PALLIATIVE SEDATION: NURSES' PERCEPTIONS

BY

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A Thesis

Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

MASTER OF NURSING

Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba

THE UNIVERSITY OF MANITOBA

FACULTY OF GRADUATE STUDIES

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A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of Manitoba in partial fulfillment of the requirements of the degree of

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Dedication

To Sheldon, my soul mate and love of my life,
I want to dedicate this thesis to you for your inspiration,
and belief in me and
reminding me everyday to dance through life,
all of which encouraged me to complete this work

Abstract

Nurses play a key role in providing compassionate end-of-life care to patients and their families. This often includes assessing and managing symptoms that patients may experience during the dying process. At times, "palliative sedation" or "terminal sedation" has been indicated in adult patients for symptoms that are not controlled. Palliative sedation is defined as "the relief of one or more intractable symptoms when all possible alternative interventions have failed, and the patient is perceived to be close to death, and for the relief of profound anguish that is not amenable to spiritual, psychological or other intervention and the patient is perceived to be close to death" (Chater, Viola, Paterson & Jarvis, 1998, p. 257-258). Current literature has focused on developing a definition for the concept of terminal sedation or palliative sedation, determining how often refractory symptoms occur in patients with advanced cancer and which medications are used to induce sedation. To date, limited research has examined the nurse's role and perspective involving palliative sedation. The purpose of this qualitative study was to explore the nurses' experience regarding palliative sedation, specifically, the knowledge, attitudes and the meaning the nurse attributed to the use of palliative sedation for intractable distress in dying patients.

Symbolic interactionism provided a perspective for exploring nurses' perceptions of palliative sedation under a variety of complex processes in which nurses understand, interpret and create their world as well as define their work in caring for palliative care patients. Data were collected through face-to-face interviews with 10 nurses working on an adult designated palliative care unit. Findings revealed

the major unifying theme of *Working Your Way Through The Quagmire.* The metaphor of the quagmire is defined as the ambiguous and variable situation nurses find themselves grappling with and captures the nature of the experience the nurses recounted during their interviews. The outcome of the nurses' working their way through the quagmire was that each had difficulty defining palliative sedation and their experience was variable. In some situations, nurses worked through the quagmire to a place of comfort and proceeding with palliative sedation, while in other situations uncertainty remained. Implications for practice, education and research are discussed.

ACKNOWLEDGEMENTS

This thesis could not have been accomplished without the ongoing support, encouragement and belief in this project from many individuals who were instrumental in its completion. I would like to express my sincere gratitude to each of them at this time.

To Dr. Pamela Hawranik, as the chair of my thesis committee, thank you for your enthusiasm, support and mentoring. I am grateful for all your research expertise, thought provoking questions and critiques of my work that guided me down the right path.

To Dr. Susan McClement, as the internal chair of my thesis committee, thank you for your valuable insight into qualitative research and challenging questions. Thank you for instilling the passion in me to initiate and complete this project.

To Dr. Paul Daeninck, as the external chair of my thesis committee, thank you for all your insight, thought provoking comments and constructive feedback.

Sincere gratitude is expressed to the ten nurses who participated in this project and shared their experiences. Without them this project would not have been possible.

Special gratitude is expressed to Marie Edwards for her wisdom and insight into the "ethical world" and assisting me with this difficult area of my thesis.

Special thank you to Louise Sabourin for her expertise in formatting and editing my thesis.

Special thank you to my family friends, who at many times despite suffering neglect on my part, remained interested and true. Thank you for your understanding and words of encouragement.

To my colleagues, Mary, Darlene, Simone and Suzanne who provided me with a listening ear when I needed it. I am grateful for your unwavering support.

Finally, I would like to acknowledge the Fort Garry Legion Poppy Trust Fund, who recognized the importance of this work and awarded me with financial support.

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CHAPTER ONE: STATEMENT OF THE PROBLEM

Introduction

Nurses play a key role in providing compassionate end-of-life care to patients and their families. This often includes assessing and managing distressing symptoms that patients may experience during the dying process. At times, "terminal sedation" (TS) or "palliative sedation" (PS) has been indicated for symptoms that "cannot be controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness" (Cherny & Portenoy, 1994, p. 31). The term 'palliative sedation' will be used for this thesis rather than terminal sedation. It is defined as "the relief of one or more intractable symptoms when all possible alternative interventions have failed, and the patient is perceived to be close to death, and for the relief of profound anguish (possibly spiritual) that is not amenable to spiritual, psychological or other intervention and the patient is perceived to be close to death" (Chater, Viola, Paterson & Jarvis,1998, p. 257-258). These symptoms are termed "refractory symptoms" (Cherny & Portenoy, 1994) and may include the following: uncontrolled pain, dyspnea, nausea, and vomiting, terminal agitation or restlessness, emotional distress, or psychosocial anguish. Although not discussed extensively in the literature, terminal sedation may also be indicated for such palliative care emergencies such as uncontrolled seizuring, hemorrhage, superior vena cava obstruction, severe acute stridor and multifocal myoclonus (Twycross & Lichter, 1998). The decision to sedate a terminally ill patient, occurs after interaction and discussion between the nurse, the physician, the patient, the family and the health care team. Even with this discussion,

it is important to recognize that some nurses of the health care team may not be comfortable with sedating a patient and disagree with the rationale used to institute palliative sedation.

Ethical implications are inherent and must be considered when sedating a dying patient with refractory symptoms. The doctrine of double effect is applied to resolve ethical dilemmas surrounding palliative sedation. The doctrine of double effect distinguishes between the effects the clinician intends and the consequences that are foreseen, but unintended (Cherny & Portenoy, 1994; Quill, Lo & Brock, 1997; Wein, 2000). Palliative sedation for intractable distress in the dying must also be distinguished from physician assisted suicide (PAS) and voluntary active euthanasia (VAE). Palliative sedation is implemented to relieve intractable distress and suffering and PAS and VAE produce death thereby relieving distress and suffering (Quill, Lo & Brock, 1997; Quill & Byock, 2000; Quill, Lee & Nunn, 2000).

The current literature refers to palliative sedation as terminal sedation and has focused on defining it, determining how often refractory symptoms occur in patients with advanced cancer, and discussion of the types of medications used to induce sedation (Chater, et al., 1998; Cherny & Portenoy, 1994; Fainsinger, Miller, Bruera, Hanson & Maceachern, 1991; Green & Davis, 1991; Morita, Inoue & Chihara, 1996; Stone, Phillips, Spruyt & Waight, 1997; Ventafridda, Ripamonti, Deconno, Tamburini & Cassileth, 1990). To date, there have been no empirical research studies published examining the nurses' experience with palliative sedation. Presently, the nurses' voice is silent in the research literature regarding the understanding nurses'

have of using palliative sedation and their perception of its role for intractable distress in the dying. A sound knowledge base about palliative sedation requires an understanding of nurses' experience with situations in which this intervention is used. This qualitative research will contextualize the highly personal nature of participating in the care of patients receiving palliative sedation, and emphasize the conscious construction of the meaning associated with such an intervention and acknowledge the socio-cultural dimensions in which these experiences are embedded.

Significance of the Study

Cancer affects the lives of most Canadians, either through their own illness or the illness of a family member or friend. The incidence of cancer is increasing and it is now the second leading cause of death for Canadians (http://statcan.ca/english). An estimated 145 500 new cases of cancer will be diagnosed and 68 300 deaths from cancer will occur in Canada in 2003 (http://www.cancer.ca/stats).

Patients with advanced cancer often experience profound symptoms that can be both physical and psychological in nature. Past studies have documented the occurrence of pain and other related symptoms in patients with advanced disease. To illustrate, pain is prevalent in 80 to 90 % of cancer patients with advanced disease (Bonica, 1985; Daut & Cleeland, 1982). Sixty percent of cancer patients may exhibit shortness of breath and 30 to 90 % of cancer patients may experience delirium during the final weeks of life (Bruera, Chadwick, Weinlick & Macdonald, 1987; Lawlor, Fainsinger, Bruera, 2000; Massie, Holland & Glass, 1983). Furthermore, in a Canadian survey of cancer patients (n = 913), 94 % of respondents reported

experiencing more than one symptom (Ashbury, Findlay, Reynolds & McKerracher, 1998). In a study by Coyle, Adelhardt, Foley and Portenoy (1990), 71% (n = 90) described three or more distinct symptoms during the last four weeks of life. These authors indicate that this group of dying patients "experienced pain and other symptoms that were difficult to control and were associated with deterioration of physical, psychological and social functioning" (p. 87). The management of patients with persistent, multiple symptoms can be extremely challenging for health care providers (Coyle et al., 1990). Ongoing monitoring and adjustments in treatment are often necessary to maintain comfort in the dying patient.

Currently, there are a variety of methods for relieving symptoms with varying levels of effect. Palliative sedation is currently being utilized in palliative care to provide relief from intractable symptoms. Based upon the writer's clinical experience, nurses and health professionals have expressed feeling uncomfortable utilizing this method of symptom relief. Based upon the published literature, there appears to be a paucity of research examining the perception and level of knowledge that nurses have in the administration of palliative sedation. This study examined nurses' perceptions and experiences of palliative sedation. Findings from this study helped nurses to clarify and express their perceptions and feelings regarding PS. In addition, this study helped nurses to identify those issues that might have contributed to their distress when palliative sedation was implemented, and provided insights regarding the types of information and support that nurses needed in relation to this particular intervention.

Purpose of the Study

The overall purpose of this qualitative study was to explore nurses' experience regarding palliative sedation using symbolic interactionism as a conceptual framework. This included examining and describing their knowledge, attitudes and the meanings they attributed to palliative sedation for intractable distress in dying adult patients they have cared for within a designated in-patient palliative care unit .

Research Questions

The following research questions were examined in the study:

Broad Question:

What are the experiences of staff nurses that have cared for a patient that has received palliative sedation on a designated palliative care unit?

Sub-questions:

1) Where did nurses obtain information about palliative sedation therapy and when it should be used?

2) What meaning do the nurses' attribute (associate) toward a patient that has received palliative sedation on a palliative care unit?

3) What factor (s) influence the nurse's attitude toward their experience with palliative sedation therapy?

4) Do specific situations influence the nurse's response to palliative sedation?

Definitions of Terms

The following terms were defined for the purposes of this study.

1) Palliative Sedation: "the relief of one or more intractable symptoms when all

possible alternative interventions have failed, and the patient is perceived to be close to death, and for the relief of profound anguish (possibly spiritual) that is not amenable to spiritual, psychological or other intervention and the patient is perceived to be close to death" (Chater et al, 1998, p. 257-258).

2) Palliative Care: "is an approach that improves that improves the quality of life of patients and their families facing the problem 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" (www.who.int/cancer/palliative/definition/en/).

3) Patient: "the person living with an acute, chronic or advanced illness" (Canadian Hospice Palliative Care Association, 2002, p. 94)

4) Family: "those closest to the patient in knowledge, care and affection. May include: the biological family, the family of acquisition (related by marriage), and the family of choice and friends (including pets)" (Canadian Hospice Palliative Care Association, 2002, p. 92).

5) Nurses Knowledge: "the awareness or perception of reality acquired through insight, learning, or investigation and expressed in a form that can be shared" (Chinn & Kramer, 1995, p. 216). Carper (1978) and White (1995) identified the ways of knowing in nursing in relation to empirical, ethical, personal knowledge, aesthetic and sociopolitical dimensions of knowledge.

6) Attitude: "a set person's beliefs and feelings toward an object that predisposes the person to act in a certain manner when confronted by that object (or class of objects)"

(Charon, 1998, p. 22).

7) Value: " a fundamental belief on which practice is based" (Canadian Hospice Palliative Care Association, 2002, p. 96).

8) Meanings: "linguistic and imagined content and the interpretation one gives to something" (Parse, 1998, p. 29).

9) Perception "the extraction and use of information about one's environment and one's own body" (The Cambridge Dictionary of Philosophy, 1995, p. 568).

Assumptions Underlying the Study

The following assumptions of the researcher underpinned this study.

1) Palliative sedation is an appropriate intervention for adults in which symptoms cannot be controlled by other means, usually after all other attempts at symptom control have failed or have been exhausted.

2) Patients, families and the health care team may hold divergent views about palliative sedation and its role in the relief of refractory symptoms.

3) Nurses will be open to sharing their perspective regarding palliative sedation.

4) Not all nurses are comfortable in the use of palliative sedation as an intervention in the management of refractory symptoms in palliative patients.

5) There may be some underlying ethical or moral influences that effect the nurse's thinking and perception about the usage of palliative sedation as an appropriate intervention.

Summary

In summary, this chapter described the significance and purpose of the study. The research questions and definitions of key concepts were presented. The assumptions that underpin this study were identified. The following chapter will review the current literature and the challenges that exist regarding the topic of palliative sedation.

CHAPTER TWO: LITERATURE REVIEW

Introduction

The use of palliative sedation (PS) is one of the more challenging issues palliative care nurses, physicians and other team members face. A review of the literature reveals the following factors contributing to this challenge: 1) confusion and inconsistency in past studies related to conceptual definitions; 2) disagreements about the clinical indications for its use; 3) inconsistency in pharmacological approaches to sedation; and 4) a paucity of qualitative research examining the contextual factors and process influencing attitudes and behaviours of health care providers and family members around the use of PS in provision of care of the dying. The purpose of this literature review was to provide an analysis of these factors and clarify some of the associated issues.

Definition Challenges

The terms of "palliative sedation" and "terminal sedation" (TS) are not well defined in the literature. A comprehensive literature review was conducted to examine historically the emergence of the phrases TS or PS and their varying definitions over time. As there are no standardized search terms for TS or PS across databases, a triangulated search approach was used to identify all published materials relevant to this review. Anecdotal reports, theses and empirical research were included in the search. A search of MEDLINE, CINAHL and EMBASE Drugs & Pharmacology, Ageline and PsychINFO databases from 1990 to 2003 was conducted in which keyword and thesaurus approaches were combined. The chief thesaurus or Medical

Subject Heading term employed in the searches were: "Palliative Care", "Terminal Care", "Hospice and Palliative Nursing", "Pain", "Symptom Distress", "Sedation", "Terminal Sedation", "Conscious Sedation", "Terminally Ill Patients", "Euthanasia Passive", "Pain-Therapy", "Hypnotics and Sedatives - Administration and Dosage". Other keywords such as refractory symptoms, existential distress, intractable distress, terminal suffering, terminal agitation, terminal restlessness, and slow euthanasia were used in the searches. The following Internet search engines and web-based resources were also utilized to identify on-line literature regarding terminal sedation: Alta Vista, Google, Cochrane Library, STAT!-Ref, UMI ProQuest Digital Dissertations. Though not exhaustive, this search yielded approximately 63 articles. Of these, 26 used the words, "terminal sedation" in either the title or the text of the article. Articles reviewed were limited to those published in English.

The phrase "terminal sedation" first appeared in the title of the article in The American Journal of Hospice & Palliative Care by Enck in 1991. However, the concept of "terminal sedation" was not defined in that work. Of the twenty-six articles reviewed containing the words terminal sedation, only nine provided a definition of terminal sedation. The remaining articles either did not define the term directly, or made reference to sedation as they relate to the management of refractory symptoms and euthanasia. Those definitions are summarized in Appendix A. The challenges in achieving consensus regarding a definition of TS or PS may account for the lack of conceptual clarity observed. TS was the term used initially. It was not until 2002 that PS became the accepted term (Broeckaert & Nunez Olarte, 2002; Jackson, 2002).

In 1998, Chater and colleagues developed a definition for terminal sedation as "there has not been a clear definition proposed for this term, nor has there been any agreement on the frequency with which this technique is used" (p. 255). An international sample of palliative care experts (n = 53) were invited for their critique. The modifications suggested by the respondents in that study demonstrated concern over appropriate and accurate wording that would best convey the inherent meaning and purpose of terminal sedation. A recommendation arising out of the work of Chater's group (1998), was to replace the term terminal sedation with the phrase, "sedation for intractable distress in the dying" (p. 255).

Such rewording is not a mere exercise in semantics, but rather a critical step in addressing existing conceptual incongruence. Krakauer and associates (2000) observed that the term "terminal sedation" conveys the negative message that sedation is intended to "terminate" or "euthanize" (p. 60), and fails to capture the idea that sedation is being used for the management of refractory symptoms when all other measures have failed. It has been argued that the use of inaccurate definitions might discourage some health care providers from implementing terminal sedation into the patient's plan of comfort care, because such an intervention would be seen as a death-hastening measure (Chater, Viola, Paterson & Jarvis, 1998; Krakauer, Penson, Truong, et al., 2000; Wein, 2000). In a recent article by Krakauer and his colleagues (2000), the abbreviation of 'SIDD Pat' is used to refer to sedation for intractable distress of a dying patient. In 2002, Broeckaert and Nunez Olarte (2002) suggested the adoption of the term palliative sedation. They defined this term as "the intentional

administration of sedative drugs in dosages and combinations required to reduce consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms" (p. 170).

Clinical Indications for Sedation

Palliative Sedation is discussed in the literature within the context of managing symptoms that are characterized as "refractory", and may include uncontrolled pain, respiratory distress, nausea and vomiting, terminal agitation, restlessness, delirium and psychological, existential or spiritual distress (Chater et al., 1998; Cherny & Portenoy, 1994; Ventafridda, Ripamonti, DeConno, Tamburini & Cassileth, 1990). Although not discussed extensively in the literature, clinical experience suggests that palliative sedation may also be indicated for such palliative care emergencies such as uncontrolled seizuring, hemorrhage, superior vena cava obstruction, severe acute stridor and multifocal myoclonus (Twycross & Lichter, 1998). The symptoms identified as warranting sedation from a review of the literature are presented in Appendix B. The most common symptoms that required sedation were delirium / restlessness or agitation, dyspnea and pain. As indicated in Appendix B, the majority of the studies used a retrospective or prospective design. Sample sizes were variable, and most of the research was conducted in designated palliative care units and hospital settings. Only one study defined "terminal sedation", however others cited an operational definition for sedation or total pharmacological sedation.

The work of palliative care clinicians, Cherny and Portenoy (1994) is instructive in the identification of symptoms that are refractory. They define a

refractory symptom as one that, "cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness" (p. 31). Cherny and Portenoy (1994) emphasize the importance of distinguishing refractory symptoms from difficult symptoms. According to Cherny and Portenoy (1994), a symptom is considered refractory when neither the invasive and noninvasive interventions provide adequate relief, when interventions are associated with excessive morbidity; and when interventions are unlikely to provide relief in a tolerable time frame. These authors have developed an algorithm to assist clinicians to identify the refractoriness of symptoms requiring sedation. This algorithm has been published elsewhere, and will not be further reported on here (Cherny & Portenoy, 1994, p. 33).

Though clinician criteria exist to identify refractory symptoms the issue of sedation for the purpose of managing such symptoms remains challenging for clinicians. Two particularly problematic areas include: 1) the variable incidence of refractory symptoms in palliative care patients; and 2) debates regarding the appropriateness of sedation for psychological symptoms, as opposed to physical in origin. Both of these will be discussed.

(1) The Incidence of Refractory Symptoms in Palliative Patients

There is a lack of consensus in the literature as to the incidence of such refractory symptoms in advanced cancer patients. Lichter and Hunt's (1990) examination of the symptoms that occurred in the last 48 hours of life in hospice patients in New Zealand (n = 200) found that 36% of patients "have some difficulties

the last 48 hours of life" (p. 7) A prospective study by Ventafridda et al. (1990) of 120 terminal care patients in an Italian home care palliative care program found that 52.5% of patients (n = 63) developed "unendurable symptoms" (p. 7) which were controllable only by means of sedation. Greene and Davis (1991) reported the use of continuous intravenous barbiturates to provide heavy sedation for "symptoms of desperation" (p. 335).

In a retrospective Canadian study conducted by Fainsinger and colleagues (1991), 16% of patients on an inpatient palliative care unit (n = 100) experienced physical symptoms that would have required sedation to achieve symptom relief. Morita, Inoue and Chihara's (1996) review of a Japanese hospice found that 69 out of 143 patients received sedation in order to achieve symptom control, and that of these patients 48% (n = 33) suffered more than one uncontrolled symptom.

A retrospective study by Stone, Phillips, Spruyt, and Waight (1997) examined how frequently sedatives were prescribed by a hospital support team and palliative care physicians in a hospice inpatient unit in England, and the indications for the use of such medications. Of 115 patients, 43% (n = 50) received sedatives for the purposes of symptom control and 26% (n = 30) received sedatives for the purposes of sedation. A major finding in this study was the significant difference between the frequency of drugs given for the purposes of symptom control in the hospice opposed to those in the hospital. Sixty seven percent of patients in the hospice received sedatives for symptom control as compared to twenty-one percent in the hospital. In this study, mental anguish was identified as a symptom in which terminal sedation

was warranted. Three other studies cite the use of terminal sedation for anguish, psychological and existential distress (Chater et al., 1998; Morita, Tsunda, Inoue, & Chihara, 1999; Morita, Tsunda, Inoue & Chihara, 2000).

Several factors may account for the variable incidence of refractory symptoms and levels of sedation reported in the literature. First, differences in how refractory symptoms are defined across studies precludes comparisons. Second, the ethos of care settings regarding the use of sedating drugs in general may vary across settings. For example, Fainsinger and colleagues (1991), explain that the low level of sedation reported reflects the mandate of that palliative care unit to avoid sedation whenever possible and reduce drugs that may inhibit the patient's level of consciousness. The nature of the palliative care service being delivered may account for the greater sedation rates seen in hospice patients versus hospital patients reported by Stone and associates (1997). Hospitalized patients would not have regular access to palliative care clinicians. Rather they would be seen on a "consult only" basis, which in turn, may affect resources available to provide adequate symptom management.

