not looked or whether she was trying to find out more about him. It would be quite interesting to ask her about that in the interview.*

Perhaps with the hassle and focus of getting tied up with the moving of beds and things like that I should be asking more specific questions of staff about how they feel about the organisation of care, the moving of beds and the involvement of patients' in this, and vice versa.

Appendix 2: Copy of local ethics research committee approval letter

Mrs Hazel C. Hill
Research Nurse
Practitioner

Dear Mrs Hill,

Full title of study: An Ethnographic Exploration of Psychosocial Nursing in an In-Patient Specialist Palliative Care Unit
REC reference number: 04150601114
Protocol number: Protocol Ref N/A

Thank you for your letter of 17 June 2004, responding to the Committee's request for further information on the above research.

This information was considered by a Sub-Committee consisting of Dr Rob Elton (Vice-Chair
-Statistician) and Mrs Laura Lee (Pharmacist Member).

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

The favourable opinion applies to the following research

site: Site: -
Principal Investigator: Mrs Hazel C. Hill

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 final list of documents reviewed and approved by the Committee is as follows:

Document Type:
Application Version: 3.0
Dated: 19/05/2004
Date Received: 19/05/2004

Document Type: Investigator

CV

Appendix 3: Sampling Framework

No.	Nurses																Patients										
---	Post		Role			Time											Diagnosis				Hospice contact			Care aim				
	AuxN	RGN	ic	tt	ot	1	2	3	4	5	6	7	8	9	10	Ca	MND	MS	O	1c	d/hc	pa	ases	resp	rhab	sc	tc
1																												
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3																												
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Sampling framework key

Post
AuxN = Auxiliary Nurse
RGN = Registered Nurse

Role
ic = in-charge of the team
tt = the nurse is working in their own team
ot = the nurse is working for the other team that day

Time
It is possible to split the day on the ward into different times during which the patients or nurses are most likely to be doing specific things. These are outlined below:

1	06.30 - 08.00	Patients starting to wake. Personal care as required.
2	08.00 – 08.30	Breakfast. Medications.
3	08.30 – 12.00	Personal care.
4	12.00 – 13.00	Lunch. Medications.
5	13.00 – 15.00	Rest period for patients. Liaison. Documentation. 'General ward chores'.
6	15.00 – 17.15	Talking with patients and visitors. Personal care. Liaison.
7	17.15 – 18.15	Dinner. Medications.
8	18.15 – 20.00	Talking with patients and visitors. Personal care.
9	20.00 – 23.00	Settling down for the night. Supper. Documentation. Liaison.
10	23.00 – 06.30	Sleeping. Providing care as required. 'General ward chores'.

Diagnosis
Ca = Cancer
MND = Motor Neurone Disease
MS = Multiple Sclerosis
O = other

Familiarity
1c = First contact with Hospice
d/hc = attends day care and/or visited by Home Care Sister, no previous admission to Hospice
pa = has been admitted to Hospice on previous occasion.

Care aim
ases = assessment of condition
resp = respite
rehab = rehabilitation;
sc = symptom control
tc = terminal care.

Appendix 4: Patient information sheet

Hazel Hill

Researcher

Tel:

E-mail: hazel@

<div style="border:1px solid black; padding:10px;">

Exploring Psychological and Social Nursing in a Hospice Ward

</div>

You are being invited to take part in a research study, which is taking place in the ward in … Hospice. Before you decide whether you wish to take part, it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully, and discuss it with relatives, friends and the staff in the hospice if you wish. Please ask myself, or a member of the hospice staff, if there is anything that is not clear, or if you would like more information. Take time to decide whether, or not, you wish to take part.

Thank you for reading this.

What is the purpose of this study?

Everyone has psychological and social needs. These needs are very individual. The types of psychological needs we have include how we feel about things, the thoughts we have, and being able to express emotions. As well as being able to relate to the people that we are close to (such as our family) in the ways that we want to, social needs are about our interests, what stimulates us and our surroundings.

Hospice care aims to look after not only your physical needs, but also your psychological, social, and spiritual needs. Healthcare staff have information that suggests the best ways to care for physical and spiritual needs, however more guidance is needed on the best ways to look after your psychological and social needs.

This study aims to describe what nurses in the ward do when you have psychological or social needs and how you feel about what they do about these needs. This will help to identify the best ways of meeting psychological and social needs.

The study will take place in the ward at ... hospice over the next year.

Why have I been chosen?

All patients in the ward who are able to discuss their care are being asked if they are willing to be involved in this study. All of the nurses working in the ward are also being asked if they are willing to be involved.

Do I have to take part?

It is up to you to decide whether, or not, to take part. If you decide that you do not wish to take part in this study your decision will not affect the standard of care you receive in the hospice. If you do decide to take part, you will be given this information sheet to keep, and you will be asked to sign a consent form (you will also get a copy of that to keep). If you decide to take part you are free to change your mind and withdraw at any time, without giving a reason.

What will happen to me if I take part?

This study is based around observation of nursing care. I am a qualified nurse and will be working with the nurses on the ward. I am instantly recognisable by my pale-blue, striped uniform. I will be researching what the nurses do for you when you have psychosocial needs by working with the ward nurses. Therefore whether you are involved in the research depends on whether I am working with the nurse that is caring for you.

The care you receive will be the same whether I am with you or not. If during your episode of care I notice a psychological or social need has arisen, then I will remember this and carry on finishing your care. After your care has finished I will write notes describing what happened. I will then return to you and ask you to take part in an interview.

The interview will take between 15 minutes and half an hour and will be talking to you about what happened during your care. The interviews will be tape-recorded. The interview will then be typed out in full. You will be welcome to read the typed copy of the interview and make comments. This will make sure that your views have been recorded accurately.

If someone close to you is also involved in the care your permission will be sought to interview him or her. (Therefore it would be useful for them to read this information sheet.) I will also be interviewing the nurses involved in the episode of care.

I will also look at the notes the nurses make concerning your care.

What are the possible benefits of taking part?

It is hoped that talking about your psychological and social needs will help hospice staff to find acceptable ways of meeting these needs. However, this cannot be guaranteed. The information gained from this study may help staff to meet the psychological and social needs of future patients better.

What are the possible disadvantages of taking part?

You may find talking about your psychological and social needs, and how they are cared for, stressful. If this distresses you, I may be able to identify ways to help remove this distress. Otherwise we will stop the interview, and, if you wish, I will arrange for a member of the care team at … Hospice, with whom you feel comfortable, to help you with your needs.

Will my taking part in this study be kept confidential?

All material (written notes, tapes, etc.) will be kept strictly confidential, and securely locked away, in a filing cabinet in my lockable office, when not in use. Any information about you will have your name and identifiable details removed so that you cannot be recognised. With your agreement, quotations from the interview may be used in the final report of this study. Information about you will be stored under a different name; quotations will be shown using the made-up name. Care will be taken that you cannot be identified in any way.

Once the study has been written up all material will be locked in a box and stored in the locked room where all hospice documentation is stored. After 5 years this box will be destroyed.

The staff in the hospice know that this research is taking place and that you have been asked to participate in it. They will not know if you decline to participate.

What will happen to the results of the research study?

This study will be written up for submission for a Masters degree at Stirling University. It is hoped that the results of the study will be published after the research is completed. Findings from the study may be presented at healthcare conferences, and may be used for teaching purposes.

You will not be identifiable in any way in these results.

You will be welcome to copies of any publications related to this study. Please let me know if this is the case.

Who is organising and funding the research?

This study is being funded with monies that were obtained specifically by … Hospice to carry out this research. The researcher is also being supported by the University of Stirling.

Who has reviewed the study?

This study has been reviewed and approved by … Ethics of Research Committee.

Research Monitoring

It is important that research is carried out in the best possible way, protecting your rights and safety. To check that this happens the Health Board may ask someone who is not involved with this study, but has research experience, to look at the data to ensure the research is of high quality.

Thank you for reading this. If you have any queries, or would like clarification on any of the above information, please do not hesitate to contact me. (My contact details are given on the first page of this information sheet.) Alternatively ask any member of the hospice staff to contact me.

Hazel Hill,

Research Nurse Practitioner

Appendix 5: Patient consent form

[on headed paper]

Hazel Hill
Researcher
Tel:
E-mail: hazel@

<table>
<tr><td></td><td>**Exploring Psychological and Social Nursing in a Hospice Ward**</td></tr>
</table>

Please initial box

I confirm that I have read and understand the information sheet dated for the above study and have had the opportunity to ask questions.

I confirm that my participation is voluntary, and that I am free to withdraw at any time, without giving any reason. This will not affect my care or legal rights.

I agree to the researcher being a participant in providing my care in order to observe it.

I agree that any words I say during interviews can be used, anonymously, in the presentation of this research.

I agree to interviews being tape-recorded

I agree to the researcher looking at the notes the nurses make concerning my care.

I agree to take part in the above study

I understand that any of the information recorded about me as part of this research study may be looked at by members of staff from … NHS Trust Board as part of the routine monitoring of research priorities. I give permission for these individuals to have access to my data.

_____   _____   _____
Name   Date   Signature

_____   _____   _____
Researcher   Date   Signature

All material (written notes, tapes, etc.) will be kept strictly confidential, and securely locked away, in a filing cabinet in my lockable office, when not in use. Once the study has been written up all material will be locked in a box and stored in the locked room where all hospice documentation is stored. After 5 years this box will be destroyed.

Appendix 6: Nurses information sheet

[on headed paper]

Hazel Hill

Research Nurse Practitioner

ext

E-mail: hazel@

<div style="border:1px solid black;">

Exploring Psychological and Social Nursing in a Hospice Ward

</div>

You are being invited to take part in a research study, which is taking place in the ward in … Hospice. Before you decide whether you wish to take part, it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information. Please ask me if there is anything that is not clear to you or if you would like more information. Take time to decide whether, or not, you wish to take part.

Thank you for reading this.

What is the purpose of this study?

Palliative care aims to look after the physical, psychological, social, and spiritual needs of patients. The evidence base on palliative care is imbalanced. The evidence into physical, spiritual and organisational aspects of palliative care is reasonably extensive. However, there is little evidence identifying what effective psychological and social care is.

