NURSING STAFF PARTICIPATION IN END OF LIFE NUTRITION AND HYDRATION DECISION MAKING PROCESSES IN A RURAL NURSING HOME

by

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Decreased or absent oral intake, common among nursing home residents nearing the end of life, often triggers decision making regarding the course of care. Residents, family members, and medical providers hold final responsibility for decisions in these situations, yet the consistent presence of nursing staff places them in a unique position to influence and support decision making processes. Despite this potential, the participation of nursing staff in these decisions is minimally described in current literature.

The purpose of this focused ethnographic study was to better understand the participation of nursing staff members, inclusive of Registered Nurses, Licensed Practical Nurses, and Nursing Assistants, in end of life nutrition and hydration decision making processes in a rural nursing home. Semi-structured interviews with 19 nursing staff members, field observations during interviews, and review of relevant documents were used to collect data from a single nursing home in a rural region of North Carolina. An adaptation of Bryon, Gastmans, and de Casterlé's striving for 'good care' framework served as the conceptual framework informing this study. The inductive approaches described by Mason, and by Roper and Shapira, were used to guide data analysis.

Nursing staff participation in end of life nutrition and hydration decision making processes in this rural nursing home was closely aligned with type of decision and participant role, of Nursing Assistant, Licensed Practical Nurse, or Registered Nurse, and influenced by a variety of other factors at both individual and group levels. Three primary themes were identified: *Formal Decision Making* (with subthemes of communicating resident issues**,** initiating and coordinating decision processes, assuring regulatory compliance, and influencing); *Informal Decision Making,* (with subthemes of knowing residents and families, instituting feeding interventions not requiring formal medical orders, respecting and honoring, and guiding the resident and family) and *Influential Factors (*with subthemes of personal experiences/beliefs, unpredictable trajectory, relationship with resident/family, and organizational culture).

Findings suggest nursing staff in this facility participate in nutrition and hydration decision making processes to a greater extent than even they realize, especially informal decision making, in their efforts to comfort and provide good care to residents nearing end of life. Factors identified as hindering their efforts include limited awareness of current evidence and best practices, delays in formal decision making, and lack of professional role clarity, especially among LPNs. Comfort with coworkers and supervisors, positive past experiences, and established relationships with residents and family members were identified as supporting participation. This study contributes to the understanding of nursing staff participation in nutrition and hydration decision making processes for residents nearing end of life in rural nursing homes. Further research in other facilities, integration of findings into interventions to

support evidence based best practices, and critical evaluation of the relationship between formal decision making and policy implementation are suggested.

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by

Gina Cahoon Firnhaber, PhD(c)

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DEDICATION

This work is dedicated to all who care for others in need. You know who you are…

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A huge thank you to all of my family, friends, and coworkers who supported and tolerated me throughout this PhD program. Completing a dissertation is a long and lonely journey but success requires sacrifice from more than just the traveler. I promise my husband Jonathon, and daughters Jessica and Julia, that this is my final degree and I *will* start vacuuming the house again soon. I assure my friends I *will* be more available for lunch dates and *will* send Christmas cards this year. And I will be eternally grateful for the forged by fire bonds of friendship I now share with Teresa Anderson, Joyce Buck, Jennifer Jones-Locklear, and April Ventura, my fellow travelers along this PhD journey.

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CHAPTER 1: INTRODUCTION

The Institute of Medicine (IOM), now known as the National Academy of Medicine (NAM), has identified improvement of care for those nearing end of life as a priority for the United States (U.S.) health care system. End of life care delivered using evidence based palliative care practices is associated with improved quality of life for the dying and their families, less distressing death experiences, and lower average cost of care (IOM, 2014). Unfortunately, palliative care best practices are not consistently implemented in delivery of end of life care in health care settings in the United States (US), including nursing homes, and further research is needed to inform future practice and care policies (Mitchell, Mor, Gozalo, Servadio & Teno, 2016; Morley et al., 2014). End of life care decisions are often complex, and best practice evidence must be balanced with the beliefs, needs, and experiences of residents, family members and care providers.

In the normal course of dying, especially among older persons and those with chronic disease, diminished or absent oral intake often occurs. The potential for dehydration and inadequate nutritional status may create a moral and regulatory dilemma in the nursing home setting, where care is controlled by both organizational policies and external agency regulations designed to assure maintenance of intake adequate to support health and well-being. Requirements to safely assure adequate intake may conflict with potentially more appropriate choices for residents nearing end of life.

Non-oral nutrition and hydration, commonly referred to as artificial nutrition and hydration, is often used in situations where residents are unable to maintain adequate nutrition and hydration orally, but is not generally suggested for those approaching end of life. In some cases, residents nearing end of life are already receiving nutrition and/or hydration via non-oral routes and withdrawal of these therapies may be considered as death approaches. When residents are at increased risk of aspiration, usual care would be to avoid oral intake, but for residents nearing end of life, the emotional benefits of allowing the resident to choose to eat or drink as they wish may be of greater value than limiting the risk of aspiration. In residents with dementia, careful hand feeding has been shown to result in similar or better outcomes than artificial feeding methods such as nasogastric or percutaneous endoscopic gastrostomy (PEG) tubes and has been gaining prominence in palliative care circles as a preferred approach to nutrition and hydration issues (American Geriatrics Society [AGS], 2014; Hanson, Ersek, Gilliam, & Carey, 2011).

Though outcome studies suggest provision of artificial nutrition and hydration offers minimal to no therapeutic benefit and may even negatively impact individuals nearing end of life, these decisions remain complex. Unless these decisions are made, agreed upon, properly documented, and accepted by all parties both prior to and when issues arise, the need for nutrition and hydration decision making frequently arises in those nearing end of life. As care providers with the most direct, continuous contact with NH residents and their families, nursing staff are uniquely positioned to support and influence the processes surrounding these decisions.

Statement of the Problem

NH nursing staff, particularly RNs, have a responsibility to assure delivery of best possible care based on current evidence while respecting patient or designated surrogate decision makers' "acceptance or refusal of food and fluids, whether delivered by normal or artificial means" (American Nurses Association [ANA], 2011, p. 1) and palliative care guidelines call for inclusion of all providers in care decisions (National Consensus Project for Quality Palliative Care, 2013). There is little literature, however, addressing the participation of nursing staff in end of life decision making processes within the culture of U.S. NHs, especially NAs. How nursing staff work together to support decision making processes is also minimally described. Greater understanding of the nursing staff participation is needed to guide development of effective interventions, organizational designs, and regulatory changes that take advantage of nursing staff to support and influence residents and families faced with nutrition and hydration issues.

Background and Significance

Prior research has shown end of life nutrition and hydration decision making for residents often involves multiple interactions over time with a variety of participants (Clarke, Galbraith, Woodward, Holland, & Barclay, 2015; Reinhardt, Boerner, & Downes, 2015). Medical providers, residents, and family members are considered the primary participants in these decisions, with residents and family members having the right to accept or reject treatment under the Patient Self Determination Act of 1990 (Forbes, Bern-Klug, & Gessert, 2000; The, Pasman, Onwuteaka-Philipsen, Ribbe, & van der Wal, 2002). Nursing staff and other select members of the health care team within the NH are positioned to influence care decisions, with the potential to impact both the outcomes and experiences of residents and family members (Bryon, Gastmans, & de Casterle, 2008; Lopez & Guarino, 2011). Despite emphasis on the role of residents and family members in decision making, delivery of nutrition and hydration therapy in NHs requires a medical order, and medical providers are not legally bound to comply with requests for treatments if they are not expected to have therapeutic value (Druml et al., 2016).

The use of advanced directives, including MOST (Medical Orders for Scope of Treatment) and POLST (Physician Orders for Life-Sustaining Treatment) is gaining in popularity but does not consistently offer adequate decision making support for nutrition and hydration issues near end of life. A systematic review by Hickman, Keevern, and Hammes

(2015) reported finding only a third of forms were being completed to the lowest therapy levels. One study of POLST form completion in nursing homes in California, where form completion is required, found approximately 70% of forms reviewed incomplete, with many missing physician or resident signatures and also having incomplete or contradictory treatment preferences (Rahman, Bressette, & Enguidanos, 2017).

Prevalence and significance of the issue

In the US, over 500,000 deaths occur annually in NHs, representing 20% of all US deaths, and almost 30% among those 65 years of age and older. Nutrition and hydration issues are common in NHs, especially among those dying of extended illnesses such as cancer, heart failure, and dementia (Mentes, 2006; Tamura, Bell, Masaki, & Amella, 2013). Studies of residents with cancer and end stage dementia have reported between 30% and 80% of residents develop oral intake issues within the final 3 months of life (Hanson et al., 2008; Hanson, Ersek, Lin, & Carey, 2013; Hui, Dev, & Bruera, 2015; Mitchell et al., 2009).

Despite significant research failing to show significant improvement in survival or functional status associated with artificial nutrition and hydration utilization in those nearing end of life, decisions regarding providing, withholding, and especially withdrawing artificial nutrition and hydration therapies are difficult (Abu et al., 2016; Goldberg & Altman, 2014; Good, Richard, Syrmis, Jenkins-Marsh, & Stephens, 2014a; Good, Richard, Syrmis, Jenkins-Marsh, & Stephens., 2014b; Lan et al., 2016; Sampson, Candy & Jones, 2009; Ticinesi, et al., 2016). Arguments supporting utilization of artificial nutrition and hydration include moral duty, provision of minimum standard of care, relief of thirst, and both physical and psychological comfort of the dying and their family members. Arguments against utilization of artificial nutrition and hydration near end of life include lack of proven benefit, pain and discomfort associated with methods of administration, increased GI symptoms, the potential for increased consciousness and discomfort, and extended suffering from lengthened time until death. Additional factors such as religious beliefs, relationship issues, inability to accept a terminal diagnosis, lack of information, and even misperceptions of the value of artificial nutrition and hydration therapies in those nearing end of life may also complicate decision making processes (del Rio et al., 2012; Lopez & Guarino, 2011).

Increasing application of palliative and hospice care principles, which discourage artificial nutrition and hydration utilization in most situations, is increasing in NHs (Zheng, Mukamel, Caprio, & Temkin-Greener, 2013; Zheng & Temkin-Greener, 2010) with one recent study by Mitchell et al., (2016) reporting the initiation of tube feeding in US NH residents diagnosed with advanced dementia decreased 50% between 2000 and 2014, from 11.7% to 5.7%.

Nursing home culture

NH culture may complicate delivery of individualized, evidence based care. NHs have traditionally operated with top down management, providing basic, standardized care, with little focus on residents as individuals. Improvement efforts have focused on increased resident choice and participation in care decisions, decentralization of services, and greater control for front line staff (Ersek & Wilson, 2003; Rahman & Schnelle, 2008). Various programs have been implemented to improve NH culture, but change is difficult and occurs over extended periods of time (Munroe, Kaza, & Howard, 2011). Thus, in this time of transition, the culture of care may vary significantly among NHs. Additional factors identified as impacting NH culture include education and training of staff, reimbursement issues, lack of psychosocial support for staff, inadequate staffing, and strict regulations within the NH industry (Ersek & Wilson, 2003; Malloy et al., 2009). The Affordable Care Act of 2010 included requirements for transition of long term care (LTC) programs toward more individualized care, yet this is a complicated process. Greater success in NH transition is associated with larger size, nonprofit status, and lower percentages of residents covered primarily by Medicaid and Medicare (Grabowski, Elliot, Leitzell, Cohen, & Zimmerman, 2014).

Nursing home regulations

Various regulations within the NH industry also challenge provision of individualized care and culture change. Bound by both state and federal regulations and outcomes requirements, care delivered in NHs may be determined more by pressure to meet preset criteria than by individual resident needs. One example is the requirement that NHs report the percentage of long-stay residents who lose greater than 5% of their weight in one month as a quality measure of the Five-Star Quality Ratings system of Nursing Home Compare, a government sponsored evaluation tool designed to provide information that will assist consumers in choosing NHs (www.medicare.gov/nursinghomecompare/search.html). Although this measure is valuable in identifying undernutrition and poor hydration which are common in NHs (Morley, 2011), weight loss is not necessarily an indication of poor care in those nearing end of life. Until appropriate documentation is in place to relieve the responsibility of meeting this expectation, however, NHs are responsible for maintaining residents' weights, with reports of weight loss increasing scrutiny by surveyors and negatively impacting Star Ratings. Additionally, financial incentives, including increased reimbursement for delivery of artificial nutrition and hydration but not for more time consuming hand feeding, have also been cited as factors encouraging inappropriate utilization of artificial nutrition and hydration in residents nearing end of life with advanced dementia (Finucane, Christmas, & Leff, 2007).

End of Life Nutrition and Hydration Decision Making

Nursing staff spend significant time and effort providing care to NH residents and are often privileged with information and opportunities for interactions with residents and family members not available to medical providers. Additionally, nursing staff are directly responsible for assessing and meeting nutrition and hydration needs on a daily basis, placing them in a position of involvement in these care processes. Nutrition support services may be limited in NHs, with current federal regulations requiring only that facilities employ “sufficient” food and nutrition staff and have a designated director of food and nutrition services with the “appropriate competencies and skills sets to carry out the function of dietary services(Centers for Medicare and Medicaid, 2016, §42 CFR 483.60). A member of the food and nutrition staff is also required to participate as a member of the interdisciplinary care team responsible for developing comprehensive care plans. (Centers for Medicare and Medicaid, 2016, §42 CFR 483.21). This new requirement also requires a NA to participate as a member of the interdisciplinary team.

Nursing staff involvement

Involvement of nursing staff in nutrition and hydration decision making near end of life has been primarily studied in acute care settings (Bryon, Gastmans, & de Casterle, 2012; Clarke et al., 2015; Dillworth et al., 2016; Ke, Chiu, Lo, & Hu, 2008; Todd, Van Rosendaal, Duregon & Verhoef, 2005) and NHs in Scandinavian countries (Horntvedt, Romøren, & Solvoll, 2014; Pasman, Onwuteaka-Philipsen, Ooms et al., 2004; Pasman, The, Onwuteaka-Philipsen, Ribbe, & van der Wal, 2004; The et al., 2002). In the majority of settings and cultures, nursing staff are at least somewhat involved in end of life nutrition and hydration decision making, though their involvement is not always acknowledged. Some previous studies addressing nutrition and hydration decision making did not choose to include nursing staff as participants (Bostrom, Slaughter, Chojecki & Estabrooks, 2012; Ke, Chiu, Lo et al., 2008).

Few published studies address nursing staff participation in nutrition and hydration decision making processes for residents nearing end of life in U.S. NHs. Wurzbach (1996) found NH nurses varied in their levels of moral certainty regarding utilization of artificial nutrition and hydration at end of life, with greater moral certainty associated with greater willingness to become involved. Although not limited to end of life or nutrition and hydration decision making, Lopez (2009) used grounded theory to create a model of nursing staff decision making for acutely ill NH residents and described them as attempting to satisfy all sides, with decisions splitting two ways: life prolonging or palliation.

As part of a focused ethnography investigating the influence of NH culture on feeding tube use among residents with advanced dementia, Lopez, Amella, Strumpf, Teno and Mitchell (2010) compared the decision making processes related to resident weight issues between the two facilities. While both facilities included nurses in the decision making process, the facility with high use of tube feeding included fewer NH staff, such as social workers, in decision making which decreased their opportunity to influence decisions. The authors also identified the presence of “knowledgeable NAs who valued hand feeding” (p. 83) and greater palliative care options within the low use facility. A second publication from this same study presented results of interviews with RNs and LPNs which identified insufficient or limited knowledge of artificial nutrition and hydration at end of life, uncertainty regarding their nursing role, and lack of clarity regarding their moral responsibility to involve themselves in feeding tube decision making for NH residents with advanced dementia (Lopez, Amella, Mitchell, & Strumpf, 2010).

How nursing staff work together

As previously noted, the impact of NAs is rarely addressed in studies of decision making at end of life in NHs. Though not specific to nutrition and hydration, Carpenter and Thompson (2008) studied NAs from three US NHs and found they worked closely with and cherished their relationships with residents, yet their opinions and expertise were not always solicited or valued, and their contributions often went unnoticed. The bulk of care in NHs, estimated at 90%, is delivered by LPNs and NAs, with RNs making up only a small percentage of nursing staff in NHs. These few RNs are responsible for leadership, assessment and delegation of care (American Nurses Association [ANA] & National Council of State Boards of Nursing [NCSBN], 2005).

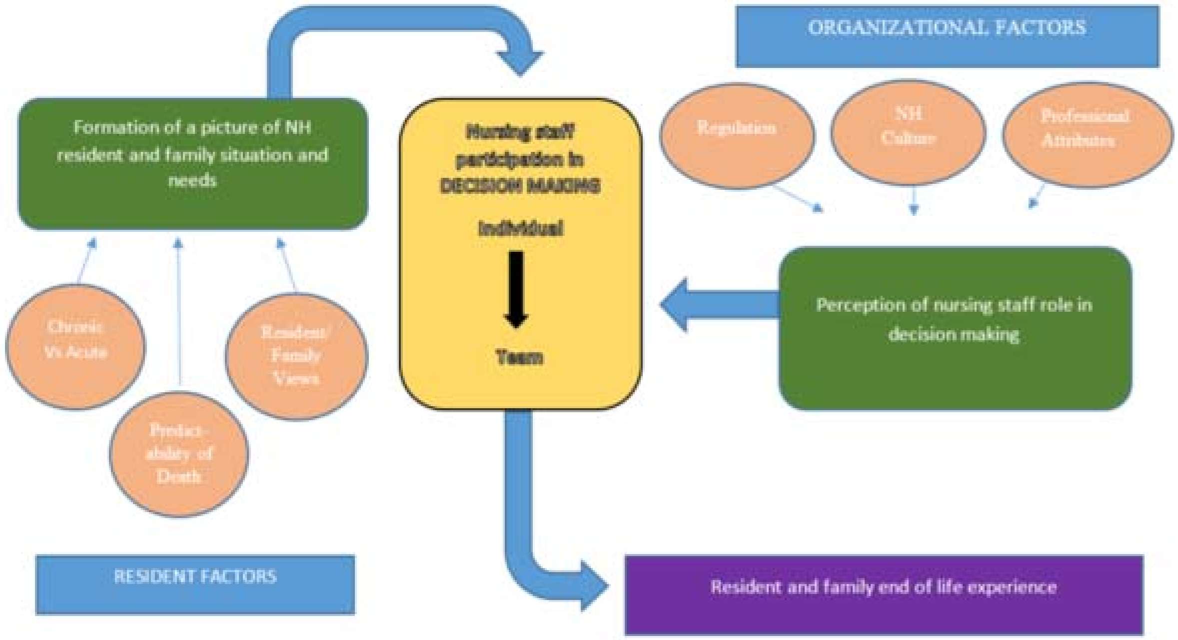
When nutrition and hydration issues are identified, communication must occur between care providers. The general chain of command has NAs, who provide the majority of hands on care and feeding assistance, expected to note and advise LPNs and RNs who then pass information further up the chain both within and outside of the facility to medical providers. Exactly how these nursing staff work together to provide appropriate care to residents with nutrition and hydration issues has not been well described in the literature.

Conceptual Framework

The conceptual framework informing this study is an expansion of the striving for ‘good care’ framework proposed by Bryon, Gastmans, and de Casterle (2010) which was based on work with Belgian hospital nurses’ involved in artificial nutrition and hydration care decisions for hospitalized patients with dementia. In this framework, delivering ‘good care’ is the overriding motivation driving nursing activities and roles in decision making processes. The steps in the framework include formation of a picture, decision making, and aftercare. In formation of a picture, nursing staff consider the patient’s situation and the patient and family’s needs. This picture impacts the roles nursing staff take in the decision making process. In preparing to make decisions nurses may take the roles of initiators, messengers or guiding communicators. During decision making the may be team players or spectators. And when taking positions on the decisions made may concur, actively resist, or passively resist. The actual steps inform forwards and backwards until the decision if finalized and there is a refocus on aftercare, no matter the decision, on the patient and family.

Based on findings from extensive review of literature, the concepts within this framework were modified to develop a new framework that includes the effects of both resident and organizational factors on participation of nursing staff in decision making. Formation of a picture based on resident factors has been expanded and an additional section for organizational factors (nursing home) added as impacting nursing staff participation in decision making. These factors impact participation at the individual level and on to the team level. The resulting nursing staff participation in decision making goes on to influence the resident and family’s end of life experience.

Figure 1: Proposed Model of Nursing Staff Participation in Decision Making



Resident factors: Formation of a picture

Bryon et al. (2010) theorized that nurses determined and implemented "good care" decisions by first forming a picture of the patient and/or family desires. Studies note a large number of realities at end of life in NHs, with each having the potential to impact nutrition and hydration decision making by residents and families and views of nursing staff members. Variables noted in the literature as impacting the 'picture' of the resident and family situation and needs include chronic versus acute onset of intake issues, the ability to accurately predict when and how death will occur, and the views of the resident and/or family members about nutrition and hydration as well as end of life and death experience expectations. This 'picture' thus impacts the perceptions of nursing staff members and may impact both amount and type of participation in decision making.

Chronic versus acute onset of intake issues. Issues with oral intake may occur over an extended period of time, as in dementia, or abruptly, as in acute illness such as pneumonia or stroke. Despite ample opportunity to plan with slow onset of intake issues, studies have shown that often little to no action is taken until an acute issue arises (The et al., 2002). When providing care to residents over extended periods of time, slow changes in intake or abilities may not be recognized as signaling a need for end of life nutrition and hydration decision making.

Predictability of death. Especially in individuals with chronic conditions, predicting when death will occur is difficult. Physicians are generally more accurate than family members at predicting timing of death but it is not a science. Issues may arise due to discordance between the physician and family expectations but optimism may maintain hope which may be beneficial to the resident and family members (White, Ernecoff et al., 2016; White, Reid et al., 2016).

Resident/family views. Common social and cultural views of access to food and fluids as a basic human right, as well as the association of love and caring with provision of food and fluids may make it difficult for residents and families to choose to withhold or withdraw food and fluids even when end of life is clearly approaching. This includes nutrition and hydration delivered by non-oral routes (artificial nutrition and hydration). Residents, family members and even care providers may have unrealistic expectations that health will improve drastically with administration of artificial nutrition and hydration, making it difficult to actively select less active intervention (del Rio et al., 2012; Druml et al., 2016; Lembeck, Pameijer, & Westcott, 2016). Additionally, limited awareness of palliative care practices by residents and families, and African-American ethnicity, are associated with greater use of artificial nutrition and hydration in NH residents nearing end of life (Lopez, Amella, Strumpf et al., 2010; Mitchell et al., 2016).

Organizational factors: Perception of nursing staff role in decision making

Regulatory factors. Care delivered in NHs is highly regulated at both the state and federal levels. Facilities with beds licensed under Medicare and/or Medicare must follow strict requirements and submit to regular inspections. Residents must be regularly assessed to ensure nutritional status is maintained, with monitoring of input, weight and laboratory values used to monitor care. If a resident has a health condition which renders maintenance of hydration and nutrition either inappropriate or impossible, the condition must be properly documented in the residents' records to relieve the facility of these responsibilities (Department of Health and Human Services [DHHS] & Centers for Medicare and Medicaid [CMS], 2008). Recent revisions to CMS regulations require determination of facility staffing be based on actual resident care needs, including adequate staff time to assure maintenance of oral intake. This view of residents as individuals with differing needs reflects a change in regulatory approach with potential to improve care delivery (Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities, 2016). The requirement to report the percentage of residents losing 5% or more of their body weight in one month remains, however, a quality measure reported on the Minimum Data Set (MDS) and reflected in Nursing Home Compare. Although not clarified by current reporting requirements, weight loss often occurs among those nearing end of life even with quality care.

As the providers directly responsible for maintaining the nutrition and hydration status of NH residents, nursing staff are responsible for identifying and addressing diminished or absent intake. How they approach this responsibility may affect care decisions, including interventions such as evaluation by a dietitian or speech therapist, addition of liquid supplements, administration of artificial nutrition and hydration, or increased focus on careful hand feeding, all of which are options that may be considered in preventing or addressing diminished or absent oral intake. When regulatory requirements are valued to a greater extent than individualized best care, interventions may be instituted based on goals of keeping lab values and weight within acceptable levels rather than resident specific goals. Communication between providers is necessary to assure information is shared and proper documentation is in place to meet regulatory requirements. Without documentation of ‘supportive care only’ status by a medical provider, unaddressed weight loss and laboratory values indicative of dehydration or decreased nutritional status may trigger citations and increase risk of legal liability. At times, interventional therapies may be initiated in an attempt to avoid decision making, even though the interventions do not reflect best care practice for the individual resident.

Nursing home culture. The nursing staff’s ability to foster open and relevant communication depends upon a number of factors. Care delivered in NHs may be determined by policies and procedures established by the organization, individual job descriptions, workload, and time, as well as care priorities of the organization. The culture of the organization is reflected in both the explicit and implicit actions of care staff. According to Cammer et al. (2014), a “hidden complexity” (p. 1016) underlies care delivery in long term care settings with each practitioner navigating multiple variables in delivering care. Personal philosophies, relationships, ambiguity, flux, resources and physical environment are contextual factors mediated by care provider experience, confidence, leadership, and mentoring. Other authors have noted poor care coordination (Dreyer, Førde, & Nortvedt, 2010, 2011), limited resources, time, and focus on physical tasks rather than relationships (Sims-Gould et al., 2010), as well as lack of clarity regarding the nursing staff role in decision making (Lopez, Amella, Mitchell et al., 2010).

Greater utilization of feeding tubes near the end of life, especially among residents with advanced dementia, is used by many end of life researchers as a surrogate marker for less appropriate care. Facility-related variables associated with greater utilization of feeding tubes in NHs among residents with terminal dementia include for-profit status, larger size (greater than 100 beds), urban location, and greater percentage of residents covered by Medicaid (Mitchell, Teno, Roy, Kabumoto, & Mor, 2003). African-American race has been repeatedly associated with greater use of feeding tubes near end of life, both in NHs and the community in general (Connolly, Sampson, & Purandare, 2012; Mitchell et al., 2016; Modi, Velde, & Gessert, 2010). It is often assumed that cultural beliefs lie behind the greater use of feeding tubes among African-Americans nearing end of life but this phenomenon warrants further study.

Professional attributes. Melnyk, Fineout-Overholt, Gallagher, and Kaplan (2012) reported that US nurses are often unaware of current research, and consequently fail to provide evidence based care. Previous studies in numerous settings have described nurses as poorly and incorrectly informed regarding palliative care practices, lacking knowledge regarding benefits and burdens of artificial nutrition and hydration, unsure of their nursing care responsibilities, and with practice attitudes often inconsistent with current evidence (Ke, Chiu, Hu, & Lo, 2008; Ke, Chiu, Lo, et al., 2008). Greater levels of palliative care training, palliative care knowledge, and personal experience caring for the dying have been linked to diminished support for use of artificial nutrition and hydration at end of life among nurses in various settings (Gorlén, Gorlén, & Neergaard, 2013).

In NHs, physicians (MDs), physician assistants (PAs), and/or nurse practitioners (NPs) are responsible for managing medical decisions, yet are generally present for only limited periods of time. While numerous staff, including social workers, physical and occupational therapists, recreation therapists, dietitians, chaplains, housekeepers, maintenance workers, and administrators support the needs of residents, the bulk of care is delivered by nursing staff. Within the hierarchical structure of the NH, RNs are responsible for assuring delivery of resident care based on medical orders and organizational policies and procedures. LPNs and NAs provide the vast majority, estimated to be around 90%, of hands on care of residents, (Corazzini et al., 2010; PHI, 2017). Nursing staff interact frequently and intimately with residents, families, and other staff members, and when issues arise they are generally the first line providers of care.

Additional variables potentially impacting nursing staff perception of their role in decision making include professional and personal experiences and beliefs (Cammer et al., 2014; Wurzbach, 1996), frequency of presence of physicians/physician assistants/nurse practitioners in NH, professional training, and their culture of origin.

