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Home Health Nurses' Knowledge and Beliefs of Suffering, Artificial Nutrition and Hydration in People with Late Stage Dementia

by

Lenora Ward Smith

A dissertation submitted to the faculty of the Medical University of South Carolina in partial fulfillment of the requirement for the degree of Doctor of Philosophy in the College of Nursing.

2014

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Home Health Nurses' Knowledge and Perceptions of Suffering, Artificial Nutrition and Hydration in People with Late Stage Dementia

Abstract

Purpose: This dissertation examined the concept and dimensions of suffering in individuals with late stage dementia and the knowledge and perceptions of home health nurses with regard to artificial nutrition and hydration and suffering in individuals with late stage dementia.

Design: Using Caron and Bowers' method of dimensional analysis, the concept of suffering in people with late stage dementia was examined. A pilot study was conducted on home health nurses in Western North Carolina to test the reliability of the instrument used in the study, and a mixed methods exploratory study was conducted to measure home health nurses' knowledge and to obtain their beliefs or perceptions on suffering and artificial nutrition and hydration in people with late stage dementia.

Conclusion: Suffering is not well defined in the literature and many individuals are considered suffering from the physical domain rather than from a holistic point of view. In individuals with late stage dementia, suffering is difficult to assess or measure due to a lack of purposive language. The perceptions of home health nurses in North Carolina are also reflective of suffering being more in the physical domain. This perception is validated in their discussions during focus group interviews, especially when discussing artificial nutrition and hydration. While most nurses feel that it prolongs life and helps with nutritional status and overall health of individuals with late stage dementia, there is no evidence in the literature that supports these perceptions or beliefs. This dissertation demonstrates that the knowledge, beliefs or perceptions, and attitudes of home health nurses influence their actions and counseling of patients and families when considering artificial nutrition and hydration in individuals with late stage dementia.

Clinical Relevance: Demonstrating the nurses lack evidence-based knowledge of suffering and artificial nutrition and hydration supports the need for further education in the clinical arena. This additional information may help facilitate decision-making for families of individuals with late stage dementia.

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Introduction to Dissertation: Home Health Nurses' Knowledge and Perceptions of Suffering, Artificial Nutrition and Hydration in People with Late Stage Dementia

Dementia is a syndrome that affects memory, behavior, thinking, and physical function, which interferes with activities of daily living as well as decision-making (Alzheimer's Disease International, 2012). Alzheimer's disease is ranked in the top six chronic diseases listed as the cause of death in those 65 years and older (Alzheimer's Organization, 2013; Miniño & Murphy, 2012). It is associated with multiple comorbidities and complications, including dysphagia (Sanderson, et al., 2002), which develops in 50-70% of those affected with Alzheimer's (Chouinard, 2000). Estimated costs in caring for individuals with dementia were $200 billion in 2012 (Alzheimer's Organization, 2013).

The age-adjusted death rates for Alzheimer's disease alone in North Carolina (NC) are 30.3 per 100,000 (Tejada-Vera, 2013), which is above the United States (US) rate of 25.1 (Tejada-Vera, 2013). The number of older adults with Alzheimer's disease or other forms of dementia in NC has reached 170,000 (North Carolina Division of Aging and Adult Services [NCDAAS], 2012). The NCDAAS (2012) estimated that this number would increase to more than 300,000 by the year 2030. In NC, over 70% of individuals with Alzheimer's or other dementias are cared for at home or in the community (National Association for Home Care and Hospice [NAHC], 2010), and in 2011, there were over 3.4 million individuals receiving home care from Medicare-certified home health agencies (HHAs) in the US (Medicare Payment Advisory Commission, 2013). Information on hospital-based admissions from the Medicare Payment Advisory Commission (2013) noted that 29% of community-admitted individuals had Alzheimer's disease or dementia compared to 21% of individuals who were admitted from a post-acute care (PAC) facility. Data from the National Center for Health Statistics (NCHS; 2010) showed an increased in the percentage of home deaths in people 65 and older (15% in 1989 to 24% in 2007) and Teno, et al. (2013) noted in their retrospective study of fee-for-service Medicare beneficiaries, of the 67,801 decedents who died of dementia in 2009, 22.8% died at home. Many of the elderly (22%; Hutchinson, Hawes, & Williams, 2005) live in rural areas (Artnak, McGraw, & Stanley, 2011), making obtaining appropriate health services challenging, especially among individuals with dementia. Many rural areas lack adequate health care services and resources, including home health agencies, as there are more home health agencies in urban areas than in rural areas (Hartman, et al., 2007; Kenney & Dubay, 1992). These statistics cause concern regarding a disparity in and access to services available in rural areas for the elderly individual who has late stage dementia (LSD). In addition, rural nurses may have different perceptions of their role in counseling patients and families as the nurses may have an existing relationship with the patients or families through living in a small community. Wilkes and Beal (2001), in their study, found that rural nurses found it more difficult to be a “friend, nurse, and counselor to families” (p. 312) when studying stress between urban and rural nurses providing palliative care in Australia.

The lack of consistency in defining the concept suffering and the lack of nurses’ evidence-based knowledge regarding artificial nutrition and hydration (ANH) may negatively impact decision-making and care with individuals with LSD (Smith, Amella, Edlund, & Mueller, in press). Both of these inadequacies may result in unnecessary suffering on the part of the individuals as well as their families and may result in a poor quality of life at end of life (Smith et al., in press). Dementia is a progressive disease involving both loss of memory and functional capacity; thus at the last stage, the individual may be completely dependent upon others for care and bedridden, which may cause complications that produce a more rapid death. Depending upon individual comorbidities, death for individuals with LSD sometimes occurs within a short timeframe (Mitchell, et al., 2009); however, for many health care professionals, LSD is not perceived as a terminal illness (Sachs, Shega, & Cox-Hayley, 2004; Wolf-Klein, Pekmezaris, Chin, & Weiner, 2007).

Poor intake is generally common in the terminally ill for a variety of reasons. In individuals with LSD, poor intake is usually due to the individuals' perception of food insignificance, cognitive and functional decline leading to dysphagia and apraxia (Cohan, 2012). This decline results in eating difficulties leading to poor nutritional status and weight loss. Over 85% of those with advanced dementia develop an eating problem, which puts them at risk for not only malnutrition but also repeated infections (Fischberg, et al., 2013). Mitchell, et al. (2003) found that between 18% and 34% of nursing home residents with LSD were fed via tubes. The decision to initiate or, after placement, to withdraw ANH is frequently discussed and left to the family or health care proxies who turn to nurses to counsel them regarding this critical decision.

Significance of Problem

Nurses often have little to no, or incorrect information, regarding ANH and decisions regarding nutrition at end of life may be affected by the nurses' inaccurate counseling (Ke, Chiu, Hu, & Lo, 2008b). Studies show that ANH can be a futile treatment that does not prolong life (Chui, Hu, Chuang, & Chen, 2002; Finucane, Christmas, & Travis, 1999; Murphy & Lipman, 2003). Indeed, the American Geriatrics Society (AGS, 2013) and the American Academy of Hospice and Palliative Medicine (AAHPM) developed recommendations to decrease detrimental or inappropriate health care utilization (Fischberg, et al., 2013). The authors of both reports recommended that health care providers should not advocate tube feedings for individuals with LSD but instead offer oral feedings. Moreover, there is evidence to support that ANH may contribute to increased suffering, with anasarca, pulmonary edema, causing pain and distress (Morita, Tei, Inoue, Suga, & Chihara, 2002).

Because LSD may not be perceived as a terminal illness, individuals with LSD may not be referred to hospice until close to the end of life. This may cause unnecessary suffering in the form of physical symptoms, such as pain, dyspnea, and pressure ulcers (Mitchell, et al., 2009). In addition to physical symptoms, there are other areas of suffering that must be considered when caring for individuals with LSD, such as emotional, spiritual, existential, and psychological (Aminoff et al., 2004; Aminoff & Adunsky, 2005, 2006; Guilio et al., 2008; Givens et al., 2010; Husebo et al., 2008; Mitchell et al., 2009; Nourhashemi et al., 2012; Shulz, McGinnis et al., 2008; Shulz, Monin et al., 2010; van der Steen, Ooms et al., 2002; and van der Steen, Pasman et al., 2010).

Knowledge Gaps

However difficult suffering is to assess in individuals with dementia, it is especially difficult to assess these domains in those persons who do not use language purposefully or have minimal volitional movement. There are few studies in the literature that address suffering in individuals with LSD, but the majority of these studies confirmed that suffering does occur in individuals with LSD by use of observation scales (Aminoff et al., 2004; Aminoff & Adunsky, 2005, 2006; Guilio et al., 2008; Givens et al., 2010; Husebo et al., 2008; Mitchell et al., 2009; Nourhashemi et al., 2012; Shulz, McGinnis et al., 2008; Shulz, Monin et al., 2010; van der Steen, Ooms et al., 2002; and van der Steen, Pasman et al., 2010).

Studies have shown that individuals with LSD do suffer; however, the majority of studies most often consider suffering from a symptomology viewpoint rather than examining it from all of the domains, including physical, psychological, existential, and spiritual. ANH in people with

LSD has been shown to be disadvantageous and may cause unnecessary suffering in those individuals. Families may view not allowing ANH as not feeding their loved one, allowing them to 'starve to death,' which presents a difficult decision for them (Fischberg, et al., 2013). However, studies have shown that with accurate knowledge and information, the decision is made easier (Hanson, et al., 2011; Monteleoni & Clark, 2004).

Theoretical Framework

Symbolic interactionism theory provides a theoretical basis for the lived experiences of home health nurses (HHNs) who will counsel families about end-of-life choices such as use of ANH. Symbolic interactionists believe the meanings of a given situation emerge over time. These meanings are based on situations that have occurred in the past and the present during social interactions (Hewitt & Shulman, 2011). Although definitions of situations may be shaped by others, "each individual must define the situation (including those others)…" (Charon, 2010, p. 125). Stryker (1972) noted that upon entering a situation, people characterize and interpret the situation, which leads them to decide about what behaviors are appropriate for themselves as well as others. Pragmatists also believe humans interpret their environment and respond to situations based on the situation's usefulness (Charon, 2010). In addition, Charon noted that pragmatists believe that humans notice only specific things in situations and focus on human action. The method of grounded theory moves beyond the experiences of a person and what is happening in a given situation to understanding the process of why the situation occurred (Artinian, Giske, & Cone, 2009). The strategy of the grounded theory method is established in interpretation of social interaction, which is studied in order to determine what relationship there is in the perceptions of the participants and their actions (Glaser, 1992). As individuals begin to understand their world and their interactions with others through the meaning of symbols (symbolic interactionism theory), grounded theory method decodes and discerns an understanding of the individuals' behaviors that are developed from the symbols that have been interpreted (Aldiabat & le Navenec, 2011).

In this dissertation, the HHNs bring varied personal and professional experiences with death, dying and suffering to their interaction with each other, families and persons with LSD. Layering on the management of end-of-life care using ANH, the nurses may be influenced by larger cultural and religious belief systems; possibly, they have developed their meanings from these beliefs and by their experiences. Thus, knowledge of and actions taken by these nurses concerning ANH are colored by myriad past social and personal interactions and can be explored from the symbolic interactionism perspective.

This dissertation is composed of three manuscripts to explore the knowledge, beliefs or perceptions of HHNs regarding suffering and ANH in individuals with dementia and how these perceptions or beliefs influence their actions and counseling to patients and their families. To arrive at a deeper understanding of these beliefs or perceptions and the meanings behind them, the concept of suffering in individuals with dementia at end of life was analyzed through a dimensional analysis (Chapter 1; Smith, Amella, Edlund, & Mueller, in press). Following a literature review and analysis of 14 studies conducted in 2012, four dimensions (pain, discomfort, holistic, and despair) and two subdimensions (communication and symptoms) emerged. These dimensions are the basis for future research in developing a more concrete definition of suffering as well as an instrument to measure suffering, especially with those who are often not able to communicate purposively.

Chapter 2 presents a pilot study in which the instrument, Knowledge Test (Knowledge of Artificial Nutrition and Hydration in the Terminally Ill), was validated and baseline knowledge

of HHNs on the benefits and burdens of artificial nutrition and hydration was established (Smith, Amella, & Mueller; submitted). The instrument was adapted from Ke, et al.'s (2008a) instrument, "Knowledge of the Provision of Artificial Nutrition and Hydration in Terminally Ill Cancer Patients." Six content experts reviewed the Knowledge Test prior to use. The study revealed that HHNs (N = 33) lack evidenced-based knowledge regarding ANH, particularly in areas of pathophysiology. Cronbach's alpha for the questionnaire was 0.71 and the instrument was deemed appropriate to use for the diagnosis of 'terminal' or late stage dementia.

The final study, Chapter 3, reports on the knowledge, beliefs or perceptions of HHNs with regard to suffering and ANH in an exploratory mixed-methods, convergent parallel design study. Quantitative data was obtained from the Knowledge Test and qualitative data resulted from open-ended questions on the Knowledge Test as well as focus group interviews. Both sets of data were merged and interpreted for convergence or divergence. Three themes resulted from interpreting the data: *patient/family comfort, futility, and symbols of suffering.* Results from the interpretations demonstrate more education of HHNs are needed so that appropriate decisions by patients and families can be made regarding ANH and suffering is diminished or eliminated in individuals with dementia.

MANUSCRIPT 1 – DIMENSIONAL ANALYSIS

This manuscript was accepted by the *Journal of Hospice and Palliative Care Nursing.*

Smith, L., Amella, E. J., Edlund, B., & Mueller, M. (in press). A dimensional analysis of the concept of suffering in people with late stage dementia at end of life. *Journal of Hospice and Palliative Nursing, 16*(5), 263-270.

A Dimensional Analysis of the Concept of Suffering in People with Late Stage Dementia at End of Life.

Abstract

Context: Alzheimer's disease is one of five leading causes of death in persons over the age of 65. The term suffering is used in all disciplines and a variety of contexts with no clear universal definition. Identifying dimensions and qualities (dimensional analysis) of the concept of suffering will assist in better understanding the concept and being able to apply it to science and practice.

Objectives: The objectives of this paper are to analyze and identify dimensions of the concept of suffering for individuals at end of life who have dementia and to establish relationships between the dimensions.

Methods: Caron and Bower's method of dimensional analysis and the symbolic interaction theory guided the analysis. Fourteen research studies were selected from databases including CINAHL, PubMed, Ovid/Medline, Academic Search Premier, and PsycInfo between 2000 and 2012. Key search terms included suffering, dementia, and end of life combined.

Results: Four dimensions (pain, holistic, discomfort, and despair) and two subdimensions (communication and symptoms) were identified in the analysis. Different perspectives were found in the literature, but each one varied in its approach to the concept of suffering.

Conclusion: The concept of suffering is complex and multifaceted and encompasses several dimensions. Understanding the dimensions of suffering provides insight into the individual with dementia as a person and not the disease. The analysis reveals that these dimensions are not well explored in the literature and establishes the importance of further research in this area.

Keywords: suffering; dimensional analysis; nurses; dementia; Alzheimer's; end of life; existential suffering; spiritual suffering.