Research into the psychosocial needs of patients has shown that patients prefer the psychosocial climate of hospices to that of hospitals. Statements have also been made that:

"the adoption of the principles of palliative care in all aspects of health care would greatly improve satisfaction with health care provision".

However, it is not clear what the "psychosocial climate of hospices" is, how it is produced and maintained, or whether hospices truly meet the psychosocial needs of patients. This research hopes to begin finding the answers to these questions.

The few studies that have looked at whether psychosocial care is provided for patients with palliative care needs found that nurses find it difficult to recognise when they are proving psychosocial care. This lack of recognition exacerbates the difficulties nurses have describing

how they provide psychosocial care. For these reasons I have taken an observational approach to this research.

The study will take place in the ward at … hospice over the next year.

Why have I been invited to participate in this study?

All nurses contracted by … Hospice to work in the ward are being asked if they are willing to participate in the study. All ward patients who are able to discuss their care are also being asked if they are willing to be involved in this study.

Do I have to participate?

It is up to you to decide whether, or not to take part. If you do decide to take part please sign the enclosed consent form and return it, sealed in the enclosed envelope, either by post or into the 'post-box' in the duty room in the ward. Please keep this information sheet; I will also give you a copy of the consent form to keep.

If you decide to take part you are free to change your mind and withdraw at any time, without giving a reason.

What will happen if I take part?

I hope to work with as many nurses on the ward as possible. Each time I am on the ward I will select a nurse, who has consented to participate in the study, to work with. If it is you I will work alongside you providing care for the patients you are working with on that shift.

If during an episode of care I notice a psychological or social need has arisen, then I will remember this and carry on finishing that episode of care. After that care episode has finished I will withdraw from the ward to write notes describing what was observed.

Once the incident has been written up I will show the notes to you for comment and ask you to take part in an informal interview. The interview will take between 15 minutes and half an hour, and will be about what happened during the episode of care. The interviews will be tape-recorded. The interview will then be typed out in full. You will be welcome to read the typed copy of the interview and make comments. This will make sure that your views have been recorded accurately.

The patient will also be interviewed, as will any other nurse involved in the care that has consented to participate in the study.

I will also look at nursing notes, and communications concerning the episode of care i.e. nursing handovers and the multi-disciplinary team meetings.

What are the possible benefits of taking part?

Carrying out this research will help to ensure that patients' psychosocial needs are cared for in the most effective ways possible. Reflecting on care episodes may allow you to consider additional, or alternative, ways of caring for your patients' current needs. It is hoped that talking about the psychosocial care you provide will help you find ways of recognising your skills and learning needs. Recognising your skills will enable you to support your colleagues and allow you to describe more clearly how you provide psychosocial care. This will enhance

psychosocial care throughout the hospice, as you will be able to share your skills with colleagues, new members of staff, and visitors.   Any learning needs you identify can be incorporated into your personal development plan.

What are the possible disadvantages of taking part?

You may find it disheartening to learn that you have learning needs around providing psychosocial care. I will not be reporting these needs to anyone; I will try to help you to identify ways of meeting these needs.

Will my taking part in this study be kept confidential?

All material (written notes, tapes, etc.) will be kept strictly confidential, and securely locked away, in a filing cabinet in my lockable office, when not in use. Any information about you will have your name and identifiable details removed so that you cannot be recognised. With your agreement, quotations from the interview may be used in the final report of this study. Information about you will be stored under a different name; quotations will be shown using the made-up name. Care will be taken that you cannot be identified in any way.

Once the study has been written up all material will be locked in a box, which only I can access, and stored with the medical records. After 5 years this box will be destroyed.

All personnel in the hospice know that this research is taking place and that you have been asked to participate in it. They will not know if you decline to participate.

What will happen to the results of the research study?

This study will be written up for submission for a Masters degree at Stirling University. It is hoped that the results of the study will be published after the research is completed. Findings from the study may be presented at healthcare conferences, and may be used for teaching purposes.

You will not be identifiable in any way in these results.

You will be welcome to copies of any publications related to this study. Please let me know if this is the case.

Who is organising and funding the research?

This study is being funded with monies that were obtained specifically by … Hospice to carry out this research.   I am also being supported by the University of Stirling.

Who has reviewed the study?

This study has been reviewed and approved by the … Ethics of Research Committee.

Research Monitoring

It is important that research is carried out in the best possible way, protecting your rights and safety. To check that this happens the Health Board may ask someone who is not involved with this study, but has research experience, to look at the data to ensure the research is of high quality.

Thank you for reading this. If you have any queries, or would like clarification on any of the above information, please do not hesitate to contact me. (My contact details are given on the first page of this information sheet.)

Hazel Hill,

Research Nurse Practitioner.

Appendix 7: Nurses' consent form

> **Exploring Psychological
> and Social Nursing in a
> Hospice Ward**

[on headed paper]

Hazel Hill
Research Nurse Practitioner
ext
E-mail: hazel@

Please initial box

I confirm that I have read, and understand, the information sheet for the above study, and have had the opportunity to ask questions about it.

I confirm that my participation is voluntary, and that I am free to withdraw at any time, without giving any reason. This will not affect my rights.

I agree to the researcher participating in the care I provide, in order to observe it.

I agree that any words I say during interviews can be used, anonymously, in the presentation of this research.

I agree to the interviews being tape-recorded.

I agree to the researcher looking at my documentation of nursing care.

I agree to take part in the above study.

I understand that any of the information recorded about me as part of this research study may be looked at by members of staff from … NHS Trust
Board as part of the routine monitoring of research priorities. I give permission for these individuals to have access to my data.

Name	Date	Signature

Researcher	Date	Signature

Please return this form, sealed in the enclosed envelope, either by post or by placing it in the 'post-box' in the duty room in the ward.
All material (written notes, tapes, etc.) will be kept strictly confidential, and securely locked away, in a filing cabinet in my lockable office, when not in use. Once the study has been written up all material will be locked in a box and stored in the locked room where all hospice documentation is stored. After 5 years this box will be destroyed.

Appendix 8a: Excerpt of NVivo coding of one case

Description & My Thoughts

Working with patient who is having problems with bowels. "It's all this food that's doing it. I think I should just stop eating." The nurse responded with "no, you shouldn't stop eating.", in such a way that she conveyed caring and concern (by the tone of her voice and the pace with which she said it), and appeared to be suggesting that although she could see there was reasoning behind him feeling this would help him, she could see other reasons why it was important for him to keep eating. *Was there reasons behind her not saying more than this, and if so what were they? Value or hindrance of giving information; letting him come up with the solution; didn't know what to say; couldn't be bothered.* **Nurses aware of things and expecting patients to be on the same wavelength, but they aren't so the implications get missed.** He repeated his thought about not wanting to eat and she replied again in the same way. This conversation then stopped.

Later on in the care episode the physio was also working with us, and the patient again said about stopping eating (I can't remember if he or the physio instigated this conversation as she was exploring whether his swallowing was affecting his chest). The physio responded by saying "what would be better for you would be to have smaller meals more often and too take smaller mouthfuls". The patient didn't comment about that idea. *How did he feel about this advice? Does he think Camille could/should've given him this advice?*

Even later in the episode of care the neurological clinical nurse specialist came in with the physio (at this point the patient was lying naked, covered only in a sheet, and was half shaven). They both stood at the other side of the bed from me and the nurse stood in the background. I can't remember for definite, but I think the nurse had stepped back from the bed as they came in. I took one step back but still stayed reasonably near the patient. The CNS asked some poignant questions which lead up to talking about going home, the patient said "but that's in the future and I'm not ready to talk about that yet", he'd previously mentioned "when I'm up walking". *At this point there were 'knowing' looks between the physio, CNS and myself – is this patient in denial, or does he know the full extent of his disease and just doesn't want to discuss it.* <u>After interview – Or is he just focussing on the here and now I wouldn't have thought this before the interview.</u> *– How did Camille & patient feel about this interaction? What are the patient's thoughts about whether Camille should have been involved in this interaction? Camille was excluded, maybe partly by my presence, but even if I hadn't been the one standing by the bed would she have been more involved? I feel she would still have been excluded and this should really be a key part of her supporting the patient.*

During the care Camille was called away to hand-over about the patients to the doctors. *How does this affect care? How does Camille & patient feel about this?*

Later in the morning the patient's wife and son met with the doctor, consultant, physio and CNS. I wasn't sure whether the patient knew about this meeting or whether ward nursing staff had been asked to attend. *It's unethical not too tell him (as the patient pointed out to me about information in general after the interview) and he should've been included in this meeting, or at least asked if wanted to. How does Camille feel about this?*

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Appendix 8b: An example of an Nvivo memo comparing concepts between cases

09.12.05

NVivo revision 2.0.161   Licensee: Hazel Hill

Project: PhD   User: Administrator   Date: 06/12/2005 - 12:18:22

DOCUMENT TEXT REPORT

Document: information - Memo   — *Maybe telling, associate info of/for p*
Created: 28/11/2005 - 15:12:50   *— Knowledge Lyn*
Modified: 01/12/2005 - 11:16:06
Document Text:

[1]
16/11/05 - 16:00:52
Millie initially suggests nurses, or at least she herself, need **information** about a patient to be able to carry out psychosocial care, feeling it is better "not to say anything" than get it "wrong", and uses a lack of this as an excuse not to provide it. However Millie then shows this not to be the case when talking about the other patient (2.9.21-24).

Assumptions can be made about the amount of information patients have or need, by nurses and families [2].

18/11/05 - 09:44:48
Patients do not have an expectation of nurses to have all information they need [3], but nurses should be able to identify information needs and offer a source to meet these.

01/12/05 - 10:29:51
Information is gained from documentation and liaison [4], but can also be gained directly from the person with whom the communication is taking place, if correct communication is used, gaining information from the latter source minimises assumptions.

Patients will ask for the information they desire, if they are given the opportunity and the time is right (my thoughts from what was said in C2 (7.9-14).

