

INTERNAL AND EXTERNAL FACTORS INFLUENCING REGISTERED DIETITIANS'
RECOMMENDATIONS FOR FEEDING TUBE USE AMONG OLDER ADULTS
WITH ADVANCED DEMENTIA: AN APPLICATION OF
THE SOCIAL ECOLOGICAL MODEL

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ABSTRACT

Background: While feeding tubes are commonly used to provide nutrition to patients with advanced dementia, research indicates that this fails to improve nutritional status or survival, and often yields harmful complications. As Registered Dietitians (RDs) are often consulted to provide clinical recommendations for older adults with advanced dementia, is important to understand factors influencing RDs' feeding tube recommendations.

Purpose: This study developed and validated a theory-based instrument to assess knowledge, beliefs, attitudes, and perceptions of RDs regarding feeding tube use among older adults with advanced dementia. Additionally, internal and external factors that influenced RDs' recommendations were explored.

Methods: The standardized survey development process included a comprehensive literature review, expert panel review, pilot testing, an efficacy survey, and test-retest analysis. A random sample of U.S. RDs was invited to participate. Exploratory factor and regression analyses determined factors associated with RDs' feeding recommendations for people with advanced dementia.

Results: Of the 662 RDs who completed the survey, 72.2% responded that they were unlikely to recommend feeding tubes for patients with advanced dementia. Factor analysis yielded five factors, each with adequate internal consistency: I) Knowledge Self-Efficacy, II) Religion/Spirituality/Culture, III) Personal Values, IV) Perceived Organization and Training, and V) Perceived Policy. Test-retest correlation coefficients ranged .602 - .812. The multivariate

regression analysis included 580 RDs who were either likely or unlikely to recommend a feeding tube ('neutral' responses were removed), revealing five factors associated with RDs making evidence-based recommendations: Total Knowledge [OR = 1.40, 95% CI (1.26, 1.57)], Personal Values [OR = 1.30, 95% CI (1.19, 1.43)], Perceived Policy [OR 1.20, 95% CI (1.02, 1.40)], Perceived Organization and Training [OR = .87, 95% CI (.77, .99)], and working in long-term care or hospice settings [OR 3.68, 95% CI (1.51, 8.93)]. This model predicted 53.2% of the variance in RDs' recommendations.

Discussion: The instrument was deemed valid and reliable. Factor analysis indicated that internal and external factors influenced RDs' recommendations, findings consistent with the Social Ecological Model. Most RDs made recommendations consistent with evidence-based guidelines, an encouraging finding. Work setting and RD knowledge were important modifiable influences, providing direction for future continuing professional education.

DEDICATION

This dissertation is dedicated to my husband, Jay Douglas. Thank you for having my back while I pursued my dreams. Without your support and encouragement, I could not have reached this goal. Thank you for every sacrifice you made along the way!

LIST OF ABBREVIATIONS AND SYMBOLS

α	Cronbach's index of internal consistency
p	The probability of an occurrence under the null hypothesis
r	Pearson's correlation coefficient
ACEND	Accreditation Council for Education in Nutrition and Dietetics
AOR	Adjusted Odds Ratio
BMI	Body Mass Index
CDR	Commission on Dietetic Registration
CI	Confidence Interval
FAST	Functional Assessment Staging Tool
M	Mean
MDS	Minimum Data Set
MMSE	Mini-Mental State Examination
OR	Odds Ratio
RD	Registered Dietitian
RR	Risk Ratio
SD	Standard Deviation
U.S.	United States

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CHAPTER 1

INTRODUCTION

Dementia is a neurological, progressive, and debilitating syndrome that results in losses in functional and cognitive capabilities due to damage to the neurons in the brain (Alzheimer's Disease Facts and Figures, 2017). Disease progression typically causes individuals to experience increasing difficulty with basic functions, such as bathing, dressing, and toileting themselves. In later stages (advanced dementia), individuals cannot walk, eat, talk, or interact with others. Eventually, the progression of this irreversible, end-of-life disease results in people becoming completely bed-bound, and requiring continuous and complete care from caregivers (Alzheimer's Disease Facts and Figures, 2017).

Alzheimer's disease, the most common form of dementia, is the sixth leading cause of death in the United States, and will afflict approximately 5.5 million Americans in 2017 (Alzheimer's Disease Facts and Figures, 2017). As the American population continues to live longer, the prevalence of Alzheimer's disease is expected to increase. The incidences of Alzheimer's disease and other dementias are also increasing, and are expected to double by 2050 (Alzheimer's Disease Facts and Figures, 2017). In 2017, it is expected that nearly half a million (480,000) new cases of Alzheimer's disease will be diagnosed among adults age 65 and older (Alzheimer's Disease Facts and Figures, 2017).

In many cases, dementia leads to serious nutritional problems as patients become unable to normally consume adequate nutrients, often due to swallowing impairments and loss of

appetite (Chung, 2012). As the disease progresses, patients with dementia may refuse to eat, spit foods out, and throw food items (Dunne, 2010). Commonly, individuals in advanced stages must be spoon-fed by caregivers, often requiring that foods be pureed due to swallowing impairments. Ultimately, patients usually experience weight loss, malnutrition, and dehydration (Chung, 2012).

This chapter will provide the background and rationale for this study (including the statement of the problem, complications associated with advanced dementia and feeding tube use, and the use of the Social Ecological Model); the purpose of this dissertation; a discussion of research questions; and the assumptions, limitations, delimitations, and definitions. The purpose of this chapter is to introduce the use of feeding tubes among older adults with advanced dementia and describe potential negative outcomes associated with tube use, as well as to propose a study to advance research in this area.

Background and Rationale

Statement of the Problem

Malnutrition is a significant problem among older adults, with as many as 66.5% of nursing home residents categorized as malnourished (Bell, Lee, & Tamura, 2015). While studies may differ in their clinical definition of malnutrition, across studies, approximately 20% of nursing home residents are malnourished (Bell et al., 2015). This decline in nutritional status is often seen among older adults with advanced dementia, with nutritional status worsening over time as dementia progresses (Douglas & Lawrence, 2015; Stanner, 2007).

In an effort to maintain the nutritional status of older adults with advanced dementia, a common intervention involves inserting a feeding tube to provide nutrition and hydration (Bell et

al., 2015). Unfortunately, the research suggests that the use of feeding tubes for this patient population not only fails to improve survival or nutritional status, but it often leads to complications that worsen the situation, such as pressure ulcers, pneumonia, diarrhea, constipation, and the use of restraints to prevent the patient from removing the tube (Attanasio et al., 2009; Chung, 2012; Cintra, de Rezende, de Moraes, Cunha, & da Gama Torres, 2014; Kaw & Sekas, 1994; Teno et al., 2011; Teno, Gozalo, Mitchell, Kuo, Fulton, et al., 2012). While research does not support the benefits of using a feeding tube in older adults with advanced dementia, approximately one third of U.S. nursing home residents with advanced dementia have feeding tubes (Kuo, Rhodes, Mitchell, Mor, & Teno, 2009). The American Geriatrics Society published a position statement in 2014, asserting that they do not support the use of feeding tubes among older adults with advanced dementia, and they advocate for alternative approaches instead. Just 3 months later, The American Society of Parenteral and Enteral Nutrition published a similar paper reiterating the lack of evidence supporting the use of feeding tubes for older adults with advanced dementia, and supporting a patient-centered approach to decision-making (as cited in Schwartz et al., 2014). The following year, The Alzheimer's Association (2015) and The European Society for Parenteral and Enteral Nutrition (as cited in Volkert et al., 2015) published position statements with similar recommendations.

In light of growing evidence over the last several decades against the use of feeding tubes for older adults with advanced dementia, several researchers have investigated how health care professionals make these feeding decisions with patients and their family members, and why some medical professionals continue to recommend feeding tubes in this patient population. However, studies on the knowledge, attitudes, beliefs, and perceptions of recommending feeding tubes by Registered Dietitians (RDs) in the United States are limited and dated (Enrione &

Chutkan, 2007; Langdon, Hunt, Pope, & Hackes, 2002; Wall, Wellman, Curry, & Johnson, 1991). Therefore, a gap exists in the literature regarding the current knowledge, attitudes, beliefs, and perceptions of RDs in the United States regarding tube-feeding older adults with advanced dementia.

Utilization of Theory

The theoretical framework for this study was the Social Ecological Model, which has its foundations in the fields of psychology and human development. Based on the work of Bronfenbrenner in 1977, the Social Ecological Model posits that the environment in which one lives and works heavily influences human behavior. As such, the various layers of an individual's environment have the potential to impact an individual's behavior. Over several decades, this concept took root in the field of health education and promotion, and experts in the field began to emphasize the need for health interventions that focused not only on the individual, but also his/her environmental influences (Baranowski, 1989; Stokols, 1992; Stokols, 1996; Winett, 1995).

In applying the Social Ecological Model to health promotion, McLeroy and colleagues emphasized the concept of reciprocity, whereby the individual impacts the environment, and the environment impacts the individual (McLeroy, Bibeau, Steckler, & Glanz, 1988). McLeroy et al. went on to define the environmental layers that influence behavior, naming them intrapersonal (or individual), interpersonal, institutional (or organizational), community, and public policy levels of influences. Intrapersonal or individual influences are one's values, beliefs, knowledge, skills, and attitudes. Interpersonal influences are those of close relationships, such as family members, peers, or friends. Institutional or organizational influences include

those of the workplace, school, church, neighborhood associations, and so forth. Community influences involve relationships between multiple organizations, geographical groups, networks, and neighborhoods. Public policy influences involve the laws, public policies, and regulations that govern society. In describing health behaviors, McLeroy posited that each of these levels of influence impacts decisions made by the individual. While several researchers in the health field developed their own versions of the model and applied their own definitions to the environmental influences that impact health behaviors, the model proposed by McLeroy and colleagues was utilized in this study because it is widely accepted and cited in the literature.

Purpose

The purpose of this study was twofold. First, the researcher developed a validated, theory-based survey instrument to assess knowledge, beliefs, attitudes, and perceptions of RDs in the United States regarding feeding tube use among older adults with advanced dementia. Second, this survey instrument was administered to a random sample of RDs across the country in order to provide data for analysis. Ultimately, these results were used to identify factors that influence RD recommendations, and this information will be used in the future to provide suggestions for personal training content.

Specific Aims

The specific aims of this study were as follows:

1. To develop, validate, and administer a survey instrument for RDs, based on previous literature and the conceptual framework of the Social Ecological Model.

2. To identify internal and external factors that influence the clinical recommendations of RDs, based on the levels of the Social Ecological Model for health promotion.
3. To identify a multivariate logistic regression model that explored RDs' recommendations.

Research Questions

The following research questions were addressed through data collection and analyses:

Research Question 1: What internal factors (knowledge, beliefs, attitudes, culture, and religion) were associated with RDs' tube-feeding recommendations?

Research Question 2: What external factors (community, organizational and policy) were associated with RDs' tube-feeding recommendations?

Research Question 3: What were the recommendations of RDs regarding feeding tubes for older adults with advanced dementia?

Research Question 4: Did RDs' feeding tube recommendations for older adults with advanced dementia vary based on their demographic information, internal influences, or external influences?

Independent Variables

Independent demographic variables assessed included age, race and ethnicity, highest level of education completed, specialty certifications earned, primary practice area, years worked as RDs, years worked as RDs with older adults, and religious affiliation. Other independent variables measured by the instrument included knowledge, beliefs, attitudes, and tube-feeding perceptions of RDs. The dependent variable was the likelihood of the RD recommending a feeding tube for older patient with advanced dementia.

Significance of the Study

The overall goal of this study was to develop and validate a theory-based instrument to measure RDs' tube-feeding knowledge, beliefs, attitudes, and perceptions. Additionally, this instrument measured external factors (organizational and policy) that were associated with RDs' tube-feeding recommendations. Prior studies lacked a theoretical framework, and were limited to examining various individual components of the Social Ecological Model, but no prior studies viewed this issue comprehensively and assessed multiple levels of the model in a single instrument.

Another significant aspect of this study was the rigorous methodology. Prior to distribution, the survey instrument underwent review by a panel of experts in the field to establish readability, comprehensibility, and content and face validity. Pilot testing using a convenience sample of RDs established the time required for survey completion, and internal consistency. Measures of internal consistency reliability determined which survey items should be removed from the survey. The survey instrument was finalized based on results from the efficacy survey, which was distributed to a random sample of RDs. Following distribution of the

finalized instrument, the survey was administered again to a subset of RDs in order to establish reliability.

Using a well-known theoretical framework and rigorous methodological study design, this study identified factors that influenced RDs' recommendations, and knowledge gaps to be addressed through academic training and continuing professional development. The results of this study will be used to direct further research in this area, and to establish a rationale for theory-based interventions.

Assumptions

The following were assumptions of this study:

1. Various levels of the Social Ecological Model influenced participants and their clinical recommendations.
2. Participants were RDs in the United States.
3. Participants were able to complete the survey instrument in English, and did so honestly.

Delimitations

The following are delimitations of this study:

1. The study sample was limited to RDs in the United States.
2. Participants had completed at least a Bachelor's degree, and were at least 18 years of age.
3. Participants provided nutritional care to the older adult population in some professional capacity, be that in community, hospital, or long-term care settings.
4. Exclusion criteria included:
 - a. Under the age of 18

- b. Unable to read and understand the survey in English
- c. Not a Registered Dietitian
- d. Did not work with older adults in some professional capacity

Limitations

The following were study limitations:

1. The study population was limited to a random sample of approximately 20% of the 25,000 dietitians who reported working in settings where they provide nutritional care to older adults.
2. As the random sample of RDs was generated based on a self-classification of primary practice areas, it was possible that RDs who failed to specify a practice area were not included in frame for the random sample. Additionally, those who misidentified a specialty practice area may have been erroneously included in or excluded from the sample frame.
3. The accuracy of the results was dependent upon self-report, which could be compromised by participant honesty, and may have been skewed by social desirability bias or poor memory.
4. The cross-sectional nature of this study only allowed for analysis at one point in time.

Outline of the Study

This chapter provided an overview of the background and rationale for the study, statement of the problem, specific aims of the study, and research questions. The remainder of this dissertation is divided into several sections. Chapter 2 is the literature review, which

provides an in-depth background on the use of feeding tubes among older adults with advanced dementia, and discusses the research on feeding tube use in this population. It also provides an expanded discussion of the theoretical framework for this study. Chapter 3 details the study methodology, including instrument development and statistical analyses. Chapter 4 is the first manuscript, which details the development and validation of the survey tool, along with the results of the exploratory factor analysis. Chapter 5 is the second manuscript, which discusses the results from the logistic regression analysis. Chapter 6 is the overall conclusions from the study. The appendices contain the Institutional Review Board letter of approval, recruitment materials, and letters of consent, along with drafts of the survey instrument.

Definition of Terms

Advanced Dementia: The terminal phase of dementia, characterized by the inability to eat, walk, talk, or interact with others. Also known as severe dementia or end-stage dementia.

Alzheimer's Disease: The most common form of dementia, accounting for 60 – 80% of cases of dementia (Alzheimer's Disease Facts and Figures, 2017).

Attitudes: “Relatively constant feelings, predispositions, or sets of beliefs directed toward an idea, object, person, or situation; they also can be considered as beliefs with an evaluative component” (Sharma & Petosa, 2014, p. 327).

Beliefs: “Convictions that a phenomenon is true or real; also, statements of perceived fact or impressions about the world” (Sharma & Petosa, 2014, p. 328).

Caregiver: Caregivers can include paid and unpaid individuals who provide care for patients with dementia (Alzheimer's Disease Facts and Figures, 2017). This term is sometimes used to address employees at long-term care facilities who care for this patient population, such

as nursing assistants or nurses. For the purpose of this study, caregivers are the family members and friends who are responsible for caring for or making decisions for the individual with dementia.

Commission on Dietetic Registration (CDR): The credentialing and governing body for RDs in the United States.

Construct validity: “The degree to which an instrument measures the same variable it purports to measure” (Sharma & Petosa, 2014, p. 329).

Content validity: “Measures whether the items on the instrument adequately assess each construct within the universe of content as operationally defined” (Sharma & Petosa, 2014, p. 329).

Cronbach’s alpha: “A summary measure of internal consistency and reliability based on calculating the amount of intercorrelation or relationship among all items of an instrument designed to measure one construct” (Sharma & Petosa, 2014, p. 330).

Dementia: Dementia is a neurological, progressive, and debilitating disease that causes losses in functional and cognitive capabilities due to damage to the neurons in the brain (Alzheimer’s Disease Facts and Figures, 2017). This includes mild to severe (or advanced) dementia. The common forms of dementia are Alzheimer’s dementia, vascular dementia, frontotemporal lobe dementia, Parkinson’s dementia, and dementia with Lewy Bodies (Alzheimer’s Disease Facts and Figures, 2017). Confusion and memory loss are not considered dementia; in some individuals, confusion and delirium are caused by depression, thyroid disease, side effects of medications, excessive alcohol intake, and vitamin or mineral deficiencies (Alzheimer’s Disease Facts and Figures, 2017). However, these individuals do not have dementia; they have a condition with dementia-like symptoms, many of which are reversible

with treatment of the underlying disease. For the purposes of this study, dementia is considered a permanent, progressive, and irreversible condition characterized by neurological damage.

Dietitian: An expert in food and nutrition sciences. Across the globe, the requirements and professional designations for dietitians vary. However, many countries have specific educational requirements for one to practice as a dietitian, and require registration with a credentialing body.

End of life: “Having an advanced incurable disease in a state of decline with a poor prognosis of weeks to several months” (Langdon et al., 2002, p. 837).

Endoscopic gastrostomy: Placement of a tube directly through the abdominal wall and into the stomach using an endoscope, which is a fiber-optic flexible tube used for visualizing the interior of a hollow organ, or to enable the passage of instruments (U.S. National Library of Medicine, 2017). Usually, the endoscope is placed down the esophagus and into the stomach to allow for visualization of the stomach’s interior. The gastrostomy tube is then inserted through the abdomen into the stomach wall and secured by a binder or balloon. Once the gastrostomy tube is secured, the endoscope is withdrawn (Vassilyadi, Panteliadou, & Panteliadis, 2013).

End-stage dementia: See Advanced Dementia.

Exploratory factor analysis: “Used for data reduction to a smaller number of factors, to ascertain the minimum number of unobservable common factors that can account for observed correlations among variables, or for exploring the underlying dimensions in a data set” (Sharma & Petosa, 2014, p. 332).

External influences: Influences outside of the individual. For the purpose of this study, this includes the community, organizational, and policy levels of influence from the Social Ecological Model (McLeroy et al., 1988).

Face validity: “Measures whether each item measures the intended construct as operationally defined and whether the instrument looks like an instrument” (Sharma & Petosa, 2014, p. 332).

Feeding tube: A tube that is inserted into the gastrointestinal tract to provide nutrients to an individual who is unable to consume adequate nutrition by mouth (Kwon et al., 2010). Two common types are the gastrostomy tube, and the nasogastric tube.

Flesch-Kincaid Grade Level Score: “Rates text on a U.S. school grade level. For example, a score of 5.0 means that a fifth grader can understand the document” (Sharma & Petosa, 2014, p. 332).

Flesch Reading Ease Score: “Rates text on a 100 – point scale; the higher the score, the easier it is to understand the document” (Sharma & Petosa, 2014, p. 332).

Gastrostomy Tube: A tube that is placed through the skin and directly into the stomach to allow for the provision of nutrition and hydration. Historically, gastrostomy tube placement required an open surgical procedure known as a laparotomy (Vassilyadi et al., 2013). Now, gastrostomy tubes can be placed endoscopically, which no longer requires an open surgical procedure (Vassilyadi et al., 2013).

Internal consistency: “The indication about how much each item in a scale relates to other items in the scale or how much the items gel together” (Sharma & Petosa, 2014, p. 335).

Internal consistency reliability: “Measures the extent to which each item in an instrument is related to other items in the instrument” (Sharma & Petosa, 2014, p. 335).

Internal influences: Influences within the individual. For example, age, race/ethnicity, years of experience, level of education, etc. For the purpose of this study, this involves the

intrapersonal and interpersonal levels of influence from the Social Ecological Model (McLeroy et al., 1988).

Knowledge: “Learning of facts and gaining of insights” (Sharma & Petosa, 2014, p. 335).

Laparotomy: A surgical procedure involving the opening of the abdominal cavity (U.S. National Library of Medicine, 2017).

Minimum Data Set: “A standardized, primary screening and assessment tool of health status that forms the foundation of the comprehensive assessment for all residents in a Medicare and/or Medicaid-certified long-term care facility. The MDS contains items that measure physical, psychological and psychosocial functioning. The items in the MDS give a multidimensional view of the patient's functional capacities and helps staff to identify health problems” (Centers for Medicare & Medicaid Services, 2012). These assessments are regularly completed for each resident in long-term care facilities, and the de-identified data are made available for research purposes by the Centers for Medicare & Medicaid Services.

Nasogastric Tube: A tube that is placed through the nose and advanced down the esophagus and into the stomach (Kwon et al., 2010). If needed, these tubes can also be advanced into the small intestine for feeding purposes. They can be placed at the bedside, or with endoscopic guidance (Kwon et al., 2010).

Older Adult: An individual aged 65 years or older (Administration on Aging, 2014).

Registered Dietitian: Registered Dietitians (RDs) are food and nutrition experts who have met the following criteria to earn the RD credential in the United States: completed a minimum of a bachelor’s degree, completed an ACEND-accredited supervised practice program, passed a national examination, and completed continuing professional educational requirements to maintain registration (The Academy of Nutrition and Dietetics, 2017).

Reliability: “The ability of the instrument to measure repeatedly the same results and be internally consistent” (Sharma & Petosa, 2014, p. 340).

Stability: See Test-retest reliability.

Severe Dementia: See Advanced Dementia.

Social Ecological Model: A theory of psychology and human development based on the work of Urie Bronfenbrenner, which posits that human behavior is heavily influenced by the environment in which one lives (Bronfenbrenner, 1977). Adapted for health education and promotion, these levels of environmental influence were later defined and specified by McLeroy and colleagues in 1988. As such, the various layers of an individual’s environment have the potential to impact an individual’s behavior.

Test-retest reliability: “The extent of association between two or more measurements of the same instrument taken over time. Also known as stability” (Sharma & Petosa, 2014, p. 343).

Validity: “The degree to which an instrument is actually measuring what it is purporting to measure” (Sharma & Petosa, 2014, p. 344).

CHAPTER 2

REVIEW OF THE LITERATURE

Chapter 1 served to introduce and describe the health problem, and provided the specific aims and research questions to be addressed by this study. The theoretical framework was also briefly discussed. This chapter provides a more in-depth discussion of the literature on the use of feeding tubes among older adults with advanced dementia. The theoretical framework for this study is also discussed in greater detail.

Search Methodology

A comprehensive literature search was undertaken using EBSCOHost and Boolean search logic to simultaneously search multiple databases, including: Health Source: Nursing/Academic Edition, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Health Source – Consumer Edition, MEDLINE, Alt HealthWatch, Academic Search Premier, Abstracts in Social Gerontology, Cochrane Methodology Register, and CINAHL Plus with Full Text. Boolean search terms can be found in Table 1. Articles were included if they addressed the use of feeding tubes in older adults with dementia and pertained to the specific levels of influence from the Social Ecological Model. Studies meeting inclusion criteria were grouped by level of the Social Ecological Model addressed in each article. Studies included in the review addressed how the use of feeding tubes impacts the individual patient who has dementia, and how it impacts their family members and caregivers. To identify literature

related to internal factors that impact health care professionals, searches were conducted to identify studies on the knowledge, beliefs, attitudes, and perceptions of professionals within the health care community regarding the use of feeding tubes in patients with advanced dementia. To examine external factors that influence practitioner recommendations, studies on organizational factors and policy factors were identified and reviewed. Additional articles were located through descendant searches of article reference lists.

Table 1
Boolean Search Logic

Search Topic	Search Terminology
Policy, regulations, reimbursement	(policy or legislation or law or regulations or reimbursement) AND (feeding tube or tube feeding or PEG or enteral nutrition) AND (older adult or elderly or geriatric) AND (advanced dementia) NOT (cancer or stroke)
Health care professionals	(feeding tube or tube feeding or PEG or enteral nutrition) AND (older adult or elderly or geriatric) AND (advanced dementia or severe dementia or cognitive impairment or end-of-life) AND (physician or nurse or dietitian or dietician or speech pathologist or speech language pathologist or speech therapist or social worker or social services)
Decision-making	(feeding tube or tube feeding or enteral nutrition) AND (advanced dementia or severe dementia or cognitive impairment) AND (decision-making or decision making or decision making process)

Background

Defining the Disease of Dementia

In some individuals, confusion and delirium are caused by depression, thyroid disease, side effects of medications, excessive alcohol intake, and vitamin or mineral deficiencies (Alzheimer’s Disease Facts and Figures, 2017). However, these individuals do not have dementia; they have a condition with dementia-like symptoms, many of which are reversible

with treatment of the underlying disease. True dementia is a neurological, progressive, and debilitating disease that causes losses in functional and cognitive capabilities due to damage to the neurons in the brain (Alzheimer's Disease Facts and Figures, 2017). Initially, this destruction of brain cells causes individuals to experience progressive losses in 'memory, language, problem-solving and other cognitive skills' (Alzheimer's Disease Facts and Figures, 2017). Symptoms include forgetfulness, and the inability to form new memories. As the disease worsens, individuals experience increasing difficulty with basic functions, such as bathing, dressing, and toileting themselves. Further disease progression yields individuals who cannot walk, eat, talk, or interact with others. Eventually, in the later stages, those with advanced dementia become completely bed-bound, and require continuous care from caregivers (Alzheimer's Disease Facts and Figures, 2017). The rate of disease progression varies by individual. While individuals with dementia typically live 4 – 8 years beyond initial diagnosis, some individuals survive as long as 20 years with Alzheimer's disease (Alzheimer's Disease Facts and Figures, 2017). Dementia is a terminal condition, and there is no cure.

There are several types of dementia, including: vascular dementia, dementia with Lewy Bodies, Alzheimer's disease, Parkinson's disease, and Frontotemporal Lobar degeneration (Alzheimer's Disease Facts and Figures, 2017; Kane, Richardson, Allan, & Thomas, 2016). Additionally, individuals may present with multiple types of dementia, a condition known as mixed dementia (Alzheimer's Disease Facts and Figures, 2017). While the various types of dementia may yield different clinical manifestations and progress at different rates, each form of dementia is irreversible and ultimately fatal (Alzheimer's Disease Facts and Figures, 2017; Kane et al., 2016).

Incidence and Prevalence of Dementia

Alzheimer's disease, the sixth leading cause of death in the United States and the most common type of dementia, was responsible for approximately 110,561 deaths in the United States in 2015, and will afflict approximately 5.5 million Americans in 2017, with 5.3 million of these individuals being age 65 and older (Alzheimer's Disease Facts and Figures, 2017; Xu, Murphy, Kochanek, & Arias, 2016). Alzheimer's disease accounts for 60 – 80% of cases of dementia in the United States (Alzheimer's Disease Facts and Figures, 2017). As the American population continues to age, the prevalence of Alzheimer's disease is expected to increase.

The incidence of Alzheimer's disease and other dementias is also increasing, and is expected to double by 2050 (Alzheimer's Disease Facts and Figures, 2017). In 2017, it is expected that nearly half a million (480,000) new cases of Alzheimer's disease will be diagnosed among adults age 65 and older. This translates to a new case of Alzheimer's disease every 66 seconds in the United States. By 2050, a new case will be diagnosed every 33 seconds (Alzheimer's Disease Facts and Figures, 2017).

The Cost of Dementia

It is estimated that \$259 billion health care dollars will be spent on dementia care in the United States in 2017, with 67% (or \$175 billion) of expenses paid by Medicare and Medicaid (Alzheimer's Disease Facts and Figures, 2017). Patients with dementia require increased hospitalization and institutionalized care. Older adults with dementia are hospitalized at twice the rate of older adults without dementia. Many individuals with dementia live in long-term care settings, which can incur substantial costs. Annual costs for assisted living care are

approximately \$43,00 per year, with the cost of nursing home care soaring to \$82,000 – \$92,000 annually (Alzheimer’s Disease Facts and Figures, 2017).

Diagnosing Dementia

Unfortunately, there is no single test that is used to diagnose dementia (Alzheimer’s Disease Facts and Figures, 2017; Cordell et al., 2013; Kane et al., 2016). A clinical diagnosis involves a comprehensive assessment by a physician, which often includes cognitive and functional assessments of the patient, a review of the patient’s laboratory values and medications, brain imaging to detect abnormalities, and an interview with the patient’s family members and caregivers (Alzheimer’s Disease Facts and Figures, 2017; Kane et al., 2016).

Health care practitioners use a number of different cognitive and functional assessment tools to evaluate whether an individual has dementia (Cordell et al., 2013; Kane et al., 2016). In fact, there are over 100 different cognitive assessment tools used in primary care practices to detect the presence of dementia (Cordell et al., 2013). In general, each assessment rates cognitive impairments on a scale, with a greater score usually associated with greater impairment (Jack et al., 2011). None of these tests are definitive, stand-alone indicators of dementia. Rather, they indicate the need for a thorough review of the individual’s medical status (Jack et al., 2011). Table 2 compares two tools that are commonly used to screen for the presence of dementia, and to assess an individual’s stage of Alzheimer’s dementia (adapted from Reisberg et al., 2010). The Functional Assessment Staging Tool (FAST) and the Mini-Mental State Examination (MMSE) each classify dementia based on a score, which is derived from the patient’s cognitive and physical assessment (Reisberg et al., 2010).

Table 2

Staging Alzheimer's Dementia: A Comparison of the FAST Tool and MMSE

FAST Stage	Clinical Characteristics	Clinical Diagnosis	Mean MMSE Score
1	No decrement	Independent adult	29 - 30
2	Subjective deficit in word finding or recalling location of objects	Subjective cognitive impairment	29
3	Deficits noted in demanding employment settings	Mild cognitive impairment	24 - 27
4	Requires assistance in complex tasks, e.g. handling finances, planning a dinner party	Mild Alzheimer's disease	19 - 20
5	Requires assistance in choosing proper attire	Moderate Alzheimer's disease	15
6 a	Requires assistance in dressing	Moderately severe Alzheimer's disease	9
b	Requires assistance in bathing properly		8
c	Requires assistance with mechanics of toileting (such as flushing, wiping)		5
d	Urinary incontinence		3
e	Fecal incontinence		1
7 a	Speech ability limited to about a half-dozen words	Severe Alzheimer's disease	0
b	Intelligible vocabulary limited to a single word		0
c	Ambulatory ability lost		0
d	Ability to sit up lost		0
e	Ability to smile lost		0
f	Ability to hold up or move head independently lost		0

Adapted from Reisberg et al., 2010

Treating Dementia

As dementia is a terminal illness, and no curative treatment exists, most treatment plans for patients with dementia involve maintaining the individual's functional capacity and quality of life (Alzheimer's Disease Facts and Figures, 2017). Pharmacologic therapy is often used to alleviate the symptoms and side effects of disease progression, such as agitation and depression (Alzheimer's Disease Facts and Figures, 2017).

