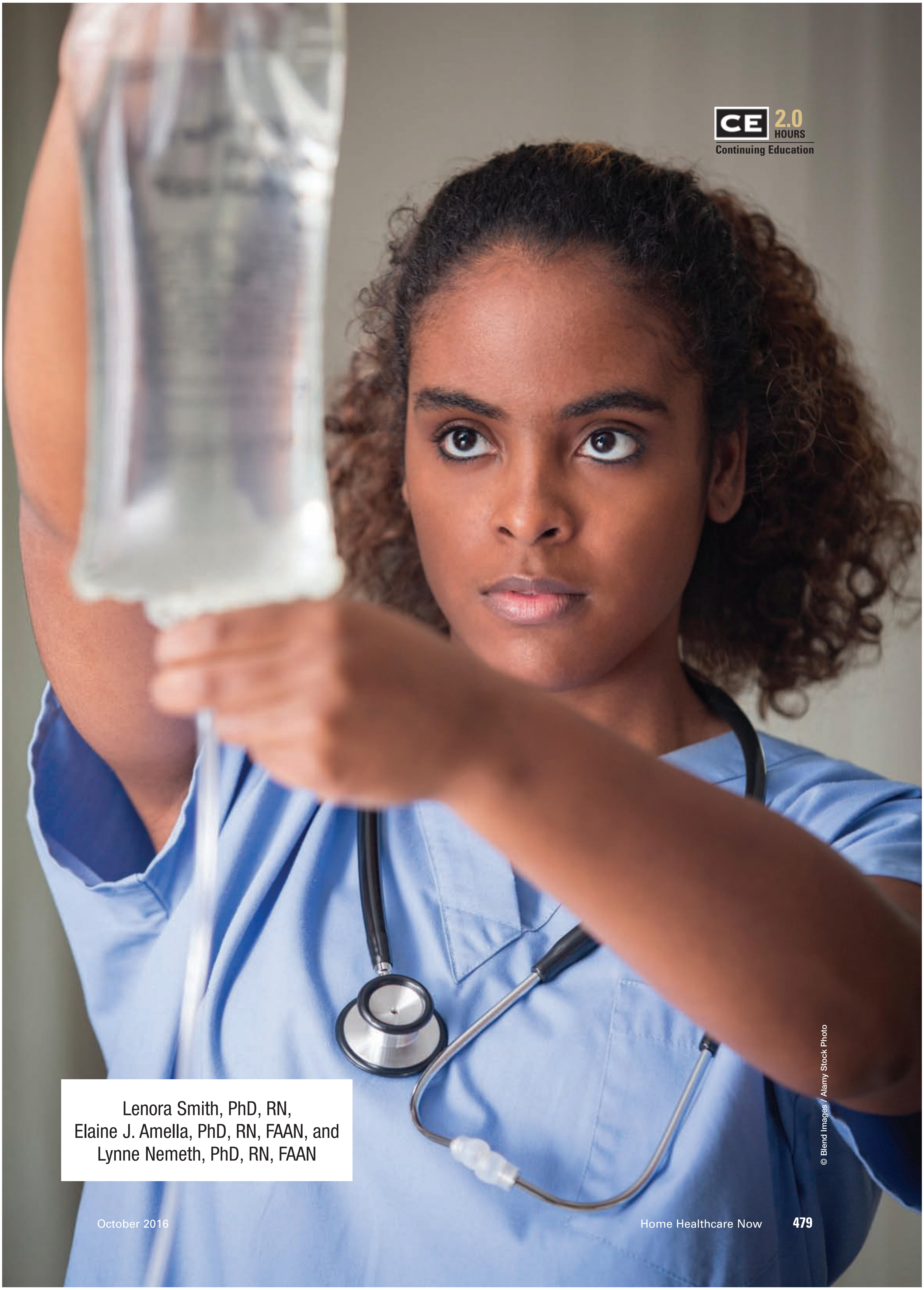
Perceptions of Home Health Nurses Regarding Suffering, Artificial Nutrition, and Hydration in LATE-STAGE DEMENTIA