However, Jimmy has many information needs that the nurses are not meeting, he hints about his queries about how much food to eat, but these hints are not dealt with according to Jimmy's desire and he makes no attempt to further elaborate on them; whereas Ralph feels his, and his wife's, information needs have been well met by the hospice staff (as were Sam's, despite me witnessing an opportunity for this being blocked), much more so than in hospitals, and relates this to 'sitting down with the staff and talking to them'.

Jimmy knows that different professionals have different ideas, views, information about subjects, but feels they should come to agreement about how these relate to him and come to him with the consensus view, instead of giving the different views to him.

Information needs of patients vary, both between patients and over time, there is little evidence of nurses assessing this and even when they are told of a patient's information needs this is ignored and not made explicit in either liaison or documentation.

Assumptions can be made about the amount of information patients have or need, and that the information given has been understood and taken on board, by nurses and families [5].

Information giving should be an inherent component of care rather than a planned, arranged progress report; this reassures a patient and gives them confidence.

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Nurses decide what they feel a patient's information need should be rather than finding out what each individual patient wants 🔵 [6].

Nurses are aware of the value of information giving, but do not always do this, they do for a patient instead, in times of trauma the latter is appreciated 📄 [7].

A challenge exists between information giving and maintaining privacy for patients in a Bay - psychosocial needs can clash, how is it decided which takes priority?

[1]	Node:	/I~E Continuum/information
[2]	Node:	/I~E Continuum/Assumptions
[3]	Document:	Interaction3
[4]	Node:	/Organisational/Liaison
	Node:	/Organisational/Documentation
[5]	Node:	/I~E Continuum/Assumptions
[6]	Node:	/Control/prioritising
[7]	Document:	Interaction8

① Nurses do not need to of pt to provide Ψ/soc support (ensure)

④ Pt → Info x in/o need

⑤ N-pt com^n ↓ assumptions (see ⑥ 1:2)

⑥ Time → Pt Req for info

⑦ If Team agree^t then pt trust

⑧ If Info/needs not document^d / liaised psychosocial support ↓

⑨ If Info giving integral then pt trust

⑩ choice of info need not given

⑪ {Informing → trust ← doing} ∴ situational
   { trauma then just doing → trust }

⑫ In Bay ↑ info ↓ privacy (dilemma of privacy)

Appendix 8c: NVivo diagrammatic representation of the concepts that emerged in the study
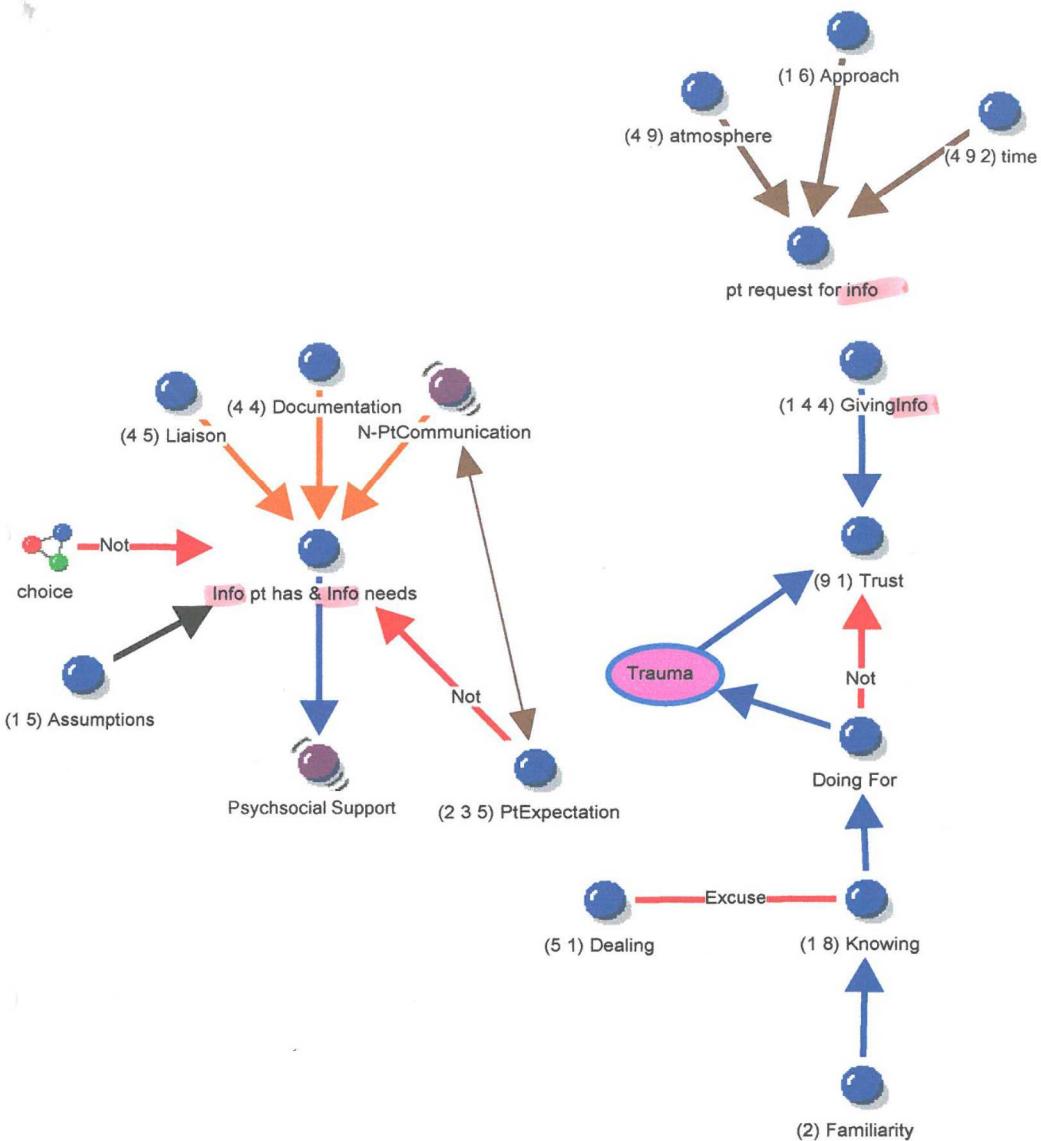
Appendix 9: Hill et al. (2014)

Abstract

Background: There is a popular belief that the professional-patient relationship is a prerequisite in the provision of psychosocial support. Studies suggest that professionals must know, or be familiar with, a patient in order to effectively provide psychosocial support.

Aim: To examine the association between familiarity and the provision of psychosocial care by professionals.

Design: A mixed method study involving participant observation, interviews, organisational, and documentary analysis was conducted over eight months in an inpatient hospice setting.

Participants: 38 nurses (registered and auxiliary) and 47 patients were included in a maximum variation sampling strategy. Data was analysed using both qualitative and quantitative techniques.

Results: The data disconfirms the belief that familiarity is either a necessary or sufficient condition for the provision of psychosocial support. Nurses familiar with patients did not necessarily respond to patients' psychosocial needs, and nurses with no prior contact with the patient immediately dealt with psychosocial needs.

Conclusion: Psychosocial support can be provided on a patient's first contact with a clinician and does not rely on building a professional-patient relationship. This suggests that high quality psychosocial care can be provided in the short timeframe available to palliative care clinicians.

Key words

Introduction

There is a global agreement that psychosocial care is a major focus of palliative care .[1-4.] It encompasses a wide range of highly specific clinical interventions, from treatments addressing diagnosed conditions (such as depression and anxiety) to the provision of routine support.[5-9] Psychosocial support should be provided on a daily basis and address a range of needs,[10-13] including quality of life, emotional wellbeing, safety, and a sense of hope.

The question is: what conditions are required for doing this? One popular view is that professional-patient relationships are prerequisites for the provision of psychosocial support.[14-22] But is this true? Studies referring to the importance of relationships are largely based on self-

report.[18-19,23-24] Very little research has tried to determine whether professional-patient relationships really are a condition of psychosocial care.

This study explored the provision of psychosocial support by nurses in a hospice, with the aim of determining whether being familiar with a patient is a necessary or a sufficient condition for the provision of psychosocial support in palliative care.

Methods

Observational research has provided important insights into palliative [22,24-28] and into nursing practice.[29-32] A mixed methods [33-36] study, largely based on participant observation (PO), supported by interviews, nursing documentation, participant demographics, and information on nurse-patient allocation, was conducted from September 2004 until May 2005, in a Scottish inpatient hospice.

Participant observation was carried out by an experienced, registered palliative care nurse (working as a supernumerary member of the team), who became familiar with ward practices prior to data collection in order to minimise researcher impact and allow unobtrusive observational data collection.[37-41] According to Gold's [42] classic taxonomy, the researcher adopted the role of participant-as-observer.

Using a mixed methods approach, where qualitative and quantitative data were collected using a concurrent-identical sampling design[34,] allowed a more robust exploration of psychosocial support. Strong conceptual consistency[34] was gained by using quantitative data and analyses to objectively define and strengthen qualitative findings.

Ethics

Ethical approval was given by the Local Research Ethics Committee (04/S0604/14), and the Research & Development Office. Data presented in this paper are anonymised, and pseudonyms applied, to preserve confidentiality.

Nurse participants knew the researcher prior to the study as a member of the hospice's education team, and were involved in discussions around the design of the study. Information sheets were distributed to all registered and auxiliary nurses working on the ward and 38 (88%) completed written consent forms.

The researcher discussed the study with all patients. Patients who were cognitively intact, and not considered to be in the last few days of life, were given information sheets outlining the research, encouraged to discuss these with their significant others and given a minimum of 24 hours to consider whether to participate. 47 patients (67.5% of those eligible) gave written consent.

Verbal verification of continued consent was sought at each phase of the study. The researcher wore a different uniform from other ward staff as a reminder of her PO role. In line with her nursing [43] code of practice, if a patient required assistance of a nurse, the researcher provided this if no other nurse was available: patients consistently received the same care as any other nurse on the ward would provide. Patients were informed if an interaction was recorded for research purposes, and given the opportunity to withdraw consent; this offer was never accepted.