Impact on Nutritional Status

Dementia often causes serious nutritional problems as patients lose the ability to normally consume adequate nutrients. While such nutritional issues can have severe consequences, they are considered a natural part of the progression of dementia (American Geriatrics Society, 2014). In early stages of dementia, patients may forget to eat or forget that they have eaten; they may also experience increasing difficulty in communicating needs and wants, leading to difficulty expressing hunger and thirst. As the disease progresses, patients with dementia may refuse to eat, spit foods out, and throw food items (Dunne, 2010). In later stages, patients frequently develop chewing and swallowing difficulties and may fail to recognize food items and eating utensils (Dunne, 2010; Sanders, Leeds, & Drew, 2008). At this point, patients often require assistance with meals. The presence of such eating difficulties is an indicator that an individual is experiencing advanced dementia (American Geriatrics Society, 2014). In many cases, individuals in advanced stages are spoon-fed by caregivers, often requiring that foods be pureed due to swallowing impairments. Ultimately, patients usually experience weight loss, malnutrition, and dehydration (Chung, 2012).

Nutritional status may also have an impact on the progression of dementia. Research has indicated that patients with dementia who are malnourished are more likely to experience rapid cognitive declines, poorer prognosis, and additional complications (Yildiz, Büyükkoyuncu Pekel, Kiliç, Tolgay, & Tufan, 2015). In a recent study of 76 patients with dementia in Turkey, those with malnutrition had more severe dementia ($p < .001$), poorer fluid intake ($p < .0001$), poorer functional abilities ($p < .001$), lower body mass index (BMI) ($p < .003$), greater hospitalization rates ($p < .007$), greater incidence of falls ($p < .028$), poorer swallowing function ($p < .012$), greater sleep disturbances ($p < .04$), greater agitation ($p < .007$), more frequent delusions ($p <$

.03), and more frequent hallucinations ($p < .005$) than those without malnutrition (Yildiz et al., 2015). While the study certainly was not able to establish cause-and-effect relationships between nutrition and dementia, it did establish that malnutrition among individuals with dementia is associated with poorer outcomes.

Use of Feeding Tubes

Feeding tubes are used in a variety of circumstances to provide nutrition to an individual who is unable to consume adequate nutrients by mouth (Kwon et al., 2010). The use of artificial nutrition (feeding by some sort of tube) has been traced back historically as far as 5,000 years ago, where the ancient Egyptians experimented with the provision of foods and fluids using rectal tubes (Vassilyadi et al., 2013). Venetian physician Capivaceus documented the first known feeding into the gastrointestinal tract through the stomach in 1598, which used a tube to push liquids into the esophagus (Vassilyadi et al., 2013). Over the last several decades, numerous advances in technology and medicine have led to the development of modern, safe, and effective options for feeding individuals through a tube.

In the early 20th century, individuals were often fed through a nasogastric tube, which was placed through the nose and into the stomach to provide nutrients directly into the stomach (Vassilyadi et al., 2013). Later, the gastrostomy technique was developed, which involved surgically placing a tube into the stomach of a patient. This procedure required an open laparotomy. In 1980, the first endoscopic gastrostomy was documented, whereby a gastrostomy tube was placed into the stomach through an endoscopic procedure (Vassilyadi et al., 2013). This breakthrough in feeding tube use made the placement of a long-term feeding tube safe, simple, and quick, no longer requiring an open surgical procedure (Vassilyadi et al., 2013). For

those who cannot tolerate feeding directly into the stomach, tubes can also be placed into the small intestine.

In clinical practice today, feeding tubes are placed for a number of clinical issues. These feeding tubes can be placed for short-term use, or used permanently for the delivery of nutrients to an individual who cannot eat by mouth (Kwon et al., 2010). Nasogastric tubes are still used, primarily for the short-term delivery of nutrients. Modern methods allow for placement at the patient's bedside (Kwon et al., 2010). For long-term access to the gastrointestinal tract, gastrostomy tubes are usually placed, often using the endoscopic procedure (Kwon et al., 2010). Gastrostomy tubes are virtually undetectable under an individual's clothing, whereas nasogastric tubes protrude from an individual's nose. Over time, nasogastric tubes tend to irritate the nasal passages, so the feeding route is often converted to a gastrostomy tube once it is realized that a patient will need a feeding tube for long-term support. Feeding tubes are commonly used for patients with head/facial trauma, stroke with subsequent swallowing difficulties, critical illnesses, and cancer (Kwon et al., 2010). For many individuals, the use of a feeding tube is life saving. However, the benefits of feeding tube use for patients in later stages of dementia are not documented.

In an effort to provide for the nutritional needs of patients with advanced dementia, feeding tubes are commonly placed to provide artificial nutrition and hydration. In fact, studies suggest that a third of U.S. nursing home patients with advanced dementia have feeding tubes for nutrition and hydration (American Geriatrics Society, 2014; Sorrell, 2010). After a review of the literature, the American Geriatrics Society stated in a position paper: "feeding tubes are not recommended for older adults with advanced dementia" (2014, p. 1590). While the placement of a feeding tube addresses the immediate problem of providing nutrition, there is no concrete

evidence to support that this provides long-term benefits to the patient, and it may even increase morbidity and mortality (American Geriatrics Society, 2014). Thus, while feeding tubes are beneficial for patients with many conditions, this practice is deemed ineffective overall and often causes a myriad of problems among patients with advanced dementia.

Unfortunately, the routine use of feeding tubes in this population is considered standard care among many health care professionals, leading practitioners to routinely recommend feeding tube placement without first considering the issue from a comprehensive approach. Thus, a strong need exists to consider this issue from the perspective of the Social Ecological Model, a health behavior model that explains behavior as the result of a dynamic relationship between multiple internal and external factors (McLeroy et al., 1988; Stokols, 1992; Stokols, 1996). Therefore, this literature review first considers the impact of feeding tube use on the individual with dementia and their family members and caregivers, addressing the individual and interpersonal levels of McLeroy's model (1988). Then, the internal and external factors that influence health care practitioner decision-making are explored, addressing the community, organizational, and policy levels of the model (McLeroy et al., 1988).

Theoretical Framework

The theoretical framework for this study is the Social Ecological Model, which has its foundations in the fields of psychology and human development. In 1977, Bronfenbrenner described how the current perspectives on human behavior were limited by the context in which they were viewed. Traditional scientific research on human development focused on how individuals behaved when placed in the 'unfamiliar, artificial, and short-lived' clinical laboratory environment (Bronfenbrenner, 1977). However, Bronfenbrenner noted that these observations

failed to depict true human behavior and could not be generalized to how humans would behave in their natural environment because of the interaction between the individual and his environment. As such, Bronfenbrenner explained that the “understanding of human development demands going beyond the direct observation of behavior on the part of one or two persons in the same place,” and it requires considering the individual within the context of his environment (1977, p. 514). He termed this perspective the ‘ecology of human development,’ and proposed that the environment of human development exists as multiple layers, each nested within a larger layer. These layers were named the microsystem, mesosystem, exosystem, and macrosystem, and this perspective hinges on the concept of reciprocity, or the notion that each layer influences the other (Bronfenbrenner, 1977). In considering methods to change human behavior or development, Bronfenbrenner discussed the concept of the ‘transforming experiment,’ an idea originally developed by Russian psychologists, whereby changing the environment would yield changes in the individual (Bronfenbrenner, 1977).

In the decades following Bronfenbrenner’s work in human development, the idea of an ecological perspective took hold in the field of health education and health promotion (Richard, Potvin, Kishchuk, & Prlic, 1996). In 1988, McLeroy, Bibeau, Steckler & Glanz described how the field’s theoretical focus on individual behavior and victim blaming failed to address how society influenced individual health behaviors (McLeroy et al., 1988). A number of others in the health promotion field followed suit (Baranowski, 1989; Richard et al., 1996; Stokols, 1992; Stokols, 1996; Winett, 1995). Baranowski identified the need for more comprehensive models to address behavior change (1989). He cited the concept of reciprocal determinism, emphasizing the relationship between an individual and his environment (1989). Stokols and Winett each identified that traditional health promotion programs have been limited by their focus only on the

individual, failing to address environmental considerations (Stokols, 1992; Stokols, 1996; Winett, 1995). Stokols also noted that the ecological perspective was growing in popularity within the health field because many were recognizing that public health issues were “too complex to be understood adequately from single levels of analysis and, instead, require more comprehensive approaches that integrate psychologic, organizational, cultural, community planning, and regulatory perspectives” (1996, p. 283).

As health education and promotion began shifting to this idea of an ecological approach, several researchers in the field applied their own definitions to the various environmental influences that impact health behaviors. Baranowski divided the environment into three categories: physical, social, and institutional (1989). The physical environment consisted of the environment in which ones lives and works. The social environment consisted of those who an individual regularly comes into contact with: family members, friends, peers, coworkers, members of one’s religious group, etc. The institutional environment consisted of the various institutions that an individual is part of: government, employers, churches, schools, clubs, organizations, etc. In contrast, Stokols divided the environment into physical and social realms (1992). The physical realm consisted of geography, architecture, and technology, while the social realm consisted of culture, economics, and politics. Stokols also mirrored Bronfenbrenner’s idea that various layers of the environment are ‘nested’ within larger, more complex layers (1992, 1996).

In applying the Social Ecological Model to health promotion, McLeroy and colleagues again emphasized the concept of reciprocity, whereby the individual impacts the environment, and the environment impacts the individual (1988). McLeroy went on to adapt Bronfenbrenner’s environmental layers, renaming them intrapersonal (or individual), interpersonal, institutional (or

organizational), community, and public policy levels of influences (McLeroy et al., 1988). Intrapersonal or individual influences are one's values, beliefs, knowledge, skills, and attitudes. Interpersonal influences are those of close relationships, such as family members, peers, or friends. Institutional or organizational influences include those of the workplace, school, church, neighborhood associations, etc. Community influences involve relationships between multiple organizations, geographical groups, networks, and neighborhoods. Finally, public policy influences involve the laws, public policies, and regulations that govern society. In describing health behaviors, McLeroy posited that each of these levels of influence impact decisions made by the individual. See Figure 1 for a diagram of the Social Ecological Model (adapted from Fitzgerald & Spaccarotella, 2009).



Figure 1. Social Ecological Model Diagram.

Several key principles of the Social Ecological Model have been identified and described over the years. First, reciprocal determinism (or reciprocity) is central to the model (Baranowski, 1988; Bronfenbrenner, 1977; Green, Richard & Potvin, 1996; Stokols 1992; Stokols 1996). Each layer of the environment impacts other layers, and human behavior is the result of a dynamic relationship between one's biological, behavioral, and environmental factors. Another key component of the model is the 'nesting' of layers within larger systems (Bronfenbrenner 1977; McLeroy et al., 1988; Richard et al., 1996; Stokols, 1992; Stokols 1996). While different schools of thought have classified and named these layers from various perspectives, they have all focused on the idea of multiple layers of environmental influence. Finally, a noted strength of the Social Ecological perspective is the comprehensive focus, which analyzes and addresses multiple environmental layers. In describing the importance of analyzing multiple layers of the environment, some researchers have emphasized the systems approach, which considers each environmental layer as a subset of the larger environmental system (Green et al, 1996).

In addition to analyzing the multiple environmental layers that contribute to behavior, proponents of this model stress the importance interventions that target multiple levels of the model (Economos et al., 2001; Golden & Earp, 2012; Green et al, 1996; Richard et al., 1996; Schölmerich & Kawachi, 2016; Stokols, 1992; Stokols, 1996). According to experts in the field, the combination of interventions that target multiple levels of the model yields a synergistic effect, whereby the results of the combined intervention are greater than the sums of the individual interventions (Schölmerich & Kawachi, 2016).

In spite of several decades with increased focus on conducting health behavior research from an ecological perspective, recent research has noted that many health researchers fail to

consistently and comprehensively incorporate the Social Ecological Model into health program planning (Golden & Earp, 2012; Schölmerich & Kawachi, 2016). As such, they have called for health researchers to work toward analyzing multiple environmental influences on behavior, and to implement behavior change programs with interventions that target these levels.

In applying the Social Ecological Model to this study, a first step is to understand the use of feeding tubes among older adults with advanced dementia from a comprehensive approach. That is, it is necessary to evaluate how the use of feeding tubes impacts the patient and his or her family members. Additionally, it is important to understand the knowledge and perceptions of various members of the health care community. Finally, one must understand how organizational norms and health policy impact this issue. These topics will be addressed through the literature review, and provided the framework for the research study.

Individual Level

In considering the impact of a feeding tube on the individual level, the medical status of the individual with dementia must be considered, as well as the patient's overall quality of life. A number of studies have explored whether the use of feeding tubes improves quality of life, survival, or clinical outcomes for patients with various disease states. Because patients with advanced dementia are generally unable to communicate, it can be very difficult to assess quality of life for these individuals. However, the results have indicated that feeding tubes fail to improve nutritional status, prolong life, or improve clinical outcomes in this patient population. Furthermore, many patients experience complications and side effects that reduce quality of life, including infections, gastrointestinal discomfort, distress related to the use of restraints to prevent tube removal, and the need for tube replacement due to tube malfunctions or complications.

Clinical Outcomes and Complications

Several studies have investigated the clinical outcomes that result from placing feeding tubes in elderly patients with dementia. In a study of 46 nursing home patients with feeding tubes, where 91% of patients had a neurological disease and 52% of patients had a diagnosis of dementia, researchers measured nutritional status, functional status, complication rates, and mortality associated with feeding tube insertion (Kaw & Sekas, 1994). In this sample population, no significant improvements were found in nutritional status or functional status in the 18 months after the feeding tube was placed. Over a third (34.7%) of patients experienced tube-related clinical complications, such as tube obstruction or tube migration, which required medical treatment outside of the nursing home. Twenty percent of patients in this study developed aspiration pneumonia. Authors concluded that feeding tube placement in elderly patients with limited life expectancy is not advised, as complications may reduce quality of life.

A similar study, published in 1992, measured nutritional status pertaining to feeding tube use in 40 elderly patients in the long-term care setting, 90% of whom had a diagnosis of neurological disease and 20% of whom had a primary diagnosis of dementia (Henderson, Trumbore, Mobarhan, Benya, & Miles, 1992). All 40 patients were medically stable prior to inclusion into the study, and had been receiving nutrition exclusively through a feeding tube for at least two months prior to baseline data collection. Throughout the study, patients were provided with an average of 123% of their estimated daily calorie needs, and 170% of their estimated daily protein needs through their tube-feeding regimen. Interestingly, researchers found that after three months, malnutrition was present in these patients in spite of receiving adequate tube-feedings to meet estimated nutritional needs. These results suggest that the use of feeding tubes may not prevent or reverse malnutrition in this patient population.

Several more recent studies have noted similar results. In a prospective, observational study of 67 tube-fed older adults with advanced dementia, investigators found that 29.9% of patients were treated for pneumonia during the 12-month study period, and that this diagnosis was significantly associated with mortality ($p = .003$) (Alvarez-Fernández, García-Ordoñez, Martínez-Manzanares, & Gómez-Huelgas, 2005). Additionally, this study measured several nutritional indices, including tricipital skinfold thickness, arm circumference, muscle area of the arm, hematocrit, cholesterol, albumin, and lymphocytes. In comparing anthropometric and laboratory values of tube-fed patients with reference values for older adults without feeding tubes, the presence of a feeding tube was associated with suboptimal nutritional parameters (Alvarez-Fernández et al., 2005).

In another retrospective study, 89 tube-fed older adults with dementia (mean age of 77.5 years) were followed for a year after tube placement (Lubart, Leibovitz, & Habot, 2004). After a year, 48% of these patients had a pressure ulcer, and 44% had anemia. Additionally, 50% of patients experienced constipation. Thus, in this population, several studies have indicated that feeding tubes failed to normalize the nutritional status of patients and may have increased the risk of other complications, such as aspiration pneumonia and constipation (Alvarez-Fernández et al., 2005; Lubart et al., 2004).

A number of other studies have documented tube-related side effects and complications among older adults with dementia. Among 108 tube-fed older patients (67% with a primary diagnosis of dementia), 15.5% of patients with a nasogastric tube and 7.9% of patients with a gastrostomy tube experienced aspiration pneumonia ($n = 45$ and $n = 62$, respectively) (Attanasio et al., 2009). Additionally, 24.5% of patients with nasogastric tubes had restraints to prevent them from removing the tube, and 62.2% of patients with nasogastric tubes experienced tube-

related complications that required tube replacement (Attanasio et al., 2009). Among patients with gastrostomy tubes, 15.8% experienced infections at the tube insertion site. Overall, 14.8% of patients experienced diarrhea and 26.9% experienced constipation (Attanasio et al., 2009).

Another more recent study of 486 family caregivers of tube-fed patients with dementia reported that 26.8% of the patients were sent to the emergency department due to a malfunctioning tube, and 25.9% of patients were physically restrained to prevent tube removal (Teno et al., 2011). Other studies have reported that up to 50% or more of nursing home patients with feeding tubes are physically restrained to prevent them from removing the feeding tube (Teno et al, 2011; Yeh et al., 2013; Yeh, Lo, Fetzer, & Chen, 2010).

In a prospective observational study, nutritional status and complications were measured among a cohort of 67 older adults with dementia and dysphagia, where 53.7% were fed orally and 46.3% were tube-fed (Cintra et al, 2014). At baseline, the only differences noted between the two groups were that those who were fed by a tube had more pressure ulcers than those fed orally ($p = .035$), and that more of the tube-fed group was recruited from the hospital than were the orally fed group (83.9% and 38.9%, respectively, $p = .001$). Patients with a feeding tube were more than twice as likely to experience aspiration pneumonia when compared with orally fed patients (RR = 2.32, 95% CI = 1.22, 4.40). There were no significant differences in nutritional indices between the orally fed and tube-fed groups. Thus, while clinical complications, such as aspiration pneumonia, were more common among patients who were tube-fed, there was no improvement in nutritional status associated with the use of a feeding tube (Cintra et al., 2014).

Another recent study evaluated whether the placement of a feeding tube among nursing home residents with advanced cognitive impairment would prevent the development of new

pressure ulcers or speed the healing of existing ones (Teno, Gozalo, Mitchell, Kuo, Fulton, et al., 2012). This study evaluated the Minimum Data Set assessments of older adults in nursing homes across the United States from 1999 - 2007. Researchers found that pressure ulcers were more likely to develop among residents who had a feeding tube, and that existing pressure ulcers were less likely to heal among those who had a feeding tube. The adjusted odds ratio (AOR) of developing a new pressure ulcer was 2.27 (95% CI = 2.14, 4.89) for those who had a feeding tube, compared with those nursing home residents who did not have a tube (Teno, Gozalo, Mitchell, Kuo, Fulton, et al., 2012). Among those who had a pressure ulcer, the adjusted odds ratio (AOR) for wound healing was .70 (95% CI = .55, .89) for those with a tube, compared to those without a feeding tube (Teno, Gozalo, Mitchell, Kuo, Fulton, et al., 2012).

Thus, in this analysis of data from nursing home residents across the nation, feeding tubes did not prevent pressure ulcers or improve existing ones. Authors proposed two possible explanations for these findings (Teno, Gozalo, Mitchell, Kuo, Fulton, et al., 2012). First, they pointed out that the frequent use of restraints (both chemical and physical) to prevent patients from removing the tube actually decreases the patient's mobility, thereby leading to increased risk for pressure ulcers. Additionally, they noted that the presence of diarrhea caused by the feeding tube could lead to increased risks for wound development.

One prospective study explored causes of hospitalization among 323 older nursing home patients with advanced dementia (Givens, Selby, Goldfeld, & Mitchell, 2012). Over the 18-month study period, tube-feeding complications were the most common cause of emergency department visits, comprising 47% of all visits (Givens et al., 2012). Authors concluded that the presence of a feeding tube is a significant predictor of hospitalization among this patient population ($p < .10$) (Givens et al., 2012). Another larger study sought to determine causes of

hospitalizations among nursing home residents using a retrospective analysis of Minimum Data Set assessments and Medicare claims to determine inpatient days, causes of hospitalization, and complications related to feeding tubes (Kuo et al., 2009). Tube complications necessitated tube replacement among 20% of patients within a year, with 28.9% of these patients requiring multiple tube replacements (Kuo et al., 2009).

Mortality and Survival in Tube-Feeding Older Adults with Dementia

Several studies have documented mortality rates among older adults with dementia who receive a feeding tube. In an older study of 46 older adults with feeding tubes, where 52% had a diagnosis of dementia, 20% of patients died within a month of tube placement, and nearly 59% of patients died within 18 months of tube placement (Kaw & Sekas, 1994). Another study in 2000 measured mortality in a retrospective analysis of 361 tube-fed patients, with 103 diagnosed with dementia (Sanders et al., 2000). Overall, the mortality rate for the cohort was 28% at one month and 63% at one year after tube placement. Among patients with dementia, authors reported a mortality rate of 54% at one month, and 90% within a year of tube placement, indicating significantly higher mortality rates among patients with dementia ($p < .0001$). This led them to conclude that patients with dementia have higher mortality rates whether or not feeding tubes are placed.

In a more recent study of 108 tube-fed older adults, where 67% of patients had a primary diagnosis of dementia, mortality was 7.4% at 30 days, 19.4% at 6 months, and 23.1% at one year after feeding tube placement (Attanasio et al., 2009). In a retrospective study of nursing home residents with advanced dementia in the United States, 64.1% of the 5,209 older adults who received a feeding tube died within 1 year of tube placement (Kuo et al., 2009).

Other studies have focused on whether tube insertion or its timing improved survival among older adults with dementia. In a large prospective study of a cohort of older nursing home residents, 36,492 residents with advanced cognitive impairment and newly developed eating difficulties were followed to compare survival rates by clinical intervention utilized (Teno, Gozalo, Mitchell, Kuo, Rhodes et al., 2012). Within a year of the onset of eating difficulties, 1,957 residents (5.4%) had a feeding tube inserted. When the survival of these residents was compared with the survival of those who did not receive a feeding tube, no significant differences were found. Furthermore, researchers examined the timing of tube placement and found no differences in survival rates among those who had tubes placed at 1 month and 4 months after the onset of eating difficulties. Authors concluded that the use of feeding tubes among patients with advanced cognitive impairment did not improve survival rates, regardless of when the tube was inserted (Teno, Gozalo, Mitchell, Kuo, Rhodes et al., 2012).

Another recent study compared the survival of orally fed patients with dementia to that of tube-fed patients with dementia (Cintra et al., 2014). At 3 months, mortality among the orally fed group was 11.1%, and 41.9% among those fed via tube. Mortality increased to 27.8% and 58.1%, respectively, at 6 months. At both time periods, mortality was significantly higher among those with a feeding tube ($p = .004$ and $p = .012$, respectively) (Cintra et al., 2014).

Similarly, a retrospective study of 1,773 hospitals and 56,824 nursing home residents measured survival and hospital feeding tube insertion rates based on Minimum Data Set assessments and Medicare claims (Cai et al., 2013). Overall, 29.5% of older, cognitively impaired patients died within a month of hospitalization and 52.2% died within 6 months. Among hospitals with high rates of feeding tube insertion, there was no significant improvement

in patient survival when compared to facilities with lower tube insertion rates (Cai et al., 2013). Authors concluded that the aggressive nutrition interventions in older adults with cognitive impairments did not improve patient survival.

Ballarè and colleagues conducted a retrospective study of 605 patients with feeding tubes (including 223 patients with a diagnosis of advanced dementia) to analyze survival after tube insertion (Ballarè, Del Piano, Micunco, & D'Andrea, 2012). While they found no difference in complication rates among patients with and without dementia, they did note that survival in patients with dementia (median of 36 months) was significantly shorter than those with other diagnoses (median of 60 months) ($p < .0001$). However, a Kaplan-Meier survival analysis indicated no significant differences in survival at 2 years after tube insertion (Ballarè et al., 2012). These contradictory results led authors to conclude that additional prospective studies should be conducted.

The literature indicates that the use of feeding tubes in patients with advanced dementia can result in harm to the patient. Studies failed to show improvements in functional or nutritional status as a result of tube placement. Additionally, patients may experience physical symptoms such as gastrointestinal discomfort. They may have medical complications that require treatment, such as pneumonia or tube malfunctions. They may be physically restrained. They may also experience mental and emotional distress in the form of anxiety, depression, and isolation. Furthermore, studies indicate that the placement of a feeding tube among patients with dementia does not lead to improved survival. Thus, it is evident that the use of a feeding tube may not be in the best interest of the individual with advanced dementia.

Interpersonal Level

Caregiver Experiences

Another level of the Social Ecological Model involves the interpersonal influences, which in this case, are the family members and caregivers of patients with advanced dementia. In many instances, these are the individuals who are responsible for making the health care decisions for the patient, and several studies have focused on how the use of feeding tubes impacts these family members and caregivers.

One such study examined the decision-making process of 486 caregivers in five states across the United States pertaining to the use of feeding tubes for a loved one (Teno et al., 2011). Caregivers, who were usually the daughter of the patient with advanced dementia, answered questions about the process of deciding whether to use a feeding tube, their experience with the feeding tube, and their perceptions of the quality of end-of-life care for their loved one. Among those who had a feeding tube inserted, family members in 13.7% of cases reported that there was no discussion with the health care team about the use of a feeding tube prior to tube insertion. When the health care team did educate families, 41.6% of families reported that the conversation lasted less than 15 minutes. Approximately 10% of families reported feeling pressured by the physician to insert a feeding tube and 25% of families felt the tube was inserted to make it easier for the staff to care for the patient. While a third of families felt that the feeding tube improved the quality of life of their loved one, nearly a quarter (23.4%) of family members regretted ever having the tube inserted. This indicates that families may not receive adequate time or education from the health care team when making end-of-life feeding decisions (Teno et al., 2011).

Unfortunately, this lack of communication to families has been documented in additional studies. For example, in a study in Belgium, physicians reported that they did not discuss end-

of-life feeding options with the patient's family during medical decision-making in 24.5% of cases (Chambaere, Loodts, Deliëns, & Cohen, 2014). These results emphasize the need to provide unbiased, evidence-based education to family members to enable them to make informed decisions.

Other studies regarding caregiver satisfaction with feeding tube use have echoed these results. One cross-sectional study of 148 nursing home residents with advanced dementia and their health care proxies measured proxy satisfaction with the care provided at the nursing home (Engel, Kiely, & Mitchell, 2006). Tube-feeding was negatively correlated with satisfaction with care ($p = .02$), and, conversely, greater proxy satisfaction resulted when the physician and proxy spent more than 15 minutes planning for end-of-life care ($p < .001$) (Engel et al., 2006).

A more recent qualitative study of caregivers of tube-fed patients in Taiwan analyzed caregiver interviews to assess the experiences of family members as it pertains to feeding tube use (Yeh et al., 2013). Several recurrent themes emerged from the caregiver interviews. Family members were concerned that the feeding tubes caused physical discomfort or pain, they were not aware of alternative approaches to end-of-life feeding, and they were uncertain about whether they made the best decision for their loved one. Again, family members experienced increased anxiety in decision-making as a result of inadequate education provided from the health care team on the options available to them. Furthermore, authors noted several cultural themes that are specific to Chinese families, including the value placed on group decision-making in end-of-life situations. Because of this, authors emphasized that the health care team must be willing to provide family education that is culturally appropriate (Yeh et al., 2013).

Caregiver Knowledge and Beliefs

In a cross-sectional study of 51 Chinese family caregivers of patients with advanced dementia, researchers investigated the knowledge of caregivers about feeding tubes (Kwok, Twinn, & Yan, 2007). More than a quarter of caregivers (26%) reported no knowledge about feeding tubes. Additionally, family members were unaware of an advance directive from the patient regarding feeding tube use. Researchers found that, due to cultural norms regarding caring for one's aging parents, Chinese family members may be reluctant to forgo a feeding tube for a family member with dementia.

Similarly, in a study involving 111 Jewish patients with feeding tubes, family members were surveyed a year after tube-feedings were initiated in their elderly family member, and only 13% felt that the tube-feedings should be stopped (Lubart et al., 2004). However, 52% of families did not know whether to stop or continue the feedings. Authors in this study highlighted the uncertainty among caregivers as to whether a feeding tube should be continued, and this reflects Jewish religious practices, which favor the continuation of feeding once the feedings have been initiated (Lubart et al., 2004). Thus, understanding cultural differences in the way families make decisions about end-of-life care can impact how health care professionals deliver this important information. This highlights the need for health care providers to exhibit cultural competence in providing care to patients and their family members.

Two other studies have investigated the knowledge and beliefs of caregivers on feeding tube use in the United States. One study, conducted in the community of Greenville, North Carolina, consisted of focus groups with Caucasian and African American participants (Modi, Velde, & Gessert, 2010). All participants voiced their desire to 'do the right thing' when it came to caring for a loved one with dementia and most participants valued quality of life over survival

time. Participants felt strongly that feeding a person through a tube represents feeding and nurturing the person; thus, for many, the provision of food, through a tube or otherwise, represents caring for the person (Modi et al., 2010). Many participants voiced that the decision should represent the wants of the patient, and that the decision must be made for each patient on an individual basis. Interestingly, while the authors initially sought to identify differences between the beliefs of Caucasians and African Americans, they concluded that these two populations were more alike than they were different.

Another study focused on African American caregivers of patients with dementia and sought to investigate the presence of advance care plans and trust in physicians (Watkins et al., 2012). They found that caregivers with more years of education were more trusting of the physicians caring for their loved one, and that greater trust in physicians was associated with decreased use of feeding tubes. They rationalize that caregivers with higher education may have greater access to information on the use of feeding tubes, leading to decreased feeding tube use. Authors also noted that culture and ethnicity may impact end-of-life care decisions.

