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Palliative care nurses' perceptions of their management of the psychosocial and spiritual pain experienced by their clients in the home hospice setting

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**Laurence Vogler
RN BN**

**This thesis is presented in fulfillment of the requirements for the degree of
Bachelor of Nursing (Honours)**

**Faculty of Nursing, Midwifery and Postgraduate Medicine
Edith Cowan University**

November, 2005.

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

ABSTRACT

Pain, in palliative care clients, consists of more than just a physical manifestation of their condition. Pain can be experienced on a psychological or emotional level, a psychosocial level or even at a spiritual level. It is widely accepted that nurses in the palliative care setting manage well the physical issues that their clients have, but perceptions can vary on their management of the “non – physical” pain experienced by their clients.

This study provided an opportunity for palliative care nurses to describe their perceptions of their management of the psychosocial and spiritual pain experienced by their clients in the home hospice setting through a qualitative, exploratory framework. Heideggerian phenomenology provided the philosophical base for the study, with the conceptual framework being established by concepts identified in a literature review of current knowledge and perceptions of psychosocial and spiritual issues, relating to palliative care nursing within the home hospice setting.

The sample comprised of six Registered Nurses working in the palliative care, home hospice setting within the Perth Metropolitan area (Western Australia). First stage of recruitment for the study was by an open invitation, with the second phase being conducted within specific parameters to ensure that a purposive sample was achieved. The researcher-conducted interviews were tape recorded for later transcription and analysis. Qualitative analysis was performed on the interview transcripts, which produced four main themes.

Existing perceptions of psychosocial and spiritual pain was the first theme identified in this study. In this theme, correlation was found between the concepts identified in the literature review and with the experience and perceptions of the nurses under study. The second theme described the nurses’ perception of their role in the management of the psychosocial and spiritual pain experienced by their clients in the home hospice setting. This perception was found to relate to existing knowledge in that the primary role of nurses in this setting was said to consist of assessment and referral.

The third theme described the factors that influenced the management of the “non – physical” pain in the clients. Factors relating to the three main stakeholders (the nurse, the client and the Silver Chain organization) were described first, followed by global factors that included all of the stakeholders. The last theme described the recommendations and advice for improvement of management of these issues. Formal assessment of psychosocial and spiritual pain, more specific training in management of these issues, and access to more spiritual resources were regarded as the main improvements to the organization, while the advice that was given related to improving holistic care, communication skills and maintenance of self care.

The recommendations made by the nurses reflect those made in other studies regarding the importance of training for the nurses in dealing with these issues, as well as the accessibility of suitable resources to aid the management of these issues. The advice given by the nurses demonstrated how central the concept of holistic nursing was to palliative care, especially in the home hospice setting.

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

- (i) incorporate, without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education.
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CHAPTER 1

INTRODUCTION

In this study, the perceptions of palliative care nurses of their management of the psychosocial (internal environment manifesting externally) and spiritual (existential and faith) pain experienced by their clients, in the home hospice setting, was explored and described. To understand the existing concepts behind home hospice based palliative care, a brief overview of the historical origins of concepts regarding “a good death” and “palliative care” is provided for the context of this study.

Background

Society’s view of death and dying has undergone many changes throughout time. These changes alter what individuals perceive to be a ‘good death’. Illich (cited in O’Gorman, 1998) suggests that a person’s view of death is directly linked to his or her perception of health. This is also recognised by Stazzari (2002) who states, “What is perceived as real and normal about events such as ageing, dying and deaths are socially constructed and depend on the historical, social and cultural context in which they occur and are given meaning” (p. 232).

Dying as a supernatural event

Illich (1990) suggested that early societies had considered death as a deliberate action of god/s. This was a prevailing view in ancient Greece, when the Greek gods were considered as active participants in all life and death. Illich (1990) theorised that a change of perception in the Middle-Ages created a change that led society to view death as a natural part of life and not the direct intervention of supernatural beings:

“... death becoming autonomous and part of human life rather than due to the intervention of a foreign agent, led to a coexistence of death as a separate agent with the immortal soul, divine providence and angels and demons.... this represents a readiness by the society of that time for a radical change in attitudes and for death to become a 'natural event'.” (p. 162)

Origins of a good death

How can any death be regarded as a “good death”? Helgeland (1985) believed that the idea of a ‘good death’ was based upon the growing movement of human dignity and the changing face of society away from the class system based on wartime honour in the 12th century. Physicians of the time were used to realise a speedy death in a manner that was controlled, in accordance with the prevailing religious view that any attempt to prolong life was blasphemous due to concepts of the afterlife that were prevalent at the time. Thus, an expediently controlled death was regarded as dignified in the Middle-Ages.

Because the care, at this junction in time, was home-based spiritual care, the priests played an important role. They prepared the person for the afterlife by blessing the soul and physicians hastened the death by allowing the client to choose the moment when they wished the last rites to proceed.

The industrial revolution and perceptions of dying

Major changes in people’s attitudes toward health and death began with the major changes in lifestyle that accompanied the industrial revolution. According to Illich (1990) the population was now seen as a resource to be managed; therefore public health came on to the agenda of the ruling class. The industrial revolution also increased wealth and the opulent of the era would pay to prevent death and maintain their lifestyle. Illich (1990) suggested that it was around this period that death became seen as untimely instead of a natural progression and fate. This idea that death was untimely suggests that people were happier with their lifestyles. Stazzori (2002) suggested that people were becoming aware of how to control their environment and destiny. Stazzori (2002) also observed that the wealth created by the revolution led to institutional changes in the 18th century and went on to describe the following changes as fundamental to the changing attitudes of health and desire for prolonging life:

- Medical interventions (e.g. vaccines and antibiotics have been credited with the decline in mortality)

- Public health measures through quarantine and sanitary reform
- Better standards of living – workplace conditions, accommodation, availability and affordability of nutritious food and education
- Establishment of hospital as a place to fight death (pp. 234 - 235)

These improvements led to the increased health of the population and made it possible for old age not just to be enviable but become accepted as normal. The introduction of the hospital started to remove the care of dying people away from the community.

The medicalisation of death

In the late 19th and early 20th century there were rapid improvements in technology and life expectancy. According to Lupton and Najman (1989) infant mortality rates decreased significantly, which in turn, increased the average life expectancy. The 20th century also saw the introduction of major public health education programs that have been made more easily accessible through the introduction of radio, television and more recently, the Internet.

Illich (1990) stated that this era gave rise to the higher social position of the physician because “Death had become the outcome of specific diseases certified by the doctor” (p. 186). Shryock (1947) also noted “that the hope of doctors to control the outcome of diseases gave rise to the myth that they had power over death. The new powers attributed to the profession gave a new status to the clinician” (p. 283).

During this period death began to be increasingly removed from the community and into the hospital, which led to people dissociating themselves from death as it started to become an ‘unnatural event’; this sentiment is echoed by Pietroni (1991) in his statement “doctors and nurses consider themselves to have failed if a patient dies” (p. 142). This affected the care of the dying as all attempts to continue ones life would be taken in the name of science.

With this transferral of death from the home to the hospital, spiritual and personal care took a back seat to the medical interventions enacted to keep a patient

alive. This was supported by Kubler - Ross (1970) who discovered that when professionals identified that a patient was dying, they withdrew from the bedside because they were unable to cope with the process of death themselves, let alone support the patient in his final moments. This also illustrated societies' inability to cope with the previously common and spiritual event of death.

A return to holism

In the last half of the 20th century a more holistic approach to the care of the dying started to become more widespread. According to O'Gorman (1998), "Elizabeth Kubler-Ross ... began her multidisciplinary seminars on the care of the dying patient. She proved that with unconditional love and a more enlightened attitude, dying could be a peaceful, even transformative experience" (p. 1130). The hospice care movement is based on this concept of caring for dying clients' without life-saving interventions. The first modern hospice service was founded in 1967 by Dame Cecily Saunders in London, England, and since that time, the concept of holistic, hospice care has spread over the world.

Palliative Care

The most recent definition of palliative care by the World Health Organisation (2002) portrays this holistic viewpoint. Palliative care is defined as:

An approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

This ends the historical background of the concepts involved in this study. In this study, the focus is on palliative care nurses and clients who are in the home setting, reflecting, in part, the return of clients' to a more holistic environment to enable their "good death".

Significance

The management of pain and other physical symptoms experienced by palliative care clients' has been well researched and documented, but the other domains outlined by the World Health Organisation (those of psychological, social and spiritual problems), are less clearly defined.

This study aims to provide insight into these other “non – physical” pain problems by describing and exploring the perceptions that nurses have of their management of these issues. It is for this reason that this research has been proposed.

Although there is no question that the nurses' role in the management of psychosocial and spiritual pain in palliative care clients is as important as their role in the management of physical pain and symptoms, there is, to date, minimal research conducted to inform this area.

It is appropriate and timely to explore the experiences and perceptions of palliative care nurses regarding their psychosocial and spiritual pain management of palliative care clients in the home hospice setting. The findings from this study will assist in developing evidence that will lead to improved nursing practice, which will lead to the improvement of the clients' holistic pain management in the community palliative care setting.

Research Objectives

The overall aim of this study was to describe the perceptions of palliative care nurses, and their experiences regarding management of the psychosocial and spiritual pain of palliative care clients in the home care setting. This study focused on the nurses' perceptions of their clients psychosocial issues, their perceptions of the nursing role in the management of these issues, factors that influenced the nurses' psychosocial and spiritual pain management and self-reported recommendations for improvement of the management of psychosocial and spiritual pain.

The specific objectives for this study originated from the literature review and were to explore and describe:

- Nurses' beliefs, attitudes and knowledge of psychosocial and spiritual issues as relating to their clients in the home hospice setting.
- Nurses' attitudes and perceptions of their role in the management of these issues.
- Factors influencing the nursing management of psychosocial and spiritual pain.
- Resources employed by nurses to enable effective nursing management of these issues.
- Existing nursing assessment methods for psychosocial and spiritual pain in the home hospice setting.
- The extent of organisational support for nurses working in the home hospice setting.

CHAPTER 2

LITERATURE REVIEW

Introduction

This chapter examines published literature related to concepts identified by the research topic as being relevant to this study. This includes current definitions of psychosocial and spiritual pain and guidelines for the management of these types of pain, the prevalence of psychosocial and spiritual pain in the home hospice setting and barriers to effective psychosocial and spiritual pain management. Data bases used to locate relevant literature were CINAHL and Medline (between 1980 and 2005). Relevant palliative care textbooks were also utilised. The concepts that emerged from this literature review were:

- Quality of life and assessment issues.
- Psychosocial and spiritual pain in the home hospice setting.
- The nurse – client relationship.
- Existing psychosocial and spiritual pain management strategies.
- Barriers to effective psychosocial and spiritual pain management.
- Clients' and families' roles related to psychosocial and spiritual pain.
- Role of the nurse in the management of psychosocial and spiritual pain.

This literature review provided the concepts and rationales upon which the conceptual framework for this study was constructed.

Quality of life and assessment issues

Because the focus of palliative care is not centered on curing the client, but rather on caring for and enabling the client, a large focus of palliative care is on quality of life issues. When the remaining time left for a client is thought to be short, quality of life becomes the greatest concern. There have been many studies reported that have explored quality of life issues in the palliative care setting (Belchamber & Gousy, 2004; Horne & Payne, 2004; Slater & Freeman, 2004; Weze, Leathard, Grange, Tiplady & Stevens 2004).

Originally, quality of life in palliative care was equated with functional status. This was measured with such instruments as the Karnofsky Performance Status Scale (Karnofsky, Abelmann, Craver & Burchenal, 1948), the Zubrod Scale (Zubrod et al., 1960) and the ECOG Scale (Oken et al., 1982.).

The main disadvantage with using these tools was that they did not address other issues such as symptom management, side effects of treatment, social strain, psychological pain, spiritual anguish, interpersonal relationships or financial concerns (Bertolino, 2000).

These limitations were addressed by McMillan (1996) and the characteristics of an effective tool for measuring quality of life were outlined. The first characteristic is that the instrument must measure all aspects of quality of life that may be affected by a life-limiting illness (Frank-Stromberg, 1988). Secondly, that the instrument should provide subjective data obtained via self – report of clients' (Wellisch, 1984). The final two issues identified state that the instrument used should be relevant to the setting in which it is being used and also that it is valid and reliable (Schipper, Clinch, McMurray & Levitt, 1984).

There are many tools that have now been devised to meet these criteria, with no one tool being universal in its application. Commonly, a combination of tools is used, especially if assessments are performed regularly (Ganz, Haskell, Figlin, LaSoto, & Siau, 1988).

Modern research using tools fulfilling the above requirements has provided the researcher with ample information regarding issues that clients' identify as impacting on their quality of life. These issues can be clustered into several domains (Ferrell & Coyle, 2001). The first quality of life issue widely identified by clients is that of physical well being, both through the illness itself, and through the interventions taken to treat the illness (Belchamber & Gousy, 2004; Horne & Payne, 2004; Slater & Freeman, 2004; Weze, Leathard, Grange, Tiplady & Stevens 2004). The second domain encompasses social well-being. This includes relationships with families, peers and work colleagues as well as financial concerns regarding cost of funerals and paying bills, especially if the client had been the primary wage owner (Rose, 1995).

The third quality of life issue, psychological pain, describes the increase in negative psychological conditions experienced by these clients' (Derogatis et al., 1983), depression and anxiety being two of the main factors involved (Breitbart, 1995; Zabora, et al., 1997). When the terminal stages of the illness are being approached, spiritual anguish is often encountered and this is regarded as a crisis that needs to be overcome to ensure that a good death will follow (Bowie, Sydnor & Granot, 2003).

Because the focus of this research is on psychosocial and spiritual pain, a definition of these two domains will follow. For the purpose of this study, spiritual pain has been defined as the pain caused by existential crisis or loss of faith, and the definition of psychosocial pain is pain caused by psychological and social limitations imposed by the disease process. It is these two domains that will now be examined in more detail.

Psychosocial and spiritual pain in the home hospice setting

Palliative care literature is full of the descriptions of the physical pain associated with palliative care, and indeed, a large focus of the interventions undertaken is to ensure that this is kept to a minimum. Because of its urgent nature, physical pain is often the primary care focus with all other concerns relegated until pain levels reach a patient tolerated level.

Less examined are the psychosocial and spiritual pains suffered by the patient in this setting even though it has been shown that once these issues are addressed, distress is lessened (Chibnall, Videen, Duckro & Miller, 2002).

Clients have identified that they would like health professionals to pay more attention to spiritual needs and for health professionals and spiritual professionals to work more as a team, rather than on a 'refer and forget' basis (King & Bushwick, 1994).

Unfortunately, like so many other problems in palliative care, one issue tends to affect other areas as well, and psychosocial and spiritual pain is no exception. It has been shown that not only are pain and psychiatric morbidity related but also that cancer pain may play a part in producing or exacerbating depression (Spiegel, Sands, & Koopman, 1994) as well as anxiety disorders in palliative care clients' (Velikova, Selby, Snaith, & Kirby, 1995).

The psychosocial impact that these issues have, such as withdrawal from social interactions (Davis-Ali, Chesler, & Chesney, 1993), changes in role function, and altered behaviour patterns have also been researched (Jacobsen & Breitbart, 1996).

Nurse – Client Relationship

Nurses have a unique role to play in the provision of palliative care, which is thought to have evolved from the special relationship that develops between the nurse, the client and the families involved within the palliative setting (Field, 1989). It has been shown that, for nurses to be effective in their role in the palliative setting, they need to fulfill certain client expectations. According to Richardson (2002), the patient identifies two types of therapeutic relationship with the nursing staff that enhances feelings of health and well-being.

Psychological well-being was enhanced by the humanistic and egalitarian interaction with the nurse, whereas the professional interaction focused on the disease itself and addressed any physical problems. Clients' acknowledged that it was the nurses' role to assist with the relief of physical symptoms, but the clients' perception of 'feeling better' focused on enhancement of psychological health and well-being.

Clients' and families' roles related to psychosocial and spiritual pain.

Although this project addresses nurses' perceptions of management of psychosocial and spiritual pain, it is acknowledged that there are other members of the caring team who can also help to address these issues. Family members were often the primary care givers of palliative care clients' (Hudson, Aranda, & Kristjanson, 2004), and thus, their assistance in identifying psychosocial and spiritual interventions is important.

Existing psychosocial and spiritual pain management strategies

Medicine and all health interventions based on the medical model of health, have traditionally taken a reductionistic and compartmental approach to health and curing. This specialisation has worked well since its introduction and quite often it is this framework that is still used today when interventions are required.

For psychological issues, a psychologist or psychiatrist was often called to intercede; for social issues, a social worker was called for. Spiritual issues are often addressed under the domain of clergy and quite often, these three separate groups of individuals work to the exclusion of the others (Wolfe, 1993).

Thus, the current role of the nurse was more of assessment and referral than of implementation of care in this instance (Abma & Widdershoven, 2005). This under-management of psychosocial and spiritual pain was endemic in palliative care nursing (Naysmith, 2004) due, in part, to the difficulty of diagnosis of this form of pain (Edwards, 2005).

Psychosocial pain tended to be chronic and its isolationistic characteristics become more intense as death approaches for palliative clients'. Socially, clients withdrew and distanced themselves from family and friends (Rose, 1995). This happened either because a patient withdrew so as not to cause any further burden on loved ones, or as a way of not having to deal with others' reactions to their state of health. This occurrence often was concurrent with other psychological issues such as depression and anxiety (the two biggest psychological issues in palliative care) (Dobratz, 2005).

Because psychosocial pain was considered chronic in nature, its onset tended to be insidious and was sometimes hard to effectively intervene unless other social support interventions were offered (Lloyd – Williams, 2003). Spiritual pain, on the other hand, tended to manifest itself in episodes, often at critical points in the palliative experience (Murray, Kendall, Boyd, Worth, & Benton, 2004).

Barriers to effective psychosocial and spiritual pain management

There are several barriers to providing effective nursing psychosocial and spiritual pain management. The first of these was of a perceived inadequate training given to nurses in dealing with psychosocial and spiritual crises (Kristeller, Zumbrun, & Schilling, 1999). The focus of nursing training centred on pain relief, wound dressing and clinically - oriented tasks; psychosocial issues were only related to clinical interventions (Rose, 1995). A reported deficit in nurse training was attention to emotional interactions with clients (nurses often had to rely on previously developed interpersonal skills to deal with these issues). Nurses, especially in the role of palliative care, needed to be especially sensitive to psychosocial and spiritual issues (Richardson, 2002), but basic nursing training did not properly prepare them for these care situations.

Role of the nurse in the management of psychosocial and spiritual pain

Most of the literature included above focused on client management from a physicians' perspective. After exhaustive searches, no nursing related literature could be found that described the role of the home hospice community palliative care nurse in assessment, management or organisation of psychosocial or spiritual pain in the home hospice setting.

Summary

This literature review has highlighted the fact that while psychosocial and spiritual problems relating to palliative care were regarded as extremely important, nursing care focused on these concerns has been poorly defined. There was a marked scarcity of literature related to nursing in this area, which made identification of existing concepts difficult.

What was identified, however, was that the nurse had a unique role in the palliative care setting for she had more contact with the patient than any other health professional, both in time and in proximity. Working in collaboration with the clients' carers, it was the nurse who often had to identify issues that the client may have had, and then seek to manage them in the best interests of both the client themselves, and any other person who may be in a caring role for this person.

Existing limitations, as identified by the literature review, concerned with adequate training for nurses to perform their duties in this setting.

CHAPTER 3

CONCEPTUAL FRAMEWORK:

The introduction section of this report provided a brief description of the historical issues leading up to the development of the modern day care modality that is palliative care. The literature review provided insight into current beliefs and perceptions regarding issues related to palliative care, and more specifically, psychosocial and spiritual issues.

To describe the research topic, the methodology needed to be chosen and matched to the question in order that meaningful information could be obtained. Valid research needs to be built on sound concepts, and it is for this reason that the rationale of the conceptual framework for this study will now be described.

A framework is necessary to provide structure to the research. It also aids in the assessment of the data obtained for it provides a 'worldview' or perspective from which to view the data. The framework is considered the skeleton of the research upon which the body of data is built and thereby contributes to the final "shape" of the research findings (Polit & Hungler, 1997).

In qualitative studies, where no theoretical basis exists, the framework used is commonly referred to as a conceptual framework (as opposed to quantitative studies, where a theoretical framework is used). (Burns & Grove, 2001) The conceptual framework is based upon concepts identified as relating to the study setting, as well as providing a philosophical perspective to the study.