Participation in decision making

Communication was noted by Bryon et al. (2010) as a primary role of the nurse in artificial nutrition and hydration decisions. The nurse relayed information from patient to physician and vice versa, assuring clarity and adequacy of information. Family members of NH residents nearing end of life have identified communication with care providers before, during and after decision making as influencing their perceptions even beyond the actual process (Hansen, Archbold, Stewart, Westfall, & Ganzini, 2005). Inclusion of various disciplines in decision making processes is also associated with improved outcomes of end of life nutrition and hydration decision making (Lopez, Amella, Strumpf et al., 2010). A study of family members of residents with dementia in a large US NH found greater frequency of treatment discussions associated with higher care satisfaction among family members, although many study participants reported never having discussed artificial hydration (51%) and artificial nutrition (41%) with a care provider (Reinhardt et al., 2015).

Purpose of the Study

The purpose of this focused ethnographic study was to better understand the participation of nursing staff members, inclusive of RNs, LPNs, and NAs, in end of life nutrition and hydration decision making processes in a rural NH. An adapted version of the 'good care' framework of nursing was used to guide this study.

Research Questions

The research questions were:

How do nursing staff participate in end of life nutrition and hydration decision making processes in a rural nursing home (NH)?

What factors impact this participation and how?

Definitions

For purposes of this study, major concepts were defined as follows:

- *Artificial nutrition and hydration (ANH).* Nutrition and hydration delivered via any non-oral route.
- *Careful hand feeding:* Oral feeding involving active attention to the resident and implementation of specific interventions that support chewing and swallowing in an effort to decrease risk of aspiration and choking. Would include such actions as reminders to swallow, encouraging coughs, small bite sizes, and adjustment of consistency to control swallowing difficulties. (DiBartolo 2006; Lee & Kolasa, 2011).

- *Decision making (DM).* Activities involving making choices among available options.
- *End of life (EOL).* A point at which death could reasonably be expected to occur within a period of approximately eight weeks or less.
- *Family*. Relatives, especially those legally responsible for patient care decisions, and other persons identified by the residents as part of their chosen support system (National Consensus Project for Quality Palliative Care, 2013)
- *Focused ethnography*. An adaptation of ethnographic research focused on a known, rather than remote from the researcher, culture or subculture that generally involves a distinct focus and context (Wall, 2015*)*
- *Hospice or hospice care.* Care delivered with a goal of caring, not curing, and a focus on comfort and support of physical, emotional and spiritual needs. When a resident is placed on hospice in the NH, hospice care protocols are put into place and facility staff are expected to contact hospice nurses and physicians for information and guidance.
- *Moral certainty*. Complete commitment to a belief or conviction that a specific action is right or wrong based on previous experiences with like situations (Wurzbach, 1999).
- *Nursing home (NH).* A facility licensed and operating to provide residential care to persons requiring non-acute nursing care on a short or long term basis.
- *Nursing home residents (residents).* Persons over the age of 18 admitted for care in a licensed nursing home. Resident is the preferred terminology for referring to persons residing in NHs as these facilities often serve as the last home for those

approaching the end of life and resident is thought to be more descriptive and dignified than patient. Although the term patient was used repeatedly by participants, the term resident is the more currently accepted terminology.

- *Nursing staff*. Registered Nurses (RNs), Licensed Practical Nurses (LPNs), and Nursing Assistants (NAs or CNAs) employed in a NH to directly or indirectly provide care of residents.
- *Palliative care.* **“**Patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering…throughout the continuum of illness… addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice” (National Consensus Project for Quality Palliative Care, 2013, p. 9)

Delimitations

Ethnography, by its very nature, is a subjective process relying on information shared by subjects and settings as well as the interpretation of the researchers, and there is limited potential for reproducibility of results. The expectations and views of the researcher, researcher presence within the culture, subjects’ perceptions of what researchers wish to hear, and subjects’ own agendas may all affect the data gathered, interpretation of the data, and final results. Despite these limitations, ethnography is an effective method of gaining understanding of situations as they exist within a specific culture.

This qualitative study was performed in a single, non-teaching NH convenient to the researcher whose owners and administrators provided permission for the researcher to recruit staff and perform interviews within their facility. Drawing participants from a single setting limits generalizability but supported the acquisition of information-rich data applicable to the population of interest. Interviewing only staff members willing to volunteer limited objectivity due to self-selection but is required by human subject participation regulations and the nature of the inquiry. Additionally, the culture of this facility may differ from others in the region as requests were sent to numerous facilities using a variety of methods including emails, phone calls, personal requests, and in-person visits yet this was one of only two facilities, neither of which was owned by a corporate chain, whose administrators and owners agreed to participate.

Summary

Improvement of care for those nearing the end of life has been identified as a priority within the US health care system, with inclusion of all care providers in decision making suggested as one way to accomplish this goal. Nursing staff, particularly RNs, have a responsibility to deliver best possible care based on current evidence while respecting patient or designated surrogate decision makers' wishes. When NH residents nearing end of life are unable to meet their nutrition and hydration needs orally, nursing staff are uniquely positioned to support the decision making processes associated with care decisions. Little is known, however, about nursing staff participation in these decision making processes, especially by NAs.

The proposed conceptual framework depicts nursing staff roles in decision making processes as impacted by both resident and organizational factors. Use of focused ethnography as the research method allowed for study of nursing practice within the culture of the NH (Cruz & Higginbottom, 2013). Understanding of nursing staff participation in these processes, as well as factors impacting that participation, is crucial for guiding educational programming as well as regulatory and organizational changes aimed at facilitating best practice in this clinical setting. The ultimate goal of this study was to contribute to the body of knowledge supporting best possible end of life care experiences for the dying and their family members.

CHAPTER 2: REVIEW OF LITERATURE

The purpose of this focused ethnographic study was to describe and understand the participation of NH nursing staff in nutrition and hydration decision making for NH residents nearing end of life within the culture of a NH located in a rural region of North Carolina (N.C.). This review of pertinent literature addresses:

- The nursing home industry in the United States
- Nutrition and hydration issues near end of life
- Participation of nursing staff in nutrition and hydration decision making
- Factors influencing nursing staff participation in nutrition and hydration decision making processes

Electronic review of the literature was conducted using multiple databases including Medline via PubMed, CINAHL, ProQuest, PsycINFO, and EMBASE. Summon ®, an institutionally based information aggregator, Google Scholar, review of cited works, and related article linking functions within various databases were also used to identify pertinent sources. Primary keywords used for searching were nursing role, nursing home, nursing staff, hydration, nutrition, decision making, and end of life. Database searching was limited to English language and publication from 2000 through 2016. Review of cited works and related article linking was not limited by year of publication.

Nursing Homes: An Overview

NHs are care facilities licensed and operating to provide residential care to persons requiring non-acute nursing care on a short or long term basis. Most residents require assistance with physical needs and many having mild to moderate cognitive issues. With over 15,600 US nursing homes supporting 1.7 million beds, these facilities served over 1.4 million people on any given day in 2014 (Centers for Disease Control, National Center for Health Statistics [CDC, NCHS], 2016). Ownership of US NHs may be for-profit, not-for-profit, or federal, which includes facilities operated by the Veterans Administration. Referred to as skilled nursing facilities (SNFs) under the Medicare program or nursing facilities (NFs) under the Medicaid program, facilities may be licensed by either or both of these programs. Medicaid, jointly funded by federal and state funds and administered based on decisions which vary from state to state, covers the majority of NH costs for long term and indigent care. Medicaid reimburses at lower rates than Medicare and private insurance plans. In 2014, Medicaid was the primary payer for 63% of residents in certified facilities. In several southeastern states the percentage of NH residents with Medicaid as primary payer exceeded 70% (Harrington, Carrillo, & Garfield, 2015).

The number of NH beds in the US dropped slightly between 2009 and 2014 but the need for NH care is predicted to rise as the US population ages and a more mobile society separates family members geographically (Harrington et al., 2015). Additionally, as pressure on hospitals to discharge patients quickly has risen, the percentage of deaths among Americans aged 65 years and older occurring in NHs has increased from 21% in 1989 to 27.9% in 2007 (Harris-Kojetin et al., 2016). This trend is predicted to continue, reaching 40% by 2020 (Temkin-Greener, Zheng, Xing, & Mukamel, 2013).

Organization and staffing in nursing homes in the United States

Historically, the management structure within NHs has been top-down and medically focused, with physicians, the healthcare professionals primarily in charge of care decisions, present only briefly and intermittently. Studies suggest, however, that greater presence of MDs, PAs, and NPs in the NH positively impacts care and is increasing (Intrator, Castle, & Mor, 1999; Shield et al., 2012). Intrator, Lima and Wetle (2014) found 25% of 1,938 US NHs evaluated had at least one MD/PA/NP on site Monday-Friday, and 5% on weekends and holidays. Frequency of presence was greater for facilities in urban areas with greater physician resources, and lower in areas with fewer physicians and in rural areas. Each facility must have a medical director. This director is not necessarily present in the facility but is responsible for providing medical input into organizational decisions, participating in certain committees and meetings, and providing medical support in situations where a resident's regular medical provider is not accessible.

In each NH, a licensed NH administrator is tasked with running the facility. The administrator is responsible for business and regulatory decisions and does not provide direct care to residents. An RN serves as director of nursing (DON), and along with other facility RNs, is responsible for assuring patient care delivery utilizing a mix of staff in accordance with federal and state level regulations.

The nursing staff in NHs is composed of approximately 14% RNs, many of whom perform activities other than direct patient care, such as developing care plans and utilization review activities (Rantz et al., 2004), with estimates suggesting that over 90% of direct care is actually delivered by LPNs and NAs (Corazzini et al., 2010; PHI, 2017). With an average yearly turnover of 43.9% and 70,000 vacant positions across the industry, maintaining high quality nursing staff presents a challenge for many NHs (American Health Care Association [AHCA], 2014).

RNs are classified as professional, licensed nurses and must attend an accredited program of study, pass the National Council Licensure Examination for registered nurses (NCLEX-RN), and register with their State Board of Nursing. In NHs, RNs frequently serve in supervisory roles and are the only members of the nursing staff authorized to complete resident assessments and delegate nursing tasks. Delegation by the RN is the mechanism through which LPNs and NAs deliver the vast majority of the care in NHs, which leaves the RN responsible for ensuring professional standards of care are met. As federal nursing home regulations only require in-facility RN coverage a minimum of 8 consecutive hours per day, LPNs and NAs often provide care with no RN or medical provider on site (Corazzini et al., 2015). RN participation in continuing education varies but is required by most states.

LPNs, known as LVNs in California and Texas, are also classified as licensed nursing staff and must complete an accredited practical nurse program, pass the NCLEX-PN (practical nurse), and obtain a license through their State Board of Nursing. LPN/LVNs are authorized to provide basic medical, nursing and personal care, discuss the care they provide with residents, listen to concerns of residents, and report resident status and concerns to RNs and medical providers. Especially in NHs, they perform numerous other activities through delegation by RNs or medical providers, serve as charge nurses, oversee and direct other LPNs and NAs, and perform more advanced treatment in some states (Bureau of Labor Statistics, US Department of Labor [BLS, USDL], 2016). LPN participation in continuing education varies but is required by most states.

NAs are unlicensed personnel who provide basic care to residents under the direction of licensed nursing staff, and generally spend more time providing direct resident care than other members of the nursing staff. NAs must take a state approved training course, pass an exam, and be listed on the State Registry to be eligible for employment. NA titles and requirements vary somewhat from state to state, but usual NA responsibilities involve providing assistance with activities of daily living (ADLs), mobilization of residents, and reporting observations or issues to licensed personnel. NAs may also be licensed at different levels which certify them to provide more advanced care activities specific to each level and varying by state. There are no consistent continuing education requirements for NAs. The quantity of time NAs spend, and the personal nature of the care they deliver to residents often result in development of close relationships between NAs, residents, and even family members (Bureau of Labor Statistics, US Department of Labor [BLS, USDL], 2015).

In addition to nursing staff, many NHs also employ a variety of Allied Health personnel on a permanent, part time or consultant basis. Physical therapists, occupational therapists, and speech therapists are often available on at least an intermittent basis in the NH setting.

The Five-Star Quality Rating System allows public access to information about nursing homes certified by Medicare and/or Medicaid and allows consumers to compare health inspections, staffing, and quality measures between facilities. Ratings range from 1 to 5 stars, with 1 being the lowest rating and 5 the highest. A 2015 analysis for the Kaiser Family Foundation (KFF) found 39% of US NHs had overall ratings of 2 stars or less, for-profit facilities had lower overall star ratings than non-profits, smaller facilities had higher ratings than larger ones, and two-thirds of US counties had at least one facility rated at 4-5 stars. Average star ratings are lower in the southeast than in the west or northeast (Boccuti, Casillas, & Neuman, 2015).

Nursing home culture

NHs are often viewed and described as having top down management and impersonal care that treats residents as consumers rather than homelike environments where they find life satisfaction and joy. Efforts to improve the culture of care within NHs frequently focus on increasing resident choice and participation in their own care decisions, decentralization of services, and extending greater control to the front line staff who actually deliver resident care.

Various models and programs have been implemented to improve nursing home culture but change is difficult and occurs over extended periods of time (Munroe et al., 2011).

The nursing culture within individual NHs results from the interaction between "beliefs, attitudes, values, and norms of the staff," (Kennerly et al., 2012, p. 468). It is complex and affects the quality of care delivered, with more positive nursing culture associated with higher quality care delivery. Improving the nursing culture in NHs can result in greater openness to change and delivery of best practice (Kennerly, et al., 2012). There has been an increasing trend toward ownership of NHs by large corporate groups. Involvement in multiple ownership changes is associated with lower quality care and higher rates of reported deficiencies although one study determined these changes occurred more frequently among facilities that already had existing issues (Grabowski et al., 2016).

In an effort to improve NH care, a portion of the Omnibus Budget Reconciliation Act (OBRA) of 1987 set facility-level standards for minimum staffing and education levels for nursing staff, including RNs, LPNs and NAs. Since that time, numerous studies have shown higher staffing levels, especially of RNs, are associated with improved outcomes, yet no federal minimum per-resident nurse staffing requirements are currently in place (Bostick, Rantz, Flesner, & Riggs, 2006; Dellefield, Castle, McGilton, & Spilsbury, 2015). Some states do set nurse-to-resident staffing requirements but these vary widely. Total nursing hours in certified NHs averaged 4.0 hours per resident day (hprd) in 2014, a slight increase over 2009 (3.9 hprd), though not the 4.55 hprd recommended in 2000 by an expert panel (Harrington et al., 2015; Harrington et al., 2000).

Nutrition and Hydration Issues Near End of Life

Assuring residents receive adequate nutrition and hydration is a primary responsibility of NH nursing staff. Near end of life, maintaining adequate intake is often difficult as limited or absent oral intake is a frequent occurrence among those approaching death. In one study of 363 residents nearing death, 60% had inadequate intake of food and water most or all of the time within the last month of life. Factors associated with diminished or absent intake included decreased alertness (36%), anorexia (70%), choking (17%), and nausea (7%) (Hanson et al., 2008). Another study following 323 NH residents with advanced dementia over 18 months found 85.8% developed feeding problems which were associated with a 38.6% mortality rate at 6 months (Mitchell et al., 2009).

Oral intake below a level that will sustain weight and hydration may trigger decisions regarding administration of artificial nutrition and hydration unless specific plans have been previously made and properly documented. Despite a large body of research failing to identify significant benefit from administration of nutrition and hydration via non-oral routes (artificial nutrition and hydration) to the majority of those nearing the end of life, nutrition and hydration decision making is complex, requiring a balance between current research evidence, resident and family emotions, and organizational and human factors.

Current research failing to show overall benefit from artificial nutrition and hydration among those nearing end of life includes several Cochrane Systematic Reviews. Other studies report greater risk than benefit (Tsiompanou, Lucas, & Stroud, 2013), lack of evidence of benefit (Clarke et al., 2015; Good et al., 2014a: Raijmakers, et al., 2011) and even reduced life expectancy (Ticinisi et al., 2016). Studies reporting positive outcomes from artificial nutrition and hydration at end of life focus primarily on psychosocial benefits or patient reported improvement in general sense of well-being (Bruera, et al., 2005: del Rio et al., 2012; Mercadante, Ferera, Girelli & Casuccio, 2005). Significant exceptions include patients with limited or no intake due to mechanical problems, such as localized cancer of the throat, which physically limit swallowing while hunger and desire to eat remain intact. In general the burdens of artificial nutrition and hydration therapy, including discomfort of procedures, anxiety, cost, and untoward side effects such as pneumonia or extension of suffering from prolonging death, appear to outweigh potential benefits.

The majority of studies addressing nutrition and hydration decision making are focused on residents with inability to maintain oral intake due to advanced dementia. Increasing rates of dementia in the US population have been predicted yet Langa et al. (2016) recently reported results of a longitudinal study of a nationally representative sample of several thousand individuals in which dementia rates decreased from 11.6% in 2000 to 8.8% in 2012. Few studies of oral feeding in dementia have included evaluation of function or survival, and the few that did found that even when high calorie supplements decreased weight loss, overall outcomes were not improved (Hanson et al., 2011). The use of percutaneous endoscopic gastrostomy (PEG) tubes in residents with dementia has also been associated with shorter time to death and limited improvement in biomarkers (Abu et al., 2016; Teno et al., 2012). Current research most strongly supports the use of careful hand feeding as best practice, rather than delivery of nutrition via non-oral routes, for best outcomes in residents in the terminal stages of dementia (Hanson et al., 2011).

Few reliable statistics are available regarding utilization of artificial nutrition and hydration at end of life, and many are limited to specific illnesses, such as cancer or dementia. A recently released analysis of data from 2000-2014 found the rate of initiation of tube feeding for residents with advanced dementia in American nursing homes dropped from 11.7% in 2000 to 5.7% in 2014 (Mitchell et al., 2016).

Participation of Nursing Staff in Nutrition and Hydration Decision Making

Multiple studies of end of life nutrition and hydration decision making in NHs were identified through extensive review of the literature. Across studies based in the US, the physician is identified as the primary clinical decision maker, with residents and families generally playing an equal or greater role in the actual decisions. While wishes of residents and families are given great weight, physicians do have the legal right to override care requests if there is clearly no therapeutic benefit from requested therapies.

Nursing role in decision making at end of life

Studies addressing NH nurses' participation in decision making have identified support roles nurses may fill without acknowledgement from either physicians, families or even themselves. Nurses bring a different perspective to the decision process (Cohen-Mansfield, Lipson, & Horton, 2006; Lopez, 2009). And additional studies have shown not all nurses perceive participation in nutrition and hydration decision making as a nursing role or responsibility (Bostrom et al., 2012; Ke, Chiu, Lo et al., 2008; Lopez, 2009). Participation in decision making is not without risk to the health care providers. Assessing decisions made for people at risk of lacking capacity in hospitals, Clarke et al. (2015) reported decision making consisted of multiple steps in which quality of life was often cited as the main factor considered. They found decision making occurred over time with a number of people and interactions involved, and often left providers and families with ethical and moral distress related to their roles in the process.

Numerous papers and studies addressing the participation of nurses in decision making processes related to nutrition and hydration at end of life show nurses play multiple roles which may vary based on perceived relationships, organizational culture and beliefs of the individual nurse. A literature review of 12 studies published between 1990 and 2007 focused on decision making about artificial feeding at end of life concluded nurses are in a unique position to participate in decision making regarding artificial nutrition and hydration (Bryon et al., 2008). Evidence from the literature review shows that nurses "remain sidelined" due to multiple factors, most specifically unclear role delineation, with degree of involvement seeming to differ based on nurses' perceptions of physician and family views as well as their own. Additionally, many nurses perceive they have little to no influence on final decisions although they often initiate the process by sharing their assessments of patients' deteriorating conditions and provide information and support for patients and families, a role often described as advocacy (Bryon et al., 2008).

Nursing role in nutrition and hydration decision making in nursing homes in the United States

Only a few studies focused on the participation of nursing staff in these decisions (Lopez, 2009; Lopez, Amella, Mitchell et al., 2010: Wurzbach, 1996). In a qualitative study of 25 baccalaureate or higher degree nurses working in US NHs, Wurzbach (1996) found nurses' greater moral certainty regarding use of artificial nutrition and hydration at end of life in elderly residents associated with a greater willingness to act on their beliefs that feeding simply 'tormented' residents. Morally certain nurses, who made up only 20% of the group, were capable of clearly expressing their viewpoints and "tended to be impervious to the influence of others" (p. 69). Their participation in decision making included limiting their support for tube or intravenous feeding and increasing their efforts to educate the family about tube feeding, sometimes to the point of assuming personal or professional risk to themselves. Greater levels of moral certainty were based on nurses' past negative experiences, and perceptions of tube feeding as “a violation of the person” (p. 71). Morally uncertain nurses (around 16% of participants) lacked experience with death, either with or without artificial nutrition and hydration, and made little effort to influence decision making when nutrition and hydration issues arose. These nurses sought input and permission from others with a goal of reaching consensus among all involved in decision making. These uncertain nurses viewed delivery of artificial nutrition and hydration as simple and held both specific and general uncertainties related to artificial nutrition and hydration at end of life in this population, with no confidence in knowing what was morally right for them to do. For both the morally certain and the uncertain, decisions were based on “gut feeling” rather than traditional ethical principles or best practices.

As part of a larger study, Lopez, Amella, Mitchell et al. (2010) interviewed 11 US NH nurses (5 RNs, 6 LPNs) with experience caring for residents with end stage dementia to investigate their beliefs, level of knowledge, and roles in feeding decisions for these residents. Analysis identified three themes: a lack of sufficient empirical evidence to support feeding decisions, ambiguous role in decisions, and uncertainty regarding their own moral agency. Participants listed identifying weight loss, notifying other care providers of weight loss or intake changes, and facilitating communication between the doctor and family members as their roles in decision making. They did not feel they had the right “to advise, guide, or influence family members in these decisions” (p. 635). Two RNs in the study stated they believed it was “against the law for nurses to talk to family members about feeding decisions” (p. 635). Most believed nurses should be neutral and support the decision made by family members, as they did perceive supporting and comforting the family as part of the nursing role. Nurses who mentioned expressing opinions did so “subtly” and often separated their personal beliefs from their nursing role, considering their beliefs to be merely personal opinion rather than moral nursing judgment. They also perceived no authority to inform and support family members as part of a decision making interdisciplinary team.

Lopez, Amella, Strumpf et al. (2010) used focused ethnographic methods to compare the organizational cultures between a NH with a high rate (41.8%) and a NH with a low rate (10.7%) of tube feeding among residents with advanced dementia. Using observation, interview of key informants including nurses and NAs, and analysis of print artifacts, the researchers identified impact of facility culture at multiple levels. Artificial nutrition and hydration decision making was influenced not only by direct participation of nursing staff in decision making but also through delivery of daily care. Both facilities included nurses in organized decision making but the high use facility failed to include other NH members, such as social workers, which prevented their expertise from influencing outcomes. The authors also identified the presence of “knowledgeable NAs who valued hand feeding” (p. 83) and greater palliative care options within the low use facility. Factors such as implicit values of the organization, administrative support, staffing levels, staff attitudes, and family participation influenced formation of nursing staff’s view of resident needs, which in turn influenced decision making.

Though not specific to nutrition and hydration decisions, Lopez (2009) found nurses’ decision making activities involved attempts to create balance by “satisfying all sides” as they juggled “competing views” of residents, families, and physicians by carefully choosing what, when, and how best to share information. In trying to reach a balance, the nurses’ communication strategies were not “consistent with the basic elements of informed consent, self-determination and autonomy” (p. 1007).

Factors Thought to Influence Nursing Staff Participation

As reflected in the conceptual framework, various factors may impact the participation of nursing staff in decision making processes associated with nutrition and hydration issues of NH residents nearing end of life.

Formation of a picture

Chronic versus acute onset. Diminished or absent oral intake among NH residents nearing end of life often occurs slowly over time, as in those with advanced dementia. In situations where intake decreases slowly, there is opportunity for multiple discussions and planning, although this does not always happen (Reinhardt et al., 2015). Even among those with chronic illness, however, it is not unusual for an acute event, such as a stroke or significant illness like pneumonia, to occur unexpectedly and trigger immediate need address nutrition and hydration issues due to diminished or absent oral intake. When issues arise acutely, nursing staff may be forced to take a more active role in decision making, with Lopez (2009) describing nurses as using their clinical judgement, communication and collaboration skills to negotiate between all sides, with greatest priority placed on the family members.

Predictability of death. Limited predictability of life expectancy and illness trajectories, especially with chronic disease processes, often serves as a barrier to end of life conversations. Physicians tend to err on the side of optimism, suggesting the terminally ill will survive longer than they actually do (Christakis & Lamont, 2000). In diseases with prolonged trajectories, such as Alzheimer’s, the dying may survive for weeks or months without nutritional supplementation and for two weeks or longer without hydration. Even very small amounts of fluid intake may lead to a protracted death (Pasman et al., 2005; Personal communication S. Redding 9/28/2016).

Even among palliative care physicians and nurses, predicting length of survival among the terminally ill is difficult. One study (Fromme et al., 2010) found only 58% of 429 patients had accurately predicted survival times. A 2016 systematic review of predicted survival among palliative care patients also found prognostic accuracy of survival time inaccurate among clinicians (White, Reid et al., 2016). Among NH residents at end of life, especially the elderly, decisions often come down to quality of life, and decisions based on whether specific therapies are extending life or extending death.

Resident/family views. Various resident and family related factors inform decision making related to nutrition and hydration at end of life in NHs. Research findings discouraging the use of artificial nutrition and hydration at end of life often conflict with family members' 'need to feed.' Provision of food and fluids holds significant value in most cultures, including those in the US. artificial nutrition and hydration may provide hope and comfort to residents and/or family members who perceive failing to provide these basic necessities of life as abandonment of care or neglect (Cohen, Torres-Vigil, Burbach, de la Rosa, & Bruera, 2012). Despite empirical data suggesting greater harm than good from artificial nutrition and hydration at end of life, differences in meanings and perceptions of artificial nutrition and hydration exist among the dying and their families, and may complicate decision making, especially when the wishes of the person nearing end of life are unknown (Bükki, Unterpaul, Nubling, Jox, & Lorenzl, 2014; Cohen et al., 2012; Raijmakers, Clark, van Zuylen, Allan, van der Heide, 2013).

Ongoing discussions of care and development of relationships between providers, patients, and family caregivers prior to end of life decision making have been shown to result in greater comfort for family members (Hansen et al., 2005; Reinhardt et al., 2015). Disappointingly, in a study of end of life treatment discussions and care satisfaction in NHs

(Reinhardt et al., 2015) 51% of subjects reported never having discussed artificial hydration, and 41% reported never having discussed artificial nutrition, with a care provider.

Perceived role of nursing staff in decision making

Regulatory factors. Federal and state regulatory factors that may impact end of life nutrition and hydration decision making in US NHs include: weight loss indicators for both short and long-stay NH residents, staffing regulations regarding staff mix and quantity requirements, facility liability, and the Patient Self Determination Act. Regulations and payment structures, such as those of the Centers for Medicare and Medicaid Services (CMS), often fail to support best practices, and may even encourage utilization of inappropriate therapies (Finucane et al., 2007; Morley et al., 2014). Monitoring and reporting markers representative of adequate nutrition and hydration, such as weight, are associated with penalties for failure to meet set criteria and may punish facilities for appropriately refraining from use of artificial nutrition and hydration at end of life. If residents are losing weight or showing signs of dehydration and interventions are not to be initiated, specific orders from the medical provider must be recorded in the resident's record clarifying the transition to supportive care or the organization will be penalized.

In addition to concerns regarding outcome measures, utilization of artificial nutrition and hydration may benefit a facility's bottom line (Mitchell, 2003). The provision of artificial nutrition and hydration results in higher reimbursement, whereas careful hand feeding may require 35 to 40 minutes of staff time per meal and creates a significant expense to the organization in terms of both time and salary without added reimbursement (Mitchell, Buchanan, Littlehale, & Hamel, 2003; Simmons & Schnelle, 2006).

