Palliative care nurse specialists' understanding and management of suffering and their individual response to working with patients who are suffering: An investigation.

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Palliative Care Nurse Specialists' Understanding and Management of Suffering and their Individual Response to working with Patients who are Suffering: An Investigation.

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Palliative Care Nurse Specialists' Understanding and Management of Suffering and their Individual Response to working with Patients who are Suffering: An Investigation.

Summary.

This thesis describes a study to explore palliative care nurse specialists' understanding and management of suffering and the personal impact of working with patients who are suffering.

Background to the Study.

Suffering is the individual's response to circumstances that befall them and are perceived to have a negative impact. Nurses aim to help patients integrate suffering into their lives, which requires a deep understanding of the patient. Palliative care can be a very difficult area of work. Arguably, what suffering means to palliative care nurses will determine the focus and practical aspects of their care, further it may influence their personal responses.

The Methodology.

The study was guided by the ideas of hermeneutic phenomenology. Thirty one palliative care clinical nurse specialists working in south and mid Wales were interviewed to determine their understanding and management of suffering and their personal response to working with patients who are suffering. Semi-structured interviews enabled the exploration of their experiences and views. The data was analysed using the principles of phenomenological interpretation.

The Findings of the Study.

The palliative care nurse specialists had difficulty articulating the concept of suffering but their descriptions, often using clinical scenarios, mirrored the literature. Their understanding of suffering influenced their care management, in particular the nurse-patient relationship. Theoretical perspectives of suffering and person centred care were demonstrated and used to underpin care, although this had been learnt experientially. Development of understanding, knowledge and skills to manage suffering influenced their own responses to working with patients. They had developed a personal philosophy towards their work and positive reappraisal to cope with the stresses that arose.

Conclusion.

Clear links between understanding suffering, management of the nurse-patient relationship and the personal impact of working with patients who are suffering were demonstrated, as well as the role of experiential learning. Education about suffering and clinical mentorship may enable palliative care nurses develop skills and knowledge in both the care of patients who are suffering and their own ability to cope.

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Last but not least, thanks to the many friends who have given their support in many different ways over the past years.

Declarations and Statements.

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed

Date 28|4|08

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote.

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Palliative Care Nurse Specialists' Understanding and Management of Suffering and their Individual Response to working with Patients who are Suffering: An Investigation.

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Palliative Care Nurse Specialists' Understanding and Management of Suffering and their Individual Response to working with Patients who are Suffering: An Investigation.

Part One: Introduction and guide to the thesis.

Introduction.

This thesis describes a study whose purpose was to explore palliative care nurse specialists' understanding of suffering, management of nurse patient relationships and the personal impact of working with patients who are suffering. It was hoped that the information gained would provide some ideas about how suffering is understood and managed by palliative care nurse specialists, and how they cope with their own response to working with people who are suffering. Of further interest was whether there were connections between palliative care nurse specialists' understanding of suffering, management of the nurse-patient relationship and coping with patients who are suffering. The research was an exploratory study and was not intended to be statistically generalisable.

This introductory section provides a brief guide to the study so that the reader can navigate through the thesis with greater ease.

Background to the study.

Suffering results from the individual's response to circumstances that befall them and are perceived to have a negative impact. A life threatening illness may bring to the fore suffering that has previously been concealed in a person's life. The suffering experience is central to the ill individual and may be alleviated through finding meaning in the experience, which can lead to the individual redeveloping goals to give life new purpose (Frankl, 1963; Cassell, 1991; 2004). Nurses and doctors try to relieve suffering (Frankl, 1963; Cassell, 1991; 2004; Morse, 2001; Radiewicz 2001; Kriedler, 1984) and nurses aim to help patients integrate suffering into their lives and rise above it (Eriksson, 1992; Kriedler, 1984; Travelbee, 1984; Goerges et al, 2002). However, despite the centrality of suffering to patient care comparatively little attention is paid to it in the health care literature (Cassell 2004; Lesho, 2003).

A deep understanding of the patient must be achieved involving empathy, caring and involvement (Martocchio, 1987; Radiewicz, 2001; Jones, 1999; Ramirez, 1996; Silva 2000) and relationships characterised by reciprocity allow patients to have control over their lives (Morse, 2001; Webber, 1997; Georges et al, 2002, Eriksson, 1992). A nurse patient relationship with open communication and understanding is an important way to manage suffering (Wright, 1994; Morse, 1991; Hagerty and Patusky, 2003) and can be very rewarding for the nurse where patients are likely to recover or adjust to a chronic condition. In palliative care the nurse-patient relationship will be broken at the patient's death and the level of involvement that may be needed to understand and manage the patient's suffering may result in emotional pain for the nurse (Davitz & Davitz, 1975; Mason, 1991; Steeves et al, 1990; Sherman, 2004; Kiedel, 2002; White, 2004; Morse et al, 1991; 2006).

Palliative care is considered a highly difficult area of work (Radiewicz, 2001; Ramirez, 1996; Vachon, 2001; Jones, 1999; Georges et al, 2002) and the need for coping and adaptation is highlighted, otherwise it can lead to stress (Copp & Dunn, 1993; Hansell, 1989; Herschenbach, 1992; Vachon, 1995; Cohen et al, 1994; Georges et al, 2002). Nurses can often feel overwhelmed by the complexity of care of the dying (Menzies, 1970; Turner, 2001; Davitz & Davitz, 1975; Vachon, 1998; Jones, 1999; Ramirez, 1996) and if unable to alleviate distressing symptoms due to lack of knowledge, they may feel inadequate and helpless (Steeves et al, 1990; Radiewicz, 2001). There are also many personal factors that influence nurses' response to suffering (Davitz and Davitz, 1975; Mason, 1991; Steeves et al, 1990; Sherman, 2004). People who are dying are often suffering and the psychological response to caring for them is important.

However, little is known about the personal impact of working with patients who are suffering (Barrett and Yates, 2002; Ergun et al, 2005). Palliative care nurse specialists have clinical, consultative, educational, leadership and research roles, with providing emotional support a central component of their clinical role (Webber, 1997). They are challenged to understand suffering so that patients in their care can be fully assessed and ways found to alleviate their distress. Arguably, what suffering means to palliative care nurses will determine the focus and practical aspects of their care, as well as their development of skills and knowledge required to work with patients who are suffering. Further, they must manage their personal responses. This study was undertaken to elicit palliative care nurse specialists' understanding of suffering, management of the nurse-patient relationship to alleviate suffering and the personal impact of working with patient who are suffering. It was also hoped to determine any connections between these three areas of interest.

The methodology.

The study is guided by the philosophy of Heidegger (1962) and others who have attempted to understand human beings and their world. It follows the ideas of hermeneutic phenomenology as described by Heidegger (1962) and utilises the hermeneutic circle of understanding, which acknowledges that as knowledge is gained, understanding is developed, and that this is an ongoing process. Heidegger (1962) clarified that the questioner's fore-structure, classified as; fore-having, fore-sight and fore-conception is an important aspect of the inquiry and to this end I have shared my own fore-structure. Semi structured interviews were used to collect data which was then analysed using the principles of phenomenological interpretation (Benner, 1984; Giorgi, 1985; van Manen, 1990; Coliazzi, 1978).

The findings of the study.

The palliative care nurse specialists had difficulty articulating the concept of suffering but descriptions were elicited using three strategies and these mirrored the literature. Their understanding of suffering influenced their care management, in particular the nurse-patient relationship. They demonstrated understanding of theoretical perspectives of suffering (Morse, 2001; 2006) and person centred care (Rogers, 1951) although they had received no education in these concepts. The knowledge had been gained through experience. The study showed ways in which the palliative care nurse specialists came to understand suffering and used this knowledge to underpin their patient management and personal response. Clear links between understanding suffering, management of the nurse-patient relationship and the personal impact of working with patients who are suffering were demonstrated as well as the role of experiential learning.

The study report.

This thesis is presented in four parts. The thesis begins with a review of the literature, designed to place the study in context and identify what is already known about the areas of interest. Thus a rationale for the study is explained. Part One consists of an introduction to the initial literature review. Three chapters discussing the concepts of suffering, the nurse-patient relationship, stress and coping are presented with a conclusion.

Part Two consists of four chapters concerning the research design. The research methodology is described, and aims to comprehensively explain why decisions about the choice of data collection and analysis were undertaken. Chapter Four contains an account of the philosophical basis for the study and why the methodology was chosen for this study. Chapters Five and Six detail the procedures used for data collection and data analysis respectively. In Chapter Seven issues of rigour are discussed with some thoughts on the known strengths and limitations of the study.

In Part Three, the study findings are presented and described. Chapters Eight, Nine and Ten present study findings in relation to suffering, the nurse-patient relationship and the personal impact of working with patients who are suffering. The analysis and interpretations are considered against the existing literature and some initial thoughts are offered as to their relevance and importance.

In Part Four, a discussion of the study is presented, together with some conclusions. Chapter Eleven considers the study findings in relation to the aims of the study and the existing theory and research knowledge and considers the meaning and relevance of what was discovered. It places the findings into context with what is already known in the area. Chapter Twelve concludes with an evaluation of the methodology, the implications of this work for nursing practice and my personal learning.

The hermeneutic phenomenological approach acknowledges the researcher's influence on the inquiry and I have presented this throughout the thesis. Some concluding thoughts are offered for the reader to consider when determining the value of the research presented in relation to their own knowledge on the subjects under investigation.

Review of the Literature.

Chapter One presents the rationale and main findings of the initial literature review and explains how the information was obtained. The initial literature review is presented in three chapters dealing with the concepts being considered: suffering, the nurse-patient relationship and stress, exploring current knowledge in these areas and placing the study in context.

Rationale for the Literature Review.

The purpose of the initial literature review was to become familiar with the existing body of knowledge in the areas for investigation, to avoid duplication and to focus on aspects where there is relatively little knowledge. This was to place the research in context and to clarify the questions to be explored. To this end, three main themes were selected for the literature review: suffering, the nurse-patient relationship and stress and coping in nursing. These are presented in three chapters with a short conclusion to bring the salient points together. The literature review also included gaining understanding about the methodology to be used for the study, which is presented throughout the study.

The research methodology acknowledges the researcher's input into the process. As such it was appropriate that a literature review was undertaken prior to the commencement of the study, but also that literature was reviewed as information and thoughts about the data raised questions that required further exploration, and to place the findings, in due course, within the existing body of knowledge.

A decision was made to present the literature, as it became pertinent to the stage and aspects of the study being discussed. Therefore, literature relevant to the study context and aims is presented in the initial literature review. Throughout the research philosophy and methodology chapters, literature relating to these areas is considered. During the chapters of analysis and interpretation of the study findings, literature relating to the themes developed is reconsidered, and introduced. The discussion chapter aims to draw together the entire study and considers the findings in relation to existing research and theory. This way of presenting the literature minimises repetition and reflects the way in which the literature was considered through the study. It is also consistent with Heidegger's (1962) view that ideas are developed in relation to ongoing information and reflective experience through the hermeneutic circle and co constitution.

Process of reviewing the literature.

An initial literature search was undertaken using Cinahl, Pubmed, Medline, BNI and Ovid databases and the search terms 'suffering', 'the nurse-patient relationship', 'the nurse-patient relationship in palliative care', 'health care professional stress', 'burnout' and 'coping', 'health care professional response to suffering' and 'suffering in palliative care'. The literature was searched with no date limit but with the proviso that documents were to be written in English. When this literature had been obtained and critically analysed, further searches were undertaken to obtain literature relating to 'nurse recognition of suffering', 'nurse involvement with patients', 'nurse response to suffering', 'palliative care nurse stress and coping' and 'communication in nursing'.

These search terms provided articles that related to the main areas of the study and consisted of research and discussion papers on suffering, nurse-patient relationships, with particular emphasis on how these are formed and involvement with patients managed, and stress and coping in palliative care. These were reviewed prior to developing the study. It was identified that there were gaps in the literature, for example the nurse's personal understanding of suffering, which may influence their response to caring for suffering patients.

Papers were procured from hand searching the journals *'Cancer Nursing'* and *'The International Journal of Palliative Nursing'* and *' The Journal of Advanced Nursing'* back to 1995. The researcher has had an interest in stress and coping and worked in the field of cancer and palliative care for twenty years and has a personal library of related literature, which was also used as background reading. References given in research articles were accessed where relevant and this ensured that other pertinent, unidentified material was obtained and studies most commonly cited were noted. Research findings, theoretical perspectives and opinions in the areas of interest were included. Primary and secondary sources of literature were used as well as general reading around the topics. This initial collection of articles formed the basis for the literature review.

Throughout the study regular literature searches were undertaken, using the same databases and search terms, to ensure that the literature review remained current. A substantial search took place but whilst extensive it was not exhaustive. As analysis took place, further literature was obtained and considered, particularly in relation to the themes developed. Search terms that were added were 'loss and suffering', 'hope and suffering', 'loss and patient care', 'hope and patient care', 'self-awareness' and 'countertransferance', 'coping and spirituality'. Additionally, nursing and counselling theory was revisited to determine the relationship of the study findings to existing theory. Literature relating to 'learning' and 'reflective practice' was explored, particularly in relation to the implications for practice of the study findings.

Chapter One: Suffering.

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Chapter One: Suffering.

Suffering: Introduction.

Suffering is a whole person concept and the experience of suffering is complex, personal and multidimensional. Cassell (2004, p3) defined suffering as the *'state of distress induced by the threat of the loss of intactness or the disintegration of the person from whatever cause'*. He explains that many aspects of a person can be sources of, or affected by, suffering. These include personality, life experiences, cultural background, roles, rights and responsibilities, relationships, the self, the body, one's activities and regular behaviours, the unconscious, one's secret life and perceived future. Cassell (1991; 2004) discussed the loss of central purpose that arises when a person is suffering and went on to explain that the person must be helped to transcend their suffering and reintegrate into their life. Suffering is a highly subjective experience that will be different for each person.

Van Hooft (1998) offered ideas about suffering in the context of a holistic conception of the human person derived from the philosophy of Aristotle. Four parts of the soul make up the human being:

- the appetitive or zest for life;
- the deliberative or practical, that is the achievement of activities to the best of one's abilities;
- the contemplative or meaningfulness of life;
- the biological or health.

Van Hooft (1998) maintained that challenge to any of these parts can result in suffering and that with this in mind, the person can be suffering without being aware of it. This is an objective concept of suffering where others can attempt to relieve suffering even if the individual is not aware that they are suffering. He argued that health care workers should base their efforts on relieving suffering at the biological and appetitive level, as effecting cure and palliation will relieve suffering. In his view, suffering that occurs at the deliberative or contemplative level is not within the scope of the healing art. However, he noted that insensitivity to suffering at these levels would add to suffering, so due cognisance should be given not to threaten the meaning that patients give to their lives. This view narrows the focus for nursing care. It encourages nurses to focus on those aspects of suffering that relate to physical aspects and what gives the person a zest for life, whilst ensuring that what they do does not interfere with what the person sees as important in their life.

Cassell (1991; 2004) viewed suffering as a subjective experience while Van Hooft (1998) had a more objective focus. Either way, the patient must be assessed to determine the real or potential source of their suffering and actions to alleviate suffering must then be employed. In the practical sense of patient assessment and care much the same activity will result following Van Hooft's (1998) or Cassell's (1991; 2004) concepts. However, using Van Hooft's (1998) ideas may result in the nurse trying not do things that will compromise what the patient finds important whilst focussing on the biological and health aspects of care, whilst in Cassell's (1991; 2004) case the aim would be to undertake activities that will relieve suffering whatever the source of the patient's suffering. Both viewpoints have advantages and disadvantages. The narrowed focus of Van Hooft's (1998) perspective means that the aims of care are realistic and sensitive but may not be what the patient exactly needs, or be addressing the cause of their suffering. Cassell's (1991;2004) perspective requires the identification of aspects of the person's life affected by the events befalling them and so causing suffering. However, it is not always possible for either the person or a third party to identify what is causing suffering. Moreover, the relief of some aspects of suffering are not within the gift of professional healers; sometimes care must be given based on assumptions that certain problems do cause suffering, and relief of these will alleviate distress. Arguably, this latter approach moves away from care strictly determined by the patient's unique and subjective experience of suffering, but maintains a realistic approach in the goals of care.

In palliative care, complete relief of suffering is often an unachievable goal. Care is a compromise for both sufferer and nurse, and often aimed at helping the person come to terms with their life. There are times where, to improve the overall well being of the person or relieve symptoms, it is not possible to avoid doing things that may cause suffering. Cassell (1991; 2004) and Van Hooft (1998) provide ideas of how suffering may be viewed but do not directly deal with the tangible sources of suffering caused by illness or treatment. Some researchers have undertaken work to explore these questions and offer some helpful ideas.

Weisman (1972) identified two types of suffering: primary, which comes from the affected organ; and secondary, which represents the significance of total distress experienced by both the sufferer and those around him. Charmaz (1983), undertook a study of 57 chronically ill people using grounded theory and discussed suffering in terms of loss of self, which develops out of daily life experiences. She identified four sources of suffering: living a restricted life, existing in social isolation, experiencing discredited definitions of oneself and becoming a burden. Copp (1990, p 35) described suffering as *'the state of anguish of one who bears pain, injury or loss'*. She found that it was the individual's response to the pain that led to suffering, and that suffering causes vulnerability, dehumanisation, challenges self-concept and is affected by time and place (Copp, 1990). Eriksson et al (1993) analysed previous research on suffering and found that it is most often associated with illness and pain, anguish and agony. In Lindholm and Eriksson's (1993) phenomenological study of both nurses and patients descriptions of suffering, pain, fear, despair, hopelessness and lack of strength emerge.

Suffering in these studies is a combination of the problems caused by the illness itself, and the effects of these problems on the person's life. This seems to equate to ideas of suffering challenging the person's identity in some way (Cassell, 2004; Van Hooft, 1998) and raises the issue of the meaning the individual puts on events befalling them. Kahn and Steeves (1986) in a paper discussing the phenomenon of suffering, recognised that suffering is not necessarily a perception or sensation but an evaluation of the significance or meaning of experience that can induce suffering. They noted that meaning has two connotations: that of attribution or cause; and the impact of suffering. Meaning, like suffering, is a whole person concept, an experience that brings one in touch with something greater than, or outside of, oneself. This latter suggests a spiritual quality with potential for growth rather like Cassell's (1991; 2004) views of transcedence.

Frankl (1963), a psychotherapist and concentration camp survivor, emphasised that suffering is part of the human condition, can be ennobling not degrading, and is one of the ways humans find meaning in life. Meaning can be discovered, according to Frankl (1985), by creating a work or doing a deed, by experiencing something or encountering someone, or by the attitude taken towards unavoidable suffering. He is also clear that meaning can still be found even if a person cannot work or enjoy life by accepting the *'challenge to suffer bravely'* (Frankl, 1985, p137).The role of the clinician is to *'enlist the patient's capacity to fulfil the meaning of his suffering'* (Frankl, 1963, p115). Illness can be an occasion for growth. Serious illness can make people more aware of other people's suffering and more attuned to act to help reduce suffering and take responsibility for each other (Kleinman, 1998). Suffering in life is accepted as inevitable and helpers urged to assist the person to make sense of their predicament. These views maybe helpful in palliative care, although it begs the question what happens if meaning in suffering cannot be found?

Descriptions of suffering (Charmaz, 1983; Weisman, 1972; Copp, 1990) mirror the conceptual thinking (Cassell, 1991; 2004; Van Hooft, 1998; Frankl, 1985). It is apparent that suffering is more than just a collection of signs and symptoms. The meaning that the individual attaches to these and the threat to the individual's sense of identity is also a source of suffering. Pain, nausea and other unpleasant effects may cause suffering, but not necessarily. Many people will experience unpleasant symptoms but will not suffer. Suffering comes from a number of sources due to disease processes or approaching the end of life (Weisman, 1972; Charmaz, 1983; Copp, 1990; Rydahl-Hansen, 2005). These interfere with day to day living, social intercourse is affected and the person experiences distress, pain and loss. However, it is often the interpretation of the meaning of events to the sufferer that seems to move a collection of bodily dysfunctions to the psychosocial space of suffering. Interpretation is what gives physical or psychosocial problems meaning and results in suffering, and is a common thread throughout these descriptions.

The nurse's role is to assist the person in coming to terms with their fate. This requires acknowledgement of suffering as experienced by the person and trying to find some meaning in it. This may involve trying to re-define suffering as having positive as well as negative factors, and enabling the patient to transcend their difficulties. In palliative care this may also mean accepting that some problems are not curable and that gradual loss of aspects of self are inevitable as death approaches.

Actual symptoms, anticipation of symptoms, memory of symptoms or identification with symptoms may all contain meanings that lead to suffering. Understanding what causes suffering and taking action to alleviate aspects amenable to relief, such as many physical symptoms, may reduce distress and give time for the person to integrate the problems into their life. However, assumptions that because a person is experiencing a disease, is terminally ill, or is undergoing unpleasant symptoms, they must be suffering will not necessarily be accurate. Physical discomfort or disabilities may result in, or exacerbate, suffering but in themselves, whilst unpleasant, are not always the cause of suffering. The same is true of being terminally ill. By the above accounts of suffering, if the person has found meaning in their lives, their suffering as a result of events befalling them may be assuaged. Suffering is highly individual and often related to the meaning placed on problems experienced by the person rather than the problems themselves, so the nurse needs to be able to identify when a person is suffering, and the cause of that suffering.

1:1 Identification of suffering.

The person suffering is experiencing emotions leading to a behavioural state. The nurse must recognise behaviours that suggest suffering in order to provide care that will help identify and alleviate the source of suffering. A number of studies give ideas of how suffering may manifest.

Soelle (1975) described three phases of suffering. In the first phase an individual is mute and speechless, overwhelmed by the situation, powerless and submissive; autonomy is lost and goals cannot be organised. The second phase is lamentation, where the sufferer finds a voice, suffering is experienced, accepted and analysed; efforts are made to conquer suffering and goals are established. The third phase is characterised by action, objectives are organised, the individual attempts to shape the situation and overcome powerlessness. Battenfield (1984) used the literature to develop a schema of suffering which was then used to rate the responses of nine people interviewed, she also identified three stages and discusses the initial impact, turmoil without resolution, and recovery, which involves coping, accepting and finding meaning.

Morse and colleagues (1997; 1999; 2000; 2001; 2003), have undertaken a programme of qualitative research exploring the behavioural-experiential nature of suffering, and describe two broad and divergent behavioural states of suffering: *'enduring'* and *'emotional suffering'*. Morse (2001) described a trajectory of suffering where the person's senses are acute as they try to make sense of what is happening. Initially the person checks out the problem and there may be denial. This is followed by recognition of what has happened and that they must function to survive or get through the situation, and the person starts enduring. Morse (2001) described behavioural states: unconscious, relaxed/normal, scared or afraid leading to some relinquishment of care, and enduring. In the enduring state, emotions are not obvious and are often blocked, thus enabling functioning at a public level. 'Terrified' and 'out of control' are classified as failure to endure.

Enduring occurs at various levels of intensity depending on the severity of the threat, and people who are enduring focus in the present, blocking the past and the future. This enables them to keep going and do what must be done to survive. Enduring can be escaped from through distraction and outbursts of emotional energy and these escapes aid in preserving the self. Three types of enduring are described:

- Enduring to survive, which occurs when there is serious physiological threat and enables the person to focus on vital physiological functions and conserve energy.
- Enduring to live occurs in untenable life situations and enables the person to focus on getting through each moment.
- Enduring to die occurs at the end of life and enables the person to conserve energy and maintain control and remain focussed on the present so to bear the unbearable (Morse, 2001).

Those who are enduring do not move to emotional suffering until they are tentatively ready to accept their loss and they may move between both states depending on energy level, context and available supports. Emotional suffering is the recognition of the meaning to one's life of whatever is lost and that the future is irrevocably altered. Emotional suffering is a distressed state in which emotions are released. There is unmistakable stooped body language and expression such as weeping and repetition. Emotional suffering uses a lot of energy and leaves the sufferer feeling exhausted, so escapes are those that conserve energy, involving mind numbing strategies such as sleeping or drinking alcohol.

The trajectory is not linear and the person may pass back and forth between enduring and emotional suffering. As enduring and emotional suffering progress, a new perspective of reality may be achieved with the person learning to see beyond themselves. The person may move from past experience to present and begin to perceive a future. Gradually, when they have suffered enough, hope seeps in and possible alternative futures are envisioned. Developing a new future begins with small incremental pieces, eventually building to either recognition of the event and identification of a goal, or acceptance of the event and identification of both a goal and the means to attain it. Eventually there is hope, people become future orientated, although the outcome may still be uncertain, and a goal and way forward are identified (Morse and Penrod, 1999).

These authors identify that the person goes through three stages to accept the meaning of their suffering and transcend their difficulties. There are ways in which the nurse may identify, from body language, that a person is suffering, as well as from any verbal communication that is shared. Nurses must respond to whatever state the person is presenting and be able to read the verbal and non-verbal cues. Morse et al, (1997) stated that the sufferer always leads comforting interactions, with the distressed sending signals to which others respond.

Support during enduring is to be present and open to communication, allow the person to endure, and be ready to give comfort when emotional suffering, a very public release of emotion, occurs. Morse (2000) emphasised that recognition of the person's state of enduring is important, as at this time what is needed is for the person to be allowed space, have their dignity, and for carers to be there encouraging the person to endure. Empathy and use of touch are inappropriate as they encourage an emotional response that the person cannot cope with at this time. Emotional suffering requires helping the person through the experience by making the suffering more bearable, which may be achieved through empathic communication. Care is more likely to be offered in emotional suffering as emotional distress is obvious and thus motivates others to try and alleviate suffering. Suffering is a shared experience, with nurses responding to the cues of suffering by expressing empathy, listening, holding and touching the sufferer. If the cues are absent, then comforting activities are also absent (Morse, 1999).

This work provides ideas about how suffering may be recognised by a third party and ways in which the sufferer may be comforted. However, Morse (2003) also commented that little work has been undertaken to determine what the cues of suffering may be, and that comforting responses are based largely on intuitive cues learnt by trial and error in everyday life and classified as intuitive knowledge in clinical practice. She undertook a qualitative study (2003) to try and identify the facial responses to suffering and found that there were patterned facial cues that indicate responses to suffering. She concluded that more work is needed in this area so that health care professionals can provide appropriate support and care for people in distress.

Consequently, given that the person may be unable to express their distress but may still be suffering, an understanding of what causes suffering in terms of events or problems may shed some further light for the nurse planning care.

Accepting that meaning is an important factor in suffering, there are nonetheless aspects of life that are significant and can be expected to cause suffering. The patient's subjective experience of suffering must be considered along with understanding of ways of relieving problems caused by the disease process.

1:2 The causes of suffering.

Kuuppelomaki (1998) used a phenomenological research approach to explore cancer patients reported experiences of suffering. Three dimensions of suffering were identified physical, psychological and social. The primary sources of physical suffering were divided into those caused by the disease and those by treatment. These further divided into general complaints, specific complaints and changes in appearance, examples being fatigue, pain, and the side effects of chemotherapy. Psychological suffering was caused by the physiologic changes associated with the disease and the imminence of death. These manifested in depression, especially at the initial stages of the disease, when the disease metastasised and when they were in particularly poor condition. General deterioration and fear of infections cause social isolation which also add to the person's distress.

Strandmark (2004) undertook a phenomenological study using interviews of 25 men and women, age range 25-77 years, to identify the different dimensions of subjective ill health based on individual experience. She found that powerlessness was the essence of the experience, resulting from feelings of worthlessness and being imprisoned in one's life situation, causing emotional suffering. The limited choices and ability available to the informants resulted in apathy, which was adapted to through relationships with others and living in the present.

Copp (1990) addressed physical problems in describing the spectrum of suffering and interviewed 148 patients in 5 hospitals at all stages of the pain experience to discover what pain means, how patients cope and what would help to relieve it. The patients described problems with pain in terms of consequences, experience, memory, anticipation, inconvenience, implications and the time frame it represented. Coping strategies were stated to be significantly influenced by the specific meaning of the illness for the individual. Focussing in various forms was a common response, as was finding value in the experience, seeing it as a challenge, punishment, having health staff just being there, and making contact with natural elements. The patients also used prescribed and non-prescribed drugs, position change, heat and cold, purposeful diversion, breathing exercises and routine.

Rydahl-Hansen (2005) in a qualitative study of 12 patients aiming to describe experienced suffering in life with incurable cancer, found that when patients were told their illness was incurable they lost the all-dominating hope of being cured. They had increasing difficulty in maintaining hope and control over their lives as their resources waned and their symptoms became more complex. They felt increasingly lonely and isolated and unable to express their suffering, as they were afraid to do so might lead to complete emotional breakdown. This lead to suffering being defined and alleviated on the assumptions of the professionals rather than the patient's description. These patients were aware that physically induced suffering was predictable and varied from day to day, reinforcing their fragile control and increasing their awareness of the threat to their bodily integrity caused by their illness. They coped by seeking to adapt to their ever changing and unpredictable situation. Whilst they had accepted that they were going to die, they maintained hope of living as closely as possible to their previous way of life. The future was uncertain, threatening and anxiety provoking so they allowed the professionals to determine their present and adapted to whatever problems presented whilst becoming increasingly dependent on others. The patients rarely expressed their suffering to the professionals, which seems to echo Morse's (2001) thoughts on enduring to die. However, it must be noted that whilst they did not talk to the professionals they did express their thoughts and feelings about suffering to the researchers.

All these studies highlight that illness causes problems that lead to the person losing aspects of their lives that are important to them. Relief of suffering involves relief of physical and psychological problems but also helping the person find meaning in their lives despite their difficulties. Mastering (Kahn and Steeves, 1986) enduring (Morse, 2001) and reconcilement (Eriksson, 1997) are different ways in which people deal with suffering. Suffering is a combination of problems caused by illness that in turn impact upon patients' understood meaning of what is happening to them. Evidently, knowledge of the problems created by illness and their significance in suffering will prepare the nurse to expect and anticipate the possibility of suffering if the patient is experiencing these events. Nurses can predict that physical problems such as pain, or psychological difficulties caused by being unable to function as normal, will cause suffering. Knowledge of disease processes may allow anticipation of suffering in the patient before the patient becomes aware of it. Alleviation of suffering may begin through the relief of real or anticipated physical or psychological problems.

Johanssen (2006) undertook a study of ill cancer patients' quality of life at the end of life, and found that alleviated physical and psychological suffering was important as it facilitated the maintenance of the ordinary things in life and significant relationships. It was also critical that patients maintained a positive life involving keeping memories alive and being needed. Carter et al (2004), support these findings in a grounded theory study using interviews of ten people with cancer, and also add the importance of maintaining dignity in the face of ongoing physical deterioration. There are suggestions that suffering is equated by nurses in terms of a medical disease model (Oberst, 1978) rather than the more general concepts described. Care is determined based on knowledge rather than the patient's account. The nurse may respond to prevent or alleviate suffering but arguably this is not individualised care based on the patients' response to suffering. The causes of suffering considered from the patient's perspective are valuable in ensuring that care is not just determined by the physical signs and symptoms.

Existential issues are of importance to palliative care patients, and finding meaning despite disease is important for overall quality of life (Moadel et al, 1999; Blinderman and Cherny, 2005). A mutual understanding between patient and nurse of the patient's illness experience is important if care is to be patient focussed. Fagerstrom (1998) undertook a phenomenological study of 38 patients aimed at understanding patients' experience of caring needs. She concluded the nurses need to expand their awareness of the existential/ spiritual needs and desires in order to help to interpret patients' suffering and enable their growth and development. This requires the development of a therapeutic nurse-patient relationship that enables communication and care to be individualised, based on understanding the patient's suffering experience (Fagerstrom, 1998; Lindholm and Eriksson, 1993). However, Lindholm and Eriksson (1993) undertook a phenomenological study to try and understand how five patients and eleven nurses see suffering. They found that patients describe the 'what' of suffering whilst nurses explained the 'why'. The patients and nurses in this study found suffering remote and intangible but were keen to try and explain it by mentioning the reason for it. The nurses tried to find a meaning for suffering whilst the patients themselves found it hard to find suffering meaningful. The nurses thought this was because the patient could see no meaning in suffering whilst undergoing it but could realise it afterwards. Interestingly, the nurses also tried to find meaning in obviously meaningless suffering. Both patients and nurses felt that suffering should be alleviated or made bearable so that the person can endure it. The nurses described the alleviation of suffering as being based in the nurse-patient relationship, confirming patients' dignity, value and responding to immediate needs and helping patients to solve their current problems.

It is apparent that often the nurse's view of suffering, particularly in terms of meaning, is very different from the patient's. Identifying what suffering means to the person suffering is a complicated process that will be influenced by a number of factors. The nurse will use her knowledge of the causes of suffering to provide relief of symptoms, and the nurse-patient relationship to assess the person's response to their illness. However, this requires assumptions and inferences to be made about possible suffering in the face of events being experienced by the person. Personal values and life and work experience may play a part in assessing and inferring suffering in another.

1:3 Factors influencing nurses' recognition of suffering.

There are both nurse and patient factors involved in the recognition and relief of suffering, and the process is complex. The research into nurses' response to suffering has focussed on how nurses infer the degree of patient suffering operationalised as pain and distress (Davitz and Davitz, 1980; Mason, 1991; Oberst, 1978; Steeves et al, 2001; Sherman, 2004). Cues that people give to illustrate their distress affect the level of empathic response from the nurse who may respond to situational cues as well as patient cues.

Davitz and Davitz (1980) undertook a series of correlational studies, using a response to suffering Likert questionnaire, to establish baselines for whether nurses agreed on situations where patients may be suffering. The nurses were then interviewed to determine their response to particular patient situations where suffering may be present, and to elicit particular nurse characteristics that may influence their response. They found that nurses have common beliefs about suffering but patients' socio-economic status, age and ethnic background influenced the amount of suffering the nurse was likely to infer. Oberst (1978) used a written questionnaire giving descriptions of patient suffering, then asked nurses to rank the degree of suffering they thought patients were experiencing, based on a written list of patients' cues. She found that nurses were more likely to infer suffering if the patient stated it and greater visible pathology inferred greater suffering.

Davitz and Pendleton (1969) undertook a series of studies examining the factors that influenced nurses' response to suffering, and found that the area of care or diagnosis had little effect on nurses' inferences of patient suffering, but individual differences of nurses and patient characteristics did. Young adults were perceived by the nurses to be suffering significantly more than aged patients, although Oberst (1978) found that nurses inferred the greatest suffering among the oldest patients. The differences in these two studies were in the types of patients. In the Davitz and Pendleton (1969) study the patients were critically ill, whilst Oberst (1978) described patients who were moderately ill. Mason (1991), trying to identify selected factors based on previous findings, found that nurses' educational background, years of experience, clinical speciality, age or position did not influence nurses' inferences of patient suffering but patients' age did. Lenburg et al (1970) found length of time in training affects nurses' inferences of physical and psychological pain.

Steeves et al (1990) explored nurses' interpretation of the suffering of their patients using an interpretative method. Suffering could not be understood in terms of the features of a medical condition open to detached, objective scrutiny but was characterised by the person's reactions to events that befell them. Passage of time and critical practice incidents were essential to these different interpretations of suffering. Kahn and Steeves (1994) used a phenomenological approach, interviewing nurses to determine what suffering, coping and caring meant to them within the context of their clinical practice. Their study found that nurses viewed patients coping with suffering in three different ways:

- a rational problem solving approach to illness
- based on the values of the patients and the nurses and equated to whether the patient complied and conformed to the expectations of the health care system
- as strength or will of the patient in the face of adversity (Kahn and Steeves, 1994).

Clearly there are distinct variations between these and no mention was made of nurse or patient characteristics that may influence how they view suffering. However, Olsen (1997) found that nurses were influenced in the amount they cared for the patient, by whether the problems were self-inflicted, and the extent to which the patient took responsibility for their plight.

Inferring suffering is plainly fraught with difficulties and requires skill on the part of those involved. Nurses must assess the sources, depth and impact of suffering on patients (Spross, 1993). They must be careful not to reduce the experience of suffering to its underlying sources, signs and symptoms, whilst still being able to assess and understand the multiple factors that cause people to suffer. Self-awareness seems an important factor for nurses to ensure that they are not biased in their assumptions about the patient, which will affect their inference of suffering. There is little mention of suffering being determined by patient behaviour.

1:4 The nurse's role in the relief of suffering.

Nurses are often in a good position to assess and explain the patient's lived experience of suffering to others, especially when the patient is unable to do so, which is important for the identification of problems for other health care professionals and friends and family involved with the patient's care. The sufferer must be helped to find meaning in their suffering and transcend the situation to recover from or integrate the experience. In the absence of cure there may still be healing where patients are able to live their lives to the full despite their condition. To achieve this, negative emotions must be replaced by a sense of acceptance about their current position.

Palliative care *'integrates the psychological and spiritual aspects of patients' care'* and *'offers a support system to help patients to live as actively as possible until death'* (World Health Organisation, 2007). Emotional, physical and psychosocial distress are common as people confront the end stages of an illness, their lives and the consequent severing of earthly ties. Nursing is aimed at maintenance of the body rather than its restoration and needs to consider the unique features of each patient's situation.

Corner (1997) discussed the nurse's contribution to cancer care, proposing an integrated view of the patient that acknowledges the inseparable nature of mind and body. Haberman et al (1994) in a phenomenological study using interviews, found the caring behaviours of oncology nurses to be: being with patients, preserving dignity at the time of death, not giving up on patients, maintaining hope, minimising suffering, protecting patient privacy, sharing self. Georges et al (2002), in a qualitative study of palliative care nurses in an academic hospital, found that palliative care nurses thought knowing and being both available and sensitive to the patient were important to understand why the patient was acting in a particular way. Knowing the patient emerges as important as it allows nurses to help the patient accept their deteriorating condition and give them strength and comfort (Rittman et al, 1997). A collaborative therapeutic relationship may be the basis for helping the patient transcend their suffering and patients place great weight on strong relationships with health care providers and holistic care (Steinhauser et al, 2000).

The thorough assessment of the patient leading to the identification of what will help requires commitment and involvement (Georges et al, 2002; Radiewicz, 2001, Morse, 1996). Travelbee (1971), describing the nurse-patient relationship, suggests that if nurses find no meaning in suffering then they cannot help others to find meaning, face reality, cope and bear suffering. She maintained that only transcendence, the ability to get beyond and outside of oneself to perceive, respond to, and be with the sufferer, enables the nurse to be effective and grow - to focus on and help another while fully realising their own being. Lindholm and Eriksson (1992) stated that suffering itself has no meaning but man can give meaning to his own experienced suffering. Suffering is more fundamental than a feeling or pain, it is a dying that leads to a new life or to death. Some human suffering can be alleviated but not eliminated by true compassion. Involvement and interaction with the patient are necessary.

Chapter Two: The Nurse-Patient Relationship.

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The nurse-patient relationship: Introduction.

The interpersonal relationship between nurse and patient is thought to be the cornerstone of professional nursing (Pearson, 1988; Salvage, 1990; Morse, 1991; Wright, 1994; Savage, 1995; Ramos, 1992; Benner and Wrubel, 1989). The nurse-patient relationship is understood as the way nurses perform nursing, and some claim that beneficial care is only possible if an effective nurse-patient relationship is established (Peplau, 1952). Martocchio (1987) described four characteristics of the nurse-patient relationship: authenticity, emotional closeness, self-representation and belonging. Nurse and patient bring their whole selves – talents, needs and wishes, but the focus is on the patient's potentials and goals (Martocchio, 1987).

Peplau (1988), Georges et al, (2002), Ramos (1992) and Jones, (1999) discuss the importance of the nurse-patient relationship in understanding the patient's needs and helping them to overcome their suffering. Communication with patients is critical to gain accurate insight to identify symptoms directly responsible for causing suffering and ensure that this is based on the patient's not the nurse's ideas. Therapeutic presence is when nurse and patient relate to each other as whole being to whole being (McKivergin and Daubenaire, 1994) with nurse and patient acting together to solve patient's problems (Peplau, 1952). Trust is important for a therapeutic nurse-patient relationship and develops from an atmosphere of caring where the nurse treats the patient as a valued human being (Chambers, 2006), and demonstrates competency in undertaking nursing care (Botti et al, 2006).

The nurse-patient relationship can often provide the energy, support and motivation to face difficulties and undergo treatment. The nurse-patient relationship is complex and there are many influences that will ensure that it achieves the goal of alleviating patient suffering, or misses the aim and results in both nurse and patient distress. Much has been written about the nurse-patient relationship and its purpose and development within nursing. The focus of this account will be on the features of the nurse-patient relationship in palliative care. It is often heightened during the process of dying when the patient is especially vulnerable. Jones (1999) applied the concept of containment to the nurse-patient relationship in palliative care. Dying patients assign their anxiety to nurses who, in turn, help the person tolerate distress.

Several studies about the perception of the nature of their work as palliative care nurses reveal the importance nurses place on their relationships with patients (Rasmunssen et al, 1997; Rittman et al, 1997, Taylor et al, 1997; De Araujo & da Silva, 2004). Building relationships with patients, developing trust, acting as advocates, facilitating acceptance, helping patients to live fully, treating symptoms and staying with them as the condition deteriorates are all seen as important.

Nurses in palliative care often have to develop different levels of relationships to manage their own and patients' emotional requirements, but still they direct their care to providing hope, easing suffering and facilitating an easy death (Rittman et al, 1997). Mok and Chiu (2004) in a phenomenological study of palliative care nurses in a Hong Kong hospice, found that nurses aimed to alleviate suffering and took the initiative in the nurse-patient relationship but only some patients revealed their fears to nurses. However, the patients found their relationship with the nurse important for helping them to cope with the process of dying and feel secure. Aranda and Street (1999) examined the nurse-patient relationship in palliative care in a qualitative study, and found two contradictory expressions used by participants, that of being authentic, and being a chameleon. The nurse strived at being authentic whilst also adjusting their style to be what the patient needed or wanted.

The nurse-patient relationship demands a deliberate use and interpretation of complex cognitive, affective and behavioural knowledge to enable nurses to communicate to achieve therapeutic goals. Initially, nurse and patient have their own perceptions of the meaning and roles of each within the encounter. As they work together, they arrive at a mutual understanding of the situation and establish common goals that are patient focussed. Evidently, complex communication and behavioural skills and caring, empathy and involvement are important to develop a therapeutic nurse-patient relationship in palliative care and will be explored in more detail.

2:1 Caring.

A positive connection with the patient enhances nursing care (Olsen, 1999). The nurse must react to the patient's plight and care sufficiently to want to get involved and be motivated to help. Caring is said to be central to nursing, arises from a deep interest in humanity, and inherent in the process of providing care is the sharing of the suffering experience (Roach, 1984). Benner and Wrubel (1989, p1, p5) describe care as *'being connected to things that matter'* and *'a caring relationship is* *central to most nursing interventions'*. Roach (1984) discussed the five Cs of caring: compassion, competence, confidence, conscience and commitment. Compassion is a response and sensitivity to the plight of others allowing a quality of presence that allows sharing with, and making room for, others. It is a relationship with others, a way of life and indispensable to the caring relationship. However, compassion presupposes competence or having knowledge, skills, judgement, experience and motivation to respond to professional responsibilities. In other words, having the technical ability and knowledge to relieve suffering. Confidence fosters trusting relationships. Conscience is a state of moral awareness which directs behaviour. Conscience develops from experience, out of valuing self and others. Heidegger also describes conscience as the *'call of care and manifests itself as care'* (1962, p319). Finally, commitment is characterised by a convergence between one's desires and obligations and a deliberate choice to act on them. These five Cs are not mutually exclusive but build on each other to achieve caring. Caring encompasses both the nurse-patient relationship and the impetus for ensuring that physical and emotional aspects of care are performed with competence.

2:2 Caring in palliative care.

Quinn (2003), in a phenomenological study of 11 nurses to explore cancer nurses' experience of helping patients find meaning, found they valued the relationships they formed with patients and recognised that for a nurse-patient relationship to develop and help the patient with finding meaning, time and being there was necessary. They recognised the need for care and the intangibility of this aspect of their work. Rittman et al (1997) report, in a phenomenological study of six nurses caring for patients dying of cancer, that nurses were committed to participating in the experience and developing meaningful relationships with patients and their families which can be both rewarding and stressful. Five themes emerged: knowing the patient and their stage of illness, preserving hope, easing the struggle and promoting a peaceful death, providing privacy, and responding to spiritual aspects of the experience for both nurses and patients.

Mok and Chiu (2004), found that the nurse-patient relationship consisted of four main processes:

- Encountering in the caring process. The relationship developed on a continuum based on the nurse and patients' expectations of the role, involvement and reciprocity.
- Forming a trusting and connected relationship. Trust was important and was based on understanding the patient's needs, displaying caring actions and attitudes, providing holistic care and acting as the patient's advocate. All nurse participants chose to continue to work in hospice care because of the job satisfaction they obtained and because they felt enriched by their encounters with patients.
- Refilling fuel. The patients felt that their relationships with the nurse gave them someone to rely on and trust and they experienced themselves as someone who mattered. It was like being refuelled and gave them energy as well as helping them find meaning in life and easing their suffering.
- Being enriched. The nurses found that although the relationship was patient focussed, it enhanced their personal growth, allowed them to reflect on their own lives and to let go of many things rather than insist on them.

Trust, caring and reciprocity were important elements of the nurse-patient relationship and there was involvement of both nurse and patient. Care and sharing meant that both patients and nurses found meaning in palliative care.

However, time is necessary for nurses to develop trust and a caring nurse-patient relationship, and is often short in palliative care. Palliative care nurse specialists are often requested to make contact with patients late in their disease trajectory, and as such must develop a nurse-patient relationship within the limited time available. Hagerty and Patusky (2003) provide a framework for nurse-patient interactions based on the theory of human relatedness, which consists of four states of relatedness: connection, disconnection, enmeshment and parallelism, factors identified from existing literature (Hagerty and Patusky, 1993). Hagerty and Patusky (2003) argued that opportunities for goal achievement and connection may be taken even if time is short, and the patient's needs can be satisfied in short interactions. This may be important in palliative care where time is often limited by impending death.

It is clear that caring is important for palliative care and that it is of benefit to both patient and nurse. Caring seems to provide the impetus for the nurse to build a nurse-patient relationship, get to know the person and form a therapeutic relationship. These studies encompass the ideas postulated by Roach (1984) and Benner and Wrubel (1989). They also demonstrate some of the difficulties in defining caring and that it encapsulates a number of activities undertaken by nurses.

2:3 Empathy.

Carver and Hughes (1990) argued that to help the patient adjust to their illness, the nurse must interact with many others, which requires empathy. There are a number of definitions of empathy which has been variously conceptualised as an experienced emotion, a behaviour and a personality dimension (MacKay et al, 1990). Whilst there seems to be some agreement that empathy is multi dimensional, how the different components contribute to aspects that build therapeutic, problem solving relationships is not clear. Morse et al (1992), in an extensive review of the literature, identified four components of empathy: moral, emotive, cognitive and behavioural, which work together. Moral empathy is internal, altruistic and motivating, leading to emotive empathy where another's emotional state is shared. Cognitive empathy is where another's feelings are identified and understood intellectually. These lead to a behavioural response where empathy is communicated. Empathy is a process where an individual tries to think and feel like another but maintains their own identity by being objective, at the same time offering support and understanding.

There is a need for two levels of empathy, to both understand the patient's world and communicate that understanding (Reynolds, 2000; Egan 1986). The first is an attitude, which Rogers (1951) described as a way of being with another person. This includes warmth, genuineness and empathic listening which may be similar to, or influenced by, the moral and emotive components of empathy. The second is an operational level of empathy as a communication skill. This includes the helper's ability to communicate warmth and genuineness as well as their cognitive awareness of another's world. Empathic listening, as described by Rogers (1951), may be compatible with cognitive empathy involving imaginative reasoning and perception.

2:4 Empathy in palliative care.

Clearly there is a need for empathy in the nurse-patient relationship, but this is complicated in palliative care as the nurse needs to protect themselves from the pain of being involved with people who are going to die soon and may be suffering greatly. Mccaughan and Parahoo (2000), found that questions posed by the dying often go beyond the realm of expertise of many nurses. Some nurses find it very hard to communicate with the dying (Mccaughan and Parahoo, 2000; de Araujo and da Silva, 2004). Inexperienced carers may find it difficult to feel empathic due to insufficient exposure to suffering or being overwhelmed by the different situations experienced by patients. Some patients prefer to detach themselves and do not allow the nurse to become involved, which may make the role of the nurse harder as they may be less able to identify the cause of the patient's suffering.

May (1995), highlighted the importance of the nurse's role in helping patients come to terms with their impending death. May (1995), describes the work as in some way pastoral with the nurse expressing sympathetic concern and the patient revealing the most private aspects of their life. However, Morse et al (2006), argued that therapeutic empathy, a term borrowed from counselling psychology, where learned cognitive and behavioural communication skills are used to convey understanding of the patient's reality, is particularly unsuited for use in the clinical setting. Rather than enabling the sufferer to gain insight, a more appropriate model is one that places emphasis on the nurse's emotive engagement or embodiment with the patient. They argued that a learnt communication style used in counselling, where people are in crisis or have not come to terms with their situation, is rarely suitable in clinical practice. People who are in a state of enduring need to be helped to remain in control, not encouraged to move to a state of emotional suffering that they may not be ready or able to deal with at that time. Empathic statements can result in refocusing the person to a state of suffering that is inappropriate for them to manage with their current resources. Morse et al (2006), described the importance to the sufferer of behaviours that are spontaneous responses to being confronted with another's suffering such as pity, sympathy, compassion, commiseration, consolation and reflexive reassurance. They maintained that when caregivers try to reduce their own emotional responses to the sufferer, thus decreasing their personal investment in the suffering, they use responses such as informing reassurance, humour/distraction and confronting learned in therapeutic empathy. Their emotional involvement is more limited and they must try to imagine what it is like for the sufferer. They argue that emotional empathy or the intuitive sensing and response to another's plight may be more appropriate.

Prolonged stress resulting from caring can lead to complete emotional blocking on the part of the caregiver, who is completely detached from the sufferer. There is a need for the nurse to protect themselves from involvement with the patient and possible overwhelming distress, but the patient needs care and this may be absent if the nurse is not involved. Morse et al (2006) described the ways in which distance is created as shielding, withdrawing and guarding which reduce the nurse's sensitivity to the sufferer's experience. There are problems with this type of communication which may lead to labelling, dehumanising, distancing and denying, which change the nurse's perception of the suffering. The resulting detachment enables the nurse to continue to give care and manage the resulting stress. However, the nurse's responses are repressed and a front is presented to the patient, who may be aware that they are not being treated as an individual. Therapeutic nurse-patient relationships depend on the ability of the nurse to comprehend the subjective world of the patient. Individualising care means having more than a superficial knowledge of the patient and knowledge of symptom relief, however there are difficulties in achieving truly person centred care.

Maeve (1998) maintains that being in a relationship with a patient means sharing any pain or suffering that may be experienced as well as any joy. She is careful to explain the difference between empathy and embodiment, maintaining that the former is the ability to imagine the subjective state of another whereas in embodiment the experiencing physical body of the nurse is not separate from the relationship with the patient, thus the nurse is able to share the emotions felt by the patient. The opposite, or disembodiment, means dissociating consciousness from one's body to avoid feeling the suffering, or other emotion, of another although it is still possible to be empathetic. Schroeder (1992) noted that nurses frequently disembody so that they do not suffer while their patients are in pain. Arguably, nurses must do this to tolerate the realities of caring for patients who are suffering. However, Schroeder (1992) maintained that disembodiment stops nurses from questioning what she termed 'morally ambiguous acts', such as inflicting painful procedures, and that it is important for nurses to remain embodied and caring. Graham (2005) undertook a study to uncover the meaning of the lived experience of mutual suffering in relation to the care of a dying patient. He found that mutual suffering is a transformational process leading to professional confusion and personal crisis, but that it involves new beginnings and clarification of beliefs and values.

2:5 Involvement.

The nurse-patient relationship can be a source of education, personal growth and self-actualisation for both patient and nurse (Mok and Chiu, 2004; Morse, 1991; Peplau, 1988; Rasmunssen et al, 1997; Turner, 2001). There are advantages to professional involvement in that it can provide job satisfaction and personal fulfilment whilst providing the patient with someone to confide in, gain support from and trust during a stressful time. There are also disadvantages, including the patient relying too heavily on the nurse and emotional pain for the nurse (Turner, 2001), and loss of patient self-reliance (Stuart, 2001). There is a need for the nurse to manage involvement with the patient, which has been considered by a number of authors.

May (1991), in a grounded theory study of nurses in Scotland, found three dimensions of nurse-patient relationships which underpin nurses' accounts of involvement. These are knowledge about the patient, reciprocity and the focussed investment of clinical and managerial skills to meet the aims of care. May (1991) relates these to three models of involvement in the nurse-patient relationship.

- Primary involvement, where an equilibrium is maintained between the nurse's private aspirations and institutional role and objectives and is patient orientated.
- Demonstrative involvement, where an overemphasis on reciprocity leads to problems in the nurse's maintenance of appropriate roles and is nurse orientated.
- Associational involvement, where reciprocity is rejected and investment is emphasised, and is organisation orientated. Care is given but patients may feel alienated from the staff who could respond to their psychosocial needs.

Morse (1991) in a qualitative study, identified four types of mutual relationship according to the duration of contact between nurse and patient, the needs of the patient, the commitment of the nurse and the patient's willingness to trust the nurse. These are clinical relationship, therapeutic relationship, connected relationship and over involved relationship.

- Clinical relationships occur when the patient is being treated for something minor and contact between the nurse and patient is brief. Interaction is superficial and there is little personal involvement.
- Therapeutic nurse-patient relationships, where the nurse views the patient as first a patient and second as a person outside. The patient expects to be treated as a patient and has their own support system. Any of the patient's psychosocial needs to be met by the nurse are routine.
- Connected relationships where, while maintaining a professional perspective, the nurse views the patient as first a person and second a patient. They have been together long enough for the relationship to have evolved beyond a clinical or therapeutic relationship and the process is accelerated by the patient's extreme need. The patient chooses to trust the nurse and the nurse meets their needs.
- Overinvolved relationships occur when the patient has extraordinary needs and the nurse chooses to meet these needs, or they have been together for a long time and mutually respect and care for each other. The relationship continues beyond work and both relinquish impersonal roles.