Interventions to Ease Caregiver Decision-Making

Knowing that the decision to insert or forgo a feeding tube for a loved one can be a difficult one for caregivers, several researchers have investigated interventions to reduce the difficulty in decision-making. Hanson and colleagues (2011) conducted a randomized controlled trial of 256 nursing home residents with dementia and their caregivers to investigate whether the provision of a decision aid pamphlet would improve decision-making for end-of-life feeding. Intervention group participants were significantly more likely to discuss feeding options with the health care team after receiving the pamphlet ($p = .04$). They were also significantly less likely

to feel conflicted about the decision, and displayed significantly more knowledge on the use of feeding tubes ($p < .001$ in both cases). An additional publication from this particular study reported on qualitative interviews conducted with the caregivers (Snyder, Caprio, Wessell, Lin, & Hanson, 2013). After viewing the decision aid, caregiver knowledge of the advantages and disadvantages of feeding tube use improved significantly ($p < .001$). While caregiver expectations regarding the feeding tube were unrealistic prior to viewing the aid, they were more consistent with medical evidence after viewing the aid. Furthermore, caregiver confidence in the feeding decision made for their loved one improved significantly ($p = .016$).

In a smaller, more recent study in Japan, researchers investigated the effect of a decision aid on the family members of 13 patients with dementia who were being considered for feeding tube placement (Kuraoka & Nakayama, 2014). After working through the decision aid, decisional conflict among caregivers decreased significantly ($p < .01$), and knowledge about feeding tube use improved significantly ($p < .001$).

Another intervention study provided group education sessions to family members and utilized a pre-test/post-test design to measure changes in knowledge and self-efficacy among 68 caregivers of African American patients with dementia (Bonner et al., 2014). Intervention group participants were provided with a 4-week group education series on dementia and life-sustaining measures (mechanical ventilation, feeding tubes, and cardiopulmonary resuscitation) (Bonner et al., 2014). Following the study, caregiver self-efficacy in making end-of-life care decisions for loved ones improved significantly in intervention group caregivers ($p = .02$), but not control group caregivers ($p = .11$). Comfort with level of knowledge about end-of-life care options improved among intervention participants, but not significantly ($p = .07$) (Bonner et al., 2014). These studies show that educating family members on nutrition in advanced dementia, either

through decision aids or through group education, can reduce angst about the decision, increase knowledge, and improve communication with the health care team.

In summary, it is very evident that caregivers bear a significant burden in making decisions about end-of-life care for loved ones. Caregivers have expressed that they do not receive adequate education from the health care team, which makes the decision about use of feeding tubes even more difficult. However, the provision of education has been shown to ease the decision-making process and increase knowledge. Thus, it is very important for health care practitioners to provide this information to families in a manner that is respectful and culturally appropriate for the patient and family.

Internal Influences: Health Care Practitioner Research

When considering the community level of the Social Ecological Model as it pertains to feeding tube use in patients with advanced dementia, evaluating the health care community is of particular interest because the knowledge and beliefs of the health care team can greatly impact the treatment. Usually, the physicians are the key decision-makers in regards to initiating a feeding tube for these patients. However, physicians have reported that their decisions are influenced by other members of the health care team, including the nurses, Registered Dietitians, social workers, and Speech-Language Pathologists (Chambaere et al., 2014; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2003). Thus, this section explores the research on health care practitioner decision-making, and, more specifically, investigates the internal factors (knowledge, beliefs, gender, age, years of experience, practice specialty, race/ethnicity, and culture) of these health care practitioners regarding tube-feeding patients with advanced dementia.

Physicians

Knowledge and Beliefs.

Several studies have investigated physician knowledge and beliefs about feeding tube use in patients with dementia. Shega and colleagues surveyed American physicians in 2001 and found that few physicians held current knowledge about the risks and benefits of using a feeding tube (2003). Despite current recommendations, the majority of physicians erroneously believed that feeding tubes would reduce the risk of aspiration pneumonia (76%), improve nutritional status (94%), and improve survival (61%) (Shega et al., 2003).

In another study, 62.4% of the 642 physicians surveyed believed that recurrent aspiration pneumonia in patients with dementia could be remedied using a feeding tube (Vitale, Hiner, Ury, Berkman, & Ahronheim, 2006). Additionally, 44.7% of physicians considered tube-feeding to be an appropriate treatment for unplanned weight loss, and 41.4% of physicians felt that it would improve nutrition-related laboratory values in this patient population.

A more recent study of Japanese geriatricians reported that 46.8% of physicians considered dementia to be an indicator for a feeding tube, but 68% of geriatricians reported following no specific clinical guidelines related to tube-feeding their older adult patients (Ogita, Utsunomiya, Akishita, & Arai, 2012). Interestingly, this study also reported that physicians who obtained input from the interdisciplinary health care team were more likely to attempt other interventions prior to using a feeding tube. These studies suggest that physician knowledge may not always be consistent with current research and evidence-based guidelines.

Gender, Age, Years of Experience, and Practice Specialty.

A study of Finnish physicians found interesting results regarding end-of-life decision-making for patients with dementia (Hinkka et al., 2002). This study specifically asked practitioners whether they would recommend ‘palliative care’ (nursing care, pain management, intravenous hydration for the purpose of symptom relief) or ‘active care’ (antibiotics, blood transfusions, intravenous hydration, and ICU care) for a hypothetical patient with dementia.

Of the 730 physicians who completed surveyed, authors found that female physicians and younger physicians were more likely to advocate for ‘active’ care of a critically ill patient with dementia ($p < .001$) (Hinkka et al., 2002). Male physicians considered euthanasia to be more acceptable than female physicians ($p = .001$). Females based ethical decisions on their religious beliefs more often than males did ($p = .022$), and considered faith in God to be more important than male doctors did (55% vs. 44%, $p = .003$). Younger doctors considered patient’s length of life to be more important than older doctors did ($p = .004$). Those with no experience of severe illness in their family were more likely to use active treatment (OR = 1.39, 95% CI = .94, 2.06). Thus, physician recommendations varied significantly by gender, with females favoring more active care, considering euthanasia reprehensible, and basing more decisions on their religious beliefs. Older physicians focused on more palliative approaches than younger ones did. Physicians with personal experience with critical illness among a family member were less likely to use active care approaches.

In a retrospective study of 53,492 hospitalizations of U.S. nursing home residents with advanced dementia, authors compared Minimum Data Set (MDS) data with Medicare claims from 2001 – 2010 to identify whether the type of attending physician in the hospital influenced chances of feeding tube insertion (Teno et al., 2014). After adjusting for the patient’s age,

gender, race/ethnicity, rural/urban location, cognitive performance score, physical functioning, and medical diagnoses, researchers found that patients who had a specialist as an attending physician were five times more likely to have a feeding tube inserted (OR = 5.0, 95% CI = 4.1, 6.0) than those with a nonhospitalist generalist attending physician (Teno et al., 2014). Additionally, patients who had a combination of a specialist and either a hospitalist or nonhospitalist generalist were 8.8 times more likely to have a tube inserted (95% CI = 7.7, 10.0). Thus, having a hospitalist or general practitioner as an attending physician during a hospitalization was associated with decreased feeding tube use (Teno et al., 2014). Authors theorized that specialists might have less training and experience in providing care to patients with advanced dementia, leaving them more likely to prescribe feeding tubes for this population. Unfortunately, the study did not analyze the different types of specialty practice areas. Therefore, it cannot be determined from this study exactly which specialties may be more likely to use feeding tubes. Overall, the results of these studies highlight the fact that personal factors, such as age, gender, years of experience, and practice specialty can significantly impact practitioner decision-making.

Culture and Race.

Just as cultural differences impact how families view the use of feeding tubes for loved ones, physicians around the world are influenced by their own cultural norms and beliefs on the subject. One qualitative study compared physicians in Australia with those in the Netherlands and found that, while Australian physicians were more likely to allow family members to make nutritional end-of-life decisions, Dutch physicians were more apt to take personal responsibility for this decision-making (Buiting, Clayton, Butow, van Delden, & van der Heide, 2011).

Authors attributed these differences to different cultural approaches to geriatric care and varying health care systems between the two nations.

Other studies have also demonstrated how cultural differences can impact the way physicians approach the topic of tube-feeding patients with advanced dementia. In one qualitative study in Japan, physicians reported that cultural norms favor family decision-making and deter physicians from allowing death without the provision of food and water (Aita, Takahashi, Miyata, Kai, & Finucane, 2007). Similar results were found in an earlier study of Japanese and Japanese-American physicians and their end-of-life care recommendations for terminally ill patients. In this study, Japanese physicians were more likely to favor family decision-making, while Japanese-American physicians favored the patient's wishes and right to self-determination (Asai & Fukuhara, 1995).

In another study of 339 Jewish physicians and 987 elderly Jewish individuals, 74.6% of physicians reported that they would recommend a feeding tube for an elderly individual with severe cognitive impairment, whereas only 22% of elderly individuals reported they would want a feeding tube in those circumstances ($p < .001$) (Carmel, 1999). Study results led authors to conclude that physicians in Israel were apt to practice according to Jewish religious traditions more so than patient wishes, indicating that the values of the Jewish culture impacted physician practices.

A study of physicians in the United States examined whether the race of the patient would predict whether the physician would recommend a feeding tube (Modi, Whetstone, & Cummings, 2007). A case study was presented to physicians in North Carolina and the responses of the 1,083 participating physicians indicated that the race of the physician was more influential in predicting physician recommendations than the race of the patient. African

American and Asian physicians more commonly recommended feeding tubes ($p < .001$), and African American physicians recommended feeding tubes for African American patients more frequently than they did for Caucasian patients ($p = .033$). This is consistent with prior studies indicating that African Americans are more likely than Caucasians to use feeding tubes in cases of advanced dementia (Mitchell, Teno, Roy, Kabumoto, & Mor, 2003). These results further highlight how cultural influences can impact the physician's approach to providing end-of-life care.

Nurses

Other studies have focused on the knowledge and beliefs of the other members of the health care team, specifically the nurses, RDs, social workers, and Speech-Language Pathologists. Several authors have closely examined the role of the nurse in decisions about the use of feeding tubes and how the situation personally affects the nurse. Nurses in a qualitative study in Belgium ($n = 21$) reported that while they were intimately involved in the care of patients, they did not feel included in the decision-making process regarding feeding tube use (Bryon, Dierckx de Casterlé, & Gastmans, 2012; Bryon, Gastmans, & Dierckx de Casterlé, 2010; Bryon, Gastmans, & Dierckx de Casterlé, 2012). Some nurses reported that they were hesitant to voice concerns and opinions regarding patient care because they believed physicians did not value their input (Bryon, Gastmans, & Dierckx de Casterlé, 2012). Nurses reported feeling intense emotions during the decision-making process because of their desire to 'provide good care' to their patients (Bryon, Gastmans, & Dierckx de Casterlé, 2010).

One study in Italy surveyed nurses and physicians and found that 59% of nurses reported feeling sadness regarding the decision to provide or forgo artificial nutrition and hydration to

these terminal patients (Valentini et al., 2014). The analysis showed that professionals who had received training in palliative care or who specialized in geriatrics were less likely to agree with the decision to provide artificial nutrition and hydration (OR = .66, 90% CI = .52, .84, and OR = .58, 90% CI = .45, .74, respectively), while those who reported feeling sadness about patient deaths were more likely to agree to provide artificial nutrition and hydration (OR = 1.41, 90% CI = 1.13, 1.76) (Valentini et al., 2014).

Another study of 11 nurses in the nursing home setting reported several common themes expressed by the nurses during interviews, including a lack of adequate knowledge on the current research surrounding the use of feeding tubes in patients with dementia, uncertainty about the legal and ethical implications involved in tube-feeding these patients, and hesitance to provide education or direction to family members on this issue (Lopez, Amella, Mitchell, & Strumpf, 2010). These studies demonstrate that, while nurses play an important role in caring for these patients, they may also be unclear about their role in the process, which could lead to emotional distress.

Speech-Language Pathologists

Speech-Language Pathologists are often involved in the care of patients with advanced dementia because, as the patient declines, swallowing ability usually declines concomitantly. Speech-Language Pathologists (or speech therapists) are often consulted to determine whether a patient can safely continue eating and drinking by mouth (Vitale, Berkman, Monteleoni, & Ahronheim, 2011). Studies have investigated the practices and knowledge of speech therapists as they pertain to using feeding tubes in patients with advanced dementia. One such study surveyed 731 American speech therapists and found that only 22% recognized that a feeding

tube would not prevent aspiration pneumonia (Vitale et al., 2011). Less than half (42.1%) of the speech therapists felt confident in managing swallowing difficulties in patients with advanced dementia, and 55% reported recommending non-oral feedings (tube-feedings) for patients with advanced dementia. In another study of 326 speech therapists in the United States, 56% reported recommending feeding tubes for this population, 78% reported that the feeding tube would improve the nutritional status of the patient, and 43% reported that feeding tubes improve survival in this patient population (Sharp & Shega, 2009). Thus, it is evident that the knowledge and practices of Speech-Language Pathologists may not be consistent with current research.

Social Workers

In many cases, social workers or social services staff members are charged with assisting nursing home patients and their family members with completing an advance directive, which states the patient's wishes regarding the provision of a feeding tube in end-stage disease. In one study of 138 nursing home social services staff members in New York, 97% of respondents said they were responsible for having advance directive discussions with family members of patients (Lacey, 2006). Unfortunately, only about half (52%) reported regularly discussing the risks and benefits of feeding tube use with families during these discussions. Furthermore, when asked about their own knowledge of these risks and benefits, only 37% responded accurately. In many cases, social services staff perceived that the medical directors and nursing directors make these decisions for the patient (45% and 25%, respectively) (Lacey, 2005). This indicates that, according to this cohort, social services staff members may not be providing family members with adequate knowledge of tube-feeding use, and that they may also have insufficient training on the topic.

Registered Dietitians

Several authors have investigated the beliefs and attitudes of dietitians who make feeding decisions in end-of-life care. The earliest study located on this topic was published in 1991, and involved a survey that was mailed to half of the membership of the Nutrition Support dietetic practice group of the American Dietetic Association (Wall et al., 1991). This survey specifically sought to identify the beliefs and attitudes of RDs who provided nutritional care to critically ill and terminally ill adults. Dietitians were asked about various scenarios where they would discontinue feedings, and about who they thought should be involved in making these decisions. Of the 590 RDs who received the survey, 42% responded ($n = 250$) (Wall et al., 1991). The majority of dietitians worked in the hospital setting, and only 2% had experience in a long-term care facility. On average, participants had 9.9 years of work experience as a RD.

Overall, dietitians felt that the physician, patient, and family members were the most important decision-makers regarding the use of feeding tubes and nutrition support in terminal illness, and 93% believed that this was the ideal (Wall et al., 1991). However, 84% also believed that the RD should be involved in feeding decisions. Over half (59%) reported being involved in feeding decisions in their facility, while 32% said they were not involved in such discussions. Overall, dietitians agreed that feedings can be discontinued when they cause pain, when death is imminent, or when the patient requests that feedings be stopped. Interestingly, researchers found that dietitian responses varied by age, with younger dietitians (age 20 - 29) less likely to favor discontinuing feedings, and older dietitians (ages 30+) more likely to agree to a patient's request to stop feedings (Wall et al., 1991). In general, most dietitians were willing to discontinue feedings in situations of terminal illness under special circumstances. While this study did not pertain directly to individuals with dementia, it is interesting that dietitian beliefs varied by age.

In a study published several years later in the United Kingdom, researchers investigated the attitudes of several health care professionals toward feeding tube use, including geriatricians, dietitians, nurses, and speech therapists (Hasan, Meara, Bhowmick, & Woodhouse, 1995). In this mailed survey, which achieved a 75% response rate, 64% of the respondents ($n = 148$) believed that decision-making for feeding tube placement should be multidisciplinary, focusing primarily on the patient's quality of life. With regards to patients with dementia who refuse food, 49% of all respondents, and 48% of dietitians reported that feeding tubes should be used (Hasan et al., 1995). This early study demonstrates that while health care practitioners favored multidisciplinary decision-making and patient quality of life, knowledge gaps existed regarding the use of feeding tubes for patients with dementia.

Another early study of Canadian dietitians sought to understand these beliefs and attitudes regarding the use of life support and euthanasia among terminally ill elderly patients (Taper & Hockin, 1996). While the scope of this study did not specify elderly patients with dementia, authors found interesting results. Of the 1,724 dietitians who responded to the mailed survey, factor analysis showed that 51% of dietitians utilized a decision-making framework that accepted removing life support, 23% used a framework based on their own religious values, 36% were accepting of euthanasia, 76% valued individual autonomy, and 95% valued ethical discourse in decision making (Taper & Hockin, 1996). While 95% of dietitians reported participating in making decisions in ethical dilemmas, only 27% reported having any ethical training on making these decisions. Interestingly, older dietitians and those who considered themselves to be spiritual tended not to favor euthanasia ($r = -.17$ and $r = -.36$, respectively), while those who had received training on euthanasia and the removal of life support were more likely to be in favor of doing so ($r = .16$). Additionally, those who worked in the clinical setting

and used nutrition support for their patients were less likely to favor euthanasia or the removal of life support ($r = -.10$). Thus, this study indicates that several factors impacted the attitudes and beliefs of these dietitians, including age, spirituality, practice area, and training.

In a study on the knowledge and practices of 153 Irish dietitians on feeding tube use in patients with dementia, 41% reported being involved in initiating tube-feedings for patients with advanced dementia (Healy & McNamara, 2002). Surprisingly, 78% reported that there was no policy in their workplace delineating the appropriate use of feeding tubes, and 21% reported that, if there was a policy, they were not aware of it. Interestingly, 67% of dietitians reported that family members did not receive adequate information about feeding tubes and 58% felt that the medical team did not thoroughly discuss the use of a feeding tube in patients prior to tube placement. Thus, it is clear that evidence-based guidelines need to be developed for nutrition professionals working with this patient population.

Researchers in Louisiana conducted a survey of RDs ($n = 777$) who were active members of the Louisiana Dietetic Association, inquiring about their beliefs and attitudes toward nutrition support at the end of life (Langdon et al., 2002). Their mailed survey consisted of 15 questions, 13 of which were adapted from the survey by Taper and Hockin, and achieved a 62% response rate (Langdon et al., 2002). Of the 464 surveys used in the analysis, 54% of RDs reported practicing in a clinical setting.

The majority of RDs agreed with removing nutrition support among patients at the end of life (73%), and with allowing patients to refuse feedings (89%) (Langdon et al., 2002). Many dietitians agreed that nutrition support is not appropriate for every patient (60%), and that the patient and family members are the most qualified to make feeding decisions (53%). Interestingly, only half of dietitians felt qualified to educate family members on the topic (50%),

and 98% of dietitians felt that ethical dilemmas should be included in continuing education for RDs. This study also found that dietitians over age 45 and those with 20 or more years of experience were less likely to agree with removing nutrition support ($p < .05$ and $p < .01$, respectively). Community dietitians were less likely than clinical and administrative dietitians to support removal of nutrition support ($p < .01$) (Langdon et al., 2002). Thus, these findings are similar to those from Taper and Hockin's study of Canadian dietitians. Registered Dietitians in this study were influenced by age, years of experience, and practice area (Langdon et al., 2002). Dietitians agreed that patients and family members, not the health care team, should make end of life feeding decisions, and that RDs need continuing education related to ethical decision-making.

In 2007, researchers in Florida published results from a survey on RD and Registered Nurse preferences regarding the use of nutrition support among elderly patients (Enrione & Chutkan, 2007). Using the state licensure board, they randomly selected 1,500 nurses and 1,500 dietitians to receive a mailed survey, which contained questions about practitioner beliefs, and asked practitioners to make recommendations for several patient case scenarios. In comparing responses from the two groups of clinicians, they noted that the RDs were younger ($p < .001$), had more education ($p < .001$), and fewer years of experience ($p < .001$) than did the Registered Nurses (Enrione & Chutkan, 2007).

Overall, they found that the nurses and dietitians answered most questions similarly, favoring patient autonomy and individual choice (Enrione & Chutkan, 2007). However, their responses did differ on the patient case scenarios, where the dietitians were more likely to feed the patient than the nurse was in all eight scenarios. Authors noted that this tendency to feed is aligned with guidelines from the Academy of Nutrition and Dietetics, which state, 'when in

doubt, feed' (O'Sullivan Maillet, Schwartz, & Posthauer, 2013). Results from this study indicate that dietitians may be more likely than nurses to feed an elderly patient using a feeding tube, and that this may be due to guidance provided by the professional organization.

More recently, researchers from New Jersey surveyed dietitians in continuing care and long-term care facilities in Ontario, Canada in order to ascertain their beliefs and roles in recommending feeding tubes for elderly patients (Szeto, O'Sullivan Maillet, Brody, & Parrott, 2014). In this study, which achieved a response rate of 13.8% ($n = 68$), most dietitians (88.9%) reported that a bachelor's degree was their highest level of education, 78% reported that they had participated in ethics training programs, and 31% held a specialty certification in dietetics (Szeto et al., 2014).

Dietitians in this study felt strongly that they should be involved in decision-making, and they reported having multiple roles in the decision-making process regarding feeding tube use among older adults, including identifying the patient's nutrition issues, and communicating feeding options to the family members (Szeto et al., 2014). Dietitian involvement in decision-making was greater when they had positive relationships with physicians ($r = .321, p = .016$), and when they reported having adequate knowledge and skills regarding feeding tube use ($r = .465, p < .001$, and $r = .520, p < .001$, respectively) (Szeto et al., 2014). Interestingly, 26 - 45% of dietitians did not feel they had adequate knowledge and skills on the topic, highlighting the need to provide continuing education to these professionals who work with older adults. It is important to note that health care in Ontario is regulated at the provincial level. Therefore, it is possible that these results may not be generalizable to dietitians from other areas in Canada, or to dietitians from other countries.

Practitioner Feelings Toward Having a Feeding Tube

Finally, several studies have examined the personal feelings of health care professionals toward feeding tubes. Specifically, researchers have asked whether these health care professionals would want a feeding tube for themselves if they became bedbound due to a terminal illness. In the case of severe mental impairment, physicians in Israel were significantly less likely to want a feeding tube for themselves, and more likely to prescribe a tube for their elderly patients ($p < .001$) (Carmel, 1999). In other studies, only 20% of speech therapists (Sharp & Shega, 2009) and 31% of dietitians (Healy & McNamara, 2002) said they would agree to a feeding tube for themselves if they developed advanced dementia. Conversely, one study found that most dietitians would want nutrition support in the event they couldn't feed themselves (63%) (Langdon et al., 2002).

In a more recent study in Japan, including 251 physicians and 1,070 nurses, only 14.4% of participants reported wanting a feeding tube for themselves (Komiya et al., 2012). Those who routinely worked with tube-fed patients were more likely to refuse a feeding tube for themselves ($p = .014$). Overall, studies show that while health care professionals may recommend feeding tubes for patients with dementia, few of them would want a feeding tube if they were in the same situation.

In summary of the multidisciplinary health care team's status on this issue, continuing professional education on nutrition and feeding in end-of-life care for practitioners who work with patients with dementia is needed.

External Influences

Organizational Level Influences

At the organizational level, research has indicated that certain facility characteristics are associated with frequent use of feeding tubes among patients with advanced dementia. It is important to understand these organizational factors so that they can be addressed. This section reviews literature that has explored some of these factors.

In a cross-sectional study of 186,835 cognitively impaired nursing home patients in 1999, researchers sought to identify patient and organizational characteristics associated with feeding tube use (Mitchell, Teno et al., 2003). All licensed nursing homes in the United States were included in this study ($n = 15,135$), which revealed that 33.8% of cognitively-impaired residents had a feeding tube, and that nursing homes with higher feeding tube rates among cognitively-impaired residents were typically larger (> 100 beds), urban, and for-profit (Mitchell, Teno et al., 2003). These facilities did not usually have a specialized dementia care unit or a nurse practitioner or physician assistant on staff.

Another study published the same year analyzed tube-feeding insertion rates among nursing home patients between 1995 and 1996 (Mitchell, Kiely, & Gillick, 2003). They found that having a full-time speech therapist on staff at the nursing homes was associated with increased rates of feeding tube insertion (OR = 2.06, 95% CI = 1.51, 2.82). Additionally, the lack of a specialized dementia unit, more licensed nurses with fewer nursing assistants, larger facilities, and a higher proportion of Medicaid beds were also associated with increased tube-feeding rates.

Authors in both studies (Mitchell, Kiely et al., 2003; Mitchell, Teno, et al., 2003) noted that patients without an advance care plan were more likely to have feeding tubes inserted. The

presence of a speech therapist and higher proportion of licensed nurses on staff may lead to increased awareness and assessment of swallowing difficulties, yielding greater feeding tube use. Facilities with specialized dementia care units may be better equipped to manage end-stage dementia and guide families through the decision-making process. Authors theorized that, in organizations where advance care planning is encouraged, family and patient education is being provided and therefore fewer feeding tubes are placed. Unfortunately, the relationships between feeding tube use and larger facilities, higher proportion of Medicaid beds, urban location and for-profit financial structure are not well understood. The results of another study support these findings, indicating that urban nursing home residents were more likely to have a tube inserted than residents of rural facilities ($p < .001$) (Gessert, Haller, Kane & Degenholtz, 2006).

In another study, two nursing homes in South Carolina were compared in order to evaluate how differences in the culture of the facility resulted in different tube-feeding rates among patients (Lopez, Amella, Strumpf, Teno, & Mitchell, 2010). In the high-use facility, 41.8% of patients with advanced dementia had a feeding tube. In the low-use facility, feeding tubes were used in only 10.7% of patients with advanced dementia. Researchers found interesting differences in the culture of the two facilities. In the high-use facility, researchers observed an institutional environment where only a few staff members were available to assist patients with meals. Staff interviews revealed that many employees in the facility favored the use of feeding tubes as a way to prevent aspiration pneumonia and avoid citations from regulatory agencies. In the low-use facility, the environment was more like a home setting and mealtimes were staffed with knowledgeable nursing assistants who were trained in feeding patients. The low-use facility also encouraged advance care planning to address end-of-life care

decisions. Researchers concluded that the culture of the organization can impact feeding options available for patients with advanced dementia.

Because feeding tubes are usually placed while patients are in the hospital, some researchers have also investigated hospital feeding tube insertion data in an effort to identify characteristics associated with high tube insertion rates. One such study found that larger (> 301 beds), for-profit hospitals associated with a medical school were more likely to place a feeding tube in a patient with dementia than a smaller, rural hospital that is not affiliated with a medical school (Teno et al., 2010). An additional study on the health care transitions of nursing home patients and rates of feeding tube insertion found that patients are more likely to receive a feeding tube when they experience multiple transitions, such as being sent to the hospital for treatment (Teno et al., 2009). As several authors have found that advance care plans decrease the likelihood of patients having a tube placed while at the hospital, it becomes increasingly important that this information is communicated from the nursing home to the hospital when a patient is hospitalized (Lopez, Amella, Strumpf et al., 2010; Mitchell, Teno et al., 2003).

While the reasons for variations in tube-feeding rates among hospitals and nursing homes are not fully understood, the research demonstrates that the use of feeding tubes in patients with dementia varies widely among health care facilities. This is thought to be related to the corporate culture of the organization, which impacts the attitudes and beliefs of the health care providers who work there. Thus, several authors have emphasized the importance of educating the entire health care team in order to modify the cultural norms within the organization (Shega et al., 2003).

Policy Level Influences

The final level of the Social Ecological Model is policy, which consists of the laws and regulations that govern health care systems. Health care policy is not only important in regulating health care and protecting patients, it is also a critical component of the financial structures within the health care system. Furthermore, legal systems may impact the practices of health care professionals. This section investigates how health policy, reimbursement, and legal considerations influence the decision to use a feeding tube in patients with advanced dementia.

In the United States, the government reimburses nursing homes for various services provided to patients who receive Medicare and Medicaid benefits. In theory, patients with feeding tubes represent higher medical acuity, and therefore require increased monitoring and care. Because of this, facilities are reimbursed at a higher rate for a patient with a tube-feeding than they are for a patient who eats by mouth (Mitchell, 2003; Teno et al., 2008). This situation is not unique to the United States; Japan and other countries have similar reimbursement structures (Aita et al., 2007). As a result of Japanese cultural norms, the legal system in Japan encourages physicians to recommend feeding tubes for patients with advanced dementia (Aita et al., 2007). This has prompted some researchers to question whether government reimbursement structures incentivize facilities for using feeding tubes.

To investigate the cost of caring for patients with feeding tubes, Mitchell and colleagues studied nutrition-related health care costs incurred by patients with advanced dementia, half who were hand-fed by staff, and half who had a feeding tube (Mitchell, Buchanan, Littlehale, & Hamel, 2003). They found that it cost an average of \$2,379 to provide nutrition care for patients who were tube-fed over a 6-month period. Surprisingly, they learned that patients who required hand feeding by staff members incurred \$4,219 in nutrition-related costs for 6 months. This was

due to the amount of staff time involved in hand feeding the patients who did not have a feeding tube placed. Thus, facilities received higher reimbursement rates for tube-fed patients, but caring for these patients actually cost less than caring for similar patients who did not have a feeding tube.

After reimbursement rates increased for tube-fed patients in nursing homes in the United States, several researchers sought to investigate whether this impacted tube-feeding rates across the country (Teno et al., 2008). While authors expected to find that the financial incentive associated with tube-fed patients led to an increase in tube-feeding rates, they found no significant changes in feeding tube rates after adjusting for confounders. However, this study only considered data from 1993 to 2004. In light of more recent financial concerns and health care reforms, this issue should continue to be monitored, as current health care policy may inadvertently promote the increased use of feeding tubes in this patient population.

The regulatory structures in the long-term care setting in the United States may also impact feeding tube use. Guidelines for maintaining adequate nutrition and hydration among nursing home patients are rigorous. Because nursing homes can be penalized when patients with advanced dementia suffer from malnutrition, health care professionals may recommend feeding tubes for these patients even though there is a lack of evidence to support the use of feeding tubes for patients with advanced dementia (Finucane, Christmas, & Leff, 2007; Lopez, Amella, Strumpf et al., 2010). In fact, the literature suggests that feeding tubes may be used in order to show regulatory agencies that ‘everything is being done’ to provide adequate nutrition and hydration to residents (Finucane et al., 2007).

The legal system is another aspect of policy that may impact the use of feeding tubes in older adults with dementia. Physicians in the United States have reported fear of legal action

taken by family members for failing to recommend a feeding tube for a malnourished patient (Shega et al., 2003). It has been suggested that because of legal fears, physicians may agree to place feeding tubes in patients with advanced dementia in order to satisfy family members and avoid litigation when a patient declines (Finucane et al., 2007). Similarly, in Japan, physicians also reportedly fear legal repercussions if they do not offer a feeding tube to a terminally ill patient (Aita et al., 2007).