(2) Palliative Sedation for Psychological Distress

The extent to which it is appropriate to use palliative sedation in the management of intractable symptoms that are emotional, psychological or existential in nature is a contentious issue, evoking considerable debate (Billings & Block, 1996; Morita et al., 2000; Mount, 1996; Quill & Byock, 2000; Quill, Lee & Nunn, 2000; Quill, Lo & Brock, 1997; Wein, 2000). Those who object believe sedating someone for psychological reasons does not allow resolution of underlying psychological

issues. Moreover, it has been argued that the provision of such sedation is a death hastening measure and is tantamount to euthanasia. Opponents argue that sedation used to relieve extreme physical distress, results in death due to dehydration, starvation or other complications (Quill & Byock, 2000; Quill, Lee & Nunn, 2000; Quill, Lo & Brock, 1997).

Arguably, the determination of the refractory nature of existential distress is complex (Morita et al., 2000). Proponents of palliative sedation for "pain of the soul" believe that such pain is as legitimate as physical pain, and should be managed with the same vigilance, aggression and professional approach (Beel, McClement & Harlos, 2002). Indeed, opponents of sedation for refractory anguish at the end of life will often maintain that rather than sedate, the staff should share the journey with the patient. The metaphors of "journeying" or "walking" are intended to imply and encourage an obligation of presence, which is a laudable goal. However, it is the patient alone who truly experiences the suffering first-hand, and to imply otherwise risks trivializing the degree of burden (Beel, McClement & Harlos, 2002).

Doctrine of Double Effect

Proponents of sedation for intractable distress frequently evoke the doctrine of double effect to support their actions. This doctrine distinguishes between the effects the clinician intends and the consequences that are foreseen, but unintended (Cherny & Portenoy, 1994; Quill et al., 1997; Wein, 2000). The principle of double effect requires that the following four criteria be met:

1. The intended end must be a good one.

2. The bad effect, such as the patient's death, may be foreseen but must not be intended.

3. The bad effect must not be a means of bringing about the good effect.

4. The good effect must, on balance, outweigh the bad effect (Thorns, 1998).

As applied to palliative sedation, this principle implies that the intervention (i.e. palliative sedation) intended to relieve the patient from intractable distress at the end of life is permissible, "even at the risk of causing foreseen but unintended side effects (i.e. death)" (Krakauer et al., 2000, p. 60). The assertion that sedation results in shortened patient survival is being disputed in the literature. A prospective study conducted by Morita and colleagues (2001) designed to examine the effects of opioids and sedatives on patient survival found no statistically significant difference in survival rates of those who received strong sedatives and those who did not. In addition, a recent study by Sykes and Thorns (2003) illustrated that an increase in sedative doses in the last hours of life was not associated with shortened survival.

No doubt, the use of sedation in the management of refractory symptoms at the end of life will continue to stimulate ongoing ethical debate. Issues concerning validity of distinctions made between assisted suicide, euthanasia and sedation (Fodras, 1996; Fainsinger, 2000); problems with the double effect argument as it relates to the practice of sedation in palliative care (Begley, 1998; Hawryluck and Harvey, 2000); and the challenges inherent in determining the extent to which psychological or existential distress is actually refractory (Cherny, 1998), are worthy ones. Accordingly, Fainsinger (2000) noted that ..."the use of sedation in the most

problematic clinical situations...inevitably draws us into complex, divisive and controversial discussions that will continue to have opposing proponents" (p. 274).

Nurses Attitudes Regarding Death Hastening Measures

Views about death hastening measures are understood in the literature as existing on a continuum. Daly and colleagues (2000) explain death hastening measures range from "withholding treatments for new symptoms that could be life threatening, continuing or stopping current life-supporting therapy, using symptom control measures that may hasten death, to taking an overt action intended to cause death, performed either by the patient alone, or with the assistance of someone else" (p. 56). It is usually the nurse that patients and families will turn to with questions regarding comfort care, pain and symptom management and withholding or withdrawing life-sustaining treatments. Previous research has indicated that nurses, at times feel obligated to provide assistance to terminally ill patients who have chosen to end their life. For example, Davis and colleagues (1995) conducted one hour semi-structured interviews with eighty nurses and found that 21 percent believed they could ethically justify active euthanasia under certain conditions. Asch (1996) examined the role of critical care nurses in euthanasia and assisted suicide and found 16 percent (n = 852) of critical care nurses had participated in euthanasia and / or assisted suicide. It has been speculated that lack of preparation, knowledge and discomfort of the nurse may interfere with the nurse's ability to effectively respond to patients and families concerns about death hastening measures (Daly, Hooks Younger, Drew and Prince-Paul, 2000). Furthermore, it is unknown the degree to which hospice nurses are

involved in helping patients make decisions regarding death hastening measures (Daly et al., 2000).

Medications Used in the Management of Intractable Symptoms

A combination of sedating and non-sedating drugs are usually required to manage refractory symptoms. The most common drugs cited in the literature that are used to produce sedation for intractable distress in the dying are benzodiazepines (midazolam, lorazepam), neuroleptics (methotrimeprazine, haloperidol) and barbiturates (phenobarbital) (Bottomley & Hanks, 1990; Burke, Diamond, Hulbert, Yeatman, & Farr, 1991; Chater et al., 1998; Cherney & Portenoy, 1994; Enck, 2000; Fainsinger, deMoissac, Mancini, & Oneschuk, 2000; Fainsinger, Landman, Hoskings & Bruera, 1998; Fainsinger et al., 2000; Krakauer et al., 2000; Morita et al., 1996; Stone et al., 1997). These are summarized in Appendix C. The sublingual (SL), subcutaneous (SQ) and intravenous (IV) routes are utilized for drug administration. However, the SL and SQ route seem to be the most common routes utilized in the home and hospital, as these routes are readily accessible for both health care providers and families. As patients often have more than one uncontrolled symptom, it is often difficult to determine which combination of drugs, both sedating and non-sedating, actually produced the terminal sedation (Chater et al., 1998). Chater and her colleagues (1998) reported in their study of the ninety-six patients, 37% received one drug to produce sedation, 30% received two drugs and 28% received three drugs. According to Enck (2000), opioids alone should not be used to induce terminal sedation, and patients being sedated for refractory distress should continue to receive

regularly scheduled opioids to maintain pain control and prevent precipitating withdrawal (Cherny & Portenoy, 1994; Enck, 2000; Krakauer et al., 2000).

The types of drugs used to induce sedation varies between countries. In the aforementioned article by Chater and colleagues (1998), all the respondents from the United Kingdom (n = 20) and three-quarters of the Canadian respondents (n = 19) used midazolam as the primary drug to induce sedation. All the respondents from the United States (n = 6) used lorazepam. Overall, the two most frequently prescribed medications from Chater's study (1998) were midazolam and methotrimeprazine. Midazolam has shown to be a therapeutic and safe drug in the palliative care setting, however, is only available in SQ and IV routes (Burke et al., 1991). Methotrimeprazine is available in SL, SQ, IV and intramuscular (IM) routes. Case reports have appeared in the literature describing the use of propofol (Diprivan, Zenica) for the management of intractable symptom distress when all other medications have been unsuccessful (Krakauer et al., 2000; Mercadante, DeConno, & Ripamonti, 1995; Moyle, 1995). However, it does not appear that propofol is being widely used in the palliative oncology population at the present time.

Methodological Limitations of Past Studies

Most of the studies reviewed used a retrospective or prospective design to study palliative sedation (see Appendix B). As discussed by Polit and Hungler (1995), these studies often "serve as a starting point for hypothesis generation or theory development" (p. 178). However, no conceptual or theoretical framework linking the factors that affect the decision to use palliative sedation in the clinical setting has been

developed from the research. There is a lack of research directed towards the development of accurate assessment tools and the examination of their psychometric properties with various population groups so comparisons can be made between studies. In addition, there have been very limited, if any, qualitative studies regarding the perceptions of staff, patients and families and the use of palliative sedation.

Summary

The literature related to TS or PS was reviewed. Definition challenges, the clinical indications of sedation, the use of PS for psychological distress and methodological limitations all contribute to the clinical practice issues that exist within the current discussion regarding PS. An examination of the literature and previous studies allowed the researcher to gain an awareness of the current research. In summary, no studies have been published examining the nurses' perceptions and palliative sedation. The next chapter will provide an overview of the conceptual framework chosen for this study.

CHAPTER THREE: CONCEPTUAL FRAMEWORK

Introduction

A conceptual framework can be compared to an architectural blueprint for a house (Feldman, 1998). Feldman (1998) describes a conceptual framework or model as "a group of interrelated concepts that fit together because of their relevance to a common theme or matrix" (p. 140). A conceptual framework assists the researcher by determining what questions are to be asked, proposes certain relationships among the variables under study and offers a structure whereby knowledge can be collected (Lum, 1977).

Research examining sedation for intractable distress in the dying is currently plagued with conceptual, methodological and ethical problems. Much of the literature examining the issue of palliative sedation is nested solidly in the logical-positivistic tradition. The positivist paradigm (also known as the experimental or empiricist approach) assumes that reality is objective and singular, and exists apart from that being researched (Creswell, 1994). It involves a process of deductive reasoning with the aim of being able to generalize and predict (Creswell, 1994). This line of inquiry has produced important information on this topic, however, it is but one pathway to knowledge generation in this area. A sound knowledge base about palliative sedation requires an understanding of how health care providers and family members experience situations when this intervention is used. People's interpretations of a situation are influenced by their social interactions with others and the socio-cultural environment in which they exist (Kleinman, 1988). Therefore, the symbolic

interactionism approach developed by Blumer (1969) was chosen as the conceptual framework for this study.

Symbolic Interaction Theory (SIT)

Symbolic interactionism (SI) is a theoretical perspective whose roots lie in social psychology (Charon, 1998; Hewitt, 1997). Symbolic interactionism is "based on the assumption that humans learn about and define their world through the interaction with others" (Streubert & Carpenter, 1999, p. 232).This approach "aims to understand the social group studied by exploring the relationship between the social structure and the meanings by which individuals interpret and create their social world" (Byrne & Heyman, 1997, p. 94-95). The individual and the context in which that individual exists are inseparable (Benzies & Allen, 2001). As emphasized by Charon (1998), "the central principle of symbolic interactionism is that we can understand what is going on only if we understand what the actors themselves believe about their world" (p. 210). The actors live and know their world, and as a researcher it is "imperative to understand what the actors know, see what they see, understand what they understand" (Charon, 1998, p. 210).

The symbolic interactionism approach can be traced back to the work of George Herbert Mead, a social psychologist from the University of Chicago (Charon, 1995; Hewitt, 1997). Proponents of this approach view "living things as attempting to make practical adjustments to their surroundings" (Hewitt, 1997, p. 7). As a student of Mead, Herbert Blumer is credited with interpreting the work of Mead and developing the term "symbolic interactionism" in 1937 (Benzies & Allen, 2001, Charon, 1995).

Blumer (1969) describes the term symbolic interactionism as a "relatively distinctive approach to the study of human group and human conduct" (p. 1) and is based on the following three assumptions:

1. "Human beings act toward things on the basis of the meanings that the things have for them" (Blumer, 1969, p. 2). Such things can include physical objects, other human beings and situations individuals encounter in everyday life (Blumer, 1969). According to Blumer (1969), "this meaning sets the way in which one sees the object, the way in which he is prepared to act toward it, and the way in which he is ready to talk about it" (p. 11). "The meaning of objects for a person arises fundamentally out of the way they are defined to him by others with whom he interacts" (Blumer, 1969, p. 11). For example, families want a comfortable, pain free, dignified death for their loved one. The nurse, in turn, will act toward the family based on how he or she perceives the family's goal of comfort for their loved one and what is important for this family during this time.

2. "The meaning of such things is derived from, or arises out of the social interaction that one has with one's fellows" (Blumer, 1969, p. 2). "Meaning for an individual emerges out of the ways in which other individuals act to define things" (Benzies & Allen, 2001, p. 544). LaRossa and Reitzes (1993) suggest that meaning can only exist when people share common interpretations of the symbols they exchange in interaction. For example, the meaning nurses have attributed to terminal sedation have been formulated through interaction with others. Furthermore, the nurse's meaning of terminal sedation may change as the patient's disease progresses

and more discussion occurs through contact with the health care team and co-workers. A number of factors may influence the nurse to ensure the patient is comfortable at the end of life and whether the use of terminal sedation is appropriate for a particular patient.

3. "These meanings are handled in, and modified through an interpretive process used by the person dealing with the things he encounters (Blumer, 1969, p. 2). This process is constantly changing, subject to "redefinition, relocation and realignments" (Benzies & Allen, 2001, p. 544). "Through selection and interpretation of stimuli, people form new meanings and new ways to respond and thus are active in shaping their own future through the process of interpreting meaning" (Benzies & Allen, 2001, p. 544). People act according to how they are thinking in a specific situation (Charon, 1998). To understand the nurses' perception of terminal sedation, exploring their cultural and religious background and examining their past experience that affects their comfort level with utilizing PS is required.

Symbolic Interactionism and the Nurses' Experience with Palliative Sedation

Symbolic interactionism was a valuable conceptual framework for this study because it provided a perspective for exploring nurses' perceptions of palliative sedation under a variety of complex processes in which nurses understand, interpret and create their world as well as define their work in caring for palliative care patients. Another advantage is that it provided a means of exploring palliative sedation from the nurses' point of view. Palliative sedation may have had a different

meaning to each nurse. The nurses' perspective regarding palliative sedation has developed through interaction with others (Blumer, 1969). In order to explore the nurses' perceptions regarding palliative sedation, the researcher interacted with the nurses through interviews to uncover their interpretation and meaning regarding palliative sedation. Furthermore, this framework also provided direction to the qualitative methodology chosen for this study by providing direction in the development of the interview questions and guiding the interpretation of the findings.

CHAPTER FOUR: RESEARCH METHODOLOGY

Introduction

The following chapter will specifically delineate the research methodology for this study. The palliative care program in Winnipeg will be briefly described. Subsequently, the research design, which includes the sample, setting, data collection methods, data analysis and ethical considerations, will be presented.

Based on the literature regarding palliative sedation and the principles of symbolic interactionism, a qualitative methodology was chosen for this study. Qualitative design is indicated when: 1) the topic has not been previously studied or explored; 2) the topic has not been studied from the point of view of the individual experiencing the phenomenon under investigation; and 3) the sample has personal experience in, or knowledge about the topic (Brink, 1989; Field & Morse, 1985; Streubert & Carpenter, 1999). According to Denzin and Lincoln (1994), "qualitative researchers study things in their natural environment, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them" (p. 2). Qualitative methods are flexible and unstructured, capturing reports and observations (Brink & Wood, 1989).

Given the paucity of knowledge regarding nurses' perceptions of palliative sedation, a qualitative design was selected for this study. Furthermore the use of symbolic interactionism as the conceptual framework for this study fits with a qualitative design and analysis.

Study Design

Exploratory research is "aimed at exploring the dimensions of the phenomenon, the manner in which it is manifested, and the other factors with which it is related" (Polit & Hungler, 1995, p. 11). Furthermore, as discussed by Brink (1989), exploratory designs have two major goals. The first goal is problem discovery which includes identifying and describing a problem area never previously studied (Brink, 1989). The second goal is problem definition which includes exploring a concept in depth "in as loose and as free ranging a way as possible to arrive at a description of an experience or its meaning" (Brink, 1989, p. 141). This design assisted the researcher to uncover the nurses' perception of palliative sedation and gain a deeper understanding of their experience of this phenomenon.

Sample Selection

Sample selection involves choosing participants "who are experiencing the circumstance and selecting events and incidents related to the social processes under investigation" (Marcus & Liehr, 1998, p. 227). Morse and Field (1995) identify two principles that guide qualitative sampling: appropriateness and adequacy. Appropriateness refers to the selection and identification of participants who can best respond to the research needs of the study (Morse & Field, 1995). Adequacy refers to a sufficient amount of data that must be generated in order to develop a full and rich description of the phenomenon under investigation (Morse & Field, 1995). Morse and Field (1995) emphasize that without meeting these two criteria, "qualitative results are thin, and the reliability and validity of studies are possibly threatened" (p. 80-81).

In exploratory studies, a target population is utilized and the investigator strives to interview individuals who have had the experience under study (Brink & Wood, 1989). Brink and Wood (1989) suggest using small, purposive samples to represent the desired perspective. Sandelowski (1995) suggests a sample size of ten may be judged adequate for certain kinds of homogenous samples to generate rich data. Data saturation occurs "when the information being shared with the researcher becomes repetitive" (Marcus & Liehr, 1998, p. 218).

The target population for this particular study consisted of a convenience sample of 10 registered nurses (diploma or baccalaureate degree prepared) who met the eligibility criteria. It was anticipated that ten participants may be adequate to achieve data saturation. However, if saturation did not occur, more nurses were to be approached until the information obtained became repetitive. The rationale for these criteria was to include participants that have had experience with the phenomenon of palliative sedation. The research participants were selected with the intent of including participants who were experienced with the phenomena of a palliative sedation or terminal sedation. The sample for the study was limited to nurses who met the following criteria:

1) Worked in an adult designated palliative care unit that focuses on the care of palliative care patients, age 18 to 100.

2) Had a minimum of six months experience caring for palliative care patients. This was based on the assumption that nurses will have had exposure to palliative sedation during this period of time.

3) Were able to speak and write English and;

4) Provided consent to participate in the study.

Recruitment and Access

Research participants were recruited from Riverview Health Centre palliative care unit. Once ethical approval from the Education / Nursing Research Ethics Board and access was obtained, (Appendix E) the researcher arranged a meeting with the Patient Care Manager of the Palliative Care Unit and requested ten minutes of time from each shift in order to explain the study and invite nurses to participate. An Invitation to Participate (Appendix F) explaining the study with the researcher's phone number and email address was left in a designated location in the conference room on the nursing unit. Posters advertising the study and requesting participants were posted in several areas on the unit. Nurses interested in participating in the study were asked to fill out the form attached to the Invitation to Participate sheet with their name, phone number and suggested time for an initial phone call, seal it in an envelope and place it in an envelope labelled with the researcher's name. The collection envelope was left in a designated location for nurses on the unit. The researcher also provided verbal explanation of the project to nursing staff she encountered at the site who may not have heard about the project. The researcher returned to the unit one to two weeks later and collected the envelope. Interested nurses were contacted to arrange a mutually convenient date and time for the interview.

Setting

The Palliative Care Program in Winnipeg: A Brief Overview

In 1997, Manitoba Health published the document titled "Core Health Services in Manitoba"and palliative care was identified as one of the ten core services to be funded by Manitoba Health. In addition, during this time, the services and programs offered by Manitoba Health were transferred to the Regional Health Authorities and the Core Health Service document was used as a program development tool for the Regional Health Authority to meet the unique needs of terminally ill patients and families (Manitoba Health, 1997).

The Palliative Care Sub-program was implemented in April, 1999 when phase one funding was approved by Manitoba Health. A palliative care proposal was submitted to the Chief Executive Officer of the Winnipeg Community and Long-term Care Authorities and the Winnipeg Hospital Authority. The purpose of the proposal was to outline a needs-based approach to care that offered a seamless system of care to patients and families facing a terminal illness. Essential components of the proposal included symptom management, an interdisciplinary team approach, nursing/medical consultation, psychosocial care, spiritual care and volunteer and bereavement programs. In April, 2000, the palliative care program received a transfer of 1.2 million dollars from the Winnipeg Regional Health Authority to implement the goals outlined in the proposal.

The program offers a wide range of services to clients. There have been four palliative care nursing coordinators hired for the Winnipeg Region and a central

intake process has been established allowing patients to be cared for in their own surroundings with the support of nursing visits and home care. Six Palliative care physicians have been hired for the program. They may be employed full-time or part-time for the palliative care sub-program and work in both hospital and community settings. They offer consultation by phone to primary care physicians and make home visits to clients wishing to remain in their own home. An evening and on-call palliative care nurse is also available to provide support to patients and their families after hours. Three palliative care clinical nurse specialists have been hired for consultation services and maintain consistent and comprehensive care through standards and education throughout the region.

There are two in-patient palliative care units in Winnipeg, at St. Boniface General Hospital (SBGH) and Riverview Health Centre (RHC). The SBGH Palliative Care unit currently consists of 15 inpatient beds and RHC Palliative Care unit consists of 30 inpatient beds. The unit at RHC has approximately 400 admissions a year either from home or other institutions. The mean length of stay is approximately 22 days. Through the palliative care coordinator, patients can be admitted to these units for symptom control should they be unable to manage in their own setting. There are strong pastoral care, social work, rehabilitation, pharmacy and dietetic components in addition to nursing and medicine.

Data Collection

Interviews

In exploratory designs, data are collected by interviews and participant observations (Brink & Wood, 1989; Marcus & Liehr, 1998; Streubert & Carpenter, 1999). Interviewing "is a flexible technique that can allow the researcher to explore greater depth of meaning than can be obtained with other techniques" (Burns & Grove, 2001, p. 420). There are two types of interviews, unstructured and semi-structured. In this study, data was collected using a semi-structured interview guide comprised of open-ended questions. This technique is used when "the researcher knows most of the questions to ask, but cannot predict the answers" (Morse & Field, 1995, p. 94). In addition, this technique ensures that the researcher obtains all of the information, while at the same time allowing the participant time to respond and clarify concepts (Morse & Field, 1995).