The relationship between nurse and patient is the result of interplay or covert negotiations until a mutually satisfying relationship is reached. It is argued that the intensity of the negotiations depends upon the patient's perception of the seriousness of their situation and their feelings of vulnerability and dependence. Unilateral relationships occur when either the nurse or patient prevents the development of an involved relationship although the commitment to care may still be present. Both nurse and patient have control over factors that increase and decrease the level of involvement.

An exploratory study by Ramos (1992) used interviews of 15 experienced nurses using critical incidents. She found that the ongoing bond between nurse and patient was described as a modified social relationship where the tenor of the bond was as variable as the personalities of those involved. Liking was the stimulus for bonding, although the relationships were professionally rather than socially driven. Three levels of often overlapping involvement in the nurse-patient relationship were described.

- The instrumental level, which was task orientated and involved little interaction, occurred when the participants were strangers, the patient was unconscious, the nurses could only spend minimal time with the patient and when instrumental needs were overwhelming. The relationship could remain at this level if the patient was receiving support from elsewhere, the nurse was too busy to talk or the patient and nurse were incompatible. It could also deepen with further contact. One possible outcome was the pure emotional impasse where there was an emotional involvement devoid of cognitive mediation and resembling sympathy. The nurses told of an emotional quagmire where they were non productively enmeshed with the patient and unable to put their feelings aside. These nurse-patient relationships were unproductive and the nurses were afraid of burning out.

- The protective level with an emotional component where nurses had the beginnings of a balanced emotional and cognitive connection with the patient. It was described as a unilateral connection, with the nurse retaining control of the process. This type of relationship preceded the deepest bond or happened when the patient was unconscious or otherwise compromised in communication. The nurses tried to understand what the patient was feeling but their actions were based on their own values, wishes and knowledge. Care was determined based on what the nurse thought the patient might want and their professional views on what was needed. There was no negotiated care. This could be the end point in the relationship if communication was not good enough to allow negotiation between nurse and patient. The relationship could also pass into level three if it did not proceed to a control impasse. The control impasse occurred where the patient failed to acquiesce to an attempt to establish a protective relationship using the nurse's expert knowledge and authority.
- The reciprocal relationship with resolved control issues. This was a mutual relationship requiring some of the nurse's energy, but energised by taking on the patient's burden. There was cognitive and emotional identification with the patient. The nurse evaluated the patient with emotional content, with her own feelings identified and isolated, but without emotional overinvolvement. The outcomes in these third level relationships were described as positive.

Reciprocity and involvement seem problematic and it is evident that whilst nurses may gain from the nurse-patient relationship, reward is not to be expected. These studies show that the most beneficial nurse-patient relationships are those that are patient rather than nurse led. It is clear from this work that there is a fine line between a productive nurse-patient relationship that allows intimacy and involvement on the part of both nurse and patient and one that is not functioning.

2:6 Involvement in palliative care.

Palliative care nurse specialists are continually developing relationships that will be broken with the patient's death. Palliative care involves sharing the suffering of patients and many nurses describe intense emotions in response to their clinical encounters (Hinds, 1992; Cohen, 1995). De Araujo and da Silva (2004), in a small qualitative study to discover how nurses cope with daily confrontation with death and dying patients, found that dealing with the suffering of patients and their families produced feelings of depression and melancholy in the nurses and that they felt the suffering of their patients. Rowe (2003) identifies reverberations with the past; expectations; guilt; vulnerability; high cost of empathy; inflicting pain; silence; healer's spiritual or philosophical beliefs as sources of threats to those who are caring for suffering people.

Nurses need to separate their own response from the patient's response so that care is tailored to the patient's feelings. Morse (1991), Vachon (1998) and Radweicz (2001) highlight the dangers of becoming over-involved whilst Wright (1994) believes that nurses should set clear limits to their involvement. It is recognised that over involvement may lead to compromised patient care and stress in nurses (Turner, 2001; Morse, 1991; Ramos, 1992). Involvement must be controlled so that other patients may be dealt with and emotional exhaustion avoided. However, despite evidence that overinvolvement is harmful and involvement must be managed, there is little literature on how this may be achieved. Turner (2001) used grounded theory, to develop a theory of managing involvement for cancer nurses. Her theory identified becoming involved, experiencing overinvolvement, developing awareness, controlling involvement and being involved as the stages of learning. She suggests that involvement needs to be kept within the boundaries of a professional relationship if it is to be sustainable. Methods of controlling involvement include detached therapeutic empathy (Morse, 2006), establishing boundaries on involvement and leaving work behind when off duty (Turner, 2001).

It may be hard to live up to the ideal of achieving genuineness, authenticity, honesty, empathy and embodiment with all patients. Some patients will be reluctant to allow the nurse to get close to them and want care without intimacy. Nurse and patient may be unable to achieve a rapport due to disliking each other or having nothing in common on which to base a relationship. Further, people are often at their worst when ill and it may be difficult to feel empathy and patience with someone who is angry, childish or unpleasant. At these times, understanding the reality of the illness experience and applying knowledge and skills to help the patient in a non involved way using therapeutic empathy may ensure that the patient continues to receive care and the nurse does not become exasperated and give up. It may be impossible to get close to every patient but good care may still be achieved. Distancing tactics clearly serve a purpose to protect both nurse and patient, although they do not coincide with the ideal of the nurse-patient relationship. The relationships formed with patients who are facing death may be difficult. Constant exposure to suffering that is shared and experienced by the nurse and evokes empathetic insight can emotionally drain the nurse.

Chapter Three: Stress and Coping.

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Chapter Three: Stress and Coping.

Stress: Introduction

Stress is an imbalance between perceived external demands on a person and their ability to cope through cognitive, behavioural and physiological adaptation (Cox, 1978). There are two major views of stress based on the models of Selye (1956) which identifies the physiological and endocrinological processes, and Lazarus (1966) and Lazarus and Folkman (1984) which propose an interactionist view. The first is concerned with the person's response to disturbing or noxious environments. The second proposes a lack of fit between the person and their environment. Stress seems to rise with a sense of futility, emotional burn out from the perception of achieving nothing, as well as factors such as individual coping mechanisms, colleagues and job factors. Cherniss (1980), clarified the difference between burnout and temporary fatigue or strain. Stress can manifest in physical symptoms, emotional and physical fatigue and complaints about the job. Burnout describes a complex of psychological responses to the strain of constant interaction with people in need. Maher (1983), described a composite syndrome including exhaustion, psychosomatic illness, insomnia, negative attitude to clients and work, use of alcohol or other drugs, altered self concept, guilt, pessimism, apathy and depression. Maslach et al (1981; 1982), focus on three processes centred on loss of respect for patients. These are emotional exhaustion, depersonalisation and perceived lack of personal accomplishment. All definitions have in common the feelings of ineffectiveness and futility, giving up all attempts to improve things and increasing conformity and rigidity.

Stress in professionals has been considered by a number of authors using mixed method research (Lazarus, 1984; Firth et al 1986; Ramirez, 1996; Vachon, 1987; Radiewicz, 2001; Georges et al, 2002). Qualitative research to assess the individual's psychological reaction and quantitative research using scales and questionnaires to determine which parts of the role are difficult. Maslach et al (1981; 1982) developed a burn out inventory to examine levels of stress and coping. These researchers assume previous work that has been undertaken on the biological (Selye, 1956) and psychological response to stress (Lazarus, 1984) and focus on factors that cause stress and individual coping mechanisms. They rely on self-reporting by professionals.

3:1 Stress in palliative care nursing.

Stress among nurses has been examined in a number of different clinical settings (Benner and Wrubel, 1989; Vachon, 1987; Herschenbach, 1992) and palliative care is considered a highly difficult area of work (Radiewicz, 2001; Ramirez, 1996; Vachon, 2001; Jones, 1999; Georges et al, 2002). Death and dying is one of the most stressful areas of care (Menzies, 1970; Turner, 2001; Davitz & Davitz, 1975; Vachon, 1998; Radiewicz, 2001; Jones, 1999; Ramirez, 1996). Nurses are affected by negative emotions when exposed repeatedly to dying and suffering patients (Menzies, 1961, Field, 1984; Benner, 1989, Morse, 1997, Davitz and Davitz, 1980; Georges et al, 2002). Stress is potentially exacerbated when individuals are constantly faced with awareness of their own mortality, and the termination of intense relationships. Barrett and Yates (2002) found emotional exhaustion a concern, findings supported by Ergun et al (2005) who found a negative impact on quality of life in oncology nurses. The need for coping and adaptation is highlighted.

Working with patients who are suffering can cause feelings of helplessness, inadequacy, depression, despair and anger (Davitz and Davitz, 1975). Nurses can often feel overwhelmed by the complexity of care, both psychological and physical. If unable to alleviate distressing symptoms due to insufficient knowledge, they may feel inadequate and helpless (Steeves et al, 1990; Radiewicz, 2001). White (2004) undertook a study in Australia to describe the impact of unrelieved suffering on nine experienced palliative care nurses using semi-structured interviews, and found that unrelieved suffering was a source of stress. The nurses put boundaries around suffering at work but some took suffering home with them and felt too depleted to give much to their personal life. Factors that increased the impact were the nurse's connection to the patient, their clinical experience, personal stress and time spent at the bedside. Strategies that helped ameliorate the impact were support from colleagues, family and friends. Help was often needed immediately rather than some days later. Davitz and Davitz (1980) suggest that for some nurses, patients' suffering may be a source of threat that elicits anxiety. They concluded that nurses who work closely with those who are suffering are likely to use selective inattention as a coping mechanism to reduce their own anxiety. A problem arises when this leads to the nurse maintaining a psychological distance from the patient. Patients' feelings are less likely to be taken into account and nurses are probably less effective at relieving patients' distress (Davitz and Davitz, 1980; Morse et al, 2006). There seems to be a need for sharing care but not becoming so emotionally involved that objective and individualised patient assessment is coloured by prior knowledge or personal feelings.

Losses in oncology nursing have been defined as loss of close relationship with the patient; identification with pain of family members; unmet goals and expectations; personal beliefs and assumptions about life; past unresolved losses or anticipated future losses; and the death of self (Papdatou, 2000). Mount (1986) reflected that in oncology, losses become an integrated part of professional life and that they can modify and augment other personal and professional life stresses. Vachon (1987) highlighted patients and families, particularly where there were coping or personality problems, where communication was difficult or where they identified with the patient and family, as a source of stress in people who worked with dying and critically ill patients. Nurses have different reactions to different patients depending on the extent to which they can identify with them (Kiedel, 2002). Omdahl and O'Donnell (1999) found emotional contagion, where emotion is shared, positively associated with burnout, whilst empathic concern and communicative responsiveness, where there is concern communicated but no sharing of emotion, was associated negatively with burnout. Their study found none of the burnout dimensions of empathy were correlated with experience, and the study was not specific to particular types of nursing.

A number of factors have been shown to affect nurses' response to working in palliative care. Radziewicz (2001) identified risk factors for psychiatric morbidity in palliative care as young age or few years in palliative care, low job satisfaction, inadequate training in communication or management skills, personal life stress and previous psychological difficulties. Younger nurses have been reported to have more manifestations of stress and fewer coping strategies (Vachon, 1987; 2004 Brewer and Shaphard, 2004; Radiewicz, 2001); being female has been found to be associated with burn out (Vachon, 2004); and spiritual and religious belief systems have been found to help (Vachon, 2004; Schaufeli and Greenglass, 2001). Certain personalities are more susceptible to stress and compassion fatigue, including people who are overly conscientious, perfectionist and self-giving (Kiedel, 2002). Hardiness, which consists of the characteristics of control, commitment and challenge, has been associated with decreased burn out in oncology nurses (Duquette et al, 1995;

Papadatou et al, 1994) as has resilience or the ability to bounce back (Wagnild and Young, 1993).

The work environment and other colleagues can be a major source of stress (Plante and Bouchard, 1996; Cohen, 1995; Steeves et al, 1994; Vachon, 1998; Georges et al, 2002). High patient to nurse ratios are associated with increased stress levels (Aiken et al, 2002). Occupational role and work environment, particularly where there is lack of control, communication problems with colleagues and unrealistic expectations from the organisation can cause stress (Vachon, 1987). Barnard (2006) and Botti et al (2006), in exploratory studies to investigate the association between perceived stress, perceived work supports and burnout, found that poor communication about patients between doctors and nurses and not having enough time to achieve all the work necessary were main sources of stress, and that most work support came from peers. Poor teamworking is also a source of frustration (Barrett and Yates (2002). Schaufer (1990), in an extensive review of the burnout literature, found that burnout is particularly associated with work overload, lack of social support and role stress. Janssen et al (1999) found that emotional exhaustion was primarily predicted by lack of support from colleagues, work overload and time pressures. The individual's personal circumstances and problems outside of the work environment can influence their ability to deal with stress within the job (Kiedel, 2002;Vachon, 1995; 1998). Participating in a network of caring reciprocal relationships has a protective effect against stress (Vachon, 1998; Larson, 1993).

However, studies have also shown that staff working in oncology and palliative care settings have less stress and burnout than other professionals (Vachon, 1987; 1995; Ramirez et al, 1995; Payne, 2001; Bruneau et al, 2004). Field (1984) found that whilst caring for dying patients was not always easy, it was also rewarding as it allows nurses to fully implement their ideal of nursing care, a view supported by da Araujo and da Silva (2004). Engaging with patients who are dying often gives nurses the opportunity to deal with their own mortality and to develop ease and familiarity with death. Nurses can feel empowered when they experience reciprocity with patients and perceive their care as meaningful (Rasmunssen et al, 1997). Professional caregivers working with terminally ill patients also report high levels of job satisfaction (Deloach, 2003). Clearly, some nurses work in palliative care for many years and suffer no stress and there are those who have learnt to cope with the stressors generated by the role.

3:2 Coping.

Coping with stress or burnout has been discussed by a number of authors (Lazarus, 1984; Firth et al 1986; Ramirez, 1996; Maslach, 1981,1982; Kiedel, 2002; Vachon, 2001) and revolves around two main approaches.

- The first is trying to change what it is possible to change.
- The second is adapting to what cannot be controlled.

The transactional model of coping (Lazarus, 1984) proposes that the environment and the individual act upon each other and that this relationship is a dynamic process. Stress is mediated by one's response to the stressors (Lazarus, 1984; Firth et al, 1986; Vachon, 1987; Steeves et al, 1994). Folkman (1997), revised existing coping theory to include the role of positive psychological states, which describe coping as a response to stress, rather than the conditions creating stress. The individual finds meaning in the events and adjusts their strategies for dealing with events to include positive benefits from essentially negative situations.

3:3 Coping in palliative care nursing.

Methods of coping often involve maintaining a distance from the patients (Davitz and Davitz, 1980; Morse, 2006). Nurses try to protect themselves from being overwhelmed with emotions by distancing themselves from the situation by focussing on tasks to be performed or sharing the care burden with colleagues. Georges et al (2002), found that nurses working in palliative care tried to remain authentic and stay close to patients even when they could not alleviate their problems, although this approach was less commonly adopted than one of distancing. The nurses recognised the pain of caring for patients who are dying and tried to preserve themselves whilst also trying to help the patient. Rittman et al (1997), discuss how nurses limit their relationships with patients to protect themselves from excessive emotional demands, an argument supported by the work of Payne et al (1998) who found that nurses focussed on physical care, thus protecting themselves from patients' emotional reaction. This distancing seems to occur over time and has been studied in the hospice setting (Rasmussen et al, 1997; Rittman et al, 1997; Payne et al, 1998; Payne, 2001).

Cohen (1995) in a study to explore the meaning of cancer nursing, found aspects that are rewarding, such as doing the job well and becoming involved with the patient, can also be difficult. Telling the truth was seen as both important so that patients and their families could make their own experiences meaningful, and difficult as it means identifying the person's ability to handle the information and cope with its implications. The nurses also noted that they suffered with patients, had emotions evoked by patients and mourned because they cannot cure all patients. They discussed the importance of time out from work and their personal relationships in protecting them from stress. Turner (2001), found that nurses employed two particular strategies to manage involvement. The first, setting boundaries, enables nurses to make a conscious decision about how far they will take their personal involvement. The second, switching off, means that the nurse stops thinking about work when they go home and is able to get on with life outside work.

The more experience and knowledge a nurse has, the better able they seem to be at managing their involvement. As they develop maturity they become more aware of the effects of their behaviour both on themselves and those around them (Turner, 2001). Farber et al (2003) and de Aruajo and da Silvas 2004), found nurses were aware of the need to attain emotional balance in order to give good care to patients and deal with the suffering encountered in their day to day work. Farber et al (2003), in a study of health care professionals including nurses, found that less experienced clinicians focussed on technical aspects of care. Those with more than 10 years experience focussed on their commitment to the patient and family and developing open and trusting relationships. They were able to recognise the stressful nature of end of life care and understand it from both the patient and family's point of view and their own. These studies indicate that coping with involvement seems to develop over time and is a balance between caring about the patient but not getting over involved.

Maeve (1998), undertook a study to explore how nurses live with suffering and dying patients. Naturalistic inquiry was used to interview nine nurses, who were asked to relate what it was like to care every day for patients who were dying. She found that the nurses did not just provide care for their patients and then go home, caring was an integral part of who the nurses were as human beings. 'Weaving a fabric of moral meaning' was identified as the core descriptive phenomenon with three supporting themes of tempering involvement, doing the right thing/the good thing and cleaning up. Aspects of tempering involvement were: setting boundaries/limits, coming to love or not love a patient, experiencing embodiment/disembodiment and using humour. Tempering involvement allowed the nurses to set limits on how involved they would become with patients and also functioned as a way for the nurses to clearly distinguish their patients' lives from their own. It also allowed them to continue to care for patients whom they did not like. They acknowledged their moral duty to care for the patient but worried about what their dislike of a difficult patient said about them as a person. Doing the right thing involved two processes of coming to know what the right thing was and being able to do the right thing; the former being a moral dilemma and the latter a matter of competency, commitment and courage. Cleaning up marked the end of the involvement and gave the nurse the chance to review the situation and what it meant to them personally.

A sense of competence, control and pleasure in work gives a sense of accomplishment and helps palliative care professionals find meaning in their work (Vachon, 1987, 1995). A personal philosophy of illness, death and one's purpose in life is essential for many care givers and may involve a spiritual or religious belief (Vachon, 1987; 2004). Ceslowitz (1989), in a study of 150 nurses, examined the relationship between use of coping strategies and levels of burnout using Maslach Burnout Inventory and Ways of Coping tools. She found that those who had lower levels of burnout used positive reappraisal, problem solving and seeking social support. Escape/avoidance, confronting and self-controlling were used by those with higher levels of burnout. Payne (2001) supported these findings in a later study of female hospice nurses.

A number of other approaches have been suggested to avoid stress and burn out, which include taking care of oneself and keeping work in perspective (Ellis, 1997; Turner, 2001; Vachon, 1998). Lifestyle management that enables the individual to recognise when they are stressed and take a break, exercise and other outside work activities, good diet and adequate rest all help (Vachon, 2002). Personal coping mechanisms described by palliative care professionals are support from family and friends and managing one's lifestyle (Vachon, 1998).

Coping skills are not innate but developed over time in response to different stressors and experience (Lazarus and Folkman, 1984), are encouraged by being successful and effective and can be taught (Krishnasamy, 1996). Coping is assisted by removing minor problems, which enables the person to concentrate on coping with major stressors. Rowe (2003), suggests that a framework for dealing with threats may be found in Soelle's (1975) three phases of suffering mute, lamenting and changing. Mute suffering is likened to burnout, lamenting allows the healer to make changes like reframing suffering and expectations of what can be accomplished, and in the changing phase the healer is able to work at changing existing work structures and find support from others. Normalising the experience of work related grief in palliative care has been found to facilitate coping in oncology nurses. It can be achieved by programmes designed to enhance coping skills to reduce stress, fostering supportive relationships and team meetings to discuss shared problems (Medland et al, 2004; Vachon, 1995).

Conclusion to the Literature Review.

Despite the centrality of suffering to the work of health care professionals there is limited literature (Cassell, 2004; Lesho, 2003). Palliative care nurses have chosen to work with patients who are undergoing a difficult life passage and must determine what is causing patients' distress and help them transcend their suffering. Understanding suffering, its causes and ways to identify and alleviate it, seem crucial if the nurse is to care for the patient.

The nurse-patient relationship enables patient suffering to be identified and facilitates patients' coping mechanisms to redefine goals (Martocchio, 1987; Morse, 1991; Wright, 1994; Peplau, 1988). It is a way to achieve understanding of what suffering means to the patient and help them transcend their distress. The problem for palliative care nurses seems to be finding ways to guard against overreaction to suffering that lead to protective psychological mechanisms, which interfere with effective nursing care and nurse functioning. Involvement with suffering influences care giving, leading nurses to comfort and sustain or diminish and/or abandon the sufferer. Nurses are challenged to find meaning, resist burn out and learn how to comfort and support the patient. Strong, often negative emotions may arise during the course of their work which they must learn to deal with whilst at the same time being authentic and empathic (Field, 1984; Menzies, 1961; Davitz and Davitz, 1975; Turner, 2001; Ramirez, 1996; Jones, 1999; Georges et al, 2002; Vachon, 1998). There is research that considers the nurse's response to caring for those for whom there is no cure and who are dying (Menzies, 1961; Field, 1984; Maeve, 1998; Hopkinson et al 2005) and into how nurses manage involvement with patients (Turner, 2001; Jones, 1999; Georges et al, 2002; Rittman 1997).

There is a recognised deficit in the literature on the personal impact of working with patients who are suffering (Ergun et al, 2005; Barrett and Yates, 2002). It is clear that there are many ways in which nurses react to, and are influenced by, suffering. It may be that the nurse's personal views on suffering influence their development of the nurse-patient relationship and subsequent goals of care, and also their ability to cope with working with patients who are suffering. The challenge is to achieve a nurse-patient relationship that enables the identification of what suffering means to the patient by being emotionally close and true to oneself, but also maintaining the necessary personal boundaries, a personal life philosophy, supportive work environment and having mechanisms outside work to manage stress and avoid burn out. Individual differences between nurses may be important factors when considering the ways in which palliative care nurses cope with patient suffering.

There would seem to be a complex relationship between the identification and alleviation of suffering, the nurse-patient relationship and palliative care nurse specialists' management of their personal response to working with patients who are going to die. Complex skills may be needed to develop a therapeutic nurse-patient relationship and an in depth understanding of suffering and how it may manifest. Finally, palliative care nurse specialists must manage the personal impact of working with patients who are suffering. The researcher was unable to find any studies that specifically explored palliative care nurse specialists' understanding of suffering and whether this influenced the development of the nurse-patient relationship and the personal impact of working with patients who are suffering.

Part Two: Research Design.

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Part Two: Research Design.

Introduction.

There is a wealth of literature stating that it is important for nurses to develop good nurse-patient relationships and become involved with the patients in their care (Kriedler, 1984; Benner and Wrübel, 1989; Morse, 1991; Jones, 1999) but it is important to avoid over involvement (Ramos, 1992; Ray, 1991; Morse, 1991; Turner, 2001). There is plenty of literature about stress and burn out in high intensity clinical areas such as oncology and palliative care but less about the personal impact of working with suffering (Ergun, 2006; Barrett and Yates, 2006). It is also not clear how palliative care nurses understand suffering and if this affects their personal response to patient suffering and management of the nurse-patient relationship.

My experiences of working with cancer and palliative care patients led to an understanding of the issues involved and have motivated me to explore what it means to others working in this field. The study was an exploration of palliative care nurse specialist's understanding of suffering, management of the nurse-patient relationship and the personal impact of working with patient suffering. Palliative care nurse specialists manage suffering and have often learnt how to cope with caring for those for whom there is no cure and who are dying, otherwise they could not continue to do the job. Their work with patients who are suffering may provide more information on the concept of suffering. Their experience and understanding of suffering, management of the nurse-patient relationship to manage suffering, and the personal impact of working with patients may be helpful and informative.

Part Two consists of four chapters that explain the research design and the reasons for selecting the approach. It Chapter Four discusses the method and why it was chosen. Chapter Five explains the data collection and Chapter Six, the data analysis. Chapter Seven discusses issues of rigour.

Chapter Four: Research Method.

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Chapter Four: Research Method.

Aims of the Study.

Exploration of palliative care nurse specialists' understanding and management of suffering and the personal impact of working with patients who are suffering was the main purpose of the study.

The research aims were to explore palliative care nurses': -

- Understanding of suffering and their experiences of working with patients who are suffering.
- Management of the nurse-patient relationship with patients who are suffering.
- Personal experience of working with patients who are suffering.

The research intended to be an exploratory study and was not intended to be statistically generalisable. However, it will have case to case generalisability and may be applicable to other settings. It will be of interest to others in the field and the information may be used for the preparation of nurses to work in the field of palliative care.

4:1 Choosing a research methodology.

The nurse's understanding of suffering and experience of working with patient suffering are likely to be very individual so a qualitative approach is an appropriate research methodology. Qualitative research involves a *'systematic, subjective approach used to describe life experiences and give them meaning'* (Burns and Grove, 1997, p 393). Exploratory or descriptive research makes no assumption of an objective 'truth' and the aim is to show up meanings that arise out of the lived experience so as to reveal meanings, skills and practices often hidden in more quantitative research (Benner, 1994). A qualitative approach will allow exploration of palliative care nurse specialists' experience of caring for patients who are suffering and enable data to be obtained about what this means to them in their work and personally.

Polit and Hungler (1999), suggest that decisions about which research methodology to employ must be guided by the purpose of the research and the questions to be answered. Many authors have noted that phenomenology as a philosophy and research approach allows exploration and description of phenomena important to the nursing discipline (Beck, 1994; Caelli, 2000; Van de Zalm and

Bergum, 2000). A holistic perspective and the study of lived experience are the foundations of phenomenological inquiry. It is a useful approach if there is a need for clarity of the chosen phenomena and/or because there is little already published research. If sharing of the lived experience is the best data source for the investigation, there is adequate time available, and the researcher's style is suitable, then a phenomenological research approach is a good method. A phenomenological hermeneutic approach is essentially designed to uncover otherwise concealed meanings in the phenomenon. It is often used in nursing, as it is a way of interpreting situations where the meaning of the phenomena is not immediately understandable. In view of the aims of the research, phenomenology was an appropriate research method.

In the phenomenological sense, knowledge does not inform practice. However, the reflection on practice results in understanding, which in turn enlightens practice (van Manen, 1997). Hermeneutic phenomenology aims at gaining greater understanding of the nature or meaning of experience (van Manen, 1997). Discovery of knowledge, that is *Verstehen* (understanding), is found in sharing common meanings of mutual history, culture and language of the world as it is lived together (van Manen, 1997). Knowledge arising from phenomenological inquiry becomes practically relevant in the way a professional communicates with, and acts towards, another. It reforms understanding and leads to more thoughtful action (Van der Zalm & Bergum, 2000). Thus an exploration of palliative care clinical nurse specialists' understanding of suffering, how they manage the nurse-patient relationship to identify and alleviate suffering and what working with patients who are suffering means to them personally, may result in greater understanding. It may change the way in which these nurses relate to their work in future.

However, in considering the methodology, it cannot be overlooked that there are many criticisms of the way in which nurse researchers describe and use the phenomenological method (Koch, 1995; Crotty, 1996). Arguably, mainstream phenomenologists and nursing phenomenologists are engaged in different tasks. Mainstream phenomenologists are interested in a phenomenon rather than a group of people, which is often the case with nursing phenomenologists. Crotty (1996) discussed the uses of phenomenology in nursing and pointed out that often nurses emphasise the subjective lived experience at the expense of the phenomenon of interest. New phenomenological research methods (Giorgi, 2000; Collaizzi, 1978;

Van Kaam, 1969) should only be used if the researcher wants a subjective understanding of the phenomenon from the participants' viewpoint. If understanding of the phenomenon itself is required philosophical phenomenology should be employed (Crotty, 1996).

The purpose of this research study was to learn about both the palliative care nurse specialists' lived experience and what is understood about suffering. The principal aim was to answer certain questions about palliative care clinical nurse specialists' experience of working with people who are suffering. The study also aimed to describe the concept of suffering as understood by the palliative care nurse specialists. These descriptions being obtained from their lived experience of suffering and the researcher's interpretations of these. The study was concerned with the phenomenon of suffering and palliative care nurse specialists were chosen as participants as they work with suffering and may have developed a view and understanding of the phenomenon. Van Manen (1997) and Giorgi (2000) observe that the aim of phenomenological research is exploring the nature of a phenomenon as essentially a human experience. Thus, the phenomenon of suffering may be explored through palliative care nurse specialists' experience, as suffering is a human experience and as such difficult to elucidate without human experience. Additionally, the study is interested in the lived experience of working with patients who are suffering and what understanding of the concept of suffering means to palliative care nurse specialists and their care.

A phenomenological approach seemed best suited, but it is in the vein of nursing phenomenological research as described by Benner (1984) and using new phenomenological methods (Collaizzi, 1978; van Manen, 1997) that the research was undertaken. The palliative care nurse specialists were well placed to comment on the concept of suffering, but also their personal experience of working with patients who are suffering lays a practical slant on the research which is highly relevant for nursing. Arguably, this research consists of both mainstream phenomenology and nursing phenomenology as argued by Crotty (1996). van Manen (1997) uses description to include both interpretative and descriptive phenomenology and provides a structure to phenomenological reflection that will be used through this research. Van Kaam (1969), Collaizzi (1978) and Giorgi (2000) employ a similar series of steps to describe, reduce and search for essential structures:

- The original descriptions are divided into units.

- Units are transformed by researcher into meanings experienced in psychological and phenomenological concepts.
- The transformations are combined to create a general description of the experience (Polkinghorne, 1989).

Collaizzi's (1978) method is regarded as suitable for Heideggerian phenomenological research as his final step involves the researcher returning to participants and asking for their view on the descriptive results compared to their experience, which suggests interpretation as well as description (Fleming, 2003).

The difficulties in using an essentially philosophical approach to explore a phenomenon through research are noted. It is acknowledged that while the researcher has tried to adhere to the principles of hermeneutic phenomenology described by Heidegger (1962) it may be subject to the same criticisms highlighted by Koch (1995) and Crotty (1996). Attempts will be made to highlight particular issues throughout the study so that the reader is aware and able to make their own judgement. The method is a vehicle for the investigation, not an end in itself. Heidegger's (1962) ideas underpin the exploration of being in the world of palliative care nurse specialists and through this an attempt at achieving greater understanding of suffering. An evaluation of the methodology is offered in Part Four, the discussion chapters.

4:2 Background to phenomenology.

Phenomenology is a science, the purpose of which is to describe a particular phenomenon of the lived experience. It is a way of thinking and perceiving as well as a method (Merleau-Ponty, 1962). The phenomenological philosophical movement consisted of three phases (Speziale and Carpenter, 2003).

- The preparatory phase consisted of the primary focus of clarifying the concept of intentionality. Intentionality means that consciousness is always conscious of something.
- The second phase focused on the idea that the philosophy should become a rigorous science (Husserl, 1965). Phenomenology was founded as a philosophy by Husserl at the turn of the century and was further developed as existential philosophy by Heidegger. The subject matter of phenomenology began with

consciousness and experience and was expanded to include the human life world by Heidegger (1962).

- The third phase deals with the primary concepts of embodiment and being in the world and was led by Gabrielle Marcel (1889-1973), Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1905-1980) (Speziale and Carpenter, 2003). These concepts rest on the idea that all acts are constructed on the foundations of perception or original awareness of some phenomena. At every point in time a person has a perspective and consciousness that exists based on the person's history, knowledge of the world and openness to the world. Experience is individually interpreted into the meaning which events may have for the individual (Merleau-Ponty, 1962) and can only be experienced through embodiment. Embodiment is awareness of being in the world through bodily sensations and consciousness.

Phenomenology tries to describe how the world is constituted and experienced. It commenced as philosophy and none of these original writers developed research methods. However, their philosophies are often used to underpin qualitative research (Fleming et al, 2003). Phenomenological research is a descriptive approach of the meaning of experience whilst hermeneutics is the theory and practice of interpretation (van Manen, 1997). The phenomenological researcher studies the way people experience their world, what it is like for them and how best to understand them (Tesch, 1990). Phenomenology attempts to get beyond immediately experienced meanings in order to articulate the prereflective level of lived meanings, to make the invisible, visible. The truth is discovered in the context of an engaged, open interaction between researcher and subject. This is achieved by obtaining descriptions from people who have lived through, and experienced, the situation by inquiring into their life world through interviews and narrative discourse (Ray, 1991).

4:3 Heideggerian phenomenology.

There are three principal assertions about Heideggarian phenomenology. It is a way of discovering meanings in day to day experiences. These meanings are shared or common. To discern the meanings, people must be viewed within their context. Heidegerrian research aims to understand the meaning of being in the world. Heidegger (1962), maintained that there are many ways to be in the world but the most significant is to be aware and capable of questioning one's own existence. He called this *'Dasein'* where the person exists authentically with awareness of their own being. Heidegger (1962) conceives of time as a fundamental structure of human existence. Time is experienced and given meaning within the life of the being in the world. Temporality is an awareness of time allowing past, present and future as a unity. Spatiality (Heidegger, 1962), situates the person in both time and space and refers to being in the world in a state of care which reveals being. The person brings things that matter close to them and relegates less important things to the background. Benner (1985; 1994), states that phenomenology's orientation to concrete experience and persons in relation to others, beliefs and practices is relevant for the purpose of understanding what all this means to the individual. The goal of a hermeneutic or interpretative account is to understand and find commonalties in everyday practices and experiences (Benner, 1994). This is clearly relevant for nursing, however, as discussed earlier, adapting a philosophical process to robust research methods to understand practice is problematic (Lawler, 1998).

Hermeneutics makes assumptions based on the Heideggerian phenomenological view of the person. This is that the researcher has a preliminary understanding of the human action being studied and that the researcher has a world and exists in time as the subject does (Heidegger, 1962). Therefore the researcher's subjectivity is an important factor and influence in the research process. Husserl (1962) requires researchers to bracket throughout the research so that a pure description of the phenomena can be achieved. Bracketing involves the acknowledgement of the researcher's preconceived ideas, and then suspension of these whilst undertaking data collection, analysis and interpretation. Husserl (1962) suggests bracketing as a means for researchers to study things as this will reduce bias and preconceived ideas influencing the data collection and interpretation. Heidegger (1962) believes the researcher contributes to understanding the phenomenon under study through their own experience. Heidergerrian phenomenologists challenge two notions: firstly that meaning can be seen in terms of a representation of an independent reality; and secondly, that theory can be generated from an observer who stands outside the situation (Koch, 1995). Researchers cannot eliminate their experience, which inevitably influences data collection and interpretation. Meaning is not totally neutral and unsullied by the interpreters' view and the interpreter participates in making data.

These elements are explained through the hermeneutic circle and co constitution and cannot be avoided (Heidegger, 1962). The hermeneutic circle is part of the analysis of the data, which moves from being naïve to an explicit understanding of the phenomena that emerges through data interpretation. Co-constitution demands that primary data be regarded as contextualised life events with the person's and the researcher perspectives specified. No interpretation is free from pre-conceptions. Co-constitution means that we are constructed by the world in which we exist and are simultaneously constructing a world based on our own experience and background. It is not possible to distinguish the person from the world. We cannot have a world or life at a cultural level except through acts of interpretation. Thus, there is no detached standpoint from which data is gathered and interpreted (Koch, 1995). The researcher brings their understanding to the work and it is not new knowledge that is acquired but that which has already been understood. The hermeneutic circle moves back and forth through interaction and understanding the phenomena that are uncovered and is never complete. Consequently, in terms of the data collected, the way in which it is collected and the interpretation of the data, it is important to be aware of these pre-conceptions, and thus influences, so that the reader can make a judgement on the information presented.

4:4 Heideggerian fore structure.

Heidegger (1962), uses the term 'pre-understanding' or 'fore-structure' to describe the fact that human beings always come to a situation with a story or pre-understanding. Pre-understanding is something we cannot eliminate or bracket as it is part of our being in the world. Therefore the researcher and participants share common practices and interpretations. Understanding the phenomenon is achieved by virtue of their common language. Fore-structure has three aspects:

- Fore-having is the ideas about the phenomena that are brought to the research.
- Fore-sight is the interpretative perspective brought to the study that orients in a particular way and is open to revision as new insights are gained.
- Fore-conception is the existing ideas we may have about what may be found in the study.

Heidegger (1962), declared that nothing can be encountered without reference to the person's background understanding. Interpretation moves within the fore structure of understanding so that we can only make explicit that which is understood. The researcher comes to the work with ideas of what they may find and with their own fore structure, and it is from this perspective that the research is undertaken.

4:5 My fore-structure.

In trying to understand the being in the world of palliative care clinical nurse specialists, I come with my own background, which will become part of my collection and interpretation of the data. It is therefore important to understand this background to enable the reader to assess the research as I present it. My own fore structure, consisting of my fore having, foresight and fore conception of the research subject, is presented below. It is descriptive and inevitably only contains what I see as relevant and wish to share. Consequently, it is not an exhaustive account and is only my interpretation of my fore structure, which may omit important detail because I have chosen not to disclose it or have not considered it.

Fore-having.

I have a 27-year experience of working with cancer and palliative care patients. I have worked with patients who are suffering and have a view of what constitutes suffering and what helps people find meaning and bear their suffering. I believe understanding suffering may be important to assist patients who are suffering. I know how it feels to witness suffering and be unable to help, and to become involved with people who are suffering and dying. I believe the nurse-patient relationship supports the identification and alleviation of suffering in palliative care. Further, that it is important to consider palliative care nurses' understanding of suffering so that greater enlightenment can be used to improve practice for both patients and nurses. I appreciate the difficulties in caring and working with those who are suffering and dying. The complexity of human suffering makes its relief a hard task. Much is written about symptom control in palliative care and the importance of addressing individual concerns of the person, but there is less about suffering as a complicated human experience, which nurses must acknowledge and help the patient integrate into their lives. I believe much of what palliative care nurse specialists know about suffering will have been learnt experientially. I think it may be helpful to others to explore, consider and share this understanding.

My experience of nurses becoming very stressed when involved with patients who are suffering, and in some cases leaving the profession or having significant periods of depression as a result of over work, stress or burn out, has led to an interest in exploring further the personal impact of working with suffering. Sick leave is sometimes in the form of an apparently unrelated physical illness, but leaves these nurses questioning the job they have been undertaking and whether they will be able to continue to do it on their return. Openly manifested depression or burn out has not been uncommon in my experience. This description, however, fails to describe the depth of feeling associated with the subject of the enquiry. The distress I have witnessed when committed, caring nurses have been unable to care any more and have either had extended periods of sick leave or are frankly unable to continue to undertake the role they have loved and have skills and knowledge in, has had a profound effect on me. I have a view of their suffering. It may be possible to pre-empt these problems and thus reduce their occurrence if there was greater understanding of palliative care clinical nurse specialists' experience of working with patients who are suffering and the issues raised and problems encountered that may lead to the development of stress and burn out. I have been involved in developing support systems for staff working with cancer and palliative care patients which involve mentoring, clinical supervision and arranging outside work activities.

My experience of working with cancer and palliative care patients has led to some understanding of the issues involved. It has motivated me in some part to explore what it means to others working in this field and to try to determine commonalties that may be shared with others working with patients who are suffering. My experience in the areas being explored means that I will be able to understand and explore further what the palliative care nurse specialists are saying at interview. This understanding and prior experience will also influence my interpretation of the data collected. Thus, I come with passionate views about the subject for investigation and experience of working with patients who are suffering, which has also had a personal impact on me.

I have worked for many years with patients who are dying and who have cancer and thus I have had experience of caring for patients who are suffering. I have never become 'hardened' to this suffering although I have learnt how to cope with the role in my own way. This involves not taking the job home, except on few occasions when a particular person in my care has 'hit a chord', having many outside work interests, and by trying to understand what is happening within the work both for myself and the people within my care. I have developed my own view of what constitutes suffering for individual people. This is based on the idea that suffering occurs when the person is challenged in such a way that it prevents them from being the person they want to be. This may be as a result of physical or psychological problems and deprivations. When their personal identity is challenged, they suffer. I believe that individuals can grow through suffering but only if they are able to integrate the experience into their lives.

I have regular severe migraine which certainly takes me into the realms of suffering. It challenges my ability to be the person I want to be by the physical symptoms caused by the migraine syndrome. Further, during the lifetime of undertaking this research, I have been treated for a chronic autoimmune condition that affected both my ability to work and study, and required many of the decisions raised by anyone facing a life threatening illness. These included life-changing treatment decisions and treatment, and the continuation and reintegration of life and personal relationships suspended and changed by the illness and treatment process. My understanding of suffering, then, is both professional and personal.

Nursing is a largely female profession and I too am female. It is likely that I will deal with more female palliative care nurse specialists than male and my gender will doubtless influence both the interview process and the interpretation of the data. I live in Wales, where the study participants also live and work. I have worked within Wales as a palliative care nurse specialist and in other roles. Consequently, I have an understanding of the cultural aspects of the geographical areas where the study participants work. These aspects will affect how nurses and patients experience suffering and how the palliative care nurse specialists will discuss their views. My understanding of the context of the study will influence the collection and interpretation of data. I have much in common with the study participants and thus, potentially, the ability to understand their viewpoint and ask relevant questions that will encourage them to explore the areas under study. However, a main difference may be that I no longer work daily as a palliative care nurse specialist and have undertaken a variety of different roles from manager to educationalist over my career.

I have been involved in both quantitative and qualitative research as both a designer and in the collection and analysing of data for 15 years. This has been in both large formal studies and small informal studies. I have worked with more experienced researchers and have learnt a great deal about the process of research, which will enable me to both develop and conduct this research inquiry. I have been interested in the subject under study for many years, and so I am familiar with much of the salient literature pertaining to the study. I have undertaken and completed Masters level study in both advanced clinical practice and management, which provides a basis for my conceptual thinking and knowledge.

Fore-sight.

My foresight is the perspective I bring to the investigation that will result in an effective interpretation of the data collected. It is what I may see in advance, taking into account my fore-having.

There is much written about palliative care nurse specialist's role in the relief of suffering but less about how they understand it. There is plenty on how nurse-patient relationships should be developed and managed (Kriedler, 1984; Morse, 1991; Jones, 1999; Hagerty and Patusky, 2003) but less about what it is like to work with, and witness, suffering. There is a wealth of literature stating that whilst it is important for nurses to get involved with the patients in their care, it is also important to avoid over involvement (Morse et al, 2006; Morse et al 1997; Mok, 2004; Ramos, 1992, Turner, 2001; Radiewicz, 2001; Jones, 1999, Kiedel, 2002), despite this, there is less on how this may be achieved. Likewise there is literature about stress and burn out in high intensity clinical areas such as oncology and palliative care (Vachon, 1998; Firth et al, 1986; Copp and Dunn, 1993; Cohen et al, 1994; Graham, 2005) but not about whether personal views of suffering influence the personal impact of working with patients who are suffering.

Considering the study participants from the perspective of being a palliative care nurse specialist, I expect to find people who have a viewpoint on suffering because they have had experience of working with those who are suffering. They may have had problems with stress or burnout as a result of the role they undertake. If they have been in the job for some time they will have developed ways to manage their involvement with suffering and prevent it from overwhelming them. The ability to get close to the patient without the patient getting close to the nurse is also an idea that I bring to the work, based on my personal experience of the role and working with others doing similar work. I expect palliative care nurse specialists to have learnt to be realistic about what can be achieved within the role. It is not always possible to alleviate all suffering and help everyone or have good relationships with everyone with whom one has contact, and this knowledge is important in managing stress.

I anticipate that because I understand the role, I will quickly be able to develop an easy rapport with the nurses and the interview data will be rich. I expect that palliative care clinical nurse specialists often find working with people who are suffering at the end of their lives hard and that it will have had a profound effect on them as individuals and will have shaped their development and being in the world.

Fore-conception.

What will I discover? I anticipate finding out that palliative care nurse specialists have developed a view of what suffering means to both them and their patients. That they will have developed ways to achieve a nurse-patient relationship that enables them to identify and try to alleviate their patients' suffering, and that they will have developed ways to cope with the job. I anticipate that some of the methods used to cope with the job will include an active life outside of work, doing unrelated activities, not taking the job home, good personal relationships, clinical supervision, good work relations and supportive colleagues. I anticipate that in developing their coping skills they will have experienced over-involvement with certain patients, and that this is part of the learning process.

This, then, is my forestructure that I bring to the investigation. Throughout the data collection and analysis and interpretation, these ideas will be in practice and the reader may thus use them to determine their influence on the research inquiry.

Chapter Five: Data Collection.

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Chapter Five: Data Collection.

Introduction to the Data Collection.

Data collection in phenomenological research is eclectic and may be obtained from interviews, documents, observation or a combination of sources. The complexity of the subject required flexibility for clarifying, and exploring further, the palliative care nurses' descriptions and was enabled by a semi-structured interview approach. As well as interviews, field notes and the literature were used as data sources.

5:1 Study sample.

In qualitative research, sample size is mainly determined by the purpose of the research, quality of the informants and the sample strategy used (Polit and Hungler, 1999). Qualitative samples do not aim to be statistically representative and a relatively small sample is often decreed sufficient if participants are knowledgeable about the area to be investigated. There are no firmly established criteria for sample sizes (Polit and Hungler, 1999) and there is general agreement that much smaller samples are acceptable in qualitative than quantitative studies but the question of sample size is controversial. There are those who consider sample size important (Sandelowski, 1995) and that sample sizes need to be large enough to defend the rigour of the study. However, Morse (1989) argues that sampling should be evaluated on the basis of adequacy and appropriateness. Adequacy refers to sufficiency and quality of the data sample. Appropriateness ensures identification and use of participants best placed to supply the information required.

The researcher did not know how many palliative care nurse specialists would agree to be involved nor how quickly themes would be developed from data collected at interview. It was also unclear at the start of the study whether more participants or sites may be indicated in the light of the emerging data; therefore a certain amount of speculation was required when developing the research proposal. In the first instance, it was planned to interview twelve palliative care clinical nurse specialists to determine their understanding of suffering, management of the nurse-patient relationship and the personal impact of ongoing exposure to patient suffering. It was anticipated that enough data would be obtained from twelve participants and that this would achieve the aims of the research study. However, it was acknowledged at the start that more interviews might be necessary or that second interviews with the individuals may be required.

Data collection should continue until no new themes are emerging and the data is repeating or data saturation is achieved (Polit and Hungler, 1999). This having being said, it is worth noting that Morse (1989) maintains that data saturation is a myth and that given another group of informants on the same subject at another time, new data will be revealed. Therefore investigations will be able to reach saturation only with a particular group of participants at a specific time. Bearing this in mind data saturation was aimed for within particular geographical, working and role boundaries. The study is exploratory and descriptive and not intended to be statistically generalisable, however the results may be transferable. With this in mind a 'thick description' (Lincoln and Guba, 1985) is provided so that the reader can determine the likelihood that the findings could be transferred to other settings with the same characteristics. A 'thick description' refers to the provision of a rich and through description of the context, processes and exchanges between researcher and subject that take place during the inquiry.

A purposive sample was taken from palliative care services in Swansea, Carmarthen, Cardiff and Pembrokeshire as these teams all have a hospital and community palliative care role and were convenient to the researcher. Purposive sampling is often used in phenomenological inquiry as it selects participants based on their knowledge of the phenomena with the aim of sharing that knowledge.

Unfortunately, there were problems within the palliative care teams in some of the sites approached. These were vacant posts, people not being in post for very long and staff sickness. Therefore, only ten interviews were undertaken and the researcher felt that in the light of the data collected and analysed, that new themes were still arising and more interviews were needed. Thus the study was extended to cover other sites: Gwent, Bro Morgannog, Powys, Ceredigionshire and the Rhondda and Cynon Valleys. All known palliative care clinical nurse specialists in these areas were invited to participate. This resulted in a total potential sample of all palliative care clinical nurse specialists working in South and Mid Wales. The aims of the study were to explore the lived experience of palliative care clinical nurse specialists working with patients who are suffering, and achieving a sample that has geographical, political and cultural characteristics in common was felt to be helpful.

It also served in terms of researcher convenience for travelling to meet participants. A decision was made to interview all those who agreed to take part in the study.

This extension of the study to cover south and mid Wales resulted in seventy palliative care nurse specialists being invited to take part in the study. Thirty-one consented to participate in the study and were interviewed. There was considerable interest generated by the study and many of those who took part expressed that they thought the work was important. Many of those interviewed had considerable experience in palliative care. Some had developed depression or burn out related to the job. It was clear that they had an in depth, personal understanding of the issues being discussed. This resulted in a large amount of data being collected, which provided a rich source of information.

5:2 Inclusion criteria.

The inclusion criterion for the study was clinical nurse specialists working in palliative care. Their role is to try and alleviate suffering or help the patient to come to terms with what is happening to them when no cure is possible. It was anticipated that these individuals would have worked with palliative care patients for long enough to gain the significant expertise and knowledge required to undertake the role. They would have had experience of working with patients who are suffering. Therefore they should be able to discuss suffering, management of the nurse-patient relationship with those who are suffering, and their personal experience of working with patients who are suffering. To have achieved positions as palliative care nurse specialists, they will have undergone education and training in palliative care and made personal decisions to make this their career. All were English speaking as the researcher felt that, since English was her first language, nuances and meaning would be lost if interviews were undertaken in any other language.

5:3 Access to participants.

Consent to approach these teams was gained from their managers via a letter (Appendix A). Managers of palliative care nurse specialists were written to and requested that they circulate the participant information sheet and consent form (Appendices B and C) to all palliative care nurse specialists working within the organisation. If the palliative care nurse specialists were willing to be involved in the study they were asked to return the attached consent form or contact the researcher to discuss the study. If there was no response within a month, this process was repeated to ensure that all potential subjects were contacted.

Once consent was given, a time for interview that was convenient for both interviewee and researcher was arranged. The interviews took place outside of the work environment where there were no interruptions and the palliative care nurse specialists were not directly influenced by patient care. The interviews took approximately one hour, ranging from 45- 90 minutes, and were audiotaped for transcription later.

5:4 The literature.

The literature constitutes a major source of data and discussion of how it was obtained and integrated has been explained in the literature review chapters. A limited literature review was undertaken prior to data collection so that preconceived ideas about what may be found through the study were kept to a minimum. The description of the researcher's fore structure explains her background and what she was expecting to find and how this may have influenced data collection and interpretation.

5:5 Field Notes.

The interviews were transcribed and pauses in conversation, changes in volume or tone and audibility were noted. The transcripts were checked for accuracy against the tape recordings when completed.

It is recognised that interview transcriptions are decontextualised abstractions of the conversation that took place and that they only make up part of the data collection. The words, their tone, pauses and emotional voice inflections were recorded and could be returned to by the researcher repeatedly if required. However, body language, facial expressions, tone of voice and the visual aspects of the interview were not recorded.

Non verbal communication is much more effective than what is being said and this should be taken into account when interviewing (Begley, 1996). The researcher often perceived difficulty in talking about situations that the participant had been involved in. Reluctance to talk, blocking tactics or emotional responses were clear from the participants' body language. Since this information was not evident from the tapes, it was recorded elsewhere to ensure a complete account of the interview.

Consequently, following the interview the researcher made field notes describing the interview and the emotional responses of those involved. The researcher made a note of the participants' body language, facial expressions and tone of voice after each interview. These field notes were used as an aide memoire for data analysis. Data analysis took into account the researcher's memory and notes of the interview as well as the recording made at the time.

5:6 Interviews.

Interviews were used to explore and gather experiential narrative material that could be used to develop a greater understanding of suffering and the lived experience of working with patients who are suffering. The purpose of the interviews was to obtain descriptions of suffering and the lived world of the interviewees in order to interpret the described phenomena. The topic was the everyday lived world of palliative care nurse specialists and their understanding of suffering, management of the nurse-patient relationship with patients who are suffering and reaction to working with patients who are suffering. The interview was theme oriented to cover the three aims of the research study, with the researcher and participant talking together about a subject that was of interest to both. Interviews provided the means for the interviewer to develop a conversational relationship with the interviewee about the meaning of the experience as suggested by van Manen (1997). The interviews were recorded and transcribed and the interview transcripts were used as the basis for analysis and interpretation.

The interview focussed on the three aims of the study to allow the interviewees to discuss dimensions they found important within the areas of interest. The interviewer thus led the subject towards certain themes but not to certain opinions about those themes. The researcher sought to interpret the meaning of central ideas in the life world of the palliative care nurse specialists, which was achieved by noting both what was said and how it was said. The interviewer sometimes formulated the implicit message from what was being said and reflected it back to the interviewee to obtain an immediate confirmation or denial of the interviewer interpretation of what the interviewee was saying. There was no attempt at quantification, only to gain knowledge from what was expressed by obtaining open, nuanced descriptions of the interviewees' life world. Precision in description and stringency in meaning interpretation correspond in qualitative interviews to exactness in quantitative measurements (Kvale, 1996). Descriptions of specific situations were elicited but also general opinions. The interviewees were encouraged to describe as precisely as possible what they thought and felt and how they act. The primary aim of the interviews was to obtain relevant and precise descriptions from which to draw interpretations.

5:7 Interview structure.

The questions were developed from the literature reviewed and the researcher's experience of working with suffering and included areas relevant to the aims of the study. Clinical practice was used to explore the nurses' experiences of working with patients who are suffering. An independent research expert and clinical expert was asked to review the questions to assess content validity. They were in agreement that the subject areas to be covered at interview would allow exploration of the themes and aims of the research. None of the interviews were highly structured but they did have some organisation.

The interview schedule was loosely structured around three areas of content:

1. Participant descriptions of their understanding of suffering and the nurse-patient relationship.
2. Descriptions of clinical practice from the participants where patients were perceived to be suffering.
3. Descriptions of ways in which patient suffering has impacted on individual palliative care nurse specialists.

5:8 Interview questions.

Questions.

- Would you tell me how long you have worked in palliative care and what education and skills preparation you have received to undertake the role? Do you have regular clinical supervision?

Biographical data on the length of time spent working with palliative care patients, qualifications and current clinical supervision arrangements were obtained as experience and knowledge have been found to influence nurses' ability to manage patient involvement (Turner, 2001; Jones, 1999; Georges et al, 2002). This information also provided an introduction to the conversation by discussing factual information and a context for the palliative care nurse specialists' views. It gave time for the participants to relax with the researcher whilst dealing with largely unemotional information.