Sampling and Data collection

Nurses were observed at various times throughout their day duty on the ward. Observations of nurses with different roles, caring for patients with different characteristics, occurred at different times (see table 1). Observed incidents constituted a large convenience sample, but with a high degree of variety.[37-38,41]

Nurses were selected from the duty rota. The selection of a nurse was determined by their availability for interview, in order to minimise recall bias. The researcher assisted the nurse with patient care. If a consenting patient expressed a psychosocial need, as defined by Thomas *et al*,[10] they became part of the study sample.

Table 1: Participant Characteristics

Patient Characteristics (n=47):		Nurse Characteristics (*n=38*):	
Age	Range: 38-91 years Mean: 65.1 years	Age	Range: 22-59 years Mean: 44.47 years
Sex	Male: 19 (40.4%) Female: 28 (59.6%)	Sex	Male: 0 (0%) Female: 38 (100%)
Average days spent in hospice at time of observation	Range: 1-221 days Mean: 31.7 days	Role	RGN: 23 (60.5%) Auxiliary Nurse: 15 (39.5%)
Care aim	Assessment: 5 (10.6%) Rehabilitation: 2 (4.3%) Respite: 9 (19.1%) Symptom Control: 20 (42.6%) Terminal Care: 11 (23.4%)	Education in psychosocial care	None: 5 (13.2%) Study day: 5 (13.2%) Short course: 11 (28.9%) Module: 17 (44.7%)
Diagnosis	Cancer: 39 (83%) Neurological: 8 (17%)	Years of palliative care experience	Range: 0.5-19 years Mean: 8.7

At each appropriate opportunity, observations were recorded digitally, and immediately following completion of these episodes of care the researcher withdrew from the ward to transcribe the data. Subsequent semi-structured interviews of patients and nurses were based

on the corresponding observations, and incorporated issues arising from ongoing data analysis.[44-47]

Patients were invited to describe their experience of the nurse's response, while nurses were asked to describe their understanding of what happened, and explain any constraints and influencing factors. Documentation and meetings data illustrated nurses' perceptions of the support provided. Demographics and organisational records permitted the exploration of possibly associated variables.

Data collection stopped once the data and analyses produced rigorous findings.

Analysis

The following expressions are used as technical terms:

- 'Episode of care' – a clinically defined period of time when a consenting nurse worked with a consenting patient to provide a specific aspect of care.
- 'Case' – all data relevant to one episode of care: observation notes, interview transcripts, copies of clinical documents, records of meetings.
- 'Encounter' – one nurse's response to one psychosocial need expressed by one patient. Typically, there would be several encounters in each episode.

Descriptive analysis [47] was used from the beginning of data collection, with each case being entered into an NVivo electronic qualitative analysis software project. Cases were analysed to identify key concepts which were compared to generate propositions. For example, whether familiarity was a necessary condition for the provision of psychosocial support was explored by determining how the nurse responded to the patient's psychosocial need (dependent variable, 'response') and whether the nurse was familiar with the patient concerned (independent variable, 'familiarity'). 'Familiarity' was defined as whether the nurse had worked with the patient before.

Following the completion of data collection, variables were entered into an SPSS project and Chi^2 tested in order to determine whether variables, such as the nurses' experience or working hours, had an association with 'response' and to allow statistical verification of the qualitative findings, for example comparing familiarity to response.

Findings

Patients expressed psychosocial needs in 25 of the observed episodes of care (which lasted on average 90 minutes); 227 encounters were identified. Nurses were identified as immediately responding in one of four ways: attempting to deal with the need at the time ('dealing'); postponing dealing with the need ('deferring'); responding to another need ('diverting'); or failing to acknowledge a need had been expressed ('ducking'). For the purposes of this paper, the dependent variable 'response' was treated as dichotomous, its values being 'dealing' and 'not dealing'. 104 (45.8%) of the encounters were classified as 'dealing'; the remaining 123 were classified as 'not dealing'.

Consistent with the literature, 37 of the 38 participating nurses claimed that their response to a patient's psychosocial needs was contingent on whether they were familiar with the patient. Familiarity was reported as facilitating psychosocial support, its absence as hindering.

However, the data showed that familiarity was neither a necessary nor a sufficient condition of a 'dealing' response. Responses to the 206 encounters in which level of familiarity (determined from the duty rota and daily patient allocation sheet) was known are shown in table 2 (χ^2=0.001, df=1, p=0.982). The likelihood of 'dealing' appears the same whether the nurses were familiar with the patients or not.

Table 2: Cross-tabulation of Dealing, or not, against Familiarity

Had the nurse worked with the patient before?	Dealt with the need at the time	Did not deal with the need at that time	total
Yes	76	82	158
No	23	25	48
total	99	107	206

The 'familiar' nurses dealt with the need 48% of the time (95% confidence interval: 40–56), and this figure (48%) was exactly the same for the 'unfamiliar' nurses (95% confidence interval: 33–63). The relative risk of dealing with the patient's need, conditional on familiarity, is therefore 1.007 (95% confidence interval: 0.528–1.923).

The analysis is complicated by the fact that several encounters comprised identical nurse/patient pairs, with nurses participating in a median of 5 encounters (range:

1–17) and patients in a median of 3 (range: 1–15). The analysis was repeated with a separate SPSS file containing only one randomly selected example of each nurse/patient pairing. Similar results to those in Table 2 were obtained ($\chi2$ = 0.022, df = 1, p = 0.881), confirming the lack of association between familiarity and the 'dealing' response.

Importance of familiarity

Nurses accounted for the 'dealing' response by claiming that it was possible, or easier, if they already knew, or had a relationship with, the patient.

"I find it really difficult talking about these issues [dying], but it's easier now because I know him." Alexa (registered nurse)

"If you've washed them a couple of times you tend to know. Looking at their eyes, you know they're wanting to speak." Celia (auxiliary nurse)

Equally, nurses explained that it was difficult, or impossible, to deal with patients' psychosocial needs (PPNs) if they were not familiar with them:

"Normally … I'm just trying to build up a rapport, initially, with that individual patient, because sometimes if it's someone you haven't worked with before they're very reluctant to go into anything in-depth because they don't know you as well." Evie (registered nurse)

> "Flora [a patient] was quite blasé about it [her first attempt at discussing her hastening death] and I wasn't sure if she was a bit tongue in check, although I'm sure there was a lot in it … but again that's when you don't know if that's their personality. Whereas, when you get to know them you know, maybe, that some of them will joke about dying … although they are serious, they are laughing about it …" Millie (registered nurse)

Although this was the account offered by nurses during interviews, the observational data did not confirm it. Familiarity was not a sufficient condition of 'dealing'.

For example, even when the nurse was familiar with a patient, she might still *fail* to deal with the PPNs. One patient, Stuart, had only recently been diagnosed with his condition. He was struggling to come to terms with his illness, and had made it clear that one of his coping mechanisms was not to discuss his illness. Camille, a registered nurse, had looked after Stuart on many occasions before I observed them together. She felt she knew Stuart well and was aware of his wishes:

> "Doctors had spoken to his family yesterday … but they said they're "not discussing it [his condition], because Stuart doesn't want to discuss it".' Camille (registered nurse)

However, while we were washing Stuart, two other members of staff – who were not ward nurses but had been asked to assess Stuart's understanding of his illness – came into the room:

> Halfway through bed-bathing Stuart, two other members of staff came into the room. As they came in, Camille stepped back from the bed into the corner of the room; she stayed there throughout their conversation. One of them asked some poignant questions about how much Stuart knew about his illness and tried to talk about what might happen to him. Stuart said: "But that's in the future and I'm not ready to talk about that yet." At which point the staff member looked across at Camille [as if to offer her the chance to participate in the conversation]. Camille said and did nothing. (Observation notes).

If the claim that familiarity prompts nurses to deal with PPNs, then Camille's familiarity with Stuart should have encouraged her to advocate for him by informing the other staff members that Stuart had expressed the wish not to discuss his illness. Instead, she 'ducked'.

Familiarity as a barrier to psychosocial support

It would appear, then, that familiarity does not guarantee that nurses deal with PPNs. It does not appear to be a *sufficient condition* of the 'dealing' response. Indeed, familiarity can actually inhibit the 'dealing' response.

Being overly familiar with patient preferences can be instrumental in a nurse 'blocking' PPNs. When nurses know a patient well, they learn how the patient prefers to do things, which can result in nurses doing things for patients without asking them. This *can* be helpful, but the nurses' assumptions can hinder psychosocial support.

This happened when Beatrice, a registered nurse, was helping Ralph out of bed. Ralph had been admitted for assessment of his mobility because his condition had deteriorated. Because this was Ralph's fifth admission to the ward, the nurses were familiar with how he normally

transferred from bed to wheelchair. However, it was unknown whether he would be able to transfer in his usual way, and assessing this was important:

> Beatrice asked Ralph how he "liked to do things". As she was asking, she lifted up the banana board [a mobility aid] towards him and he said, "Oh, here we go again! People always do this before I tell them." His condition has changed since his previous admission. His deterioration in mobility is one of the main reasons for admission, and a main aim of his care is to assess, and, if possible, rehabilitate this. Ralph guided us in how he wanted to move, and managed with no more assistance than on his previous admission. Once he was up in the wheelchair he asked for his foot-rests. Beatrice tried to put these on for him. I could see Ralph was not only trying to do this himself, but that it would be easier that he did this and Beatrice lifted his legs, as he was requesting. (Observation notes)

Beatrice's familiarity with Ralph resulted in her automatic insertion of the banana board and wheelchair foot-rests. On previous occasions this would have made Ralph's transfer faster. However, on this occasion, it prevented Ralph from discovering whether he could transfer independently:

> "I wanted to ask you about when Beatrice was getting you up the other day and I was wondering about … how we work with patients' independence." Hazel

> "One of the reasons for my admission was to find out how independent I am still, because of the changes in my balance, and … obviously there's been a deterioration in my condition. So, one of the reasons for the admission this time was … for assessment … to find my balance, to know where the limits are … and what I can and can't do." Ralph

Beatrice did not meet Ralph's psychosocial need for independence and for an understanding of his changing condition. Familiarity can lead the nurse to make unwarranted assumptions, failing to recognise the patient's changing needs, thereby blocking rather than facilitating psychosocial support.

