

## ABSTRACT

### THE LIVED EXPERIENCE OF HOME HOSPICE NURSES MANAGING PATIENTS WITH TERMINAL RESTLESSNESS

By Marcia Smith

Terminal restlessness is a set of observable, unsettled behaviors at end of life. It is often described as a form of delirium and may occur in up to 85% of dying patients (Breitbart & Alici, 2008). Signs and symptoms may include impaired consciousness, confusion, physical restlessness, moaning, involuntary muscle twitching, fidgeting, or seizures (Burke 1997).

The National Hospice and Palliative Care Organization (NHPCO) reports that in 2006, 47.1% of patients died in private residences (NHPCO, 2007). Patients who choose to die at home receive specialized nursing care from home hospice nurses who provide expertise in symptom management and emotional support, with much attention also given to caregivers. Studies representing home hospice care are few, as are studies that examine the experiences of home hospice nurses with terminal restlessness. The purpose of this study was to describe the lived experiences of home hospice nurses managing patients with terminal restlessness.

Kolcaba's theory of comfort provided the theoretical framework for this study. A purposive sample included ten home hospice nurses from three home hospice agencies and three nurses with hospice experience referred through snowballing. Semi-structured interviews were conducted and included questions about experiences with terminal restlessness, use of pharmacologic and non-pharmacologic interventions, and teaching done with families regarding terminal restlessness. Audio taped interviews were transcribed verbatim. Phenomenological analysis was conducted using Colaizzi's methodology.

Four major themes emerged which described management of patients with terminal restlessness as experienced by home hospice nurses. These themes included: (a) putting together the puzzle, (b) knowledge deficit, (c) fill the tank, and (d) team effort. Subthemes were also identified and discussed for each theme.

Terminal restlessness has many labels in the medical literature and is often related to the diagnosis of delirium that is defined in the Diagnostic and Statistical Manual of Mental Disorders 4<sup>th</sup> edition (DSM-IV, 1994). Home hospice nurses cannot diagnose delirium in the home but need to dialogue with physicians to develop protocols for assessment and management plans for these end-of-life symptoms. Research to understand further the various aspects of management decisions and techniques used by home hospice nurses was recommended.

THE LIVED EXPERIENCE OF HOME HOSPICE NURSES  
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by

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I would like to dedicate this clinical research paper to my husband, Jim; my son, Curtis; and my family and friends. Jim, you were always there for me, encouraging me, listening to me, even when you had no idea what I was talking about. I appreciate your constant love, support and help around the house while I was up to my eyeballs in school work. Curtis, I look forward to your last year of school and sports, when I don't have to carry my books with me. Thanks to my mom and small group from church who offered many prayers for me during my four years. I am thankful for all of you.

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## CHAPTER 1

### INTRODUCTION

Terminal restlessness is a set of observable behaviors many patients demonstrate at end of life. Depending on the criteria and definition used, it has been found to occur in up to 85% of patients in the last weeks of life (Breitbart & Alici, 2008). Many patients with terminal restlessness receive skilled care in the home by hospice nurses. Hospice is a concept of care that provides symptom management to a patient who has a life limiting illness and is no longer receiving cure-oriented treatments (Hospice Foundation of America, 2009). The National Hospice and Palliative Care Organization (NHPCO) estimates that 1.3 million patients received hospices services in the United States in 2006 (NHPCO, 2007). Many people prefer to die at home and are admitted to a home hospice program. Although patients die in private residences 47.1 % of the time, few studies represent home hospice care (NHPCO, 2007).

The International Association for Hospice and Palliative Care (IAHPC) defines terminal restlessness as an agitated delirium that occurs in some patients during the last few days of life (2008). Patients with terminal restlessness have agitation, restlessness, an impaired conscious state, muscle twitching, multifocal clonus, distressed vocalization, and occasional seizures. Hospice nurses who care for patients in the home manage many symptoms, including terminal restlessness. Since home hospice nurses rarely provide continuous care, the family or other caregivers must be taught how to administer medications and other non-pharmacological interventions to help the patient remain calm, comfortable, and safe. Management of terminal restlessness in the home requires early recognition and excellent collaboration with caregivers.



In a study by Ryan (1992), primary caregivers perceived that some of the most helpful nursing behaviors in the home hospice setting were providing the patient with necessary emergency measures, if the need arose, and being available 24 hours a day, 7 days a week. The home hospice nurse is critical in the management of terminal restlessness in home hospice patients

In researching how to manage terminal restlessness, the first obstacle is the lack of consensus in the medical literature on the definition and label. Terms such as terminal delirium, terminal agitation, terminal anguish, delirium, confusion at end of life, psychiatric disturbances at end of life, and cognitive impairment (Kehl, 2004; Pereira, Hanson & Bruera, 1997) are used to explain the same or similar spectrums of signs and symptoms. A universally accepted definition of terminal restlessness is not available, yet health professionals who care for terminally ill patients are readily familiar with restlessness signs in the days before death. It is not customary for hospice patients to have laboratory or other diagnostic tests to determine an underlying cause for a change in condition. The causes and contributors of agitated behaviors at end of life may include infection, organ failure, medication adverse effects, uncontrolled pain, electrolyte disturbances, hypoxemia, dehydration, encephalopathy, depression, emotional stress, and unfamiliar environment (Breitbart & Alici, 2008; Casarett & Inouye, 2001). Hospice nurses working with patients at home strive to alleviate terminal restlessness if it occurs. If symptoms are not managed well, the patient may not be able to have their wish to die at home granted, as family may be too distressed and exhausted to provide care (Breitbart & Alici, 2008).

It is generally accepted that management of terminal restlessness focuses on prevention, early recognition, reversible causes, sedation, and emotional or spiritual

support (Back, 1992; Boyle, 2006; Breitbart & Jacobsen, 1996; Burke, 1997; Hermann & Looney, 2001; Lawlor, Fainsinger, & Bruera, 2000; Thomas & Guerrero, 2002; White, McCann, & Jackson, 2007). Management of end of life symptoms in practice are often guided by (a) data from other populations, (b) small samples in single institutions, and (c) anecdotes and hearsay from medical practice instead of evidence based research (Von Guten, 2005). It is important for the medical community to agree on the label, definition, and clinical manifestations of this disturbance at end of life for consistency of discussion, review of literature, and evidence based management. Home hospice nurses can provide input into the research process as management of terminal restlessness is examined for improvement.

Most studies involving end of life come from inpatient hospital or palliative care units. Many studies do not have samples that include only nurses. The home hospice setting has been poorly represented in research, particularly in relationship to terminal restlessness. A qualitative study by Brajtman, Higuchi, and McPherson (2006) explored palliative and home care nurses' experiences in caring for patients with terminal delirium, as well as family reactions and needs. They found four themes: (a) experiencing distress, (b) the importance of presence, (c) valuing the team, and (d) the need to know more. Thomas and Guerrero (2002-2003) gathered survey data from 300 hospices about identification and management of terminal restlessness. However, it is unclear how many of these were home care hospices and how many were hospice in-patient residences. Brajtman (2005a) studied the interdisciplinary team's perceptions of the families' needs and experiences related to terminal restlessness, with nurses being part of that team. Head and Faul (2005) used a survey to assess hospice professionals'

perceptions of terminal restlessness. Of the sample of 130, 52 % of these participants were nurses and 64.9% of all participants worked in hospice home care.

Because of the prevalence of terminal restlessness and the frequency of death in the home hospice setting, it is valuable to study how it is being managed. Hospice is an established and proven model of palliative care at end of life, providing optimal symptom management for patient and support to the family (National Consensus Project for Quality Palliative Care, 2004). Therefore, understanding the experiences of the home hospice nurse in managing the patient with terminal restlessness gives representation and voice to the importance of this contribution to nursing and the community.

### Significance to Nursing

Nurses are highly respected and trusted professionals who are trained to approach a patient using physical, psychological, social, environmental, cultural, and spiritual assessment. Home hospice nurses are particularly cued in to family structure and home environmental contexts to provide personalized care. Family caregivers become active participants with the home hospice nurse as a care manager coordinating the plan of care with the hospice team. This holistic approach to care is welcomed by patients and families, who desire being active in discussing options and treatments. As patients and families embrace the goals of palliative care, they seek to focus on quality of life and prevention of suffering (IAHPC, 2008).

Any nurse may receive additional training in end of life care through a program such as End of Life Nursing Education Consortium (ELNEC) (American Association of Colleges of Nursing, 2009). Many hospices provide training to their nurses on an ongoing basis to keep them current on policies, practices, research, and medications.

The Journal of Hospice and Palliative Nursing and the International Journal of Palliative Nursing are good resources for hospice nurses to use for nursing research and would benefit from more studies representing home hospice.

Advanced practice nurses (APNs) work in a variety of settings, providing expert health care to individuals and families. Although many APNs promote health and work to prevent disease, it is also common for them to manage chronic disease. In addition to family practice and internal medicine clinics, APNs are working in oncology clinics and gerontology practices (Bush & Waters, 2001). Some APNs provide care to frail elderly patients who are homebound (Dick & Frazier, 2006). At this time, the Medicare Hospice Benefit does not reimburse for APNs to make home visits. However, APNs may assist home hospice nurses in discussions of assessment, interventions, and management of patients at end of life. Advanced practice nurses and clinical nurse specialists (CNSs) have the opportunity to take the exam to become an Advanced Certified Hospice and Palliative Nurse (ACHPN) and earn the formal recognition and ability to educate others in end of life care (National Board for Certification of Hospice and Palliative Nurses, 2009).

Through examination of this study of the lived experiences of home hospice nurses managing terminal restlessness, nurses at all levels can gain an understanding of current practices and effective strategies, as well as challenges. In this study, home hospice nurses described how they cared for patients with this syndrome of signs and symptoms in a setting that has not been well represented in research.

### Problem Statement

No studies have described the lived experiences of home hospice nurses managing patients with terminal restlessness. Brajtman et al. (2006) conducted an exploratory qualitative study with five nurses from a palliative care unit in a hospital and four nurses from palliative home care. In their study, nurses described their experiences with both patients and families when a patient had an episode of terminal restlessness. This study did not focus on management. They identified that a nurse's presence and continuity of care was important. Studies related to terminal restlessness have been done on palliative care units with their staff or with bereaved families of patients who were in palliative care units. With terminal restlessness occurring in up to 85% of patients at end of life (Breitbart & Alici, 2008), it is a significant problem for home hospice nurses to manage. It is well accepted that terminal restlessness has many physical, emotional, psychological, or spiritual causes and requires keen assessment skills and management strategies (Blanchette, 2005; Head & Faul, 2005). It is not known how home hospice nurses describe their experiences managing terminal restlessness.

### Purpose of Study

The purpose of this study was to describe the lived experience of home hospice nurses managing patients with terminal restlessness.

### Research Question

What is the lived experience of home hospice nurses managing patients with terminal restlessness?

## Definition of Terms

### *Conceptual Definitions*

*Lived experience:* Experience is the practical knowledge, skill, or practice derived from direct observation of or participation in events or in a particular activity (Merriam-Webster's Online Dictionary, 2009). Lived experience is a term used by phenomenologists to describe how a person's experience gives meaning to the perception of a particular phenomenon (Polit & Beck, 2008).

*Home hospice nurses:* Professional, college educated individuals employed by home health agencies who use skilled nursing assessment and intervention to promote comfort care for patients at end of life, under the direction of a primary care provider.

*Managing:* To handle or direct with a degree of skill; to work upon or try to alter for a purpose (Merriam-Webster's Online Dictionary, 2009)

*Terminal Restlessness:* Agitated delirium that occurs in some patients during the last few days of life (International Association for Hospice and Palliative Care, 2008). Delirium is a disturbance of consciousness, attention, cognition, and perception but can also affect sleep, psychomotor activity, and emotions (American Psychiatric Association, 1999)

### *Operational Definitions*

*Lived Experience:* The lived experience in this study is the perception of events that surround activities performed as a home hospice nurse. This is subjective recollections verbally communicated during an interview.