- From your experience as a palliative care nurse what does suffering mean to you?

This question gave the interviewees an opportunity to give their ideas about suffering. It was a broad opening question designed to try and relax the interviewee whilst at the same time allowing them to be specific about their views on suffering in relation to their work and experience in palliative care.

- Describe a clinical situation or case study where you felt that the patient was suffering. One where you were able to help the person and one where you were not. How did you respond to the patient and what did you do to try to alleviate their suffering? How did you feel about dealing with the patient and their suffering?

These questions enabled the interviewee to relate their ideas about suffering to a clinical situation and consider how they dealt with, and felt about, it. They are specific questions that allowed the interviewee to explore their experiences. Consideration of how suffering was alleviated or not and the emotional response to a patient in distress enabled further exploration of suffering, the nurse-patient interaction and coping strategies employed by the palliative care nurse specialists to both relieve suffering and their own emotional response to the situation.

- How do you endeavour to develop a nurse-patient relationship to manage suffering?

This encouraged the palliative care nurse specialists to consider aspects they felt were important for developing a nurse-patient relationship.

- What is your personal experience of caring for those who are suffering?

The interviewee had the opportunity to explain their personal response to working and dealing with patients who are suffering. This question is highly personal and it was hoped that by the time the interviewee was considering their response, that they would be at ease with the interviewer and able to give an open and honest account of their feelings.

5:9 Interview technique.

The research interview is an interaction between two people where each acts in relation to the other, and a reciprocal influence is exerted. It was recognised that the interview process may be viewed as a positive attempt to obtain greater knowledge or may induce feelings of anxiety which evoke defence mechanisms and hinder both the interviewee and researcher. The researcher was conscious of the interpersonal dynamics and took them into account both in the interview situation and in later analysis of the transcribed interview.

It was recognised that the first few minutes of the interview are important and that the subjects would want to weigh up the interviewer before they talked freely, exposing their experiences and feelings to a stranger. A good contact can be established by attentive listening with the researcher showing interest, understanding and respect for what the subject says, whilst also being at ease and clear about what information is being looked for. The researcher tried to achieve this by providing the interviewees with a context for the interview through a prior briefing. The purpose of the study, the use of a tape recorder, confidentiality and how the information would be used, was explained and the interviewee asked if they had any questions before starting. There was an opportunity for debriefing after the interview. This was important, as the subject had talked about personal, and often emotional, experiences. The purpose of the study was reiterated by the researcher who also explained that a transcript of the interview would be sent to the interviewee for checking and signing as a correct record.

It was intended that the interview would proceed like a normal conversation but with a specific purpose and a systematic form of questioning. The questions asked were broad, allowing for dialogue to explore further themes during the interview. The interviewer's experience in the area under study increased her ability to sense the immediate meaning of the answer and to decide about issues that needed further exploration. The interviewee was encouraged through active listening to proceed at their own rate of thinking and speaking. They were encouraged to put forward any unconventional ideas they had. Any emotional issues were supported through listening and further exploration, or allowing the interviewee to decline to talk about areas that caused them problems if that is what they wanted. The emotional message of the interview was noted, as well as anything that was not being said. At times the interviewee had strong views and became quite emotional about their work. The study held a lot of interest for those palliative care nurse specialists who were interviewed and they were keen to share and explore their views.

Questions were also aimed at testing the reliability and validity of what was being said and to check for logical consistency in the content of what was being discussed. Sometimes an interviewee's statement was ambiguous with several possible interpretations, or what they said was contradictory throughout the interview. The researcher tried to clarify as far as possible whether ambiguities and contradictions were as a result of failed communication within the interview or whether they reflected real inconsistencies, ambivalences and contradictions within the interviewee. During the course of the interview subjects sometimes changed their descriptions of, and meanings about, a theme. This may have been because they discovered, through talking, new aspects of the themes they were describing and suddenly saw relations that they had not been conscious of earlier. This may happen as a result of the process of reflection that takes place through consideration of previous events and lived experiences (van Manen, 1997). The researcher attempted to clarify meanings relevant to the study during the interview in order to improve the veracity of the later analysis. This process of clarification during the interview may have also communicated to the interviewee that the researcher was listening to, and interested in, what they were saying.

The researcher summarised the ideas explored in the interview with the interviewee to check that understanding had been reached. The interviewee was asked if there was anything else that they would like to add or discuss. If exploring a difficult area of practice had caused any distress, the interviewer planned to check that the interviewee was all right or that they had access to clinical supervision if required. In the event, this was not necessary, as although the interviews often raised emotional events or thoughts, this did not cause undue distress. In fact, many of the interviewees stated that discussing their thoughts had been helpful to clarify their own views.

Tape recording the interviews allowed the researcher to concentrate on the topics and dynamics of the interview without having to rely on memory or taking notes throughout. This enabled the interview to be more of a conversation between the researcher and subject.

In order to ensure that there was good quality tape recordings, a good tape recorder was used and extraneous noise from outside the room was kept to a minimum. The microphone was placed close to both the interviewer and interviewee who was encouraged to speak clearly and at a volume that allowed the recording to be audible when played back. On two occasions there were problems with recording and when the tape was played back it was found not to have recorded or to have recorded intermittently. In these instances detailed notes were made of the interview, sent to the interviewee, with apologies about the recording difficulties, and requesting their comments.

The taped interviews were transcribed and the transcripts checked by the researcher for accuracy. Transcripts of the interviews were given to the interviewees to ensure that they were accurate and conveyed what the interviewee meant to say. Participants were encouraged to comment on the transcripts and make any changes as they thought necessary. Lincoln and Guba (1985), state that member checks, where the data, categories, interpretations and conclusions are checked with those who provided the data, are crucial for establishing credibility of the research. The participants were encouraged to add any other thoughts they may have had in the interim on the interview or subjects discussed. In the event, few changes were made, mainly to clarify meaning. No new information was introduced and no information removed as a result of the process.

5:10 Ethical issues.

The study ensured that ethical principles were adhered to and the following areas were given particular attention.

Ethical approval.

Initial ethical approval was sought and obtained via the Dyfed/Powys Multicentre Research Ethical Committee to approach palliative care clinical nurse specialists in Pembrokeshire, Carmarthenshire, Cardiff and Swansea. The study was extended to include other research sites: Gwent, Bro Morgannog, Powys, Ceredigionshire and the Rhondda and Cynon Valleys and an amendment to the original ethical approval was obtained from the same ethical committee. This allowed other sites to be approached and included in the study. Research and Development approval was sought and obtained from each organisation (Appendix D) where palliative care clinical nurse specialists were approached to take part in the study.

Researcher supervision.

The researcher was supervised throughout the study by an experienced supervisor to ensure that the research is conducted appropriately. The work will be submitted for Doctorate in Nursing Science assessment and forms part of the researcher's ongoing training and education. Results will be shared in refereed professional journals and conferences.

Emotional issues.

Suffering is an emotive subject and thinking about it and remembering patients who suffered may cause distress to the nurses. The researcher came to know the participants in a personal way but it was noted that the interview intended to gather information about the subject in question, and was not a therapeutic interview. It was recognised that given the nature of the subject being discussed, which may involve deeply personal and emotional issues for the interviewee; the interview may bring forth deeper personal problems requiring assistance. The information sheet for participants made it clear that clinical supervision would be available for participants if needed. The researcher is an experienced palliative care nurse and clinical supervisor. The researcher was available to discuss any issues and recommended a clinical supervisor that the nurses could talk to if required.

Anonymity and Confidentiality.

Confidentiality is a guarantee that any information the participant provided will not be available to anyone other than those involved in the research. However, the provision of a 'thick description' means that there is considerable information available to the reader, which may decrease the confidentiality of the participants. Anonymity occurs when the data cannot be linked with the participants (Polit and Hungler, 1999). The personal one-to-one interaction in interviews allows the researcher to know the participants in ways that make it impossible to achieve anonymity at all stages. However, any descriptions or data extracts used in writing up the data were anonymised so that only the researcher and participants would recognise them. Fictitious names and places replaced those of the participants to protect confidentiality.

Allowing the participants to withdraw interview material aided in the process of ensuring confidentiality and anonymity, although in the event no participants exercised this option. All the interviews were taped and the researcher ensured that the tapes were kept securely locked and only available to her and her supervisor. Any information gained will be held in the strictest confidence and all information was anonymised so that the interviewees cannot be recognised. The data collection was kept on a password-protected computer and will be destroyed when the study is complete.

When sending the transcripts to the participants the envelopes were clearly marked 'confidential to be opened by addressee only'.

Informed consent.

All those to be involved in the study were written to and the study explained fully to them. The participants were sent an information sheet (Appendix B) explaining the purpose of the study. Written consent (Appendix C) was obtained and it was made clear that they could discontinue their involvement in the study at any time. The researcher was not in any way involved in the day to day working of the clinical nurses specialists approached and no information was given to anyone else without it being anonymised or with the consent of the individual participants.

Once they had consented, and prior to starting the interview, the researcher explained again the purpose of the study and how the data would be used. The participant was given the option to ask questions and asked again if they were willing to continue to be involved.

Permission to use direct data extracts was acquired from the participants and care was taken to ensure that these did not reveal the participants' identity. The participants were made aware that the research findings would be written up as part of a Doctoral thesis and also shared through journal and conference papers. Confidentiality and anonymity has been maintained throughout this process.

Returning transcripts to the participants.

The participants were sent copies of the transcripts so that they could amend or delete data as they wished. The process of returning transcripts illustrates that participants were seen as collaborators in the research, sharing their knowledge and experience in the pursuit of greater understanding. However, since they have already given time for being interviewed this is arguably an imposition requiring more time.

The practice was discussed with the participants before the start of the interview so that they could decide whether or not this was acceptable.

There is the problem of a participant changing or withdrawing some or all of the data when reconsidering it via a transcript. The researcher has been exposed to the original version and is inevitably going to be influenced by it, however much they may try to forget it. Sandelowski (1993) argued that participant stories are remembrances about the past and asking participants to relive these moments may have unknown consequences. The narrative nature of interview data makes determining accuracy of meaning and intention a deeply theoretical and moral problem.

All rights of the participants needed to be considered. The issues of suffering, the nurse-patient relationship and coping are deeply personal and there was a chance that the participant may want to change their minds about the information shared after the interview has taken place. The transcript allowed them to do this. In the event, only a few transcripts were altered and these were corrections of typing or grammatical errors.

Consequences.

The consequences of the study concern the information obtained during data collection and the latter effects of findings that may emerge as a result of the study. These may be related to particular individuals' ability to cope with the job they are undertaking. More generally, they may determine a need for greater support for palliative care nurse specialists in undertaking work that has emotional repercussions.

Chapter Six: Data analysis.

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Chapter Six: Data Analysis.

Data analysis.

Analysis of the data took place after each interview and categories were derived as data collection proceeded. Consequently, the analysis inevitably influenced the researcher undertaking further interviews. In the light of information gained from the analysis the researcher, having elicited an open-ended response from the interviewee, sometimes chose to explore the response further in relation to information gained from other interviewees. Lincoln and Guba (1985), argue that this reflexivity is important where there is a need to seek out salient factors and follow up on them, as in exploratory research. Arguably, this also reflects the hermeneutic circle (Heidegger, 1962) with the researcher exploring ideas further as their own views on the subject develop.

Morse and Field (1998), identify four intellectual processes that are involved in qualitative data analysis.

- Comprehending, where the researcher strives to make sense of the data and learn what is going on. When comprehension is achieved the researcher is able to prepare a description of the phenomena being studied and new data will not add much to the description. Thus, comprehension is achieved with data saturation.
- Synthesising involves getting a sense of what is typical and the range and variation regarding the phenomenon. Thus, some generalised comments can be made about the phenomenon and research participants.
- Theorising involves systematic sorting of the data and the provision of explanations for the phenomena, which are compared with the literature.
- Recontextualising involves a further development of theory that may be explored in other contexts or with other research subjects.

It is recognised that the researcher had a perspective on what is being investigated and will have interpreted the interview from this perspective. The researcher has considerable experience in the area being investigated and brought this to the interview to explore the information and views being shared. The researcher imposing interpretations on the data is always a problem. It is suggested that, to overcome this, having another researcher with expertise in phenomenology to check out interpretations, or returning more than once to the data and to the participants to check the validity of the interpretations (Crotty, 1996). The researcher was supervised throughout by an experienced researcher who commented on the analysis and interpretation of the data. A summary of the interpretations (Appendix E) was sent to the participants for comment as suggested by Coliazzi (1978). The researcher has previously given an account of her fore-structure so that the reader may consider the data analysis and interpretation in relation to her background.

There are a number of possible styles of analysis described but all suggest:

- Reviewing the data to get a sense of the whole.
- Reflecting on the data and identifying meanings.
- Organising formulated meanings into themes.
- Writing an exemplary narrative to illustrate each theme (Benner, 1994; Giorgi, 1985; Van Manen, 1990).
- Validation via participants (Colaizzi, 1978).

The approach used aimed to derive themes from the data which join together to form a comprehensive description of the whole phenomena. The analysis was guided by the interpretative strategies developed by Benner (1994) and Coliazzi (1978). This procedure follows a process of identifying themes, exemplars and paradigm cases that are used to form the descriptions of the individual's lived experience.

- The first stage involved reading the transcripts as a whole in order to describe the individuals experience. Fieldnotes and impressions from the interview were also used to form beginning interpretations. Thus the relative importance of an event to the individual was assessed.
- In the second stage, all verbatim statements related to the three areas were extracted and grouped according to similarities. They were then labelled with a category name. Categories were then grouped in themes. Themes are the meaning of a point being made and the form of capturing the phenomenon that is being explored to establish understanding.
- The third level of analysis involved locating exemplars of experience that appeared to be especially meaningful.
- The fourth stage, identification of paradigm cases, involved exploring relationships between the themes and examining whether the case material generated in the previous stages could be grouped by similar meanings. This phase looked for similar material that was presented throughout all the interviews and used to attempt to answer the study aims. Categories were compared with

existing literature and checked for interviewer and informant bias (Benner, 1994).

- The fifth level involved sending a summary (Appendix E) of the researcher's interpretation of the data to the participants to determine whether these reflected their views and experiences.

This process was achieved using phenomenological reflection which involves uncovering thematic aspects in the life world descriptions and isolating thematic statements (van Manen, 1984). Reflection was the means by which essential meanings of the phenomenon were revealed and facilitated the interpretation of the interview text to themes. The interviews were analysed with respect to the life world described by the person being interviewed. Through a process of writing and rewriting, reflection and deeper meaning were revealed. van Manen (1997) says that this is because this encourages distance and thus the perspective and closeness to focus on the phenomenon. Benner (1994) suggests that moving between the parts and wholes of paradigm cases and exemplars in cycles of understanding and interpretation reflects Heidegger's (1962) influence. The data analysis was then organised and written up.

A brief summary of the findings was sent to the participants for their comments about the accuracy of the interpretation. Since there were thirty-one participants and a consequent cross-section of ideas generated, interpretation of individual data was limited and participants could only comment on general themes developed. However, this did allow a limited validation of the interpretation of the data, which was combined with the original participant review of the transcripts. This helped to confirm that the researcher's interpretation of the data was a real account of what the participants thought and felt at the time of being interviewed.

Chapter Seven: Issues of Rigour.

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Chapter Seven: Issues of Rigour.

Assessing rigour.

Generalisability, validity and reliability are seen as important as a scientific measurement of the worthiness of the research undertaken (Polit & Hungler, 1999). There are difficulties in achieving these concepts in qualitative research where studies may be small and based on specific leading questions. Their subjectivity means that they are not generalisable or reliable or even valid in the usual quantitative meaning of the terms. Sandelowski (1993), argues that it is important not to get too embroiled in trying to prove rigour in qualitative research. She argues there is a rigidity that often accompanies the search for validity and cautions against the threat to validity that the search for reliability may pose. The goal of rigour is to accurately represent the study participant's experiences.

Qualitative research requires interpretation by the researcher and thus will have an element of subjectivity to it. Every situation is unique and each phenomenon has its own structure and logic. There is inevitably some creativity in the research process that means that the researcher selects those areas that they wish to discuss or see as important from the data collected. This does not make the research any less rigourous or representative of the findings, but like a scene viewed by different observers, it is a version of the truth.

In terms of the research undertaken, an understanding of verification of the research starts in the lived world of the subjects and researcher. As already discussed, Heiderggerian phenomenology accepts that the researcher has a view that will influence data collection, analysis and interpretation, and that this is important and beneficial to the research process. Application of the rules for ensuring the rigour of the research will be made with cognisance to not becoming too rigid to the rules and thus defeating the object of the exercise. The basic issue is whether the researcher can persuade their reader that the findings of the research are worthy of taking into account. Lincoln and Guba (1985), suggest that the truth value of the research is in relation to the context in which it occurred, whether it can be applied to other settings with other respondents, whether the findings would be repeated if it was replicated within the same context and with the same participants, and whether the findings are those of the study or over influenced by researcher bias. Lincoln and Guba (1985), discuss concepts such as trustworthiness, transferability, credibility, dependability and confirmability to discuss the truth-value of the research undertaken.

7:1 Trustworthiness.

Trustworthiness asks how the researcher can state that the findings are worth taking into account. Are the findings true and applicable to the participants and context, and to what extent would they be repeated in other contexts? The trustworthiness of the questions put to participants depend on the extent to which they allow discussion of the participants' experience as opposed to the researcher's theoretical knowledge of the topic under study.

In this study the questions were open-ended giving the opportunities for participants' views on the topics under study. Asking the participants to describe a clinical example of a patient they perceived was suffering assisted in this process, as this laid a very personal slant on the concept. Specifically they were asked for a situation where they were able to help and one where they were not able to help, which allowed for comparing and contrasting the experiences and data.

7:2 Transferability.

Transferability refers to the extent that the study findings have meaning to others in similar situations. Transferability was addressed by ensuring that a 'thick description' consisting of a thorough and rich description of the context of the data collections is presented (Lincoln and Guba, 1985). Lincoln and Guba (1985) maintain that it is the users' of the study findings responsibility to determine whether the findings are transferable. The researcher's role is to provide a 'thick description', to make this judgement possible.

Analytical generalisation involves a reasoned judgement about the extent to which the findings from different studies can be used as guide to the development of a theory about what might occur in another, similar, situation. It is based on the analysis of the similarities and differences of situations (Kvale, 1996). Naturalistic generalisation (Kvale, 1996), rests on personal experience developed from a tacit knowledge of how things are and leads to expectations rather than formal predictions. Thus, it is different from statistical generalisation, where the use of inferential statistics allow the calculation of a confidence level for predicting the likelihood of generalising from the study population to the population at large. The study did not select randomly from the population and thus statistical generalisation was not possible. The goal of phenomenology is to accurately describe the experience of the phenomena under study not to generate theories or general explanation (Morse and Field, 1998)

The interpretative research paradigm assumes that reality is multiple and constructed rather than singular and tangible (Lincoln and Guba, 1985), and therefore the repeatability of the research is not essential or even possible. Whilst the importance of transferability of the data to other settings or groups is recognised, the emphasis of the study was to explore the experience of the study participants to gain knowledge, not to prove that all palliative care nurse specialists have the same experience. The information gained may be helpful for the future preparation or support of nurses planning to work in palliative care. It was anticipated that the research would elicit palliative care nurse specialists' experiences of suffering and the findings may be transferable to other palliative care nurse specialists working with suffering.

7:3 Credibility.

Credibility includes activities that increase the probability that credible findings will be produced. The aim of credibility is to report the perspectives of the participants as accurately as possible. It concerns all the stages of the research involving issues of truth and knowledge. Validation of this research is not a final verification but built into the research design and happened at each stage of the research. This process has been discussed throughout the research design. It includes checking the questions to be asked against the available literature, checking for understanding of what is being said throughout the interview process, acknowledging the researcher's experience and knowledge as a possible source of bias in the research process, member checking of interview transcripts and summary of the researcher's interpretations, looking closely at surprises, extreme cases and rival explanations when analysing the data.

- Credibility refers to the confidence in the truth of the data. Lincoln and Guba (1985) suggest: Persistent observation where the researcher focuses on aspects of the interview that are relevant to the phenomena being studied. Field notes were taken at the time of interview. These highlighted initial thoughts about the interview and the general points made that related to the phenomena being studied and were used in data analysis.

- Prolonged engagement or the investment of time to ensure that the researcher had an in depth understanding of the views of the subjects being studied and the development of a good rapport between researcher and subject. The researcher has a background in palliative care that aided in this process and the interview technique is described in detail elsewhere.
- Member checking is the provision of feedback to the study participants regarding the data and the researcher's emerging findings and interpretation. Feedback was given to the study participants in the form of the interview transcripts. This allowed the researcher to check that the information that was given by the interviewee was what was meant and allowed the interviewee to correct any error of fact. It also allowed the interviewee to add any other information they felt was relevant to further understanding. The interviewee was able to acknowledge that the researcher was right or wrong in their transcription of what was being said. This process checks the reliability of the data. A summary of the researcher's interpretations (Appendix E) was sent to the participants for comments after being fully analysed. This process checks the validity of the data.

Sandelowski (1993) argues that member checking may not prove rigour as participants may forget what they said or meant, or be looking for their own contribution rather than overall themes. Morse and Field (1998) counsel that enough of the analysis must be sent to the participants to ensure that they have a full picture of the findings and interpretation too little invalidates member checking. The summary of the findings (Appendix E) sent to the participants obtained seventeen responses, all of which were very positive that the interpretation reflected their views. Some particpants had moved to different jobs and the summary was returned as undeliverable.

7:4 Dependability.

Dependability of qualitative data refers to the stability of the data over time and conditions. Reliability is seen as part of a larger set of factors associated with observed changes. Dependability takes into account both factors of instability and factors of phenomenal or design induced change (Lincoln and Guba, 1985). It accounts for everything that is normally accounted for in reliability plus some other factors as discussed. An inquiry audit is available for an external reviewer to assess the dependability. Dependability is the criterion reached once credibility is demonstrated. Lincoln and Guba (1985) say that there can be no dependability without credibility.

7:5 Confirmability.

This demonstrates as clearly as possible the evidence and thought process that led to the conclusions in the inquiry. Confirmability or the objectivity of the data will be enhanced by an inquiry audit (Polit and Hungler, 1999). The audit trail consists of the raw data process notes (field notes, interview transcripts), process notes (member checks), instrument development information and drafts of the final report.

The researcher is the data collection instrument as well as the creator of the analytic process. Therefore her credibility in terms of experience, qualifications and background are important for establishing confidence in the data. These background details are explained in the account of her fore structure, which will enable the reader to make a judgement in this respect.

However, it was recognised that although an audit trail may be available which highlights the process of the research and the researcher's thoughts at the time, another person looking at the information may not agree with the conclusions developed by the original researcher. However, although readers may not agree with the interpretations offered by the researcher they should be able to follow the pathway that leads to the interpretation (Benner, 1984). The researcher's background in palliative care and personal fore structure was taken into account both in selection of the methodology and when writing up the data, so that it was clear how this may have affected the data collection and interpretation. Sandelowski (1998), argues that only the researcher who has collected the data and been immersed in it can confirm the findings.

The researcher has worked with a supervisor throughout the research process who offered comments about the method. Further, the Doctoral thesis provides an extensive account of the research.

Conclusion to the Research Design.

The research design was selected to obtain high quality data in a way that was appropriate to hermeneutic phenomenological research design. Data collection and analysis took place as described.

Part Three: Study Findings.

Chapter Eight: Suffering.

Section One: Difficulties with describing the concept of suffering

Section Two: Loss

Chapter Nine: The Nurse-patient Relationship.

Section One: Developing the nurse-patient relationship

Section Two: Barriers to developing the nurse-patient relationship

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Chapter Ten: The personal impact of working with patients who are suffering.

Part Three: Study Findings.

Introduction to the study findings.

The way in which data analysis was conducted has been described in Chapter Six. Chapters Seven, Eight and Nine describe the findings and interpretations in relation to suffering, the nurse-patient relationship and the difficulties and coping mechanisms employed within the role. The data were analysed to themes and categories and these are presented. Throughout the following chapters, extracts from the data that illustrate the themes and categories being discussed are presented. Comparison to the literature has been made and some points highlighted and discussed. However, the main discussion of the data is to be found in Part Four, the discussion chapters. The data overlapped and interwove and thus, whilst points are explored in relation to the separate concepts, the decision was made to discuss the findings as a whole. In this way the aims of the study are evaluated as a whole lived experience of the palliative care nurse specialists.

In the first instance, the palliative care nurse specialists were asked for the length of time they had spent working in palliative care and the education and skill preparation they had received to undertake the role and their arrangements for clinical supervision.

Length of time working in palliative care.

The participants were all female and their time in the role ranged from six months to 20 years as shown in Figure i.

All were trained as Registered General Nurses - Adult, and one had dual registration as a Registered General Nurse - Mental Health.

Figure i: Length of time working in palliative care.

Number of years in palliative care	0-2 years	2-5 years	5-10 years	10 years or more
Number of palliative care nurse specialists	2	5	5	19

Education preparation for the role.

Their educational preparation ranged from no specific training in palliative care to Masters level study and is presented in Figure ii.

Figure ii: Education preparation for the role.

Education	Currently studying BSc.	BSc. Palliative Care	BSc. Nursing/Professional Practice	Currently studying MSc. Nursing/ MSc. Nursing
Number of palliative care nurse specialists	**9**	**15**	**7**	**6**

Their skill development had taken place through clinical practice and learning from others with more, or different, experience. Multi-professional team working was a valuable source of education, as was sharing and discussing experience with other colleagues. Reflective practice, both at the time of encountering a patient and later, was central to the development of both knowledge and skills. This was largely undertaken through informal discussion with colleagues and focussed around specific case studies. All participants discussed personal reflection on the effects of the role on themselves and their lives.

Clinical supervision.

Formal clinical supervision was limited, only three having allocated time and clinical supervision on a regular basis. A further six had occasional clinical supervision sessions, usually when there had been a particularly difficult problem they wished to discuss. All acknowledged that clinical supervision was important, but those who did not have formal sessions stated that their organisations did not provide it, or that they were unable to find a suitably experienced clinical supervisor. In some cases clinical supervision had been available in the past and proved beneficial but the clinical supervisor had moved on and no suitable replacement had been found. There was a general view that individual rather than group supervision was of most benefit.

Chapter Eight: Suffering.

Chapter Eight: Suffering.

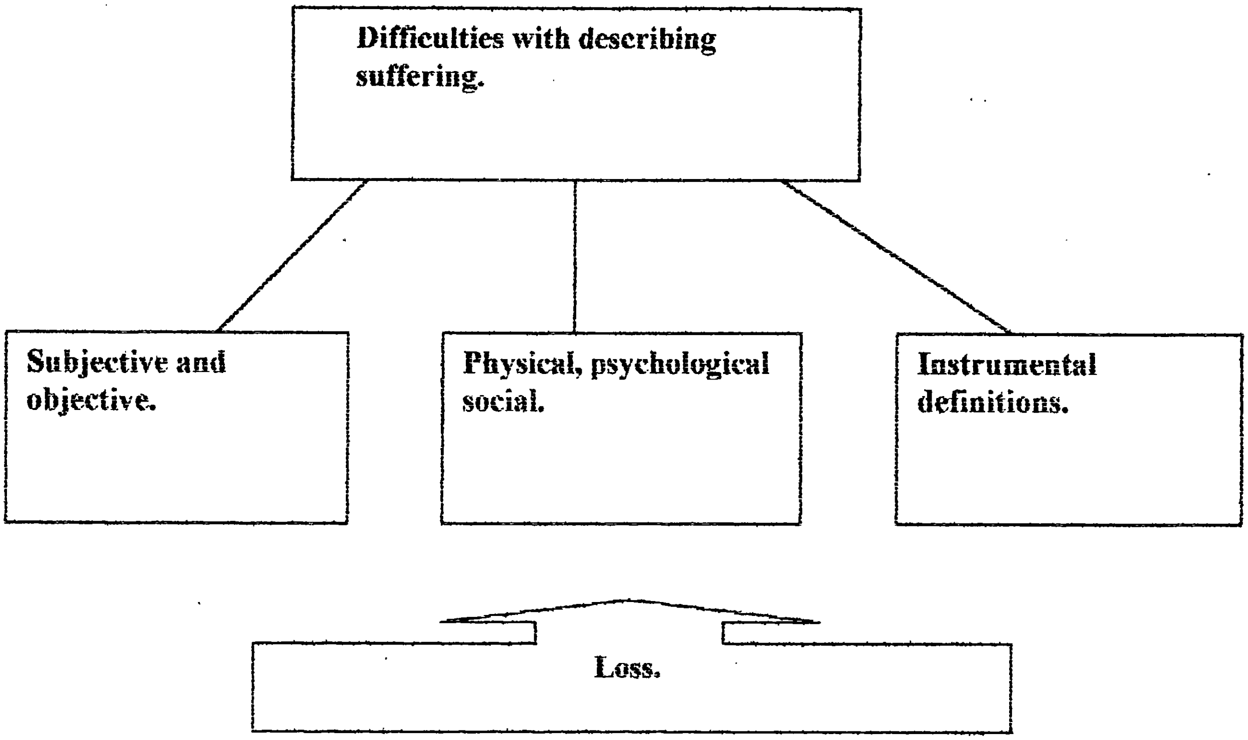
Suffering: Introduction

The relief of suffering is the essence of palliative care (World Health Organisation, 2007) and aims to promote the physical and psychosocial well being of patients for whom there is no cure. Nursing is aimed at maintenance of the body rather than its restoration. Morse (2006), argues that *'nurses are the caretakers of suffering'* (p268) and have the primary responsibility of care for those who are suffering. The palliative care nurse must develop a relationship with the person suffering and their family and both manage care and witness their suffering. Kriedler (1984) maintains that sharing the suffering experience is inherent in the caring process, and Kahn and Steeves (1994) discuss the moral obligation to speak of suffering. Palliative care nurses are challenged to understand suffering in order to manage it and help patients integrate the experience into their lives. The meaning of suffering to palliative care nurses may determine the focus and practical aspects of their care. Suffering may be whatever the person says it is leading to a further challenge for the nurse in identifying and responding to what it is for a particular patient.

The aim of this part of the study was to explore the palliative care nurse specialists' understanding of suffering and their experiences of working with patients who are suffering. The palliative care nurse specialists were asked what suffering meant to them using the questions outlined in Chapter Five.

The data collection was considered in terms of the palliative care nurse specialists' understanding and experience of working with patients who are suffering. The palliative care nurse specialists all felt that a large part of their role was to understand and alleviate, where possible, patients' suffering. Two main areas emerged from the data that related to suffering: problems with definition and description and the strategies used to articulate the concept of suffering, and that of suffering being caused by loss. The first of these will be described in Section One and the second in Section Two of Chapter Eight.

Figure iii: Palliative care nurse specialists understanding of suffering.



Section One: Difficulties with describing the concept of suffering.

8:1 Introduction.

The palliative care nurse specialists talked of having a mental picture of what suffering looked like but acknowledged that describing the concept of suffering was hard. The themes developed from the data collection that relate to difficulties with definition are described below. As analysis progressed it was clear that although they found suffering hard to articulate, the palliative care nurse specialists were able to describe it using several different approaches. Difficulties with definitions of suffering became an overarching theme with three sub themes of the strategies used to describe suffering.

Suffering is considered in the literature review. A number of studies have shown that there are many and varied definitions of suffering (Cassell, 1991; 2004; Van Hooft, 1998; Kahn and Steeves, 1986) and that patients and nurses see it differently (Lindholm and Eriksson, 1993; Steeves et al, 2001; Sherman, 2004). Rodgers and Cowles (1997) reviewed literature from 1987 to 1994 and applied concept analysis to inductively generate a definition of the concept of suffering and clarify various contextual aspects of the concept. They commented on the relatively small amount of literature on the subject despite the acknowledged importance of the concept to nursing. They identified suffering as an individualised, subjective, complex experience characterised primarily by the negative meanings or threats attached by persons to situations. This meaning involves the loss of one's integrity, autonomy, and actual humanity and may mean diagnosis or describe physical symptoms. Problems were found in extracting exactly what suffering might mean in terms of nursing practice (Rodgers and Cowles, 1997). They concluded that whilst the current status of knowledge concerning suffering leaves many unanswered questions, the definition of suffering identified was remarkably compatible with the values commonly espoused by nurses, for example individualised care, emphasis on the nurse-patient relationship, interpersonal skills, existential precensing and empathy.

These variations in descriptions and definitions of suffering demonstrate the difficulties in both communication and interpretation of what constitutes suffering, which were echoed by the palliative care nurse specialists in this study. Articulation was difficult for the palliative care nurse specialists when trying to elucidate the concept of suffering. There were two main problems identified: that suffering was hard to describe, and that they had a mental picture of what it looks like. These are explored further below.

8:2 Difficulties with describing the concept of suffering.

Figure iv: Difficulties with definitions of suffering.

Difficulties with definitions of suffering:	*hard to define* *mental picture of what suffering looks like*

Hard to define.

The nurses' experience of working with suffering is central to nursing practice, but nurses can find suffering difficult to understand in a detached way, preferring to describe it as a subjective experience (Kahn and Steeves, 1990). Nurses try to understand suffering by finding reasons and meaning for it and can often see that the patient is suffering without knowing the reason why (Lindholm and Eriksson, 1993). The nurses' experience and reactions to suffering can influence their interpretation (Kahn and Steeves, 1990). All the above were clear as the palliative care nurse specialists really struggled to articulate what suffering meant to them. However, despite acknowledging how hard it was to define and describe, they were also keen to explore the concept and to try to explain it.

'So it's difficult to pin down saying what I think suffering is. I mean it's not always vocalised. It's sometimes something that we see and are aware of and feel but don't have it sort of said. Sometimes it's said sort of quite openly. You know, I'm in pain, I am suffering, I'm hurting.' Interview 16

'I've thought long and hard about this because people often speak about suffering or somebody suffering with cancer or suffering with this disease and it's not really the way that I look at suffering because what they mean is a disease really you know. And thinking about it I think sometimes the spiritual side of it like the anguish that some people have seems to make me think of the word suffering more than the physical pain. Although some people do have physical symptoms that we have difficulty controlling and the family feel that sometimes that may be their suffering but the psychological, spiritual side of it that sometimes I feel a bit more the meaning to it.' Interview 17

Mental picture of what suffering looks like.

The palliative care nurse specialists talked about suffering being difficult to describe but that they had a mental picture of suffering based on their experiences of working with people who are suffering.

'It's really difficult to describe. I see some patients and you think oh they are really suffering but there is never anything specific it's always everything in a whole, psychological issues, there's physical issues, there's a picture of suffering. Patients who are sad, who are distressed and that's what I link in as being suffering but I don't know whether that it is, what is, what suffering is. It's having an image of a patient who is suffering with their diagnosis or struggling to cope with their diagnosis'. Interview 9

The palliative care nurse specialists were very clear that a large part of their role was to try to alleviate suffering and thus they must understand what it means to the patient. To do this they must themselves have an understanding of suffering. As a result of this commitment to patient care, they used a number of strategies to try to describe suffering and thus three further themes emerged relating to their understanding of suffering and their experience of caring for patients who are suffering. They used case study examples to identify problems encountered by their patients that epitomised suffering for them.

8:3 Strategies used to describe the concept of suffering.

There were three strategies that enabled the palliative care nurse specialists to discuss their understanding of suffering and experience of working with patients who are suffering. Within these overall themes are sub themes further identifying different aspects of the concepts described and explained below. The themes have similarities to the definitions found in the literature by Rodgers and Cowley (1997). However, in this study physical, psychological and social problems were thought to cause suffering in themselves, which is also described in other studies, especially those that involve the patients' perspective (Copp, 1990; Kupplemaki, 1998; Rydahl-Hansen, 2005)

There was some overlap in the categories within the themes and sub themes. Overlapping categories were an objective assessment of psychological suffering manifesting as physical suffering and a composite description where the meaning attached to physical problems was thought to cause psychological problems. The uniqueness of the suffering experience, which has been placed in the subjective sub theme was evident throughout the descriptions of suffering.

Figure v: Strategies to describe the concept of suffering.

Subjective and objective.	
Subjective:	*impact of disease on life* *unique to the individual*
Objective:	*helplessness in face of disease progression* *psychological manifests as physical*
Combined:	*sufferer and nurse's perspective on individuals' suffering are related but different*
Physical, psychological or social definitions.	
Physical:	*symptoms and problems*
Psychological:	*emotional, social and spiritual*
Composite:	*meaning of suffering to the person's life* *physical combines with psychological*
Instrumental definitions.	
Alleviating suffering:	*taking control/transcending* *being there* *working with and accepting the patient's view of suffering* *accepting limitations of helping with suffering*

8:4 Subjective and objective.

- 'Subjective' describes suffering from the sufferer's point of view and therefore relies on the sufferer's account and is unique to that person. These are definitions given by the patient.
- 'Objective' is where suffering is reliant on a third person or the palliative care nurse specialists' inference on someone else's suffering. The sufferer may communicate their problems or may not be aware of their suffering. Suffering in this instance may not include meaning nor require mental consciousness. Others

witness the suffering but the sufferer may or may not themselves be aware of it. This relies on the accuracy of the interpretation of the inferences.

- 'Combined'. It was clear that there were times when there were combined objective and subjective approaches to describing suffering. In these cases the palliative care nurse specialists described when the sufferer expressed suffering arising out of one problem in their lives and the palliative care nurse specialists could see that other problems were also causing suffering, but the person was either unaware or unwilling to acknowledge these.

8:4:1 Subjective.

Suffering is a whole person concept and the experience of suffering is complex, personal and multidimensional. Cassell (2004, p3) defines suffering as the *'state of distress induced by the threat of the loss of intactness or the disintegration of the person from whatever cause'*. Many aspects of a person can be sources of, or affected by, suffering. Essentially, suffering occurs as a result of the individual's identity being threatened. What is thought to be important in terms of identity is highly individual; thus suffering is whatever the person says or experiences. The palliative care nurse specialists understood that suffering was highly individualised and resulted from the meaning placed on events that threaten the person's identity.
'So suffering, I just think suffering is so personal to everybody. It's not something you can just put an umbrella over and call it suffering.' Interview 24

' Patients that we see with lots of different types of suffering we see suffering because of symptoms, physical symptoms, we'll see suffering because people are in pain, we'll see suffering because they're being sick or because, whatever physical symptom. And then there's the emotional symptoms and that's multifold isn't it? That's suffering because they have been given the diagnosis that they have been given, a limited prognosis because their life has changed, suffering because they are no longer able to work, they are no longer able to lead the life that they had. So I think that suffering is just a heading for a massive, it's a different for everybody isn't it?' Interview 31

Impact of disease on life.

Kahn and Steeves (1986) and Cassell (1991; 2004) maintain that suffering is more than just a collection of signs and symptoms and that it is about the meaning that the individual gives to those signs and symptoms. The palliative care nurse specialists understood that suffering was highly dependent on the person's interpretation of what was happening to them.

'I think suffering is, I think everybody knows what suffering is, whether you work with people who are suffering or just life, throughout life people suffer don't they? And suffering means different things to different people. I think depending on your experience as to the severity of suffering perhaps, I mean some people who'd got a common cold would feel they're suffering. They feel ill they can't do what they want to do but their suffering comes to an end as they improve and they go back to their normal life.' Interview 31

The palliative care nurse specialists also realised that how the patient was able to adapt to what was happening to them would influence how their experience impacted on their life.

'It's not an easy concept at all, I think to some extent it's probably, there's a bit of adaptation there. Because I think a lot of patients we see go through awful, awful things yet not everyone will suffer. Well, there will be degrees of suffering and I suppose to some extent it feels a little bit about coping strategies and about people's perception of their experience. That's quite an objective, it's a very personal sort of thing.' Interview 28

These data extracts reflect Frankl's (1985) views that suffering is a part of life and the person's ability to accept *'the challenge to suffer bravely'* (p137) will help them to cope.

Uniqueness.

Suffering causes interruption to the person's normal way of life or ability to be the person they wish to be, it is unique to the person (Cassell, 1991; 2004). The palliative care nurse specialists realised that understanding this fact was an important factor in their ability to help the person.

'I think it's very much an individual thing isn't it? So different patients may experience different things but may suffer at different levels.' Interview 2

'It can't be separated and I think it's linked sort of, I don't think it can be separated from the person and their wider sort of network of people, and how it's affecting them and how it impacts. Because you can see the same situation with one person and in another the reaction is so totally different so it's about how that person is, you know where they are in their journey in life and how they cope and manage with that and what their reactions are. It's just so different.' Interview 16

'I mean suffering is all different aspects of it isn't it? It's not just symptom control where they're suffering with pain and that in itself is a huge subject, the different types of pain, the nausea, vomiting, the intestinal obstruction or a fungating wound or whatever. I mean suffering is the emotional turmoil that the patient goes through. Suffering for me is, it's almost like the old philosophy you know, pain is what the patient says it is and that goes for suffering as well. Because you look at patients who you think physically they have no symptoms, mentally you're a tortured soul.' Interview 25

The palliative care nurse specialists were very cognisant of the uniqueness of suffering and were willing to accept the patient's experience and interpretation of their problems.

8:4:2 Objective.

Van Hooft (1998) maintains that challenge to any parts of the human being described in the context of Aristotle's four parts of the soul can result in suffering, and that with this in mind the person can be suffering without being aware of it. Others may perceive suffering based on what they see as challenges to the soul even if the individual is not aware that they are suffering.

The palliative care nurse specialists discussed suffering in terms of problems that they can see the patient has and the potential impact on their life. Their descriptions were of how they see the person's life rather than how the person themself describes it. This is based on their inference of the situation and may not actually be suffering for the person.

Helplessness in the face of disease progression.

The palliative care nurse specialists felt that one factor that caused suffering was the feeling of helplessness experienced by the patient when faced with progressing disease that interferes with their ability to live their lives as they had previously.

……… 'you'd see suffering physically because of pain, the physical effect of cancer if they have got pain in various parts of their body. And that obviously leads them to suffer because they are hurting, but I think when I think about suffering as a whole I think of the psychological component of it in that the whole impact of what cancer has on their life and the suffering with changes in role, changes in the family network, they can't work, can't move. Those sort of issues'. Interview 9

Psychological manifests as physical.

The palliative care nurse specialists understood that sometimes physical suffering may be used to highlight psychological or spiritual distress. The person may be unaware that their distress is due to psychological or spiritual factors. The palliative care nurse specialists could often see that although the patient may be complaining of physical problems their suffering was not just physical but psychological. They appreciated that that sometimes physical problems are seen by people as generally more acceptable or easier to articulate than emotional or spiritual suffering. They were aware though that no amount of interventions were going to help if they were addressing the wrong problem.

'And so, and so I suppose there's lots of different types of suffering that we see but I find that they all feed into each other and if somebody is suffering spiritually and psychologically because of what they are losing then that very often exhibits in physical pain…… You have certain cases in your career that sort of stick in your mind when you have thought of somebody who is holistically suffering then that, that the pain that they were describing may actually be the physical pain and all linked in with the psychological agony. Do you know what I mean? You get young women with young families and who have got, who are losing a lot and all their loss of role and their loss of function and their loss of identity and oh gosh there is so much and I find that they all feed into each other.' Interview 4

Defining psychological problems that may be manifested physically requires an objective inference by the palliative care nurse specialists on what is happening to the sufferer. The palliative care nurse specialists must respect the patient's view, but to manage suffering they must also maintain an open mind on what may be exacerbating complaints of a physical nature. Thus, they can explore possible psychological problems further with the person and attempt to help with these. This is fraught with difficulty as the person may be deliberately focussing on the physical aspects of their condition to avoid contemplating the psychological, as this latter may be more difficult to live with if acknowledged totally. Further, the palliative care nurse specialist's inference may be incorrect and psychological problems they envisage may not be problems for the person. A delicate line of maintaining an open mind on what may be troubling the patient whilst accepting what the person is stating to be the problem must be achieved. The person should lead the way in terms of what suffering is for them and what help they require. However, the palliative care nurse also needs to anticipate difficulties and be ready to help with these, so must observe and infer a certain amount from how the person behaves as well as what they say.

8:4:3 Combined.

Sufferer and nurses' perspectives on individuals suffering are related but different.

The palliative care nurse specialists thought that suffering was a whole person concept as described by Cassell (1991; 2004). However, it was often hard for them to distinguish between what the patient described and how they saw suffering. They often had to accept what suffering was stated to mean by the patient, although privately thought that other aspects of the disease or treatment process were either worse, or sometimes better, than the patients' perceptions.

' Thing is that sometimes you see people, you know we may think that with a patient that for them pain is going to be the worst form of suffering but when you're actually talking to patients it is not the pain that is there as they see why they're suffering. It's because they can't go for a walk with their children or they can't bring money in to support their family and that is a greater suffering to them than pain.' Interview 31

The objective and the subjective aspects of suffering became intermingled and hard to extricate. It was unclear what effect this may have on planning and executing care but one could speculate that it is possible that care planning could be influenced by the palliative care nurse specialists' perceptions of suffering as opposed to what the patient stated the problem to be for them.

' Well I think it is very complex and I think that it's very difficult to separate physical from emotional suffering and that is what I think why it becomes so difficult so that I think that the skills that you need are to observe it, to notice it and, and see what it is

for that particular person rather than what you in your own mind may think is suffering, no sort of preconceived ideas.' Interview 1

8:5 Physical, psychological or social definitions of suffering.

These descriptions relate to actual problems that result in suffering. The palliative care nurse specialists discussed individual situations where suffering was clearly arising as a result of problems of a physical, psychological or social nature being experienced by the person.

There was also a composite definition where suffering is multidimensional and the psychological, emotional, physical, spiritual and intactness of the person may be affected. Each of these dimensions can suffer separately but affect the others. Suffering in this case often arises out of the meaning placed upon the problems being experienced by the individual and the resulting life changes. The impact of physical and psychological problems on the patients' quality of life have been studied and the effects of these problems are often the reason for suffering, not necessarily the problems in themselves (Charmaz, 1983; Weisman, 1972; Rydahl-Hansen, 2005, Kupplemaki, 2005).

'I mean I suppose very basically possibly I would have to divide it into physical suffering and psychological suffering. They are obviously very, very vast and different in their own ways. The physical suffering, I do feel that a large percentage of that can be managed and we are actually quite comfortable in managing the large proportion of physical suffering symptoms or whatever you want to call it. Psychological suffering I feel is again much wider, vast then really and cannot as easily be managed or supported, you know I suppose that there's things such as spiritual issues, financial possibly and obviously financial more often than not again you can manage but there's the spiritual issues and psychological issues about coming to the end of your life and how patients manage that.' Interview 3

8:5:1 Physical.

Physical problems were recognised and discussed as a source of suffering. However, the palliative care nurse specialists repeatedly noted that it was hard to discuss physical problems in isolation from other causes of suffering.

'I mean, and pain again would be a way that I would say somebody suffers and you can see very often when somebody's in pain but very often you can't, very often a

patient is suffering pain in a way that is not outside the obvious perhaps unless you spend time with that person, finding out what matters to them and what that pain means to them. .... So, physical, yeah I think is probably easier because people have more vocabulary for physical suffering and it's more widely understood to be a good reason to suffer.' Interview 11

'Well I suppose there is lots of different sufferings. You could say if they were suffering physically or emotionally. Probably the worse would be emotional suffering. Because, sometimes I think if they are suffering physically then they are so, they are feeling so ill that they don't really feel as bad emotionally you know because they are concentrating so much on their symptoms. So sometimes even if they're not that symptomatic their emotional symptoms are much, much worse and that's much more difficult to help them with sometimes.' Interview 6

The palliative care nurse specialists were confident in their ability to relieve suffering and cognisant that physical symptoms would often be discussed although the person's suffering was greater than just these. They also understood that suffering could be made worse by the alleviation of physical problems as then the patient had room to consider the meaning of their problems in relation to their life.

8:5:2 Psychological.

The palliative care nurse specialists were aware of the suffering caused by the psychological impact of the disease process.

'Oh I have one at the moment who's extremely complicated. When I see her whole picture, there's suffering but I think she's probably suffered all her life because psychologically she does not have the normal patterns of coping. She is very very self-conscious of her cancer and the effect that it has on her body. She is a very private lady and doesn't want anybody even the immediate family to know that she has cancer. And goes to long, huge lengths to avoid that being discovered. And I see her suffering because physically she could lead a fairly normal active life but psychologically because of this fear of what cancer is and what she perceives it to be, it's making her suffer and stopping her doing things'. Interview 9

'The emotional at the moment we're talking about. The physical response to it, to suffering, maybe I'm being a little bit blasé about it but because we have such good

symptom management today you know, 98/99 per cent of pains, physical pains, physical symptoms we can deal with, we can certainly minimise them to an acceptable level. Most of the suffering that is more difficult to control and deal with is the emotional side of it. It's the unknown. What's going to happen.' Interview 24

'There are people who are suffering from a social point of view because they are, they maybe, I suppose they are usually elderly people. Somebody that may be in here, (hospital) *when they left their home didn't know that they had left their home for the last time or their cat, or whoever, you know and, and it seems now that they are probably not going to be able to get home again, that they are going to be going to the hospice, or nursing home or residential home or whatever, and, I think that's pretty a unique type of suffering for people. 'Interview 4*

It was clear that suffering occurred as a result of the impact of illness on the person's life and that it was more than just any one aspect of the disease or treatment. The palliative care nurse specialists, whilst acknowledging that suffering could be of a physical or psychological origin, thought it was most likely to be a combination of both these factors, which also has an effect on the person's social circumstances.

'I would perceive for me suffering is somebody not being able to maintain the sort of life that they are used to due to illness, their quality of life is not as it was and to try to adapt to that, for me, but I am sure it causes suffering in that respect, so I would say for me a person finding it difficult to adapt to a new way of life caused by illness.' Interview 12

The palliative care nurse specialists saw changes to the patient's social circumstances or their inability to fulfil their social functions as a source of suffering.

8:5:3 Composite.

Meaning of suffering to the person's life.

Suffering is more than just a collection of signs and symptoms. Studies show that it is not the disease that causes terminally ill patients to feel unhealthy, but the fact that they cannot live their lives as they would wish (Fryback, 1993; Post White et al, 1996; Benzoin et al, 2001). It is about the meaning that the individual gives to the signs and symptoms and the threat to the individual's sense of identity (Kahn and Steeves, 1986). It is a collection of problems and the person's interpretation of these in relation to themselves and their life. It is difficult to separate the physical, social, psychological and spiritual aspects of suffering as their impact on the individual's life and the meanings associated with them are interrelated. Meaning has two connotations: that of attribution or cause, and the impact of suffering. The meaning that the person places on what is happening to them seems crucial to whether they are suffering and the palliative care nurse specialists certainly recognised this.

'For me, for me as I talk now it's sort of the physical and the psychological aspect of suffering so suffering as far as difficult symptoms to control but definitely sort of psychologically the spiritual aspect of. It's the why me, isn't it? And the trauma and the sort of internal feelings and the regrets and the often, you know reflection isn't it? And the suffering that that may bring going into that.' Interview 18

'Suffering for me isn't just about obvious pain, it's about how people feel and that's hugely significant, impacts hugely on how they, how they are, just everything about them and the suffering for me is the feeling, feeling, inability of not being able to cope with what's there be it pain, physical pain or emotional pain or just a way of expressing that they're not dealing with whatever's there for whatever reason.' Interview 29

Physical combines with psychological.

Suffering was clearly seen by the palliative care nurse specialists as physical and psychological and often a mixture of both. The palliative care nurse specialists recognised the importance of identifying the source of suffering, as without this there was little chance of relieving the person's distress, although they also thought that just being with the person to support them could help.

' I think it means different things at different times and I think, I suppose, different things at different times. I mean it's about the whole sort of you know the split between the sort of physical suffering and psychological suffering and I don't think you can separate the two. But I done quite a lot of sort of thinking and unpicking about how the two impact on each other. And I think that suffering is linked probably.' Interview 16

'I really believe that that the two are very much entangled in that if you have got someone who is emotionally suffering you won't be able to do anything or it would be

very difficult to do anything about the physical suffering.....If somebody has got a nausea problem for some reason and they are terrified you are not going to completely do it without addressing the sort of emotional issues as well. And sometimes I think there are emotional issues, it is not about addressing them and doing something about it. It is actually supporting being with somebody through them.' Interview 1

8:6 Instrumental definitions, palliative care nurse specialists describe how they manage suffering.

Suffering was described in terms of what might be done to try and alleviate it. Descriptions include what helps the person overcome their suffering. Often the palliative care nurse specialists found it easier to explain suffering in terms of measures that may be taken to try and help the sufferer. This may be because describing help for suffering gives access to ideas and vocabulary that gives suffering a structure for discussion, rather than it being a nebulous concept dependent on individual ideas.

8:6:1 Alleviating suffering.

The uniqueness of suffering was present throughout the data, with suffering being a highly subjective experience for each individual. The palliative care nurse specialists were very aware that to alleviate suffering they must have an understanding of what was causing the person to suffer. This was often achieved through just talking to the person to develop a relationship. Several studies (Georges et al, 2002; Rasmussen et al, 1997; Rittman, 1997) have shown that nurses working in palliative care see their role as developing the nurse-patient relationship to try and alleviate suffering.

The palliative care nurse specialists were sure that to help with suffering, they needed to help the individual to identify the source of their suffering for themselves. The view was that otherwise all attempts to help would fall short as they would not be addressing the right issue. However, they accepted that the patient had to acknowledge what the problem was in their own time and meanwhile they ensured that they were available and did what they could to relieve presenting problems, particularly of a physical nature.

Taking control/ transcending.

Cassell (1992), discusses the loss of central purpose that arises when a person is suffering and goes on to explain that to overcome suffering, the person must be helped to reintegrate into their life. If the sufferer can be helped to take control and maintain their identity their suffering, whilst objectively the same, is often more bearable for the person. The palliative care nurse specialists realised this and tried to work with the person to help them take control or transcend their suffering.