Key Concepts in this Study

The parameters for the literature review were determined by the research topic. Additional concepts identified through the literature review were then added to these original concepts to form a concept map. This concept map provides a pictorial representation of the issues under study, and also provides the beginning of a framework for the data collection and analysis phase of the study (a copy of this concept map can be found in Appendix I of this report).

The concept map, by identifying issues and the relationships between them, was then used as an aid in determining the philosophical base of the study. As previously identified, the core concept of palliative care was that of holistic care. This concept of holism leads to the philosophical perspective for the study (described in the Research Design section in the following chapter) and provides the overall perspective of this study. The other concepts mentioned in the literature review fall within this perspective as well.

The nurses' perception of their management of the clients' psychosocial and spiritual care was the focus of this study, therefore concepts such as the nurse - client relationship, and psychosocial and spiritual management strategies also needed to be addressed.

The literature review also identified existing barriers to effective management and concepts relating to "under management" of clients' psychosocial and spiritual pain by nurses. All of these concepts determined the structure of the research as well as influenced the philosophical perspective of the study.

CHAPTER 4

METHODOLOGY

This chapter outlines the qualitative methodology used to explore the nurse's perceptions of their management of the psychosocial and spiritual pain experience by the client in the home hospice setting. The methodology selected defined the context in which the study was undertaken, as well as the process used to answer the research question. The qualitative methodology chosen ensured a collection of rich, narrative data, which illustrated the perceptions that the nurses interviewed, held regarding their psychosocial and spiritual management issues. The primary advantage of using this methodology was that complex issues could be explored, and that these issues (and any emergent issues) could be explored during the data collection phase.

Research Design

The research design chosen for this study was a descriptive, qualitative design. Following a review of the different qualitative research methodologies, phenomenology was chosen as being the most appropriate to this project, for reasons outlined below.

Phenomenology

Phenomenology has been defined as a subjective, descriptive research methodology that focused on the lived experiences of individuals (Polit & Hungler, 1997) and is "committed to descriptions of experiences, not explanations or analyses" (Moustakas, 1994, p. 58). It is a term used to encompass several different philosophical approaches to research. This study approaches phenomenology based upon the philosophy of Martin Heidegger, which is "based on an existential perspective which considers that an understanding of the person cannot occur in isolation from the person's world." (Walters, 1995, p.792). Heidegger argued that every person has their own world, as defined by their meaningful relationships, practices and language, and cultural context and thus, a persons' individual reality is

unique and this reality forms the context in which they can be understood (Burns & Grove, 2001).

Walters (1995) goes on to explain that Heideggarian philosophy is existential in nature for it explores “knowledge embedded in our everyday activities” (p. 795) and thus a person cannot be understood unless you can understand their worldview. This philosophy determines the structure of the interview process, and also outlines the responsibility that a researcher has regarding the understanding of their own subjectivity to the research topic.

Wimpenny and Gass (2000) explained that the interview was the predominant method of data collection in phenomenological studies, with the condition that the interviewer remain centred on the experience of the participants. They also describe the need for some form of structure to guide the interview. Further to this Lowes and Prowse (2001) caution that the interview questions should be open – ended and that preconceptions of the interviewer are identified through reflective practices during the research process, to ensure transparency of data.

Heideggarian phenomenology was chosen for this study because of its holistic perspective towards the relationships that exist in data collection. It understood the importance of the relationship between the interviewer and the interviewee in the collection of data and it has particular relevance to this setting for it mirrors the relationship that exists between the nurse and the client in the home hospice setting. It also reflects the understanding that the nurse cannot fully understand the issues of the client unless they attempt to understand the client themselves, and this occurs through the relationship between the two.

Not only does Heideggarian phenomenology reflect the concepts within the framework of this study, but it also guides the process and attitudes in which the study is conducted. A brief section follows describing the difference between Husserlian (the most common form of phenomenology) and Heideggarian (chosen for this study) processes.

Variation in Phenomenological process

The most commonly cited “phenomenological process” is that based upon Husserlian philosophy (a philosophy, based upon scientific principles, which regards man’s relationship to the world in terms of objects). It is a four-step process (bracketing, intuiting, data analysis and descriptive), which leads to understanding of the data.

One major difference between Husserlian phenomenology and Heideggerian phenomenology is the concept of “bracketing” out preconceived beliefs about the topic under study. Heideggerian phenomenological researchers acknowledge “that they can only interpret something according to their own beliefs, experiences and preconceptions” (Lowes & Prowse, 2001, p. 474) and also that data generated by the interview is a “co-creation between the researcher and the researched and not just the interpretation of the researcher” (Wimpenny & Gass, 2000, p.1487).

As mentioned above, the phenomenological methodology chosen for this study was that based on the Heideggerian philosophy. Not only was it conceptually based in the literature review, it also allowed the concepts found in the literature review to be introduced by the researcher without affecting the rigour of the study. It differs widely from Husserlian phenomenology in this respect.

In conclusion, Heideggerian philosophy was a fitting philosophical perspective for this study because of it’s holistic outlook, it’s acceptance of all members involved as contributing to the data, and it’s flexibility in enabling new concepts to be introduced to aid data collection. By providing an opportunity to explore issues identified by other sources, data on a wider range of emerging themes could be obtained, thus adding to the richness of the data collected.

Research Setting

The participants for this study were recruited from the Silver Chain Hospice Care Service (SCHCS). This service employed approximately 100 registered nurses and provides care 24-hour care to approximately 500 clients' with life limiting illnesses and their families, at any one time. The SCHCS is divided into three geographic locations that encompass the 1.5 million people living in the metropolitan area of Perth, Western Australia. This service provider was chosen, as it was the only organisation that employed home hospice care nurses, on a 24-hour basis, for palliative clients' and their families in the Perth Metropolitan region.

Research Sample

To obtain as much richness from the data as possible, and considering the small size of the research group, purposive sampling was used to select informants who met the inclusion criteria for this research. Burns and Grove (2001) explained that purposive sampling involved the researcher selecting subjects with certain characteristics who might be expected to be typical of the phenomenon under investigation and to be information rich sources of data. Because of the scope of the research problem, and to facilitate an in depth exploration, a provisional sample size of eight participants was expected to be drawn from the palliative care nursing population working in the home hospice setting with the inclusion criteria for participation being a minimum of Registered Nurse status (Level 1 & 2), and currently providing palliative care, in the home hospice setting.

Through a purposive sampling approach, participants would represent the range of characteristics currently existing within the population of home hospice based palliative nurses. These included dimensional issues such as gender, age, length of time in current home hospice setting, level of experience prior to home hospice role, geographical location and varying shift times (i.e. day shift or evening shift). It was hoped by purposive sampling, a representation of the all aspects would be included in this study.

Negotiating access

Ethics approval for the study was obtained from the Human Research Ethics Committee at Edith Cowan University as the supporting educational institution for this research (Appendix II). Approval was also sought and obtained from the Research Committee at Silver Chain Nursing Association Services to conduct the study using their personnel (Appendix III).

After ethical approval was received from both ethical committees, recruitment for the study began. Clinical Nurse Coordinators were contacted and asked whether they were willing to assist recruitment by distributing an information flyer briefly outlining the details of the study to the home hospice nurses in their respective areas (a copy of this flyer can be found in Appendix IV). Respondents were encouraged to reply to the researcher whereby more information regarding the research was provided.

If, after discussion with the researcher, respondents were willing to take part in the interview, arrangements were made for the interviews to occur. Due to time constraints and geographical isolation, several respondents were interviewed over the telephone. An information letter (Appendix V) was sent out to these participants, with a consent document (Appendix VI) for the respondent to sign and a brief demographic questionnaire (Appendix VII) for them to complete and return via an included stamped, self addressed envelope provided by the researcher.

A copy of this same information letter, consent document and demographic questionnaire was also provided to the respondents who were interviewed in person. Once informed consent was received by the researcher (in the form of a signed consent document), the interview was then conducted.

Data collection and protocol

Interview guide

A semi-structured interview format, based upon the literature review, was used to gather information regarding the perceptions that palliative care nurses working in the home hospice setting have regarding their management of the psychosocial and spiritual issues experienced by their clients. All interviews began with the primary research question: "What are your perceptions of the management of the psychosocial and spiritual pain issues experienced by your clients?" This was followed by the clarification of the term psychosocial as being, "Not only psychological issues such as depression or anxiety, but rather how the changes in their [the clients] internal [psychological] environment affect their interactions with the outside world."

This opening statement served as a framework for the remainder of the interview, but allowed the respondent to explore the issues, as they perceived them. The interview was loosely structured in two parts. The initial part of the interview allowed the respondents the opportunity to describe, with minimal interviewer interruption, their own perceptions of psychosocial and spiritual pain, what they thought their role was in the management of these issues, and general resources used for management. This was designed to serve two purposes. Firstly, it gave the participants opportunity to reflect on the core concepts of psychosocial and spiritual pain and secondly, it served to establish rapport with the interviewer.

The questions in the second part of the interview were structured to allow further exploration of the nurses' perception of existing management techniques, influencing factors and limitations to their current management as well as to offer opportunity to suggest improvements, based upon their reflection of these issues.

The conclusion of the interview consisted of two questions designed to allow the participant resolution of reflection on these topics. The first question asked the participant to rate their psychosocial and spiritual pain management as opposed to their physical pain management. This was an artificial device designed to allow the participant to link one kind of management with another. The final question asked the

participants what advice they would give to a new nurse in the area. This was done to succinctly identify nurse's perceptions of key issues in the management of psychosocial and spiritual pain in the home hospice setting.

This interview format was pre-tested with a palliative care nurse working in an in-patient hospice setting as well as an experienced vocational interviewer (from a non-nursing background). It was the feedback from these pre-test interviews that was reflected in the interview structure and recommendations regarding interview technique and clarification of language and terms used.

The demographic data tool (Appendix VII) was utilised to collect necessary information to determine the extent to which the sample achieved was representative of the range of variable deemed to be relevant in the purposive sampling approach.

The interviews for this study were conducted over a three-week period in late September and early October 2005 with data analysis conducted concurrently.

Data Analysis Plan

Demographic information obtained in this study, was analysed to describe the profile of the sample. The results of the demographic analysis can be found in the beginning of the Findings chapter of this report.

Qualitative analysis of the recorded interviews commenced immediately after the verbatim transcription to paper of each interview and was guided by the following steps, as outlined by Colaizzi (1978).

1. Read the transcripts several times.

Each transcript was initially read in one sitting immediately after transcription. It was then put down for several hours and then re-read, again in a single sitting.

2. Extract significant phrases or statements.

Once the transcripts had been read several times, they were read again, but this time significant phrases and statements were highlighted.

3. Formulate meanings from statements and validate with another researcher.

The highlighted statements and phrases were then assigned contextual meanings.

4. Cluster the formulated meanings into themes and refer themes back to transcripts for verification.

Examples of themes are, "nurses' role", "management strategies", etc.

5. Describe the phenomenon by integrating statements, meanings and themes and validate with another researcher.

Analysis of this study was conducted by the researcher, with validation of significant phrases and statements, meanings and themes being performed by his supervisor. Provisional copies of the findings of the themes were returned to selected participants for final validation. Once final validation was received, these findings were included as Chapter 5: Findings in this report.

Ethical Considerations

This study was conducted in accordance with ethical guidelines published by Edith Cowan University. Ethics approval for the study was obtained from the Human Research Ethics Committee at Edith Cowan University as the supporting educational institution for this research. Approval was also obtained from the Research Committee at Silver Chain Nursing Association to conduct the study.

Informed consent was obtained from all participants in this study. All participants were provided with an Information Letter that outlined the details of the study (Appendix V). Confidentiality of respondents was assured and that the information obtained from this study would only be used for the purposes of this research and all data obtained would be de-identified. Copies of the transcripts were stored electronically and encoded on a password protected computer and the audio-taped recordings of the interviews and the consent forms were stored separately, and locked in the researchers' office in the Postgraduate Room at ECU, Churchlands campus.

The researcher was the only person who knew the identity of the participants in this study, and only the researcher and his supervisor had access to the complete de-identified transcripts, as per analysis guidelines. Tapes were stored safely and will continue to remain securely stored separately from all other identifying information for 5 years (as per NH&MRC standards) in the researchers office, after which time, they will be destroyed.

Because of the potential of emotional issues to arise from the interviews, details were provided of Silver Chains Employee Assistance Program, and this resource was made available in each interview.

Rigor and Trustworthiness

Rigor in qualitative research “is associated with openness, scrupulous adherence to a philosophical perspective, thoroughness in collecting data, and consideration of all the data ...” (Burns & Grove, 2001, p. 64). As mentioned previously, this study was conducted following Heideggerian phenomenology and by doing so, acknowledged the presence of the researcher in the area under study.

This philosophical perspective allowed the researcher to guide the semi-structured interview by structuring the interview, using open questions, around pre-identified concepts. Thoroughness of data collection was ensured by allowing the participants to explore and describe the issues without interruption by the interviewer and all data obtained was analysed to obtain the findings.

Trustworthiness, in qualitative research, deals with credibility, dependability, confirmability and transferability (Lincoln & Guba, 1985). Credibility, in this study, was ensured via triangulation. This was achieved by using different participants in an interview setting that was similar for all participants. This is known as “Data Source Triangulation”. Another test of credibility of data is feedback from external checks such as member checks. This was achieved by providing copies of tentative findings to several of the participants for review and feedback.

Dependability and confirmability was built into this study by the choice of data analysis plan. Peer review was integral in the analysis stage, and this measure ensured both the dependability of the data as well as the confirmability.

Transferability implies whether the findings of the data can be applied to another research setting. This occurs by providing the consumers with enough descriptive data in the presentation of the findings (in this instance, through direct quotes), so that they can draw their own conclusions.

Limitations

This sample size of this study was small, and a purposive approach to sampling was used to obtain rich and in-depth data. Only a limited number of nurses were required to ensure that a purposive sample would be achieved.

Although the conceptual framework was selected to represent broad issues such as psychosocial pain, spiritual pain, nursing perceptions, nurse – client relationship and the like, the findings may be able to be transferable to other palliative care settings where these issues are considered as well. However, the nature of the setting itself can influence the data obtained and thus the findings from this study may be limited to the area of study itself. Due to the nature of the home hospice setting, and the autonomy afforded to nurses that work in that area, perceptions expressed by the participants may not be readily transportable to other areas.

This study examined nurses' perceptions at a specific moment in time and in a particular setting. The perceptions that nurses' held were a product of their knowledge, training and experience, as well as being defined by the social context in which they worked. All of these things can change, and thus the findings in this study, are only true in the fact that they describe the perceptions of the nurses interviewed, at this moment in time, and in this particular setting.

A cited limitation to any form of self – report method of data collection is that described by Polit and Hungler (1997), which describes the concept that participants may not act and feel the way they report they do. This is a universal limitation with self – report studies and thus needs to be described here. This limitation was minimised in this study by the interviews being conducted in a non-threatening setting and the structure of the interview being designed to allow rapport to be established between the participant and the interviewer (in accordance with the philosophical perspective).

Summary

This study used a qualitative methodology, based on phenomenology, to describe the perceptions that palliative care nurses, working in the home hospice setting, have regarding their management of psychosocial and spiritual pain issues of their clients. The role of the palliative care nurse, the factors that influence the management of these issues and the recommendations made by these nurses on improvement of their management have been described.

Upon receipt of ethical approval from both Edith Cowan University and Silver Chain Ethics committee, a purposive sample of six Registered Nurses (Level 1 and 2) were recruited from the three separate bases operated by Silver Chain. Once informed consent was obtained from the participants, data was collected through six recorded, semi – structured interviews, between the researcher and the respondent. Data was analysed according to Colaizzi's algorithm with the data being translated through three levels of coding to identify permeating themes and concepts relating to the perceptions of palliative care nurses of their management of psychosocial and spiritual pain in the home hospice setting.

The findings of this study are outlined in the next chapter. Direct quotes from the interview transcripts are used to illustrate emerging concepts. For clarity purposes, editing of repetitive speech or irrelevant words has been performed and indicated by three dots "...". All authors clarification notes are in square brackets [such as this]. All quotes are removed from the main body of text, and are formatted and italicised to clarify the distinction between the two.

CHAPTER 5

FINDINGS

This chapter represents the findings of the study by describing the demographic nature of the participants and then by providing an in-depth description of the findings of the qualitative analysis.

Participant Characteristics

The aim of this study was to describe the perceptions and experiences of a purposive sample of palliative care nurses, working in the home hospice setting. The parameters for the purposive sample were age, gender, length of palliative nursing experience, and usual shift time.

It was stated in the previous chapter that a sample size of eight Registered Nurses would be interviewed to ensure that saturation of data was achieved and that a purposive sample could be represented. The purposive parameters for this study were fulfilled within six interviews and saturation of data had also occurred by this stage.

Age

Of the six nurses interviewed, the youngest was within the age group of 30 to 39 years old. The oldest participant was over 60 years with the remaining four participants split equally within the 40 to 49 and 50 to 59 age groups.

Gender

Five of the six nurses were female, with one nurse being male.

Palliative Care Experience

The shortest period of time cited for palliative care experience was of 3 years whereas the longest duration of palliative care experience was 20 years. Half of the nurses interviewed had more than 10 years of experience in palliative care, with two of these nurses employed by Silver Chain for their entire palliative care nursing career.

Prior Nursing Experience

All of the nurses interviewed for this study had prior nursing experience before joining Silver Chain. Several had prior palliative care experience (inpatient hospice based) and others had prior community experience. Most of the nurses had performed several roles before starting with Silver Chain in various settings.

Nursing Qualifications

All of the nurses interviewed for this study were originally hospital trained. One nurse had also obtained university qualifications.

The usual shift time worked

This was included as a purposive parameter of the study to allow nurses working at various times to describe their perceptions of the issues arising from the management of their clients' psychosocial and spiritual pain. Five of the nurses interviewed currently worked during the day. One of these five had recently finished night shift and gave perspective on issues arising at this time. One nurse currently worked during the evening.

Four of the six nurses worked on a part time basis for Silver Chain, whereas the other two were employed full time.

Qualitative analysis of interviews

Interviews were conducted to describe and explore the perceptions of home hospice based, palliative care nurses in regards to the management of the psychosocial and spiritual pain experienced by their clients. Phenomenological analysis of the interview transcripts identified four major themes relating to these perceptions. These were the nurses' perceptions of psychosocial and spiritual issues, their role in the management of these issues, factors that influenced the management of these issues (and the limitations of existing management), and nurses reflections of their approach to care (including suggestions for improvement and advice for successful management). While these findings are presented as four distinct themes, linking issues between these themes do exist.

Theme 1: Perceptions of psychosocial and spiritual issues

The first theme identified was existing perceptions of psychosocial and spiritual issues that nurses working in the home hospice setting possessed. This theme began by describing the perceptions that nurses have of what constitutes psychosocial and spiritual issues and then went on to discuss how these issues manifest themselves in the clients' and their families. This first theme also illustrated the differences that existed amongst nurses concerning spiritual issues, which bore a large impact of the management style that nurses chose in dealing with these issues in the home hospice setting.

Nurses define psychosocial and spiritual issues

The research question for this study asked home hospice based, palliative care nurses what their perceptions were of the management of psychosocial and spiritual pain experience by their clients. The question was structured in such a way that nurses needed to reflect upon the concept of psychosocial and spiritual issues, and it allowed them to define their management from within this context. This structure was also built into the interviews so as to allow initial reflection upon these issues, before specific management options were discussed.