Introduction

In 2010, there were nearly 1.8 million deaths of persons aged 65 and older. The five leading causes of death in those persons were heart disease, cancer, chronic lower respiratory diseases, stroke, and Alzheimer's disease[1]. All of these disorders can be, and usually are, chronic and debilitating, leading the individual to 'suffer' with their affliction. Many of these chronically ill individuals have an impaired quality of life because of their decline in function, cognitively and physically, making suffering difficult to define in the dying. Although it is difficult to assess and describe in persons who do not use language purposefully and may have minimal volitional movement, this paper will assume that individuals with dementia suffer, even in the last stages of the disease. McCarthy, et al.[2] conducted a retrospective study in which people with dementia (PWD) had similar symptoms to cancer patients, but there were differences in that PWD had their symptoms more frequently and for a longer duration than the cancer patients. Unlike persons with cancer who are often considered 'terminal,' lay people frequently do not realize that people with LSD actually are terminal[3-4]. While people with LSD are eligible for the hospice benefit under Medicare, hospice and palliative care are frequently withheld until the person is near death[3], but palliative care should be initiated at diagnosis to help prevent suffering and provide better comfort. Unless culturally or religiously dissuaded, care that is focused on relieving symptoms and providing comfort should be the goal of end-of-life care rather than prolongation of life at whatever cost[5].

This paper will address the following questions: What are the dimensions of the concept of suffering? How will knowing the relationships between the dimensions and qualities of the concept 'suffering' ensure widespread acceptance, understanding, and applicability in research and practice of suffering in individuals with dementia at end of life? The aim of this paper is to analyze and identify dimensions in the concept of suffering for individuals at end of life who have dementia and to establish relationships between the dimensions.

Application to nursing knowledge and clinical applications

Nurses must deal with the suffering of patients on a daily basis, sometimes suffering with them empathically through invasive procedures they know are unnecessary, or with conflicts with their own spiritual and cultural beliefs. Nurses have felt that suffering is difficult to assess[6]. Indeed, instruments have been developed and used to assess suffering in individuals with dementia and have been shown to be reliable indicators of suffering[7-10]. Nurses often provide care that helps patients recapture control over their lives and deal with life's distresses; although this is not always possible in individuals with dementia, nurses can ".... accompany patients on their journey..."[11 (p 110)].

International Relevance of Concept

To date, there is no standard definition of suffering or a consensus as to what constitutes suffering. Suffering is used interchangeably with pain, distress, stress, anxiety, and a myriad of other terms, symptoms, and conditions. Studies have shown that people with dementia suffer[8-10]; however, are the perceptions of suffering accurate, especially from a caregivers' viewpoint? A review of the literature noted a lack of consistency in the manner that suffering is defined[12]. Given recent discussions regarding end of life issues and palliative care with the chronically ill, it is imperative that suffering be defined to ensure that individuals with terminal or chronic conditions maintain quality of life during their illness.

Background

The term suffering is used in all disciplines and a variety of contexts. The medical model tends to look at suffering from physical conditions or symptoms and treatments, which is the paradigm followed by nursing for many years. Cassell[13] pointed out that there has always been a distinction in medicine that separates mind and body. Cassell notes that physicians do not think of suffering abstractly; rather, they tend to provide treatment for a diagnosis in which suffering is associated. Cassell and Rich[14] noted, however, "There is no such thing as a pain or nausea, vomiting, or dyspnea that solely occurs in the body without having an impact on the conscious person…" [p 436]. Suffering is unique to each individual and only the individual can put into context his or her 'suffering'[14-16]. From a nursing perspective, Ferrell and Coyle[11] developed principles of suffering, which define suffering in a different context. Their principles of suffering include the person as a whole and again, only the individual can explain what he or she is feeling; it "… represents a deeply personal state" [p 16]. This suggests a movement to a more holistic approach by both disciplines[11, 13].

Real, everyday situations can have an effect on one's state of suffering[17]. A child's perspective on suffering refocuses from the physical to the psychological realms[17]. A catastrophe, such as an act of terrorism or a tsunami, has been shown to produce a large amount of suffering, not only physically but psychologically as well[18, 19], creating feelings of helplessness and worthlessness. Spiritually, some have suggested that suffering brings people closer to their God and provides meaning to their lives[20], while others view spirituality as influencing the process of suffering[21]. Existential and spiritual suffering are often classified as the same in the literature[12].

Depictions of suffering have also been illustrated in art, religion, and the sciences. Art has been used to depict suffering over the ages. "The Sick Child," painted by Edvard Munch in 1896 is one example (22). The painting shows a young girl (his late sister Sophie, who died of tuberculosis) propped in a chair; an older woman (his aunt Karen) with her head bowed on the arm of the chair holds the girl’s left hand.

Suffering is an essential component in Christianity. While one is suffering, God reveals his love and suffering are replaced with “salvation and cure”[23 (p 234)]. The Buddhists have four noble truths regarding suffering: 1) suffering is part of life; 2) suffering is caused by egocentric yearning; 3) suffering can be stopped; and 4) when suffering ends, true happiness will be revealed[23, 24].

Philosophers and social scientists have termed positive and negative effects as pleasure and suffering respectively. Max Horkheimer negatively viewed happiness as freedom from suffering, although he believed that shared suffering could improve society, that the oppressed’s feelings of compassion as well as one’s own suffering could work together to effect this change[25].

In a concept analysis, Rodgers and Cowles[26] defined suffering as “an individualized, subjective, and complex experience that involves the assignment of an intensely negative meaning in an event or a perceived threat”[p 1048]. Although they felt that their clarification and meaning would advance an understanding of human suffering, the concept continues to be nebulous when viewed from these authors’ perspective. Carnevale[27] argues in his conceptual analysis that suffering is an emotion, which can include physical symptoms such as pain. He also notes that suffering can comprise “expressive behaviors”[27 (p 176)] that are either voluntary, such as calling out, or involuntary, such as moaning[27]. He posits that suffering is a subjective emotion; it cannot be objectively assessed as it is only lived by the person who is suffering.

Data Sources

Concept analysis is one method of clarifying concepts, by defining them in order to use them to develop knowledge[28]. Dimensional analysis is beneficial to researchers when attempting to contextualize and understand the various perspectives of a concept. Dimensional analysis explores how a concept is constructed. The dimensions or qualities of the concept are established and relationships formed between the dimensions or qualities[28]. These dimensions are used to define or develop the essential meanings associated with a concept. In the analysis, explicit and implicit assumptions of suffering will be identified. Caron and Bowers'[28] method of dimensional analysis guided this analysis, as did the theoretical framework of symbolic interactionism. Because social behavior and actions cannot be realized unless their meaning is revealed, symbolic interactionism has an important role in dimensional analysis[28].

Computerized databases were searched, including CINAHL, PubMed, Ovid/Medline, Academic Search Premier, and PsycInfo. Key search terms included *suffering*, *dementia*, and *end of life* singly and then combined. The search criteria used for inclusion and exclusion was very broad in nature because dimensional analysis requires a wide ambit in which to explore the concept. Inclusion criteria were: 1) publication between Jan. 2000- July 2012; 2) English language; and 3) adult participants.

The number of articles found with the term *suffering* alone netted 127,000 publications (see Table 1). When combined with *dementia*, this number dropped significantly to 4,541. Performing a search for all three key words – *suffering, dementia, and end of life* – revealed 326 articles. Reading the abstracts, and in some cases, the entire article, revealed that the majority of the articles did not meet the criteria for inclusion, such as using the term *suffering* in the context of 'suffering with…' rather than using *suffering* as a condition. The number of articles was therefore reduced to 43. The references of these 43 articles were reviewed, and as a result seven additional articles were identified. Of these 50, only those publications of studies conducted on suffering were selected, thus leaving 14 articles for dimensional analysis.

Table 1. Search Results

Database	Suffering	Suffering & Dementia	Suffering, Dementia, & End-of-Life	Reading of abstracts and articles
CINAHL	116	156	16	14
PubMed	97,119	1,628	38	9
Ovid/Medline	1,108	1,414	226	13
Academic Search Premier	23,797	885	25	3
PsycInfo	5,000	458	21	4
Review of references within selected articles				7
TOTAL included for review N = 14				

Theoretical Framework

A major framework of sociological theory, symbolic interaction theory is based on the hypothesis that humans discover and delineate the meaning associated with the world around them through interactions with others. Behavior is defined by symbols or the meanings related to symbols[29]. When humans interact within their environment, their behavior responds to symbols related to those social interactions. Likened to the self-fulfilling prophecy, where predictions come true with the actions of the person, Leming and Dickinson[29] explain: “We define situations as real, and they become real in their consequences”[p 32].

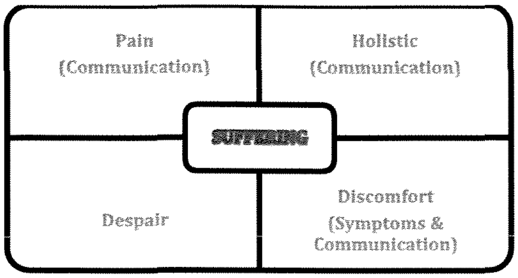
Dimensional analysis is predicated on the theory that concepts are defined within a specific perspective and different meanings are attributed to those meanings based on whose perspective is being represented as well as the context in which it is used (28). Symbolic interactionists believe the meanings of a given situation emerge over time and are based on situations that have occurred in the past and the present during social interactions[30]. By examining the concept through dimensional analysis and symbolic interactionism, new meaning and perspectives can be illustrated.

Hopes of individuals induce responses that corroborate what one originally anticipated, resulting in what some would term the self-fulfilling prophecy. For example, a person with dementia may have expectations of suffering at end of life (EOL). The care providers may have expectations or beliefs that people with dementia do not suffer at EOL, and may be oblivious to the person's suffering. When suffering is not recognized and therefore not alleviated, the individual's fears or responses are confirmed. However, it is difficult for providers to make a connection with PWD when PWD have little to no purposive language therefore providers have limited interactions with which to evoke meaning.

Results

Four dimensions and two subdimensions were identified during the analysis (See Figure 1). These dimensions and subdimensions (in parentheses) were: pain (communication); holistic (communication); discomfort (symptoms and communication); and despair. While some of the authors whose manuscripts were included in the analysis considered a certain dimension as suffering, other authors did not and thus suffering was inferred from the authors' discourse.

Figure 1. Dimensions of Suffering Model



Pain (Communication)

Questions have been raised whether people with dementia have pain, especially in late stage dementia when individuals are unable to purposefully communicate their needs. Two articles were identified relating *pain* to suffering as a dimension. Husebo and colleagues[31] found that patients with severe dementia did not experience less pain intensity than those with mild, moderate, or no dementia. In fact, those with severe dementia on opioids were assessed as having greater pain intensity than patients with no dementia. Their findings suggest that suffering is complex, including under-treatment of pain. Nourhashemi et al.[32] conducted a two-year study, which showed that patients who may have been suffering were not given pain medications. Pain was assessed and documented by the patients' caregivers or care provider with "an 8-item behavioral scale to rate the intensity of pain in non-verbally communicating patients. The scale is divided into two parts (before and during nursing care) and scored from 0-4"[32 (p 458)]. Out of 112 subjects in the study, 32% of patients with advanced dementia with a pain score of 7 or greater received no analgesics. The authors' findings suggest that adequate treatment of pain may relieve suffering and possibly decrease or prevent behavioral issues. The observation scales used in both of these studies were documented by caregivers of the patients, leading to possible variations in observed behaviors. Nourhashemi et al.[32] also noted that patients with varying types of dementia may exhibit different facial or behavioral expressions and may not receive the same treatment as other individuals with dementia. Both of these studies suggest that pain in individuals with dementia may go untreated due to this lack of ability to purposefully communicate.

Holistic (Communication)

Suffering encompasses more than just physical disorders; it also involves individuals' perceptions or beliefs and interactions with others. Therefore, suffering should be evaluated not from one single aspect but the perspective of the entire being[7-9, 10, 33], thus suffering is *holistic*. Schulz, McGinnis et al.[9] noted suffering was moderate to high in the emotional and existential aspects of suffering, such as sadness, depression, hopelessness, worthlessness, and feelings of being a burden. Because their study showed a correlation between caregiver depression and patient suffering, results suggest that goals should be aimed at eliminating suffering, which will "require monitoring of patient affect, physical symptoms, and their spiritual/existential concerns…"[9(p 175)]. While Schulz, McGinnis, and colleagues[9] conducted their study with a validated instrument (Revised Memory and Behavior Problems Checklist), Schulz, Monin et al.[10] developed an instrument to measure suffering from three domains: physical, psychological, and existential suffering. These authors felt that suffering is more than just physical attributes the patient may have and that suffering results from processing information from all domains. Three different groups were used in their study: individuals with Alzheimer's disease; patients with osteoarthritis and their spouses; and caregivers of individuals with Alzheimer's. The first sample, individuals with Alzheimer's, were able to self-report their suffering, according to the authors. The authors' results showed that caregivers overestimated the degree of suffering of patients who self-reported[10]. While the authors' instrument can be used for self-reporting, individuals with late stage dementia (LSD) are unable to purposefully communicate their needs, and therefore the instrument would be used based on observation; observation as well as caregivers' perceptions are subjective.

Aminoff et al.[7] also developed an instrument to measure suffering in LSD patients and used it to assess patients in a memory clinic. This instrument was also used to study the level of suffering during the final hospital stay of patients with dementia[8] and again in a study to evaluate the relationship between the level of suffering and survival rates of patients with LSD dementia[33]. As with Schulz, McGinnis et al.[9], who felt that continuous monitoring is needed for the elimination of suffering, Aminoff and colleagues[7] felt that their instrument will be beneficial in providing continuous monitoring and control of suffering. However, the authors' beliefs that suffering should encompass the domains of physical, psychological, and spiritual suffering is not evidenced in their 10-item instrument, which embraces only the physical domain and is based on observation with eight of the items; the last two items are based on subjective opinions from medical staff and caregivers.

Discomfort (Symptoms and Communication)

Discomfort is generally associated with a lack of comfort or making someone feel bad. While pain can be discomfort, *discomfort* as a dimension of suffering (distinct from pain) was identified in five studies[34-38]. Indeed, in the study conducted by van der Steen, Ooms, et al.[37], one of the research questions addressed was "Is suffering (discomfort) due to pneumonia recognizable in demented nursing home patients and is this different in differing treated patients?"[p 1682]. The studies identified for this dimension showed an association between symptoms, such as dyspnea, fever, drowsiness, fear, anxiety, agitation, aspiration, pressure ulcers, and discomfort[34-38].

Van der Steen, Ooms et al.'s[37] study revealed that suffering is more severe right before death from pneumonia than from other causes because of the discomfort associated with pneumonia symptoms. They also concluded that those patients not treated with antibiotics had more discomfort than those treated with antibiotics. While Givens et al.[35] found that antibiotics were not associated with improved comfort in nursing home patients, van der Steen, Pasman et al.'s[38] study did find a correlation between the use of antibiotics and decreased discomfort and felt that pneumonia was a cause of increased suffering. The authors' study also revealed that discomfort with pneumonia was higher than in patients with issues with intake of food and fluids.

In their Italian study, Guilio et al.[34] focused on the last month of life for severely demented older adults. Results of this retrospective study revealed that 124 out of 141 patients were noted to be in discomfort due to severe symptoms. Physical restraints, causing discomfort, were used in 58% of the patients and 29 of the patients were artificially fed through a tube. The authors also noted that 88% of the patients studied had experienced severe physical symptoms such as dyspnea, fever, bedsores, emesis, etc. during the month prior to death[35]. In a study conducted by Mitchell et al.[36], symptoms were also the focus of the study. Over the course of 18 months, the study revealed that 55% of nursing home residents died[36]. Of those, 46% had dyspnea, 39% had Stage II or greater pressure ulcers, 54% had agitation, and 41% aspirated. Among the residents who died, the percentage of residents who had those symptoms increased as end of life drew nearer. The authors found that health care proxies felt the main goal of care should be comfort but noted that, "physical suffering was common among residents"[36 (p 6)].

Most of these studies[35-38] used instruments that relied on observation or evaluation and proxy reporting by care providers due to the individuals' inability to purposefully communicate their needs. Guilio et al.[34] used chart reviews, but focused on physical symptoms, treatments, and life-sustaining procedures to gather their data. None of the authors examined how important communication was in addressing discomfort of symptoms at end of life in dementia patients but all felt that alleviating symptoms is essential at end of life.