Nursing home culture. Organizational policies and procedures, role expectations (both stated and perceived), workload (Harrington et al., 2015), social expectations, communication (Lopez, 2009; Zheng & Temkin-Greener, 2010), relationships between providers (Carpenter & Thompson, 2008; Malloy, 2009), and availability and practice patterns of medical providers (Mitchell et al., 2003) may all influence decision making related to artificial nutrition and hydration at end of life.

In one study of NH culture focused on residents dying over a 7 year period in one NH visited by a physician or physician assistant at least three days a week and where palliative care practices were supported, 25% of residents were receiving hospice care, 86% had an order restricting cardiopulmonary resuscitation (CPR), 62% had “do not hospitalize” orders, and 52% had withhold artificial nutrition and hydration orders at the time of death. Additionally, NH as location of death rose to 91% during the seven year study period (Ackerman & Kemle, 1999). NH culture supporting palliative care was also associated with lower rates of tube feeding among residents with advanced dementia in a comparison study of two NHs in the southern US. Positive cultural variables included homelike environment, focus on food as an important component of life, knowledgeable and adequate staff, and inclusion of family in planning (Lopez, Amella, Strumpf et al., 2010).

Professional attributes. Professional factors may also influence nursing staff members’ perceptions of decision making at end of life. Professional and ethical expectations (American Nurses Association, 2011; Druml et al., 2016), professional and personal experience (Wurzbach, 1996), level of palliative care knowledge (Lopez, Amella, Mitchell et al., 2010; Miller, Lima, & Thompson, 2015), and personal convictions regarding end of life care (Wurzbach, 1996) may all factor into nursing staff participation in nutrition and hydration decision making for residents nearing end of life.

As licensed nurses, RNs and LPNs are responsible for assessing and assuring care for residents while NAs, though not formally responsible for assessment and planning, may serve an important role in communicating issues and information to the RNs and LPNs within the NH setting (Zheng & Temkin-Greener, 2010). Discord may exist between the various levels of nursing staff, however, with the contributions of NAs not always valued (Carpenter & Thompson, 2008).

The ANA mission statement *Forgoing Nutrition and Hydration* clarifies the organization’s expectations of RN participation in end of life nutrition and hydration decision making in all settings. RNs are to be advocates, communicators of information, and guides for persons nearing end of life and their surrogates, supporting legitimate choices even if the RN personally disagrees with these choices, even making arrangements for alternative care providers if necessary (American Nurses Association, 2011). The code of ethics also supports respect for patient decisions even when the nurse does not agree with or support the decisions, and requires the nurse to support patient self-determination through provision of “accurate, complete, and understandable information in a manner that facilitates an informed decision, and to be assisted in weighing the benefits, burdens, and available options.” Nurses are also expected to “be familiar with and understand the moral and legal rights of patients” as well as “preserve, protect, and support those rights by assessing the patient’s understanding of the information presented and explaining the implications of all potential decisions” (American Nurses Association, 2015, p. 2-3).

Summary

As primary providers of direct patient care in NHs, nursing staff are intimately involved in meeting residents’ nutrition and hydration needs. When residents approaching end of life experience difficulties meeting their nutrition and hydration needs orally, care decisions must be made even when formal plans have already put into place. Despite evidence showing little benefit and potential for increased adverse events related to artificial nutrition and hydration utilization in residents nearing end of life, decisions regarding these therapies are ethically complex and ideally entail multiple interactions between caregivers, residents, and families. Whether active or passive, participation in decision making processes by nursing staff has the potential to positively impact end of life care decisions and experiences of both residents and their family members. The participation of nursing staff in end of life nutrition and hydration decision making in the NH setting has not been well described, with very little reported about the participation of NAs as few studies have included them as participants.

This review supports conceptualization of nursing staff participation in end of life nutrition and hydration decision making within the culture of NHs as complex and influenced by patient specific, organizational (internal), regulatory (external), and human factors. Greater understanding of the participation of nursing staff in these processes is needed to inform training, organizational design, and regulatory changes that enhance the potential for nursing staff to positively impact end of life experiences of NH residents nearing the end of life.

CHAPTER 3: METHODS

The purpose of this focused ethnographic study was to better understand the participation of nursing staff members, inclusive of RNs, LPNs, and NAs, in end of life nutrition and hydration decision making processes in a rural NH. The purpose of this chapter is to describe the research methodology used to address the following research questions:

How do nursing staff participate in end of life nutrition and hydration decision making processes in a rural nursing home (NH)?

What factors impact this participation and how?

Research Design

Ethnography

With origins in anthropology, ethnography is one of the oldest qualitative research methodologies, and is characterized by study of an intact cultural group within a natural setting, which allows the researcher to view participants' lived realities. Traditionally performed using a generalist, interpretive approach with researcher observation and immersion in an unfamiliar group over prolonged periods of time, it is used to describe culture through analysis of social interactions, interview results, and artifacts from the viewpoint of both the subjects and researchers (Bryman, 2004; Creswell, 2014; Roper & Shapira, 2000; Wall, 2015). Findings are specific to local meaning structures and, as such, not necessarily generalizable to other settings. Traditional ethnography is time and resource intensive with great value placed on the researcher as instrument (Knoblauch, 2005; Wall, 2015).

Ethnomethodological indifference, a classic expectation of ethnography proposed by Garfinkel and Sacks (1970), suggests the researcher should attempt to "temporarily suspend all commitments to *a priori* or privileged versions of the social world” in order to focus on and actually “see” the realities of the culture under study (Holstein & Gubrium, 2011, p. 342). However, Draper (2015) suggests that in the interpretive paradigm of ethnography, researcher reflexivity is central and should be explicitly recognized. By respecting and acknowledging insider knowledge the researcher can “make strange the familiar” (p. 39) as culture is not a fixed entity and a range of data gathering methods and observation methods should be utilized and reported in first person to provide "as rich an account as possible including making “the writer part of writing project’” (p.40).

According to Berger (2015), reflexivity involves “turning of the researcher lens back onto oneself to recognize and take responsibility for one’s own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation” (p. 220). I approached this study informed and appearing to participants as a Caucasian female from a university setting who brought shared experience in caring for NH residents nearing end of life who developed nutrition and hydration issues but who was an outsider in this facility.

Focused ethnography

Focused ethnography, classified by Polit and Beck (2017) as microethnography, can be used to study a narrowly defined issue and culture within a limited community or group using key informants with experience and knowledge of the group’s culture. It evolved over time from classic ethnography as systematic evaluation, narrowed focus, and interpretation were infused into traditional ethnographic work (Muecke, 1994). While the original goal of ethnography was simply to describe, the goal of focused ethnography is interpretation and analysis of cultural meanings (Wall, 2015).

Focused ethnography is problem-focused and context-specific in a discrete community with researchers entering the research setting with background or insider knowledge, rather than developing insider knowledge through field study, and generally maintaining a field observer rather than participant role (Higginbottom, Pillay, & Boadu, 2013; Knoblauch, 2005). This methodology is often characterized by single researcher orientation, inclusion of a limited number of knowledgeable participants with whom interviews are recorded, transcribed, coded and analyzed, and limited or absent participant observation (Higginbottom et al., 2013; Muecke, 1994). In nursing research, focused ethnography has been used to study the integration of health beliefs, the meaning of experiences, and nursing as a cultural phenomenon (Higginbottom et al., 2013; Roper & Shapira, 2000).

This Study

With the assistance of a committee member with existing relationships in the NH sector, I requested approval to perform this study from numerous non-teaching NHs in a rural region of North Carolina. I received offers from two facilities willing to host the study. Site recruitment was complicated by the large number of facilities in the region with corporate ownership not interested in granting approval for the project in any of their facilities. I chose to work with the first facility to volunteer.

After obtaining proper approval from the facility administrators and owner (Appendix E), and the University and Medical Center Institutional Review Board (Appendix A), I recruited participants, gathered data through in-person, semi-structured interviews with RNs, LPNs and NAs, reviewing pertinent organizational and regulatory documents, and observing participants and their interactions with each other during interview sessions and while recruiting. I intentionally recruited from and used a non-teaching NH to capture the experiences of nursing staff operating in a facility with limited in-house medical support as is often found in rural NHs. I also offered a $25 gift card to each participant as a token of appreciation for sharing their opinions and time. I made sure to verbally reinforce the volunteer nature of study participation during both the permitting and interview processes.

I utilized individual interviews (Krueger & Casey, 2000) to obtain an emic perspective from participating members of the NH nursing staff, and my observations of participants during these interviews and interacting with coworkers provided etic perspective. Relevant documents I reviewed included professional practice guidelines, state and federal regulations, and institutional policies and procedures addressing nutrition and hydration of NH residents. I repeatedly analyzed data for alignment with the proposed conceptual framework to determine need for modification or refinement of study processes.

Population and Sample

My population of interest in this study was the entire nursing staff, inclusive of RNs, LPNs, and NAs, in this single, non-teaching NH located in a rural region of North Carolina. This population included 80 individuals of whom approximately 8 (10%) were RNs, 16 (20%) LPNs, and 56 (70%) NAs. Although a high level of enthusiasm and interest in participation was desired, for qualitative analysis Sandelowski has noted 50 interviews as “perhaps too large” for accomplishing detailed analyses (1995a, p. 180) and cited Morse (1989) as recommending “about 30 to 50 interviews and/or observations” for ethnographies (p. 182). I set an initial data collection goal as completion of between 15 and 30 interviews/observations/document reviews, with this number to be adjusted based on the richness of data and findings during ongoing analysis.

Criteria for inclusion

Criteria for inclusion of interview participants included being an RN, LPN, or NA employed in the study facility for a minimum of 2 months on at least a part-time basis, being at least 18 years of age, understanding and speaking English adequately to participate in an in-depth interview, and having experience caring for residents nearing the end of life. Inclusion criteria for documents was content related to nutrition and hydration of NH residents applicable to care delivery in this facility.

Recruitment of participants

Recruitment of participants was initiated after receipt of institutional permission from the facility administrators and operators (Appendix E) and study approval through the University and Medical Center Institutional Review Board (UMCIRB) (Appendix A).

As they are the gatekeepers in this facility, I consulted the nursing home administrator and DON regarding acceptable methods of recruiting participants. With their agreement, I placed two posters and multiple fliers on information boards in employee entryways, break rooms, nursing stations, and near the time clock. Anyone interested in volunteering or obtaining more information was instructed to contact me at the provided phone number or email address.

Materials invited participation of all eligible nursing staff in the facility, with interviews to be scheduled ahead of time or performed at the convenience of participants on a first come, first served basis when the researcher was present in the facility. I noted that participation in the study would take approximately an hour and include signing a consent to participate in research form, completing a short demographic form, and sharing their experiences and feelings with the researcher through one on one conversations that were recorded to allow for precise transcription. As a measure of appreciation for volunteering their time and efforts, I offered a $25 gift card to a local merchant to each volunteer participating in the study.

Two weeks after I placed fliers and posters, not a single potential volunteer had emailed or phoned. Discouraged, I dropped by the facility and asked the DON for suggestions on recruiting participants. She was working at the main nursing desk with several other nursing staff at the time and started asking everyone around if they wanted to volunteer. Her endorsement of participation in the study broke the ice. Within a matter of minutes I had 8 interviews scheduled for the coming week. From this point on, interviews were scheduled directly with me when I was in the building or volunteers showed up during interviews I was doing with other participants and asked to go next. Although staff appeared comfortable approaching me in the facility, only one participant initiated contact through means other than face to face, and this was to reschedule a planned interview due to illness.

Ethical considerations

I discussed the study with potential volunteers and 19 received and signed informed consent forms containing information about the study and their rights as participants, including the right to choose not to participate. As past researchers working with NAs have expressed concerns regarding suspicion of researchers and research studies as well as susceptibility to the influence of institutional pressures to participate due to their location within the staff hierarchy (Lingler, Jablonski, Bourbonniere, & Kolanowski, 2009) For this reason, I initially attempted to recruit participants without involving any administrative staff, and made sure information sheets and fliers stressed the voluntary nature of participation. What I found though was suspicion of me, the unknown researcher, and comfort and trust in the DON. As previously noted, once the DON stated support for the study and a few staff completed interviews, I had a steady stream of volunteers. When consenting participants I emphasized the voluntary nature of participation by highlighting this section of the consent form and verbally explaining that they were free not to participate or could stop at any time during the interview. I verbally covered the highlights from the form and encouraged participants to choose a name I could use in publications, not their own name but one they would remember and recognize. All but one chose a name, I chose a name for the one who did not. When each interview was being recorded, I left the recorder in full view on the table and informed the participant when it was turned on and turned off.

I secured signed consent forms, recordings, and transcripts with identifiable information in a locked cabinet in a private, locked office when they were not in use for research purposes. I had the original audio recordings loaded onto a secure, password protected university drive and assured all other documents and files were de-identified and labeled with the pseudonyms chosen by the participants, or by me in one case. Access to the original audio recordings was limited to the researcher, dissertation chair, transcriptionist, and committee members.

Instrumentation

Ethnographic research often utilizes a variety of forms of data collection including observation, interview, related documents review, researcher field notes, and researcher journaling. The researcher is often referred to as a human instrument whose reflexivity is crucial in assessing the effect their presence and research techniques have on the data collected (Higginbottom et al., 2013). In health care research, the uniqueness of situations often dictates selection of data collection methods. In this study, I gathered basic demographic data using a paper questionnaire, one on one interviews guided by a single primary question supplemented with refining questions as needed which were audio-taped and transcribed, review of relevant artifacts such as policy and procedure manuals and regulatory documents, and researcher field notes created during and following each interview.

Demographics

Demographic information obtained from each participant included primary role, years of work in healthcare, age, gender, race, and personal experience with nutrition and hydration decision making with family or close friends who were nearing end of life. After observing the first several participants struggle with the question about personal experience, and realizing this information was being addressed in interviews, I instructed the remaining participants not to bother writing a response unless they preferred to provide one. I used the pseudonyms selected by participants, or assigned if none were provided, to align demographic information and interview data. Actual names mentioned in interviews were redacted from transcribed interviews prior to data analysis. A copy of the demographic questionnaire can be found in Appendix B.

Interview guide

I used a semi-structured interview guide with a single global question and a list of refining questions to help guide interviews (Appendix C). Participants were initially asked to share a personal story of caring for a NH resident nearing end of life who was no longer able to eat or drink enough by mouth to maintain good nutrition and hydration status, then simple prompts and further questions were used to explore their experiences and opinions. I made use of refining questions only when a topic was not spontaneously addressed in discussion.

The global question used to begin each interview was: *Please tell me a story about a time (or times) you cared for a NH resident nearing the end of life who was no longer able to eat or drink enough to stay alive.*

Data Collection

With administrative approval from both the partnering facility and the UMCIRB, I collected data in this non-teaching NH located in a rural region of North Carolina using one on one participant interviews as the primary information source. I additionally reviewed relevant organizational and industry documents including policies and procedures, government regulations, and professional guidelines, as well as my reflective field notes. I used participant interviews to gather emic data regarding nursing staff members' personal experiences and perceptions of their participation in nutrition and hydration decisions for residents nearing end of life, as well as the participation of other members of the care team in these decision making processes. Personal reflections and views, while not generalizable, are valuable in understanding the experiences of group members within a specific culture and add depth and value to the data obtained.

Data collection timeline

During the month of April, 2017, I recruited and interviewed 19 participants. One on one interviews were performed during a variety of shifts, on weekdays and weekends, and on both a scheduled and drop in basis. Seventeen of the interviews were performed in a large meeting room near the main nurse's desk in the front of the facility, while two took place in the corner of a large dining room during the late afternoon. After the 19th interview I had no additional volunteers and a good mix of participants. Preliminary review of interview transcripts revealed in-depth discussions and recurring concepts and responses.

I scheduled interviews prior to or after scheduled shifts or during other non-work times as requested by participants although around half of participants were interviewed on a drop-in basis before or after scheduled interviews. Some interviews, with administrative approval, were conducted during work time. I asked participants to anticipate approximately 60 minutes for study completion. Recorded interviews ranged from just under 10 minutes to approximately 45 minutes in length.

Data Management

During interviews, I audiotaped participant interviews using a recording device placed on the table directly between myself and the participant. These recordings were then transcribed s into text with some assistance from a paid transcriptionist. I redacted all identifiable names or references to specific residents, inserting the chosen or assigned pseudonyms to transcripts for tracking purposes. Texts were then formatted with content limited to the left half of the page and two columns created to the right side left for coding purposes. Voice recordings were uploaded onto a secure university server and then deleted from the recorder. All print copies of permission forms and demographic responses were kept in a locked cabinet when not in use. De-identified data were saved and processed using password protected computers meeting university standards.

Data Analysis

In coordination with my dissertation chair, I analyzed data using processes suggested by Mason (2002, pp. 148-150) and Roper and Shapira (2000). Mason’s method consists of an initial literal read followed by categorization and theme development involving at least two investigators. The investigators continue discussions and ongoing reevaluation of categories and themes until consensus is reached. As a new researcher with less experience analyzing data and developing themes, I personally also utilized the inductive method described by Roper and Shapira (2000), which consists of coding with descriptive labels, memoing, sorting for patterns, evaluation of outliers, and creation of constructs to inform my data analysis processes.

Ongoing interaction between myself and my dissertation chair, as described by Mason (2002), was crucial in developing themes and subthemes, with coding and theme identification accomplished individually and then collaboratively over multiple meetings to minimize bias and assure inclusion of the emic view of participants' shared culture (Munhall, 2007). To assure maintenance of the emic perspective, I included a variety of comments and opinions in participants' own words when developing these themes and subthemes. We used the proposed adaptation of the striving for 'good care' framework by Bryon et al. (2010) as a comparative framework to inform both performance of the study and analysis of findings.

Argument for use of the Adapted 'Good Care' Framework

Nurses provide care in the real world, interacting with patients, families and other health care providers on multiple levels in a multitude of situations. The world views of individuals differ based on personal experience, knowledge and their own truth perceptions. The proposed conceptual framework illustrates the forces that may impact participation of nursing staff in decision making processes associated with nutrition and hydration issues among residents nearing end of life. The nurse's view, or picture, of the resident and family situation and needs, is based on various characteristics, including chronic or acute onset of issues, predictability of death, and the views of the resident and/or family members. Organizational factors affecting perceptions of their role in decision making also impact participation. Providing 'good care', which may be simply an easier death or less difficult experience for loved ones, provides the focus for the individual nurses' actions. When nurses' personal constructs are supported within this framework, there will be no change in their actions and beliefs. When personal constructs no longer fit within the system, however, challenges to current thinking and actions may result in changes in their actions and beliefs.

Trustworthiness

As qualitative constructivist approaches do not necessarily yield results with stability (reliability) or wide applicability (external validity), conventional criteria for evaluating the quality of quantitative (logical positivist) studies are not necessarily appropriate for assessing qualitative ones (Higginbottom et al., 2013). The most frequently cited qualitative inquiry evaluation method in nursing research is Lincoln and Guba’s trustworthiness framework which includes evaluation of credibility, aligned with positivist internal validity; dependability, aligned with positivist reliability; confirmability, aligned with positivist objectivity; transferability, aligned with positivist external validity; and authenticity (Lincoln & Guba, 1985; Polit & Beck, 2017; Shenton, 2004).

Credibility

Use of semi-structured interview methods with audio-recording of participants’ own responses obtained in a non-threatening environment as well as triangulation of findings from interviews, document review and researcher filed notes can be reasonably expected to result in authentic data. I provided additional support for credibility by including a mix of nursing staff and many comments and quotes from participants in developed themes and subthemes.

Member checking and follow-up opinions of key informants were planned to support credibility of data and interpretation. Though several participants expressed interest in reading the final paper written about the interviews, none were interested in receiving print copies of their interview transcript when invited to review their personal transcripts for accuracy and make comments or changes, action that would have served as member checking. Following initial coding and analysis of data, I took several printed copies of themes and subthemes to the facility for review by nursing staff but only one participant, an RN, offered feedback. Her response included agreement with the identified themes and findings but no specific comments or suggestions. This combination of methods is designed to verify findings and assure a more accurate reflection of participants’ experiences and perceptions but there was little participation by nursing staff from the study site.

My limited experience as a researcher was addressed by accepting a larger number of participants than is often used in qualitative research as well as guidance from experienced mentors (Sandelowski, 1995b). Additionally, this report includes select data elements from each of the collection methods to allow readers opportunity to personally interpreting findings.

Dependability

I performed this study over a short span of time based primarily on data gathered from the personal viewpoints of nursing staff, review of document sources to illustrate organizational and industry expectations, and my descriptions of the setting and related factors. Sharing specific information regarding data gathering, analysis, and interpretation provides support for dependability of findings. Based on findings in the earliest interviews, however, I did adjust the depth and exploration of some areas resulting in differences in information obtained from participants across the interview process.

I attempted to remain aware of and adjust for my personal biases by listening to the words of participants and attempting to hear their views. I also chose to dress in street clothes and maintained an awareness of my word choices when performing interviews in an attempt to minimize being perceived as having privileged outsider status. I attempted to maintain reflexivity throughout interviews and data analysis processes to minimize bias and strengthen objectivity. My interpretation of findings within the social and cultural context of the NH was ongoing throughout the study period and findings were used to guide ongoing study activities, as evidenced in my informing participants not to bother to complete one section of the demographic form.

Confirmability

I made an effort to acknowledge and “temporarily suspend all commitments to a priori or privileged versions of the social world” and focus on the reality of participants rather than pass judgements that skew results (Denzin & Lincoln, 2011, p. 342). To support objective interpretation of data, I included triangulation from multiple sources and a structured evaluation method for analysis and coding was utilized by the first researcher (Miles, Huberman, & Saldaña, 2014). A second, more experienced researcher collaborated on transcript review and coding, and a third serving as moderator for inconsistencies, (Munhall, 2007).

Transferability

Although it is possible that replication with similar participants, situations, and variables could produce similar results, the subjective nature of interpretation in ethnography, as in other forms of qualitative inquiry, means the findings of this study are not necessarily generalizable or reproducible (Guba, 1981). Additionally, both healthcare environments and nursing practice are constantly evolving, so results in other or future settings would be susceptible to changes in multiple variables.

In an effort to address transferability, I have attempted to include sufficient contextual information in this study report to allow readers to experience findings in relation to their own situations (Lincoln & Guba, 1985; Firestone, 1993). Additionally, the adapted striving for ‘good care’ framework used for interpretation of results can be used to guide evaluation in similar settings with similar residents.

Authenticity

I chose quotations and descriptions specifically to convey meaning and assist readers in experiencing the reality of participants' lived experiences for inclusion in the results section of this paper and these will be incorporated into published study results as a powerful means of engaging understanding and buy-in among readers.

Limitations

Limiting this study to a single facility does limit transferability of findings yet supports the goal of acquiring in-depth understanding of nursing staff participation in nutrition and hydration decision making at end of life within the culture of the NH. Adjustments for my limited experience as a researcher in interviewing and analyzing qualitative data were addressed by inclusion of a large number of participants, extension of analysis beyond the point where saturation of data was perceived, and the assistance of an experienced qualitative researcher in analysis, coding and thematic development. I believe limiting data collection to a single interview when participants did not know me was both uncomfortable and provided less descriptive data than a series of repeated interviews would provide. Recording was also a limitation for several participants as they were quite intimidated and spoke more freely after the recording device was turned off.

Chapter 4: Results

Focused ethnography is useful in revealing relationships between individuals' perceptions and behaviors in real life situations and settings. In studying nursing staff participation in end of life nutrition and hydration decision making, use of focused ethnographic methods gave voice to individual staff members and allowed analysis of themes, perceptions, and choices at the individual, role, and group level. I gathered data through in-person interviews with nursing staff, review of relevant organization and industry policies and procedures, and observations of nursing staff during interviews and interactions with other staff members. From these data, in concert with my dissertation chair, I identified three primary themes: formal decision making, informal decision making, and influencing factors, with multiple subthemes (Table 1). This chapter begins with a description of study participants and then presents themes and subthemes identified through analysis of participant interview transcripts for each research question, followed by findings from review of pertinent documents and participant observations.

Table 1: *Themes and Subthemes*

Themes	First level subthemes	Second level subthemes
Formal Decision Making	Communicating resident issues	
	Initiating and coordinating decision processes	
	Assuring regulatory compliance	
	Influencing	
Informal Decision Making	Knowing residents and families	
	Instituting feeding interventions not requiring formal medical orders	Use of trial and error Favorite foods Repeatedly and frequently offering foods and fluids
	Respecting and honoring	Physical comfort Emotional support Maintaining resident dignity
	Guiding the resident and family	
Influential Factors	Personal experiences/beliefs	Nutrition and hydration experiences/beliefs End of life nutrition and hydration experiences/beliefs
	Unpredictable trajectory	
	Relationship with resident/family	
	Organizational culture	

Characteristics of the Study Sample

The target population for this study included all nursing staff working in the study facility, a private, for-profit, non-teaching facility with between 100 and 150 beds in size, located in a rural region of North Carolina, and not part of a large corporate chain. The facility employed 80 individuals as nursing staff during the final week of April 2017, excluding those listed as working only as needed. Of this number, 8 (10%) were RNs, 16 (20%) were LPNs, and 56 (70%) were NAs. Approximately a quarter of staff members volunteered to participate, resulting in a final sample of 19 individuals of whom 4 (21%) were RNs, 5 (26%) were LPNs, and 10 (53%) were NAs. Of participants reporting their years of healthcare experience (n=16), results ranged from 1.5 years to 45 years, with RNs reporting an average of 9.5 years, LPNs an average of 26 years, and NAs an average of 10.5 years. When asked for tenure in this specific facility, however, results ranged from 3 months to 22 years (N=17), with RNs reporting an average of 3¾ years, LPNs an average of 4¾ years, and NAs an average of 6¼ years. Half of RNs and LPNs and 80% of NAs reported their race as African American, with the remaining participants listing Caucasian, Latina, or multiracial status.

All participants reported caring for residents nearing end of life. Despite each participant having completed either a NA, LPN, or RN program which would be expected to include end of life training, only 13 participants reported specific end of life training, with others reporting they didn’t remember or leaving this question blank. When asked specifically about training regarding non-oral nutrition and hydration, 11 responded having had training, 2 reported they did not have training, 3 didn’t remember, and 3 did not respond. When asked where they went to for help or information regarding nutrition and hydration issues answers included nurses (9), doctors (4), family members (4), medical charts (2), social worker (1), policies and procedures (1), speech therapy (1), hospice (4), dietary manager (1), dietitian (1), and online (1).

Participants were asked to choose a pseudonym for crediting any direct quotes from interview transcripts. Almost all participants provided a name for this purpose. I selected names for those not doing so.

Research Question One

How do nursing staff participate in end of life nutrition and hydration decision making processes in a rural nursing home (NH)?

Theme 1: Formal decision making

Formal decision making, in this study, refers to the processes through which decisions are made and implemented by persons with legal authority to make decisions regarding delivery of care in the nursing home setting. These decisions are legal and binding and part of the resident's medical record. They are influenced and constrained by both internal and external regulations and policies. Subthemes identified within formal decision making included communicating resident issues, initiating and coordinating decision processes, assuring regulatory compliance, and influencing.

All participants mentioned formal decision making in the form of medical orders which dictated how resident care was delivered. One participant, an LPN, initially responded she never had the opportunity to have input in nutrition and hydration decision making as the resident's "wishes are put into place and noted in the chart and put into orders by the time they come under my care." But went on to describe contacting the doctor and "doing what we can…until we get some kind of orders, either from the doctor or speech therapy or the family, or some decision is made to mitigate the circumstance."

The majority of NAs perceived their interactions with residents and family members, but not medical providers, as influencing formal decision making, but only when they had relationships with the residents or family members. Without established relationships, NAs were less comfortable sharing their opinions. One NA, Michonne, said that without knowing the family well she doesn't give her opinions but will "just kinda give them (family members) the information for them to make the decision" and that "a lot of times the families will pretty much go with whatever the nurse'll say."