The purpose of this study was to explore perceptions of home healthcare nurses related to suffering, artificial nutrition and hydration in people with late-stage dementia, and if these perceptions influence care to people with dementia and their families. Part of a mixed-methods study, the qualitative portion examined perceptions of home healthcare nurses in a rural area in the southern United States. Seventeen home healthcare nurses participated in this study. Semistructured focus group interview questions were used. Constant comparative analysis was the method used for coding transcripts. Three themes emerged from the analysis: patient/family comfort, futility, and symbols of suffering. Although many of the nurses reported that artificial nutrition and hydration was of comfort to the patient and family because of the potential for "starving," they also felt it prolonged the patient's suffering due to the invasive procedure, need for restraints, and possibility of fluid overload. Several nurses felt that artificial nutrition and hydration gave a sense of false hope to the family that the patient would live longer. The perceptions of these home healthcare nurses influence their care to people with dementia and their families related to artificial nutrition and hydration, possibly based on experience. Their perceptions could influence family decisions regarding treatment options. Further research and education with home healthcare nurses is vital to ensure nurses are appropriately caring for patients with dementia and their families.

Dementia is a chronic, progressive disease that involves deterioration of cognitive function, including thinking, orientation, language, and judgment (World Health Organization [WHO], 2015), and usually affects those older than 60 years of age (National Library of Medicine, 2013). It eventually results in decreased ability or inability to perform activities of daily living, including walking and swallowing (Alzheimer's Association, 2015). Globally, there are 47.5 million people with dementia, with 7.7 million new cases each year (WHO). Dementia is one of the major causes of disability and dependency for older people worldwide (WHO).

In North Carolina (NC), where the study took place, the number of adults with dementia has reached over 160,000 and is projected to be more than 210,000 in the year 2025, an increase of more than 30% (Alzheimer's Association, 2015). It is estimated that 70% of older people with dementia are cared for at home in NC (National Association for Home Care and Hospice, 2010). There has also been an increase in the number of home deaths of people with dementia 65 years or older—from 15% in 1989 to 24% in 2007 (National Center for Health Statistics, 2010).

For individuals with late-stage dementia (LSD), physiologic changes in the progression of the disease result in decreased nutritional and caloric needs (Wolf-Klein et al., 2007). In addition, poor food and fluid intake is prevalent due in part to an individual's perception of food, as well as cognitive and functional decline to the point of dysphagia and apraxia (Cohan, 2012). This increases the person with dementia's risk for malnutrition as well as infections (Fischberg et al., 2013), and often, families do not understand this as part of the progression of the disease. These issues introduce discussions of initiating artificial nutrition and hydration, with decisions and outcomes left to families or surrogates, who often turn to nurses to counsel and guide them on making an informed decision. Nurses and other clinicians may lack the evidence-based knowledge needed to help these families in this vital decision, potentially causing more suffering and pain for the patient and resulting in undesirable decisions made by families (Lopez et al., 2010).



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The concept of suffering has no conclusive definition in the literature. It also has many dimensions, including physical, psychological, spiritual, and emotional, which may be prevalent in LSD (Smith et al., 2014). The initiation of artificial nutrition and hydration may produce pain and discomfort, and advance additional complications, such as fluid overload and aspiration pneumonia (Sampson et al., 2009). A lack of understanding of the concept of suffering or LSD by healthcare professionals may result in poor decisions by proxies for people with LSD, as well as unnecessary suffering by individuals with dementia and their families. This may also lead to a poor quality of life at end of life (Smith et al.).

With the increase in dementia-related deaths at home, ensuring that individuals with LSD have a quality end of life is important. Therefore, the aim of the qualitative study was to assess whether home healthcare nurses' perceptions and beliefs about suffering and artificial nutrition and hydration in individuals with LSD influence them when caring for patients and their families with LSD.