Psychosocial support without familiarity

In contrast, nurses might have *no* familiarity with a patient, but still deal immediately with psychosocial needs. Consequently, familiarity is not a *necessary condition* of the 'dealing' response.

This was most strongly evidenced when nurses had no knowledge of the patient. They were often observed dealing with PPNs when working with a patient for the first time, having received little information about that patient.

For example, after receiving only cursory information at handover, Chrissie, a registered nurse, explained her desire to work with Helen:

> "I spent a lot of time with Helen yesterday [while admitting her to the ward; Helen's first contact with the Hospice] discussing her difficulties with her families, how difficult it was to cope with her increasing dependence, and her fears of dying. I want to see if she wishes to continue discussing these today." Chrissie

Helen had told Chrissie: 'it was so good to be able to share things that she had been keeping closed in for a long time.' Chrissie said more about this conversation during her interview:

> "I never asked her any questions about her admission; it was really all about the reasons why she came in, her anxieties, and her fears for other peoples' futures. It's almost as if she's been ready to talk. I think it would have happened anyway, but yesterday she was talking [about] her son, and things like that, I actually can really empathise with her and I was actually able to share that with her. You could see her opening up and becoming so comfortable with telling me that." Chrissie

Helen's openness with Chrissie could not have been due to familiarity, as her concerns were being voiced for the first time, and Chrissie and Helen had never met before. This suggests that nurses can enable patients to express psychosocial needs in the absence of familiarity, and that these needs can be immediately dealt with.

The question arises as to what nurses do to facilitate this openness.

In the encounters in which the nurse had no previous contact with the patient, but dealt with the PPNs nevertheless, inter-personal skills were used to encourage the patient to express their needs openly. Sybil, an auxiliary nurse, did this by asking patients about themselves:

> "They'll tell you about the characters in their family, they'll give you a wee smile ... there's something funny about that, or maybe a quirk about that person. I think it helps me as a nurse to get to know the patient. It puts you at your ease with the person, and if you're comfortable, it makes it more comfortable for the patient, I think. If you feel awkward with them, well, they're not going to feel comfortable with you." Sybil

Sybil had stated that she 'needed to be familiar with a patient in order to provide psychosocial support'; however, she was observed dealing with PPNs, regardless of whether she had worked with the patient concerned before. What Sybil did, on her first contact with patients, was ask them about themselves and their lives, thereby forming an interpersonal connection.

Similarly, it was suggested by some nurses that they could feel familiar enough with the patient to provide psychosocial support from information gained from colleagues or documentation.

> "When I know that people have had significant conversations with other people, that I'm maybe not the first person to explore something quite sad or upsetting with them ... I've heard that's the way they cope, and that's their way of communicating. I feel comfortable then to go in; it's less risky for me." Annie (registered nurse)

In this statement, Annie suggests that, because she has heard from colleagues that patients are willing to discuss emotionally painful issues, she is more likely to respond to their psychosocial needs.

The impact of nurses' attributes on their immediate response to psychosocial needs

It is tempting to assume that nurses' individual attributes enable them to provide immediate psychosocial support, that an immediate 'dealing' response is mediated by experience, education, or something of that sort. However, this was not found to be the case.

Statistical analyses suggest that variations in nurses' responses were rarely associated with individual characteristics. For example, neither palliative care experience (table 3, χ^2=2.079, df=3, p=0.556), nurses' education (table 4, χ^2=5.312, df=3, p=0.15), nor whether the nurse was working in the team to which she is normally allocated (table 4, χ^2=5.482, df=3, p=0.14), appeared to have any association with whether psychosocial needs were immediately dealt with or not.

Table 3: Cross-tabulation of dealing, or not, against total palliative care experience

	Total Palliative Care Experience (years)					Total
Combination of responses to dealing or not	<4	4-7	7-10	10-17	17-19	
Not dealing	16	21	26	21	18	102
Dealing	22	13	19	20	16	90
Total	38	34	45	41	34	192

Table 4: Dealing or not dealing: Encounters by extent of psychosocial education and whether the nurse was working in their "own" team

Combination of responses to dealing or not	Extent of Psychosocial Education					Nurses' Role Within Team				
	None	Study Day	Short Course	Module	Total	Bank	Other Team	Own Team	In Charge	Total
Not dealing	4	7	22	70	103	13	3	49	55	120
Dealing	9	7	28	51	95	5	3	56	39	103
Total	13	14	50	121	198	18	6	105	94	223

Some individual factors did appear to affect the nurse's response to PPNs. One was the number of shifts worked per week (table 5, χ^2=11.568, df=1, p=0.001). Nurses working a larger number of shifts were more likely to 'deal'. Another was the nurses' qualification (table 6, χ^2=6.069, df=1, p=0.014). Surprisingly, perhaps, auxiliary nurses were more likely to 'deal' than registered nurses.

Table 5: Cross-tabulation of dealing, or not, against shifts contracted to work per week

Combination of responses to dealing or not	Shifts Contracted to Work per Week		
	3 or less	3.5 - 5	Total
Not dealing	78	42	120
Dealing	44	60	104
Total	122	102	224

Table 6: Cross-tabulation of dealing, or not, against the role of the nurse

Combination of responses to dealing or not	Role of Nurse		
	RGN	Auxiliary	Total
Not dealing	96	24	120
Dealing	68	36	104
Total	164	60	224

Discussion

These data challenge the suggestion that familiarity with patients is either a necessary or sufficient condition for providing psychosocial support. Nurses *dealt* with the psychosocial needs of patients with whom they were *not* familiar, and *failed to deal* with the needs of patients with whom they *were* familiar. Nevertheless, the nurses continued to cite familiarity (or lack of it) as the reason for their response. Arguably, the idea that 'familiarity' is a basis for the provision of psychosocial support is a myth. The rhetoric about the importance of building a relationship with a patient [14-22] in order to provide psychosocial support could be abandoned. Psychosocial support has been observed to be an integral component of clinical care in areas where relationship building and attaining familiarity are not possible,[29] and additional observational research has shown that relationships are not central to the provision of nursing care.[16]

Previous studies [14-15,19-21] suggest that clinicians use interpersonal skills, such as making themselves available to patients and communicating openly about patient's priorities, to create familiarity and build professional-patient relationships. In this study, nurses reported using interpersonal skills to acquire familiarity; however, the observational data shows that the relationship-building stage can be bypassed. Being attentive to patients when psychosocial needs are expressed enables provision of immediate psychosocial support.[7,14]

Despite general agreement that psychosocial support should be an intrinsic component of the care offered by all practitioners [12], there is little empirical research into how this happens. Using observational data permitted an analysis of how nurses actually respond to PPNs, providing a

more reliable and robust alternative to understanding the provision of psychosocial support than the more common strategy of eliciting of individuals' perceptions.[16]

Limitations

Participant observation by one researcher points to a significant limitation of this study. It was only possible to accurately record nurses' *immediate* responses to PPNs. It is unknown whether needs not dealt with were followed up later. It was impractical to observe night shifts as it would have been difficult to complete interviews at a suitable time following the episode of care.

Researcher bias is a particularly high risk in observational studies. However, various steps were taken to minimise this risk, including: combining qualitative and quantitative data to substantiate the findings; using interviews to verify what had been observed; spending time working as a nurse on the ward during the 10 month preparatory period; and sharing observational data with participants.

This is a study of one hospice, and the findings are therefore not generalisable to other specialist palliative care institutions (or to healthcare in general). Indeed, they are not definitive, even in the context of this one hospice, since the sample is relatively small, and the confidence intervals associated with Table 2 are quite wide. However, while the data do not establish the claim that familiarity is neither a necessary nor a sufficient condition for psychosocial support, they are certainly consistent with it, and this consistency suggests that further exploration of the relationship, if any, between familiarity and psychosocial support would be worthwhile.

Implications

The study gives an insight into the reality of how psychosocial support is put into practice – a reality which is at odds with what has previously been self-reported by both providers and recipients of care – and has identified factors which are associated with the provision of psychosocial support. It suggests that health practitioners should be suspicious of the claim that they need to develop a relationship with clients in order to provide psychosocial support.

Moreover, the study demonstrates that practitioners' individual characteristics are not associated with their response to PPNs, and although there is a suggestion that the amount of time spent with a patient may be associated with response, analyses of the organisational findings (reported elsewhere) show this is not the case. Future studies could build on the data presented here by determining whether unmet needs are followed up subsequently, observing overnight care, and comparing different clinical areas. The awareness that familiarity does not necessarily facilitate psychosocial support could be used, in education and clinical supervision, to encourage practitioners in the belief that they can provide psychosocial support as and when the patient desires it.

Conclusion

The majority of nurses in this study believe that being familiar with a patient enables them to provide psychosocial support. However, it has been shown that psychosocial support can be provided on a patient's first contact with a clinician, and does not rely on building a relationship. The finding that 'familiarity' is not, in this sample, associated with the provision of psychosocial support – but other factors are – is a contribution to the building of this model, which can be used as a basis for future studies on psychosocial support. This paper

demonstrates that high quality psychosocial care can be provided, even in the short timeframe that is sometimes available to palliative care clinicians.

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Appendix 10: Hill et al. (2015)

Abstract

Background: Psychosocial support is considered a central component of nursing care but it remains unclear as to exactly how this is implemented in practice. The aim of this study was to provide a descriptive exploration of how psychosocial needs (PNs) of patients in a hospice ward are expressed and met, in order to develop an understanding of the provision of psychosocial support in practice.

Methods: An embedded mixed-methods study was conducted in one hospice ward. Data collection included observations of patients' expressions of PNs and nurses' responses to those expressed PNs, shift hand-overs and multi-disciplinary meetings. Interviews about the observed care were conducted with the patients and nurses and nursing documentation pertaining to psychosocial care was collated. Descriptive statistical techniques were applied to quantitative data in order to explore and support the qualitative observational, interview and documentary data.

Results: During the 8-month period of observation, 227 encounters within 38 episodes of care were observed among 38 nurses and 47 patients. Within these encounters, 330 PNs were expressed. Nurses were observed immediately responding to expressed PNs in one of four ways: dealing (44.2%), deferring (14.8%), diverting (10.3%) and ducking (30.7%). However, it is rare that one type of PN was clearly expressed on its own: many were expressed at the same time and usually while the patient was interacting with the nurse for another reason, thus making the provision of psychosocial support challenging. The nurses' response patterns varied little according to type of need.