Psychosocial and spiritual pain exists at diagnosis

After psychosocial and spiritual issues were defined within the context of the setting, the incidence of psychosocial and spiritual pain was identified. While psychosocial and spiritual pain can occur at any time throughout a persons' life, diagnosis of a potentially terminal disease often leads to psychosocial and/or spiritual pain. The following extract describes how one nurse perceived this fact:

I think it's [psychosocial and spiritual pain] something that every patient has, but not many people find it easy to talk about it, or even the patient, for that matter. You know, that's what I feel. a) they've got the diagnosis, b) they've got the treatment and how they are going to manage at home and the rest of their family and everybody else around them, and c) they've got this inner feeling, be it an understanding, or a fear. (Nurse 6)

This was also noted by another nurse who went on to discuss how a client verbalised the pain that they had experienced on diagnosis:

I actually go and see people that have been newly diagnosed, and the first thing they say when they've been told they've got cancer is not, "Oh, I will get pain", it's just, "My God, I've got cancer". I see it's spiritual and psychological pain that they are feeling first, before they ever even think about anything else. They're thinking about, "How will I tell my family? How will they react to it? How will I react to it? ... Will I see this ones birthday, will I do this?" Um, you know, "oh, I'm going to die". I see that those things, to me, usually come into play, in my experience. (Nurse 3)

Of course, many of the clients' who were undergoing home hospice treatment had been diagnosed for some time, and have had opportunity to address issues and so had different needs:

We have a percentage of people ... who've had breast cancer or prostate cancer, and who have been diagnosed for a long time. Gone through a lot of treatment, gone of through a lot of peaks and troughs. Um, and then we sort of get them at the end and there are, there's a lot of issues that they've already run through. (Nurse 3)

Clients' introduced to management options on admission

Regardless of how long the patient had to deal with their psychosocial and spiritual issues prior to beginning the hospice treatment, Silver Chain nurses introduced management options in the form of counsellors and chaplains as part of the admission process. A typical introduction to this process is described below:

I try to introduce the concept, when we do the admission, that we have access to chaplain, social worker, counsellor to begin with and I do try to gently remind the people of that, as we go through, as appropriate. (Nurse 2)

Nursing assessment of the clients' psychosocial and spiritual needs also began at assessment, as described by one nurse here:

A lot of people think, start thinking about themselves when they are diagnosed and start asking questions. So I try and see where the clients' are at with my introduction to various, open-ended questions, to try and see where they are at, so I can give them support. (Nurse 6)

Importance of psychosocial and spiritual assessment

While the literature review reflects a paucity of nursing related literature in this area, there can be no argument as to the importance of the psychosocial and spiritual pain management of the client. By adopting a holistic approach to nursing, an imbalance in one aspect of the clients' being must lead to disturbances in other areas. One nurse considered the impact of psychosocial and spiritual pain issues on physical issues:

All physical symptoms are affected by psychosocial things anyway. Spiritual, I mean people who are in spiritual pain feel more physical pain and um, you know sometimes, you have to address the psychosocial and spiritual side to address the physical problems as well. (Nurse 3)

Owing to the nature of the palliative care setting, psychosocial and spiritual issues took on a greater importance for the client and thus assessment of these issues needed to have a greater importance as well:

Palliative care is an area where psychosocial and spiritual needs are really important. You know, all those end of life issues. (Nurse 3)

Nurses perceptions of Silver Chains priorities

It is interesting to note, at this point, that even though the nurses interviewed considered the value of psychosocial and spiritual assessment as quite high, they did not believe that this perception extended to the Silver Chain management. This topic will be discussed under another theme, but it is included here to illustrate an aspect of the nurses' perceptions of psychosocial and spiritual issues within the home hospice environment:

Has Mrs Smith got inner harmony? Is that just as important as Mr Smiths back pain is? I don't think it's rated as highly as the physical, and I think it should be. I think it's, "oh, well, let's do the psychosocial at the bottom, if we've got time." I don't think it's prioritised enough. (Nurse 2)

Different people in different ways

Because psychosocial and spiritual pain was experienced internally, and thus experienced uniquely, it was no surprise to find that the manifestation of this pain was unique as well. This was illustrated by the common perception of nurses that different people respond to psychosocial and spiritual pain in different ways:

Different people deal with it in different ways and that's huge, you know, that's what we've got to say first off, because like when we tell the clients' this there is no normal. (Nurse 1)

Owing to these differences amongst clients', nurses needed to remain open to their clients' so that they can fulfill their role effectively:

Everybody is different. You can't treat everybody the same. You can't go in with your attitude and your opinion, um, sort of locked in. (Nurse 5)

This difference in views of psychosocial and spiritual issues not only related to the clients' in the home hospice setting, but also the nurses that looked after them. An example of this is shown in the following excerpt, where the nurse describes psychosocial and spiritual pain in terms of lifestyle:

My philosophy as a general rule, is that you tend to die the way you've lived and if you've had a very frantic, controlling sort of life, and you've been involved with everything, sometimes what happens is that it's difficult to try and control death like you've tried to control life. (Nurse 4)

This concept was developed later on in the interview when this nurse went on to describe manifestations of psychosocial and spiritual pain in the following way:

People senses, I think, from a spiritual point of view, in their days, or the last weeks or months, become very heightened, you know. Some people close themselves off in denial and that's another big psychosocial issue. But others who, and I think what I was saying at the very beginning was that, my personal opinion, is that you tend to die the way you've lived. And if you've been open, honest, spiritual yourself, then on the whole you tend to have a good death. If you've been somebody who's been maybe quite hard on yourself and your family, etc, you tend to [have] a lot more psychosocial, spiritual problems like terminal restlessness and anger and denial. All those things will happen to a patient anyway, but why is it that somebody you go to see, and they're totally accepting and others don't even want you to mention the word cancer without them getting upset and angry? (Nurse 4)

While consideration of the lifestyle of the client allows an interpretation of the psychosocial and spiritual pain that they may be feeling, looking at the environmental issues that they currently have also allows the nurse to understand the manifestation that a client may have:

She's a bit depressed about that, although I don't like to use that word with her because a lot of our clients, you find people say are depressed when in fact they're sad. It's a sadness rather than a depression and, you know, you've got to be with them and sort of say, you know, they're allowed to be sad because what's happening in their life is pretty bloody sad, you know what I mean? (Nurse 1)

Yet another approach utilised by nurses was to view the relationship between the client and family as a means of identifying extant issues, and offering management based upon these issues:

It's like bringing up kids. They are all different and, yeah, and there [are] basic guidelines, but at the end of the day and if we can help them, I mean we are looking at them dying in peace, because the carer has got that memory ...

If they can ... see a happy time or a comfortable time in their own minds, yeah, it makes a big difference. (Nurse 5)

Regardless of the nature of the differences between people, the communication skills employed by the nurse were regarded as important in determining the management strategies utilised for the client:

How I communicate to each of them [my patients] is probably different, because all their needs are different and they are different types of people. (Nurse 5)

Specific issues: Psychosocial

Even though the research question made no distinction between psychosocial and spiritual pain, they were two completely different areas with different manifestations of pain. This section deals with specific perceptions identified relating to psychosocial issues.

Psychosocial pain leads to changes in clients' relationships

Psychosocial pain, by its very nature, manifested in such a way as to have an influence on the relationships that the client had with those around them. An example of such an influence was described by one nurse concerning the changed relationship that a parent had with their child:

You feel it's really bad that's she's got to ask this son to take her to the bank or if she needs pads and stuff like that but she's going, "I can't ask my son to get my pads." Because that's not the kind of relationship they've ever had. She was the strong mother who, brought these kids up and looked after the house and studied and worked and did everything. (Nurse 1)

Anger as a common expression of psychosocial pain

An interesting finding to come from this study concerned that of anger being an expression of psychosocial and spiritual pain. It has been included in this section dealing with perceptions of psychosocial and spiritual pain, for it provides another example of the manifestation of psychosocial pain. In the following excerpt, a nurse describes the reaction of a client on being told that their condition was deteriorating:

You think, "What could I have done there, when you told me to tell you the truth. Do you want me to be truthful?"

"I do."

"Well actually, I think you're deteriorating and things aren't going well and you should get things in order. And you've got a daughter who is in England and I think I would tell her to come back if she wants to spend some time with you."

"Are you saying I'm dying?"

"Well, I think that you're deteriorating and I think that yeah, you know I think ... " So then the anger turns onto you and that's really hard to deal with when they do that [because] it was like, "Bloody hell, I thought they wanted me to tell them. What did I do wrong? Did I do something wrong?" (Nurse 1)

Psychosocial pain often arose from frustration over one aspect of the clients' life or another. One example of this frustration leading to anger in the client is dealt with in the next excerpt, where a client's frustration of the medical profession is described:

A lot of people feel they've got nowhere else to go 'cos the medicine has failed them. You know. Unfortunately, medicine does set itself up as being very much omnipotent and people feel very let down by that. And sometimes quite a lot of anger from that as well. (Nurse 2)

There are times when anger was just a part of the environment, and thus management options concerning management relied upon fundamental assessment techniques such as looking and listening:

Anger has really come up in what I'm seeing in terms of, for whatever reason. I don't delve into it, I listen and I pick up why the situation I'm going into with a dysfunctional family, or dysfunctional household, why it's like that, and I just find there's a lot of anger in peoples lives, for whatever reason. (Nurse 6)

Anger, as relating to the client within the family context, will be discussed as a management factor in detail later in this report, but it is mentioned here because not only was a management factor for the client, but also an issue that existed for the family as well:

What you can do is, refer the other daughter to the counselor, and say, "Maybe this would be really good for you to talk this out with somebody who's away from this situation, otherwise you're going to get angry and

you're going to get angry with mum and dad and the other sibling and then afterwards you're going to feel really bad." (Nurse 1)

Impact of psychosocial issues on carers

Even though it was the changes occurring within the clients' that provoked the development of psychosocial issues, it is the carers that also experience the most profound psychosocial pain. When considering psychosocial within the context of relationships, it was easy to understand why this was the case. This is alluded to in the following excerpt:

The counsellor, more the carer because the carer is the one feeling the strain and feeling confused and frightened of being on their own. So the chaplain more for the patient and the counsellor more for the carers, but after a few visits, it tends to sort of mingle. (Nurse 2)

Specific issues: spiritual.

Just as there were different perceptions and issues arising from the psychosocial domain, spiritual perceptions and issues were also identified as unique.

Variance in perceptions of spirituality

An interesting finding of the study was the varied perceptions of what constituted spirituality by both the clients, and the nurses themselves. A popular perception was that spirituality was synonymous with religion:

I actually think that some people don't have, they don't have an actual grasp of what..., of what spirituality is, and because I know that some nurses say, "Do you practice a religion?" then no, not spiritual. ... I think people do need um, they see spiritual equals religious, and I think a lot of nurses don't, but a lot do. (Nurse 3)

Spirituality, rather than being based on a belief system, has also been defined as anything that brings meaning to a persons' life. Thus, spirituality may not encompass a defined belief system, but rather as an approach to life. One nurse who

described the holistic management of their clients' as being spiritually based, reflected this sentiment:

Spiritual in the sense that we are always, ask our clients' if they want, if they are religious, whether they want a referral, but from a spiritual point of view, I think, these are clichés. You look as, from a holistic point of view, um, you relate to them. What I always tend to do, and I've always done this, I'm really interested in peoples backgrounds and what they've done, their families, and what they did in the war etc, and most people open up if you ask them, you know, where do they come from. What part of Australia? Or, what is their sort of ethnic origin. But spiritually, it's a hard question to answer really. (Nurse 4)

When encouraged to describe spirituality, some nurses found it to be difficult to verbalise. Even though they had their own beliefs and could conceptualise spirituality, the cognitive rationalisation required to verbalise this subject proved challenging:

I would also class spiritual to be the, you know, you show a degree of love to your patients and um, I think they sense that, as well, you know. (Nurse 4)

Even though nurses may have differed between their definitions of spirituality, they regarded a client's spiritual knowledge as being an important factor in coping with the situation that they were in:

If they understand spiritually what's happening to them, I think they cope much better. (Nurse 6)

Spiritual assessment and management difficult

Spiritual pain, due to its internal nature, can really only be properly assessed through an open dialogue with the nurse. Considering the difficulties that some nurses had in describing spirituality, it was easy to understand similar problems with clients. This problem was even more difficult when the clients' themselves don't recognise spiritual pain:

I think we have clients' who don't recognise spiritual pain either. Cos you've actually go to, you've got to know you've got a spiritual aspect to your life. To actually get a better understanding of this anyway. (Nurse 3)

Silver Chain, as mentioned earlier, has chaplains to whom clients' can be referred to if they need to discuss spiritual issues. This allows the nurses the opportunity to introduce spiritual issues through talking about the chaplain:

There is this question about the chaplain. I approach it by, "Do you have any religious connections or spirituality within yourself? How are you placed now?" (Nurse 6)

Spiritual crises

If spiritual assessment proves unsuccessful, and spiritual pain remains unresolved, it can lead to a spiritual crisis. There were a number of leading causes of spiritual crises, with fear being the cited as the primary one:

If there is a fear there, it becomes painful and I understand that there must be fear, and questions like, "Why me?" (Nurse 6)

A spiritual crisis need not be a bad thing. In fact, when crises occur, it may encourage the clients' to seek resolution of the spiritual pain that they feel. This point was illustrated in the next interview excerpt:

It tends to be at a later stage where, you know, the fear factor comes in, and they think back to maybe their school time where they were taught that, you know, that a lot of them would have been Catholics when they were kids and have grown out of it as adults, but then it's in there, you know, I really need to see the priest before I die because, do you know what I mean, and they haven't got one of their own. (Nurse 1)

Fear was not the only precipitating factor for spiritual crises. A sense of a loss of hope could also develop into a spiritual crisis for the client:

A lot of people, a big, maybe not a majority, but a big chunk of people, even if they are on palliative treatment, they actually see hope in palliative treatment. They've sort of blocked out the palliative bit. And I think often when ... treatments aren't working, then there is a peak there [spiritual pain]. Um, you know, that sort of, when hope goes. (Nurse 3)

Management when client was ready (timeliness)

The spiritual crises mentioned above provide an extreme illustration that spiritual issues needed to be addressed when the client was ready. This timeliness of management extends all throughout the spectrum of spiritual pain:

We don't want to rub it in their face all the time, we don't want to keep saying, "Do you want the chaplain? Do you want the chaplain?" Do you know what I mean? But we also want them to know that the chaplain is there, the counselors are there, you only have to tell us. (Nurse 1)

Not only does this concept of timeliness influence the nursing perception of when intervention should be offered, it also encompasses the concept of giving the client time to act upon recommendations:

Quite often, spiritually, at the beginning, the patient might be a little bit unsure and I can see, and I will then maybe class it as, I'm offering you the opportunity to have our chaplain visit you. "Are you saying, not at the moment" and they'll say, "yes, not at the moment" and then later on, I'll see whether nurses are saying, "she's asked to see the chaplain" So, it's sometime the type of their, where they're at in their disease as when we are asking whether the need is there now or later. (Nurse 1)

Spiritual pain explored more when physical symptoms controlled

As well as timeliness, physical symptom management was also considered advantageous in encouraging clients' to address spiritual pain issues that they may be experiencing:

What they are coping with, more than anything else, and if their symptoms are controlled, even more their spirituality and what is happening to them comes up to the fore and sometimes they do want to talk about it. (Nurse 6)

Perception that clients' will talk about spiritual issues when ready

Having described the differences in perceptions of spirituality and the difficulties in assessment and management, it is easy to understand why spiritual pain occurs in clients. Another perception of spiritual pain, and one that also adds to the difficulty in assessment is the perception that clients' will talk about spiritual issues when they are ready to:

I think it's an area they feel that, if people want to talk about it, if clients' want to talk about it, they will. (Nurse 3)

The role perception (discussed in the next theme) also limits the amount of assessment that a nurse will do for spiritual pain:

Most people are happy to talk about their spiritual needs. I don't see it as a huge thing. If it is a big thing, they usually talk about it. And so you can see it's a big thing and we do, I mean, when we first go in, we sort of ask what their needs are. I mean, cos it's very big, it's very important side of it, I just don't see me as a nurse, having a huge role there because um, you know, unless I'm on the same wavelength with them spiritually. (Nurse 5)

Psychosocial and spiritual pain towards the end, and beyond

Having started this discussion by describing the presence of psychosocial and spiritual pain at diagnosis, and having shown that it exists at various times throughout palliation, it is now timely to show the perceptions of psychosocial and spiritual pain in the end stages of the clients' illness:

I feel that the psychosocial issues, people often lose control near the end and need a lot of support. (Nurse 4)

The death of the client does not mark the end of these issues though, for the clients' family suffers psychosocial pain after the client has gone:

I called them aside, and I said, "Where do you think your dad's at?" and they told me and I said, "Had you thought about the funeral?" "No, nobody has talked to us about that." You see, until that time, it wasn't, it wasn't appropriate to talk about the funeral. It's not until you get the symptoms

controlled and you can see that what is going to happen, so I had time and I was able to say to them everything about what we do at the time of the death, what the decisions they have to make, about when to call the funeral director, which funeral director, what we do, the death certificate. That the doctors not called out, that the nurse follows you up for four months. And they went away as if I'd given them a million dollars (Nurse 6)

Summary of Theme 1

The first theme identified by phenomenological analysis described the nurses' perceptions of psychosocial and spiritual issues, relating to their clients' and within the home hospice setting. It was shown that psychosocial and spiritual issues can arise at any time throughout palliation, that different people have different interpretations of these issues, and that these interpretations determine perceptions of psychosocial and spiritual pain in both the nurses, and the clients.

Theme 2: Nurses Perception of Role.

This second major theme deals with the nurses' perception of their role in the management of psychosocial and spiritual pain of their clients. Having looked at nurses' perceptions of psychosocial and spiritual issues under the previous theme, a discussion of their perceptions of their role is the next step. This theme is divided into three categories.

The first category describes how nurses perceive their primary role in the management of psychosocial and spiritual pain as being one of assessment. The next two categories describe different nursing management strategies of the psychosocial and spiritual pain experienced by their clients. It begins by describing the management of the nurse as being a part of a nurse – client relationship and deals with issues regarding primary nursing. The theme concludes with a category describing the perspective of nursing management as part a team, and thus, talks about how the team was utilised in the management of these issues.

Assessment as nurses' primary role.

A fundamental aspect of nursing management, regardless of what setting the nurse is in, is that of assessment. This is true in a hyper acute hospital setting (such as emergency), through to the ward setting and into the community setting, which was where this study was conducted. To effectively implement an intervention, a needs assessment needs to be carried out. This also holds true for management of psychosocial and spiritual needs that a client may experience in the community setting. The nurses interviewed in this study split the management of the clients' psychosocial and spiritual needs broadly into assessment and intervention, with the main role of the nurses being that of assessment:

I see the role as an assessment role and not so much as a role to manage psychosocial issues. (Nurse 3)

Given that the perceived role of the nurse in this setting was that of assessment, what does the nurse then do with the information obtained? At the very

minimum, the nurse then referred the client on to somebody who could then manage his or her psychosocial or spiritual pain:

I can certainly find out what their needs are and refer them to the right person, you know, say, "Do you need to see someone like this?" (Nurse 5)

Spiritual management, as described previously, can sometimes be quite difficult for the nurse to perform. By assessing that a spiritual problem exists for the client and then referring on to somebody (such as the Silver Chain chaplain), a nurse can enable an effective intervention:

I think that it is an area that I would be very comfortable talking about cos it's an area that's very important to me. I'd, I think, I'd be very, I'd be really talking to the clients' and finding out whom they would be comfortable talking to. And, that would, should be the person they should talk to. If, yeah, that would. And if they didn't know where to go, then I guess, if somebody actually identified with a certain religion, then and they didn't know who'd they go and talk to, then I guess I would be directing them in that way, but if they were happy just, you know, to talk to somebody, to anybody, then depending where they lived and who the chaplain was, I would be happy to get the Silver Chain chaplain. (Nurse 3)

Assessment on an ongoing basis

Because psychosocial and spiritual pain can occur at any time for the client, (or the family), assessment needs to be conducted on an ongoing basis. This ensures that problems are identified early, and that early intervention can occur:

So that's up to me, as the next member of the team coming in to continue on and listening to what she is saying and then introducing what things we can do. (Nurse 6)

Assessment not only identified existing problems for the client but also played an important part of minimising future psychosocial and spiritual:

What we plan with our visits is how is this patient going to get through to the next day. What are the things that are likely to happen and you say to them, or say to them, I think staff needs to come in here. Now, night visits, for some families is intrusive, and to other families, "He must be dying because the night staff are coming in", so, you know, this sort of thing. Support and also, you've got to look at what staff have got what on, all those sort of things so,

my plan is how this family is going to stay together and get through to the next day. And think ahead, and know that day staff, they are not going to get much in before ten am. (Nurse 6)

Based upon both verbal and non-verbal cues.

As mentioned previously, it was often hard for a client to verbalise their spiritual pain, and thus the assessment undertaken by the nurse needed to consider both the verbal and non – verbal cues provided by the client. While the nurse – client relationship in management is described in the next section, the relationship between the nurse and the client also aids in assessment, for if the nurse knows the client well, then any changes, can act as indicators of psychosocial or spiritual pain:

... try to sort of see from their home, kind of what their values are, like sort of, observation in that way. And to see how they are with their non-verbals. The way they dress, the way they present themselves. Try to sort of look at all of that as well. And just, yeah, to try and generally, how interested, how engaged are they in the world. How engaged are they about their condition. (Nurse 2)

Nursing Attributes for Successful Assessment

Having established that assessment was the fundamental role of the nurse in the management of psychosocial and spiritual pain, this section describes the attributes that a nurse needs to bring to assessment to enable successful assessment of their clients.