Methods

Sample and Recruitment

After approval for the study from the Institutional Review Boards of the authors' universities, home healthcare nurses in NC were recruited through convenience sampling over a 4-month period. Although originally 27 registered nurses (RNs) were recruited for the study, 17 RNs actually participated. Inclusion criteria were: a) work in a Medicare-certified home healthcare agency only in the home healthcare section (if the agency was 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 healthcare nurse. Nurses were excluded if they were in management positions within the agency, worked in the hospice section (if combination agency), or did not provide direct care to patients. Written consent was obtained prior to enrollment and then screened to ensure inclusion criteria were met. A drawing was held at the conclusion of each focus group for a $25 gift card.

Table 1. Focus Group Interview Questions

1. What does the word "suffering" mean to you?
2. What do you know about the positive and negative effects of artificial nutrition and hydration (ANH) in persons with LSD?
3. Tell me your thoughts on suffering individuals with LSD. Do you believe people with dementia suffer as the disease progresses and how?
4. Describe a time in your career when you felt a person with dementia was suffering. What happened and how did it make you feel?
5. Describe your thoughts on families' perceptions of ANH in individuals with LSD.
6. How would you measure suffering in individuals with LSD?
7. Describe a conversation you have had with either a patient or family member regarding ANH. What information did you give him/her about ANH?
8. If you believe that suffering is more than physical symptoms, how would you expect to know that someone is suffering?
9. What are your thoughts and experiences about ANH prolonging life in persons with LSD?

Note. LSD = late stage dementia.

Theoretical Framework

Grounded theory and symbolic interactionism guided this study and were used to develop the dimensions and themes from the participants' interviews. Symbolic interactionism is based on humans developing their knowledge and means from interactions they have with others (Corbin & Strauss, 2008) and with the surrounding environment. However, Charon (2010) posits that individuals apply meaning to their environments through interpretation. Qualities of lived experiences then can be described through symbolic interactionism (Hall et al., 2013), which was used to explore and understand how the nurses' lived experiences contributed to their meanings of suffering and artificial nutrition and hydration in individuals with LSD.

Methods

The nurses in this study brought unique personal and professional experiences with end of life and suffering to their interaction with each other, families, and persons with LSD. The nurses may also have been influenced by cultural and religious belief systems. The use of grounded theory and symbolic interactionism methods allowed the researchers to develop themes and meanings of suffering in LSD and to understand if the meanings are influenced by events in their lived experiences.

Data were collected via focus groups and a scenario on care of a patient with LSD. Focus groups were held in four locations. Semistructured interview questions were used during the focus groups. Open-ended questions were asked to explore the nurses' perceptions of artificial nutrition and hydration and suffering in individuals with LSD (Table 1).

An expert in qualitative research reviewed the focus group interview questions to ensure face validity. One of the authors took field notes to capture body language and key words from the participants and the interviews were digitally recorded and later transcribed verbatim.

In addition to the focus groups, a scenario with five open-ended questions was used to explore nurses' responses to a hypothetical patient with LSD. The scenario depicted an aging man with a diagnosis of dementia who had weight loss and the physician who was suggesting artificial nutrition and hydration. As part of the scenario, the family explored their father's suffering and pain, and questioned whether artificial nutrition and hydration would be beneficial for their father (Table 2).

Data Analysis

One of the authors documented key words used by the participants in answering the interview questions and saturation was achieved when multiple participants used the same or similar information or when no new information occurred during the interviews. A graduate teaching assistant transcribed the audio files, which were then verified for accuracy by the researcher by listening to the audio and reading the transcripts simultaneously. The researcher read the transcripts and highlighted specific key words or phrases to categorize elements of the data.

Table 2. Scenario With Questions

David Smith is a 79-year-old male otherwise healthy with dementia for 8 years. Although he was getting along well at home, he has progressively worsened over the last several months. He has lost 25 pounds over the last 6 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 1 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?