After nurses agreed to participate, written consent was obtained (Appendix F). Data was obtained through semi- structured face-to-face interviews using an interview guide developed for this study (Appendix G). As data collection and coding proceeded, modification of the interview schedule may have been required to explore more fully emerging themes. The interviews were audio-taped and transcribed with the permission of the participants. Two scheduled interview appointments were made with each nurse. The first interview was for the purposes of conducting the initial interview. The second interview was to meet with the nurse to review with him or her the final findings, invite critique or revision. No notes were taken during either

interviews. Given that all the participants were nurses from Riverview Health Centre, the interviews was conducted outside of working hours at a location convenient to the participant. The first interview appointments were made for approximately 1-1 ½ hours in length. Interviews began with an explanation of the study and assurance of confidentiality. Demographic information was also collected during this time from participants (Appendix H). Then, general questions were asked to explore the nurse's experience in caring for patients that have received palliative sedation.

Questions were developed by the researcher using the principles of symbolic interactionism, the literature review and clinical experience as a guideline. Probes were used to clarify the meaning of responses followed by more specific focused questions. Probes were used to elicit more detailed information from the participant (Polit & Hungler, 1995). Probes usually ask participants to elaborate on what they have already volunteered to a given question (Berg, 1998). Examples of probes are: "tell me more about that", and "what happened next". At the end of the interview the researcher asked participants for permission to conduct a follow-up interview for clarification of data as necessary. The second interview was approximately thirty minutes in length.

Fieldnotes

In addition to interviewing, fieldnotes were also maintained during the course of the study to capture the nonverbal communication observed during an interaction. Fieldnotes are a "written account of the things that the researcher hears, sees, experiences and thinks in the course of collecting or reflecting on data in a qualitative

study" (Morse & Field, 1995, p. 112). Fieldnotes "represent an attempt to provide a literal account of what happened in the field setting - the social processes and their contexts" (Bogdewic, 1999, p. 59). According to Emerson, Fretz and Shaw (1995) fieldnotes provide a "distinctive resource for preserving the experience close to the moment of occurrence and, hence for deepening reflection upon and understanding those experiences" (p. 13). The fieldnotes were used to supplement the taped interviews. Data with regards to the interaction between the researcher and the nurse, the environment, mannerisms and the emotions felt and expressed were recorded.

Data Analysis

Data analysis requires a fluid, flexible, somewhat intuitive interaction between the data and the researcher (Brink, 1989). Essentially, the investigator "lives with the data, reading and re-reading field notes on a daily or frequent basis and deciding what has been learned so far, what is puzzling, what is unanswered, and what does not fit" (Brink, 1989, p. 151). Audio-taped interviews were transcribed verbatim by a hired transcriptionist and analyzed by the researcher using thematic content analysis (Brink, 1989; Burnard, 1991; Glaser & Strauss, 1980; Morse & Field, 1995). Along with reading the transcripts, the tapes were reviewed four to six times each by the researcher for accuracy. The thesis chair reviewed two of the transcripts independently of the researcher and developed categories. The results were compared, discussed and categories were agreed upon that accurately represented the data. If there was disagreement, the interview or the relevant section would be reread and through discussion, consensus was reached. As no previous research regarding

palliative sedation has been published in the nursing literature, thematic content analysis was chosen as the approach for data analysis for this study.

Thematic analysis involves searching and identifying common threads throughout an entire interview or set of interviews (Morse & Field, 1995). The first task in thematic analysis is to read and reread the interviews and reflect on the interview as a whole until general themes emerge (Morse & Field, 1995). Next, memos were written to summarize the interview, noting that more than one theme may exist in the interview. Then, coding of the interview transcripts was completed. Streubert and Carpenter (1999) outline three levels of coding. In the first level open coding in the margins of the transcripts of the interview would occur line by line, and then categories were developed from the codes (Streubert & Carpenter, 1999). In the second level, the categories were clustered and collapsed into broader categories. In the third level of coding, the central themes that emerged from the data were identified.

To assist with data analysis, the Corel Wordperfect computer program was utilized to facilitate cutting and pasting of similar codes and categories together. This enhanced organization of the data and allowed easy retrieval. Demographic data was analyzed using descriptive statistics.

Measures to Enhance Methodological Rigor

In order to demonstrate that research findings are justifiable, valuable and trustworthy, rigor of the research process must be established (Rose & Webb, 1998; Sandelowski, 1993). The goal of rigor in qualitative research is to accurately represent

the participants' experiences (Streubert & Carpenter, 1999). Criteria to establish trustworthiness of the data will be applied in this study and consist of the following dimensions: credibility, transferability, dependability and confirmability.

Credibility

Credibility refers to the "confidence in the truth of the data" (Polit & Hungler, 1995, p. 362) and whether research participants "recognize the description of the experience as their own" (Streubert, 1998, p. 463). Lincoln and Guba (1985) suggest credibility is established through prolonged engagement with the participants and member checks or member validation. Researchers can informally engage in member checks by seeking clarification or elaboration of meaning and intention during the interview process (Sandelowski, 1993). In this study credibility was enhanced through investment of sufficient time in data collection, informal member checks as data was being collected, clarifying data with a follow-up interview with participants and formally after data was analyzed with the thesis chair.

Transferability

Transferability is the "probability that the study findings have meaning to others in similar situations" (Streubert & Carpenter, 1999, p. 29). Lincoln and Guba (1985) emphasize that it is the responsibility of the researcher to provide sufficient data so that the applicability to other settings can be evaluated. In this study, it is unknown whether the data will be transferable to other palliative care units as there have been no other studies regarding the topic of nurses' perceptions regarding palliative sedation therapy. There is one other palliative care unit in Winnipeg located

at St. Boniface General hospital in which the philosophy of care may differ.

Dependability

Dependability is described as "the stability of data over time and over conditions" (Polit & Hungler, 1995, p. 363). One approach to assessing dependability is the "inquiry audit" (Polit & Hungler, 1995, p. 363). This consists of an external reviewer scrutinizing the data and supporting documents, such as field notes. To facilitate dependability, the chair of the thesis committee oversaw the coding of data, the categories and themes that emerged.

Confirmability

Confirmability refers to "the objectivity or neutrality of the data" (Polit & Hungler, 1995, p. 363). Confirmability addresses the extent to which the findings are in fact reflective of the participants experiences and not that of the researcher. In this study, fieldnotes were kept to verify the assumptions of the researcher during data collection. In addition, information obtained during the initial interviews were confirmed in follow-up interviews.

Ethical Considerations

Ethical approval for this study was obtained from the Education / Nursing Research Ethics Board (REB) of the University of Manitoba (Appendix E). Permission to perform the study at Riverview Health Centre's, Palliative Care Unit was requested from their Access Committee (Appendix D). A presentation on the unit was made to nursing staff to invite them to participate in the study (Appendix F). A poster was placed on the unit in key staff areas announcing the study and requesting

participants (Appendix J). Nurses interested in participating were contacted by phone and given an explanation of the study again. Once they gave verbal consent, an appointment was made for the interview. The interview began by obtaining written consent for the current interview and the follow-up interview to clarify any information from the initial interview and completing the Demographic Data Form (Appendix I).The interview started with general open-ended questions and proceeded to more sensitive questions (Appendix H). This study provided information about the experience of caring for palliative care patients that received palliative sedation therapy from a nursing perspective. Such information is necessary to help palliative care nurses in their practice. Potential risks could be the stress induced by discussing events related to the ethical issues surrounding the use of palliative sedation therapy. If at any time the participant became distressed the researcher asked if they would like to stop or continue with the interview. If the participant was unduly distressed, and could have benefited from further discussion, and with the participant's permission, they were referred to the Employee Assistance Program or Occupational Health Program.

Tape-recorded interviews were immediately reviewed in privacy by the researcher. A transcriptionist was hired to transcribe the interviews verbatim. The audiotapes and the transcriptions were assigned a code number and the participant's names and corresponding code number were locked and kept separate from the data. The consent form was kept separate from the data and data associated with this study is held in locked storage for 7-10 years after which it will be destroyed.

Summary

This chapter provided an overview of the research design and methodology to explore nurses' perceptions regarding palliative sedation therapy. Measures to enhance methodological rigor and the ethical considerations were also presented.

CHAPTER FIVE: FINDINGS OF THE STUDY

Introduction

The overall purpose of this qualitative study was to explore nurses' experience regarding palliative sedation (PS). The analysis of the data allowed the researcher to uncover and identify major themes and categories that emerged from the interviews related to this issue. This chapter will outline a description of the participants in this study, followed by a presentation of the findings that emerged from the interviews.

Description of the Participants

The registered nurses for this study (N = 10) were recruited from an adult designated palliative care in-patient unit of Riverview Health Centre, located in Winnipeg, Manitoba. The participants are described in terms of their demographic characteristics (Table 5.1). To protect the identity of the nurses gender was not reported; however, the majority of study participants were female. The ages of the nurses ranged from 35 to 60 years with a mean age of 46.9 years. Nurses had between 1 to 39 years of nursing experience with approximately 1 to 19 years experience working with palliative care patients. Three of the nurses worked full-time and seven worked part-time.

The researcher conducted three presentations on the unit inviting nurses to participate in the study. Approximately five to six nurses attended each presentation. From these presentations, ten nurses approached the researcher by completing an invitation to participate, which indicated their interest in being interviewed for this study. Nurses were not directly approached individually.

Follow-up interviews were conducted with eight of the ten participants for the

purposes of clarifying information obtained in the initial interview and inviting participants to critique the emerging findings. Follow-up interviews could not be conducted on two of the ten participants due to lack of response to several phone calls to arrange follow-up interviews. Those participants who did review the emergent findings agreed that the initial themes and categories accurately reflected their experience and perceptions. These follow-up transcripts were also included in the data analysis phase of the study.

Table 5.1 Demographic Data of the Nurses

Variables	Participants (N=10)
Age	
Mean (years)	46.9
Range	35 – 60
Nursing Education	
Basic Diploma	9
Baccalaureate Degree	2
Other Educational Background	2
Marital Status	
Never Married / Separated / Divorced	4
Married	6
	10
Number of years of Nursing Experience	
0 – 19	3
20 - 39	7
	10
Number of years working with palliative care patients	
0 – 9	6
10 – 19	4
	10
Number of years practising on current palliative care unit	
0 – 9	6
10 – 19	4
	10
Employment Status	
Full-time	3
Part-time	7
	10
Combination of Shifts	
Days / Nights	4
Days / Evenings	6
	10

Themes and Categories

Data collected through face-to-face audio-taped interviews with nurses were transcribed verbatim, and analysed using the process of thematic content analysis as described in Chapter 4. Open coding of the transcripts allowed the researcher to compare data bits within and between interview transcripts. Then similar codes were grouped together into categories. When appropriate, similar and overlapping categories were collapsed and clustered together to form major themes. Operational definitions were written for each sub-theme and category emerging from the data (Table 5.2).

Table 5.2 Summary of Operational Definitions

Major theme, Sub-themes and Categories	Operational Definition
MAJOR THEME: Working Your Way Through the Quagmire	▪ Refers to a process whereby nurses had to sort out a myriad of issues related to their personal beliefs, values, past experience, and relationship with the patient and family when PS was implemented. The metaphor of the quagmire is defined as, the ambiguous and variable situation nurses find themselves grappling with and captures the nature of the experience the nurses' recounted during their interviews.
Sub-theme: Definitional Quagmire **Category:** ➢ Ways in which nurses define PS	▪ Describes the difficulty nurses had with defining what is meant by terminal sedation or palliative sedation. ▪ Nurses willing to share their definition of PS, but found it difficult to do so as they did not have the language to define it or were unsure of the exact definition.
Sub-theme: Indications for Use Quagmire **Categories:** ➢ Blurring between the use of crisis medications and PS	▪ Indications for using PS in a variety of circumstances. ▪ Involves nurses being unsure about the distinction between the use of sedating medications in the context of a medical crisis and the use of such medications when such a crisis did not exist. Nurses described the use of crisis medications as a temporary "one time" intervention for emergencies such as respiratory distress and seizures, in which the

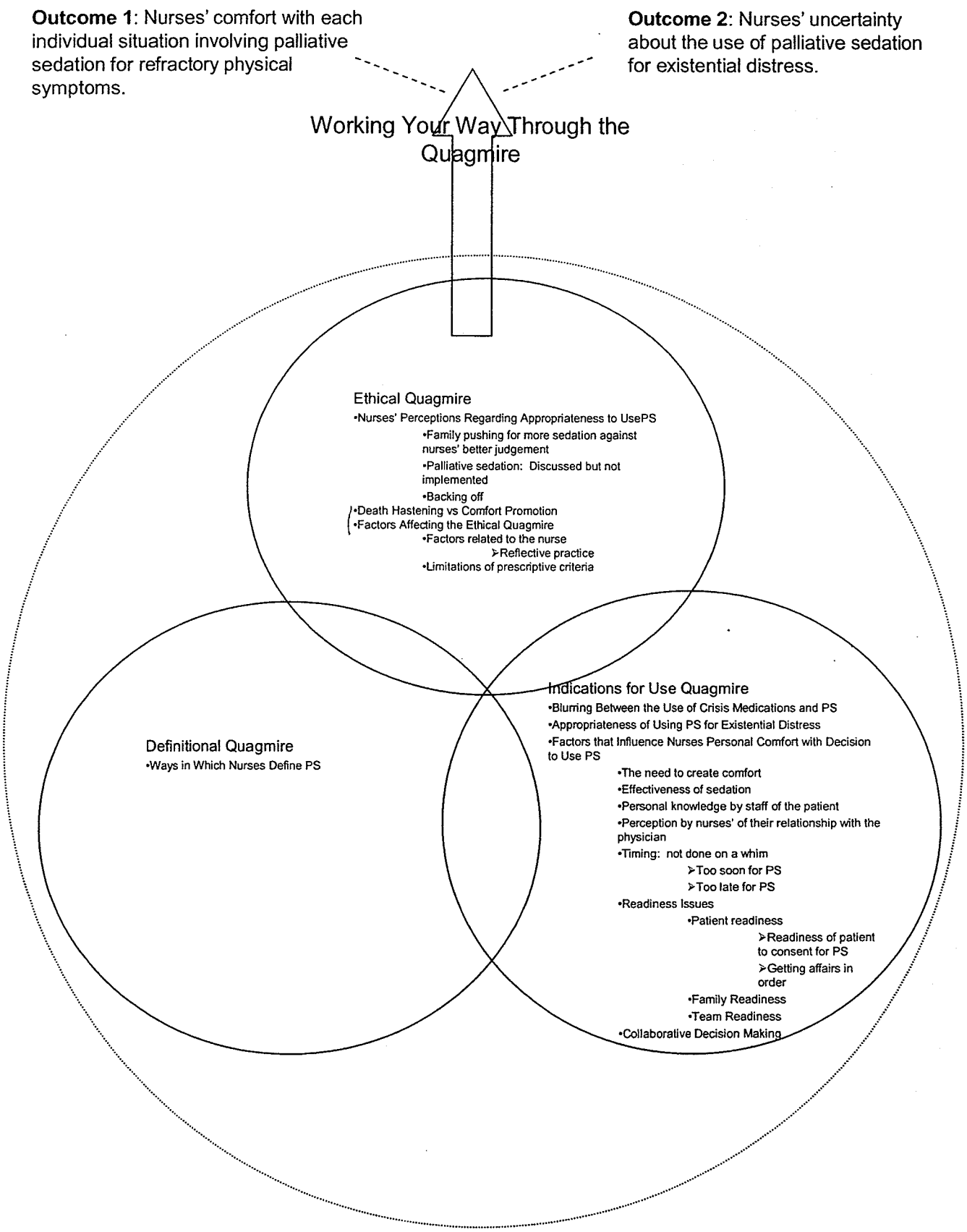
	patient is sedated for a short period of time. Depending on the crisis, the patient may or may not become conscious again.
➢ Appropriateness of using PS for existential distress	▪ Some nurses in this study expressed uncertainty about the appropriateness of using palliative sedation to relieve existential distress that patients experienced. Existential distress refers to PS used "for the relief of profound anguish (possibly spiritual) that is not amenable to spiritual, psychological or other intervention and the patient is perceived to be close to death" (Chater et al., 1998, p. 264).
➢ Factors that influence nurses' comfort with decision to use PS	▪ Analysis of the interviews indicated that a number of factors contributed to the extent of comfort the nurses felt in implementing PS. These factors included: i) the need to create comfort for the patient, family and the nurse; ii) the effectiveness of sedation; iii) the personal knowledge by staff of the patient; iv) perception by nurses' of their relationship with the physician; v) timing: not done on a whim; vi) readiness of the patient, family and team to proceed with PS; and vii) collaborative decision making.
Sub-theme: Ethical Quagmire	▪ Refers to the use of PS in the management of refractory symptoms at the end of life raising ethical questions, and at times causing controversy with the nurses caring for patients receiving PS.

Categories: ➢ Nurses' perceptions regarding appropriateness to use PS	▪ PS refers to situations in which a decision was made regarding PS and the nurse had conflicting views about the timing, amount of sedation and the care of the patient and family receiving this intervention. This category consists of the following sub-categories: i) family pushing for more sedation; ii) palliative sedation: discussed but not implemented; and iii) backing off.
➢ Death hastening versus comfort promoting	▪ The delicate balance between the use of PS as a comfort promoting intervention and walking the fine line with death hastening measures.
➢ Factors affecting the ethical quagmire	▪ The factors that affect the ethical quagmire include aspects that ease the ethical challenges inherent in using PS and those that complicate the ethical challenges inherent in its use. This category consists of two sub-categories: i) factors related to the nurse; and ii) limitations of prescriptive criteria.

"Working Your Way Through The Quagmire"

The major unifying theme arising from the data was that of, *Working Your Way Through The Quagmire* (See Figure 1). The theme *Working Your Way Through The Quagmire* refers to a process whereby nurses had to sort out a myriad of issues related to their personal beliefs, values, past experience, and relationship with the patient and family when PS was implemented. The metaphor of the quagmire is defined as: the ambiguous and variable situation nurses find themselves grappling with and captures the nature of the experience the nurses' recounted during their interviews. In some situations, nurses worked through the quagmire to a place of comfort proceeding with PS. In other situations, uncertainty (i.e. related to the appropriateness of PS, who was benefiting from PS, etc.) remained (see Figure 1). Underlying this major theme are the three sub-themes of "Definitional Quagmire"; "Indications for Use Quagmire"; and "Ethical Quagmire". The outcome of nurses working their way through the quagmire of PS was variable and fluctuated with each circumstance in which the nurse was involved. Each nurse had a different perception and definition of PS. This perception was shaped by various factors, such as past experience, and patient and team contact. There were no policies or guidelines regarding PS to provide structure or direction in this clinical setting. The bottom line of working through the quagmire for the nurses was that they gained temporary comfort with the use of PS within each individual situation, but the decision to use palliative sedation could not be generalized from one situation to the next. As well, working through the process of PS for each individual patient, nurses' feelings and perceptions fluctuated depending on the patient's symptoms, family reactions, and team

Figure 1


Outcome 1: Nurses' comfort with each individual situation involving palliative sedation for refractory physical symptoms.
Outcome 2: Nurses' uncertainty about the use of palliative sedation for existential distress.
Working Your Way Through the Quagmire
Ethical Quagmire
•Nurses' Perceptions Regarding Appropriateness to UsePS
•Family pushing for more sedation against nurses' better judgement
•Palliative sedation: Discussed but not implemented
•Backing off
•Death Hastening vs Comfort Promotion
•Factors Affecting the Ethical Quagmire
•Factors related to the nurse
➢Reflective practice
•Limitations of prescriptive criteria
Definitional Quagmire
•Ways in Which Nurses Define PS
Indications for Use Quagmire
•Blurring Between the Use of Crisis Medications and PS
•Appropriateness of Using PS for Existential Distress
•Factors that Influence Nurses Personal Comfort with Decision to Use PS
•The need to create comfort
•Effectiveness of sedation
•Personal knowledge by staff of the patient
•Perception by nurses' of their relationship with the physician
•Timing: not done on a whim
➢Too soon for PS
➢Too late for PS
•Readiness Issues
•Patient readiness
➢Readiness of patient to consent for PS
➢Getting affairs in order
•Family Readiness
•Team Readiness
•Collaborative Decision Making

discussion. There was no standardized pattern to using PS, not only from one patient to another, but also within each patient situation. By the end of each interview, there was no firm definition of PS articulated and each nurse continued to hold a different perception about the use of PS.

Excerpts from the initial interviews and follow-up interviews that best illustrate the themes, sub-themes, categories and sub-categories that emerged from the data are presented. In the data excerpts, pseudonyms for the participants are used to preserve anonymity. All the participants are referred to as "she".

Definitional Quagmire

The first sub-theme, *Definitional Quagmire* describes the difficulty nurses had with defining what is meant by terminal sedation (TS) or palliative sedation (PS). This theme consists of one category, "Ways in which nurses define PS".