Despair

Two studies linked suffering to being unbearable and hopeless[39-40]. Hopelessness implies despair, especially if one has a terminal illness, as there appears to be no hope. The studies by these authors were conducted in The Netherlands where advance directives for euthanasia (ADEs) in dementia are legal. These directives, however, have strict criteria for implementation, including "the physician is convinced that the patients suffering is unbearable, and that there is no prospect of improvement"[39 (p 257)]. The results of the study by de Boer et al.[39] revealed that more than half of the physician participants (n = 434) felt it was impossible to know if someone who is cognitively impaired experiences hopeless and unbearable suffering. A little more than one third of the physicians felt that severe suffering in a patient with advanced dementia was the result of additional illnesses rather than dementia itself; however, 40% of the participants disagreed with this statement. In the study by Rurup et al.[40], even though most of the nursing home physicians (n = 410) thought there was some degree of unbearable and hopeless suffering in the patients with dementia (n = 40), the nursing home did not comply with ADEs. Their survey was divided into unbearable and hopeless suffering, which was rated from 'did not' to 'to a very high degree.' Nine of the nursing home physicians felt their patients suffered unbearably to a high or very high degree, while 18 were of the opinion that their patients suffered hopelessly to a high or a very high degree. These studies revealed that physicians did feel that patients with dementia are suffering, but to what extent remains unclear, potentially leaving the patients in despair (See Table 2 for matrix of studies).

Table 2. Dimensional Analysis of Suffering.

Authors	Dimensions	Research Question/Purpose	Method	Sample	Outcomes/Measure	Relationship to Dimension
Aminoff & Adunsky (2005)	Holistic	Evaluate the suffering of terminal dementia patients over time (Israel)	-Evaluated upon admission and weekly (Mini-Suffering State Examination [MSSE]) scale -tool used to measure suffering (low 0-3; mid-range 4-6; high 7-10) -other data such as lab results, medications, etc.	-71 ESD patients (28 women, 43 men) -admitted to geriatric ward with diagnosis of dementia (Mini-Mental State Examination)	-Mean MSSE scores increased from 5.62± 2.31to 6.89±1.95 during last week of life -most patients died with a MSSE score in the high range (45/71 or 63%).	-Dementia patients unable to communicate their physical, emotional, or spiritual needs -unable to communicate the amount of suffering they are enduring.
Aminoff & Adunsky (2006)	Holistic	Investigate true ESD patients and the possible interrelations existing between the level of suffering and survival of the patients (Israel)	-Evaluated upon admission with the MSSE scale	-134 ESD patients (74 males, 60 females) -admitted to geriatric ward -diagnosis of dementia -died while on the unit	-Mean survival time shorter for those with high MSSE scores (upon admission to the unit). -Survival time was 57.7±9.7 days in those with a low score (0-3) as compared to 27.5±4.1 days in those with a high score (7-10).	-Dementia patients are unable to communicate their physical, emotional, or spiritual needs -unable to communicate amount of suffering being endured -Study is important for initiating palliative care for those with dementia
Aminoff, Purits, Noy, & Adunsky (2004)	Holistic	Evaluate the inter-observer reliability and validity of a tool designed to clinically evaluate suffering of ESD patients – Mini-Suffering State Examination (MSSE). [Israel]	-Patients examined by two physicians independently -MSSE used -other data (lab results, medication, and if patient had feeding tube	-103 ESD patients (45 males, 58 females) with diagnosis of dementia	-Total MSSE scores were 4.8±2.5 and 4.42.4 by Physician 1 and Physician 2 respectively -high Pearson's correlation (*r* = 0.929). -Cronbach *a* coefficients were	-Suffering includes perceptions, emotions, and thoughts -dementia patients are unable to communicate these at end of life.

					0.735 and 0.718	
de Boer, Droes, Jonker, Eefsting, & Hertogh (2010)	Despair	Obtain insight into current practices regarding advanced directives for euthanasia (ADE) and euthanasia in incompetent patients (Netherlands)	-Questionnaire given to all elder care physicians caring in Netherlands -questions pertained to incidence of ADEs among PWD -cases of euthanasia based on ADE	-434 physicians completed questionnaire (42%)	-89% of the physicians surveyed treated PWD -only 3 of the physicians indicated use of medication for intent of ending life. - -due care requirements of ADEs include patient's suffering is unbearable -54% of physicians' opinions due care requirement impossible to determine due to mental capacity	-Suffering may be considered unbearable and hopeless -leads to despair, causing more suffering. -PWD are unable to communicate their despair.
Giulio, Toscani, Villani, Brunelli, Gentile, & Spadin (2008)	Discomfort	Describe the last month of life of severely demented elders in LTC institutions and clinical decisions in management of their EOL events (Italy)	-Retrospective exploratory study -diagnosis, MMSE, and cause of death -data collected from records referring to last 30 days of life	-141 eligible patient records out of 476 deaths (29.6%)	-124 patients (88%) experienced severe symptoms -nearly ½ suffering dyspnea -most frequently reported symptom drowsiness -physical restraints were used in 58.2% of patients -29 patients were artificially fed (NG, PEG)	-Attention to suffering was fair -uncomfortable procedures and symptoms (not necessarily pain) described in the last 48 hours of patients' lives.
Givens, Jones, Shaffer, Kiely, & Mitchell (2010)	Discomfort	Examine effect of antimicrobial treatment for suspected pneumonia on survival and comfort in patients with advanced dementia (US)	-Baseline resident data, quarterly medical record reviews, nurse interviews, brief clinical examination	323 NH residents from - 22 nursing facilities -participants recruited from the Choices,	-133 residents experienced 225 episodes of pneumonia with only 8.9% of episodes not treated with antimicrobials	-higher the aggressive treatment the more severe the residents' discomfort.

			-subjects followed 18 months or until death -health care proxies' (HCPs) data obtained at baseline, quarterly via phone -comfort evaluated by the Symptom Management End-of-Life in Dementia (SM-EOLD) scale	Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study	-improved survival noted with antimicrobials vs no antimicrobial -SM-EOLD scores were highest (meaning greater comfort) among episodes not treated with antimicrobials	
Husebo, Strand, Moe-Nilssen, BorgeHusebo, Aarsland, & Ljunggren (2008)	Pain	Explore the relationship between nursing home patients with different stages of dementia and different dementia diagnoses and use of pain medication according to pain intensity (Norway)	-Cross-sectional study -data extracted from medical records -pain intensity assessed with Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID-2);	-181 residents at Norwegian NH -admitted to rehab unit, skilled nursing unit, palliative care unit -dementia diagnosed by 4 physicians with ICD-10 and DSM-IV -various stages of dementia were included	-Patients with severe dementia have less pain intensity compared to other stages of dementia -severely demented patients receiving opioids demonstrated higher pain intensity than non-demented patients (mean 4.4 vs 2.9, respectively) and received less pain treatment	-Suffering caused by pain -patients with severe dementia at high risk for severe pain, resulting in suffering -adequate pain management may relieve unnecessary suffering.
Mitchell, Teno, Kiely, Shaffer, Jones, Prigerson, Volicer, Givens, & Hamel (2009)	Discomfort	To better understand the clinical trajectory of ESD to help improve the care of patients with this condition (US)	-Data obtained from CASCADE study participants and their families	-323 NH residents from 22 nursing facilities	-55% of residents died over 18 months -46% of residents had dyspnea -39% had pain -39% had pressure ulcers (stage II or higher) -54% had agitation -41% had aspiration	-Discomfort common in ESD patients -discomfort increases as death approaches -burdensome interventions at EOL increase discomfort.

					- symptoms increased as EOL approached -30% of these residents received hospice referrals	
Nourhashemi, Gillette, Cantet, Stilmunkes, Saffon, Rouge-Bugat, Vellas, & Rolland (2012)	Pain	To better understand the clinical trajectory of advanced dementia and to identify palliative care needs of these patients (France)	-Observational prospective study -followed quarterly during 2 years -interviews provided data regarding pain (Elderly Pain Caring Assessment scale) -Alzheimer & FIN de viE (ALFINE) study	-112 patients (77% women) recruited from geriatric wards	-Pressure ulcers noted in 42 patients -pain assessment mean score of 8.58 -32% of patients with scores more than 7 had no analgesics -of these patients 23 had pressure ulcers	-Suffering caused by pain -patients with severe dementia at high risk for severe pain resulting in suffering -adequate pain management may relieve unnecessary suffering.
Rurup, Onwuteaka-Phillipsen, van der Heide, van der Wal, van der Maas (2005)	Despair	Estimate the incidence of compliance with advance euthanasia directives of patients suffering from dementia; to gain knowledge about experience of physicians (Netherlands)	-Retrospective interview study -semi-structured interviews	-410 physicians (NH physicians = 77; general practitioners = 125; and specialists = 208) -40 patients with dementia discussed in the interviews	-63% physicians said they may comply with advance euthanasia directive if the patient suffered unbearably and hopelessly as a consequence of an additional disease -in 26/39 cases NH physicians' opinions that the patient experienced states in which the ADE was intended -and applied more often if the patients' suffering was severe -in 13 cases, physicians did not agree (patient was not suffering unbearably)	-Suffering considered unbearable and hopeless -leads to despair -causing more suffering -PWD are unable to communicate their despair.
Schulz,	Holistic	Assess the relationship	-Cross-sectional,	-1222 dementia	-High percentage of	-Dementia patients

McGinnis, Zhang, Martire, Hebert, Beach, Zdaniuk, Czaja, & Belle (2008)		between dementia patient suffering, caregiver depression and antidepressant medication use (US)	longitudinal analysis -participants from Resources for Enhancing Alzheimer's Caregiver Health (REACH) study -MMSE -suffering assessed with depression subscale (9 items) of Revised Memory Behavior Problems Checklist (RMBPC) -caregivers answering survey -RMBPC subscales for memory problems (7 items) and disruptive behavior (8 items)	patients and their caregivers from 6 sites in multiple states over 4 years (1996-2000)	caregivers reported patient exhibited anxiety (64%). sadness and depression (63%) -caregivers reported that the patient exhibited hopelessness (35%), feelings of worthlessness or being a burden (28%); crying and tearfulness (27%)	unable to communicate physical, emotional, or spiritual needs -unable to communicate amount of suffering -caregivers perceive patients with dementia to have holistic suffering.
Shulz, Monin, Czaja, Lingler, Beach, Martire, Dodds, Hebert, Zdaniuk, & Cook (2010)	Holistic	Assess psychometric properties of scales developed to assess experience and perception of physical, psychological, and existential suffering in older individuals	-3 scales to assess three domains of suffering (physical, psychological, and existential) -scales administered to 3 different populations and/or their family members -those receiving care completed self-report -caregivers rated perceived suffering of care recipients	-Sample 1 -105 dyads individuals with Alzheimer' s disease and caregivers -Sample 2 - 53 dyads married couple with 1 partner with osteoarthritis -Sample 3 - 121 African-American and Hispanic caregivers of individuals with	Cronbach's *a* 0.83 for all samples, except for osteoarthritis patients, alpha of .77 for existential suffering -caregivers for the Alzheimer's patients in Sample 3 rated care recipient's suffering significantly higher on all three scales	-Dementia patients unable to communicate their physical, emotional, or spiritual needs -unable to communicate amount of suffering -caregivers perceive patients with dementia to have holistic suffering.

				Alzheimer's		
van der Steen, Ooms, van der Wal, & Ribbe (2002)	Discomfort	Assess suffering in demented nursing patients with pneumonia treated with antibiotics or without antibiotics (Netherlands)	-Prospective cohort study -observational scale Discomfort Scale – Dementia of Alzheimer Type (DS-DAT; 0-27) -assessed at time of pneumonia treatment, quarterly or until death	-662 patients with dementia in psychogeriatric wards of 61 nursing homes	-Patients treated with no antibiotics showed a higher discomfort level throughout the study -increase in discomfort from 2 weeks before treatment decision similar in no antibiotics patients and those with antibiotics (3.6 and 4.4 respectively) -breathing problems most prominent symptom -discomfort higher shortly before death when pneumonia was the cause of death.	Discomfort is common in ESD patients and increases as death approaches. Burdensome interventions at EOL for treatment of illnesses incurred near end of life increase this discomfort.
van der Steen, Pasman, Ribbe, van der Wal, & Onwuteaka-Philipsen (2009)	Discomfort	To compare discomfort in dementia patients dying after a pneumonia with patients dying after intake problems; to assess associations with treatment	-Combined 2 Dutch prospective studies – Pneumonia Study and Artificial Nutrition and Hydration Study (ANH Study) -used the Discomfort Scale – Dementia of Alzheimer Type (DS-DAT)	Pneumonia study had 61 NHs and ANH study had 39 -683 patients from pneumonia study (out of original 706) -all 190 patients of ANH study selected based on physician's diagnosis of dementia	-linear regression unadjusted and adjusted, discomfort in patients with pneumonia was higher both at t0 and before death -in adjusted analysis antibiotic treatment associated with less discomfort (β – 3.5, CI -2.2- -0.03) -invasive rehydration associated with more discomfort (β – 3.5, CI 0.6-6.5)	-Discomfort common in ESD patients -increases as death approaches -burdensome interventions at EOL near end of life increase discomfort.

Perspective

While there are many studies in the literature on suffering that encompass many illnesses and catastrophes, relatively few studies have been published on the suffering of patients with dementia. Most of the studies in this analysis focused on the patients' perspective of suffering, usually from observation rather than through communication with the patient[7-10, 31-32, 34-38]. It is difficult to assess those who do not use language purposively, such as individuals with LSD. Shulz, McGinnis et al.[37] and Shulz, Monin et al.[38] also provided perspectives from caregivers in their studies, assessing the caregivers' perceptions of their loved ones' suffering. Providers' perspectives were studied by de Boer et al.[39] and Rurup et al.[40], but focused on whether the providers felt that suffering was unbearable and hopeless and their thoughts on euthanasia in PWD. There were no studies found that focused on nursing's perspective regarding suffering in PWD.

Contextual Elements

Most of the studies selected for this analysis were conducted with nursing home residents[31, 34-38] or in hospital geriatric wards[7, 32]. The two studies by Shulz, McGinnis *et al.*[9] and Shulz, Monin et al.[10] were conducted in the community setting and the PWD were assumed to be living at home. Although the same vulnerable population participated in all of the studies, one cannot exclude that the hospital-based participants may have been more acutely ill than those in the nursing home or in the community settings. de Boer et al.[39] and Rurup et al.[40] conducted studies with physicians who were practicing in the community and within nursing home settings to determine their opinions and use of advance directives for euthanasia in dementia (ADEs). In Rurup et al.'s[40] study, nursing home physicians were interviewed more comprehensively than the other physicians, but only about their most recent case with a resident with dementia who had an advance directive for euthanasia.

Assumptions

An explicit assumption is that suffering can be measured in PWD. Aminoff, et al.[7] and Aminoff and Adunsky[8, 33] used scales that observed PWD's suffering and assessed the opinions of family and health care providers. Shulz, Monin et al.'s[10] study was based on the caregivers' perceptions of the PWD's suffering as noted in the scales developed by the authors.

An implicit assumption identified is that PWD do not suffer. Based upon the observations and assessments of Aminoff et al.[7] and Aminoff and Adunsky[8, 33], that assumption seems unwarranted. Shulz, Monin et al.[10] developed scales to measure physical, psychological, and existential suffering that were self-administered, rating their own suffering. One group had Alzheimer's disease and was deemed capable (by 3-minute interview) of answering their own questions, while caregivers of another Alzheimer's group answered for the individual based on their observations and perceptions of the individual's suffering. In another study, Shulz, McGinnis et al.[9] had caregivers assess the PWD's emotional and existential suffering using the Revised Memory and Behavior Problems Checklist (RMBPC). These patients had moderate to severe cognitive impairment and the caregivers, again, completed the instruments based on their perceptions of the PWDs' suffering.