Thus, it is evident that multiple policy-level factors can impact the use of feeding tubes in patients with advanced dementia. Several researchers have called for policy reform and restructuring of reimbursement rates to address these issues (Finucane et al., 2007). They reason that the quality of patient care could be improved if health care professionals made evidence-based recommendations for these patients, rather than making recommendations in an effort to maximize financial reimbursement for patient care, or out of fear of legal or regulatory penalty.

Need for Instrument

While a number of studies have been conducted to evaluate health care practitioner knowledge and practices regarding feeding tube use among patients with advanced dementia, a significant need still exists for the development of a reliable and valid measurement tool that is based on the literature and current evidence-based guidelines, grounded in theory, and specific to RDs. None of the survey tools identified in the literature review were grounded in a theoretical framework. Previous studies that were specifically developed for RDs are now dated, as new evidence-based guidelines have emerged since those instruments were utilized. Furthermore, prior studies were limited in scope in that they focused on limited components of the Social Ecological Model. It is clear from the review of literature that the issue of feeding tube use

among older adults with advanced dementia is a complex one, requiring assessment at multiple levels of the Social Ecological Model. With these factors in mind, this study sought to develop and validate a survey based on the Social Ecological Model, targeted at RDs, and based in current evidence-based practice guidelines. The integration of these components allowed for a more comprehensive analysis of the problem, which will provide direction for future interventions to target each level.

Summary

As described in this chapter, dementia is a leading cause of death and a very prevalent condition among older adults in the United States (Xu et al., 2016). As the population continues to age, prevalence is expected to significantly increase (Alzheimer's Disease Facts and Figures, 2017). Unfortunately, the impact of dementia on nutritional status is progressive and severe, often leaving individuals with advanced dementia unable to feed themselves or eat by mouth (Chung, 2012; Dunne, 2010; Sanders et al., 2008). While feeding tube use is common among this population, a growing body of evidence suggests that this practice may be harmful to patients, and present a myriad of difficulties for family members and caregivers. Unfortunately, the literature also shows that many health care practitioners lack current knowledge of evidence-based guidelines on this topic. Furthermore, there is limited information on how external influences impact the decisions of clinicians. Thus, after developing a valid and reliable survey tool, this study sought to assess current knowledge, beliefs, attitudes, and perceptions of RDs on this subject. Additionally, the study aimed to identify internal and external factors that influence RDs' recommendations for patients with advanced dementia.

CHAPTER 3

METHODOLOGY

Institutional Review Board Approval

Ethical research practices are of utmost importance. As such, approval for research with human subjects was obtained from the Institutional Review Board (IRB) at The University of Alabama prior to data collection. The IRB approval letter, recruitment materials, and letters of consent can be found in Appendix A.

Population and Sample

This study sought to understand the knowledge, attitudes, beliefs, and perceptions of RDs in the United States who work with older adults, along with the internal and external factors associated with the recommendations of RDs. The Commission on Dietetic Registration (CDR) is the credentialing body for RDs in the United States, and provides access to the registrants for research purposes. According to CDR's website, there are approximately 95,000 RDs across the United States, who are mostly females (93.7%), and mostly Caucasian (80.6%) (CDR, 2017). While research on other health care professionals has indicated that differences in knowledge and practices exist based on gender, this study was unable to identify such differences among RDs due to the homogeneity of the profession.

The demographic information on registrants is also classified by practice area, with approximately 25 practice areas listed (CDR, 2017). Of these, the researcher identified four

areas that most likely represent RDs who work with older adult patients: clinical nutrition (general), gerontology, long-term care, and nutrition support. These four areas represent approximately 25,000 RDs, or 27% of the RDs in the United States. The CDR agreed to provide contact information for a random sample of 5,000 (or 20%) of these 25,000 RDs, who were invited via email to participate in this study.

Determination of Sample Size

The researcher utilized established methods to determine the sample size needed to adequately power statistical analyses to detect significant differences at an alpha level $\leq .05$. Krejcie and Morgan (1970) recommended a sample size of 382 – 384 participants for a population of 75,000 – 1,000,000 individuals. More recently, Gay and Airasian (2003) recommended that a sample size of 400 participants was adequate for a population of 5,000 or more. In order to evaluate construct validity through exploratory factor analysis, the literature suggests a sample of at least 300 (Tabachnick & Fidell, 2007). Thus, a sample size of approximately 400 RDs was desired. This represented a minimum response rate of 8%, which was very feasible to attain based on the response rates from similar studies (Enrione & Chutkan, 2007; Langdon et al., 2002, Szeto et al., 2014).

Study Procedures

Development of Instrument

As prior studies lacked a theoretical framework, this study aimed to develop a survey instrument that operationalized the levels of the Social Ecological Model according to McLeroy and colleagues (1988). As such, several scales were utilized to assess the various levels of the

model. Instrument development followed the steps outlined by Sharma and Petosa (2014). Prior to survey distribution to the sample of 5,000 RDs, an expert panel of seven participants critiqued the instrument in order to establish readability, comprehensibility, and face and content validity through two rounds of expert panel review (Sharma & Petosa, 2014). After adjusting the instrument according to the expert panel recommendations, the survey was distributed to a pilot sample of RDs to determine the amount of time required for survey completion. The responses from this convenience sample ($n = 70$) were analyzed using Cronbach's alpha and item-to-total correlations in order to reduce the number of items on the survey as needed prior to distribution for the efficacy study. See Figure 2 for a flow diagram illustrating tool development, assessment of reliability, and validation.

Drafting Instrument.

The first draft of the survey instrument was written based on a comprehensive review of the literature on the topic. Several subscales were developed in order to assess the various levels of the Social Ecological Model. Some items were gathered from existing survey tools; the researcher developed others. All scales included at least two items in order to evaluate internal consistency (DiIorio, 2005). The survey concluded with a series of demographic questions about RDs and the facilities where they worked.

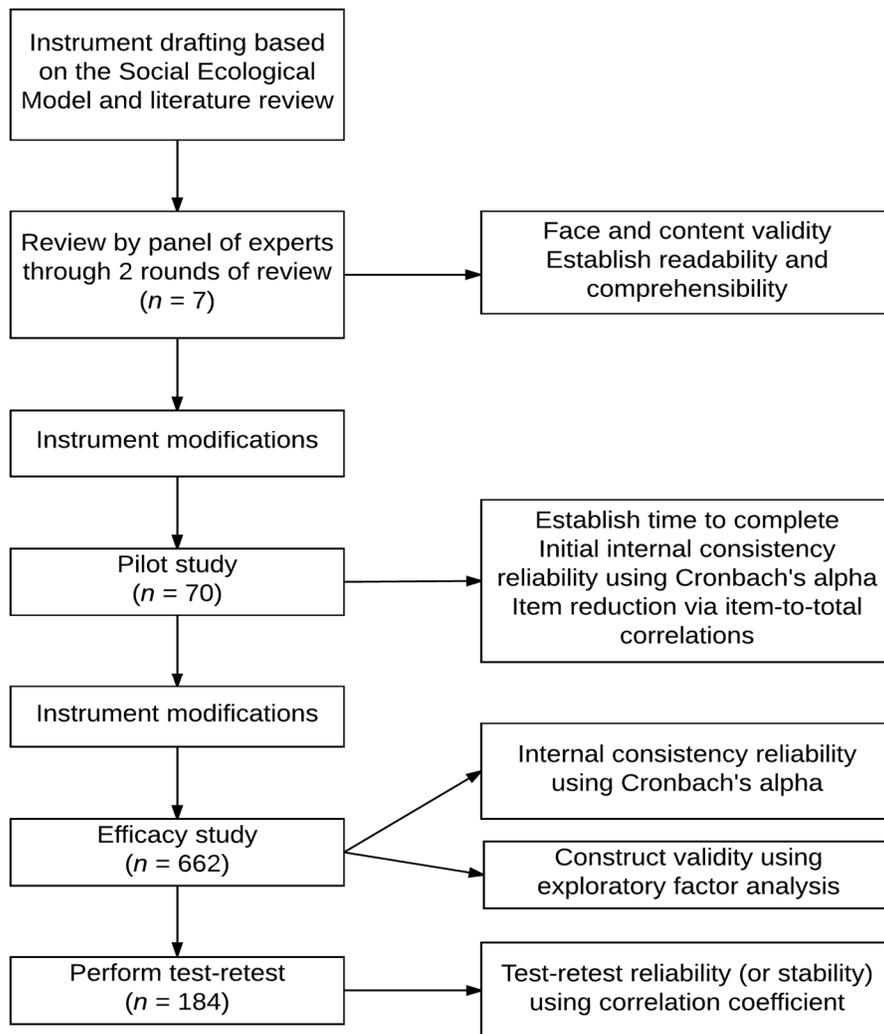


Figure 2. Instrument Development and Validation Process.

Once the instrument had been drafted, readability was assessed using the readability tools within Microsoft Word. The Flesch Reading Ease score indicates the ease of understanding, and provides a score on a scale of 1 – 100 points. The drafted survey tool scored 43.2 on this scale. While a score of 60 – 70 is considered acceptable (Sharma & Petosa, 2014), this survey tool likely scored less than the desirable range due to the medical terminology that was an inherent

part of the survey. The Flesch-Kincaid Grade Level score indicates the grade level at which a document is written. The final survey tool was assessed at the 11th grade level, which was appropriate for the sample population, whose minimum education level was a bachelor's degree. The initial drafted survey instrument can be found in Appendix B.

Panel of Experts.

Once the instrument had been drafted, the survey was distributed to an expert panel for review of readability, comprehensibility, and face and content validity. Panelists were asked to identify items that were unclear. They were also asked for suggestions on how to improve readability. Face validity involves determining whether the instrument appears to measure what it should (Sharma & Petosa, 2014). Content validity addresses whether each construct is adequately assessed according to its operational definition (Sharma & Petosa, 2014). Sharma and Petosa (2014) recommended that at least six individuals comprise the expert panel. As such, seven experts on the topic and target population were asked to provide feedback on the instrument through two rounds of panel review. Panelists included four RD content experts who have published on this topic, two RDs who provided managerial oversight to other RDs in clinical practice, and one measurement expert. These experts were provided with the survey and review instructions through email. They were asked during each round of review to provide comments and feedback within a 2-week period.

The instrument was revised as needed according to expert panel feedback. This resulted in the addition of five survey items, along with definitions of terms at the introduction to the survey tool. The instrument also underwent revisions to improve readability and comprehension, as recommended by Sharma and Petosa (2014). As a result of these modifications, the Flesch

Reading Ease Score decreased to 39.4, and the Flesch-Kincaid Grade Level Score increased to the 12th grade level. Again, the survey tool was inherently complex due to the medical terminology associated with the topic. However, it was appropriate for this population of college-educated professionals. Following two rounds of expert panel review, the survey instrument was entered into the Qualtrics™ survey platform. (See Appendix C for the pilot survey instrument.)

Pilot Study.

In order to establish the time required to complete the survey, the instrument was distributed to a convenience sample of RDs (Sharma & Petosa, 2014), who were recruited through email and social media (Facebook™). Registered Dietitians known to the researcher were invited via Facebook™ to complete the survey through the Qualtrics™ platform, and they were asked to forward the invitation on to other RDs who may be eligible to complete the survey.

The results from the pilot survey were analyzed using Cronbach's alpha and item-to-total correlations in order to determine which items would be removed from the survey. Survey items with an item-to-total correlation of .30 or less were removed from the survey instrument (Cronk, 1999). The University of Alabama Internal Review Board approval of the survey instrument, protocol, and consent forms prior to the distribution of the survey to the pilot sample.

The time required to complete the survey was assessed using a trimmed mean, where the top and bottom three completion times were deleted to account for those who left the survey window open for an extended amount of time prior to completing the survey. A total of 10 items were eliminated from Section 2 of the pilot survey as a result of weak item-to-total correlations.

Thus, Section 2 consisted of 28 items after analysis of the results of the pilot study. This yielded the Efficacy Survey Instrument, which can be found in Appendix D.

Instrumentation

In addition to the demographic information collected, several subscales were included in this study instrument to measure the various levels of the Social Ecological Model. To assess which factors influenced whether RDs would recommend a feeding tube for a patient with advanced dementia, RDs were first asked to answer a question on the likelihood of them making such recommendations. The response set included: ‘Highly Unlikely,’ ‘Somewhat Unlikely,’ ‘Neutral,’ ‘Somewhat Likely,’ and ‘Highly Likely.’ Responses to this question were later collapsed to served as the dichotomous outcome variable in a logistic regression analysis.

To address the internal and external influences that impacted RDs’ recommendations, their knowledge, beliefs, attitudes, and perceptions were measured using two response sets. Knowledge statements were written based on The American Geriatric Society’s position paper on the subject (2014). The scale contained 22 items, and RDs responded to each statement using the following response set: ‘True,’ ‘False,’ and ‘Don’t Know.’ The answers were summated to produce a knowledge score, with a greater score indicating greater knowledge of evidence-based guidelines.

Questions on other internal factors (including attitudes and beliefs, religion, spirituality, and culture) and external factors were written based on a thorough review of the literature of various health care providers and organizational- and policy-level influences. Participants originally responded to 38 statements, indicating their agreement with the written statements by selecting from the following response set: ‘Strongly Agree,’ ‘Agree,’ ‘Neutral,’ ‘Disagree,’ and

‘Strongly Disagree.’ These responses were scored such that a greater score indicated attitudes, beliefs, and perceptions of policy and organizational influences that were more consistent with evidence-based guidelines, or avoiding the use of feeding tubes for older adults with advanced dementia. After the pilot study, the number of items in this section was reduced to 28.

Finally, demographic data were collected, including 10 items about RDs and the facilities where they were employed. Personal information included gender, age, race and ethnicity, level of education, specialty certifications earned, primary practice area, religious affiliation, and years of experience as a RD, both in general and in a setting where they provide nutritional care to older adults.

Validation of Instrument

As recommended by the literature, the survey instrument must be deemed valid and reliable (Sharma & Petosa, 2014). As previously discussed, an expert panel reviewed the instrument for readability, comprehensibility, and content and face validity, and adjustments were made as needed. See Figure 2 on instrument development (page 68). To assess construct validity, exploratory factor analysis was utilized to ascertain factors onto which the various survey questions loaded (Sharma & Petosa, 2014). As questions were written about internal and external factors, it was expected that these factors would emerge from the factor analysis. From the factor extraction, components with an eigenvalue of 1.0 or greater were retained as factors (Pallant, 2005). At this stage, six factors were identified. However, two of the six factors contained less than three items. Because it was desirable to have at least three items loading onto each factor (Pallant, 2007) the extraction was then forced to five factors, which all had at least three items. Once the five factors were identified, they were named based on the content of the

items loading on that factor. The items loading onto each of the five factors were then used to create five new scales, where results were summated to provide a score for that factor. Higher scores indicated attitudes, beliefs, or perceptions that were more consistent with evidence-based practice, or avoiding the use of a feeding tube. These scales were utilized in the logistic regression analysis. Confirmatory factor analysis utilizing Structural Equation Modeling was beyond the scope of this study, but could be addressed in future research.

In addressing the reliability of the survey instrument, internal consistency reliability and test-retest reliability (or stability) were evaluated using established statistical methods (Sharma & Petosa, 2014). Test-retest reliability was measured using a group of 184 RDs. At the end of the efficacy study, RDs were asked if they would be willing to complete the survey again in several weeks. If so, they provided their email address at the end of the survey, and they were sent the survey link again after the efficacy survey closed. By using email addresses to pair the responses of the first and second survey completion, test-retest reliability was established using a correlation coefficient (Sharma & Petosa, 2014). According to Nunnally and Bernstein, a correlation coefficient of .70 - .80 was better, and .90 was excellent (as cited in Sharma & Petosa, 2014).

Following data collection from the efficacy survey, Cronbach's alpha was used to establish internal consistency reliability according to published benchmarks (Sharma & Petosa, 2014). Because the survey instrument contained multiple scales, a Cronbach's alpha value was generated for each subscale. According to the literature, a Cronbach's alpha of .70 or greater indicated adequate internal consistency (Carmines & Zeller, 1979; Nunnally & Bernstein, 1994).

Data Collection

Once the survey was deemed valid by the expert panel and it had been evaluated based on the results of the pilot study, it was distributed to the random sample of 5,000 RDs provided by the CDR. Potential participants received an email with an invitation to participate in the study, and a link to direct them to the survey. Upon clicking the survey link, they were first directed to the letter of consent, which was adapted from a template provided by the Institutional Review Board at The University of Alabama. Upon reviewing the Informed Consent form and clicking to agree to participate in the study, participants were directed to the survey instrument. Using the Qualtrics™ software, participants answered one screening question to determine eligibility. This question established whether potential participants were RDs who provided nutritional care to older adults. If they answered ‘no’ to the screening question, they were directed to a page explaining that they were not eligible for this survey. If they answer ‘yes,’ they were able to proceed to the remaining survey items. After sending out the initial invitation to the survey, participants received a reminder email weekly for 3 weeks, asking them to complete the survey if they had not done so already. The survey remained open to participants through the email link for 5 weeks. At the end of that time period, the survey closed and the researcher began data cleaning and analysis.

In the final item of the efficacy study, RDs had the opportunity to enter into an incentive drawing. RDs clicked on a link, which redirected them to a separate survey, where they answered a single question (Identification of the ‘RD’ acronym (Registered Dietitian)) and provided their email address. Those who answered the question correctly were entered into a drawing for one of twelve \$50 gift cards. RDs who did not answer the question correctly were not entered into the drawing. RDs who completed the test-retest component completed the

survey twice, so they were entered into the drawing twice. Following data collection, 12 email addresses were randomly selected to win the gift cards, and the corresponding RDs were notified by email.

Data Management

Upon the completion of data collection, the data from Qualtrics¹ were converted into an IBM SPSS[®] file. The data were cleaned to remove incomplete surveys and erroneous entries. Surveys were only considered usable if they were complete, as SPSS would not analyze surveys with missing items. For this reason, RDs were asked to complete all items. Additionally, the survey software did not allow RDs to skip questions.

For those who agreed to participate in the retesting of the instrument for the reliability assessment, email addresses were culled from the survey responses and kept in a secure file on the researcher's computer. Once the test-retest surveys were completed and matched by email address, they were assigned a participant number, and all email addresses were deleted.

In order to distribute the gift cards, those email addresses entered into the separate link at the end of the survey were gathered and entered into a spreadsheet and assigned a number. Twelve of these email addresses were randomly selected in the raffle for the \$50 gift cards, and the RDs were notified by that email address. Following delivery of the gift cards, all email addresses were deleted.

Research Questions and Statistical Analyses

The following research questions were addressed through data collection and analysis using IBM SPSS[®] version 24 (SPSS Inc., Chicago, IL, 2016).

Research Question 1: What internal factors (knowledge, beliefs, attitudes, culture, and religion) were associated with RDs' tube-feeding recommendations?

It was hypothesized that internal factors influenced RDs' tube-feeding recommendations. This was verified using exploratory factor analysis, where several internal factors emerged from the survey items.

Research Question 2: What external factors (community, organizational, and policy) were associated with RDs' tube-feeding recommendations?

It was hypothesized that external factors influenced RDs' tube-feeding recommendations. This was verified using exploratory factor analysis, where several external factors emerged from the survey items.

Research Question 3: What were the recommendations of RDs regarding feeding tubes for older adults with advanced dementia?

It was hypothesized that some RDs would recommend a feeding tube for a patient with advanced dementia, a recommendation that is not consistent with evidence-based guidelines. This was evaluated using descriptive statistics.

Research Question 4: Did RDs' feeding tube recommendations for older adults with advanced dementia vary based on their demographic information, internal influences, or external influences?

It was hypothesized that knowledge, internal factors, and external factors were associated with whether RDs would recommend feeding tubes for patients with advanced dementia. This was analyzed using a multivariate regression, where the outcome variable was whether RDs were likely or unlikely to recommend a feeding tube for a patient with advanced dementia.

Independent variables that were significantly associated with the outcome variable in the univariate analyses were then entered into the logistic regression analysis, which included the variables of Total Knowledge score, Knowledge Self-Efficacy score, Religion/Spirituality/Culture score, Personal Values score, Perceived Organization and Training score, Perceived Policy score, race, presence of specialty certifications, and primary work setting.

Summary

This chapter has detailed the methodology for this research study. Following established recommendations for instrument development, the researcher created a survey instrument that was based on the literature and the theoretical framework of the Social Ecological Model. Once the instrument was drafted, it underwent expert panel review and pilot testing. The Institutional Review Board (IRB) of The University of Alabama approved the survey document and protocol prior to pilot testing. The efficacy survey involved a random sample of RDs, and was followed by a second distribution to those who volunteered to establish test-retest reliability. Based on prior research, the sample size was more than adequate to provide a response rate that was appropriate for data analysis. Study completion involved establishing the validity and reliability of the instrument, along with statistical analysis of the data.

Appendix A

Institutional Review Board Approval Letter, Recruiting Materials, and Letters of Consent

November 16, 2016

Joy W. Douglas, MS, RD, CSD, LD
Department of Health Sciences
College of Human Environmental Sciences
The University of Alabama
Box 870311

Re: IRB # 16-OR-283-ME (Revision # 2) "Internal and External Factors Influencing Registered Dietician Recommendations for Feeding Tube Use Among Older Adults with Advanced Dementia: An Application of the Social Ecological Model"

Dear Ms. Douglas:

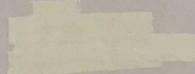
The University of Alabama Institutional Review Board has reviewed the revision to your previously approved expedited protocol. The board has approved the change in your protocol.

Please remember that your approval period expires one year from the date of your original approval, August 18, 2016, not the date of this revision approval.

Should you need to submit any further correspondence regarding this proposal, please include the assigned IRB application number. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants.

Good luck with your research.

Sincerely,


Stuart Usdan, Ph.D.
Chair, Non-Medical Institutional Review Board
The University of Alabama

Pilot Study Email and Facebook™ Invitation

Hello all,

As part of my dissertation research, I am seeking approximately 50 Registered Dietitians who work with older adults to complete a pilot survey. From this study, I hope to learn about the knowledge, attitudes, beliefs, and practices of dietitians regarding the use of feeding tubes for individuals with advanced dementia, and to understand the various factors that influence how dietitians make these clinical recommendations. The results of the pilot survey will be used to refine and edit the survey instrument prior to distribution to a random sample of Registered Dietitians across the U.S. later this year.

If you decide to participate, you are being asked to complete an online survey that will take approximately 20-25 minutes to complete. Based on your responses, the survey will be edited prior to the larger study.

This is an anonymous electronic survey. No identifying information will be asked or collected.

Following the survey link below will allow you to begin the survey, which will be submitted electronically upon survey completion. Please feel free to share the survey link with other clinicians who may be interested in participating.

If you have any questions about this study, please contact Joy Douglas by email at warre044@crimson.ua.edu, or you may contact Dr. Jeannine Lawrence by email at jlawrence@ches.ua.edu.

Thank you for your time and input on this very important topic!

Warmly,
Joy W. Douglas, MS, RD, CSG, LD

Pilot Study Consent Form

INFORMED CONSENT STATEMENT (Online Survey)

Internal and External Factors Influencing Registered Dietitians' Recommendations for Feeding Tube Use Among Older Adults with Advanced Dementia: An Application of the Social Ecological Model

Dear Potential Participant:

You are invited to participate in a research study conducted by Joy Douglas, MS, RD, CSG, LD from The University of Alabama, Department of Human Nutrition. The title of the study is, *Internal and External Factors Influencing Registered Dietitians' Recommendations for Feeding Tube Use Among Older Adults with Advanced Dementia: An Application of the Social Ecological Model*. From this study, I hope to learn about the knowledge, attitudes, beliefs, and practices of dietitians regarding the use of feeding tubes for individuals with advanced dementia, and to understand the various factors that influence how dietitians make these clinical recommendations. You are invited to participate in this pilot study because you are a Registered Dietitian in the U.S. Approximately 50 Registered Dietitians in the United States are being invited to participate in this pilot survey. Please feel free to share the survey link with other clinicians who may be interested in participating. The results will be used to refine and edit the survey instrument prior to distribution to a random sample of dietitians across the U.S. later this year.

Study Inclusion Criteria:

1. Each participant must be a Registered Dietitian in the United States, and has therefore completed a bachelor's degree and is able to read and write in English.
2. Participants must be at least 18 years of age.
3. Participants must provide nutrition care to the older adult population in some professional capacity, be that in the community, hospital, or long-term care setting.

If you decide to participate, you are being asked to complete an online survey that will take approximately 20-25 minutes to complete. The survey contains questions about your educational background and years of experience, race/ethnicity, and your attitudes toward the use of feeding tubes in older adults with advanced dementia. Based on your responses, the survey will be edited prior to the larger study. Following the survey link at the end of this page will allow you to begin the survey, which will be submitted electronically upon survey completion. Completion of the following survey implies your agreement to take part in this research study.

This is an anonymous electronic survey. No identifying information will be asked or collected. Only my research team and I will have access to the data, which will be password protected. Only summarized data will be presented at meetings or in publications.

There will be no direct benefit or incentive provided to you for completing this survey. However, your feedback will be useful for the purpose of creating a quality survey instrument for the larger nationwide survey later this year.

There are no known risks or discomforts associated with your participation in this study. However, there is a possibility that some of the questions may make you uncomfortable.

If you have any questions about this study, please contact Joy Douglas by email at warre044@crimson.ua.edu, or Dr. Jeannine Lawrence by email at jlawrence@ches.ua.edu. If you have any questions, concerns, or complaints about your rights as a research participant you may contact Ms. Tanta Myles, The University of Alabama Research Compliance Officer, at 205-348-8461, or toll free 877-820-3066. If you have complaints or concerns about this study, file them through the UA IRB outreach website at http://osp.ua.edu/site/PRCO_Welcome.html. After you participate, you are encouraged to complete the short survey for research participants that is found online at this website. This helps UA improve its protection of human research participants.

Your participation is completely voluntary. Your decision whether or not to participate will not affect your relationship with the University of Alabama, the principal investigator, or anyone else. You are free to stop participation any time before your answers are submitted.

If you are at least 18 years of age, understand the statements above, and freely consent to participate in this study, please click on the survey link below to begin the survey.

Waiver of Written Documentation of Informed Consent

**AAHRPP DOCUMENT # 148
THE UNIVERSITY OF ALABAMA
HUMAN RESEARCH PROTECTIONS PROGRAM**

FORM: Request for Waiver of Written Documentation of Informed Consent

Directions: Address the criteria listed below and attach this form to your application. Also, state in your application that you are requesting a waiver of written documentation of informed consent and describe what you will do to obtain consent in the procedure section of your application. The IRB often requires investigators to provide participants with a written information statement about the research when written documentation is waived; you may wish to include one in your initial application.

NOTE that the UA IRB does not allow passive consent.

You are welcome to call Research Compliance staff at 205-348-8461 to discuss your need for a waiver in advance of application submission.

(1) The only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality; subjects must be asked whether they want documentation linking themselves to the project or not (and the participants' wishes will prevail);

OR

(2) The research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

Response: This project involves a web-based survey and presents no more than minimal risk to participants, as it is anonymous. In place of the written informed consent form, the researchers are utilizing the template for the informed consent statement for online surveys, as provided through The University's IRB website. Participants will be presented with this informed consent statement prior to beginning the survey. Should they agree to the terms of the consent form and agree to participate in the survey, they will click the link at the bottom of the page to begin the survey.

NOTE: The first criterion is not included in FDA. The second is in both FDA and HHS regulations, 21 CFR 56.109 (c). In cases where documentation is waived, the IRB may require PIs to provide subjects with a written statement about the research.

Efficacy Study Email Invitation

Dear Registered Dietitian:

You are invited to participate in a research study conducted by Joy Douglas, MS, RD, CSG, LD from The University of Alabama, Department of Human Nutrition. The title of the study is, *Internal and External Factors Influencing Registered Dietitians' Recommendations for Feeding Tube Use Among Older Adults with Advanced Dementia: An Application of the Social Ecological Model*. From this study, I hope to learn about the knowledge, attitudes, beliefs, and practices of dietitians regarding the use of feeding tubes for individuals with advanced dementia, and to understand the various factors that influence how dietitians make these clinical recommendations.

If you decide to participate, you are being asked to complete an online survey that will take approximately 10-15 minutes to complete. This is an anonymous electronic survey; no identifying information will be collected unless you volunteer to complete a test-retest component, in which case your email address will be requested. As soon as the retest component is completed, your email address will be deleted.

In appreciation of your time and input, you do have the opportunity to enter into a drawing to win one of twelve \$50 gift cards upon survey completion.

Following the survey link below will allow you to begin the survey, which will be submitted electronically upon survey completion.

If you have any questions about this study, please contact Joy Douglas by email at warre044@crimson.ua.edu. You may also contact Dr. Jeannine Lawrence by email at jlawrence@ches.ua.edu.

Thank you for your time and input on this very important topic!

Warmly,
Joy W. Douglas, MS, RD, CSG, LD

Efficacy Study Consent Form

INFORMED CONSENT STATEMENT (Online Survey)

Internal and External Factors Influencing Registered Dietitians' Recommendations for Feeding Tube Use Among Older Adults with Advanced Dementia: An Application of the Social Ecological Model

Dear Potential Participant:

You are invited to participate in a research study conducted by Joy Douglas, MS, RD, CSG, LD from The University of Alabama, Department of Human Nutrition. The title of the study is, *Internal and External Factors Influencing Registered Dietitians' Recommendations for Feeding Tube Use Among Older Adults with Advanced Dementia: An Application of the Social Ecological Model*. From this study, I hope to learn about the knowledge, attitudes, beliefs, and practices of dietitians regarding the use of feeding tubes for individuals with advanced dementia, and to understand the various factors that influence how dietitians make these clinical recommendations. You are invited to participate in this study because you are a Registered Dietitian in the U.S. Approximately 5,000 Registered Dietitians across the United States have been randomly selected and are being invited to participate in this survey.

Study Inclusion Criteria:

1. Each participant must be a Registered Dietitian in the United States, and has therefore completed a bachelor's degree and is able to read and write in English.
2. Participants must be at least 18 years of age.
3. Participants must provide nutrition care to the older adult population in some professional capacity, be that in the community, hospital, or long-term care setting.