Conclusions: The provision of psychosocial support is very complex and PNs are not always easily recognised. This study has allowed an exploration of the actual PNs of patients in a hospice setting, the way in which they were expressed, and how nurses responded to them. The nurses faced the challenge of responding to PNs whilst carrying out the other duties of their shift, and the fact that nurses can provide psychosocial support as an inherent component of practice was verified. The data included in this paper, and the discussions around the observed care, provides nurses everywhere with an example against which to compare their own practice.

Keywords: Hospice nursing, Psychosocial, Observation, Palliative

Background

Psychosocial care is a component of all nurses' work [1, 2]. Palliative care, in particular, has psychosocial care as an essential focus [3-5]. Palliative care patients' psychosocial needs (PNs) have been identified in research studies in a number of ways. Some studies have identified PNs by enquiring directly about them [6, 7]. Other researchers have inferred the presence of PNs by discussing patients' and/or nurses' views about their experiences of care [8-10], with studies that assess satisfaction or quality of care assessment arguably also falling within the psychosocial sphere [11, 12].

A wide variety of PNs are reported in a variety of ways in existing literature, for this study these were categorised by the researchers into four groups: rights, coping, identity, and expression.

'Rights': Patients' need for self-determination, safety, and security. These include the wish to be self-determining [13, 14], through continued involvement in decision-making [8, 15] and autonomy, to the level patients desire [16, 17]. Alongside these are the rights to maintaining maximum quality of life [6, 18] and independence [9, 19], being treated with dignity [19, 20], given privacy [14, 21] and feeling safe and secure [22, 23].

'Coping': The need for patients to have understanding and acceptance of their condition and their approaching death, whilst maintaining hope. Palliative patients need to adjust and cope [6, 8] with many changes occurring as a consequence of deterioration in their condition which can be facilitated through understanding [24, 25] and acceptance [24, 26]. Coping includes PNs around fear for the future [27] and of death [28].

'Identity': The need for patients to have feelings of self-worth and to sustain relationships where possible. Patients seek to maintain an identity [17, 26] as an individual [8, 29] with a continuing role in life [24, 30] rather than assuming the persona of 'patient'. Sustaining relationships [22, 26] and creating companionships [31, 32], through another PN: communication [23, 33], assists patients to meet PNs surrounding having a positive self-concept [17, 34] and self-esteem [30, 35].

'Expression': The feelings palliative care patients have and how they express them [36-38], ranging from elation to despair and the desire for quality of life. These include anxiety and depression.

Despite numerous studies identifying the PNs expressed by palliative care patients, there is very little empirical evidence on how nurses actually provide psychosocial care in practice alongside their other duties in busy ward environments [19, 39, 40]. It may be that as psychosocial care is recognised as a fundamental aspect of palliative care for all practitioners [41-43], nurses leave this aspect of care to their colleagues from other disciplines. The aim of this study was to investigate the types of PNs expressed by patients in a palliative care setting and how nurses immediately responded to them; in other words how nurses operationalise the term psychosocial support.

Methods

This study used an embedded mixed-methods approach [44] to explore patients' expressions of PNs and nurses' responses to them in a hospice ward in Scotland, which serves both urban and rural populations. Participant observation was combined with qualitative interviews and analysis of nursing documentation, such as care records. The study site was a 24 bedded ward, with both single and shared rooms, in a specialist palliative care unit. Patients had active, progressive, non-curative diseases (90% had a malignancy; the majority of the remaining patients had a neurological illness). Patients

were admitted to the hospice with at least one of the following five care aims: symptom management, therapeutic respite, terminal care, assessment or rehabilitation. The researcher (Hazel), an experienced palliative care nurse, completed this study, whilst employed as a research nurse practitioner, in order to gain a PhD. Having previously known the researcher as an educator in palliative care, the nurses were aware of her background and contributed to discussions around the study's aims design. The researcher worked on the ward during the study design period to become an unobtrusive member of the ward team to minimise researcher impact [45], then adopted a participant-as-observer role [46]. A reflexive diary was kept throughout the duration of the study to identify and balance researcher bias.

Information sheets were distributed to all registered (RGN) and auxiliary (AuxN) nurses working day-duty on the ward and 38 (88%) gave written consent for their care to be observed. Twenty-three were RGNs, fifteen were AuxNs. The five nurses who did not offer to participate were all AuxNs. The researcher then introduced herself to all ward patients. Patients who were cognitively intact, and not thought to be in the last few days of life, were offered an information sheet outlining the research. After at least 24 hours, during which time patients were encouraged to discuss the study with their significant others, they were approached for written consent. 47 patients (67.5% of those eligible) provided consent, which was re-checked verbally throughout the duration of the study; 12 patients approached declined to participate. Participant characteristics are shown in Table 1.

On each shift, a nurse was selected to be observed, depending upon her availability over the subsequent days for interview. Sampling matrices were used to ensure greatest possible variety of nurse roles and times throughout ward day duty. Patient sampling occurred by chance by being the first consenting patient to express a PN to the observed nurse that shift. This approach resulted in a large convenience sample with a high degree of variety [45, 47].

Data Collection

Observation took place over an eight month period. The observational skills the researcher had developed during her nursing career were enhanced through extensive reading on observation as a research tool and discussions with her PhD supervisors. Wearing a different uniform to distinguish herself from the other nurses, the researcher worked alongside consenting nurses. If a consenting patient expressed a PN, as defined by Thomas et al (2001), data collection commenced. A description of the observed care was captured by digital audio-recording notes immediately after the observation. This was transcribed as soon after the interaction as possible and shared with participants to verify the account. Semi-structured interview schedules, for both patient and nurse, were then created around the PNs, the nurses' responses to them, and other emerging issues [48, 49]. Participants were only interviewed once. Nurse documentation and discussions around the observed PNs were also recorded, including shift handovers and multidisciplinary meetings.

Data collection ceased when a substantial sample size [50] produced clear, supportable claims.

Analysis

Data was analysed primarily by the researcher and verified independently by two experienced researchers. The first seven interactions formed a pilot study. Among the

consenting patients and nurses, an episode of care was defined as a discrete period of time during which a nurse worked with a patient to provide a specific aspect of care. Within these episodes of care, an encounter was defined as one nurse's response to one or more PNs expressed by a patient at one time. These were categorised into PNs relating to rights, identity, coping, and expression.

All qualitative data relating to encounters were entered into an NVivo electronic qualitative analysis software project and descriptive analysis [49] began during transcription of the first observation. This analysis identified key concepts which emerged from the data and were compared to each subsequent nurse-patient interaction to generate propositions.

During analysis a categorisation of nurse responses emerged, entitled the '4Ds'. Chi squared tests were carried out to determine whether type of PN (rights, identity, coping, and expression) was related to the nurses' responses ('dealing', 'deferring', 'ducking', or 'diverting').

Findings were verified with participants during subsequent data collection and discussed with nurse participants via presentations.

Ethical approval and consent

Ethical approval was given by Forth Valley Research Ethics Committee (04/S0604/14) and NHS Research and Development Office. Confidentiality was maintained by the use of pseudonyms and ensuring any potentially identifying details were removed from all data.

Results and Discussion

227 encounters within 38 episodes of care were observed among 38 nurses and 47 patients. Within these encounters, 330 PNs were expressed. All of the PNs outlined in the literature summarised above were expressed at some point during the fieldwork in the hospice. A maximum of eight were expressed during any one encounter.
Analysis of the observational data identified that nurses immediately responded to patients' PNs in one of four ways: 'dealing', 'deferring', 'ducking', or 'diverting'. Nurses could acknowledge the PNs and 'deal' with it directly in accordance with the patient's wishes. Some nurses recognised that a PN had been expressed but 'deferred' dealing with it, either until later or until another hospice healthcare professional (HCP) could deal with it. At times nurses would realise that a patient had a PN but would 'divert' their support to another aspect of care that would benefit the patient. Alternatively, nurses did not acknowledge the patient's signal at all, effectively 'ducking' the PN as if it had not been expressed. The nurses were observed using different responses during most episodes of care, ranging from one type of response to all four. However, these labels do not imply any judgment as to the appropriateness of the nurses' actions; for each type of response there may be valid reasons for that particular response.

Table 2 shows the distribution of responses within each category of type of PN. Overall, the nurses 'dealt' with around 44% of needs, and 'ducked' around 30%, while 'deferring' and 'diverting' rates were around 15% and 10% respectively.

The patterns of responses to PNs relating to rights and coping displayed similar proportions to the overall sample. When identity PNs were expressed, compared to the three other types, nurses tended to either 'deal' with them or not: 'deferring' or 'diverting' was the response for only three of these PNs (χ^2=11.57, p<0.01). There was also a statistically significant lower proportion of expression PNs that were

immediately 'dealt' with (as opposed to 'ducked', 'deferred' or 'diverted') compared with the other types of PNs (χ^2=6.18, p=0.01). These findings suggest that there may be some association between the type of PN expressed and the response provided.

Dealing

When encounters were assigned to the 'dealing' category the nurse was either observed dealing with a patient's PN, or had described the provision of psychosocial support in documentation or liaison. 104 PNs were 'dealt' with. Allocating encounters to the dealing group was, in the majority of cases, straightforward: a PN was expressed and immediately dealt with. However, nurses also demonstrated 'dealing' when patients did not explicitly express a PN; this occurred in three ways: (i) recognising implied PNs, (ii) adapting nursing practice, and (iii) responding to previously expressed needs.

Detecting implied PNs are exemplified in the following excerpt where a patient, Wendy, was to attend the local hospital for an x-ray and requested to spend some time at the shops after her appointment. This was the first time she had tried shopping since her condition had deteriorated. As Ellen (RGN) and Hazel were helping Wendy to get ready for her trip out of the hospice, she started to talk about going to the shops:

Fieldnotes

Wendy was talking excitedly about going to the shops after her x-ray, 'but I'm not sure how long I'll be, I do get very weak all of a sudden and if that happens I'll just need to come back'. She appeared despondent about this. Ellen suggested 'why don't you take a wheelchair with you? You don't have to use it, but it would be there as a safety-net and if you do get too weak your husband can push you round in it. That way you won't have to come home until you are ready.' Wendy was quiet, then after a short while replied 'hmm, I'm not keen on taking a wheelchair'. Ellen said 'okay, but if you change your mind before you go, just say.'