Another implicit assumption is that providers will alleviate suffering at EOL. However, in de Boer et al.'s study[39], more than half of the physicians felt it was impossible to determine whether a person with cognitive impairment is suffering unbearably or hopelessly. Close to one third of care providers for older adults believed that severe suffering is a direct cause of additional illnesses or complications that are untreatable[39].

Although observation may be able to partially address suffering in PWD, it only addresses the physical or clinical aspects of suffering. In addition, even though family caregivers have discussions with PWD prior to their losing their cognitive awareness, the dimensions of suffering may change during the course of the disease and the caregivers' perceptions may not be accurately portraying the suffering of PWD, especially under the holistic dimension.

Discussion

Although not considered a terminal diagnosis by many, for those who are given a diagnosis of dementia, the realization that they will most likely die from this distressing illness is real. They acquire their thoughts and ideas from interactions with others and the environment and give new meanings to their diagnosis and the suffering they will endure. The meanings for this particular situation, according to symbolic interactionists, developed from the individuals' experiences over the past and during the present[30] but are defined by the individual[41]. Although not communicated, the meanings are validated when health care providers fail to understand the meanings defined by the individual, resulting in a self-fulfilling prophecy and suffering by the individual.

This dimensional analysis identified four dimensions of the concept of suffering as it relates to end of life in individuals with dementia. The relationships of these dimensions should be considered when evaluating one's suffering in individuals with dementia, especially since individuals with late-stage dementia are usually unable to communicate their needs. The data gathered from this analysis reveal that individuals with dementia do suffer in all aspects of their lives and assessment and evaluation of their suffering needs to be consistent, personalized, and encompass all of the identified dimensions.

In addition, two subdimensions were discovered that were deemed important. Communication is a significant sub-dimension that has important implications related to individuals with dementia, especially at end of life, as these individuals are not able to purposefully communicate their needs. Discomfort was identified from authors who used symptoms assessment in their studies, and while not all of the studies focused on suffering, suffering could be inferred from their results.

Limitations

Although an exhaustive search was carried out for studies that explored suffering in PWD at EOL, it is possible that significant articles have been missed. The search was limited in that there are relatively small numbers of studies conducted on PWD, especially with regard to suffering at EOL. In addition, because this analysis was theoretically based, other researchers may interpret the concept differently and produce different results and conclusions.

While results of studies using observations scales were deemed valid by the researchers, the use of observation scales in measuring suffering is subjective. Carnevale[27] acknowledges that suffering is also subjective based on the person's experience and therefore cannot be measured objectively or "validly assessed by another"[p 177].

Conclusion

Suffering has not been clearly defined yet in the literature; however, suffering is unique to each individual and needs to be consistently assessed. The issue of suffering affects everyone at EOL, but particularly PWD, because they often are not able to communicate their needs effectively and most often, not at all. Although a specific conceptual definition cannot be agreed upon, health care researchers need to develop an instrument aimed at measuring all dimensions of suffering from a holistic approach so suffering for that individual can be eased or relieved.

These dimensions should be aimed at the physical and psychological aspects as well as existential and spiritual domains. Efforts should be made to assess individuals' perceptions of suffering to ensure PWD are treated effectively at EOL.

The concept of suffering is complex and multifaceted and takes on several dimensions. Understanding the dimensions of suffering provides insight into the individual with dementia as a person and not the disease and helps alleviate the suffering of not only the patient but the family and perhaps the care staff as well. A dimensional analysis of suffering was not found in the literature; therefore this analysis may represent relatively unfamiliar views. However, the analysis reveals that these dimensions are not well explored in the literature and establishes the importance of further research in this area.

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MANUSCRIPT 2 – Descriptive Study/Instrument Reliability

Submitted:

Smith, L., Amella, E. J., Mueller, M. Instrument Development and Measurement of NC Home Health Nurses' Knowledge of Artificial Nutrition and Hydration at End of Life. *Research in Nursing and Health.*

Instrument Development and Measurement of NC Home Health Nurses' Knowledge of Artificial Nutrition and Hydration at End of Life.

Introduction

Providing food and fluids is considered an essential part of life, especially in the sick. In the terminally ill, poor intake is often common, due in part to the dying process (Raijmakers, et al., 2011). The lack of intake can be related to a variety of reasons, such as apraxia, appetite loss, dysphagia, or aspiration (Ferrell & Coyle, 2010). These conditions raise the issue of starvation (Suter, Rogers, & Strack, 2008) and can cause much distress among those who must make the decision whether to initiate artificial nutrition or hydration.

Artificial nutrition and hydration (ANH) has become a complex and an ethical issue for the dying (Geppert, Andrews, & Druyan, 2009; Holmes, 2010). There are confusing opinions as to the whether ANH is of benefit to dying individuals, which results in inconsistent communication by health care providers (Dev, Dalal, & Bruera, 2012). In turn, inconsistencies in information from their health care providers result in confusion for the patients and families having to make decisions regarding ANH.

Decisions regarding ANH become challenging when the person or persons making the decisions are not well informed of the consequences or the risks involved, or even the reason why ANH should be initiated or withheld (Biola, et al., 2007; Vitale, et al., 2006; Shega, et al., 2002). Todd, Rosendaal, Duregon, & Verhoef (2005) found in their mixed-method study that nurses feel they have a role in the ANH decision-making process, for example as educator. Indeed, Pasman, et al. (2004) found that nurses spend more time with the patients than physicians and develop a more trusting relationship with the patients and their families. For nurses in home health, their autonomous roles accentuate this finding.

In their qualitative study, Bryon, de Casterlé, & Gastmans (2011) found that nurses tend to have moral and ethical conflicts regarding ANH at end of life, such as providing basic care over patient suffering. This lack of knowledge regarding benefits and burdens of artificial nutrition and hydration (ANH) at end of life can create barriers to a quality end of life. Patients and their families frequently rely on nurses to discuss and provide answers to their questions after their physicians have informed them about ANH. However, nurses often have little to no, or incorrect information, regarding ANH, and decisions regarding nutrition at end of life may be affected by this lack of information (Ke, Chiu, Hu, & Lo, 2008).

Ke, et al. (2008) developed a questionnaire aimed at examining the knowledge of nurses in a veterans hospital in Taiwan. Their study revealed that nurses appear to have inadequate knowledge of ANH while also having misconceptions about ANH and its effects on the terminally ill. This led the investigators to conclude that nurses have insufficient knowledge to provide terminally ill individuals and their families when making these important decisions (Ke, et al., 2008). Home health nurses have a crucial role in collaborating, supporting, and teaching patients and families in end-of-life issues and care (Suter, Rogers, & Strack, 2008). More terminally ill individuals are dying at home (National Center for Health Statistics, 2010) and ANH for the terminally ill is now frequently delivered in the home (Suter, Rogers, & Stack, 2008). Knowledge of current evidence regarding ANH may be lacking among home health nurses, leading to inappropriate education of individuals and their families, causing more distress than comfort at end of life.

The Knowledge of Artificial Nutrition and Hydration (ANH) in the Terminally Ill (Knowledge Test) used in this study was adapted from Ke, et al.'s (2008) questionnaire. The questionnaire contains three information questions related to professional characteristics and 23 questions on ANH. The purpose of this pilot study was two-fold: to determine the reliability of the instrument, Knowledge Test (adapted from Ke et al., 2008), while also assessing North Carolina (NC) home health nurses' knowledge of ANH.

Methods

Sample

Home health nurses (HHNs) in western North Carolina were recruited for this study from eight home health agencies (HHAs) in the area. Eligibility criteria included being a registered nurse (RN), age 21 years or older, and able to communicate in English. The Knowledge Test (adapted from Ke et al., 2008) was used to assess the knowledge of the HHNs regarding ANH. The questionnaire was distributed to home health nurses at their agency office immediately after their weekly or monthly staff meetings. Some agencies employ both hospice and home health nurses, but the departments are separate and only nurses in the home health departments were given the questionnaires. Envelopes containing the questionnaire, a stamped, self-addressed envelope, and a business card for the Principal Investigator (PI) were handed to the nurses with instructions to return within a specified time frame. The business cards had a specific code for the agency and the nurses were to write a code (unique to themselves) on the card for a drawing for a $10 gift card per each participating agency. Institutional review board (IRB) through the Medical University of South Carolina gave approval for the study and 91 questionnaires were distributed to the nurses.

Measurement

In the study by Ke, et al. (2008) in which the original questionnaire was used, the authors reported a Kuder-Richardson 20 score of 0.68 for 15 items, an acceptable score of consistency between items. Six experts in the area of terminally ill and end of life assessed content validity for the Knowledge Test (adapted from Ke et al., 2008). Based on the recommendations of the experts, revisions to the questionnaire were completed. For example, in the original questionnaire, artificial nutrition and hydration were combined in one statement. One recommendation by the content experts was to separate these into two statements, as the nurses might answer the question differently as to one over the other (nutrition over hydration and vice versa). The professional characteristics variables included the nursing degree held, number of years employed as a RN, and number of years employed in home health. The other items on the questionnaire (questions 4-26) pertained to information about ANH and were scored as 'true,' (2) 'false,' (1) and 'don't know' (0).

Statistical Analysis

For analysis purposes, reverse scoring was used for items 4, 5, 6, 7, 8, 9, 11, 12, 13, 14, 16, 19, and 20. Degree was dichotomized recoded into less than BSN versus BSN and higher. Instrument reliability was measured using Cronbach's alpha coefficients for internal consistency for all questions except demographics. Analysis of data was conducted using SPSS v. 21 (SPSS, Inc., Chicago, IL). Frequency distribution was used in the analysis of all variables. Significance was defined as p value of 0.05 or less.

Results

Thirty-three home health nurses completed and returned the questionnaire. Table 1 reports the demographic characteristics of the respondents. The highest degree among the nurses was a bachelor of science (BSN). Three nurses identified their nursing degree as a diploma degree and one answer was missing. The number of years' experience as a nurse ranged from 1 to more than 20 years, with 45% of the nurses reporting greater than 20 years experience. Twelve nurses worked in home health for 1-5 years, while three nurses worked in home health less than one year.

Table 1. Professional Characteristics

Characteristics	Frequency	Percentage
Degree		
Unknown	1	3%
ADN/Diploma	22	67%
BSN	10	30%
Years as RN		
<20	18	55%
>20	15	45%
Years in Home Health		
<5	15	45%
>5	18	55%

Internal consistency was assessed using Cronbach *a*, which is noted as a number between 0 and 1. Internal consistency, as described by Tavakol and Dennick (2011), is the level in which "all of items on a test measure the same concept or construct and hence it is connected to the inter-relatedness of the items within the test" (p. 53), or a test of homogeneity between items. Cronbach's *a* for the Knowledge Test was 0.71, an indication of adequate internal consistency. Individual analysis of each item was conducted and results revealed no significant increase in the Cronbach *a;* questions 15, 24, and 25, if deleted, would result in a Cronbach *a* of 0.72, 0.73, and 0.73 respectively.

The top four accurate answers were in response to question 21, "The provision of either artificial nutrition or hydration lowers the anxiety of patients and their loved ones" (90.9%); question 26, "Invasive procedures, such as placement of feeding tubes, cause pain and discomfort in terminally ill patients" (78.8%); and questions 5, "Artificial hydration is beneficial for terminally ill patients" and 25, "In terminally ill patients, fluid overload is likely to result in pleural effusion or pulmonary edema" (both 75.8%; see Table 2). The three items that were least accurately answered were in response to question 13, "Terminally ill patients are often hungry" (9.1%); question 10, "Artificial nutrition replacement can result in tumor growth" (18.2%); and question 16, "Ketoacidosis as a consequence of lack of eating often results in an increase in physical pain in terminally ill patients" (24.2%; see Table 2). The mean total score of the Knowledge Test was 32.3 (SD 5.27; range 21-42); the highest score possible was 46.

Table 2. Results of Knowledge Test

Questions	Correct Answers N (%)	Incorrect Answers N (%)	Don't Know N (%)
4. Artificial nutrition is beneficial for terminally ill patients.	22(66.7)	11(33.3)	0
5. Artificial hydration is beneficial for terminally ill patients.	25(75.8)	8(24.2)	0
6. Artificial nutrition can improve the strength of terminally ill patients.	21(63.6)	9(27.3)	3(9.1)
7. Artificial hydration can improve the strength of terminally ill patients.	23(69.7)	7(21.2)	3(9.1)
8. Artificial nutrition replacement is necessary in preventing terminally ill patients from starving to death.	16(48.5)	16(48.5)	1(3.0)
9. Artificial hydration replacement is necessary in preventing terminally ill patients from starving to death.	13(39.4)	18(54.5)	2(6.1)
10. Artificial nutrition replacement can result in tumor growth.	6(18.2)	15(45.5)	12(36.4)
11. Artificial nutrition replacement signifies empathy and care for the patient from medical personnel and family members.	17(51.5)	12(36.4)	4(12.1)
12. The sensation of mouth dryness and thirst in terminally ill patients is mainly caused by dehydration.	14(42.4)	16(48.5)	3(9.1)
13. Terminally ill patients are often hungry.	3(9.1)	27(81.8)	3(9.1)
14. Artificial nutrition replacement can improve hunger status in terminally ill patients.	12(36.4)	17(51.5)	4(12.1)
15. Aggressive nutritional support by tube feeding cannot change the nutritional status or the weight of terminally ill patients.	12(36.4)	19(57.6)	2(6.1)
16. Ketoacidosis as a consequence of lack of eating often results in an increase in physical pain in terminally ill patients.	8(24.2)	15(45.5)	10(30.3)
17. Artificial nutrition can prolong the life of terminally ill patients.	11(33.3)	20(60.6)	2(6.1)
18. Artificial hydration can prolong the life of terminally ill patients.	10(30.3)	21(63.6)	2(6.1)
19. Artificial nutrition improves mouth dryness and thirst in terminally ill patients.	10(30.3)	19(57.6)	3(9.1)
20. Artificial hydration improves mouth dryness and thirst in terminally ill patients.	16(48.5)	13(39.4)	4(12.1)
21. The provision of either artificial nutrition or hydration lowers the anxiety of patients and their loved ones.	30(90.9)	2(6.1)	1(3.0)
22. The provision of either artificial nutrition or hydration aids in developing trust from terminally ill patients and their family members.	17(51.5)	11(33.3)	5(15.2)
23. Providing either artificial nutrition or hydration can prevent despair from worsening in terminally ill patients.	9(27.3)	16(48.5)	8(24.2)
24. Activities of terminally ill patients are restricted by in-dwelling tubing.	14(42.4)	19(57.6)	0
25. In terminally ill patients, fluid overload is likely to result in pleural effusion or pulmonary edema.	25(75.8)	3(9.1)	5(15.2)
26. Invasive procedures, such as placement of feeding tubes, cause pain and discomfort in terminally ill patients.	26(78.8)	6(18.2)	1(3.0)

ANH knowledge was compared via *t*-test for the group with degrees less than BSN vs. BSN or higher degree and with home health experience less than 20 years and 20+ years. The results for the degree comparison revealed there were no statistically significant differences in the means between the two groups in all questions ($p = < .05$). Higher scores, however, were associated with being in the group 'BSN or higher' degree with five of the questions (14, 16, 22, 23, and 24). A small sample size may have contributed to the lack of statistical significance. There was a statistical significance noted between the HH experience groups, although with only two of the questions (12 and 24, where $p = 0.28$ and 0.15 respectively). These questions deal with empathy (question 12) and despair (question 24) in patients and families regarding ANH, which may suggest that nurses with more experience are better prepared to handle these situations than those with less experience.