Holistic approach

This first nursing attribute that nurses needed to bring to assessment was the attitudinal aspect of the holistic approach. This holistic approach was a fundamental concept in palliative care, with special relevance to the home hospice palliative care setting itself. The nature of the setting lends itself to a holistic interpretation, for the environment itself allows holistic care:

I think that one of the big issues for me in the home situation is that you are in a home, you see the whole situation and it's easier to identify a psychological issue for starters. (Nurse 5)

This approach was not only a fundamental part of home hospice based palliative care; it was also an important attribute to aid in the assessment as a whole. Nurses in this study identified that the client needed to be assessed holistically, for successful intervention to occur:

So I think you've just got to look at the big picture, look at why they are, why psychologically they are changing because of what's going on with them, and deal with each little bit as it happens and as it is. (Nurse 1)

The holistic approach to nursing does not just end with assessment. This nurse describes the concept of "complete care" in terms interpersonal relationships:

It's much easier to give complete care to someone you know well and that's why ... I like to go into the home, cos you're seeing the whole situation. (Nurse 5)

Knowledge

The next key component of assessment falls under the category of knowledge. Knowledge, in this sense, encompasses all areas of knowledge that the nurse possesses:

Because I think I've had the knowledge and the experience I feel very comfortable and because I know how much it makes a difference in families. That is the reason I do this type of nursing. Because I can see families, because of knowledge and ways of demonstrating to them how to manage somebody at home, and empowering families with that, you get the satisfaction doing that. (Nurse 6)

Experience

Past experience was also an important aspect of assessment and management of psychosocial and spiritual pain:

I don't think anybody taught me to do that. I think common sense taught me to do that. (Nurse 1)

Some nurses believed that it was this experience that gave them the necessary assessment skills rather than the training that they had received:

I think it's probably my life experience that certainly has equipped me to be comfortable to talk it about, about the areas. Certainly not training that's done that. (Nurse 3)

Communication skills

A fundamental part of the assessment was attributed to communication skills that the nurses had such as acknowledgement of the clients' situation and being able to communicate this to the client:

Acknowledge the whole thing and, you know, it's fine that you feel this way. Of course, it's all right and, and the fact that they are telling you this, you know, is a big thing in itself. (Nurse 1)

This acknowledgement pertained not only to the situation that the client was in, but also to client holistically:

Acknowledging that they are doing well. Acknowledging the fact that the problem that they are having at the moment, where their thinking can help, we will try and get over that and that you'll be, it will be at an acceptable level, hoping that you can say to them, which is what we want. And that is giving her assurance that we are not just going to wipe her off because, her alternative way of doing things is not acceptable to us. (Nurse 6)

Tact

Not only were knowledge, experience, communication and the holistic approach regarded as important to the assessment of clients' suffering psychosocial and spiritual pain, but the manner in which the situations were handled was also regarded as important. For this reason, tact was regarded as an important assessment component when dealing with clients, and their families, in the home hospice setting. In the following instance, a nurse describes how tactfully they assess and then make recommendations in the home hospice setting:

Sometimes with the counselors we can say, the families, the stress that the families are under, the dynamics maybe that's going on in the family, maybe when we are out, maybe when the families are out in the kitchen and we are just with the client, maybe we see that, hmm, maybe they're getting a bit tetchy with me, then we might mention the counselor in the kitchen on the way out, you know. Have you thought anymore about the counselor, you know, because they are very good, they're used to these things, they brief counselors, you know, they could really help you and sometimes it just helps to have that person you've never met before, you'll never see again. You know they are

not making any judgments on you. You know, this is what the counselors are for. That sometimes sways them. (Nurse 1)

The tactful handling of assessment issues extends to the preservation of meaningful relationships with both the client and their family. Sometimes a tactful referral to an outside agent can remove the pressure from the nurse to choose sides. Thus, assessment and referral in this instance, helps to maintain a therapeutic relationship with all parties involved:

You don't want to criticise people. And you don't know what their relationship was before. You, know, just cos people stay together doesn't mean their happy in their marriage. And you don't know, he might have had affairs before, their might be other issues and that's why I think she's seeing the counsellor rather than me cos we can't take sides. (Nurse 2)

It needs to be remembered however, that even with the best assessment skills available, it is a difficult area of care, and nurses don't always get it right:

Trying to sort of be tactful without being judgmental. It's a very fine line and we don't always get it right. (Nurse 2)

Management in terms of nurse – client relationship

Depending upon their assessment, and their confidence in dealing with psychosocial and spiritual issues, nurses tended to manage in one of two ways. Nurses who felt confident in tackling these issues took the responsibility of managing the psychosocial and spiritual pain experienced by clients, themselves. This section describes the nursing management of clients' through the context of the nurse client relationship.

It has been shown that nurses perceive their primary role to be that of assessment, and that assessment was facilitated when key components came together, but perhaps the most important aspect of the assessment was the development of the relationship between the nurse and the client. Assessment became easier over time, once the nursing relationship was established:

It's easier for me than it is for others, because I have my own caseload so I have a chance to develop my relationship with my patients. (Nurse 2)

The relationship between the nurse and the client not only enabled assessment, but it also permitted nurses the opportunity to offer intervention, without repercussions:

As I try to get to know them, I try to judge it personally, how they are, and hopefully, I know them and develop that trusting relationship, I'm able to offer that without them feeling threatened and criticised. (Nurse 2)

Nurses that were comfortable in dealing with psychosocial and spiritual pain of their client approached management from a "helping" perspective. The following extract not only illustrates the relationship, but also another crucial factor in management, time:

I like to help them explore the issues more. I myself, being working in the evenings, do find that I have a bit more time. (Nurse 6)

For resolution of issues in any relationship, both parties need to understand what these issues actually are. Because of this, the ability to handle these issues depended upon the nurse, and their ability to accept these issues themselves:

When you're dealing with spiritual, psychosocial issues, it's also about you. You know, it's not just about the patient. It's about how you react to their spiritual pain. (Nurse 4)

Understanding of the issues was only the beginning. To effectively manage them, the intervention needed to be appropriate. One example of an appropriate intervention (to spiritual pain in this instance) is cited below:

Where you sort of give them a hug, or a stroke on the shoulder, etc. I think those sort of things are important spiritually cos then you can relate to each other as well. (Nurse 4)

Appropriate intervention not only included the suitability of the intervention to bring about resolution, but it also needed to be appropriate within the psychosocial or spiritual context in which they occurred. This is reflected in the following exemplar where a nurse described the way she/he managed after the death of a client:

I went back in and this women wasn't, she was like lying on top of him, crying and of course, we wanted to, you know, I wanted to wash him and I wanted to put him in clean pyjamas and take his pump off and straighten him out, but it wasn't appropriate. It wasn't appropriate to do that, and I think that psychosocially, you have to get head around that. (Nurse 1)

This appropriateness of intervention was determined by the nature of the relationship that the nurse had with the client. Because of this fact, assessment played an important role in management, and not only in ascertaining psychosocial and spiritual issues, but also in establishing rapport with the client:

So in approaching the actual subject with them, I'd start at the bottom and find out where they're at and then try and support the level wherever they're at. (Nurse 6)

Primary nursing of these clients in the home hospice setting had an advantage in that it allowed positive relationships to develop between the nurse, the client,

and the carer. Through this relationship, assessment was improved, and interventions were based on trust and respect, which lead to better outcomes for everybody involved:

You tend to find that if they relate to their primary nurse [better than] relating to three or four people, the psychosocial [and spiritual] issues, ... tend to be managed a bit better. (Nurse 4)

Nursing as part of Silver Chain team approach to management

Having described role perception in term of assessment issues and nursing management through the nurse – client relationship, the last category to be described under this theme is the nursing management through the Silver Chain team.

It has been shown that some nurses were happy to tackle psychosocial and spiritual management themselves, as members of a nurse - client relationship, but many of the nurses regarded their management of the psychosocial and spiritual pain experienced by their clients as being that of a participant in a team approach. Even those nurses who first attempted interventions through their relationships, were sometimes required to refer clients on to other members of the Silver Chain team for resolution.

Silver Chain Team

The Silver Chain organisation was set up to enable quick access to multiple management resources quickly. This is facilitated by the fact that the members of the team actually work for Silver Chain, and thus their management as resources is more efficient. A description of the Silver Chain team, as offered by one nurse, follows:

... a doctor has an area each and then you have a chaplain who covers all of the team and you have a counselor who covers all of the team and you have volunteers, and you have care aids. So your care aids are attached to a team and then the volunteers, you have a volunteers' coordinator, and she has a little core of volunteers under her. (Nurse 1)

Silver Chain, as an organisation, deals with many areas of nursing, and not just community based hospice. But the team concept, as utilised by Silver Chain, was an important one within the context of home hospice, palliative care. This sentiment is expressed below:

You're a team player when you work in community; I think that when you work in palliative care as a whole, you're a team player. You can't keep things to yourself. You'll get burnout. And you just won't last. (Nurse 1)

Not only does the team structure provide alternative management options for the client, it was also considered an asset for the nurse:

The support is there for you. You're a part of a team, for a start, so you have your other team members. (Nurse 1)

Even though the primary nursing approach was advantageous in allowing relationships to build between nurses and the clients, there were always situations where a nurse could not go into their usual client, and somebody else needed to fill their shift. Thus, it was also important that the clients and their families saw that there was a team looking after them, and not just a single nurse:

We need to talk about our team. We need to talk about it and give the family the impression that we work as a team and that sometimes we can't have the same nurse all the time. (Nurse 6)

The role of Volunteers

Nurses certainly have an important role in the assessment of the psychosocial and spiritual pain that the clients' in the home hospice setting are feeling, but the volunteers also aid significantly in the management of these issues. The volunteers in the Silver Chain team are all trained to perform their duties, and are considered to be very valuable team members. The role of the volunteers is described in the following excerpt:

We have volunteer drivers who take them to radio-therapy or for clinic appointments, um, and then you know, the same one, or different ones could go in and take her shopping, or take her out to the beach or to the cinema, or... , it's purely, you know, these are people, the volunteers are people that we train. They've put their hand up to Silver Chain, phoned up and said, "I want to be a volunteer at hospice" for whatever reason. Most of them are that they've had some, something in the past where they feel they are very, very grateful for hospice and want to give something back. So they tick the box, where, how do you want to help? Do you want to help in our office, putting the notices together; do you want to help you know in the stores, or do you want to help with the patients. Do you want to be with them? Do you want to be a volunteer driver, do you want to be companion, do you want to be a night sitter, do you want to be... you know, this kind of thing. So they get trained for whichever area that they want to be in. We train them up. They are as valuable as valuable. They're fantastic. (Nurse 1)

Another advantage that the volunteers in the Silver Chain have over the nurses was that the volunteers actually have the time to talk about issues that the clients may have and the pain they are experiencing:

We have volunteers that we, in this instance, you know, we'll sort of say well, you know, we can maybe get the volunteers to come in and have a chat with you, you know, woman to woman kind of chat. (Nurse 1)

Yet another advantage that the volunteers had was that, not only could they take the time to talk to the client, they could be called on to offer respite care for the carers. This added another dimension to their helpfulness and their value as members of the Silver Chain team:

They do feel guilty and I've got a few now but we have volunteers that will go and sit with the client while the carer goes out for a couple of hours to have a cup of coffee or go and do some shopping, but the carers seem to cling on to the fact that they can't leave. (Nurse 5)

Peer Support

As shown above, the volunteers at Silver Chain are important in the support of the management of the psychosocial (and spiritual) issues of the clients in the home hospice setting. Nurses, however, also required support in their management of these issues and thus quite often called upon their peers for the support that they required. All of the nurses interviewed described at length the peer support network that they utilised at Silver Chain. It was considered an aspect of the nurturing culture of Silver Chain in the following interview extract:

I think that as a group we really nurture one another and we actually, and I would say that most of the bases have this, that we, we have built um, a nurturing culture so that we, we debrief and any time we actually discuss this, which is fairly often, what always comes up is that we ..., we do debrief to one another. So, and that's, I think that if people want the information, they can and I think that what happens to some nurses who are not so comfortable talking to clients' but may have a feeling that there are some unmet needs there, they probably seek out certain people. Um, either as mentors or as people they know would be good resource people and they do go to them. We are all fairly cluey about other peoples' strengths. (Nurse 3)

Several of the nurses interviewed believed that the peer network was the first option in dealing with management issues because the validity of the assistance obtained was greater because it came from another nurse, who was also working in the setting. This peer perspective was regarded as very important:

Our manager here now, ..., she was an evening girl, a night girl, so she's done the job, she knows. She's been doing it a long time; she's very experienced. Same as our assistant manager So they know what the job holds. And you know yourself, it's quite a specialist thing, and if I went to the Employee Assistance Program, would I be speaking to someone who's done this job? And that's important to me. <pause> and that's something that's never been explained. And that's something I always feel, a lot happier talking to a fellow nurse about. (Nurse 2)

This was shown to be the case, even when other options were available:

If we can meet up with our colleagues and we do, unfortunately, we don't have a lot of time, especially this last week, it's been terrible. Um, so we are all stressed and we're going in and trying to look unstressed, yeah, it is, it can be quite um, emotionally draining and yes, there are lots of times where you do need to talk to someone. And we do talk to our colleagues. We go in sometimes in the morning and um, yeah and we've got our clinical nurse coordinators who always listen, but um, it's probably better to talk to our colleagues cos we know what it's all about. (Nurse 5)

Not only did members of the peer network understand the problems that other nurses had, they were also available at any time and with the solo nature of this particular setting, flexibility of communication options was a big advantage. One nurse explained how they overcome the problem of working alone when needing access to the peer support network:

The phone is really important, you can ring anybody with a question at any point in time. (Nurse 1)

By utilising the peer network, not only did nurses have feedback from somebody who was working in that area, it also allowed nurses to share their experiences:

You talk about that to your colleagues and, you know, like, I remember when that happened to me. We've all got those kind of stories. (Nurse 1)

Whether it was due to the nature of the setting, or as a consequence of the closeness of the peer network, it was found that members of the peer network often regarded themselves as friends whose friendships extended outside of working hours:

How do I deal with it? I've got a couple of good friends here. ... and I did the induction together. We are both ... nurses, come from a similar background. We meet up every few weeks, and my other good friend, we meet up in our own time. (Nurse 2)

This perception of friendship extended to all of the nurses within the setting, and once again illustrated the flexibility of the nurses that worked in the home hospice setting:

I genuinely think of all of us, there is a lot of support going on outside work between friends. Meeting up for coffees, this stuff, is all done outside work. (Nurse 2)

This last excerpt describes the importance of the peer network for the support of nurses working in the home hospice setting:

Whenever we've had discussions, cos we have regular breakfasts together with the counsellor, and um, what comes up time and time again is that people get more support from their peers. Which is why we're actually trying, I mean, it's not just, if there is a better way, then we will look at a better way, but you know, with all the time constraints, there's less and less time with people almost being encouraged to start from home and finish at home, and not go into the office, cos you know if you are talking, they just see that as chatting. Um, but if they can see that that's actual valuable time where you actually not. Cos often when we are chatting, we're chatting about clients' and if they can see that that's the kind of stuff that keeps your brain healthy, that makes you come back to work the next day and not jack it all in, then it's actually saving the company money. And, um, if we can actually make them see that and try and include that debriefing time somehow, into funding, then that will be quite valuable. (Nurse 3)

Clinical Nurse Consultants

Even though the peer network was regarded as the primary support mechanism for the nurses in the home hospice setting, the Clinical Nurse Consultants were also cited as good sources of information, but limited somewhat by their clinical perspective:

We can contact our C.N.C. Very good for clinical. Our C.N.C.'s are very good. (Nurse 2)

One advantage that the C.N.C.'s had over other organisational support offered by Silver Chain, was the availability of the C.N.C.'s:

C.N.C.'s are always readily available to us and I can always voice my concerns with them. (Nurse 2)

The clinical focus of the C.N.C.'s did not preclude them from dealing with other, non – clinical issues and their availability was certainly considered an asset. A limitation, however, was their location. If a nurse wanted to see a C.N.C., they needed to go to the C.NC.:

Probably would be nice to have someone, I mean, our clinical nurse coordinators are always there for us, I mean they are more clinical and they will sit, if we've got a problem, they will certainly sit and listen but because we are out there on the road, to see them is not that easy. (Nurse 5)

Counsellors and chaplains

The final members of the Silver Chain team that were identified as being involved in the management of psychosocial and spiritual pain were the counselors and chaplains. These two management options were introduced to the client on admission to Silver Chain (as described above), and it was to them that the nurses referred the psychosocial and spiritual issues that they could not handle.

Not only were these avenues of support available for the clients, but also the nurses could use them as well to debrief, if required. The following passage describes the process in which a nurse can request debriefing with a counselor:

Anytime that we feel that we need a debrief, we just need to get onto the counselor for that team and say, "any chance I can have an hour with you this afternoon or whenever?" (Nurse 1)

Lastly, if the nurses felt that they needed to talk to somebody concerning their own personal psychosocial or spiritual issues, the counsellor or chaplain were available, if they chose to use them:

There is support there, whether people use it. Certainly at our base, we, the chaplains and the counsellors are available to us. Um, the counsellor actually available one morning a week. He has to come in and make himself available for any staff who want to talk to him. (Nurse 3)

Summary of Theme 2

This theme described the nurses' perception of their role in the management of the psychosocial and spiritual pain experienced by their clients in the home hospice setting. It was found that nurses divided their management role into assessment and management component, with management options differing depending upon numerous factors. These factors influencing management are the subject of the third theme identified.

Theme 3: Factors influencing management

The third major theme describes the perceptions of factors that influence the management of psychosocial and spiritual pain of clients in the home hospice setting. Thus far, perceptions of psychosocial and spiritual issues have been described, as well as the nurses' perception of their role in the management of these issues. Influencing factors are the next step in describing the overall perception that nurses have regarding their management of psychosocial and spiritual pain of their clients in the home hospice setting.

This theme is organised into four main categories. The first two categories describe factors relating to the nurses followed by client - based factors. The third category is dedicated to factors related to the Silver Chain organisation with the last category discusses global factors, or factors that influence these other areas.

Nurse Factors

The first group of influencing factors was classified under the heading of nurse factors. These factors were regarded as factors pertaining to the nurses themselves, and nurses went on to give examples of how each of these influenced them.

Several of these factors have already been described in a different context. Previously, knowledge and experience were considered to be important attributes that the nurse needed for assessment of a clients' psychosocial and spiritual pain. They are included here as nurse factors influencing management because while knowledge provided a base for assessment, it also serves as an influencing factor in determining the type of management selected. In the same way that experience made assessment easier, experience also influenced the choice of management option that the nurse would use

Knowledge

Knowledge was widely identified as an important factor in influencing the management of psychosocial and spiritual pain. This knowledge included knowledge of alternatives modalities (whether it be adjunct treatments, or religious beliefs), knowledge of self as well as the limitations of others and knowledge of available resources for management. This first example describes this knowledge of alternatives:

I think we need to be going out there and meeting people more, and having a little talk to pastors and ministers and the local Buddhist community. (Nurse 2)

Another important component of knowledge was that of self. This included both knowledge of strengths, as well as weaknesses, and also an appreciation of the limits:

I think it's really important that you know yourself. Know thyself. And know what your limits are, you know? (Nurse 4)

While knowledge of self was important, having an understanding of the limits of others also aided in the provision of effective management:

I was taking over her round, and all she kept on saying when we went to see this mum was this is a terrible thing, why do these things have to happen, why do these things have to happen, you know. I mean, it was sad obviously, and I looked at her and thought, that's why you've leaving, because it's hard to cope and see how unfair life is. (Nurse 4)

Knowledge of the factors involved in the current situation was important, but as equally important was the knowledge of what resources existed to aid in management (for instance, who to turn to for assistance):

I think that if I had a problem, I'd know who to approach and that a lot of the problems that I find, that the newer staff are coming on and finding quite stressful. (Nurse 6)

Experience

Experience, regardless of the profession, is one of the cornerstones of developing proficiency. Because of this fact, nurses interviewed regarded experience as being essential to the proficient management of psychosocial and spiritual pain:

You obviously come with your own background, your own knowledge, your own experience. (Nurse 4)

In the home hospice palliative setting, (or any palliative care setting) the prospect of dealing with loss was guaranteed. Because of this, the experience of having suffered a personal loss was regarded as important:

One of the things I've found, speaking to my colleagues. We've all had a personal experience of death. You know, near enough all of us, and that's made us what we are as a person and are quite accepting of death. (Nurse 4)

This life experience not only encompassed the personal experience of death, but it also included other aspects of life:

I think that's probably because of my own nursing experience, plus my own personal experience of death as well. And I don't know if it's been quoted before, but you tend to find nurses who've had to deal with some trauma in their life, tend to be quite good at dealing with other peoples traumas if they've come to terms with it and accepted it, you know. (Nurse 4)

This experience also extended to include experience in dealing with people of all ages. This experience helped in developing meaningful interpersonal relationships:

I find the young nurses, if they come from a family where they are involved in their own extended family, their grandparents, or as a child, they've been brought up in that manner, they understand how older people think. I find they're very good, but young nurses who don't, I find they struggle, and think sometimes their thinking needs to be, need to bring them back. (Nurse 6)

Vocational experience also offered perspective to the setting. Not only through the personal experience of the nurse, but also the experience of other nurses accessed through the peer network structure, as outlined above.