'You know they have had that sort of hope and then it gets to the point where it's then unrealistic and unachievable, the goals that they're going for. If you can intervene before that and recognise when further treatment may be inappropriate before it starts making somebody really poorly without actually achieving anything, and change gear and have the conversation. Talk about hope, talk about the things that are available and comfort. And then think about putting them in control of what's happening and, making preparations so that they feel that they are in control; making preparations for their children; preparations for what they want. And I think that control-having control is a good thing. I think when they feel out of control, then desperation can set in.' Interview 3

'I think a big part of it is helping them to adapt to their new level which can be quite difficult for many people, that they can't do the things that they were doing before but if you can allow them try and concentrate on different things or things that they can actually do, it may not seem a great loss to them that okay, they may no longer be able to go for their 10 mile walk but perhaps they could manage a half a mile walk and perhaps focus on that rather than the more negative things all the time.' Interview 12

'She had terrible pain and had an awful lot of different analgesia and we were just sticking with her but despite the terrible pain she had she had an extremely full life. She took off abroad, and she didn't take any health insurance, and she took risks and she went off and lived in France and died in France on a barge you know but had terrible pain for the whole two years when I knew her.' Interview 2

Being there.

The concept of being there was seen as important in trying to identify and alleviate suffering. This also involved being realistic about what can be achieved, being honest about the present and the future whilst staying with the person throughout their experiences. This aspect of the palliative care nurse specialists' role arose again in the nurse-patient relationship and was a feature in the difficulties and coping with the role. It will be explored more fully in the discussion chapter.

'Yes, I mean I think in relation to the sort of illness that we are looking after then, I don't, for me I, obviously they are all suffering in some shape and form. I think sometimes you can't take that suffering away, but by being there for people, by taking a lot of the responsibility off them, they don't feel so isolated and to a degree their suffering is perhaps minimised. You can take measures perhaps to make their physical suffering better, you can take measures to perhaps improve their quality of life but they're never going to be the person they were previously, so I think you can minimise a lot of suffering to a point but there will always come a time when that suffering can no longer be minimised I suppose.' Interview 12

Being available helps the sufferer through restoration of self-esteem and being connected to others (Clarke and Kissane, 2002). The palliative care nurse specialists acknowledged that witnessing suffering is very difficult and that it may be impossible to alleviate or even identify the source of suffering but that staying with the person was an important part of care.

'So it is not because I think it is very painful for people around is to observe, witness that emotional suffering which is what I was doing earlier on in my career, was running away from it because I wanted to be able to do something about it and mend it and you can't so therefore you run away from it. But now I have much more confidence to actually just stay with that person. That doesn't mean sitting with them it means that you do go back.' Interview 1

'So I saw him every day because he encouraged me to do so. But we didn't really talk about much at all and I have no, I have no sense of that now really. In terms of he died very peacefully so I hope he wasn't suffering, but I have no sense of what he thought about dying, I have no sense of what he thought about you know what he was thinking because he never really allowed me to go there.' Interview 28

Working with and accepting the patient's view of suffering.

The palliative care nurse specialists recognised that as suffering is personal and subjective to the sufferer so they needed to accept the patient's view of suffering and work with that view to try and alleviate their distress. The palliative care nurse specialists also felt that their role was to support the person on that individual's terms regardless of their own personal views of what might be going on.

'I think you have to accept as well how people want to go along this journey. We may not always agree with it and you may not always understand it but if it works for them then it's right for them.' Interview 25

Their role was often frustrating, as they were unable to help the sufferer in a holistic way.

'That's why in the mix of patients that we see in this area there is diverse mix of groups of people and there are pockets of areas where they're not so well educated, not so well supported, who are struggling financially, may be unemployed, social issues and they tend to be a group of people who don't see the finer issues, shall we say, of cancer and I would class some things as the finer issue if that makes sense. They may see cancer as okay, they have lost the use of their bowel or they've got a brain tumour, something like that. It's a physical disability. If they can't work, or can't get benefit or can't do certain things then they don't see the whole picture of suffering and they don't see the impact and they always block you. You can do one thing, like sort out their pain because they have pain in their bowels but they don't let you sort out the other issues by offering support, just being there to talk to. They marry your care to certain practical things. You don't know what the impact is of their diagnosis of their cancer, physically or psychologically because you are only there to sort out their pain or just to do one aspect of their problem. And that's a really difficult situation'. Interview 9

However, the palliative care nurse specialists recognised that they needed to work with the individual to achieve patient centred care that was helpful to the sufferer.

'But if you can get that balance of trying to again flush things out and look at things in their wholeness that can help you to do that and also just to remember that this isn't your story, this is their story, this is somebody else's suffering and it's not yours to have.' Interview11

'I think the one thing I would say as well is, is you know the people that we say will only also let you in as much as they want to let you in and I think there's probably a lot more suffering in these people that we will never know about and never touch on and I think you know I feel very much that they we're invited into in a way into a very precious, very, very, important part and time of their lives. And we will only see what they will let us in a way which I think is good and sometimes in a smaller community you learn things about patients once they've actually died.' Interview 15

Allowing the person to fully express how they felt about what was happening to them was thought to be part of helping to reduce their anguish. The palliative care nurse specialists accepted the patient's interpretation of their problems and the level of support they wanted from them. They adjusted their care to satisfy the patient's wishes.

' So it's (suffering) *almost like a frenzied anxiety inside really and allowing them to express, if they want to, how they feel. And obviously trying to understand, you only get a microcosm of their life don't you? But you try and understand why they're where they're at really so that often includes lots of factors about their lives, their working lives, their relationships. And looking at the family dynamics as well within that suffering because it's not just the patient, it's, its, the whole family how they, they interact and react with each other which can accentuate the suffering really can't it? Because if there's poor communication within the family that sort of accentuates how they all feel you know privately.' Interview 18*

Accepting limitations of helping with suffering.

The palliative care nurse specialists also acknowledged that due to the individuality of suffering there was a limit to what they, as caring professionals, could do to help. Often their role was to accept the person's interpretation of suffering and try to support them through it without trying to 'take away' their perceptions. Existential suffering that is part of coming to the end of life was seen as difficult to reduce and the palliative care nurse specialists accepted their limitations in being able to alleviate the person's spiritual pain.

'I think suffering is a very individual thing and what suffering to one person isn't suffering to another. Suffering, when patients are suffering is when they're not coping or dealing or accepting what's actually happening to them and when they are just finding it so distressing that they can't deal with either their symptoms, their

condition, what it's doing to their family, when they are suffering either in a physical way, a psychological way, a spiritual way. When somebody is just so distressed that they can't deal with what is happening to them. That is suffering. And you, and you as a professional can't make that better. You can't take their cancer away. You know. You can make their symptoms better in most cases. Not always but you can't take away their psychological suffering or their spirit suffering or to answer many of the questions they have - Why me? You know. Why has this happened I've always been a good person? ' Interview 20

8:7 Discussion: Difficulties with describing the concept of suffering.

There were clearly difficulties in describing suffering but despite this it is plain from the accounts that the palliative care nurse specialists understood what suffering was and could identify it when they saw it. Their strategies to describe suffering clearly enabled them to communicate what they thought suffering was and led to graphic accounts of the suffering they had witnessed patients experiencing. Physical causes of suffering, whilst real and sometimes hard to overcome, were seen as relatively easy to work with and relieve. Existential suffering was clearly seen as the most difficult type of suffering for the patients to endure and the palliative care nurse specialists to help. The data demonstrates that suffering manifests in many different ways and may arise from a number of factors, but often it is the meaning that the patient puts on the events or problems occurring that causes them to suffer.

The difficulties with defining suffering from the palliative care nurse specialists' perspective raises some interesting issues for practice. The literature reveals a number of definitions and ideas about suffering but there is a comparative paucity of research in this area (Morse, 2006; Rodgers and Cowles, 1997; Cassell, 2004). This is interesting and important since the relief of suffering is thought to be central to the nurse's role (Morse, 2006; Kriedler, 1984; Kahn and Steeves, 1994). Their descriptions were similar to the literature but were a composite of all the descriptions discussed by both researchers and philosophers (Morse, 2001; Radiewicz, 2001; Kahn and Steeves, 1986; Van Hooft, 1998; Cassell, 1991; 2004). There was no one account to which they all subscribed. Their understanding of suffering was as individual as the suffering experience, except for the common threads of the unique and subjective nature of suffering and loss. They recognised the difficulties and their problems in describing suffering and thus the potential implications of assessing the patient and providing care. Arguably if the concept cannot be defined and described, then identifying when somebody is suffering and taking action to alleviate it is hard, especially for a novice nurse.

One clear element that underpinned the palliative care nurse specialists' descriptions and definitions was that of loss which was seen as central to the suffering experience. This will be explored in greater depth in the next section.

Section Two: Loss.

8:8 Introduction to Section Two: Loss.

Suffering in the literature is often viewed as a response to loss. Loss of a pain free existence (Chapman and Gavrin, 1999), of health (Jones, 1999), of future or of self (Charmaz, 1983; Morse and Johnson, 1991). By the time a person is requiring palliative care they have often experienced a great number of losses, including loss of status or self esteem, bodily functions, job, role within the family and future expectations. Shaver (2002), suggests that human suffering can be distilled to three general categories; abandonment of self, isolation and loss of significance.

Loss associated with suffering was apparent throughout the data and acknowledged as a central feature that causes suffering for the person. Loss underpinned many of the ideas being described and arose in many different forms: of control, identity, hope, social relationships, bodily function. It was present, but not necessarily called loss, in the descriptions about what the person was experiencing when the palliative care nurse specialists were discussing other aspects of suffering such as the impact of the disease or the uniqueness of the suffering experience.

'So I think it is, there are elements of control definitely within it. And it's about loss isn't it, suffering I suppose is about people grieving for what they've had, what they don't have at the moment. And I think that you know probably support and the ability to seek support actually helps with suffering. I think some people unfortunately are very independent and stay with that and sort of lock themselves in.' Interview 28

This quote seems to epitomise the problems of loss of control, identity, hope and the ability to either develop, or maintain, relationships that may result in the person feeling supported or part of society.

Loss is considered as a theme that is core to the definitions described previously, with a number of categories is outlined in Figure vi, and explored more fully through this section with illustrative data extracts used to substantiate the thematic structure.

Figure iv: Loss.

Loss:	*loss of control* *loss of identity* *loss of hope* *loss of social relationships/isolation and loneliness* *loss of bodily function*

8:9 Loss.

Loss of control.

Loss of control refers to the person's perceived ability to make choices that affect their lives (Northouse and Northouse, 1987). Incurable illness results in powerlessness and the need to adapt to ever changing bodily problems (Rydahl-Hansen, 2005). The human ability to make choices and take action to influence life can be swiftly abolished in the final phase of an illness, leaving the person without plans or future aspirations and feeling helpless. Loss of control can bring with it a sense of dependence, lack of autonomy and feelings of vulnerability (Blumberg et al, 1980). Flemming (1997), maintains that loss of control can result in deep inner pain that can be linked to loss of hope. Baugh et al (1988) argue that control is fundamentally important in life and being out of control is one of the most frightening experiences. Johannson (2006), found that having control of life and being able to make decisions were important for patients who were terminally ill. Carter et al (2004), found that taking charge was central to all other themes in a study to determine patients' priorities in living with a terminal illness. The palliative care nurse specialists could see that having a feeling of control was critical to whether the person was suffering.

'So she's suffering because she's uncertain about her future... ...So it's more a sort of social and emotional side of things rather than the physical at this moment in time. But yes to me this lady is suffering. Because she's no longer, she's afraid she's no longer in control of her life. And she's been fortunate in that yes we've been able to

address the physical symptoms as they've come along but this is a lot more complex you know and she's suffering.' Interview 27

'And he keeps using the words "It's knocked the stuffing out of me". But he can't quite pinpoint at the moment where his trauma anxiety is but it's definitely there and I think he's feeling he's suffering from his total change.' Interview 15

The palliative care nurse specialists reflected that the individual's personal reaction to their circumstances would paralyse or enable them in taking control of their situation. Loss of control was seen both subjectively and objectively and helping the person to regain a feeling of control over their life was central in trying to alleviate suffering.

'And I think that's really the real suffering, is when you are not ready to die, when you are dying and you are fighting to stay alive and you are desperate for some sort of hope, some sort of treatment to be available to you. And you are searching for that and it's preventing you from accepting what is to come.' Interview 10

'The consequences of that really, not being in control, not being able to be what she'd planned to be and do what she planned to do. So she's for me, sums up suffering in all sorts of ways because there were lots of facets to her as a person. And her suffering was significant. It really was, the whole person was affected.' Interview 29

However, a difficulty in palliative care is that of trying to give the person a sense of control whilst at the same time prepare them for worsening bodily function that will lead to increased loss of control. This palliative care nurse specialist seems to recognise this dilemma in the acceptance that ultimately death is inevitable.

'I think the spiritual aspect of it more and more now I see the pain being more as a spiritual pain, a pain that will never, never heal, and never get better. The whole thing of being ill and not being able to be in control. Not being able to take an Aspirin and get rid of the pain, not being able to go and make a change of lifestyle or change of job, which will take all this pain, and suffering away. This misery that you're waking up with every day. You can't change it and the whole. Even thinking about it from a patient's point of view really upsets me. The whole thing to waking up that morning and think - I'm going go die and I can't do a single thing about it. To me that's suffering and they're suffering.' Interview 14

The importance and the need to overcome loss of control and set new goals so that the person may feel more in control of their lives again was recognised by the palliative care nurse specialists in their descriptions of ways in which they would alleviate suffering. This may mean changing the focus from aspects of their lives that they cannot control to those that they can. They identified the need to reconsider life priorities and thus take charge or control of the situation as a major priority for patients.

'It's about being there whatever their decisions are. I mean they have to feel that they have some control or all of the control depending on the patient. Some patients don't want all the control but it's important that they have their opportunity to be in control and to make decisions whether they're there for their good or they're bad because they need that.' Interview 20

'So she really just adapted to the situation I guess. She took control of it all. And I think you know what can we do help to help that. Again it was a listening, listening to what they've got to say you know running things by us. And that was really painful as a team but actually when she did die it was very satisfying because she did everything that she wanted to do. Even though she did have an element of pain, physical pain she was accepting of that physical pain, the emotional pain, she'd got everything right. She had an opportunity to, she got married to her longstanding partner, she sorted out who was going to look after the little boy when she'd gone.....She felt she'd got control over everything and even the emotional pain that was there from when I first met her dissipated because she took control of it. So I guess why I perceive suffering as a control issue almost because they were two very different people but who've kind of got somethings in common, similar personalities. Yes, I mean the whole personality prevented one person but enabled the other person.' Interview 29

Loss of identity.

A sense of identity can be described as the way in which a person perceives themselves and may include concepts such as personhood, self-esteem or self-concept. Threats to personal identity include especially the threat of death or the loss of self which can be threatened by both real and imaginary factors. Cassell (1991; 2004), highlights the suffering wrought by changes to health, personality, character, roles and relationships that stop the person functioning as the person they would want to be. Kahn and Steeves (1986), discuss the suffering caused by the interpretation or meaning of changes to the person's life, which cause loss of identity and ability to continue to live the way they have previously. Although people are continually adjusting throughout life to changes in identity due to marriage, having children, change of career, many of these changes will not cause suffering. Death, however, represents the ultimate threat to identity and thus is perceived as a cause of suffering. The palliative care nurse specialists described loss of identity as a source of suffering and used case studies to illustrate their thoughts.

'I mean I whole-heartedly suggest that suffering is about not being who you want to be and being understood for who you are…… Yes, to be misunderstood, to be uncared for, to be feeling that you're worthless is very, adding to any kind of feeling of suffering.' Interview 11

'It completely challenges her identity as an individual, because she's afraid that she looks like a cancer sufferer, she looks like a cancer patient. And she doesn't want to be that person.' Interview 9

Strandmark (2004) found that the sense of powerlessness caused by ill health resulted in feelings of worthlessness and a sense of being imprisoned in one's helplessness causing emotional suffering and leading to apathy. The palliative care nurse specialists discussed this kind of loss of identity and were clear that this sort of suffering was particularly difficult to deal with and could exacerbate other types of suffering, such as physical or emotional problems, and lead to despair. The quote below is about a man who was also struggling with loss of control over his life and clearly saw suicide as a way of expressing his distress, or possibly as a way of regaining control.

'.....Everything sort of came pouring out about his loss of identity; he had so much spiritual suffering he felt he wasn't a husband any more. It was like it came out of a textbook. He said I see a man outside mowing my lawn, I see somebody else walking my dog, I can't drive my car I am not a man anymore, I'm not a husband anymore. I just think (threatening to kill himself) *this was an expression of how helpless he felt and his helplessness and disempowerment. This is what suffering is about as well it's completely disempowered whether being physical symptoms or through your inability to emotionally cope with what's going on. It's a complete disempowerment*

and having no real power in your life or feeling of autonomy and no feeling of any sort of grip on life. At all.' Interview 2

It was observed by the palliative care nurse specialists that the person may not be aware of where there is gradual erosion of their life. This potential suffering is nevertheless observable by those around them.

'She doesn't look the image of what she is which is a 60 year old, fit, active, attractive woman and she doesn't perceive herself as being that way any more and I think now as the disease has progressed there are changes physically. Her mobility isn't so good, she is walking differently, she can't walk as well, and that's where I see her struggling and suffering. It's the disease, the image of it.' Interview 9

Loss of hope.

The importance of a sense of meaning and purpose in life was identified by Frankl (1985), who found that concentration camp prisoners fared better if they had reason, purpose and hope in their lives. Rusteon (1995), commented that hope acts as a foundation for dealing with life stresses. Hope is important in palliative care as it helps the individual to transcend the present situation by having a sense of purpose and fostering a positive new awareness of being (Herth, 1990). Farran et al (1995), suggested that hope and coping are inextricably linked and Weisman (1979), that hope is a prerequisite for effective coping. Prolonged suffering where individuals are forced to relinquish control and aspects of their identity as well as bodily function can lead to loss of hope. Loss of hope was seen as an important aspect of suffering by the palliative care nurse specialists and was described throughout the interviews.

'But they're all different aren't they? Some sort of acknowledge that their life span is very, very short and must make the most of it, however, there are patients who, although aware of that, cannot bring themselves to be positive however hard they try. They are stuck in the fact that they are dying and what's the point in trying.' Interview 3

Several studies have reported the importance of hope for palliative care patients which has been associated with coping (Herth, 1990; Flemming, 1997; Benzien et al, 2001). Elderly palliative care patients describe their worst pain as psychosocial pain, defined as loss of relationships, faith and independence, which they deal with by maintaining hope (Duggleby and Wright, 2004). Hope fostering strategies used by palliative care nurses are good symptom control, achieving short term goals, supportive relationships, faith, acceptance or reconciliation to life situations and a positive outlook (Herth, 1995). Duggleby and Wright (2004) comment that elderly patients may need different ways of maintaining and fostering hope than younger people as they are integrating illness into a life mostly lived. They found in a qualitative study that leaving a legacy and focussing on symbols of hope were found to be important to older patients. Also, using distraction techniques to forget their bodies and reconnect with the world was important. Arguably, these strategies may also be true of younger patients. The palliative care nurse specialists were aware of the importance of hope in maintaining quality of life.

'- And I can see him sitting in the chair just, and his wife looking anxious and saying' it's very difficult' and she's very realistic but I just get the feeling that it's never going to end for him and I think he is going to die and have pain until he dies and it's actually stopping him from actually living his life in any sort of quality. You know he just sits in the chair.' Interview 2

'He still was praying and hoping, he had a 4 year old grandson, that he was going to get through this and he said to me – I'm going to beat this- but I knew that he wasn't going to beat it and he knew that he wasn't going to beat it. And I found that quite hard because he didn't want to talk about it to anybody and I knew that he knew inside but then after he died and I went to speak with his wife and they both knew like he had spoken to her about it and they'd both prepared themselves. And he died at home very peacefully.' Interview 18

Hope has to be active and based on realistic goals (Hockley, 1993); hope will lead to an action, setting goals, and action towards goals (Carson, 1989). A person with hope may be more willing to participate in achieving important, realistic and significant goals. Lindholm et al (2005), in a study of hope and hopelessness in 50 breast cancer patients, found that communicating with others and meaning in life are sources of hope that will give the will to live and endure hopelessness. The women wanted caregivers to support them by listening and giving information, encourage and care. Hope and hopelessness exist together when there is a threat to life, and hopelessness brings a desire for renewal which opens the way for hope and vitality if there are the possibilities of activities that are good for body and spirit. The relationships that are formed within palliative care bring hope to scenarios that seem desperate and empty of any possibility (Hennezel, 1997). Carter and MacCleod

(1999), conclude that the positive presence of meaningful relationships with doctors and nurses provides a sense of hope and being valued as a person having a future. However, hope is future orientated and in patients who are dying, planning for the future is difficult. The palliative care nurse specialists recognised that they trod a delicate line between fostering hope whilst being realistic in the face of disease processes.

' I think suffering is when is when a person can't find anything positive in their situation or no end to something which is bad happening to them. So for example it could be somebody who has got intractable pain that you can't get on top of, physical suffering which even though you remain optimistic to try and relieve it, the person may have had it for months and months and months and I suppose they might sometimes get to the point when they think this is just never going to end. Whereas if they would know for sure that it's going to improve they have got something to work towards and I suppose emotional suffering a lot of the time is actually again not finding an end not coming through the distress of what's happening around them, not only the brighter patches. It's almost like having goals and you know thinking am I always, people who always seem to be, seem to find no – Oh how to put it into words – find no, hope, there is a lack of hope really of things changing. Its hope isn't it and hope I suppose about things changing. And sometimes I think perhaps I think of patient's suffering because I get to the point sometimes if you're a, if you work as a professional sometimes I think you have to actually, although you need to remain optimistic in moving forwards sometimes you need to accept that there is a possibility that things might not change even though you remain proactive in trying to change things. I think trying to keep a balance on reality and in that acknowledgement you may acknowledge that that person is suffering. Because if you're thinking things aren't going to change, imagine what they might be thinking.'
Interview 2

Loss of social relationships/isolation and loneliness.

Those suffering were seen by the palliative care nurse specialists to be very isolated and loneliness and withdrawal were features of suffering. Brown (2006), discusses the loneliness of dying, describing the defining attributes of loneliness as it pertains to palliative care as involving: the social meaning of death; based upon peoples' relationship with those around them; an individualised process;

characterised by loss; a subjective experience. The experience is unique to the individual. Connectedness is a sense of being part of something that is greater than ourselves which may be experienced as being part of a community. People who are suffering have often lost this feeling of being part of a whole universe, of their role in the whole. Younger (1995), commented that concepts such as separation and alienation are part of the experience of suffering. She suggests that in suffering, one becomes most aware of aloneness and separateness from others.

'... ... ..Sometimes with suffering people. I think about it as being a very alone place as well and perhaps people suffer more because they do withdraw or do they withdraw because they are suffering, I don't know. It's very much a place of isolation I think sometimes as well. Not always but we all at the end of the day are alone in our own heads and bodies that way and nobody can suffer for us.' Interview 2

'But we see lots of people who you know you can help but through fear or just anger they just don't want you. And I think the other thing that isolates patients from support is a lack of understanding, a lack of education.' Interview 9

'He went to his bed because he couldn't move and he just slept. And he was, he was suffering. He was suddenly hit with the fact that he was going to die and he was going to die in a few weeks. There was no arguing about it. He didn't want to know the time but it didn't make any difference because as we told him he did the exact same as if they had told him. He just shut himself and shut himself in bed and he wouldn't let anybody in. He wouldn't speak to his wife, she said he was quite aggressive with her at time.' Interview 14

Loss of bodily function.

Disease processes require treatment and threaten the individual's social or personal psyche as aspects of disease increasingly engulf the person. Lawton (1998), suggests that dying patients experience a total loss of selfhood and social identity once their bodies become severely and irreversibly unbounded, often as a result of the symptoms of illness such as uncontrolled vomiting, diarrhoea, fungating tumours or gross oedema. They may withdraw from society. Carter et al (2003), found people who were dying were concerned about maintaining their dignity in the face of increasing loss of bodily functions, of maintaining life as usual whilst there was a loss of their original plans, and a gradual withdrawal from involvement. Increasing symptoms and poor symptom control that has the effect of stopping people live as they would wish also causes loss of hope (Benzoin et al 2001).

The palliative care nurse specialists saw loss of bodily function as a problem that often led to other types of suffering. Often they were confident that they could overcome many physical problems, but that emotional problems were much harder to bear and alleviate. However, it was clear that loss of bodily function was a source of suffering and it was tacitly referred to throughout the data.

'I suppose it's quite difficult because everybody's got their own idea. Initially, I might have gone in and seen their suffering as their loss of dignity because people are doing things for them; the debilitating disease itself in the fact that they can't move around and do the daily things we take for granted, washing and dressing themselves and cooking a meal and going out and enjoying a nice day. The pain is an issue which is probably when people say suffering you initially think of pain but more so my year has taught me that there's more to suffering than pain.' Interview 14

8:10 Discussion: Loss.

The palliative care nurse specialists' descriptions of suffering were underpinned by the idea that loss was prevalent in the suffering experience. Robinson and McKenna (1998), analysing the concept of loss in relation to nursing, discuss three critical attributes:

- That someone or something one has had, or ought to have in the future, has been taken away.
- That which has been taken away must have been valued by the person experiencing the loss.
- The meaning of loss is determined individually, subjectively and contextually by the person experiencing it (Robinson and McKenna, 1998).

Uncertainty about the future or absolute loss of a future associated with patients who are dying leads to a loss of control and subsequent loss of hope. Moreover, losses of other aspects of personhood cause suffering. Flemming (1997), explored the meaning of hope to palliative care cancer patients and found that loss of control due to physical deterioration and lack of family support led to loss of hope.

Lesho et al (2006), found that health care professionals often underestimated loss and physical non painful symptoms as sources of maximal suffering whilst overestimating communication and emotional and systems problems. Conversely, the palliative care nurse specialists in this study thought the person who is dying experiences a gradual loss of all that they hold dear which causes suffering. They seemed to accept the causes of suffering and honed down on loss as central, encompassing everything that is happening to the person. However, loss was often inferred by the palliative care nurse specialists rather than discussed directly by the people in their care. Consequently, caution is needed when planning care based on these inferences, which may result in inaccurate assumptions of problems.

Loss was a common thread throughout their descriptions of suffering. It may be that suffering is the individual's response to loss, which would encompass all other descriptions of suffering provided by the literature and the data from this study. Development of understanding of the importance of loss to patients may provide the key for understanding suffering. It may also account for the importance placed on the meaning of events, which result in suffering. Suffering isolates the person from their past, present and hoped for future. It fractures their sense of personhood and relationships with others. Williams (2004), found that dying patients worried about becoming a non-person and this intensified their suffering. Anticipation of how others would react to the person being ill, anticipated suffering and social isolation added to the feelings of loss of self. This is in accord with Cassell's (1991; 2004) view of suffering being a threat to the integrity of the person and the subsequent loss of self.

The palliative care nurse specialists accepted that the patient was losing large parts of their life and the distress that this caused. They acknowledged loss of identity and control as suffering and used the nurse-patient relationship to develop a partnership to enable the patient to maintain their identity and control as far as possible within the confines of their illness. Their care was very patient focussed to alleviate problems and enable the person to function as independently as possible. They acknowledged the unique and subjective experience of suffering with loss of things dear as central, and used the nurse-patient relationship to develop a partnership to enable the patient to maintain their identity and control and integrate their experience into their lives. Flemming (1997), found that hope was maintained by nursing and medical staff being there and showing an interest in the individual.

Structuring care so that control can be maintained for as long as possible seems important in maintaining hope.

Conceptually, thinking about suffering as based in loss may provide a focus for those working with patients who are dying and thus losing parts of their life, themselves or their relationships. Identification of what the person might be losing is necessary to try and help. Once more, this requires assumptions that losing aspects of life will cause suffering and anticipating this as a cause of suffering. However, it may be better to stay with descriptions of loss and find ways to accommodate loss into their life than trying to identify each individual's suffering. This may be too much for the palliative care nurse specialists to do within the time available, individual emotional resources or skills. Further research into the connections between suffering and loss and, in particular, how palliative care nurse specialists manage loss as a cause of suffering is needed to explore these ideas further.

8:11 Discussion: Suffering.

Suffering was discussed objectively, as well as from the subjective experience of the sufferer. This is understandable to some extent as the palliative care nurse specialists were being asked to discuss their views on how they understood suffering. Thus, they are identifying suffering from their experiences of caring for patients and suffering they have witnessed whether vocalised by the sufferer or not. This may make inference and objective descriptions inevitable. However, it highlights the difficulties in identifying the source of a highly subjective experience and the need for good assessment and understanding of possible sources of suffering.

There are difficulties in separating suffering and factors that potentially lead to suffering. Inclusion of known physical symptoms into definitions of suffering may mean that different concepts are being discussed than actual suffering. These difficulties were clear when the palliative care nurse specialists were trying to explain or describe suffering. The palliative care nurse specialists used both their own ideas and the patient's in their choice of care. The individuality of the experience means that it is not always possible to predict that certain factors will inevitably lead to suffering and therefore to anticipate these and act to minimise or prevent them. Moreover, relief of symptoms may result in more suffering for the patient who, free from symptoms, can then contemplate their situation and the impact of their problems on their life. The patient may be dealing with symptoms that are all consuming and thus the meaning of these symptoms is irrelevant beyond the symptom itself. Good symptom control may lead to other, more profound suffering in other aspects of the person's life.

Additionally, the palliative care nurse specialist may be able to see or anticipate suffering when the patient is not ready, or able, to acknowledge the problem. Suffering is an individual response and dependent on the meaning the person puts on it. Whilst recognising the patient's experience as important, they also have the dilemma of seeing suffering and having their own interpretation of what is happening and how this may be affecting the patient. Both communicated suffering and the inferences of those around them influence identification of the individual's suffering. Assumed suffering may be a good thing as it may inspire those witnessing it to move to alleviate suffering but may also mean that an assessment of suffering is made where there is none. Dealing with the patient thus becomes more difficult and also moves away from individualised care and identification and alleviation of suffering specific to the patient. The palliative care nurse specialist must to some extent infer when suffering may be present, based on knowledge of the causes of suffering, but must also ensure that the patient is leading their care. The palliative care nurse specialists discussed that the patient may present physical problems that are masking psychological suffering and that time or personality factors got in the way of good communication. They saw asking the patients for the cause of their distress as crucial but that it may not always be possible to identify the cause of suffering and action must be taken anyway. Their inference on what may be causing suffering complicates the issue. There are both nurse and patient factors involved in the identification of suffering. There are factors that may confuse identification of patients' suffering and consequent understanding of the meaning of problems to the patient. Consideration of these demonstrates some of the difficulties in caring for patients who are suffering in terms of both care and for the palliative care nurse specialists themselves.

The person may be unconscious or unaware of anything better or unable to comprehend the meaning of what is happening to them (through extreme poverty, learning disability or degenerative brain disease) and is therefore unable to give meaning to what is happening. Subjectively suffering may not be communicated, but to those witnessing it is clear. Conversely, if the person cannot communicate their plight they may be seen as not suffering when in fact they are. Bauby (1999), suffered a brain haemorrhage that left him paralysed apart from one eye. He revealed aspects of care that were causing huge distress and may never have been known if it were not for the laboriously developed method of communication through blinking. These problems were not mentioned by the palliative care nurse specialists other than one saying that sometimes it would be easier for them if the patients were unconscious so that they did not have to see their suffering.

There are difficulties when the patient is unwilling to acknowledge, or is unaware of, the source of suffering and the palliative care nurse specialist then has to work with the patient's acknowledged needs, even if they can see what the real source of suffering may be. However, if 'unique and subjective' is the philosophy behind nursing care, and the patient does not want to share obvious sources of suffering but only what they wish to acknowledge, it is their choice. The values and beliefs of the person witnessing may result in dismissal of seemingly irrelevant problems which may be a major cause of distress to the person. The palliative care nurse specialists were able to accept the limitations of their assessment of suffering. They knew suffering when they saw it but not necessarily the reason for it. A combination of knowledge of the causes of suffering and patients' behaviour when suffering were used to provide relief. They used the nurse-patient relationship and symptom relief to support the person whilst waiting for them to come to terms with, or express, what was happening to them. In reality, the palliative care nurse specialists have to work with the patient's view and often witness suffering that they cannot alleviate. This, as described in Chapter Ten, is hard for them. They understood the need to allow the patient to react as they want to and that their role was to be ready to support whenever needed. Rogers (1975), discusses the need for unconditional positive regard in person centred relationships. This means accepting and understanding the person as they are and caring and being there to demonstrate this.

Chapter Nine: The Nurse-patient Relationship.

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Chapter Nine: The Nurse-patient Relationship

The Nurse-patient Relationship.

The interpersonal relationship between nurse and patient often provides the energy, motivation and source of strength for the patient to undergo their suffering (Chambers, 2006), and is crucial if the meaning of patients' individual suffering is to be identified, and relief provided. The nurse-patient relationship is often heightened during the process of dying when the patient is especially vulnerable.

Therapeutic relationships are considered important for those experiencing threats to their health, and the goal is to develop supportive communication to understand the person's needs, empower them to cope and reduce and resolve their problems. Therapeutic relationships aim to initiate supportive interpersonal communication so to understand the perceptions and needs of the other person and empower them to cope more effectively with their environment and reduce and resolve problems (Forchuk and Reynolds, 2001). They differ from social relationships in terms of goals. Whilst both involve personal disclosure and intimacy, only a therapeutic relationship has the aim of facilitating recovery or adjustment from illness (Peplau, 1952). Therapeutic nurse-patient relationships depend on the ability of the nurse to comprehend the subjective world of the patient. Understanding suffering and individualising care means having more than a superficial knowledge of the patient and knowledge of symptom relief.

This part of the study explored the nurse-patient relationship with patients who are suffering, as this was central to the management of suffering but also had the potential to be the most difficult work area for the palliative care nurse specialists to cope with, and manage. The palliative care nurse specialists were asked about how they develop and manage the nurse-patient relationship using the questions outlined in Chapter Five. The data collected was considered in terms of using interpersonal skills to develop intimacy in order to understand the source of, and manage, patient suffering.

A salient view throughout the palliative care nurse specialists' thoughts on suffering was the need to understand the patients' view of what is causing them to suffer. The nurse-patient relationship is seen as the vehicle for achieving this understanding. Chapter Nine discusses how the palliative care nurse specialists endeavour to develop a nurse-patient relationship that will support the management of suffering.

The palliative care nurse specialists all felt that a large part of their role was to develop relationships with patients. The themes developed from this part of the data collection are described below with examples of categories from each theme. Illustrative data extracts are used to identify and substantiate the thematic structure. Four themes were identified as outlined, all were interrelated and
will be discussed in Section One of this chapter. Concepts, which constitute barriers to developing relationships, were also considered and will be described in the Section Two of this chapter.

Section One: Developing the nurse-patient relationship.

The ways in which the palliative care nurse specialists developed the nurse-patient relationship largely reflected existing literature relating to building intimacy in cancer and palliative care (Turner, 2001; Mok and Chui, 2004; Rittman et al 1997). There were striking resemblances between the techniques used by the palliative care nurse specialists to develop the nurse-patient relationship and those described by others (Turner 2001; Peplau, 1984; de Haes and Teurisen, 2006). The palliative care nurse specialists in this study emphasised the need to use their communication skills to develop trust and partnership. The aspects that underpinned their work with patients were behaving empathetically with shared decision making and getting to know the patient to provide care and support which echo the findings of others (Georges et al , 2002; Rittman et al, 1997; Mok and Chui, 2004; Raudonis, 1993). Being there emerged as crucial for helping the patient, especially with their existential suffering and for allowing time to get to know the patient well enough to identify their individual suffering and ways to alleviate it.

Figure vii: The nurse-patient relationship.

Developing nurse-patient relationships	
Communicating	*introduction* *social interaction* *giving patients time to talk* *rapport*
Developing relationships	*self disclosure* *developing trust and confidence* *time*
Person centred care	*reciprocity* *empathy* *caring* *partnership*
Presencing	*being there* *involvement*
Barriers to developing nurse-patient relationships	
Personal	*lack of rapport* *superficial relationships*
Organisational	*lack of time*

9:1 Communicating

Good skills in both verbal and non-verbal communication are fundamental to identify the needs of patients and develop and maintain the nurse-patient relationship (Clark et al, 2000; Dunne, 2005; Sheldon et al, 2006). The palliative care nurse specialists often discussed communication skills as central to their development of a nurse-patient relationship and many were confident in their interpersonal skills to achieve this.

'Again, it's down to your communication skills and I think my communication skills are very, very good and that's only just through experience and being aware how you actually talk to people, listening to yourself from the outside and from reactions you get from people so it's using tone of voice, the words you use, the way you speak to allow people to get used to you. And it might be that you're having a really bad day in the office and really frustrated but when you're on that phone the focus is

your patient and using communication that way to try and get in there, it's about communication.' Interview 9

Non verbal communication is often used as an important therapeutic tool that conveys to the person that they are not alone and may take the form of touch, facial expression and presence (de Araujo and da Silva, 2004; Bartoff and Morse, 1993). Bottroff and Morse (1994) and Bottroff et al (1995), defined four caring activities described as types of attending with different types of touch that accompany these activities. Touch is used to both give care and to increase communication.

'I mean often just sort of sitting with people in terms of showing that you've got space to do that, showing an interest. On first meeting I tend to sort of, also just do a lot of listening, ask questions you know if people are actually giving me lots of information without prompting I will just let them take control of the situation. So, I suppose it's something about feeling, allowing the person to feel safe and comfortable too, that you'll listen to their story without judging them and that you're interested in them. So I suppose you do that sometimes by listening, by verbal, by facial expressions. You know if somebody cries you'll touch him or her and reassure them that it's okay with them. So I suppose it's sort of trying to be with them in that situation so whatever techniques you might think of appropriate at the time.' Interview 28

Luker (2000), emphasised the importance of knowing the patient as central to achieving high quality palliative care. Early contact, continuing care and spending time with the patient all enabled the formation of positive nurse-patient relationships. The palliative care nurse specialists used a number of strategies to get to know their patients and develop a therapeutic nurse-patient relationship.

Introduction.

Many of the palliative care nurse specialists discussed the importance of the initial meeting with the patient as being where the relationship was established. They approached this with considerable thought and care.

'Introduction plays a big part. How you come over to that patient, and your body language whether or not you're interested or not interested, because patients are, I think they're very sensitive and they pick up on little things where we take it for granted this is how we deal with it. Whether you've got the time and it is about time. It's about you, the whole person, you, your approach, and your attitude – things like

that.' Interview 23

'For me, developing a relationship with a patient and their families because of course the families are very important in all of this because they're going through this as well and they need some positivity as well to encourage the person who suffers, who's going through the actual disease. I mean for me the important thing for me is always the initial meeting with the patient and I've had one today and you know that initial meeting is always very important to me. I often find sometimes if a colleague has visited someone because I'm on holidays and I go and pick up where they've left off, sometimes it takes you longer to develop a, a relationship than if you've been the one to instigate it.' Interview 12

Aranda and Street (1999), found that nurses described being a chameleon in order to become the nurse that the patient required. The palliative care nurse specialists recognised the need for allowing the relationship to develop and of the benefits of adjusting their communication style to suit the patient in order to create understanding and rapport.

'I am very much more conscious of how to talk to people and I use their language to try and get in, build a relationship but that takes a long time. I'm not saying that I'm an expert at it but I'm just saying that I do know I can change the way I talk to people. You know I can be in a house where they are extremely well educated and very posh and prim and I can deal with myself there or I can be at the other end of the spectrum where they are effing and blinding, I don't say I would eff and blind but I would use similar language. If I go in and ask how are you and they say I'm effing knackered. Then the next time I go in I'll say are you knackered, rather than say are you lethargic and weak. So it's knowing your patients and knowing how you work. It's the only way you can work successfully in palliative care.' Interview 9

The palliative care nurse specialists were very conscious of adjusting their communication style to make the patient feel comfortable and therefore maximise the benefit of their interactions.

'I think hearing and listening to that person is the first way. Well no, I'll go back a step really because I would say that the first way that I would develop a relationship with a person is to approach them in a way that is sensitive and open and with an empathetic approach. You know if I approach somebody calmly and quietly and I'm willing to spend time with them and sit down and, and in an environment that would

be conducive to begin a relationship then I think that is the beginning of the relationship. So, rather than sort of rushing by and saying "Oh Hiya". It's not quite, quite that easy. So then I would hope that if the person did want to use that time that I was willing to give to that person then they could, I would wish to listen to what they had to say; I would wish to be supportive in a way that that person would feel that they could discuss how they felt without being judged, without being categorised, so that I would not have any preconceived ideas about them, so I would hope that that's what they would feel that they could do. So I am listening to them, trying to hear what they were really wanting to say rather than my preconceived ideas of what they are saying. So that, that would be how I would start to develop that relationship.' Interview 11

Social interaction

Hunt (1991), Langley-Evans and Payne (1997) and Jarret and Payne (2000) illustrated how, despite the emotionally charged atmosphere, nurses and terminally ill patients and their relatives conducted mostly normal, ordinary conversation that was social and superficial.

'So basically a very sort of informal introduction and almost a general chit chat initially just to make them appreciate that you are human and they've got to be comfortable with you'. Interview 27

Hagerty et al (2004), found lower depression scores in patients with metastatic cancer who never wanted to discuss prognosis. Reluctance to embark upon deep discussions about diagnosis, prognosis or feelings may nevertheless be a pre-requisite for deeper communication, and therefore for developing relationships. Patients are probably less likely to launch into in-depth exploration of their feelings without at least some social interaction first.

You know they get used to you, you get used to them and talk about lots of other things other than illness and as time goes on that relationship is certainly well developed then'. Interview 12

Humour is claimed to be an essential aspect of nurse-patient relationships (Pierlot and Warelow, 1991; Lotzar and Bortroff, 2001), and was used by the palliative care nurse specialists to soften discussions of unresolved issues surrounding care, improve patients' mood and relieve monotony as well as lightening underlying tensions related to differences of opinion.

'I think that you know a sense of humour when it's appropriate is very helpful and also I think it's actually valuing the other person as a person not as a patient; talking about their lives, having a laugh with them as a human being or having a chat about other things; developing some sort of rapport is important. I think it's a very rare thing when you come across somebody that you just cannot find anything where you can connect.' Interview 2

Giving patients time to talk

Eifried (1998), found that listening and being present were two of the ways nurses helped patients find meaning in their suffering. The study showed that the nurses were attuned to the suffering of their patients and care and support can helped them makes sense of their suffering. Duggleby (2001), found that making meaning of their lives gave hospice patients a sense of self worth, strength and hope that they would cope with their suffering. Spending time communicating with patients was highly valued by the palliative care nurse specialists as it was perceived to be crucial to the development of relationships. They encouraged patients to talk about their feelings.

'Well, again you, you have to be led by them on that and you know you just have to be very gentle again, cautious, you just take time with people. Be understanding, realise that you know, you know people have every right to keep things from you, that's not a problem but if they you know if they have concerns again trying to address those, but perhaps you know through a relationship building process they might start to trust you enough to be able to discuss those things. I mean it's quite, you know you are seeing people at their most vulnerable state very often and that's again something that you must never lose sight of I think and it's just taking things very slowly and as I say it's a two way process just, just you know, just taking time with people really.... Inevitably you get people who do take that little bit of extra time as perhaps even I would or anybody would to reveal things to you, whatever's concerning them. Sometimes you get people who you know just take that bit of extra time to do that.' Interview 13

The palliative care nurse specialists were happy to allow time to get to know the patient and let the relationship develop.

Rapport

Another element of effective communication is establishing rapport, which may enable the palliative care nurse specialist to be more intuitive and sense when something is troubling a patient. The palliative care nurse specialists acknowledged that sometimes it was easy to develop a relationship with the patient and at other times they had to work at developing a rapport over time.

'It's, just how you interact with that person. Because you may get on with somebody instantaneously and I think oh that's brilliant and we've already got a relationship. Other individuals you have to work at. You pick up those vibes. So it's different, it's different with every one. I don't think there's any one way to do it. I think it's something that you either do or you don't do. There are people that we may not like instantly or warm to and the other way round. We may get to know them and think they're okay and then dislike them but I don't think there's any one aspect you can say you'll go in and just say we'll do it this way because everybody is different. You have to do it per individual.' Interview 23

They were also aware that it was not always possible to achieve a rapport with the patient but that it was nevertheless possible to help them.

9:2 Developing relationships.

The palliative care nurse specialists were aware that it was important to develop a nurse-patient relationship that was helpful for the patient and deliberately used their communication skills to try and achieve this. Some relationships happened quite spontaneously, whilst others needed to be worked at.

'I think it's just about giving some of you. The relationships that you have that come with sort of being reliable in what you are, being accessible and just trying to build relationships and you get a feel sometimes of how relationships are and whether the people want you at arm lengths or they want you a little bit more or what makes them tick. How can I get in here? 'Interview 20

'Some people will bare their soul as soon as they meet you. You know maybe it's the first opportunity they've really had to talk about it. It's a skill you learn, to actually get people to talk... I'm looking for cues, doing things in their own time, not

pressurising, it is part of building a relationship but some people will realise you are prepared to listen that you're not rushing through.' Interview 19

'And if any of us in that position I don't know how many people I would want coming into my home either. So I think that you know it's about being, assessing the situation and being understanding and reasonable about it. I mean I think some people maybe who are less experienced would take that, would worry about it and feel that there are issues but keep trying to get in but I think you know some people have to make decisions and you can only be there at the right time and at one point it was the right time and we dealt with some issues and now is not the right time.' Interview 31

The palliative care nurse specialists made a conscious and purposeful effort to develop a relationship, which depended on their interpersonal skills, as well as willingness to invest personal energy in the process.

'I think it's building that confidence up of me in that role. In a way it's, it's using interpersonal skills I feel to show people that you're interested in them and you want to listen to them and through experience when you do show that then I do feel that's when they will then trust you and come out with some of their problems.' Interview 15

They acknowledged that a good time to get to know the patient was whilst undertaking aspects of physical care. They and the patient were generally alone at these times, which gave them an opportunity to talk without interruption.

'You know chemotherapy administration is tedious but actually gives you an opportunity to get to know the patient. Talk about nothing less, but then things develop and at the end of talking about life and what's going on and who's going to continue, you know what's happening and how they're feeling and all of those things and they're sitting there having them injections and chemotherapy. ... ... I remember sitting having lengthy listening rather than chats at night and I guess that's probably quite a significant way of getting to know people is in fact the middle of the night when everything's there and exposed and there's nobody there. Yes it's a safe place because there aren't usually family members there and there aren't normally people that know them there so it's a good opportunity to spill the beans and I think that's probably where the majority of the relationship was built. It was a case of listening rather than advising and chatting there. And I guess that was

probably, I don't know I think we clicked for some reason, I don't know. We had some things in common.' Interview 29

Self-disclosure

The palliative care nurse specialists described self-disclosure as a way to make the patient feel comfortable with them. They revealed personal aspects of their life to appear more human and thus more approachable and accessible to patients. It also seemed to equalise the relationship between palliative care nurse specialist and patient. The patient could relate to them on a level that enabled them to maintain their identity and a level of control over the interaction despite their health care needs.

'It's actually very difficult to actually get in knowing that as a nurse she might need my input. But knowing that as a person she didn't want it. It's a lot of hard work. The contact, building up a relationship and being very open. I think part of the way that I as an individual work is being very open with patients and letting them in almost into my life and I think when they feel that they can identify with you and know things about your life, if you are closer to them you have a better working relationship then. I don't go in saying everything that's going on in my life but they know certain aspects, they know about my family, my interest, things that may link in with things that they do.' Interview 9

'I feel very much, it's on building relationships and one thing I do it is, I do put time there for the visit make sure if I can I will spend an hour there and in developing relationships I tend to touch into their background, what their interests are. Like with him the bikes and everything, I used to ride bikes so I try and make that a sort of a bit of a connection, and talk about his sort of, basically talk about his past in a way and what he did and what his interests were and he's got a lot of photos on the wall of him and his bikes and farming and machinery and I find that's one way of sort of developing that relationship. I do feel then that they do become more trusting of you and I have found from past experience that some psychological things that are worrying them that they will then, hopefully, start discussing those as well as time goes on.' Interview 15

'And I do, from past experience, I do try and as well bring in the fact that, and this is going to sound stupid as well, but with the intensity of the talk and the initial assessment you go through all the practical things, you go through all your assessments, telling them what, what you can offer them and perhaps their expectations of the service etc, and often especially in this area you bring in a personal aspect of you know, they always want to know who you are, who you're related to you know family and it's trying to sort of make you a bit more of a person and not just somebody that they see sometimes. We have, sometimes they see that you're going to take over and make things much better but I try and make it that I am a person as well.' Interview 18

There is much debate about the amount of personal information that nurses should share with patients. Benner (1984) encourages involvement whilst others encourage maintaining boundaries and distance (Ramos, 1992; Morse 1991). The amount of personal information that the palliative care nurse specialists were prepared to share was variable, with some palliative care nurse specialists uncomfortable with sharing their personal life. Personality, both the palliative care nurse specialist' and the patient's, and rapport often influenced the level of self disclosure and involvement. Some palliative care nurse specialists had deliberately taken jobs in towns away from where they lived so that they would not have contact with patients outside work. They felt that this helped them maintain boundaries between their work and home life. Others were happy to be part of the community where they worked and were comfortable with sharing their personal life with their patients.

Developing trust and confidence.

Trust develops from creating an atmosphere of openness, honesty, warmth and understanding through presence (Heron, 1990). It has been found to be an important factor for relationship building (de Haes and Teurisen, 2006). Genuineness and concern are important to help the person feel valued and respected, thus enabling a relationship to develop. Trust is important and based on understanding the patient's needs, displaying caring actions and attitudes, providing holistic care and acting as the patient's advocate (Mok, 2004). The palliative care nurse specialists were clear that the nurse-patient relationship needed to be based on trust.

'I am very, very, very truthful I think about what I can do and what I can't do. So I

don't make false promises and if I say I am going to do something I do it and if I wasn't able to do it I ring them up to tell them that I wasn't able to do it and I think that forms quite a basis of trust.' Interview 1

'Open, being very open and honest with people is extremely important and listening to people and certainly carrying things through as you've promised people is very, very important. If you, you know, if you've said you're going to do something and you don't do it they immediately think – Oh gosh, do I trust you to do something else sort of thing. I think that's very important that the relationship you develop with people is based on trust and confidence and that I think is developed over a period of time when people do become confident in you and trust you they are happy to go along with whatever suggestions you can make. The majority of people are because so many people want to help themselves if they can and want to push themselves and want to fight and while they are still able to. If you can gain their trust and confidence they believe in you then and they know that you are obviously doing this to, for the good then really.' Interview 12

The palliative care nurse specialists felt they needed to approach patients with openness and honesty for trust and confidence to develop. Honesty might be demonstrated by acknowledging not knowing the answer to a question or answering difficult questions about death and dying or the progress of the disease.

'We try as much as possible to avoid collusion and certainly we do still get cases where patients don't know the diagnosis because family members have refused hospital consultants to tell them and then it's almost as if you're expected to carry on with that collusion because the person making the diagnosis has and it does have huge impact on the relationship with the nurse and patient and the only way in dealing with this and say, okay I won't mention the word cancer but I will be led by that patient and if they ask them what is wrong with me, such as why am I having this treatment or why am I having the pain, then I will explore those issues and I will be honest and not lie.' Interview 9

The palliative care nurse specialists believed it was important for patients to feel that they could confide in them, and express their concerns without feeling that they were going to look stupid, which also helped with establishing trust and confidence.

'And once they realise they can ask what they perceive as silly questions and not get

slated for it then they're much more trusting. Because I think trust is quite important. But delivering the goods I think is the other thing that is really important, to delivering, to having a relationship with the patient. Because if you say you're going to do it and you don't do it then end of your relationship, or non-started. If you provide even the small things that you said you were going to do then, they build on that. And it is quite interesting that being introduced to them at a really early stage makes a better relationship, so even though they don't remember when they met you, it's clear that the patients that I met, that I have met prior to their diagnosis or at time of diagnosis are more likely to use the service that I provide than those patients that I am introduced to at the point when they are going to have to see the oncologist and take over their treatment. And I don't know why that is but that is, as times gone on, that has been something that I've noticed you know that people I've met really early or have come back and they've been the ones that have rang with problems and or they're the ones who feel able to come back to me. The others do as well but not as much. So I think it's in their heads seeing that you gave them the little things that they wanted to get by, the plugs almost to just get by. So when they do kind of think back they don't remember when they met you but they remember that you were the person who had all those at that point.' Interview 29

Bortroff et al (1998) and Morse (1991), found that the more vulnerable the patient feels, the likelier they are to assess the competence and dependability of the nurse. Trust and confidence was perceived to go hand in hand with competence, and several palliative care nurse specialists commented that they would start by trying to address the patient's immediate concerns in order to develop confidence. They would allow the relationship to develop slowly, often via the alleviation of physical symptoms, and this would encourage trust and confidence in their competence to grow.

'And very often on the first meeting there's huge symptoms and there's physical symptoms and you can do something about them quite quickly, I mean for some patients if they are in a lot of pain, it's all they want to talk about is their pain and that's fine and I'll just basically go in there and say you know I hear you've got pain. Is that the biggest problem for you today? And if it is then we'll address that and we'll do one step at a time.' Interview 27

'I think it's just dealing with individuals really and asking them what have they been through and picking up on bits that they are saying really, showing some empathy and, and things that are important to them, dealing with them. You may see that somebody is in terrible pain but like I said that might not be his or her biggest issue. So it's picking up on what they feel is the bigger issue, dealing with that so they can then move on to perhaps what you feel are relevant issues.' Interview 31

It was also important to the palliative care nurse specialists that they are reliable and deliver what they promise. This often meant maintaining a realistic approach to what can be achieved within the confines of the disease.

'But yes so I think delivering what you say you're going to deliver and if you're not able to deliver making sure that you communicate that with them. Then its the fact that you're human, the same as they are and it's a way of building the relationship that you need.' Interview 29

Time

Another factor that has an important influence on the development of relationships is time, which affects the relationship in various ways. The nature of palliative care nursing means that often the palliative care nurse specialist has to work with limited time. Frequently, patients are referred to them late in the disease process, often within weeks of death. At this time the patient may be very ill with many difficult symptoms which will take priority in care.