*Home hospice nurses:* Registered nurses with a minimum of a two year degree employed by a home hospice agency and who have at least one year of experience caring for patients enrolled in a home hospice program.

*Managing:* Physical, psychological, emotional, social, or spiritual interventions aimed at patient comfort as reported by home hospice nurses.

*Terminal Restlessness:* Observable signs in hospice patients identified by participant home hospice nurses as terminal restlessness.

### Assumptions

1. Terminal restlessness can be identified and described by home hospice nurses.
2. Participants honestly report their experiences with terminal restlessness management.
3. Home hospice nurses manage terminal restlessness.

### Chapter Summary

Terminal restlessness in patients at end of life has been documented and described in the medical literature. Home hospice nurses observe, assess, and manage patients with terminal restlessness and can share their experiences to better understand this phenomenon. Nurses at all levels of education can benefit from improved end of life awareness and training. This chapter included an introduction to the problem under study, a critical literature review, the significance to nursing, a problem statement, the purpose of the study, the research question, definition of terms and assumptions.

## CHAPTER II

### THEORETICAL FRAMEWORK AND LITERATURE REVIEW

#### Introduction

The purpose of this study was to describe the lived experience of home hospice nurses managing terminal restlessness. The theoretical framework used in this study was Kolcaba's theory of comfort (1994). A literature review as it relates to terminal restlessness follows.

#### Theoretical Framework

The theory of comfort was developed by Katharine Kolcaba and is based on four assumptions (Kolcaba, 2001). The first assumption is that human beings have holistic responses to complex stimuli. The second assumption is that comfort is a desirable holistic outcome that is germane to the discipline of nursing. The third assumption is that human beings strive to meet, or to have met, their basic comfort needs. The fourth and final assumption is that institutional integrity has a normative and descriptive component that is based on a patient oriented value system.

In this study, these assumptions hold true. The first assumption is demonstrated well by the dying patient who will experience such symptoms as anorexia, asthenia, xerostomia, confusion, and constipation (Conill et al. 1997). Patients in a palliative care setting have been found to experience delirium from infections, electrolyte imbalances, uncontrolled pain, medication adverse effects, or organ failure (Breitbart & Alici, 2008). It is clear that patients nearing end of life have complex, integrated responses to the dying process.



The second assumption is demonstrated in this study by the home hospice nurses' goal to bring comfort to the patient to fulfill the hospice concept of care. The home hospice nurse provides specific physical and psychosocial needs in the home setting (Ryan 1992; Vendlinski & Kolcaba, 1997). Ryan (1992) studied primary caregivers and home hospice nurses' perceptions of the most helpful nursing behaviors in the home hospice setting. Patient's psychosocial needs and physical needs were ranked by both groups. Behaviors that caregivers perceived were most helpful included such activities as listening to the patient, providing the patient with emergency measures if the need arises, and staying with the patient during difficult times. Home hospice nurses provide support and interventions to relieve physical discomfort.

Hospice care in the United States has been increasing (NHPCO, 2007), suggesting that patients desire assistance with symptom control at end of life. The patient or power of attorney for health care, who signs a contract for coverage by a hospice benefit, is electing to have symptomatic treatment, not curative treatment (NHPCO, 2007). This choice to have hospice involvement is fulfillment of the third assumption that humans will seek basic comfort needs.

The fourth assumption is related to institutional involvement in keeping a patient's values in high regard. Nurses strive to give patients autonomy in decisions whenever possible, and in hospice nursing, this is especially true (Ryan, 1992). As part of a hospice organization, the home hospice nurse values the patient by listening to what the patient wants, answering questions honestly, talking to the patient to reduce fears, staying with the patient during difficult times, and teaching the patient how to be physically comfortable (Ryan, 1992). The hospice agency provides staff nurses around

the clock every day of the week, as well as a hospice team to assist the patient with spiritual, financial, and personal care needs.

Kolcaba's theory of comfort is relevant for hospice patients in the home setting. One of the elements of comfort is the strengthening quality that it provides (Venlinski & Kolcaba, 1997). The home hospice nurse not only allows the patient as much control in his/her care as possible, but also provides a variety of helpful physical and psychosocial behaviors to patients and caregivers to support and strengthen them (Ryan 1992).

As a second part of Kolcaba's theory of comfort, the nurse teaches the patient and family to enhance the patient's comfort by being actively involved (Venlinski & Kolcaba 1997). Medication administration is one way the home hospice nurse teaches the family to manage terminal restlessness to be able to maintain the patient in the home. A patient who is having serious problems with delirium, or its related signs and symptoms, may not have their wishes granted to die at home (Brietbart & Alici 2008). Nursing interventions are developed based on needs identified, such as physical, psychospiritual, environmental, and social. Kolcaba (Vendlinski & Kolcaba 1997) defines these needs in the following way: (a) physical needs pertain to bodily sensations; (b) psychospiritual needs arise from an internal awareness of self, including esteem, concept, sexuality, meaning in life, and relationship to a higher order or being; (c) environmental needs refer to the external background of human experience; and (d) social needs come from interpersonal, family, and societal relationships. As the four contexts of needs are considered, so are the experiences of being strengthened and comforted. Types of comfort can be (a) relief, or the state of the patient who has had a specific need met; (b) ease, or a state of calm or contentment; and (c) transcendence, or the state in which one rises above one's problems or pain (Vendlinki & Kolcaba 1997).

In this process of providing comfort care, the patient and family are involved in decision making and evaluation of effectiveness of interventions as the dying patient declines. Often other disciplines are involved in promoting and managing comfort in addition to nurses (Vendlinki & Kolcaba 1997). Objective and subjective data are gathered to assess the patient and family and a unique, holistic plan of care is devised with a process of comforting and strengthening as the desired outcome (Vendlinski & Kolcaba 1997).

Hospice nursing recognizes that at times total relief of discomfort is not possible, but ease or transcendence may be more attainable. Interventions are individualized and are based on physical, psychospiritual, social, or environmental components (Vendlinski & Kolcaba 1997). Kolcaba's framework offers a theory-based foundation to practice comfort based nursing in the setting of home hospice nursing.

## Review of Literature

### *Definitions of Terminal Restlessness*

To understand the nature of a review of literature for the sets of signs and symptoms that might be understood as terminal restlessness, it is necessary to review how terminal restlessness has been defined in medical literature and to also examine similar labels used for these clinical manifestations. No consistent definition exists for terminal restlessness. The International Association for Hospice and Palliative Care (IAHPC) defines terminal restlessness as "an agitated delirium that occurs in some patients during the last few days of life" (IAHPC 2008). Similarly, Burke (1997) defines terminal restlessness as a specific form of delirium exhibited in the last days or hours of life by some patients, adding that the term "terminal agitation" is synonymous with

terminal restlessness. Back (1992) agrees that terminal agitation is the same as terminal restlessness. He describes “terminal” as meaning an “ill-defined period of irreversible decline that heralds imminent death” and “restless” as “being unable to keep still or to be worried, uneasy or anxious” (p. 293).

Head and Faul (2005) define terminal restlessness with symptoms, and assert that terminal delirium is a symptom of terminal restlessness, rather than synonymous with it. In Thomas and Guerrero’s study (2002-2003), the criteria for terminal restlessness was defined as “restlessness/agitation within the last 24 to 48 hours prior to death, AND not relieved by medications prescribed from...preprinted orders for restlessness/agitation” (p.86). This would indicate a resistance to medication management.

White et al. (2007) define terminal restlessness as a “clinical spectrum of unsettled behaviors in the last few days of life” (p. 345). They suggest that terminal restlessness may be a reversible acute delirium. Lawlor and Bruera (2002) note that the terms “reversible dementia, pseudosenility, cognitive impairment, terminal restlessness, and confusional state” have been used somewhat synonymously for delirium (p. 702). Delirium is a term commonly used surrounding terminal restlessness.

From these definitions it is clear that at end of life, a restless, agitated behavior may occur during the last hours or days. Associated signs and symptoms may be anxiety, worry, and confusion. As described above, many medical professionals connect this set of unsettled behaviors to delirium with no agreement on whether it is reversible. The Diagnostic and Statistical Manual of Mental Disorders (DSM) IV 4th Edition (American Psychiatric Association, 1994) has specific criteria for delirium. This diagnosis includes hypoactive, hyperactive, and mixed forms of psychomotor abnormalities. The

presence of a hyperactive form of delirium at end of life in patients in a palliative care setting is likely to be the reason some experts call terminal restlessness a form of delirium (Brietbart & Alici 2008). The practice guidelines for treatment of delirium provided by the American Psychiatric Association (APA) (1999) cite a study by Massie, Holland and Glass (1993) where up to 80% of patients with terminal illness developed delirium as they neared death.

The guidelines recognize that delirium in the medically ill is associated with significant morbidity, but no specific discussion is provided with an association with dying. The APA calls the symptoms of restlessness, anxiety, irritability, distractibility, or sleep disturbances a “prodrome” or “subclinical” case of delirium, that often progresses over 1 to 3 days. This is not described in relationship to end of life. Terminal restlessness is not a medical term that is used in the APA guideline for treatment of delirium, even though many experts associate it with delirium. The use of the term delirium is most likely due to its assignment to a medical billing code. Terminal restlessness has no billing code and is not, therefore, considered a medical diagnosis.

It is notable that when reading studies on terminal restlessness, terminal delirium, or terminal agitation, palliative care textbooks contribute little to defining or examining this set of clinical manifestations. Similarly, The National Hospice and Palliative Care Organization, National Hospice Foundation, Hospice International, International Hospice & Palliative Care Organization, and End-Of-Life Nursing Education Consortium are not referenced when this topic is investigated. Terminal restlessness is common and yet at times ignored in resources commonly used by medical professionals and the general public.

### *Clinical Manifestations of Terminal Restlessness*

To find symptoms which might indicate terminal restlessness, it is necessary to compare and contrast literature that describes symptoms at end of life. The IAHPC (2008) identifies clinical features of terminal restlessness as agitation, impaired conscious state, muscle twitching, multifocal myoclonus, seizures, and distressed vocalizing. The International Association for Hospice and Palliative Care (2008) also includes acute confusion and delirium in its discussion of symptoms in palliative care. The general clinical features IAHPC uses for delirium are an acute or subacute onset, global cognitive impairment, attention deficit, and impaired conscious state (2008). Perception and speech are commonly impaired in delirium, and hallucinations are frequently present. Delirium may be reversible. Since the IAHPC calls terminal restlessness an agitated delirium, it is not clear which signs and symptoms from the description of delirium would also apply to terminal restlessness.

Breitbart and Alici (2008) note delirium in dying patients is often not reversible. Medication adverse effects, organ failure, and infection are some of the multiple causes in the terminally ill, causing significant physiological disturbances. At other times, restlessness may not be related to delirium, but may be from such causes as fecal impaction, urinary retention, uncontrolled pain, medication induced akathisia, mania, or panic attacks without a disturbance in consciousness or cognition (Breitbart & Alici, 2008).

The Hospice Patients Alliance (HPA) (2008) gives a description of terminal restlessness or agitation. This is more of a practical, lay perspective of what a caregiver would observe. Patients want to get up when they are too weak, they complain of being uncomfortable even if pain is managed, and they yell with occasional accusatory

language. Patients may exhibit paranoia and hallucinations. Safety is a common concern. It may appear that the patient is confronting an old enemy of the past. An inability to be objective about one's condition is also a part of terminal agitation, according to HPA.