Discussion

There is little to no literature about nurses' knowledge regarding ANH in the literature and a search revealed no studies conducted in the United States on both nutrition and hydration. This pilot study examined home health nurses' knowledge of ANH in the terminally ill and found their knowledge to be inadequate in several areas. These results are consistent with findings from other research (Ke, et al., 2008). The study identified specific knowledge gaps among the nurses, specifically in the areas of pathophysiology at end of life, such as hunger in the terminally ill and ketoacidosis causing pain. In Ke et al.'s (2008) study in Taiwan, a similar question regarding ketoacidosis was noted to be one of the least accurately scored answers, which validates the need that nurses should have more education in end-of-life pathophysiology. While the majority of the participants in Ke et al.'s study had a baccalaureate degree or higher, in this pilot study the majority of nurses have associate degrees, which may have a direct correlation to associate degree programs not containing a pathophysiology course.

This study also highlighted misperceptions from the nurses regarding ANH. More than half the nurses perceived that ANH prolonged the life of terminally ill patients. However, this misperception is not supported in the literature; studies showed that the initiation of ANH does not prolong life in the terminally ill, especially those near death (Callahan et al., 2000; Meier et al., 2001; Chiu et al., 2002; Murphy & Lipman, 2003).

Over 90% of the nurses accurately determined the statement, "The provision of either artificial nutrition or hydration lowers the anxiety of patients and their loved ones" as true. Mercadante, et al. (2005), in their study on patients' and relatives' perceptions about artificial hydration in palliative care, found that intravenous hydration was perceived to be "psychologically effective" and an "acceptable burden" (p. 356).

There are limitations to this study. While the Knowledge Test is not an exhaustive questionnaire regarding ANH, it does encompass evidence-based information, thus adequately assessing nurses' knowledge in this area. Although 90 questionnaires were given out to home health nurses, the response rate was only 36% leading to a sample size smaller than anticipated, which may have implications not only for correlations between degrees and experience but also with internal consistency.

Conclusion

As more terminally ill request to die at home, home health nurses will be challenged to provide quality care at the end of life. The instrument used in this study revealed NC HHNs' knowledge regarding ANH at end of life is lacking in current evidence and based on misconceptions. The instrument is reliable for use in future research as well as identifying areas of knowledge deficits regarding ANH as well as contributing to the evaluation of education programs initiated for in-services or continuing education programs in nursing. Implementation of evidence-based knowledge regarding ANH may help patients and families make appropriate decisions regarding this medical treatment.

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Smith, L., Amella, E. J., Nemeth, L., Mueller, M., Edlund, B., and Ferrell, B. A mixed methods study examining home health nurses' knowledge and perceptions of suffering and artificial nutrition and hydration in people with late stage dementia.

A Mixed Methods Study Examining Home Health Nurses' Knowledge and Perceptions of Suffering and Artificial Nutrition and Hydration in People with Late Stage Dementia

Abstract

Purpose: The purpose of this mixed-method, convergent parallel design study was to identify home health nurses' knowledge, beliefs or perceptions toward suffering in persons with late-stage dementia and to investigate whether their knowledge, beliefs or perceptions may have an effect upon their actions and counseling of families of individuals with late-stage dementia regarding artificial nutrition and hydration.

Methodology: A sample (n = 17) of home health nurses, recruited from four Western North Carolina home health agencies, completed a questionnaire and participated in focus group interviews. The Knowledge of Artificial Nutrition and Hydration in the Terminally Ill questionnaire, an instrument adapted in a prior study was used to explore the knowledge of artificial nutrition and hydration with late stage dementia. A convergent parallel design was used to interpret the results from analysis of both the quantitative and qualitative data.

Results: The mean age of the participants was 47 +/- 12.07 years and all of the participants were white. Twelve out of 17 (71%) of the participants had an Associates degree in nursing; 9 of the 17 participants (53%) had greater than 20 years experience as a registered nurse while 10 of them had 10 years or less experience in home health. Internal consistency as measured by Cronbach's a was 0.70. The mean total score of the Knowledge Test was 31.4 (SD=6.23, range 21-43) where the highest score possible was 46. Three themes were generated from the focus group interviews: *patient/family comfort, futility, and symbols of suffering.* These themes were compared to the quantitative data obtained from the Knowledge Test, which corroborated the qualitative analysis.

Conclusion: This study suggested that HHNs' lack evidence-based information in their practice regarding ANH. Results of the mixed-methods design presented their beliefs or perceptions regarding ANH and suffering, which combined with their lack of knowledge, could influence their counseling of patients and families toward initiation of ANH.

Introduction

Dementia is a loss of brain function that usually affects those older than 60 years of age and involves memory, judgment, behavior, and language disturbances (National Library of Medicine [NCBI], 2013). Dementia eventually results in the inability to perform activities of daily living (ADLs; Alzheimer's Association, 2014), including walking and swallowing. Although there are different types of dementia, Alzheimer's disease (AD) is one of the most common among those who are 65 years or older (Alzheimer's Organization, 2013). In the later stages, one may become bedbound, become uncommunicative and cachexic, requiring constant care and death becomes imminent. AD has become one of the top leading causes of death in people 65 years of age or older (Alzheimer's Organization, 2013). There are an estimated 5.2 million Americans who have AD (Alzheimer's Association, 2014), 5 million of whom are aged 65 or older (Alzheimer's Association, 2014).

The number of older adults with AD or other forms of dementia in North Carolina (NC) has reached 170,000 and it is estimated that this number will increase to more than 300,000 by the year 2030 (North Carolina Division of Aging and Adult Services [NCDAAS], 2012). Over 70% of individuals with AD or other dementias were being cared for at home in NC (National Association for Home Care and Hospice, NACH, 2010), with more than 3.4 million individuals receiving home care from Medicare-certified home health (HH) agencies in the United States (US) in 2011 (Medicare Payment Advisory Commission, 2013). The majority of these Medicare-certified agencies (84%) are found in urban areas (Medicare Payment Advisory Commission, 2013). Many of the elderly (22%) reside in rural areas according to the US Census Bureau (Hutchinson, Hawes, & Williams, 2005). The large number of agencies located within urban areas plus the number of elderly living in rural areas creates concern that there is disparity in and access to services available in rural areas for the elderly individual with late stage dementia (LSD). In addition, as resources became available to support these individuals, there was an increase in home deaths of those with dementia who were 65 years or older, from 15% in 1989 to 24% in 2007 (National Center for Health Statistics [NCHS], 2010), which increases this cause for concern.

In individuals with LSD, poor intake is common and usually due to the individuals' perception of food insignificance, cognitive and functional decline leading to dysphagia and apraxia (Cohan, 2012), which puts them at risk for not only malnutrition but also repeated infections (Fischberg et al., 2013). These issues introduce discussions of initiating artificial nutrition and hydration (ANH) and outcomes are left to family or health care proxies who often turn to nurses to counsel them regarding this critical decision. Nurses are in key positions to help families make informed decisions regarding ANH; however, they may lack knowledge of evidence-based practice related to ANH, potentially resulting in undesirable decisions made by family members (Palan-Lopez, Amella, Mitchell, & Stumpf, 2010).

The concept of suffering is not well defined in the literature, especially with regard to persons with dementia, specifically as to how it is experienced in the later stage of the disease (Smith, Amella, Edlund, & Mueller, in press). Because LSD may not be perceived as a terminal illness, individuals with LSD may not be referred to hospice until close to the end of life. This may cause unnecessary suffering in the form of physical symptoms, such as pain, dyspnea, and pressure ulcers (Mitchell et al, 2009). In addition, the initiation of ANH may facilitate other complications, such as fluid overload, aspiration pneumonia (Sampson et al., 2009), and additional pain and discomfort, increasing the suffering of one with LSD. While studies have shown that people with dementia suffer (Aminoff et al., 2004; Aminoff & Adunsky, 2005, 2006;

Guilio et al., 2008; Givens et al., 2010; Husebo et al., 2008; Mitchell et al., 2009; Nourhashemi et al., 2012; Shulz, McGinnis et al., 2008; Shulz, Monin et al., 2010; van der Steen, Ooms et al., 2002; and van der Steen, Pasman et al., 2010), there have been no studies that examined the perceptions or beliefs of nurses with regard to suffering in people with LSD. Inconsistent definitions and understanding of the concept of suffering may result in unnecessary suffering on the part of the individuals as well as their families. In addition, the patient may experience a poor quality of life at end of life (Smith, Amella, Edlund, & Mueller, in press). Because of the increase in home care and deaths, home health nurses can play a vital role ensuring that individuals with LSD have a quality end to their lives.

Therefore, the research questions for this study were: 1) what are home health nurses' (HHNs) knowledge, beliefs or perceptions regarding suffering in persons with LSD; and 2) how does this information influence their actions and counseling of families of persons with LSD, especially with regards to ANH? The specific aims were to: a) identify HHNs' beliefs or perceptions about suffering and ANH in persons with LSD via semi-structured interviews; b) identify, through an exploratory descriptive study, HHNs' baseline knowledge of ANH with use of the Knowledge of Artificial Nutrition and Hydration (ANH) in Terminally Ill Patients (Knowledge Test), as adapted by Ke, Chiu, Lo, and Hu (2008a); and c) assess whether HHNs' counseling with families and actions toward affected persons are influenced by their knowledge, beliefs or perceptions through a convergent parallel design methodology for corroboration and validation between the two methods of data collection (quantitative and qualitative).

Theoretical Framework

The theoretical framework of grounded theory and symbolic interactionism guided this study and was used to develop dimensions and themes from the participants.

Symbolic Interactionism

George Mead first postulated the underpinnings of Symbolic Interactionism (SI), but the term SI is credited to Herbert Blumer (Carlson, 2012). Symbolic interactionism developed from a pragmatist view that humans develop their knowledge and meanings from their interactions from and with others (Corbin & Strauss, 2008) and with their environment. Charon (2010) posits that individuals do more than respond to their environments; they apply meaning to them via interpretation. Individuals are not controlled by the environment but instead define and use it based on their interpretations of it (Charon). These meanings then determine the behavior and the actions that are performed by individuals (Hall, Griffiths, & McKenna, 2013) and begin to form behavior or conduct as individuals interact with one another (Hewitt & Shulman, 2011). Meanings change based on variations in the interpretive process (Kunklin & Greenword, 2006). Thus, symbolic interactionism proposes a method that can easily describe qualities of lived experiences (Hall et al, 2013). With the use of the SI perspective, exploration and understanding of how the nurses' lived experiences contributed to their meanings of suffering and ANH in individuals with LSD could be undertaken more thoroughly. Although the nurses had comments and opinions of their own during focus group interviews, many of them agreed with their colleagues on salient points in the discussion, supporting the concept that individuals form their behavior with interactions of others.

Grounded Theory

Grounded theory (GT) is an inductive method for establishing a theory from data (Cohen, 2006); the theory is not "predetermined by any theoretical perspective" (McCann & Clark, 2003, p. 9). GT's main focus is identifying concerns among individuals and to discover what and how the individuals solve the concern (Glaser, 2014; Artinian, Giske, & Cone, 2009; Glaser &

Strauss, 1967) so that human behavior can be conceptually explained (Aldiabat & le Navenec, 2011). This theory is developed when conceptual dimensions are generated from data collected or evidence from the data and although the evidence may change, the dimensions or concepts will not (Glaser & Strauss, 1967). The concepts are actually relevant "abstractions about what is going on in the area studied" (Glaser & Strauss, 1967, p. 23).

From an epistemological GT perspective, meaning comes directly from the individual and is subjective because meaning is placed on the object (Levers, 2013), much like the symbolic interactionist's theoretical perspective. This is especially true of nursing, where social interaction is "at the heart of the caring process…" (McCann & Clark, 2003, p. 16). In other words, GT assumes that individuals are people who take on essential roles in problematic situations while they change their actions and behaviors to those with whom they interact (SI).

In this study, the HHNs bring varied personal and professional experiences with death, dying and suffering to their interaction with each other, families, and persons with LSD. Layering on the management of end-of-life care using ANH, the nurses may be influenced by larger cultural and religious belief systems. Thus, knowledge of and actions take by these nurses concerning ANH are colored by myriad past social and personal interactions. The GT method in conjunction with SI, as described by Charon, was used in this study to convey categories that generate distinct meanings of suffering in LSD among these HHNs as well as their perceptions and knowledge of ANH at end of life. Using these methods allowed the investigator to understand if those meanings are influenced by social, organizational, or events in their lived experiences.

Methods

This exploratory mixed-methods study utilized both qualitative and quantitative methods, interpreted via a convergent parallel design.

Recruitment

Convenience sampling was used in recruitment. Initially, HHNs were to be recruited from Alabama (AL) and North Carolina (NC); however, after repeated requests for attendance at nurses' staff meetings at local home health agencies in AL, permission was not received. Nurses were recruited from four home health agencies in western NC over a four-month period. Inclusion criteria were: a) work in a Medicare-certified home health agency in the home health agency department (if combined with a hospice); b) work in the field (seeing patients in their home or residential care facility); and c) care for at least one patient with LSD during their time as a home health nurse. Nurses were excluded if they were in management positions within the agency or did not provide direct care to the patients. A total of 17 nurses participated in the study, although initially, 27 nurses had agreed to participate.

Supervisors or branch managers were contacted via email or phone to request attendance at one of the monthly nurses' meetings held by the agency. At the meeting the principal investigator (PI) explained the exploratory study to the nurses. Interested meeting attendees were then asked to complete an initial enrollment log with name, cell phone number, work and alternate email addresses, implying their agreement to participate. The attendees were also asked about dates and times that would be most conducive for their attendance at the focus group meeting. Once a date and time had been scheduled, participants were notified by email and informed of the meeting location; follow-up emails were also sent out as reminders. Four focus group meetings were held; locations included a hotel meeting room, a restaurant (private room), and two agency offices. At each focus group meeting, the PI explained the study and obtained the participants' written consent prior to enrollment and then screened them to ensure inclusion criteria were met. At the conclusion of each focus group meeting, the PI held a drawing for a $25 gift card.

Instruments

An adapted version (Smith, Amella, & Mueller; submitted) of a Taiwan instrument, Knowledge of Provision of Artificial Nutrition and Hydration for Terminal Cancer Patients (Ke, et al., 2008a) was used. The Knowledge of Artificial Nutrition and Hydration for the Terminally Ill questionnaire (Knowledge Test; see Appendix A) included a total of 29 items; the first six inquired about demographic and professional characteristics. The following 23 items were statements regarding ANH. In the pilot study conducted by Smith, Amella, & Mueller (submitted), the questionnaire was developed and coded as True (1), False (1), and Don't Know (0). In further discussion after the study was concluded and before this study was initiated, the researchers changed the choices to a Likert style scale; they decided that Agree, Disagree, and Neutral were congruent and better suited than True, False, and Don't Know as the stem statements focused not only on facts but also perceptions or beliefs. Thus, the questionnaire choices were changed to Agree, Disagree, and Neutral.

In the original study, the authors coded the statements Agree (1) and Disagree/Don't Know (0) (Ke et al., 2008a). For purposes of this study the Knowledge test was coded in two ways: 1) as the original authors did (Agree 1, Disagree/Neutral 0); and 2) to determine how many disagreed and how many did not know (Agree 2, Neutral 1, Disagree 0); for purposes of this study, the latter was used for the results. The modified instrument was used in a pilot study by this PI and found reliable with a Cronbach's alpha of 0.71 (Smith, Amella, & Mueller;

submitted). Because the questionnaire does not encompass suffering in its questions, a case scenario with five questions was added. The scenario was of an elderly man with a diagnosis of dementia who was experiencing weight loss and the family had questions for the nurse regarding pain, suffering and whether ANH was of benefit for their father.