Confidence

The next factor influencing management came as no surprise. It was a factor internal to the nurses and built upon the two previous factors. This third factor described the confidence of the nurses to perform their role:

I think I've had the knowledge and the experience I feel very comfortable and because I know how much it makes a difference in families, that is the reason I do this type of nursing. Because I can see families, because of knowledge and ways of demonstrating to them how to manage somebody at home, and empowering families with that, you get the satisfaction doing that. (Nurse 6)

It was found, under the previously identified theme, that nurses have different perceptions of their role and that these perceptions determined the management options that they utilised for their client's psychosocial and spiritual pain:

I actually feel that I'm not equipped to deal with their severe problems, but then, we employ counsellors, um, who are specifically trained, in, or are qualified to deal with palliative, psychosocial issues. (Nurse 3)

Because confidence of management was based upon experience and knowledge, confidence was bounded by the limits that the nurse had. Knowledge of these limits determined at what level the nurse could confidently manage up to, and thus it determined the point in which the client was referred on:

I think I'm fairly competent. I wouldn't say I'm an expert. I'd always say, you know, there's area that I can learn. Um, there's ways of doing things better. I recognise that, but I think, I think that I'm fairly competent to assess certain needs. Um, as far as meeting needs. I think I can help some people to meet some needs, um, but I'm not a spiritual counsellor, neither am I am psychosocial counsellor, and I'm always happy to listen and I know, for some people, listening is really important for them. But then there are other areas where listening is not the whole thing. (Nurse 3)

Confidence of management can also be determined by the nature of the relationship with the client. This was a different concept than the one described later regarding client factors, for in this instance, it described how the nurse felt about dealing with clients' who had a specific trait. The example given below describes the confidence issues that some nurses feel when dealing with very young clients' in the home hospice setting:

It doesn't matter how complex the case is, how up and down and how trying and how really, with children it's really hard, and babies. Some of the girls don't feel really confident at all. They say, "I don't feel confident here at all." (Nurse 6)

Acceptance of limits

This section may seem redundant after the discussion about knowledge of limits above, but it was included for there was a fundamental difference between knowing limits, and accepting them.

Even though there are no direct quotes by the nurses in the interviews, this acceptance of limits was a fundamental part of nursing practice in that it determined how they approached the management of the psychosocial or spiritual pain that the client was experiencing.

Intuition

When these three factors (experience, knowledge and confidence) come together, the product was the next factor influencing management. Intuition was hard to quantify, for it was an entirely internal factor that the nurses brought into the equation of management, yet it played an important part:

We are just going on our own sort of, gut feeling about how we feel about things, um, and yeah, what you should say to that particular person. (Nurse 5)

Intuition could be described as the ability to make decisions without all of the information. The nurses interviewed in this study did not explicitly identify intuition as a factor of management, but, after analysis of the data, it occurred quite frequently,

and it was often intuition that determined when clients were ready to respond to recommendations or referrals. It was also described as an important factor when nurses first went in to see new clients:

You've got to have the art of going and trying to find out, in your short time that you're in there. (Nurse 6)

Not only was intuition considered a factor in the process of assessment of the clients' in the home hospice setting, it could also factor considerably in all aspects of the clients' care. This intuitive care approach could be described as a secondary intention of intuition, for it could also be used as a management technique:

I think you've got to show a lot of love, and patients sense that. They sense that if you've given them some unconditional love, you know, that might sound a bit far fetched in most professions but I think in palliation or palliative care where you are dealing with somebody who's going to die and they know that you know, that they may die. May not be talked about, but its there, you know. (Nurse 4)

Because the nurses interviewed never identified intuition explicitly, it was a somewhat unexpected factor cited in the management of their clients, but the use of intuition was implied in almost all interviews. It was interesting to note that many of the nurses, rather than using non-words in their conversation such as, "Um", or "Er", tended to fill with, "You know". At first it was thought that this was due to the participants seeking reassurance for expressing their opinions, but on reflection, it could be considered an apt descriptive for their mind - sets towards these issues.

Gender

The factors described so far can all be regarded as nurse dependent factors. They vary from nurse to nurse, and no two nurses could be regarded as having the same experience, knowledge, confidence or level of intuition. The next factor identified as being influential on management of psychosocial and spiritual issues was that of the gender of the nurse. One nurse in this study described these gender issues in considerable detail. In this first excerpt dealing with gender issues, gender role conflict was identified:

People have actually said they'd rather prefer a female nurse; these are male patients wanting a female nurse. Which was really odd, and I discussed it with my colleagues etc, and I think, what it is, they're used to female nurses, you know, being the primary or principal carers, and when they get a guy coming in, a guy brings a masculine point of view to things. (Nurse 4)

Even though gender role conflict did exist in some instances, gender issues were not always negative:

I would say that 99% of my male patients relate to me extremely well and are really pleased that there is a masculine or a gender difference, you know, there's somebody with a different way of looking at things, etc. And that can, from a psychosocial point of view, I can often relate to the wife of a male patient by saying that this is often a guy thing, where men will not concede that they are not in a lot of pain when they are, or they'll underestimate their pain score, and I'll say to both the patient and his wife, it's a male thing, it's a masculine thing. You don't show your pain, your hurts, etc, but I know where you're coming from. That often helps as well. (Nurse 4)

Gender was also found to have an effect, not only on the relationship between the nurse and the client, but also from an organisational perspective when it came to staffing and workload:

There's only a few full time nurses who work at [here]. Part of that is gender related in the sense that my female colleagues are mostly part time because they have family or domestic commitments. (Nurse 4)

Relationships

Nursing, as a profession could not exist were it not for the relationship that exists between nurse and client and thus, the nurse's ability to form meaningful, therapeutic relationships with their clients' must be regarded as a factor in the management of psychosocial and spiritual issues as well. This relationship factor was implicit throughout this study. Just as successful assessment was reliant upon an establishment of rapport with the client, so to was the implementation of interventions. One factor, relating to relationships, was the maintenance of professional boundaries:

Some people you get more attached to than others and you've had them for a little while. You might have had them for six months and they've become your friends, even though they [Silver Chain] tell you that that is not supposed to happen. (Nurse 5)

The professional relationship that exists between the nurse and each client does vary, and this variance can be an intrinsic factor within the nurse:

I've been told you don't own the patient. You know, they are not yours. But, they are. And you do get involved and you just can't help it. But I like that. I like to get involved, but you do have to learn that there is a cut off point, and I mean, you can't just befriend everybody because basically everybody, all our patients, are going to die and I mean, you know if you are going to befriend them all, you just, you just couldn't do it. (Nurse 5)

Having described the importance of the nurse – client relationship, the lack of one must also be important for the management of the psychosocial and spiritual needs of the client. As one nurse put it:

Sometimes you just don't get on, you don't connect. It happens sometimes. Or you've got nothing in common with them. (Nurse 2)

This interpersonal conflict does occur, which limits the ability of the nurse to manage their issues. Management then becomes challenging and it changes the way in which these clients are managed:

That [personalities] can be a big thing and you can often tell when you first walk into a home if you are going to click with these people or not. And you do deal with different people differently. (Nurse 5)

Client factors

Considering the importance of the relationship in the management of psychosocial and spiritual pain, and having already looked at one side of this relationship, the client factors shall now be described. Because of the holistic outlook of palliative care, client factors are considered on this holistic basis.

Age

The first client factor described was that of the age of the client. Because many of the clients' in palliation are aged, age related factors impacted upon management of psychosocial and spiritual pain. Elderly clients have a history of care, and a perception of the role of the nurse. This perception could influence the relationship that existed between the nurse and the client:

He's now in his nineties, but he actually said he didn't want a male nurse in the house, which is really odd, but when we discussed it, my colleagues were saying that he's particularly, he's one of the stereotypical, old fashioned consultants that you'd see on those doctor at large movies. You know, and to actually have a guy, an RN, in the house chatting away to him like an equal. This is my colleague's opinion, I think he found a bit difficult. (Nurse 4)

Even though nurses have traditionally been female, and male nurses can come across some of this gender bias, this was not the only age related issue that occurred. Sometimes, the elderly client did not expect young nurses to have the ability to deal with their issues, and thus, a barrier was formed between the young nurse and the elderly client:

Old men will say, "What's that young glamorous thing" and there are some very nice nurses out there who present very well, who've got a lovely manner, and to the older man, "What's that young thing know what I'm going through" and I sit down and say, "What makes you say that?" "Well, she's beautiful" and I say, "Well, you're handsome too, you know". They just laugh, and I said, "Was there anything that she didn't ask about?" and he said, "I can't talk to her about my..." "Why can't you? She's trained in this area". (Nurse 6)

It was not just elderly patients that posed management issues for nurses. Young patients could also cause other management issues for the nurses involved:

However, with children, we've got some children on our books at the moment, but the girls are finding that very hard, two four year olds and they say, "oh, gosh, I hope I don't have to go in there" (Nurse 6)

Gender of the client

The gender of the client was also regarded as a major factor influencing the management of the psychosocial and spiritual pain. It was perceived that some male clients could suffer psychosocial pain when they were forced to give up control:

Especially if it's a guy, because that leaves the woman back in control and that can quite often be a difficult situation for them too. (Nurse 5)

Female clients, however, were not immune to gender issues relating to their management. It was found that some female clients did not want male nurses or carers, and thus imposed restrictions on their care:

We have a male nurse and he's excellent, but we do have women who say, this woman won't allow her husband to come into the bathroom with her. She's not going to let <name> come in so she made her, she told her husband that she doesn't want a male nurse coming in, so her husband had to ring up the manager and say, we've got a problem here with my wife. It's just her; she's got a female doctor. She won't allow her husband in the bathroom with her, and she wants to be in control. (Nurse 6)

Gender also played a part in the psychological and emotional makeup of the client. One nurse perceived that:

There can be a gender issue because majority wise, the woman as the carer copes better than the man as the carer. Generally speaking, but that's not always the case, but generally speaking. Yeah, the woman copes, on an emotional level I suppose I'm talking here. (Nurse 5)

Health issues

Remembering that clients in the home hospice setting were actually dying, it was easy to understand why health issues could be regarded as considerable management factors for the clients' psychosocial and spiritual pain:

I think it depends where you, and what stage you get them at and whether they are still quite well, how ill they are and that has a really big influence on it [assessment and management]. (Nurse 2)

It also paid to remember that even though the client was dying, there might be other co-morbidities involved as well. In the following excerpt, a nurse described the mental health of a client as being a factor in their management:

I went there to start this [intervention] and I asked the carer, (who I didn't know at the time, but picked up straight away that he's got a memory problem), and the son was there who is a lawyer from <place> visiting and he was trying to, I could see, he knew that dad didn't have it [a grasp of the concept], didn't have it enough to know what mum was having. When I went into the bedroom and talked to the patient, she just said, "I wish people would just talk to me, I know what my medications are." But on talking to her (the husband I don't think picked it up but the son picked it up), she really didn't know what she was doing, why she was talking the medications. (Nurse 6)

Fatigue (as being a part of their health status) in palliative care clients was another major factor to consider when managing psychosocial and spiritual pain:

Fatigue is a big one as well for our clients. They feel so tired, they just actually getting up and having a wash and eating or drinking, they don't care, they don't want to talk about it, so fatigue is a real issue for our clients, I think, with regards to how much they want to talk about things. And how much psychosocial care we then give them. (Nurse 2)

Socio-economic

When thinking about client factors influencing the management of psychosocial and spiritual pain of clients' in the home hospice setting, socio – economic did not spring quickly to mind. Yet, these client-based factors did contribute significantly to the ease in which psychosocial and spiritual management was undertaken:

I do find class makes a big difference. Like the lower class type of people are so much easier to deal with. They are a lot easier to communicate with whereas the, and I'm making this a broad thing, the upper class people are people that can't handle it so well because, you know, this just doesn't happen to them. (Nurse 5)

It was found that the socioeconomic background of the client lead to different expectations of the nursing management of the client. An example of this follows:

Middle class expectations are that they would rather have one nurse that they get to know. (Nurse 4)

Not only did socioeconomic factors contribute to the clients' attitudes towards the nurse and nursing care, but these factors could also directly contribute to the clients' psychosocial pain in so far as their condition prevented them from sustaining their usual standard of living:

We cross a big socio-economic area and I mean some people would never apologize for the mess of the house and that's just the way that they live, but others, you know they do because they feel that they are not living up to their normal standards and you want to get that straight out of the way, you know. (Nurse 1)

A perception also existed that socio-economic factors contributed to the clients' coping systems. When speaking of more affluent clients, control issues could become a source of considerable psychosocial and spiritual pain:

The idea of terminal restlessness seems to be a bit of a problem in areas where social class is quite different. ... I have worked in a poor area and people tend to be a bit more accepting of what's happening in their life. Whereas in, I work in a very rich area now, of Perth and I find, again, this is a personal observation, that people, the moneyed class and I'm talking about people with a lot of money have been used to the idea of buying and controlling things because of their wealth. The problem with dying is that you can't really control the hospice, the palliative part of that aspect of dying. And I find in my experience that they have psychosocial issues of control. They demand a lot more, um, not all of them. The majority of them are nice and accepting, but I find that maybe in the upper middle class areas, or the attitudes, tends to be a bit more of a demand. (Nurse 4)

As can be seen from the examples given above, socio economic factors contributed considerably to the amount of psychosocial and spiritual pain that a client experienced, and thus played a significant part in the assessment and management of these issues.

Family

Generally speaking, in home hospice based palliative care, it was a family member who was also the primary carer for the client. Whether it is a husband or wife, son or daughter, the principal carer tended to be a close family member. Participants reported that these family members also experienced psychosocial pain related to the clients' condition. Therefore, family issues tended to become major factors in the management of psychosocial pain.

In order to minimise the negative psychosocial impact of the family dynamics, communication within members of the family was described as being important:

Other times, the daughter or the husband or whatever gets you in the kitchen and the client gets you in the bedroom. So you have to make sure that you're telling both of them that you are talking to the other one. And you really want to bring it together to make it clear, you know, miscommunication is a huge thing, because how she sees it, how he sees it, you know, it's one thing but they are both coming at it from a different angle. And you're trying to bring them both together. (Nurse 1)

Regardless of the intervention and skills of the nurse, family conflict could often arise, and this was seen as opportunity to attempt to resolve pre existing psychosocial issues:

I think if they have extensive family support, that tends to be a plus and a minus as well. ... you tend to find that um, you can get family conflict and family conflict can often be more focused at this very special, ..., particular time, so family conflict can come out in the fore, but it's also an opportunity for the nurse to sometimes, without being a sort of referee, you can calm things down and often help families to come together you know, there can be reconciliation with sons and daughters who have not been here for a long time. So I think the nurse can often help directly or indirectly by bringing families together, you know. And that often helps, but then, you know, there's been conflicts within families right up until the day, you know, the day or the hour the patient has died and that's really sad. (Nurse 4)

Mention has been made before concerning the prevalence of anger as a response to psychosocial and spiritual pain. This anger can be quite evident in families, and particularly if there was existing, ineffective communication prior to palliation:

Sometimes it's, you know, within the family itself, there's a lot of anger and you're looking to people, their partner and the patient and they are looking at the whole differently. Like I've got one at the moment, who the patient himself has gone very negative. Um, and his wife is trying so hard to be positive but it's really pulling her down because he's so negative and so she, you come in and she's all jolly and trying to pick on this brave front and he just goes and locks himself away in a dark room. So, yeah, it's just the different personalities within the home can make it difficult as well. (Nurse 5)

This anger can be expressed in the family context for different reasons. Another nurse interviewed identified the anger existing as being part of the break down of the family unit. Considering that home hospice clients are predominately cared for by members of their family, the degradation of the family unit can be considered to be quite a large source of frustration for the client:

I find there is less family unity, there's less family support, and in so-called families, there is a degree of anger much higher than what it was. (Nurse 6)

It was important for the nurse to be able to identify the family support structure, regardless of how it was constructed. By appreciating that it was valuable, in whatever form it existed, the nurse was showing that variance from what was once the norm need not be a handicap:

I'm acceptable with whatever is called a family unit today. Family unit might be a partner, it might be a friend, it might be, people of the same sex. Whatever people term to call it, I'm very acceptable to that, and I always recognise the unity in a relationship, and might say something about that it's nice to know that there is friends, or that it's lovely to see that you've got support, whatever, so that they know that I recognise their situation, which might be a bit different from their first husband or wife. (Nurse 6)

Successfully handled, families can be valuable influencing factors for the management of psychosocial and spiritual pain for clients' in the home hospice setting.

Coping mechanisms

Even though the issues previously identified as factors all influenced the coping ability of clients within the home hospice setting, a brief section was included here because of the importance of coping mechanisms as a whole in the management of psychosocial and spiritual pain:

How are they coping and um, you know, of course all those things are how people cope, I mean is so different because it depends on their cultural background, their educational background, you know, there are lots, so many variables. (Nurse 3)

The closest mention to cultural differences made by the nurses interviewed for this study was that of socio-economic issues. That these issues exist, there can be no doubt from the previous excerpt, but more was spoken about “alternatives” within the context of adjunct therapies or relaxation techniques as can be seen in the next interview extract:

I think a lot more people are turning to the alternatives, plus listening to their doctors, but having that an adjunct to what the doctors are saying. That helps them cope sometimes because I don't think there is one person who walks the street who doesn't know somebody that's got cancer, had cancer or been through this sort of thing. And listens to what people do and how they try something and what helps them, might help this, and that sort of thing. (Nurse 6)

The last identified client factor was their sense of loss. It corresponded to the loss of hope described under the first theme, but it was also a management factor in that clients needed to come to terms with this loss before effective management of their other psychosocial and spiritual needs could be undertaken. This sentiment was reflected in this last statement:

She's feeling the loss of this independence. And that's a huge thing as well, the loss of independence. So again, we have to deal with that in a way to kind of overcome it. (Nurse 1)

Organisational factors

The next group of factors identified falls in a category of organisational factors. These factors relate to Silver Chain and the way in which the organisation was structured and run.

By looking after the nurses, Silver Chain also ensured that their clients were cared for. Factors such as adequate training for the nurses (and for students), the implementation of an assessment tool for psychosocial and spiritual pain, workload and staffing, plus remuneration and conditions all served as factors relating to nursing management of psychosocial and spiritual pain in this setting. An organisational issue amongst Silver Chain nurses (in the way of documentation) was also described. Finally, knowing that the relationship between nurse and client was critical in management of psychosocial and spiritual pain, the perception of the relationship between the nurse and the organisation will also be described.