When Burke (1997) uses the term *terminal restlessness*, he describes it as a palliative care emergency. Burke describes signs and symptoms of terminal restlessness as impaired consciousness, confusion, physical restlessness, moaning or crying out, involuntary muscle twitching or jerking, and relatively coordinated, semi-purposeful movements which may be described as "fidgeting" or "tossing and turning", or convulsions. Burke also recognizes anxiety as a component, as well as spiritual or emotional turmoil, which is sometimes called "terminal anguish."

Back (1992) differentiates between patients with terminal restlessness who have involuntary, spontaneous muscle contractions, and those who have coordinated movements with some voluntary control. By looking at these two variations, he proposes multiple causes and various modes of associated management. No other studies make this differentiation.

Cobb et al. (2000) did a retrospective chart review of 210 patients with cancer admitted to an in-patient hospice facility. The third most common reason for admission was delirium. Signs documented in the chart that were used to classify patients with delirium included confusion, paranoia, wandering, wakefulness (especially at night), hallucinations, verbal aggression, fear, combativeness, disorientation, and alternating lethargy and agitation. Groups with delirium and without delirium were compared, and survival did not differ significantly between the group admitted with delirium and those

admitted for other reasons (log rank test  $p = 0.3$ ). However, the median survival time for both groups was only 5 days. These patients were at the end of life.

Conill et al. (1997) performed a prospective study of 176 patients who died in the hospital, at home, or in a hospice facility. The symptoms in the last week of life were not described as terminal restlessness, but confusion (68.2%) and anxiety (45.5%).

Confusion in hospice patients was estimated by hospice nurses in various settings in a cross-sectional descriptive study by Nowels, Bublitz, Kassner, and Kutner (2002). Of 147 patients, 95 had moderate, severe, or disabling confusion. Mantel-Haenszel analysis on data revealed less likelihood of confusion among patients with cancer than patients with non-cancer diagnosis regardless of age. Problematic confusion was associated with agitation (57%,  $p = 0.0001$ ) and altered sleep-wake cycle (63%,  $p = 0.029$ ). Patients in the home setting were confused 47% of the time. Nurses identified 14% of confused patients as having delirium as described by the *DSM-IV* (1994). Patients identified as having delirium, had shorter length of stay ( $p = 0.015$ ), were more likely to live at home ( $p = 0.029$ ), and had cancer diagnoses more often ( $p = 0.052$ ) than patients without delirium. These studies identify individual signs observed in patients at end of life.

The presence of cognitive changes in delirium can explain why some end of life studies merely call changes “confusion.” Ng and Von Gunten (1998) studied 100 hospice patients admitted to an acute palliative care unit during a 5-month period and found that confusion was present in 37 patients. Within a week of admission, 60% of patients expired. Rapp and the Iowa Veterans Affairs Nursing Research Consortium (2001) provide a research-based protocol for the assessment and management of acute confusion/delirium. However, it is not intended for end of life care. Rapp and the Iowa



Veterans Affairs Nursing Research Consortium note that acute confusion is a label that can be applied to a patient before the criteria for delirium from DSM-IV is met.

Since many studies refer to delirium at end of life, it is useful to review the *DSM-IV 4<sup>th</sup> Edition* (American Psychiatric Association, 1994) criteria for delirium due to a medical condition. Patients exhibit problems with focusing, sustaining or shifting attention. Any changes in cognition should not be attributable to pre-existing or evolving dementia. The changes in consciousness and cognition have a sudden onset of a few days or hours, and improvements may be observed for short periods of time during the day. A thorough medical evaluation reveals evidence of physiological imbalances associated with a medical condition (Lawlor, 2002). Studies by Lawlor et al. (2000), Bruera et al. (1992), and Massie, Holland and Glass (1983) demonstrate that of 28% to 48% of patients admitted to the hospital with advanced cancer, 90% experience delirium in the hours to days before death.

Physical decline as a person nears death is complex and contributes to variations in reported clinical signs and symptoms. Boyle (2006) performed a comprehensive review of literature for evidence based findings related to delirium in older adults with cancer. Numerous potential physiologic etiologies of delirium were listed. Metabolic disturbances, pulmonary abnormalities, and cerebral disturbances are just some of the causes of delirium. Medications are culprits in the development of delirium (American Psychiatric Association, 1999; Boyle, 2006; Lawlor, 2002; Bond, Neelon & Belyea, 2006). Pharmacokinetic changes in older people also change drug metabolism, and other physiologic changes may reduce drug clearance. Many predisposing factors are related to the development of delirium in older adults. It can be difficult to discern if a general decline in condition, and particularly a change in mental

status, is due to disease process, infection, hypoxia, metabolic imbalances, medication, or dehydration (Foreman, Wakefield, Culp & Milisen, 2001). Risk factors for the development of delirium, such as advanced age, medical illness and medication use, have been identified with associated prevention strategies (Burns, Gallagley, & Byrne, 2004; Cobb et. al 2000; Elie, Cole, Primeau & Bellavance, 1998; Foreman et al., 2001; Lawlor, 2002; Lawlor et al., 2000; Weber, Coverdale, & Kunik, 2002; Wiesenfeld, 2008).

### *Recognizing Terminal Restlessness*

The recognition of terminal restlessness might be facilitated by an assessment tool. Jones, King, Speck, Kurowska, and Tookman (1998) developed a terminal restlessness instrument in hospice in-patients. After four versions, they had created a tool with five items. This tool had strong face validity and moderate inter-rater reliability. Items on the scale included impaired consciousness, distress, agitation, anxiety, and withdrawal. To further assess if hospice interdisciplinary teams agreed with the five components from the Jones et al. instrument (1998), Head and Faul (2005) surveyed 130 individuals. The majority of participants worked in home hospice (64.9%) and most were nurses (52%). This group perceived distress, agitation, and anxiety to be the most common signs and symptoms of terminal restlessness. When asked to estimate the percentage of patients experiencing terminal restlessness, the mean was 40.18%. Most respondents cited multiple physical causes of terminal restlessness, as well as spiritual, spiritual and/or psychosocial, or psychosocial causes. Almost three quarters of respondents reported that terminal restlessness occurs in the last days of life.

It is not known if any established instruments, such as Confusion Assessment Method (CAM) (Inouye et al., 1990), Delirium Rating Scale (DRS) (Trzepacz, Baker, & Greenhouse, 1988), Delirium Symptom Inventory (DSI) (Albert et al., 1992), and

NEECHAM Confusion Scale (Neelon, Champagne, Carlson, & Funk, 1996) that assess mental status changes could be used as is, or modified for use in terminal restlessness assessment.

Thomas and Guerrero (2002) surveyed 302 hospice managers/coordinators and found that only 13% utilized an assessment tool and 35% used a treatment protocol for terminal restlessness. Data obtained in this survey indicated that 64% called it a medical emergency, 22% called it a psychosocial emergency, and 8% called it a spiritual emergency. This diversity continued when asked about primary treatment for terminal restlessness. Most respondents (85%) used medication, while others listed primary interventions as psychosocial (17%), spiritual (14%), and complimentary and alternative medicine (8%). This study is consistent with other literature that indicates multiple etiologies of terminal restlessness and no consistent use of protocols.

Braitman et al. (2006) used a qualitative method to find out palliative care inpatient and home care nurses' experiences with terminal delirium. These nurses expressed difficulty watching patients and families suffer while terminal delirium was occurring. They noticed that having a nurse's presence seems to calm both patients and families, particularly if continuity of care was provided. The interdisciplinary team was critical for support for the nurses and families. Educational needs were expressed to be able to identify and manage terminal delirium more confidently.

### *Managing Terminal Restlessness*

Braitman et al. (2006) explored experiences of palliative care unit nurses and palliative home care nurses in caring for patients with terminal delirium. This study did not focus on management of the symptoms, but one management related question was included in the interview questions. The care of families of patients with terminal delirium

was also addressed. The four themes that were identified as experiences of nurses caring for patients with terminal delirium were (a) experiencing distress, (b) the importance of presence, (c) valuing the team, and (d) the need to know more.

Braitman (2005a) used focus groups from palliative care interdisciplinary teams to discuss their perceptions of the families' experiences and needs, and their own experiences and feelings surrounding terminal restlessness. Four themes were identified and included (a) suffering, (b) maintaining control, (c) feelings of ambivalence, and (d) valuing communication to reduce conflict.

Braitman (2005b) conducted in-depth interviews and focus groups with families who watched loved ones experience terminal restlessness on an in-patient palliative care unit at a teaching hospital. Five themes were identified from this qualitative study that relate to the understanding of caring interventions needed when a patient is experiencing terminal restlessness. These themes were (a) the multidimensionality of suffering, (b) the need for communication, (c) feelings of ambivalence, (d) the need for relevant information, and (e) valuing sensitivity and respect. Since families are so involved in caring for family members in home hospice, this study helps to provide insight into caring behaviors hospice nurses can incorporate into practice.

In a qualitative study, 17 female caregivers were interviewed to understand the process of medication management of symptoms in patients with terminal cancer in the home (Kazanowski, 2005). Included in the most common symptoms of distress was the symptom of agitation. The caregivers described the experience of managing medications for patients as a process from which six stages were identified. These stages were (a) committing to be caregiver, (b) taking on the role of medication manager, (c) achieving balance, (d) recognizing changes near death, (e) allowing adjustment of the balance,

and (f) evaluating self-efficacy and use of medication after the patient's death. Most of the medications given by caregivers in this study were scheduled with the assistance of a home hospice nurse. The caregivers feared making mistakes, giving medications at the wrong time, or giving too much medication. Strategies used to assist them in managing medications included using pre-filled medication boxes, pre-filled syringes, written schedules, and/or diaries.

Newton, Bell, Lambert, and Fearing (2002) collected data from hospice patient caregivers who filled out questionnaires related to difficulty managing physical, emotional, and behavioral symptoms in the home. Confusion, hallucinations, memory loss, and anger were among the most difficult symptoms to manage. Respondents indicated that holistic care provided by hospice, as well as advice from the hospice nurse, was the most helpful to them. Hull (1991) examined caring behaviors of home hospice nurses in a qualitative study as perceived by family caregivers. The four areas identified as the most caring behaviors were (a) 24 hour accessibility, (b) effective communication, (c) a non-judgmental attitude, and (d) clinical competence.

Morita et al. (2007) obtained multi-center questionnaires from 560 bereaved family members of cancer patients who developed delirium during their last 2 weeks in eight palliative care units in Japan. Agitation in patients caused distress in family members and caused ambivalent wishes between symptom control and maintaining communication. Families often interpreted the delirium as pain and physical discomfort, medication effects, psychosis, mental weakness, and death anxiety. Family-identified professional care practices, such as compassionate care, respecting the patient and family, and teaching the pathology of delirium, as what they experienced when patients experienced delirium. Although this study is not related to home care, and it takes place

in another culture, it represents the family distress while witnessing agitated behaviors at end of life.

Medication kits are commonly used in the home hospice setting for the management of uncontrolled symptoms. These are typically used when severe symptoms arise after hours or on weekends when the on-call hospice nurse must assist the family in managing the patient's comfort level (Bishop, Stephens, Goodrich, & Byock, 2008). Bishop et al. (2008) surveyed 22 licensed home hospice programs in New Hampshire to obtain information about how medication kits were used. These kits were commonly called an e-kit, emergency kit, symptom kit, or comfort kit. Most were ordered by the primary physician or the medical director. The kits were dispensed on admission to hospice or within 3 days of admission, most often. The contents of the kits varied by agency, but all kits contained morphine for pain management. For agitation, lorazepam was a component of 62% of kits, 52% contained a compound with haloperidol included for topical or rectal application, 14% contained haloperidol as an oral or rectal single agent. LeGrand, Tropiano, Marx, Davis, & Walsh (2001) developed a standard emergency kit for home use. This kit included chlorpromazine suppositories for restlessness and agitation. They concluded that the use of the kits was cost effective and contributed to family and nurse satisfaction.