Patient Interview

Hazel: "Sometimes [nurses] persuade you to do things, such as when you went out the other day taking the wheelchair with you. Did you feel okay about us doing that to you?"

Wendy: "Yes, I did. I wouldn't have asked for a wheelchair, but I was glad of the opportunity of having one, knowing that for several months previously I would have died to have had a wheelchair to sit in…it was quite good to know that I had the opportunity to use it, I didn't need it, but the opportunity was there for me."

Ellen's suggestion to use the wheelchair, and the way it was put to Wendy, had positive impacts on Wendy's psychosocial well-being. Wendy had control over whether to take the chair; taking the chair gave her a sense of security; the time she had at the shops gave her a chance to be herself, doing something she enjoyed, and the time with her husband allowed them to have a 'normal' interaction. Thus Ellen's intuitive actions dealt with Wendy's PNs.

'Dealing' encounters also occurred when psychosocial support was provided by the nurses adapting their behaviour, and/or actions, to provide care in a way that was preferred by, but not essential for, a patient. Care would still be effective without this

change of practice, but by the nurse adapting their style of care, a patient could meet a number of PNs.

Other ways in which nurses changed their behaviour to interact with individual patients in order to offer psychosocial support related to the transfer of information. Some patients liked to be told about everything the nurse was doing for them, whereas other patients preferred the nurse to '*just do things*'. Some patients expected the nurses to know how to work with them and what their needs were, whereas other patients preferred to tell nurses about their condition. When nurses matched these patients' preferences, encounters were classified as 'dealing', as the nurses were respecting the patient's rights.

Thirdly, 'dealing' could relate to a previously expressed PN which had not yet been addressed. An example of this occurred when Ann (RGN) eventually found out that Bruce did not want to move to a single-room. During Bruce's stay he had seen many other patients admitted to the bay and some had died. Several of the ward staff were concerned that witnessing these deaths was having a negative effect on Bruce, thereby warranting a move to a single-room.

> **Fieldnotes**
>
> *Ann - who had hinted to Bruce this morning about moving to the single-room - said 'I'll talk to Bruce about it'.*
>
> *Ann told Bruce 'there's still another side-room available, but it's up to you'. Bruce was not sure whether to go, saying 'I would quite like to be able to play my music when I like without having to worry about other people, but I quite enjoy the company'. He seemed very hesitant to move to the single-room. After a short pause Ann suggested to him 'but you're quite happy here, aren't you?' and he said 'yeah, so I'll stay here, today.'*
>
> *After this conversation Ann told me 'it was important that Bruce had the opportunity to make that choice'.*

Ann's consideration of Bruce's moving to a single room identifies a number of potential PNs, including: fear of dying, loss of relationships, anxiety, and the need for safety. These PNs were not discussed with Bruce during any observations. However, this example does demonstrate the nurse dealing with a PN that had previously been deferred by both her and others: giving Bruce the choice of whether to move rooms. The nurse put aside what she, and other members of the hospice staff, felt would be best for Bruce. The nurse focussed on what the patient wanted, thereby meeting a number of PNs, including autonomy and a sense of belonging.

The common factor in all of the 'dealing' encounters is that the nurse immediately supported the patients' PNs.

Deferring

Responses that involved 'deferring' occurred when nurses delayed dealing with a PN so that it could be dealt with at a later time, either by themselves or someone else. Forty-nine PNs were deferred, (some of which may have been responded to by 'deferring' initially and 'dealing' later). For a PN to be 'deferred' the nurse had to

indicate to the patient that they had recognised the PN and that it would be dealt with later. This happened when Bruce's need for information about his disease progression was 'deferred' to a later date by Evie (RGN).

Fieldnotes

Bruce said 'there is one thing nobody's ever told me: what the results of those x-rays were that I had four weeks ago'. Evie paused for a wee while, then replied 'oh, that's right, we must chase that up. Try not to worry about that just now.'

Evie's response to Bruce's desire for information was representative of most of the 'deferring' responses, she indicated that she heard Bruce's PN and attempted to placate him. Placation was a common response when nurses felt they required more information before a patient's PN could be dealt with. What classifies Evie's response as a 'deferring', rather than 'ducking', response is that immediately following Bruce's episode of care, she reported his concern to a doctor.

'Deferring' encounters left the nurse with two options. In some cases, they would get another member of staff to deal with the PN because they felt that the other HCP had better skills or knowledge to deal with that situation. The alternative was that they would return to the patient themselves at a later time to offer support.

PNs were also 'deferred' when another HCP was directly involved in the episode of care. When other HCPs were working with a patient alongside a ward nurse, it was observed that the nurse always gave the HCPs control over what care should be provided. If a patient expressed a PN, and the other HCP did not pick up on this, the nurse was inhibited from dealing with the patient's requirement but could return to deal with it later:

Fieldnotes

Later that morning, Marianne (RGN) was crouching beside Eliza's bed obviously in deep conversation. When they had finished the conversation I asked Marianne about it. She told me, she had 'gone back to discuss Eliza's earlier concerns about her deteriorating condition. I didn't deal with at the time because [the other HCP] had different things to discuss'.

Nurses 'deferred' psychosocial support either because they felt they did not know enough about the patient and/or their PN or because they felt it was another staff member's role to deal with the need. At other times, 'deferring' occurred when another member of staff redirected the conversation. However, when 'deferring' occurred nurses always showed patients they had recognised their PN and indicated that the required psychosocial support would be offered later.

Diverting

When nurses used a 'diverting' response, the support they offered did not correspond with meeting the expressed PN: the nurses' actions were aimed at meeting another need, which was not necessarily psychosocial. There were 34 PNs that were 'diverted'. Nurses adopted a range of ways of 'diverting' PNs, for example, focussing on only one of a number of needs; offering practical solutions; and acting upon different care aims.

The first way nurses 'diverted' was by dealing with only part of a patient's requirements, rather than addressing the patient's full range of needs. It was common, in these circumstances, for a nurse to focus on patients' physical needs and, often unwittingly, omit PNs. This type of 'diverting' occurred when Millie (RGN) was bed-bathing Flora:

Fieldnotes

A short time later Flora said 'it's about time I'm not here anymore'. Millie did not say anything for a while, then responded 'things are much worse for you now?' Flora agreed. Millie explained to Flora how her symptoms could be managed as her condition deteriorates, telling her 'we'll be able to keep you comfortable right up until the end'.

In this example, Flora was expressing a number of PNs including worries about the future and difficulties coping with her deteriorating condition. Millie diverted the conversation away from these needs, rather than checking with Flora what her concerns were and allowing Flora to prioritise which to support.

The second type of 'diversion' was to offer an easily achievable practical solution to one issue, rather than exploring and managing the more complex but actual PN. For example, one patient Eliza liked to keep busy. Throughout her stay in the hospice she was always finding different ways to occupy her time. As her condition deteriorated, she continued to express a desire to find ways of occupying her time. However, instead of doing this, Marguerite (RGN) offered what she thought would be a quick solution to Eliza's problem and Lily (RGN), facilitated this offer:

Documentation

"[Eliza's] *fed up with 4 walls, missing getting out of the room,* [query] *consider change of environment, move to* [another room] *would mean she could have patio doors open." Marguerite.*

"[Eliza] *agreed to move to* [the other room] *and very pleased with brightness and open aspect." Lily.*

In these excerpts of documentation both RGNs recognised that Eliza was unhappy with her current situation. However, their solution to this problem only had a temporary effect: Eliza's boredom returned later that day and the move of rooms did not help her to accept her changing condition.

Differences in care priorities arose when patient expectations did not match the care offered. This occurred when Stuart, a patient whose mobility was deteriorating, wished to focus on improving his current mobility. The nurses' aim was to support him to mobilise when he got home, with a consensus that Stuart's mobility would not improve and, at best, he would reliant on a wheelchair. Stuart had not come to terms with the fact that he would not regain full independence with his mobility. In an attempt to facilitate Stuart's acceptance, the nurses had asked another HCP, who would also be involved with Stuart's care on discharge, to come and talk to him about his mobility:

Fieldnotes

> *The HCP came in to talk to Stuart, as requested, when Camille (RGN), and I were bed-bathing him.*
>
> *When Stuart, the HCP, and Camille were talking, Stuart mentioned 'when I'm up walking'. Camille and the HCP looked at each other, then steered the conversation to talking about how Stuart would manage at home. Stuart said 'but that's in the future and I'm not ready to talk about that yet'.*

Although the nurses and Stuart were concerned about his mobility, their different care aims, and time, were preventing them from supporting Stuart to accept his changing condition. This incongruence between short and long-term goals of care meant that Stuart's current PN was being diverted.

During all of the 'diverting' encounters the nurses responded to a patient's needs. However, the support they provided did not deal with the patient's immediate PNs.

Ducking

'Ducking' responses were when a patient had a PN which the nurse did not attempt to support. In these circumstances no recognition was made by the nurse of the existence of the patient's PN at the time it was expressed. There were 74 observed PNs that were 'ducked'. 'Ducking' occurred under five conditions: (i) when nurses did not recognise PNs had been expressed; (ii) when the nurses' current state of mind clouded their ability to respond; (iii) when nurses failed to engage with patients; (iv) when nurses did not want to disrupt the shift's planned work; or (v) when the nurses felt not responding to the PN was in the patient's best interest.

There were times when nurses simply did not recognise patients were expressing PNs. This most commonly occurred when patients hinted concerns about their disease progression:

Fieldnotes

> *After Nina (AuxN) and I finished assisting Eve to wash and dress, Nina supported Eve whilst she transferred into the arm-chair. Eve found this transfer difficult and had to rest during it. Both Eve and Nina's moods were light-hearted and jovial throughout Eve's care, even during the difficult transfer. However, when she was settled into the chair Eve's mood changed and she sombrely said 'you know, I was up and walking when I first came in here and now I can't.' Nina made no response to this.*

At interview, Nina told me she had not realised Eve was voicing worries about her condition. Nina related her inability to recognise Eve's PNs to her lack of education concerning what PN are. Nina felt she had "*never had any training in psychosocial care*".