'You can almost get them too late to be able to be able to make a connection to make a bond or you know to be supportive. They've almost already withdrawn. And I suppose that's lesser in the hospital where I am now because we tend to have a quick turnover of patients. Average length of involvement with somebody might be 5-6 days. But when I was a community Macmillan nurse and you've got a much longer length of involvement with people then sometimes you really felt that you've missed the boat almost. It was as if, if you could have had an earlier intervention then maybe you could have been able to help.' Interview 4

'The difficulty is when sometimes you only have a very short space of time to develop that relationship and that can be very difficult but also in those times it can be very intense as well because maybe diagnosis, prognosis is extremely short and you've got an awful lot of work to cover in such a short space of time.' Interview 12

The palliative care nurse specialist tried to spend time with each individual. They were clear about the inextricable link between time and relationships and the importance of developing patient centred care that is supportive for the patient in whatever time was available. The aim was always to enable the patient to be involved in their care and benefit from the nurse-patient relationship. This echoes Hagerty and Patusky's (2003) views that a relationship can be developed even in a short space of time.

' I think you can only develop a relationship that time allows really and it depends what, in what environment you are. Some patients we see on the ward and it's very difficult to form the same relationship because you talk to patients who are sort of perhaps going through an acute problem that's the reason why they might be here or they're having investigations, they've been given bad news, they you know the disease might, new diagnosis or might have progressed. They might be in hospital for a very short space of time and feel very vulnerable and you know being in bed clothes makes people more vulnerable. So I think you, the others now would be you'd see somebody in clinic and they might have a half hour appointment and you know people make it quite obvious that you've only got that amount of time so you have to try and build a relationship with that within that amount of time or you've got the community where you can meet people, you can go back and see them, you can see them in their own environment' Interview31

The palliative care nurse specialists also had nurse-patient relationships that lasted for a long time and they were aware that they needed to approach these differently. They aimed to develop a relationship that allowed the patient to remain in control of their care and the type of relationship they will have with the palliative care nurse specialists. This often required patience and careful consideration of the best way to develop the nurse-patient relationship to ensure that the patient benefits.

'They're very much now included in the treatment plan and symptom control and having the psychological support.' Interview 31

'But I think that's the sort of thing, and it's, and you do have to have, it's about making a calculated investment knowing what you want the return to be and the return is that you are going to be able to help that person better. It's not an investment that you have back. It's an investment that they will have back.' Interview 2

'And sometimes you can more damage than good, do you draw it out, do you not draw it out but I think a lot of the patients, because the relationships I have, 'cause it's not over just a couple of days, you talk sometimes months even years. I think most of them have the confidence in talking to you.' Interview 23

9:3 Person centred care.

Morse (1991) states that the relationship between nurse and patient is the result of interplay or covert negotiations until a mutually satisfying relationship is reached. She identified four types of mutual relationship influenced by the duration of contact between nurse and patient, the needs of the patient, the commitment of the nurse and the patients' willingness to trust the nurse. The palliative care nurse specialists were cognisant of reciprocal aspects of their nurse-patient relationships that embrace the concept of sharing to develop mutual understanding. Respect was also important so that the patient was able to maintain control of decisions about their life.

'I just felt even before I came into palliative care that I just had an affinity with people and people seem to be able to speak to me you know. And I think I do try to let the patients take the lead as well...... You know there are some patients that you would go in and you would do a full assessment with and you know you do the whole lot and then there's others that you just know that it's just not appropriate to do that you know...... Sometimes you can just feel what's right to do and what isn't right to do and letting the patient take the lead to actually build that relationship.' Interview 22

Person centred care means developing a nurse-patient relationship that is helpful for the patient. It involves reciprocity and caring as well as empathic understanding of the patients needs.

Reciprocity

Reciprocity is the two-way dimension to nurse-patient relationships by which both nurse and patient give to the relationship, and by giving also gain. Mok (2004), found that nurse-patient relationships developed on a continuum based on the nurses' and patients' expectations of the role, involvement and reciprocity. The patients found their relationship with the nurses important for helping them cope with the process of dying and helping them feel secure. The nurses found that although the relationship was patient focussed, it enhanced their personal growth allowing them to reflect on their own lives. Engaging with patients who are dying often gives nurses the opportunity to deal with their own mortality and to develop ease and familiarity with death; nurses can feel empowered when they experience reciprocity with patients and perceive their care as meaningful (Rasmunssen et al, 1997).

'I always feel that we're privileged, we're privileged in our sort of relationship with the patients and their family and it's you know we're invited, we're very much invited into their world and I think it's trying to nurture that a little bit but at the same time respecting it as well.' Interview 18

Although it is the palliative care nurse specialist's role to care for the patient, a patient centred relationship allows the patient to reciprocate.

'I probably never heard of the therapeutic relationship until I read about it but when I read about it I realised that I was doing it you know? So the theory of therapeutic relationship is of protection for the health professional and the patient as well. But it's a relationship that can be very real and, and it can be, it can have a very positive personal impact. But the intent isn't about the personal impact. The intent is about what the patient will get out of this.' Interview 2

Reciprocity was very important for coping with the difficulties associated with involvement with patients who are dying and will be discussed further in the next chapter.

Partnership

Egan's (1998) model of skilled helping is grounded in the belief that helpers assist others to manage their lives more effectively. Establishing the person's story as the present, moving towards new goals and a commitment to the future and developing strategies to achieve these goals form the basis for care. Partnership means that both the palliative care nurse specialist and the patient work together to develop care that is right for the individual. The power is evenly distributed, rather than being predominantly with the palliative care nurse specialist. The palliative care nurse specialists were aware that to manage suffering, their role is to work with the individual and adapt to whatever they need. They realised they had skills that could help the patient but allowed the patient to guide them and determine what they thought would be helpful for them.

'I just try and listen I suppose to what they're saying and ask them what they see as their biggest problem. That's one of my favourite, most favourite questions is what do you see as your biggest problem because what they may have been referred to us for may not be concerning them at all it could be something completely different, very simple so it's just actually trying to find out what they need and not just accepting what they have been referred for. And working down those lines.' Interview 3

'I think it's assessing each individual, it's not going with a plan. You know its going to each individual and dealing with what occurs on that, during that visit. I think if you go with a plan then it may not be the same plan or same agenda as the patient and their family so I think you go with a, you know you can have a rough plan but I think you go with the idea that you are meeting the patient and relatives needs. There may be need to direct them with conversations so it maybe that the things that obviously they haven't considered and that you can direct them towards them and assist with. But I think you just, patients are different. You pick up communications cues, non-verbal where your patients are, the way relatives are with you, some relatives don't want to come into the room, you know.' Interview 31

'But I would work very therapeutically with somebody so that I have got a sort of as equal as I can in the relationship so I'm not sort of being too dominant but at the same time not making them feel that they've got to make decisions if they want to make decisions for them, or to help them make decision. So I think that that starts when I first meet somebody and I, I guess it's about letting them know verbally that they can share information and that I will do something about it and that I won't hold back from answering questions if they want questions answered by my behaviour.' Interview 16

Empathy.

McCance et al (1999), in a concept analysis of caring, identified one of the defining attributes of caring as getting to know the patient, thus identifying what is important to the patient. Raudonis (1993), identified two major categories of empathy in a hospice setting. Affirmation, where the nurse acknowledges the person as an individual regardless of their disease, and friendship which is an intense deep meaningful relationship between patient and nurse where feelings and information are shared reciprocally. Empathy was seen as a joint approach to care between the palliative care nurse specialist and patient. It is collaborative and essentially based in trying to help the patient with problems that they have identified and allows the patient to remain in control of their care.

'Well again, I would be led by them on that really you know it would be what's important to them and what's concerning them at that time.' Interview 13

The palliative care nurse specialists used their understanding of suffering to influence the nurse-patient relationship, in that they acknowledged the aspects of suffering associated with loss of control and identity and tried to allow the patient to maintain their independence for as long as possible. They communicated empathetically to help the relationship develop.

'I think we've got to be very, intune with people to pick up whether our visits are actually taking people back into their illness, in a way when in actual fact they don't want that, their way of coping is to actually get on with it and get out and about and do things and I think we've got to be quite clear and be very careful on individual assessment on which way you feel that that's going.' Interview 15

They also used their own experiences to help them to understand what was troubling the patient.

'And then I guess my own experiences with my own past, personal and professional life would come into play because I would recognise situations from other experiences from before or I would have some kind of empathy or identification with the situation or the feelings that they were discussing. So that would then help me to develop that relationship and hopefully I would use building blocks like that to get to a place that meant something where they could talk to me openly.' Interview 11

Empathy enables the palliative care nurse specialist to become involved in the patient's life and to develop a relationship that allows the patient to lead their care. This enables the identification and alleviation of suffering and the palliative care nurse specialists appreciated this and developed a nurse-patient relationship that was person centred with the patient setting the pace.

Caring

Rogers (1975), considered congruence an essential part of a therapeutic relationship, with openness, honesty and warmth as characteristics. In this way human beings communicate that they care about each other and thus facilitate the development of trust. The palliative care nurse specialists understood that conveying caring was important for the development of a nurse-patient relationship that would enable the identification and alleviation of suffering.

'I suppose something I would like to go on is that I think that the nurse/patient relationship is absolutely fundamental to the alleviation of suffering. Because despite how nurses may be unskilled, lacking in communication skills or knowledge or education or culture knowledge or whatever, the fact that they are caring about that person I think adds a certain, dimension to the alleviating of suffering that is fuels that relationship. And I think many patients would not cope in any way nearly as well if they didn't have the relationship that they have with nurses. The nurse/patient relationship is a very special thing and it helps to alleviate suffering. The very caring nature helps.' Interview 11

Caring is both an emotional feeling and a practical occupation, and providing nursing care for patients usually encompasses both of these aspects (Roach, 1984).

'It is the relationship, the therapeutic relationship whereby one person actually cares about the other and that is, essential, even you know that relationship that nurses are doing is caring for that individual, that person, that human being whether they know how to dress that wound or talk about end of life issues or how they're going to die.' Interview 11

Caring was seen to help the person to feel less alone and was considered central to the care of patients who are suffering. Being there was seen as essential for enabling the identification and relief of suffering and was seen as therapeutic for patients in itself.

9:4 Presencing.

Slevin (1999), defines 'presence' as a way of being that promotes a therapeutic nurse-patient relationship. Benner (1984), discussed the notion of presencing or being with a patient and commented that nurses often believe that they are most effective when doing for a patient. However, the palliative care nurse specialists were sure of the essential importance of just being with a patient.

Being there

The palliative care nurse specialists were aware of the importance of being there and used it as a way to develop the nurse-patient relationship. They felt that if they could be there for a patient when needed, the relationship was more likely to develop. This echoes Morse's (2001) work on being available while the person is enduring so that comfort can be given when the person is ready to acknowledge their emotional suffering. Being there is not simply about being physically present, but about being able to offer emotional support to a patient at a time of need and can only be achieved if one is there at the time.

'I think part of it with him is sitting and being there with him is, I know it sounds a bit of a cliché, but accompanying him along his journey really and having the confidence, and in away the expertise to do that.' Interview 15

'I think, I think to show that, you have the time to stay with the, that you're willing to listen, that your open to listening, to hearing what they've got to say. Like I say things like trying to empathise with them but I don't know what they're going through, you can't. You know, like I couldn't put myself in that position because you know it's never happened to me. I have never had anybody close dying to me so I can't even imagine what they're going through. But I think just by showing that your there for them and you know if they want to talk you can talk; if they don't want to talk you know that's also fine. But they've got the opportunity if they want to.' Interview 7

'He was discharged from an in-patient unit still in pain and then no one sort of wanted to go near him so I have made a point of going, and just and saying that there is nothing I can do to help you with your pain from a medication point of view but I am still here with you and I'm going to stick with you and support you if that's what you want' Interview 2

Involvement

Being there also involves demonstrating understanding of, and being involved in, the patient's situation. The palliative care nurse specialists brought their own identity and personal characteristics to the relationship and shared them with the patient. They used both their communication skills and their personal characteristics to develop a relationship that would be helpful for the patient. They discussed the importance of being involved in the nurse-patient relationship and would share aspects of their lives to make themselves more approachable and accessible to the patient. They would be open and genuine in their ongoing interactions with the patient. Potentially, this aspect of the role leaves the palliative care nurse specialist vulnerable to negative feelings when the person dies, but was thought to be important for the person suffering and to encourage closeness, trust and confidence in the nurse-patient relationship.

'I think introducing myself and being open is probably the most successful way. I think that's probably the most successful way of developing a relationship that's going to be meaningful to the patient and is definitely meaningful to me and I'd much rather people see me as me than some kind of obscure nurse who does strange things. So I think being informal, letting people know that I'm here, who I am and being approachable being able to make them feel as if they've got questions they're not daft.' Interview 28

They worked empathetically to achieve understanding of the patient's problems and to plan care. This often meant that they used their personal experience to understand how the patient may be feeling.

'It depends I think it helps sometimes if you have had bad times in your life because you can relate back to them and have a bit more of an idea of how terrible it is for these patients and be easier to stand in their shoes and kind of imagine. Obviously it's never going to be the same experience but it is a bit easier then so it does help if you've sadly had some horrible times in you life that you could relate back to, not to them obviously but you can manage how awful it is for them.' Interview 6

There are different amounts that the palliative care nurse specialist may be prepared to personally invest in different relationships, and they were aware of the importance of protecting themselves as well as the patient. They were cognisant that some nurse-patient relationships would result in close involvement with the patient because of aspects of the situation that the palliative care nurse specialist could identify with. However, they were also aware that they needed to manage their own feelings and level of involvement so that they can continue to work with patients who are suffering. This aspect of the nurse-patient relationship will be explored more fully in the next chapter and discussion.

'But then, I remember when I did a counselling course and I was actually nursing my friend's husband and I said to them – How do I deal with this? Because every time I go in there I want to cry because I know this chap. And he said to me – The best

thing you can do is mentally put your emotions in a box in the car, go in, you do the job, you come out and then you put your emotions back. So I've often come out and park the car and had to compose myself for a while before I go into the next patients. But I think again, nurses especially are very good actresses and I reckon I could go on the stage myself. Because you do, you act a part, you give the patient what they need for that small time that you're in there.' Interview 25

Developing the nurse-patient relationship clearly took considerable skills and thought. There was often acknowledgement of the fragility of the nurse-patient relationship and the need to use all of the techniques described to achieve the desired outcome of a nurse-patient relationship that would support identifying and alleviating suffering.

'I think that it's important that you've got the skills to walk a tightrope sometimes where you are not going to fall over the edge to actually become overinvolved but you actually need to use yourself in developing that relationship in developing, developing trust is the first thing. If you say you're going to do something you do it; you don't make promises that you can't keep. I think that's a constant throughout everything and if you actually show that you are reliable to somebody when you're actually got somebody that's been through the Health Service and had so much promised and so much not delivered. Even, every single thing, I always return phone calls. I always get back and if I didn't I would feel terrible and I would also feel very worried that that would damage the trust in the relationship that you're building.' Interview 2

Thus, the four themes of communicating, developing relationships, patient centred care and presencing all contribute to the development of nurse-patient relationships. However, at times it was not possible to achieve a close nurse-patient relationship for a number of reasons, which will now be discussed further.

Section Two: Barriers to developing relationships.

Many factors can act as barriers to the developing relationship, falling into two main themes: personal barriers and organisational barriers.

9:5 Personal barriers.

The palliative care nurse specialist's or patient's personality or personal circumstances could interfere with the development of a close nurse-patient relationship. The patients may not want intimacy and just want the knowledge and skills the palliative care nurse specialist has to offer. This may be because the patient avoids involvement or because they are too ill to participate fully in the interpersonal aspects of the nurse-patient relationship. Since the palliative care nurse specialists felt that the nurse-patient relationship was important for facilitating the management of suffering, this will presumably have an adverse effect on their ability to achieve this.

Lack of rapport.

It may be impossible to achieve rapport due to the plain fact of the palliative care nurse specialist and patient not liking each other or having nothing in common on which to base a relationship. The palliative care nurse specialists understood and accepted this reality.

'They're not going to relate to you regardless. We're all human... I think again it's just personalities of people I think. Personalities of people and obviously the intensity of their needs of you. If their needs of you whether it's physical or emotional are high then obviously you're going to have a more intimate relationship with patient and family because you're going to be talking about lots of things and, it may be bearing their whole soul to you which maybe another family may never want to do and therefore you are perhaps not as close to them as what you are with others. I would say there's times that no, nothing is ideal in life I suppose and no not every family you are involved with do we get a good relationship with and that might be for reasons for example that that's just the sort of people they are and they don't particularly want a relationship with you they just want you there to do, I suppose, to do a small amount as possible and that they're just not the sort of people that want to communicate with you. So yes, there are a number of people where you might get

that incidence. You might get other people that just, just don't want to accept that they've got the disease and therefore they don't particularly want you there and that's another scenario. Or basically I suppose you might get some people, not that I've come across it yet and hopefully I wont but you might get some people who think – Oh well I don't like her, you know and therefore you're in that predicament. I mean, as I say hopefully it doesn't happen to me but that's also there.' Interview 12

They also knew that some patients only want the skills and knowledge the palliative care nurse specialist has to offer. Sometimes this lack of involvement with the patient was easier to manage as their role was clear and purely professional.

'With the ones that you develop a rapport with it's very easy. With the ones that you know basically don't want you there but they accept you because you're doing a job, I think it becomes very factual. Because it's not personal, you're helped them by actually just giving information when it's needed. And why they have to attend for this outpatients, what's going to happen at that appointment and it's quite what's the word I want, not cold. There's no real getting to know them. You're a nurse doing a job and that's actually easier than somebody who welcomes you in with open arms and say you know – you do what ever you want kind of thing.' Interview 24

Whatever the reason, however, the result is the same. The palliative care nurse specialist simply does not engage with the patient on anything more than a superficial level.

'Some won't let you as well; I just nursed somebody who's died and he always kept that "I'm fine, I'm okay" and down to the point where he did the same with his wife. So people keep you at bay because it's safe, it's safe and not getting close.' Interview 14

Superficial relationships

Boyle (2000), identified that nurses encountered some patients who become special to them, whilst Savage (1995), suggested that few nurse-patient relationships ever become close or intimate. The palliative care nurse specialists were realistic that not every nurse-patient relationship would result in closeness but good care could still be achieved.

'They get exactly the same care. They possibly don't, they don't want you there I won't say they don't want you there and there's no warmth there, but I think that's the way that they cope with an illness that they don't want is by saying – you were

here to help me with this illness, you're not here as a friend, you're not here, and they don't want the interaction other than – This is what I'm gonna do, this is what I'm gonna organise, this is what I'm gonna see to. They're very thankful. They're not, people who take you for granted but I think the only way they can cope with having people come into their homes is on that understanding.' Interview 24

They were philosophical that for care to be individualised the patient must choose the level of involvement that was comfortable for them. They accepted that a superficial nurse-patient relationship may compromise their own ideal of care and were also able to acknowledge their frustrations.

'It's difficult because you want to help everybody but there's some people who just don't want to go there. They just want to try and block everything out and just deal with the physical side and don't want to deal with the emotional side. I find that difficult because you want to help you know. You feel as if you've got something to offer them but not all patients want to go there.' Interview 28

There may be a number of reasons for distance in the nurse-patient relationship, and the palliative care nurse specialists were accepting that the patient would lead the nurse-patient relationship. They would aim to create something that would be of help to them even if that resulted in their own ideal of the nurse-patient relationship being compromised. Respect for what the patient wants from the relationship was part of trying to develop a nurse-patient relationship that will support the identification and relief of suffering. However, this philosophical position of acceptance of the patient's right to choose had often developed with time, experience and maturity and become part of their way of coping with the difficulties encountered in their role. This will be explored in more detail in the next chapter and discussion.

9:6 Organisational barriers.

The main organisational barrier to developing a therapeutic nurse-patient relationship was lack of time. Lack of time, whether as a result of late referral, holidays or too many patients on the caseload and too many other activities, was often given as a major deterrent.

Lack of time

Continuity of care was clearly thought to be important as was working with the rest of the multi-disciplinary team to ensure good communication and the achievement of the agreed goals of care.

'Oh gosh, when I've had cases, just thinking of one of late where it was, a very difficult situation and certainly being available when they need you was one criteria although that can be quite difficult, and as well I think for the sake of the patient and the family having continuity, the same nurse which is what we do obviously but there is always the problem when you're on holiday you know you're obviously not going to be available but continuity is very important. And communication with lots of other health professionals is a priority as well that we're all in the picture we all know what's going on that therefore the patient obviously feels comfortable with the GP, district nurse, ourselves, social workers you know whoever's called in, but yes certainly the continuity the availability of yourself and the appreciation of the situation that they're in. You know the ups and downs and how we understand that things can change on a day to day basis and that they feel that they can call on you if there's a problem rather than think – Oh we'd better not contact them because of this, that and the other or we've seen them once already and you know.' Interview 12

The difficulties with developing the nurse-patient relationship and the resources available to the palliative care nurse specialist will be explored further in Chapter Ten, and are an important factor in working with patients who are suffering.

9:7 Discussion: The Nurse-Patient Relationship.

Peplau (1988, p9) emphasised the potential therapeutic value of the nurse-patient relationship, maintaining that it is educative and therapeutic when nurses and patients *'come to know and respect each other as persons who are alike, and yet, different, as persons who share in the solution of problems'*. Peplau (1984) emphasised the need for communication to lead to therapeutic effect. Communication has a purpose and is different from social interaction amongst friends and family. The nurse must gain information about the patient to determine care needs. Peplau (1984) accentuated intuitive or non-verbal expressed communication in this process of coming to know the person. She placed stress on lasting involvement based on skills of empathy, judgement and the ability to see what is needed. Meutzel (1988) also discussed the nurse-patient relationship as a therapeutic process highlighting intimacy, partnership and reciprocity as key concepts. Both Meutzel (1988) and Peplau (1988) stress the importance of encouraging the patient to find their own solutions to problems through a non-directive approach to care and the nurse-patient relationship. The palliative care nurse specialists emphasised the importance of the nurse-patient relationship in the management of suffering and their ways of achieving a therapeutic nurse-patient relationship were similar to those found by others (Turner, 2001; Peplau, 1984; de Haes and Teurisen, 2006). Further, their value system for the nurse-patient relationship reflects the literature (Georges et al , 2002; Rittman et al, 1997; Mok and Chui, 2004; Raudonis, 1993).

The nurse-patient relationship was seen as helpful for patients as they approach death. As can be seen, a great deal of thought and care was given to the skills required to develop the nurse-patient relationship. Whilst the palliative care nurse specialists realised that it was important for enabling the administration of the practical aspects of relief of suffering, they also recognised that the nurse-patient relationship in itself had therapeutic value. A therapeutic nurse-patient relationship will help the person feel less alone and thus assists in relieving distress. The palliative care nurse specialists worked empathetically, allowing the patient to lead the relationship so that maximum relief of suffering could be gained.

The palliative care nurse specialists discussed the importance of alleviating physical symptoms to establish credibility and commence a basis of trust for the nurse-patient relationship. Understanding the causes of suffering enables the palliative care nurse specialist to provide relief whilst continuing to develop a nurse-patient relationship, which may provide more specific information to work with. It is hard to separate factors, such as pain, that could cause suffering, but may not, depending on the person's response. Often, assumptions are made based on prior knowledge of suffering, so that care can be given. This may mean that care is not completely patient led. However, giving care to relieve suffering has the dual function of providing support and also enabling contact and communication to identify and alleviate individual suffering. The nurse-patient relationship was also, of itself, therapeutic and a way of providing relief of suffering. This is regardless of whether the causes of the patient's suffering can be ascertained or are amenable to relief. They could help reduce the person's distress, both by good symptom control and through the effects of the nurse-patient relationship. The palliative care nurse specialists knew that later, meanings might be made explicit. Benner and Wrubel (1989, p xi), maintain that *'caring is a basic way of being in the world'*. Georges et al

(2002) and Quinn (2003), found that palliative care nurses thought knowing and being available and sensitive to the patient were important to understand why the patient was acting in a particular way, and to help the patient find meaning in their experiences. This concept of presence or being there relates to the importance of the nurse being in a position where they can develop a nurse-patient relationship to empower the patient to make choices about their lives. It requires being available both physically and existentially. Caring has been argued to be a central premise in nursing, necessary to enable nurses to help patients.

A level of personal involvement is required to develop a nurse-patient relationship that allows for the identification and alleviation of suffering in people close to death. The palliative care nurse specialists realised that their involvement in the patients' lives often went beyond a professional role and provided a feeling of respect and connectedness that the patients appreciated.

Chapter Ten: The personal impact of working with patients who are suffering.

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Chapter Ten: The personal impact of working with patients who are suffering.

Introduction.

There is evidence that providing emotional support for patients and their families is a source of stress amongst oncology nursing staff (Hersechenbach, 1992; Catalan et al, 1996; Vachon, 1987). Palliative care nurse specialists may feel strong, often negative emotions, during the course of their work, which they must learn to deal with whilst at the same time being authentic and empathic with the patient (Field, 1984; Menzies, 1961; Davitz and Davitz, 1975; Turner, 2001; Ramirez, 1996; Jones, 1999; Georges et al, 2002; Vachon, 1998). Cumulative losses can be stressful and lead to burnout, especially if there is no opportunity to assimilate the death of a patient before becoming involved with another (Sherman, 2004). French et al (2000), identified workload, poor communication problems with colleagues and dealing with dying, death and patients and their families as stressors. Stress is potentially exacerbated when individuals are constantly faced with awareness of their own mortality and the termination of intense relationships. However, there is also evidence that those working in palliative care have lower levels of stress (Payne, 2001; Bruneau et al, 2004). There are a number of ways stress is managed in palliative care and these largely revolve around maintaining distance from the patients (Morse, 2006; Rittman et al, 1997) and having time out from work (Cohen, 1995; Turner, 2001).

This part of the study explored the personal impact of working with patients who are suffering. Data analysis revealed a number of difficulties and coping strategies. Most of the themes identifying the difficulties and coping strategies overlapped, suggesting that what is stimulating and rewarding is also challenging. There may be a point where the challenge, if not successfully met, becomes stressful. Chapter Ten is divided into two sections. Section One will discuss the difficulties whilst Section Two will deal with coping.

Section One: Personal Impact of working with patients who are suffering: Difficulties.

10:1 Personal Impact of working with patients who are suffering: Difficulties.

There were five themes developed from the data that related to the difficulties that palliative care nurse specialists experienced when working with patients who are suffering. These will be discussed and data extracts used to illustrate the points being made.

Figure viii: Personal Impact of working with patients who are suffering: Difficulties.

Suffering:	*witnessing suffering* *unnecessary suffering* *not being able to alleviate suffering* *responsibility for relieving suffering*
Relationships:	*age of patient* *identification with patient* *personal involvement*
Job structure:	*communication difficulties/poor teamwork* *work environment*
Personal:	*problems outside work* *taking work home* *changed/ aged because of job*
Burnout.	

10:2 Suffering.

Patients' suffering was a source of difficulty for the palliative care nurse specialists for a number of reasons. The difficulties arose fundamentally from the same source, that of not being able to alleviate it. There were a number of reasons for this, but basically the palliative care nurse specialists found it stressful if the patient was suffering and nothing could be done to help. This links closely to the next section of coping, where suffering is a theme again and the palliative care nurse specialists had often developed strategies to deal with patient suffering and thus cope with the difficulties.

Witnessing suffering.

Witnessing suffering has been found to be a source of distress for nurses (Quinn, 2003; Kahn and Steeves). The palliative care nurse specialists also found this difficult, particularly if the suffering was emotional and due to fear.

'If you really actually look at it, if you look at a wildlife thing on the television. And there is an animal just about to be. And you see those, I can't watch it and the deer and it's just about to, or antelope or whatever that look of somebody on their face, it's awful isn't it, to witness.' Interview 1

'Oversedating would relieve our suffering as well at times. What a terrible thing it is to lose somebody who is absolutely terrified. And if you actually think very deeply about it and try to have a sense of empathy about yourself in that situation it's unbearable to think about.' Interview 2

'I think, I think it's because I feel quite helpless. You know you haven't got answers for patients. You can't take away that suffering.' Interview 7

Witnessing suffering was difficult, and related to this was not being able to alleviate suffering and thus having to go on watching it whilst feeling helpless. The difficulties in witnessing patient suffering were often easier for the palliative care nurse specialists to articulate if they talked about actions they would take to try and alleviate suffering. It may be that it is easier to take action to help than to helplessly watch a person suffer. The problems with witnessing suffering seemed to be related to the problems of unnecessary suffering, which the palliative care nurse specialists also found hard.

Unnecessary suffering.

The palliative care nurse specialists found it difficult when the patients suffered unnecessarily. The reasons for needless suffering were manifold and could be due to the palliative care nurse specialists not having the necessary knowledge and skills to help the patient or because of staff ignorance or poor teamwork, resulting in treatments not being started as soon as they should. Poor communication and teamwork is highlighted as a source of stress in healthcare (Botti et al, 2006; Barnard, 2006).

'If somebody was particularly vulnerable who maybe didn't have an advocate or you could see something that really shouldn't have happened, walking in and seeing cockups and someone that's looking after them who has actually caused them suffering, which we do see sometimes and you know that it didn't have to happen. That affects, that would probably affect me more than anything when you know that something has been needless and it's been either other health professionals lack of competence or you know or something else you know. I find that the most difficult when this has actually been needless because it didn't have to happen this way.' Interview 2

'I can quantify or explain other suffering and let go if you have done what you can. But accepting it is a tragic, tragic situation. Accept that as that but if it is more suffering and it is not needed then that I find quite difficult.' Interview 1

'It's more frustration if anything if things haven't been done as you've wanted them to be done because, you know this is an advisory service and they haven't got to follow the advice and it is so frustrating when somebody is still suffering when they don't need to.' Interview 6

They could accept that patients suffered in palliative care but found it difficult to cope with if the suffering could have been alleviated but was not. Needless suffering was often a motivator for improving their understanding, knowledge and skills, both in communication and relief of symptoms, so that similar situations could be avoided in future.

'Just somebody dying with terrible, terrible agitation and I didn't have the skills at that time to be able to challenge the Consultant who was a renal consultant who was still dialysing him not really knowing the boundaries of when to give up. And I just remember this man just in distress, agitated and disorientated and desperate and that actually stuck with me that he was suffering terribly. He stuck with me and I remember worrying for weeks afterwards worrying, not worrying about it but being upset about it and just thinking, I wish I had done it different. What are you doing, or what are you not doing, you know and I suppose in any situation where there has been suffering I suppose there has always been an element of that, of needlessness and I am not saying that any suffering is needful, or has to go through but you know

that if something had have been done that the suffering would have gone away or could have been relieved.' Interview 2

Not being able to help alleviate suffering.

The inability to alleviate distressing symptoms due to the complexity of care can make nurses feel overwhelmed, inadequate and helpless (Davitz and Davitz, 1975; Menzies, 1961; Benner, 1989; Steeves et al, 1990; Radiewicz, 2001; Georges et al, 2002) and be a source of stress when caring for patients who are dying (Kent et al, 1994; Alexander and Ritchie, 1990; Quinn, 2003; White, 2004). This can be exacerbated by close patient relationships, personal problems, clinical experience and time spent at the bedside.

Nurses have different reactions to different patients, depending on the extent to which they can identify with them and their personal adequacy in being able to alleviate the patient's suffering (Kiedel, 2002). Nurse have problems with grief if they have not been able to help the patient die a good death (Saunders and Valente, 1994; Papadatou, 2000).The palliative care nurse specialists found being unable to alleviate a patient's suffering to be a significant source of difficulty.

'If you can't get somebody's symptoms under control I would find that stressful. And you know that's something that you can't always get under control straight away and I would potentially worry about that. This person that I've been dealing with today who has got nausea and vomiting then I would worry about that. I would think because I'm not here tomorrow I will ring up tomorrow morning and ask Dr to go and see the patient because I can't trust that that will happen. Because I've seen the patient after six o'clock and that may not get handed over until tomorrow afternoon. So if I was here in the morning I could see to this first. So I will, if I can't do something about that, I will, that will distress me.' Interview 11

'I mean's there's only been one patient and that was, the reason it got to me was just because the complexity of trying to control her pain and the amounts of different drugs and the support that everybody needed in looking after her. Not just the family but the district nurses and the GPs because we were introducing new drugs and drugs at high doses and others were upset about the amount of pain she was in and that did, you know I was obviously sort of – can't say I was upset – but I was you know, I did take that home with me

because I just felt that you know it was terrible for the patient to suffer because she clearly was suffering and for the staff to feel so inadequate even though they were treating appropriately.' Interview 31

'It affected a number of us within the team and I have to say in all my years in palliative care, he actually was one man who I think died suffering. I genuinely don't believe that he wanted to die. And again he was a young man, with all his life ahead of him really and he we just couldn't relieve his suffering.' Interview 7

Many of the descriptions of situations where they were not able to alleviate suffering were from many years ago and were clearly very formative in the palliative care nurse specialists' development of coping mechanisms. They seemed to be able to vividly recall situations where they had to witness suffering.

'When I came to palliative care I'd find it very frustrating that I couldn't help. I'd almost feel, we talked about it in clinical supervision actually, almost let down because you can't actually "do anything" and almost misplaced in your role, possibly a bit of anger as well, and I've heard me and my colleagues, sounds funny, where patients have died sooner than you thought. 'I haven't finished yet; I haven't done that bit.' So a frustration really. I'd also say a lack of wanting to follow up on a patient like that inside; a sort of you know do I keep persevering and keep trying here or do I sort of pull out and back off completely. I think that might say something about sort of me as a, as a failing, not failing but I'm not getting anywhere here and do I have the energies to keep going back or should I sort of pull away when things are better. And I think it's an instinct in me that when you're not getting anywhere you're not feeling as though you're able to do anything. All right I'll block that and shut that door you know that's how I get on with it in a way. It would be easier to do that.' Interview 15

The palliative care nurse specialists also found having responsibility for the alleviation of suffering to be a problem especially if they were unable to provide relief and had known the patient for a long time or had a close nurse-patient relationship.

Responsibility for relieving suffering.

Sheldon (2006), found that nurses wanted to help patients and found that communication where they were dealing with negative emotions very difficult. The onus for the relief of suffering was a pressure for the palliative care nurse specialists. Patients and families were looking to them to help, and yet the palliative care nurse specialists were aware that it was not always possible to alleviate suffering.

'And there are times when you have patients particularly the young patients who are difficult to symptom manage and you say to district nurses – Look I'll leave my pager on over the weekend because you know there are going to be problems. ' Interview 20

'But I think the responsibility you feel doing this job as a CNS in the community is great you know because you really do feel I think the weight of you know these people being well maintained at home and being safe and being symptom controlled and how can I say, psychologically supported. I think that does weigh on you because you want everything to be right for them and you want everything to be as smooth as it possibly can for them and perhaps for their last days to be as, for the quality of life to be as good as you, well not obviously you can make, but as good as they can get you know so there is there weight of that.' Interview 13

A close nurse-patient relationship, where the nurse was involved and liked the patient, exacerbated this feeling of responsibility.

'I knew a patient for quite a long time and I had developed a very good relationship with them where they trusted me and you enjoy their company, you do, you know I really like this person you know and if you, if you've got the point of there that person is suffering you may actually feel more anxious because they've invested a huge amount of trust and reliance on you so the pressure is on you, on yourself then to actually continue to help them. And especially when you've had a good relationship with somebody who's had a lot of problems and you've been able to help solve problems along the say and I can't think of anyone in particular at the moment but if you were to have come to a problem where you couldn't help someone with I suppose that would be difficult because you've been able to fix everything so far" Interview 2

10:3 Relationships.

The relationship with the patient could be challenging for the palliative care nurse specialists. Their emotional involvement with the person led to care, empathy and compassion whilst they were also aware that they were unable to change the ultimate outcome of the illness. A number of factors were highlighted and point to the need for managing involvement and developing self awareness which is further discussed in the next section.

Age of patient.

Mason (1991), found that the patients' age influenced the nurse's inferences of suffering. Davitz and Davitz (1975), found that nurses thought that younger, critically ill patients suffered more, whilst Oberst (1978), found that nurses thought older, moderately ill patients had more suffering.

Younger patients who had not had a chance to experience a full life were harder for the palliative care nurse specialists to care for. They were thought to suffer more because they were losing more, and the palliative care nurse specialists were able to imagine how they must be feeling.

'And I think as well we're seeing a lot of younger patients with you know sort of terminal disease as well. And I don't know if that hits home a little bit as you're getting older and you've got your own children and you really can sort of think you know well, how would it be like for my children.' Interview 22

' Well obviously there are times where you are in a situation where a young couple (are) *you know desperate, young children involved and it can be quite heart-rendering when you are there and yes you do get quite emotional sometimes. For me that's what I find difficult. Not that I'm saying that you know when they're older its easier to accept because the disease has no barriers does it? You know, even when people are older you can equally get attached or it can be quite difficult but for me it's certainly the younger people, with the young children. You can identify with that and you think – 'Oh gosh it's too close to home you know. ' Interview 12*

'And I think the age groups are harder to deal with. You see when I was in my 30s I nursed patients who were in their 60s. And their families were grown up and they were looking after them. Now I'm in my 50s and I'm looking after people who are in their late 20s and 30s who've got babies and young children and teenagers and that's emotional, because you've been there and done it and my son's grown up and this poor lady is never going to see her kids grow up. So I think, there is a lot of, a lot of turmoil that goes on..... I think there are times when you do want to change things,

you do want that person to see her daughters grow up, a first grandson or you know and it's, I suppose it's the unfairness of it sometimes that actually does get to you.' Interview 24

'It's always worse when people are younger I find.' Interview 4

The palliative care nurse specialists found it easier to accept that older patients were going to die as they had experienced a full life. It seemed easier for them to be philosophical, which may also be because they are less able to identify with them.

'I think it's much harder when they're young, or younger. I think others who have been maybe in their 80s and it's happened and it's gone quite smoothly and they've died quietly and peacefully, you think that's the right end to their life. It was peaceful they didn't have any pain. They had their family there. They'd lived a good full life.' Interview 14

'The pain of the treatment you know. The aggressiveness of the treatment. The patients are taken to the brink really sometimes. And the isolation you know, separated from their families and children. And I guess that in itself, their whole life has changed and that is, how do you deal with that? In a young person, I guess I'm thinking of perhaps you know a person of a similar age to myself, but older people it's more you can justify things more I think. Yes, although all patients are different and they don't always think that and they suffer just as much as a younger person. But you can rationalise it more if somebody's older and have lived a full life if you like. I find for me personally, I find the young families with the young children hard because that's too close to home for me because I have young children myself.' Interview 8

Identifying with the patient.

It seemed that many of the problems of dealing with young people were often because the palliative care nurse specialists could identify with them. It is not unusual for nurses to bond more strongly with someone who reminds them of someone special in their lives or who has similar characteristics or life circumstances as their own (Vachon, 1987; Kiedel, 2002).The palliative care nurse specialists found it difficult when they could identify with the patients.

'I think invariably it does go home particularly when there's a family that have got things in common with you and you tend to you can identify much more.' Interview 20

'It's something that's said that just sort of seems to resonate and I suppose it's when it sort of breeches the sort of the professional and the personal sort of boundary where it sort of starts to feel different. Recognition isn't it? Sometimes it's not somebody that I could say that I could say well I'm like them or they're like a, you know, a relative or a friend of mine but just something they say feels more sort of, I don't know, difficult to handle than the others.' Interview 16

'Its too close to home it is you know. And I think some people that you see, the patients affect you more than others. You know, you can have I don't know I've dealt with a lot of sad cases you know. I had a 41-year who was just kept on for months and months. She was in hospital a long time and I found that it's just when it comes close to home and it really affects me. It's like being a nurse on the ward then isn't it? When you see them all the time you know and you're talking to the families endlessly and it affects you. But then I feel that's part of the job that if you're not affected by things then, not that you're hard but at the same time you're doing the job but you're still a human being aren't' you?' Interview 21

'It depends very much on a huge amount of variables – how well you know the patient, if you identify with the patient, strongly, what the circumstances of that suffering are because there's different sort of degrees.' Interview 2

There was considerable insight and self-awareness displayed by the palliative care nurse specialists into the problems caused by being able to relate to, or identify with, individual patient circumstances.

'The situations I've found most difficult are when as younger people have to leave families and leave children. That sort of, knowing that they have to leave that behind. That causes suffering and you can't even contemplate what they must be feeling and when people are the same age as myself who have got families the same age as my family, that's when I feel it most acutely I think and I empathise with them. I mean you empathise with everybody but when you can actually see yourself in that situation I think you empathise even more strongly and when you are talking to them

and they say – I'm not ready to die, I'm not ready to leave my family and I can't be dying and you have to be able to do something for me – and you just can't help them. You just sit there and you can't say anything and there is nothing that you can do.' Interview 10

Interestingly, this palliative care nurse specialist was finding the role harder to cope with as she got older, contrary to the evidence that suggests that age and maturity help (Turner, 2001; Payne, 2001)

'The older I'm getting, emotionally the harder it is to cope. I think when you're younger, you don't see people so much at your age with the cancer and you don't relate to them as much. But as you get older you see people your own age who've got grandchildren, who've got children your age or people who are younger like this young woman today and you think God I can give you 20 years and you're not going to have those 20 years and who's going to look after those 11 year old twins and, so for you, I mean I find it particularly difficult not to go home and worry about that little family. I mean not, not to the point that it spoils my life or anything but you find yourself doing something and because you get to know these families, it's a privilege to be in their house isn't it and meeting the whole family and because of this there'll be something that you may do. Like my, with this young family, I actually have great nephews that are the same age you know. And to watch them with their parents on the weekend, you can't, you can't but fail to think of her and her situation and how would they cope you know. I mean I'm not saying it's the focus of your, of your night or your weekend but there are little triggers that you can't, I can't help.' Interview 25

The age of patients and being able to identify with them was a considerable source of difficulty for the palliative care nurse specialists and will be explored further later. Being able to identify with the patient seemed to mean that the palliative care nurse specialists got more personally involved with them, and this would also be a source of stress.

Personal involvement.

Benner and Wrubel (1989) have linked the concept of stress and caring, stating that stress cannot be avoided and is the inevitable result of living in a world where things matter to one. Rittman et al (1997), reported that nurses were committed to participating and developing meaningful relationships with patients and their families, which can be both rewarding and stressful. Being in a relationship with a patient means sharing any pain or suffering that may be experienced, as well as any joy (Maeve, 1998; Hinds, 1992; Cohen, 1995). It is recognised that over involvement may lead to compromised patient care and stress in nurses (Turner, 2001; Morse, 1991), and studies show that nurses are affected by negative emotions when exposed repeatedly to dying and suffering patients (Menzies, 1961, Field, 1984; Benner, 1989, Morse, 1997, Davitz and Davitz, 1980; Georges et al, 2002; De Araujo and da Silva 2004). The palliative care nurse specialists were aware that involvement with patients was an important, but difficult, part of their role.

'I feel sometimes for certain peoples situations but I don't think it's something you can make them better because I'm realistic and that's not what this is about but sometimes it's not the young person, the one you expect with all the family, it could be another person you know so maybe that's something about how you feel about that person, the relationship.' Interview 30

There was recognition that whilst they would not be personally involved with all patients, there were some with whom they would develop a closer personal relationship, especially if the person had many complex problems that required care.

'I think when you're heavily involved with patients, for me personally I need closure for myself so be able to follow it through to the end would help me in dealing with it. And fortunately I haven't been in the situation were I've thought – Oh I can't deal with this you'll have to sort it out. So I've never come to that situation but you know for me I would need closure for specific cases as well you know that I'm dealing with it because you're obviously more involved with some than others and that's all to do with, I suppose it's just the sort of relationship you develop with people. I think again it's just personalities of people I think. Personalities of people and obviously the intensity of their needs of you………I would, when, I suppose of course when I say intensity that would include symptoms I suppose wouldn't it you know whether it's the emotional or physical symptoms because you're constantly trying to get on top of things, you know your constantly developing that relationship. Perhaps it doesn't necessarily mean the length of time you see somebody. They may be on your books for the same period of time but may have a more intimate or, or a deep relationship with one patient family than you do the other because your input there has been more because of the physical or psychological symptoms that they are experiencing.' Interview 12

'Some of them are personalities and it doesn't matter you know I have patients that have died last month and I have to struggle to call them to mind. There are others I've nursed for a very short amount of time and I will never ever forget, purely because either their personality or the family's personalities. Something, yes, yeah, and even when they've been you know cantankerous old buggers, you still have that kind of feeling for them and that never goes away. There are quite a few people I'll never ever forget. They stay with you.' Interview 24

Relationships with patients were a source of both reward and difficulty. Often, the way the job was structured exacerbated the problems with both the themes of suffering and relationships.

10:4 Job structure.

The palliative care nurse specialists found the way in which the job could be performed, in terms of interactions with others and available resources, were important factors in whether the role was rewarding or caused frustration. In some cases, job structure itself was a problem, but mainly it was difficulties hindering the relief of suffering or lack of support in the nurse-patient relationship. Job structure was the backdrop for achieving the aims of their role. If there were problems, then it was possible that the already hard task of relieving suffering in palliative care would be unachievable. All the other hardships were increased if there was poor communication within the team.

Communication/poor teamwork.

Occupational role and work environment, particularly where there is lack of control over role or environment, communication problems with colleagues and unrealistic expectations from the organisation, can be a source of stress (Plante and Bouchard, 1996; Cohen, 1995; Steeves et al, 1994; Vachon, 1998; Georges et al, 2002; Barnard, 2006; Payne, 2001; Norberg, 2007). The palliative care nurse specialists felt that poor teamwork and communication difficulties were stressful for them, particularly if it resulted in unnecessary suffering for the patient.

'The time it mostly goes home with me is when I'm feeling frustrated when I've reached the end of the line of my expertise, experience, skills whatever and I have expectations of someone else and the someone else doesn't see things in the same priority order as I sometimes do and so that's the time it goes home most of all. You

know if I've made a referral to someone because I feel inadequate for whatever reason and they then put it on hold and yet for me it was priority that's why I referred on.' Interview 2

'So I suppose it, it was just a bit frustrating really but again it isn't to do with the patient's, the frustration was not looking at somebody suffering so much as it was because the system was going wrong.' Interview1

'You get very frustrated when you get referrals where the information hasn't been clear or you know that you have made a phone call and you've caused distress to a family member or to the patient because they haven't known the full information and it makes you feel sad and it makes you feel frustrated and you come off the phone and sometimes you're fuming because Oh my God I've hurt someone or you feel awful because you've done something but not willingly it's just that you've gone by the information you have been given.' Interview 9

Work environment.

Lack of time and high workload have been found to be factors that impact negatively on nurses' job satisfaction (Botti et al, 2006; Barrett and Yates (2002).

'I think sometimes I have had situations in which I have been extremely stressed but it's not usually to do with patient care. It's often politics of the NHS and lack of resources and management issues, things like that that cause me more stress and then my focus then often switches back to patients and then I think well actually it's a relief being able to get out of all this and go and see patients and focus on really what is important, their care and leave the rest behind.' Interview 9

Not having enough time to identify and try to alleviate suffering, due to receiving referrals late or having too many patients on the caseload, were sources of significant stress. The palliative care nurse specialists felt the intensity of the care required for patients had increased as treatments have improved and people are living longer with their disease. This meant that often the palliative care nurse specialists have more patients, for longer and with more intense problems. Additionally, they develop close nurse-patient relationships over time but the complexity of care can be overwhelming at times.

'Well there are times when it's tough. Some of the last few weeks have been incredibly tough. I've had patients with terrible symptoms, really difficult to manage you know. Where they're so complicated and so intense. I'm visiting, problem after problem to sort, different drug regimes, the availability of drugs – all these things non-stop every day. And it's hard enough if you have one patient who's extremely difficult on your caseload but to have a handful at the same time is, you know heavy going and it's been quite hard.' Interview 19

'I think in some respects it's got more difficult. Yeah, I think it has. It's busier for a start. We haven't got as much time to spend with all the patients that you would want to spend time with.' Interview 22

'But I think the intensity, from an organisational point of view, the focus on the patient numbers, the caseload numbers which seem to sort of ring bells elsewhere Oh great you've got that amount. But what's not taken into consideration is perhaps the dependency of the people you are seeing. I think we just feel that the heat is being stepped up quite a bit as the years are going on we've noticed a difference. And I think perhaps its the complexity of the people that we're seeing, plus I think the length of life in some people because of treatments of various things, seems to be longer.' Interview 13

Too many complex patients increases the intensity of the work but, due to lack of time, also prevents the palliative care nurse specialists from undertaking activities that would help them to cope, such as the education of others that would also ultimately reduce their workload. Time and communication with others was critical in enabling patient care to run smoothly. If there were problems with either of these factors, the palliative care nurse specialists were more likely to run into the difficulties outlined in the themes of suffering and relationships. Job structure was crucial as a facilitator of good care and thus job satisfaction. However, there were also a number of personal factors that influenced how well the palliative care nurse specialists coped with the role.

10:5 Personal.

Personal problems outside the job.

Personal circumstances and problems outside of the work environment can influence dealing with stress within the job (Kiedel, 2002;Vachon, 1995; 1998). Recent bereavement and family or social problems can increase the likelihood of depression and burnout (Kash et al, 2000; Vachon, 2004). The palliative care nurse specialists were aware that it was important that their personal lives were supportive and knew that problems outside work make the job harder.

'It's much more difficult and I would say that if you are having a bad time in your life you are not able to support others well really. I think if you're feeling a bit down yourself then, then sometimes that helps on occasion because you can make somebody else feel better. If you're having a rubbish time yourself, then it was probably easier on a ward to look after these patients because there is a lot more menial kind of basic, routine work. Whereas here you do have to give a lot more of yourself in this role so you can't, you don't do it as well if you're having a bad day yourself.' Interview 6

Taking work home.

There were times when the palliative care nurse specialists took their work home with them, which they recognised as a problem as it stopped them from switching off, having a rest and enjoying their lives outside work.

'Sometimes my husband will say to me – 'Oh what's the matter with you tonight, you seem a bit low'. And I'll say 'I've had a particularly bad day today, it's just been a bit sad; you know a sad day.' You know, another sad day and I'll switch off. I'll manage to switch off, cook the tea and I'll switch off and unwind. But, yes, some nights you can't stop thinking about people. Most of the time I manage to switch off. I think I've been doing it long enough to know how to protect myself.' Interview 10

'The biggest thing I'd say from the job that affects my home life is just sometimes when you talk to people all day and dealt with their problems, sometimes when you get home you just can't talk anymore. And so sometimes its you know I might go with my children and the dog and my husband say down to the beach and you know just sort of so that I can just not talk for a while. It's not that I think about anything it's just that I'm exhausted.' Interview 31

They were very aware of the need to leave the job at work in the interests of having an outside life and being able to continue to function in the role.

Changed because of job.

Many of the palliative care nurse specialists worried about the long-term effects of being exposed to suffering and death. They were aware of the difficulties involved with the job and afraid that they may suffer personal damage from their experiences of others' suffering. They found it hard to express what they really thought the long-term effects would be, but were very conscious of the possible sequelae of working for many years with death and dying.

'But I'd hate to think you know sometimes you know you question yourself you think Oh God I've been in it 10 years now you know. You hear this word about being hardened and things like that and think Oh Crikey am I getting hardened? But it's not becoming hardened to it, it's becoming more confident and philosophical in a way for me about the whole situation and yes, there were always cases right at the beginning that some would really get to you and some were less, you know and that's still the case now and it's usually those one's that you can relate to, that young girl with children but it's, it is easier to manage as time goes on but God forbid that I ever get hardened.' Interview 15

'But I just think back, about I suppose the general wear and tear that I feel that I can honestly say that I've experienced and I have certainly seen it in other people. In the team here the experience of doing the job. I mean by far I'm not saying that it's the worst job in the world or anything like that but there is something about it, which I think inevitably, does cause wear and tear on an individual. I remember when I first came out as a CNS they talked about a sort of broad figure of how long you should do the job for and I thought Oh gosh I can't see that, I could manage to do this forever and a day or whatever but the more I do it, the more I think no you're quite right, you know whoever came up with that. I think there is a life expectancy in that respect in this job. I'm feeling it more perhaps because my workload is different, perhaps because the focus of what I'm doing is different but there is I think a limit I think to how much an individual can do you know. What it's done to me personally, I think I feel aged as a result of it.' Interview 13

They were very conscious of how working with patients who are suffering may affect them in the long term and had witnessed problems other palliative care nurse specialists had experienced. There seemed to be fears about the long term effects of the role but they also enjoyed their work and wished to continue to work with those who are dying.

'I think I'm probably more serious as I've got older I think. I don't know really. I had a secondment for year three years ago, I took a year out and not particularly related to the job, I just needed some time from here really. And my husband said I was a different person when I was on secondment to how I'd been before.' Interview22

It was hard for them to be specific about what they thought the ill effects of working with patients who are suffering would be but almost all the palliative care nurse specialists brought up fears of the long term effects at some point in the interview.

'To be honest with you, as time goes on and the longer I work in this area and more so of late, I don't know if it's coincidental, I do worry about the effects, emotional effects that this job has, not particularly on a day to day basis but what effect it will have in the long term on me. Right okay, I think as I get older perhaps that's more of it, as I get older and appreciate life and my family and how important quality of life is and knowing how quickly that can be taken from you, that's something that I've become very much more aware of and that is certainly something that worries me that the older I get. How can I, it's very difficult to explain. I think I'll try again now. Yes, it's the impact of the job on a day to day basis, you go about, you know have your days, you carry on, you carry on, you carry on but for me the impact of how is that going to affect me as I'm getting older, that mentally you know seeing all these people, all these emotions, all the suffering which we get through on a day to day basis but the accumulation of that over a period of time is, what's it going to do to my mind? You know it is something that does worry me. Because it's not like I'm going to work in a shop every day, not that I'm being derogatory to that in any way but I'm not dealing with death. But every day I'm dealing with death and dying and all the suffering that goes with that and you know the longer you do it how much more can you take really..... I want to make the most of every day in my life and, and will I still be able to do that if, if I carry on doing the job that I do and will it have an effect on me in the future that won't enable me to be I don't know. You just see some people who do the job for many years and they get to such a stage they just say –

that's it I can't do any more, and then there's terrible depression and you think oh, and that's the thing for me I don't want to be in that situation, I don't want my job to affect me like that in years to come. I think that's what I'm looking at.' Interview 12

One of the benefits of working with people who are dying is the ability to let go of the things in life that are of little consequence and make the most of time available (Mok and Chui, 2004). The palliative care nurse specialists were also aware of this more positive change to their lives.