If you decide to participate, you are being asked to complete an online survey that will take approximately 10-15 minutes to complete. The survey contains questions about your educational background and years of experience, race/ethnicity, and your attitudes toward the use of feeding tubes in older adults with advanced dementia. At the end of the survey, you will be asked to provide your email address if you are willing to volunteer to complete the survey again in two weeks to establish the reliability of the survey instrument.

Following the survey link at the end of this page will allow you to begin the survey, which will be submitted electronically upon survey completion. Completion of the following survey implies your agreement to take part in this research study. Please do not share the survey link with any other clinicians.

This is an anonymous electronic survey. No identifying information will be collected unless you volunteer to complete a test-retest component, in which case your email address will be requested. As soon as the retest component is completed, your email address will be deleted. Only my research team and I will have access to the data, which will be password protected. Only summarized data will be presented at meetings or in publications.

There will be no direct benefit or incentive provided to you for completing this survey. However, if you choose, you may follow a link in the last item of the survey, which will ask that you answer one question to enter your email address (which will be collected separately from the survey) into a drawing to win one of twelve \$50 gift cards for completing the survey. The findings of this survey will be useful to myself and other researchers for the purpose of developing continuing education programs on this topic, and better understanding the decision-making processes of Registered Dietitians.

There are no known risks or discomforts associated with your participation in this study. However, there is a possibility that some of the questions may make you uncomfortable.

If you have any questions about this study, please contact Joy Douglas by email at warre044@crimson.ua.edu. You may also contact Dr. Jeannine Lawrence by email at jlawrence@ches.ua.edu. If you have any questions, concerns, or complaints about your rights as a research participant you may contact Ms. Tanta Myles, The University of Alabama Research Compliance Officer, at 205-348-8461, or toll free 877-820-3066. If you have complaints or concerns about this study, file them through the UA IRB outreach website at http://osp.ua.edu/site/PRCO_Welcome.html. After you participate, you are encouraged to complete the short survey for research participants that is found online at this website. This helps UA improve its protection of human research participants.

Your participation is completely voluntary. Your decision whether or not to participate will not affect your relationship with the University of Alabama, the principal investigator, or anyone else. You are free to stop participation any time before your answers are submitted.

If you are at least 18 years of age, understand the statements above, and freely consent to participate in this study, please click on the survey link below to begin the survey.

Efficacy Study Reminder Email

Dear Registered Dietitian:

You recently received an emailed invitation to participate in a research study conducted by Joy Douglas, MS, RD, CSG, LD from The University of Alabama, Department of Human Nutrition. The title of the study is, *Internal and External Factors Influencing Registered Dietitians' Recommendations for Feeding Tube Use Among Older Adults with Advanced Dementia: An Application of the Social Ecological Model.*

If you have already completed the survey, thank you very much! If not, we invite you to complete the survey at your convenience. We anticipate that the survey link will remain active for an additional 2 weeks from today.

This study involves an online survey that will take approximately 10-15 minutes to complete. This is an anonymous electronic survey; no identifying information will be collected unless you volunteer to complete a test-retest component, in which case your email address will be requested. As soon as the retest component is completed, your email address will be deleted.

In appreciation of your time and input, you do have the opportunity to enter into a drawing to win one of twelve \$50 gift cards upon survey completion.

Following the survey link below will allow you to begin the survey, which will be submitted electronically upon survey completion.

If you have any questions about this study, please contact Joy Douglas by email at warre044@crimson.ua.edu. You may also contact Dr. Jeannine Lawrence by email at jlawrence@ches.ua.edu.

Thank you for your time and input on this very important topic!

Warmly,
Joy W. Douglas, MS, RD, CSG, LD

CHAPTER 4

DEVELOPMENT AND VALIDATION OF A SURVEY TO EVALUATE FACTORS ASSOCIATED WITH REGISTERED DIETITIANS' TUBE-FEEDING RECOMMENDATIONS FOR OLDER ADULTS WITH ADVANCED DEMENTIA

Dementia is a progressive, degenerative brain condition that impacts millions of people across the world. Dementia is characterized by the irreversible damage or destruction of the neurons in the brain, which can be caused by vascular damage, neuronal atrophy, and changes in neuronal protein metabolism (Alzheimer's Disease Facts and Figures, 2017). The most common types of dementia include: Alzheimer's disease, vascular dementia, Parkinson's dementia, mixed dementia, Dementia with Lewy Bodies, and Frontotemporal lobar degeneration. In 2015, Alzheimer's disease was the sixth leading cause of death in the United States, responsible for 110,561 deaths (Xu, Murphy, Kochanek, & Arias, 2016). In the United States, an estimated 5.3 million older adults (aged 65+) will live with Alzheimer's dementia, the most common form of dementia, in 2017 (Alzheimer's Disease Facts and Figures, 2017).

People in the early phases of dementia may experience a number of different symptoms, which may vary based on the etiology of the dementia. Some common symptoms include: difficulty with memory and recall, impaired language and decision-making, changes in personality, and difficulty with gait and movement (Alzheimer's Disease Facts and Figures, 2017). As neuronal damage progresses, people with dementia have increasing difficulty with basic tasks of self-care, including maintaining personal hygiene, self-feeding, and toileting. When dementia advances, extensive neuronal damage results in the loss of the ability to

communicate, ambulate, and swallow. In this advanced stage, patients are at risk for malnutrition and dehydration due to the inability to safely swallow, and their reliance on others for care (Alzheimer's Disease Facts and Figures, 2017; Chung, 2012).

A common practice in the United States involves supporting nutritionally at-risk dementia patients by inserting a feeding tube (Bell, Lee, & Tamura, 2015). From 2000 – 2003, Kuo and colleagues (2009) estimated that approximately a third of nursing home patients with advanced dementia had a feeding tube for nutritional support. Current literature indicates that the use of a feeding tube not only fails to improve nutritional status in people with advanced dementia, but it may lead to other complications, such as pneumonia, pressure ulcers, diarrhea, constipation, and can require the use of restraints to prevent an agitated patient from removing the tube (Attanasio et al., 2009; Chung, 2012; Cintra, de Rezende, de Moraes, Cunha, & da Gama Torres, 2014; Kaw & Sekas, 1994; Teno et al., 2011; Teno et al., 2012).

As a result, several professional organizations have published position statements favoring the use of careful hand-feeding over the use of feeding tubes for these patients, including The American Geriatrics Society (2014), The American Society of Parenteral and Enteral Nutrition (as cited in Schwartz et al., 2014), The Alzheimer's Association (2015), and The European Society for Parenteral and Enteral Nutrition (as cited in Volkert et al., 2015). Recent studies of tube-feeding trends from 2000 – 2014 indicate that feeding tube use in this patient population decreased (Mitchell, Mor, Gozalo, Servadio, & Teno, 2016). However, some researchers are not convinced of the negative effects; they believe that feeding tubes may be beneficial for patients with advanced dementia (Ribeiro Salomon & Carvalho Garbi Novaes, 2015).

It is important to consider factors that influence whether various members of the health care team (nurses, physicians, Speech-Language Pathologists, etc.) will recommend a feeding tube for a patient with advanced dementia. Not all health care practitioners appear to be aware of current guidelines on the subject (Hasan, Meara, Bhowmick, & Woodhouse, 1995; Lacey, 2005; Lacey, 2006; Lopez, Amella, Mitchell, Strumpf, 2010; Ogita, Utsunomiya, Akishita, & Arai, 2012; Sharp & Shega, 2009; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2003; Vitale, Berkman, Monteleoni, & Ahronheim, 2011; Vitale, Hiner, Ury, Berkman, & Ahronheim, 2006). Practitioner recommendations vary based on the personal traits of the clinician, such as: gender, age, specialty practice area, level of education, years of experience, religion, race and ethnicity, and cultural background (Aita, Takahashi, Miyata, Kai, & Finucane, 2007; Asai & Fukuhara, 1995; Carmel, 1999; Hinkka et al., 2002; Langdon, Hunt, Pope, & Hackes, 2002; Mitchell, Teno, Roy, Kabumoto, and Mor, 2003; Modi, Whetstone, & Cummings, 2007; Taper & Hockin, 1996; Teno et al., 2014). Factors such as regulatory issues, financial reimbursement, and legal issues also influence how clinicians make these recommendations for their patients (Aita et al., 2007; Finucane, Christmas, & Leff, 2007; Lopez, Amella, Strumpf, Teno, & Mitchell, 2010; Mitchell, 2003; Mitchell, Buchanan, Littlehale, & Hamel, 2003; Shega et al., 2003).

Studies regarding how Registered Dietitians (RDs) in the United States make recommendations for feeding tube use among older adults with advanced dementia are limited and dated (Enrione & Chutkan, 2007; Langdon et al., 2002; Wall, Wellman, Curry, & Johnson, 1991). RDs are crucial members of the health care team and this lack of information presents an important research gap. Furthermore, no theoretical model has been utilized to describe the factors that influence RDs' tube-feeding recommendations. Thus, the purpose of this study was

to develop and validate a theory-based survey tool to identify factors that influence RDs' recommendations regarding the use of feeding tubes for older adults with advanced dementia.

The Social Ecological Model was utilized as the theoretical framework for this study. This model, which is based on the work of Bronfenbrenner in 1977, hypothesizes that human behavior is shaped by a number of influences (or layers) within one's environment. While the model originated in psychology and human development, it has been used in health education and promotion to explain how individuals make health-related decisions. Furthermore, the utility of the Social Ecological Model within the health field focuses on the need for health interventions that consider both the individual, and the environment where the individual lives and works (Baranowski, 1989; Stokols, 1992; Stokols, 1996; Winett, 1995). In 1988, McLeroy and colleagues defined the layers of one's environment, including: individual, interpersonal, organizational (or institutional), community, and public policy levels of influence, as seen in Figure 1 (page 29). Some of these influences are internal to the person, such as knowledge, age, values, attitudes, beliefs, and gender. Other influences are external to the person, such as community, organizational, and public policy influences. The primary aim of this study was to develop a validated survey tool that would identify both internal and external factors that influence how RDs make recommendations regarding feeding tube use for older adults with advanced dementia.

Methods

Survey Development Process

The survey development process, as recommended by Sharma and Petosa (2014), involved several steps, including: document drafting, expert panel review, pilot testing, the

efficacy survey, and retesting for the purpose of test-retest analysis. The Institutional Review Board at The University of Alabama approved the project during document drafting, prior to pilot testing, and prior to the efficacy survey. Figure 2 depicts the instrument development and validation process (see page 68).

Drafting and Instrumentation

In order to identify the internal and external influences that impact the recommendations of RDs, the knowledge, beliefs, attitudes, and perceptions were measured using two response sets. In the first section, knowledge questions were written based on The American Geriatrics Society's (2014) position statement on the topic. This section contained 22 items, and RDs responded to each statement by selecting 'True,' 'False,' or 'Don't Know.'

In the second section of the survey, questions on other internal factors (including attitudes and beliefs, religion and spirituality, and cultural influences) and external factors (organization and policy) were written based on a thorough review of the literature on various health care providers, and a literature review of organizational- and policy-level influences. In this section, RDs indicated their agreement with the written statements using a 5-point Likert Scale with responses that ranged from strongly agree to strongly disagree.

The final section included a set of 10 demographic questions, including information about the RDs and the facilities at which they were employed. Personal information included gender, age, race and ethnicity, religion, level of education, specialty certifications earned, primary work setting, and years of experience as an RD, both in general and in a setting where they provide nutritional care to older adults.

After initial instrument drafting, the instrument's Flesch Reading Ease Score and Flesch-Kincaid Grade Level Score were generated using a feature in Microsoft Word. The Flesch Reading Ease Score assesses ease of understanding on a scale from 0 – 100, with a greater score indicating improved readability (Sharma & Petosa, 2014). The drafted survey instrument scored 43.2 out of 100 on this score. While a score of 60 – 70 is generally desired (Sharma & Petosa, 2014), such a score was likely unattainable for this survey due to the amount of medical terminology inherently present in such a survey instrument. The Flesch-Kincaid Grade Level Score indicates the estimated grade level at which a document is written. On this scale, the drafted survey instrument was assessed to be at the 11th grade reading level, which is appropriate for the target population of RDs, whose minimum education level is a Bachelor's degree. The drafted instrument can be found in Appendix B.

Expert Panel Review

Once the survey instrument was drafted, it underwent two rounds of expert panel review to assess readability, comprehensibility, and face and content validity. The expert panel consisted of two practicing RDs who provide managerial oversight to other RDs in clinical settings, four RDs who are subject experts and who have previously published on this topic, and one expert in measurement. The expert panelists received the survey and reviewer instructions through email. They were asked during each round of review to provide comments and feedback within a 2-week period.

The instrument was revised according to the expert panel feedback after each round of review, yielding the addition of five survey items. When the readability scores were reevaluated after changes were made as recommended by the expert panelists, it was noted that the Flesch

Reading Ease Score decreased to 39.4, and the Flesch-Kincaid Grade Level Score increased to the 12th grade reading level. The pilot survey instrument can be found in Appendix C.

Pilot Study

In order to assess the initial internal consistency reliability, and to reduce the number of items in the survey prior to the efficacy study, the instrument underwent pilot testing. The pilot study involved a convenience sample of RDs who were recruited through email and social media (Facebook™) and provided with a link to the survey in Qualtrics™ (Qualtrics 2017, Provo, UT). RDs known to the researcher were invited to take the survey if they were eligible, and were asked to share the survey link with other RDs they knew. The researcher sent reminder emails and posted reminders on Facebook™ over a 4-week time period, requesting additional survey participation.

Of the 92 surveys that were started, 70 were completed and used in the analysis. The time required to complete the full pilot survey was calculated using a trimmed mean, where the top and bottom three completion times were eliminated to account for those who left the survey browser window open for an extended period of time before completing the survey. This resulted in a mean completion time of 19.97 minutes.

Next, the survey responses were subjected to an internal consistency reliability assessment using Cronbach's alpha, and item reduction using item-to-total correlations. Analysis of the first and second sections of the survey instrument yielded initial Cronbach's alpha values of .741 for 22 items, and .827 for 38 items, respectively. As the first section only consisted of true/false knowledge statements, there was no need to further analyze these items. However, the second section of the survey instrument contained items regarding beliefs,

attitudes, personal values, and perceptions of organizational and policy influences, and was further analyzed using item-to-total correlations, which ranged from .036 - .677. All items with an item-to-total correlation less than .30 were then removed, one by one, starting with the lowest correlation (Cronk, 1999). After eliminating 10 items with weak item-to-total correlations (#48, 33, 39, 51, 50, 25, 53, 54, 56, and 29), the revised scale for Section 2 was determined consisting of 28 items with a Cronbach's alpha coefficient of .859. Of the remaining 28 items, the item-to-total correlations ranged from .306 - .677, suggesting that most of the items significantly contributed to the total scale. High item-to-total correlations support the internal consistency reliability of the scale. The completion of these edits resulted in the Efficacy Study Instrument, as seen in Appendix D.

Efficacy Study

Registered Dietitians in the United States are credentialed through The Commission on Dietetic Registration (CDR), who provides access to registrants for research purposes. According to the CDR, there are approximately 95,000 RDs in the United States, who are predominately female (93.7%) and White/Caucasian (80.6%) (CDR, 2017). Demographic information on registrants is also available from CDR by practice area. When RDs renew their credentials, they are prompted by CDR to self-select their primary practice area(s). Of the 25 practice areas listed, the researcher identified four areas that she felt most likely represented RDs who work with older adults: clinical nutrition (general), gerontology, long-term care, and nutrition support. These four areas represent approximately 25,000 RDs, or 27% of the total RD population in the United States. The CDR agreed to provide contact information for a random

sample of 5,000, or 20% of these 25,000 RDs, who were invited via email to participate using a link to the Qualtrics™ survey.

Potential participants received an email invitation, which explained the study and contained a link to the letter of consent. As an incentive, RDs who completed the survey had the opportunity to enter a drawing to win one of twelve \$50 gift cards. If participants agreed to start the study, they then clicked a link at the bottom of the letter of consent, and began the survey. The first question established eligibility, by specifying whether each potential participant was an RD who worked in a facility or setting where they provide nutritional care to older adults. If potential participants did not meet the eligibility criteria, they were redirected to a page that informed them of this and thanked them for their time. If they met the eligibility criteria, they were able to begin answering survey items. The last item in the survey was a link to another site, which allowed RDs to enter their email address into the incentive drawing, if they wished. Reminder emails were sent weekly for three weeks thereafter. Five weeks after the initial invitation was sent, the survey link was closed.

Responses to the efficacy study were subjected to an internal consistency reliability assessment using Cronbach's alpha, and item reduction using item-to-total correlations. For Section 1, the Cronbach's alpha increased slightly from the pilot survey from .741 to .742 for the 22 items. The Cronbach's alpha for Section 2 increased from .827 for 38 items in the pilot study to .865 for 28 items in the efficacy study. In order to ensure that all items contributed significantly to the overall scale, item-to-total correlations were evaluated, and ranged from .152 to .648. All items with an item-to-total correlation less than .30 were then eliminated, one by one, starting with the lowest correlation (Cronk, 1999). After dropping two items with weak item-to-total correlations (#25 and 36), the final scale for Section 2 was determined consisting of

26 items with a Cronbach's alpha coefficient of .867. Of the 26 remaining items, the item-to-total correlations ranged from .328 to .644 and can be found in Table 3. The standard error of measurement was found to be 4.298. The final survey document can be found in Appendix E.

Table 3
Efficacy Study Item-to-Total Correlations, Mean, and Standard Deviation

Item Number	Item-to-Total Correlation	Item Number	Item-to-Total Correlation
25	Omitted	39	.520
26	.365	40	.527
27	.443	41	.644
28	.414	42	.572
29	.585	43	.593
30	.338	44	.576
31	.573	45	.339
32	.521	46	.328
33	.517	47	.337
34	.610	48	.362
35	.591	49	.467
36	Omitted	50	.566
37	.636	51	.419
38	.536	52	.436
Total Mean		101.8187	
Total Standard Deviation		11.78452	

Test-Retest

The final step of instrument development and validation involved assessing the stability, or test-retest reliability of the instrument using a correlation coefficient. At the end of the efficacy survey, RDs were asked if they would be willing to volunteer to complete the survey again in the coming weeks in order to establish instrument stability. As an incentive, RDs who completed the survey the second time would be entered twice into the gift card drawing. If they wished to participate, volunteers provided an email address, which would be used to send the

second survey link to the RDs, and for the purpose of matching the responses of their first and second survey attempts. Volunteers received an invitation by email 3 weeks after the final efficacy survey reminder was sent. A reminder was sent 1 week later, and the link was deactivated 2 weeks after the initial invitation.

Data Analyses

Once data collection was complete, responses were transferred from the Qualtrics™ software into IBM SPSS® version 24 (SPSS Inc., Chicago, IL, 2016), which was used for all data coding and analysis. Only completed surveys were analyzed. Responses to the first section of the survey were summated to produce a knowledge score, with a greater score indicating accurate knowledge of current evidence-based guidelines. Responses to the second section of the survey were scored such that a greater score indicated attitudes, beliefs, and perceptions of policy and organizational influences that were more consistent with evidence-based guidelines, or avoiding the use of feeding tubes for older adults with advanced dementia. This required reverse coding for approximately one third of items in this section (10 out of 28).

Because no model exists that defines which factors impact RD recommendations for feeding tube use for older adults with advanced dementia, exploratory factor analysis was utilized to determine the construct validity of the instrument, and this provided a framework for understanding which factors influence RDs' recommendations. Responses from Section 2 were subjected to exploratory factor analysis using principal components with a varimax and Kaiser Normalization rotation in order to provide evidence of instrument validity and to define the underlying constructs within the instrument. Initially, factors with eigenvalues > 1.0 were identified. However, the final number of factors retained was restricted to ensure at least three

items loading on each factor (Tabachnick & Fidell, 2001). Item loadings greater than .30 indicated adequate construct validity for the instrument (Tabachnick & Fidell, 2001). Descriptive statistics were used to depict the demographic characteristics of the sample. A *p* value of .05 or less was considered statistically significant for all 2-tailed tests.

Results

Of the 5,000 email addresses randomly selected and provided by CDR, 64 were duplicate emails, indicating that 64 of the RDs in the sample selected more than one of the four practice areas chosen for inclusion in this study. Therefore, Qualtrics™ only sent email invitations to 4,936 email addresses. A total of 932 potential participants clicked on the survey link, representing a response rate of 18.9%. After clicking the survey link, 836 potential participants initiated and gave consent for the survey and proceeded to the screening question. A total of 748 individuals met the eligibility criteria and began answering survey items. Of those, 662 RDs completed the survey, representing a completion rate of 71% among those who started the survey. In general, 662 of the 4,936 RDs in the sample completed the survey, for an overall completion rate of 13.4%. Surveys were only analyzed if all questions were answered. Thus, responses to the 662 completed surveys were analyzed. Figure 3 depicts the recruitment process, along with the response and completion data.

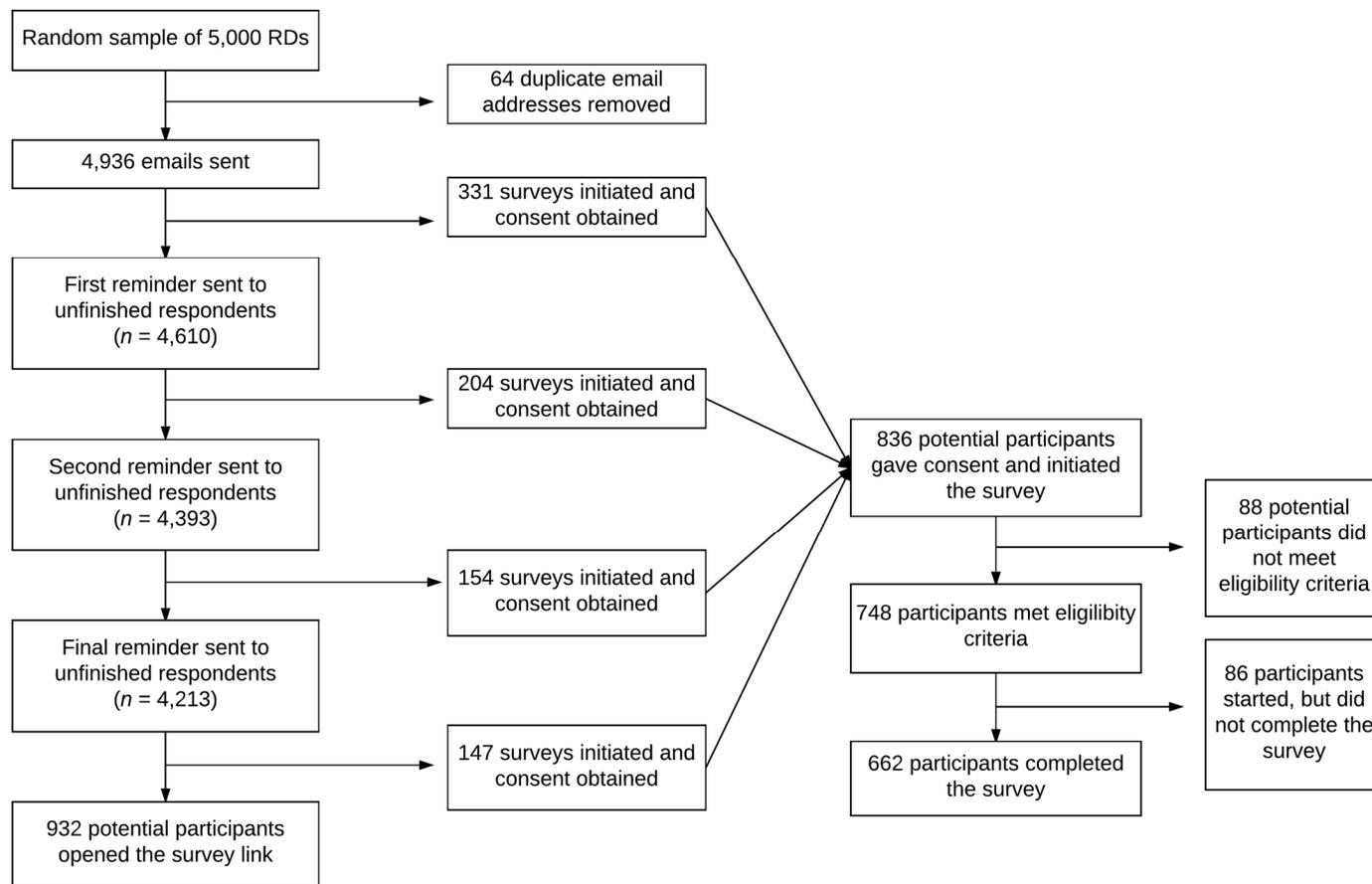


Figure 3. Efficacy Study Recruitment and Survey Response and Completion.

Registered Dietitian Participant Demographics

Similar to the general population of RDs (CDR, 2017), the 662 RDs who completed the survey were mostly female (95.6%) and White/Caucasian (92.4%). Approximately half of the RDs had earned a graduate degree (47.4% with a Master's, and 0.8% with a doctoral degree), and approximately 45% of RDs had completed a specialty certification, with 17.7% of RDs certified as a Board Certified Specialist in Gerontology. Approximately one third of RDs worked in the hospital setting (36.9%), and another third worked in the long-term care/nursing home setting (37.8%). The mean RD age was 46.7 ± 11.7 years, and participants had a mean of 20.3 ± 11.4 years of experience as an RD. Additional demographic data are shown in Table 4.

Table 4
Registered Dietitian Participant Demographics ($n = 662$)

Demographic	<i>n</i>	%
Biological Sex		
Male	27	4.1%
Female	633	95.6%
Prefer not to disclose	2	0.3%
Hispanic, Latino, Spanish origin?		
Yes	12	1.8%
No	639	96.5%
Prefer not to disclose	11	1.7%
Racial Background		
Asian	18	2.7%
Black/African American	9	1.4%
White/Caucasian	612	92.4%
Native Hawaiian or other Pacific Islander	1	0.2%
Two or more races	4	0.6%
Other	3	0.5%
Prefer not to disclose	15	2.3%

(Continued)

Table 4 Continued

Demographic	<i>n</i>	%	
Education Level			
Bachelor's degree	343	51.8%	
Master's degree	314	47.4%	
Doctoral degree	5	0.8%	
Specialty Certification			
Board Certified Specialist in Gerontology	117	17.7%	
Other CDR Specialty	22	3.3%	
Certified Nutrition Support Clinician	86	13%	
Certified Diabetes Educator	29	4.4%	
Multiple specialty certifications	29	4.4%	
Other certification	16	2.4%	
No specialty certification	363	54.8%	
Primary Work Setting			
Hospital/Acute care	244	36.9%	
Rehabilitation facility	30	4.5%	
Long-term care, extended care, or assisted living facility	250	37.8%	
Outpatient care	61	9.2%	
Community nutrition	9	1.4%	
Home health care	19	2.9%	
Hospice	3	0.5%	
Government agency or department	19	2.9%	
Dialysis center/unit	10	1.5%	
Other	17	2.6%	
Religious Affiliation			
Christian/Protestant	299	45.2%	
Catholic	179	27%	
Jewish	26	3.9%	
Mormon/Latter Day Saints	10	1.5%	
Muslim	4	0.6%	
Buddhist	8	1.2%	
Hindu	2	0.3%	
Other	19	2.9%	
None	91	13.7%	
Prefer not to disclose	24	3.6%	
Demographic	<i>n</i>	<i>M</i> ± <i>SD</i>	Range
Age	662	46.7 ± 11.7	24 - 77
Years of experience as an RD	661	20.3 ± 11.4	1 - 54
Years of experience as an RD working with older adults (age 65+)	662	16.8 ± 10.0	1 - 54

Of the 26 items in the second section of the survey, there were initially six factors extracted with eigenvalues of 1.0 or greater. The first factor explained 14.45% of the variance,

with all six factors explaining 62.61% of the variance in the overall score for Section 2. However, one of the six factors only contained two item loadings. As it is desired to have at least three items loading on each factor (Tabachnick & Fidell, 2001), the data were analyzed again, with the number of factors forced to five. In this new analysis, the first factor explained 14.92% of the variance, with all five factors explaining 58.53% of the variance in the total score for Section 2. All item loadings were greater than .30, indicating adequate construct validity for the instrument, as seen in Table 5.

The underlying concepts identified by each factor were as follows: I) Knowledge Self-Efficacy, II) Religion/Spirituality/Culture, III) Personal Values, IV) Perceived Organization and Training, and V) Perceived Policy. Each factor was then computed into a scale, consisting of the items that loaded onto the factor. Mean scores for each factor can be seen in Table 6, where higher scores indicate greater compliance with evidence-based guidelines. The internal consistency reliability of each of the five scales was then calculated using Cronbach's alpha, and can also be found in Table 6. Tests of normality showed that each scale was normally distributed. Therefore, the scales were correlated using Pearson's r , which showed weak to moderate correlations amongst the five variables, as seen in Table 7. This indicated that the variables were moderately related, but still measured independent constructs.