Non-pharmacologic interventions have been documented for managing delirium (Casarett & Inouye, 2001; Breitbart & Alici, 2008). These include such interventions as avoiding immobility, monitoring nutrition, monitoring for dehydration, and monitoring fluid and electrolyte imbalances (Breitbart & Alici, 2008). However, these have often not been appropriate for the goals and patient abilities at end of life.

Complementary and alternative therapies have been proposed for use with terminal restlessness. Studies testing complementary and alternative therapies in medicine (CAM) in end-of-life have had limitations in study designs, sample sizes; and results have been inconsistent across studies (Lafferty, Downey, McCarty, Standish & Patrick, 2006). No studies have been found that test massage, aromatherapy, or music for terminal restlessness.

A randomized trial was conducted to test massage effect on pain and mood in patients with advanced cancer (Kutner et al. 2008). Results indicated no difference in pain or mood after intervention when patients received simple touch by an untrained “therapist” and massage performed by a massage therapist. Therapeutic massage was found to have some perceived reduction in anxiety when used as a nursing intervention in hospitalized cancer patients (Ferrell-Torrey & Glick, 1993). A review article by Mansky and Wallerstedt (2006) showed that anxiety may be improved with music therapy and massage.

A systematic review of twelve randomized controlled trials on aromatherapy was done by Cooke and Ernst (2000). The authors found that the studies were methodologically flawed. They concluded that aromatherapy appears to have a transient effect and may reduce anxiety, but they also found that no published literature provides sound rationale for introducing it into medical intervention. One study by Louis and Kowalski (2002) found where aromatherapy was used in hospice patients in the home was. Seventeen cancer hospice patients were measured on 3 different days, before and after a 60-minute session consisting of either a control of no treatment, water humidification as a control, or a 3% lavender aromatherapy humidified treatment. Vital signs, levels of pain, anxiety, depression, and sense of well being were measured in

patients. Lavender was chosen for its documented quality of increasing comfort, relieving pain, improving comfort, and improving coping, according to the researchers. Results indicated an overall difference between no treatment, water humidification treatment, and lavender humidification treatment as indicated by multivariate repeated measures analysis, but differences in pre- and post-treatment scores were not significant when analyzed with paired t-tests. The researchers felt that with increased sessions, the effect may also increase.

Music therapy for pain control, physical comfort, and relaxation in hospice patients was studied by Krout (2001). Using single sessions with behavioral observations and subject self reporting, the results suggested that these sessions were effective in increasing physical comfort, pain control, and relaxation. The music therapy services were conducted in various settings by board certified music therapists. In another published article by Krout (2003), case examples are given that describe actual experiences families had where music facilitated a sense of release at or near the time of death of a loved one. Music can serve to help family, as well as the patient, in the hospice setting.

Despite many studies on agitated kinds of behaviors surrounding end of life, few have examined the lived experience of the management of terminal restlessness by home hospice nurses. Further research is needed to increase our understanding of how home hospice nurses manage terminal restlessness, since many patients are dying in private residences and are experiencing these signs and symptoms.



### Chapter Summary

In this chapter, Kolcaba's theoretical framework was presented for this study. Kolcaba's theory of comfort provides a foundation for how home hospice nurses provide individual care using physical, psychospiritual, social, and environmental assessments and interventions to provide care for patients with terminal restlessness.

A literature review of both quantitative and qualitative studies was included in this chapter. Few studies were found that described the lived experiences of home hospice nurses managing terminal restlessness. This study was unique in its design and purpose to describe the lived experiences of home hospice nurses managing patients with terminal restlessness.

## CHAPTER III

### METHODOLOGY

#### Introduction

The purpose of this study was to describe the lived experience of home hospice nurses managing patients with terminal restlessness. In this chapter, the research design, population, sample, setting, data collection instrument, data collection procedure, and data analysis procedure are discussed.

#### Research Design

A qualitative design using a phenomenological approach to describe the lived experiences of home hospice nurses managing patients with terminal restlessness was used in this study. This allows an investigation of subjective experiences in poorly defined topics and brings to light the perceptions of the essences and meanings in that lived experience (Polit & Beck 2008). Through in-depth conversations about terminal restlessness, insights were gained to enrich and gain understanding of the phenomenon experienced by home hospice nurses in caring for terminally ill patients. This study allowed the researcher to study the lived experiences of home hospice nurses managing patients with terminal restlessness.

#### Population, Sample and Setting

The target population for this study consisted of all home hospice nurses in the United States. It is probable that management of hospice patients at home in other countries differs because of the availability of alternative medications and treatments.

The accessible population is home hospice nurses in Wisconsin. A purposive, convenience sample of 10 home hospice nurses was drawn from three home hospice agencies within a 100 square-mile radius of the researcher's university affiliation. After analysis of those interviews were completed, a snowball sample of three experienced, but not currently practicing, home hospice nurses were interviewed.

Home hospice nurses selected as participants were required to have at least a 2-year registered nurse degree and at least 1 year of experience as a home hospice nurse.

#### Data Collection Instrument

Interviews were semi-structured, focusing on individual experiences with patients who had terminal restlessness, definitions of terminal restlessness, clinical manifestations of terminal restlessness, pharmacological and non-pharmacological management of terminal restlessness, teaching related to terminal restlessness, and perceived causes of terminal restlessness. Participants also discussed hospice team involvement and benefits.

A demographic questionnaire was filled out by all participants (Appendix B). This questionnaire included gender, age, type of nursing degree, years as a home hospice nurse, training in end of life care, presence/absence of assessment protocol for terminal restlessness, presence/absence of management protocol for terminal restlessness, and average daily hospice census.

### Data Collection Procedures

Institutional Review Board approval was obtained through University of Wisconsin Oshkosh prior to data collection (Appendix A). Nurse managers/supervisors from three home hospice agencies were contacted by telephone and asked to participate in the study. The purpose of the study and basic procedure for data collection was revealed. Specific information about inclusion/ exclusion criteria of participants was described and the nursing manager/supervisor was asked to find willing participants for a study on a hospice related topic. The nursing managers/supervisors were asked not to reveal the exact topic of terminal restlessness, so the nurses would not prepare for the interview. Two of the home hospice agencies required documents for review, such as a project outline, consent document, and abstract. One of the home hospice agencies required the researcher to sign a confidentiality form. All of the three home hospice agencies asked for a written or personal presentation by the researcher with results of the study when it was completed.

The researcher was asked by the nursing supervisor from one agency to contact the home hospice nurses directly to set up times for interviews at their office. Nurse managers/supervisors arranged times for interviews at their offices at the other two agencies. At the time of the interviews, participants were informed that they would remain anonymous and that they may refuse to participate in the study or withdraw at any time during the study. In the case of emotional distress from discussing the sensitive topic of terminal restlessness, provision of a list of counseling centers was given to participants. No participants became distressed or needed assistance with referral. The interviews were face-to-face, tape recorded, and lasted 20 to 40 minutes. Interviews of the 10 participants from the home hospice agencies took place in private rooms at their

offices. The three interviews performed through snowballing referral took place at the researcher's home, a conference room provided by a participant, and a library room. Questions varied slightly from person to person, with probes used to reflect, clarify, or redirect participants as needed. Data were collected until saturation was achieved. Interviews were transcribed verbatim by the researcher.

Data were analyzed using Colaizzi's method (1978). These steps included reading all protocols to acquire a feeling for them. The protocols were reviewed and significant statements were extracted. Meanings were formulated from significant statements. The formulated meanings were clustered into themes. Clusters were referred back to original protocols to validate them or to find discrepancies in them. The results were integrated into an exhaustive description of the phenomenon under study. Three participants were asked to validate findings as a final step.

Using Lincoln and Guba's framework as described in Polit & Beck (2008) for establishing trustworthiness in qualitative research, the criteria of credibility, dependability, confirmability, transferability, and authenticity was the goal of this research and discussed during the process with the researcher's academic advisor.

#### Limitations in the Methodology

Despite steps taken to eliminate bias and maintain bracketing during this study, the researcher may have influenced the interview process or data analysis. Terminal restlessness is closely related to the dying process and associated symptoms, making research on this topic difficult to tease out. Home hospice nurses have unique experiences with terminal restlessness and personal opinions related to causes of terminal restlessness may affect their responses. Home hospice nurses work in assisted

living, long term care facilities, and hospitals providing hospice care. Providing answers pertaining only to experiences in the home may have been difficult for them to separate in their memories.

### Chapter Summary

A qualitative phenomenological design was used for this study. Participants were audio taped using semi-structured interviews related to experiences with patients with terminal restlessness. Participants were able to withdraw from the study if desired. Trustworthiness was supported through constant evaluation during the study. Colaizzi's method of analysis was used to extract themes from data collected. Limitations to methodology were discussed.

## CHAPTER IV

### FINDINGS AND DISCUSSION

#### Introduction

The purpose of this study was to describe the lived experiences of home hospice nurses managing patients with terminal restlessness. This chapter will describe the demographic data, the sample, the interview process, and discuss findings of the study. Literature as it relates to the findings will be reviewed.

#### Demographic Data

Initially, a purposive, convenience sample of 10 home hospice nurses from three home health agencies in Wisconsin were interviewed about terminal restlessness. Upon review of interview transcripts, it was determined that additional data was needed that focused on the management of terminal restlessness. Three more participants were obtained through snowball sampling. These nurses had home hospice experience but were not currently practicing as home hospice nurses. The final total sample size was 13.

Participants filled out a demographic questionnaire. Data collected included gender, age, nursing degree, years experience as a home hospice nurse, training in end of life care, presence of agency assessment and management protocol for terminal restlessness, and average daily agency hospice census. The data is presented in Table 1.

All participants were female, ranging in age from 25 to 60 years. Eight participants had a Registered Nursing degree; five had a Bachelor of Science in Nursing

degree. The number of years participants had worked as a home hospice nurse ranged from 1.5 to 18 years.

The participants had varied answers when asked to describe their training in end-of-life care. Eight participants answered that they had received training in end-of-life care from on-the-job training or from their employer; seven answered “seminars.” Single answers by participants included in-services, ELNEC training, CHPN certification exam, mentor who authored hospice books, articles, self-taught, patients and families, life experience, and in-patient hospice.

The participants were asked if their agency had an assessment protocol and a management protocol for terminal restlessness. Five participants answered yes, their agency had an assessment protocol; eight answered no. Seven participants felt their agency had a management protocol for terminal restlessness, and six said that their agency had no protocol. Interestingly, participants within the same agencies answered differently for both assessment and management protocols being available.

The final question asked for an estimation of average daily hospice census at their agency. Those participants obtained through snowballing answered for the census that they most frequently had when they were working as a hospice nurse. The average daily census was 67.8.



Table 1

*Demographic Data*

Data	Number	Percent
Gender		
Male	0	0%
Female	13	100%
Age		
25 – 35	4	30.8%
36 – 45	2	15.4%
46 – 55	4	30.8%
56 – 60	3	23.0%
Degree		
RN	8	61.5%
BSN	5	38.5%
Years worked as a hospice nurse		
1 – 5	7	53.8%
6 – 10	2	15.4%
11 – 15	2	15.4%
16 – 20	2	15.4%
End of life training		
One the job	8	61.5%
Seminars	7	53.8%
Single answer (see text)	9	69.2%
Agency assessment protocol for terminal illness		
Yes	5	38.5%
No	8	61.5%
Agency management protocol for terminal restlessness		
Yes	7	53.8%
No	6	46.2%
Average daily agency hospice census		
0 – 50	7	53.8%
51 – 100	4	30.8%
151 – 200	2	15.4%

### The Interview Process

All participants were agreeable to being audio taped. Interviews were face-to-face using semi-structured questions. The first three participants were asked to define terminal restlessness and then to describe the clinical manifestations of terminal restlessness. When asked to define terminal restlessness, they often talked about the clinical manifestations, so the second question to describe clinical manifestations was somewhat redundant. An adjustment was made so that the next interviews began with the statement, "Describe an experience that you have had with terminal restlessness in a home hospice patient." The participants were asked to describe clinical manifestations of terminal restlessness, experiences with terminal restlessness, experiences with pharmacological and non-pharmacological management of terminal restlessness, and teaching they might do regarding terminal restlessness. Some participants were asked how their views of terminal restlessness had changed over time. Probing and clarifying questions were used. Interviews lasted from 20 to 40 minutes.