'It changes you completely. It does. Because before I did this job I was extremely house proud. Extremely house proud. I would be gardening in the dark you know that sort of thing, everything would be done, plumping up the cushions before going to bed nothing out of place. And now things like that don't matter. Life is too short. You know you do it now, you do what you have to. And I think that's most of us in the field.' Interview 19

Whilst they clearly enjoyed their jobs they were also very conscious of what it may be doing to them. The awareness of the difficulties with the role and the possible long-term effects were very much in the minds of the palliative care nurse specialists. Unfortunately, some had already had periods of time off due to stress.

Burnout.

Burnout is characterised by exhaustion, cognitive dysfunction and cynicism from a prolonged period of high stress with ineffective coping. In the time before burnout, there is a feeling of being trapped between trying to satisfy stimulating demands but being unable to make any progress. This leads to threats to personal identity over responsibility towards the job demands and failure to utilise normal coping mechanisms (Ekstedt and Fagerberg, 2004). A number of the palliative care nurse specialists had experienced illness as a result of their work and described these feelings graphically. They had suffered as a result of their work and had learnt from the experience.

'Well when my mum died 6 years ago I think I was burnt out at that time but I didn't realise I was burnt out until after my mum had died 'cause I never take sick time but had 19 weeks off work and that was, it took me about a month to get over feeling guilty 'cause I had time off work. But I think I must have been on a low ebb then. I mean my dad was ill at the time and he had surgery so that took, that was part and

parcel of why I was off as well. But I think basically when I look back I was depressed, I was clinically depressed. But that came and went.' Interview 23

Powerlessness in influencing the valuation of the work of nurses, which included patient and organisational expectations, lack of time and resources, have been shown to be important in stress and the development of burnout (Billeter-Koponen and Freden, 2005) and was clearly a factor for the palliative care nurse specialists who had suffered with work related stress.

'Well I came to a point where I didn't feel like I was coping and so what I did, I do things dramatically when I don't cope and what I did was I went to work in Pakistan in the cancer area but doing something I'd never done, and I had a fantastic time but went there with all my baggage ..... I was so kind of wrapped up in this horrible kind of hamster wheel environment that I just didn't see what I could do and what I couldn't do. So moving out of that in a completely different way, doing something, stretching myself and doing stuff that I'd never done before. ....But obviously it did me good because I went back and was able to kind of get rid of all my demons. Yeah, because I'd obviously taken a huge amount of baggage with me and I brought a lot of it back but I gave it back and so I think that probably, that was the turning point for me, realising that the life didn't revolve around, if I didn't go to work then somebody else would do my job. Before I went to Pakistan I always felt to be obliged to be there until late at night if the staff didn't turn in I would be the one to volunteer to stay over and you know, I was stupid really but I didn't think I was stupid at the time I thought I was committed.' Interview 29

Ekstedt and Fagerberg (2004) undertook a phenomenological study of 8 people suffering from burn out to explore the complex interaction between the person and their life world during the burnout development period. They found that the main feeling experienced was one of feeling trapped between stimulating challenges, and responsibilities and demands. There was a drive for life that gave meaning, which gave a sense of satisfaction as long as they didn't stop, as the demands kept coming. Feeling responsible with extreme work demands and a sense of responsibility that they could not live up to all demands preceded burn out. This led to an increasing focus on work and the progression of the burn out symptoms. As they became increasingly aware of losing control and of their failures and short comings, they tried to protect their shortcomings and self image. Eventually they cut off from everything that interfered with their struggle, as well as the warning signs from their bodies and minds, colleagues and family members. Bodily problems increased, as did psychological manifestations, sleep disorder and fatigue. Finally, they reached the bottom line where they felt alienated and could no longer see a meaning to life. This scenario was described by some of the palliative care nurse specialists.

' Well I just sort of kept on plodding really. I did it by sort of doing the normal survival things you try to do when you try to keep on top of things which is really stupid, coming in early, staying in late taking things home. You know trying to keep up with all of this and really not doing justice to anything including myself. And then well, saying that had a holiday period in July and just absolutely nearly hit the deck looking back. And I thought, gosh I can't do this any more it's stupid and I actually felt angry with myself. What have you been doing?' Interview 13

'I think we're not supported enough to support these patients on a long term basis and going back about 3 years ago I had a severe depressive episode which I didn't realise I was having. Well I was driving down the AX looking at crash barriers and thinking, if I could touch that now, how much time could I have off work. I felt so physical and emotional but because there's only the one of you you keep pushing and pushing and pushing and it had got to a point where I did want some sort of physical injury so I had a legitimate reason not to go into work. Because again as nurses you don't say that you can't cope emotionally. If I broke a leg see... I actually sat in a patient's house for 2 hours. Er, a very ill patient and the family and came out and sat in the car and I couldn't remember a word what they'd said to me. Not one word and when I looked at my notes at what I'd written down it really was a load of rubbish. And I'm fortunate because I have a twin sister that does exactly the same job. So I phoned her up and I'd said what had happened and she said – you go into work tomorrow, less trouble. I ended up going to the doctor and had 4 months off. If I'd taken time off when I really felt it wouldn't have been such a traumatic experience but out of that comes that we do a lot of caring but nobody really cares a lot about us.' Interview 24

10:6 Discussion: Personal Impact of working with patients who are suffering: Difficulties.

The difficulties with working with patients who are suffering were very clearly linked to the desire to alleviate suffering and the nurse-patient relationships developed to achieve this. Problems arose, particularly as a result of poor job structure and teamwork, emphasising the importance of having enough time and good communication in enabling achievement of the role. Many of the factors that were a source of stress were also a source of job satisfaction and enabled the palliative care nurse specialists to continue to undertake the work. Consequently, the issues will be discussed in relation to coping at the end of Chapter Ten and in Chapter Eleven, the discussion chapter.

Section Two: Personal Impact of working with patients who are suffering: Coping.

10:7 Introduction: Personal Impact of working with patients who are suffering: Coping.

Coping with stress or burnout has been discussed by a number of authors (Lazarus, 1984; Firth et al 1986; Ramirez, 1996; Maslach, 1981,1982; Kiedel, 2002; Vachon, 2001) and revolve around two main approaches. The first is trying to change what it is possible to change. The second is adapting to what cannot be controlled. Planful problem solving, reappraisal of problems and seeking social support are all associated with reduced burnout levels (Ceslowitz, 1989; Payne, 2001). There were four themes that emerged from the data that related to how the palliative care nurse specialists coped with working with patients who are suffering. These will be explored further below with illustrative data extracts.

Figure ix: Personal Impact of working with patients who are suffering: Coping.

Suffering:	*alleviating* *patients not palliative care nurse specialists suffering* *acceptance/perspective on suffering* *realistic expectations of role*
Relationships:	*setting boundaries on involvement* *personal* *colleagues/good teamwork*
Job structure:	*not taking work home* *ongoing education, clinical supervision, case conferences and* *reflection leading to increased knowledge and skills* *management of work other work activities*
Personal:	*maturity/ life/job experience* *outside activities* *looking after oneself* *putting things into perspective/acceptance* *recognising signs of stress and taking action* *personality* *faith* *job a privilege/job satisfaction*

10:8 Suffering.

Suffering was accepted as part of the palliative care nurse specialists' reason for being in the role. They were able to cope with difficulties raised by the role providing they were able to make some progress in alleviation of, and had a personal philosophy about working with, suffering. Interestingly, whilst working with suffering was a source of stress, it was also a source of job satisfaction and thus part of how they managed the role.

Being able to alleviate suffering.

When nursing care is of a high standard and suffering can be alleviated, nurses feel their role is meaningful and rewarding (Field, 1984; da Araujo and da Silva; Rasmussen et al, 1997). The palliative care nurse specialists were clear that being able to alleviate suffering made their role worthwhile.

'You do feel sad about a patient isn't it but if you know that you've done your best that's satisfaction and you feel okay about it.' Interview 22

'I am very happy doing my job. I love, I get a bit of a buzz about knowing that I'm helping people who are poorly if that sounds right, who are dying? You know you are making it better for them and it's so nice if someone's in a lot of pain and you have sorted their pain out and you think – Oh it's an achievement you know.' Interview 12

They were able see the positive aspects of their work as well as the difficulties and much of their job satisfaction came from being able to help people who are suffering achieve as good a quality of life as their problems would allow.

'I absolutely love what I do. That's the first thing because I actually do feel that I can make a difference. I do get very frustrated and distressed when such a case as this occurs but I always look on the more the broader perception and think well I can, if I can't do anything about this individual case then I can do something to perhaps work towards making it easier for the future for patients in this situation. So the more I become familiar with the area, the people and the circumstances then the more influence I can have on changing that environment. So I maintain that sort of optimistic outlook in some ways. So, I do think that I make a difference and I do think that the difference that I make is positive even if I cant do that all the time then I always do my best and always try to do my best so even if it doesn't work it isn't that I haven't tried or that I haven't wanted to.' Interview 11

'You also see a lot of the time we get called into situations where it is a horrible mess and you are able to do something about it a lot of the time and that is very rewarding.' Interview 1

'I genuinely think that there is an awful lot of job satisfaction to be gained from what I do. So I try to focus a lot on the positives of things. Like this ladys going home next Monday. I mean we did that. We certainly helped then do that, do you know what I mean? So there are an awful lot of positives that you can say-oh that's a good one. If somebody is just dying and they want to go home and you get them home the same day, well that's job satisfaction in that. So you know I try to focus on some of the positives.' Interview 4

Focussing on the successes and being philosophical about suffering were sources of strength. Arguably, they had some degree of control and had found meaning in the suffering.

Acceptance/ perspective on suffering.

Acceptance that it is not possible to change difficulties in palliative care can be hard. The pressure to ensure that the patient has a 'good death' and does not suffer unduly is immense but achieving this may not be possible. A personal philosophy of illness and death that accepts that it is not within the nurses' control and they can only do so much to alleviate suffering is helpful, as is acknowledging the deaths of individual patients (Vachon, 2002). A sense of competence, control and pleasure in work gives a sense of accomplishment and helps palliative care professionals find meaning in their work (Vachon, 1987; 1995). This coping strategy also involves accepting that one cannot control illness or death.

'I view it that I'm actually nursing people that are living until they die. Again, a bit of a cliché but I do believe that very strongly and you know I say to people you know these people are dying anyway whether I'm there or not and if I can help them throughout their journey to alleviate suffering in all those forms, if I can, then that's beneficial to me yeah? And I do truly believe that you know we can make a big difference in some people's lives, not everyone's lives at all but in some people's lives who are receptive to the services. It is very sad but I do feel my philosophy on death has changed that I do believe you know it is inevitable yeah? And I say there's so much we can do and I'd hate to think if we weren't there some of the situations that may happen.' Interview 15

Over time they had developed this philosophical approach to the stresses of working with death and dying. As they matured both personally and professionally they were better able to cope.

'I think as well when you, if there is suffering going on that you can't do anything about for some reason I, I am quite good at accepting that it isn't that sad. You know. It is, accept that it is sad but what else could be done about it.' Interview 1

'But now I think I handle stress quite well and I haven't got to the point where I think 'Oh I can't do it'. You learn to cope with it. You put in perspective you know and when you have a family of your own as well you feel, you appreciate what you've got you know? You think well I've got nothing to worry about. And not to personalise things that happen in work.' Interview 8

'If you know that's all you can do I've got to the stage and maturity in life I suppose were I sort of think well I could not have done any more and I also feel that because the job is so demanding and because you know there is so much going on, that I can't afford to dwell too much as well on certain things. I have to move on because theres so much to move on to if you know what I mean. There is so much coming my way. So you know, er not trying to be in any way blasé because I really do soul-search but at the end of the day I've done all I can and certain things are gong to be out of your control anyway because you're reliant on other health care professionals and treatments and you know Oncology centre and other people to play a part in this and sometimes that doesn't materialise either and that you know frustrating. But you now as long as, you know I can always say with a clear conscious that I did all I could. That's it for me.' Interview 13

'In the ideal world you would be great but people make their choices and we can only suggest but I think you just have to accept that as well because if you beat yourself up about it you're not going to be able to go through it to continue to do the job. I think if you're with every patient then I would be worried about the skills that you use as a team but I think there is a small percentage of patients, like the pain management things, a small percentage of patients you will not get rid of that pain. You can't take away everybody's suffering because sometimes it's more deep-rooted and long before the cancer has even taken a hold. So I think that's beyond our skills. It's most important that if we, if we are using other team members from psychiatry, psychology and to see, you know considering all different options here, then we may

not change a thing. And I don't mean that defeatist in any shape or form.' Interview 30

Working with death and dying has a profound effect, resulting in personal growth and enjoying life to the full. Those who cope have a tendency to live in the present and score highly on factors such as existentiality and spontaneity (Cohen, 1995; Mok, 2004). Working in palliative care and seeing patients suffer had changed the palliative care nurse specialists' perspective on life as well as on work.

'It's also when you go home it is very sad you know, and you have to put it into perspective you know. I can only do what I can do and like I said, having a cwtch off my husband and a glass of wine and a nice meal, makes my appreciate what I've got because there but for the grace of God go any of us isn't it? And I don't think you can't internalise that either. I mean I know the longer I live theres more, you know there's a risk I'm going to develop a cancer at some stage. But if I got fixated on that I'd never do the job. But it's that you know, it's going home and appreciating what I have and just enjoying what I have and it gives me, it gives me the strength to get up the next morning and go back in and do it again.' Interview 25

'Gaining understanding is very, very helpful and it helps to just make sense of feelings and put things in perspective and understand that no one's perfect and you all muddle through in a way and some people muddle through more than others. Shall we say so long as they get it of their chest and muddle through on me I don't mind? But, I you know I think usually intentions are good and it's maintaining a sense of optimism again in a sense of understanding about a life in your own understanding of what life is and how life. This is what happens in life you know, and people suffer and people suffer everywhere not just in my little world that I see people suffering in. People suffer everywhere and in some part of the world suffering is normal, rather than something unusual and it's trying to get a sense of perspective really and step back from it and depersonalise it slightly as well. And I think you know in nursing and I think in palliative care in particular, my own personal philosophy helps me in my outlook on life you know and the reasons why I am involved in palliative care.' Interview 2

Thoughts on how working with death and dying leads to making the most of life seems to link with the negative aspects of being afraid that the job may lead to lasting damage. Working with patients who are suffering was clearly very formative in the palliative care nurse specialists' personal development.

Patients not palliative care nurse specialists suffering.

The palliative care nurse specialists recognised that suffering was the patient's experience and not theirs, they were just there to do what they could to help.

'Just to remember that this isn't your story, this is their story, this is somebody else's suffering and it's not yours to have. That suffering isn't mine to have a piece of, it's somebody's experience, it's a profound experience that their going through in their lives and although it can be distressing to be someone who's suffering, to actually claim part of it as your own I think it very, very, unfair and very unfair to the patient and I just think it's the wrong thing to do, and I think that is actually part of that that feeling of perhaps a behaviour which is not helpful in this job is actually diving into somebody else's experience for your own needs.' Interview 2

'I can't really specify exactly how, what it is that prevents me from taking all these issues on board and making them my own because that way I don't think I would be able to do my job adequately. But that doesn't mean that when I'm actually with the patient I'm not trying to be as supportive as I can and making these issues as important to me as they are to them. As I say I think having the support of the team and all around you and trying not to make it personal. It isn't happening to me it's happening to them.' Interview 3

'I don't take it on as my own personal issue. It's their problem. Sort of it's not mine it's theirs. And I am there to help in the best way that I can so I separate it from that point of view.' Interview 1

Accepting that it is the patient's suffering and not personalising it was an important coping strategy and links to having realistic expectations about what can be achieved within palliative care.

Realistic expectations of the job.

Realistic expectations of themselves within the role were very helpful in reducing stress generated by feeling responsible for relieving suffering. Suffering is inevitable and only so much can be done, linked to having a personal philosophy of suffering.

'Professionally I think it is developing a trust and I am very careful to separate the professional from personal. I didn't come into this job to sort of save the world and save these poor people. It was something that I found very interesting and felt that I could do something with skills that I admired that I would like to develop so, I have never sort of. I am always very upfront with people in the first place about what my role is that I am just an add on to the you know, they may not see me, that it is the GPs and everybody else is the major thing and actually set some realistic things with them about what they can do, you know that if they ring me that I may not ring them back until the next day and you know that I am out and about and this sort of thing.' Interview 1

'I suppose a pragmatic approach is that these groups of patients are going to be having their suffering regardless and actually if I can be positive in that, if I can actually make a difference to that, I will do. And that's I suppose that's the place I come from.' Interview 28

Being realistic about symptom control and having realistic expectations about what could be achieved within the role were also seen as important. This seemed to reduce the responsibility the palliative care nurse specialists felt, and also shared the onus of care with others. It saved them from feeling they had to achieve miracles in difficult situations where the ultimate outcome of care is an inevitable compromise.

'I think it's the practicalities of it and the reality that I can only do what I can do you know. And as long as I go home in the night thinking - Well I've done everything that I can and I'm not the only one involved in this care you know. There's the GP, there's the district nurses, there's the palliative care team you know and they maybe able to do better than I am and it's realising your limitations and as long as you've done everything you can like if you're going off for a weekend you've got the district nurses to call there and you've given them advice on what do to then, you know yes you think about them but you won't worry about the fact that they haven't got anybody. That's how I think.' Interview 25

'I think professionally I've developed and my management experience and skills have developed and I've become more realistic. Because you do you want to change the world but you can't always do it.' Interview 30

'I try and look at it in a much more positive way and like you say if I've managed to control somebody's symptoms and they've died at home and everything's gone hunky dory then that's a real achievement and you know with the help of the others, the bigger part of the picture we've enabled somebody, somebody's wishes, we've achieved their wishes which perhaps without us it wouldn't have been achieved because you know they could end up in hospital etc, etc. So for me it's about when I first came into palliative care I did find it very difficult initially to adapt to death and dying because it was constant it was everywhere you looked you know. But with time it was just looking it in a much more positive way and you know yes it is hard but you're making some good, you're doing good out of a bad thing if you see what I mean. You're making perhaps their lives a little bit more bearable at the most difficult time really.' Interview 12

It was recognised that those working in palliative care inevitably deal with existential crisis and that there will always be problems for people who are dying. The palliative care nurse specialists accepted that there was only so much they could do to help the person with existential suffering. A realistic approach that focussed on aspects of care where they could offer relief, such as physical problems, was helpful for achieving a feeling of accomplishment from their role.

'Sometimes I think, what are you doing in this job, what are you supposed to be doing in it? And you're supposed to be doing lots of things actually and it doesn't always amount in a good death and that bit I have to remember and if I achieve a large part of what we're supposed to do, I've done it. I can't cure all unfortunately. I can't take away somebody's spiritual pain. I can't take away the suffering that they've got because they are never going to see those they love and do the things they love doing and that is beyond us. All we can do is try to make them feel better as much as we can and support the family and maybe help the family afterwards to feel that they did everything and that they did all the right things' Interview 14

Acknowledging that they were part of a team helping the patient, that responsibility for relieving suffering was shared and that suffering cannot always be relieved was crucial to their ability to cope. Often this philosophical view had developed over time with maturity and experience, which may account for why the palliative care nurse specialists' descriptions of patient cases that were difficult often came from early in their careers.

10:9 Relationships.

The relationships that the palliative care nurse specialists were involved in were important for coping with the role. Good outside work and collegiate communication were supportive, whilst they recognised the need to maintain professional relationships with patients and families.

Setting boundaries.

Working with suffering can be experienced as a threat to some nurses, eliciting feelings of anxiety (Menzies, 1961; Davitz and Davitz, 1975) and coped with by distancing tactics (Georges et al, 2002). Rittman et al (1997), discussed how nurses limit their relationships with patients to protect themselves from excessive emotional demands whilst Payne et al (1998) found that nurses focussed on physical care, thus protecting themselves from patients' emotional reaction. This distancing seems to occur over time and has been studied in the hospice setting (Rasmussen et al, 1997; Rittman et al, 1997; Payne et al, 1998; Payne, 2001).

Setting boundaries enables nurses to make a conscious decision about how far they will take their personal involvement and nurses undergo a process of managing involvement with patients (Turner, 2001). This involves gaining maturity, both in themselves and experience within their role and life in general and was often difficult and painful, but necessary if the nurse is to continue to work with patients with life threatening disease (Turner, 2001). It is argued that these adjustments are necessary to avoid burnout (Payne, 2001) and because they are expected to cope by both themselves and their colleagues (Rasmussen et al, 1997).

The palliative care nurse specialists were conscious of using the same skills with every patient and of protecting themselves from becoming involved. They were aware that not all patients wanted a personal relationship and that despite this, they still had something to offer. They allowed the patient to lead the relationship and gave the assistance required whilst working within the boundaries defined by the patient. Whilst they acknowledged that they would be more personally involved with some patients than others, they would try and protect themselves by keeping the relationship on a professional footing and maintain some distance.

'I do give of myself as well but I judge what I give of myself so, you know people ask you questions about your life and I'm willing to give information about who I am.' Interview 2

'But for whatever reason I have developed a way of working that actually makes me feel a bit separate. Every now and again, you know of course you have somebody who you really identify with or identify with a family member or you know you think – Gosh I need to live life to the full because that will be me in ... But you can't do that. Because I think if you do then you get into really, really difficult ground where you personalise things, where you can't really advocate the person because you're caught up with your own needs. And so it's, it's trying to keep a bit of distance and, and I don't mean that by being cold I mean that by thinking well actually this is about this person and you should not be arrogant enough to think that you know what this person needs, you have to work with them to find out what's important in their life.' Interview 28

'I think you know there are some personalities that you would gel with more than others as well but again, this is me now and the way I cope with things, I always have to, I am always a warm character because that's my nature but, and there are some people that you would get more involved with than you know, would be perhaps more sad say when they died. Yes and relatives you now that you build relationships with as well but I still have to maintain that, there still has to be that professionalism. And I'm not saying it's not easy you know it is, it is a difficult thing and you do get very attached to people but in a professional way?' Interview 13

There may be complex and legitimate reasons why the palliative care nurse specialist does not become personally involved in every nurse-patient relationship. They may need time to recover from a recent involvement, or be struggling with personal problems outside work that is using up their emotional resources.

'You don't always have to get that close if it's painful and taking its toll on you. I can't do everything for patients. It's knowing where to stop isn't it? It's knowing were to stop. They're not your friend. You are there. They're somebody that you are helping to look after. It might sound hard but I don't mean it to sound hard. You

know, you have to draw the line. Imagine losing a friend every time somebody dies. Perhaps it's as I've got more confident, and I've got more mature and I know perhaps I can get the information I need more easily because I'm not that involved... ...It wasn't like one day I thought right I'm not going to get so attached. I think it was something I recognised that I had been doing in order to preserve my sanity. I looked back and I thought, I don't seem to get so close to patients as I used to and I think I thought I've probably done that in order to cope really.' Interview 10

'I suppose there is something that actually stops me becoming completely and fully involved. I have never, ever been able to actually identify what that is. I mean I have family. So when I go home I have to forget about what's going on. I've got different roles and responsibilities and different needs being expected of me when I get home.' Interview 7

The ability to share the onus of care and hand over care to another member of the team if it was becoming overwhelming was important. Bringing colleagues to see a patient that the palliative care nurse specialist was finding difficult was a supportive safety net that stopped them feeling isolated.

'I mean it's a good team. We work as a good team I think and wherever I've worked there's always been a great team it seems to me. There's always been somebody. We would talk about difficult patients about anything that was really bothering us, very easily with anybody else in the team and you know if you are having a particular bad time one of the others might come with us.' Interview 6

'I don't want to be the be all and end all for the patient. When I go home at the end of the day I don't want the family to be waiting for me to come back in the morning. Because it's not me who's the magic person. You know I'm part of the team and I think that's really important.' Interview 10

Supportive relationships.

The individual's personal circumstances and problems outside of the work environment can influence their ability to deal with stress within the job (Kiedel,

2002;Vachon, 1995; 1998). Participating in a network of caring reciprocal relationships has a protective effect against stress (Vachon, 1998; Larson, 1993).
'When I go home my husband has a totally different job, he's a carpenter. So I can actually go home and I say to him - 'Give me a cwtch' – and he says 'why?' and I say – 'Because we can.' And he gives me a cwtch and I don't tell him anything and he doesn't ask but I just know he knows how I'm feeling. So that night he's more attentive, he'll cook food and he'll keep the atmosphere as light as he can.' Interview 25

Kahn and Steeves (1994) found that although suffering is witnessed by nurses in many ways, many are reluctant to talk about their experiences. The palliative care nurse specialists knew that their outside work relationships were supportive of their work with patients who are suffering, but also knew that it was best to discuss work issues with colleagues rather than personal relations or friends.
'Mainly by talking to my colleagues. I mean I spoke to my husband you know obviously not all the details although he's, he was a nurse many years ago. So he has an understanding. I think one of the hardest things to perhaps deal with is where people say – Oh I don't know how you do your job - so if you talk to your colleagues you get structure and discussion. Because I think if you talk about your job to anybody else its – Oh no don't tell me I don't know how you do your job - so I would never speak to anybody outside of work because you know. There isn't they don't understand, they're not going to be helpful because they don't understand your job and it's something that is difficult for people to understand why somebody would do it and I say why somebody would do it but how you can cope with doing it. And I suppose the hardest things is when people like I said - how do you do it, or I could never do it, or don't tell me and you know. So I think you just, you have to have a good network within your work.' Interview 31

Taking to colleagues.

Palliative care nurses may try to protect themselves from being overwhelmed with emotions by sharing the care burden with colleagues (Georges et al, 2002; De Araujo et al, 2004; Menzies, 1961). Support from colleagues has been shown to be important for dealing with work related stress and opportunities to discuss problems has been shown to be a way in which hospice nurses deal with stress (Alexander and Ritchie, 1990; Georges et al, 2002; Vachon, 2004). The need for a good team where difficult patient situations can be discussed with colleagues was seen as very important by the palliative care nurse specialists in this study.

'I think you need to have a good team and a proper team, not just individuals working along side each other. You know, a proper team which involves support, supporting each other on a daily basis.' Interview 4

'It is reflective as a norm and, and it's reinforced every day and every day you know I work with somebody who challenges me and I am able to challenge and I am able to talk about my experiences with, and can challenge my thoughts and my experiences and the other way around. And that constant, that constant drive to think of things critically is very, very, very helpful to me, I have to say. It's extremely empowering and I think that's a real cornerstone of how suffering can be, dealt with isn't the right word and how, what my attitude to suffering is.' Interview 2

'So it does inevitably get to you but I feel that we're very lucky in as far as the team I'm in I use them for support and we all bat off each other really as far as support is concerned.' Interview 18

'I have very good support as I say within the team here and you know I think personally if I come back and have had a very difficult visit or have come back a little bit frustrated because I don't feel I've achieved, something, within a visit or whatever, then we will sit down and discuss it very, very briefly within the team when we can. I think it is, it is an extended team across the whole Trust. I think we are very supportive of each other in that respect and also you know, realise that we are all individuals and we all manage our, not insecurities, but our anxieties in different ways.' Interview 7

Conversations that were seen as supportive were those that involved difficult problems. Discussions that involved releasing emotions or feelings about patients or the job were also helpful. These allowed reflection on care with a view to learning and gaining skills that were helpful for future patient situations.

'I'm very fortunate in that I work with a close team, very supportive team and we work very hard and we all come from different backgrounds and different levels but we are all very aware of the difficulties in this job and the stresses that we are under and we share and so we work in an office where there are 6 or 7 people in there and

we can share a difficult conversation or we can report a difficult situation and you are honest and you care and you say, how are you dealing with that, how are you with that, do you want me to take on some of that, do you want me to share that patient. So we do an awful lot of discussion about patients and with clinical supervision and support.' Interview 9

'For me, because I work very closely with district nurses who are equally involved with the patient, we are able to sort of talk very openly and we've just recently got somebody who we've all become very close to you know a young patient who died yesterday, and again as I say we've got very close relationships and we are able to talk constantly about how we're feeling and equally coming back here having people and saying you know this was really hard you know, this has happened and this is how I feel and knowing at any time if I can't do it then a colleague will take over from me.' Interview 12

The relationships the palliative care nurse specialists were involved with were a source of both difficulty and support. There is a need to attain emotional balance in order to give good care to patients and deal with the suffering encountered in day to day work (de Araujo and da Silvas 2004) and the palliative care nurse specialists were aware of this.

10:10 Job structure.

The structure of the job was important for being able to undertake activities that would facilitate coping. Autonomy and control were foremost in assisting the palliative care nurse specialists plan their work in such a way that stressors would be minimised.

Not taking work home.

'Switching off', means that the nurse stops thinking about work when she goes home and is able to get on with her life outside work (Turner, 2001). Sheldon (2006), found that nurses did not want to discuss work at home because they did not want to think about it anymore and friends and family did not understand the job. They had learnt to compartmentalise and deny in order to cope.

A number of palliative care nurse specialists mentioned the difficulties when taken unaware by a patient situation or were in tears unexpectedly when discussing a patient during interview. They have a work persona, clothes etc which clearly helps them to maintain boundaries. Many mentioned that it was easier to look after patients outside of their home area and had moved jobs so that they travelled to a different area to work. They also understood the importance of having a home life free of work.

'I don't take it with me. I absolutely don't I think, I feel very strongly you can't help other people if you take on board their problems and, and we have all got this life to live and I am going to enjoy mine. You know, so I'll, have my own and I will deal with those in my way and there is probably more for me around the corner so they don't help me and I don't help them by getting over-involved and taking it home and worrying about it..... I've got a very good coping mechanism of you know when my day finishes I switch off my mobile phone as soon as I finish and it doesn't go back on until the next morning. You should go home and almost, you know, either get in the shower, get out of your work stuff straight away, you get in the shower and you cleanse yourself of those days and those cases or do something, stop the car, get out in a lay-by, things like that. I don't actually have to do that consciously now but I think I do do that in a way and I think it's self-preservation seeing what other people have been through and I think no I can't go down that road. I've got, my home life is so, so precious and I've got a wonderful, wonderful home life and I'm sorry, you know I love my work, I do my work and everything but you know I mean I have to do that cutting off.' Interview 1

'I've got 3 boys anyway so I'm really busy at home, so I go home and I'm able to switch off most of the time. I've got a good network of friends, and I've got a caravan that I go to every weekend and I just chill out. I think I used to take an awful lot of work home with me. I don't do that any more and I haven't done so for the last couple of years.' Interview 22

'Certainly leaving work at work. I mean I'm fairly good at doing it. I think that there are occasional times when I feel the need to sort of pick up and ring and find out whether somebody, how they're going to be because you know that the ward may not be so keyed up but I actually usually stop myself from doing that because I feel if you start that road, it's a very slippery path so I try and keep boundaries and focussed.' Interview 28

They were very cognisant that working with patients who are suffering could take over their whole lives if they were not vigilant about their work and personal life boundaries.

'I can quite easily leave the job here and go home. Occasionally you do get bad days and you know you go home and it was quite sad today and whatever but that's usually as far as it goes. I don't think you know, I don't think it affects home or what I do at home. You know I go in the park or library and the drive home and by the time you drive home you are not thinking about work you are thinking about feeding the kids and everything else. You know and occasionally you know there are patients who you think about over the weekend. You think oh, you know I wonder if they are still with us, you know I hope they're comfortable that sort of thing but that's as far as it goes.' Interview 7

'I don't take my work home which is great. It is very rare for me to be worried about a patient when I've left here.' Interview 6

The ability to leave work at work and have a separate home life seemed to be a learnt coping mechanism that had developed as the palliative care nurse specialists gained maturity and experience of the job and life.

'I don't have any time anymore. No it does go home with me sometimes but not like it used to. You know I used to..... I took my work home with me and I lived, ate worked, breathed everything to do with work, work was my life. And my husband worked at sea so it was really quite an unhealthy kind of life that I had. I had a very nice social life but actually the social life was with people that I worked with because of where I'd moved to and they were my friends and did very little other than work related, worked with friends, it was all very unhealthy and I did used to take it home with me a lot of the time and really struggled with that and felt very unsupported in a cancer environment which is why I now strive to listen to those people who look like they're suffering again. Staff members I mean. Because I know what that feels like to take that home and you're constantly battling with it and thinking, and cancer becoming the norm. It's not the norm. ' Interview 29

'Not to get stressed about it. Because you are on a daily basis, you enter into very stressful situations and you can't take that stress with you because you'd never survive. The ability to switch off when I get home. You know I have got two small

children so I can't wait to get home and work is forgotten which, you know, as a younger nurse, perhaps 10-15 years ago then I would have taken things home with me and worried about them all night you know but now I can see now that as I've matured as a nurse that that's changed the way I deal with the stress and the problems associated with work that's definitely changed. I think, I guess, to try and discuss it with somebody else before you leave the office really. But saying that, you know there have been situations where I've gone home and thought 'Oh guess what happened today', you know. Because you can't, somethings do, you can't let go and you need to tell somebody else.' Interview 8

The palliative care nurse specialists realised that they needed a separate home life but also knew that there were some patients that they would think about outside work. Learning to reflect on clinical cases enabled learning for the future and was important for reducing the likelihood of previous stressors being a future problem.

Education/clinical supervision/case conferences/ reflection leading to increased knowledge and skills.

As was clear from the palliative care nurse specialists' understanding of suffering, they had learnt much from experience. The palliative care nurse specialists talked of reflecting on care as being important for learning and development as well as relieving stress. They also recognised that by evaluating care they could learn from patient encounters and gain knowledge and skills for the future.

'I go to clinical supervision once a month, every month and have done for the last I don't know, 10 years. I would not do without it. I value it highly. I mean with some colleagues that you work with you can have very meaningful discussions about the cases that you're dealing with, and the way that you feel and your own experiences of life and death and your own sort of, your own suffering then in many ways. Because you know I'm not, immune to suffering myself so you know I, you can discuss some of these things with some colleagues in a professional way but I don't find any benefit in the kind of gossipy discussions that I have around trivial things in patients lives or in their personal lives. But, in, as far as clinical supervision is concerned I know that I have that time that I can really just offload really about issues where I feel out of control or that I need to pick over. But also the other supportive mechanism that is in a similar line to that would be the multi-disciplinary team discussions that I have about patients and these discussions that are held by the

palliative care team or by the Consultant, myself and a few other individuals and only once a week.' Interview 11

'I think constant analysis of your approach. This is the way I've always done this, I'm constantly looking at what I'm doing, what I'm saying what I'm, you know, the actions that I'm taking and their reactions to me and you know the suggestions I'm making that sort of thing. That's the way I function and I do re-evaluate things an awful lot.' Interview 13

'I guess you'd use, when things do happen, when you are able to make a positive difference and you alleviate suffering obviously you take that knowledge and that what you've done there and what you've done there and take it to the next patient. So you carry that experience and that knowledge with you so I guess it does transfer to other patients because you use the knowledge and experience that you've learned from other situations, if that makes sense.' Interview 8

Clinical supervision has been found to be effective in reducing job stress and improving skills (Crowe and Wilkes, 1998). Maeve (1998), in a study of nurses working with dying patients, found two processes of coming to know what the right thing was, and being able to do the right thing. The former is a moral dilemma and the latter a matter of competency, commitment and courage. Cleaning up, marked the end of involvement and gave the nurse the chance to review the situation and what it meant to them personally. Personal reflection and identifying the emotional response to clinical situations was thought by the palliative care nurse specialists to be important for helping to process the job and moving on into new clinical cases.

'I go home with it in my head and try to sort it through and then I try to put it aside. Mostly you do. I think the nurse in you always comes up to the front and self-preservation comes in and you think I have to put this aside because there was nothing else I could do.' Interview 14

'You know I think you do a lot of personal reflection as well. I think you do, you question yourself all the time. I find I question myself especially in this new post and questioning and I keep talking about the area being so big but it's quite nice to have that journey sometimes. Just to sort of put it in boxes really. And time to think about approaches and think about certain things that you need to discuss and when you

will approach that and sort of difficult subjects that may be difficult for the person to think about. But yeah, I think you're very, I'm for me I'm very good at sort of shutting it down and bringing it up the next day.' Interview 18

'You can deal with suffering without education through experience I think but it's intuitive. You rely solely on intuition and on your experience of experiential things. When you've got the education and the theory there you've got, a structure to actually refer to so if you come across a situation where you feel you're at risk you've got something to actually use and you are being intuitive as well and you are using all those sort of interpretative knowledge and skills that are at your disposal but you've got something which is more concrete and more of a safety net there that you can use with which I think is a far more sound way of dealing with everything really thinking critically about everything you come across.' Interview 2

Interestingly, despite the obvious benefit derived from reflection, few of the palliative care nurse specialists had formal clinical supervision and relied on their colleagues to provide discussion. The problem with this latter approach was that if it was busy, their colleagues were absent or there were problems with the team, then it was not possible for these talks to occur.

Another aspect of the job structure that made a difference was having enough staff and a manageable workload so that other supportive activities could happen.

Management of work/ other job activities.

Maintaining emotional distance and having control over work have been shown to reduce stress (Vachon, 2001; Ellis, 1997). The palliative care nurse specialists realised that other activities within their role, such as education and administration, could give breaks from dealing with difficult patient problems and provide emotional distance from distressing situations.

'You've got more autonomy and in the role of the Clinical Nurse Specialist I think it's just an excellent job because you're self-defining and you do have a sense of freedom and self-definition and be able to actually use your skills and develop yourself in a way as a professional which is not bounded really, you know so much.' Interview 2

'I think it is also important, is the structure actually of how you work and what the role is so that a lot of people that I meet think that what I do is go from house to

house to house and seeing that we have a case load of 60 patients which I think happens in some places and you are just go 'Oh what a nightmare that would be'. It is the other things that you do within the role that we are out educating and developing that field and we, we are now really, really pleased that we are teaching and we get them three times a year the medical students about breaking bad news, service development that sort of thing so you are not going from one (patient) *to the other' Interview 1*

'I had management duties I could spent time in the office doing that as well I did a lot of reorganisation of the teaching and I delivered a lot of the teaching. I think why, because it was partly distancing myself. When you work as a team as a palliative care nurse you are probably spending 90% of your time seeing patients. Whereas in the hospital as a Team Lead I was probably spending more like 50% of my time. So I think part of the distancing is making your role more diverse as well.' Interview 10

Ensuring that they finish on time or take time back was also important as it allowed a home life and other activities and also meant that their workload was within manageable limits.

'I think what we do is caseload scheduling, I'm quite disciplined in my time management and I work to time, I didn't always used to be. You can get very burnt out very easily and it's recognising isn't it really you know you're one big team. You don't have to do everything. It's recognising that there is 24-hour cover and taking the knocks and good time management I think as well. We can't change the world, we can do our best.' Interview 30

Clearly, having control over their role was important for a variety of reasons and enabled coping. Lack of control reduced the quality of their working and personal lives.

10:11 Personal.

There were a number of personal factors that affected the palliative care nurse specialists' experience of working with patients who are suffering.

Maturity/job experience.

Younger nurses have been reported to have more manifestations of stress and fewer coping strategies (Vachon, 1987; 2004; Isikhan et al, 2004). Work experience is thought to make health care professionals more flexible in adjusting to workload and adapting to pressure. Coping skills are not innate but developed over time in response to different stressors and experience (Lazarus and Folkman, 1984) and arguably can also be supported and taught (Krishnasamy, 1996). As nurses develop maturity, they become more aware of the effects of their behaviour both on themselves and those around them, and are better able to manage the care of patients (Turner, 2001; Farber et al, 2003).

'I guess with maturity I think and experience. I don't often feel stressed if you like whereas I think earlier in my career I did.' Interview 8

'It's definitely become more manageable over time with experience and now having the confidence in the role. You know when I first started I've just remembered there was three of us that started at the same time with very little palliative care experience and we always used to say 'What are we doing, what are we doing for these people, how are we helping these people - Oh God'. You know we were in such turmoil as to how we were actually helping anyone in a way.' Interview 15

'Because I suppose I have changed as a person in that time and most definitely I have and you know life is very different for me now, but you know I can think back to quite a few times early on when I thought – my goodness this is immense really, - and then you seem to get over that and then you're okay for a while and then you hit you know a particular point again you think, - oh gosh here we go again -. But again you soldier on and you just don't I don't know you know it wouldn't have been something that would have been very obvious perhaps to everyone else but maybe at home it would have been obvious to my husband say. You know family would see it maybe more than my work colleagues would have ever seen it sort of thing.' Interview 13

Coping is obviously learnt with experience and maturity. Over time the palliative care nurse specialists had developed ways of protecting themselves from stress or burnout.

'It's about experience, it's about learning about it and what it means. So it's putting all the experiences I've had to some use to make it better or different for the person I may be dealing with and for me as well.' Interview 16

'I think when I first started in the job, maybe I did think a bit more about them probably because I wasn't used to it. I suppose I have got used to it in a way. But having said that, when you have, when you actually do get a bit older the implications of all the sadness is more, particularly if you have your own family. You think about the space somebody is having to leave behind sometimes and that's quite bad.' Interview 6

They had learnt how to cope over time and were also aware of the changes in their outlook and behaviour that had developed in order to manage their involvement with patients who are suffering.

Other activities.

Lifestyle management that enables the individual to recognise when they are stressed and take a break, exercise and other outside work activities, good diet and adequate rest can be ways to reduce stress and burnout (Vachon, 2002). The palliative care nurse specialists had a variety of outside activities that helped them put the job behind them when they went home.

'I play badminton twice a week with a team from here. Again it's a way of relieving stress and it's very supportive in that as well.' Interview 9

'I've got two dogs who I walk miles so I should be thin, I've got a garden so I do a lot there. I like to go away, I've got lots of friends and go out and do different things you know. So I'm single, I live alone but I've got a fit family so there's always someone I can turn to if I want to.' Interview 30

Not only did they have clear outside work activities but they were aware of the importance of these to their ability to cope with working with patients who are suffering.

'Theres a badminton group that we run and we let off steam and that sort of thing. And I've got an excellent supportive husband who doesn't work in health care at all which I think helps so he just sits there and listens to me.' Interview 4

'And, I think that I cope with it as well because I enjoy the rest of my life so much – that I have friends and family and I like nice wine and I like nice food. Oh, yeah, I mean I have my family and I have you know, life outside isn't always very smooth

you know. Occasionally! But it is life outside yes, so I do, I have a complex fabric of life outside my work.' Interview 11

'My friend said that to me once, she said – 'What do you do to relax yourself?' and I've got a caravan in the country and of a friday night we just pack a bag and we go off there for the weekend….That started because my husband is quite stressed in his job and we had the caravan to start with and you could see him relaxing as soon as he got up there. And it's the same with me you know. During the week I like gardening. I'm not very sporty so it's not walking around but I do like gardening and I love my home. I've got a son who's still living at home. So it's just being a house wife really.' Interview 21

'Just getting out, getting you know diversional therapy, other activities. I enjoy singing so I go to singing lessons all that sort of thing. They're all things that just give you light relief, which is really nice. I think when I get to a singing lesson I'm exhausted but I think this is really great that I'm here you know when I get there. I think oh it was worth coming because some days you feel like – no I'll cancel.' Interview 13

'I have a good social network, I've got a good home life, I've got a fairly, fairly good work/life balance fairly good.' Interview 2

Looking after oneself.

The palliative care nurse specialists were able to recognise when they needed to step back from patient care and undertake other activities. They had learnt that it was important to look after themselves and not overwork.

'I actually give myself permission now not to visit patients if I'm feeling everything is a little bit too much for me. Because we do not have clerical support either, so everything that pertains to all our patients we have to go back and do. So the paperwork can be quite extensive. Keeping up with the notes is quite extensive. We have far more patients than you know is recognised as being healthy, but that's countrywide, but Im better now at saying I will phone X, Y and Z. they don't really need me to visit, everybodys okay. And I will sit in the office and I will do this…. Sometimes it works very well, Sometimes it doesn't work and you find yourself still

thinking - Oh Ill have to go and see so and so today.... But Im getting better at recognising that theres only a certain level I can get to and I don't, I try not to go beyond that.' Interview 24

'I don't go to evening meetings, I can't be doing with that and I can't do work out of work and I cope quite well, I really do yeah. Because I used to work ridiculous hours when things were really short and it was busy and then I am working 8 'til 4 but sometimes it's more but then I'll finish earlier another day then and if I can't do it today it will wait. And that's really a fantastic coping strategy.' Interview 30

'I think within palliative care I think you are privileged in that you are allowed to care for yourselves, your colleagues and I think in other aspects of nursing and medicine you are not. You are very task orientated such as surgical and medical environments and, this is from past experience you are just told to get on with the patient care regardless of how much it is costing you but within palliative care because so much of the focus is on psychological support of patients' need you can only do that if you are mentally okay and to do that you need to be able to take. So we are given permission, we are very lucky, we are given permission to talk whether we are having a bad day or whether we have a difficult patient.' Interview 9

'I think you also have to know when you need time out and you need to have regular holidays and if you've got a particularly difficult patient you know that it may be that you've dealt with that patient for perhaps a lot of the afternoon, you don't then go and see an outpatient afterwards. One because the other patient afterwards probably won't get your full attention and also it for your well being as well. It wouldn't be safe for you. I think then you need to, before you need to go home you do something else and that's when we may plan an education session or you know you may catch up with some paperwork or do some e-mails or you know.' Interview 31

Clearly, this was linked to having a good working environment and autonomy over their work. The ability to change activities and give themselves a break from patients was important and again seemed to have been developed with experience and maturity. Obviously, recognising signs of stress was also crucial for taking steps to manage it.

Recognising signs of stress.

The palliative care nurse specialists were able to recognise when they were becoming stressed and tried to act on this as part of looking after themselves. Unfortunately this knowledge had often developed at considerable personal cost following previous stress, illness or burnout.

'If I find myself thinking too much about that I do sort of say to myself – I think you need a holiday, or I think you need some time out. I'm not sure whether I get it right all of the time but I try to be and I try to sort of recognise the early warning signs before I've got into the that pit which is much more difficult to pull yourself out of. I mean I think I had that there, I think I was fairly good at doing that even when I was doing my, I think I was fairly good at it but I've got better at it. And I think that I've got better at it partly, I have to be honest, because perhaps this job isn't quite so busy and demanding as some of the others I've done.' Interview 28

'I think it was because I was tired all the time. Because you were on-call they were ringing you at home you see and if were on-call the weekend you couldn't go anywhere you had to stay in the house because I didn't have mobile phone reception where I lived at the time because mobile phone coverage wasn't so good at the time so I had it put through to my home phone when I was on-call. So I was fairly tired and I think the family thought every time the phone rang you had to answer. You felt like you were constantly on duty really.' Interview 10

'I start to feel very tired and I feel myself withdrawn. I mean when I first went into palliative care you, you think you've changed the world and death and reality slips in and you realise. Whose agenda is this? Patients or mine. But it (serious depression) *did me a big favour.' Interview 26*

They were aware of recognising signs that they were becoming stressed and doing something to reduce the feelings of pressure.

'And I think in any job like this always, things can slide sometimes and you find that you're staying at work later and later and then you think Mm hang on a minute, this isn't right. Take my time owing and go at 5 o'clock for an hour, so you've got good intentions to keep your balance and I think it 's actually just think it's actually realising that things have slid rather than being in a permanent landslide. Things do slide sometimes and you just think Gosh I'm knackered, or, I'm stressed. I've got this

thing you know, the warning bells are ringing and I've got to go on holidays. So I know what my, triggers are for when I am actually getting stressed from work; if that impacting on me out of work and I act on them. My triggers are I'm waking at 4 o'clock in the morning worrying about work that's the main one. If I start to think about work at home and worry about work at home, I know that that needs to be acted on. Because I'm fairly good at separating out the two. .... If my sleep patterns are disturbed or if I'm finding I'm thinking about problems at work at home I need to actually take action and I do and I take action and it becomes resolved. It's usually have a holiday or address the problems that are going on at work or change something in my personal life that can help me to tackle stress like you know get out a bit more shall we say. I must go out a bit more. Increase up your time with friends; increase your time doing things, which actually immerse you in life outside of work so that you don't have time to think about it really. So it's actually trying to actually not just putting it to the back of your mind but trying to proactively do something about it, do something about it at work whether it be clinical supervision, talking about things, making sure you leave work on time. I don't take work home with me but I think doing things like an MSc Stuff like that which I've done at home and that puts me in a high risk situation so I'm actually doing work at home but outside of work it doesn't give me the emotional, it doesn't give me the head space away from work as much as I would like.' Interview 2

'I know when I'm getting stressed with certain patients or I'm not dealing with things as well and usually it's that that manifests itself in that I get very quiet and start muttering and pottering around the office and getting annoyed with things easily and I know then, right I need to sit down and stop and think about it. So a lot of it is knowing how stress affects you ' Interview 9

Self-awareness was obviously a big part of being able to recognise the signs of stress and the palliative care nurse specialists understood this.

Personality and self-awareness.

Certain personalities are more susceptible to stress and compassion fatigue, especially people who are overly conscientious, perfectionist and self-giving (Kiedel, 2002). Unrealistic expectations, low self esteem, being over committed, authoritarian and needing to control others are associated with a propensity to burn out (Maslach, 1982). Hardiness, which consists of the characteristics of control, commitment and challenge, has been associated with decreased burn out in oncology nurses (Robbins, 1991; Papadatou et al, 1994). Gambles (2003) in a study of personality characteristics, found that palliative care nurse were more likely to be extrovert, empathic, open, trusting and group orientated and that these were factors that were helpful for the role. However, they also tend slightly towards being anxious and guilt prone. The palliative care nurse specialists were aware of how personality played a part in managing the role.

'I think, I think I'm quite laid back and I do take a lot of things in my stride. Although I am, I do like things I suppose I'm not a perfectionist but I do like things you know quite right and I think I get more frustrated with medical teams being with slow at writing things up than the stress of the job itself.' Interview 7

'Things that you've learnt but also I think a lot of it is personality as well and I think and home life I suppose and you know, personality is down to it if you are a worrier. Whatever job you'd be in you'd probably take things home with you anyway. Home life I suppose it depends doesn't it if your home life is quieter then perhaps you have that time when you're at home when you can think about things. I don't know but if you go home to an environment where your attention is needed there but then people who have perhaps got a quiet home life may go the gym or go to you know and go to things like that.' Interview31

The development of self awareness was thought to be a factor in managing stress, as apart from being able to recognise how they were responding to situations, they could also determine when they were starting to be overwhelmed and take action to reduce their stress.

'But I think looking back in the beginning it used to affect me quite a bit more. Not that you would have noticed I wouldn't have thought that in me in a working situation because again I would have been this professional you know I can cope, come on lets do this, always looking on the positive side but I think when I went home or when I stopped for holidays, annual leave I would very often hit the you know go down with you know an illness or 'flu or you know like you do when you relax it all comes on. And that I can say is less than it was. Even the stress is different now in this job and it is more stressful in effect but.' Interview 13

'Its developed with me over time and you come to a realisation that the more you get put in situations where something is out of your control, the more you need to think about the strategies of how you cope with them. And I think, there's certain ways of reflecting that can help you with that, and, I've got my favourite tools of reflection and stuff like that..... I think with experience if you're able to anticipate variables and anticipate how things are going to affect you, you can better deal with things.' Interview 2

Other factors that affected coping were having faith or a philosophical view of their part in the patients' suffering and lives.

Faith.

A personal philosophy of illness death and one's purpose in life is essential for many care givers and may involve a spiritual or religious belief (Vachon, 1987; 2004; DeAraujo et al, 2004). Some of the palliative care nurse specialists found that their faith gave structure, meaning and a life philosophy that allowed a greater acceptance of the suffering encountered in their role. A sense of religion or spirituality may help to put experiences into perspective and lead to acceptance that it is all part of a bigger plan (Papadatou, 2000) and has been associated with lower death anxiety in the general population (Neimeyer et al, 2004).

'I have a faith. Possibly that helps me in looking at how these patients suffer. However distressing, however difficult it is, I have, I still have this ideal perhaps, I don't know that there is a reason for it. We may never found out what that reason is and I don't think I could do this job if I didn't believe that death is not the end and whatever there is there is something after that. Otherwise, I think I would find this job personally very difficult to manage.' Interview 7

'And of course my faith helps tremendously....My faith is undoubtedly the thing. Oh it helps me in a million ways really looking back. Because I mean initially when I started in palliative care I didn't have that faith. I mean I had a faith but not you know in the know if you like, as I am now. It's a different matter now but it's helped me, well it just gives you so much strength. I suppose the reassurance for me is that help, I mean I'm in God's hands and if, you know, I'm safe so It's okay. You know, I'll deal with whatever if it came along you know and I have that faith and that strength to be able to do that. And the people around me would be able to ... So I

suppose that's a great comfort you know on a personal level and I think well I'll do the very best that I can for everybody else while I can do it you know.' Interview 13

Faith was the underpinning philosophy for some and for others it was seeing working with patients who are suffering as a privilege.

'I suppose a bit of the job that is good if you like that you can take home is you think 'well God life is for living' and make the most of every day. Yes, perhaps you haven't got money to do whatever but okay well, not get into loads of debt or anything but live the moment if you like because you never know what's round the corner. I think that's the key thing really. That's the nice bit to take away from the job.' Interview 20

Privilege/ job satisfaction.

Blegon (1993), in a meta analysis, found job satisfaction to be most strongly associated, negatively, with stress. Cancer nurses value relationships with patients as important for job satisfaction and nurses feel that they learnt to value life from their involvement with patients (Saunders and Valente, 1994; Cohen, 1995). The satisfaction derived from the job made the difficulties of the role worthwhile for the palliative care nurse specialists.

'I just think that in this job you're kind of in a very privileged position I think. Its a bit like birth you know, it's very private and it's very close and often when people are dying, often other family members are excluded, that your very much taken in and made part of it and that is obviously quite a privilege when that happens. And I think we often see sides to patients that sometimes not even their partners, spouses or whatever see, and that doesn't always become, you're not always aware of that.' Interview 29

The feeling of the job being a privilege was mentioned at some point during almost all of the interviews, so is evidently fundamental in the palliative care nurse specialist's feelings of job satisfaction. It links with being able to alleviate suffering, with the nurse-patient relationships developed and was obviously a source of motivation.

10:12 Discussion: The personal impact of working with patients who are suffering.

The palliative care nurse specialists found the role difficult and rewarding and often the same factors featured in both aspects. It would seem that factors that provide job satisfaction can also cause stress, particularly if other parts of life are not supportive. The palliative care nurse specialists had learnt how to cope with the role, although this point had often been reached through problems they had encountered and learning through experience.