Table 5
Item Loadings

Factor and Items	Item Loadings
Factor 1: Knowledge Self-Efficacy	
I have knowledge regarding current research on the use of feeding tubes in patients with advanced dementia.	.883
I am aware of current research on the use of feeding tubes in patients with advanced dementia.	.864
I lack adequate knowledge on the current research surrounding the use of feeding tubes in patients with advanced dementia.	.753
I feel confident in my clinical nutrition recommendations for patients with advanced dementia.	.700
I am uncertain about the legal implications associated with making recommendations for feeding tube use among patients with advanced dementia.	.596
I am uncertain about the ethical implications associated with making recommendations for feeding tube use among patients with advanced dementia.	.582
Factor 2: Religion/Spirituality/Culture	
My faith in God (or a higher power) is an important factor that impacts my clinical nutrition recommendations.	.875
My religious beliefs play an important role in how I make clinical nutrition recommendations for my patients.	.868
My spirituality is an important factor that impacts my clinical nutrition recommendations.	.849
My cultural background influences how I view allowing a patient with advanced dementia to go without or refuse a feeding tube.	.639
My personal experiences with my own family members have impacted how I make clinical nutrition recommendations for patients.	.605
Factor 3: Personal Values	
Allowing a patient to go without a feeding tube violates my personal values.	.740
Due to my spiritual background, I am uncomfortable allowing a patient with advanced dementia to go without or refuse a feeding tube.	.709
I believe that the health care team should do everything possible to prolong the patient's life, including provide nutrition support.	.708
Due to my religious background, I am uncomfortable allowing a patient with advanced dementia go without or refuse a feeding tube.	.694
My cultural background makes me uncomfortable allowing a patient with advanced dementia to go without or refuse a feeding tube.	.668
I believe that it is acceptable to allow a patient to go without a feeding tube.	.614
I believe that prolonging the patient's life is an important consideration.	.539

(Continued)

Table 5 Continued

Factor and Items	Item Loadings
Factor 4: Perceived Organization and Training	
I believe that I have been adequately trained to provide nutrition education for older adults with advanced dementia.	.667
I believe that I have been adequately trained to provide clinical nutrition recommendations for older adults with advanced dementia.	.657
Registered Dietitians are included in the decision-making process regarding feeding tube placement.	.563
Initiatives have been taken to make the dining experience resemble a home-like setting (i.e., open dining times and seating plans, multiple menu options available, encouraging patient choice in dining.)	.521
Honoring advance directives is encouraged by the health care team.	.499
Factor 5: Perceived Policy	
Feeding tubes are commonly recommended for patients with advanced dementia because reimbursement is greater for tube-fed patients.	.730
Feeding tubes are commonly recommended for patients with advanced dementia in order to speed their discharge to a nursing home.	.699
Fewer regulatory citations occur when patients with advanced dementia have a feeding tube. (Regulatory citations from the state health department, Centers for Medicare & Medicaid Services, or The Joint Commission.)	.624

Table 6
Scale Means, Ranges, and Cronbach's alpha

Factor Name	Potential Scale Range	<i>M ± SD</i>	Scale Cronbach's alpha
Factor 1: Knowledge Self-Efficacy	0 - 30	22.2 ± 4.3	.865
Factor 2: Religion/Spirituality/Culture	0 - 25	18.7 ± 4.3	.851
Factor 3: Personal Values	0 - 35	29.1 ± 4.1	.820
Factor 4: Perceived Organization and Training	0 - 25	20.6 ± 2.9	.656
Factor 5: Perceived Policy	0 - 15	11.6 ± 2.2	.653

Table 7
Correlations Between Factors (using Pearson's r)

	Knowledge Self-Efficacy	Religion/Spirituality/Culture	Personal Values	Perceived Organization and Training
Knowledge Self-Efficacy				
Religion/Spirituality/Culture	.172 ^a			
Personal Values	.352 ^a	.364 ^a		
Perceived Organization and Training	.546 ^a	.106 ^a	.164 ^a	
Perceived Policy	.289 ^a	.123 ^a	.274 ^a	.294 ^a

^a Correlation significant at $p < .05$

At the conclusion of the efficacy survey, a total of 498 RDs volunteered to complete the survey again for test-retest analysis. Of those, 184 surveys were completed and analyzed. As the final instrument included the knowledge score from the first section of the survey, and the scores for each of the five factors obtained from the factor analysis of the second section of the survey, the test-retest reliability analysis was based on a total of six subscales from the efficacy survey. Scores for each subscale were computed, and were normally distributed. Thus, Pearson's correlations were computed for each score, using the first and second set of survey responses from each RD. Correlation coefficients can be found in Table 8.

Table 8
Test-Retest Reliability

Factor Name	Time 1 <i>M ± SD</i>	Time 2 <i>M ± SD</i>	<i>r</i>
Knowledge Score	15.6 ± 3.5	16.2 ± 3.7	.766
Knowledge Self-Efficacy Score	22.8 ± 4.3	22.6 ± 4.4	.719
Religion/Spirituality/Culture Score	18.8 ± 4.3	18.5 ± 4.5	.812
Personal Values Score	29.5 ± 4.0	29.2 ± 4.4	.765
Perceived Organization and Training Score	20.6 ± 2.9	20.5 ± 2.9	.602
Perceived Policy Score	11.8 ± 2.2	11.6 ± 2.4	.689

Discussion

This study aimed to develop and validate a theory-based survey instrument to measure knowledge, beliefs, attitudes, and perceptions of RDs regarding the use of feeding tubes for older adults with advanced dementia, and to define factors that influence RD recommendations. The results of the study were a valid and reliable survey tool, based on the Social Ecological Model that assesses levels of influence on RDs' recommendations. This survey had two components: the knowledge survey, which measured RDs' knowledge of current evidence-based guidelines for feeding older adults with advanced dementia, and the section on attitudes, beliefs, and perceptions of organizational- and policy-level influences. The final revised survey instrument contained 26 items in the second section, with the overall Cronbach's alpha and item-to-total correlations indicating adequate internal consistency.

Construct validity was established using exploratory factor analysis (Huck & Cormier, 1996), whereby five factors were identified and named based the items they contained. Items in Factor 1 involved RDs' self-efficacy regarding their own knowledge, and as such, Factor 1 was named 'Knowledge Self-Efficacy.' This is supported in the literature, where studies have shown that knowledge gaps exist among health care clinicians (Langdon et al., 2002; Lopez, Amella, Mitchell, et al., 2010), and that these clinicians are at times unsure of their own knowledge regarding the use of feeding tubes for older adults with advanced dementia (Vitale et al., 2011).

Factor 2, named 'Religion/Spirituality/Culture', included items regarding cultural, spiritual, and religious beliefs that impact how RDs make recommendations regarding feeding tube use among older adults with advanced dementia. Several other researchers found that the religion, cultural background, and spirituality of practitioners may influence their clinical recommendations. A qualitative study of physicians in Japan revealed that physicians' decisions

regarding feeding patients with advanced dementia were influenced by cultural norms (Aita et al., 2007). In another study, physicians varied in the degree to which they reported basing end-of-life feeding decisions on their own personal religious beliefs (Hinkka et al., 2002).

Factor 3 involved personal values and personal comfort regarding feeding tube use among older adults with advanced dementia, and thus was named ‘Personal Values.’ This is supported in the literature by studies that have indicated that some clinicians are uncomfortable allowing a person to go without a feeding tube, and that clinicians vary in their feelings about prolonging life using a feeding tube (Hinkka et al., 2002; Langdon et al., 2002). One study reported that physicians’ personal values toward length of life can vary considerably, and some physicians are more comfortable with euthanasia than others (Hinkka et al., 2002). In a study of RDs, participants varied in their opinions on whether the removal of nutrition support in an end-of-life situation would impact their personal morals (Langdon et al., 2002).

The items loading onto Factor 4 involved RDs’ perceptions of organizational culture and the training provided by the organization, and was thusly named ‘Perceived Organization and Training.’ The literature and the Social Ecological Model support the idea that corporate culture and organizational norms influence the use of feeding tubes in health care facilities (Lopez, Amella, Strumpf, et al., 2010). Studies indicate that not all facilities take a multidisciplinary approach to decision-making for feeding tube use, and that corporate culture does not always allow all clinicians to be involved in decision-making (Bryon, Dierckx de Casterlé, & Gastmans, 2012; Bryon, Gastmans, & Dierckx de Casterlé, 2010; Bryon, Gastmans, & Dierckx de Casterlé, 2012). However, RDs have reported that they feel they should be a part of these decisions (Healy & McNamara, 2002; Langdon et al., 2002). Research also indicates that some clinicians do not feel adequately trained to provide education to patients and family members regarding the

use of feeding tubes in cases of advanced dementia (Langdon et al., 2002). Other studies have shown that clinicians who have received specialized training on this topic are less likely to agree with feeding tube use for this patient population (Valentini et al., 2014). Thus, organizational norms and the training provided to clinicians can significantly impact clinicians' recommendations.

Factor 5, named 'Perceived Policy,' contained items regarding health policy and legislation. A number of studies have indicated that health care regulations and reimbursement can impact feeding tube use. One study of nursing home patients with advanced dementia compared the nutrition-related costs associated with caring for patients with and without a feeding tube, and showed that health care costs are actually greater for those who forgo a feeding tube and are hand-fed instead, due to the amount of time required to hand-feed a person with advanced dementia (Mitchell, Buchanan, et al., 2003). Thus, facilities receive greater reimbursement for tube-fed patients, but caring for these patients actually costs less than caring for similar patients who are hand-fed. This reimbursement structure may inadvertently promote the use of feeding tubes in this patient population (Finucane et al., 2007; Mitchell, 2003). Physicians and nurses have reported feeling unsure of the legal implications associated with forgoing a feeding tube in patients with advanced dementia (Aita et al., 2007; Lopez, Amella, Mitchell, et al., 2010). Additionally, research indicates that some facilities may favor the use of feeding tubes in patients with advanced dementia in order to avoid regulatory citations for patients who are malnourished (Lopez, Amella, Strumpf, et al., 2010).

According to the Social Ecological Model, it was hypothesized that factors both internal and external to RDs would influence whether they recommended feeding tubes for older adults with advanced dementia. Results of the exploratory factor analysis are consistent with this,

whereby the knowledge, knowledge self-efficacy, and personal values of the RD are internal factors. Similarly, organizational and policy factors emerged as external influences. Thus, the findings of this survey are consistent with the constructs within the Social Ecological Model. Additionally, the factors identified here are similar to those found in another study of the attitudes of Canadian dietitians toward the provision of nutrition support for terminally ill elderly patients (Taper & Hockin, 1996), which determined six factors that constituted a decision-making framework for participants in their study, including factors related to religion and personal values.

In order to evaluate the internal consistency reliability of the items loading onto each factor, the Cronbach's alpha of each factor was compared to established benchmarks. According to DeVellis (2003), a Cronbach's alpha between .65 and .70 is minimally acceptable. Other benchmarks indicate that a Cronbach's alpha of .70 or greater yields adequate internal consistency (Pyrczak, 1999). While the first three factors have Cronbach's alpha values that are adequate (see Table 6), the last two factors, Perceived Organization and Training, and Perceived Policy, have values indicating minimally acceptable internal consistency reliability ($\alpha = .656$ and $.653$, respectively).

In evaluating the test-retest reliability of the survey, scores were generated for each of the six subscales identified. According to Nunnally and Bernstein, a correlation coefficient of .70 – .80 is better, and .90 is excellent for test-retest reliability (as cited in Sharma & Petosa, 2014). As seen in Table 8, the first four subscales achieved correlation coefficients $> .70$ (Knowledge Score, Knowledge Self-Efficacy Score, Religion/Spirituality/Culture Score, and Personal Values Score), but the last two fell between .60 – .70, limiting the reliability of those scales (Perceived Organization and Training Score and Perceived Policy Score).

Thus, the results of the internal consistency reliability and test-retest reliability analyses indicate that, while Perceived Organization and Training and Perceived Policy were important factors that contributed to how RDs made recommendations for the use of feeding tubes among older adults with advanced dementia, these are the weaker scales within the instrument. It is likely that these factors would be strengthened by the addition of more survey items, which would likely make the analysis of each factor more meaningful.

Several limitations are inherently present in the methodology utilized in the development and validation of this study. First, the study population was limited to a random sample of approximately 20% of the 25,000 dietitians who work in settings where they may provide nutritional care to older adults. Thus, while the demographic data provided by participants indicated that the sample was similar to the larger population of RDs in the United States, there is always a question of generalizability, as it is possible those who participated in the study are somehow different from other RDs in the larger population. The use of an electronic survey may also be a limitation, as response rates are often lower with online surveys compared to mailed surveys. However, the response and completion rates (18.5% and 13.4%, respectively) were slightly better than another recent electronic survey of dietitians (Szeto, O'Sullivan Maillet, Brody, & Parrott, 2014). This method of data collection may also involve selection bias, as it is possible that not all RDs are comfortable completing an online survey. Therefore, invitations to some potential participants may have been ignored. Additionally, as the random sample of RDs was generated based on a self-classification of primary practice area, it is possible that RDs who failed to specify a practice area were not included in the frame for the random sample. Furthermore, those who misidentified a specialty practice area may have been erroneously included in or excluded from the sample frame. The accuracy of the results depends upon self-

report, which may be compromised by RD honesty, and may be skewed by social desirability bias or poor memory.

In spite of several limitations, this study also has several strengths. Using a structured approach to instrument development, the instrument underwent expert panel review and pilot testing (Sharma & Petosa, 2014). The survey utilized a random sample of RDs, which was similar to the overall population of RDs in the United States. The final survey instrument had adequate internal consistency and test-retest reliability. Furthermore, it revealed factors that were consistent with a well-known theoretical model.

Conclusions

This study yielded a valid and reliable survey instrument, which was subjected to expert panel review and pilot testing prior to the efficacy study. The exploratory factor analysis yielded five factors, which are consistent with the constructs of the Social Ecological Model: I) Knowledge Self-Efficacy, II) Religion/Spirituality/Culture, III) Personal Values, IV) Perceived Organization and Training, and V) Perceived Policy. Thus, the results of this study indicate that the Social Ecological Model is an appropriate theoretical framework for approaching the issue of RDs' recommendations for feeding tube use for older adults with advanced dementia. Future research should seek to further explore the factors identified by this study, particularly the Perceived Organization and Training and Perceived Policy factors. Additionally, further testing of this survey instrument with other members of the health care team (nurses, physicians, Speech-Language Pathologists) would improve the generalizability and usefulness of the tool.

References

- Aita, K., Takahashi, M., Miyata, H., Kai, I., & Finucane, T. E. (2007). Physicians' attitudes about artificial feeding in older patients with severe cognitive impairment in Japan: A qualitative study. *BMC Geriatrics*, (7)22. doi:1471-2318-7-22
- Alzheimer's Association. (2015). *Feeding issues in advanced dementia*. Retrieved from http://www.alz.org/documents_custom/statements/Feeding_Issues.pdf
- Alzheimer's Disease Facts and Figures. (2017). *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 13(4). 325-373. doi:10.1016/j.jalz.2017.02.001
- American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement. (2014). *Journal of the American Geriatrics Society*, 62(8), 1590-1593. doi:10.1111/jgs.12924
- Asai, A., & Fukuhara, S. (1995). Attitudes of Japanese and Japanese-American physicians towards life-sustaining treatment. *Lancet*, 346(8971), 356-359.
- Attanasio, A., Bedin, M., Stocco, S., Negrin, V., Biancon, A., Cecchetto, G., & Tagliapietra, M. (2009). Clinical outcomes and complications of enteral nutrition among older adults. *Minerva Medica*, 100(2), 159-166.
- Baranowski, T. (1989). Reciprocal determinism at the stages of behavior change: An integration of community, personal and behavioral perspectives. *The International Quarterly of Community Health Education*, 10(4), 297-327.
- Bell, C. L., Lee, A. S. W., & Tamura, B. K. (2015). Malnutrition in the nursing home. *Current Opinion in Clinical Nutrition & Metabolic Care*, 18(1), 17-23. doi:10.1097/MCO.0000000000000130
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513-531. doi:10.1037/0003-066X.32.7.513
- Bryon, E., Dierckx de Casterlé, B., & Gastmans, C. (2012). 'Because we see them naked' - nurses' experiences in caring for hospitalized patients with dementia: Considering artificial nutrition or hydration (ANH). *Bioethics*, 26(6), 285-295. doi:10.1111/j.1467-8519.2010.01875.x
- Bryon, E., Gastmans, C., & Dierckx de Casterlé, B. (2010). Involvement of hospital nurses in care decisions related to administration of artificial nutrition or hydration (ANH) in patients with dementia: A qualitative study. *International Journal of Nursing Studies*, 47(9), 1105-1116. doi:10.1016/j.ijnurstu.2010.01.011
- Bryon, E., Gastmans, C., & Dierckx de Casterlé, B. (2012). Nurse-physician communication concerning artificial nutrition or hydration (ANH) in patients with dementia: A qualitative

study. *Journal of Clinical Nursing*, 21(19-20), 2975-2984. doi:10.1111/j.1365-2702.2011.04029.x

- Carmel, S. (1999). Life-sustaining treatments: What doctors do, what they want for themselves and what elderly persons want. *Social Science & Medicine*, 49(10), 1401-1408.
- Chung, A. M. (2012). Percutaneous gastrostomy feeding tubes in end stage dementia: Don't 'just do it'. *Journal of the Canadian Association of Radiologists*, 63(3), S5-S6.
- Cintra, M. T., de Rezende, N. A., de Moraes, E. N., Cunha, L. C., & da Gama Torres, H. O. (2014). A comparison of survival, pneumonia, and hospitalization in patients with advanced dementia and dysphagia receiving either oral or enteral nutrition. *The Journal of Nutrition, Health & Aging*, 18(10), 894-899. doi:10.1007/s12603-014-0487-3
- Commission on Dietetic Registration (CDR). (2017). *Registered Dietitian (RD) and Registered Dietitian Nutritionist (RDN) by demographics*. Retrieved May 1, 2017 from <https://www.cdrnet.org/registry-statistics?id=2092&actionxm=ByDemographics>
- Cronk, B. C. (1999). *How to use SPSS : A step-by-step guide to analysis and interpretation*. Los Angeles, CA: Pyrczak.
- DeVellis, R. F. (2003). *Scale development. Theory and applications* (2nd ed.). Newbury Park, CA: Sage.
- Enrione, E. B., & Chutkan, S. (2007). Research: Preferences of registered dietitians and nurses recommending artificial nutrition and hydration for elderly patients. *Journal of the American Dietetic Association*, 107, 416-421. doi:10.1016/j.jada.2006.12.008
- Finucane, T. E., Christmas, C., & Leff, B. A. (2007). Tube-feeding in dementia: How incentives undermine health care quality and patient safety. *Journal of the American Medical Directors Association*, 8(4), 205-208. doi:S1525-8610(07)00022-9
- Hasan, M., Meara, R. J., Bhowmick, B. K., & Woodhouse, K. (1995). Percutaneous endoscopic gastrostomy in geriatric patients: Attitudes of health care professionals. *Gerontology*, 41(6), 326-331.
- Healy, S., & McNamara, E. (2002). Tube feeding controversial patients: What do dietitians think? *Journal of Human Nutrition & Dietetics*, 15(6), 445-453.
- Hinkka, H., Kosunen, E., Lammi, U., Metsänoja, R., Puustelli, A., & Kellokumpu-Lehtinen, P. (2002). Decision making in terminal care: A survey of Finnish doctors' treatment decisions in end-of-life scenarios involving a terminal cancer and a terminal dementia patient. *Palliative Medicine*, 16(3), 195-204.
- Huck, S. W., & Cormier, W. H. (1996). *Reading statistics and research* (2nd ed). New York, NY: Harper Collins.

- Kaw, M., & Sekas, G. (1994). Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing home patients. *Digestive Diseases and Sciences, 39*(4), 738-743.
- Kuo, S., Rhodes, R. L., Mitchell, S. L., Mor, V., & Teno, J. M. (2009). Natural history of feeding-tube use in nursing home residents with advanced dementia. *Journal of the American Medical Directors Association, 10*(4), 264-270. doi:10.1016/j.jamda.2008.10.010
- Lacey, D. (2005). Tube feeding, antibiotics, and hospitalization of nursing home residents with end-stage dementia: Perceptions of key medical decision-makers. *American Journal of Alzheimer's Disease and Other Dementias, 20*(4), 211-219.
- Lacey, D. (2006). End-of-life decision making for nursing home residents with dementia: A survey of nursing home social services staff. *Health & Social Work, 31*(3), 189-99.
- Langdon, D. S., Hunt, A., Pope, J., & Hackes, B. (2002). Perspectives in Practice: Nutrition support at the end of life: Opinions of Louisiana dietitians. *Journal of the American Dietetic Association, 102*, 837-840. doi:10.1016/S0002-8223(02)90186-0
- Lopez, R. P., Amella, E. J., Mitchell, S. L., & Strumpf, N. E. (2010). Nurses' perspectives on feeding decisions for nursing home residents with advanced dementia. *Journal of Clinical Nursing, 19*(5-6), 632-638. doi:10.1111/j.1365-2702.2009.03108.x
- Lopez, R. P., Amella, E. J., Strumpf, N. E., Teno, J. M., & Mitchell, S. L. (2010). The influence of nursing home culture on the use of feeding tubes. *Archives of Internal Medicine, 170*(1), 83-88. doi:10.1001/archinternmed.2009.467
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly, 15*(4), 351-377. doi:10.1177/109019818801500401
- Mitchell, S. L. (2003). Financial incentives for placing feeding tubes in nursing home residents with advanced dementia. *Journal of the American Geriatrics Society, 51*(1), 129-131.
- Mitchell, S. L., Buchanan, J. L., Littlehale, S., & Hamel, M. B. (2003). Tube-feeding versus hand-feeding nursing home residents with advanced dementia: A cost comparison. *Journal of the American Medical Directors Association, 4*, 27-33.
- Mitchell, S. L., Teno, J. M., Roy, J., Kabumoto, G., & Mor, V. (2003). Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *Journal of the American Medical Association, 290*(1), 73-80.
- Mitchell, S. L., Mor, V., Gozalo, P. L., Servadio, J. L., & Teno, J. M. (2016). Tube feeding in US nursing home residents with advanced dementia, 2000-2014. *Journal of the American Medical Association, 316*(7), 769-770. doi:10.1001/jama.2016.9374

- Modi, S. C., Whetstone, L. M., & Cummings, D. M. (2007). Influence of patient and physician characteristics on percutaneous endoscopic gastrostomy tube decision-making. *Journal of Palliative Medicine, 10*(2), 359-366. doi:10.1089/jpm.2006.0145
- Ogita, M., Utsunomiya, H., Akishita, M., & Arai, H. (2012). Indications and practice for tube feeding in Japanese geriatricians: Implications of multidisciplinary team approach. *Geriatrics & Gerontology International, 12*(4), 643-651. doi:10.1111/j.1447-0594.2011.00831.x
- Pyrczak, F. (1999) *Evaluating research in academic journals: A practical guide to realistic evaluation*. Los Angeles, CA: Pyrczak.
- Ribeiro Salomon, A. L., & Carvalho Garbi Novaes, M. R. (2015). Outcomes of enteral nutrition for patients with advanced dementia - A systematic review. *Journal of Nutrition, Health & Aging, 19*(2), 169-177. doi:10.1007/s12603-014-0517-1
- Schwartz, D. B., Barrocas, A., Wesley, J. R., Klinger, G., Pontes-Arruda, A., Márquez, H. A., . . . DiTucci, A. (2014). Gastrostomy tube placement in patients with advanced dementia or near end of life. *Nutrition in Clinical Practice, 29*(6), 829-840. doi:10.1177/0884533614546890
- Sharma, M., & Petosa, R. L. (2014). *Measurement and evaluation for health educators* (1st ed.). Burlington, MA: Jones & Bartlett Learning.
- Sharp, H. M., & Shega, J. W. (2009). Feeding tube placement in patients with advanced dementia: The beliefs and practice patterns of speech-language pathologists. *American Journal of Speech-Language Pathology / American Speech-Language-Hearing Association, 18*(3), 222-230. doi:10.1044/1058-0360(2008/08-0013)
- Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2003). Barriers to limiting the practice of feeding tube placement in advance dementia. *Journal of Palliative Medicine, 6*(6), 885-893.
- Stokols, D. (1992). Establishing and maintaining healthy environments: Toward a society ecology of health promotion. *The American Psychologist, 47*(1), 6-22.
- Stokols, D. (1996). Translating social ecological theory into guidelines for community health promotion. *American Journal of Health Promotion, 10*(4), 282-298.
- Szeto, M. O. P., O'Sullivan Maillet, J., Brody, R. A., & Parrott, J. S. (2014). Registered Dietitians' roles in decision-making processes for PEG placement in the elderly. *Canadian Journal of Dietetic Practice & Research, 75*(2), 78-83. doi:10.3148/75.2.2014.78
- Tabachnick, B. G., & Fidell, L. S. (2007). *Using multivariate statistics* (5th ed.). Boston, MA: Pearson/Allyn & Bacon.

- Taper, L. J., & Hockin, D. (1996). Life sustaining nutrition support for the terminally ill elderly: Dietitians' ethical attitudes and beliefs. *Journal of the Canadian Dietetic Association*, 57(1), 19-24.
- Teno, J. M., Gozalo, P., Mitchell, S. L., Kuo, S., Fulton, A. T., & Mor, V. (2012). Feeding tubes and the prevention or healing of pressure ulcers. *Archives of Internal Medicine*, 172(9), 697-701. doi:10.1001/archinternmed.2012.1200
- Teno, J. M., Mitchell, S. L., Kuo, S. K., Gozalo, P. L., Rhodes, R. L., Lima, J. C., & Mor, V. (2011). Decision-making and outcomes of feeding tube insertion: A five-state study. *Journal of the American Geriatrics Society*, 59(5), 881-886. doi:10.1111/j.1532-5415.2011.03385.x
- Teno, J., Meltzer, D. O., Mitchell, S. L., Fulton, A. T., Gozalo, P., & Mor, V. (2014). Type of attending physician influenced feeding tube insertions for hospitalized elderly people with severe dementia. *Health Affairs*, 33(4), 675-682. doi:10.1377/hlthaff.2013.1248
- Valentini, E., Giantin, V., Voci, A., Iasevoli, M., Zurlo, A., Pengo, V., . . . Manzato, E. (2014). Artificial nutrition and hydration in terminally ill patients with advanced dementia: Opinions and correlates among Italian physicians and nurses. *Journal of Palliative Medicine*, 17(10), 1143-1149. doi:10.1089/jpm.2013.0616
- Vitale, C. A., Berkman, C. S., Monteleoni, C., & Ahronheim, J. C. (2011). Tube feeding in patients with advanced dementia: Knowledge and practice of speech-language pathologists. *Journal of Pain and Symptom Management*, 42(3), 366-378. doi:10.1016/j.jpainsymman.2010.11.017
- Vitale, C. A., Hiner, T., Ury, W. A., Berkman, C. S., & Ahronheim, J. C. (2006). Tube feeding in advanced dementia: An exploratory survey of physician knowledge. *Care Management Journals: Journal of Case Management; the Journal of Long Term Home Health Care*, 7(2), 79-85.
- Volkert, D., Chourdakis, M., Faxen-Irving, G., Frühwald, T., Landi, F., Suominen, M. H., . . . Schneider, S. M. (2015). ESPEN guidelines on nutrition in dementia. *Clinical Nutrition*, 34(6), 1052-1073. doi:10.1016/j.clnu.2015.09.004
- Wall, M. G., Wellman, N. S., Curry, K. R., & Johnson, P. M. (1991). Feeding the terminally ill: Dietitians' attitudes and beliefs. *Journal of the American Dietetic Association*, 91(5), 549-552.
- Winett, R. A. (1995). A framework for health promotion and disease prevention programs. *The American Psychologist*, (5), 341-350.
- Xu, J., Murphy, S. L., Kochanek, K. D., & Arias, E. (2016). Mortality in the United States, 2015. *NCHS Data Brief*, (267), 1-8.

Appendix B
Drafted Survey Instrument

1. Screening question: Are you currently employed as a Registered Dietitian in a facility or setting where you provide nutrition care to older adult patients (ages 65+)?
 - a. If yes, proceed to IRB letter of consent.
 - b. If no, end survey.

2. In general, based on your knowledge, beliefs, and experiences, how likely are you to recommend a feeding tube for a patient with advanced dementia?
 - a. Highly unlikely
 - b. Somewhat unlikely
 - c. Neutral
 - d. Somewhat likely
 - e. Highly likely

Section I. Based on your knowledge of evidence-based guidelines for the use of feeding tubes among older adults with dementia, please answer the following questions.			
	True	False	Don't Know
Among older adults with advanced dementia,			
3. Feeding tubes are recommended for use when feeding difficulties arise.			
4. Patient survival improves when feeding tubes are used.			
5. Feeding tubes prevent aspiration pneumonia.			
6. The use of a feeding tube will prevent pressure ulcers from developing.			
7. The use of a feeding tube will promote the healing of pressure ulcers.			
8. Tube feeding improves nutritional status.			
9. Tube-related complications are common when feeding tubes are used.			
10. Tube-related infections are common when feeding tubes are used.			
11. Chemical restraints are common when feeding tubes are used.			
12. Physical restraints are common when feeding tubes are used.			
13. Those with a feeding tube who reside in a nursing home are more likely than those without a tube to be transferred to the hospital or emergency department.			
14. Careful hand-feeding is an acceptable alternative to tube feeding.			

Among older adults with advanced dementia,	True	False	Don't Know
15. Feeding tubes are a cheaper and easier way to provide nutrition than hand-feeding.			
16. The family members should be able to accept or decline a feeding tube for their loved one based on the patient's advanced directive or what they feel the patient would want.			
17. Eating difficulties are a part of the natural progression of the disease.			
18. The presence of persistent eating difficulties signals a transition into the end stage of dementia.			
19. Feeding tubes are often placed during in-patient hospitalizations for an acute illness.			
20. The health care team should determine the plan of care, regardless of the input of the patient or his/her family members.			
21. Decisions about the use of feeding tubes should be shared between the patient's family members and the health care team.			
22. It is the professional obligation of the health care team to inform patients and their families of the risks and benefits associated with feeding tube use.			
23. Health care professionals must honor the autonomy of the patient while being sensitive to the patient's cultural and religious values.			