Ten of the interviews were conducted in private rooms provided by the home hospice agencies. One interview was conducted in a conference room provided by a participant. The researcher's home was the place of one interview. One interview was conducted in a public library conference room. Several interviews were interrupted briefly by telephone calls to the participants, but the interviews were continued with no compromise in data collection.

### Discussion of Analysis of Data

Each participant described her thoughts, feelings, and experiences related to managing patients in the home with terminal restlessness. The interviews were audio

taped and transcribed verbatim. They were analyzed using Colaizzi's methodology for data analysis (1978). Protocols were read to acquire a feeling for them. They were then reviewed to find and extract significant statements. Meanings were formulated from each significant statement. These meanings were organized into clusters of themes. The themes were referred back to the original protocols to validate them. Discrepancies were noted among and between the clusters. Data were not ignored, and themes that did not fit were included. Results were integrated into an exhaustive description of the phenomenon of terminal restlessness. An unequivocal statement regarding the lived experience of home hospice nurses managing terminal restlessness was formulated. Finally, three participants were approached and asked about the findings as a final validating step.

As themes emerged from the formulated meanings in the data, sub-themes were also developed to further describe each theme. The four major themes, along with their sub-themes include:

1. Putting together the puzzle
  - a. The dovetail
  - b. Marching through the body
  - c. Unresolved issues
2. Knowledge deficit
  - a. Preparing the family
  - b. Breaking down barriers
  - c. Being there

3. Fill the tank
  - a. Trial and error
  - b. Emergency kit
4. Team Effort
  - a. Contribution to nurse
  - b. Assistance to patient
  - c. Assistance to family

*Theme 1: Putting Together the Puzzle*

The participants described many aspects they considered in the assessment of patients with terminal restlessness at end of life and many factors involved in the development of a plan to manage terminal restlessness. They stressed how each situation, each patient, and each family is different. It was very common to hear phrases such as “it depends,” “there are a lot of variables,” and “you have to adjust.” One participant described having to have “wide eyes” when assessing patients at end of life. The nurses used knowledge, experience, observation, and discussion with patient, family, and the hospice team to assess when terminal restlessness was occurring and to determine possible causes and interventions. Many of the nurses felt that identifying terminal restlessness was not easy, but that with time, they had improved in their assessment skills.

The nurses knew that at times it was impossible to determine an exact cause of terminal restlessness, but they searched for causes or contributors that might be treatable with nursing interventions. Participants were not asked what caused terminal restlessness, but they did have opinions about what may effect the development of it. Two participants looked for physical reasons for terminal restlessness, such as

uncomfortable body position, severe constipation, or a distended bladder and addressed those needs. Several participants had personal opinions and experiences they shared regarding patients with no faith system or belief in a life after death, and that these patients were much more restless at end of life than those patients who were at peace with their faith and their destiny after death. Another participant felt that terminal restlessness could affect those who were ready to die and those who were not ready to die, those who had faith, and those who did not. The participants had much to say, along with some differences.

While the home hospice nurses searched for possible contributing factors to the terminal restlessness, they found clues or pieces of a puzzle. They all had ways of describing these various causes or contributors to terminal restlessness. These are grouped into sub-themes. The majority of participants described elements of the three sub-themes under the “Putting together the puzzle” theme heading. The sub-themes are: (a) The dovetail, (b) Marching through the body, and (c) Unresolved issues.

#### *The Dovetail*

The dovetail sub-theme refers to the frequent coexistence of pain and restlessness in patients at end of life. Since the goal of the home hospice nurse is to provide as much comfort to the patient as possible, the presence of discomfort of any kind would be cause for intervention. The home hospice nurse is faced with the difficulty of trying to determine if restlessness is caused from pain or another cause. If the patient is unable to communicate effectively, which is often the case at end of life, the nurse must use the best assessment skills and knowledge to identify pain, and if possible, its source. Often morphine is given for discomfort at end of life, and effectiveness of its use would be measured using a pain scale.

Patients with terminal restlessness are typically given medications such as lorazepam or haloperidol that do not treat pain. A patient with pain would need additional medication to be comfortable. It is necessary for the home hospice nurse to determine what behaviors might mean in patients who are unable to communicate discomfort. This can be challenging and not at all clear, causing many home hospice nurses to report giving morphine and lorazepam when a patient is restless and difficult to settle. A participant explained this dovetail effect of pain and restlessness:

The other thing that I have actually found to be helpful is checking out their pain medication. Are they getting enough pain medication? Because I feel that restlessness and pain will go hand in hand and especially if we are finding that a patient is lethargic and can't talk anymore, I'd be paying attention to what they are getting for pain. Has it been effective, are we seeing any therapeutic effect, when are we giving a scheduled pain medication? Because maybe it's time for a pain medication increase and the only way that the patient can tell us is through severe restlessness.

The participants see comfort care and end of life on a continuum, with terminal restlessness as a part of that continuum. They do not necessarily see a need to differentiate terminal restlessness from pain, but often will simply treat for both if they suspect that pain may be causing the restlessness.

### *Marching Through the Body*

This sub-theme describes the natural process that takes over the body as the patient shows signs of dying. Symptoms such as pain, dyspnea, dysphagia, terminal congestion, constipation, bowel and bladder incontinence, as well as lethargy (Hermann & Looney, 2001) can reflect various body systems failing. Participants have various

descriptions of this process. One of the participants describes trying to manage terminal restlessness this way:

And sometimes I've come to the conclusion that all the medicine in the world may not take this away. You know? And we can always do the best we can with what we have, you know, and certainly it does mean more trying different medications, trying different therapies, but sometimes I explain to families just that -- that all the medications in the world may not change this toll...It is a lot to do with their neurological things, or is it medical, or is it metabolic, or what's happening in their bodies that's causing this, it's anybody's guess.

Another participant described how she explains terminal restlessness to families and what she said in a particular experience she had when called to a home for a patient with terminal restlessness:

I like to describe it as kind of the "aha moment" in my mind, that, and the way I explain to families and what I did in this situation, for this daughter caring for her mother, is to really explain that the disease process is really marching through the body. It's really kind of taking over the body and that our bodies are pretty amazing machines and that our nervous system is really responsive to what's happening with our body, and once you see that nervous agitation really becoming a profound terminal aspect of it as we can see it, it really tells us that the disease process is really taking over.

The participants are aware that the presence of terminal restlessness is an end-of-life phenomenon and they seek to manage the symptoms to provide comfort to the patient. It isn't necessary to correct the overwhelming decompensation of the disease

process, but the goal is to provide the comfort and quality of the last few hours in that patient's life.

### *Unresolved Issues*

It was common for the participants to discuss the possibility that unresolved issues may be causing a hospice patient to have terminal restlessness. The exact origin of the unresolved issues was not always identifiable from the patient. The participants had strong beliefs that they should at least try to find out if the patient had unresolved issues, so the patient may be able to find a resolution and have peace. The perceptions of unresolved issues included the need to talk with an estranged relative, the need to discuss spiritual issues with a chaplain or clergy member, the need to say good-bye, and the need to accept that death was imminent.

One of the participants had this experience with unresolved issues and hospice patients:

They just don't have their house quite in order yet and I have found, I'll ask the family, "Is there somebody yet that they need to say good-bye to, is there somebody?" And all of a sudden somebody will pop into their mind. "Oh, his brother still doesn't know" or "Her son who she's been kind of estranged from doesn't know." And we'll try to get ahold of those people. And honestly, all they have to do is get that person on the other end of the phone and having told that person what is happening, then put the phone to the person's ear even though they're not responding, all they have to say is mom or dad or brother, "I'm here and I know what you are going through, but I want to let you know that I'm sorry for the things we didn't patch up" or "I want to let you know that it's OK, I give you permission to go." And I can't tell you how many times I've seen that person just



gently, they become so less stressed and more quiet. Then it doesn't take much longer for them to be able to go to heaven.

The home hospice nurse is able to assist the patient with unresolved issues and intervene with restlessness by helping the family identify possible psychosocial needs. Another participant explained similarly:

You know, trying to talk to the family if there is anything that can make this right. You know, sometimes there is, sometimes there's somebody they're waiting to come from out of state or a daughter and once they come, they go. So you know, is there, sometimes trying to find another reason for just the, what we want to say is the physiological reason for that restlessness, maybe there's other reasons. And trying to get to the bottom core of that. Are they angry? Are they still in denial? Are they angry that they're dying, or they're not ready to go, which in a 45-year-old, that's totally understandable...they may never be ready to go.

Evans and Hallett (2007) explored the meaning of comfort care for hospice nurses using a hermeneutic phenomenologic study. Hospice nurses in this study perceived comfort as very individualized, and if a patient had a higher degree of emotional or spiritual discomfort than physical discomfort, then the patient would seek a transcendental or psycho-spiritual comfort. This study is consistent with the holistic care that participants conveyed in this sub-theme, where psychological needs were considered in caring for patients with terminal restlessness.

### *Theme 2: Knowledge Deficit*

A large part of managing terminal restlessness for the home hospice nurse included teaching families or other caregivers about signs and symptoms, possible causes, and ways of managing difficult behaviors in patients. Some of the participants

reported that they prepared the families or caregivers before the signs of terminal restlessness occurred. Other participants did not feel it was necessary to bring up the topic until the signs were present. Other reasons participants taught families and caregivers about terminal restlessness were to help them administer medications and other comfort measures, to avoid having to move the patient out of the home, and to decrease the distress of the family when the restlessness occurred.

When asked about terminology that they personally used, the participants preferred to call the signs “restlessness” or “agitation” with the families, not “terminal restlessness” or “delirium” or “terminal delirium” or another label. With co-workers, they called it “terminal restlessness,” “terminal agitation,” “restlessness,” or “agitation.” These participants did not use the term “delirium,” even though much of the literature reflects that terminology for the signs and symptoms at end of life causing the same behaviors.

Different aspects of teaching the family were brought out by the participants in the interviews. They were very dedicated to this part of hospice care and were empathetic for the distress that families felt when they witnessed terminal restlessness. The descriptions of the family struggles with understanding terminal restlessness and the treatment is described in the sub-themes of *preparing the family* and *breaking down barriers*. The importance of the home hospice nurse to be available 24 hours a day, 7 days a week, for family support is described in the sub-theme *being there*.

#### *Preparing the Family*

Participants had different approaches for preparing the family for terminal restlessness. One of the participants explained that she included the patient in the discussion about pain and restlessness at admission to assess their desire for sedation:

And we try to assure them that we are going to do the best that we can, because on admission, we ask the people if they want to be more alert or if they want to be sedated, if they have pain or if they become restless, whatever their desire is. And that's how I base it. Because if they say, "No I want to be calm, cool, and collected, and I want you to medicate me," then that is what I do. And if they say, "Nope, I want to be as alert as I can," then we try all the other avenues besides the drugs.

In this way, the participant was able to establish goals with the patient and family and inform them of the possibility of restlessness.

When asked what she tells families about terminal restlessness, another participant shared this:

There are different ways, the road that they can travel. They might become lethargic and become unresponsive and go into a semi-coma and it will be hard to arouse them, and they'll be very quiet and content and seem peaceful. On the other token, they may become very restless, and it seems like you can't settle them down, and they're very busy-body. I try to explain to them...and start preparing them, I often will say that there's different ways that the end of life can happen and we can't know that.