Of the five LPNs, one clearly felt she had some responsibility to participate in decision making related to nutrition and hydration issues of residents nearing end of life, three initially denied participating yet went on to describe activities that could be perceived as participation, and one stated that participation in these decisions was "not my job" and did not discuss any activities to the contrary.

Three of the four RNs perceived their interactions with residents, family members, and medical providers as influencing formal decision making and described a willingness to do so. One denied having influence on formal decision making yet went on to describe activities such as initiating contact between family members and physicians, not perceiving these actions as contributing to formal decision making. Another described actively influencing decision making, although more specifically regarding emergency decisions rather than nutrition and hydration. Jade (RN) described her job as "to make sure that they are making the best decision that they can and not to second guess theirself." Subthemes identified within this theme included communicating resident issues**,** initiating and coordinating decision processes, assuring regulatory compliance, and influencing.

Interestingly, despite the push to utilize advanced directives including MOST and POLST forms, only two participants, both RNs, mentioned MOST forms. There were no specific mentions of POLST or advanced directives. As noted previously, one LPN did mention having orders in place on the chart prior to coming to the NH but these were not specifically noted as advanced directives. Among these participants, the most frequently mentioned formal decision making involved referring a resident for hospice.

Communicating resident issues. As the primary providers of direct care to NH residents, nursing staff are ideally positioned to observe changes and problems. When noted, any changes and problems are communicated up a hierarchical chain of command to the medical provider with the appropriate knowledge, skills and authority to address them.

Information generally moves up the chain with NAs reporting to the nurse assigned to the care of the resident during that shift, which could be either an LPN or RN. In this study, these direct care nurses were referred to by participants as hall nurses because the assignments were generally broken up by hallways. These hall nurses would then report any issues to charge nurses, generally though not always RNs, who served as the lead member of the nursing staff during that shift. Charge nurses would then report to either the ADON or the DON who was responsible for passing information to the resident’s medical provider, or to the facility’s medical director if the primary medical provider was not available. The ADON and DON were not always available, however, especially on evening and night shifts, weekends and holidays. In these cases, the charge nurse was responsible for interacting with the appropriate medical providers, Allied Health providers, residents, and families when issues arose.

All participants described communicating information as part of their role. As the nursing staff members providing the most direct resident care, much of the communication regarding issues and problems begins with the NAs. This was, interestingly, noted by almost all participants. "Personally I will tell the nurse because, me, I’m with them, I’m hands on. The nurse givin’ them their medicine but I know their changes," shared Deborah Ann (NA) while Kim (RN) described the NAs as “our eyeballs (LPNs and RNs), in a lot of situations as far as their (resident’s) eating’s concerned.” All LPNs also addressed verifying, adding to, and passing this information up the chain of command.

In addition to communicating with other nursing staff, all RNs, the majority of LPNs, and several NAs discussed passing information on resident status directly to physicians, speech therapists, dietitians, or hospice providers in an effort to assure appropriate care was provided. Eula (NA) described reporting issues “to the speech therapist, and he is great! The one here, now that we have him, I love’em! Because if you report something to him he is on it!” When asked if she felt involved in nutrition and hydration decision making for residents nearing end of life Miranda (LPN) replied “Not really. Most of the time I would tell either the DON or the speech if something is wrong with the swallowing…” while Lauren (LPN) responded with “I do have a little input, you know, sometimes." Along with the other RNs, Jade was comfortable sharing her assessments and suggestions with physicians as “They pretty much listen to us, you know, what we say, where they’re at and what they need…”

Documentation of changes or problems was mentioned by several participants, including NAs, as an additional method of communicating issues. Although NAs did not document in the formal record, they described responsibility for recording activities and information in specially designated notebooks so this information was consistently available and communicated to others. The importance of documentation as a legal responsibility was expressed by participants from all groups, especially for residents nearing end of life who were at risk of dehydration, weight loss and aspiration from nutrition and hydration issues. Several mentioned involving hospice as a way of assuring appropriate end of life care goals were in place to relieve the facility and staff of legal responsibility for maintaining intake and preventing aspiration when these goals are not appropriate for the individual resident’s situation.

Initiating and coordinating decision processes. Registered nurses in particular reported contributing to formal decision making by initiating discussions regarding nutrition and hydration issues as well as coordinating discussions or meetings between physicians and residents/family members. Almost all members, including several NAs, mentioned suggesting or initiating evaluation by speech therapy when nutrition and hydration issues arose. Kim (RN) described initiating and coordinating hospice decision making as a way of addressing end of life nutrition and hydration decision making, as goals change to comfort care with hospice and families bear less decision making responsibility once hospice care is implemented.

> … we’re always the first to identify that there is something different about the patient, that the patient’s not eating as much, or that their mental status has just declined, or they’re you know not as alert and this is consistently going on and that we’ve done everything at that point to rule out, and maintain contact with the family to make sure they’re on board so it’s almost, it’s a process to get them to that point, um, so hospice is that last option, and it’s kind of just introduced, initially, just kind of tossed around, give them time to think about it, talk to other family members and then, when it’s time, we say, ‘Well, it’s time for hospice or you know, have you already talked to your family members, and what are you all leaning towards?' because we’ve done as much as we can do and it’s all about quality at the end of your life, you know, that’s my belief. Now I try not to push that on other people, but, you know most of the families have been accepting

> because we do, I feel like, an awesome job of caring for our residents here and it's not just a job for us, we just, I love my job.

Assuring regulatory compliance. All participants described responsibility for delivering care based on medical orders and for assuring information was documented appropriately, from the designated notebooks used by the NAs to the medical record documentation of the LPNs and RNs. When residents were noted by staff members as having issues with swallowing, such as coughing or strangling, or "failing" a swallow test administered by speech therapy, continuing oral intake was contraindicated due to increased risk of aspiration and medical staff were consulted for orders. Especially if the resident or family wished to continue to take liquids or solids by mouth in the presence of identified swallowing issues, proper documentation was mentioned by most participants as essential to assure nursing staff, and the facility, were not held liable for any negative outcomes associated with this intake.

As previously mentioned, in addition to notifying physicians for medical orders, participants in each group also described notifying, or the need to notify, dietitians and/or speech therapists to assure appropriate care and orders were put in place. Additionally, in lieu of obtaining specific medical orders, pursuing referral to hospice was mentioned by several as a means of addressing the NH's legal responsibility for maintaining adequate nutrition and hydration in residents nearing end of life. Several participants expressed concerns regarding conflicts between regulatory requirements or expectations and appropriate end of life care. Sandra (LPN) described her experience with one situation in which hospice was used to support appropriate care:

> And, the only way that we could actually let him eat was to get hospice involved, and that way the patient could have what he wanted. And could eat what he wanted, and any

> consistency… Because, we, as professionals, with him not passing a swallow test we could not feed him, we could not give him food. Tube feeding was the only option… But, if we got hospice in, they were able to say “hey, he’s hospice, and, he’s near, you know, he’s made a drastic change in his eating. His brother is responsible. His power of attorney does not want him to have a g-tube.

In some cases, decisions are not made in a timely manner, and several participants described incidents in which they struggled to reconcile their legal responsibility to follow existing medical orders with their ethical duty to respect the rights and desires of residents and family members. Nicole (LPN) recounted struggling with a situation many years prior, in which a nonverbal resident repeatedly refused g-tube feedings yet the family was unwilling to commit to withholding fluids and feedings and no order was in place to cover the actions of the nursing staff members to withhold the feedings.

> …they had, had put a G-tube in her some months prior, of which she was not fond of at all, and um, she just…absolutely refused to allow us to put anything in that G-tube. She would grab the G-tube, she would grab our hands, we would call her family, and her family would say well, if that’s what she wants then that’s what she needs to have done. There were at that point no orders to withhold fluids, to withhold feeding, um, it was more of an ethical dilemma for a lot of the younger nurses that were there. You know if we don’t do something she’s going to die, and it was a question of, of, it was her time anyway and, uh, she had made that decision she was just unable to verbalize it in such a fashion nor was her family. Her family was not able to verbalize that they accepted her choice. So it was a bit difficult and a bit dicey, both legally and medically, but personally, I understood what she was doing and why, and, did it sit right with me to not have things

> in place and not well understood all around? No. Did I acquiesce to the patient's wishes? Yes.

Influencing. Several nursing staff, including three of the four RNs, reported actions or discussions with residents, families, or other health care providers intended to and perceived as influencing formal nutrition and hydration decision making. Jade (RN) described being willing to influence decision making to some degree when she perceived it was in the best interest of the resident and family:

> It's, um, and then the other situations are where all the family members are on the same page but one, and they're unrealistic, and it's usually the family member that's been the least involved, that you've seen the least, you didn't even know they existed 'til mama or daddy started dyin', or whoever, and they tend to make the people, other people maybe feel some guilt, and that you know I feel like that, at that point my job is to make sure that they are making the best decision that they can and not to second guess theirself, and then to again point out what their family member's quality of life has been.

One RN, who described herself as "a fairly new nurse, just over a year," did not perceive herself as influencing decision making, focusing more on comfort and acceptance of resident and family decisions. She did describe finding it difficult to watch residents with little quality of life being kept alive. In these cases was willing to share personal experiences to help the family understand what was going on and initiate the formal decision making process.

Theme 2: Informal decision making

In this study, informal decision making refers to processes through which decisions not requiring medical orders are made and implemented by nursing staff. Sometimes, but not always, these processes involve residents, other healthcare providers, and/or family members. Informal decisions are made many times over each and every day by all nursing staff members. They may be supported or constrained by a variety of factors including internal and external regulations and policies, and such factors as time, resources, and perceptions. Fueled primarily by the needs of residents and family members, these decision making processes were described as primarily aimed at providing comfort for residents and family members. In relation to nutrition and hydration issues near end of life, this comfort was primarily focused on physical aspects with the resident and emotional aspects with the family. Excepting two NAs who did not work with residents unable to feed themselves, all study participants described decision making related to the comfort of residents, and all but one addressed comforting family members.

Participation in informal decision making activities was described at length by almost all participants. Subthemes identified within informal decision making include knowing residents and families, instituting feeding interventions not requiring formal medical orders, respecting and honoring, and guiding the resident and family. Instituting feeding interventions not requiring formal medical orders is further broken down into second level subthemes of use of trial and error, favorite foods, and repeatedly and frequently offering foods and fluids. Respecting and honoring is further broken down into second level subthemes of physical comfort, emotional support, and maintaining resident dignity.

Knowing residents and families. In the NH setting, many residents stay for extended periods of time, some for years. As staff members may also work in the same facility for long periods of time, the intimate and prolonged nature of interaction between residents, staff, and family members often offers the opportunity for staff members to know and understand the wishes and desires of individual residents and their family members. This familiarity allows staff to form a big picture of the situation and make better care decisions. Michonne (NA) described knowing family members as helping nursing staff support end of life decision making including for nutrition and hydration issues:

> You have some families who are really emotional um, they’re not making smart decisions, I shouldn’t say smart, but they, they’re goin’ off emotions, so a lot of time is getting’ to know the family, building that rapport with that family, cause like a lot of times the family looks to us like, “you guys are here with them most of the time, so what do you think?”

Kim (RN) also expressed the importance of “knowing” the residents and families and perceived it as part of her professional responsibility:

> It just depends on that person. I mean I, I, I make it my business to know the families. I make it my business to know the residents, and have a good relationship, therapeutic relationship, working relationship, with the residents and with the families. Of course that’s gonna be different, like I know I can do this with this patient, but I definitely can’t with another patient, so it definitely depends on them.

Instituting feeding interventions not requiring formal medical orders. When oral intake drops below the level needed to meet a resident’s fluid and caloric needs, nutrition and hydration issues need to be addressed. In the nursing home, oral intake is monitored primarily by the NAs who observe and record the percentage of food intake at meals and snacks, and may be tasked with recording the volume of oral fluid intake and urinary output if nutrition and hydration concerns are present. Intake by other routes, such as intravenously (IV) or via a gastric tube of some type (g-tube) would be monitored by the nursing staff members providing this therapy. Body weight or laboratory values may be monitored to evaluate the resident’s nutrition and hydration status. Weight loss over a certain percentage over time or unaddressed abnormal laboratory values will result in citations for the facility without proper documentation.

When a resident is still able to take some food and fluids orally, nursing staff often go to great lengths to maintain oral intake. Interventions identified by participants included trial and error with different textures and temperatures, feeding methods including varying utensils, assisting versus self-feeding support; favorite foods; and repeated and frequent offering of food and fluids. "Offer them, and speak to them, let them know this is, for you, you know, to make you feel better or at least to make you comfortable” and if the resident still is not eating or drinking it’s time to “improvise, and figure out ways you can do it without them having to put too much effort into it.,” said Katherine (NA).

Use of trial and error. Trial and error with a variety of feeding methods was described by the majority of participants as a way to continue assessing the residents’ status and maximize oral intake for as long as reasonably possible. Participants reported using a variety of interventions that could be implemented without consulting medical providers. Although self-feeding was encouraged, many NH residents were described as needing assistance getting their meals set up, getting started, and even being fed by hand. Unless a family member was available to do so, feeding residents generally fell to NAs.

Methods mentioned by participants included varying the consistencies of foods and/or fluids, changing feeding methods or body position for feeding, offering different portion sizes, varying utensils, using different approaches including a calm approach and assigning familiar staff members, offering food or fluids frequently, and adjusting the temperature of foods and fluids, and adjusting location of meals.

Katherine (NA) described using a kind, gentle approach and a variety of techniques to get anything in, even a little water:

> …so if you want to get someone to eat, or who isn't drinking, come with that same soft, kind, gently approach and you can probably get almost anybody to do anything you know. If sometimes if you can't get them to drink out of a cup or a straw, improvise! Get different things to at least get some water in their mouth or some food in their mouth. That's pretty much all I can say.

Even in residents nearing end of life, diminished or absent intake must be addressed and recorded on an ongoing basis unless the resident is in hospice or has specific orders addressing this issue. Michonne (NA) shared the story of a new resident who initially refused to eat and speech therapy noted she would eat if her food was in a bowl. This observation provided nursing staff with a way to improve her intake that required no further consultation or testing. It just required good communication:

> The speech therapist noticed it. And then, it was brought up to me as the aide, "Hey look, she hasn't been eating" and I thought, so I went to the kitchen and said "Hey, can ya'll put her stuff in bowls for her?" and went back to the room and she ate everything, whereas she'd been her for like two or three days and we couldn't get her to eat anything. It was just a matter of knowing that patient, observing that patient. She shared it with me and I'm able to share it with the other aides on the floor "Hey look, if I'm off that day make sure her stuff is in a bowl.

Michonne shared an additional story in which her own observations identified the reason for a resident's poor intake. It was perceived that the resident was not eating because she was dying, and she was receiving IV fluids for dehydration. Then Michonne had an idea:

> And one day I was at home and I had ate a Popsicle or somethin' and "oh I got a cavity" and it hurt and I thought "I wonder when the last time she been to the dentist?" And I came to work and I say "Hey look, maybe she has a bad tooth in her mouth and maybe that's why she won't drink her, maybe it's too cold for her." "Well, I don't think that's it, I don't know." So I went and warmed up her drink and it wasn't cold, didn't have ice in it, and she drank all of it…"Hey, I think she needs a dentist appointment cause I just warmed up her tea, she drank all of it." "No way, you're kiddin'." "No, come on let me show you again." I warmed up another cup. Hey she drunk, drank it no problem…It didn't hurt. She had sensitive teeth. So I think just, just little things that could be a stumble-, and it, and come to find out she had a bad tooth. They pulled the tooth out, she was drinking everything. So you know, I think a variety of things, it's just making observations.

Sandra (LPN) talked about getting even small amounts of fluids in by pulling thickened liquids into a straw and emptying it under the resident's tongue. Lauren (LPN) discussed looking for alternatives like "a g-tube or, you know you work with the family, or the patient."

The location where meals were taken was also adjusted based on resident need and request. Residents were given the option of eating in one of several group dining rooms, in their own rooms, or if identified as having feeding problems by a therapist or nursing staff member, assigned to eat in small groups where they were assisted and monitored by NAs specifically assigned to support residents' efforts to feed themselves. Being out of bed for meals was encouraged but the stated wishes of the residents were respected. Location and level of assistance was adjusted to maximize intake and resident satisfaction.

Favorite foods. Favorite foods may be brought in by family or staff or requested through dietary channels to encourage resident intake. In cases where the resident is unable to eat, this may still bring comfort to the family, and even the resident, according to some participants, including Sandra (LPN) who said “Even though they may not eat a bite, but a bite after they get it, they’ll request it, family will bring it, and it makes’em happy.” Across the board, participants expressed a belief that near end of life, providing happiness and comfort with favorite foods takes precedence over nutrition and hydration needs. Two NAs and one LPN mentioned the soft drink Pepsi as a recurring favorite request among residents.

Repeatedly and frequently offering foods and fluids. Repeated offering of foods and fluids is another way many nursing staff, especially NAs, reported addressing nutrition and hydration issues without needing to obtain a formal order. As long as some level or oral intake remains possible, frequently repeating offers may contribute to increased volume of intake. For residents taking only amounts of food or fluids at a time, or having periods of lower responsiveness or energy levels, adjusting times and frequencies of attempts at intake was also mentioned as a way to potentially impact intake. Awareness of the intake issues of individual residents was described as helpful in planning the size and timing of meals or snacks as well as patterns of repeated offering. Kim (RN) provided one example of a specific resident’s “episodes where he’s kind of lethargic, and then he’ll come back around, but this time it’s just kind of been, well trending down, to where those episodes kinda last a little longer, um, and so then he’ll stay up a lot at night.” In response to this particular resident, meals and snacks were saved and offered in small amounts throughout the evening and night so food was available because when he was most alert but the kitchen was closed. This schedule goes above and beyond the legal requirements for facilities to maintain constant access to drinking water and to provide meals and snacks throughout the day to avoid excessive time periods between offers of food.

Respecting and honoring. Nursing staff reported showing respect and honor for residents and families by providing for physical comfort, offering emotional support, and making efforts to maintain resident dignity in decisions and care activities.

Physical comfort. Physical comfort was described by participants as a major goal of care for residents nearing end of life, and mentioned physical comfort as a factor in nutrition and hydration issues. Improvement in physical discomfort was described as sometimes leading to improved intake or tolerance of food and/or fluids. Others expressed concerns that not eating and drinking, referred to as “starving” by several participants, is or may be associated with suffering. Several, especially the NAs, expressed uncertainty with their knowledge of current evidence regarding nutrition and hydration near end of life and were not quite sure what they should be telling residents and family members.

In regard to a resident nearing end of life with nutrition and hydration issues for whom the decision is made not to intervene with artificial nutrition and hydration, Michonne (NA) described her experiences as “… I see it, I mean I’m still sad, but this is what happens, so for me, my job is, okay let’s make this person so comfortable, let’s make this family so comfortable. Let’s give this person 10 plus care you know, let’s, let’s give them the care they, they deserve, you know.” Ramona (RN) expressed her feelings as “if they could eat and drink I think they should have that option. But I know everybody can’t do that when they get to end of life, so, I guess pretty much keepin’em comfortable is the best way."

Emotional support. Participants discussed providing for resident and family emotional needs in a variety of ways. Listening, physical presence, assuring privacy, sharing their own personal experiences and condolences, and being accepting were all mentioned as ways to provide emotional support for residents and families dealing with end of life nutrition and hydration issues. It was almost impossible to teach nutrition and hydration decision making near end of life from death experiences because these issues were so closely linked. This was summed up perfectly by Michonne (NA) when she described adjusting her approach to families based on her existing relationship with them “cause the families are grieving, I mean even when they’re still alive they’re grieving.”

Similarly, Deborah Ann (NA) described basing her approach on the reception of the resident and family and her perception of what would be best for them: "…depending on if you were acceptable to it I would kind of comfort you, cause I’m church going, I’m saved, so my whole conversation would be about God and how she (the resident) done what she do on this, on earth, what she is, and how you gonna see your family member again, and all those things that can help..."

Interestingly, providing food and fluids for family members was also used as a method of providing emotional support. Nicole (LPN) gave a nice description of a service mentioned by multiple participants including several NAs:

> So, then again, it’s whatever needs to happen for the peace and tranquility of the patient, that’s paramount to me. The family is integral to that as long as it doesn’t aggravate or agitate the patient. If I see the patient becoming agitated because of 27 people in the room all going boo-hoo-hoo, I ask them, “Would you like to come in here and have a cup of coffee? And just sit here for a few minutes? We need to do a couple of things in there and it’d be a little bit easier if you could all kind of sit here in the break room and have a…I’ve gone into the kitchen and got you a care cart. Would you like to come with me

> and have a little something to eat or drink, just to collect yourselves?" So, you're doing both things at the same time.

Avoidance of words viewed as harsh, and instead using those perceived as comforting and peaceful, was yet another way nursing staff described providing emotional support for residents and families facing nutrition and hydration issues perceived as preceding imminent death. Participants reported most frequently using passed, passing, passed away, decline, declined, expired, and the phrase 'gone to heaven' when speaking with residents and family members, as these terms were viewed as less distressing than the terms death and dying. Only one participant said she used the words death and dying with family members intentionally, choosing to do so when clarity was needed for families who were struggling and in denial. Several others said they did use death and dying when they perceived this terminology was desired by the family but not usually. Respectful and simple, Michelle (LPN) reported using the phrase "I'm so sorry for your loss."

Janelle (NA) described avoiding the words death and dying "because, you know, some people take words in different ways. Some, some, some of it sounds soothing and some of it just, people just can't deal with it." And Lady D (NA) explained "I use pass because dyin' just don't sound, I mean, I mean I know it's the word for it but it doesn't sound right. I mean passin' sound a whole lot easier, smoother."

One RN addressed having to notify family members of deaths over the phone. "I'd probably do more like passed away, or, I wouldn't use, I wouldn't, I wouldn't use dying. I mean, cause it seem like it's a little more harsh, saying dying, and I think saying passing away that's the way I, that's the way I was raised… Or for somebody that lives out of state you, you know you do have to say, you may not want to say, they passed away, or you know just kind of ease it on them and not just like, you know, kind of be compassionate about it, you know so they'll take it a little easier than you not sounding like you're compassionate about it because if people take it, I think harder if you just act like you don't care."

Many participants expressed empathy for what the residents and family members were going through, and several mentioned openly sharing their own feelings of sorrow with them regarding the impending or recent death, especially when they had developed relationships over time. They also expressed interest in doing the "right thing" to emotionally support residents and family members through difficult decision making and end of life situations but weren't always confident in knowing what that was. The majority of participants expressed strong feelings about the choice of terminology used to discuss death and dying, with pass or passing being most frequently used to discuss death with residents and families. Several expressed interest in having more knowledge regarding nutrition and hydration near end of life as well as dealing with death and dying. One NA mentioned using Google to find answers to any questions she had, but "what I don't understand I'll always go to our DON." Only a few participants discussed where they went for information but sources mentioned included coworkers, the DON, hospice nurses, and hospice orders.

Maintaining resident dignity. Respect for resident and family choices was voiced by almost all participants, and described as an expectation of care delivery within the organization. Many participants voiced empathy for residents and family members, acknowledging the difficult decisions and issues they faced. One way of maintaining resident dignity mentioned by the majority of participants was not forcing, or attempting to force them to eat or drink. As Miranda (LPN) put it, "Cuz I definitely don't force it!" And Ashley LPN described valuing resident dignity by realizing **"**you're, you're takin' care of a life, that's in your hands, you know.

When you’re here they’re your responsibility, so, that’s hard work to take on, so, it’s just like, you know, I, you do it. But I like what I do."

Additionally, all participants stated or implied that decision making was up to the resident and family and they had to respect decisions whether they agreed with them or not. In most all cases, these decisions were respected and followed without interference or criticism, with Kim (RN) specifically stating “we might not always agree with the decision making but we have to respect it.” Eula (NA) shared a difficult experience for her when a favorite resident experienced nutrition and hydration issues and "…his family refused the g-tube, they said they just let him be comfortable. Jes, they don' wanna do that, put him through a whole bunch of changes. Which, that was hurtful for us because a g-tube woulda fixed it probly, but, you know, you can't go over the family..."

Guiding the resident and family. Nursing staff are often involved in situations where residents and family members facing end of life must make decisions, both large and small. Nursing staff support and guide residents and families by educating them about normal end of life process, providing appropriate information specific to the resident’s status, sharing their own experiences and opinions, and arranging for contact between the resident and family dyad and the medical provider. Helping residents and family member balance hope and false hope was also addressed. Participants, especially the RNs, had a lot to say about guiding the resident and family.

All participating RNs viewed influencing decisions as part of their role. Ramona (RN) said:

> I would talk to the family cause a lot of times family, depending, some families take, it’s harder for them to accept, you know, when their family member is, at that point, that

> sometimes we talk to them and try and explain it to'em on their terms...And just kinda break it down so that they can understand, you know what the person's going through as far as, you know, the end of life and you know trying to make them comfortable, you know, through the transition, you know, I think, is, helps a lot.

Kim (RN) shared an issue she was dealing with at the time as an example. She reported feeling that even though the goal should be comfort, the family must also be on board.

> We have a patient right now who's declining, um not really eating, the family's kind of borderline about hospice, so I mean I called Dr. X today, and this is probably our third conversation about hospice. Daughter's kind of borderline, not yet there but working on getting there, she's understanding that, that in and out of the hospital, and that at this point you just think about, and that's what I told her today, you need to think about, about long term goals for the end of his life. Do you want him to have, be in and out of the hospital, and be put through all this stuff, like right at the end, or do you want him comfortable in a facility where he's, you know he's here, we kinda know him, somewhat, he's not been here too long, you know, somewhere he can be comfortable and just kind of pass on peacefully.

Just half of LPN participants expressed comfort offering guidance regarding end of life nutrition and hydration decisions, with one specifically stating she did not discuss end of life nutrition and hydration with family members. One expressed comfort with discussions as long as documentation, for liability purposes, was appropriately completed. If issues arose where they felt intervention was needed, these LPNs passed responsibility for intervening on to either the RN on duty or the DON. When asked if she participated in decision making, Michelle (LPN) responded, "Oh yeah, not a decision, uh, I always redirect them back to either my DON or to their internal, you know, their doctor."

Interestingly, one very experienced LPN did feel that guiding resident and family decisions fell within her professional duty. She also expressed a belief that, over time, the influence of nurses has improved the levels of communication between physicians, residents, and families dealing with end of life issues including nutrition and hydration.

> I think over the past 15 years or so there’s been much more education done, certainly on the part of nursing staff, but even doctors have improved in their presentation of the, the continued hope against hope, you know… Even some doctors who have always been famously reticent to address death and dying, I mean, we’ll save everybody ‘til they’re 943 years old, you know Methuselah will have lots of buddies. But they have always been very reticent to deal with that head on with their patients, or with their patient’s families, and I seem to get the feeling that is a better part of the doctors, and I seriously believe it’s because of all the work that nurses have done in hospice, and, and, and in end of life things that they have been the educators, and in some cases educated the doctors, and said “Hey! You have got to talk to these people! You have got to get past your own angst and deal, and help them deal.” And so I’m hoping that, we’re at least at a point where we have a 50-50 shot at making it better for people.

The reported comfort of NAs in guiding residents and families in relation to nutrition and hydration issues near end of life varied significantly. While some reported discomfort providing any opinions or information to residents or family members, others were quite comfortable sharing, as long as they perceived the resident or family was interested in what they had to say.

All however, were comfortable passing on any questions or concerns to their hall nurse, charge nurse, or DON.

As mentioned previously, Michonne (NA) reported basing her participation on her relationships with the families. When asked for suggestions, she describes her approach as focusing on information rather than guidance, offering comments like the resident "'does better with this", or "I've been noticing that he does better with that." Nursing staff do not always have the opportunity to support the resident and family members in nutrition and hydration decision making near end of life. Deborah Ann (NA) recollected working with family members "who was so private where they wouldn't accept that this is not my mother, this is not her norm, but for us to tell'em that it is, who are we to tell this to this mother's child?"

Research Question Two

What factors influence this participation and how?