Suffering is composite and mulitfactorial and therefore could be anything. The uniqueness and subjectivity of the suffering experience means that each patient must be individually assessed and managed. A clear understanding that suffering was unique and subjective according to the patient's interpretation seemed to be a crucial element in how the palliative care nurse specialists worked with patients and managed the difficulties presented by the role. However, it was hard to not intervene, despite realising that the patient must come to the realisation of their suffering themselves. Taylor et al (1997), described making a difference as a major goal of palliative care nurses. The ability to reduce suffering was a crucial factor in enabling the palliative care nurse specialists to cope with the difficulties of the role. In this way, it would seem they found meaning and job satisfaction.

Control of suffering, expected by patients or family, or indeed the palliative care nurse specialists, is not always possible to achieve and may also disempower sufferers. If suffering is unique and subjective, it is also only within the control of the patient to determine its effect. Others may provide the conditions for the person to come to terms with their suffering but they cannot necessarily alleviate it. The experience must be lived through until death; not all pain can be alleviated and not all people will come to a stage of acceptance of their fate. It is not always possible to either relieve symptoms or to help the person find meaning in their suffering. Some symptoms are resistant to interventions. Many patients never reach acceptance that they are losing aspects of their personhood or life. They *'do not go gentle into that dark night'* (Thomas, 1971), causing distress to those witnessing their distress. This can be difficult, as they may have to witness unnecessary suffering. Witnessing suffering is highly stressful. Morse and Mitchum (1997) explored 'compathy' when physical reaction is experienced in response to witnessing similar or related distress. They argue that this reaction may either motivate the caregiver to give care or overwhelm them, and that caregivers must learn to selectively block their own response in order to give care. White (2004), found that unrelieved suffering was a source of stress in experienced palliative care nurses. Witnessing suffering was problematic for the palliative care nurse specialists especially if it was suffering that they were unable to relieve or thought was unnecessary. This was especially true early in their careers when it would be a motivator to work long hours, cover extra shifts and get overinvolved with the patients. Recognising that this is unrealistic and learning how to distance and share care with other members of the team was part of managing the role. Over time they learnt that they were not the only member of the team caring for the patient and developed more realistic expectations of themselves.

The palliative care nurse specialists had learnt through experience that suffering was the patient's experience and reaction to events, and that they could only do so much to help. They had developed a personal philosophy that allowed them to see suffering as belonging to the patient, and realistic expectations of their role as trying to help, but accepting that this may not always be possible. They must do what they can to relieve symptoms and then be ready to help with other problems that may come to light. They had developed ways of coping with the difficulties of witnessing suffering and having to wait until the patient was ready to share their distress. They had also had to learn to accept that although their desire and role may be to relieve suffering, this is not always possible. In effect, having realistic expectations of the job and accepting the realities of the job were key factors in coping and required an in depth understanding of patient suffering.

One difficulty with working with patients who are suffering was the feeling of responsibility that went with a long or very intense nurse-patient relationship. Personal involvement with the patient heightened their sense of responsibility and helplessness. The palliative care nurse specialist may feel that they should always be able to offer some relief for the suffering experienced by the patient or their family. Consequently they had developed techniques of maintaining distance from personal involvement with patients, as unrelieved suffering was painful to watch. These difficulties were often coped with by developing knowledge and skills so that the situation did not arise again in the future. In this way they were gaining control, thus mirroring what they were trying to help sufferers to do. Another way of coping was through having a faith or philosophy of life, which accepts that there is a grand scheme to everything, regardless of how awful things may seem at the time. Death is inevitable and awareness of this can lead to compassion and caring. Thus, they accepted that suffering is unique and subjective and do what they can for the patient, whilst accepting that it is not always possible to achieve all they would wish.

The palliative care nurse specialists were clear that being able to identify with the patient or the patient being young made suffering more personally difficult for them. They recognised that this was because of their own identification with the events befalling the patient. However, they did not explore further the effect of this on their ability to manage suffering for the patient in an individualised way. Overidentification with patients by the palliative care nurse specialists may lead them to expect suffering where there may not be any. The palliative care nurse specialists may expect the patient to suffer through events happening to them that would cause suffering to the palliative care nurse specialist if it was happening to them, that is with sympathy rather than empathy. They may react to events happening to the patient as they would themselves react if they were happening to them. Hartman (1995), stated that overinvolvement is a problem of countertransference where the nurse's response to the patient is unconscious and as a result of overindentification or the need to resolve personal issues such as grief. Self awareness is crucial for the identification of countertransference which may impede care or result in the nurse taking on feelings that rightly belong to the patient (Morse, 1995; O'Kelly, 1998; Peplau, 1952). Their ability to grasp the situation in an expert way (Benner, 1984) was imperative, but so was their self-awareness about their own influence on assessment and care.

The palliative care nurse specialists had less difficulty if the person was older and had lived their lives, suggesting that their objective and inferred assessment also affected their coping with working with patients who are suffering. Their values and beliefs may influence their assessment of suffering, with assumptions made about what experiences mean to individuals depending on their longevity. This is complicated and may be based on complex values such as right to life and deservedness, which were not explored in this study but may be important for future research.

Conclusion to Part Three: Study Findings.

The personal impact of working with patients who are suffering was clear from the data and the palliative nurse specialists had learnt from experience of life and their role how to cope with the difficulties presented. Suffering was central to their work, as was developing the nurse-patient relationship to facilitate the management of suffering. The palliative care nurse specialists demonstrated a deep understanding of the concept of suffering and there were clear links to how this impacted on their management of patients who are suffering through the nurse-patient relationship, and how they managed their own response. These will be discussed further in Part Four, the discussion.

Part Four: Discussion.

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Chapter Twelve: Conclusion.

Part Four: Discussion.

Introduction.

The study explored palliative care nurse specialists' understanding of suffering, the development of nurse-patient relationships to support the management of suffering and the personal impact of working with patients who are suffering. It was hoped that it would provide some insight into the lived experience of palliative care nurse specialists. Of further interest was whether there were connections between palliative care nurse specialists' understanding of suffering and the development of the nurse-patient relationship to support patients who are suffering, and the personal impact of working with patients who are suffering.

Descriptive research involves observation of a phenomenon in its natural setting with the aim of exploring characteristics and commonalities. The interview data provided rich information. Themes were identified with shared characteristics, and relationships between these observed. The study findings outlined in Part Three highlight some salient issues, and offer some initial thoughts relating to their relevance, comparison with the existing literature and possible connections.

Chapter Eleven is a more in-depth exploration and hermeneutic reflection. It has been split into three main sections of suffering, the nurse-patient relationship and the personal impact of working with patients who are suffering. For ease of reading, these are further divided into subsections dealing with particular ideas. All the sections and ideas overlap and interweave. The personal impact of working with patients who are suffering was present throughout the data, and had clearly influenced the palliative care nurse specialists' professional and personal development. It had shaped their view of their role and their personal lives. Consequently, these factors are discussed as their relevance to other concepts arises within each of the sections. Consideration of the findings has been made against the existing literature throughout this thesis and this process will continue.

Chapter Twelve offers some concluding thoughts, an evaluation of the methodology and the implications for practice and future research that arise from the study are discussed.

Chapter Eleven: Discussion.

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Chapter Eleven: Discussion.

Contribution to knowledge.

Arguably the value of any research is how it fits with, and expands on, previous work. The study offers deeper understanding and confirmation of some existing knowledge in the areas explored and also highlights some new contributions to knowledge.

Deepening knowledge in application to practice.

An important finding in this study is the difficulty in articulating the concept of suffering. Understanding what suffering means to the patient is crucial if care that helps them transcend their difficulties is to be achieved. More importantly, although it is hard to describe the concept of suffering it is also possible to do so, and understanding suffering can be used to inform practice. The palliative care nurse specialists had learnt about suffering through caring for those who are suffering and had much to offer in confirmation of previous writing on suffering and how it might be managed (Cassell, 2004; Rodgers and Cowles, 1997). The study reflects what is already known (Cassell, 2004; Rodgers and Cowles, 1997; Van Hooft, 1998; Morse, 2001; Kahn and Steeves, 1986) reinforcing that knowledge whilst enhancing the complexity of suffering. The importance of loss in suffering is clear and the difficulties in inferring suffering in another person are also shown.

The previous chapters of analysis and interpretation discuss the findings in relation to existing studies and writing. They are presented as parts of the whole and some specific discussion points have been raised. The study offers some greater insight as to how suffering and the nurse-patient relationship is managed in palliative care and the impact of this on the nurses involved. It is acknowledged throughout the literature that the nurse-patient relationship is crucial for the relief of suffering and that individualised care is a key component (Morse, 1991; Benner and Wrubel, 1989; Georges et al, 2002). The palliative care nurse specialists' understanding of suffering was central to their care management and the development of the nurse-patient relationship. It lead to a person centred model of care (Rogers, 1951), which enables the patient's experience of suffering and their coping needs to be identified and care planned in a highly individual way. The palliative care nurse specialists showed awareness and described application of empathy and sympathy in working with patients who are suffering. Their understanding of the importance of person centred care links clearly to Morse's (2001) praxis of suffering and the caring response needed. They had developed a way of working, which incorporated theoretical ideas about suffering and person centred care despite a lack of specific education in these concepts. This suggests that theoretical descriptions apply in practice.

Considering suffering and the nurse-patient relationship separately provides knowledge that is interesting and confirmatory but not new. It does not provide any fresh insights, notwithstanding that deepening knowledge is, of course, of benefit. The similarities in the findings of this study with existing knowledge is relevant for confirming what is important in the area and raising the importance of the issues and therefore of value to palliative care nursing. However, significantly in this study, the findings show that these separate parts are linked, and combine to make a whole experience for both palliative care nurse specialist and patient. The parts are important in themselves but more importantly they interweave and influence palliative care nurse specialists' management of suffering and how they respond to working with patients who are suffering.

New knowledge

The importance of 'being there' and individualised care is discussed in the literature relating to the nurse-patient relationship in palliative care (de Araujo and da Silva, 2004; Mok and Chui, 2004; Georges et al, 2002). However, links between understanding the concept of suffering and how this informs the nurse-patient relationship has not been previously explored. Likewise many factors have been shown to cause stress and aid coping in palliative care (Vachon, 1998; Payne, 2001; Maeve, 1998) but links between understanding suffering, management of the nurse-patient relationship and the personal impact of working with patients who are suffering have not been determined. The ways in which palliative care nurses develop, gain understanding of suffering and learn how to manage patients who are suffering and their own response to their work is described in this study. The information gained goes some way to explaining how knowledge of suffering underpins the way in which palliative care nurse specialists' management of suffering informs the nurse-patient relationship and influences their own response to working with patients who are suffering. This study makes connections between understanding the concept of suffering and how this influences coping with the role explicit and gives insight as to the influence of understanding suffering and why the parts are important to the whole. Experience and reflection are shown to be key elements involved in how the palliative care nurse specialists learnt how to manage the suffering of both themselves and their patients.

11:1 Summary of learning about suffering and how this influences care, and the personal impact of working with patients who are suffering described in this study.

The palliative care nurse specialists had gained experience and undergone a formative journey to achieve understanding of suffering that then influenced their care and personal response. They entered the role with knowledge of symptom control and patient care. Their contact with patients lead them to an understanding that suffering is often as a result of the meaning attached to the events befalling the patient, as well as the disease and associated symptoms. Gradually they came to understand that the suffering of those who are dying is often existential, as well as resulting from disease or symptoms. They learnt that they must work with individual interpretations of what events mean to the person if they are to help them transcend their difficulties and gain control of their lives. Consequently, they must develop a nurse-patient relationship that allows the identification of the person's suffering and enables them to help the person transcend their difficulties.

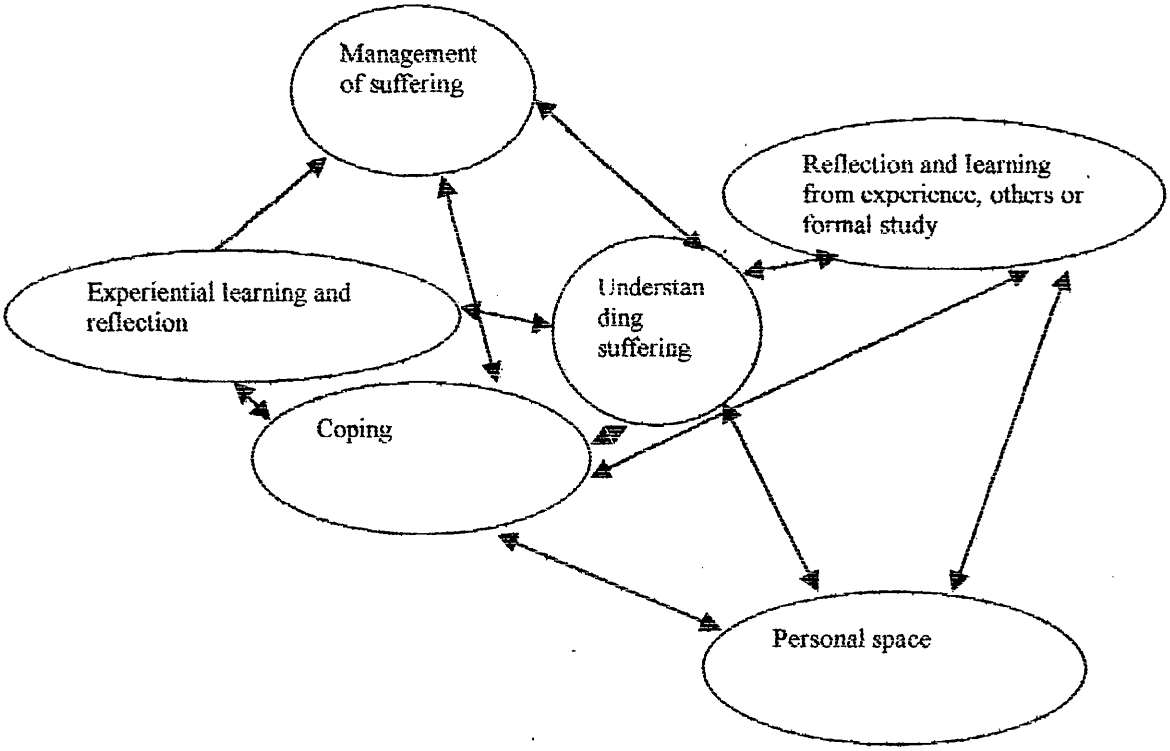
However, suffering is not easily shared and often the patient is unable, or unwilling, to talk about what is happening, so the palliative care nurse specialist must also be an expert in identifying patient suffering from behavioural cues. This is no mean task, especially as there is little work in this area to inform their knowledge (Morse, 2003). Unfortunately, and certainly in the case of the palliative care nurse specialists in this study, suffering and the behavioural response to suffering is not taught as part of preparation for working in palliative care. It is a complex area of nursing care that has not been well researched (Morse, 2003; 2006;Lesho, 2003; Cassell, 2004). They must understand factors that may lead to suffering, so that they may judge what care will be most beneficial. However, the emphasis for education is more likely to be in symptom control and general nursing concepts and often there is little education in end-of-life care for nurses (White et al, 2001), most nurses learn through experience on the job (Levy, 2001). Consequently, the palliative care nurse specialists learnt through working with patients who are suffering, often at considerable personal cost. They learn about suffering and the behavioural responses to suffering, from experience and reflection on, and in, practice. Their experiences expressed knowledge of existing research and theory but they were unaware of this knowledge. They had developed their knowledge and skills through practice.

The journey to being able to managing suffering and their own response to working with patients who are suffering often involved getting overinvolved with patients, especially when they felt responsible for alleviating suffering, even when this was an impossible task. Over time developing understanding of suffering, patient centred care and, crucially, themselves, enabled them to undertake the role with care and compassion but controlled personal involvement. Understanding suffering was central. The palliative care nurse specialists' understanding of suffering influenced their care, in particular the nurse-patient relationship, and enabled them to work with more than just symptom control and give attention to the existential suffering of their patients. Witnessing suffering was difficult and stressful, and only with time and insight into suffering did they learn to manage their involvement with patients and develop realistic expectations of their role in the relief of existential suffering. This knowledge in turn resulted in them being able to manage their own response to patients who are suffering and to look after themselves. The development of positive psychological states (Folkman, 2000) facilitated this stress management.

Self-awareness and the ability to reflect are required and are crucial for patient care, especially in relation to the cause of suffering in another. Inference of suffering is complicated and the palliative care nurse specialists recognised that they need to be cognisant of their own emotional reactions and influences on patient assessment. They had learnt about their own response to particular patients and situations and how this affected their care and ability to cope with, and manage, the role. The development of self awareness of their own contribution, personal limitations and coming to a personal philosophy of the role of suffering in life allowed them to transcend their own difficulties and continue to undertake the role.

Critically, learning about suffering, how to manage patients who are suffering and their personal response to the work was experiential with only personal reflection, which may in turn lead them to other sources of learning, informing their views and development. Eventually, they developed ways of coping with the ongoing stress of working with patients who are suffering. These involve solving problems where they can, but also reappraising the stressful events encountered in working with patients who are suffering and learning to use positive psychological states. Reflection on different patient situations and continued exposure to suffering that lead them to learning from experience seemed to be key. Ultimately, their understanding of suffering informed their care but also helped them cope with the difficulties encountered in the role. En route there were stopping places where more knowledge or experience was gained, and diversions where they sometimes needed space from ongoing exposure to suffering in order to think or reflect further. However, what was clear was that ultimately it was a combination of exposure to suffering leading to understanding the patient's behavioural responses to suffering and being able to relieve suffering, and the development of positive psychological states that enabled coping within the role. This process is illustrated in Figure x.

Figure x: Developing understanding of suffering and its centrality to patient and personal management.



What this study demonstrates is how suffering, the management of the nurse-patient relationship and the personal impact of working with patients who are suffering interweave and the importance of experiential learning and reflection. The 'why' of the importance of the parts that make up the whole.

The palliative care nurse specialists' descriptions of the concept of suffering confirm existing theory and also demonstrate the difficulties in describing suffering. Arguably a greater understanding of the phenomenon of suffering has been achieved through their lived experience of working with patients who are suffering. It was clear that these palliative care nurse specialists had learnt about suffering, managing patients who are suffering, and the personal impact of working with patients who are suffering through experience. They had developed an in depth understanding of suffering and this influenced the way they managed patients who are suffering. Further, their understanding of suffering helped them cope with working with patients who are suffering. Whilst not wishing to lay too much emphasis on what has been found in a small, contextual qualitative study and noting that more work is needed to confirm whether these experiences are the same for other palliative care nurse specialists. This work nevertheless assists in understanding why aspects of suffering, management of the nurse patient relationship and stress management found in previous work are important and how they connect. It would seem that no one part of this complex picture has the complete answer, all parts link to make a whole. This study shows this and, thus, has an important contribution to make to the existing knowledge base.

The study aimed to develop greater insight into how understanding of suffering influenced the management of patients who are suffering and the personal impact for palliative care nurse specialists working in this area of care. This has been demonstrated through replication of previous findings and consideration of how these combine to form a whole. The discussion below explores this in more depth. It also offers insights into the study findings and comparisons with existing theory and literature and the implications for nursing practice. The implications for practice will be considered throughout Chapter Eleven and in Chapter Twelve with ideas for future research.

11:2 The elusiveness of descriptions of suffering.

Suffering was central to the palliative care nurse specialists' work with patients and they had invested a great deal of themselves in the relief of suffering. This is unsurprising, since throughout the literature the connections between palliative care and the relief of suffering are paramount (Frankl, 1963: Cassell, 1991;

2004, Morse, 2001; Radiewicz, 2001; Kriedler, 1984; World Health Organisation, 2007).

An initial assumption was made by the researcher that palliative care nurse specialists, having worked with patients who are suffering, would be able to describe suffering and would develop a nurse-patient relationship to facilitate identification and alleviation. This is explained in the researcher's fore structure. It became clear that the palliative care nurse specialists found suffering very difficult to describe and had realised since agreeing to take part in the study that they had never given suffering, as an abstract concept, much consideration. The palliative care nurse specialists were aware of the need to understand suffering and to understand the patient's perception of it. The palliative care nurse specialists in this study had problems defining suffering and their descriptions laid emphasis on the nurse-patient relationship, interpersonal skills, existential presencing or being there, individualised care and empathy. In addition, involvement with the patient was important and, throughout their descriptions, suffering was a unique and subjective experience with loss as a core feature. They recognised the need to understand the causes of suffering, especially physical aspects, so that they could take steps to provide relief, but also accepted that they often worked without knowing the cause of patients' suffering and they were confident in their ability to provide relief.

The palliative care nurse specialists articulated their problems in identifying suffering as an abstract concept, but despite this, reckoned they could recognise it, and knew it, when they saw it. Wittgenstein (1999) discussed the meanings of words and maintains that people will intuitively recognise instances of the same concept despite there being no features common to all the instances. He uses the analogy of family resemblances, pointing out that families have shared characteristics but these are not the same for each family member. Nevertheless it is clear to an outsider that they are members of the same family. This process of recognition may not be conscious but is made through observing enough shared features to realise the overall family resemblance. The palliative care nurse specialists seemed to use a similar process in the recognition of suffering. They had a number of different ways to articulate it, which have been explored in Chapter Eight. Two factors that were present throughout their descriptions were that suffering is a unique and subjective experience that had loss as a central feature. The process of reaching this understanding was through their lived experience of working with patients who are suffering and provides some interesting insights. They had learnt about suffering from practice rather than theoretical ideas.

11:3 The need for understanding suffering.

Commonalities of descriptions of the basis of suffering may be needed for communication and education and training. Clinical reasoning is based on acquiring cues, generating a hypothesis, interpreting cues against that hypothesis and evaluating the hypothesis (Elstein and Bordage, 1988). Understanding the causes of suffering enables the nurse to quickly assess the person and develop, or dismiss, presenting features as being important or not and the nurse can take steps to provide relief, particularly in terms of symptom control. Lack of knowledge of the causes and manifestation of suffering could reduce the chances of both identifying suffering and providing relief.

Understanding, and being alert to, suffering were clearly part of the skills and knowledge needed to work with patients who are suffering. Knowledge about the causes of suffering was demonstrated by the palliative care nurse specialists, especially the need to control difficult physical and psychological problems, and this knowledge informed their practice. It was clear that suffering caused by physical symptoms must be understood to provide symptom relief, and without this knowledge suffering would continue. Symptomatic relief, in its own right, was an important aspect of the palliative care nurse specialists' role to relieve patients' distress. Additionally, relief of physical symptoms enabled identification of other suffering and removed causes of distress, such as loss of bodily function, and gave the person greater personal control over life. They were often confident that they could relieve physical symptoms and thus reduce suffering but acknowledged that emotional problems were harder to both identify and alleviate.

Inability to relieve physical and emotional symptoms were a source of difficulty for the palliative care nurse specialists. Many had examples of situations, particularly early in their careers, where they had been unable to help the patient due to lack of knowledge about causes of suffering and ways to alleviate symptoms. They were then forced to witness ongoing and possibly unnecessary suffering. This had resulted in considerable stress for them and was formative in decisions to understand suffering and gain a greater repertoire of suffering relieving skills.

11:4 The role of experience in learning about suffering.

There were aspects of suffering that the palliative care nurse specialists described, such as pain relief or other symptom control, where it was clear that a technical rational approach had been used, with theory informing practice. Schon (1987), describes the technical rational approach as derived from the positivist philosophical view that practitioners are problem solvers selecting the means best suited to particular problems. Theory and technique are derived from systematic, preferably scientific knowledge. Most of the palliative care nurse specialists had undergone education in symptom control, although this knowledge had been augmented by clinical practice experience.

However, although the palliative care nurse specialists had received education in the relief of symptoms they had not been taught, or indeed in most cases even discussed, the significance of this in relation to suffering. A technical rational approach was used by the palliative care nurse specialists for some aspects of their role, such as the relief of symptoms, but for the most part they had learned about suffering through practice. The unique and subjective nature of suffering and its association with loss had been learnt from practice, with the development of paradigm cases and exemplars that were used to inform future care. They had learnt through practice to develop a therapeutic nurse-patient relationship.

This development of knowledge from practice can be considered further. Benner and Tanner (1987) and Carper (1978) have identified other types of knowledge in nursing practice. Carper (1978) discusses four fundamental patterns of knowing in nursing.

- Empirics describes the science of nursing which provides theoretical factual explanations for aspects of nursing care.
- Aesthetics is the art of nursing or the actions taken for care and the overall perception gained by the nurse of the patient's situation. Empathy is an example of this, where the patient's situation is perceived and this understanding communicated.
- Personal knowledge involves being engaged with persons in one's care and is subjective, concrete and existential. It promotes integrity and authenticity in the nurse-patient relationship.

- Ethics focuses on the moral obligation of what ought to be done and doing the right thing (Carper, 1978).

Carper's (1978) ideas give a more complete account of a theoretical basis for the care described by the palliative care nurse specialists, which requires more than just technical knowledge. The palliative care nurse specialists used empirical knowledge to alleviate distressing symptoms. In the nurse-patient relationship, empathy was apparent, as was an overall view on what was happening to the patient. Care was very much based on what the individual person needed or desired and the palliative care nurse specialist's engagement was evident. There was also acceptance that it is enough to know the patient is suffering and that care and presence are needed, without necessarily understanding the reasons why the person is in distress. Their ethical knowledge was evident and often the cause of many of the difficulties encountered in the role, especially if they knew what should be done but were unable to deliver this due to time, poor teamwork or knowledge constraints.

Benner and Tanner (1987) emphasise intuitive knowledge. Agyris and Schon (1978) developed the idea of *'theory in use'* where practitioners share their actions based on the situation and use theories generated by their experience, education, values, beliefs and past strategies. These theories are often implicit in spontaneous behaviour and only apparent on reflection, or when a person has to think deliberately about what to do in relation to a particular problem encountered. Whilst there are some fundamental differences in the emphasis of intuition and the uses of experience, both theories are advocating practice as a basis for learning and understanding care.

The palliative care nurse specialists clearly had a substantial knowledge of suffering developed from practice but they had, by their own admission, not previously given it much thought. Reflecting during the interview process made the implicit explicit, and revealed a wealth of previously unspoken information. They were aware that they had not received education in suffering although they had been taught about symptom control. However, refined symptom control had also often been learnt experientially, which resulted in many instances, especially early in the palliative care nurse specialist's careers, in unnecessary suffering due to ignorance or not understanding the true nature of the patient's problems. Their theoretical knowledge was based on the causes of suffering rather than suffering itself. They had learnt from practice that the two were different and used a combination of knowledge in the course of caring for their patients.

Benner and Wrubel (1982) describe clinical knowledge as that embedded in the practice of nursing. They discuss the differences between *'knowing that'* (theoretical knowledge) and *'knowing how'* (practical knowledge) as pointed out by the scientific philosophers Polanyi (1962) and Kuhn (1962). Skilled practice may be learnt without knowing the underlying theoretical principles which may not be reducible to objective measurement, known as tacit knowledge (Polanyi, 1962). Polanyi (1962) describes those who do this as connoisseurs where qualitative, critical discriminative judgements are made. Skilled knowledge allows the nurse a perceptual grasp of the situation because of previous experience. It relies on perceptual awareness that distinguishes relevant from irrelevant information and grasps the whole situation rather than a series of tasks. This is accomplished rapidly without deliberate analysis of individual factors, and is developed through experience. Reflection about individual parts of the situation are not necessary to understand it, although may be needed to determine a solution. This level of skill is described by Benner and Wrubel (1982) as expert practice where theory is refined through practice and past experience used as paradigm cases (Benner and Wrubel, 1982). Benner and Wrubel (1989) assert that excellence is embodied in practice and is a moral art, not an applied science. Theory is derived from practice based on the Heideggerian (1962) view that practical engaged activities are more basic than, and prior to, reflective theoretical thinking.

In this study, academic or educational qualifications did not help the palliative care nurse specialists to discuss suffering in any greater depth or offer any more insight, but length of time in the role, and age and maturity definitely did. The longer the palliative care nurse specialists had worked with suffering, the better able they were to describe it and the clearer they were about all aspects of suffering in the patient's life and their own. They were clear that suffering was more than just a collection of symptoms but was based in the meaning of these to the person's life. They were also aware of how their experiences had helped them arrive at these views and how much they had matured over time working with patients who are suffering.

The palliative care nurse specialists recognised that the person was suffering even when there was no obvious cause. They identified causes of suffering that echoed the literature (Copp, 1990; Kupplemaki, 1998; Weisman, 1972; Charmaz, 1983; Van Hooft, 1998) but they had learnt this through experience rather than from theory. Education had been largely about symptom control rather than suffering as a concept. Pain is often synonymous with suffering, but whilst pain may cause suffering, not everyone in pain will suffer. Suffering is different and is closely related to the meaning placed on the experience being undergone by the person (Frankl, 1984; Cassell, 2004; Eriksson, 1992; Georges et al, 2002). Their expressed difficulties in describing suffering, and statements that they had not really considered it as a concept, suggest that education about pain or other physical symptoms is not the same as education about suffering.

11:5 Working with suffering to develop understanding.

Professionals are faced with situations of uncertainty, instability and complexity which are unique and insoluble by the strict application of technical rational approaches. Schon (1983), exploring the nature of professional practice, suggests a model of learning where professionals learn by reflecting within a practicum. Reflection is advocated as a way to develop skills for practice (Schon, 1991) and two types are distinguished: *'reflection in action'* which occurs whilst practising, influencing decisions and care and involves tacit knowledge; and *'reflection on action'* which occurs after the event and contributes to the development of practical skills. Schon (1987) argues that reflection is a more flexible and realistic approach to practice than the technical rational approach.

The palliative care nurse specialists used reflection to develop their understanding of suffering and their knowledge and skills for practice. Their descriptions of suffering were often based on case studies and often these were the preferred vehicle for discussing suffering. Much of their theoretical knowledge had developed from practice. They demonstrated the characteristics of expert practice (Benner, 1984) with an intuitive grasp of the situation which allowed them to dispense with irrelevant diagnosis and hone down on the crux of the problem and use solutions they knew to work. The palliative care nurse specialists recognised that their patients may use physical symptoms to communicate that they were suffering, and often they could see that it was not the physical symptoms but the person's emotional response to these symptoms that was causing distress. Throughout the data the palliative care nurse specialists described formative experiences that enabled them to develop common meanings, assumptions, expectations and sets, paradigm cases and personal knowledge, maxims and unplanned practices that are characteristic of expert practice (Benner, 1984).

The palliative care nurse specialists often found describing suffering easier using case studies or talking about how they would attempt to relieve suffering rather than discussing it as an abstract concept. There may be many reasons for this, but two points are noted below in terms of their importance to *'knowing that'* and *'knowing how'*.

Firstly, nursing care gives a way of describing how suffering manifests and what may be done about it. The agreed language of nursing includes the relief of physical and psychological symptoms that may cause suffering although may not in themselves be suffering. The palliative care nurse specialists may have found case studies describing suffering more accessible than discussing an abstract concept of suffering.

Secondly, talking about suffering via descriptions of actions to alleviate it means the palliative care nurse specialist is doing something rather than helplessly watching. Witnessing suffering is hard. Helping with overcoming suffering may be easier than being helpless in the face of the person's distress and thus easier to think about and articulate. This had further relevance when the palliative care nurse specialists discussed the difficulties inherent in working with patients who are suffering and the strategies employed to reduce the stress generated by their work.

The data collected showed that both technical rational and reflective approaches were used by the palliative care nurse specialists and that, whilst they were practising at expert level and their ideas matched theories of suffering (Morse, 2001; Cassell, 1991; 2004 Eriksson, 1992; Van Hooft, 1998), they were unaware of these theories. A number of approaches to learning were present, but these had developed by accident rather than design.

Unrelieved or unnecessary suffering due to ignorance were often the prompt for further learning as well as stress for the palliative care nurse specialist. Personal survival strategies were also learnt from experience rather than theory, and this process often resulted in considerable pain for the palliative care nurse specialists. Since unrelieved suffering was often a source of education, this method of learning was obviously not good for the patient either. Greater use of theories developed about the manifestation of suffering (Morse, 2001) and causes (Eriksson, 1991; Kahn and Steeves, 1986; Cassell, 2004) may help in the preparation of palliative care nurses. Briefly, it may be helpful if not everything had to be learnt through experience.

11:6 The influence of understanding suffering on the management of patients.

The palliative care nurse specialists felt able to recognise suffering and discussed the manifestations of suffering. They were aware that the person was suffering even if this had not been openly communicated. Moreover, they would have ideas about the causes of the person's distress. The person's response to suffering involves aspects of being unable to communicate, or overwhelming physical problems may interfere with communication (Morse, 2001; Soelle, 1975; Battenfield, 1984). Nevertheless the person may need help. The palliative care nurse specialists often recognised the causes of suffering even when the patient was not expressing them, and that these could manifest as physical symptoms when really existential problems were causing distress. They had learnt that physical problems or the disease process were only part of the suffering experience. They also realised the sufferer could only deal with so much at any given time and that their role was to support the person in developing understanding and readiness to deal with the events befalling them. Morse (2001) discussed two states of suffering and the behavioural responses of the person in each state. In enduring, the person does not express emotion, as the aim is to get through the experience, and to do so, emotions are often blocked and the person is in a state of denial or stoicism. Their suffering may not be obvious to those witnessing. In emotional suffering, emotions are shared and there are obvious manifestations of distress such as weeping. At this time the person feels able to acknowledge and share their suffering and is trying to find a way to integrate the experience into their life. The palliative care nurse specialists demonstrated awareness of the patient's behavioural response to suffering and described enduring (Morse, 2001). They also talked about the difficulties of caring for patients who were terrified or failing to endure (Morse, 2001). They recognised that the person often just needed to get through the experience, and when they were ready they would share their feelings.

The palliative care nurse specialists recognised the importance of accepting the patient's view of suffering and they tried to identify what this view was through the nurse-patient relationship. It is not always possible to develop a nurse-patient relationship that will allow the identification and relief of suffering before the identification and relief of suffering is needed. They realised they must act off what they know about suffering as well as what the patient says is the problem. They recognised that whilst a close nurse-patient relationship was not always possible they were still able to help. This suggests that the nurse-patient relationship, in itself, is helpful for the relief of suffering. Morse (2001) comments that the release of emotional suffering will occur if the person feels safe, and requires energy and support. It may be that supporting the patient when enduring, without knowing the cause of their suffering, paves the way for emotional releasing.

The palliative care nurse specialists knew to respect the patient's need to endure and to be there. This reflects Morse's (2003; 2006) view, that it is important to allow the person to come to terms with what is happening to them in their own time, and not to pre-empt this process by using empathic statements that break through the limited control that the patient has left to them. Sacks and Nelson (2007) in a study using grounded theory to consider what patients found helpful when suffering, found that many sufferers did not share their experience with others, even those with whom they were close. They would share with nurses only when they felt that the nurse was trustworthy and had proved themselves by being there. Being there involved the nurse keeping promises, answering questions, checking on the patient, following up and setting expectations. The palliative care nurse specialists in this study showed considerable insight into the patient's need to have control of their response to what was happening to them and managed the situation by being there and allowing the patient to lead the way in expressing themselves.

The palliative care nurse specialists understood behaviours that indicate suffering, and the nurse-patient relationship in providing support. However, they were not familiar with studies that explain that those who are suffering are often mute and that it takes time to reach the stage of being able to acknowledge what is happening, or has happened, and integrate it into their lives (Morse 2001; Battenfield, 1984; Soelle, 1975; Sacks and Nelson, 2007). The palliative care nurse specialists had, after long practice, come to understand the nuances of behaviour that indicate suffering and that each patient responds to events differently. This implies a person centred approach to care as described by Rogers (1951), which will be explored later.

11:7 A unique and subjective experience.

Much has been written about the unique and subjective nature of suffering (Kahn and Steeves, 1986; Cassell, 1991; 2004; Eriksson, 1992) and the importance of the meaning of events in causing suffering. The palliative care nurse specialists were clear that suffering was unique and subjective and occurred as a result of the meaning placed on problems encountered by the patient. However, the unique and subjective nature of suffering often presented difficulties for them in planning care. As a highly subjective experience, understanding what suffering means to the individual sufferer is imperative. Arguably, without proper assessment of the sufferer's experience, the nurse is unlikely to be able provide comfort or alleviate suffering. The patient must allow the nurse to get close and disclose what their experience means to them so that the nurse can help them transcend their difficulties. The practicalities of this, given the individuality of both nurse and patient, are complex. It may be only fully achievable with some patients.

There is a dilemma that if care is to be patient led, this also means allowing the person to express their suffering in their own time. In this way the unique and subjective nature of suffering is respected and the patient supported. However, much time may be wasted if all assessment of suffering is to be based on the gradual development of a nurse-patient relationship aimed at an entirely individual and custom made care package determined by patients' communicated suffering. Care may be needed regardless of whether the palliative care nurse specialist has a full picture of the causes of the person's distress, and they may have to use their knowledge of the causes of suffering to plan care. The palliative care nurse specialists thought that suffering often may either not be identifiable or not until late in the illness trajectory. This identification seemed unimportant in terms of being able to help the patient. They recognised that the person was suffering, dealt with those aspects of their symptoms amenable to technical intervention, and used the nurse-patient relationship to continue to support the person. Some assumptions about what problems may be arising, given the patient's circumstances, may be helpful. Thus, symptoms can be relieved quickly, improving the patient's status and their ability to communicate.

11:8 The nurse-patient relationship in working with patients who are suffering.

The nurse-patient relationship was the vehicle for patient care throughout the data and was clearly central for relieving suffering. Development of the nurse-patient relationship is known to be a complicated process that places demands on the nurse to have excellent communication skills and to become involved with the patients in their care (Skilbeck and Payne, 2003). Nurse-patient relationships that are productive and supportive for the patient are necessary to manage suffering (Morse, 1991; Benner and Wrubel, 1989; Georges et al, 2002; Jones, 1999). Rogers (1951) believed that the therapeutic relationship is where all healing can take place. He emphasised that the person must be treated with empathy and unconditional positive regard and that care should be person centred. The palliative care nurse specialists described these concepts when talking about their relationships with patients.

An important factor for Rogers (1951) is congruence, where helper emotions match their communicated emotions. In this way the helper is being genuine and the helped feels that the relationship is real. Congruence when faced with overwhelming suffering may be hard to achieve, as to be completely honest about the person's problems may mean acknowledging that they look awful, smell or are never going to be able to do certain things again, which may lead to the patient losing all hope. Often the palliative care nurse specialists had their own views on the person's problems and these may be different to what the patient was expressing. Also, they had knowledge about the likely outcome of the disease and probable physical problems that the patient would encounter as a result of their condition. They were always working with deteriorating patient conditions and the reality of death being imminent. Rogers (1975), recommended not trying to uncover feelings that the person may be unaware of as this may be too threatening. A view echoed by Morse (2006) who argues that if the patient is in a state of enduring, empathic communication should not be used as it may result in emotional suffering that the person is not ready for, and which increases their sense of loss of control. Green (2006), argued that to be congruent with patients facing terminal illness, the nurse must have self-awareness, understanding of the important aspects of the dying trajectory and the importance of loss. This notion of congruence seems similar to Morse's (2006) ideas that the nurse's response to the suffering person should be genuine with expressions of comfort and sympathy rather than learned expressions of concern.

The palliative care nurse specialist has the delicate task of being empathic and genuine whilst maintaining hope and not increasing the persons suffering through too much honesty. The palliative care nurse specialists clearly recognised this and let the patient lead the way, accepting that suffering was whatever the person experienced and trying to help when they could whilst accepting the limitations of their role.

They were only too aware that the person was suffering and that although some aspects, particularly physical symptoms, could be alleviated, existential suffering was much harder to change. The palliative care nurse specialists coped by having a realistic view of their role, enjoying their own lives and having a philosophy that enabled them to put suffering into perspective. They were honest with the patient about what they had to offer and this allowed them to develop trust and be congruent and real in their dealings with the person and their personal reaction to their plight. The palliative care nurse specialists were aware that the nurse-patient relationship was important. They demonstrated caring, empathy and involvement in the nurse-patient relationship and relief of suffering, echoing the literature (Martocchio, 1987; Radiewicz, 2001; Jones, 1999; Ramirez, 1996; Silva 2000).

11:9 Caring.

Roach (1984) argued that whilst caring is a human mode of being, nursing is the professionalisation of that mode. The palliative care nurse specialists clearly understood and demonstrated the importance of caring. Caring was discussed throughout the interviews and caring caused both difficulties and rewards within the role. Being present communicated to the person that they were cared about and this was seen to be important in the relief of suffering. It is the patient who will decide what they wish to share with the carer, and they who will ultimately make sense of their suffering. The palliative care nurse specialists felt that being there was important for helping the person cope with their suffering and they were aware that at times it was all they may be able to offer. Suffering as a unique, subjective experience is not easily shared with another. The palliative care nurse specialists knew that they needed to be patient and gradually build a nurse-patient relationship if they were to fully identify suffering and find ways to help the person transcend their distress. Just being present was viewed as a way to achieve this as it allowed the development of trust. It also gave them time to assess what may be troubling the patient.

Compassionate care is possible by being present and engaging with the sufferer. This needs commitment and also exposes the palliative care nurse specialists to their own vulnerability. A caring relationship sets up trust that enables the patient to ask for, and receive, help and the nurse to notice and react to changes in the patient. Effective care that results in the patient feeling valued needs time to develop trust and communication (Evans and Hallett, 2007). Georges (2002), suggested that a contextual praxis of suffering would need to take a highly individualised approach to each encounter between sufferer and nurse and the nurse would need to create an authentic feeling of presence and being with. The nurse would have to be willing to fully engage with the sufferer and create a nurse-sufferer bond. This would not be without risk to the nurse. Benner and Wrubel (1982), acknowledged that the caring relationship is a source of stress and stated that whilst detachment and distancing strategies allow situations to be put in perspective (Morse et al, 2006) they are not preferred ways to cope as they require people to not care, which is not always possible and not desirable. These differing views on how nurses should cope can cause confusion. The palliative care nurse specialists felt they needed to maintain distance and look after themselves in their relationships with patients but also that they would become more involved with some patients.

The palliative care nurse specialists acknowledged that they established boundaries on their relationships with patients in order to protect themselves. This was a learnt response and they were very aware of the effects of overinvolvement. This requires self-awareness on the part of the nurse and seems necessary for the achievement of a therapeutic encounter. Self awareness develops over time with experience and experienced nurses who have developed self awareness can care intimately without getting over involved (Henderson, 2001; Burnard, 2002; Aranda, 2007). The palliative care nurse specialists' self-awareness allowed them to recognise their personal signs and symptoms of stress and to take action to relieve the pressure. Although they maintained a distance and tempered their involvement with patients they were also aware of the emotions being generated by their clinical encounters and the impact of the work on themselves.

Being there is important in relief of suffering and development of the nurse-patient relationship and causes difficulties as the palliative care nurse specialists witness suffering that they may not be able to alleviate. The palliative care nurse specialists witness suffering which reinforces the imperative to develop supportive nurse-patient relationships that will help the patient. Being there, balancing the relief of suffering and the positive aspects of the nurse-patient relationship with realistic expectations of the job and having a philosophical view enabled them to continue to care. However, this balance is strikingly complicated and had developed with experience and maturity. The ways of coping were mulitfactorial.

The palliative care nurse specialists were clearly motivated by compassion. Whilst there were aspects of being involved with patients who are suffering that caused difficulties, for the most part the palliative care nurse specialists were able to be philosophical that forming relationships with people who were going to die went with the territory. However, unrelieved suffering due to lack of knowledge or skills, time or poor communication were hard to bear.

Jones (1999) applied the concept of containment to the nurse-patient relationship in palliative care. Nurses allow dying patients to assign their anxiety to the nurse, who in turn helps the person tolerate distress. The development of close intimate relationships with patients who then die can be stressful, and often there is no chance to grieve the loss of a patient before the next patient death (Sherman, 2004). Cumulative losses may lead to anger, guilt, irritability, frustration, feelings of helplessness and inadequacy, sleeplessness and depression. The development of a nurse-patient relationship, especially if it was long or intense, meant that the palliative care nurse specialists felt responsible for relieving suffering and, if this was not possible, it caused them considerable distress. It was not always possible for them to develop therapeutic nurse-patient relationships due to personality problems between nurse and patient, lack of time or the patient only wanting a superficial relationship. Patients who are difficult in other ways, such as being extremely angry, frightened or depressed exacerbated the palliative care nurse specialists' feelings of distress. Their compassion towards their patient's plight motivated them to help but also caused them pain and their coping mechanisms were important.

Competence was viewed by the palliative care nurse specialists as important as this was the route to alleviate suffering by using technical knowledge to relieve symptoms. This has been discussed earlier and technical interventions could be used even when the nurse-patient relationship was not fully developed or was difficult. The development of symptom relief was crucial to all aspects of the role. Relief of symptoms that cause suffering is central to palliative care; therefore non-relief is a source of stress, especially if it is due to poor communication between teams or ignorance that causes unnecessary suffering. Development of knowledge and skills to relieve suffering, if at all possible, was very important for coping. It may be achieved by reflecting on difficult situations where suffering was not relieved in order to identify ways in which to avoid repeats, as well as education in symptom control. The way in which the palliative care nurse specialists had gained knowledge had often been uncomfortable. They recognised their own reaction to patients' suffering which could result in feelings of helplessness when faced with patients' distress. There were a number of reasons for this, ranging from projection to feeling demoralised if they are unable to achieve the aims of the job.

Conscience develops from experience, out of valuing self and others and is the *'call of care and manifests itself as care'* (Heidegger, 1962, p 319). Conscience and commitment were present and often caused difficulties as they resulted, especially early in their careers, in the palliative care nurse specialists becoming overinvolved and making themselves available even when they were off duty. They were keen to do the right thing for the patient. Health care staff have a troubled conscience if they fail to achieve the goals of care (Sorlie al, 2004; Norberg et al, 2007). Stress of conscience contributes to emotional exhaustion and may result from lack of time and not being able to live up to the expectations of others as well as taking work home (Norberg, 2007; Maslach et al, 1997). Lack of resources, either organisational or personal, lead to the palliative care nurse specialists trying harder to do the right thing and becoming overinvolved. Suffering that was witnessed as a result of changeable factors such as insufficient time or resources to do the job properly, greater knowledge and skills or better teamwork and communication amongst colleagues was very difficult to bear and often lead to stress and burnout.

Time was a crucial factor. Time to be there facilitated the nurse-patient relationship and the relief of symptoms with interventions that often require close monitoring for effect. Lack of time caused frustration for the palliative care nurse specialists and impeded symptom relief and the development of the nurse-patient relationship. Other aspects of building the nurse-patient relationship, such as partnership and trust, could not be achieved without adequate time, leading the palliative care nurse specialists to being unable to identify and alleviate suffering which caused them distress.

Often, prior to episodes of stress or burn out, they had been struggling to do too much work in too little time, which led to feelings of guilt and they then tried to do more for patients by always being available. A vicious circle was created that meant there was no respite from work, little job satisfaction and no support. There was a great deal of anger amongst the palliative care nurse specialists at lack of organisational support. Much of their support came from their immediate colleagues. The importance of good collegiate communication and having sufficient time to undertake the demands of the role cannot be overstated.

11:10 Empathy.

Empathy assists in understanding another human being and seems to be essential to identify what suffering means to the person, while compassion motivates to alleviate distress (Orlando, 1972; Carver & Hughes, 1990; Reynolds & Scott, 2000). Reynolds (2000), explored the importance of empathy in nursing and concluded that empathy enables the creation of a climate of trust to establish the patient's needs and respond to their health problems (suffering). Empathy enables the nurse to judge the patient's readiness to talk and results in positive health outcomes. It requires a range of human emotions and leads to a more complete commitment by nurses, enabling them to be more perceptive to the needs of their patients (Reynolds, 2000). It is an important motivator to achieve understanding of what the other person is feeling.

Empathy is the ability to enter into the life of another person and perceive their feelings and the meanings attached to them. Whilst empathising, the person may feel the other's pain in order to understand it, but they are always aware of their separateness and that the suffering experience is not theirs. The palliative care nurse specialists recognised this, as discussed in Chapter Ten.

It is also important that the empathiser does more than just understand. They need to communicate that understanding to the patient in a way that they can understand. Egan (1994), discussed being with the person through attending, observing and listening that enables the development of understanding. He suggested that verbal and non-verbal communication skills are used to communicate understanding. Perceptiveness, know how and assertiveness are the communication skills needed to respond to, and engage with, others. The emphasis that the palliative care nurse specialists put on developing the nurse-patient relationship and communication and the ways they achieved this is outlined in Chapter Nine. This clearly demonstrates that they understand, and try to communicate empathy. They spent time getting to know the person, adjusted their communication style to enable understanding and rapport and accepted the patient's view of their experience.

The ability to respond to another may depend on the extent to which one infers another's affective state. Therefore, understanding suffering may inform assessment and how the palliative care nurse specialists may respond to alleviate it. This again presents the difficult problem of inferring suffering and separating personal feelings from what is happening to the patient. The palliative care nurse specialists' difficulties in over identifying with patients and obvious ability to imagine the pain young people were going through suggests a sympathetic reaction rather than an empathic response and also begs the question: why is it easier for them to imagine? Sympathy can be seen as having pity for where a personal emotional response is evoked that is not detached and is about the individual's feelings in response to another's distress. Sympathy is the carer's response to another's plight (Morse, 2006). Sympathy may motivate others to care (Wispe, 1986; Travelbee, 1972) or interfere with their ability to help (Forsyth, 1980). Both sympathy and empathy may motivate one to help another but empathy enables the response to be patient led and is about patients' feelings rather than nurses'. The palliative care nurse specialists had often learnt this over time and had also experienced over involvement and over identification with patients which had resulted in stress and pain to themselves. Self-awareness is important for patient focussed empathy, with reflection to evaluate what the experience means for nurse and patient (Thompson, 2006) and the palliative care nurse specialists had learnt this through experience.

Morse et al (1992; 2006), argued that it is not always possible to have an empathic relationship with the patient and that at times sympathy is more appropriate. Morse (2006), commented that often it is not possible for nurses to relieve suffering and they are forced to witness the patient's endured agony. This does not leave the nurse unaffected and produces empathetic insight, involvement and shared suffering, which, if not controlled, can leave the nurse drained. Morse et al (2006) explored empathy in clinical practice, arguing that learned therapeutic empathy as advocated in counselling, where the aim is to help the person gain insight, is not appropriate when working with patients who are suffering. Emotive engagement or the intuitive sensing and response to another's plight is more apt.

They explored the patient's need for sympathy and pity and promoted their value. Emotional empathy is learned through experience and modelling and nurses know implicitly what to do when a patient is distressed.

The palliative care nurse specialists seemed to demonstrate both responses and arguably at times, especially if the patient is not ready to acknowledge their feelings, sympathy may be the most helpful response. However, whilst this might be true for some situations, the palliative care nurse specialists did not seem to be making a judgement based on the patient's needs, but on their own response. Omdahl and O Donnell (1999), propose that to reduce nursing burnout, education needs to help the nurse effectively communicate, differentiate between empathic concern and emotional contagion and identify when they are experiencing each, and use effective strategies to promote empathic concern and reduce emotional contagion.

The palliative care nurse specialists found that an emotional distance enabled them to continue to care for patients and undertake the demands of the role because they are not themselves feeling what the patient is feeling. They had learnt to recognise that some patients, because of their plight, situational factors or personality, would result in a more emotionally involved nurse-patient relationship, but for the most part the palliative care nurse specialists maintained a distance. They understood the patient's suffering but they did not suffer with them. Although there is closeness in the nurse-patient relationship, there is also a detachment from becoming too involved. They seemed to have learnt, in most situations, to be motivated by empathy rather than sympathy and to recognise that the pain was the patient's not theirs. Acceptance that it is the patient's not the palliative care nurse specialists' suffering helps with overinvolvement and countertransference issues. It allows the palliative care nurse specialists to work empathetically and gain understanding of the problems but remain separate themselves. This was a key to their survival in the role and enabled them to establish boundaries on their care and accept their role in alleviating suffering.

11:11 Reciprocity.

A further aspect of an empathic response, with aspects of maintaining distance and working to the patient's agenda, is that there is no expectation of reciprocity. Therapeutic reciprocity is a mutual exchange of meaningful thoughts, feeling and behaviours, is probabilistic, collaborative, instructive and empowering, and is subjectively and objectively referenced by personal empirical data through the nurse-patient relationship (Marck, 1990). Many have argued that the nurse-patient relationship is reciprocal (Li, 2004, Marck, 1990) with both patient and nurse benefiting from the interactions. Marck (1990) discusses reciprocity as a phenomenon of caring and, having reviewed the literature, suggests a common theme of mutual exchange. Therapeutic reciprocity, where nurse and patient remain open to feelings generated by the meaning of a situation, is central to decision making. Reciprocity involves shared experience, generating therapeutic outcomes in both nurse and patient. The ongoing nurse-patient relationship with exchange of information enables continuous decision-making and changes to treatment in the light of effects and changing circumstances. At the expert level of practice, *'knowing'* the patient's perspective with its attendant grasp of whole situations, may be happening at an intuitive level. The knowledge received and acted on by the palliative care nurse specialists cannot necessarily be broken down to its analytic principles but is more a perception of the whole situation. If there is mutual exchange, and thus therapeutic reciprocity, arguably responsibility for care is shared. The nurse-patient relationship enables the patient to ask for help and the palliative care nurse specialists to give help that is appropriate.

Aranda and Street (1999), argued that the nurse cannot act alone and that any greater understanding of the patient is only possible if the patient can give of themselves to encourage the nurse to seek greater interaction. Their study explored interactions where the nurse acts as a chameleon and adjusts to the environment and wishes of the patient and is in effect a passive respondent, and authenticity where the nurse gives of herself to enhance the nurse-patient relationship. Li (2004) argued that in palliative care *'symbiotic niceness'*, where both the patient and the nurse are nice to each other, enables the relationship to be managed, especially as the disease progresses. Symbiotic niceness helps to maintain social order and progress personal, professional and organisational aspirations. She suggests that by developing niceness as a skill, difficulties can be managed, particularly if the patient or situation is difficult, there is no easy rapport between nurse and patient, or if they do not like each other. Li's (2004) research suggests that whilst palliative care nurse specialists may benefit from the nurse-patient relationship, it is an indirect benefit and one that is not expected.