Ways in Which Nurses Define PS

To understand the nurses' perception of palliative sedation, it was important to explore the ways in which they defined this term. All of the participants indicated that they had heard of the term terminal sedation (TS) or palliative sedation (PS). Although nurses indicated that they had heard of this term, most stated that until recently, they did not know the meaning of PS. All the nurses interviewed for the study though willing to share their definition of PS, found it difficult to do so as they did not have the language to define it or were unsure of the exact definition. Contained within their definitions were varying levels of understanding of the purposes of PS, and the appropriateness of its use. The definitions are summarized in Table 5.3. Nurse generated definitions tended to

include descriptions of the desired clinical outcome that would occur as a result of PS, (e.g. "to create comfort..." "...the objective is to sedate them with the objective of giving them a peaceful and comfortable death") and reflected the notions of timing (e.g. "death imminent) and the serious consideration involved in using this intervention ("as a last resort"; "exhausted everything" "...the patient themselves are at the point where they know they're going to pass away").

Nurses' definitions of PS were informed by discussions they had with palliative care physicians on the unit. Other sources of information that assisted the development of their personal definition of PS came from discussions with nursing colleagues, reading research literature, and their clinical experience over time on the palliative care unit.

Table 5.3 Definitions of PS as Defined by the Participants

NURSE	DEFINTION OF PALLIATIVE SEDATION PROVIDED
1. Cindy	...in our unit, we do comfort measures. I guess it's really at the end stage where the families are really distressed and the patient is, the patient themselves are at the point where they know they're going to pass away and they're not comfortable. They've got everything in order, all their affairs are done. They've got a good relationship with their families, and have communicated with them, said what they really needed to say about the past, or the present, or whatever in the future.
2. Susan	I guess it means to me when you can't, um, control somebody's pain. Um so you explore terminal sedation as a last resort. Now pain being physical pain, emotional pain, spiritual pain, any kind of pain. And it just means...um helping the patient through the last days of life until they can pass away peacefully.
3. Bev	At this point, um, whether you're awake and struggling through the next two to three days, or whether you just sleep through them makes no difference to your prognosis. It's not going to make you die any sooner or any later for that matter. It's rather the difference is that, um the issues you're dealing with are tremendous and causing you a great deal of suffering. And so for you to sleep through the next few days rather than have to struggle through them, would bring you relief.
4. Louise	Palliative sedation means to me when someone is dying and they want to sleep. They want to sleep away the last part of their life.
5. Carol	I think it means, to me it means that um, for whatever reason I probably am agitated or having a lot of pain, I am dying and I would like to die peacefully and comfortably. And if that means I have to be sedated then my life's business is sort of taken care of then.
6. Anne	I think it means sedation that is imposed on a patient with the objective in mind to sedate them so that they are comfortable. I'm aware of the fact

	that terminal sedation, because it's called terminal, when they are sedated over a period of time they will gradually succumb to death. But the objective of it is to um, sedate them with the objective of giving them a peaceful and comfortable death.
7. Jane	I thought that it was that we were going to be helping our patients who are terminal die an easier death…helping them to die more comfortably and peacefully.
8. Sandy	Um, when somebody has come to the point in their disease process where they have become either way beyond restless, short of breath. The disease has taken over their body and at this point now the family or even perhaps the patient's wish prior to that is just to be kept comfortable. And if death comes upon them that way, that would be okay too.
9. Mary	Um, palliative sedation means to me it's if somebody has reached the point in their terminal disease, we've tried everything to make them comfortable and they just can't seem to get comfortable, i.e. short of breath, pain or let's say a brain tumour. They're not even aware that they're restless… um it's very near the end. And the family is very upset that their loved one is in this agitated, symptom like state and they usually say, isn't there something you can do about this. And it's usually kinda the last, we've tried all other avenues and they are not working, so then you go to sedation.
10. Judy	I think it's providing ongoing sedation to a patient to put them in a state where they're not physically aware of the death, the dying process and it comforts them and the family during the end stages of life.

Indications for Use Quagmire

The second sub-theme, *Indications for Use Quagmire* was identified in the interviews. Participants described indications for using PS in a variety of circumstances. Most had experience with using PS for the relief of intractable physical symptoms. Only a

few nurses had experience with using PS for refractory psychological or spiritual distress in which all other possible treatment interventions had failed. Only one nurse indicated that she had been involved with the use of PS for refractory psychological distress, but not for intractable physical symptoms. This sub-theme consists of three categories, "Blurring between the use of crisis medications and palliative sedation", "Appropriateness of using PS for existential distress" and "Factors that influence the nurses' personal comfort with the decision to use PS".

Blurring Between the Use of Crisis Medications and Palliative Sedation

A significant factor that contributed to the quagmire of the experience of using PS involves nurses being unsure about the distinction between the use of sedating medications in the context of a medical crisis and the use of such medications when such a crisis did not exist. Some nurses had a clear idea of the set of symptoms that would indicate the use of crisis medications, while others expressed that the use of crisis medications could result in PS. Nurses described the use of crisis medications as a temporary "one time" intervention for emergencies such as respiratory distress and seizures, in which the patient is sedated for a short period of time. Depending on the crisis, the patient may or may not become conscious again. Crisis medications were pre-ordered by the physician in anticipation of a medical crisis and usually consisted of three or four medications, such as an analgesic, a benzodiazepine and an anticholinergic. Crisis medications could be given every thirty minutes until the patient became comfortable. If medications were required to keep the patient comfortable and sedated after the crisis, then new medication orders would be obtained from the physician. Some nurses

indicated that the use of sedating medications for a medical crisis had a purpose and outcome distinct from their use for palliative sedation.

> Interviewer: When you're giving those crisis meds, you wouldn't really consider that sedating somebody?
>
> Cindy: No, well, you sedate them for a short period of time. They'll come out of it. Sometimes, if you're doing it towards the end.... and they're in crisis and you've got your crisis meds then. That may happen [and] then that will be the terminal sedation, because they won't come out of it. But, in some cases, we just give it one time to deal with- then they come out of that and they're okay (Interview, p. 26-28).
>
> Cindy: [Follow up Interview, Re: crisis medications] Say if you're giving crisis meds, for breathing or whatever... and after that the next day they could be fine again... crisis is separate from terminal sedation, kind of thing, crisis is not sedation... But in a couple of hours, their breathing is fine. They're back to kind of normal or half normal, but that's not sedation. Sedation is for a small period of time for the crisis that you're giving it for. But the terminal sedation is where you're giving it all the time (follow-up Interview, p. 11-13).

In contrast, some nurses thought crisis medications "sort of go hand in hand with PS" because, at times, sedation was the goal and an acceptable by-product of giving the medications. This created ambiguity for some nurses regarding the meaning of PS.

> Bev: Palliative sedation occurs, um less formally as, a defined goal and course of action. It actually does occur because we're giving crisis meds for agitation, for example. And so they're giving medications that make them sleep, you know. And then they end up getting them fairly regularly. And then it becomes palliative sedation without it really being talked about, um [then] in a more dramatic sense where it's like...this patient would struggle and get up to her wheelchair for her last smoke... and then they'd start the drug and then she'd go to sleep. And then that seems like this very definite and defined, this is palliative sedation. They've decided this course of action and when we're gonna do it (Interview, p. 5).
>
> Susan: [Follow-up Interview, Re: crisis meds] So that's why you would sedate, to get them through an acute problem and then, so that's not

necessarily terminal sedation...(p. 10). Sometimes after an acute phase, they will just become very sedated.... so you stop those crisis meds at that level. But then you, you then get other orders then, to follow (p. 31)

Interviewer: Is that considered terminal sedation in your mind?

Susan: Depends on what the situation was (p. 31).

Appropriateness of Using PS for Existential Distress

Some nurses in this study expressed uncertainty about the appropriateness of using palliative sedation to relieve existential distress that patients experienced. Existential distress refers to PS used "for the relief of profound anguish (possibly spiritual) that is not amenable to spiritual, psychological or other intervention and the patient is perceived to be close to death" (Chater et al., 1998, p. 264). Some nurses felt comfortable using PS for refractory psychological distress, while others expressed uncertainty about the decision to use PS for this purpose. Many nurses shared how difficult or "hard" it is to assess and determine whether the use of sedation for psychological purposes is appropriate. The difficulty in assessment and understanding of refractory psychological distress seemed to be related to the lack of clinical objective measurements to help inform the nurse, the fluctuation of the subjective degree of distress exhibited by patients, the proximity to death of the patient and the frequency with which PS is used for this purpose on the unit. Some nurses indicated that PS is not used very frequently for existential purposes, hence is a "journey not too many [patients] on the unit take" (Cindy, p. 46).

Cindy: That's hard, cause... I don't know. When I see signs that there's pain - I am more to the physical than I am to the psychological. I don't know how I would have dealt with that one. I mean, I'm for sedation but.... [jocularly] I have to see something to – [laugh] well inner suffering, but that. That's hard for me, I think (Interview, p.

40-41).

Bev: It becomes more difficult issue when that suffering is psychological or spiritual. Because that's something we can't easily see or even define or understand well. And I think there's perspective in our culture when there's something wrong with you mentally that you should just pull yourself up by your own boot straps. You know, if you're depressed, well just stop being depressed. You know it's just a matter of attitude. Whereas in reality we know people dealing with depression, or severe spiritual anguish suffering in a very real way. And there's no simple drug or mental trick or we're sitting under a satellite or something like that, that's gonna suddenly change everything (Interview, p. 3).

Louise: And there is... my feeling is... because you can't see physically, you can't see the physical, the emotional stuff, the emotional pain. Doesn't mean it's not there. And I think, you know the stuff we bring we bring to this job is it happened in our own lives that we bring, of course. You know reflect on that. I don't know, like why, why is it that, why do feel that the physical stuff, you know, we can see it, so it's real. And the emotional stuff we can't see so maybe it's not as real. But that's not right. Just because you can't see something, doesn't mean it's not there. It's like because you can't see God, you don't believe in him? (Interview, p. 10).

Carol: I guess in some ways we can't see it, um you can't necessarily fix it. ...I guess if you have a really sore leg I can do something about it and fix it because I can see the physical dressing, give you something for the pain...so if it's mental, emotional, psychological, I don't know. I don't know how I would know because lots of people don't talk to you. Lots of people just sort of pull back. (Interview, p. 18).

Judy: So sometimes stuff gets resolved, sometimes it doesn't. And when it doesn't. Like this young guy that was just in such anguish, because it just, I can't deal with this yet. I'm dealing with the pain of dying, physical pain, emotional pain, and then I've got all this going on. I can't, I don't want to be here anymore, let me out of here, end it now. And just that, it's hard to tell where the physical pain ends and the spiritual emotional pain starts, cause that spiritual emotional pain is just so intense (Interview, p. 41).

Factors That Influence Nurses' Personal Comfort with Decision to Use PS

Analysis of the interviews indicated that a number of factors contributed to the extent of comfort the nurses felt in implementing PS. These factors included: i) the need to create comfort for the patient, family and the nurse; ii) the effectiveness of sedation; iii) the personal knowledge by staff of the patient; iv) the perception by the nurses' of their relationship with the physician; v) the timing: not done on a whim; vi) the readiness of the patient, family and team to proceed with PS; and vii) the presence of collaborative decision making.

The need to create comfort. One of the common threads in all the interviews was the need nurses had to "create comfort" for both the patient and their family. Nurses expressed the ability to offer comfort measures was a high priority for their patients. Creating comfort refers to nurses ensuring that a patient's physical and psychological symptoms are well managed so as to minimize symptom distress. The patient does not appear to be exhibiting distress from the disease so the family does not have to watch the patient struggle to the end and be left with this last image and memory of their loved one.

Cindy: it's really at the end stage where the families are really distressed and the patient is...You can't watch this. I mean suffering. For what reason would you watch her- in such distress?... They [family] can't watch that... That's very difficult. (Interview, p. 10, 17). You can't watch it, never mind you, the family can't watch that. And they came to me and said, "Whatever you gave, it's wonderful and we're so at peace" (Interview, p. 20).

Anne: in situations, um... let's say having a hard time breathing or something like that. There you can really see um, the need for somebody to be sedated because they have a real discomfort there, or a real need that needs to be fulfilled (Interview, p. 4).

Sandy: We've tried all medications, any kind of things to help. Whatever

> we could give them and just wasn't working and they were in distress. The family was in distress. Something else has to be done for the patient. When I can see that there's something there that can actually make people peaceful and restful as compared to a fight to the finish, give me the medications to help that patient. And so I would rather be giving something to make them comfortable than to have to watch and endure, who knows for how long... (Interview, p. 5).

The need to create comfort also applied to nurses themselves. Interview data suggested that like family members, nurses at times also had great difficulty watching patients struggle and suffer unrelieved symptoms. If the symptoms were relieved with the use of PS, nurses defined this experience as positive and this enhanced their comfort level with the decision to use PS.

> Cindy: This is mom's wish and not our wish: we [the nurses]don't want to see her....especially with the shortness of breath. She was working so hard. So you know with the shortness of breath: it is a real anguish. (Interview, p. 6-7).

> Susan: So there's two ways to look at this. You know, sometimes your kinda flipping the picture and you know how you terminally sedate to make you feel better if they're uncomfortable. But then there's this other picture where they become uncomfortable because you're treating your anxieties for treating them (Interview, p. 23).

Effectiveness of sedation. The effectiveness of sedation is a factor that influences the nurses' comfort level with PS. Some nurses discussed various incidents in which they experienced a failure of sedation. Failure of sedation refers to when nurses felt that the medication used for PS failed to provide adequate sedation. Nurses considered that sedation had failed when intractable symptoms, such as an agitated delirium, did not respond to high doses of medications used for PS. Nurses also indicated that a failure of sedation could be related to physical factors, such as the patient adversely reacting to the

medication, the medications being inadequately absorbed and metabolized in the body, while others thought a failure of sedation was related to spiritual factors, such as an inner struggle or unresolved issues. Nurses conveyed in the interviews that a failure of sedation was very rare, but when it did occur, was extremely traumatic for the patient, family and nurses involved.

Failure of sedation became frustrating when the nurse would do everything a reasonable practitioner would do to alleviate suffering and yet the desired effect of the medications was not achieved. One nurse discussed the limitations of nursing practice in that in these rare situations it would be ideal to give medications by intravenous push, however at the present time, nurses are unable to perform this function in the clinical setting.

Susan: Like we find, I don't know, sometimes these drugs aren't as effective as they used to be. Or something's changing. I used to really focus on you know, that they'll probably be sleeping a lot, and they will not wake up. You know that, that is always a possibility. But I find more and more they do wake up. And then the families are upset because they're still waking up and we said we were going to be sedating them. And they've said their goodbyes. And they've gone through the whole thing. That's hard (Interview, p. 19).

Bev: I thought for some of the people I've given it to and seen them just sleep, that it was just like this thing was magic. There was this young man I'm speaking about. You know, physically he didn't look any different. He didn't look like he was a person dying of cancer. But he had nothing left in his lungs. He wasn't even emaciated yet. He still had muscle mass. But there was basically nothing left of his lungs. There was just no ability for his lungs to provide oxygen to the rest of his body. And we were giving him…just about everything. And regularly. Just incredible. And he became almost completely awake (Interview, p. 16).

Jane: I just remember them using it and it made the patient violent, the

other way for him. And he, I came into the room in time to see him grab the nurse's aid by the neck and he was going to push her out the window. So he had a different reaction to it, he died about a week later. But with him we could not use the medications because it made him too violent for us (Interview, p. 10).

Sandy: We had one lady awhile ago that we gave her a heavy dose of medications and she still would come around. ...just with the eyes opening or just sorta like half a grin or something, but she knows that people are still in her room. She had a lot of love in that room. And I'm wondering if she was fighting it. That's what my personal opinion is when they're doing that, is that they're fighting. They're fighting the drugs, they're fighting the disease process and what we're doing is against her will (Interview, p. 14).

Judy: ...it was painful for her to have to say goodbye, but she knew she was dying. And the next time I see her she was literally screaming and flaying around...And she was in anguish cause she could not die. It was like struggling to die.

Interviewer: And when the sedation started did it work?

Judy: Not at first, because you know what, there's so many factors that are just beyond us and I don't question them (Interview, p. 19-20).

Personal knowledge by staff of the patient. Another common thread nurses indicated that increased their comfort with the use of PS was how well they knew the patient. Knowing the patient refers to how familiar the nurses were with the patient and their family as individuals, above and beyond information that pertained solely to the patient's medical condition. Familiarity depended on how long the patient was on the unit and how much personal information patients and families shared with the nurse caring for the patient. In the following exemplars, nurses clearly stated how their knowledge of the patient influenced their comfort with the use of PS.

Louise: I think it depends, it depends on the patient. It depends how long I know them. If it's one of my primary patients, who I know very well. I'm either going to say, I think that's a positive thing for that person, or I may have reservations (Interview, p. 5).

Judy: I'll give you an example, there was a patient that I had a close relationship [with]. When you're working with people that closely and you're doing those intimate things for them, you're with them and you get a sense of them wanting to talk. That we've talked, and you know, I want to sleep, and I can just remember him saying you know, I don't want to suffer. I don't want to know what's going on, I just want to go to sleep and not wake up (Interview, p. 18).

Perception by nurses' of their relationship with the physician. Nurses' knowledge of the physician ordering the PS affected their comfort level with its use. Knowledge of the physician refers to nurses becoming acquainted through contact or experience with the physician they were working with. The nurses' perception of the physician's skill level as a palliative care practitioner and the approachability of the physician enabled the nurses to feel supported. When the nurses in this study felt they were able to establish rapport with the palliative care physician, they could discuss their concerns regarding the use of PS with a particular patient more readily. Nurses discussed the approach used by the physician in speaking with patients, families and staff regarding PS. One nurse characterized her first experience with PS as positive and stated "but in large part due to [the physician] and the way he [the physician] did it". Some nurses felt supported by the physician and trusted they could discuss their discomfort with him/her if necessary, while other nurses seemed more cautious discussing their discomfort regarding PS.

Cindy: And then Dr. [personal name] was very supportive. [he/she] came to me after: 'Are you okay?' 'Do you want to talk?' [personal name] knew I was okay, in an okay sense. I'm okay with what the family wants and what the patient wants. But it's hard. I mean it was like Dr. [personal name] was going to comfort me- No words can express that. But [he/she] knew, just by looking at the nurse...could tell, you know, that you're comfortable (Interview, p. 12).

Louise: You need to go to somebody who is with you. Who knows the

plan. Who knows what you're doing. Rather than somebody whose, you know, like, like the resident (Interview, p. 16).

Carol: ...be doing this with somebody [referring to doctor] that you trust. That you know will be okay (Interview, p. 28).

Anne: Well I guess, I've known Dr. [personal name] and I, like I said, I feel there's always, you know, like I talked about people having opportunity to grow, but yet Dr. [personal name] is a good physician. And I respect, you know, respect [his/her] decisions in many ways. And um, if [personal name] conferred with the family then you know, they went ahead and did it. It's just that I think it can be tricky, you know, um but I think for it to actually give her that regular medication that was ordered, I think you know um, I don't know. I guess that decision, I guess I kinda have to respect what, what Dr. [personal name] did (Interview, p. 6).

Timing: not done on a whim. The issue of "when" PS was implemented held great significance for nurses in this study. Ideally, the use of PS occurred neither too early nor too late. Rather, the decision to implement PS was a thoughtful gradual process:

Cindy: ... It took about a week and I think the family finally did get on board and they were okay with it so then the nurse was alright" (Interview, p. 45).

Susan: I think each case is individual. And to sort of sit here and say, "well, I think ya know at this point in time it should be used". I don't think you could be so black and white when it's an issue like this (Interview, p.4).
The patient and that family have to be ready for it. And depending on where they are in their disease and where their family is, and where the whole dynamics of that.... family is, will depend on when you use terminal sedation So, I don't think I can just sit here and pick a time (Interview, p. 4-5).

Many nurses described how discussions regarding PS with patients and families occurred over several days and sometimes weeks. The decision to use PS in each particular circumstance was described by participants as a "feeling that builds" with PS being implemented on a "case by case basis" only after the team had exhausted all other

measures.

Too soon for palliative sedation. Nurses sometimes had the "gut feeling" that PS had been started too soon. One reason nurses suggested they struggled in this instance was the fact that patients are already very ill and could change very quickly from day to day. At times, a patient's symptoms could be so well controlled that it may mask how sick patients actually are in reality.

Jane: We thought the patient did have signs and symptoms of impending death. However, there are about one percent of patients that come back for whatever reason and that's what happened with this patient. We withdrew the terminal sedation after the family said no. She became quite confused. And after that she's up and walking around now and that's been about three weeks now. So that's the only time I've seen it (Interview, p. 9).

Anne: I asked the patient directly actually. I came in there… and the son asked me what are you giving him, and I'm giving him some medication to make him sleep. And it just twigged, I don't know what the patient said to me, but I just said you do not want to be asleep, do you want to be more awake? And he said yes. And then I brought all the sons out and said, what's going on here, you know. And they said to me, well you know he said I just want this all to end, but he really doesn't mean it. And I kinda thought how did we get so far off base (follow-up Interview, p. 6).

Sandy: He stayed very comfortable but he lasted a long time because he was a gentleman I didn't feel that should have been initiated on terminal sedation so soon. I had to struggle with initial, initiating of terminal sedation but I wasn't part of the initial discussion of it. I had to question it all when I came on for my night shift because I said, how did that happen so fast cause I didn't think he was. But anyways that was up to the doctors and the families. I was there to carry it out, which I did, but I did have my limits to where I felt this was okay (Interview, p. 12).

Mary: There was one of my patient's that I guess in my eyes sedation had been started too soon. And I didn't think that it had been explained enough to the family. And then we backed off and she actually had some quality time.