Theme 3: Influential factors

A variety of factors were consistently noted by participants or perceived by researchers as influencing nursing staff perceptions, beliefs, and actions in relation to end of life nutrition and hydration issues of residents. These factors influenced the participation of nursing staff in decision making processes. Identified subthemes included personal experiences/beliefs, unpredictable trajectory, relationship with resident/family, and organizational culture. Personal experiences/beliefs is further broken down into second level subthemes of nutrition and hydration experiences/beliefs, and end of life nutrition and hydration experiences/beliefs.

Personal experiences/beliefs. Past experiences are often the basis of personal beliefs, and personal beliefs form the lens from which individuals view and interact with their world. In regard to nutrition and hydration, participation in decision making may be influenced by both global views as well as specific experiences with nutrition and hydration issues, whether personally or professionally.

Nutrition and hydration experiences/beliefs. In general, participants discussed nutrition and hydration, primarily using the terminology food, fluids, eating, and drinking, as comforting and life-sustaining. This value extended into the NH setting from their personal life experiences and cultures. Of the 19 participants, 13 identified as African-American or part African-American, and all resided in a southeastern state where the influence of southern culture, especially southern African-American culture, on food experiences and beliefs is inescapable. The professional responsibility for maintaining nutrition and hydration intake of residents on a day to day basis as imposed by regulations and facility policies and procedures also added to the experiences and beliefs of participants (Table 2).

Providing favorite foods represented a personal way of providing comfort, not just a means of increasing intake, and focused the care on the individual as a person. Jessica (NA) described making one 101 year old resident happy by personally organizing and throwing a birthday party with “all of her foods.”

Having a global perception of food and fluids as life-sustaining, or curing, was a source of distress for participants, in both personal and professional situations. Michelle (LPN) described trying every way possible to get her mother to eat as a way of caring for her and making her better. She described her experience as frustrating until, “I’ve had to really deal with that in my head mentally, like we tried everything, I mean, you name it I tried it.”

End of life nutrition and hydration experiences/beliefs. To participate in this study, nursing staff were required to have at least some experience caring for residents nearing end of life who developed nutrition and hydration difficulties. Most reported multiple experiences providing care for NH residents nearing end of life who developed nutrition and hydration issues. Several noted their opinions, and the opinions of others they encountered, were often based on past experiences. In regard to decisions addressing end of life nutrition and hydration, including use of alternative methods of delivery, attitudes differed among participants and did not correspond consistently with role, race, or years of experience in health care. Although they held varying views, most expressed comfort dealing with end of life nutrition and hydration issues because they had previous experience doing so.

Deborah Lea (NA) described being “comfortable because I’m used to, you know when you done seen and experienced it, done seen it, you know you just used to it, you know.” She did, however, express feeling frustration with family members who continue to push residents to eat when they choose not to. She feels they don’t really understand because “when they dyin’ that’s why they don’t, they just quit.”

One NA described having to harness her feelings when caring for a resident nearing end of life "...and he couldn’t hardly eat or drink anything, and I remember being focused on him just, you know, sips here sips there...I never felt so helpless"

All but one participant reported involvement in end of life nutrition and hydration decision making involving a member of their own family or close friend nearing end of life. Around half reported participating in decision making for family members, although not as solo decision makers. In several cases, decision making consisted of assuring the expressed wishes of the dying family member were honored. In other cases, especially among very old or extremely ill family members, decision processes included continuing attempts to provide oral intake as long as possible, with no further intervention considered.

Sandra (LPN) had clearly thought about these questions herself, and shared a variety of ways she viewed use of artificial nutrition and hydration in those nearing end of life:

> I think by being at work and seeing things, seeing the people, seeing the people that are laying here, not knowing what's going on, the only thing that's keeping them alive is a g-tube; This may sound ugly, but I think that some of the families are selfish. When they just want them to lay here, and they don't know where they are, who they are, you know they're just like, the only thing keeping them alive is that feeding tube...And, but, I can see if you're alert and verbal, because we have situations where the patients have a g-tube and they have a physical reason like cancer, or some, throat cancer, and that's why they have the g-tube, because they can't eat…
>
> It bothers me that they're not able, not able to eat anymore. Now I don't like that, I don't like, 'cause we don't use NG tubes here. Unless it's just for short term. But the, I think the g-tubes to me are so much, I mean everybody can't see what's going on and they can't see the g-tube and you can't see the, do you know what I'm saying?... I'm comfortable with'em if that's what the family chooses, and because you know, um, as a matter of fact, and I think age wise has a lot to do with it. I can't see, I would have, have a very, wouldn't agree with somebody putting a g-tube in a 97 year old person.

Several participants discussed being involved in decision making regarding end of life nutrition and hydration issues with their own parents. Lady D (NA) recalled how she struggled to do what she thought her mother would want, saying "I wouldn't want her…to lay up there and just suffer, wid tube, tube feeding, knowing that that ain't what she wanted anyway." Michelle (LPN) described caring for her mother during a stressful terminal illness and her own struggles to accept decline of her eating and drinking as this required her to face the inevitability of death:

> I allowed her to make her own decisions, and, and I would get upset with her like “Mom, you’re gonna die if you don’t eat.” And she says “I can’t eat that food it doesn’t have any taste.” “Well what do you want?” and I would bring it to her and it didn’t matter. I think she was just saying things to compensate, or just to placate you, because when I wasn’t around she would say things like, “I just wanna die” and thing like that. Yeah, that’s what the other people said. But she never said that to me.

One NA whose mother is experiencing early dementia already knows and accepts that her mom doesn’t wish to be tube fed when the dementia begins to affect her intake “’cause she’s experienced it, what her brother went through." Her own beliefs regarding tube feeding and other such interventions have also been impacted by this experience. Interestingly, several participants reported selecting one care option for their dying family member yet stated a different option for themselves, and expressed a belief in the value of making decisions on an individual basis. Scout (RN) clearly expressed this sentiment when she said “"I'm DNR (do not resuscitate)-don't let me in this condition...I wouldn’t want that.” Acknowledging the inherent difficulty faced by those making end of life nutrition and hydration decisions, Lady D (NA) shared the following:

> Yeah, I mean, you know it’s, there’s always the point that you don’t want to see your loved ones go. And a lot of’em struggle with that and, you know, over the years I learned, even with my mom, I was puttin’ her through all this pain because I wanted her to stay here. And you know because, well, you know, I called it bein’ selfish, I wanted her to stay here, not to leave, even though with her, she was sufferin’, more than I realized.

Unpredictable trajectory. The relationship between nutrition and hydration issues and timing of death is often unpredictable and inconsistent among NH residents approaching end of life. Although diminished intake was mentioned by almost all participants as a sign of impending death, it is not specific to end of life and may worsen or improve unpredictably. Dealing with this lack of predictability requires nursing staff and family members to repeatedly make decisions with incomplete information. Accepting this lack of predictability involves valuing continued efforts to support nutrition and hydration, coping with deaths occurring sooner than expected, and advising family members that death is not easy to predict.

Study participants shared a variety of ways they approached oral intake issues in the short term. The most common option involved making sure it was reported and recorded, and accepting decreased intake as a normal but often temporary occurrence. Several participants shared their observations that even when nearing end of life residents did not consistently worsen, there were times they actually improved, although, most specifically regarding nutrition and hydration issues for the purposes of this study, they would then experience more issues, often ending up in a worse situation than prior to the improvement. Jessica (NA) described intake in those nearing end of life as “declines and inclines. It's to somebody's abilities as to what we can get'em to do or not do. Yeah, just that it's unfortunately, in the elderly, it's mostly declines." Miranda (LPN) reported occasionally handled new intake issues by telling NAs “maybe this is an off day, let’s try, try again in a little while” then if the issue continues “maybe they really do need some help swallowing, and then we normally pass that on.” Jade (RN) added that “…sometimes it may’ve just dropped off a bit and sometimes it may have been progressive so we’re kind of maybe in a worse spot…”

Situations where residents with nutrition and hydration issues were expected to die within a short period of time were reported as easier to accept than those where death was expected but not perceived as imminent. Deborah Lea (NA) "Well especially if I know they’re dyin’, but it’s something, it’s just, it’s just, only time it really shock you is like you know this person didn’t eat and all of a sudden everything just stop. And you be like ‘okay, what happened?’ you know. Yeah.”

Despite the focus of the interviews being nutrition and hydration, many participants focused significantly on their feelings and experiences dealing with death among this population of residents**.** Janelle (NA) said “Well I, I feel like this. You get attached to somebody, and somewhere down the line you get attached to somebody, and as far as making it easier for me, if I know they’re passing that would make it easier for me then to actual see them pass without knowing, you understand?” Lady D (NA) expressed the same sentiments**:**

> I mean, when you workin’ widdem a while like that and they pass, it’s still not easy but it’s worse when they go quicker, I mean even though you know they passin’ but it’s like they went too quick or they shouldn’ta went like that...So I’ve had a lot of unexpected ones and I’ve had some that I knew they won’t gonna make it through my shift. So you know, dem the ones that were more easier for me than the one that pshhheew.

The lack of a predictable death trajectory can be difficult on family members as well as nursing staff, especially when they are responsible for making decisions regarding withholding or withdrawing nutrition and hydration when a resident has limited to no intake and is no longer competent to make their own decisions. A few participants, including Ramona (RN) reported having experiences “where patients get fluids and sometimes they come back, you know they pop up, you know for a little bit…" The potential for residents experiencing nutrition and hydration issues near end of life to slightly improve or remain alive with artificial nutrition and hydration can be confusing and make decisions more difficult. In Michelle’s (LPN) words:

> So, sometimes, people cannot, they don’t think it’s gonna take as long as it takes. “Did I do this too soon?” Like “I didn’t realize she was so strong.” So I think they were going

> through some back and forth family wise, were not totally on the same page but she was, she was, she was definitely near her end of life. Her quality of life would've not been great to stay. And um, they aksed a lot of questions, and it was like I told them, "I cannot tell you the answer to that, I'm not even gonna try and guess that, like you know how long it's gonna be?" "No."

Relationship with resident/family. Although some NH residents come only for short stays after acute illness or injury, many reside in the facility for months or years. Over time, nursing staff develop both professional and personal relationships with residents and their families. Among study participants, these relationships sometimes made nutrition and hydration issues easier to handle, and other times more difficult. The relationships with residents and families described by participants varied somewhat by professional role. In some cases nursing staff serve as the only family available to dying residents.

All NAs reported experiencing close relationships with at least some of the residents, and many also with family members, and described these relationships as "like family." For the majority of the NAs, these relationships were associated with a level of communication between themselves and the residents and families that did not occur in resident care situations where these relationships did not exist. Janelle (NA) related this story of the death of a favorite residents:

> So I was sitting on her bed talking to her that day and she said "I'm tired. I'm'n stop eating." And I told her, I said "well you know that you have to eat in order to live." But eventually she stopped, and she died. She died right out. And then even issues like "well, I guess I'll eat" but mentally she stopped. And she died...You know I'd do whatever she said but sometimes it hurts you worse when you're closer to somebody and something

> happens to them.; It all depends on how you treat people, how you do stuff. The way you do it, if the way they like it, and they get a bond with you.

Interestingly, LPNs discussed relationships with residents and families less than RNs and NAs. One LPN did note that sharing opinions and information with residents and family members was more comfortable when relationships were already formed and another mentioned the importance of relationships when assessing for changes in status. Sandra (LPN) said “You learn their personalities. You learn their normal ways. And when something changes…It catches my attention. Like when you have someone that’s real bubbly and, and all of a sudden they’re not bubbly no more, and they’re just layin’ in bed, and quiet…”

RNs reported building relationships with families, often intentionally, as a means of improving care by learning more about the resident and maintaining communication to help guide care. Jade (RN) described her relationship with one resident’s son as “a thorn in my side…in a good way.” Ramona (RN) found “a lot of times families know things that might help, you know, with their loved one, eating or drinkin’ better or something that we could do, cause I like to involve the family so they’ll know, you know, asking them sometimes helps that they feel like they’re involved in it and we’re not just doing it and not asking them at all on their opinion.” Kim (RN), who believes in taking a proactive role in resident care, shared her approach to relationships with residents and families:

> I make it my business to know the families. I make it my business to know the residents, and have a good relationship, therapeutic relationship, working relationship, with the residents and with the families. Of course that’s gonna be different, like I know I can do this with this patient, but I definitely can’t with another patient, so it definitely depends on them.

Organizational culture. Organizational culture is a set of shared values, beliefs, and expectations within an organization that affects the behaviors and role performance of members. It also includes and impacts individual relationships between coworkers. Based on the comments of practically all participants, the culture within this facility placed great value on supporting residents and families in experiencing a comfortable, peaceful death. This included respecting nutrition and hydration choices of the residents and family members and, at times, assisting in their decision making. Nursing staff described nutrition and hydration as having physical, emotional, and social importance for residents and family members and making efforts to respect these values in their delivery of care to residents nearing end of life. Although well-defined roles and responsibilities protected staff from requirements to function outside their job descriptions, several reported feeling empowered to extend their efforts beyond assigned responsibilities if they felt these actions would improve resident experiences and they were comfortable doing so.

Comments by several NAs reflected the influence of an organizational focus on caring and respect for the individual in their views of both their care responsibilities and their potential to influence the care of residents with nutrition and hydration issues nearing end of life. "It’s just that we all, you know, gotta’ care. You got to care for them just as well as the ones that’s livin’, you know, that’s still in, you know, you got to provide daily care for them as well" according to Deborah Lea (NA). The DON described doing whatever it took to benefit residents, including empowering staff. She explained that “as for the residents, this is their home, but this is our facility, so whatever needs we see and can identify for our residents we can get them in place. So the CNAs are good about, if they identify something they come and tell us right away. We try and get it implemented.” Ashley (NA) provided a good example of feeling empowered to impact care when she shared her observations and concerns regarding nutrition and hydration decision making for a particular patient:

> I went and asked the nurse, I was like “Well, how do you go about suggesting that she gets a feeding tube or something because it’s like her, it’s like she’s not doing it her tongue is just pushing it out” so I asked the nurse and the nurse pretty much told me that it was just kind of up to the family members, if that was something that they want to do, so I told the nurse well maybe that’s something she may need because she’s not getting, you know we sit down and we feed her and it’s just comin’ you know, right back out.

Caring was expressed as a valued part of the organizational culture in the provision of care carts for family members when death drew near, three participants mentioned providing comfort to the family by means of a care cart. Michelle (LPN) described this as “a service tray or cart, like you know with some, a variety of things, coffees, juices, snacks…”

Interestingly, this organizational focus on resident care and respect for the individual occasionally resulted in frustration with care delivery when hospice care was implemented in the facility. Multiple participants expressed positive opinions of hospice care based on their personal and work place experiences, but several told stories of frustration with hospice nurses “not being there” until after death, not providing support for families, and sometimes placing extra financial burden on families. In fact, in some situations hospice was not pursued because nursing staff felt they could deliver care as or more appropriately than hospice staff and wanted to protect the family from additional financial burden as long as it was appropriate to do so.

Review of Relevant Documents

Review of relevant documents was included to enhance understanding of the environment in which nutrition and hydration decisions were being made.

Table 2. *Pertinent Document Review*

	Name	**Type**	**Relevant Content**	**Comments**
1	Hydration management	Facility policy	Provision of adequate liquid intake	Prevent dehydration
2	Hydration management (Requiring the use of thickened liquids)	Facility policy	Physician orders required	Prevent dehydration
3	Quality of care 42 CFR 483,25 Section g Assisted nutrition and hydration (including non-oral GI feedings) Section h Parenteral fluids	Regulatory-U.S. Code Requirements for states and LTC facilities	Maintain nutritional status by weight and electrolytes Offer of sufficient fluids to maintain hydration Offer a therapeutic diet as indicated by need and provider orders	Maintenance of nutrition and hydration in accordance with physician orders plan of care, and residents goals and preferences

4	Food and nutrition services 42 CFR 483.60	Regulatory-U.S. Code Requirements for states and LTC facilities	Dietary program	Nutrition staffing and program
5	10 A NCAC 13D .2305 Quality of Care	State	(d) Assist ADLs including eating (h) Feeding assistance (i) Enteral tubes only when unavoidable (j) Appropriate care if enteral feeding	Legal care expectations/ requirements
6	10A NCAC 13D .2701 Nutrition and Dietetic Services	State	(a)Palatable diet (c)Nutritional status weight and protein levels unless clinical condition demonstrates not possible	Legal care expectations/ requirements

Organization level

With the assistance of a staff member, I identified two relevant documents in the facility policy and procedures manual utilized by nursing staff, with one addressing general hydration management and the other hydration management for residents requiring thickened liquids. The hydration management policy emphasized assuring residents receive adequate fluid to prevent dehydration, with symptoms and lab values for detecting dehydration specifically noted. Required procedures included providing fluids on each meal tray, keeping water and ice within reach at the bedside, passing water and ice each shift, offering fluids at each snack time, assuring proper calculation of fluid intake for residents with tube feedings by having a dietitian or physician to run the proper calculations, and offering a minimum of 4 ounces of water with each medication pass. The policy addressing use of thickened liquids required residents with a physician order for this therapeutic intervention be assessed for dehydration similar to other residents and specifically described how the thickened liquids would be maintained and delivered, and included instructions for marking the room so staff were made aware of the resident’s requirement.

Although several participants mentioned hospice documents were used in the facility, these were not part of the facility’s policies and were not available for review. Additionally, use of the MOST form was mentioned as new to the facility but was also not included in the policies and procedures manual. Regulations also require policies and procedures be maintained in the dietary department but these were not used by nursing staff and were not reviewed. Training specific to end of life care delivery had been provided to nursing staff in the past but not within the most recent calendar year.

State level

In North Carolina, state level requirements are similar to federal guidelines and fall under 10A NCAC 13D .2700 Dietary Services. Section (c) states that "Based on a resident's assessment, the nursing home must ensure that a patient maintains nutritional status, such as body weight and protein levels, unless the patient's clinical condition demonstrates that is not possible and section (i) that "All diets, including enteral and parenteral nutrition therapy, shall be as ordered by the physician or other legally authorized person, and served as ordered." Identified documents provided rules and requirements requiring maintenance of adequate intake yet offered little specific guidance for nursing staff caring for residents with difficulty maintaining intake. Although palliative care or hospice orders could be put into place to support more appropriate care delivery, excepting the MOST form which was being trialed in the facility, there were no procedures or protocols to guide nursing staff in seeking a transition of care. Nursing staff primarily described seeking guidance from coworkers and information in resident charts or other resident specific instructions or from coworkers.

Federal level

The legal responsibility for NHs to maintain adequate nutrition and hydration of residents falls under sections 42 CFR 483.25-Quality of Care and 42 CFR 483.60 Food and nutrition services of US Code. These federal regulations that all facility residents receive quality care based on professional standards of practice, their comprehensive person-centered care plan, and their own choices. Sections of 483.25 specifically address the use of assisted nutrition and hydration (g) and parenteral fluids (h) as required to be delivered based on physician orders, in accordance with the resident's comprehensive person-centered care plan, and based on the resident's goals and preferences. Sections of 483.60 describe requirements for staffing and training as well menu, training, and food preparation, including the requirement that a member of the food services staff participate on the interdisciplinary team responsible for comprehensive care planning. Regulations also require specialized training for employees designated specifically for feeding residents.

Observation

Observation of participants during their interactions with their coworkers and with me, the researcher, also provided data considered in this ethnographic analysis. I initially observed a discomfort with my presence in the facility, which I perceived as a lack of trust as I was not known to nursing staff members. I did note, however, that staff members worked together, chatting and laughing, and I couldn't immediately determine the specific roles of each individual but was able to do so after watching interactions between them. Although the DON was sometimes dressed in professional business attire, everyone else wore similarly colored scrubs with an occasional patterned top. As previously noted, my attempts to recruit participants using flyers was unsuccessful but the DON's verbalized support of my project immediately resulted in a steady stream of volunteers.

Participants ranged from in a hurry but completely uninhibited when speaking with me, to very nervous and distrustful, to appearing to really enjoy describing their experiences. After the first several interviews, I felt the participants began the interviews more comfortably, talked longer, and were less careful in their comments. I was told that everyone knew everything in the building, including about me being in the building to talk to people. My field note journals contained descriptions such as "anxious to finish interview" and "initially nervous but less body movement and improved focus as interview progressed." I also perceived myself having greater comfort with interviewing with experience.

The room used for the majority of the interviews was a large conference room which was private but noises constantly drifted in from the hallway. I found the noises distracting but they didn’t seem to distract the participants. The majority of interviews were interrupted at least once by someone knocking on and opening the closed door of the room. The nursing staff were aware of the ongoing interviews but would interrupt to set up appointments to participate or to see if it was their turn. Those interrupting did not appear to see this as a problem and only once did the person being interviewed appear bothered by the interruption. The staff members appeared comfortable interacting together and cooperated in arranging interview scheduling. Participants also arranged to have coworkers covering any ongoing responsibilities they maintained during interview sessions, which resulted in occasional interruptions.

Most participants reported personal experiences with loved ones having nutrition and hydration issues as they neared the end of life, although only a few had participated in formal decisions. Their descriptions ranged from calm reports, appearing completely accepting of their experiences, to cracking voices and eyes brimming with tears. Some also expressed strong emotions when describing their experiences caring for residents with nutrition and hydration issues near the end of life.

Several participants were uncomfortable with having their interviews recorded although all agreed to do so. One did insist the recorder be turned off while she discussed a particularly emotional topic and then requested it be turned back on once she was more composed. Some looked at the recorder suspiciously but grew accustomed to it as we talked.

Observations supported the stated perceptions of participants regarding their individual and team roles as well as pride regarding their importance within the organizational hierarchy. The range of emotions noted during interviews also supported researcher perceptions of the personal emotional involvement experienced by many participants when caring for residents nearing end of life who experience issues with maintaining adequate nutrition and hydration.

Summary

This focused ethnographic study explored the following questions:

How do nursing staff participate in end of life nutrition and hydration decision making processes in a rural nursing home (NH)?

What factors influence this participation and how?

Three primary themes, *Formal Decision Making, Informal Decision Making*, and *Influential Factors*, were identified through analysis of interview transcripts, document review, and observations including a researcher journal. Analysis was performed using techniques described by Mason (2002) and Roper and Shapira (2000). Participants' own words were used extensively to assure emic perspective was maintained. Findings are consistent with the proposed adaptation of the striving for good care framework but suggest the addition of *personal experiences/beliefs*, and *relationship with resident/family* as factors impacting participation of nursing staff in decision making. Additionally, both work and personal end of life experiences were described as affecting nursing staff members' subsequent opinions and participation in decision making.

CHAPTER 5: DISCUSSION

The purpose of this focused ethnographic study was to better understand the participation of nursing staff members, inclusive of RNs, LPNs, and NAs, in end of life nutrition and hydration decision making processes within the organizational culture of a rural nursing home. This chapter presents a synopsis of study findings in relation to the proposed research questions and conceptual framework, addresses strengths and limitations of the study, and concludes with a discussion of implications for future directions.

The need for improvement in end of life care has been identified as a priority within the U.S. healthcare system by the Institute of Medicine (2014) and there is a need to focus on providing evidence based care, especially when complex decisions such as those prompted by nutrition and hydration issues must be made (Morley et al., 2014). Residents, family members, and medical providers are responsible for formal decisions in these situations, but the consistent presence of nursing staff places them in a unique position to influence and support ongoing decision making processes. Despite the potential for nursing staff to positively impact these decisions, few published studies address the participation of nursing staff in nutrition and hydration decision making for NH residents nearing end of life.

Current research addressing nutrition and hydration decision making for residents nearing end of life in NHs focuses heavily on formal decision making regarding use of artificial nutrition and hydration, with participation of nursing staff reported minimally or not at all, especially the participation of NAs. Only a handful of studies were identified that specifically addressed the participation of nursing staff in nutrition and hydration decision making in U.S. NHs, and only one of these included NAs as participants. Seminal work by Wurzbach (1996) explored the convictions of long term care nurses, all with at least baccalaureate degrees, regarding withdrawing and withholding tube feeding from elders nearing end of life. More recent studies by Lopez and associates focus on nurses' participation in decision making for acutely ill NH residents, including nutrition and hydration (Lopez, 2009), nurses' perspectives on nutrition and hydration decision making especially in relation to feeding tubes (Lopez, Amella, Mitchell, Strumpf, 2010), and the impact of organizational culture, including NAs, on the use of feeding tubes (Lopez, Amella, Strumpf, Teno, & Mitchell, 2010).

This Study

This ethnographic study was performed in a single nursing home located in a rural region of North Carolina. A total of 19 semi-structured interviews with nursing staff members, observation of participants during interviews, and review of pertinent documents were used to obtain data regarding the participation of nursing staff in nutrition and hydration decision making for residents nearing end of life. The study was focused using two research questions and an adaptation of the he striving for 'good care' framework (Bryon, Gastmans, & de Casterle, 2010). Three primary themes and multiple subthemes were identified using the analysis methods suggested by Mason (2002), and Roper and Shapira (2000). Primary themes identified were formal decision making, informal decision making, and influential factors. Findings are described in greater detail in Chapter 4.

Research Question One

How do nursing staff participate in end of life nutrition and hydration decision making processes in a rural nursing home (NH)?

Theme 1: Formal Decision Making

Formal decisions are legal, documented, care-directing instructions for which the resident, family, and medical provider share primary responsibility and the medical provider is ultimately responsible. Medical orders in the resident’s record are the primary method of communicating these decisions. They are influenced and constrained by both internal and external regulations and policies. Most LPNs and NAs interviewed did not describe themselves as active participants in formal nutrition and hydration decision making processes although the majority of RNs did view themselves as active participants. Nursing staff described communicating nutrition and hydration issues, initiating and coordinating decision processes, making efforts to assure regulatory compliance, and influencing decisions. In general, participation in formal decision making varied by role, with NAs primarily passing information on and contributing to regulatory compliance, and LPNs and RNs communicating information, assuring regulatory compliance, and initiating and coordinating decision making processes.

Communicating resident issue. Resident changes and problems were described as communicated up a hierarchical chain of command to the medical provider with the appropriate knowledge, skills and authority to address them. Information generally moves up the chain with NAs reporting to either an LPN or RN, who report to the charge nurse, ADON, or DON, who is then responsible for passing information to the resident’s medical provider or the facility’s medical director. All participants described communicating information as part of their role, both verbally and in written format. As they provide the most direct resident care, much of the communication regarding issues and problems begins with the NAs. The role of NAs as the first line of communication was acknowledge by nursing staff at each level.

Initiating and coordinating decision processes. RNs in particular reported contributing to formal decision making by initiating discussions regarding nutrition and hydration issues as well as coordinating discussions or meetings between physicians and residents/family members.

Almost all members, including several NAs, mentioned suggesting or initiating evaluation by speech therapy when nutrition and hydration issues arose.

Assuring regulatory compliance. Assurance of adequate nutrition and hydration for residents is required by regulatory agencies and addressed in organizational policies. The nursing staff share this responsibility and assurance is accomplished as a team, with all participants having responsibility for maintaining adequate nutrition and hydration, delivering care based on medical orders, and assuring adequate documentation of care. Both formal and informal methods of documentation were mentioned, ranging from designated notebooks used by the NAs to the medical record documentation of the LPNs and RNs.

Residents no longer able to maintain adequate nutrition and hydration orally, and those deemed unsafe to continue oral intake but wishing to do so presented challenges for nursing staff. Nursing staff were responsible for assuring appropriate medical orders were in place so proper care was delivered and the facility was not held liable for provision of care deemed inadequate or unsafe based on usual care expectations. When formal decisions were documented ahead of time issues did not arise in regard to meeting policy requirements. Several participants mentioned transferring responsibility for resident care to hospice as a means of assuring appropriate documentation and care delivery of residents nearing end of life when issues arose and appropriate documentation of end of life status was not in place. In some cases, formal decisions were not made in a timely manner, and several participants described incidents in which they struggled to reconcile their legal responsibility to follow existing medical orders with their ethical duty to respect the rights and desires of residents and family members.