The home hospice nurses did not expect families to know about the dying process. They did expect families to be overwhelmed and fearful, with many questions. They were aware of a knowledge deficit and anticipated having to teach patients and families throughout the hospice admission.

The participants were asked about teaching resources that they used. A common resource that was discussed with and given to families was "Gone from My Sight"

(Karnes, 2005) which describes signs and symptoms at various stages of the dying process. This pamphlet was provided by the participants' hospice agency to families, usually at admission. Another book that participants mentioned was "Final Gifts" (Callahan & Kelley, 1997) that they might recommend for families to read to understand the experiences that are common to dying patients.

### *Breaking Down the Barriers*

To keep the symptoms of terminal restlessness controlled, the participants stressed the need to give medications to patients on a scheduled basis. The family was involved in administering medications to keep their loved one comfortable and calm. This was a source of anxiety for those caregivers responsible for giving the medications, as they had concerns about overdosing their sick family member. The participants had to teach the families the importance of giving the medications, so that the symptoms did not return and help them feel confident in their actions. This was a barrier in the management of terminal restlessness in the home setting.

Kazanowski (2005) used grounded theory to identify the process of managing medications for symptoms in patients with cancer near death from the perspective of family caregivers. Family members were particularly concerned about their dying loved one suffering and they feared that symptom control would not be achieved. They also feared that the patient would not be able to be maintained in the home. Although administering medications was anxiety provoking, they were committed to their loved one.

Medications used for the management of terminal restlessness are often unknown to the layperson, or they may have a familiarity with a negative reputation. Most people know that medications to calm a person down could be dangerous. The

home hospice nurse is not able to confidently tell the family that the medication will work and the exact dose to use, since patients can be very different in how they react to medications. In fact, the participants reported seeing paradoxical effects in some patients. This creates a dilemma for the home hospice nurse. Medications are almost always necessary for the management of terminal restlessness, and families must be willing and able to give medications regularly for effective control of symptoms. The home hospice nurses felt a burden to be able to confidently teach and guide families in their medication administration, as well as other management techniques, to care for restless loved ones in their final days.

Participants did not have overarching techniques that they used for breaking down barriers. They were aware that the barriers existed from experience with many families. The essence of their descriptions about managing terminal restlessness was that they used individualized plans of care and one-on-one time with patients and families. They would adjust to each situation based on many factors that they decided upon during the visit.

The home hospice nurses did not know how the family would react to the terminal restlessness once it occurred, or how they will react to the task of giving medications they are not familiar with. A qualitative study by Brajtman (2005b) that explored and described the impact of terminal restlessness and its management on family members revealed multidimensional suffering of family as they witnessed family members with the physical, cognitive, and personality changes during terminal restlessness. Family members also identified the need for communication with their loved ones and felt ambivalent about sedating them. Family members wanted very clear and relevant information, so they felt confident in the medical staff. Sensitive,

professional, respectful nursing care was valued and remembered by family members being interviewed.

The home hospice nurse must skillfully break down the barriers that create anxiety for family members in caring for patients with terminal restlessness. It is important for families to have a positive memory of their loved ones' last days, and the hospice nurse plays a big part in making that a reality.

### *Being There*

The participants recognize that managing patients at end of life takes time. Patients with terminal restlessness can be distressing to families, and they may need medication adjustments. The symptoms occur at any time of the day or night. The home hospice nurse must be available to make a home visit at any time. Besides scheduled visits, many times the on-call nurse will be asked to respond to questions or make a visit for terminal restlessness that has started or has escalated.

The participants know that the caregivers of the dying patient depend on their presence during the difficult times. A participant explains:

I think the best thing that you do for patients and family is really making sure that they're comfortable, knowing what they are doing, that you are there, that they are not alone, because they have a fear, a horrible fear of being alone and taking care of somebody dying. And it's also very helpful, and they just need to know that they do have that hospice nurse that they can use, call any time, day or night, and that they have that nurse and physician and they're gonna help them through it. And they will get through it. Difficult, yes. The hardest thing for them that they will ever go through, caring for someone who is dying.

Home hospice is unique in that the family often receives more attention from the nurse than the patient. It is impossible to describe management of any symptom in home hospice without confronting the task of teaching caregivers and building a relationship with them. *Being there* is a responsibility that the participants are willing to carry out, as they feel a burden for the patients and families that they care for.

### *Theme 3: Fill the Tank*

The use of pharmacological and non-pharmacological means to control terminal restlessness was discussed by participants. The creativity and willingness to try interventions which might calm patients was evident. Medications prescribed in the participants' practices for terminal restlessness were discussed freely with associated challenges. Home hospice nurses have many ideas for managing terminal restlessness, but the main goal was to find the most effective way to provide comfort for the patient and calm the restlessness.

The participants were in agreement that medications were almost always needed for terminal restlessness and using them on a scheduled basis was most effective. In this way, the patient had a "full tank" at all times. With the addition of non-pharmacologic interventions, all efforts were made to give the patient the best chance at comfort. The two sub-themes that further explain the management of terminal restlessness when the patient needs to have the "tank filled" are *trial and error* and *emergency kit*.

#### *Trial and Error*

Massage, aromatherapy, and music were common techniques that the participants used to try to calm patients with terminal restlessness. The participants did not report any overwhelming success with any of these non-pharmacologic interventions, but they felt that the attempts were "worth trying." When asked about

interventions to manage terminal restlessness, participants often responded with phrases like, “it’s very individual,” “you have to keep trying,” “it is a lot of one-on-one care,” and “it is trial and error.” Managing terminal restlessness did not have any rules or protocols that could guarantee a quick and complete response with all patients. Medications and non-pharmacologic interventions were often tried until the patient became sleepy or extremely calm.

Some participants described the non-pharmacologic interventions as a way to “get over the hump” while medications were taking effect during an extremely restless period. One participant described the use of interventions to help manage terminal restlessness as an “arsenal.” Another described the interventions as “tools.” Both of these word pictures are effective for characterizing the creativity of the home hospice nurse. Just the named non-pharmacological interventions for managing terminal restlessness are quite varied and long. The home hospice nurses mentioned using oxygen, prayer, holding hands, talking to the patient, dimming the lights, providing a calm environment, using fans to circulate air, frequent position changes, massage, lavender aromatherapy, warm towels, using other hospice members/volunteers, and using family members. Participants spent time and used creativity, knowledge, and experience to try various interventions to provide relief from terminal restlessness.

Non-pharmacologic interventions typically documented for managing delirium (Casarett & Inouye, 2001; Breitbart & Alici, 2008) have not necessarily been appropriate for the goals and patient abilities at end of life. These include such interventions as avoiding immobility, monitoring nutrition, monitoring for dehydration, and monitoring fluid and electrolyte imbalances (Breitbart & Alici, 2008). This would not be reasonable in the home setting and in a patient who may be hours from death. The non-pharmacologic



interventions that are amenable for the home setting are reasonable in a patient at end of life and that may involve the family are interventions that seem to be chosen by the home hospice nurses.

The participants were very open to using complementary and alternative therapies (CAM) for patients with terminal restlessness. They were trying massage, aromatherapy, and music regularly in their practices. Studies testing complementary and alternative therapies in medicine (CAM) in end of life have had limitations in study designs and sample sizes, and results have been inconsistent across studies (Lafferty et al., 2006). No studies have been found that test massage, aromatherapy, or music for terminal restlessness. A randomized trial was conducted to test massage effect on pain and mood in patients with advanced cancer (Kutner et al., 2008). No difference was found between improvement in pain and mood when patients received massage by a massage therapist or simple touch by an untrained "therapist." Therapeutic massage was found to have some perceived reduction in anxiety when used as a nursing intervention in hospitalized cancer patients (Ferrell-Torry & Glick, 1993). A review article by Mansky and Wallerstedt (2006) showed that anxiety may be improved with music therapy and massage.

Aromatherapy was chosen by home hospice nurse at times, with many of the participants using lavender to decrease terminal restlessness. Studies which included the use of lavender oil were reviewed by Cooke and Ernst (2000), and they noted that many of the studies where degrees of anxiety or distress were assumed by the investigators left a question of scientific rigor. They concluded that in general, aromatherapy studies that relate to relaxation are probably not strong enough to be considered for treatment of anxiety.

Medications chosen by participants for treating terminal restlessness were from standing orders given by attending physicians or the hospice medical director. These orders gave the home hospice nurse the ability to give medications to the patient frequently, with the goal of achieving comfort. The nurses most frequently used lorazepam and haloperidol for terminal restlessness, but they also used morphine if they suspected pain was contributing to the restlessness. A paradoxical effect from lorazepam, which caused an increase in agitation, occurred at times, making participants less confident in this medication. The dosing to treat terminal restlessness was highly individual according to participants.

Kehl (2004) performed a review of studies about pharmacologic treatment for terminal restlessness. Only one randomized, double blind comparison trial was found, and in it the lorazepam arm was discontinued due to distressing side effects and lack of efficacy. Six observational studies, three case studies, and nine review and expert opinion articles were analyzed. Neuroleptic medications were recommended by most as the first or second line of treatment, and haloperidol was a commonly recommended treatment. Kehl's review also summarizes two clinical practice guidelines. The first is by Casarett and Inouye (2001), who wrote for the American College of Physicians-American Society of Internal Medicine (ACP- ASIM) End-of-Life Care Consensus Panel. The guidelines suggested using haloperidol first, although they admitted that data is scarce to guide use in end of life. The second clinical practice guideline (Kuebler, 1997) comes from the Hospice and Palliative Nurses Association Protocol and recommended opioid analgesics as the first line of therapy. Case studies analyzed by Kehl (2004) varied in recommendations and included medications such as haloperidol, midazolam, propofol, chlorpromazine, lorazepam, barbituates, opioid analgesics, olanzapine,

risperidone, and methotrimeprazine. Kehl (2004) suggests that a consistent definition of terminal restlessness would improve research. An accepted scale for sedation or arousal would also improve interpretation of comfort. Optimal doses and routes were also not adequately studied in the articles reviewed (Kehl, 2004).

The *trial and error* sub-theme describes using non-pharmacologic and pharmacologic interventions in a way that recognizes that each patient with terminal restlessness may react differently. The effectiveness of each intervention will vary from patient to patient, and the home hospice nurse must have perseverance and patience when managing this syndrome of behaviors that can occur at end of life.

#### *Emergency Kit*

Terminal restlessness can occur at any time during a hospice admission, and any time of the day or night. Most of the participants in this study discussed the role of emergency kits, sometimes called comfort or “s” (symptom) kits that might contain medications for terminal restlessness. These sealed kits would be placed into the home at admission, or shortly thereafter, and would contain medications that the attending physician or hospice medical director prescribed for emergency use. Such kits are common in hospices and often contain medications for pain, dyspnea, nausea, and vomiting and seizures (Bishop et al., 2009).

The emergency kits used in the participants' practices were not to be used for routine symptoms, but were reserved for new symptoms or a worsening of a symptom. The emergency kits were opened at the discretion of the home hospice nurse. The standing orders were in place to guide the administration of medications. The family had to be taught many times how to give the medication if it was going to be given on a scheduled basis.

The participants often stressed the importance of keeping the medications scheduled once the symptoms of terminal restlessness started. In patients who develop restlessness, the family and hospice nurse were relieved to have medications in the emergency kit to avoid the typical delay while orders were being obtained from the physician and prescriptions were being filled. In this way, the patient could receive medications that would potentially create a full “tank.” to alleviate restlessness. The family could also feel relieved that their loved one was less agitated and receiving quality care.

#### *Theme 4: Team Effort*

The home hospice nurses worked in hospice agencies with at least one medical director, a nursing supervisor, other hospice nurses, home health aides, social workers, bereavement coordinators, chaplains, a volunteer coordinator, and volunteers. Other professionals included pharmacists, physical therapists, occupational therapists, and nutritionists. The team worked together and collaborated on patient care.