> There was a lot of things that went through my mind when she was sedated, you know I just had this gut feeling...And I talked to the doctor about it and we talked to the family and we pulled back and it was a good month and a half... I just remember that I was glad at that point in time that we had pulled back on the sedation. We had to go forward from that, I mean everybody can make a mistake in that, you know, it's hard to figure sometimes, you know (Interview, p. 20).

Some nurses recognized that their thoughts about certain cases involving PS may fluctuate from time to time and the need to use PS may have to be re-evaluated.

> Susan: You know, it's just like you're torn. And every situation will be different. And that, even that one situation will change as time goes on. So even though one day you might be comfortable with terminal sedation the next day you could be struggling again (Interview, p. 23).

> Louise: [follow-up interview] Two weeks ago there was a lady who wanted to be sedated. She said she couldn't stand this anymore, she had cancer of the pancreas and was vomiting four, five, six times a day. And she said this was enough and couldn't do this anymore, she was a nurse and she wanted to be sedated, and talked about it with every nurse she had all three shifts for about two to three days. And then I put down a levine tube and hooked it up to the suction and she said she felt better and didn't want to be sedated anymore. So you have to be sure you've done all the physical stuff you can cause that made her feel better... so your viewpoint can change from day to day (follow-up interview, p. 3).

Too late for palliative sedation. Some nurses discussed certain cases in which the patient became extremely restless and agitated to the point that it was "too late for terminal sedation" (Cindy, p. 20). This usually occurred when patients were admitted urgently to the unit with an acute event. Their symptoms were so severe that nurses had no time to create life closure with the patient and family and manage the symptoms comfortably within such a short time frame. Because the patient's symptoms had not been addressed, nurses felt that families had already suffered by having witnessed severe

symptoms, so that the use of sedation at this point would not have spared the families from this event.

> Bev: And there are people for sure I have had a bad, very bad experience actually, where it was never specifically said that sedation was the goal… I guess his body was strong enough to fight and struggle. And he was on so much regularly…and he woke up and fought and fought. And he, there was a loved one there who watched him go through this and it was absolutely horrific (Interview, p. 6).

> Mary: …it [PS] had been discussed with the family about sedation. The person had a brain tumor and just totally not herself. It was to the point where the family couldn't come in and visit her because she was saying things and doing things and stuff, they just couldn't stand to see it cause it wasn't her. They had discussed it, the family and had requested sedation. But the doctor thought she wasn't quite ready for it so held back until it flared up….and it was not a nice scene…. And then the family came in and they were a little upset that this had happened because they had requested the sedation last week and it hadn't happened (Interview, p. 14).

Readiness Issues. Nurses described a "readiness" of the patient, the family and the health care team regarding the decision to proceed with PS, which increased the nurse's comfort with using PS. Readiness refers to the patient and / or family taking the steps and paving the way so that the patient has their affairs in order as they approach the end of their life, thereby laying the foundation to prepare for PS. Readiness includes: a) patient readiness; b) family readiness; and c) team readiness.

Patient readiness. Patient readiness depends on a number of factors including: i) readiness to provide patient consent for PS; and ii) getting affairs in order.

Readiness of patient to consent for PS. Patient consent for PS involved behaviours and comments by the patient that indicated they were, or were not ready for this intervention to occur. It was often clearer for nurses to determine when patients were

not ready for PS with comments such as:

Louise: Whereas the patient that we didn't use it for, they'll talk about what they're going to do tomorrow. My daughters coming in from the coast tomorrow. And you know I need to get my hair done. So they're still talking about tomorrow and the plans they have. So they're not ready. I mean they have terminal cancer and they're gonna die from it, but they're still making plans, so they're not ready (Interview, p. 6-7).

Judy: This is not just a matter of medicine or a matter of, you know, physical, cause it's so way beyond the physical. And you know we can sedate the body but that doesn't mean that the spirit is ready. (Interview, p. 25).
Her ex-husband who had passed away twenty years before was there. She's going, go away, I'm not ready, I'm not ready, he keeps telling me it's time to go, but I'm not ready yet, cause she had three daughters that never got along. She would not leave them till she had them, all three of them there at the same time (Interview, p. 40).

Susan: ...we had a gentleman who's very, you know, don't worry about my pain, don't worry about my pain. And he had three boys and they were okay with don't worry about his pain. And then we saw how much pain he was in...So I know that terminal sedation was used to help the patient through that time even though the family really wasn't onboard, they weren't ready for this yet (Follow-up Interview, p.6).

Nurses indicated that discussions surrounding the use of PS were usually initiated by the patient, or the physician and/ or nurse caring for the patient when seeing them struggle with physical symptoms, such as profound dyspnea. Some nurses revealed it was "helpful" or almost a relief if the patients themselves verbally communicated to the nurse that they were at a point in their illness where their situation had become unbearable. Although nurses indicated that most patients did not directly use the term PS or were aware of this intervention as an option available to them, many patients would convey statements such as "I can't do this anymore" or "I can't bear another day".

Cindy: And then they're ready - I mean, that's really the word... they're *ready* to pass away peacefully (Interview, p. 3).

Susan: I guess that's when I'm the most comfortable using terminal sedation, is when the patient can be part of that. And they just say I need, I need help. I need somebody to help me get through this time more comfortably than what I am (Interview, p. 15).

Sandy: ...we like to talk about it when the patient is able to say, yes, to voice their own concerns and their own pain and their own struggles. I like patient consent. I feel more comfortable giving that kind of sedation when the patient has been approached (Interview, p. 16).

One nurse indicated at the end of her interview:

Louise: Do you know, when I think about it now the three patients that come to my mind, I was involved with. Patients' all asked . They said they can't do this anymore. You know. What can you do? What can you give me...so I can get over this, so I can bear this? (Interview, p. 17).

Affairs in Order. Another factor that enhanced nurses' comfort with PS was the patient having all his / her "affairs in order". This refers to the patient having done everything they have wanted to do with the time remaining prior to their death. In particular, nurses tried to ensure that the patient had been provided with the opportunity for final communication with family members. Nurses would ask patients questions regarding life closure such as, "have you done everything?" and "have you said all your goodbyes?".

Cindy: They've got everything in order, all their affairs are done. They've got a good relationship with their families and have communicated with them, said what they really had to say... (Interview, p. 2-3).

Louise: ...And probably by just talking with them. Like the one lady that we did use it for, when I would speak with her about it, I would say, you know "have you done everything?" And I would get answers like, "I've said goodbye to my children and to my

> grandchildren and I've hugged them and I've kissed them all and I've done it three or four times. I've said goodbye to them." And she even said to me that she couldn't bare to say good bye again (Interview p. 4).

Family readiness. Family readiness includes having the family in agreement with PS. The family were comfortable and were assured the time was right for PS through their previous discussions of life closure with their loved one and saying their goodbyes. Family readiness may overlap with patient readiness to implement PS.

> Judy: The children when I spoke to them did not all agree. One of them wanted the death hastened…When is it going to end? How are you going to speed it up? The other one is upset with the daughter, because he says well he's still got quality. You know, he can still watch a hockey game, go outside. And the other one is torn between those two. So what do you do? So I've been very clear, I don't think you can sedate him based on what I see about the family (Interview, p. 28).

> Mary: We have tried a lot of anti-anxiety medications until we've gone there cause the whole family wasn't all in agreement. One person would have sedated immediately, like a month ago, one's in the middle of the road and one is like absolutely not. But we got them all, you know, they're all on the same page now because they've gone through ups and downs with their dad. And finally realized, like we have tried every avenue (Interview, p. 5).

> Sandy: …When it becomes a family struggle to do this for their loved one, I think the family becomes a little bit um, what's the word I want to use, when the family thinks they want to keep their loved one comfortable and perhaps when we've talked about palliative sedation the route they want to go. It's almost a selfish act on their part sometimes, I feel because they now just want it all over. But then they're also loving that person and don't want to see them suffer. So I have a little bit of a struggle with that personally sometimes, when it's family initiated and not patient initiated. Is it the selfishness of the family that say, you know, let's just get this over with because I don't want to watch this anymore (Interview, p. 15).

> Anne: I think because of the natural hills and valleys we go through in

> life. You know, we see the rain one day and then we see the sunshine. You know we're in the rain, but we don't see the sunshine till the next day or the next three days. I don't know. I think we always want to, I don't know, it's just, will they come out of that or, you know, are we doing them a disservice by you know, it's like the person who's delirious and the family saying this isn't that person or the person with body image. I can't stand to look at myself. But still I don't know, you just sorta have to give them an opportunity. Maybe there will be growth, you know for them. You just don't know, so it's hard. Really it's a tough, it's a tough decision. You don't want to have situations where people have missed opportunities (Interview, p. 6, 18).

Team readiness. Team readiness includes having the health care team in agreement with each other to implement PS. Due to the various perceptions of the health care team regarding PS, nurses, at times, experienced conflict with their nursing and medical colleagues. This also had an impact on collaboration and whether PS would be implemented.

> Interviewer: So then sometimes what can happen, is because of the different views of the staff, there could be some conflict.
>
> Susan: Oh yeah there is. Because if many times there would be orders, that are heavy duty sedation orders, and the next person will come on and say "wow, like what are you trying to do, you know knock my patient out." Aw, well, no. Like they have a lot of pain today. And you hear comments like that. Where you hear um, someone's had three breakthroughs, they've been restless and then it'll be like "well why didn't they get the midazolam on board?" And you know exactly what that's for. To sedate them you know (Interview, p. 11-12).

> Interviewer: ...in your experience on the unit do all shift members agree with that?
>
> Mary: No, it's actually getting better, but I can remember as far back as only a year ago, well it wasn't so much verbally, but you can tell by especially if there's a PRN that's not being used.
>
> Interviewer: And how do you cope with that?
>
> Mary: I usually try and talk with the person to see where they're coming from or what their feelings are or whatever. Sometimes I might have information that they're not aware of. You know just make

sure everyone's in agreement with it, it's what the patient wants, it's what the family wants (Interview, p. 12).

Interviewer: Do you ever think are we doing the "right" thing here?
Judy: Yeah, cause that happened. Cause I was gone for two days and I came back and they started my patient [on PS]. And as soon as I saw it, even before I started in report I talked to the nurse on days, who was the primary nurse, and I said, you know why are we doing this? Like the family was not in agreement the last time I was here, which was like three days ago. You know. "Well they're all the same page now" Okay that's strange. And then, so I read it in the IPN, yeah the family's all on the same page, but I don't know that (Interview, p. 36).

Palliative sedation must be consistent between shifts as one nurse stated, "your shift had to follow with the next shift, on the same wavelength to do the terminal sedation". Occasionally consistency did not occur, hence, the concept of "playing catch-up" was described in a few interviews.

Cindy: ...and then you're playing catch-up. Because if you give on evenings, and you could have like a quarter page filled out with everything you gave....
And then you've done so many prn's, got them comfortable and then you tell nights, and you write in the book to follow up please and check for everything.... Then the day shift comes on and she'd still be jumping around. And they look at the prn's; nothing was given. Well that's 8 hours that have gone by- And you're doing the same thing all over again (Interview, p. 22-23).

Susan: And you see that, that's what happens actually quite a bit. We will, you know give, give, give, give, give all one shift. And then of course the next shift, they're comfortable and sleepy. So they don't give. But, then the shift after that they're restless and they're in pain and it's like now we play catch up and you give, give , give, give again. And it can just be a vicious circle (Interview, p. 21).

Collaborative decision making. Collaboration includes working together not only with the patient and family, but with the other members of the health care team. Frequent, constant discussion occurred with patients, family members and team members regarding

the use of PS. Most of the nurses in this study shared feelings of relief that the decision to implement PS was "not our decision". Rather the patient and family worked collaboratively in making this decision along with the physician. Nurses commented that the decision to use PS should be a gradual process and not made in haste. All of the nurses indicated that everyone, including the patient must be in agreement with this approach. Nurses expressed concerns regarding litigation and that they were hastening death if everyone was not on the same page. Once consensus was reached, PS could be implemented.

Interviewer: Has there ever been a time when a patient agreed to it but the family was not on board with this at all?

Cindy: No! Oh no! Dr. [personal name] wouldn't do it then
No definitely not. You can't. If you don't have everybody on board, it doesn't work. It doesn't work. I mean, I can't even see proceeding (Interview, p. 31-32).

Anne: So you know, I think, not to make that a hasty decision and to check with them [the patient] more often (Interview, p.5).

Susan: We have to be careful not to make it an easy decision, cause then we've lost what we're trying to do, and we've gone down the wrong path (Interview, p. 26).

Sandy: We don't just use it on anybody. You know, so it's something that's done over a period of time, with much thought processes and decision making (Interview, p.26).

Some nurses emphasized the significance of having the patient involved, and if possible, directing the process.

Louise: We need to be sure we do it because the patient wants it. Not because the family wants it, or the staff. ...you'll see families who will say "I'm so tired of coming here. You know is there anything we can do, is there anything you can give them?" We need to be sure that we do it for the right reasons (Interview, p. 3).

Sometimes issues of disagreement regarding PS ensued with the patient's family. In regards to collaborating with the family, one nurse stated, "again it comes back to your family, comes back to your nurses". And that's what sometimes sort of interferes with a good terminal sedation picture". Some nurses described conflict occurring occasionally with family members.

> Sandy: And I said to the daughter when she was out in the hallway sitting there, she was reading a magazine, she said to me you're not comfortable with this. There's a few nurses that aren't comfortable with this. I said, you know what, I am comfortable giving palliative sedation, I'm just not sure your dad was ready for it. She started to laugh like it was…she says ahh what do you mean by that? I said, well because the way your dad came in here verbalizing and talking to us, I didn't think he was in much distress at the time. But she bluntly told me I'm not to be the judge of that. And I said well that's fair enough. So that's sort of where we left that conversation. So, she picked up on a few nurses, that they weren't comfortable with that. So she was sharp (Interview, p. 29).

Ethical Quagmire

The third sub-theme *Ethical Quagmire* refers to the way the use of PS in the management of refractory symptoms at the end of life raised ethical questions, and at times caused controversy with the nurses caring for patients receiving PS. This sub-theme consists of three categories, "Nurses' perceptions regarding appropriateness to use PS", "Death hastening versus comfort promoting", and "Factors affecting the ethical quagmire".

Nurses' Perceptions Regarding Appropriateness to Use PS

Nurses' perceptions regarding the appropriateness to use PS refers to situations in which a decision was made regarding PS and the nurse had conflicting views about the timing, amount of sedation and the care of the patient and family receiving this

intervention. This category consists of the following sub-categories: i) family pushing for more sedation; ii) palliative sedation: discussed but not implemented; and iii) backing off.

Family pushing for more sedation against nurses' better judgement. There were a number of situations in which the family wanted the nurse to administer more medication, but based on the nursing assessment, the nurse withheld the medication. Nurses indicated that these situations were distressing because of the continual pressure from family to administer medication although the patient appeared comfortable. Nurses would not go into detail and describe how they would manage this distress. Distress is used here to refer to the mental or physical discomfort nurses experienced regarding PS. Some nurses would discuss this with their nursing colleagues while others would keep their thoughts to themselves.

Susan: So we had medication on board. But you know we couldn't quite get that terminal sedation. You know, and it's almost like there, okay we're ready for them to die now, well how come they're still awake? And you know, and the patient wasn't that uncomfortable....
So there's this family, who, the patient is awake. Was not able to respond. Seemed physically comfortable. And many times you can sort of tell if they're emotionally and spiritually comfortable, you know, they're struggling, to a point. And they seemed comfortable. But not sleeping. And the family's just like, you said you were going to give this medication and they're not sleeping. And it's just like I had a really hard time to continue to give sedation medication when they weren't uncomfortable. And the family wanted it. But the patient of course couldn't respond (Interview, p. 7).

Sandy: And I said to the daughter, I am not giving him this three o'clock, she said why not? And I explained to her why I'm not, I think he's comfortable. His respirations are very low and if I was to give him another dose I would feel I'm going beyond my boundaries here and this may be his last respirations. But the daughter was quite adamant that I go ahead and give it...But my criteria says no and my personal judgement says no, he's quite comfortable. I said I'll

> be back in half an hour and if I see him coming out of it and restless it's not a problem (Interview, p. 12).

Palliative sedation: Discussed but not implemented. Another example included nurses describing situations in which PS was discussed with the patient and family so they knew this option was available, but the decision to proceed with PS was not implemented. A few nurses stated that PS is usually discussed and then followed through with, while others suggested the opposite. The following examples illustrate situations in which PS was discussed, but not followed through with for various reasons. This may cause distress for the nurse because although the patient may experience symptoms that may become refractory, the patient did not want PS as a comfort measure. The nurse would need to work with the patient and family regarding how to adequately deal with the patient's symptoms and fears surrounding death and dying.

> Susan: ...there was this patient who was saying when she was having a lot of pain and well enough to speak, when I get to that end point you just sedate me. But when that end point became very close...and towards the end she did not want terminal sedation. And she said, "I'm scared to go to sleep" (Interview, p. 8).

> Sandy: So, yes there's been some case scenarios we haven't really had to use them because their death ended up being very peaceful. But, we had approached a few patients, just recently, thinking that they might you know, have this restlessness, but they never needed it [PS]...And they [the family] wanted to know everything that's available to help their mom through the end. Dr. [personal name] spoke to them about terminal sedation, because when the family would go back they were afraid [to find their mom in a distressed state]. So we covered all our bases with this one particular family and patient about the whole, things, possibilities (Interview, p. 6).

Backing off. One dilemma nurses faced involved the idea of "backing off" on the palliative sedation. A dilemma refers to a situation the nurse finds herself faced with

choosing between equally unsatisfactory alternatives. "Backing off" on PS refers to decreasing or discontinuing the medications used for PS. Backing off situations usually occurred because of a family member changing their mind about the use of PS. This scenario constituted an ethical dilemma for the nurse because continuing to proceed with PS would cause concern and anxiety for the family because they may feel guilty and think they are killing their loved one. On the other hand, backing off may appease the family, but may lead to an increase in discomfort for the patient. These situations likely occurred in instances in which the patient could not fully participate in the decision making process. Usually this change in decision making arose because families did not realize how sleepy the patient would be when PS was instituted and wanted to spend more precious time with their loved one. The first example illustrates the confusion and discomfort the nurse experiences surrounding the question of whether backing off on the PS is a good decision:

> Carol: Well, when I first heard that they backed off, I thought, well what is this? You know, this is a, once that doors open and you're gone through, that's it. You know and if that's your wife and you terminally sedate her and she dies and she's, that's it. You know, whereas, with this family they, they sedated her for awhile and then sort of thought, I think wait. So they backed off a bit and they had a few more days (Interview, p. 8).

However in some instances, backing off had a positive outcome:

> Interviewer: Has there been a time where you did sedate but then pulled back a bit?
>
> Judy: Uh hum. She was just there for four months and we thought she was gone, and we would increase her sedation cause she was uncomfortable. We called all her children in and the next thing you know she's sitting up asking for pizza. Because when people, I think we have to realize that sometimes when people are dying they get depressed at times because they're dying. And they go into

> that state where I'm going to die, it's today, I know. And then the energy of the family around them, the love and the energy of the children and the grandchildren and that positive love around them recharges them and it renews their desire to stay. And they still have some quality of life after that (Interview, p. 23).

Death Hastening Versus Comfort Promoting

Another category nurses described was the delicate balance between the use of PS as a comfort promoting intervention and walking the fine line with death hastening measures. Some nurses experienced ambiguity when using PS for psychological distress, as it was difficult to verify if the patient was in fact physically dying at this particular point in time. Nurses felt situations in which PS was used for physical distress were very different from using PS for emotional distress. This difference was related to the idea that when using sedation for someone with physiological reasons as one nurse stated, "you're really trying to make that person comfortable" (follow-up Anne, p. 3). Some nurses identified that the intent of PS for psychological distress was not to end a patient's life, but to end their suffering, while others thought that this was euthanasia.

> Bev: ...this one was less clear in the terms of, it was this person's psychological suffering was at least probably greater than their physical burden of disease. So I can't say without a medical background absolutely, I don't know if anybody can that, that person would have died anyways within three days....So the difference there is that, I mean whether the persons' physically dying or not is really the key thing. If the person is suffering profoundly, spiritually, but not actually physically dying at that point, then if you sedate them, they're not going to intake fluids or food, and then they're gonna starve and dehydrate to death. See that's different than the disease taking it's course through that persons body...So those times when it's a little more murky to you, you're a little less clear whether that person would have passed away anyway or in a couple of days (Interview, p. 8-12).

> Bev: [follow-up interview, referring to using PS for psychological

distress] You know they are maybe in the more days to weeks state… but if their suffering is psychological and then they wish to be sedated, then um, you're definitely hastening, hastening death in that instance. And the other scenario where the person is actually dying, it's a matter of days and the body is shutting down (follow-up interview, p. 2).

Louise: And I called Dr. [personal name] and he/she said give her this much of nozinan and increase the versed to this. Both? And I said "did you just tell me to give this and this much?" And [the physician] said "yes". And I said, "but Dr. [personal name] we are giving her I think 20 mg of nozinan and 50 mg of versed every four hours". It was unbelievable…It was unbelievable…And I kept saying to Dr. [personal name], this is so much. And [personal name] said "I know, but it's okay". So I finally needed to say to him / her and I needed him / her to answer me before I could give it "But if I give her this, is it going to kill her?" Cause it was just incredible doses. And Dr. [personal name] said "no". That this isn't going to kill her, that it's okay, but Dr. [personal name] knew why I was hesitant….and Dr. [personal name] admitted after she had died that [personal name] had never done that much either… Because you know if I give her this medicine and half an hour later she dies, I'm going to think I killed her (Interview, p. 11).