Influencing. Influencing formal decision making was reported primarily by RNs, although one RN with limited experience did not perceive herself as influencing but rather providing comfort and accepting resident and family decisions. Influencing was described as aimed at decisions perceived by the nursing staff as in the best interest of the resident and family.

Theme 2: Informal Decision Making

Informal decision making refers to processes through which decisions not requiring medical orders are made and implemented by nursing staff. Informal decisions are made many times over each and every day by all nursing staff members. They may be supported or constrained by a variety of factors including internal and external regulations and policies, and such factors as time, resources, and perceptions. Fueled primarily by the needs of residents and family members, these decision making processes were described as primarily aimed at providing physical comfort for residents and emotional comfort for family members. Participation in informal decision making activities was described at length by almost all participants.

Knowing residents and families. The intimate and prolonged nature of interaction between residents, staff, and family members often offers the opportunity to know and understand the wishes and desires of individual residents and their family members. This allows staff to form a big picture of the situation and make better care decisions. It also guides the options staff members offer and provide. Several participants described their relationships with residents as “like family” and thought of them even when not working. One described having tooth pain and thinking perhaps her resident with oral intake issues was having the same issue. It turned out this was the case and after appropriate dental care the resident resumed her previous level of intake. Some nursing staff even expressed feeling that they knew residents better than the residents’ own family members although still acknowledged it was the family’s right and responsibility to make decisions.

Familiarity with individual residents' routines, especially by NAs, allowed them to notice subtle changes and issues those less familiar might have missed. Some residents and family members also expressed their feelings and concerns to nursing staff during the course of their care. Participants expressed greater comfort acting on their observations when they felt they had a good relationship with residents and family members and when residents had resided in the facility for an extended period of time. To some participants, "knowing" the resident and family was part of their professional responsibility.

Instituting feeding interventions not requiring formal medical orders. When a resident is still able to take some food and fluids orally, nursing staff often go to great lengths to maintain oral intake. Food and fluids are provided and monitored by NAs, who often employ a variety of efforts to maintain intake when residents nearing end of life begin to decrease their intake. Many of these efforts require no change in medical orders, such as switching from a plate to a bowl, varying feeding times, or adjusting temperatures of foods or fluids when served. NAs are aware of the need to maintain body weight and hydration. Katherine (NA) referred to this as the time to "improvise." Several stories illustrated the care and concern

Use of trial and error. Trial and error with a variety of feeding methods was described by the majority of participants as a way to continue assessing the residents' status and maximize oral intake for as long as reasonably possible. Participants reported using a variety of interventions that could be implemented without consulting medical providers. Methods mentioned included varying the consistencies of foods and/or fluids, changing feeding methods or body position for feeding, offering different portion sizes, varying utensils, using different approaches including a calm approach and assigning familiar staff members, offering food or fluids frequently, and adjusting the temperature of foods and fluids.

Favorite foods. Favorite foods, brought in by family or staff or requested through dietary channels, may still bring comfort to the family and even the resident, even if the intake is minimal to none. Across the board, participants expressed a belief that near end of life, providing happiness and comfort with favorite foods takes precedence over nutrition and hydration needs. Sandra (LPN) said “Even though they may not eat a bite, but a bite after they get it, they’ll request it, family will bring it, and it makes’em happy.”

Repeatedly and frequently offering foods and fluids. As long as some level of oral intake remains possible, for residents taking only small amounts of food or fluids at a time, or having periods of lower responsiveness or energy levels, adjusting times and frequencies of feeding attempts was mentioned as a frequently implemented practice not requiring formal consultation or orders. Awareness of the intake issues of individual residents was described as helpful in planning the size and timing of meals or snacks as well as patterns of repeated offering.

Respecting and honoring. Participants reported showing respect and honor for residents and families by providing for physical comfort, offering emotional support, and making efforts to maintain resident dignity in decisions and care activities.

Physical comfort. Physical comfort was described by participants as a major goal of care for residents nearing end of life and as a factor in nutrition and hydration issues. Improvement in physical discomfort was described as sometimes leading to improved intake or tolerance of food and/or fluids and not eating and drinking, referred to as “starving” by several participants, was viewed by some as potentially causing suffering. Several participants, primarily the NAs, expressed uncertainty with their knowledge of current evidence regarding nutrition and hydration near end of life, and were not quite sure what they could or even should tell residents and family members.

Emotional support. Listening, physical presence, assuring privacy, sharing their own personal experiences and condolences, and being accepting were all mentioned as ways to provide emotional support for residents and families dealing with end of life nutrition and hydration issues and death. Many participants focused on the death process in combination with nutrition and hydration decision making. They described offering religious support, providing food and drinks for grieving family members, and carefully selecting the terminology they used to avoid increasing resident and family member distress. Providing a food cart for the family near the hour of death, describing events as in God's hands, and avoiding use of the terms death and dying were specific ways nursing staff provided emotional support for when nutrition and hydration issues, and death, occurred.

***Maintaining resident dignity*.** Respect for resident and family choices was voiced by almost all participants, and described as an expectation of care delivery within the organization. Many participants voiced empathy for residents and family members, acknowledging the difficult decisions and issues they faced. One way of maintaining resident dignity mentioned by the majority of participants was not forcing, or attempting to force them to eat or drink. Additionally, all participants stated or implied that decision making was up to the resident and family and they had to respect decisions whether they agreed with them or not.

Guiding the resident and family. Nursing staff support and guide residents and families by educating them about normal end of life process, providing appropriate information specific to the resident's status, sharing their own experiences and opinions, and arranging for contact between the resident and family dyad and the medical provider. Helping residents and family member balance hope and false hope was also addressed. Participants, especially the RNs, had a lot to say about guiding the resident and family, and all participating RNs viewed influencing decisions as part of their role. Just half of LPN participants expressed comfort offering guidance regarding end of life nutrition and hydration decisions, with one specifically stating she did not discuss end of life nutrition and hydration with family members. The reported comfort of NAs in guiding residents and families in nutrition and hydration issues near end of life varied significantly.

Research Question Two

What factors impact this participation and how?

Theme 3: Influential Factors

This theme identified factors consistently noted by participants or perceived by researchers as influencing nursing staff perceptions, beliefs, and actions in relation to end of life nutrition and hydration issues of residents. These findings supported inclusion of the concepts in the proposed conceptual model and identified several additional factors for consideration.

Personal experiences and beliefs. Personal experiences and beliefs of nursing staff members, which are not represented in the proposed model, were identified as factors in decision making participation of all participants. This subtheme included both global and specific views of nutrition and hydration issues from both personal and professional viewpoints. A cultural view of provision of food and fluids as caring and life-sustaining was shared by all participants, and reflected in organizational documents as well as regulatory documents dictating care within the facility. The social value placed on foods and fluids creates a moral discord when residents nearing end of life are unable to take food or fluids, and each nursing staff member must deal with this issue individually. All nursing staff had experience providing care for residents nearing end of life who experienced nutrition and hydration issues, and the majority also with family members or close friends in this same situation. Through their shared stories, it became clear that most, though not all had struggled to develop a comfort with end of life nutrition and hydration issues and each approached care in their own way although their personal views did not always impact the care they provided. Interestingly, their personal beliefs were not even used to guide decision making processes for their own family members.

Unpredictable trajectory. The inability to predict death makes it difficult to decide when to accept the inevitable and remove nutrition and hydration versus maintaining hope and continuing to offer sustenance. Although diminished intake was mentioned by almost all participants as a sign of impending death, it is not specific to end of life and may worsen or improve unpredictably, described by several as ‘declines and inclines.” Dealing with this lack of predictability requires nursing staff and family members to repeatedly make decisions with incomplete information. Accepting this lack of predictability involves valuing continued efforts to support nutrition and hydration, coping with deaths occurring sooner than expected, and advising family members that death is not easy to predict. Caring for residents on a day in, day out basis allows nursing staff to identify patterns but, as several alluded to, only God knows when death will arrive.

Another issue related to trajectory of death involved nursing staff members’ own ability to accept that the resident can no longer eat and drink and adjust to the loss death or impending death of a resident. Multiple participants described difficulty accepting cessation of nutrition and hydration when the resident developed issues rapidly or when the resident’s death was not expected, especially among residents with whom they had developed close attachments. Several described frustration and even anger toward family members who did not aggressively treat a resident who worsened acutely, yet also had frustrations when treatments were prolonged beyond what they felt was reasonable. In general, worsening or death occurring without warning caused greater distress for nursing staff and family members than situations that evolved slowly and could be somewhat predicted.

Relationships with residents and family members. Relationships between nursing staff and residents and their family members also factored into participation of nursing staff in nutrition and hydration decision making near end of life. Among study participants, these relationships sometimes made nutrition and hydration issues easier to handle, and other times more difficult. Relationships with residents and families described by participants varied somewhat by professional role, and in some cases nursing staff were described as the only family available to dying residents. The participation of NAs was strongly based on relationships with residents and families, with the absence of a relationship limiting their willingness to offer opinions and suggestions. If there were no previously existing relationships with the resident and family, NAs reported providing care and factual information but being less engaged, and passing questions and concerns more quickly to the LPNs and RNs. LPNs focused less on relationships than did NAs, although presence of relationships was noted as increasing comfort in communication and potential to notice changes. LPNs described passing medications, providing treatments, monitoring care delivered by NAs, and intervening when issues arose. The time used to complete these technical duties left them with less time to spend with individual residents. RNs used existing relationships with residents and families to improve care and communication, even describing intentionally building relationships for this purpose.

Organizational culture. The culture of the organization, which in this facility placed great value on assuring positive experiences for residents and families, was also identified as impacting nursing staff participation in nutrition and hydration decision making processes. Several staff members specifically reported feeling empowered to extend their efforts beyond their assigned responsibilities if they felt these actions would improve resident and family experiences and they were personally comfortable doing so. Well-defined roles and responsibilities protected staff from being required to function outside of their job descriptions, yet participants reported actions that were often intangible yet valuable on a human level, that were employed to support residents and families faced with these difficult decisions. These included making care suggestions, expressing care to family members, and continuing to provide quality care no matter how dire the resident's circumstance.

Compatibility of Findings with Existing Literature

Comments of participants in this study aligned with the findings of Wurzbach (1996) who found the willingness of baccalaureate registered nurses to participate in decision making was higher when they were more morally certain regarding use of artificial nutrition and hydration at end of life than when they held weaker and less established beliefs. Wurzbach reported nurses with past negative experiences more likely to perceive artificial nutrition and hydration negatively and more likely to act on this belief. Those lacking experience with death, either with or without artificial nutrition and hydration, made little effort to influence decision making when nutrition and hydration issues arose. Among participants in this study, especially the RNs, those with negative opinions with regard to artificial nutrition and hydration were more likely to describe specific situations in which they perceived a resident experienced greater suffering because of the use of artificial nutrition and hydration. Participants' experiences with nutrition and hydration issues at end of life, whether involving artificial feeding or not, appeared to influence the strength of the views of many participants. This included experiences both with NH residents and their own family members and friends.

Lopez, Amella, Mitchell et al. (2010) investigated the beliefs, level of knowledge, and roles in feeding decisions of 11 NH nurses and identified three themes: a lack of sufficient empirical evidence to support feeding decisions, ambiguous role in decisions, and uncertainty regarding their own moral agency. In the current study, several participants, primarily NAs, mentioned a desire for greater knowledge and understanding regarding end of life nutrition and hydration. Although perception of responsibility for participating in decision making varied between the three levels of nursing staff and even among individuals at each level, the majority of NAs and RNs seemed fairly comfortable with their perceived role in decision making processes. Several LPNs, however, seemed unsure of the full extent of their potential to participate in decision making within their roles. Beliefs regarding the appropriateness of various approaches to nutrition and hydration issues near end of life ranged from strong to having little opinion one way or the other. Variations in these opinions did not appear to align with race, age, or level of nursing practice.

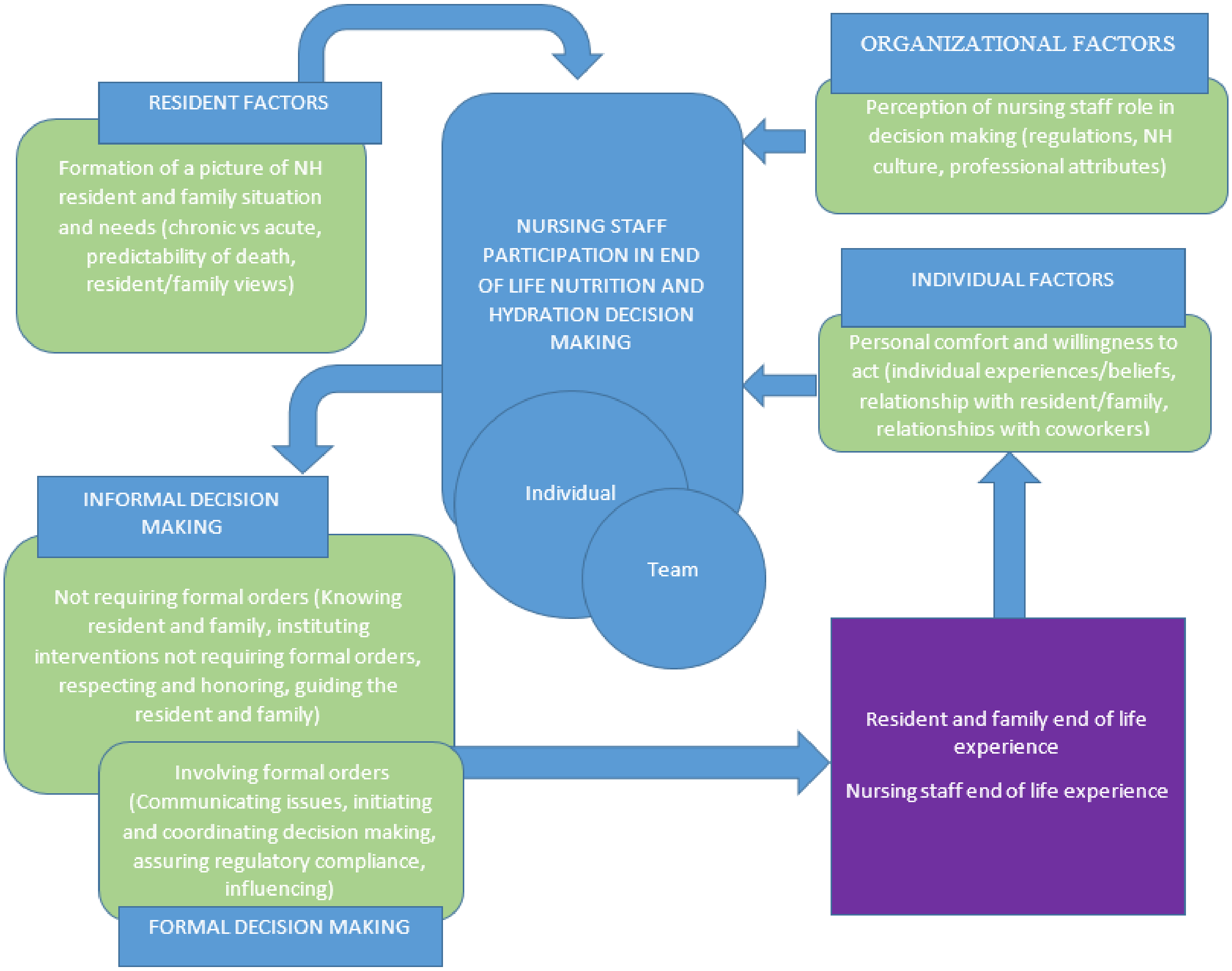
A study comparing the organizational cultures of two NHs, one with a high rate and one with a low rate of feeding tubes for residents with dementia found impact of facility culture at multiple levels (Lopez, Amella, Strumpf et al., 2010). Both facilities included nurses in organized decision making but the high use facility failed to include other NH members, such as social workers, which prevented their expertise from influencing outcomes. In this facility nursing staff describe working as a team, with input valued at all levels. It was noted by two NAs that they are not, however, included in required resident care conferences. Additional factors including NAs who valued hand feeding and administrative support of nursing staff participation in meeting resident needs were also mentioned by participants in this study when describing their participation in nutrition and hydration decision making for residents nearing end of life. Though not specific to nutrition and hydration decisions, Lopez (2009) found nurses’ decision making activities involved attempts to create balance by “satisfying all sides” by carefully choosing what, when, and how best to share information. Many of the participants in this current study reported being selective regarding information they shared, for reasons ranging from it not being their job, to lack of a relationship with the resident or family, to trying to limit potential for confusion by having the RNs deal primarily with information sharing.

Conceptual Framework

The framework supporting this study, an adaptation of the striving for ‘good care’ framework initially developed with ICU nurses caring for patients with dementia (Bryon, Gastmans, and Dierckx de Casterlé, 2010), was adapted to the NH setting using findings from extensive review of the literature. The original framework described care as beginning with formation of a picture based on patient factors, led to a decision making process across which nurses took a variety of roles, and then addressed aftercare delivered to patients and families. The adapted framework included additional resident and organizational factors with potential to impact care. These factors then influenced participation of individual staff members as well as team participation in decision making processes, with these actions eventually impacting the experiences of residents and family members.

Findings of this study support retention of concepts included in the proposed framework, as well as the addition of several others. Resident/family related factors and organizational factors were clearly influencing nursing staff participation in nutrition and hydration decision making for residents nearing end of life when both formal and informal decisions were being made. Individuals performed tasks according to their assigned roles and delivered care as a team with a formal though somewhat flexible hierarchical structure, with the primary goal of providing ‘good care’ as described in the original framework. The provision of comfort, primarily of the resident but also of family members, was highly valued and mentioned over 100 times within the 19 interviews.

Figure 2: *Adapted Model of Nursing Staff Participation in End of Life Nutrition and Hydration Decision Making*



In addition to factors initially included in the proposed model, this study identified personal experiences and beliefs of individual nursing staff members as well as relationships with residents and family members as impacting participation in nutrition and hydration decision making processes for residents nearing end of life. Relationships between nursing staff members, though mentioned by only a few participants, also appear to impact actions of staff members. Specifically prescribed tasks and responsibilities and a hierarchical communication structure control much of the work flow in the NH, yet participation of nursing staff in nutrition and hydration decision making for residents nearing end of life is most frequently associated with informal decision making and falls outside of specifically dictated responsibilities. A combination of informal decision making and formal decision making is utilized in providing care for these residents and impacts the end of life experiences of the resident and family members as well as the nursing staff providing this care. Additionally, past experiences with both nursing home residents and with their own family and friends influence nursing staff members' subsequent views and participation in decision making processes associated with end of life nutrition and hydration issues.

Conclusions

Findings suggest nursing staff in this facility participate in nutrition and hydration decision making processes to a greater extent than even they realize, especially informal decision making, in their efforts to comfort and provide good care to residents nearing end of life. Factors identified as hindering their efforts include limited awareness of current evidence and best practices, delays in formal decision making, and lack of professional role clarity, especially among LPNs. Comfort with coworkers and supervisors, positive past experiences, and established relationships with residents and family members were identified as supporting participation. The reality of nutrition and hydration decision making for NH residents nearing end of life is far more complex than a single decision, and formal decisions are made far less frequently than informal ones.

Participants reported a variety of signs they look for to signal impending death, but as several noted, only God can truly predict when death will occur. Thus identifying when residents are actually nearing death is a difficult and inexact task which significantly contributes to feelings of doubt regarding decision making. Hope of continued life, though generally positive, at times stands in the way of appropriate decision making near end of life, as does the need to meet policy requirements designed to assure adequate nutrition and hydration of nursing home residents.

Although not specifically captured in the questions guiding this study, all but one NA and two of the five LPNs focused solely on the present when discussing care. One NA, three LPNs, and all of the RNs referred to both providing care in the present and also starting beginning to prepare residents and families for what will likely occur in the future. Present care is important, but laying groundwork to support future decision making offers great potential to improve care delivery and experiences of residents and families facing these difficult situations. As decisions regarding end of life nutrition and hydration issues generally occur over time, staff often have multiple opportunities to provide education and support to residents and family members struggling with these issues.

Several participants expressed concerns that they had inadequate knowledge upon which to base care decisions, and many did not recall having specific training regarding end of life feeding practices. As a group, however, they described continually assessing intake issues, instituting interventions currently suggested in literature as careful hand feeding practices, and communicating information up the nursing staff hierarchy that triggered or contributed to formal decision making.

Participants from each of the three levels of practice presented the organizational culture in this NH as valuing the experiences of residents and families and empowering nursing staff to provide for identified needs. Despite this perceived support, however, there was some confusion regarding the appropriateness of certain actions within their designated roles, especially among LPNs. A discomfort with offering opinions was also shared, especially by NAs and LPNs, as many felt it inappropriate to share personal thoughts or opinions with residents and their family members.

Strengths and Limitations

Focused ethnography provided for in-depth data gathering directly from participants as well as inclusion of organizational and policy elements with potential to influence care. The similarity of representation of RNs, LPNs, and NAs within the sample to overall facility staff mix assured each group was appropriately represented, and a wide variety of descriptions and opinions were captured. Inclusion of observation and document review provided an added level of information, resulting in a more thorough picture than would have been possible using a methodology relying on a single data source.

Although appropriate for focused ethnography, utilization of a single facility limits generalizability of findings. Other facilities may differ in organizational culture, business structure, staff and resident populations, as well as a variety of other factors. This facility is, however, fairly typical of other facilities in the region as far as size, reimbursement struggles, and resident population. Several participants did, however, mention previously working in other

NHs, both local and in other states, and described this facility as more supportive of good care and with better access to supplies.

As this study relied on interviews only with volunteers, it would be helpful to know something about the experiences of staff members who did not volunteer and why they chose not to participate. The percentage of RN, LPN, and NA participants was, however, very similar to the percentage of each group across facility staff. Additionally, I had no pre-existing relationship with participants and the first few interviews were somewhat limited in depth. Initial volunteers chose to participate based on their trust in the DON, who openly supported this project, yet were a bit suspicious initially. As I continued to appear intermittently for interviews, later volunteers were more trusting, talked more, and shared greater detail.

Implications for Future Directions

This study identifies nursing staff as extensively involved in nutrition and hydration decision making processes for residents nearing end of life and attempting to provide the best care and support possible for these residents and family members. The quantity of time they spend with residents offers them the opportunity to notice changes and identify resident needs. The nursing staff interviewed were quite resourceful and expressed a desire to provide comfort and best possible care yet most were unclear regarding current end of life nutrition and hydration best practices. Respect for the family as involved and responsible for end of life nutrition and hydration decision making was also expressed, and their needs for information and support also acknowledged by participants.

The primary future directions suggested by these results are assuring all nursing staff are kept up to date regarding end of life nutrition and hydration best practices, developing job descriptions that provide greater guidance for nursing staff participation in end of life nutrition and hydration decision making as specifically as possible by role (NA, LPN, RN), and initiating end of life nutrition and hydration decision making processes earlier in the course of care. Additionally, the contributions of nursing staff to these processes should be acknowledged to a greater extent.

Assuring nursing staff are informed of current evidence based practices and beliefs would offer a simple and feasible method for increasing resident and family member access to timely information and support in situations where difficult nutrition and hydration decisions as frequently encountered. Repeated interactions with nursing staff at all levels would offer continual reinforcement and potentially improve the decision making experiences, and ultimately the decisions made, by and for residents nearing end of life dealing with nutrition and hydration issues.

Nursing staff need ongoing access to up to date, simple and short, inexpensive or free educational programming addressing nutrition and hydration issues among NH residents nearing end of life. Although a variety of quality end of life educational programs such as the End of Life Nursing Education Consortium (ELNEC) program are available, access to offerings more easily integrated into daily practice are needed. Programs should include current evidence of outcomes associated with different ways of approaching nutrition and hydration at end of life, delineation of nursing staff roles and practice responsibilities, and examples of care delivery that empower nursing staff to be comfortable providing care, and offer information and support to residents and family members along the spectrum of care.

Designation of a specific selection of educational materials available for sharing with residents and family members should also be considered. Evaluation of these interventions should include interviews with nursing staff, other providers, and family members of residents or past residents with end of life nutrition and hydration issues as well as observation of care practices. Studies should specifically include assessment of the impact of end of life nutrition and hydration evidence-based practice knowledge of nursing staff on the decision making experiences of residents and family members.

Evaluation of policies both inside and outside of the NH is also indicated. Several participants mentioned policies requiring maintenance of weight and lab values as resulting in pressure to provide inappropriate care to residents nearing end of life. These situations could be resolved, however, with earlier formal decision making resulting in earlier placement of medical orders within the resident record. As resident care meetings are required on a routine basis, there are recurring opportunities for interprofessional decision making to occur, at least for longer term residents.

With only two participants mentioning MOST (Medical Orders for Scope of Treatment) forms as a factor in nutrition and hydration decision making, the use and impact of these forms in this facility is an area ripe for further study. MOST and POLST are useful tools for clarifying nutrition and hydration decisions prior to the time decisions must be made and offer the most value in regard to formal decision making. Additionally, ongoing training in evidence based feeding techniques such as careful hand feeding, should be provided to nursing staff who assist residents with oral intake as the ability to support residents at all levels impacts care decisions and patient and family experiences.

As current evidence does not support the use of more aggressive feeding and hydration such as PEG tubes or intravenous feedings, decisions based on current evidence would not only result in improved end of life experiences for residents, families and nursing staff but could potentially result in cost savings through avoidance of procedures and hospitalizations. Careful hand feeding is, however, labor intensive and could result in increased staffing need and cost. Replication of this study in other NHs with different organizational cultures and with different corporate structures is needed to verify applicability of results across settings. Use of institutional ethnography to further study specific factors impacting nursing staff participation in decisions, especially policies and regulations, is also suggested.

Final Comments

Increased exposure to evidence based knowledge and best practice training, greater clarification of practice extent by role, and earlier initiation of decision making processes related to nutrition and hydration issues have the potential to improve end of life experiences for residents and family members as well as nursing staff members who provide care in the nursing home setting.

Nursing staff spend the most time caring for NH residents of any healthcare providers, and often develop close relationships with residents and their families. They are an existing resource whose potential has yet to be fully appreciated or utilized in supporting nutrition and hydration decision making for residents nearing end of life. They are ideally placed to reinforce accurate information and provide guidance and support for residents and families facing these challenging decisions. The 19 participants in this study are immersed in this reality, as hands on caregivers on a day to day basis. Their perceptions, comments, and experiences are, in actuality, those of the experts.

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APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL

EAST CAROLINA UNIVERSITY

University & Medical Center Institutional Review Board Office

4N-70 Brody Medical Sciences Building· Mail Stop 682

600 Moye Boulevard · Greenville, NC 27834

Office **252-744-2914** · Fax **252-744-2284** · **www.ecu.edu/irb**

Notification of Initial Approval: Expedited

From: Social/Behavioral IRB

To: Gina Firnhaber

CC: Elaine Scott

Date: 3/29/2017

Re: UMCIRB 17-000469
Nursing staff participation in end of life nutrition and hydration decision making

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 3/28/2017 to 3/27/2018. The research study is eligible for review under expedited category #6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the

UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Name	Description
GFirnhaber Demographic form	Surveys and Questionnaires
GFirnhaber Demographic form	Data Collection Sheet
GFirnhaber Informed Consent No-More-Than-Minimal-Risk-2 26 17.doc	Consent Forms
GFirnhaber Interview Question and refining questions	Interview/Focus Group Scripts/Questions
GFirnhaber Nursing Staff Participation in End of Life Nutrition and Hydration Decision Making Processes in a Rural Nursing Home IRB version.docx	Study Protocol or Grant Application
GFirnhaber Recruitment Flyer	Recruitment Documents/Scripts

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418

IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

APPENDIX B: DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

Licensure/Certification

____Nursing Assistant   ___Licensed Practical Nurse   ____Registered Nurse

Highest professional training

_____ Certified Nurse Assistant Course   _____ Licensed Practical Nursing Program

_____ Nursing Diploma Program   _____ Associate's Degree Nursing

_____ Bachelor's Degree Nursing   _____ Master's Degree Nursing

Years or months in this nursing home: ______   *Years other healthcare positions:* ______

Age: _______

Gender: _____ Male   _____ Female   _____ Transgender

How you classify yourself

_____ African-American/Black   _____ Asian/Pacific Islander

_____ Caucasian/White   _____ Latino/Latina (Hispanic)

_____ Native American   _____ Multi-racial

_____ Other (please specify___________________)

Religious affiliation: _____________________________

Have you provided care for dying patients with problems eating and/or drinking?