Training issues

Allied health care organisations have a responsibility to ensure that all of their employees have adequate training to ensure that they can competently fulfil their role. This study has already described the perceptions of the role of the nurses in the management of psychosocial and spiritual pain of clients, and it was found that the main role was that of assessment and referral. Some nurses believed that their role extended beyond this to include interventions based upon the nurse – client relationship:

You should be able to take anybody and um, and train them and that's actually what we're going to look at in our what, how should we, how should we address um, ..., how should we actually do the assessment, cos the nurses are the first people in and we're actually should make it some kind of formal assessment. Something that actually has to be done, but then if you're doing that, you then have to train people to be able to do it. (Nurse 3)

This excerpt introduces training from an assessment perspective, the following talks more about specific training relating to management:

Teaching is difficult. The teaching could perhaps prepare you for the fact that things are different and sort of give certain scenarios. You know, you walk in and you find a messy house and everybody is sort of all very laid back, um, yeah and you can pick that up. Or you've got a house where everything is completely in order, you know, so you're too scared to put down a glass of water on the table. You can pick them up as you go in but I think probably, from the teaching point of view, they can teach you that everything is different and give scenarios. (Nurse 5)

Regardless of the context of training, the need for support was still there for the nurses:

I think you can train people to a certain extent, um, I think they will need a lot more support. (Nurse 4)

Another factor relating to the training of nurses was the level of specialisation required. Do nurses need to be given counseling training in order to perform their role? It was mentioned under the theme of perceptions of psychosocial and spiritual issues, that some nurses had undertaken specialised training in order to help them. From an organisational perspective, the role of the nurse seems to be blurred:

I guess that it comes back to the training again, I think maybe we should have training. Lack of training, counselling training, I suppose, that would help. (Nurse 5)

Another factor related to training was that of students. The presence of students in the home hospice setting was a factor to consider when assessing and managing psychosocial and spiritual pain. In this excerpt, a nurse described the impact that having a student present had on the relationship with the client:

Having students as well. I mean, I've a student this week and I haven't had a chance to prepare any of my patients that I'm taking a stranger with me and of course, then I'm having to, I've not even got consent really from the patients and of course then it's impacting on the way I'm talking to them. I noticed quite a change yesterday, not that she's not a lovely girl, but they were far more closed than what they would be normally. So having a student is definitely an influence. (Nurse 2)

Students also add another dimension to the psychosocial and spiritual management that the nurse needs to deal with. The same nurse went on to describe the necessity to protect the student from the client in this following extract:

We do ask, with regards to students, we do ask them if they have had bereavement in the last year or so. They are not supposed to come to us before..., but a lot of our students come here thinking this is a nursing home and they've got no idea that we deal with children as well, so I think that impacts both on our relationship with the patients and our relationships with the students as well, cos you kind of, not hardened to it, but you kind of get used to the sadness and the grief and the way people pour their heart out to you and the emotional burden. But the students aren't prepared for that and then, of course, you're then perhaps, gating your client a bit. Two or three clients, students have had a really heavy morning, then you go to your fourth or fifth client and they want to pour their heart out and you can see the students are quite fatigued, sometimes you feel you need to block your client. And that has impact on the psychosocial well-being of the client because you're thinking, "this client needs me, but the students really exhausted and quite distressed." It's a bit of a balancing act. And because we are out and about, you can't just nip your student off to somebody else, because you can't. And then that gates on how we deal with the psychosocial aspect of our patients. (Nurse 2)

Formal assessment

This section on formal assessment followed directly on from formal training, in that it was another organisational factor in aiding the nurses to manage the psychosocial and spiritual pain of their clients. The lack of a formal assessment tool for psychosocial and spiritual pain was perceived to be an organisational issue for the nurses interviewed in this study:

If we have something, we actually include something on an assessment, if we have a piece of paper that's mandatory, then it will actually have to be addressed. And that's the whole point about getting the tool that can be used. That we can actually train people to use, cos there is no point having something that is marvellous, but there is no way on this earth that you could ever train anybody to use it and it has to be, and it has to be user friendly, as well as client friendly. But if there is something there, then yes. And if you can get people, making people comfortable and recognising that these issues are just as important and often more important, um, than anything else. (Nurse 3)

Workload

The first two sections dealt with fixed, existing organisational factors, while the next two factors identified describe the daily functional factors. The workload of the nurse can vary daily, and it was an influencing factor on the ability of the nurse to offer effective psychosocial and spiritual management:

From a management point of view, I mean, there's just this classic, we sometimes don't get the support because we are too busy, you know? Um, I think management are too busy managing to sometimes recognise that um, we have needs ourselves. (Nurse 4)

Staffing issues

The workload factor identified in the last section can be seen as a consequence of staffing issues that exist in Silver Chain. This next excerpt describes the workload problems in terms of understaffing:

There's no limit on the amount of caseload you've got, you're just dumped on. Patient after patient after patient and you rely on your colleagues and your coordinator to support you and help distribute and redistribute and help you out on the bad days. We're quite understaffed. You never know if you are going to get enough staff. (Nurse 2)

Another nurse identified staff shortages as a factor as well. In this instance, however, the willingness of the organisation to employ nurses on whatever terms the nurses asked was illustrated:

There always tends to be a staff shortage, that people are reluctant to work for Silver Chain and the reason why a lot of female colleagues work part time, Silver Chain give them the hours that they do to attract nurses and that's part of the reason why, older nurses with family commitments will do all late shifts, or all evening shifts or night shifts. (Nurse 4)

Documentation

Even though documentation in the form of formal assessment has already been described under this theme, other administrative issues (relating to documentation) have also been identified. As an example of this, one nurse talked about the difficulties of the documentation that Silver Chain use:

In the home notes, there is only at the end of that pink sheet, the questionnaire about, it's very hard I suppose, um, trying to document what families are going through, you can't document what families are going through, you've got to find out, don't you? You can't sort of put it and you can't, in the bottom it says, something about have you introduced the hospice doctor, the counsellor, and the girls tick them, the volunteers and the chaplain. Well, the chaplain, you've ticked as they've introduced it, but then you've got to find out, she may have just asked the question, or may have just stated that we do have a chaplain if there is a need. (Nurse 6)

Perceived lack of spiritual management

This section begins to look at nurses' perceptions of the organisation as factors influencing management of psychosocial and spiritual issues. A perception existed that the organisations spiritual management was lacking due to the Christian focus of the chaplains:

I do think that the organisation tends to look at, they do tend to look through a Christian chaplain and that is something as an organisation, we are actually trying to look at. And look at whether we do actually call them chaplain. Cos that's another thing that is a completely secular organisation. And, um, and we do, you know, say that we aim to meet the needs, the, you know the physical, cultural, emotional and spiritual needs. (Nurse 3)

This sentiment was reflected by another nurse who reiterated the above sentiment, and when on to give the following recommendation:

I do feel, at our organisation, that we don't know enough. We're not a Christian organisation, but we don't know enough about other religions. ... we've got no religious file here. And no spiritual file here about, I don't know, Wiccan or less mainstream things. (Nurse 2)

Nurses Perceptions of Management

The perception that each nurse had of the Silver Chain management determined the amount of trust that the nurse had in utilising Silver Chain based resources. This, in turn, had a follow on effect in the management of the psychosocial and spiritual pain that their clients felt. One nurse described their perception of management as follows:

I think that management in Silver Chain is very perceptive ... they know how busy we are, they know the complexities. ... they know what you've got on, and therefore they support you through it. (Nurse 1)

At the other end of the spectrum, a nurse depicted their perspective of management in a completely different light:

The other thing I'd like to mention is the fact of the lack of support that we get here ... I mean, basically, management really, really don't care. (Nurse 2)

These findings tended to show that nurses were happy with immediate management, but that their trust in management decreased the further management was removed from the client. This was demonstrated by their extensive utilisation of the peer network (direct contact with clients), through to the C.N.C.'s (one step outside of direct client contact), and on to the lack of confidence or understanding in other areas in the higher levels of management.

Global factors.

The global factors identified here are a group of factors that transcend the categories given above. They are regarded as critical factors covering all domains of the palliative care setting. These three factors could be considered to be universal, regardless of the nursing setting. The first of these factors was time. The next factor was that of communication with the last factor dealing with environmental issues

Time

Time was cited as a factor in most of the interviews. Time to the nurse determined the amount of care that could be provided. This related equally to physical care, emotional care, psychosocial care and spiritual care of the client. From a client's perspective, in the palliative care setting, time was the one thing that they are always aware of, and thus it marked, and determined the relationships that they had, thereby having a large psychosocial impact. Time, from an organisational perspective, was a factor in caseload allocation. It was also the predominate factor in remuneration, both to the company, and for the nurse.

Time was the biggest influencing factor for the management of psychosocial and spiritual pain in the client in the home hospice setting:

Sometimes I don't have any time and wish that I did have a bit more time to explore these [issues]. (Nurse 6)

This sentiment was reflected by all of the nurses interviewed. Time has already been described as an important factor in assessment (in terms of time to explore issues) as well as in assessment (timeliness of intervention) and yet there was never enough. This was not always the case, as seen in the next excerpt:

Time is certainly, is certainly a factor. One that wasn't always the issue. You know, if you wanted to spend three hours in a house, you could do. That's no longer the case. You have time issues because we are just so much busier. (Nurse 3)

Workload, and the nature of the nursing in the home hospice setting also minimised the time for the nurse:

The time factor again. The fact that it's not acknowledged in the stats. The being paged. Being half way through a quite intimate conversation and you get an urgent page and that does interrupt things. (Nurse 2)

Not only did time constraints set limits to nursing assessment and management, they could also cause dissension between the nurse and the organisation. In this instance, a nurse described the lack of understanding by Silver Chain management in relation to time management issues:

A while ago, it seemed to be that if you didn't get off on time, you weren't managing your time. And depending on your manager, not so much now, but I have said, I just said, they said, "Why did you get off so late? Did you not call night staff? Could they not come in and take over from you?" So I explained the situation, and they said, "Well, you need to manage time better" and I was really incensed with that. Really incensed with that and thought, you know there is only three of us on in four or five areas and we've gotta cover, and sometime tells you you've got to manage your time better. (Nurse 6)

Communication

The second global factor fell under the category of communication. Communication for nurses was essential in establishing relationships, assessing needs and offering support. Communication qualities and they how relate to assessment have been described previously in this study, but communication in management influenced many different areas of management and thus it's inclusion here.

Communication, when dealing with the client, was not just about talking and listening, but actively "being with" the client. Almost all of the advice that the nurses interviewed gave for improvement of management stemmed around communication issues. Communication, from the client's perspective, was essential in maintaining healthy relationships. It was often a mark of psychosocial and spiritual pain when client based communication broke down. Communication, at an organisational level, not only described the administrative components essential for the functioning of the

organisation, but also was a measure of trust and respect between the organisation and the nurse.

Communication skills, in the nurse, tended to be an intrinsic factor, and one that stemmed from their experience. These skills formed the foundation of their ability to effectively manage their clients:

I don't think I have been taught communication skills. When I think about it. It's just something you do when you go in there. (Nurse 5)

The ability to effectively communicate was important in opening up avenues to explore psychosocial and spiritual pain. This aspect was described in the following excerpt:

I suppose communication is a huge thing and I find if I can talk to the client about their cancer and where they're going with it, that makes them feel a lot easier, and it enables them to talk about it a lot more. So if they can talk about it to friends and family, it sort of opens up the channels of communication. (Nurse 5)

For the client, communication issues can be the cause of psychosocial pain. When the clients' friends discover that the client has cancer, communication roadblocks come up:

A lot of their friends don't know how to communicate with someone with cancer. Um, and so they find they lose a lot of friends, because they just can't face up to it. (Nurse 5)

Communication between the nurse and Silver Chain tended to be a positive factor in management. Considering the fact that the nurses in the study were spread all around the community, this finding was somewhat surprising:

Nothing is ever too much trouble, nothings too time consuming, nothings too, you know, the communication is just there, there, there, all the time and I think that's a huge thing. (Nurse 1)

For communication to be successful, a direct approach was considered to be the best way to minimise any problems:

I know I only talk to the person that's involved. I find that if you talk to another, she never passes on to the nurses involved so that that, and I just say my findings. (Nurse 6)

Environment

The final global factor identified related to the environment in which psychosocial and spiritual management occurred. For nurses, it described the factors associated with providing psychosocial and spiritual support in the home setting. Environmental factors for the client included the home in which they lived and also the internal environment in which they functioned. These internal environmental factors led to psychosocial and spiritual issues that the client faced and were thus, very important. Environmental factors, from an organisational perspective, related more to ensuring adequate staffing, occupational health and safety as well as providing sufficient training to ensure competence amongst staff.

Many of these environmental factors have already been alluded to in other sections of this report, and thus, only the environmental factor, as relating to nurses will be described here:

Sometimes you go to a visit, and there's a really nice atmosphere there, quiet; others times you go there, friends have dropped in, you know, or the dog's ill or something and you don't get that opportunity to do so, so I think environmental factors as well. (Nurse 2)

Summary of Theme 3

As can be seen by these factors that have been identified in this section, there are considerable areas of overlapping. Many of the excerpts used to provide richness to this data also included other aspects, identified in other places of this report. This adds further proof regarding the interplay of factors, and how extensively they contributed to the way that nurses' managed the psychosocial and spiritual pain experienced by clients' in the home hospice setting.

Even though all of these factors influenced the management style that the nurse used, there were several factors that could be regarded as limitations. Nurses knew that knowledge played a fundamental role in deciding the form of psychosocial or spiritual management for their clients, as did experience. The other limiting factor identified was the lack of formal assessment of psychosocial and spiritual pain.

Recommendations based on these three factors can be found in the next theme, dealing with the nurses' reflection upon management.

Theme 4: Nurses Reflections on their Management

The first theme identified in this study dealt with nurses' perceptions of psychosocial and spiritual issues. The last theme identified by the phenomenological analysis outlines the reflections of the interviewed nurses of their management of the psychosocial and spiritual pain of their clients' in the home hospice setting. It was divided into three categories. The first category suggested improvements for management (divided between organisational and nursing factors), the second category provided advice for new nurses in the setting, and the third category described how they rated their psychosocial and spiritual management in terms of their total management of the client.

Recommendations

This first section describes nurses' recommendations for improvement of their psychosocial and spiritual pain. The nurses interviewed in this study were not asked for recommendations, but they were encouraged to reflect at the end of the interviews on their practice, and this allowed some nurses who felt strongly enough about several issues to offer some recommendation for improvement.

Organisational

One identified factor influencing the management of psychosocial and spiritual pain of the clients was that of the lack of a formal assessment tool that nurses could utilise to assess psychosocial and spiritual pain of their clients. This was considered to be a limitation by nurses because it was perceived that these issues must not be as important to Silver Chain as the physical issues, which did have a formal system for assessment of pain. Thus, the first improvement to be described was the development of such a tool:

If we have something, we actually include something on an assessment, if we have a piece of paper that's mandatory, then it will actually have to be addressed. And that's the whole point about getting the tool that can be used.
(Nurse 3)

One nurse suggested including the domain of psychosocial and spiritual pain on the official form as a possible way to address this limitation. This would also ensure that psychosocial and spiritual issues would need to be conducted for auditing purposes:

We have to fill this every time. It's called a "symptoms assessment scale". We've got insomnia, appetite, nausea, bowels, breathing, fatigue, pain. As you seen, there is nothing there about mood or psychosocial. ... we are audited on each of those and if the patients then has to be stable, we only really need to be in there for 30 mins. So they can appear quite stable on these symptoms, but they might be really struggling with having bad news about having no more chemotherapy or, one of my gentlemen, because of his prostate cancer, becoming more and more incontinent. It's not painful for him, of course it's affecting his psychosocial well being, you know. ... That doesn't actually show up on there so we then have to enter, make them unstable but the government says, "Why is this person unstable? They haven't got any pain, they're eating well, they're not sick, they're breathing well."
(Nurse 2)

As has been shown in a previous section, it was identified that psychosocial and spiritual issues impacted upon a client's physical condition, and thus, by including this assessment, physical management may also be improved:

All physical symptoms are affected by psychosocial things anyway. Spiritual, I mean people who are in spiritual pain feel more physical pain and um, you know sometimes, you have to address the psychosocial and spiritual side to address the physical problems as well. (Nurse 3)

The second recommendation was based upon the lack of spiritual resources available at Silver Chain regarding minority religious beliefs and cultural customs:

A big resource file would be good. We haven't yet got Internet access here, so we've got no way of looking up a database on the computer. It would be handy, you know, if I could just look up something on Seventh Day Adventists', or something like that. Just have a few concepts to say and some guidance.
(Nurse 2)

It has been mentioned before that the Christian base of the Silver Chain chaplains was regarded as an issue and part of increasing the knowledge of spiritual issues would include education regarding other modalities:

I think, as an organisation, we need to expand our religious education. (Nurse 2)

The third recommendation made by the nurses in this study was that of improved training in the management of psychosocial and spiritual issues. By improving this area, management options would also be improved:

I think lots of things could be included in a training package. Definitely. To prepare, I mean to, Silver Chain itself is a different area, but when you go into palliative care as well, I think, yeah I do, and I think it would be helpful. (Nurse 5)

Characteristics of nurses

The reflection of the nurses also led them to consider the characteristics that made for a successful nurse in this setting. Age of the nurse was considered to be important for it provided more opportunity of life experience:

You bring your life experiences with you. I think it's important to have family life so you have something that's out with palliative care. I think you should be an experienced nurse as well. (Nurse 4)

It was also suggested that nurses who had a personal experience of death knew better how to deal with clients' and families in palliation:

I think from a psychological point of view, it would be hard for some of the younger, single nurses, I think, if you..., one of the things I've found, speaking to my colleagues. We've all had a personal experience of death. ... near enough all of us, and that's made us what we are as a person and are quite accepting of death, whereas, in a [younger nurse], they've mainly done acute care. Which is very much about saving lives and not seeing people sometimes dying in agony, ... , when it's difficult to control their death. I think, personally, that it would be a lot more difficult for the younger nurses to cope with some of the experiences the older nurses have. (Nurse 4)

It was acknowledged, however, that these conditions would place unfair restriction on the number of nurses and thus training should be improved to allow new nurses the opportunity to increase experience in a controlled setting. It was recommended that new nurses would benefit most by scenario-based training, as this

offered the necessary experience in a controlled environment, with feedback occurring instantly:

The teaching could perhaps prepare you for the fact that things are different and sort of give certain scenarios. You know, you walk in and you find a messy house and everybody is sort of all very laid back, um, yeah and you can pick that up. Or you've got a house where everything is completely in order, you know, so you're too scared to put down a glass of water on the table. You can pick them up as you go in but I think probably, from the teaching point of view, they can teach you that everything is different and give scenarios. Situations that might arise. (Nurse 5)

Advice:

As part of the interview structure, the nurses interviewed were given the opportunity to crystallise the salient points of their recommendations into a list of advice that they would give to a new nurse in the home hospice based palliative care setting. The advice given by the nurses described communicating with the client, attitude towards management and other nurse based issues.

The first three items of advice all fall under the heading of communication issues. The importance of communication of a factor in management has been discussed in the previous theme, and nurses had several specific pieces of advice to new nurses regarding this concept.

Talk

This may appear obvious, but talking was considered to be essential in the management of psychosocial and spiritual pain of the client. Sometimes, this was all that the nurse needed to do to assist the client in dealing with their problems themselves:

Even if it's on an emotional level and sometimes you go in there and there's nothing physical to do but you're there as a support and someone to talk to. And that's a huge part of their treatment. (Nurse 5)

Talking also extended to the fellow nurses. The peer support network was considered an essential part of the management of psychosocial and spiritual issues of the clients, and thus talking amongst that network was considered a valuable piece of advice:

If there is spiritual or psychosocial issues, they need to come back and talk to us so we can all share experiences in dealing with..., peer support is very important. (Nurse 4)

Ask questions

The next piece of advice concerning communication for nurses espoused the need for nurses to ask questions. Just as the interviews in this study were guided by inquiry, so too was assessment of psychosocial and spiritual pain. If a nurse needed to know a clients' problem, they shouldn't wait for the client to tell them, they should ask instead. This was another obvious piece of advice, but one that was offered by most of the nurses interviewed in this study:

Ask them [the clients], "What do you say that's your problem?" (Nurse 1)

Knowledge, as a concept, was shown to be important in this study in both assessment of psychosocial and spiritual pain, as well as management and thus was regarded as a key nurse related factor in the findings of this report. The nurse asking the right questions often obtained knowledge:

Ask for something that you can read, um, if it becomes about religion and you've gone into a Hindu, just ask them, have you got any printouts about the Hindu religion. (Nurse 6)

Listen

Talking with a client was an excellent way of establishing and maintaining rapport, and asking questions was important in information gathering, listening is also an important skill. Without listening skills, all the talking and listening serves nothing. Listening is an active process and effective listening occurs on many levels, as described in this next example:

My advice would be, um, to just you know listen to the client ... listen to what they've got to say on every level. (Nurse 1)

Just as talking can be a management technique by itself, listening can be regarded as well for it allows the clients' to identify their issues. This can be as much intervention as they require to resolve their psychosocial and spiritual pain:

I do try to emphasise the psychosocial side and I see it possibly because I see it as a very important thing and I do try to spend some time on that and hopefully I've got quite a few of my patients seeing the counsellor, seeing the chaplain. But yes, sometimes, you just have to sit down with people and listen to them. (Nurse 2)

The next cluster of advice given by the nurses dealt with attitudes towards management. These attitudes were all based upon the fundamental concept of holistic care.