Section II. Please indicate your agreement with the following statements regarding the use of feeding tubes for older adults with advanced dementia.					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
24. Considering the use of feeding tubes for older adults with advanced dementia, I believe that the patient's quality of life is the most important consideration.					
25. Considering the use of feeding tubes for older adults with advanced dementia, I believe that the patient's wishes are the most important consideration.					
26. Considering the use of feeding tubes for older adults with advanced dementia, I believe that prolonging the patient's life is the most important consideration.					
27. Considering the use of feeding tubes for older adults with advanced dementia, I believe that the health care team should do everything possible to prolong life, including provide nutrition support.					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
28. Considering the use of feeding tubes for older adults with advanced dementia, I believe that terminally ill patients should be allowed to refuse a feeding tube.					
29. Considering the use of feeding tubes for older adults with advanced dementia, I believe that it is acceptable to forgo a feeding tube.					
30. Considering the use of feeding tubes for older adults with advanced dementia, forgoing a feeding tube for a patient violates my personal values.					
31. Considering the use of feeding tubes for older adults with advanced dementia, my personal experiences with my own family members have impacted how I make recommendations for patients.					
32. Considering the use of feeding tubes for older adults with advanced dementia, I feel sadness when a patient dies.					
33. Considering the use of feeding tubes for older adults with advanced dementia, I think that my religious beliefs play an important role in how I make recommendations for my patients.					
34. Considering the use of feeding tubes for older adults with advanced dementia, I think that my faith in God (or a higher power) is an important factor that impacts my clinical recommendations.					
35. Considering the use of feeding tubes for older adults with advanced dementia, I think that my spirituality is an important factor that impacts my clinical recommendations.					
36. Considering the use of feeding tubes for older adults with advanced dementia, due to my religious background, I am uncomfortable allowing a patient with advanced dementia to go without food and water (or deny a feeding tube).					
37. Considering the use of feeding tubes for older adults with advanced dementia, due to my spiritual background, I am uncomfortable allowing a patient with advanced dementia to go without food and water (or deny a feeding tube).					
38. Considering the use of feeding tubes for older adults with advanced dementia, my cultural background favors allowing individuals and their family members to make decisions regarding end-of-life care.					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
39. Considering the use of feeding tubes for older adults with advanced dementia, my cultural background favors allowing the medical team to make decisions regarding end-of-life care.					
40. Considering the use of feeding tubes for older adults with advanced dementia, due to my cultural background, I am uncomfortable allowing a patient with advanced dementia to go without food and water (or deny a feeding tube).					
41. Considering the use of feeding tubes for older adults with advanced dementia, my cultural background influences how I view allowing a patient with advanced dementia to go without food and water.					
42. Considering the use of feeding tubes for older adults with advanced dementia, I believe that I have been adequately trained to provide nutrition recommendations and education for this patient population.					
43. Considering the use of feeding tubes for older adults with advanced dementia, I lack adequate knowledge on the current research surrounding the use of feeding tubes in patients with dementia.					
44. Considering the use of feeding tubes for older adults with advanced dementia, I believe that Registered Dietitians need more training on ethical decision-making.					
45. Considering the use of feeding tubes for older adults with advanced dementia, I feel confident in my clinical recommendations for patients with advanced dementia.					
46. Based on my experience in the facilities where I have worked, speech therapists are often involved in decisions regarding feeding tube use.					
47. Based on my experience in the facilities where I have worked, policies are in place, which specify how to address the use of feeding tubes among patients with dementia.					
48. Based on my experience in the facilities where I have worked, Registered Dietitians are included in the decision-making process regarding feeding tube placement.					
49. Based on my experience in the facilities where I have worked, my professional input is valued by the physicians I work with.					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
50. Based on my experience in the facilities where I have worked, there is adequate staffing to hand-feed patients who need assistance.					
51. Based on my experience in the facilities where I have worked, initiatives have been taken to make the dining experience resemble a home-like setting (open dining times and seating plans, multiple menu options available, encouraging patient choice in dining).					
52. Based on my experience in the facilities where I have worked, the dining experience is very institutional (pre-assigned dining times and menu selections, assigned dining room seating, limited patient choices allowed).					
53. Based on my experience in the facilities where I have worked, the use of advance care planning is encouraged by the health care team.					
54. Based on my experience in the facilities where I have worked, feeding tubes are commonly recommended for patients with dementia in order to speed their discharge to a skilled nursing facility.					
55. Based on my experience in the facilities where I have worked, I am uncertain about the legal implications associated with making recommendations for feeding tube use among patients with advanced dementia.					
56. Based on my experience in the facilities where I have worked, I am uncertain about the ethical implications associated with making recommendations for feeding tube use among patients with advanced dementia.					
57. Based on my experience in the facilities where I have worked, feeding tubes are commonly recommended for patients with dementia because reimbursement is greater for tube-fed patients.					
58. Based on my experience in the facilities where I have worked, the use of feeding tubes helps to prevent regulatory citations.					

Section III: Please complete the following demographic information. Understanding more about our participants helps us to better understand how you make clinical decisions.

59. Please indicate your biological sex

- a. Male
- b. Female
- c. Other/Prefer not to disclose

60. Please indicate your age in years: _____

61. Are you of Hispanic, Latino, or Spanish origin?

- a. Yes
- b. No
- c. Prefer not to disclose

62. Which of the following best describes your racial background?

- a. White
- b. Black/African American
- c. Asian
- d. American Indian or Alaska Native
- e. Native Hawaiian or other Pacific Islander
- f. Two or more races
- g. Other
- h. Prefer not to disclose

63. Please indicate the highest level of education you have completed:

- a. Bachelor's degree
- b. Master's degree
- c. Doctoral degree

64. Please indicate any specialty certifications you have earned. Select all that apply.
- a. Board Certified Specialist in Gerontological Nutrition
 - b. Certified Nutrition Support Clinician
 - c. Other CDR Board Specialty Certificate (Pediatrics, Sports, Renal, Oncology)
 - d. Other certification: _____ (Example: Certified Lactation Consultant, Certified Diabetes Educator, Certified Health Education Specialist, etc...)
 - e. None
65. Please indicate the type of facility where you primarily practice:
- a. Hospital/Acute care facility
 - b. Rehabilitation facility
 - c. Long-term, extended care, or assisted living facility
 - d. Outpatient care
 - e. Community nutrition
 - f. Home health care
 - g. Hospice
 - h. Government agency or department
 - i. Other _____
66. How many years have you been in practice as a Registered Dietitian? _____
67. How many years have you worked as a Registered Dietitian in a setting where you provide nutrition care to older adults?

68. What is your religious affiliation?

- a. Protestant (Baptist, Methodist, Lutheran, Episcopalian, Pentecostal, Presbyterian, Non-denominational, etc...)
- b. Catholic
- c. Jewish
- d. Muslim
- e. Buddhist
- f. Hindu
- g. Other: _____
- h. None

69. If you would be willing to repeat this survey in the coming weeks to assist the researcher in establishing the reliability of this survey instrument, your name will be entered twice into the drawing to win one of twelve \$50 gift cards. If you are willing, please enter your email address here: _____

70. Thank you for your participation! Please click the link below to register for the drawing to win one of twelve \$50 gift cards.

Appendix C Pilot Survey Instrument

1. Screening question: Are you currently employed as a Registered Dietitian in a facility or setting where you provide nutrition care to older adult patients (ages 65+)?

If yes, proceed to next item. (If no, end survey.)

The following definitions may be useful in answering the survey questions:

Advanced Dementia: The terminal phase of dementia, characterized by the inability to eat, walk, talk, or interact with others. Also known as severe dementia or end-stage dementia.

Dementia: Dementia is a neurological, progressive, and debilitating disease that causes losses in functional and cognitive capabilities due to damage to the neurons in the brain. This includes mild to severe (or advanced) dementia. For the purposes of this study, dementia is considered a permanent, progressive, and irreversible condition characterized by neurological damage.

Feeding tube: A tube that is inserted into the gastrointestinal tract to provide nutrients to an individual who is unable to consume adequate nutrition by mouth. Two common types are the gastrostomy tube, and the nasogastric tube.

Older Adult: An individual aged 65 years or older.

Registered Dietitian: Registered Dietitians (RDs) are food and nutrition experts who have met the following criteria to earn the RD credential in the United States: completed a minimum of a bachelor's degree, completed an ACEND-accredited supervised practice program, passed a national examination, and completed continuing professional educational requirements to maintain registration.

1. In general, based on your knowledge, beliefs, and experiences, how likely are you to recommend a feeding tube for a patient with advanced dementia?
- a. Highly Likely
 - b. Somewhat Likely
 - c. Neither Likely nor Unlikely
 - d. Somewhat Unlikely
 - e. Highly Unlikely

Section I. Based on your knowledge of evidence-based guidelines for the use of feeding tubes among older adults with advanced dementia, please select the best response to the following statements.			
Among older adults with advanced dementia,	True	False	Don't Know
3. Feeding tubes are recommended for use when oral feeding difficulties arise.			
4. Patient survival improves when feeding tubes are used.			
5. Feeding tubes prevent aspiration pneumonia.			
6. Feeding tube use prevents pressure ulcers from developing.			
7. Feeding tube use promotes the healing of pressure ulcers.			
8. Tube feeding improves nutritional status.			
9. Tube-related complications (such as aspiration pneumonia, tube malfunctions, and discomfort) are common when feeding tubes are used.			
10. Tube-related infections are common when feeding tubes are used.			
11. Chemical restraints (such as sedating medications) are common when feeding tubes are used.			
12. Physical restraints are common when feeding tubes are used.			
13. Nursing home residents with a feeding tube are transferred to the hospital or emergency department more frequently than residents without a tube.			
14. Careful hand-feeding is an acceptable alternative to tube feeding.			
15. Feeding tubes are a cheaper and easier way to provide nutrition than hand-feeding.			
16. The family members should be able to accept or decline a feeding tube for their loved one based on the patient's advanced directive.			
17. The family members should be able to accept or decline a feeding tube for their loved one based on what they feel the patient would want.			
18. Eating difficulties are a part of the natural progression of dementia.			
19. Persistent eating difficulties signal that dementia is progressing into advanced or end-stage dementia.			
20. Feeding tubes are often placed during in-patient hospitalizations for an acute illness.			
21. The health care team should determine the plan of care, regardless of the input of the patient or his/her family members.			
22. Decisions about the use of feeding tubes should be shared between the patient's family members and the health care team.			
23. It is the professional obligation of the health care team to inform patients and their families of the risks and benefits associated with feeding tube use.			

Among older adults with advanced dementia,	True	False	Don't Know
24. Health care professionals must honor the wishes of the patient, being sensitive to the patient's cultural and religious values.			

Section II. Please select the response that best reflects your opinion regarding the use of feeding tubes for older adults with advanced dementia.					
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
25. Considering the use of feeding tubes for older adults with advanced dementia, I believe that the patient's quality of life is an important consideration.					
26. Considering the use of feeding tubes for older adults with advanced dementia, I believe that the patient's wishes are an important consideration.					
27. Considering the use of feeding tubes for older adults with advanced dementia, I believe that prolonging the patient's life is an important consideration.					
28. Considering the use of feeding tubes for older adults with advanced dementia, I believe that the health care team should do everything possible to prolong the patient's life, including provide nutrition support.					
29. Considering the use of feeding tubes for older adults with advanced dementia, I believe that patients with advanced dementia should be allowed to refuse a feeding tube (as previously expressed through an advance directive).					
30. Considering the use of feeding tubes for older adults with advanced dementia, I believe that it is acceptable to allow a patient to go without a feeding tube.					
31. Considering the use of feeding tubes for older adults with advanced dementia, allowing a patient to go without a feeding tube violates my personal values.					
32. Considering the use of feeding tubes for older adults with advanced dementia, my personal experiences with my own family members have impacted how I make clinical nutrition recommendations for patients.					
33. Considering the use of feeding tubes for older adults with advanced dementia, I feel sad when a patient dies.					

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
34. Considering the use of feeding tubes for older adults with advanced dementia, my religious beliefs play an important role in how I make clinical nutrition recommendations for my patients.					
35. Considering the use of feeding tubes for older adults with advanced dementia, my faith in God (or a higher power) is an important factor that impacts my clinical nutrition recommendations.					
36. Considering the use of feeding tubes for older adults with advanced dementia, my spirituality is an important factor that impacts my clinical nutrition recommendations.					
37. Considering the use of feeding tubes for older adults with advanced dementia, due to my religious background, I am uncomfortable allowing a patient with advanced dementia go without or refuse a feeding tube.					
38. Considering the use of feeding tubes for older adults with advanced dementia, due to my spiritual background, I am uncomfortable allowing a patient with advanced dementia to go without or refuse a feeding tube.					
39. Considering the use of feeding tubes for older adults with advanced dementia, my cultural background favors individuals and their family members making decisions regarding end-of-life care.					
40. Considering the use of feeding tubes for older adults with advanced dementia, my cultural background favors the health care team making decisions regarding end-of-life care.					
41. Considering the use of feeding tubes for older adults with advanced dementia, my cultural background makes me uncomfortable allowing a patient with advanced dementia to go without or refuse a feeding tube.					
42. Considering the use of feeding tubes for older adults with advanced dementia, my cultural background influences how I view allowing a patient with advanced dementia to go without or refuse a feeding tube.					
43. Considering the use of feeding tubes for older adults with advanced dementia, I believe that I have been adequately trained to provide clinical nutrition recommendations for older adults with advanced dementia.					

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
44. Considering the use of feeding tubes for older adults with advanced dementia, I believe that I have been adequately trained to provide nutrition education for older adults with advanced dementia.					
45. Considering the use of feeding tubes for older adults with advanced dementia, I lack adequate knowledge on the current research surrounding the use of feeding tubes in patients with advanced dementia.					
46. Considering the use of feeding tubes for older adults with advanced dementia, I am aware of current research on the use of feeding tubes in patients with advanced dementia.					
47. Considering the use of feeding tubes for older adults with advanced dementia, I have knowledge regarding current research on the use of feeding tubes in patients with advanced dementia.					
48. Considering the use of feeding tubes for older adults with advanced dementia, I believe that Registered Dietitians need more training on ethical decision-making.					
49. Considering the use of feeding tubes for older adults with advanced dementia, I feel confident in my clinical nutrition recommendations for patients with advanced dementia.					
The next set of questions focuses on the organization, setting, or facility where you currently work.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
50. Based on my experience in the most recent facility where I have worked, Speech-Language Pathologists are often involved in decisions regarding feeding tube use.					
51. Based on my experience in the most recent facility where I have worked, institutional policies are in place that specify how to address the use of feeding tubes among patients with advanced dementia.					
52. Based on my experience in the most recent facility where I have worked, Registered Dietitians are included in the decision-making process regarding feeding tube placement.					

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
53. Based on my experience in the most recent facility where I have worked, my professional input is valued by the physicians I work with.					
54. Based on my experience in the most recent facility where I have worked, there is adequate staffing to hand-feed patients who need assistance.					
55. Based on my experience in the most recent facility where I have worked, initiatives have been taken to make the dining experience resemble a home-like setting (i.e., open dining times and seating plans, multiple menu options available, encouraging patient choice in dining).					
56. Based on my experience in the most recent facility where I have worked, the dining experience is institutional (i.e., pre-assigned dining times and menu selections, assigned dining room seating, limited patient choices offered).					
57. Based on my experience in the most recent facility where I have worked, honoring advance directives is encouraged by the health care team.					
58. Based on my experience in the most recent facility where I have worked, feeding tubes are commonly recommended for patients with advanced dementia in order to speed their discharge to a nursing home.					
59. Based on my experience in the most recent facility where I have worked, I am uncertain about the legal implications associated with making recommendations for feeding tube use among patients with advanced dementia.					
60. Based on my experience in the most recent facility where I have worked, I am uncertain about the ethical implications associated with making recommendations for feeding tube use among patients with advanced dementia.					
61. Based on my experience in the most recent facility where I have worked, feeding tubes are commonly recommended for patients with advanced dementia because reimbursement is greater for tube-fed patients.					
62. Based on my experience in the most recent facility where I have worked, fewer regulatory citations occur when patients with advanced dementia have a feeding tube. (Regulatory citations from the state health department, Centers for Medicare & Medicaid Services, or The Joint Commission.)					

Section III: Prior literature on health care professionals in other disciplines has indicated that knowledge and practices can vary based on the characteristics of the individual, and on the facility where they work. Therefore, understanding more about our participants helps us to better understand how RDs make clinical nutrition decisions. Please complete the following demographic information.

63. Please indicate your biological sex:

- a. Male
- b. Female
- c. Other
- d. Prefer not to disclose

64. Please indicate your age in years: _____

65. Are you of Hispanic, Latino, or Spanish origin?

- a. Yes
- b. No
- c. Prefer not to disclose

66. Which of the following best describes your racial background?

- a. White
- b. Black/African American
- c. Asian
- d. American Indian or Alaska Native
- e. Native Hawaiian or other Pacific Islander
- f. Two or more races
- g. Other
- h. Prefer not to disclose

67. Please indicate the highest level of education you have completed.

- a. Bachelor's degree
- b. Master's degree
- c. Doctoral degree

68. Please indicate any specialty certifications you have earned. Select all that apply.
- a. Board Certified Specialist in Gerontological Nutrition
 - b. Certified Nutrition Support Clinician
 - c. Other CDR Board Specialty Certificate (Pediatrics, Sports, Renal, Oncology)
 - d. Other certification: _____ (Example: Certified Lactation Consultant, Certified Diabetes Educator, Certified Health Education Specialist, etc...)
 - e. None

69. Please indicate your primary work setting:
- a. Hospital/Acute care facility
 - b. Rehabilitation facility
 - c. Long-term, extended care, or assisted living facility
 - d. Outpatient care
 - e. Community nutrition
 - f. Home health care
 - g. Hospice
 - h. Government agency or department
 - i. Other _____

70. How many years have you been in practice as a Registered Dietitian? _____

71. How many years have you worked as a Registered Dietitian in a setting where you provide nutrition care to older adults (ages 65+)? _____

72. What is your religious affiliation?

- a. Christian/Protestant (Baptist, Methodist, Lutheran, Episcopalian, Pentecostal, Presbyterian, Non-denominational, etc...)
- b. Catholic
- c. Jewish
- d. Muslim
- e. Buddhist
- f. Hindu
- g. Other: _____
- h. None
- i. Prefer not to disclose

Appendix D Efficacy Survey Instrument

1. Screening question: Are you currently employed as a Registered Dietitian in a facility or setting where you provide nutrition care to older adult patients (ages 65+)? (This can include the hospital, long-term care, outpatient settings, community settings, etc...)
 - a. Yes (Proceed to next item)
 - b. No (End survey)

The following definitions may be useful in answering the survey questions:

Advanced Dementia: The terminal phase of dementia, characterized by the inability to eat, walk, talk, or interact with others. Also known as severe dementia or end-stage dementia.

Dementia: Dementia is a neurological, progressive, and debilitating disease that causes losses in functional and cognitive capabilities due to damage to the neurons in the brain. This includes mild to severe (or advanced) dementia. For the purposes of this study, dementia is considered a permanent, progressive, and irreversible condition characterized by neurological damage.

Feeding tube: A tube that is inserted into the gastrointestinal tract to provide nutrients to an individual who is unable to consume adequate nutrition by mouth. Two common types are the gastrostomy tube, and the nasogastric tube.

Older Adult: An individual aged 65 years or older.

Registered Dietitian: Registered Dietitians (RDs) are food and nutrition experts who have met the following criteria to earn the RD credential in the United States: completed a minimum of a bachelor's degree, completed an ACEND-accredited supervised practice program, passed a national examination, and completed continuing professional educational requirements to maintain registration.

2. In general, based on your knowledge, beliefs, and experiences, how likely are you to recommend a feeding tube for a patient with advanced dementia?
 - a. Highly Likely
 - b. Somewhat Likely
 - c. Neither Likely nor Unlikely
 - d. Somewhat Unlikely
 - e. Highly Unlikely

Section I. Based on your knowledge of evidence-based guidelines for the use of feeding tubes among older adults with advanced dementia, please select the best response to the following statements.			
Among older adults with advanced dementia,	True	False	Don't Know
3. Feeding tubes are recommended for use when oral feeding difficulties arise.			
4. Patient survival improves when feeding tubes are used.			
5. Feeding tubes prevent aspiration pneumonia.			
6. Feeding tube use prevents pressure ulcers from developing.			
7. Feeding tube use promotes the healing of pressure ulcers.			
8. Tube feeding improves nutritional status.			
9. Tube-related complications (such as aspiration pneumonia, tube malfunctions, and discomfort) are common when feeding tubes are used.			
10. Tube-related infections are common when feeding tubes are used.			
11. Chemical restraints (such as sedating medications) are common when feeding tubes are used.			
12. Physical restraints are common when feeding tubes are used.			
13. Nursing home residents with a feeding tube are transferred to the hospital or emergency department more frequently than residents without a tube.			
14. Careful hand-feeding is an acceptable alternative to tube feeding.			
15. Feeding tubes are a cheaper and easier way to provide nutrition than hand-feeding.			
16. The family members should be able to accept or decline a feeding tube for their loved one based on the patient's advanced directive.			
17. The family members should be able to accept or decline a feeding tube for their loved one based on what they feel the patient would want.			
18. Eating difficulties are a part of the natural progression of dementia.			
19. Persistent eating difficulties signal that dementia is progressing into advanced or end-stage dementia.			
20. Feeding tubes are often placed during in-patient hospitalizations for an acute illness.			
21. The health care team should determine the plan of care, regardless of the input of the patient or his/her family members.			
22. Decisions about the use of feeding tubes should be shared between the patient's family members and the health care team.			
23. It is the professional obligation of the health care team to inform patients and their families of the risks and benefits associated with feeding tube use.			

Among older adults with advanced dementia,	True	False	Don't Know
24. Health care professionals must honor the wishes of the patient, being sensitive to the patient's cultural and religious values.			

Section II. Please select the response that best reflects your opinion regarding the use of feeding tubes for older adults with advanced dementia.					
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
25. Considering the use of feeding tubes for older adults with advanced dementia, I believe that the patient's wishes are an important consideration.					
26. Considering the use of feeding tubes for older adults with advanced dementia, I believe that prolonging the patient's life is an important consideration.					
27. Considering the use of feeding tubes for older adults with advanced dementia, I believe that the health care team should do everything possible to prolong the patient's life, including provide nutrition support.					
28. Considering the use of feeding tubes for older adults with advanced dementia, I believe that it is acceptable to allow a patient to go without a feeding tube.					
29. Considering the use of feeding tubes for older adults with advanced dementia, allowing a patient to go without a feeding tube violates my personal values.					
30. Considering the use of feeding tubes for older adults with advanced dementia, my personal experiences with my own family members have impacted how I make clinical nutrition recommendations for patients.					
31. Considering the use of feeding tubes for older adults with advanced dementia, my religious beliefs play an important role in how I make clinical nutrition recommendations for my patients.					
32. Considering the use of feeding tubes for older adults with advanced dementia, my faith in God (or a higher power) is an important factor that impacts my clinical nutrition recommendations.					
33. Considering the use of feeding tubes for older adults with advanced dementia, my spirituality is an important factor that impacts my clinical nutrition recommendations.					

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
34. Considering the use of feeding tubes for older adults with advanced dementia, due to my religious background, I am uncomfortable allowing a patient with advanced dementia go without or refuse a feeding tube.					
35. Considering the use of feeding tubes for older adults with advanced dementia, due to my spiritual background, I am uncomfortable allowing a patient with advanced dementia to go without or refuse a feeding tube.					
36. Considering the use of feeding tubes for older adults with advanced dementia, my cultural background favors the health care team making decisions regarding end-of-life care.					
37. Considering the use of feeding tubes for older adults with advanced dementia, my cultural background makes me uncomfortable allowing a patient with advanced dementia to go without or refuse a feeding tube.					
38. Considering the use of feeding tubes for older adults with advanced dementia, my cultural background influences how I view allowing a patient with advanced dementia to go without or refuse a feeding tube.					
39. Considering the use of feeding tubes for older adults with advanced dementia, I believe that I have been adequately trained to provide clinical nutrition recommendations for older adults with advanced dementia.					
40. Considering the use of feeding tubes for older adults with advanced dementia, I believe that I have been adequately trained to provide nutrition education for older adults with advanced dementia.					
41. Considering the use of feeding tubes for older adults with advanced dementia, I lack adequate knowledge on the current research surrounding the use of feeding tubes in patients with advanced dementia.					
42. Considering the use of feeding tubes for older adults with advanced dementia, I am aware of current research on the use of feeding tubes in patients with advanced dementia.					
43. Considering the use of feeding tubes for older adults with advanced dementia, I have knowledge regarding current research on the use of feeding tubes in patients with advanced dementia.					

44. Considering the use of feeding tubes for older adults with advanced dementia, I feel confident in my clinical nutrition recommendations for patients with advanced dementia.					
The next set of questions focuses on the organization, setting, or facility where you currently work.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
45. Based on my experience in the most recent facility where I have worked, Registered Dietitians are included in the decision-making process regarding feeding tube placement.					
46. Based on my experience in the most recent facility where I have worked, initiatives have been taken to make the dining experience resemble a home-like setting (i.e., open dining times and seating plans, multiple menu options available, encouraging patient choice in dining).					
47. Based on my experience in the most recent facility where I have worked, honoring advance directives is encouraged by the health care team.					
48. Based on my experience in the most recent facility where I have worked, feeding tubes are commonly recommended for patients with advanced dementia in order to speed their discharge to a nursing home.					
49. Based on my experience in the most recent facility where I have worked, I am uncertain about the legal implications associated with making recommendations for feeding tube use among patients with advanced dementia.					
50. Based on my experience in the most recent facility where I have worked, I am uncertain about the ethical implications associated with making recommendations for feeding tube use among patients with advanced dementia.					
51. Based on my experience in the most recent facility where I have worked, feeding tubes are commonly recommended for patients with advanced dementia because reimbursement is greater for tube-fed patients.					
52. Based on my experience in the most recent facility where I have worked, fewer regulatory citations occur when patients with advanced dementia have a feeding tube. (Regulatory citations from the state health department, Centers for Medicare & Medicaid Services, or The Joint Commission.)					

Section III: Prior literature on health care professionals in other disciplines has indicated that knowledge and practices can vary based on the characteristics of the individual, and on the facility where they work. Therefore, understanding more about our participants helps us to better understand how RDs make clinical nutrition decisions. Please complete the following demographic information.

53. Please indicate your biological sex:

- a. Male
- b. Female
- c. Other
- d. Prefer not to disclose

54. Please indicate your age in years: _____

55. Are you of Hispanic, Latino, or Spanish origin?

- a. Yes
- b. No
- c. Prefer not to disclose

56. Which of the following best describes your racial background?

- a. White
- b. Black/African American
- c. Asian
- d. American Indian or Alaska Native
- e. Native Hawaiian or other Pacific Islander
- f. Two or more races
- g. Other
- h. Prefer not to disclose

57. Please indicate the highest level of education you have completed.

- a. Bachelor's degree
- b. Master's degree
- c. Doctoral degree

58. Please indicate any specialty certifications you have earned. Select all that apply.
- a. Board Certified Specialist in Gerontological Nutrition
 - b. Certified Nutrition Support Clinician
 - c. Other CDR Board Specialty Certificate (Pediatrics, Sports, Renal, Oncology)
 - d. Other certification: _____ (Example: Certified Lactation Consultant, Certified Diabetes Educator, Certified Health Education Specialist, etc...)
 - e. None

59. Please indicate your primary work setting:
- a. Hospital/Acute care facility
 - b. Rehabilitation facility
 - c. Long-term, extended care, or assisted living facility
 - d. Outpatient care
 - e. Community nutrition
 - f. Home health care
 - g. Hospice
 - h. Government agency or department
 - i. Other _____

60. How many years have you been in practice as a Registered Dietitian? _____

61. How many years have you worked as a Registered Dietitian in a setting where you provide nutrition care to older adults (ages 65+)? _____

62. What is your religious affiliation?
- a. Christian/Protestant (Baptist, Methodist, Lutheran, Episcopalian, Pentecostal, Presbyterian, Non-denominational, etc...)
 - b. Catholic
 - c. Jewish
 - d. Muslim
 - e. Buddhist
 - f. Hindu
 - g. Other: _____
 - h. None
 - i. Prefer not to disclose

63. If you would be willing to repeat this survey in the coming weeks to assist the researcher in establishing the reliability of this survey instrument, your name will be entered twice into the drawing to win one of twelve \$50 gift cards. If you are willing, please enter your email address here: _____

64. Thank you for your participation! Please click the link below to register for the drawing to win one of ten \$50 gift cards.

Clicking the link in item #64 will direct participants to the following survey:

In order to be entered into the drawing for a gift card, please answer the following questions.

1. In the health care context, what does the acronym 'RD' indicate?
 - a. Road
 - b. Registered Dietitian
 - c. Review date
 - d. Reader's Digest

2. What is your email address? _____

Appendix E Final Survey Instrument

1. Screening question: Are you currently employed as a Registered Dietitian in a facility or setting where you provide nutrition care to older adult patients (ages 65+)? (This can include the hospital, long-term care, outpatient settings, community settings, etc...)
 - a. Yes (Proceed to next item)
 - b. No (End survey)

The following definitions may be useful in answering the survey questions:

Advanced Dementia: The terminal phase of dementia, characterized by the inability to eat, walk, talk, or interact with others. Also known as severe dementia or end-stage dementia.

Dementia: Dementia is a neurological, progressive, and debilitating disease that causes losses in functional and cognitive capabilities due to damage to the neurons in the brain. This includes mild to severe (or advanced) dementia. For the purposes of this study, dementia is considered a permanent, progressive, and irreversible condition characterized by neurological damage.

Feeding tube: A tube that is inserted into the gastrointestinal tract to provide nutrients to an individual who is unable to consume adequate nutrition by mouth. Two common types are the gastrostomy tube, and the nasogastric tube.

Older Adult: An individual aged 65 years or older.

Registered Dietitian: Registered Dietitians (RDs) are food and nutrition experts who have met the following criteria to earn the RD credential in the United States: completed a minimum of a bachelor's degree, completed an ACEND-accredited supervised practice program, passed a national examination, and completed continuing professional educational requirements to maintain registration.

2. In general, based on your knowledge, beliefs, and experiences, how likely are you to recommend a feeding tube for a patient with advanced dementia?
 - a. Highly Likely
 - b. Somewhat Likely
 - c. Neither Likely nor Unlikely
 - d. Somewhat Unlikely
 - e. Highly Unlikely

Section I. Based on your knowledge of evidence-based guidelines for the use of feeding tubes among older adults with advanced dementia, please select the best response to the following statements.			
Among older adults with advanced dementia,	True	False	Don't Know
3. Feeding tubes are recommended for use when oral feeding difficulties arise.			
4. Patient survival improves when feeding tubes are used.			
5. Feeding tubes prevent aspiration pneumonia.			
6. Feeding tube use prevents pressure ulcers from developing.			
7. Feeding tube use promotes the healing of pressure ulcers.			
8. Tube feeding improves nutritional status.			
9. Tube-related complications (such as aspiration pneumonia, tube malfunctions, and discomfort) are common when feeding tubes are used.			
10. Tube-related infections are common when feeding tubes are used.			
11. Chemical restraints (such as sedating medications) are common when feeding tubes are used.			
12. Physical restraints are common when feeding tubes are used.			
13. Nursing home residents with a feeding tube are transferred to the hospital or emergency department more frequently than residents without a tube.			
14. Careful hand-feeding is an acceptable alternative to tube feeding.			
15. Feeding tubes are a cheaper and easier way to provide nutrition than hand-feeding.			
16. The family members should be able to accept or decline a feeding tube for their loved one based on the patient's advanced directive.			
17. The family members should be able to accept or decline a feeding tube for their loved one based on what they feel the patient would want.			
18. Eating difficulties are a part of the natural progression of dementia.			
19. Persistent eating difficulties signal that dementia is progressing into advanced or end-stage dementia.			
20. Feeding tubes are often placed during in-patient hospitalizations for an acute illness.			
21. The health care team should determine the plan of care, regardless of the input of the patient or his/her family members.			
22. Decisions about the use of feeding tubes should be shared between the patient's family members and the health care team.			
23. It is the professional obligation of the health care team to inform patients and their families of the risks and benefits associated with feeding tube use.			