_____Yes   _____No

Have you had specific end of life or palliative care training?

_____Yes   _____No   _____Don't remember

If yes, did your training include information on food or fluids given ways besides by mouth?

_____Yes   _____No   _____Don't remember

If you need information or help caring for a resident who’s nearing end of life and not taking enough food or fluids, where do you go for information or help?

____

____

Have any of your close family members or friends experienced trouble eating or drinking before they died? If yes, how did this affect you?

____

____

____

____

APPENDIX C: INTERVIEW GUIDE

Semi-structured Interview Guide

Global question:

- *Please tell me a story about a time (or times) you cared for a NH resident nearing the* end of life *who was no longer able to eat or drink enough to stay alive*

Refining questions:

- *Food/fluid related interactions (verbal and nonverbal) with the resident, family members, other nursing staff, and the physician/physician assistant/nurse practitioners involved in care*
- *Activities they performed that addressed the resident's nutrition and hydration*
- *How they perceived their actions contributed/didn't contribute to food/fluid decisions*
- *How nursing staff worked together to include (engage) the resident, family members, and physician/physician assistant/nurse practitioner in decision making*
- *Information they considered when determining food/fluid needs*
- *Things that supported/inhibited their impact on food/fluid decision making*
- *Comfort contributing to end of life food/fluid decisions*
- *Training specific to food/fluid (nutrition and hydration) near end of life*
- *Words/terms used for end stages of life*
- *How they know a resident is near the end of life*
- *Words/terms used to refer to nutrition and hydration*
- *Personal feelings about artificial nutrition and hydration for residents nearing end of life*
- *Anything else they would like to add*

APPENDIX D: INFORMED CONSENT FORM

East Carolina
University

Informed Consent to Participate in Research

Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: Nursing staff participation in end of life nutrition and hydration decision making processes in a rural nursing home

Principal Investigator: Gina Cahoon Firnhaber, PhD(c)

Institution, Department or Division: College of Nursing, East Carolina University

Address: Health Sciences Building #xxxx, East Carolina University, Greenville, NC 27858

Telephone #: xxx-xxx-xxxx

Study Sponsor/Funding Source: N/A

Researchers at East Carolina University (ECU) study issues related to society, health problems, environmental problems, behavior problems and the human condition. To do this, we need the help of volunteers who are willing to take part in research.

Why am I being invited to take part in this research?

The purpose of this research is to better understand how nursing staff in nursing homes contribute to decisions about food and fluids for nursing home residents nearing the end of life who have problems with eating and/or drinking. Understanding what nursing staff do and the factors impacting what they do can help guide changes in both practice and training that help support better experiences for dying residents and their families. You are being invited to take part in this research because you are a member of the nursing staff in this rural, non-teaching nursing home and provide care for residents near the end of life who experience eating and drinking issues. The decision to take part in this research is yours to make. By doing this research, we hope to learn more about the activities of nursing staff that support these end of life care decisions and what factors support or hinder these activities.

If you volunteer to take part in this research, you will be one of about 30 people to do so.

Are there reasons I should not take part in this research?

You should not take part in this study if you are under 18 years of age, unable to communicate in English, have worked at this facility nursing home for less than two months, or have no experience providing care for residents experiencing eating and drinking issues near the end of life.

What other choices do I have if I do not take part in this research?

You can choose not to participate.

Where is the research going to take place and how long will it last?

The research interviews will be conducted at East Carolina Rehab and Wellness in a quiet, private location. The total amount of time you will be asked to volunteer for this study is approximately one hour. You will also be asked to review and comment on the transcript created from your interview if you would like.

What will I be asked to do?

You will be asked to do the following: If you agree to participate in this study, you will be asked to sign this consent form, complete a brief demographic form, and talk with the researcher about your experiences caring for residents nearing the end of life who aren't eating or drinking enough to stay alive. It will take approximately 5 minutes to complete the demographic survey, and then the interview will last approximately 20-45 minutes. You can pause or stop the interview at any time if you become upset or uncomfortable.

The interview will be audio recorded using two recorders, so your words can be typed out exactly as you said them. The interviews will be typed by the researcher or a paid transcriptionist, and your name will be removed during the typing process. Once the interview is completed and typed, you will be offered an opportunity to review the typed interview and change or add anything to your statements on the transcript. This can be done through the mail, by email, or over the telephone, depending on what you prefer. This process should only take about 10 minutes. After you have had the opportunity to review and change and/or add anything to your statements on the transcripts, the recordings will be erased. The researcher will keep a notebook for jotting down ideas and assessments during the interviews.

What might I experience if I take part in the research?

We don't know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. We don't know if you will benefit from taking part in this study. There may not be any personal benefit to you but the information gained by doing this research may help others in the future.

Will I be paid for taking part in this research?

We will not be able to pay you for the time you volunteer while being in this study. You will, however, be offered a $25 gift card to compensate for your time and effort, which must occur during non-work hours.

Will it cost me to take part in this research?

It will not cost you any money to be part of the research

Who will know that I took part in this research and learn personal information about me?

ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.

The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.

How will you keep the information you collect about me secure? How long will you keep it?

The tape recorded interviews will be erased after they have been typed and you have had the opportunity to review them. The tape recorders and informed consent documents will be stored in two separate locked drawers in the researcher's private office when they are not being used for this study. The typed interviews will not have your name or identifying information on them, and will be stored electronically in a password protected file on a secure server at East Carolina University. The documents will be shredded six years after the project is completed.

De-identified findings from these interviews will be used to complete the researcher's current study, may be presented at conferences and included in academic publications, and may be used in future research studies.

What if I decide I don't want to continue in this research?

You can stop at any time after it has already started. There will be no consequences if you stop and you will not be criticized. You will not lose any benefits that you normally receive.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at 252-864-7462 (between 8 am and 5 pm).

If you have questions about your rights as someone taking part in research, you may call the Office of Research Integrity & Compliance (ORIC) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the ORIC, at 328-9474.

Are there any Conflicts of Interest I should know about?

There are no identified conflicts of interest.

I have decided I want to take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

I have read (or had read to me) all of the above information.

I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.

I know that I can stop taking part in this study at any time.

By signing this informed consent form, I am not giving up any of my rights.

I have been given a copy of this consent document, and it is mine to keep.

Participant's Name (PRINT) **Signature** **Date**

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

Person Obtaining Consent (PRINT) **Signature** **Date**

APPENDIX E: RESEARCH SITE PERMISSION LETTER

February 2, 2017

Name, Director of Nursing

Name, Nursing Home Administrator

Facility Name

Town, State, Zip code

RE: Permission to Conduct Research Study

Dear Name DON and Name Administrator,

I am writing to formally request your support in a research project proposed as part of my Nursing PhD work with East Carolina University. The title of the study is *Nursing Staff Participation in End of Life Nutrition and Hydration Decision Making in a Rural Nursing Home*. Although residents, families, and physicians are the primary decision makers in these situations, I believe nursing staff provide significant support in the process. Reporting new eating issues, listening to concerns of family members, or taking extra time to feed a resident who's having trouble eating or drinking are but a few examples of things nursing staff do every day that quietly contribute to these decisions. Little previous research has focused on describing these activities. Greater understanding of the contributions made by these staff members, as well as the factors impacting these contributions, is needed to inform future practice and improve the experiences of the residents and family members faced with these difficult decisions.

This study will represent the culmination of my doctoral work in the College of Nursing at East Carolina and results will be used to complete my dissertation. This letter of permission to conduct my study at your institution will be included in my submission for formal approval through our University and Medical Center Institutional Review Board.

For this study, I would like to invite nursing staff members to participate in in-person interviews about their experiences providing care for residents nearing the end of life who have eating and drinking difficulties, especially in regard to their perceptions of activities they themselves perform that may influence decisions made by or for these residents. Ideally, I would like to perform these interviews March through May, with a goal of between 15 to 30 interviews, to avoid summer staffing issues. Specifically, I am requesting permission to:

- Recruit nursing staff volunteers from a single, rural, non-teaching nursing home (Registered Nurses, Licensed Practical Nurses, and Nursing Assistants) to participate in one-on-one interviews lasting around 30 to 60 minutes and performed during non-work time, with each participant offered a $25 gift card to compensate for their efforts
- Have intermittent use of a private space, such as an empty room or office, for conducting interviews
- Obtain the number of full and of part-time nursing staff employed by your facility at the time of the study, broken down into RN, LPN, and NA groupings (for describing percentage of participation)
- Review facility specific nutrition and hydration policies and procedures followed by the nursing staff

This study, including methods and consenting procedures, will meet established requirements for human subject research and be approved by the University and Medical Center Institutional Review Board. Individual interview results will be de-identified to assure anonymity of participants and any publications will provide only a general description of the facility to prevent identification. I am happy to provide more specific details if desired.

If you are in agreement with this request, please at the bottom of this letter or, if you prefer, provide a signed letter of permission on your institution’s letterhead acknowledging your understanding and consent allowing this project to be performed on your institution. If you require more specifics or would like to discuss my request in greater detail, please feel free to contact me at my email address firnhaberg86@students.ecu.edu or by phone at 252-xxx-xxxx.

Respectfully,

Gina Firnhaber

Gina Cahoon Firnhaber MSN, MLS, MPH, RN
PhD Student, East Carolina University College of Nursing
Greenville, NC 27858
Email firnhaberg@ecu.edu or firnhaberg86@students.ecu.edu
Office xxx-xxx-xxxx or Cell xxx-xxx-xxxx

Approved by:

Print name_________________________ Signature_____________________________

Title_________________________________ Date______________

Print name_________________________ Signature_____________________________

Title_________________________________ Date______________

(Signed and returned 2/14/17)

APPENDIX F: SELECT QUOTES

Select Quotes from Nursing Staff Interviews

Nursing Assistants

They just…they didn’t think that it was gonna come that fast. No, she just completely shut down…She just stopped talking, stopped eating, stopped drinking.

I’ll report it to the nurse that’s working my hall…And then I have to write it down in the book. Yeah. We weigh’em. Whatever the nurses they call for us to do if it’s weighin’em or a temp.

They knew it was gonna happen but they didn’t know how soon it was gonna happen.

Mmm, well, actually I get kinda close to a lot of these residents out here and it’s like, you know, they get comfortable with you being around I guess to help support them and stuff, and to help them through it.

Well I, I feel like this. You get attached to somebody, and somewhere down the line you get attached to somebody and as far as making it easier for me, if I know they’re passing that would make it easier for me then to actual see them pass without knowing, you understand? And then all of a sudden this just happened, would be kinda difficult for me,

Well, my grandma passed. But before she passed you know she just like one month she was up and then at the end of the month, right before her birthday, she went down, stopped eating and everything.

You know I feel like this. If that’s (tube feeding) their only source to get their food then feed’em. Because if you don’t eventually they gonna fade away too. Know what I’m sayin’?

You know I’d do whatever she said but sometimes it hurts you worse when you’re closer to somebody and something happens to them.

I giver’ some food and giver’ something to drink. So that they clearly will just wash it down. Or either I will give’er something to eat hot, and then give’er something cold and she swallows better. It’s just, just the way I learnt how to do her. And once you, once you learn your routine, that is what you go by.

You always report it. To their nurse. Report it to them and then write it down. If that’s for, in case something comes up. You have it on your paper and the nurse’ll have it.

Oh the decisions get made by first the doctor then the nurses, then the nurses passes on to us, as far as we need to deal with it.

I’ll try my best to feed you. As long as you’re swallowing. But when it gets to the point that you're not that’s when I would have to let the nurse know, and then you know they got some of’em, like I said they close to passing on, and if they have that tube in their belly it’s okay, but when they don’t have that tube in their belly we can’t do, well I can’t do but so much.

(tube feeding) It doesn’t bother me at all. It doesn’t bother me to make sure that they’re comfortable, getting their nourishment, and things like that. That’s why I’m so persistent about trying to get them to swallow as long as they’re swallowing, um, and as far as them leaving us we get so close to them you wanna to see them, if they gonna leave us, you wanna see them go peacefully.

And me, personally I will tell the nurse because, me, I’m with them, I’m hands on. The nurse givin’ them their medicine but I know their changes

I'm saved, so my whole conversation would be about God and how she done what she do on this on earth what she is, and how you gonna see your family member again, and all those things that can help to

I would put either passing on or um expiring.

Me I start from the bottom up, so I'll go to my nurse, but I don't get that answer that I want I'll go to the next person, which is the DON. And she'll pretty much give you, pretty much what I was kind of lookin' for.

So that's just something like implementing um, like their favorites, what they love. I think that's important at the end, when they don't want, they refuse anything else. Because hey, I knew it was the end. He knew it was the end. He loves Pepsi. He loves Vanilla Wafers. Hey, why not give him Pepsi and Vanilla Wafers you know, so that's something that I think should be looked at as far as the patient himself, for him anyway.

The main thing I do to see, well maybe the food is nasty you know maybe to see, "Is the food nasty? Is it off?" Okay, if, then, my next step would be, you know, the patient, "Well, what does the patient love? Oh, I see, she loves uh fish sticks and French fries. Okay, let's get her some fish sticks and French fries. Somethin' that they love, let's try to offer them that, and if that doesn't work then it's, okay, let's move to the next step so it would be finding out what they love and offering them something that they love.

The family's brought in if they're, they're not able to get'em to eat then I think it goes to the doctor, to try and get an order in because the family has to decide tube or no tube. And you know, how that goes, if they say no, then it's just a matter of offerin' it, and just keep offerin' it, you know, 10 minutes later they may want it, you know, it's you know, constantly offering and offering and offering and offering.

Um, I think it depends on the family. You have some families who are really emotional um, they're not making smart decisions, I shouldn't say smart, but they, they're goin' off emotions, so a lot of time is getting' to know the family, building that rapport with that family, cause like a lot of times the family looks to us like, "you guys are here with them most of the time, so what do you think?" And we can't really say "Well I would do" you know so it's moreso "Well, I've noticed is that he, you know, he does better with this" or "I've been noticing that he does better with that" and, and just kinda give them the information for them to make the decisions.

It depends on the family. Cause you have some families who are a little more aggressive with the care of their loved one, they don't want your opinion, they don't want your observation, it's what they want…

But it just, it depends on the family. You know, you have some families who are just set on how they want it and then you have some families, "okay, well if you guys think, well your observation is saying this is better well let's go with that."

I noticed she likes orange juice a lot. So hey let's um, who do we, talk to the dietitian, let's get her you know extra orange juice instead of an extra coffee." It's just a matter of knowing the patient.

Like we have a lady um, when she first came, she wouldn't eat. We couldn't figure out why she wouldn't eat. And then in, one of the therapists noticed, if all of her food is in a bowl, she'll eat everything. And it was strange I've never seen anything like it. If it was on a plate, she wouldn't eat it. If it was in a bowl, she would eat it. Literally we have all of her foods in different bowls, and then she’ll eat it and then give her another bowl and she’ll eat it. She will not eat it any other way. The speech therapist noticed it. And then, it was brought up to me as the aide, “Hey look, she hasn’t been eating” and I thought, so I went to the kitchen and said “Hey, can ya’ll put her stuff in bowls for her?” and went back to the room and she ate everything, whereas she’d been her for like two or three days and we couldn’t get her to eat anything. It was just a matter of knowing that patient, observing that patient. She shared it with me and I’m able to share it with the other aides on the floor “Hey look, if I’m off that day make sure her stuff is in a bowl. And I think it’s moreso of independency. She can hold it.Yeah, and she can do it herself. And so you’re kind of givin’ them, even though they’re declinin’, and like you said, they’re at the end of life, “Hey, I still can feed myself” and it makes the patient feel so much better. And a lot of times they eat more when they feed themselves versus somebody just shovin’ it in. So, it’s just noticin’ and pickin’ up different things from patients.

Well um, mouth care is a very important part. Um, had a lady who would not, she just wouldn’t drink any fluids, could not figure out why, could not figure out why. She would eat but she wouldn’t drink anything. She had a bad tooth in her mouth. …And one day I was at home and I had ate a popsicle or somethin’ and “oh I got a cavity” and it hurt and I thought “I wonder when the last time she been to the dentist?” And I came to work and I “Hey look, maybe she has a bad tooth in her mouth and maybe that’s why she won’t drink her, maybe it’s too cold for her.” “Well, I don’t think that’s it, I don’t know.” So I went and warmed up her drink and it wasn’t cold, didn’t have ice in it, and she drank all of it. It didn’t hurt. She had sensitive teeth. So I think just, just little things that could be a stumb-, and it, and come to find out she had a bad tooth. They pulled the tooth out, she was drinking everything. So you know, I think a variety of things, it’s just making observations.

It depends on you know, if I have a rapport with the family, um, you know, “Sorry your mom passed away.” Or not, a lot of times I tend to say passed away. Just it’s, it’s just gentler then dying, cause the families are grieving, I mean even when they’re still alive they’re grieving.

I think that’s the number one thing, just makin’ everybody comfortable.

“Hey, I’m noticin’ you know, Mr. So-and-So, he’s having a hard time swallowing. Ya’ll might want to do a swallow test on’em.” His diet may need to be changed from regular to mechanical soft, or you know, bein’ a pureed.

I literally would beg’em “Please, please eat.” You know like I would literally try to like literally beg and plead all day long. Like one time it was like 2 o’clock and I still had a breakfast tray and I was “Please, please just eat somethin’, please just.” You know now it’s more like, it’s moreso like you know what, “Hey, is there somethin’ you would like?” “Well, no.” “Well, you know, okay, let me know if there is.” And just now it’s just totally different.

The last four days she would not eat or drink anything, but the decision was made not to do any IV fluids, you know, no artificial feedings, or anything.

I see a lot of, moreso the family’s wishes. I don’t deal directly with the doctors, I honestly couldn’t tell you what the doctor out here looks like, but um, yeah, I think now it’s moreso the family’s decision. They tell the doctors “Hey look. This is what we think, decided, this is what we want.” And I think that’s pretty much how it is. Um, from what I’ve seen.

Well, like you were saying, the nurses are very important, the nurses’ aids, are very important. I like to consider the nurses’ aids the first line of defense. I mean, our hands are on the patients more than anybody in the building, so hey, if Mr. So-and-So, something’s wrong, I think I, I’m the first to know something’s wrong.

If they, uh, you know, the first place I would go first of all is the nurse. And I would let her know, uh, you know she pretty much workin' with uh, the hall nurse. And she'll uh let them know on the hall, you know the family members on the hall actually you know this is why we're doing this, and this is why we're doing that.

You got to bring it to the family "this is what's goin' on, this is a natural stage of life or whatever might be the medical situation. And uh, it is really their decision as to where, how far along they want to take it to keep nourishing mom or dad.

You know, so, but we hate to do that because, you know, you don't want to eat baby food, it takes away from your quality of life, but on the other hand you can't, really, you have to sometimes. I mean they can't chew it, they can't swallow it, it becomes a problem to their um safety of living so we have to. So the, lot of residents, some of them I know they don't mind the pureed so much but some of them, it's like, it takes a lot for them to adjust to pureed diet, yeah. But some of them that are real cognitively distant it don't make a difference to them, it's not really making a difference to their life, the quality of life. But some of them that do have it cognitively together like, I don't want this mess, you know…You have to talk to them. You have to change people's perception about everything. At different times. And when it's cognitively challenged changing someone's perceptions sometimes can be difficult so it takes a little gift of knowing what, you know working with people.

It's actually declines and inclines. Yeah, just that it's unfortunately, in the elderly, it's mostly declines…

Um, my personal opinion, I was raised, my aunt told me, that while in many ways that we would die we would never starve to death. So, to me, and I know and I did some studies that it's not, that it’s a painful death, to starve to death, so unless the re-, the patient was able to tell me “no, I don’t want that” I would tube feed a patient. .

I mean with some of’em, I mean with a lot of’em that I have experienced it’s like, you know, when they get to that point it’s like they just tired, they just tired. They don’t wanna eat, they don’t wanna eat like my momma, she got to that position that end of life she didn’ wanna eat. She just said that the food didn’ taste good, she was tired. So all we can do is, you know, try and encourage to eat…or do different types of things to try to get’em to eat.

I always feel like I could do more, which I know I couldn’, but you always get that feelin’ that you could do more.

Well, if they say no they’re not goin’ to eat we can’t force’em.

But I can see it’s hard for the family to accept, and then let’em go.

And you know sometimes they’ll talk to us about it, and…or, they might even come and say like “Um, mom just ain’t getting’ no better is she?” And if, if they’re not getting’ better why should I say “Oh yeah, she’s doin’ fine, she’s getting’ better…When I already know she’s not. That’s like to me, that’s giving them hope that’s not really there, or I’ll say somethin’ like “Well, you know it’s in God hands, whatever it gone be, it’s in his hands now.”

I use pass because dyin’ just don’t sound, I mean, I mean I know it’s the word for it but it doesn’t sound right. I mean passin’ sound a whole lot easier, smoother.

So I’ve had a lot of unexpected ones and I’ve had some that I knew they won’t gonna make it through my shift. So you know, dem the ones that were more easier for me than the one that pshhheew

You know, most of the time, if you, if you worked with them before, and you know how they, you know, how they normally do through, doin the activity, and you know they been eatin' and then all of a sudden they stop eatin' when they stop eatin', and most of the time when they stop eating they, they tired, they ready to go, they no longer wantin' to be here. You know, and that's what I experienced.

We just can't, just talk to the resident because ah, if you talk to the ah family members and then some of them might say "and then she told me such and such and she told me this" and so we cain't goin through that so it's best to go to your charge nurse, and let her know what's goin' on…And then she could inform the family, you know…But like as far as goin' into detail about, do I, no…I say, you have to ask the nurse, cause we just only here to do the care, not, I mean we could talk to the family members but we just can't inf, give a lot of information out because it's not our place

I would told'em, I would just come right out and say it to them. I would come right out and say you know they dyin', I would just tell'em that they, you know

'Cause you know I used to be scared of, you know, the dead, but when you experience death in your own family then you really, finally realize that hey, something that happens.

Any information, pass on to the nurse

I'd rather say passed, yes, because dying they be like huh? Cause they don't really, they comprehend better to the word pass than they do dying. You say dying you see, if you just like, they just panic, you just say "know don't think she's passing." It'll be better that way.

I would just say eating and drinking because you know, ut, the, they, most people understand, don't waste the words

And sometimes, um, like them doin’ the tube feeding, sometimes it be a little too late or you know be, you know what I’m sayin’, it’s, to do the tube feeding because some, some of’em be done, done, uh, uh, went too far along not eating and when they put the tube feeding in they, and, and some of’em don’t make it, you know, because they, they, the body won’t take it you know, and some people’ll take the tube feedin’ and stuff where after, you know when they die, and then some it ain’t doin no, it just, to me it just a waste of time if they, if they not doing anything, they body not responding to it why should you keep, you know.

Well then, you know, everybody got to make they own decisions, you know.

It’s just that we all, you know, gotta’ care, you got to care for them just as well as the ones that’s livin’, you know that’s still in in, you know, you got to provide daily care for them as well.

If you don’t know them you don’t know how they gonna’ take it. And so, that’s why they always tell us to don’t give out information to the family. Go to the nurse, and let her inform them of what’s goin’ on so they won’t be a whole lot of miscommunication.

You can offer them, and speak to them, let them know this is, for you, you know, to make you feel better or at least to make you comfortable. If they don’t wanna do it you can’t make them do it. At that point that’s when you kinda take matters into your own hands, to improvise, and figure out ways you can do it without them having to put too much effort into it. That’s, that’s just what I do.

Yeah, yeah, the little swabs, and dip it in the water and put it in their mouth. Water’s gonna come off of it and it’s gonna keep their mouth from being dry, it’s gonna help them in some way (loud, unintellible male voice in the background), if they don’t wanna feed themselves you feed them but at this point, when someone is dying, I think that’s the last thing they’re worried about is eating. If they have any, if they don’t even have the strength to give themselves the thing to drink, you know.

Oh, I’m a big talker on family, like, and in a situation like that because, it’s sad, most families want their space and they’ll tell you, you know, if they want they space and they don’t wanna be bothered, if, you know, my mom’s okay I don’t think she’d want any water, I don’t think she want anything to drink, they will let you know. On our, on our ends, you know, to comfort them is to bring them water, if they need something, you know just pretty much make everybody comfortable at that same time, and, you know, to just inform them that they need, if they need you that you’re there.

Yeah, pretty much that, yeah that’s just what we did, we pretty much had the whole cart, that had water and tea, and little snacks and danishes and stuff, you know, and put it in there, you know, cause nobody never know how long it’s going to take for somebody to pass away, they could be on their dying bed and it could take them one, two or even three days before they pass away, you know. So, it’s moreso their family gonna be there, family want to come and stay overnight so they can be there when it happens, so they can, that you know, if they need anything, whatever they ask for, pretty much try and get it for’em.

Right, but you would never know how anybody would feel unless it happened to you.

You just look at it and you see people go through that is stuff every day and you be like I don’t know what I would do if that was to happen to me. Until you in that situation…

You take care of somebody’s mom and you got to care about somebody to take care of them, you know.

Well, think of it as if I’m taking care of my grandma I would want this done that way because if this is not done that way I would be pretty upset you know, so that’s how

Yeah, it’s all, it’s all how you approach a person. Somebody could be dyin’ but if you come in there with a attitude, and they’re dying, no matter what they’re gonna remember that, no matter what. That’s, you’re the last person that they got to see, and I’m like this, I’m very big on how you approach people.

The end of life, and I would just say, approach the situation very calmly ‘cause there’s a time when most people panic, everybody don’t know how to deal with that, so if you want to get someone to eat, or who isn’t drinking, come with that same soft, kind, gently approach and you can probably get almost anybody to do anything you know. If sometimes if you can’t get them to drink out of a cup or a straw, improvise! Get different things to at least get some water in their mouth or some food in their mouth. That’s pretty much all I can say.

And I say “You have to eat because your weight is dropping” and she said “I know honey, I’m sorry, just come on and weigh me. I know I’m not gonna weigh the same but I just can’t eat” she said, and like I said, “I don’t have a taste for pretty much anything” and she said “I really believe your taste buds leave when you’re about to leave” and I’m like “Don’t talk like that because you’re not goin’ anywhere” and she said “Well, I’m just lettin’ you know.” Your taste buds, they’ll leave, you know. She died like three weeks later.

He didn’t give up on eatin’ even though he couldn’ swallow but his family, the speech therapist and the facility talked it over with his family, and of course they let us know because he was part of our program, his family refused the g-tube, they said just let him be comfortable. Jes, they don’ wanna do that, put him through, a whole bunch of changes. Which, that was hurtful for us because, a g-tube woulda fixed it probly, but, you know, you can’t go over the family…

So, the next step was to put in a tube, so they bring the family in- just talk to them and ask them. You know, that is an option to try to keep them alive and some family members are okay with it and some family members be like no that’s not what they want to do. But, that family that I experienced that with, they did it and it worked.

Mmhmm I really do feel that I am making a difference because I talk to them and you know with giving them their bath or whatever. And it’s just kind of like they know because they have been there when they were able to understand.

Yeah, I’m comfortable with it because sometimes it’s their way- the resident or the patient’s way they want to do it.

I kind of realize that we all live and we all gotta die. But, it’s gotten better. It’s still kind of hard to see when you’ve been there with them, but I know it’s just another way of life- another form of life.