Three sub-themes became apparent when participants described the hospice team. They were (a) contribution to the nurse, (b) assistance to the patient, and (c) assistance to the family. These separate areas helped to illuminate how the hospice team managed terminal restlessness.

##### *Contribution to the Nurse*

Participants were appreciative of their co-workers and the expertise that they brought to the hospice team. When faced with any challenges, such as a patient with terminal restlessness that may not be responding to usual medications or non-pharmacologic interventions, the participants felt like they could always approach members of the hospice team to ask for their input. This was done informally or in a

team meeting. Participants went to other nurses, to their nursing supervisor, or to the medical director with questions or concerns. The hospice team was helpful for the home hospice nurse in the management of terminal restlessness.

#### *Assistance to the Patient*

Participants brought out several ways that hospice team members were used for terminal restlessness. Hospice volunteers could come to the home and sit with the patient, so that family members could leave the room for short periods of time. This would prevent the patient from getting up and falling when nobody was supervising the patient. Chaplains could do the same thing, and they also would pray with the patient if appropriate or simply talk calmly with the patient.

Home health aides often made several visits in a day if a patient was very agitated and would provide personal care to keep the patient clean and dry. Many of the participants had extreme respect for the skills and compassion that these individuals had for the patients. Some of the home health aides provided massage to the patients who had terminal restlessness. They provided much of the hands-on care to the patients and assisted the families when the nurses were busy with other visits.

The on-call nurse was frequently called when terminal restlessness occurred during after hours. Participants described how difficult this could be for the nurse who was not familiar with the patient and family, and how some nights could be very long for the hospice nurse on-call managing terminal restlessness. Some participants thought that terminal restlessness tended to occur more in the 12:00 a.m. to 6:00 a.m. time frame.

One participant described a patient that had such extreme terminal restlessness, which was resistant to all usual medications, that an expert in the state was contacted

for recommendations. The patient was put on a continuous infusion of a medication and palliative sedation was used. In this case, even the medical director had to consult with an expert to manage terminal restlessness. The patient and family benefit when the hospice team is committed to the patient and utilize their areas of expertise to provide excellent hospice care.

#### *Assistance to the Family*

The hospice team provided the family of the patient with terminal restlessness support and physical presence. Chaplains came to pray with the family. Home health aides provided care to the patient, so the family could get some time away from the patient for rest or other tasks. Social workers assisted the family with counseling or help in setting up a 5-day respite. Volunteers sat with the patient and provided short periods of respite. Pharmacists were available to answer questions about medications. The family was a big part of the plan of care in managing terminal restlessness. Participants involved them, and the family became recipients of the hospice team's expertise and compassion.

### Chapter Summary

Ten home hospice nurses were interviewed about terminal restlessness. Data were analyzed, and it was decided that more data would be useful to focus on the management of terminal restlessness. Three more semi-structured interviews were carried out with nurses obtained through snowballing. These nurses were experienced in home hospice, but were currently working in other positions. Four major themes emerged from experiences of the participants managing terminal restlessness: (a) Putting together the puzzle, (b) Knowledge deficit, (c) Fill the tank, and (d) Team effort.

This study is unique, and no research has been done in the same way. One study, which is somewhat comparable, explored experiences of palliative care unit nurses and palliative home care nurses in caring for patients with terminal delirium (Brajtman et al., 2006). This study did not focus on management of the symptoms, but one management related question was included in the interview questions. The care of families of patients with terminal delirium was also addressed. The four themes that were identified as experiences of nurses caring for patients with terminal delirium were (a) experiencing distress, (b) the importance of presence, (c) valuing the team, and (d) the need to know more. The second theme, *importance of presence*, correlates with the sub-theme in this study of *being there*. The third theme, *valuing the team*, correlates with the fourth theme of this study, *team effort*.

Managing patients with terminal restlessness in the home is challenging for home hospice nurses. The home hospice nurse approaches this challenge by viewing each patient as an individual with unique needs and circumstances. Family members who care for loved ones in the home with terminal restlessness at end of life need much support from home hospice nurses.

Table 2

*Summary of Findings*

Theme	Sub-theme
Putting together the puzzle	The dovetail Marching through the body Unresolved issues
Knowledge deficit	Preparing the family Breaking down barriers Being there
Fill the tank	Trial and error Emergency kit
Team effort	Contribution to nurse Assistance to patient Assistance to family



## CHAPTER V

### SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

#### Introduction

The purpose of this study was to describe the lived experiences of home hospice nurses managing terminal restlessness. Conclusions from the study are summarized in this chapter and recommendations are given for nursing practice and research.

#### Summary

Terminal restlessness is a complex syndrome of observable unsettled behaviors with multiple causes exhibited by some individuals at end of life. Few studies have been done that examined the experiences of home hospice nurses managing patients with terminal restlessness. Phenomenological research can add to the understanding of critical truths through people's lived experiences, helping others to perceive or think about something in a different way (Polit & Beck, 2008).

A qualitative, phenomenological approach was utilized to explore the experiences of home hospice nurses managing terminal restlessness. Kolcaba's theory of comfort provided the theoretical framework for this study. This theory was consistent with the individualized interventions provided by the participants to manage terminal restlessness based on patients' physical, psychospiritual, social, and environmental needs.

Thirteen participants were interviewed for this study. Interviews were semi-structured, audio taped and transcribed. Responses were analyzed using Colaizzi's

method (1978). Four main themes emerged from the data: (a) putting together the puzzle, (b) knowledge deficit, (c) fill the tank, and (d) team effort.

The first theme, *putting together the puzzle*, captured the different ways that the home hospice nurses perceived the contributors or causes of terminal restlessness. These perceptions guided choices of interventions or choices of how they explained terminal restlessness to others. The sub-theme of *the dovetail* described the connection of pain and terminal restlessness. The sub-theme of *marching through the body* related terminal restlessness as part of the dying process. The third sub-theme was *unresolved issues*, which highlighted the psychological distress that many feel when faced with dying.

The second theme, *knowledge deficit* indicated the experience of identifying learning needs of the caregivers of patients with terminal restlessness in the home. The participants expressed that much of their time was spent teaching caregivers/family about terminal restlessness and engaging them in the care and management of the symptoms. The sub-theme *preparing the family* was a belief by many participants that families should be taught about the possibility of terminal restlessness before it occurs. The participants described how they approached this and some teaching resources that they used. *Breaking down barriers* was a sub-theme describing the need to have family members become less fearful to administer medications and other interventions as needed to manage terminal restlessness. A final sub-theme, called *being there* emphasized the family's need for reassurance that a home hospice nurse was available at all times for advice or a visit.

The third theme was *fill the tank*. This communicated a need to keep the patient with terminal restlessness filled with medications on a scheduled basis and to use non-

pharmacologic interventions, as well, until the patient was comfortable. The participants stressed that each patient and situation was individual, creating the sub-theme of *trial and error*. The participants would have emergency kits placed into the home with medications that could be used if the patient suddenly had terminal restlessness and they had no medication in the home already, or their current medications were ineffective. The sub-theme of *emergency kit* was the way that patients could have their “tank filled” if terminal restlessness became a management problem in a hurry or after hours.

The final theme was *team effort*. The hospice team can be utilized in a number of ways to manage terminal restlessness. The first is to assist the home hospice nurse through collaboration with other nurses or other professionals to exchange ideas, knowledge, or experience. The sub-theme of *contribution to nurse* was birthed from these comments by participants. The hospice team can provide *assistance to the patient*, the next sub-theme, by being at the bedside, providing personal care, holding their hand, assuring safety, and reassuring them. Home health aides, volunteers, chaplains, social workers, and other members of the hospice team may be called upon to help when patients are having terminal restlessness. In the same way, members of the hospice team may be asked to provide *assistance to the family*, the last sub-theme, to provide some respite, to assure patient safety, to pray with the family, or to provide reassurance. Participants in this study identified many areas of hospice team effort and how the team assisted in terminal restlessness.

This study is unique in its design and is not directly comparable to other studies. A summary of the findings of the lived experiences of home hospice nurses’ experiences managing terminal restlessness include four major themes: (a) putting together the

puzzle, (b) knowledge deficit, (c) fill the tank, and (d) team effort. Sub-themes served to further explain each theme.

Kolcaba's theory of comfort provided the theoretical framework for this study, especially as it relates to hospice (Vendlinski & Kolcaba, 1997). The various contexts of needs described by Kolcaba are (a) physical needs that pertain to bodily sensations; (b) psychospiritual needs that arise from an internal awareness of self, including self esteem, concept, sexuality, meaning in life, and relationship to a higher order or being; (c) environmental needs from the external background of human experience; and (d) social needs from interpersonal, family and societal relationships (Kolcaba, 1994). These needs are consistent with the needs that the home hospice nurses in this study considered as they sought to determine causes of terminal restlessness and effective means of comfort. The participants were aware of physical causes, such as constipation or bladder distention, as well as pain from a variety of causes. The participants were aware of spiritual needs, often considering calling the chaplain or praying with the patient or family themselves. Unresolved issues of many kinds were considered as a contributor to terminal restlessness, with participants seeing patients unready to die because of these issues.

Kolcaba's theory of comfort stresses holistic care, with comfort as a strengthening feature. The patient and family are involved in the plan of care and other disciplines assist the nurse in managing the patient during the dying process (Vendlinski & Kolcaba, 1997). The participants in this study were committed to involving the patient, if possible, in decision making about use of medications to ease symptoms, and families were a focus of much teaching and support during the management of terminal restlessness in the home. The home hospice nurses knew that their presence

strengthened the family, and the family's presence strengthened the patient. Comfort was provided to the patient in many ways.

Kolcaba identified three types of comfort. The first type of comfort is relief. Relief is the state of needing a specific need met (Vendlinski & Kolcaba, 1997), which is what participants tried to accomplish as individual interventions were developed. This correlates with the many ways the participants described using experience and knowledge to assess each situation and to try various methods to manage terminal restlessness in patients. The participants tried to relieve specific needs in patients of overstimulation, environmental temperature dislikes, unresolved issues with family members, and spiritual concerns.

The second type of comfort is ease, which induces calm or contentment (Vendlinski & Kolcaba, 1997). Medications such as lorazepam or haldoperidol could produce this effect. Non-pharmacological interventions could also produce relaxation in some patients. The participants of this study gave many examples of alternative and complementary therapies that they used to calm patients. These were not specific to any particular need, but just served to provide relaxation and comfort.

The third type of comfort was not identified by the participants in terminal restlessness. This type of comfort is transcendence and requires the patient to rise above their condition (Vendlinski & Kolcaba, 1997). The participants saw terminal restlessness as a part of the dying process and patients were overcome with the progression of the disease.

The theory of comfort provided an effective framework for explaining how home hospice nurses manage terminal restlessness using individualized, holistic care for

patients and their families. The participants act proactively to provide relief and ease to patients, involving families and using the hospice team for support.

### Conclusions

The lived experiences of home hospice nurses managing terminal restlessness were explored through use of a qualitative design. The phenomenological approach to this study allowed the complexity of the subjective experiences of the participants to be explored through face-to-face interviews, using clarifying and probing questions. The sample size was large enough to permit data saturation. The range of age, experience, and training varied enough among nurses to provide a heterogeneous mix for analysis. The participants cared for hospice patients in nursing homes, assisted living facilities, and hospitals, as well as the home. They were asked to comment only on home hospice patients; however, it is possible that their memories may have not separated out only patients from the home setting.

Terminal restlessness has not been well defined and has many alternate labels in the medical literature. If the term “terminal restlessness” is used in medical literature, it is often related to delirium. Yet the home hospice nurses in this study do not use the term “delirium” in practice and can readily describe and discuss terminal restlessness when questioned. The use of the term delirium is most likely tied to the medical diagnosis that carries a billing code. Thus, studies reflect what physicians would typically call a disease, symptom, or behavioral process. The physicians use the *DSM-IV* to guide their definition of delirium, yet delirium is not represented at end of life in the *DSM IV* (American Psychiatric Association, 1994).