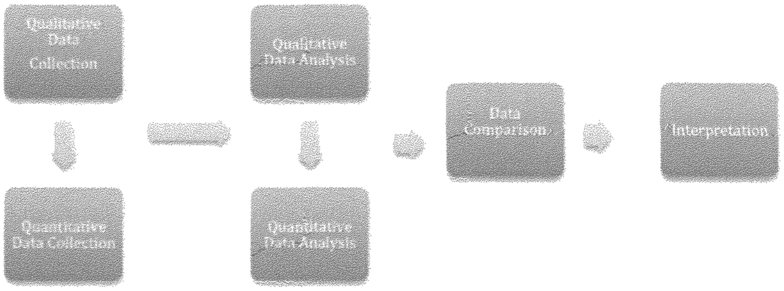
Data Collection

Data collection was carried out during four focus groups. Participants in each of the focus groups first completed the Knowledge Test. The test took approximately 15 minutes and additional 10 minutes for the scenario questions, depending on how in-depth the nurses delved. After the last questionnaire was completed, semi-structured focus group interviews were conducted to develop a more thorough understanding of nurses' perceptions of suffering and ANH and how it affects their counseling of patients and families toward ANH. Experts in qualitative research (LN, BE) reviewed the focus group interview questions to ensure face validity. Open-ended questions were asked to explore nurses' beliefs or perceptions of ANH and suffering. The PI took field notes to capture body language and key words from the participants. The interviews were digitally recorded and later transcribed verbatim. Transcripts were organized via the software program, Evernote®. Commonalities among the nurses were developed and compared using the constant comparative analysis of GT.

Data Analysis

Using the convergent parallel design by Creswell and Plano-Clark (2011), quantitative and qualitative data were collected concurrently; however, each set was analyzed separately. This type of design is more suited for the paradigm of pragmatism within grounded theory and symbolic interactionism while it provides an opportunity to obtain answers from different perspectives. It is the goal of a convergent parallel design to merge both quantitative and qualitative data and then interpret the findings from both, examining whether the two sets of data converge or diverge (Creswell & Plano-Clark, 2011; see Figure 1).

Figure 1. Convergent Parallel Design



While the questionnaire provided the PI with information regarding the nurses' knowledge of ANH, the qualitative data informed on their beliefs or perceptions, resulting in a more comprehensive understanding related to the research question (Creswell & Plano-Clark, 2011).

Questions were checked for accuracy twice, once upon entering the data into REDCap, a secure database within the Medical University of South Carolina (MUSC) and when imported into SPSS (IBM, Armonk, NY: 2013). The data were then analyzed using SPSS v. 22. For analysis purposes, those items that had a correct answer of disagree were reversed scored (13 items).

Quantitative data were analyzed via descriptive statistics for demographics (age, race, and gender) and professional characteristics (degree in nursing, nursing experience, and home health experience) using frequencies and percentages. Instrument reliability was measured with Cronbach's alpha coefficients for internal consistency. Knowledge Test questions were analyzed across the entire sample using frequencies then categorized by nursing experience (<15 years and

>16 years) again using frequencies and percentages. A total score was obtained for the overall sample and by years of nursing experience (dichotomized).

The guidelines for the constant comparative method by Glaser and Strauss (1967) were used to analyze the qualitative data. During the interviews, the PI documented important key words used by the participants in answering the interview questions; saturation occurred when multiple participants contributed the same or similar information and when there was no new information occurring within the interviews. Focus group interviews were audio-recorded using Evernote® software. A graduate teaching assistant transcribed the audio files; the PI verified accuracy by listening to all of the audio files and reading the transcripts simultaneously. First, the PI read the transcripts and highlighted specific keywords or phrases to categorize dimensions of the data. Applying an iterative inductive process, these keywords and phrases were compared to the notes generated at the interviews. In addition, keywords and phrases were highlighted from the answers to the scenario questions found at the end of the questionnaire. These keywords or phrases were compared to those found in the interview transcripts and notes. Cycles of immersion and crystallization (Borkan, 1999) were used to continue developing themes and subthemes. Further immersion and crystallization, where the PI and senior qualitative researcher (LN) discussed and analyzed the themes, asked questions of the data and about the analytic process, ensured accuracy of the analysis.

According to Blumer (1969), humans develop their feelings toward things or objects based on what meanings those things represent to them, which are inferred from the interactions they have with themselves and with others. These meanings change during interpretation and are therefore not static (Blumer, 1969). It is through the use of the participants' words regarding the meanings they shared about their social interactions with patients experiencing suffering as well as the decision-making process of ANH that integration of categories occurred. Categories were noted to overlap with the use of an iterative process, thus providing validation with symbolic interactionism theory. With the final step, homogeneity occurred, and three overarching themes evolved from the process. After the themes emerged from the qualitative data, both sets of data were assembled into a table format to provide a better comparison of the results. The outcomes of these analyses are presented in the results section.

Results

Quantitative

The mean age of the participants was 47 years (range 23-66; n = 15; 2 failed to answer; see Table 1). The majority of the participants were female (82% 14/17) and all were white. Seventy-one percent of the participants (12/17) held an associates degree in nursing while 18% (3/17) held a baccalaureate degree and two participants did not answer. While nearly 53% of the nurses had more than 20 years experience as a registered nurse (RN), 47% of the nurses had worked 1-15 years in home health (35 % reported <1-5 years of experience totaled while 6-15 years experience while 12% reported 6-15 years). Eleven nurses worked in rural and 6 in urban HHAs. Based on symbolic interactionism, nursing experience was considered a potential influence on beliefs or perceptions; therefore, RN experience was dichotomized into those nurses with 15 years of experience or less (n = 8) and those with more than 16 years experience (n = 9; see Table 2).

Table 1. Demographics and Professional Characteristics.

Characteristics/Demographics	Overall
Age (Mean 47; SD 12.07)	
Missing/unknown	11.8 (2/17)
20-30	11.8 (2/17)
31-40	11.8 (2/17)
41-50	29.3 (5/17)
51-60	23.5 (4/17)
> 60	11.8 (2/17)
Gender	
Male	17.6 (3/17)
Female	82.4 (14/17)
Race	
White	100 (17/17)
Degree	
Missing/Unknown	11.8 (2/17)
ADN	70.6 (12/17)
BSN	17.6 (3/17)
Years as RN	
< 1	5.9 (1/17)
1-5	5.9 (1/17)
6-10	23.5 (4/17)
11-15	11.8 (2/17)
16-20	0
> 20	52.9 (9/17)
Years in Home Health	
< 1	11.8 (2/17)
1-5	35.3 (6/17)
6-10	11.8 (2/17)
11-15	0
16-20	23.5 (4/17)
> 20	17.6 (3/17)
Urban vs. Rural	
Urban	35.3 (6/17)
Rural	64.7 (11/17)

Table 2. Total Scores with RN Experience

Category	≤15 Years RN Experience Mean (SD)	≥16 Years or Greater RN Experience Mean (SD)
Original Scoring (Agree 1, Disagree 0, Neutral 0)	16.0 (2.6)	16.6 (2.1)
Modified Scoring (Agree 2, Neutral 1, Disagree 0)	31.3 (7.6)	31.6 (5.7)

Internal consistency as measured by Cronbach's α was 0.70. All items seem appropriate for the questionnaire. Several items, if deleted from the questionnaire, would increase *alpha* but only marginally: question 13, would increase α to 0.72 and questions 19, 26, and 29 would raise α to 0.71, therefore all questions were retained.

For purposes of this study the Knowledge test was coded in two ways: 1) as in the original authors' version (Agree 1, Disagree/Neutral 0); and 2) to allow determination of how many disagreed versus how many did not know (Agree 2, Neutral 1, Disagree 0); results are reported with option number 2. The number of correct and incorrect answers determines the knowledge of ANH of the nurses. The mean total score of the Knowledge Test was 31.4 (SD = 6.23, range 21-43); the highest score possible was 46. A higher score correlates to more knowledge. Confidence interval (CI) for the mean was (28.0155, 34.9178). Table 3 represents the percentages of correct and incorrect responses of the nurses as well as those who chose 'neutral' as a response.

Only two questions had an accurate answer rate of 70% or above were in response to question 18, "The provision of either artificial nutrition or hydration lowers the anxiety of patients and their loved ones (82%); and question 22, "In terminally ill patients, fluid overload is likely to result in pleural effusion or pulmonary edema (71%). Three questions had an accurate response rate of greater than 50% (but less than 70%; questions 14, 15, and 23). The least accurately answered questions with response rates of less than 10% were in response to questions 16, "Artificial nutrition improves mouth dryness and thirst in terminally ill patients (0%); question 5, "Artificial nutrition replacement is necessary in preventing terminally ill patients from starving to death" (6%); and question 6, "Artificial hydration replacement is necessary in preventing terminally ill patients from starving to death" (6%).

Table 3. Knowledge Test Results

Questions	Correct	Incorrect	Neutral
1. Artificial nutrition is beneficial for terminally ill patients.	4(23.5)	8(47.1)	5(29.4)
2. Artificial hydration is beneficial for terminally ill patients.	6(35.3)	5(29.4)	6(35.3)
3. Artificial nutrition can improve the strength of terminally ill patients.	5(29.4)	11(64.7)	1(5.9)
4. Artificial hydration can improve the strength of terminally ill patients.	5(29.1)	8(47.1)	4(23.5)
5. Artificial nutrition replacement is necessary in preventing terminally ill patients from starving to death.	1(5.9)	15(88.2)	1(5.9)
6. Artificial hydration replacement is necessary in preventing terminally ill patients from starving to death.	1(5.9)	16(94.1)	0
7. Artificial nutrition replacement can result in tumor growth.	3(17.6)	9(52.9)	5(29.4)
8. Artificial nutrition replacement signifies empathy and care for the patient from medical personnel and family members.	4(29.4)	9(52.9)	4(23.5)
9. The sensation of mouth dryness and thirst in terminally ill patients is mainly caused by dehydration. *	2(11.8)	8(47.1)	6(35.3)
10. Terminally ill patients are often hungry.	2(11.8)	14(82.4)	1(5.9)
11. Artificial nutrition replacement can improve hunger status in terminally ill patients. *	3(17.6)	11(64.7)	2(11.8)
12. Aggressive nutritional support by tube feeding cannot change the nutritional status or the weight of terminally ill patients.	6(35.3)	9(52.9)	2(11.8)
13. Ketoacidosis as a consequence of lack of eating often results in an increase in physical pain in terminally ill patients. *	2(11.8)	8(47.1)	6(35.3)
14. Artificial nutrition can prolong the life of terminally ill patients.	10(58.8)	6(35.3)	1(5.9)
15. Artificial hydration can prolong the life of terminally ill patients.	9(52.9)	6(35.3)	2(11.8)
16. Artificial nutrition improves mouth dryness and thirst in terminally ill patients.	0	13(76.5)	4(23.5)
17. Artificial hydration improves mouth dryness and thirst in terminally ill patients.	5(29.4)	8(47.1)	4(23.5)
18. The provision of either artificial nutrition or hydration lowers the anxiety of patients and their loved ones.	14(82.4)	1(5.9)	2(11.8)

19. The provision of either artificial nutrition or hydration aids in developing trust from terminally ill patients and their family members.	5(29.4)	5(29.4)	7(41.2)
20. Providing either artificial nutrition or hydration can prevent despair from worsening in terminally ill patients.	3(17.6)	7(41.2)	7(41.2)
21. Activities of terminally ill patients are restricted by in-dwelling tubing.	5(29.4)	10(58.8)	2(11.8)
22. In terminally ill patients, fluid overload is likely to result in pleural effusion or pulmonary edema.	12(70.6)	3(17.6)	2(11.8)
23. Invasive procedures, such as the placement of feeding tubes, cause pain and discomfort in terminally ill patients.	11(64.7)	4(23.5)	2(11.8)

*One participant omitted the answer for these questions.

Qualitative

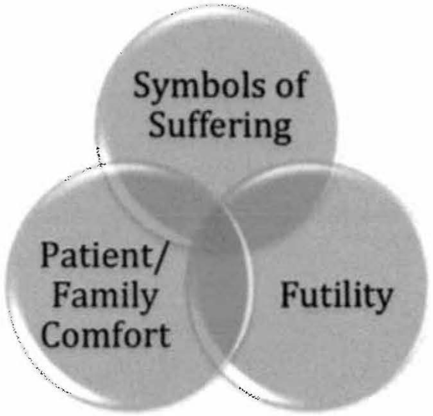
In addition to the focus group interviews, a qualitative component was administered after the Knowledge Test questionnaire and completed in writing. All of the individuals participating responded to each of the questions. A scenario with five open-ended questions of an aging man with a diagnosis of dementia who was experiencing weight loss was represented; the family had questions for the home health nurse regarding pain, suffering and whether ANH was of benefit for their father. The first question asked how the nurse would respond to the daughters' concerns that initiating a tube feeding would cause pain, discomfort, or suffering for their father. Most of the nurses reported that they would explain the procedure; however, there was conflicting responses related to pain and discomfort – some (7) felt there would be little to no discomfort while others (6) felt it would cause the person to be 'uncomfortable' or have complications, such as nausea, vomiting or diarrhea.

When asked in questions 2 and 3 about advantages and disadvantages of ANH, some (5) felt that prolonging life was the greatest advantage and that it helped strengthen and make the patient healthier. They (5) also noted another considerable advantage was that it was a source of comfort for the family. On the other hand, some nurses (15) reported disadvantages included increased risk of infection and aspiration, pain and discomfort, prolonging suffering, and prolonging life.

The last two questions involved recommendations by the nurse (question 4) as well as what the nurses would do if it the person in the case study was their father and if their recommendations would change if this was a personal choice (question 5). Recommendations proffered included considering the patient's wishes; explaining to the daughters that the body knows how to respond to disease processes; informing the daughters that it might prolong life where there is no quality of life; recommending for and against the tube; and referring to hospice. As for whether the nurses would tell the daughters what they would do if it were their father and if recommendations would be the same, some nurses (n = 4) felt that yes, their recommendations would be the same – respect the patient's wishes; let him go peacefully; think about the focus of the treatment; and each situation is different. However, the majority (n = 10) of the nurses' answers were no, it would not be different – they would not do the same for their father; keep opinions to oneself; it's a futile measure; and discuss options.

Initially, themes from the scenario questions and focus group interviews emerged into four categories, yet as similarity and consistency in the concepts was noted, the emergence of symbolic interactionism theory with an interconnectedness of themes, resulted in a more concise three-themed framework of the perceptions of the nurses (see Figure 2). The overarching themes that evolved from the analysis include *patient/family comfort, futility, and symbols of suffering*.

Figure 2. Suffering and ANH Framework



Patient/Family Comfort

The majority of the nurses' comments in both the interviews and when describing what they would attempt to do in the scenario focused on the concept of 'patient or family comfort,' which can be used to describe ANH and suffering. Some of the keywords that came up during discussion were "comfort measure;" "comfort for the family;" "[ANH] makes it harder on them [patients and families];" "makes them more uncomfortable;" and "promotes comfort." Although comfort is one of the purposes of nursing care, many shared that they felt helpless in knowing how to care for people with dementia and their families who are having to decide whether to initiate ANH and some felt that it increased the patients' suffering. This was verified in the qualitative questions on the Knowledge Test, with comments such as, "hydration promotes comfort;" "makes family feel better;" "helps the family more than the patient;" and "hydration may provide some comfort from thirst."