Um, if I, if I, definitely if I notice a change in their condition, me personally if I’m able to speak to the resident if they’re able to talk back like “what’s going on? Are you not feeling well? Are you in pain” You know, just try to figure out what caused the change. Um, if they’re able to tell me then I definitely, definitely notify the nurse, once we find out a condition change the nurse is the next person to know. And then, I guess the nurse then consult with the doctors and the family members to let them know what’s going on and they um, that’s when they sit down and come up with the decision if this is their ending part of…

Definitely encourage them, you know when you're making your rounds or, you walk in there "Are you thirsty, do you wanna have something to drink" you know, um, you know, um it's, because it's like a lot of resident be like "you know, I didn't eat dinner" and I ask them like "why you didn't eat dinner?" and they say "oh I didn't like what was on the menu today" or whatever. And then "you want a snack?" You know, something to or sometimes I talk to them and say "you know you need to drink fluids, plenty of fluids, definitely water, you got to build yourself up" because when you don't eat or drink you just kind of, you know.

(tube feeding) I think you should do it. I'm not against it if you have a chance to save them in a way because it's just like, if they're not, if they're not takin' it one way why not try another way

(tube feeding) Because basically if you stop there, they, it's like you don't care whether they eat or drink or not. You know what I'm saying? It's kind of like, I think it's definitely something you should try, if it comes to that point. I'd try.

Um, I feel like the aids, I feel like the nursing field period, the medical field period is very valuable. Um, it helps save people, saves lives. I also know I love what I do, just to make a difference in anybody's day makes you feel better. Um, they, there's really no downside to it. I know most of the people just feel like that they're not compensated enough, that's basically…Yes, that's basically the issue with the medical field period, and it's not just Aides, it's the nurses, it's the doctors, it's everybody.

Cause you have to realize what you're, you're takin' care of a life, that's in your hands, you know. When you're here they're your responsibility, so, that's hard work to take on, so, it's just like, you know, I, you do it. But I like what I do.

Licensed Practical Nurses

Generally speaking, those patients have been already been determined to be hospice patients, so their wishes and the family wishes have been noted and entered into the record and in general we follow those. Withholding uh, uh, fluids via G-tube except for possibly water, even though most times water is also withheld. Um, my input into that seldom comes into it because, as I said, most times in nursing homes, at least in the last fifteen years, those wishes are put into place and noted in the chart and put into orders by the time they come under my care.

…absolutely refused to allow us to put anything in that G-tube. She would grab the G-tube, she would grab our hands, we would call her family, and her family would say well, if that’s what she wants then that’s what she needs to have done. There were at that point no orders to withhold fluids, to withhold feeding, um, it was more of an ethical dilemma for a lot of the younger nurses that were there. You know if we don’t do something she’s going to die, and it was a question of, of, it was her time anyway and, uh, she had made that decision she was just unable to verbalize it in such a fashion nor was her family. Her family was not able to verbalize that they accepted her choice. So it was a bit difficult and a bit dicey, both legally and medically, but personally, I understood what she was doing and why, and, did it sit right with me to not have things in place and not well understood all around? No. Did I acquiesce to the patient’s wishes? Yes.

Usually, uh, if their intake starts to diminish and we can identify a medical reason why, they have an infection brewing, they have thrush, they have a tooth bothering them, um, then I will do some preliminary looking in their mouth to see if they have mouth sores or thrush or anything like that going on that causes them difficulty swallowing. I’ll then contact our speech therapist, have them do an evaluation, to find out if this is a mechanical issue. Is this a new issue? If it, if it continues the doctor is contacted, you know, patient is refusing to eat, has not had X amount in X number of hours, um, we’re doing what we can to encourage fluids, we do frequent mouth care to try to stimulate something going on in there and we just keep plugging on until we get some kind of orders, either from the doctor or speech therapy or the family, or some decision is made to mitigate that circumstance.

I try to discuss just as gently and completely with them what seems to be going on, and kind of suss out what they understand about their family member’s condition, where they’re at, in the, in the whole scheme of things. And then give them what information I have and then inform them that we are trying to work with the doctor to resolve this and I will keep you informed.

But it’s not our place to judge what the dynamic of a family is.

I speak to them frankly, but politely, and try…to, um, understand where their feelings are at the moment. Cause people go through all kinds of things when they put family members into long term care and, and we are not privy to what happened before, we are not privy to anything about their life before they came through these doors and it is not up to us to judge.

Or what they indicate they understand, I try to feel out their understanding of the situation. Mostly they talk to me and if they ask me a direct question I will give them a direct and simple answer. Not simplified, but fairly simple and straight forward with no drama, no exaggeration. I will ask them “Do you understand what is happening to your parent or uncle or whatever?” And if they don’t, and they ask questions, I will try to answer those questions in a way that is able for them to understand because, I’m sorry, people today are a lot more informed medically than they used to be….You know, and it, it is so involved in family dynamic that has gone on for years that you really have to evaluate it moment to moment how you deal with the questions and the communications, absolutely with the utmost of respect, always, for both the patient and the family. If there is a question of the family, of their behavior being detrimental to the patient, I will do what I can to mitigate that even if it means calling my DON and saying “Look, I need, need some help here, this family is very obviously over agitated, it is agitating the patient, I’m gonna need more help than just me here. Because…the patient…comes first.

“Would you like to come in here and have a cup of coffee? And just sit here for a few minutes? We need to do a couple of things in there and it’d be a little bit easier if you could all kind of sit here in the break room and have a…I’ve gone into the kitchen and got you a care cart. Would you like to come with me and have a little something to eat or drink, just to collect yourselves?” So, you’re doing both things at the same time.

“Your mother is not eating or drinking. And we’re concerned because her, her level of fluid intake has dropped way down, uh, we seem to be having difficulty convincing her that she needs the fluids.” Um “We’re doing our best but we don’t want her to have any issues, uh, swallowing either, so, uh, has this happened before? Was this going on at home? Uh, maybe you could give us some clues that would be helpful to help us help her.”

Starting to go downhill can happen as many as six or eight weeks out.

When I think they’re really coming close it could be from a week to two days before they die.

I wouldn’t choose to have a tube feeding put in to begin with!

Um, death’s death. It’s a part of life. However when you’re dealing with other people’s family members, again it goes back to we are not the judge what is right and wrong. We do deal with what is, and we help them deal with what’s coming. No matter, er, what our feelings are about our own mortality, uh, and our own end of life wishes, it doesn’t matter, that’s not what we’re here for. Our own wishes and our own feelings should not, and I say should not purposefully, should not come into play when trying to help family members and patients through, through the dying process. It just shouldn’t. Um, for me, try to put a G-tube in me. I’ll get up and walk off the table! Try to put a vent in me! I will pull it out and, I will probably haunt you after I die. I’ll guarantee it.

From the standpoint of things like, um, like reflux and aspiration, yeah, repeated pneumonias from aspiration from a g-tube or a feeding tube of any kind because the family can’t let go, can’t understand that this is your family member but is this your family member? You know, so, sometimes I get a little miffed if you will, at the inability for most Americans to accept death as part of the living process, you know.

We actually had one little man who could not pass a swallow test and we were very concerned his brother did not want him, initially his brother wanted him to have it, a g-tube, um, well, then he changed his mind, that he did not want him to, changed his mind. And, the only way that we could actually let him eat was to get hospice involved, and that way the patient could have what he wanted. And could eat what he wanted, and any consistency…Because, we, as professionals, with him not passing a swallow test we could not feed him, we could not give him food. Tube feeding was the only option…But, if we got hospice in, they were able to say “hey, he’s hospice, and, he’s near, you know, he’s made a drastic change in his eating, his brother is responsible, his power of attorney does not want him to have a g-tube.

Yeah hospice, they come in, they do their evaluation, do all the proper paperwork, get the proper documentation.

They (NAs), they’re our eyeballs, in a lot of situations as far as their eating’s concerned

Right, right, a lot of times I will go in, like some of the CNAs, you know, occasionally I'll have a CNA, will say "they're not eating" and I'll go in and if I got, a lot of times, I'll stop my med pass and, just go in and, if…it doesn't take that long to feed somebody. If, if they will start eating. But sometimes you have those that, it takes a longer time.

And you know it's just, it's like, and it's just some patients eat better for one person than they will another…And then I'll go in and, I can't get, once in a while I can't get'em to eat, but this person goes in and they're more familiar with them

We would monitor the, notify the doctor this patient's not eating, cause we have patients that will eat some days and not eat other days. So if it goes on for any length of time, or we can't get anything in them we definitely, we, we notify the doctor.

Even though they may not eat a bite, but a bite after they get it, they'll request it, family will bring it and it makes'em happy.

It bothers me that they're not able, not able to eat anymore. Now I don't like that, I don't like, 'cause we don't use NG tubes here. Unless it's just for short term. But the, I think the g-tubes to me are so much, I mean everybody can't see what's going on and they can't see the g-tube and you can't see the, do you know what I'm saying?

I'm comfortable with'em (g-tubes) if that's what the family chooses, and because you know, um, as a matter of fact, and I think age wise has a lot to do with it. I can't see, I would have, have a very, wouldn't agree with somebody putting a g-tube in a 97 year old person.

No, he was at death's door when he came in. But over the time, he progressed, because he was young

This may sound ugly, but I think that some of the families are selfish. When they just want them to lay here, and they don't know where they are, who they are, you know they're just like, the only thing keeping them alive is that feeding tube…And, and, that just kinda, and it's just, they were just laying there being alive by the feeding tube.

And, but, I can see if you're alert and verbal, because we have situations where the patients have a g-tube and they have a physical reason like cancer, or some, throat cancer, and that's why they have the g-tube, because they can't eat.

Of course offer it! Umm, if they feel like they can take a sip…or if they're comfortable coming around and actually speaking again…because sometimes they do pop back up! Umm, I would say if they ask for a Pepsi, give'em a Pepsi! I mean if they're end of life and they want a Pepsi I'm gonna give'em a Pepsi, that's my thinking! Um, yeah if they perk back up I'd definitely try anything, um, whatever, whatever they can intake.

Most of the time I would tell either the director of nursing or the speech if something is wrong with the swallowing, I'll notify one of them and normally the speech comes in and they'll either sit with'em a meal or kinda see how they do or they may pick'em up…

(Talking to family members) That's not my role. I tell'em the same thing. You can offer it all day long but unless that patient wants it don't force it.

Many a times the aids will go in there and it's kinda like, they try but they'll come to you because, they're kinda scared sometimes, and they don't know exactly what to do so, of course, I'll go in and see how they're, I mean, see, I try and see how the patient reacts, and if of course they don't want it they don't want it. And if they do then we'll offer what we can and if they don't then we'll just try again.

So if they come to me and say so and so has some problem swallowing, if I go in and notice the same thing, I would contact or tell the director of nursing. And then normally they would say, well, we'll let the doctor know and then they would consult speech.

… if a order's gonna be made, then uh speech has probably done that and then of course if I take the order off I will call the family and let them know that this, this, and this has been done, but, and that's the only time I would call the family.

I think the only thing you can support it with is if you yourself go and try, and see how they do swallow, and you can either vouch that yeah, they're having a little bit more difficulty than they had before or either, naw, maybe this is an off day, let's try, try again in a little while, and maybe they really do need some help swallowing, and then we normally pass that on…

Normally I, I notify somebody else if the problem's swallowing.

I've kind of come to grips with it. I've seen a lot of death over the past six years that I have been doing this. And sometimes, you know, they eat up until they die and then sometimes they stop eatin'. Um. It really varies by patient. And if, like I said, the patient preferences, I mean, if they're on thickened liquids and they're dying and they want a Pepsi, I'm givin' 'em a Pepsi! (both laughing). I mean for real!

I mean if they're dying, they're dying. Why not let'em be happy?

Um, I have dealt with patients who are end of care life and there was one in particular that she had a g-tube where she was being given her fluids through her stomach and nutrition through her stomach and she was getting flushes and um feedings through the g-tube. So she was actually, you know, getting the nutrition in effect, you know it didn't prolong her life but she was getting the nutrition. The stuff that she needed through the g-tube.

What I find mostly that if the patient is being given the comfort care that they need as far as keeping fevers down, turning them, repositioning them, and talking to them, that this um, helps them too sometimes, you know take more nourishment than if you, you know, just left the person there and didn't interact and try to help them.

I really feel that if you offer a person the comfort that they need, you know, that it helps them to, you know, have a little normalization as far as taking in fluids and things like that.

Well, you can't force them to take anything, um, I'm saying you would just report it, um to your supervisor, uh note it in your notes that this person is not, is having poor nutrition, that's the most you can do and with the team you look for some kind of, maybe there's an alternative like I said of, they get a g-tube or, you know you work with the family, or the patient.

Well you know you have family members who are always concerned so they come to you asking questions like why aren't they eating or um, are they being fed, or being offered food, you know, so um, you have to speak to them about that, you know, let them know that you are offering them food that they're not taking it in. Sometimes it's a process, you know, of the disease that they have, and uh, you try to offer the family comfort as well. But lettin' them know you are doing whatever you can to help their family member.

But um, my role as an LPN, I usually implement what has already been discussed and set into motion.

I see more where family members uh, are doing it (making decisions) for them, you know, making a decision after uh something has already happened. You know what I'm saying?

I feel like I try to do whatever's necessary to, to make that patient comfortable and the family as well.

… we have directives, and a nurse book and a MAR, the medication book that tells you which should they be doing. That lets you know exactly how much fluid they want you to encourage that person to have per shift.

The typical person that even starts to go down the doctor would order, uh, let’s say, um, they’ll say um, fluid intake, fluid output, they would like you to encourage this much per shift. They encouraged that much per shift, let’s say they encourage 120 which is one cup, one Dixie cup, and then they ask you the percentage that actually went in.

But you’ll go ahead and you’ll try to attempt to give them…the recommended fluid intake but these people, I know you have to know that, are, older people kind of lose their thirst mechanism, they do not feel that heat rising up. They do not feel that thirst, and they’ll literally take a sip that can’t even count as a 1%. Like they’ll take a sip and you’re like come on, come on and they’re adamant, they’re very adamant about what they’re gonna do and what they’re not gonna do at that time as well.

Oh yeah, not a decision, uh, I always redirect them back to either my director of nursing or to their internal, you know, their doctor.

You kind of think it’s gonna happen like that but it doesn’t happen like that. They can sit with us for about a week and you’re sittin’ and wondering like about… “did I do this too soon?” Like “I didn’t realize she was so strong.”

So you just basically, you let them know, I’m here for you. Ask them “Do you need anything?” We provide, you know, a service tray or cart, like you know with some, a variety of things, coffees, juices, snacks for them.

No, you should definitely use the word death. It’s, it’s not a great word to use but you must make very clear that this person is no longer here.

“I’m so sorry for your loss.”

But at that time, before I left that morning, we ended up waiting for the family to come and we brought them coffees and, you know, a continental type of set up. And um, the last thing I heard before I left that morning was they were ready to call the funeral home.

We call it a stop and watch moment. You’re walking and just something goes “hm, are you okay?” just something causes you to stop for a moment and check that resident out, even if you see, sometimes behaviors start to change… You record that by charting to your doctor, or you could do an immediate communication and say “this is happening, this is the third time this is happening. What is your advice, what do you suggest?” and next time you look the doctor has answered that for you. So things just a person just dying at the nursing home is not too frequent. You would kinda know about this at times. The whole building knows about it, whether it’s your load or the next load it’s the talk.

She had the will to eat but her body would not let her eat, she could not eat. I’ve had to really deal with that in my head mentally, like we tried everything. I mean, you name it I tried it. I brought it over there for her to eat. It was so frustrating…And she says “I can’t eat that food it doesn’t have any taste.” “Well what do you want?” and I would bring it to her and it didn’t matter.

And I don’t believe that you should force them to put a nasal gastric tube.

And I started really noticing that the thing is that when they stop eating I believe, this is my first experience with this so close up, is their system is unable to process that food.

Sometimes I can’t even sleep thinking about these things, and that’s why I would never, ever subject someone if I can help it to that kind of care. You, you do as much as you can, you do absolutely as much as you can…You’re definitely there to support. My philosophy, I’m very literal, I read palliative care, and I read hospice, and I know the difference okay, it doesn’t transcribe in real life, it doesn’t happen. When you’re, when you give this person to hospice, they’re not present, they’re not. They say “call us when they’re dead.”

So I’ve learned that, in real life, things are not how they say it should be in the books. And I’ve had to learn to adjust because I think my expectations sometimes are too high.

They will remember a good, or a bad. And if some, they have another family member they will consider us on that term. Like how you ended with them. But we do the best we can here.

Registered Nurses

… preparing the family is a big thing for, they always wanna know when, how long. “How long? How long can they go without eating? How long can they go without drinking?” And um I’ll take’em back to where it declined and sometimes it may’ve just dropped off a bit and sometimes it may have been progressive so we’re kind of maybe in a worse spot…

We’re not trying to give them anything to pick up their nourishment or um their hydration, but there are problems that come with being dehydrated and when those symptoms appear you have to do something. But just, you know, just keepin’ their mouth moist, comfortable, Vaseline on their lips, you don’t want’em to be cracking. …the whole time kinda educating the family.

… even though they knew they had failed swallowing studies and they would sign waivers, dietary and against medical advice, because they, the family, wasn’t eatin’ at all anyway, the patient wasn’t, so at that point what’s the worst? Which one’s the best? You know, the worst of the two evils. So um and, let them know that whatever they decided was okay, you know it was different for different people. I don't think I've ever, prior to them going on hospice, when I would see the decline, and you can you know seein'em every day, just like when you give'em their medicine, they may drink the whole cup, and then you notice a couple of swallows is all they want, you know that kind of stuff. Um and um, I don't even know what I was going to say about seein' the decline but one, and then you start, you know, tryin' to pick it up, to pick up their po intake, and if they don't I would always usually explain especially if they had like three or four days of poor po intake, we'd try an IV, and we would do that for about 24 to 48 hours.

I would call the doctor, the medical director usually, and especially and it that's like if they had been doing really pretty good, and like maybe they started out with a cold or something and they got down, and usually though if they're gonna pick up and start back eatin' and drinkin' it's gonna happen in that first 24 hours. And so after that point, if they weren't doin' any better, or showin' any in-, desire to drink or anything, you know, kinda, having some energy come back and alertness come back, then we would just take the IV, stop the IV, and…

When's the family, um, and that's a large part, cause a lot of it, when I'm with the families, and I always try to be, just to get a feel for where they're at.

You know the purpose of all that is dignity, and comfort, and just to have a peaceful transition for the family and for, obviously the patient. I would ask "Anybody got any questions?" after someone died, saying "These are the things they had. This is how you've seen her. This is, that was the best she was ever gonna be." You know to make'em just understand that, we're all dyin' too you know. But it's um, it's, it's not um, I do think the more you're exposed to it, and it is different if it's your family.

… and then the other situations are where all the family members are on the same page but one, and they're unrealistic, and it's usually the family member that's been the least involved, that you've seen the least, you didn't even know they existed 'til mama or daddy started dyin', or whoever, and they tend to make the people, other people maybe feel some guilt, and that you know I feel like that, at that point my job is to make sure that they are making the best decision that they can and not to second guess theirself, and then to again point out what their family member's quality of life has been. And um, um to look at it as a dignity, and a passing of, especially if they're older, they've had a good life, then you can say "Wow, you're here with'em, what better way to pass?" Everybody's gon' die. And at times, like, they've wanted to go to the hospital, to die, and I be like "Why would you want them to go to the hospital? They've been here for the past three years. They know the staff, they know all of us, and we're like their family.

They pretty much listen to us, you know what we say, where they're at and what they need and, and really the physicians that we, when we know someone is heading toward hospice, now the first thing you gotta make sure they have a diagnosis they changed those guidelines.

My dad was on hospice. He …couldn't hardly eat or drink anything, and I remember being focused on him just, you know, sips here sips there, just um…Yeah, I never felt so helpless, yeah.

Um, but, a lot of it depends on the situation goin' on with the family. As how you, um how you upfront you are with it, and how you kinda ease into it because you don't wanna turn them to have any negative feelings about it. Um most of the time, the families are tired, and they, and they, I know they want them to die. And that's bad to say and I don't judge them as in a bad way but if they've lingered a long time… And I tell'em "You can do everything you wanna do for'em and it’s not gonna come back, you know.” But, I just try to, and I guess I don’t say a lot of death, I focus on if they’ve had a good life, and more about dignity, and what they think dignity is, um, and most of the time it, I’ve never had a bad experience that has been like on the nursing end of it.

It’s um, I think the patient decides when they’re going to stop eatin’ and drinkin’ we don’t, you know, even if they can swallow they just won’t.

Um, basically I kept them updated about his vitals. Um, just tried to give moral support…Um, education to the family. They just really wanted to know when, when, when, you know, like everybody else wants to know and only God knows when.

Because, he himself will hold his stomach. He doesn't want you to feed him. The peg tube- if you don't wrap it up and have the abdominal binder- he will pull it out. He's not demented- he's alert. He just is not vocal. He has dysphagia…His family doesn't see him very frequently. At least, not when I'm here- I have never seen them. But, I just think that is cruel. I wouldn't want that.

Um, I am the one that makes the first referral because I am hands-on. I'm on a cart, so to speak. I am the one handing the meds, taking care of the resident, at the bedside.

I tell them (families). I give them personal experiences so they can understand.

I don’t believe in somebody starving to death. You know that kind of, kind of does something to me, cause I feel like, people, should be able to have comfort food, you know, if they’re at the end of life, if they want to eat, if they can eat they should be allowed to eat…I’ve seen where patients get fluids and sometimes they come back, you know they pop up, you know for a little bit, but I just, think about somebody starve to death, I don’t like that, it’s just, I don’t know, I just have a thing about that.

Um, if they could eat and drink I think they should have that option. But I know everybody can't do that when they get to end of life, so, I guess pretty much keepin'em comfortable is the best way.

A lot of times people don't want to eat you know…They're hurting so bad they just really just want something for pain to kinda help them, transition.

I would talk to the family cause a lot of times family, depending, some families take, it's harder for them to accept, you know, when their family member is, at that point, that sometimes we talk to them and try and explain it to'em on their terms. Sometimes they will see it or accept a little more than you just throwing all these medical terminology into'em. And just kinda break it down so that they can understand, you know what the person's going through as far as, you know, the end of life and you know trying to make them comfortable, you know, through the transition, you know, I think, is, helps a lot.

Just more, being supportive to'em, and also to the family, and just try and make the resident as comfortable as possible. And just making sure the family doesn't need anything, just kinda being, that emotional support helps.

… especially if they're declining we always call the doctor anyway to let them know they are not doing well.

And a lot of times if they're hospice we'll call the doctor anyway and then usually call hospice and the hospice nurse usually comes in and, to see'um.

I wouldn't, I wouldn't use dying. I mean, cause it seem like it's a little more harsh, saying dying, and I think saying passing away that's the way I, that's the way I was raised.

I would tell’em different things that we want to put in place to try to see if we can get them to eat, you know increase their appetite and, or try and get them to drink, and ask them their opinions on what they think, you know, might help their loved one because a lot of times family knows things that might help, you know, with their loved one, eating or drinkin’ better or something that we could do, cause I like to involve the family so they’ll know, you know, asking them sometimes helps that they feel like they’re involved in it and we’re not just doing it and not asking them at all on their opinion so

… kind of helping the family with, you know when it comes down to, when that person, that patient is like at the point when they need that end of life talk, to, you know, to the family or getting the doctor to come on board to talk to the family because a lot of times it’s, the doctors don’t talk to the family and let them know, you know, the quality of life, and that’s the biggest thing we have to push, is to try and get the doctors to sit down and talk to the families and let them know, you know, your loved one’s not gettin’ better, you know, maybe want to look into comfort care, or end of life care, you know, and that’s the biggest thing, we try and be advocates for the patients so they’re not suffering, that, you know

Cause sometimes depend on how you approach with the family, depends on how they take it because you have some families that are accepting and some just not willing to accept that their loved one is at that point yet. But that’s the hardest thing, is getting them to accept, that their loved one, may not get better.

…if you’ve been working with someone for a while then you can just tell by their, their decline, and you just know there’s something, they’re just not getting better, or you just have that feeling that, you know, it’s getting’ close to time.

It’s just a hard decision, you know, at that point, you know, so, well.

If there’s an issue, a change as far as like eating, if they don’t eat they’re (NA) supposed to tell us anyway so that way we can go in and assess them to see if they’re, you know, if they’re declining from where they were previously, so…

And a lot of times I think, you know, the family’s not really talking about it before they get to that point, you know. I think everybody should, when you get to a certain point in age you should talk to your family, let’em know what, you know, what your wishes are. When you get to that point.

… it’s different, it’s individual cause they, re, families are different.

I feel like I made a difference in most of the situations cause, cause we are always the, we’re the forgotten but always the first, first to identify, yes we’re always the first to identify that there is something different about the patient, that there is something different about the patient, that the patient’s not eating as much, or that their mental status has just declined, or they’re you know not as alert and this is consistently going on and that we’ve done everything at that point to rule out, and maintain contact with the family to make sure they’re on board so it’s almost, it’s a process to get them to that point, um, so hospice is that last option, and it’s kind of just introduced, initially, just kind of tossed around, give them time to think about it, talk to other family members and then, when it’s time, we say, well, it’s time for hospice or you know, have you already talked to your family members, and what are you all leaning towards because we’ve done as much as we can do and it’s all about quality at the end of your life, you know, that’s my belief. Now I try not to push that on other people, but, you know most of the families have been accepting because we do, I feel like, an awesome job of caring for our residents here and it's not just a job for us, we just, I love my job.

We know our families as well so we aren't just gonna go to um XX, who's one of our patients, and tell her family, you know she's been declining… We know they're not gonna be on board with hospice but we have kind of introduced a MOST form.

When these issues start happening, a lot of times lately we've been giving them fluids.

We try and minimize sending them out to the hospital, if we've notice they have like increased admissions we might um just ask the doctor if we can keep'em in house, maybe do labs.

So if his period at night is where he's up and a little more alert so then maybe we can feed him, at night… so I said maybe we can just give him like a snack or a little more at night, and see if that will bring him around. And increase his fluids at night, give him Ensure at night, and then maybe right around dinner time maybe give'em Ensure then, cause like during the day he's knocked out, but he's also declining so, you know.

It's a job trying to figure out the families, and just trying to figure out what is going to work for each patient, but just, when that time comes, we just rule out, we just try to give'em fluids and if that doesn't work, if they continue to decline, um, we might just do a hospice consult, or we, you know, it's family's choice, but of course we let the families know we have a good relationship with certain hospice agencies um , and I know that certain hospice agencies, depending on the patient and the situation…

…the brother wanted him to continue eating, even though it was kinda risky, he wanted him to continue eating. Hospice is an option at that point…and um I'm very particular about the patients so, as needs arise with certain patients I make sure the staff does not have that patient in the room eating, he needs to be pulled out of the room , he needs to be monitored. Meaning sitting upright, he's in our restorative program, although we don't kind of, we don't get any reimbursement for that because he is hospice but because I know he has problems swallowing I know he needs to be monitored.

I try and empower other staff members that this is our facility, and as for the residents this is their home but this is our facility so whatever needs we see and can identify for our residents we can get them in place. So the CNAs are good about, if they identify something they come and tell us right away, we try and get it implemented.

I feel like our actions definitely benefit our patients, I think we make the major, nah I'm not even gonna say major decisions because it's the family's decision, but we kind of direct the car, and the boat

I, I make it my business to know the families. I make it my business to know the residents, and have a good relationship, therapeutic relationship, working relationship, with the residents and with the families. Of course that's gonna be different, like I know I can do this with this patient, but I definitely can't with another patient, so it definitely depends on them.

… expire, or um, you know, declining…

They're our people. So you know, we might not always agree with the decision making but we have to respect it. Um, so there was a situation where that happened and it really, really bothered me… he, did not want a tube um, but he was a candidate and I, I get it, and I am not a big fan of g-tubes but he, it could've been some kind of turnaround. You know, I just felt like there was some glimmer there that we probably could've explored a little more

The nurses here have worked with these patients for so long, I’ve worked with these patients for so long, I can identify that patient looks different. Um, and it has been on a consistent basis that they’re not eating, they’re not talking as much, they’re withdrawn, family is noticing, and I don’t know but it’s, it’s just…a pattern of not eating, of um maybe not taking medications, not opening their mouth, of just little things.