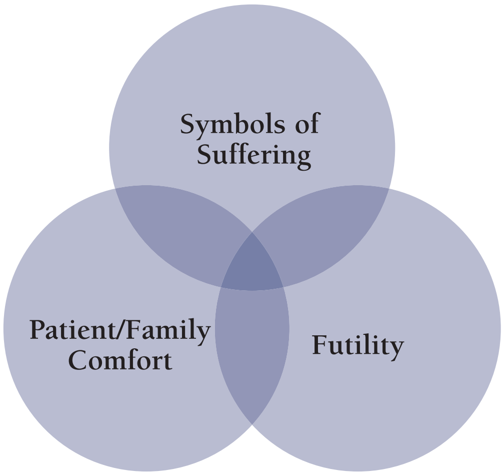

Figure 1. The triad of suffering in late-stage dementia.

Key words and phrases were highlighted among the answers to the scenario questions and were then compared with notes generated at the interviews using an iterative inductive process. Themes began to emerge from both the focus groups and the scenario and the authors discussed and analyzed the themes to ensure accuracy of the analysis. Categories were noted to overlap with the iterative process. Initially four themes emerged, yet as similarity and consistency in the concepts were noted, a more succinct three-themed framework of the nurses' perceptions was revealed and characterized as The Triad of Suffering in LSD (Figure 1). This framework showed the interconnectedness of the three themes.

Results

The majority (71%) of the nurses had an associate degree in nursing and more than 20 years' experience as an RN (53%). More than half (58%) had less than 15 years' experience as a home healthcare nurse. The entire sample was white and the majority were female (males = 3). The themes that developed from the data analysis into the framework (The Triad of Suffering) include patient/family comfort, futility, and symbols of suffering.

Patient/Family Comfort

The majority of the nurses' comments in focus group and scenario questions focused on the concept of patient or family comfort. Some of the key words that nurses used were that artificial

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nutrition and hydration were comfort measures for the patient and for the family. However, some nurses explained that artificial nutrition and hydration makes it harder on patients and their families to make decisions about care at end of life. Although comfort is one of the purposes of nursing care, many of the nurses felt helpless in knowing how to care for people with dementia and believed artificial nutrition and hydration only increased patients' suffering. Nurses explained that with this type of nutrition, a painful invasive procedure is performed, which may then lead to the patient having to be restrained to keep from pulling the tube out. It may also result in increased fluid, often causing discomfort, nausea and vomiting, and diarrhea, all increasing the patient's suffering. Although many nurses noted that they would rather not see the patient suffer in this manner, they would always consult with the family regarding the patient's wishes.

Futility

The concept of futility was one of the themes that emerged from the nurses' responses. Many felt that artificial nutrition and hydration prolonged a person's life, which might be of benefit to the family but not to the patient. Statements such as "poor quality of life"; "false hope"; "frustration"; "prolonged discomfort"; and "prolongs the inevitable" were noted throughout the interviews and in the scenario responses. Some of the participants voiced feelings of sadness at seeing patients and families in the throes of this disease and its complications. Many noted that because LSD caused so much suffering, artificial nutrition was a futile measure.

Symbols of Suffering

Symbols of suffering emerged as the third theme from the focus group and scenario responses. The majority of the comments were directed toward physical symptoms, physical appearance, or patient's discomfort. Nurses described patient's involuntary movements such as restlessness and constant moving of arms and legs. They explained how difficult it was to assess a patient's pain and needing to use body language and facial grimacing to decipher whether the patient was in pain. Other nurses perceived patients to be scared. They also shared experiences of patients crying and moaning and their need to rely on these responses to justify medication or decide what action to take.

Additionally, comments from the scenario responses included the risk of aspiration and infection, and that initiating artificial nutrition may cause some pain and distress because the procedure is invasive. In the scenario responses, nurses expressed feelings of frustration for patients because the nurses had "no way of knowing" whether the patients were suffering in this later stage when the patients have no purposive language.