The palliative care nurse specialists certainly recognised that it was not always possible to like the patients or to develop a close nurse-patient relationship, but that the relief of suffering could nevertheless be achieved. They provided care and accepted that they would have a one sided intimacy with the patients. They recognised that the nurse-patient relationship was asymmetric, with the patients exposing more of themselves than the nurse. They often had strong views about simply being there to do a job, not as the be all and end all in patients' lives. They recognised that they would not like all patients, would not always have more than a superficial nurse-patient relationship, and that recognition of this was important for their coping. They felt that they should not have expectations about being liked and had relationships and lives outside work that satisfied their personal needs for liking and respect.

Hopkinson et al (2005) undertook a phenomenological study of 28 newly qualified nurses to explore how they cope with caring for the dying in hospital. They found that reciprocal relationships and controlling involvement were used. The nurses also revised their ideas on the ideal way to die, and shaped ideas about expected outcomes. They valued being able to relieve suffering and positive feedback. These authors developed a theory of how nurses cope with caring for the dying which they called a translucent web of support. The patterns of thought and behaviour that formed this web of support were directional; motivated by the need to sustain or restore a sense of personal comfort; situational; adapted according to circumstance and personal history; dynamic; changed across time with new experiences; translucent: were only partially in a nurses' awareness or control. Their study suggested that it is not realistic to become involved with every patient and that controlled involvement is important and that help for nurses to learn how to develop this would be useful. The palliative care nurse specialists also demonstrated this web of support with reciprocity gained through being able to help the patient and controlling involvement, and had learnt this through experience.

Reciprocity was present in their work with some nurse-patient relationships but for the most part their job satisfaction came from alleviating the person's suffering, doing the job well and using their skills. Reciprocity in palliative care was viewed as indirect, with the palliative care nurse specialists very aware that they were there to offer a service, but that they were not able to be all things to all people. They were able to work with patients if they didn't like them or the nurse-patient relationship was poor. They accepted that they worked in a team and were aware that they were not the most important people in the patient's lives. However, they achieved job satisfaction through being able to help the patient, relieve suffering and achieve a feeling of doing the job well. In this way it was a reciprocal relationship with both parties giving and receiving.

11:12 Involvement.

The nurse-patient relationship can be very rewarding for the nurse where patients are likely to recover or to achieve a level of adjustment to a chronic condition, but a nurse working in palliative care is likely to be developing relationships with patients who are soon to die. Patients frequently have huge and complex needs and it can be difficult to establish limits on what nurses can realistically offer. Cohen (1995), in a study to explore the meaning of cancer nursing, found that nurses described three main roles: maintaining the goals and values of health care; participating in the patient's experience; and reconciling health care goals and values and the patient's experiences. Aspects that are rewarding, such as doing the job well and becoming involved with the patient, can be difficult. The nurses noted that they suffered with the patients, have emotions evoked by the patients and mourn because they cannot cure all patients.

The palliative care nurse specialists knew they need to balance helping the patient to support and find solutions for themselves, whilst helping them with complicated symptomology that requires specialist knowledge. They need to separate their own needs and feelings from patients and view them as inherently capable. The level of involvement needed to understand patients' suffering may result in emotional pain for them when the patient dies. They were able to acknowledge that some patients, especially if young or if they could identify with them, would lead to more involvement. However, for the most part they kept some distance in the nurse-patient relationship. They recognised that there was only so much they could do within the limitations of the patient's situation and the available resources. They were committed to achieving the best possible outcomes for the patient and their involvement was controlled. Over time the palliative care nurse specialists learnt that in order to continue to care they needed to establish boundaries, maintain distance and ensure that they left work at work.

The nurses' ability to distance themselves from the patient develops over time and is necessary to protect themselves from being emotionally overwhelmed (Rittman et al, 1997; Rasmussen et al 1997; Payne et al, 1998; 2001). Turner (2001), in a grounded theory study of oncology nurses, developed a theory of managing involvement that nurses go through when learning to manage their involvement with patients. She identified becoming involved, experiencing overinvolvement, developing awareness, controlling involvement and being involved as development stages. Overinvolvement may result in excessive need to control and dominate the situation to protect one's own interest. Boundaries between self and others are blurred, and the carer may become an omnipotent rescuer rather than allowing the person to take responsibility and use their own resources. The palliative care nurse specialists had clearly undergone a similar process to arrive at their current position of a managed involvement with their patients. Through experience, either their own or others, they had learnt to manage their involvement.

Whilst they used aspects of their own lives and invested themselves in the nurse-patient relationships, they seemed to do this consciously. They used skills or techniques rather than with the openness that other personal relationships might be approached. They protected themselves and managed their involvement, thus enabling them to continue to undertake the role. This was important to ensure that they could go on forming nurse-patient relationships that always end on the patient's death. As one palliative care nurse specialist put it, you cannot get so close that every time someone dies you are losing a friend. Conscious decisions were made about how involved to get with patients. This ability to maintain some distance had been learnt, and was often achieved at considerable personal cost when the palliative care nurse specialists had been hurt by nurse-patient relationships where they failed to achieve a distance and had became very involved with the patient.

11:13 The personal impact of working with patients who are suffering.

In many ways, the palliative care nurse specialists' lived experience hinged on understanding suffering and being there to develop the nurse-patient relationship and identify and alleviate suffering. They were aware that being there was crucial to achieving relief of suffering. They were aware that they could only achieve their goals by being present in the patient's care and understanding the patient's suffering. They were clear about their role in the relief of suffering and that achieving this resulted in reciprocity and job satisfaction. Conversely, being unable to relieve suffering for whatever reason was a source of stress. They were aware that if they did not care for themselves, the goals of care would be unattainable.

Sharing experiences of working with patients who are suffering with others seems important if the existential loneliness of suffering is to be understood and responded to. The palliative care nurse specialists felt the onus of relief of suffering to be on them, whilst the nurse-patient relationship and a feeling of helping with suffering aided job satisfaction and hence coping. Understanding suffering and the memory of what poor care can do to a person can give a deeper understanding about suffering and what it is like to have to rely on others for support, have no control and, in effect, be vulnerable. The palliative care nurse specialists were aware that their work and life experience had deepened their understanding of suffering. They felt this had further enhanced their ability to understand the patient's experience.

There were many aspects of the role that were difficult and these have been described in Chapter Ten and previously in this discussion. They appreciated that working with patients who are suffering is hard and that they could only achieve the goals of care by being available to the patients and present in their care. However, this meant that they bore witness to some of the most traumatic aspects of existential suffering as the patient approached death.

In working with patients who are suffering and thus experiencing suffering and being aware of its effect is like opening Pandora's box. Once experienced, it cannot be forgotten and will forever be with the individual. If one does not understand suffering and is not involved it cannot be experienced. Understanding suffering and being present in the patient's care and its impact on themselves seemed to be where fears of what the job may be doing to them came from. The palliative care nurse specialists describe their own suffering, mirroring the literature and, as people do when suffering, they looked for meaning and to take control of their situation. However, it is not clear whether they could see the similarities themselves, although they had clearly developed insight as a result of their experience. In trying to take control of their situation and alleviate suffering and thus achieve their reason for undertaking their role, they overworked. Consequently, they lost their personal supports of home relationships, activities and also increasingly lost insight into the problems, as they became more tired. In effect they lost the ability to find meaning, rather than gaining it, and certainly lost control as they worked harder and harder.

The palliative care nurse specialists had learnt about suffering through working with patients who are suffering. Maintaining boundaries on personal involvement with the patient, having realistic expectations of the role in the relief of suffering and developing a personal philosophy of life and suffering were all ways of coping. Aspects of working with patients who are suffering that were hard to bear were approached with reflection and education to increase their skills and try to reduce the likelihood of the situation arising again.

11:14 Coping with the personal impact of working with patients who are suffering.

Coping is a process that develops in the context of a situation that is considered by the individual to be stressful and is initiated as a result of the individual's assessment that important goals have been harmed, lost, or threatened (Lazarus and Folkman, 1984). Problem focussed coping involves addressing the problem, and emotion focussed coping aims at altering one's reaction to the problem. Folkman (1997) modified this theory to include positive psychological states. This involves three pathways:

- Meaning based processes that cope with the stressor itself. These may involve positive reappraisal where people find meaning by interpreting the situation in terms of deeply held values; revising goals and planning goal directed problem focussed coping which fosters meaning in terms of purpose and control; activating spiritual beliefs through which existential meaning is found.
- Coping as a response to distress rather than the conditions that cause distress. This is primarily emotion based but involves ascribing positive meaning to ordinary events thereby providing respite from the negative situation.
- Positive reappraisal helps the person redefine and focus on positive meaning in dealing with a chronic stressful situation.

Meaning has been conceptualised as general life orientation, personal significance, causality, coping activities and outcome (Park and Folkman, 1997), and finding meaning in adverse situations seems to be critical to adjustment and coping. Global meaning includes people's basic goals and beliefs and is developed as a result of life experiences and expectations about life; and situational meaning is the significance of an event in terms of its relevance (Park and Folkman, 1997).

Situational meaning has three major components: appraisal of meaning or the initial assessment of the personal significance of specific stressful events; coping processes that are activated once initial appraisal of the event has occurred; and finally the meaning that the person arrives at after the event, following the first two stages. Positive reappraisal is important, particularly if the situation has unsatisfactory outcomes and coping needs to be ongoing.

Cognitive appraisal describes the process by which the meaning of an event is evaluated in respect to its significance for a person. It is influenced by the person's global beliefs and whether they see potentially stressful events as a challenge or threat. Options about what can be done to change the situation, particularly in relation to coping resources and expectations regarding possible outcomes, are also important. The stressful impact of the situation may be buffered by responses to control the meaning of the problem. A stressful event can be re-evaluated as positive and a reason found for why the event occurred. Understanding changes to the person's life that have occurred as a result of the event and making sense of the event all help in coping with stress (Park and Folkman, 1997). In this way the incongruence between the person's pre-existing beliefs and goals and the appraised meaning of a situation is reduced, thereby achieving cognitive integration (Park and Folkman, 1997).

These reappraisals can decrease the threatening nature of an event and also increase the positive aspects of an event (Park and Folkman, 1997; Folkman and Moskowitz, 2000). Changing the way a situation is seen so that it has inherent meaning in relation to one's life helps in the process of accepting the situation and redefining goals so that they are achievable within available circumstances. This, in turn, gives a sense of control over the events. The process is ongoing throughout the coping process and results in reconciliation of the discrepancies between the person's global meaning and appraised meaning of a particular event. In this way the person develops meaning from the situation and may emerge from the process with new global meaning and understanding and a sense of personal growth.

The palliative care nurse specialists seemed to have learnt to positively reappraise their work with patients who are suffering and place it into a framework that reflected their global meaning. It was clear that many aspects of the role were stressful but they had developed ways to cope with the ongoing stress, which also affected their personal development and lives outside of their work.

The ways of coping described by the palliative care nurse specialists is complicated but reflects Folkman's (1997) work on the value of positive psychological states in situations of chronic stress. The palliative care nurse specialists applied meaning based processes in the form of seeing the job as a privilege, accepting that they were there to help but could only achieve as much as circumstances would allow. Many of the palliative care nurse specialists felt it was a privilege to be involved with people who are dying and that this was a source of strength for them. This is supported by Williams (2001), who found that intimacy in the nurse-patient relationship was a source of satisfaction for nurses. Suffering can open up new understanding about life and those working with suffering can learn from the insights gained from suffering. However, to achieve this, the palliative care nurse specialists must be present actively and share the moment with the sufferer. They must listen to the patient's story and receive the insight that the person shares.

Desbiens and Fillion (2007), in a study of nurses to examine the association between coping strategies and spiritual quality of life, found that positive reinterpretation and turning to religion were important for ensuring well being in nurses working in palliative care. Similarly a philosophy for life seemed to enable the palliative care nurse specialists to be more acceptant of the stress generated by working with patients who are suffering. They had developed a philosophical framework for their life and work with patients who are suffering. This may have been in the form of having religious faith or may have been described as accepting that it was the patient's not their suffering, or suffering being a part of life. Their philosophy gave them a framework for how their work contributed to, and meshed with, their grand scheme of life. They had learned how to cope with the role through painful experience and had found meaning through their personal suffering. A philosophical perceptive is helpful as it is not in the gift of the palliative care nurse specialists to relieve the suffering of all their patients. Reaching these conclusions had been hard work, but their suffering may well have helped them. Understanding others, described by Lindholm and Eriksson (1992) and Graham (2005), is transformational and leads to growth.

Positive affect, where the person derives pleasure from some aspect of the circumstances, seems to be important for the reduction of physiological and psychological effects of chronic stress. Folkman and Moskowitz (2000), in a review of the literature on positive and negative affect in chronic stress, conclude that both can occur during adverse conditions. The palliative care nurse specialists ascribed meaning to events such as being able to relieve suffering and helping the person to be able to undertake activities despite their illness. Pleasure was gained from their collegiate relationships and job satisfaction in general. They had learnt that humour, outside work activities and their families and friends provided respite from working with suffering and dying. Further, they became self-aware and could recognise when they were feeling stressed and needed to take a break. The palliative care nurse specialists were very clear that they had activities and relationships outside work and that they switched off when they got home. These factors seemed to act as a buffer against the effects of their stressful job. At times when they were unable to maintain these activities the results had often been illness or depression.

Experience of working with people who are suffering means that death and dying was often integrated into the palliative care nurse specialists' lives. This can be positive, in that it enables greater understanding about life, and negative because it exposes the palliative care nurse specialists to having to deal with the difficulties associated with suffering. Heidegger (1962), discusses temporality as not being experienced in the abstract but specific and determined by what has happened before and what is anticipated. Benner and Wrubel (1989), maintained that stress and coping are shaped by temporality, arguing that by addressing experienced emotions when caring for patients, it is possible to reinterpret and reconstitute past history. The palliative care nurse specialists demonstrated self-awareness and could easily talk about their feelings relating to the patients in their care. They had developed a variety of approaches to coping with the role. Experience and maturity lead to better descriptions of suffering, better ability to cope with the involvement of the nurse-patient relationship, and a learnt philosophy about the job that enabled them to leave the job at work and look after themselves.

The process of learning to cope with working with those who are dying is developmental and continuous and does not seem to have an end point (Fischer, 1996). The palliative care nurse specialists had developed coping strategies that had been learnt over time and often at considerable personal cost. The palliative care nurse specialists had eventually integrated their work with their general life view and it had changed them. Moreover, they were aware that their experiences had altered their personal development and outlook and this may be why some were acutely aware that continued working with patients who are suffering may result in further changes, and these may be negative rather than positive. There was acceptance that working with suffering and dying is stressful. There was no denial of this and the palliative care nurse specialists were aware that the stresses did not change but their ability to cope had and did, depending on the events encountered.

There are inevitable compromises in palliative care and a realistic view of what may be achieved seems key to being able to continue to undertake the role. The palliative care nurse specialists were aware of the inherent danger in being involved with people who are dying. This seems to reflect Frankl's (1985) ideas that meaning in suffering is discovered through doing a deed (relieving suffering), experiencing or encountering something or someone (working with patients who are suffering) and the attitude taken towards the unavoidable (personal philosophy of suffering, accepting that it is the patient's not the palliative care nurse specialists' suffering, and acceptance of suffering,). This not only gave meaning but acceptance that complete control over what is happening is not possible, and also reduced the source of suffering.

Working with death and dying patients has been shown to change one's attitude towards death and dying, and those who cope have a tendency to live in the present and score highly on self directedness, self actualising value, existentiality, spontaneity, self esteem factors and capacity for intimate contact (Robbins, 1991; Prochnau et al, 2003). Spirituality has been argued to be the vital life force that motivates people (Goldberg, 1998), influencing life, behaviour and relationships and goes beyond organised religion (Matthews, 1997). Spirituality is where meaning in life is found, and spiritual reflection enables the person to understand how relationships and events affect them and what their purpose in life may be and is important for making sense of situations that are felt to be stressful (McSherry and Draper, 1997). Cancer nurses value relationships with patients as important for job satisfaction and nurses feel that they learn to value life from their involvement with patients (Cohen, 1995).

Folkman (1997) also commented that coping processes are influenced by characteristics of the person and environment, especially in terms of the controllability of the situation and the available resources for coping. Personal coping mechanisms change over time and circumstances and support from colleagues and good team working is important. Extra stressors such as overwork and problems at home would influence negatively their ability to cope and they had learnt to manage these factors as far as possible. It was not that the palliative care nurse specialists did not find the job stressful but that they had learnt to cope with the stress using the mechanisms described.

There are interesting parallels between the palliative care nurse specialists' situation and that of their patients. They clearly described their own suffering when they talked about the effects of the job and burn out. They were describing a threat to their identity and goals in life, which they saw as the relief of suffering for their patients. If this was not possible to achieve due to lack of knowledge, poor communication with colleagues or lack of time, they suffered. In addition to this threat to their identity they are forced to witness the results of their inability to relieve suffering satisfactorily. It is one thing to accept that suffering happens due to factors that cannot be controlled, another to have to witness suffering that could have been relieved if the resources were available. There is an irony that those who aim to relieve suffering should suffer because of compromises to these factors. Arguably, greater understanding of suffering could be a powerful incentive to improve their working conditions, level of knowledge and skills and provision of support.

Chapter Twelve: Conclusion.

Chapter Twelve: Conclusion.

Evaluation of the methodology.

The methodology used for this study requires evaluation. The procedures used for the collection and analysis of data has been discussed in chapters Five and Six, and it is not the intention to repeat these. However, it is worth considering whether the methodology enabled appropriate and worthwhile investigation of the areas under study, and whether it was conducted with due attention to rigour.

The purpose of the study was to explore palliative care nurse specialists' understanding of suffering, management of the nurse-patient relationship with patients who are suffering, and the personal impact of working with patient suffering. Suffering, the nurse-patient relationship, and nurses' personal response to working with patients who are suffering are very individual so qualitative approaches are an appropriate way to research these subjects. The study findings arising from the interviews and subsequent analysis and interpretation were relevant to the individuals involved in the study. Whilst it cannot be assumed that their experience will be the same as every other palliative care nurse specialists the information gained may provide valuable insight into ways to prepare nurses for working in palliative care. Thus, the study is a beginning rather than a definitive account. There is a need for theory development in these areas and grounded theory, phenomenological or ethnographic studies provide a basis. Human science research is not an exact science and cannot problem solve although it is more than speculative enquiry. Until more is known about the way nurses understand and respond to working with patients' suffering, large quantitative studies that can be generalised would be difficult.

A hermeneutic phenomenological approach was used to gain understanding, which may inform practice, both for the nurses in the study and other nurses who read the work. The phenomenological approach is concerned with the subjective experience of the involved person. Good phenomenological description is collected and validated by lived experience, and recollects and validates lived experience (Van Manen, 1997). The hermeneutic circle of understanding is never ending and will always lead researchers and readers to consider further possible interpretations of the information collected. A hermeneutic investigation cannot be completed but only offers insights before returning to a deeper enquiry in what becomes the hermeneutic circle (Mulhall, 1990). The hermeneutic circle, described by Heidegger and explained in Chapter Four, has been in action throughout the study, and it is for the reader to consider the interpretation and discussion in relation to their own experience.

Drauckcr (1999) criticised the lack of Heideggerian terms in nursing studies, arguing that if this is not discussed then how can the report claim to have a Heideggerian perspective. The criticisms of the use of phenomenological method within nursing have been noted elsewhere (Crotty, 1996; Paley, 2005). As far as possible the researcher has tried to remain true to the Heideggerian philosophy. Heidegger (1962) describes four existential lifeworlds and their interconnectedness in a person's life: spatiality or space, corporeality or lived body, relationality or lived human relations, temporality or time. Heidegger's (1962) concepts are incorporated throughout this exploration and particular ideas have been specifically highlighted where relevant. Crotty (1996), said that nurses tend to use descriptions of experiences to understand phenomena and that 'experience' and 'phenomena' are used interchangeably, creating confusion. This study asked the palliative care nurse specialists to discuss suffering, thus looking at the phenomenon of suffering, and to talk about their experience of working with patients who are suffering. Arguably then, both the phenomenon and the experience were explored.

My interest was in gaining greater understanding of suffering and the experience of palliative care nurse specialists working with patients who are suffering. The discovery of knowledge that is Verstehen (understanding) is found in sharing common meaning of mutual history, culture and language of the world as it is lived together (Van Manen, 1997). Hermeneutic phenomenology that aims to achieve this was an appropriate approach. Van Manen (1997, p30) contended that six research activities form the methodological structure of hermeneutic phenomenology and are necessary to investigate lived experience effectively:

1. Turning to a phenomenon which seriously interests us and commits us to the world. My interest and experience of the phenomenon has been described elsewhere.
2. Investigating experience as we live it rather than as we conceptualise it. The palliative care nurse specialists and myself had what were effectively conversations about suffering, the development of the nurse-patient relationship to manage suffering and their experience of working with patients who are suffering. These conversations were about their lived experience.

3. Reflecting on the essential themes, which characterise the phenomenon. These reflections are presented through the three chapters discussing the data findings and the discussion.
4. Describing the phenomena through the art of writing and rewriting. This has also been undertaken through the analysis, interpretation and discussion of the investigation.
5. Maintaining a strong and orientated relation to the phenomenon. Throughout the study the researcher has endeavoured to remain focussed on the aims of the investigation. The methodology and subsequent interpretation and discussion have been about those aims.
6. Balancing the research by considering the parts and the whole. The overall interest of the study was to explore palliative care nurse specialists' experience of working with suffering. To achieve this the experience was broken down into parts that might make up the whole experience. This informed all aspects of data collection, analysis and interpretation. In Chapter Eleven the discussion of the findings, these parts have been considered in relation to the whole.

12:1 Limitations of the Study.

The study is limited to palliative care nurse specialists working in South and Mid Wales and therefore it cannot be claimed that similar findings would emerge with a different sample. Nevertheless the interpretations have similarities with other research undertaken in palliative care. This suggests that the findings may be comparable to that of other palliative care nurse specialists and consequently it provides valuable insights, which may be transferable to other palliative care nurse specialists. Whilst the findings can only apply to the palliative care nurse specialists involved in the study, some further information on suffering, as observed by the palliative care nurse specialists, has been gained.

The palliative care nurse specialists interviewed were those who were still working with patients who are suffering and the majority of them had many years experience. Therefore it is not possible to assess palliative care nurse specialists who may have left the role due to the personal impact of working with patients who are suffering and not reached this stage of knowledge and ability to cope. In addition to this, the palliative care nurse specialists who chose to be interviewed may be those with a particular interest in working with suffering or stress in palliative care and thus the findings would not be the same in a more randomly selected group. Further research is needed to both test the generalisability of the findings, and to see if learning and development could be achieved or aided through the technical-rational route.

Throughout the process of undertaking the research I have been continually aware that it is important not to allow my own biases to over-influence the collection of data and interpretation of the findings. In Heideggarian phenomenological study, hermeneutic understanding is based on the researcher's perspective and beliefs, which are an important part of the study (Draucker, 1999). The study methodology and my fore structure have been described in detail in Chapter Four thus explaining how I may have influenced the study.

I anticipated finding out that palliative care nurse specialists would have developed a view on what suffering means to both them and their patients, would have learnt ways of developing a nurse-patient relationship that supports the identification and alleviation of suffering, and have found ways to cope with working with patients who are suffering. I also expected that their coping skills would include having many outside activities and supportive relationships and that these would have been learnt as a result of becoming over-involved with patients in the past. The arrangement of the data into themes with thoughts about the relevance of these findings clearly points to my own thoughts and presents the lived experience of the palliative care nurse specialists interviewed. The struggle they had to describe suffering, the honesty with which they tried to elucidate the development of the nurse-patient relationship, and the difficulties in working with patients who are suffering, clearly comes from their own lived experience. Data extracts can only reflect some of what was discussed at interview and it has been my choice, which to include to support my interpretations. However, through the chapters of analysis and discussion there are quotes from all but two of the palliative care nurse specialists interviewed, which help to support the claims that the findings were true for most of the participants. The two interviews not used were those where there were problems with the transcribing. The data extracts used are also of sufficient length and quantity for the reader to be able to see the context of the information presented. I have allowed the text to speak as suggested by Van Manen (1997).

12:2 Implications for practice and further research.

There are significant ethical issues in undertaking research of this type, notably in what happens to the information once it is gained. It may be that the ideal of the nurse-patient relationship is not emotionally possible for the nurse to sustain, especially when they are working on an ongoing basis with extreme suffering or patients who are dying. It is important that the information gained is used to improve both patient and nurse care.

At the start of this thesis it was stated that the purpose of the study was to gain greater understanding of palliative care nurse specialists' understanding and management of suffering and the personal impact of working with patients who are suffering. It was hoped that this may help in the future preparation of palliative care nurse specialists to undertake their role as well as increasing understanding of how suffering is understood and managed in practice. This section will return to this intention, and highlight the key implications for nurses working in palliative care.

12:2:1 Educational implications.

It is clear that experiential learning and reflection were the way in which the palliative care nurse specialists came to understand the concept of suffering and this influenced their care management and coping with working with patients who are suffering. The evident difficulties in describing suffering and the fact that the palliative care nurse specialists had reached understanding of the concept through experience is important. It would seem that those who work with suffering are in a good position to share their knowledge. The use of experiential learning to develop theory that is then used in practice seems a logical way to develop experts in the relief of suffering. This may result in greater *'know how'* faster and help underpin the *'know that'* of practice. Most importantly, it may enable quicker recognition of suffering and techniques to alleviate it. It could potentially reduce the difficulties experienced by professionals when suffering is not relieved due to lack of knowledge.

Suffering taught as a concept to those who work with patients who are suffering may give greater insight into the demands of the role. Accepting suffering as a unique, subjective experience based in loss, as outlined in this study, may provide a starting point for the development of a theoretical basis for care and sharing ideas. Specific education in suffering as well as symptom relief may help to better prepare palliative care nurse specialists for working with patients who are suffering. There may be a way of using existing theory to increase palliative care nurses' understanding of suffering so that they can learn from other's experience as well as their own. There is already work on suffering, albeit limited, that could be used to underpin practice. Further studies are required to determine more about suffering. It may also be helpful to further explore whether the difficulties in describing the concept of suffering encountered in this study are common to other palliative care nurse specialists.

There may be less onerous and personally painful ways of gaining expertise and the ability to cope with working with patients who are suffering. However, there is also a question about whether the experience is an important part of learning. It is possible that it is only through experience of practice and life that this development can occur. Certainly some aspects, such as personal development, may be difficult, but enhancing palliative care nurse specialists' understanding of suffering and the difference between suffering and symptom control, patients' behavioural responses when suffering and the principles of person centred relationships may assist palliative care nurse specialists' development and patient care. Further work is needed to determine whether this is so.

Reflection about the descriptions of suffering may be of benefit in preparing and supporting palliative care nurse specialists for the role. Working with a mentor who is more experienced, and discussing individual patients, may enable learning and the development of knowledge and skills required for both undertaking, and coping with, working with patients who are suffering. A system of clinical supervision to ensure ongoing reflection and learning from the job in order to develop knowledge and skills and also explore the emotions generated by the role may be helpful. The experiential nature of learning revealed in this study suggests that clinical supervision and working with others with more experience would facilitate learning the role. This would potentially reduce the negative effects of working with patients who are suffering and enable faster development of competent palliative care nurse specialists who cope well with the stress of the role. It would be of interest to introduce such as system and undertake evaluative research to determine the effect.

12:2:2 Implications for clinical practice.

The nurse-patient relationship identified in this study is clearly patient centred (Rogers, 1951) and it may that this is the best model for this type of work. The adoption of this approach and proper education in it's use would be helpful, especially in aspects such as how to remain empathic and congruent in the face of overwhelming suffering and impending death, which may evoke sympathy and horror.

More work is needed to determine the behavioural responses to suffering, particularly to identify the cues that people use when suffering to elicit help, or that indicate they are suffering.

Factors affecting the inference of suffering need further exploration especially in relation to the age of the nurse and patient.

12:2:3 Support for those working in palliative care.

The structure of the palliative care nurse specialists' role needs to contain good communication systems; including early referral systems with clear criteria for patient referral. It is possible to establish these organisational supports with a little care and creativity. Further, there need to be clear limits on the numbers and types of patients in palliative care nurse specialists' care and systems to facilitate covering absences. Regular multi-disciplinary team meetings for case discussion and the early identification of difficulties may enable communication and teamwork.

The understanding of the concept of suffering, management of patients who are suffering, and coping are connected in this study and further exploration to unravel those connections and determine their generalisability for other palliative care nurse specialists would be helpful. Further exploration is needed to establish whether suffering and coping with working with patients who are suffering is generally learnt on the job. Additionally, are the difficulties described by these palliative care nurse specialists in describing suffering common to all?

It was clear that the palliative care nurse specialists managed themselves to avoid stress and burn out and enabled them to continue to be there for the patients. Coping was all about enabling ongoing being there as well as personal survival. It is possible that these two factors are inextricably linked due to the possible connections with palliative care nurse specialists achieving meaning and satisfaction in the role and the importance of this to their personal identity; this may be an area for further research.

12:3 Personal learning.

This study has been undertaken as part of a Doctorate in Nursing Science and has been a process of personal learning, academically, professionally and personally. Academically, I have gained greater understanding of the role of theory in underpinning taken for granted and experientially learnt knowledge and skills. I have explored literature new to me in an attempt to place my own work and thoughts into recognised theoretical frameworks that explain how the findings of this study relate to existing knowledge, and go some way to further explaining what is happening in practice. This has been a challenge, especially as I have worked with suffering and dying for a long time. It would have been easy to have just accepted that the findings from this study echoed what I already thought to be true within the work. It is a human trait when very familiar with a subject to take for granted that everyone else will have the same awareness and to stint on the theoretical explanations necessary for the development of well grounded knowledge. I found the process of trying to ensure that I was not over-influencing the data a challenge, especially in light of my personal experiences and awareness of this pitfall has helped in the process of undertaking a hermeneutic study. I think my own experience and the work involved in this thesis has been mutually beneficial to the process of gaining new knowledge.

Professionally the findings of this study make sense to me and have reinforced my opinion that helping nurses working in palliative care come to terms with the stress of the role is important, and that it is a process that can be assisted through clinical support, supervision and mentorship. At the start of this thesis I laid out my own fore-structure (Heidegger, 1962) which explained what I expected to find. At the end of the thesis I found some, but not all, of what I expected. I was surprised at the difficulties that the palliative care nurse specialists had in describing the concept of suffering and considered with respect the ways that they used to try and explain a difficult concept for them and the subsequent depth of understanding of the concept conveyed. The amount of experiential learning and the extent to which their views and experience of suffering influenced their working with patients who are suffering and consequent coping strategies was also unexpected. Despite this I realise that my own experiences are not dissimilar to those described by the palliative care nurse specialists. However, my thinking about suffering and ability to describe it was probably more fluent at the start of the study than theirs, and certainly so by the end. I have chosen not to make explicit my personal experience through the presentation of the data, as I believe the data speaks for itself and provides a thick description of the phenomena under study.

Conclusion to Part Four.

This thesis has detailed the methodology and findings of a study to explore palliative care nurse specialists' understanding of suffering and their lived experience of working with patients who are suffering. It has revealed a number of interesting issues. It has achieved the aims set out at the beginning of this account. These were to elicit greater understanding of suffering and the experience of working with patients who are suffering is the main purpose of the study by exploring:

- Understanding of suffering and their experiences of working with patients who are suffering.
- Management of the nurse-patient relationship with patients who are suffering.
- Personal experience of working with patients who are suffering.

A vast amount of data was collected and only some aspects of this have been discussed in any detail. It is clear from this study that understanding and managing suffering develops through experience. The palliative care nurse specialists' views on suffering informed their care particularly in terms of the nurse patient relationship. However, it also changed their life view and influenced their personal development. They ultimately learnt how to cope with the job through positive reappraisal and developing a coping strategy that helps them to be realistic in their expectations of what they can achieve within the role. They had learnt to manage the nurse-patient relationship and themselves over time and with experience. The findings reflect and reinforce other work in the areas explored and thus demonstrate the importance of these in practice.

The connections between understanding suffering and how this influences patient care and the personal impact of working with patients who are suffering is clear and an important contribution to understanding suffering and care of the dying.

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Appendix A: Letter to Palliative Care Nurse Specialists' Managers.

Heather M Davies
Swansea University,
Swansea

Dear Palliative Care Nurse Manager,

I am undertaking a research study to explore palliative care nurse specialists understanding and management of suffering and the personal impact of working with patients who are suffering. The research is part of my Doctorate of Nursing Science and will be written up as my thesis.

I would like to interview palliative care Clinical Nurse Specialists and ask questions about their experience of caring for patients who are suffering. The interviews will take approximately one hour and will be tape-recorded. The tape recordings will be stored in a safely locked cabinet and only my research supervisors and myself will have access to them. All data collected will be anonymised and used only for the purposes of the research and sharing the results in a way that does not identify the nurses interviewed. The study has been agreed by Local Research Ethical Committees.

I would be grateful if you could pass the enclosed letter requesting participation, information sheet and consent forms to the palliative care clinical nurses specialists for whom you manage for their consideration.

I am very happy to answer any questions you may have regarding this research and can be contacted via the above address or on telephone number 07970 772684.

I look forward to hearing from you in due course and in the meantime if I can be of any assistance please do not hesitate to contact me. Thankyou for giving this research your consideration.

Yours Sincerely,

Heather M Davies
Senior Lecturer in Cancer Care.

Appendix B: Participant information sheet.

Heather M Davies
Swansea University,
Swansea

Dear Palliative Care Nurse Specialist,

I am undertaking a research study to explore palliative care nurse specialists understanding and management of suffering and the personal impact of working with patients who are suffering. The research is part of my Doctorate of Nursing Science and will be written up as my thesis..

I would like to interview palliative care Clinical Nurse Specialists and ask questions about their experience of caring for patients who are suffering. The interviews will take approximately one hour and will be tape-recorded. The tape recordings will be stored in a safely locked cabinet and only my research supervisors and myself will have access to them. All data collected will be anonymised and used only for the purposes of the research and sharing the results in a way that does not identify the nurses interviewed. The study has been agreed by Local Research Ethical Committees and permission to approach you to take part has been given by your managers.

I would be grateful for your participation in this study. If you are willing to be involved please read the enclosed information and return the signed consent form in the self-addressed envelope. I will then contact you to arrange a mutually convenient time and place for the interview to take place.

Thankyou for giving this research your consideration.

Yours Sincerely,

Heather M Davies
Senior Lecturer in Cancer Care.

Appendix B.

Palliative care nurses understanding and management of suffering and their individual response to working with patients who are suffering: an investigation.

Participant information sheet.

I would like you to participate in this research study. You should only participate if you want to, choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part it is important for you to understand why this research is being done and what your participation will involve. Please take time to read the following information and discuss it with others if you wish. Ask me if there is anything you are not clear about or you would like more information.

Why am I doing this study?

The study aims to explore palliative care nurses understanding and management of suffering and the personal impact of caring for patients who are suffering. I am conducting this study to gain a greater understanding of the meaning and management of suffering to palliative care Clinical Nurse Specialists and the personal impact of working with patients who are suffering. The research will provide insight into the area and may prove useful for the future preparation and support of palliative care nurses working with patients who are suffering.

How do I plan to gain this information?

Palliative care nurse specialists working in Carmarthen, Pembrokeshire Cardiff and Swansea will be asked to participate in a semi-structured interview which be tape recorded and will take approximately one hour.

Can you participate?

If you are a Palliative Care Nurse Specialist working in Carmarthen, Pembrokeshire, Cardiff or Swansea and are willing to share your experiences I am keen to hear from you.

What does taking part involve?

If you want to take part there are three things I ask you to do:

1. Read this information sheet carefully and complete the consent form provided.
2. Send the consent form back in the stamp addressed envelope provided.
3. Take part in an interview which will take approximately one hour. This interview will be tape recorded and take place at a mutually convenient time and place.

Is the information you provide confidential?

Yes. The researcher only will know the identity of who is participating in the study. Interviews will be anonymised and anonymity will be further sought by carefully editing the content including removing any references to names, places and institutions that could lead to identification.

Consent forms will be filed separately from the interview data.

Interviews will be given a reference number which will be used to identify the data collected.

Computer disks, taped transcripts and all notes will be stored under lock and key when not in use.

Computer screens will not be left unattended when displaying confidential information pertaining to the study.

Security measures will be put in place to prevent unauthorised access to data stored on computer.

Appendix B.

What are the risks of taking part?
The risks to you of taking part in this study are minimal. Although unlikely it is possible that you may be upset as a result of sharing your experiences of working with patients who are suffering. Support would be available to you in these circumstances through clinical supervision.

How long will the study last?
Data collection will take approximately six months. However the study is expected to take approximately two years.

Who to contact for more information:
If you have any questions please do not hesitate to contact me.
It is up to you to decide to take part. I have sent you a copy of the information, two copies of the consent form and contact details for me. If you decide to take part please keep the information sheet, sign the consent form, and return one in the pre-paid envelope provided along with your contact details written on the form provided.
If you decide to take part you are still free to withdraw at any time and without giving a reason.

Heather Davies
Telephone number 07970 772684.
E mail address Heather @mdavies63.fsnet.co.uk.

Consent slip

I am willing to be involved in this study.

Am not willing to be participate in this study.

My contact details are:

Name

Address

Telephone number

Email address

Appendix C

Consent slip

I am willing to be involved in this study.

Am not willing to be participate in this study.

My contact details are:

Name

Address

Telephone number

Email address

Appendix D: List of Organisations involved in the study.

Bro Morgannwg NHS Trust.
Princess of Wales Hospital
Coity Road,
Bridgend,
CF31 1RQ

Cardiff and the Vale NHS Trust.
University Hospital of Wales
Heath Park
Cardiff
CF14 4XW

Llandough Hospital
Penlan Road
Llandough
CF64 2XX

Carmarthenshire NHS Trust.

Prince Philip Hospital
Bryngwynmawr, Dafen,
Llanelli,
SA14 8QF

West Wales General Hospital
Dolgwili Road
Carmarthen
SA31 2AF

Ceredigion NHS Trust.
Bronglais District General Hospital
Aberystwyth
Ceredigion
SY23 1ER

George Thomas Trust.
Tŷ George Thomas
Whitchurch Hospital Grounds
Park Road
Whitchurch
Cardiff
CF14 7BQ

Appendix D.

Gwent NHS Trust.
Ystrad Mynach Hospital
Caerphilly Road
Ystrad Mynach
Hengoed
CF82 7XU

Nevill Hall Hospital
Brecon Road
Abergavenny
NP7 7EG

North Glamorgan NHS Trust.
Aberdare Hospital,
Abernant Road.
Aberdare.
Mid Glamorgan
CF44 0RF

Prince Charles Hospital
Merthyr Tydfil,
Mid Glamorgan
CF47 9DT

Pembrokeshire and Derwen NHS Trust.
Withybush Hospital,
Fishguard Road,
Haverfordwest

Pontypridd and Rhondda NHS Trust.
Llwynypia Hospital
Llwynypia,Rhondda,
Mid Glamorgan,
CF40 2LX

Pontypridd & District Cottage Hospital (Y Bwthyn)
The Common, Pontypridd,
CF37 4AL

Royal Glamorgan Hospital
Ynys Maerdy,
Llantrisant,
CF72 8XR

Powys NHS Trust.
Bronllys Hospital
Bronllys
LD3 OLU

Appendix D.

Llandrindod Wells Hospital,
Temple St,
Llandrindod Wells,
LD1 5HF

Swansea NHS Trust.
Morriston Hospital
Heol Maes Eglwys
Morriston
Swansea SA6 6NL

Singleton Hospital
Sketty Lane
Sketty
Swansea SA2 8QA

Velindre NHS Trust.
Velindre Hospital
Whitchurch
Cardiff
CF14 2TL

Appendix E.

Summary of the data analysis.

The data collected was considered in terms of the palliative care nurse specialists understanding and experience of working with patients who are suffering. The palliative care nurse specialists all felt that a large part of their role was to understand and try and alleviate, where possible, patients suffering. Two main areas emerged from the data that related to suffering. These were problems with definition and articulation of suffering and that of suffering being bound up with loss.

The palliative care nurse specialists found discussing suffering difficult. They talked of having a mental picture of what suffering looked like but acknowledged that describing suffering was hard. The themes developed from the data collection that relate to difficulties with definition are described below with examples of categories from each theme. Initially the data identified difficulties the palliative care nurse specialists found in defining suffering. As analysis progressed it was clear that although the palliative care nurse specialists found it hard to articulate they were able to describe suffering using a number of different approaches. The data was considered to try and identify how they actually achieved descriptions of suffering and what it meant to them. Difficulties with definitions of suffering became an overarching theme with three sub themes of the strategies used to try and describe it.

Difficulties with definitions of suffering: *hard to define*
mental picture of what suffering looks like

Difficulties with definitions of suffering.

Hard to define.

The palliative care nurse specialists really struggled to articulate what suffering meant to them but despite acknowledging how hard it was to define and describe they were also keen to explore the concept and to try to explain it.

Mental picture of what suffering looks like.

The palliative care nurse specialists talked about suffering being difficult to describe but that they had a mental picture of suffering based on their experiences of working with people who are suffering.

Strategies used to understand and describe suffering

Subjective and objective:

Subjective: *impact of disease on life*
unique to the individual
Objective: *helplessness in face of disease progression*
psychological manifests as physical
Combined: *Sufferer and nurse's perspective on individuals suffering are related but different*

Physical, psychological or social definitions.

Physical: *symptoms and problems*
Psychological: *emotional, social and spiritual*
Composite: *meaning of suffering to the persons life*
physical combines with psychological

Instrumental definitions.

Alleviating suffering;

Strategies used to try and describe suffering.

The palliative care nurse specialists were very clear that a large part of their role was to try and alleviate suffering and thus they must understand what it means to the patient. To do this they must themselves have an understanding of suffering. As a result of this commitment to patient care they used a number of strategies to try and describe suffering and thus three further themes emerged relating to the palliative care nurse specialists understanding of suffering and their experience of caring for patients who are suffering. The palliative care nurse specialists used case study examples to identify problems encountered by their patients that epitomised suffering for them.

There were three strategies that enabled the palliative care nurse specialists to discuss their understanding of suffering and experience of working with patients who are suffering. These are explained below. There are three main strategies but within these overall themes are sub themes further identifying different aspects of the concepts described. There was some overlap in the categories with these themes and sub themes. Physical, psychological and social problems were thought to cause suffering in themselves.

Overlapping categories were an objective assessment of psychological suffering manifesting as physical suffering and also a composite description where the meaning attached to physical problems was thought to cause psychological problems. Another area of overlap was that of the uniqueness of the suffering experience which has been placed in the subjective sub theme but was evident throughout the descriptions of suffering.

Subjective and objective.

- Subjective describes suffering from the sufferer's point of view and therefore relies on the sufferer's account and is unique to that person. These are definitions given by the patient.
- Objective where suffering is reliant on a third person or the palliative care nurse specialists inference on someone else's suffering. The sufferer may communicate their problems or may not be aware of their suffering. Suffering in this instance may not include meaning nor require mental consciousness. Others witness the suffering but the sufferers may or may not themselves be aware of it.
- Combined. It was clear that there were times when there were combined objective and subjective approaches to describing suffering. In these cases the palliative care nurse specialists discussed the difficulties when the sufferer expressed suffering arising out of one problem in their lives but the palliative care nurse specialists could see that other problems were also causing suffering but the person was either unaware or unwilling to acknowledge these.

Physical, psychological or social definitions of suffering.

These descriptions relate to actual problems that occur and result in suffering. The palliative care nurse specialists discussed individual situations where suffering was clearly arising as a result of problems of a physical, psychological or social nature and being experienced by the person suffering.

There was a further composite definition where suffering is multidimensional and acknowledges that psychological, emotional, physical, spiritual and intactness of the person may be affected. Each of these dimensions can suffer separately but affect the others. Suffering in this case often arises out of the meaning placed upon the problems being experienced by the individual and the resultant life changes.

Instrumental definitions where the palliative care nurse specialists describe how suffering is dealt with.

Suffering was described in terms of what might done to try and alleviate it. Descriptions include what helps the person overcome their suffering. Often the palliative care nurse specialists found it easier to explain suffering in terms of measures that may be taken to try and help the sufferer.

Alleviating suffering.

Suffering arose with suffering was seen as a highly subjective experience for each individual. The palliative care nurse specialists were very aware that to alleviate suffering they must have an understanding of what was causing the person to suffer. This was often achieved through just talking to the person to develop a relationship.

The palliative care nurse specialists were sure that to help with suffering they needed to help the individual to identify the source of their suffering for themselves. The view was that otherwise all attempts to help would fall short as they would not be addressing the right issue. However they accepted that the patient had to accept what the problem was in their own time and meanwhile they ensured that they were available.

Loss.

Suffering in the literature is often viewed as a response to loss. Loss of a pain free existence (Chapman and Gavrin, 1999) of health (Jones, 1999), of future or of self (Charmaz, 1983;Morse and Johnson, 1991). By the time a person is requiring palliative care they have often experienced a great number of losses including loss of status or self esteem, bodily functions, job, role within the family and future expectations. Shaver (2002) suggests that human suffering can be distilled to three general categories; abandonment of self, isolation and loss of significance.

Loss associated with suffering was apparent throughout the data and acknowledged as a central feature that causes suffering for the person. Loss arose in many different forms, of control, identity, hope, social relationships, bodily function. The idea of loss was present throughout the descriptions of suffering and seemed to underpin many of the ideas being described. It was present but not necessarily called loss in the descriptions about what the person was experiencing when the palliative care nurse specialists were discussing other aspects of suffering such as the impact of the disease or the uniqueness of the suffering experience.

This theme is explored more fully below as it seems to be a central concept when discussing what suffering means to the palliative care nurse specialists interviewed. It is described below as a separate theme that is core to the definitions described previously.

Loss: *loss of control*
loss of identity
loss of hope
loss of social relationships/isolation and loneliness
loss of bodily function

The nurse patient relationship.

The palliative care nurse specialists all felt that a large part of their role was to develop relationships with patients. The nurse patient relationship was seen as important for helping the patients with their suffering as they approached death. Whilst the palliative care nurse specialists realised that it was important for enabling the administration of the practical aspects of relief of suffering they also recognised that the nurse patient relationship in itself had therapeutic value. A therapeutic nurse patient relationship will help the person feel less alone and if itself assists in relieving distress. The palliative care nurse specialists realised that their involvement in the patients lives often went beyond a professional role and provided a feeling of respect and connectedness that the patients appreciated. This was considered in detail and the themes developed from this part of the data collection are described below with examples of categories from each theme. Five themes were identified as outlined, all were interrelated will be discussed first. Concepts which constitute barriers to developing relationships were also considered and will be described in the second section.

Developing nurse patient relationships.

Communicating: *introduction*
social interaction
giving clients time to talk
rapport
Building and maintaining relationships: *self-disclosure*
time
building trust and confidence

Mutuality: *reciprocity*
caring
partnership

Presencing: *being there*
investing self

Barriers to developing relationships

Personal barriers: *No personal rapport*
superficial relationships

Organisational barriers: *lack of time*

Communicating

Good communication skills in both verbal and non-verbal communication are fundamental in order to identify the needs of patients and develop and maintain the nurse patient relationship (Clark et al, 2000; Dunne, 2005; Sheldon et al, 2006). The palliative care nurse specialists often discussed communication skills as central to their development of a nurse patient relationship and many were confident in their interpersonal skills to achieve this.

Building relationships

Every nurse-patient relationship will be unique because each nurse and each patient is an individual. Some relationships appear to happen quite spontaneously, whilst others need to be worked at and built up deliberately.

Mutuality

Morse (1991) states that the relationship between nurse and patient is the result of interplay or covert negotiations until a mutually satisfying relationship is reached. She identified four types of mutual relationship influenced by the duration of contact between nurse and patient, the needs of the patient, the commitment of the nurse and the patients' willingness to trust the nurse. These reciprocal aspects of nurse-patient relationships embrace the concept of 'give and take' between the patient and the nurse, and concern the development of mutual understanding.

Presencing

Slevin (1999) defines 'presence' as a way of being that promotes a therapeutic nurse patient relationship. This essentially concerns the idea of the nurse 'being there' for the patient. The process by which individual investment in the relationship occurs, and as a result often becomes personally involved. The palliative care nurse specialists were aware of the importance of being there and used it as a way to develop the nurse patient relationship. They felt that if they could be there for a patient when needed, the relationship was more likely to develop. Being there of course is not simply about being physically present, but about being able to offer emotional support to a patient at a time of need and can only be achieved if one is there at the time.

Barriers to developing relationships.

Many factors can act as barriers to the developing relationship falling into two main themes, personal barriers and organisational barriers.

Personal barriers

These were when the nurse or patient personality or personal circumstances interfered with the development of a close nurse patient relationship. The patients may not want intimacy and just want the knowledge and skills the palliative care nurse specialist has to offer. This may be due to a lack of openness or the patient avoiding involvement with the nurse.

Organisational barriers

The main organisational barrier to developing a therapeutic nurse patient relationship was lack of time. Lack of time, whether as a result of late referral or holidays or too many patients on the caseload and too many other activities was often given as a major deterrent.

Difficulties and coping with involvement with patients who are suffering.

This part of the study explored the personal impact of working with patients who are suffering. Data analysis revealed a number of difficulties and coping strategies. Most of the themes identifying the difficulties and the coping strategies overlapped suggesting that what is stimulating and rewarding is also challenging. There may be a point where the challenge if not successfully met becomes stressful. This chapter is divided into two sections. The first section will discuss the difficulties whilst the second will deal with management and coping.

Difficulties made up five themes with categories and these will be discussed with illustrative quotes.

Themes.

Difficulties.

Suffering:	*witnessing suffering* *unnecessary suffering* *not being able to alleviate suffering* *responsibility for relieving suffering*
Relationships:	*age of patient* *identification with patient* *personal involvement*
Job structure:	*communication difficulties/poor teamwork* *work environment*
Personal:	*problems outside work*

taking work home
changed/ aged because of job

Burnout.

Suffering.

Patient suffering was a source of difficulty for the palliative care nurse specialists for a number of reasons described. The difficulties arose fundamentally from the same source that of not being able to alleviate it. There were a number of reasons for this but basically the palliative care nurse specialists found it stressful if the patient was suffering and nothing could be done to help. This links closely to the next section of coping where suffering is a theme again and the palliative care nurse specialists had often developed strategies to deal with patient suffering and thus cope with the difficulties.

Witnessing suffering has been found to be a source of distress for nurses (Quinn, 2003; Kahn and Steeves). The palliative care nurse specialists also found this difficult particularly if the suffering was emotional and due to fear. Witnessing suffering was difficult and related to this was not being able to alleviate suffering and thus having to go on witnessing it whilst feeling helpless.

The palliative care nurse specialists found it difficult when the patients suffered unnecessarily. The reasons for needless suffering may be because of staff ignorance or poor teamwork resulting in treatments not being started as soon as they should.

The inability to alleviate distressing symptoms due to the complexity of care can make nurses feel overwhelmed, inadequate and helpless (Davitz and Davitz, 1975; Mezies, 1961; Benner, 1989; Steeves et al, 1990; Radiewicz, 2001; Georges et al, 2002) and be a source of stress when caring for patients who are dying (Kent et al, 1994; Alexander and Ritchie, 1990; Quinn, 2003; White, 2004). The palliative care nurse specialists found being unable to alleviate a patients suffering a significant source of difficulty. The onus for the relief of suffering was a pressure for the palliative care nurse specialists. Patients and families were looking to them to help and yet the palliative care nurse specialists were aware that it was not always possible to alleviate suffering.

Relationships.

The relationship with the patient could be challenging for the palliative care nurse specialists whose emotional involvement with the person lead to care, empathy and compassion whilst also being aware that they were unable to change the ultimate outcome of the illness.

Younger patients who had not had a chance to experience a full life were harder for the palliative care nurse specialists to care for. They were thought to suffer more because they were losing more and the nurses were able to imagine how they must be feeling. The palliative care nurse specialists found it difficult when they could identify with the patients.

Job structure.

The way in which the job could be performed in terms of interactions with others and available resources were important factors in whether the role was rewarding or caused frustration. In some cases job structure itself was a problem but mainly it was difficulties hindering the relief of suffering or lack of support of the nurse patient relationship. Job structure was the backdrop for achieving the aims of their role and if there were problems then it was possible that the already hard task of relieving suffering in palliative care would be missed altogether. All other hardships were increased if there was poor communication within the team. The palliative care nurse specialists felt that poor teamwork and communication difficulties were stressful for them particularly if it has resulted in unnecessary suffering for the patient.

Coping.

Coping with stress or burnout has been discussed by a number of authors (Lazarus, 1984; Firth et al 1986; Ramirez, 1996; Maslach, 1981,1982; Kiedel, 2002; Vachon, 2001) and revolve around two main approaches. The first is trying to change what it is possible to change. The second is adapting to what cannot be controlled. Planful problem solving, reappraisal of problems and seeking social support are all associated with reduced burnout levels (Ceslowitz, 1989; Payne, 2001). There were four themes that emerged from the data that related to how the palliative care nurse specialists managed their involvement and coped with working with patients who are suffering.

Coping themes.

Suffering:	*alleviating* *patients not palliative care nurse specialists suffering* *acceptance/perspective on suffering* *realistic expectations of role*
Relationships:	*setting boundaries on involvement* *personal* *colleagues/good teamwork*
Job structure:	*not taking work home* *ongoing education, clinical supervision, case conferences and reflection leading to increased knowledge and skills* *management of work other work activities*
Personal:	*maturity/ life/job experience* *outside activities* *looking after oneself* *putting things into perspective/acceptance* *recognising signs of stress and taking action* *personality* *faith* *job a privilege/job satisfaction*

Suffering.

Suffering was accepted as part of the palliative care nurse specialists reason for being and they were able to cope with the difficulties providing they were able to make some progress in the alleviation of problems and had a personal philosophy about working with suffering. Interestingly whilst working with suffering was a source of stress it was also a source of job satisfaction and thus part of how they managed the role.

Relationships.

The relationships that the palliative care nurse specialists were involved in were important for coping with the role. Good outside work and collegiate communication were supportive whilst they recognised the need to maintain professional relationships with patients and families.

Job structure.

The structure of the job was important for being able to undertake activities that would facilitate coping. Autonomy and control were foremost in assisting the palliative care nurse specialists to plan their work in such a way that stressors would be minimised.

Personal.

There were a number of personal factors that affected the palliative care nurse specialists experience of working with patients who are suffering.