Anne: …we have to consider the emotional as well as the physical. Cause the emotional suffering can be as great as physical. Well, yeah it can be I guess and you know we have to be sensitive to that. But I think it's a slippery slope… and Dr. [personal name] has also said it's very, very hard to um, when you're into the emotional and psychological issues of… suffering, it's tough to make that decision whether or not you should terminally sedate somebody. And how do I know that they've made all those journeys that, she's feeling depressed one day, but maybe she won't be feeling like that in four days (Interview, p. 5).

Interviewer: Have you had experiences of using sedation with somebody for psychological reasons and how do you know it's okay?

Judy: Uh hum, …You got that: how do you know? You know you can feel it the minute you walk in the room. You can feel the sadness, you can feel the heaviness. It's so hard to say that it's a tangible thing. You can see it when you look in their eyes. Patients call me over and whisper in my ear, could you help me end it, could you please stop this for me? And just whispering it, you can hardly even hear it sometimes, cause they know you can feel the anguish

Interviewer: And are you comfortable using sedation for those approaches? [psycho-social]

Judy: It depends on, the situation. What kind of sedation, how much, cause you know, like I said there's a very fine line between palliative sedation and what I see as hastening somebody's death. I think you've got to be very careful (Interview, p. 21-22).

Factors Affecting the Ethical Quagmire

The factors that affect the ethical quagmire include aspects that ease the ethical challenges inherent in using PS and those that complicate the ethical challenges. This category consists of two sub-categories: i) factors related to the nurse; and ii) limitations of prescriptive criteria.

Factors related to the nurse. Many of the nurses discussed how their own personal background, experience and spiritual wellness affected their inner comfort with regards to using PS. Many felt that you really have to know yourself and "know why you're there." Factors related to the nurse also include the ability to engage in reflective practice as this also influenced the nurses' perceptions related to PS.

Cindy: Don't forget it's your upbringing. You know, you've got to be comfortable with yourself. It depends how you are with your loved ones, your parents, your beliefs. It could be religious belief, spiritual, whatever. I think you have to have an inner peace with yourself before you can probably do it with the patients. - I think all of us who are on palliative must have some inner peace (Interview, p. 64).

Anne: I'm sure I bring my own spiritual life with me when I make some of those decisions. Or you know, some of these thoughts I have or these feelings. I think some of my own spirituality needs might be in there. Spiritual ideologies I call them. Maybe that's part of it or maybe because I'm my age too, I'm saying that I'm older so, I realize life does have its ups and downs. I think maybe because I'm older, the idea of the sunshine and the rain, certainly I had more of an opportunity to experience the sunshines and the rains (Interview, p. 21).

Sandy: I'm a Christian, so I find a lot of comfort in the Bible, in God, in praying. I think then I can find my solace and saying, you know it's okay. I've done what God has called me to do. He's has given me the abilities to nurse and this is the direction he put me in (Interview, p. 33).

Judy: But I think it does have to do with how much work somebody has done on their stuff. If they're carrying a lot of, I see there's a lot people that carry, still haven't dealt with their stuff and that affects with how they deal with stuff now and on the unit. So I think it depends on where you are in your level of awareness (Interview, p. 50).

In contrast, some nurses commented that they did not always have an inner comfort with use of PS. Inner comfort refers to the nurse feeling at ease within herself as a person thereby having confidence she was doing "the right thing" with using PS in the clinical setting. They expressed that their initial lack of experience with PS when they started on the the palliative care unit, their spiritual background, their past relationships, and past thinking about life and death all affected their thoughts about PS.

Cindy: ....and you don't get it the first day you start out on palliative, let me tell you. I had lots in my life that wasn't there when I started on palliative. I had lots of personal problems. But it took me I am sure 2 or 3 years before I could come to terms with myself - not my job- And now my personal life is okay....If you've got turmoil, you're probably gonna have some of it on the unit (Interview, p. 69).

Sandy: I had to support a person who did it [PS], but struggled with it and that was just recently. I had talked to her about it too... because she was struggling with it, but she did it because it was an order [Laugh]. It's funny how sometimes you do things. She went through with it because this is what the patient and family had agreed upon. And she did it, but she made a beeline out of that room in a hurry, there's no chit chat, I'm outta here because I'm not comfortable with the situation (Interview, p. 24, p. 27).

Reflective Practice. With reflexivity about the practice of PS, nurses gained self-

awareness. Reflective practice is the awareness and means of surfacing the experiential knowledge of the practitioner (Heath, 1998). It involves the nurse's ability to examine herself, her past experience, her personal comfort level with PS, and her confidence with other team members. This results in knowing when and what may be appropriate. Also, continuous reflection by questioning the situations in which PS is used and examining her confidence in her ability to communicate with patients and families is significant as each case in which PS is used is unique.

> Bev: Just to reiterate I think it is as much an art as much as it is a science, and understanding how and being the litmus as to how you feel. Do you feel comfortable as a nurse or as a doctor? You know, offering it in this case, and if you do well then maybe that there is something, something wrong.
> And so that's the way we approach it (Interview, p. 19).

Some nurses openly discussed their inner "struggles" when patients were sedated for the relief of psychological distress. Nurses indicated that they would have an internal dialogue with themselves as they talked their way through this process. They tended to delay the use of PS in an attempt to try other alternatives; assuming that it may not be that bad or that their psychological distress will go away or try other interventions before resorting to PS.

> Cindy: It was hard because she really didn't have any other signs that she kinda had it. She talked with the family and I think the family tried to change her mind, if I'm not mistaken. I can't remember all of it. But she said no, And there were psychological problems but... I can't remember. That's hard.

> Susan: I've struggled a lot with this terminal sedation... a very big struggle. It's sad because you're changing somebody's life. And that's what you're doing. You're bringing death closer to that person. And I don't know somebody must be in an awful lot of pain to want that. I bring a lot from my own personal experience....

> So I always think, like I would never want, never want that decision to be made for me. But you see I'm at that time right now in my life. So when that patient makes that decision, I respect it completely, because of where they're at. But to give that first medication, I think you've gotta be in a lot of pain...Sad decision... Like you just think somebody makes that decision to die. And I don't know how anybody can be there. I don't know. So when you give that first medication it's like, it's actually a relief when they wake up a little bit. It really is. And you know that just goes against everything we're trying to do (Interview, p. 15-16).

Anne: I can't be indifferent to emotional needs versus physiological needs in regards to terminal sedation. But I just kinda wonder, have we discussed it enough? .... where are we going here? We always want to give that person and that family, those family members as much growth and opportunity to live to the end of their death (Interview, p. 17-18).

Limitations of prescriptive criteria. Some nurses referred to using their own criteria to determine when to use PS. Their own criteria seemed to be based on passed experience with palliative care patients, knowledge and intuition. However when asked during follow-up interviews whether written protocols for PS existed on the unit, all of the nurses indicated there were no written guidelines on the unit. Others felt a list of prescriptive criteria for PS, or a clinical practice guideline, would be too limiting and expressed concern about the cases that do not fall within the criteria. There maybe cases in which patients would not meet these established criteria for PS and nurses expressed concern that in these unique circumstances those cases could be re-examined.

Sandy: I had to struggle with that one, only one out of maybe the dozen that I've actually had to do, the terminal sedation, that I was not comfortable with. Because to me the patient never met the criteria for terminal sedation.
Only once where I have had a really hard time with a terminal sedation and I have withheld during the night because the resps were so low. Cause we do have criteria, right? (Interview, p. 3, 12).

> Bev: This is one of those areas where our work is more of an art than a science. And to, and to think that we could come down with a, like a list, a criteria for example and then if you meet this then you are definitely, um , the right candidate for this. Or it definitely is appropriate in this situation. It's so difficult in reality. And yet I think the strongest thing you go by is the sense that this seems appropriate, at this time, in this place (Interview, p. 3).

Summary

This chapter described the nurses' personal meanings and experiences when caring for patients that have received PS on a designated adult palliative care unit. The major or core theme of the study, "Working Your Way Through the Quagmire" and the three sub-themes that emerged from the interview transcripts were identified and discussed in detail with excerpts from the data. The interpretation of the data was supported by utilizing the conceptual framework of symbolic interactionism.

The first sub-theme, *Definitional Quagmire*, examined the ways in which nurses define PS in their clinical setting, as well as how their interpretation became blurred with the use of sedating crisis medications and the medications for the use of PS.

The second sub-theme, *Indications for Use Quagmire,* included information about the tensions between using PS for physical versus existential distress, and factors that increased nurses comfort in using PS. The emphasis placed on each situation being unique illustrates why PS is implemented on a case by case basis. Furthermore, readiness and collaboration among patients, families and the health care team was necessary for PS to be a successful intervention.

The third sub-theme, *Ethical Quagmire,* takes into consideration the ethical concerns PS raises for nurses, such as descriptions of situations regarding PS being a

death hastening versus comfort promoting intervention and dilemmas where the family may want sedation used and the nurse feels it is excessive. Issues related to the nurse that affect his/her own experience and perception of PS, including reflective practice and the use of prescriptive criteria were explored. As nurses work through the quagmire of PS they came to a place of comfort within certain situations; however in situations involving PS for refractory existential distress uncertainty remained.

CHAPTER SIX: DISCUSSION OF THE FINDINGS

Introduction

The findings of this qualitative study examining nurses' experience with PS will provide a valuable contribution to the research literature. The discussion is organized around the major theme of the study, *Working your way through the quagmire.* This major theme, interacts with the three sub-themes of Definitional Quagmire, Indications for Use Quagmire and Ethical Quagmire. This chapter presents a discussion of the research findings in relation to the current literature and the conceptual framework: symbolic interactionism. Methodological strengths and limitations are explored along with recommendations for nursing practice, education and research. Lastly, reflection and insights gained from the study from the researcher will be included.

Relationship of the Findings Compared to the Literature

The findings that emerged from the data of this study will be compared to current literature regarding PS. The schematic model (Figure 1, p. 49) will be used to discuss the relationship between the major theme, sub-themes and categories with the literature.

Working Your Way Through the Quagmire

The nurses in this study described the complexity of working their way through the quagmire of palliative sedation. This image of the quagmire can be depicted as a little child having her rubber boot "stuck" in a mud puddle and unable to rescue it. The Webster's dictionary defines quagmire as shaky or muddy ground or a piece of firm ground transformed by rain or flooding into a sea of mud (Cayne, 1988). Often nurses had to work their way through the quagmire of a definition for PS where they at times,

became "stuck". Retrospectively, insight was gained that once they could articulate their own definition of PS, they could recall reasons for using PS and reflect on their feelings surrounding this intervention.

Definitional Quagmire

A significant factor that contributed to the quagmire of the nurse's experience of using PS was the lack of precise meaning and definition of TS or PS in their practice. Although PS for terminally ill patients may have been practiced for some time, definitional challenges of TS or PS continue to exist in the literature (Beel, McClement & Harlos, 2002; Morita, Tsuneto & Shima, 2002). This lack of conceptual clarity was described in Chapter Two and continues to be discussed in the current literature. A similar finding was confirmed in this study as each of the nurses had their own definition of PS based on their own perceptions and life experiences (see Table 5.3, Chapter 5, p. 10-11). The various definitions the nurses provided in the context of this study acknowledges the lack of consensus and clarity regarding a conceptual definition of the term PS. I would expect differences with nurses working outside of the unit, but even within a unit specializing in palliative care, staff nurses had a difference in definition. Nurses had different experiences on the unit with various patients and their perception may also differ depending on their life experiences and background; this may have influenced the context in which each nurse defined PS.

Nurses in this study have heard of the term "terminal sedation", however many did not know what it was or the reasons for use. For many, including the researcher, this term holds uncomfortable and negative connotations. The term TS has been

misinterpreted as the intent to terminate life rather than provide alleviation of refractory symptoms and suffering (Broeckaert & Nunez Olarte, 2002; Morita, Tsuneto & Shima, 2002). Broeckaert and Nunez Olarte (2002) indicate that sedation, if viewed from this perspective, increases the confusion between the use of sedation and euthanasia. This was expressed by the nurses interviewed. Broeckaert and Nunez Olarte (2002) suggest the term "palliative sedation" and Morita et al. (2002) propose the term "palliative sedation therapy" rather than terminal sedation. Broeckaert and Nunez Olarte (2002) define palliative sedation as "the intentional administration of sedative drugs in dosages and combinations required to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms" (p. 170). As discussed by Broeckaert et al. (2002) and Morita et al. (2002), this definition includes sub-categories of sedation, such as continuous or intermittent, reversible or not, mild or deep. This term has a more positive connotation and suggests an active effort to relieve symptoms and suffering (Broeckaert & Nunez Olarte, 2002). No nursing studies that have specifically defined this term could be found.

An interesting finding in this study was the confusion surrounding the distinction between crisis medications and PS. Some of the nurses indicated that the use of crisis medications could lead to PS, while others thought that the use of crisis medications was a separate and distinct occurrence from PS. The researcher could not find an accurate definition for crisis medications and its relationship to the use of PS in the literature to guide nurses in regards to the differences between crisis medications and PS. Contact was

also made with the palliative medicine list serve and no definitions were provided by any of the subscribers.

Indications for Use Quagmire

The most frequent reasons cited in the literature for implementing PS are refractory delirium, dyspnea and pain (Ventafridda et al, 1990; Cherny & Portenoy, 1994; Chater et al, 1998). The nurses interviewed for this study indicated they felt comfortable using PS for these purposes. However, the issue of using PS for refractory psychological issues and suffering was less clear. Similar to the expressions by the nurses in the study, Cherny (1998) and Morita et al. (2000) also report that determining the refractory nature of psychological distress is complex as the desire for death may be variable. The literature review by Morita et al (2002) indicates that it is difficult to determine when target symptoms are severe enough for PS. These authors report that suffering and distress are subjective and only patients can determine when the symptom is intolerable.

The following quote by Cherny (1998) resembles the uncertainty the nurses encountered when determining if the use of PS for psychological purposes was appropriate: "it is neither desirable to subject patients with refractory psychological or existential suffering to protracted trials of therapies that provide inadequate relief, nor to sedate patients when viable alternatives remain unexplored" (p. 405). In addition to the difficult nature of assessing refractory existential distress, Morita et al (2002) also noted that "target symptoms should be classified according to standard diagnostic criteria...as terms such as mental anguish, terminal restlessness and confusion are often listed as an indication for sedation, but they are poorly conceptualized" (p. 451).

Nurses also reported several factors that influenced their personal comfort with the decision to use PS (See Figure 1). These factors included the need to create comfort; the effectiveness of the sedation; personal knowledge by the staff of the patient; the nurse's perception of their relationship with the physician; timing of the sedation; readiness issues; and collaborative decision making. Some of these factors from this study are comparable to the principles or guidelines for decision making surrounding the use of palliative sedation discussed by Quill and Byock (2000) and Wein (2000). The factors identified in this study that correspond to factors in the literature include: severe unrelievable symptoms, unable to relieve current suffering, proximity to death, informed consent from the patient or by proxy must be obtained, and involvement of staff and family participation in decision making. Fainsinger (2000) suggests PS should be discussed and evaluated during case conferences to avoid individual clinician bias regarding the decision to use PS and including a multidisciplinary assessment of the family to ensure their views are assessed and understood.

In this study the importance of involving family in discussions surrounding the use of PS became apparent. The literature emphasizes that cancer is experienced not only by the patient, but the entire family (Davies & Oberle, 1990; Kristjanson & Ashcroft, 1994). Cherny (2003) emphasizes that families suffer along with the patient and will "live on with the memories, pain and the potential guilt for not having been effective advocates for their loved one either because the patient died in unrelieved pain or remorseful that the patient may have been sedated when other options were not given a fair chance" (p. 9).

In this study, nurses emphasized that their comfort level with PS also depended on their personal knowledge of the patient. The essence of knowing the patient as a person is a central aspect of nursing practice. Whittemore (2000) emphasizes that "knowing the patient" is a complex, dynamic process whereby the nurse obtains an understanding of a specific patient as a unique individual, which guides the selection of optimal nursing interventions and influences clinical decision making. In a qualitative study examining how nurses wean patients from mechanical ventilation, Jenny and Logan (1992) identified that knowing the patient is both a cognitive and relational process dependent upon continued contact with patients over time. In this study, nurses indicated that the length of time the patient was on the unit and the rapport and trust they established with the patient influenced their clinical judgement and comfort level with using PS.

The nurses' perception of their relationship with the physician they were working with also impacted on their personal comfort level with the decision to use sedation. In this study, the nurse's level of trust and open communication with the physician they were working with is illustrated in comments such as "be doing this with somebody who's with you, who knows the plan" and "be doing this with somebody you trust". Although little work has been done in the area of using PS and nurse-physician relationships, there is literature that illustrates the complexity of the relationship between the medical and nursing professions (McIntyre, 2002). McIntrye (2002) emphasizes "where collaborative and collegial relationships exist, effective communication and trust are enhanced, leading to a reduction in interprofessional tension" (p. 27). On the other hand, team communication problems have been reported in other studies as a major

source of stress (Deery, 1997; Vachon, 1987). Although nurses in the current study did not outwardly verbalize frustration with the physician they were working with regarding PS, they did express feelings of uneasiness such as, "it's just that it can be tricky.... But yet Dr. [personal name] is a good physician... I guess that decision, I guess I kinda have to respect what, what Dr. [personal name] did".

In relation to interprofessional relationships, two other basic principles in palliative care that relate to the findings in this study are interdisciplinary teamwork (IDT) and collaboration. (Canadian Hospice and Palliative Care Association, 2002). Interdisciplinary teamwork refers to a team of caregivers who work together to implement a plan of care (Canadian Hospice and Palliative Care Association, 2002). Collaboration is a component of IDT and has been described as "true partnership, in which the power on both sides is valued by both, with recognition and acceptance of separate and combined spheres of activity and responsibility, mutual safeguarding of the legitimate interests of each party, and commonality of goals that is recognized by both parties" (American Nurses Association in Patronis Jones, 1994). Ideally, the relationship between individuals involved in collaboration is non-hierarchical, power is shared and is based on knowledge and expertise (Henneman, Lee & Cohen, 1995). Collaboration involves individuals viewing themselves as a member of a team that contributes to a common goal thereby ensuring continuity of care (Egan & Labyak, 2001; Henneman, Lee & Cohen, 1995). A concept related to collaboration is conflict resolution in which there is high assertiveness and cooperation, or at the other extreme, high avoidance and uncooperativeness. In this study, collaboration included both nurses working with each other and working with the

patient and family. Nurses sometimes experienced a lack of teamwork and collaboration that occurred with nursing colleagues and with family members once a decision was reached to implement PS. Some expressed conflict with their nursing colleagues because divergent views about PS, and a lack of consistency between shifts with sedating medications being withheld for a variety of reasons. Although rare, some conflict did occur in this study with nurses and family members surrounding the use of PS.

Some nurses also indicated that their comfort with the decision to use PS was enhanced if the patient could participate in the decision making process and inform the nurse he/she was ready. This aspect aligns with findings regarding readiness to provide informed consent. Hence, as noted by Morita et al (2002), when the patient can "express the degree of symptom severity, they themselves should determine if the symptom is severe enough for palliative sedation therapy" (p. 449). The aspect of patient consent was also noted in a recent retrospective seven year chart analysis by Muller-Busch and colleagues (2003) which found that sedation increased from 7% in 1995 to 19% in 2002. The authors cite the reason for this increase was that sedation was used more often in situations with psychological distress and also the patients' own request for sedation indicates an increased awareness of the availability of this intervention.

One of the interesting findings of this study was the sub-category of "the effectiveness of sedation", which influenced the nurses' comfort level with PS. Some nurses reported a failure of sedation when intractable symptoms did not respond to high doses of medications. A failure of sedation has also been acknowledged in other reports and the underlying reasons for this occurrence is multi-factorial (Cheng, Roemer-Becuwe

and Pereira, 2002; Krakauer, 2000; Mercandante, DeConno, Ripamoniti, 1995; Moyle, 1995). There is a lack of literature and investigations on the impact of failed PS on the caregiver.

Ethical Quagmire

The "ethical quagmire" relates to the numerous ethical issues that arise in this area. In the findings, nurses experienced ethical dilemmas, ethical distress and uncertainty related to the use of PS. Each will be briefly discussed.

There is a growing recognition in that the complexity of ethical dilemmas nurses are involved with is increasing (Redman, 1997; Raines, 2000; Scanlon, 1998). An ethical dilemma involves "situations arising when equally compelling ethical reasons both for and against a particular course of action are recognized and a decision must be made" (Canadian Nurses Association (CNA), Code of Ethics, 2002, p. 5). There is much discussion and debate in the literature regarding the use of palliative sedation for refractory symptoms that are emotional, psychological or existential in nature as opposed to physical in nature (Billings & Block, 1996; Broeckaert & Nunez Olarte, 2002; Morita et al, 2000; Mount, 1996; Muller-Busch, Andres & Jehser, 2003; Quill et at, 1997; Quill & Byock, 2000). The literature suggests dissenting points of view regarding the appropriateness of PS for existential purposes, but the authors are certain about their respective positions. Thus, there is no dilemma. However, these conflicting points of view may lead to uncertainty for health care practitioners. For example, Cherny (2003) illustrates certainty in the use of PS by stating, "there is no distinct ethical problem in the use of sedation to relieve otherwise intolerable suffering for patients who are dying.