Consider client's perspective

It was identified earlier in this report that different people have difference perceptions of psychosocial and spiritual issues. Because of this fact, an important piece of advice offered by the nurses was to consider the perspective of each client. As palliative care was based on a holistic focus, it stands to reason that consideration of the client's perspective would be regarded as an important piece of advice:

A thing that I often think about is, try and put myself in the patients' shoes. You know, how do they, how must they feel when they get that referral or they are told that Silver Chain nurses are coming in and the nurse is walking down their driveway or have knocked on the door and coming down the corridor,

you know? Do they see this angel of death or do they see somebody who comes in who's gonna, who's gonna accompany them on their journey.
(Nurse 4)

Deal with clients' problems

Consideration of the client's perspective makes it easier to deal with the client's problems. A nurse may perceive a problem to exist where the client sees none, or alternatively, the nurse may not perceive a problem that the client has. It is important to deal with the client's problems, and not the nurses. This piece of advice was summarised in the next excerpt:

Listen to what they are saying, and take it on board, and deal with that. Don't try and make a problem where they don't see it. You know what I mean? Um, just deal with the problems that they see. (Nurse 1)

Don't be afraid to tackle the tough issues

This advice offered was an extension of the previous piece of advice that described dealing with clients' problems. To deal with the clients' problems, you first needed to identify them, and thus don't be afraid to tackle the tough issues:

Don't be scared to tackle the issue. ... Don't ever be scared [to ask] the clients' how they are. "Are you anxious? Are you depressed?" We ask people, "Are you in pain? Have you had a poo today? ... Are you hurting somewhere else? Are you upset? How does this affect you?" People think [that if] you ask them if they've had their bowels open, it's not an intrusive question. [But] I think it's fairly intrusive. I wouldn't like someone to ask me that everyday. Um, but I think that they are intrusive questions, certainly, but that's what palliative care is all about. (Nurse 3)

Address the issues when they arise

Timeliness of intervention was mentioned previously as an important consideration of management. Nurses sometimes will not address an issue in a timely manner if they do not perceive it to be important. This advice recommends that once the client has identified the issues, they need to be addressed in a timely manner. The following example draws in the importance of timely response to an issue with that of dealing with the clients' problem:

Whatever is an issue for them is their issue. For us it might not be an issue and you might just want to go, ... but you can't do that in the home cos you've got to address the issue. (Nurse 1)

Issues needed to be dealt with when they arose, otherwise they could be forgotten by the nurse. Because experience had been identified as a crucial factor in the management of the psychosocial and spiritual pain experienced by the clients, if an issue was not dealt with, then a learning opportunity for the nurse had passed:

You need to address them at the time and so that you've got some more information that you can take on when the next time it arises, you know how better to better manage that. (Nurse 6)

Be flexible in approach to management

By being flexible in the approach to management of psychosocial and spiritual issues, the different needs of different clients' can be more readily achieved. This is also true for changes that occur within clients' on a daily basis:

I think you have to just be upfront and honest with people, you know? And be flexible. ... because every client needs change on a day-to-day basis, you know. (Nurse 4)

Learn what you can

Experience was not the only method of learning, however. Another piece of advice dealt with learning as much as you can:

You get as much information on board so that when the various things come up, that you feel confident either addressing them, or finding out how to do that. (Nurse 6)

Accept people in a non-judgemental fashion.

The holistic approach to management can be seen in this next piece of advice. Being in a relationship with the client means that you need to accept them for what they are:

But I think they feel that I'm not dismissing their beliefs and that I'm accepting of what the alternatives are. But there's a lot, with the other more minorities, Buddhists and the Hindus' and that I definitely accept their understanding and go along with everything and I always make sure I ask first if, at the time of death, and they are of that ilk, I'll ask, "where do I fit in to your preparation now?" And they will tell me. (Nurse 6)

Be open and honest

Part of acceptance of the client involves being open and honest in all dealings with them. This reinforces the acceptance of the nurse and validates the client's experiences and circumstances:

I think you have to just be upfront and honest with people. (Nurse 4)

The last two articles of advice offered by the nurses on reflection of their management talk about nurse related issues involving self-assessment.

Look after yourself

Self-care was regarded as an important aspect in all areas of nursing. In this instance, the self-care suggested by the nurses dealt more on an emotional level than on a physical one. One aspect involved utilising support networks to ensure self care needs were met:

Because we all hurt a lot, and I don't think it's dealt with, to find someone to talk to. Try and bond with somebody, and feel that you can talk to somebody ... self care is talking to other people and I'm lucky I've got a lovely husband who is very supportive and hopefully they'll have somebody who is supportive for them. (Nurse 2)

It also involved taking time out to debrief between clients so as to prevent premature burnout:

Take a break between patients, um, to take time to sort of, sit back ... to look after themselves, they need to have that little break, and their own little debrief between people because otherwise they'll just burn out too quickly. (Nurse 5)

Don't take yourself seriously

The last piece of advice offered by the nurses described the overall attitude of the nurse in the home hospice setting. In the following exemplar, the nurse advises not to take yourself too seriously:

One of the things I've learnt in palliative care is that um, don't take yourself too seriously in the job. Take the job seriously, because, at the end of the day, it's their grief ... I don't take myself too seriously at all in the job. I don't get too angry or too upset all the time, just take it in my stride. (Nurse 4)

Physical vs. “Non – Physical” Management.

The interview structure for this study allowed nurses to reflect upon their personal management of the psychosocial and spiritual pain felt by their clients in the home hospice setting. As part of this reflection, nurses were asked to compare their management of these issues to that of the physical management.

All of the nurses in this study perceived their management of psychosocial and spiritual pain to be on par with that of the physical pain that the client experienced:

I would probably put them both on the same score. I certainly wouldn't give myself 10 out of 10 on either of them, um, and I definitely think that if I went into that house there, and I was dealing with a psychosocial, I might get 8 out of 10, but I might go into that house there and deal with a psychosocial and I might only get 4 out of 10. Um, but I think that's the same as physical too. I think that your scores might be different in a different house, different client, and different situation. Um, simply because of the client. (Nurse 1)

The perception of their management was determined by their role perception. This next extract makes that distinction between assessment, and intervention:

From an assessment point of view, I think I'm fairly competent. I wouldn't say I'm an expert. I'd always say, you know, there's area that I can learn. Um, there's ways of doing things better. I recognise that, but I think, I think that I'm fairly competent to assess certain needs. Um, as far as meeting needs. I think I can help some people to meet some needs, um, but I'm not a spiritual counsellor, neither am I am psychosocial counsellor, and I'm always happy to listen and I know, for some people, listening is really important for them. But then there are other areas where listening is not the whole thing. And um, I don't see that as my role. I actually see my role then, to actually pass that on. (Nurse 3)

Some nurses regarded experience to be the main factor in their determination of competence in this setting:

I would say very good. I'd say maybe, seven out of ten. But I think that's probably because of my own nursing experience, plus my own personal experience of death as well. And I don't know if it's been quoted before, but you tend to find nurses who've had to deal with some trauma in their life, tend to be quite good at dealing with other peoples traumas if they've come to terms with it and accepted it, you know. (Nurse 5)

Summary of Theme 4

Reflection by the nurses on the management of the psychosocial and spiritual pain experienced by their clients in the home hospice setting included three sub themes. The first sub theme identified was that of recommendations of practice, with these recommendations further divided into organisational recommendations and nurse related recommendations. The second sub theme identified was that of advice for new nurses in the setting and described three further divisions in this theme. The first described was based on communication issues, the second dealt with attitudes of management and the third described internal nurse factors.

The last sub theme described the reflection of nurses regarding their management of psychosocial and spiritual pain as opposed to physical pain. It was found that all of the nurses interviewed believed that they were competent to deal with psychosocial and spiritual issues, with some providing the condition of role perception as a limitation of management intervention.

Summary of findings of Qualitative Analysis

In this chapter of the report, the findings of the phenomenological analysis were described. The chapter was organised into four themes, which corresponded to the four main themes identified from the analysis. These four themes were, “Nurses’ perceptions of psychosocial and spiritual issues”, “Nurses’ perception of role”, “Factors influencing management”, and “Nurses’ reflections on their approach to care”.

It was found that the nurse’s viewed psychosocial and spiritual issues as existing from diagnosis of the illness and that psychosocial and spiritual pain arose at various times along the palliative journey. While psychosocial issues occurred as a result of the clients’ condition, these issues tended to be manifested in the carers, rather than the clients. Spiritual pain, on the other hand, was experienced by the client, and, if not resolved before the end stages of the disease, tended to manifest in spiritual crises.

The role of the nurse was perceived to be that of assessment and referral primarily, with management intervention being considered on a case-by-case basis. Nurses tended to utilise one of two management methods when dealing with psychosocial and spiritual pain experienced by their clients. The first method described was intervention of the nurse through the nurse – client relationship. The second method of intervention described the intervention of the nurse as a member of the Silver Chain team. This method was utilised when intervention through the nurse – client relationship was not possible, and also by the nurses who perceived their role to be that of assessment and referral, with referral being primarily to other team members within Silver Chain (i.e., chaplains and counselors).

The factors influencing management of psychosocial and spiritual pain was divided into four categories. The first category identified nurse related factors such as experience, knowledge, confidence, gender, and intuition. The second category described client issues such as age, health status, gender, family and socio-economic factors. The third category in this theme identified organisational factors like formal assessment and training, plus workload, staffing and nursing perception of

management. The fourth category described global factors such as time, communication and the environment.

Recommendations for improvement were to clarify the role of the nurse in the management of psychosocial and spiritual pain, improve assessment of spiritual pain, and formal documentation of assessment. Recommendations for nurses were that they have life experience, a past experience of death and an ability to deal with clients' from all walks of life (including both age and socio economic background). Advice was given for new nurses in the home hospice setting, which included numerous suggestions concerning communication skills, attitudinal issues and nurse related issues. Nurses also compared their perceptions of psychosocial and spiritual pain management with their physical pain management and it was found that the nurses interviewed rated all types of pain management (both physical and "non – physical") equally.

CHAPTER 6

DISCUSSION AND CONCLUSION

Introduction

This study has described the experiences and perceptions of nurses in relation to their management of the psychosocial and spiritual pain that their clients' were experiencing, in the home hospice setting. This chapter presents a discussion of these findings in relation to existing knowledge of the relevant concepts to the setting. It also offers a description of the data in terms of the philosophical context in which this study was undertaken.

Discussion of Findings

Nurses' Perceptions of their Management

The major finding of this study describes the nurses' perceptions of their role in the management of the psychosocial and spiritual pain experienced by their clients' in the home hospice setting.

Assessment and referral as primary role

It was found in this study that the common perception of the management role amongst the nurses interviewed was that of an assessment and referral basis. The particular setting of this study was found to have a paucity of literature regarding nursing management issues, and this was one reason why this study was conducted. Existing literature did suggest that this role of assessment and referral was quite common for nurses in the palliative care setting. Abma and Widdershoven (2005), described this in their study on responsive evaluation

This assessment and referral role of palliative care nurses was also found to apply in the study conducted by Hu et al. (2003) in their study of willingness of nurses to provide palliative care in rural Taiwan.

Nursing management as part of a team

This perception of their role was reflected in the management approach of nurses acting as members of the Silver Chain team. This was considered an acceptable management technique for it provided team members who were more qualified to deal with the presenting issues to become involved, which then left the nurse to continue with her core nursing duties. This assessment and referral option was considered to be the minimum that a nurse would do regarding management.

The third theme identified by this study described factors that influenced the management of the psychosocial and spiritual pain of the clients'. All of the factors described by the third theme contributed to the selection of the management method that the nurses chose to use.

If nurses felt confident in their abilities to manage their client's psychosocial and spiritual pain (after taking into account all of the management factors), they did attempt to manage their client's psychosocial or spiritual pain. This confidence being a factor in management was also found in the study conducted by Hu et al. (2003). Management intervention tended to differ between psychosocial and spiritual pain, so these two issues will now be discussed separately.

Psychosocial management

At the very least, all of the nurses interviewed attempted psychosocial management by talking to the clients and their carers. The nurses in this study quite often cited this mediator role as a step towards psychosocial intervention, with the result of this mediation sometimes being resolution of the issue. This mediator role of the nurse in palliative care was the focus of an Australian study by Hart, Yates, Clinton, and Windsor (1998). Even when mediation of the nurse did not resolve the issue, it enabled other management options to be introduced (i.e. counseling), which could then open other avenues of intervention.

It was found that the management of psychosocial pain was fairly linear because psychosocial pain in the clients tended to manifest itself externally through

changes in the relationships with those around them (Nolan & Lundh, 1999). Assessment, thus, often did not involve ascertaining whether psychosocial pain existed, but rather what had caused it (which could then be obtained by talking to the client and their family).

It is interesting to note, at this point, the findings that psychosocial pain tends to be manifested by the clients' carer rather than the client, even though the issues themselves are based upon the client's condition. This aspect was also implied in the study by Nolan and Lundh, (1999).

Spiritual management

Spiritual assessment was done on admission, as part of Silver Chains admission process and, in some instances, was then left for the client to decide upon their own spiritual management. Even though Silver Chain is a secular organisation, Christian trained chaplains were cited as the only spiritual referral that nurses could refer to if needed. Flannerly, Flannerly and Weaver, (2002) also noted the existence of this perception that religion was synonymous with spirituality.

As described earlier, spiritual assessment was difficult due to the wide variance in perceptions of what actually constituted spirituality. The "team based" management option was limited to Christian chaplains in Silver Chain, and this, as well as a lack of spiritual resources, was considered to be a limitation impacting on spiritual pain management by the nurses interviewed. The lack of spiritual resources for nurse is apparent in the general nursing literature thus it is not surprising that the nurses reported limited support in this area.

Personal management of spiritual pain tended to be dependent upon the nurses own concept of spirituality (Belcher & Griffiths, 2005) as well as confidence in their abilities (Hu et al., 2003).

The nurses studied, however, were aware of the difficulties of spiritual management and had recommendations of ways in which spiritual management could be improved.

Factors influencing Management

Having discussed the nurses' perceptions of their role in the management of their clients' psychosocial and spiritual pain, as being primarily one of assessment and referral, with other management options depending upon a host of factors, it is now time to describe these other influencing factors. Some aspects of this theme were identified in the literature review under the heading of barriers to management. A scarcity of literature exists regarding nursing management of these psychosocial and spiritual pain issues, with factors influencing the nurse's management being no exception.

This theme was divided into four categories, with the first three categories dealing with factors relating to specific stakeholders in this study, and the last category talking about global factors which influenced the management of psychosocial and spiritual pain in the home hospice setting.

These factors were considered to play a part in both the assessment of the client as well as the contributing to the selection of the management option employed by the nurse (i.e., refer to team members or deal with themselves) and thus will be discussed at length in this category.

Nurse Factors

Nurses were regarded as the primary stakeholders in this study, for it was through them, and their perceptions, that the data was obtained. For this reason, the first group of influencing factors was described under the heading of nurse factors. These factors were regarded as factors pertaining to the nurses themselves, and nurses went on to give examples of how each of these influenced them.

All of the nurses interviewed in this study regarded experience as being essential to the effective management of psychosocial and spiritual pain (Richardson, 2002). Life experiences, and particularly the experience of having suffered a personal loss, were regarded as important. Vocational experience also offered perspective to

the setting. Not only the personal experience of the nurse, but also the experience of other nurses was accessed through the peer network structure, as outlined above.

Knowledge, as distinct from experience was also cited as being important in providing management options for clients in the home hospice setting. The knowledge of what alternatives exist was cited as being important. The knowledge of self, in respect to your limits, was also regarded as a factor. Finally, by having knowledge of available resources, such as who to turn to for assistance, was also considered an essential component of knowledge.

On consideration, the next factor identified came as no surprise, for essentially it is based upon the prior two factors. Confidence was the third factor identified by the nurses interviewed in this setting. Having the confidence to tackle difficult issues was regarded as an asset in aiding the management of psychosocial and spiritual pain. This aspect of having the confidence to tackle difficult issues was described by Tan, Braunack-Mayer and Beilby (2005) in their article dealing with the impact of the hospice environment on patient spiritual expression.

Knowledge of their role gave nurses the confidence to approach their duties, and also gave them confidence to know when to refer cases on. This confidence also extended to nurses knowing their capabilities, and verbalising when they are outside of this confidence zone.

This confidence led to acceptance of their limits and empowered them to walk away when the management of psychosocial and spiritual issues became too difficult. This awareness of self led into the last factor identified by nurses as an important component in their management of the psychosocial and spiritual pain.

Intuition was a somewhat unexpected factor cited in the management of their clients' but it was mentioned on several occasions and implied in almost all interviews. In the researchers opinion, this intuition is based upon all of the preceding factors, and thus to have an intuitive approach, the nurses would also need to have experience, knowledge and confidence.

Other factors identified included the gender of the nurse as having both a positive, and a negative influence on the management of their clients, the interpersonal relationship between the nurse and the client, both in terms of interpersonal conflict and also the development of friendships between the nurse and the client. This last factor lead to a discussion regarding the fluidity of professional boundaries in the home hospice setting, and how this can be a factor in the management of the clients' psychosocial and spiritual pain. Similar ethical implications (including professional boundaries) in palliative care have been discussed by Woods, Beaver, and Luker (2000).

Client factors

The clients were considered the secondary stakeholders in this setting for the psychosocial and spiritual pain that they experienced was the dependent topic under study. For this reason, the second group of factors identified dealt with issues that the clients' contributed to the research setting.

Because many of the clients in palliation are aged, age factors also impacted upon management of psychosocial and spiritual pain. The perceptions of the aged clients, and their own personal life experience, affected the way in which nursing assessment and management was conducted.

Gender was regarded as a major factor influencing the management of the psychosocial and spiritual pain. It was perceived that male clients could suffer psychosocial pain when they were forced to give up control. Some female clients did not want male nurses or carers, and some male clients also preferred female nurses or carers, thereby imposing restrictions on their care.

Another common factor cited was the health condition of the clients themselves. This included factors such as physical health, as well as mental health stability of the client and the fatigue that clients were enduring.

For the researcher, the biggest surprise in this study pertains to the socio-economic factors cited by nursing as impacting on their management of the psychosocial and spiritual pain of their clients.

Psychosocially, families contributed factors that influenced management. Indeed, it was described on several occasions, that it was the families that presented the major management issues of psychosocial pain. Miscommunication, family conflict and even the structure of the family unit itself impacted on psychosocial pain.

Surprisingly, cultural factors did not emerge significantly in this study. It was only mentioned in passing when talking about the coping mechanisms employed by the clients, and with other issues as gender affecting coping, and alternative therapies as part of coping. The researcher's own experience generally in nursing, and specifically in palliative care indicated that cultural issues could have been a greater factor than what was reported.

Organisational factors

The last stakeholder considered as contributing factors to the psychosocial and spiritual management of the client was that the employing organisation. Because Silver Chain was the organisation that provided the nursing service for the clients, factors relating to it were deemed organisational factors. These factors cover such issues such as training and assessment issues, workload and staffing issues, remuneration and conditions, as well as nurse perceptions of management.

Because the home hospice nurses need to work independently and are autonomous, the training required for the nurses needs to be quite high. This training issue was considered to be a factor in choosing the management method. As well, as this, a lack of a structured assessment tool for psychosocial and spiritual pain was considered a factor in effective management. Silver Chain is currently conducting research to improve both of these areas for they have been identified previously as issues.

The lack of an effective assessment tool was perceived to be an embodiment of the deficiency of spiritual management options that exist within the Silver Chain organisation itself. This perception was also based on the fact that the only spiritual guidance offered by Silver Chain was through Christian based chaplains, and that a perceived paucity of resources existed for alternative spirituality.

Some nurses interviewed reflected on the role of Silver Chain management as bearing on their management of the clients' psychosocial and spiritual pain. An interesting observation is that the further that management was removed from the actual nursing setting, the less well perceived they were. Nurses as peers were regarded strongly, with case coordinators and CNC's also being viewed positively. Chaplains and counsellors were also regarded as useful, but not entirely practical in matters, with upper management being regarded as the least favourable or accessible aspect of the psychosocial and spiritual pain management of their clients.

Some nurses attributed high workload factors to staffing issues, but this occurred less frequently than the researcher had anticipated. Also surprisingly less frequently cited than expected was the remuneration and conditions that the nurses were subjected to. Considering that these factors (workload, remuneration and work conditions) are often cited as being major sources of dissatisfaction within the nursing community as a whole (Kingma, 1999). It is the researcher's belief that this was possibly due to nurses having a much higher satisfaction in their role than those working in the wider nursing population.

Global factors

The last group of factors identified were a group that transcended the categories discussed above. They were regarded as critical factors covering all domains of the palliative care setting.

The first factor identified was time. Time is important in many ways. Time to the nurse determines the amount of care that can be provided. This relates equally to physical care, emotional care, psychosocial care and spiritual care of the client (Tan,

Braunack-Mayer & Beilby, 2005). From a client's perspective, in the palliative care setting, time is the one thing that they are always aware of, and thus it marks, and determines the relationships that they have, thereby having a large psychosocial impact. Time, from an organisational perspective, is a factor in caseload allocation. It is also the predominate factor in remuneration, both to the company, and for the nurse.

Another global factor falls under the category of communication.