Futility

Many of the nurses expressed the concept of 'futility' in their responses to interview questions and in response to the scenario. They felt that ANH prolonged a patient's life, which was beneficial for the family but caused more suffering for the patient. Statements such as, "poor quality of life;" "false hope;" "frustration;" and "prolonged suffering" were used throughout the interviews. In addition, the scenario answers expressed some of those same thoughts, with statements like, "prolonged discomfort;" "prolong life;" "prolong suffering;" and "prolonging the inevitable." Some of the nurses expressed thoughts of sadness at having to see patients and their families deal with the disease process and its complications.

Symbols of Suffering

The concept 'symbols of suffering' was used throughout the focus group interviews and was reflected in responses to the scenario. Most of the comments generated were in regards to physical symptoms, discomfort, or physical appearance in trying to assess or measure suffering as well as with regard to ANH. "Involuntary movements," "it's subjective," "scared," "crying," "moans and groans," "pain," and "fear and distress" were only a few of the comments made by the nurses to describe their perceptions of suffering and use of ANH in people with dementia. This theme was continued in the scenario questions with comments such as, "risk of aspiration and infection;" "may cause some pain and discomfort;" "procedure is invasive;" "nausea and diarrhea;" "distress;" and "edema and fluid retention." Some of the nurses described feeling frustrated for the patients because they had 'no way of knowing' whether they were suffering, especially in the later stages when the patients had no purposive language, but felt that in that stage, ANH was only comforting to the family, not the patient. Table 4 provides exemplars of the nurses' statements for the three concepts.

Table 4. Exemplars of Nurses' Statements

Theme	Statements
Patient/Family Comfort	"It kinda sets up this false hope for the family too of waiting each day to see if they've [the patient] has gotten better because of the feeding." "We are able to maintain an adequate calorie and protein intake to promote health and well-being." [Speaking to artificial hydration] "She couldn't stand the thoughts that he wasn't eating or drinking; she fed him through this little IV going nowhere. That's all she needed; it got her through. She was able to live life." "The perception is if you don't give them something to eat or drink then they're suffering or they're starving." "I think sometimes it makes the families feel better."
Futility	"I just think it's the helplessness; that's what you do feel because you can't fix it. You just want to fix it." "Making it impossible for the body to die." "It was just frustrating because you know what you are doing is not what should be done." "Prolongs what shouldn't be prolonged." "It's hard to tell because they are so flat so we really have no way of knowing."
Symbols of Suffering	"When they have a moment of lucidity, they cry and they want to be normal." "They come in [to the ED], they're screaming, they're crying. They don't know where they are. They're sick, infected, have bed ulcers; they're scared, fighting. That's when I go into 'I pray these people don't know what's happening to them." "To me I guess, generally, would be any type of pain, hardship, distress, be that mental, emotional, or physical."

	"I guess you could [measure suffering] with expression." "They definitely feel pain." "I used to go by restlessness." "But it comes out in different ways like agitation, combativeness, and they're just trying to communicate but they don't know how."

Convergent Parallel Results

In a convergent parallel design, quantitative and qualitative data are collected concurrently but analyzed separately then merged and interpreted (Creswell & Plano-Clark, 2011). Results of this merged data are shown in a side-by-side comparison (Table 5) that reveal how the different sets of data converge. The results show that the quantitative and qualitative data are convergent to demonstrate nurses' beliefs or perceptions regarding suffering and ANH. There were three questions on the questionnaire, however, that were not merged with the qualitative data, as they did not relate to any of the themes that developed (questions 13, 25 and 27).

Table 5. Comparison and Correlation of Qualitative and Quantitative Data

THEME	QUALITATIVE SUBTHEMES	QUANTITATIVE SURVEY FINDINGS
Patient/Family Comfort	• Family comfort • Helping • Nurturing • Patient comfort • Facilitates health/nutrition • Prevents decline • Hospice needed • Comfort measures • Keep comfortable	Question 8 – feel artificial hydration is beneficial to patients (35%). Questions 9&10 – Feel ANH can improve the strength of individuals (65% and 47% respectively). Questions 11&12 – feel ANH is necessary for prevention of starving (88% and 94% respectively). Question 14 – feel that artificial nutrition signifies empathy from medical personnel and family members (53%). Question 17 – feel that nutrition replacement can improve hunger status (65%). Question 24 – feel ANH lowers the anxiety of patients and loved ones (82%). Question 26 – feel ANH can prevent despair from worsening in patients (41%); however, just as many marked 'neutral' for this question.
Futility	• False hope • Frustration • Prolongs life • Prolonged suffering • Poor quality of life	Question 7 – feel artificial nutrition is not beneficial to patients (47%). Question 18 – feel that aggressive nutrition cannot change the weight of or nutritional status of terminally ill (53%). Questions 20&21 – feel ANH cannot prolong the life of terminally ill (59% and 53% respectively).
Symbols of Suffering	• Prevents weight loss • Scared	Question 15 – feel that a sense of mouth dryness and thirst is caused by dehydration (47%).

	• Fear • Restless • Agitation • Mood outbursts • Grimacing • Pain • Body language • Moans/groans • Patient uncomfortable • Distress • Fluid overload • Loved one starving • Invasive	Question 16 – feel that terminally ill patients are often hungry (82%). Question 19 – feel that ketoacidosis from lack of eating can increase pain (47%). Questions 22&23 – feel ANH improves mouth dryness and thirst (76% and 47% respectively). Question 28 – feels fluid overload will result in pleural effusion or pulmonary edema (71%). Question 29 – feel invasive procedures such as a tube feeding, will cause pain and discomfort (65%).

Percentages represent nurses who agreed with the statement/question.

Discussion

In the literature, perceptions of suffering in people with dementia are reported in the physical, psychological, existential, and spiritual aspects of suffering with most studies examining suffering from the physical realm, such as pain, symptoms, discomfort, etc. (Mitchell et al., 2009; Monin & Shulz, 2009; Shulz, McGinnis et al., 2008; and Shulz, Monin et al., 2010). No studies were found that examined nurses' knowledge or perceptions of ANH and suffering in the US. This study may be the first to explore not only the knowledge of HHNs with ANH but also the nurses' perceptions of how ANH relates to suffering in people with dementia and how both of these concepts correlate with the information HHNs give to families who are contemplating ANH.

As noted in the knowledge test results (Table 3), the top least accurately answered questions on the questionnaire dealt mainly with the pathophysiology of dying. Ke, et al (2008a) also found the least accurately answered questions pertained to pathophysiology. In the US, there may be a correlation between this information and 71% of the nurses having associate degrees rather than baccalaureate degrees, as pathophysiology is not generally a course offered in Associate Degree Nursing (ADN) programs. This topic is usually either a prerequisite or co-requisite of Bachelor of Science nursing (BSN) programs. In an interventional study conducted by Ke, Chiu, Hu, and Lo (2008b), an educational module was introduced to hospital nurses on ANH and pre- and post-tests were completed. Results showed that their knowledge scores significantly improved on the post-test (Ke, et al., 2008b). Having knowledge of the disease trajectory and the pathophysiology of death could possibly assist nurses in discussions with families about ANH.

The mixed-method design provides a more comprehensive look at these HHNs' perceptions and knowledge while providing insight into the meanings behind their perceptions, supporting the theory of symbolic interactionism (see Table 4). The three themes (*patient/family comfort, futility,* and *symbols of suffering*) that developed from the focus group interviews and scenario responses lend support to the quantitative data obtained from the questionnaire.

While many of the nurses perceived artificial nutrition and hydration as being beneficial to patients in providing them comfort, from the scenario answers, they also felt that artificial nutrition was a futile measure in people with late stage dementia (see Table 4). Because of the misperceptions by the nurses about ANH being beneficial, this may result in inaccurate information being given to patients and families, leading to conflicting decisions. Ke, et al. (2008b) found in their study that while nurses had experience caring for terminal cancer patients, their lack of evidence-based knowledge resulted in the nurses still wanting to supply ANH for these patients.

There was conflict among the nurses as to whether ANH prolongs life and whether prolonging life was perceived as good or bad; one nurse wrote, "it prolongs life, but why would you want to?" In addition, responses to questions 14 and 15 (whether artificial nutrition [14] or hydration [15] prolonged the life of the terminally ill) were conflicted with answers to the interview question about their experiences with ANH prolonging the life of someone with LSD; 59% (question 14) and 53% (question 15) of the nurses felt ANH cannot prolong life, but stated in interviews that this was a negative effect of ANH. Those who felt that it would prolong life also felt that quality of life would be poor. Many felt that ANH would only prolong suffering due to the complications and invasiveness of placement.

The scenario answers in this study revealed a paradoxical perspective from the nurse, contradicting at times what was answered on the questionnaire. While some of the nurses felt that they could not recommend tube feedings to the family, others reported that they would, even though they felt that ANH would prolong the person's life and their suffering and worsen the patient's quality of life. Wurzbach (1996) noted in her qualitative study on ethical convictions of nurses regarding tube feedings that moral conflicts are profoundly influenced by an individual's knowledge, experience, and differences in values or morals. Her study revealed that nurses with moral certainty, or having convictions based on evidence that the person believes to be right, were more likely to educate the family, presenting options, and supporting the family in the decision-making process. Thus, conveying evidence-based knowledge to families is essential to their making these ethical decisions.

The convergent parallel design (Table 5) corroborated the assumption that nurses' knowledge, beliefs or perceptions influence their counseling of patients and families with regard to decision-making for ANH initiation. The nurses felt that the decision should be left up to the family without offering any recommendations. Some reported not making any recommendations based on their personal preferences; one nurse stated, "I keep my opinions to myself regarding care decisions." A study conducted of nursing home nurses regarding feeding decisions in people with advanced dementia revealed ambiguity in 'moral agency,' or "individual responsibility for moral judgments and actions that comport with morality" (Palan-Lopez, et al., 2010, p. 635). Even though the nurses had knowledge regarding feeding options, they felt that this information was personal opinion rather than nursing judgment and felt that as a nurse, they were only able to discuss the benefits and risks or provide care to the patient (Palan-Lopez, et al., 2010).

Many nurses mentioned in the scenario answers that they would refer the family to the patients' wishes. Taking into account the patients' or families' wish was an important consideration in end-of-life decision making for health care professionals in a study by Foo, Zheng, Kwee, Yang, and Kirshna (2013). Similarly, Day, Drought, and Davis (1995) found that nurses would ask the family about the patient's wishes and abide by those wishes; therefore indirectly using the principle of substituted judgment (Torke, Alexander, & Lantos, 2008). Quality of life was the most frequently cited reason in their study for following patients' and families' wishes (Day, Drought, & Davis) and correlates with findings in this study. In addition, participants in a mixed methods study by Todd, Rosendaal, Duregon, and Verhoef (2004) reported they felt tube feedings were a means to keeping a person alive without "any measurable quality of life" (p. 191).

Another belief or perception of the HHNs involved ANH providing "essential nutrients" and "maintaining an adequate caloric and protein intake to promote health and well-being," making the "person stronger and overall healthier." This perception or belief is echoed in Todd, et al.'s (2004) study, where the nurses felt that nutrition was essential to "healing and recovery" (p. 191).

HHNs in this study felt that the decisions should be based on evidence and not their opinions. The majority of the nurses felt that they needed more education concerning evidence-based practice with regard to ANH and suffering in order to provide patients and families with accurate information so that better informed decisions could be made. This finding was validated with the questionnaire results. Todd, et al. (2004) and Ke, et al. (2008a) both revealed that nurses felt they needed more education in order to be better prepared to discuss this issue with family members. As noted earlier, Ke, et al's (2008b) study revealed that nurses' knowledge of ANH increased significantly post-intervention as compared to pre-intervention of an educational module. Therefore, HHNs would benefit from educational modules on ANH and its effects on suffering in the terminally ill.

Limitations

There were several limitations noted with this study. The sample size was smaller than anticipated; 91 nurses were invited to participate and of those, 27 nurses were initially recruited but only 17 participated in the focus groups. Because of the small sample size, Knowledge Test results cannot be generalized or considered representative of all HHNs. Another limitation was the use of the word 'terminal.' Three nurses told the PI after taking the Knowledge Test that they were unsure how to answer a few of the questions because it was unclear as to 'how terminal' the patients were or their stage of dying. The nurses stated that knowing how 'terminal' was defined would have assisted them in answering the questions better and possibly more accurately. Additionally, comments were written on the questionnaire such as, "depends on stage [of dying] and circumstances" for questions 1-3 and, "depends, case by case" for questions 1-2. It would have been helpful to define 'artificial nutrition and hydration.' Three nurses asked whether the ANH was given intravenously (IV) or through a tube. The PI instructed them to consider all ANH. Lastly, there was no diversity of ethnic backgrounds as all participants were white; this is an issue with convenience or nonprobability sampling (Hesse-Biber & Leavy, 2011; Tappen 2011) and should be addressed in future studies.

Implications for Practice and Further Research

This study emphasizes the importance of educating home health nurses on evidence-based practice, and specific education provided regarding ANH at end of life. Accurate information and counseling can be given to families who may face these decisions. Families need to know that the decisions to not choose ANH are not going to prolong suffering in the individual with LSD. A larger sample size as well as more research into whether there is a difference in urban and rural nurses' beliefs or perceptions would be beneficial as historically, there has been a difference in service availability in these two locales. By developing an ELNEC-type (End of Life Nursing Education Consortium) module for HHNs and then testing knowledge and perceived actions with the use of the Knowledge Test, educational intervention studies could be conducted within health care institutions or agencies as well as nursing programs to improve accuracy of information being communicated to nurses in clinical areas. Most importantly, future research should be geared toward conceptualizing and measuring suffering in people with LSD.

Conclusion

Current evidence demonstrates that ANH does not prolong life, prevent aspiration pneumonia or pressure ulcers, or help with nutritional status (Finucane, Christmas, & Travis, 1999; Murphy & Lipman, 2003; Sampson, Candy, & Jones, 2009) and can prolong suffering with complications such as fluid overload and aspiration pneumonia (Sampson et al, 2009). In addition, two major medical organizations recently recommended against the use of ANH in persons with LSD (American Geriatrics Society [AGS], 2013; American Academy of Hospice and Palliative Medicine [AAHPM], 2013). This study revealed that in this sample of NC HHNs' knowledge regarding evidence-based research regarding ANH was insufficient. Results of the mixed-methods design presented their beliefs or perceptions regarding ANH and suffering, which combined with their lack of knowledge, influences their counseling of patients and families toward initiation of ANH. While the nurses felt that people with LSD suffer, they were uncertain how to assess or measure suffering in these individuals. Only by enhancing our knowledge and understanding of the concept of suffering and ANH in people with LSD can we reduce the suffering inflicted upon these individuals and improve not only our care but more importantly, their quality of life until death.

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Summary and Conclusions

The manuscripts presented in this dissertation describe the issues surrounding suffering and ANH in individuals with dementia and their families as well as the pivotal role nurses play in these issues. The first manuscript, "A Dimensional Analysis of the Concept of Suffering in People with Late Stage Dementia at End of Life," identified four dimensions (pain, discomfort, holistic, and despair) and two subdimensions (communication and symptoms) in an attempt to clarify the concept. Most of the studies analyzed from the literature review used observational scales to measure or assess whether individuals with dementia were suffering. While observations may be pertinent in understanding whether one is suffering, observations can only assess pain, discomfort and symptoms; it cannot assess the spiritual and emotional suffering that one may be experiencing. Conceptualization of suffering would be beneficial in assisting health care providers, such as HHNs, in better assessment and treatment of individuals with dementia who are suffering at end of life.