Rather, the decision making and application of this therapeutic option represents a continuum of good clinical practice" (p. 13). While Fainsinger (2000) emphasizes that PS used in the "management of refractory psychological or existential problems is more difficult to justify, as it may be harder to establish that these conditions are truly refractory" (p. 270).

Nurses in this study also experienced moral distress when PS was used for refractory existential distress. Raines (2000) defines moral distress as "the phenomenon of knowing or deciding what is right to do, but not being able to act on or to implement that decision in a particular situation" (p. 30). Raines (2000) noted that moral distress produces negative feelings and psychological discomfort and if not resolved, can lead to anger, frustration and guilt. It was very difficult to ascertain from the nurses why they felt the way they did with regards to hastening the death of a patient. Some nurses felt that PS could be seen as a death hastening measure and an alternative for terminally ill patients requesting euthanasia or physician assisted suicide, while others thought PS was being used for symptom control.

A number of researchers who object to using PS argue that the provision of such sedation is a death hastening measure because the sedation used to relieve extreme refractory symptoms results in death due to dehydration, starvation and other complications (Quill et al, 1997; Quill and Byock, 2000; Quill et al, 2000). The role of sedation in shortened survival is currently being disputed in the literature. Morita et al. (2000) and Sykes and Thorns (2003) found no significant differences in survival rates between patients receiving PS and those that did not. According to the European

Association for Palliative Care (EAPC) Ethics Task Force, palliative sedation in those imminently dying must be distinguished from euthanasia (Materstvedt, Clark, Ellershaw, Forde, Gravgaard, Muller-Busch, Porta Sales & Rapin, 2003). This has been summarized in the table 6.1.

Table 6.1 Distinguishing PS from Euthanasia

Palliative Sedation	Euthanasia
▪ *Intent* is to relieve intolerable suffering.	▪ *Intent* is to kill.
▪ The *procedure* is to use a sedating drug.	▪ The *procedure* is to administer a lethal drug.
▪ The successful *outcome* is the alleviation of distress.	▪ The successful *outcome* is immediate death.

In this study nurses' expressed a moral uncertainty surrounding the decision to use PS for existential distress. Moral or ethical uncertainty arises "when one is unsure what ethical principles or values to apply or even what the ethical problem is" (Jameton in CAN, Code of Ethics, 2002, p. 19). One nurse expressed PS should be a difficult decision requiring much thought when she stated, "we have to be careful not to make it an easy decision, cause then we've lost what we're trying to do, and we've gone down the wrong path (Susan, Interview, p. 26). Box 6.2 illustrates the nurses' uncertainty surrounding the use of PS, and nurses questioning, "Am I doing the right thing in this situation?"

Box 6.2 Niggling / Nagging Questions Surrounding Nurses' Uncertainty

- Is this the right thing to do?
- If what I have done provides someone with comfort, and as a secondary result, without intent I've shortened their life, have I done something morally wrong?
- Are we killing?
- Are we doing good?
- Am I harming the patient in this process?
- Who is benefiting?
- Line between sedating versus comfort?
- Case by case basis
- Even after death, we still don't know if we did the right thing

Part of the uncertainty for the nurse is related to the conflict between doing good versus causing harm and the question of who is the patient. According to the literature regarding ethical issues in palliative care, the three ethical principles of beneficence, nonmaleficence, and autonomy have particular relevance when decisions regarding clinical issues have to be made (Fainsinger, 2000; Scanlon, 1998; Webb, 2000). The principle of beneficence, is defined as a "duty to prevent or remove harm or a duty to promote good" (Prouse, 2000, p. 109). With regards to PS, the nurses' intent is directed towards the alleviation of pain and suffering rather than causing or hastening the death of a patient. Alternatively, the principle of nonmaleficence is a "duty not to do harm which forms a core of morality exhorting us not to cause further pain and suffering, not to kill" (Prouse, 2000, p. 109). However, what constitutes good versus harm regarding PS can be a difficult decision when a patient is close to death. In addition, the family is often seen as the unit of care and appeasing the family by administering PS when it is not warranted may harm the patient in the process. In these situations the nurse may question, who is

benefiting and is anyone being harmed?

Autonomy is "an individual's right to make choices about one's own course of action" (AARN in CAN, Code of Ethics, 2002, p. 19). In this study, patient consent increased nurses' comfort with implementing PS and enhanced patients' autonomy about the choices surrounding their care. On the other hand, although the health care team must respect the patient's and family's wishes regarding PS, doing so must not violate moral obligations and cause harm to others. For example, the use of PS as a form of assisted suicide even at the patient's request, would be viewed as morally wrong and illegal by many individuals.

Utility of the Model for the Study

The conceptual framework of Symbolic Interactionism (SI) was used in this study to explore staff nurses' experiences regarding patients that they had cared for that had received palliative sedation. As indicated by Charon (1998), SI "focuses on the nature of social interaction.... (p. 27) and "tries to understand human behavior" (p.12). Individuals are constantly changing during interaction and are influenced by one another as they interact back and forth with each other (Charon, 1998). Out of the interpretation of this interaction each person arrives at a perspective that informs us about what is really happening (Charon, 1998).

The three basic tenets of SI developed by Blumer (1969) guided the interpretation of the data. The following three assumptions are: (1) "human beings act toward things on the basis of the meanings that the things have for them" (p. 2); (2) "the meaning of such things... arises out of the social interaction that one has with one's fellows" (p. 2); and (3)

"meanings are handled in, and modified through an interpretive process" (p. 2). The findings of this study and the relation to the conceptual framework and the three basic tenets will be discussed.

The first sub-theme, *Definitional Quagmire* overlays the three premises of SI. In order for the researcher to gain an understanding of the nurses' perceptions of palliative sedation, the meaning nurses constructed for palliative sedation had to be initially established. There seemed to be some hesitancy with the participants when asked to provide a definition during the interview. Several nurses pointed out that the term, terminal sedation (TS) itself caused anxiety, angst and "just sounds too deadly" and they thought of TS as a "euthanasia kinda thing" until, they became "more familiar with it through hands on experience". They could "live with" the term, palliative sedation (PS) as the word "terminal" implies using a "death hastening" measure. This hesitancy could also be related to a lack of a formal definition within the palliative care community along with inconsistency in the literature regarding a formal definition of terminal or palliative sedation.

Secondly, given that the meaning of PS also arises out of the interaction with one's self and other members of the health care team, the patients and their families, this interaction also contributed to the development of the nurses' understanding and perception of PS. In this study, the nurse's own personal meaning of PS appeared to be influenced by their own personal background, previous experience with PS and interaction with patient, family and other health professionals. Thirdly, meanings are modified through an interpretive process and hence, learning, interacting with others and

reflecting about PS assists nurses to work their way through their thoughts and feelings about of PS.

In the second sub-theme, *Indications for Use Quagmire,* nurses indicated that each situation involving PS is unique and must be examined on an individual basis. Although certain factors influenced the nurses personal comfort with the decision to use PS, nurses expressed that their opinion of using PS sedation can change from minute to minute or day to day. This was particularly evident regarding the lack of clarity surrounding the use of PS for existential distress. Most nurses felt that "there's just a lot of different dynamics that goes along with the terminal sedation... the staff, different families..." and sometimes "assessing when they need that PS is not always so easy". According to Charon (1998), "people are constantly undergoing change in this interaction... interaction means that the acts of each individual are built up over time depending what others do in the situation in relation to them (p. 27). Therefore, this sub-theme is related to SI because "once in a situation, the individual can change their perspective or find that the initial perspective is being transformed as he or she interacts with others" (Charon, 1998, p. 11). Hence, the nurse's perspective regarding PS may change from situation to situation depending on how each nurse interprets, defines and acts to what is happening in that particular situation.

In the third sub-theme, *Ethical Quagmire,* nurses gained further insight and understanding into their own experience with PS through an interpretive process of self-interaction. Nurses appreciated the time to verbalize their thoughts about examples in which PS was discussed and implemented or not implemented, situations in which

"backing off" with PS and the fine line between PS being a death hastening versus comfort promoting intervention. As stated by Blumer (1969) "the actor selects, checks, suspends, regroups and transforms the meanings in the light of the situation in which he is placed and the direction of his action" (p. 5). Therefore, the nurse's ability to examine her own experience of PS, reflect on the indications for sedation and the ethical issues encountered was necessary so she could work her way through the quagmire of palliative sedation. The nurses' comfort with PS still fluctuated and varied with each patient. At times nurses felt confident that they made the right decision while at other times they still felt uncertain.

Methodological Observations

This section addresses both the strengths and methodological limitations surrounding this study. One strength of this qualitative study is the descriptive data generated by the interview process. Nurses were willing to share their personal experience regarding PS and provided the researcher with rich and complex examples for discussion. However, a limitation to consider is interview bias. Interview bias can occur when the "interviewer unwittingly leads the respondent to answer in a certain way" (Grey, 1998, p. 319). However, the use of a structured interview tool and follow-up interviews to clarify parts of the initial interview and using the nurses' own words when coding the data and generating major themes addresses the extent to which the findings of this study are reflective of the nurses' experiences regarding PS and not that of the researcher. Another possibility is the nurses only recalling and sharing information that they were willing to share. Although the nurse's recall was recent, their emotions may affect how they

interpret the event. This criticism however, could be levied against any type of research, including quantitative approaches wherein people may answer in a particular way that might be socially acceptable.

Measures to enhance the methodological rigor as described by Lincoln and Guba (1985), Sandelowski (1993) and Streubert and Carpenter (1999), were applied in this study. Credibility was enhanced through informal member checks as the data were collected during the interview process and clarified with follow-up interviews. To facilitate dependability, the thesis committee oversaw the coding of the data and the themes and categories that emerged. Confirmability was enhanced through follow-up interviews and using the nurses' own words when coding the data.

Another strength of this study is that there was no difficulty in recruiting participants for this study. Considering the sensitive nature of the topic, the researcher initially thought it would be difficult to recruit nurses. Although a sample of ten nurses was easily recruited from an in-patient palliative unit, another limitation that must be considered is that of potential selection bias. A selection bias may exist because those nurses who find the topic of PS emotionally charged may have decided not to participate in this study. Also, the issue of gender and its influence on responses may impact the results of the study. Although there was an overrepresentation of female participants in this study, nursing is a predominantly female profession and a majority of nurses on the palliative care unit were female. Other perspectives would be gained had more males been recruited.

One issue identified was the difficulty in conducting the follow-up interviews

within a two-week time frame. A variety of reasons were identified for the difficulties the researcher experienced. One reason is the interviews could not be transcribed quickly and returned promptly to the researcher for data analysis. When arranging the follow-up interviews it took a significant amount of discussion to find a time that was suitable for both the researcher and the participant, considering that most nurses work varying shifts and have family obligations. Due to the time lag between the first and second interview, the researcher often had to restate quotes asked in the initial interview to refresh the nurse's memory as to what had transpired.

Another limitation of this study is a lack of triangulation of the research sites to facilitate diverse data collection. Data triangulation refers to the use of "multiple data sources in a study and interviewing multiple key informants about the same topic" (Polit & Hungler, 1995, p. 362). This study was conducted on one designated palliative care unit, and it is unknown whether the application of the data to other palliative care units could be supported. However, triangulation did occur with this thesis committee due to their various clinical backgrounds and orientations and diverse expertise.

Recommendations

The findings of this study have implications for nursing education, practice and research. The recommendations for each section will be discussed.

Nursing Education

The results of this study have implications for nursing education, including both nursing educators and nursing students. Palliative care nursing courses and courses on ethical issues should include a component on the use of palliative sedation at the end of

life. This should also include teaching about ethical decision making and ways of managing ethical issues that arise. This is significant because in this study nurses did not know what PS was even though they were involved with it on the unit. Nursing students and educators need to be aware that the words "terminal and palliative sedation" are used in the clinical setting and several factors occur before this intervention is implemented. Nursing education surrounding the use of PS being implemented on a case by case basis, emphasizing the importance of the multidisciplinary team discussion and the ethical issues surrounding this topic can assist nurses and nursing students to be aware of the array of factors that influence the decision to use PS in the clinical setting and assist them to become comfortable and follow through with this intervention, if indicated. Nursing students and graduates must also be aware that the family and patient are considered equal partners in this decision and incorporate them in the assessment and plan.

Nursing Practice

Nurses must recognize that they must work together as a multidisciplinary team and include the patient and family in decision making. Nurses must recognize the importance of a holistic family assessment and other informal caregivers supporting the patient during this difficult time. Nurses must be aware of the resources available within their facility and community and readily consult palliative care services to assist them as needed. There is a need for improved discussions surrounding the use of PS with other disciplines, such as pastoral care and clinical ethics. Strategies such a multidisciplinary ethics committees and ethics rounds allow for the opportunity to openly address ethical issues involving the use of PS in palliative care. Through discussions with other

disciplines, various viewpoints about life and death and the use of PS can be shared. The role of expert nurses mentoring novice staff and students on the unit as they encounter issues surrounding the use of PS in the clinical setting needs to be expanded. In order to minimize the uncertainty surrounding the use of PS for existential distress nurses must engage in discussions with each other regarding questions such as "why are we doing this?" and "who is benefiting?"

Assisting palliative care nurses to use reflexivity in their practice will enable them to uncover the knowledge that has guided decision making in patient situations and understand the nursing interventions that were implemented regarding PS (Howell,1999; Howell & Pelton, 2001). Reflective practice can be described as a "process of creating and clarifying meaning of experience in terms of self in relation to both self and the world." (Boyd & Fales, 1983, p. 101). Howell and Pelton (2001) note that the reflective process "stimulates nurse's personal growth and development, deepens their individual practices, enhances relationships with patients and improves problem solving" (p. 182). Reflective practice incorporates five steps, self-assessment, peer review, and the creation, implementation and evaluation of a learning plan (Witmer, 1997). The cancer nurses' framework for reflective practice described by Howell and Pelton (2001) is instructive here (See Appendix J). This framework assists nurses to explore ways of knowing in relation to aesthetic, personal, ethical, empirical, socio-political and unknowing dimensions of knowledge (Howell & Pelton, 2001). Promoting a reflective practice environment in monthly team meetings with an experienced facilitator will not only enhance relationship with colleagues and patients, but will identify new ways of

practising and positively influence their experience with PS.

Nursing Research

There has been limited nursing research published regarding the use of PS in the clinical setting. Much of the literature is based in the positivist paradigm (also known as the experimental or empiricist approach) or is anecdotal. Recommendations for research include expanding on this research to include other palliative care units in which the philosophy of care and the use of PS may differ. In addition, research examining whether there are differences in ethical concerns regarding the use of PS depending upon the location of the patient (i.e. medical and surgical units, long term care) is also needed. Also, expanding this research into the community home setting and community hospital to determine if the nurses' perception and experience regarding the use of PS differs, is warranted. A research topic that needs to be studied is the family members' perspectives and experience in which this intervention was used. Presently, the family members' interpretation in situations in which PS was utilized and how this compares with the health care team's experience is unknown. Further, there is a pressing need to resolve the current conceptual confusion regarding the inconsistencies and inadequate descriptions in the definitions of PS that currently exist. This can be accomplished through consensus building through focus groups with other disciplines in a variety of settings.

Personal Reflection

My interest in this topic has occurred over several years. As a novice practitioner on an in-patient palliative care unit to an advanced palliative clinical nurse specialist, I remained curious about the use of PS in the clinical setting and why some nurses have

difficulty with this intervention and the stigma surrounding its use. Throughout this research project, I reflected on my own thoughts and feelings through my fieldnotes.

Looking back on this research experience, two images became apparent. One of the novice researcher conducting an intense study without having any previous research experience and the other of competent palliative care clinical nurse specialist in which I had to use this intervention in the clinical setting to relieve distress for patients who were suffering. As the novice researcher, I questioned my own abilities, am I asking the questions in a way that I will get "the right answers"? Am I really capturing the perceptions and experience of the nurses? What will my thesis committee think? I remember being so emotionally exhausted after feeling privileged to interview these nurses and wondering, is this normal? Is it okay to cry and feel helpless with some of the stories that unfolded? If nurses express emotion, including myself, will they still be seen as competent professionals or does expressing emotion go beyond the boundaries of a therapeutic relationship? This certainly involved much more hard work than I anticipated. It involved my own self-reflection as a person and not just the researcher or clinical nurse specialist. I started to re-think my past personal experiences with suffering and death and although I had already grieved and processed all of this in a healthy way, it came back to the surface. I had to take some time just to be still, which was the most difficult aspect of this entire process. To illustrate how difficult this was, a friend and physician colleague gave me a pendant in the shape of a turtle to remind me to slow down whenever I wear it. I have learned to appreciate and understand me for who I am with both my strengths and weakness and how I relate with others and my interactions with them affects them not

only as a patient but as an entire person.

Summary

In this chapter the findings of this study were discussed in regards to the nurses' overall experience regarding palliative sedation. The findings were described in relation to a model that was developed by the researcher and the current literature. The conceptual framework of symbolic interactionism guided the researcher through the interview process and analysis of the study. The methodological observations and the recommendations for nursing education, practice and research were highlighted. In summary, this study has contributed to the understanding of the nurse's experience of PS and will continue to challenge nurses and stimulate ongoing debate.

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Appendix A

Definitions

Author	Term Used	Definition
Billings, J.A., & Block, S.S. (1996)	Slow Euthanasia	"is the clinical practice of treating a terminally patient in a fashion that will assuredly lead to a comfortable death, but not too quickly" (p.21).
Chater, S., Viola, R., Paterson, J., & Jarvis, V. (1998)	Terminal Sedation	"the intention of deliberately inducing and maintaining deep sleep, but not deliberately causing death in very specific circumstances. These are: 1. for the relief of one or more intractable symptoms when all other possible interventions have failed and the patient is perceived to be close to death, or 2. for the relief of profound anguish (possibly spiritual) that is not amenable to spiritual, psychological, or other interventions, and the patient is perceived to be close to death" (p. 257-258).

Author	Term Used	Definition
Cherney, N.I., & Portenoy, R.K. (1994)	Refractory Symptoms	"when a symptom cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness" (p.31).
Fainsinger, R.L. (1998)	Terminal Sedation	"the prescription of psychotropic agents to control physical and psychological symptoms by making the patient unconscious" (p.52).
Fainsinger, R.L., Landman, W., Hoskings, M., & Bruera, E. (1998)	Terminal Sedation	Uses Paterson and Chater (1998) definition "the intention of deliberately inducing and maintaining deep sleep but not deliberately causing death in specific intractable circumstances" (p.145) and Fondras (1996) definition "the prescription of psychotic agents to control physical and psychological symptoms by making the patient unconscious" (p.145-146).
Fainsinger, R., Miller, M.J., & Bruera, E., Hanson, J., Maccechern, T. (1991)	Sedation	No definition provided by the authors.
Fleischman, A.R. (1998)	Terminal Sedation	"Sedation at the end of life to alleviate severe and unremitting pain" (p.260).

Author	Term Used	Definition
Fondras, J. (1996)	"Sedation derived from the Latin sedare, to calm" (p. 17)	"Sedation may be defined as the prescription of psychotropic agents, in the main benzodiazepines and neuroleptics, with a view to controlling physical symptoms (insomnia, anxiety crises, agitation) or to make a patient unconscious in certain dramatic situations (eg. sudden hemorrhage)" (p.17).
Green, W.R., & Davis, W.H. (1991)	None	"Symptoms of desperation shortly before death" (p.335).
Hallenbeck, J. (1999)	Terminal Sedation	"the induction and maintenance of a sedated state with the intent of relieving otherwise intractable distress, both physical and mental, in a patient close to death" (p.222).
Kraukauer, E.L., Penson, R.T., Truog, R.D., King, L.A., Chabner, B.A., Lynch, T.J. (2000)	SIDD Pat - Sedation for Intractable Distress of a Dying Patient.	"use of sedating medications to relieve severe symptoms that cannot be controlled adequately despite aggressive efforts without sedation" (p. 60).
Morita, T., Inoue, S., & Chihara, S. (1996)	Sedation	"a medical procedures to palliate patient's symptoms by intentionally making their consciousness unclear. It includes an increase in morphine doses resulting in secondary somnolence, and the use of sedative drugs" (p.32).

Author	Term Used	Definition
Morita, T., Tsunoda, J., Inoue, S., and Chihara, S. (1999)	Sedation	" a medical procedure to palliate patients' symptoms refractory to standard treatment by intentionally diminishing their consciousness" (p.20). Levels of sedation defined as primary, secondary, intermittent, and continuous. Mild and deep sedation also defined.
Morita, T., Tsunoda, J., Inoue, S., and Chihara, S. (2000)	Sedation	" a medical procedure to palliate patients' symptoms by refractory to standard treatment by intentionally dimming their consciousness" (p.191). Levels of sedation defined as primary, secondary, intermittent, and continuous. Mild and deep sedation also defined.
Peruselli, C., Di Giulio, P., Toscani, F., Gallucci, M., Brunelli, C., Costantini, M., Tamburini, M., Paci, E., Miccinesi, G., Addington-Hall, J.M., & Higginson, I.J. (1999)	Total Pharmacological Sedation	"the administration of drugs to obtain total loss of consciousness" (p.235).
Quill, T.E., Lo, B., & Brock, D.W. (1997)	Terminal Sedation	"suffering patient is sedated to unconsciousness, usually through ongoing administration of barbiturates or benzodiazepines" (p.210).