For the remaining four groups of 'ducking' responses, the nurses were aware that PNs had been expressed, but did not respond. For example, on one occasion they stated that they '*had noticed a patient's PN but chose not to respond*'. In one instance, a nurse who possessed the knowledge and skills to carry out psychosocial support and was

observed on other occasions dealing with some very complex PNs, reported that she can temporarily lose her ability to respond to PNs:

Nurse interview

Annie: "there [have] *been times when people have given me cues and I've been aware that I've not picked up on* [them], *maybe because of the way I've been feeling at the time myself"*

Thirdly, nurses 'ducked' when they failed to engage with patients on a personal level when they were providing their care. This occurred when nurses were focused on the tasks of care rather than the requirements of the individual patient, or because the patient's PN clashed with the only way the nurse could see of carrying out their duties. The latter is exemplified below as Sybil (AuxN) and Hazel transferred Polly to and from her chair.

Nurse Interview

Hazel: "With Polly yesterday, when you had her in the hoist, how did you feel about how she was?"

Sybil: "Well she wasn't comfortable. She was frightened, but I didn't know how else we were actually going to get her off the bed and onto the chair. So, I think it's a case of having to try and reassure people that they're safe, and that they're actually secure, and that they're not going to fall out."

Although Sybil could not have made Polly happy with the use of the hoist, she recognised that by telling Polly what she was doing throughout the lift she could have made her more accepting and less frightened. The dilemma of having no immediately available alternative means of safely moving Polly prevented Sybil from meeting a number of Polly's PNs, including: expressing emotions, acceptance, safety, and security.

The fourth type of 'ducking' occurred when patients' PNs disrupted the nurse's plans for the shift. When the nurses focussed on '*getting their work done*' rather than the patient's individual needs, they failed to provide the patient with the care they required. This usually happened because nurses felt there was pressure on them that '*they must complete a set of duties during their shift*'. If a patient had an unexpected PN this gave the nurse an extra duty to manage which could disrupt their plans for the day. In order to prevent this disruption, nurses ignored patients' PNs. This situation occurred when Julie (AuxN) had assisted Teresa with a shower and to return to her bedside, where the doctor then attended to her:

Fieldnotes

When the doctor left, I went behind the screens to put Teresa's Lidocaine patch on. Teresa was very upset. I sat down in the chair beside Teresa's bed and had a long chat with her. Teresa told me all about: her fears for the future, especially that she 'wouldn't be able to cope at home'; how difficult she'd found her illness; her family difficulties; and why she had such a lack of support. Teresa cried throughout this conversation and was visibly distressed.

During this conversation Julie came in and out three times to put things in Teresa's locker, tidy things away, and leave the hairdryer.

At another point later in the conversation Rhona, the nurse in charge of the team this morning, shouted 'Hazel, we're away for tea, here's the keys'. Her hand appeared under the curtains with the keys.

Later Julie said 'I didn't want to disturb you to say we were away for our tea, 'cause I could see you were in something deep'.

It is noteworthy that Julie found it acceptable to interrupt an in-depth conversation in order to tidy up after Teresa's shower, but not to actually disturb the conversation, leaving the more senior nurse to do this. On other occasions disruptions like these, or a patient's awareness that their PNs were holding the nurse back from her work, could inhibit patients from requesting psychosocial support.

The final reason the nurses gave for 'ducking' was paternalism: the nurse did not respond because they thought this would be too upsetting for a patient, or they felt they knew what was best for the patient. One example of this occurred during an episode of care with Vera, a patient who had been admitted to the ward for one week's respite. She had deteriorated shortly after her admission, but was back to her normal state of health by the time of the multi-disciplinary team meeting (MDTM). The suggestion was made that Vera's respite should be extended for both her and her husband's sake, although she wished to return home on the originally planned day of discharge. However, the general consensus among the MDTM was that Vera's admission should be prolonged.

Fieldnotes

Maria (RGN) told me 'I'm going to have another chat with Vera and try to persuade her to stay in a bit longer. But I want to make sure we have plenty time to do this.' Maria planned her morning's care to allow time to spend with Vera to discuss her discharge date. Despite Maria's attempts to negotiate that Vera should stay in the Hospice longer, Vera was very insistent and still said 'I'd like to go on Friday'.

Despite Vera's clarity of choice the team decided it would be in her best interests to stay in the hospice longer and Vera's choice was denied. The outcome of this was a frustrated and mistrusting patient, a husband who agreed with a foregone conclusion, and a nurse who had to obey the paternalism from the ward hierarchy and duck the patient's PN.

In summary, the common factor in all of the 'ducking' encounters was that the nurses and patients did not share an acknowledgement that a PN existed.

Discussion

The 4D categorisation demonstrates for the first time how PNs are responded to in practice. This study has demonstrated that patients' PNs are rarely expressed to nurses as a standalone entity, which is how they are usually explained in nursing textbooks [51-53]. PNs arise during the various aspects of practice and are often subtly implied. This subtle expression of PNs contributes, at times, to the inability of nurses, in this study and others

[31, 54], to recognise a request for psychosocial support. Conversely, nurses were observed providing holistic care by recognising and responding to patients' PNs in a way that required much skill. The varied use of the 4Ds by individual nurses, even within one episode of care, indicates response does not depend upon nurses' roles, education or belief that 'it was their place to provide psychosocial support'. Both registered and auxiliary nurses gave the range of 4D responses, though AuxNs use of 'deferring' and 'diverting' response were limited. Auxiliary nurses felt psychosocial support was part of their remit but felt they were 'letting the patient' down if they could not immediately support their needs. Educating AuxNs in the provision of psychosocial support within the reality of the organisational challenges of care could reduce their use of 'ducking' responses.

The study suggests that there may be some association between the type of PN expressed and the response given. For example, the most noticeable difference in the type of PN categories related to expression PNs which were least likely to be 'dealt' with immediately. Nurses' hesitancy in dealing with difficult emotions verifies findings of previous studies into nurses' palliative psychosocial support which found nurses lacking in confidence to deal with the difficult issues [37, 55], regardless of whether they had been educated in this area [56, 57]. One reason nurses attribute to lack of dealing with PNs, especially those relating to emotional expression, is *not knowing a patient* [58, 59]. However, despite this idea being repeated by the nurses - 37 of the 38 participating stated this claim – the idea that familiarity is required to provide psychosocial support was unproven [60].

The other challenges faced by the nurses in this study relates to balancing psychosocial support with the organisational demands of working as nurse in a ward. Examples have been included in this paper which demonstrate nurses facing the dilemma of following ward routines and completing their work for the day or meeting patients' PNs.

Limitations

This study is limited in that it only gives an overview of the PNs observed by one researcher, in one hospice ward, using convenience sampling. However, no claim is made that this is an exhaustive list of PNs, or that these findings are generalisable to other settings. The snapshot provided illustrates how PNs are expressed and responded to as part of ward nurses work. The challenges presented by the participant-observation methodology were minimised as much as possible. The potential of incorrectly recording observations was reduced by the collection of other data, especially matched interviews, carried out as soon as possible after the care, with the patients and nurses involved and about their interaction. Participant verification [61, 62] of the overall findings was carried out by feedback sessions to the nurses and observer impact reduced by the researcher's experience and the time take to develop the team's ways of working.

Conclusions

This study has allowed an exploration of the actual PNs of patients in a hospice setting and the way in which they were expressed. This paper also demonstrates how nurses respond to PNs. The participating nurses, who work in an area which has a key aim of providing psychosocial support, faced the challenge of responding to PNs whilst carrying out the other duties of their shift. The PNs were clearly associated with the palliative stage of the patients' conditions. The idea that nurses can provide psychosocial support as an inherent component of practice was verified. The data included in this paper, and the discussions

around the observed care, provides nurses everywhere with an example against which to compare their own practice.

List of abbreviations used
AuxN: auxiliary nurses
HCP: healthcare professional
RGN: registered nurses
PN: psychosocial need

Competing Interests

Authors' contributions

HH designed the study, carried out the fieldwork and wrote the first draft of the paper. All authors were involved in data interpretation. LF and JE advised on analysis and critically revised the paper for important intellectual content. All authors read and approved the final manuscript.

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Tables

Table 1- Participant Characteristics

Patient Characteristics (*n=47*):			Nurse Characteristics (*n=38*):	
Age	Range: 38-91 years Mean: 65.1 years		Age	Range: 22-59 years Mean: 44.47 years
Sex	Male: 19 (40.4%) Female: 28 (59.6%)		Sex	Male: 0 (0%) Female: 38 (100%)
Average days spent in hospice at time of observation	Range: 1-221 days Mean: 31.7 days		Role	Registered General Nurse: 23 (60.5%) Auxiliary Nurse: 15 (39.5%)
Care aim	Assessment: 5 (10.6%) Rehabilitation: 2 (4.3%) Respite: 9 (19.1%) Symptom Control: 20 (42.6%) Terminal Care: 11 (23.4%)		Education in psychosocial care	None: 5 (13.2%) Study day: 5 (13.2%) Short course: 11 (28.9%) Module: 17 (44.7%)
Diagnosis	Cancer: 39 (83%) Neurological: 8 (17%)		Years of palliative care experience	Range: 0.5-19 years Mean: 8.7

Table 2 – Distribution of response type against category of psychosocial need

Response	Type of psychosocial need expressed				Total per response
	Rights	Identity	Coping	Expression	
Ducking	45 (27.3%)	18 (36%)	13 (31%)	25 (34.2%)	101 (30.6%)
Deferring	25 (15.2%)	1 (2%)	8 (19%)	15 (20.5%)	49 (14.8%)
Diverting	20 (12.1%)	2 (4%)	3 (7.1%)	9 (12.3%)	34 (10.3%)
Dealing	75 (45.5%)	29 (58%)	18 (42.9%)	24 (32.9%)	146 (44.2%)
Total	165	50	42	73	330