In the second manuscript, "Measuring the Knowledge of Home Health Nurses in NC regarding Artificial Nutrition and Hydration at End of Life," a pilot study was conducted, in which the instrument, Knowledge Test of Artificial Nutrition and Hydration in the Terminally Ill (adapted from Ke et al., 2008a), was tested for reliability and baseline knowledge regarding ANH among HHNs in NC was obtained. The findings of this study revealed that HHNs lack evidence-based knowledge of ANH, which may, and probably does, affect their discussions and counseling of individuals with dementia and their families during the decision-making process. The instrument was deemed reliable with Cronbach's alpha of 0.71.

The third manuscript, "A Mixed-Methods Study Examining Home Health Nurses' Knowledge and Perceptions of Suffering and Artificial Nutrition and Hydration in People with

Late Stage Dementia," reports findings from an exploratory study utilizing a convergent parallel design. This study validated the research question, "Does HHNs' knowledge, beliefs or perceptions, and attitudes have an influence on their actions and counseling of individuals with dementia and their families?" with the three themes that emerged. The study also validated the dimensions identified in the dimensional analysis, from nurses' beliefs or perceptions of the word 'suffering,' although the HHNs rarely mentioned emotional or spiritual in their discussions unless mentioned by the PI. Reliability of the Knowledge Test was again confirmed with Cronbach's alpha of 0.70.

There are limitations to these studies, in particular the literature review for the dimensional analysis. As it was conducted in 2012, there may be other studies of significance since that time. The theoretical base of the analysis may lead researchers to different conclusions. While the Knowledge Test does include evidence-based practice information regarding ANH, it is not an extensive questionnaire; however, more questions would likely not appeal to nurses due to time constraints. Small sample sizes for the pilot and mixed-methods studies may have implications for correlations and internal consistency and nonprobability sampling led to issues in diversity. More importantly, clarification of potentially confusing concepts for study participants could have resulted in different outcomes.

Implications for Future Research (Next Steps)

It is evident that HHNs have inadequate or no evidence-based knowledge regarding ANH and suffering at end of life for individuals with dementia. This lack could lead to inappropriate decisions being made by patients and families. Interventional studies are needed to address this issue and provide educational modules to ensure that the nurses are addressing the needs of these individuals and their families. These educational modules could be presented not only in health care organizations but also in nursing programs. The concept of suffering must be conceptualized and defined more clearly so that all aspects of suffering are being treated and eliminated. Finally, future research should encompass developing methods to assess and measure suffering in people with LSD.

Contributions to Science and Nursing

While suffering occurs in potentially everyone at end of life, people with LSD frequently suffer in silence owing to no purposive language and cognitive dysfunction. Understanding dimensions of suffering that encompass more than the physical realms or symptoms is challenging to health care providers. ANH contributes to suffering and many times patients and families make inappropriate decisions based on the information conveyed to them by their nurses, possibly causing their loved ones to suffer more.

This dissertation study adds to science and nursing by demonstrating that HHNs' knowledge, beliefs or perceptions and attitudes influence what they inform patients and families. The instrument used in the pilot and mixed-methods studies confirmed that HHNs lack evidence-based knowledge regarding ANH. Changing their knowledge may also influence their beliefs or perceptions and attitudes, thereby improving an individual's suffering at end of life.

APPENDIX A- INSTRUMENT

Knowledge of Artificial Nutrition and Hydration in the Terminally Ill Questionnaire

Coding ID ______________ HHAgency ID ___________

Instructions - Based on the knowledge you have as a nurse, please circle the choices that best describes your knowledge of the sentence. The first three questions may possibly be used for future statistical purposes related to this research. (Adapted from Ke, Chui, Lo, & Hu, 2008)

DEMOGRAPHICS

What is your highest degree in nursing?			Assoc.	BSN	MSN	PhD or DNP
How long have you been a RN (in years)?	< 1	1 to 5	6 to 10	11 to 15	16-20	> 20
How long have you been in home health care (in years)?	< 1	1 to 5	6 to 10	11 to 15	16-20	> 20
What is your age?						
What is your gender?					Male	Female
What is your race?		White	Black	Hispanic/Latino	Asian	Other

KNOWLEDGE TEST

1. Artificial nutrition is beneficial for terminally ill patients.	AGREE	DISAGREE	NEUTRAL
2. Artificial hydration is beneficial for terminally ill patients.	AGREE	DISAGREE	NEUTRAL
3. Artificial nutrition can improve the strength of terminally ill patients.	AGREE	DISAGREE	NEUTRAL
4. Artificial hydration can improve the strength of terminally ill patients.	AGREE	DISAGREE	NEUTRAL

5. Artificial nutrition replacement is necessary in preventing terminally ill patients from starving to death. AGREE DISAGREE NEUTRAL

6. Artificial hydration replacement is necessary in preventing terminally ill patients from starving to death. AGREE DISAGREE NEUTRAL

7. Artificial nutrition replacement can result in tumor growth. AGREE DISAGREE NEUTRAL

8. Artificial nutrition replacement signifies empathy and care for the patient from medical personnel and family members. AGREE DISAGREE NEUTRAL

9. The sensation of mouth dryness and thirst in terminally ill patients is mainly caused by dehydration. AGREE DISAGREE NEUTRAL

10. Terminally ill patients are often hungry. AGREE DISAGREE NEUTRAL

11. Artificial nutrition replacement can improve hunger status in terminally ill patients. AGREE DISAGREE NEUTRAL

12. Aggressive nutritional support by tube feeding cannot change the nutritional status or the weight of terminally ill patients. AGREE DISAGREE NEUTRAL

13. Ketoacidosis as a consequence of lack of eating often results in an increase in physical pain in terminally ill patients. AGREE DISAGREE NEUTRAL

14. Artificial nutrition can prolong the life of terminally ill patients. AGREE DISAGREE NEUTRAL

15. Artificial hydration can prolong the life of terminally ill patients. AGREE DISAGREE NEUTRAL

16. Artificial nutrition improves mouth dryness and thirst in terminally ill patients. AGREE DISAGREE NEUTRAL

17. Artificial hydration improves mouth dryness and thirst in terminally ill AGREE DISAGREE NEUTRAL

patients.

18. The provision of either artificial nutrition or hydration lowers the anxiety of patients and their loved ones. AGREE DISAGREE NEUTRAL

19. The provision of either artificial nutrition or hydration aids in developing trust from terminally ill patients and their family members. AGREE DISAGREE NEUTRAL

20. Providing either artificial nutrition or hydration can prevent despair from worsening in terminally ill patients. AGREE DISAGREE NEUTRAL

21. Activities of terminally ill patients are restricted by in-dwelling tubing. AGREE DISAGREE NEUTRAL

22. In terminally ill patients, fluid overload is likely to result in pleural effusion or pulmonary edema. AGREE DISAGREE NEUTRAL

23. Invasive procedures, such as the placement of feeding tubes, cause pain and discomfort in terminally ill patients. AGREE DISAGREE NEUTRAL

SCENARIO

(Continue on next page if you run out of room)

David Smith is a 79-year-old male otherwise healthy with dementia for eight years.
While he was getting along well at home, he has progressively worsened over the last several months.
He has lost 25 pounds over the last six months, and in the past 8 weeks he has lost 10 pounds.
His daughter reports that he no longer has an interest in food, although she is able to get him to eat a few bites at each meal.
He is not interested in supplements and refuses them when

offered.
His last doctor's visit was one week ago; at this visit,
the doctor informed the daughters that it appeared that Mr. Smith needed a feeding
tube for
artificial nutrition and hydration in order to provide better nutritional status for Mr.
Smith.
The daughters are now asking a number of questions regarding this tube
feeding.

1. The daughters feel that initiating a tube feeding will cause pain, discomfort or suffering for their dad. How would you respond to each of these concerns?

2. They ask you the advantage of artificial nutrition and hydration for him. What is your response?

3. They ask you the disadvantages of artificial nutrition and hydration for him. What is your response?

4. The daughters ask what you would recommend in this situation? How do you respond?

5. If the daughters asked what you would do if this was your father, would your response be different and if so, how?

Appendix B – IRB Approval for Pilot Study

MUSC
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Institutional Review Board for Human Research (IRB)
Office of Research Integrity (ORI)
Medical University of South Carolina

Harborview Office Tower
19 Hagood Ave., Suite 601, MSC857
Charleston, SC 29425-8570
Federal Wide Assurance # 1888

APPROVAL:
This is to certify that the research proposal **Pro00017924** entitled:
Home Health Nurses' Knowledge of Artificial Nutrition and Hydration in North Carolina

Submitted by: **Lenora Smith**
Department: **Medical University of South Carolina**

for consideration has been reviewed by **IRB-I - Medical University of South Carolina** and approved. In accordance with 45 CFR 46.101(b)(2), the referenced study is exempt from Human Research Subject Regulations. No further action or Institutional Review Board (IRB) oversight is required, as long as the project remains the same. However, you must inform this office of any changes in procedures involving human subjects. Changes to the current research protocol could result in a reclassification of the study and further review by the IRB.

Because this project was determined to be exempt from further IRB oversight, consent document(s), if applicable, are not stamped with an expiration date.

Research related records should be retained for a minimum of three years after termination of the study.

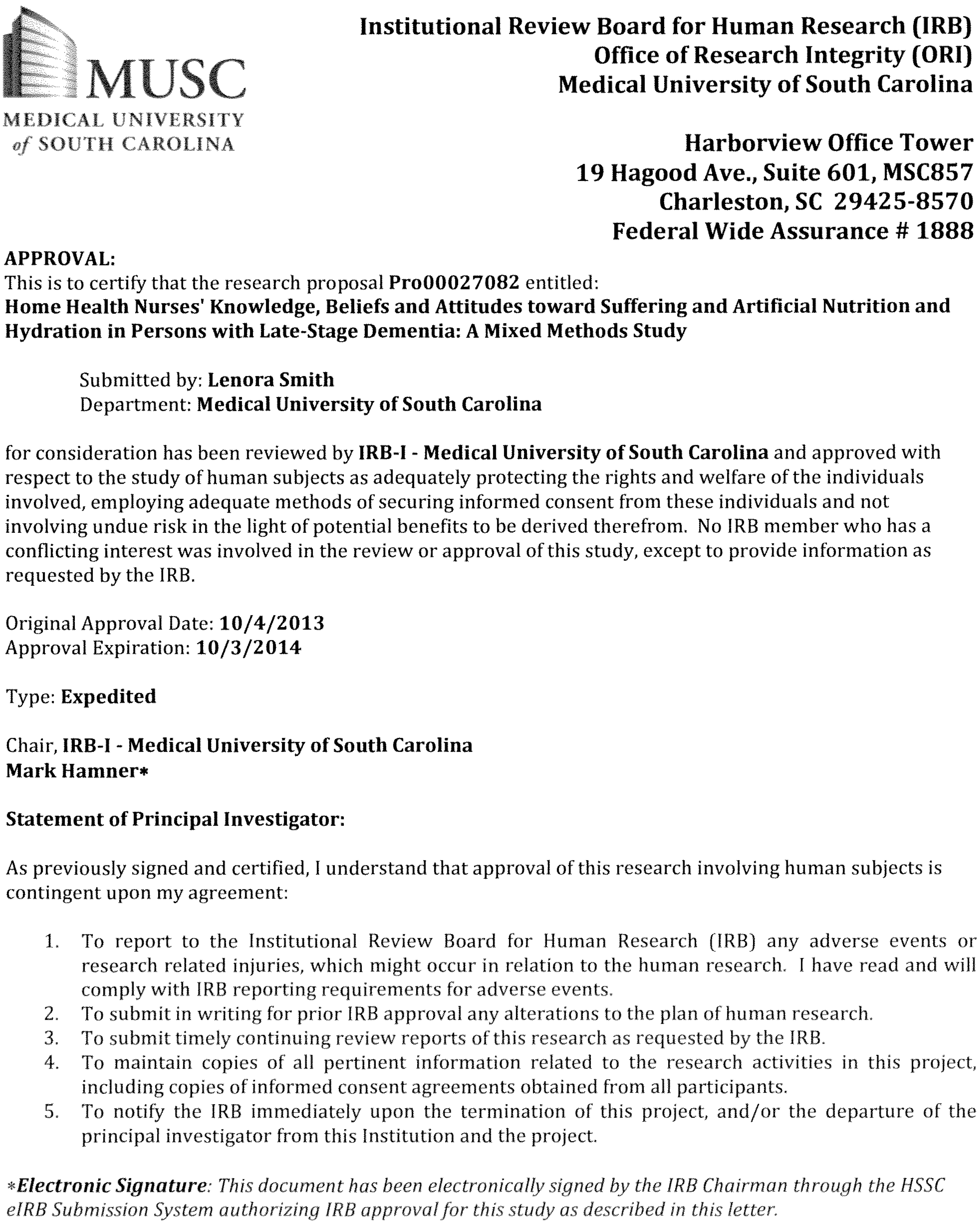
Approval Date: **10/10/2012**

Type: **Exempt**

Chairman, **IRB-I - Medical University of South Carolina**
Mark Hamner*

***Electronic Signature**: *This document has been electronically signed by the IRB Chairman through the HSSC eIRB Submission System authorizing IRB approval for this study as described in this letter.*

Appendix B – IRB Approval for Mixed Methods Study



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Institutional Review Board for Human Research (IRB)
Office of Research Integrity (ORI)
Medical University of South Carolina

Harborview Office Tower
19 Hagood Ave., Suite 601, MSC857
Charleston, SC 29425-8570
Federal Wide Assurance # 1888

APPROVAL:
This is to certify that the research proposal **Pro00027082** entitled:
Home Health Nurses' Knowledge, Beliefs and Attitudes toward Suffering and Artificial Nutrition and Hydration in Persons with Late-Stage Dementia: A Mixed Methods Study

Submitted by: **Lenora Smith**
Department: **Medical University of South Carolina**

for consideration has been reviewed by **IRB-I - Medical University of South Carolina** and approved with respect to the study of human subjects as adequately protecting the rights and welfare of the individuals involved, employing adequate methods of securing informed consent from these individuals and not involving undue risk in the light of potential benefits to be derived therefrom. No IRB member who has a conflicting interest was involved in the review or approval of this study, except to provide information as requested by the IRB.

Original Approval Date: **10/4/2013**
Approval Expiration: **10/3/2014**

Type: **Expedited**

Chair, **IRB-I - Medical University of South Carolina**
Mark Hamner*

Statement of Principal Investigator:

As previously signed and certified, I understand that approval of this research involving human subjects is contingent upon my agreement:

1. To report to the Institutional Review Board for Human Research (IRB) any adverse events or research related injuries, which might occur in relation to the human research. I have read and will comply with IRB reporting requirements for adverse events.
2. To submit in writing for prior IRB approval any alterations to the plan of human research.
3. To submit timely continuing review reports of this research as requested by the IRB.
4. To maintain copies of all pertinent information related to the research activities in this project, including copies of informed consent agreements obtained from all participants.
5. To notify the IRB immediately upon the termination of this project, and/or the departure of the principal investigator from this Institution and the project.

****Electronic Signature****: This document has been electronically signed by the IRB Chairman through the HSSC eIRB Submission System authorizing IRB approval for this study as described in this letter.*

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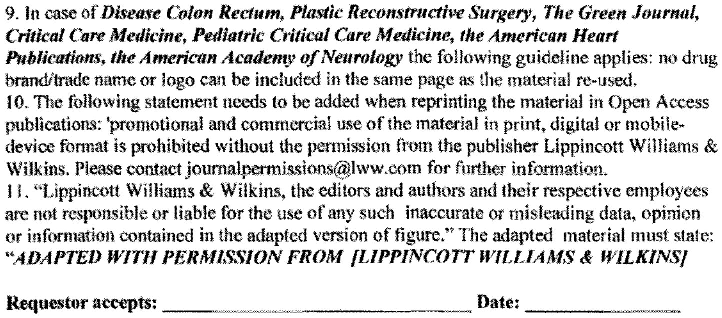

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