Discussion

The Triad of Suffering framework identified the relationships between the themes from the nurses' perceptions and the manner in which the nurses cared for patients and families considering artificial nutrition and hydration. Applied to this study, symbolic interactionism would suggest that each clinician develops a personal meaning toward suffering and artificial nutrition and hydration in individuals with LSD through interactions with family, friends, and society as a whole. The meaning and beliefs then become critical factors in understanding how the clinician interacts in any situation that invokes that symbolic meaning.

As can be seen throughout the themes that emerged, the nurses perceived artificial nutrition and hydration as being beneficial to patients by providing them comfort, but also felt it could be a futile measure in people with LSD. This information may result in inaccurate information being given to patients and families, leading to conflicting decisions among those involved. Ke et al. (2008) found in their study that although hospital nurses in Taiwan had experience in caring for terminal cancer patients, their lack of evidence-based knowledge resulted in the nurses still wanting to supply artificial nutrition and hydration for these patients.

There was conflict among the participants as to whether artificial nutrition and hydration prolongs life and if prolonging life was good or bad. One nurse wrote, "it prolongs life, but why would you want to?" Some of the nurses voiced that prolonging life was a negative effect of artificial nutrition and hydration and led to even poorer quality of life. Many nurses indicated that artificial nutrition and hydration prolonged suffering because of the invasiveness of the procedure and the complications associated with it and the debilitating nature of the disease.

Although some of the nurses stated they could not recommend tube feedings to the family, others reported that they would, even though they felt artificial nutrition and hydration would prolong the person's life and increase their suffering and worsen their quality of life. Wurzbach (1996) noted in her qualitative study on ethical values of nurses regarding tube feedings that moral conflicts are influenced by an individual's knowledge, experience, and differences in values or morals. Bryon et al. (2008) also suggested that nurses might change their views on artificial nutrition and hydration depending upon an order by the physician or based on the beliefs of the patients, families, or co-workers.

Many nurses noted that they would refer to the family as to the patient's wishes, which was an important consideration in end-of-life decisions for healthcare professionals in a study by Foo et al. (2013). In another study, nurses perceived tube feedings as a means to keeping a person alive with no measurable quality of life (Todd et al., 2005).

Current evidence indicates that artificial nutrition and hydration does not prolong life, prevent aspiration pneumonia or pressure ulcers, or help with nutritional status (Hanson, 2013; Sampson et al., 2009; Teno et al., 2012). The use of artificial nutrition and hydration in persons with LSD is also not recommended by the American Geriatrics Society (2014) or the American Academy for Hospice and Palliative Care Physicians (2013). The majority of nurses in this study believed that more education was needed about artificial nutrition and hydration and suffering so they could provide more accurate information to families. Todd et al. (2005) and Ke et al. (2008) both validated this finding in their studies. Therefore, it would be beneficial for home care clinicians to have education on artificial nutrition and hydration and its effects on patient outcomes and quality of life.

Implications for Practice and Clinical Relevance

Nurses' perceptions of artificial nutrition and hydration and suffering in people with LSD play an important role in the information given to patients with LSD and their families and the decision-making process. The importance of having knowledge of, and utilizing evidence-based information, is emphasized in this study, especially with decisions involving artificial nutrition and hydration at end of life. Families need to know and understand the effects of decisions to initiate artificial nutrition and hydration for individuals with LSD. Most importantly, future research should be directed toward a more concise definition of suffering and measuring suffering in people with LSD.

Conclusion

The perceptions of these nurses exposed the importance of one's beliefs in caring for patients with LSD and their families. This qualitative study revealed home healthcare nurses' perceptions can influence their care of patients and families contemplating artificial nutrition and hydration. Enhancing understanding of artificial nutrition and hydration in people with LSD among home care clinicians can help reduce the physical suffering imposed upon these individuals and improve their quality of life at end of life. ☗

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