Author	Term Used	Definition
Quill, T.E., Byock, I. (2000)	Terminal Sedation	"use of high doses of sedatives to relive extremes of physical distress" (p.409). "when applied to patients to who no substantial prospect of recovery, terminal sedation refers to a last-resort clinical response to extreme, unrelieved physical suffering" (p.409).
Quill, T.E., Lee, B.C., & Nunn, S. (2000)	Terminal Sedation	"heavy sedation to escape pain, shortness of breath, other severe symptoms" (p.489). "The patient is sedated to unconsciousness to relieve severe physical suffering and is then allowed to die of dehydration or some other intervening complication: (p.491).
Stone., P., Phillips, C., Spruyt, O., & Waight, C. (1997)	Sedation	"the prescription of sedative drugs where reducing the level of consciousness was part of a treatment strategy with the aim of relieving distress" (p.141).
Ventafridda, V., Ripamonti, C., Deconno, F., Ramburini, M., & Caaseleth, B. (1990) (double check)	Sedation-induced sleep	No definition provided by authors, however, mention made of sedation-induced sleep for physically unendurable symptoms.

Author	Term Used	Definition
Wein, S. (2000)	Terminal Sedation/Sedation in the Imminently Dying Patient	Uses Chater et al (1998) definition of terminal sedation, however, emphasizes the term terminal sedation should be avoided because it could be interpreted as "meaning sedation intended for terminally ill patients or sedation for the purpose of terminating of terminating the patient's life". Wein suggests using the term "sedation in the imminently dying" (p.26).

Appendix B

Summary of Studies Utilizing Sedation for Intractable Distress in the Dying

AUTHOR(S) YEAR	STUDY DESIGN	SAMPLE SIZE	DEFINITION OF TERMINAL SEDATION PRESENT?	RESULTS	REASONS FOR SEDATING
Fainsinger, R.L., DeMoissac, D., Mancini, I., Oneschuk, D. (2000).	Epidemiological survey to assess the prevalence of difficult symptoms requiring sedation at the end of life.	N = 50 at each of a tertiary palliative care unit; consulting palliative care program; and hospice in-patient unit	No	80% of patients in all three settings developed delirium. Pharmacological management of delirium needed by 40% of pts in acute care setting, and 80% in tertiary setting. Sedation varied from 4% to 10%	Delirium, Dyspnea

AUTHOR(S) YEAR	STUDY DESIGN	SAMPLE SIZE	DEFINITION OF TERMINAL SEDATION PRESENT?	RESULTS	REASONS FOR SEDATING
Fainsinger, R.L., Landman, W., Hoskings, M., & Bruera, E. (1998)	Retrospective Patient Chart Review to describe the experience of sedating terminally ill patients for uncontrolled symptoms in a South African Hospice	N = 76	Yes	30% received sedation	Delirium, Dyspnea, Pain, Nausea
Fainsinger, R.L., Miller, M., Bruera, E., et al. (1991)	Retrospective Patient Chart Review to compare nit practices regarding the sedation of terminal cancer patients for physical suffering with those reported in the literature	N = 100	No	16% sedation to control symptoms	Pain Delirium

AUTHOR(S) YEAR	STUDY DESIGN	SAMPLE SIZE	DEFINITION OF TERMINAL SEDATION PRESENT?	RESULTS	REASONS FOR SEDATING
Fainsinger, R.L., Waller, A., et al. (2000)	Multicentre international survey to characterize and describe the use of deliberate pharmacological sedation for problematic symptoms at end of life.	N = 100 N = 100 N= 94 N = 93	No	>90% of pts required medical management for uncontrolled symptoms in the final week of life. Intent to sedate varied from 15% to 36%	Delirium, Dyspnea, Existential Distress, Family Distress, Pain, Nausea/Vomiting
Greene, W.R., & Davis, W.H. (1991)	Retrospective Review Study Reports	N = 17	No	All 17 patients received barbiturates for sedation	Pain, Prolonged Vomiting, Seizures; Restlessness
Lichter, I., & Hunt, E. (1990)	Prospective Study	N = 200	No	36% experienced troublesome physical symptoms in the last 48 hours of life	Pain, Dyspnea, Nosy and moist breathing, Restlessness and agitation, etc.
Morita, T., Inoue, S., & Chihara, S. (1996)	Retrospective Case Review	N = 143	No, however an operational definition for sedation was cited.	48.3% received sedation	Dyspnea, Pain, General malaise, Agitation, Nausea

AUTHOR(S) YEAR	STUDY DESIGN	SAMPLE SIZE	DEFINITION OF TERMINAL SEDATION PRESENT?	RESULTS	REASONS FOR SEDATING
Morita, T., Tsunoda, J., Inoue, S., Chihara, S. (1999)	Prospective Study to identify: I) the condition of patients prior to being sedated; ii) whether life support care is withdrawn after sedation begins; iii) cases where physicians increase doses of sedatives despite adequate symptom control; and iv) whether sedatives are prescribed in amounts that will hasten death.	N = 71 sedated patients	No, however operational definitions for sedation, primary sedation and secondary sedation are cited.	In this study patients were already sedated	Physical restlessness with or without Delirium, Dyspnea, Pain, Nausea, Multifocal, myoclonus, Psychological distress
Morita, T., Tsunoda, J., Inoue, S., Chihara, S. (2000)	Retrospective Cohort	N = 248	No, however sedation defined	52% received sedation	Dyspnea, Agitated delirium, Pain, Psychological distress

AUTHOR(S) YEAR	STUDY DESIGN	SAMPLE SIZE	DEFINITION OF TERMINAL SEDATION PRESENT?	RESULTS	REASONS FOR SEDATING
Morita, T., Tsunoda, J., Inoue, S., Chihara, S. (2001)	Prospective Study to examine the effects of opioids and sedatives prescribed in the final 48 hours	N = 209	No, however authors recognize definitions for "sedation" had not been established	60% received some sedative medication in the last two days of life. No significant difference between those who received sedatives and those who did not	Reduced oral intake, Edema, Dyspnea at rest Delirium
Peruselli, C., et al. (1999)	Prospective multicentre study to describe the place, circumstances, and quality of death of patients admitted to home palliative care.	N = 401	No, however an operational definition for total pharmacological sedation was cited.	25% sedated	Pain, Dyspnea, Nausea and Vomiting

AUTHOR(S) YEAR	STUDY DESIGN	SAMPLE SIZE	DEFINITION OF TERMINAL SEDATION PRESENT?	RESULTS	REASONS FOR SEDATING
Stone, P., Phillips, C., Spruyt, O., & Waight, C. (1997)	Retrospective Chart Review to determine the frequency, indications, and doses of sedative drugs used in a hospital support team and in a hospice setting.	N = 115	No, however an operational definition for sedation was cited.	43% given sedatives for symptom control (67% at the hospice and 21% at the hospital)	Agitated delirium, mental anguish, pain, dyspnea
Ventafridda, V., Ripamonti, C., DeConno, F., Ramburini, M., & Cassileth, B. (1990)	Prospective Study to examine how long before death physical symptoms controllable only by sedation appeared.	N = 120	No	52.5% required sedation for unendurable symptoms	Dyspnea, Delirium, Vomiting

Appendix C

Common Medications Used For Terminal Sedation in the Adult Population

Class of Drug	Drug	Routes Available	Comments
Benzodiazepines (Observe for paradoxical reactions)	Midazolam (Versed)	IV/SQ/IM	Rapid, short acting
	Lorazepam	IV/SQ/SL/PO	Tablets available for SL use
	Diazepam	IV/SQ/PO/PR/ IM	Can be irritating given SQ.IV
	Clonazepam	SQ	
	Flunitrazepam	SQ	
Neuroleptics (Observe for extrapyramidol effects)	Methotrime-prazine (Nozinan)	IV/SQ/IM/PO	Can be irritating given SQ
	Haloperidol	IV/SQ/IM	Decanoate form only for IM use
	Chlorpromazine	IV/SQ/PR/PO/ IM	
Barbiturate	Phenobarbital	IV/SQ/IM/PR	Long acting
	Pentobarbital	IV	Long acting
	Thiopental	IV	Used as a last resort, Infusion pump required
General Anesthetic	Propoful	IV	Rapid onset of action

**IV is intravenous; SQ is subcutaneous; IM intramuscular; PO is per oral; SL is sublingual; PR is per rectum

References: - Quill & Byock, 2000; Cherny & Portenoy, 1994; Enck, 2000

Appendix D

Letter of Approval from Riverview Health Centre Research Committee

RIVERVIEW
HEALTH CENTRE

October 10, 2002

Alexandra Beel
150 Barron Drive
Winnipeg, MB R3K 0G5

Dear Ms. Beel:

As we discussed on the phone yesterday, please be advised that at our meeting on October 9, 2002, the Riverview Health Centre Research Committee reviewed your proposal "Palliative Sedation Therapy: Nurses' Perceptions". The committee approved your request for access to the Centre. It is recommended that you make contact with Donna Goodridge, the Patient Care Manager on the Palliative Care Unit (478- 6137) at your convenience.

Please note that a condition of access to RHC is that you provide us with a summary of your findings when available. If you have any questions, please feel free to contact me at 478-6151. Best wishes for the successful completion of your study and program.

Sincerely,

Marie Edwards

Marie Edwards
Co-chair, Research Committee

1 Morley Avenue ♦ Winnipeg, Manitoba, Canada ♦ R3L 2P4
Telephone (204) 452-3411 ♦ Fax (204) 287-8718

Appendix E

Letter of Approval from Ethics Committee

UNIVERSITY OF MANITOBA | OFFICE OF RESEARCH SERVICES

ORS
244 Engineering Building
Winnipeg, Manitoba R3T 5V6
Telephone (204) 474-8418
Fax (204) 261-0325
www.umanitoba.ca/vpresearch/ors

APPROVAL CERTIFICATE

10 October 2002

TO: **Alexandra Beel**
Principal Investigator

FROM: **Lorna Guse, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2002:077**
"Palliative Sedation Therapy: Nurses' Perceptions"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Appendix F

Invitation to Participate
Palliative Sedation Therapy: Nurses' Perceptions

My name is Alexandra Beel, I am a registered nurse and graduate student in the Master of Nursing Program at the University of Manitoba in Winnipeg. As a nurse involved in the care of hospitalized palliative cancer patients, you are invited to take part in a study entitled: "Palliative Sedation Therapy: Nurses' Perceptions." The purpose of the study is to explore the experiences of staff nurses' that have cared for a patient that has received palliative sedation therapy. We know that some patients have received palliative sedation for intractable distress, however the experience of the nurse with palliative sedation therapy has not been studied. I would like to explore this with nurses. Some of the questions I will be asking you include palliative care nursing and how long you have worked in this area. You will also be asked questions about your experience with palliative sedation, discussing examples in which you have been involved with this intervention and your feelings about participating in palliative sedation.

Your participation in this study is entirely voluntary, and you may withdraw from the study at any time without any negative consequences. You may choose not to answer some of the questions if you feel uncomfortable or distressed by them. Your participation would involve two interviews. Both interviews will occur outside of working hours and at a location and time of your choosing and will be audio-taped. During the interviews you will be asked to answer a number of questions and complete a short sociodemographic questionnaire. The first interview will be approximately 1 - 1 ½ hours in length. The second interview will be a follow-up interview and will be conducted in two weeks after the first interview to clarify parts of the initial interview and invite critique or revisions. It will last approximately 30 minutes. The interview discussions will be transcribed and then analysed. Only the person doing the transcribing, myself and my thesis chair will see the individual interview information. Your identity will not appear in the transcribed data or in the audiotapes. Only the researcher will know the identity. The consent form will be kept separate from the data and data associated with this study will be held in locked storage for 7-10 years after which it will be destroyed. Your confidentiality will be maintained during the study. The information gathered will be grouped to avoid identification of individual participants. The results of this study will be summarized in a final report and may be published in a journal / article and/or presented at scientific conferences. The findings may also be used for teaching or educational purposes. In any instance, no names will be used, and your identity would not be revealed. At the end of the study, a summary of the findings will be sent to you, if you so desire.

If you are interested in participating in the study or want to know more about the study, please complete the form on the next page, detach it and leave it in the envelope marked "Palliative Sedation Study" that will be left in your conference room. I will be contacting you by phone within 1-2 weeks to make arrangements for your interview. If you have questions in regards to the study please contact myself, Alexandra Beel at 832-0295 or 931-2312 (pager) (email beelac@cc.umanitoba.ca) or my study advisor Dr. Pamela Hawranik, Faculty of Nursing, University of Manitoba at 474-6716.

Thank you very much for your consideration of this study.

Sincerely,

Alexandra Beel, R.N., B.N.

I am interested in participating in the study "Palliative Sedation Therapy: Nurses' Perceptions." conducted by Alexandra Beel, Master of Nursing program, graduate student

Name:_____

Address:_____

Phone Number:_____

The best time to reach me is:_____

Appendix G

Palliative Sedation Therapy: Nurses' Perceptions
Consent Form

My name is Alexandra Beel, I am a registered nurse and graduate student in the Master of Nursing Program at the University of Manitoba. You are being invited to participate in the study entitled "Palliative Sedation Therapy: Nurses' Perceptions". The purpose of the study is to explore the experiences of staff nurses' that have cared for a patient that has received palliative sedation therapy. We know that some palliative care patients have received palliative sedation for intractable distress, be it physical or psychological, however, the experience of the nurse with palliative sedation therapy has not been studied. I would like to explore this with nurses. Some of the questions I will be asking you include palliative care nursing and how long you have worked in this area. You will also be asked questions about your experience with palliative sedation, discussing examples in which you have been involved with this intervention and your feelings about participating in palliative sedation.

Your participation in this study is entirely voluntary, and you may withdraw from the study at any time without any negative consequences. You may choose not to answer some of the questions if you feel uncomfortable or distressed by them. Your participation would involve two interviews. Both interviews will occur outside of working hours and at a location and time of your choosing and will be audio-taped. During the interviews you will be asked to answer a number of questions and complete a short sociodemographic questionnaire. The first interview will be approximately 1 - 1 ½ hours in length. The second interview will be a follow-up interview and will be conducted in two weeks after the first interview to clarify parts of the initial interview and invite critique or revisions. It will last approximately 30 minutes. The interview discussion will be transcribed and then analysed. Only the person doing the transcribing, myself and my thesis chair will see the individual interview information. However, your identity will not appear in the transcribed data or in the audiotapes. Only the researcher will know the identity. The consent form will be kept separate from the data and data associated with this study will be held in locked storage for 7-10 years after which it will be destroyed.

Your confidentiality will be maintained during the study. The information gathered will be grouped to avoid identification of individual participants. The results of this study will be summarized in a final report and may be published in a journal / article and/or presented at scientific conferences. The findings may also be used for teaching or educational purposes. In any instance, no names will be used, and your identity would not be revealed. At the end of the study, a summary of the findings will be sent to you, if you so desire.

Although, there are no direct benefits to you for participating in the study, this research may provide valuable information that will help us understand the issues in caring for patients that have received palliative sedation and improve the future care of these patients and their families. There are no direct risks involved in participating in the study, although you may feel some distress or sadness discussing the issues surrounding palliative sedation. Should this occur, the researcher will ask if you would like to stop the interview. You may experience some inconvenience in having to be interviewed for one to one and half hours in answering some of the questions.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take time to read this carefully and to understand the accompanying information.

Your signature in this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

If you have any questions about the study, feel free to contact myself, Alexandra Beel at 832-0295 or 931-2312 (pager) or my thesis chair, Dr. Pamela Hawranik (Chair), Faculty of Nursing, University of Manitoba, 474-6716.

This research has been approved by the Education / Nursing Research Ethics Board (REB) of the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

_____

Participant's Signature Date

_____

Researcher and /or Delegate's Signature Date

Request for a Summary of the Study Results
Palliative Sedation Therapy: Nurses' Perceptions

Please indicate if you wish to receive a summary of the study results. If yes, please provide your name and full address. A copy will be mailed to you when the study is complete

YES: _____

NO: _____

Send to: _____

Address: _____

_____

Appendix H

Palliative Sedation Therapy: Nurses' Perceptions
Interview Guide

Greeting:

My name is Alexandra Beel, I am a registered nurse and graduate student in the Master of Nursing Program at the University of Manitoba. Thank you for agreeing to participate in this interview. You have a copy of the explanation of the study which I am conducting, but in addition I would like to take a few moments to review the process and to have you sign a consent form which indicates you are voluntarily participating in the study.

Introduction:

The purpose of the research study is to explore the experiences of staff nurses' that have cared for a patient that has received palliative sedation therapy on a designated palliative care unit.

First I would like to ask you some general demographic questions about you and your nursing experience. Thank you. Now I would like to ask you questions about how you feel about palliative sedation therapy based upon your personal experience. There are no right or wrong answers.

Do you have any questions at this time?

Interview Questions:

1. Have you heard of the term palliative sedation or terminal sedation?
   Probes: What do you think it means?
   When did you first hear of this term?
   What situations?

For the purposes of this study, terminal sedation or palliative sedation therapy will be referred to as "the relief of one or more intractable symptoms when all possible alternative interventions have failed, and the patient is perceived to be close to death, and for the relief of profound anguish (possibly spiritual) that is not amenable to spiritual, psychological or other intervention and the patient is perceived to be close to death" (Chater et al, 1998, p. 257-258).

2. Where / or how did you obtain information about sedation at the end of life?
   Probes: other staff, unit manager, physician, written information

3. When do you think palliative sedation therapy should be used?
    Probes: What interventions would you say would be appropriate to provide comfort at the end of life for intractable symptoms?
        What does it mean when it has been used?
        What are your goals for quality end of life care for palliative care patients?
        How can that be achieved?

4. Can you describe a situation in which palliative sedation was discussed and used or discussed and not used?
    Probes: What was different in these two situations?
        Who benefited? Patient, Family and/or staff?

5. How did you know that this patient was receiving palliative sedation?
    Probes: Who usually suggests when palliative sedation should be used?
        How do you usually respond when it is suggested?
        How is it began and how is it followed-up with?

6. How do you and the team arrive at the decision to use palliative sedation?
    Probes: Insistence of the family
        After all other alternatives have been tried?

7. What factors lead you to agree to participate in or not participate in the use of palliative sedation? (patient's symptoms, patient's behaviour, psychological distress, family distress)
    Probes: Do family members inform you and/or the team how they feel about palliative sedation?
        What sorts of things do you say to a patient and / or family member in which palliative sedation is being implemented?

8. What affects palliative sedation being effectively carried out for the patient?
    Probes: Do all shift team members agree?
        Does family have to agree?
        Does the stage of cancer, other illnesses, cognitive impairment and staffing affect this?

Conclusion:

9. Is there anything important that I have missed in respect to your experience in regards to palliative sedation therapy that you would like to mention?

Thank you for taking time to participate in this study. It is greatly appreciated.

10. Do you have any questions before we conclude?

May I interview you again in about two weeks to clarify information regarding this interview?
Thank you, it has been a pleasure to have this opportunity to talk with you.

Appendix I

Palliative Sedation Therapy: Nurses' Perceptions
Demographic Data Form

Code #_____ Date Form Completed:____/___/____
Day Month Year

Please complete the following questions:

1. Your gender: Male Female

2. Your age:_____years

3. Nursing Education: (please indicate level currently completed below)
   - Basic Diploma_____
   - Baccalaureate Degree_____
   - Master of Nursing Degree____
   - Other Degree(s)_____
   - Certification Courses_____

4. Current marital status?
   - Never Married_____
   - Married_____
   - Divorced_____
   - Widowed_____
   - Separated_____
   - Common-Law_____

5. Religious affiliation_____

6. Number of years of nursing experience_____

7. Number of years of experience working with palliative care patients_____

8. Number of years practising on current palliative care unit_____

9. Employment Status:

   - Full-time_____
   - Part-time_____
   - Casual_____

10. What combination of shifts do you work?

Days/Nights_____
Days/Evenings____
Days only____
Evenings only____
Nights only____

Thank you very much for participating in this study.

Appendix J

NURSES NEEDED FOR RESEARCH STUDY

As a nurse involved in the care of hospitalized palliative care patients, you are invited to take part in the study entitled: "Palliative Sedation Therapy: Nurses' Perceptions.

You may be interested if you:

- Currently work on a designated Palliative Care Unit that focuses on the care of palliative patients
- Have a minimum of six months experience caring for palliative patients
- Are able to speak and write English and;
- Provide consent to participate in the study

This study is being conducted by Alexandra Beel, a student in the Master of Nursing program at the University of Manitoba.

For more information please call Alexandra at 832-0295.

Appendix K

Cancer Nurses' Framework for Reflection

Ways of Knowing	Questions for Reflection
Aesthetics	Art of nursing care What was I trying to achieve? What feelings are described to me by the patient? Why did I respond the way I did? What were the consequences?
Personal	How did I feel in this situation? What internal factors, belief system or values were influencing me?
Ethics	How did my actions match my beliefs? What ethical principles were involved?
Empirics	What knowledge should have informed me? What theory might have helped describe the situation? What evidence exists for the interventions utilized?
Sociopolitical	Where and how can my voice be heard? What change action is needed to respond to these patient needs?
Unknowing	What is unable to be explained in the patient situation and is just the person's way of being in the world?

Source: Howell, D., & Pelton, B. (2001). Advancing the quality of oncology nursing care: Interlink community cancer nurses' model for reflective practice. Canadian Oncology Nursing Journal, 11(4), 182-186.