The participants identified clinical manifestations of terminal restlessness that highlighted the difficulty of keeping the patient safe. The patient felt the need to move, to get out of bed, and to be busy, even if at times the purpose was not known. Patients would pick at their bed linens and sometimes at the air. They would see people who others could not and call out. Often patients would overestimate their strength, forgetting that they were weak. On the other hand, those who were incredibly ill found unbelievable strength and needed several people to assist them back to bed so they did not injure themselves.

Identifying terminal restlessness was challenging for participants, as the signs were subtle at times. As behaviors escalated, the participants searched for medications and non-pharmacological interventions that might be effective to calm the patient. The families would be taught about the signs and symptoms of terminal restlessness and the possible causes, and the patient would be assessed for individual interventions that may be used to alleviate causes. Psychospiritual needs were addressed, and often the hospice team was consulted if they were not already involved. Although the participants found it challenging to manage terminal restlessness, they knew it was part of the dying process, and they accepted it as part of their goal to provide quality of care at end of life.

The themes that emerged were reflective of the nursing process and fit into the theoretical framework chosen for this study. It is not known if hospice nurses learn much of the process of caring for dying patients from each other, therefore, creating much consistency in answers. Many of the participants had attended seminars, but they did not seem to identify if it was within their agency or outside their place of employment. The participants mostly gathered their knowledge from other nurses, independent reading, and a few seminars. End of life care is difficult to study due to ethical and

Institutional Review Board constraints. Evidence based studies in end of life care are few. Home hospice and home care is particularly poorly represented in research.

Participants expressed a desire for better techniques and medications to manage terminal restlessness. It was difficult for them to watch patients experience paradoxical responses to medications or to receive no comfort from multiple attempts to calm them. The home hospice nurses wanted to be able to give medications confidently and to reassure families that the patient would calm down quickly. Many participants knew that some patients just could not be managed well, and they had difficult hours before their death. This left unsettled memories for the home hospice nurses and for families.

Since patients at end of life are often receiving opioids and are having difficulty communicating, it is challenging for nurses to assess the difference between terminal restlessness and pain. If the nurse assumes that the patient has pain, and more opioids are administered, confusion and agitation may escalate. On the other hand, uncontrolled pain can cause restlessness. Without a clear assessment tool to differentiate pain from terminal restlessness, the hospice nurse must administer medications using his/her best judgment. How nurses interpret observable behaviors and decide to treat them can vary greatly. For the participants of this study, the goal was to keep the patient comfortable, not to clearly differentiate between pain and terminal restlessness from other causes. They were willing to consider all causes of terminal restlessness, but in the end, they were judicious with all comfort measures, whether it was for pain or for terminal restlessness. The participants were committed to striving for peaceful deaths for their patients and creating the best possible experiences for the families.



## Recommendations

### *Nursing Practice*

This study can be used to enlighten others working with patients in end of life care who are unaware of how home hospice nurses manage terminal restlessness. Most studies in end of life have been done in palliative care or other in-patient units. The home care setting is a rich area for research. Too often medical management in the home is forgotten in medical literature, since much of the research is written by physicians who rarely visit the home.

The advanced practice nurse, who has received a certification in Palliative Care or Oncology, would be an effective teacher for home hospice nurses. This APN could help home hospice nurses develop decision trees to decide if a patient has pain or terminal restlessness, or both. The APN could assist with the development of protocols along with the hospice medical director, pharmacist, and members of the hospice team. Teaching strategies for families could be developed with nurses. The APN could be a consultant to the hospice team.

Advanced practice nurses manage hospice patients in their primary care practices and in oncology practices. Hospice nurses communicate with APNs about their patients and receive orders for medication changes. This study can enlighten the APN to understand the experiences of the home hospice nurse managing the dying hospice patient who develops terminal restlessness. The APN can understand the management approach of the hospice nurse better and perhaps collaborate more actively with the hospice nurse, exchanging information more frequently to assist with patients who are agitated.

The discrepancy between labels used for terminal restlessness needs to be addressed, as nurses and physicians are not using the same terminology. Typically, “delirium” is diagnosed by a physician using a screening and evaluation tool. In the home hospice setting that is not feasible. Most delirium tools are meant to be carried out by a physician or specially trained clinician (Rapp et al., 2000). Even if a tool was developed for hospice nurses to assess for delirium, they may not be motivated to carry out an extensive mental status evaluation on a patient who is at end of life just to document a diagnosis. Furthermore, families may find such an assessment disturbing. Unless nurses and physicians can identify and discuss the differences in how they perceive and manage this syndrome of behaviors, they will have difficulty agreeing on plan of care. The home hospice nurses must communicate effectively to physicians how home assessments and management differs from in-patient palliative care. Perhaps physicians should receive some home care experience as part of their training to be more aware of this aspect of patient care.

Since teaching families is such a large part of the home hospice nurse's experience, it is critical that end of life programs show nurses how to critically think about issues they may face. How do you explain a process, such as terminal restlessness, to families when you have no exact way of knowing what is causing it? How do you teach families to give a sedative for restlessness when they very much want to keep their loved one awake and alive as long as possible? End of life issues are difficult and take some planning, confidence, and insight. Seasoned hospice nurses can be excellent resources for the less-experienced.

Nurses are leaders who are respected and who have opportunities to impact many in the community. Home hospice nurses leave lasting impressions on many

families. They do not work as hospice nurses for the money, because of the good hours, or because they are in the spotlight; they work behind the scenes. It is this researcher's hope that this study will inspire others with the work and dedication of home hospice nurses who truly make a difference to the nursing profession and to the world.

For those who do not understand how a hospice nurse can carry out his/her daily duties, here is what one of the participants said:

I know that not everybody can do it, and you know there are other folks that say, "Oooo, I don't know, that's an awful hard job that you have, isn't it?" and I say, "Not for me, it's where I'm meant to be." I enjoy, and I always consider it a privilege and an honor, to be where I am with each individual because not everyone gets that opportunity to help someone to the very, very end of life and to make it as pleasant and comfortable as possible. Not just for the patient, but for the family themselves. And I hope that I can do that. I think I do that.

### *Nursing Education*

Many nurses cannot recognize terminal restlessness signs and symptoms, because they have little experience with patients at end of life. Nursing curriculums may be weak in end of life courses, and information about terminal restlessness may be neglected. The Committee on Care at the End of Life recommended that educators and other health professionals initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to care well for dying patients (Field & Cassel 1997, p. 269). If nurses are only getting one or two lectures on end of life, but they are caring for patients at this stage of their life regularly, then these nurses have not been adequately trained.

Home hospice nurses have the opportunity to become a Certified Hospice and Palliative Care Nurse (NBCHPN, 2009). Many do not go through this because the training involves independent study, with the need to purchase many texts and study resources, and the cost of the exam is not paid for by most employers. The certification status often does not increase salary or improve hours. Home hospice nurses need more opportunities and financial rewards for substantial training in end of life care. Education needs to be based on evidence based studies as much as possible, not just tradition or opinion of peers.

Home hospice nurses do a great deal of teaching in their practices. But are they taught how to teach? This is a skill that many nurses would like to improve upon. Nursing schools should focus on teaching strategies and techniques to prepare nurses for the many times that they must change from hands-on work to teaching someone else to do the task at hand.

### *Nursing Administration*

Nursing administrators are in a position to encourage active communication and sharing of ideas between home hospice and in-patient management of end of life patients. Administrators can help facilitate dialogue with physicians and nursing supervisors about differences in these two settings and bring attention to the challenges of home hospice nurses managing terminal restlessness. Nursing administrators can be key in helping to determine if nurses and physicians can agree upon a label for terminal restlessness/delirium. Nursing administration can assure that home hospice nurses get quality, evidence based education on end of life topics.

### *Research*

This study could easily be replicated in a different part of the country to compare data. Various aspects of the management of terminal restlessness could be further explored, such as (a) occurrence of paradoxical effects of medications to treat terminal restlessness in a given time period, (b) comparison of lorazepam and haloperidol effectiveness, (c) number of times emergency kits were used in a given period of time, (d) medications used from emergency kits in a given period of time, and (e) ranking of families' top concerns regarding giving medications. Home hospice nurses could be asked to document how they perceived unresolved issues to have affected their patients during the dying process during a period of time. Non-pharmacological interventions could be researched in a number of ways. Home hospice nurses could be asked to keep a record of how many of these interventions they used during a certain time period. Families could be asked to rate effectiveness of interventions, or the patient could be monitored by the nurse for behavioral changes after the non-pharmacologic intervention.

It would be very interesting to have home hospice nurses' assessments of patients with terminal restlessness followed by physicians' home visits and assessments to see if patients met the criteria for delirium. This would provide a way to verify if terminal restlessness and delirium are being similarly identified. Better dialogue about assessment and treatment protocols can take place if physicians and nurses can agree that they are identifying the same medical problem.

Research on the experience of dying or the care of patients at end of life should not be viewed as treatment failure or uninteresting. End of life care is a medical specialty requiring expertise and knowledge that can be gained and shared with others through research, expert opinion, and clinical experience. The need for quality end of life care

will never be obsolete. Research is necessary to help improve the death experience for patients and to find new ways to manage symptoms at end of life.

### Chapter Summary

In this chapter, the summary of results, conclusions, and recommendations from this study were presented. Further research is needed to add to our understanding of how home hospice nurses manage terminal restlessness.

## APPENDIX A

UW Oshkosh IRB Approval Letter



October 13, 2008

Ms. Marcia Smith  
1592 Milton Circle  
Oshkosh, WI 54904

Dear Ms. Smith:

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Participants (IRB), I am pleased to inform you that your application has been approved for the following research: Terminal Restlessness from the Home Hospice Nurse's Perspective.

Your research protocol has been classified as EXEMPT. This means you will not be required to obtain signed consent. However, unless your research involves **only** the collection or study of existing data, documents, or records, you must provide each participant with a summary of your research that contains all of the elements of an Informed Consent document, as described in the IRB application material. Permitting the participant, or parent/legal representative, to make a fully informed decision to participate in a research activity avoids potentially inequitable or coercive conditions of human participation and assures the voluntary nature of participant involvement.

Please note that it is the principal investigator's responsibility to promptly report to the IRB Committee any changes in the research project, whether these changes occur prior to undertaking, or during the research. In addition, if harm or discomfort to anyone becomes apparent during the research, the principal investigator must contact the IRB Committee Chairperson. Harm or discomfort includes, but is not limited to, adverse reactions to psychology experiments, biologics, radioisotopes, labeled drugs, or to medical or other devices used. Please contact me if you have any questions (PH# 920/424-7172 or e-mail:rauscher@uwosh.edu).

  
Sincerely,

Dr. Frances Rauscher  
IRB Chair

cc: Mary Ellen Wurzbach  
1447

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## APPENDIX B

### Demographic Questionnaire

## Demographic Questionnaire

1. What is your gender?

\_\_\_\_\_ Male      \_\_\_\_\_ Female

2. What is your age? \_\_\_\_\_

3. Nursing degree:

\_\_\_\_\_ RN      \_\_\_\_\_ BSN      \_\_\_\_\_ MSN      \_\_\_\_\_ Doctoral

4. Years as a home hospice nurse? \_\_\_\_\_

5. Describe your training in end-of-life care:

6. Does your agency have an assessment protocol for terminal restlessness?

\_\_\_\_\_ Yes      \_\_\_\_\_ No

7. Does your agency have a protocol for management of terminal restlessness?

\_\_\_\_\_ Yes      \_\_\_\_\_ No

8. What is the average daily hospice census at your agency? \_\_\_\_\_

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