Communication for nurses is essential in establishing relationships, assessing needs and offering support. Communication, in this sense, is not just about talking and listening, but actively "being with" the client (Tan, Braunack-Mayer & Beilby, 2005). Almost all of the advice that the nurses interviewed gave for improvement of management stemmed around communication issues. Communication, from the client's perspective, is essential in maintaining healthy relationships. It is often a mark of psychosocial and spiritual pain when client based communication breaks down. Communication, at an organisational level, not only describes the administrative components essential for the functioning of the organisation, but also as a measure of trust and respect between the organisation and the nurse.

The final global issue identified relates to the environment in which psychosocial and spiritual management occurs. For nurses, it describes the factors associated with providing psychosocial and spiritual support in the home setting. Environmental factors for the client include the home in which they live, but also the internal environment in which they function. These internal environmental factors lead to psychosocial and spiritual issues that the client faces and are thus very important. Environment factors, from an organisational perspective, relates more to ensuring adequate staffing, and occupational health and safety as well as providing sufficient training to ensure competence amongst staff.

Existing Limitations Identified

Originally, the existing limitations to the nurses' management of psychosocial and spiritual pain was going to be an extra theme obtained by analysis, for there were a number of issues identified by the nurses in the study that could be regarded as

limitations. Many of these limitations were consolidated under the theme factors influencing management because these limitations served to be factors in the way in which nurses perceived their management of the clients' psychosocial and spiritual pain. Both of the limitations that were explicitly identified by nurses were considered to be organisational limitations. The first one related to adequate training for nurses in assessment and management of these psychosocial and spiritual pain issues. The second limitation concerned expressed the need for a formal assessment tool for psychosocial and spiritual pain. The last existing limitation was the lack of spiritual resources that the nurse could refer to.

Recommendations and advice for improvement

The recommendations and advice for improvement offered by the nurses in response to the existing limitations will now be discussed.

Considering that the research topic for this study was to describe the perceptions of the home hospice based nurses of their management of the psychosocial and spiritual pain experienced by their clients, the inclusion of a theme titled recommendations in the findings seems to be outside the scope of the parameters implied by the title. The justification for this theme lies within the concept of nursing management. Nursing management is an active, continual process. It consists of assessment of the situation, diagnosis of problems, planning and implementation of intervention and evaluation of results. With this understanding of the nursing process, the theme of recommendations and advice can be seen as a part of the process that nurses use in management and therefore, included as part of this study.

Having established the validity of this theme within the context of the study, the improvements suggested by the nurses shall now be discussed. Holistic care was a fundamental concept demonstrated by all of the nurses interviewed in this study. This holistic care of the client included acceptance of all aspects of the client, and their situation, but this holistic acceptance did not extend to include the limitations of the organisation. The recommendations made by the nurses in this study involve the perceived limitations of the organisation.

Recommendations

The three limitations described in the previous section provided the basis of the recommendations of the nurses in this study. These recommendations made by the nurses are to:

- i) Improve the training of nurses so that they are more competent and confident in assessing and managing these issues,
- ii) Add a section to the official symptoms assessment form (thereby ensuring that these issues are dealt with regularly), and lastly,
- iii) Provide more resources (either paper based, or training based) on spiritual issues, and more specifically, existing alternatives in the community.

Advice:

The advice offered by the nurses extended and exemplified the factors identified by the nurses in the findings section. If the advice of the nurse were to be summed up as one concept, it would be holistic care. The nurses interviewed for this study based their care approach upon this core concept of palliative care. It included effective communication, therapeutic relationships, acceptance of the client and consideration of their perspective, and self care advice based upon attitudinal approaches to care and taking time to debrief so as not to “burn out”.

Summary of findings

Nursing within the palliative care, home hospice setting is still nursing, and thus issues relating to general nursing practice relate also to this setting. Effective communication in nursing is essential regardless of the setting. By being effective in all aspect of their communication, the nurse is not only involved in the distribution of knowledge and information, but is also developing a therapeutic relationship in which both the nurse and the client can grow.

Relationships play an important part in all aspects of life. Psychosocial pain tends to be expressed when there is a breakdown somewhere in a client's relationship. This can be due to perceptions that the client has concerning their condition; it can also be caused by the condition itself in so far as it affects their ability to engage with another person. Nurses need to have an understanding of the causes of psychosocial pain to be able to effectively assess and manage them, and this understanding needs to occur within the context of the nurse-client relationship.

Spiritual pain, although an internal factor of the client can also be managed more effectively in the context of the nurse – client relationship if a relationship exists that is open, built on trust and acceptance of the clients' situation, and allows honest expression. This holistic approach to the caring relationship epitomizes the core concept of palliative care, which is to allow the client the opportunity to experience a good death, within the context of their life.

Recommendations from the study.

The recommendations made by nurses in relation to perceived issues in the management of psychosocial and spiritual pain has already been discussed in this report. They were found to be organisation in origin, and reflected both the importance of these “non – physical” pain and the perceived shortcomings of the organisation. The recommendations made by the nurses mirror those made in other settings and outline a conceptual difference between what is ideal and what is actual.

Silver Chain is currently undertaking research to shorten this gap between then ideal situation and the actual in the form of formal assessment tools for psychosocial and spiritual pain. The perceptions that some nurses have are that they should be able to manage psychosocial and spiritual pain as well as physical pain, and this comes down to an issue of role perception. Silver Chain does provide management options through their team structure, and are also working on training volunteers to aid in this area as well.

The third recommendation by the nurses in this study involved enhancing spiritual resources so that nurses can have, at hand, a ready source of information on “other” spiritual modalities. The difficulty in spiritual management has been described on numerous occasions throughout this report, and having access to such information (remembering that knowledge is regarded as a factor in management) would aid nurses in improving their spiritual pain management of their clients.

The researcher’s recommendations from this study are more conceptual in nature. It was impossible to describe psychosocial pain in the home hospice setting without relating it to the carers that were involved in the clients’ care. In an inpatient setting, where the nurse is the primary carer of the client, the simple perspective of the nurse – client relationship is quite acceptable, but research is emerging that in the home hospice setting, management relationships need to involve the primary carer as well. It has been shown in this study, that the carer manifests psychosocial pain caused by the client’s condition, and thus they need to be considered in the management equation. This reflects the World Health Organisation’s definition of palliative care and it is also incorporated in Silver Chains mission statement.

Because the framework for this study was based on concepts relating to nursing perceptions, nursing management, psychosocial issues, spiritual issues, and relationships, it is possible that the findings of this study would be relevant in describing these issues in another setting. The setting chosen for this research contributed richly to the data in relation to these concepts.

Suggestions for further study would include the following:

- Does being happy help patients live longer?: psychosocial, spiritual and attitudinal issues as indicators of survivability among palliative care patients.
- Adding experience to training: effectiveness of scenario based training packages in providing education to nurses in complex situations.
- What do nurse's believe?: a descriptive study of nurse's spirituality and how it affects their coping mechanisms.
- Perceptions of existing psychosocial care for families after a client's death.
- The Child as a palliative care patient, how do nurses deal with their personal issues in this context?

As well as these suggestions, a parallel study involving clients' and their carers about the issues they face as they journey along the palliative care path.

Conclusions

This study was designed to describe, through a phenomenological framework, the perceptions and experiences that nurses, working in the home hospice setting, had regarding their management of the psychosocial and spiritual pain of their clients.

The study utilised a Heideggarian philosophical base in conjunction with a conceptual framework created using concepts identified by the literature review of the issues arising from the research topic.

It was found that nurses considered their primary role in management of these issues as one of assessment and then referral. Distinctions were made between the concepts of psychosocial pain and spiritual pain, with management varying between these two forms of pain. It was found that while psychosocial pain was easily assessed, spiritual pain assessment was considerably more difficult for the nurse to perform.

While psychosocial pain was manifested in the relationships between the client and those around them, and thus management options were easier to assess, spiritual management tended to be based upon the nurse's own concept of spirituality, and confidence in dealing with these issues and thus intervention, varied considerably amongst nurses.

The nurses in this study perceived that their management of the psychosocial and spiritual pain was acceptable, within the limits of their own role perception. All of the nurses would attempt some form of intervention if they considered it appropriate, but a lot of the time in the interviews was spent by the nurses in this study outlining the factors that influenced their management.

Recommendations made by the nurses were based upon perceived limitations which included the implementation of a formal assessment tool for non – physical pain issues, training of the nurses in effective management techniques for these kinds of pain, and providing more spiritual based resources (both paper and training based) to improve the knowledge base of the nurses.

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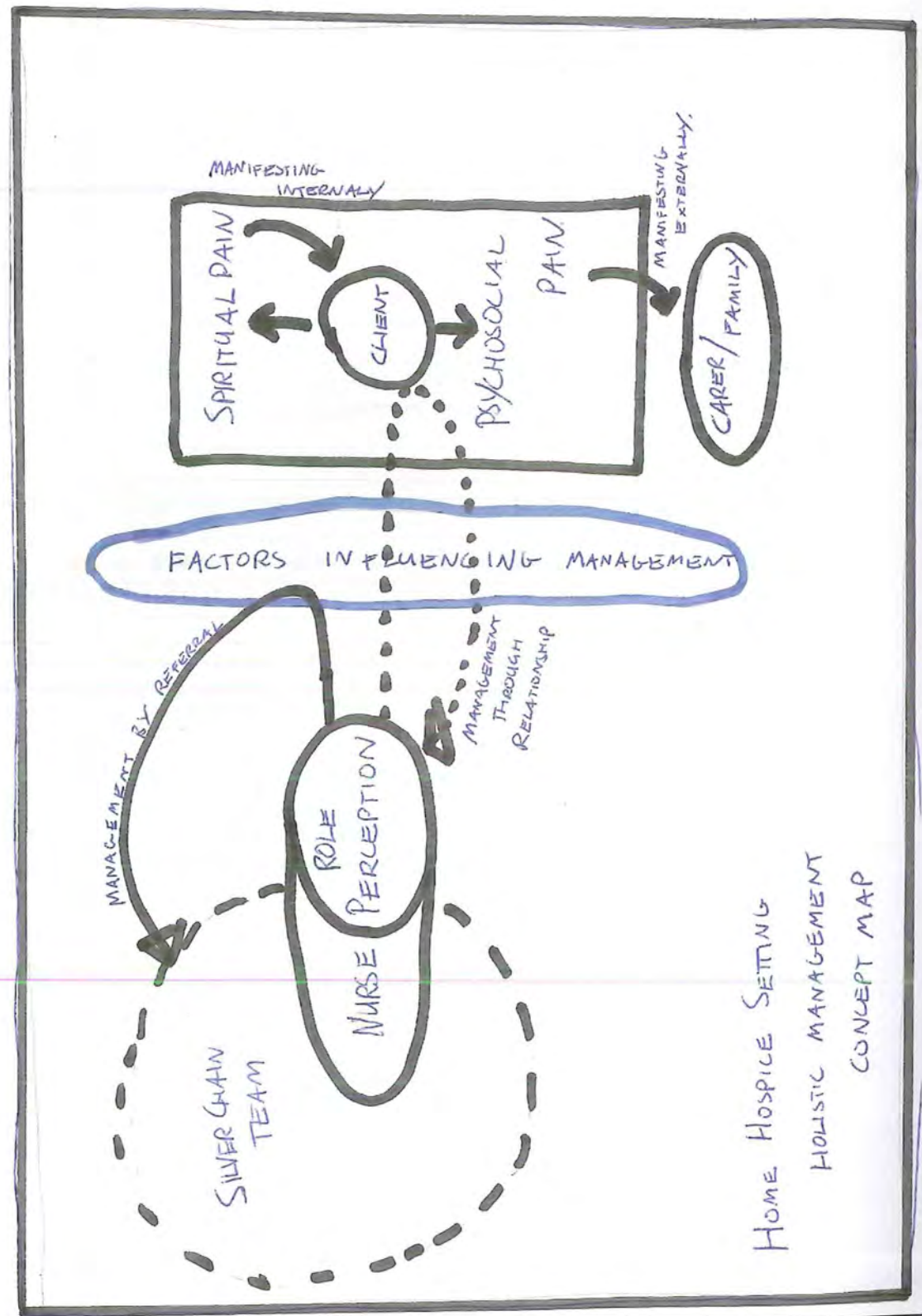
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Appendix I: Concept Map



Concept map for conceptual framework.

Appendix II: ECU Ethics Approval Letter

16 August 2005

Mr Laurence Vogler
13 Kooyong Road
Riverdale 6103

Student # 2003688

Dear Mr Vogler,

Course: *Bachelor of Nursing Honours*

Thesis Title: *Palliative care nurses' perceptions of their management of the psychosocial and spiritual pain experienced by their clients in the home hospice setting.*

Date Proposal Approved: *4th July 2005*

Date Ethics Approved: *9th August 2005*

Please be advised that your application for Ethics Clearance has been approved by the Faculty of Computing, Health and Science Ethics Sub-Committee for the conduct of Human Research.

This approval is granted subject to the procedure/s as outlined in your application and the conditions, if any, as outlined by the Committee in the attached memorandum. Please note that the collection of data for your research must adhere to these conditions.

As you received already received approval for your Honours proposal you are now authorised to commence data collection.

If you have any queries or need assistance during the course of your study please contact the Administrative Officer - Higher Degrees on 6304 2593.

Further guidance and information can be obtained from the Faculty of Computing, Health and Science *Honours and Masters by Coursework Handbook* that is available from the following web address:

<http://www.chs.ecu.edu.au/org/rhd/admin.html#higher>

I wish you all the best in your studies.

Regards,



A/Professor Paul Lavery
Acting Associate Dean (Research & Higher Degrees)
Faculty of Computing, Health and Science
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Appendix III: Silver Chain Ethics Letter



SILVER CHAIN

Caring In The Community

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13 September 2005

Mr L Vogler
13 Kooyong road
RIVERVALE WA 6103

Dear Laurence

Ethics Application 022 – Palliative care nurses' perceptions of their management of the psychosocial and spiritual pain experienced by their clients in the home hospice setting

I refer to your application for ethics approval for the above mentioned study. I am pleased to advise that final approval has been granted, as all the conditions outlined in my letter of 12 September 2005 have been met.

Silver Chain ethics approval is valid from 12 September 2005 to 11 September 2008 (3 years).

It is a condition of approval that a report be provided to the Committee at least annually and on completion of the study. Any adverse experiences associated with the study should be reported to the Committee as they occur.

The Silver Chain Ethics Committee is constituted and functions in accordance with NHMRC National Statement on Ethical Conduct in Research Involving Humans (June 1999) and the NHMRC Statement on Human Experimentation and Supplementary Notes 5 and 7 as issued in October 1983 and November 1992, respectively.

Please quote *EC App 022* on all future correspondence relating to the study.

I wish you every success for the conduct of the study.

Sincerely

Dawn Woods
Research Support Officer

DW [EC/L.22]

Psychosocial and Spiritual Management Issues in Home Hospice Based Palliative Care



Allow me to introduce myself.

My name is Laurence Vogler and I'm currently undertaking research at Edith Cowan University. I am interested in interviewing palliative care nurses (who are currently working in the community setting) to find out what their perceptions of psychosocial and spiritual pain management in the home hospice setting are.

Who can take part?

If you are a registered or clinical nurse working in the home hospice palliative care setting, regardless of how long you've been working there, then I would love to speak to you!

Where?

Where ever you like. I am available to travel anywhere (well, within the Perth Metropolitan area anyway), at any time. Alternatively, telephone interviews are perfectly acceptable too.

How long will the interview take?

I understand how important time issues are and thus only intend on taking about half an hour (or thereabouts) of your time.

What do I get out of participation?

That one is easy, the satisfaction of being part of research that is related to your field of employment (I wish I could offer money, but all I've got spare is gratitude!).

Ethical concerns.

Any information that you give will be strictly confidential and all data will be de-identified. You will also be free to stop the interview at any time and any information given will be destroyed, if you so request.

Sounds great, what do I need to do?

If you think you might be interested in being a part of this study, please feel free to contact me on 0412 769 690 or at

lvogler@student.ecu.edu.au, or alternatively, Dr. Lynn

Oldham on 0438 944588 (l.oldham@ecu.edu.au).

Appendix V

Nurses' Perceptions of Psychosocial and Spiritual Pain Management.
Information Letter

Interview regarding Psychosocial and Spiritual Management Issues

Dear <Participants' name>,

My name is Laurence Vogler and I'm currently undertaking research at Edith Cowan University. I am interested in interviewing palliative care nurses (who are currently working in the community setting) to find out what their perceptions of psychosocial and spiritual pain management in the home hospice setting are.

If you consent to take part of this study, you will be asked to participate in an interview that will be tape recorded for later analysis. Once this tape recording has been transcribed onto paper, the tape will be stored in a safe and secure location.

Any information that you give will be confidential and only used for the purposes of this study and all information obtained will be de-identified so that nobody can associate you with the findings.

Participation in this project is voluntary. If you choose to participate, you are free to withdraw from at any time without giving a reason and with no negative consequences. If you do choose to withdraw, any information given by you will be destroyed and not included in this study. You are also free to ask for any information that identifies you to be withdrawn from the study.

On completion of the transcription of the interview to paper, you will be provided with a copy of your transcribed interview and asked if you are happy for this interview to be used for analysis. If you agree to this, your interview will be analysed with the other interviews undertaken and a summary of the findings of this study will be forwarded to you, at your request.

If you would like to take part in this study or have any questions or require any further information about this research project, please feel free to contact me on 0412 769 690 or via email at lvogler@student.ecu.edu.au

Alternatively, you can contact my supervisor, Dr. Lynn Oldham on 92738164 or via email at l.oldham@ecu.edu.au.

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact:

**Research Ethics Officer
Human Research Ethics Committee
Edith Cowan University
100 Joondalup Drive
Joondalup WA 6027
Phone: 08 6304 2170
Email: research.ethics@ecu.edu.au**

Sincerely Yours,
Laurence Vogler

Appendix VI:

CONSENT DOCUMENT

Study Title:

Qualitative Interview regarding Psychosocial and Spiritual Management Issues

Principal Investigator:

Laurence Vogler BN

I have been provided with a copy of the Information letter, explaining the project.

I have been given the opportunity to ask questions and any questions have been answered to my satisfaction.

I understand that participation in the research project will involve:

- participation in a 30 to 45 minute interview, which will be recorded using an audio tape recorder that will be securely stored on completion of transcription to paper of the contents.

I understand my interview transcription will only use de-identified data.

I understand that the information provided will be kept confidential, will only be used for the purposes of this research and I will not be identified in any written assignment or presentation of the results of this project. I understand that I am free to withdraw from further participation at any time, without explanation or penalty and that on withdrawal, any information provided by me will be destroyed.

I freely agree to participate in the project.

Name _____

Signature _____

Date _____

Study title: Nurses' Perceptions of Psychosocial and Spiritual Pain Management

Demographic Information

ID: _____

1. Gender Female Male

2. Age (years): 20 – 29 _____
 30 – 39 _____
 40 – 49 _____
 50 – 59 _____
 60 + _____

3. Details of nursing qualifications obtained (including Post Graduate)

 ? RN ? Hospital diploma ? University degree
 ? EN
 ? Postgraduate _____

 ? Other _____

4. Palliative care experience (years): _____

5. Number of years in current role: _____

6. Employed: ? Part time ? Full time

7. Usual Shift ? day ? afternoon
 ? evening ? night

8. Other clinical experience: _____

Nurses' perception of psychosocial and spiritual pain management in the home hospice setting.

Main Question:

Global question:

What are your perceptions of the management of the psychosocial and spiritual pain experienced by clients' in the home hospice setting overall?

Concepts identified by Literature Review:

Experiential Learning:

How do you perceive your management of these issues?

Describe a situation where your intervention has had the desired effect with regards to psychosocial or spiritual issues?

Can you describe a situation where you did not know how to handle these issues?

Education issues:

Can you think of ways that training for your role could be improved with regards to these issues?

Would you utilise a training package that dealt with "non – physical" pain management?

Workplace factors:

What factors influence the management of these issues in the home hospice setting?

What do you perceive to be constraints to effective management in the hospice setting?

Competence for role:

Do you employ specific strategies for managing these situations?

How would you handle a client experiencing a "spiritual crisis"?

Support:

Do you believe that you have adequate support for management of psychosocial and spiritual issues in the home setting?

What advice would you give to a new nurse in this setting regarding psychosocial and spiritual management?

Self assessment:

How would you rate your ability to handle psychosocial and spiritual issues as opposed to physical issues that the patient manifests with?

These topics cover the concepts identified by the literature review as areas of potential further investigation. Depending upon the feedback resulting from the pilot interview, these areas may be expanded further or minimise