Among older adults with advanced dementia,	True	False	Don't Know
24. Health care professionals must honor the wishes of the patient, being sensitive to the patient's cultural and religious values.			

Section II. Please select the response that best reflects your opinion regarding the use of feeding tubes for older adults with advanced dementia.					
Knowledge Self-Efficacy Scale Considering the use of feeding tubes for older adults with advanced dementia,	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
25. I have knowledge regarding current research on the use of feeding tubes in patients with advanced dementia.					
26. I am aware of current research on the use of feeding tubes in patients with advanced dementia.					
27. I lack adequate knowledge on the current research surrounding the use of feeding tubes in patients with advanced dementia.					
28. I feel confident in my clinical nutrition recommendations for patients with advanced dementia.					
29. I am uncertain about the legal implications associated with making recommendations for feeding tube use among patients with advanced dementia.					
30. I am uncertain about the ethical implications associated with making recommendations for feeding tube use among patients with advanced dementia.					
Religion, Spirituality, and Culture Scale Considering the use of feeding tubes for older adults with advanced dementia,	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
31. My faith in God (or a higher power) is an important factor that impacts my clinical nutrition recommendations.					
32. My religious beliefs play an important role in how I make clinical nutrition recommendations for my patients.					
33. My spirituality is an important factor that impacts my clinical nutrition recommendations.					
34. My cultural background influences how I view allowing a patient with advanced dementia to go without or refuse a feeding tube.					

Considering the use of feeding tubes for older adults with advanced dementia,	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
35. My personal experiences with my own family members have impacted how I make clinical nutrition recommendations for patients.					
Personal Values Scale Considering the use of feeding tubes for older adults with advanced dementia,	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
36. Allowing a patient to go without a feeding tube violates my personal values.					
37. Due to my spiritual background, I am uncomfortable allowing a patient with advanced dementia to go without or refuse a feeding tube.					
38. I believe that the health care team should do everything possible to prolong the patient's life, including provide nutrition support.					
39. Due to my religious background, I am uncomfortable allowing a patient with advanced dementia go without or refuse a feeding tube.					
40. My cultural background makes me uncomfortable allowing a patient with advanced dementia to go without or refuse a feeding tube.					
41. I believe that it is acceptable to allow a patient to go without a feeding tube.					
42. I believe that prolonging the patient's life is an important consideration.					
Perceived Organization and Training Scale	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
43. Considering the use of feeding tubes for older adults with advanced dementia, I believe that I have been adequately trained to provide nutrition education for older adults with advanced dementia.					
44. Considering the use of feeding tubes for older adults with advanced dementia, I believe that I have been adequately trained to provide clinical nutrition recommendations for older adults with advanced dementia.					
45. Based on my experience in the most recent facility where I have worked, Registered Dietitians are included in the decision-making process regarding feeding tube placement.					
46. Based on my experience in the most recent facility where I have worked, initiatives have been taken to make the dining experience resemble a home-like setting (i.e., open dining times and seating plans, multiple menu options available, encouraging patient choice in dining).					

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
47. Based on my experience in the most recent facility where I have worked, honoring advance directives is encouraged by the health care team.					
Perceived Policy Scale Based on my experience in the most recent facility where I have worked,	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
48. Feeding tubes are commonly recommended for patients with advanced dementia because reimbursement is greater for tube-fed patients.					
49. Feeding tubes are commonly recommended for patients with advanced dementia in order to speed their discharge to a nursing home.					
50. Fewer regulatory citations occur when patients with advanced dementia have a feeding tube. (Regulatory citations from the state health department, Centers for Medicare & Medicaid Services, or The Joint Commission.)					

Section III: Prior literature on health care professionals in other disciplines has indicated that knowledge and practices can vary based on the characteristics of the individual, and on the facility where they work. Therefore, understanding more about our participants helps us to better understand how RDs make clinical nutrition decisions. Please complete the following demographic information.

51. Please indicate your biological sex:

- a. Male
- b. Female
- c. Other
- d. Prefer not to disclose

52. Please indicate your age in years: _____

53. Are you of Hispanic, Latino, or Spanish origin?

- a. Yes
- b. No
- c. Prefer not to disclose

54. Which of the following best describes your racial background?

- a. White
- b. Black/African American
- c. Asian
- d. American Indian or Alaska Native
- e. Native Hawaiian or other Pacific Islander
- f. Two or more races
- g. Other
- h. Prefer not to disclose

55. Please indicate the highest level of education you have completed.

- a. Bachelor's degree
- b. Master's degree
- c. Doctoral degree

56. Please indicate any specialty certifications you have earned. Select all that apply.

- a. Board Certified Specialist in Gerontological Nutrition
- b. Certified Nutrition Support Clinician
- c. Other CDR Board Specialty Certificate (Pediatrics, Sports, Renal, Oncology)
- d. Other certification: _____ (Example: Certified Lactation Consultant, Certified Diabetes Educator, Certified Health Education Specialist, etc...)
- e. None

57. Please indicate your primary work setting:

- a. Hospital/Acute care facility
- b. Rehabilitation facility
- c. Long-term, extended care, or assisted living facility
- d. Outpatient care
- e. Community nutrition
- f. Home health care
- g. Hospice
- h. Government agency or department
- i. Other _____

58. How many years have you been in practice as a Registered Dietitian? _____

59. How many years have you worked as a Registered Dietitian in a setting where you provide nutrition care to older adults (ages 65+)? _____

60. What is your religious affiliation?

- a. Christian/Protestant (Baptist, Methodist, Lutheran, Episcopalian, Pentecostal, Presbyterian, Non-denominational, etc...)
- b. Catholic
- c. Jewish
- d. Muslim
- e. Buddhist
- f. Hindu
- g. Other: _____
- h. None
- i. Prefer not to disclose

61. If you would be willing to repeat this survey in the coming weeks to assist the researcher in establishing the reliability of this survey instrument, your name will be entered twice into the drawing to win one of twelve \$50 gift cards. If you are willing, please enter your email address here: _____

62. Thank you for your participation! Please click the link below to register for the drawing to win one of ten \$50 gift cards.

Clicking the link in item #62 will direct participants to the following survey:

In order to be entered into the drawing for a gift card, please answer the following questions.

1. In the health care context, what does the acronym 'RD' indicate?
 - a. Road
 - b. Registered Dietitian
 - c. Review date
 - d. Reader's Digest

2. What is your email address? _____

CHAPTER 5

FACTORS ASSOCIATED WITH THE USE OF EVIDENCE-BASED GUIDELINES BY REGISTERED DIETITIANS MAKING FEEDING TUBE RECOMMENDATIONS FOR OLDER ADULTS WITH ADVANCED DEMENTIA

Dementia is a progressive and debilitating neurological condition characterized by the death and destruction of neurons in the brain. While several different types of dementia exist, the majority of cases (60 - 80%) are due to Alzheimer's disease, which is attributed to changes in protein metabolism within and surrounding the neurons (Alzheimer's Disease Facts and Figures, 2017). Other types of dementia include: vascular dementia, Dementia with Lewy Bodies, Parkinson's dementia, and Frontotemporal lobar dementia. Among older adults with dementia, approximately half present with multiple types of dementia, also known as mixed dementia.

Across types of dementia, early symptoms can range from difficulty with speech, language, and memory, to impaired muscle movements and gait (Alzheimer's Disease Facts and Figures, 2017). Functional and cognitive impairments worsen over time, rendering individuals unable to care for themselves (Chung, 2012). As neuronal damage continues and dementia progresses, the parts of the brain responsible for swallowing are damaged, leaving people with advanced dementia at high risk for aspiration (Chung, 2012). They often become unable to feed themselves, causing them to rely on others for nutrition and hydration. Unfortunately, this places people with advanced dementia at high risk for malnutrition and dehydration (Alzheimer's Disease Facts and Figures, 2017; Chung, 2012). Dementia is ultimately fatal, and the presence

of swallowing and eating difficulties indicates that the person is transitioning into end-stage disease (Chung, 2012).

In many disease states, the use of a feeding tube to provide nutrition and hydration for patients is appropriate and necessary. However, among older adults with advanced dementia, the literature reveals that not only does feeding tube use fail to improve nutritional status; it may further complicate the patient's condition. It can lead to gastrointestinal distress (constipation or diarrhea), aspiration pneumonia, and pressure ulcers (Attanasio et al., 2009; Chung, 2012; Cintra, de Rezende, de Moraes, Cunha, & da Gama Torres, 2014; Kaw & Sekas, 1994; Teno et al., 2012). Some patients with advanced dementia who receive tube-feedings become agitated and attempt to remove the tubes; health care providers then have to use restraints, which are upsetting to the patient and family (Chung, 2012; Teno et al., 2011).

In spite of the negative effects of tube-feedings on patients with advanced dementia, approximately one third of older adults with advanced dementia in nursing home settings continue to receive feeding tubes (Kuo, Rhodes, Mitchell, Mor, & Teno, 2009). Because research has failed to show benefits of feeding tube use on older adults with advanced dementia, the practice has recently been discouraged by a number of professional associations, including The American Geriatrics Society (2014), The American Society for Parenteral and Enteral Nutrition (as cited in Schwartz et al., 2014), The Alzheimer's Association (2015), and The European Society for Parenteral and Enteral Nutrition (as cited in Volkert et al., 2015). Instead, careful hand feeding has been encouraged for this patient population.

Several different members of the health care team may be involved in recommending feeding tube placement for older adult patients with advanced dementia. American physicians reported that nurses, speech therapists, and hospital nutrition teams heavily influenced their

decisions to place feeding tubes in patients with advanced dementia (Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2003). As such, some research has focused on which factors may make various members of the health care team more likely to recommend a feeding tube. Studies indicate that the race, age, gender, culture and religion, years of experience, training, and specialty practice areas of clinicians may impact their feeding recommendations for patients at the end of life (Aita, Takahashi, Miyata, Kai, & Finucane, 2007; Asai & Fukuhara, 1995; Carmel, 1999; Hinkka et al., 2002; Langdon, Hunt, Pope, & Hackes, 2002; Mitchell, Teno, Roy, Kabumoto, and Mor, 2003; Modi, Whetstone, & Cummings, 2007; Taper & Hockin, 1996; Teno et al., 2014; Valentini et al., 2014; Wall, Wellman, Curry, & Johnson, 1991).

Other studies have indicated that feeding decisions at the end of life may be influenced by other factors, such as health care regulations and reimbursement policies, and legal repercussions (Aita et al., 2007; Finucane, Christmas, & Leff, 2007; Hinkka et al., 2002; Lopez, Amella, Strumpf, Teno, & Mitchell, 2010; Mitchell, 2003; Mitchell, Buchanan, Littlehale, & Hamel, 2003; Shega et al., 2003). These findings are consistent with the components of the Social Ecological Model, which states that individuals and their behaviors are influenced by multiple levels within the individuals' environment, including personal factors (knowledge, skills, beliefs, and attitudes), interpersonal influences (religion and cultural background), community and organizational factors, and policy-level influences (McLeroy, Bibeau, Steckler, & Glanz, 1988).

Until recently, the research exploring how Registered Dietitians (RDs) in the United States make tube-feeding recommendations for people with dementia was limited and dated. Furthermore, existing literature lacked a theoretical framework. As such, the author recently surveyed RDs in the United States, using exploratory factor analysis to provide evidence of

several important factors related to RDs' recommendations for feeding tube use among older adults with advanced dementia. These included: confidence in personal knowledge (termed 'Knowledge Self-Efficacy'), religion and spirituality, cultural influences, personal values, RDs' perceptions of the organizations where they are employed and the training they have received, and RDs' perceptions of health policy (Douglas et al., 2017). Utilizing that validated survey tool, the purpose of this study was to develop a multivariate model to determine factors associated with RDs' recommendations regarding the use of feeding tubes for older adults with advanced dementia.

Methods

Sample and Recruitment

The Commission on Dietetic Registration (CDR), the credentialing body for RDs in the United States, provided contact information for a random sample of RDs who, during their most recent registration renewal, reported working in the following practice settings: clinical nutrition (general), gerontology, long-term care, and nutrition support. These practice areas were selected because they represented settings where RDs would most likely provide nutritional care to older adults with advanced dementia. Approximately 25,000 RDs in the United States reported working in these four areas (CDR, 2017).

The desired sample size for this study was based on established benchmarks. Krejcie and Morgan (1970) recommended a sample size of 382 – 384 participants for a population of 75,000 – 1,000,000 individuals. More recently, Gay and Airasian (2003) recommended a sample size of 400 participants for a population of 5,000 or more. Therefore, the researcher desired a minimum sample size of 400 completed surveys. A recent web-based survey of Canadian dietitians

reported a survey completion rate of 13.8% (Szeto, O'Sullivan Maillet, Brody, & Parrott, 2014). Based on this, the researcher requested from CDR a random sample of 5,000 RD email addresses from the desired practice areas, as a completion rate of only 8% would yield the desired sample size of ≥ 400 completed surveys.

Invitations were sent to the email addresses on file with the CDR in late 2016, inviting RDs to participate in the electronic survey using Qualtrics™ (Qualtrics 2017, Provo, UT). Reminder emails were sent weekly for 3 weeks, and the survey link was closed in mid-January 2017. RDs in the United States were eligible to participate if they were at least 18 years of age and worked in a setting where they provided nutritional care to older adults. The University of Alabama Institutional Review Board approved this study.

Survey Instrument

The survey instrument used for this study was based on the Social Ecological Model developed by Bronfenbrenner (1977), and was validated for use among RDs in the United States in 2017. The survey development and validation process is described elsewhere (Douglas et al., 2017).

The survey instrument consisted of several parts. First, RDs were asked to indicate the likelihood that they would recommend a feeding tube for a patient with advanced dementia, using the following response set: 'Highly likely,' 'Somewhat likely,' 'Neither likely nor unlikely,' 'Somewhat unlikely,' and 'Highly unlikely.' To utilize this item as a dichotomous outcome variable in the regression analysis, the response categories were collapsed. Thus, those who responded that they were 'Highly likely' or 'Somewhat likely' to recommend a feeding tube for a person with advanced dementia were then coded as 'Likely.' Those who responded that

they were ‘Highly unlikely’ or ‘Somewhat unlikely’ to recommend a feeding tube were coded as ‘Unlikely.’ Those who responded ‘Neither likely nor unlikely’ were removed from the analysis ($n = 82$).

In the next section, RDs responded to a total of 48 items, which yielded calculated scores for six scales: Total Knowledge, Knowledge Self-Efficacy, Religion/Spirituality/Culture, Personal Values, Perceived Organization and Training, and Perceived Policy. With the exception of the Total Knowledge score, these scales were derived from the exploratory factor analysis conducted by Douglas et al. in 2017, which revealed factors that influenced RDs’ recommendations when feeding older adults with advanced dementia. To obtain the Total Knowledge score, RDs responded to 22 true/false knowledge statements. These items were summated to create a knowledge score for each RD, with higher scores indicating greater knowledge regarding evidence-based guidelines for feeding tube use in advanced dementia.

The Knowledge Self-Efficacy score was derived from responses to six items, with greater scores indicating that RDs had confidence that their knowledge was adequate to provide evidence-based feeding recommendations for older adults with advanced dementia. The Religion/Spirituality/Culture score was derived from five items, which encompassed RDs’ faith in a higher being, and influences from their cultural backgrounds. Higher scores on this scale indicated that RDs provided feeding recommendations based more on evidence-based guidelines, and less on their own religious, spiritual, or cultural backgrounds. Similarly, the Personal Values score was based on seven items, with higher scores indicating that RDs made recommendations based on evidence-based guidelines, rather than their own personal values.

The Perceived Organization and Training score was calculated based on responses to five items, with higher scores indicating that RDs perceived that the organization they worked for and

the training they received followed evidence-based guidelines (or avoiding the use of feeding tubes for people with advanced dementia). More specifically, the items included whether RDs felt confident in the training they received, whether RDs were included in decision-making regarding feeding tube use at their facility, whether the facility promoted the use of advanced directives, and whether the facility had taken initiatives to promote person-centered care. Finally, the Perceived Policy score was derived from responses to three items, with higher scores indicating that RDs perceived that health policy, regulations, and reimbursement coincided with evidence-based guidelines (or avoiding the use of feeding tubes for people with advanced dementia).

Demographic data were collected in the last section; these items were based on the findings of prior research with other health care professionals. Each RD provided their age, gender, race and ethnicity, religious affiliation, level of education, specialty certifications held, practice setting, years of experience (both as an RD in general and years as an RD working with older adults).

Data Analyses

IBM SPSS® version 24 (SPSS Inc., Chicago, IL, 2016) was used for data analyses. Descriptive statistics portrayed RDs' demographic information. The outcome variable of interest was the likelihood of RDs recommending feeding tubes for people with advanced dementia. This variable was collapsed into a dichotomous outcome variable for analysis.

Independent predictor variables were based on a review of the literature, and included a combination of continuous and categorical variables. Continuous variables included Total Knowledge score, Knowledge Self-Efficacy score, Personal Values score,

Religion/Spirituality/Culture score, Perceived Organization and Training score, Perceived Policy score, RD age, and years of experience, both as an RD in general, and as an RD working with older adults. Independent *t*-tests were conducted with the outcome variable and continuous variables to evaluate univariate significance.

Categorical independent variables included level of education, religion, race, specialty certifications, and work setting. Chi-square tests were utilized to evaluate the univariate significance of categorical variables on the likelihood of RDs recommending feeding tubes for people with advanced dementia.

Response categories for each categorical variable were collapsed due to inadequate numbers of responses in each cell. As such, analysis only allowed race to be considered as ‘White/Caucasian’ or ‘Other.’ Due to the small number of RDs with doctoral degrees, the education variable was collapsed to simply ‘Undergraduate degree’ and ‘Graduate degree.’ Similarly, categories for religion and work setting were also combined to allow for analysis. Thus, Christian/Protestant and Catholic were each analyzed, but the remaining religious responses were grouped into the ‘Other’ category. Work setting was collapsed to allow for analysis of employees of hospital or acute care settings, which included long term acute care hospitals and rehabilitation hospitals. Collapsing the categories of nursing homes, assisted living facilities, extended care settings, and hospice care settings created a separate long-term care category. All other work setting selections were combined into the ‘Other’ category, which included RDs in private practice, Program of All-Inclusive Care for the Elderly, adult day care, primary care offices, community nutrition programs, home health care, dialysis centers, government agencies, and others. Specialty certification was reduced to a dichotomous ‘Yes’ or

‘No’ response. A *p* value of .05 or less was considered statistically significant for all univariate analyses.

Multivariate logistic regression analysis was employed to determine which factors were associated with whether RDs would recommend feeding tubes for patients with advanced dementia. Only variables with univariate significance were entered into the multivariate model. A confidence interval (CI) of 95% was considered statistically significant in the multivariate model.

Results

Survey Response

Of the 5,000 email addresses that were randomly selected by CDR from the four chosen practice areas, the electronic survey system (Qualtrics™ 2017) identified 64 duplicated email addresses, indicating that 64 RDs selected more than one of the four practice areas. Therefore, the survey system sent the email with the survey invitation to a total of 4,936 RDs in the United States. Throughout the recruitment process, 932 individuals clicked on the survey link, representing an initial response rate of 18.9%. Only completed surveys were analyzed; any surveys with missing responses were removed. A total of 662 RDs completed the survey, representing an overall completion rate of 13.4%. After removing those who responded ‘Neither likely nor unlikely’ to the outcome variable ($n = 82$), the final sample size for analysis contained responses from 580 RDs, as seen in Table 9.

Table 9

Registered Dietitians' Likelihood of Recommending a Feeding Tube (n = 662)

Response	n (%)
Likely to recommend a feeding tube	102 (15.4%)
Unlikely to recommend a feeding tube	478 (72.2%)
Neither likely nor unlikely to recommend a feeding tube	82 (12.4%)

Registered Dietitian Participant Characteristics

Of the 580 RDs included in this analysis, 92.9% and 95.9% of participants were White/Caucasian and female, respectively. Approximately half of the RDs (51%) reported a Bachelor's degree as their highest level of education, and approximately half (45.9%) reported holding a specialty certification. The majority of RDs worked in the acute and long-term care settings (74.4%), with the remaining RDs working in a variety of other settings. The Christian/Protestant religious affiliation was most commonly reported (45.2%), followed by Catholic (27.2%). Mean RD age was 46.5 ± 11.5 years. RDs reported an average of 20.1 ± 11.2 years of experience in the profession, with an average of 16.6 ± 9.8 years providing nutritional care to the older adult population. Demographic information can be found in Table 10.

Table 10

Registered Dietitian Participant Demographics

Demographic (n = 580)	n	%
Biological Sex		
Male	22	3.8
Female	556	95.9
Prefer not to disclose	2	0.3
Education Level		
Bachelor's degree	296	51
Master's degree	280	48.3
Doctoral degree	4	0.7

(Continued)

Table 10 Continued

Demographic (<i>n</i> = 580)	<i>n</i>	%
Religious Affiliation		
Christian/Protestant	262	45.2
Catholic	158	27.2
Jewish	20	3.4
Mormon/Latter Day Saints	8	1.4
Muslim	4	0.7
Buddhist	7	1.2
Hindu	2	0.3
Other	18	3.1
None	79	13.6
Prefer not to disclose	22	3.8
Hispanic, Latino, Spanish origin?		
Yes	9	1.6
No	561	96.7
Prefer not to disclose	10	1.7
Racial Background		
Asian	14	2.4
Black/African American	8	1.4
White/Caucasian	539	92.9
Native Hawaiian or other Pacific Islander	1	0.2
Two or more races	3	0.5
Other	3	0.5
Prefer not to disclose	12	2.1
Specialty Certification		
Board Certified Specialist in Gerontology	108	18.6
Other CDR Specialty	19	3.3
Certified Nutrition Support Clinician	76	13.1
Certified Diabetes Educator	23	4.0
Multiple specialty certifications	26	4.5
Other certification	14	2.4
No specialty certification	314	54.1
Primary Work Setting		
Hospital/Acute care	216	37.2
Rehabilitation facility	26	4.5
Long-term care, extended care, or assisted living facility	216	37.2
Outpatient care	59	10.2
Community nutrition	8	1.4
Home health care	18	3.1
Hospice	3	0.5
Government agency or department	17	2.9
Dialysis center/unit	9	1.6
Other	8	1.4

(Continued)

Table 10 Continued

Demographic	<i>n</i>	<i>M</i> ± <i>SD</i>	Range
Age	580	46.5 ± 11.5	24 - 73
Years of experience as an RD	579	20.1 ± 11.2	1 - 50
Years of experience as an RD working with adults age 65+	580	16.6 ± 9.8	1 - 46

Total Knowledge

An analysis of responses to the knowledge portion of the survey revealed that all of the RDs in this study correctly responded that it is the professional obligation of the health care team to inform patients and their families of the risks and benefits associated with feeding tube use. Similarly, 99% of RDs correctly responded that health care professionals must honor the wishes of the patient, being sensitive to the patient's cultural and religious values. Additionally, 97% of RDs correctly answered that decisions about feeding tube use should be shared between the patient's family members and the health care team, and 96% of RDs correctly responded that eating difficulties are a part of the natural progression of dementia. Eighty-four percent of RDs correctly responded that feeding tubes fail to reduce the risk of aspiration pneumonia in patients with advanced dementia, and 72% correctly acknowledged that feeding tubes fail to improve survival in these patients. Approximately one third (36%) of RDs correctly answered that tube-feedings fail to improve nutritional status among older adults with advanced dementia, and 35% correctly recognized that tube-related infections are common when feeding tubes are used in this patient population. Similarly, one third of RDs correctly recognized that physical and chemical restraints are common when feeding tubes are used for these patients (35% and 33%, respectively). Additionally, 36% correctly responded that feeding tubes fail to promote the healing of pressure ulcers in this patient population.

Univariate Analyses

Total Knowledge Scores, Knowledge Self-Efficacy Scores, and Personal Values Scores were significantly higher among RDs who indicated that they were not likely to recommend a feeding tube when compared to those who were likely to recommend a tube ($p < .001$ for all). Similarly, RDs who reported that they were unlikely to recommend a feeding tube had significantly higher scores for Religion/Spirituality/Culture ($p = .007$), Perceived Organization and Training ($p = .037$), and Perceived Policy ($p < .001$). The RDs' age and years of RD work experience were not statistically significant. (Table 11 displays these findings.)

Table 11
Differences in Social Ecological Model Attributes of RDs by the Likelihood of Recommending a Feeding Tube (n = 580)

Attribute	Range	Overall $M \pm SD$	Likely to recommend tube-feeding $M \pm SD$	Unlikely to recommend tube-feeding $M \pm SD$	P
Total Knowledge Score	7 - 22	15.4 ± 3.4	12 ± 2.7	16.1 ± 3.1	< .001
Knowledge SE Score	9 - 30	22.2 ± 4.3	19.9 ± 4.1	22.7 ± 4.2	< .001
Personal Values Score	9 - 35	29.1 ± 4.1	24.9 ± 4.4	30.0 ± 3.5	< .001
Religion/Spirituality/ Culture Score	5 - 25	18.7 ± 4.3	17.7 ± 4.3	19 ± 4.3	.007
Perceived Organization and Training Score	8 - 25	20.6 ± 2.9	20.1 ± 3.2	20.8 ± 2.9	.037
Perceived Policy Score	5 - 15	11.6 ± 2.2	10.5 ± 1.9	11.8 ± 2.2	< .001
Participant Age	24 - 73	46.5 ± 11.5	46.3 ± 12.0	46.5 ± 11.4	.865
Years Experience as an RD	1 - 50	20.1 ± 11.2	19.8 ± 11.4	20.2 ± 11.2	.734
Years Experience as an RD working with older adults	1 - 46	16.6 ± 9.8	16.1 ± 9.9	16.7 ± 9.8	.523

As seen in Table 12, feeding tube recommendations varied significantly by race, such that White/Caucasian RDs were significantly less likely to recommend a feeding tube than those of other races (15% vs. 51.2%, respectively, $p < .001$). Significant associations were also found

between the outcome variable and whether the RDs had specialty certifications, such that those with specialty certifications were significantly less likely to recommend a feeding tube for a person with advanced dementia than those without such certifications (12.4% vs. 22%, respectively, $p = .003$). The likelihood of recommending a feeding tube varied significantly by the work setting of the RDs: those who worked in long-term care settings were least likely to recommend a tube (7.8%), followed by those in the hospital/acute care settings (21.1%), and finally RDs in other work settings were most likely to recommend a tube (28.6%) ($p < .001$). There was no significant association between level of education and likelihood of RDs recommending a feeding tube ($p = .828$). Additionally, no significant association existed between the outcome variable and the religious affiliation of the RDs ($p = .232$).

Table 12
Association of Demographic Attributes of RDs with the Likelihood of Recommending a Feeding Tube (n = 580)

Attribute	Likely to recommend tube-feeding <i>n</i> (%)	Unlikely to recommend tube-feeding <i>n</i> (%)	<i>P</i>
Education level			.828
Undergraduate	51 (17.2%)	245 (82.8%)	
Graduate	51 (18.0%)	233 (82.0%)	
Religion			.232
Christian	46 (17.6%)	216 (82.4%)	
Catholic	26 (16.5%)	132 (83.5%)	
Other	20 (24.7%)	61 (75.3%)	
None	10 (12.7%)	69 (87.3%)	
Race			< .001
White	81 (15.0%)	458 (85.0%)	
Other	21 (51.2%)	20 (48.8%)	
Specialty certification			.003
Yes	33 (12.4%)	233 (87.6%)	
No	69 (22.0%)	245 (78.0%)	
Work Setting			< .001
Hospital/acute	51 (21.1%)	193 (78.9%)	
Long-term/hospice	17 (7.8%)	202 (92.2%)	
Other	34 (28.6%)	85 (71.4%)	

Multivariate Analysis

The multiple logistic regression model was designed to explain factors associated with the likelihood of RDs following evidence-based guidelines, or not recommending a feeding tube, for older adults with advanced dementia. The model included the following variables, which had a significant relationship with the outcome variable in the univariate analyses: Total Knowledge score, Knowledge Self-Efficacy score, Religion/Spirituality/Culture score, Personal Values score, Perceived Organization and Training score, Perceived Policy score, race, presence of specialty certifications, and work setting. The results of the regression analysis can be found in Table 13.

The final model showed that Total Knowledge [OR = 1.40, 95% CI (1.26, 1.57)], Personal Values [OR = 1.30, 95% CI (1.19, 1.43)], Perceived Policy [OR 1.20, 95% CI (1.02, 1.40)], Perceived Organization and Training [OR = .87, 95% CI (.77, .99)], and working in the long-term care or hospice settings [OR 3.68, 95% CI (1.51, 8.93)] were significantly related to the likelihood that RDs would follow evidence-based guidelines. The race of the RDs, presence of specialty certifications, Knowledge Self-Efficacy scores, and Religion/Spirituality/Culture scores were not significant in the multivariate analysis. This model predicted 53.2% of the variance in the likelihood of RDs following evidence-based guidelines for feeding tube recommendations among older adults with advanced dementia. The Hosmer-Lemeshow test indicated good model fit ($p = .900$) (Hosmer & Lemeshow, 1980).

Table 13

Factors Associated with the Likelihood of RDs Making Recommendations Consistent with Evidence-Based Guidelines (or Avoiding Placing a Tube) (n = 580)

Factor	B	S.E.	Wald	p	Odds	95% C.I	
					Ratio	Lower	Upper
Total Knowledge Score	.339	.056	37.170	< .001	1.404	1.259	1.566
Knowledge Self-Efficacy Score	.028	.046	.368	.544	1.028	.940	1.125
Religion/Spirituality/Culture Score	-.052	.040	1.664	.197	.949	.877	1.027
Personal Values Score	.266	.047	32.574	< .001	1.304	1.191	1.429
Perceived Organization and Training Score	-.136	.062	4.742	.029	.873	.772	.986
Perceived Policy Score	.180	.080	5.093	.024	1.197	1.024	1.399
Race (White/Caucasian)	.883	.470	3.529	.06	2.417	.962	6.072
Specialty Certification (Yes)	.096	.315	.093	.760	1.101	.593	2.042
Hospital/Acute Settings	-.404	.366	1.217	.270	.668	.326	1.368
Long-term care and Hospice Settings	1.302	.453	8.267	.004	3.675	1.513	8.925
Constant	-10.358	1.579	43.030	< .001	.000		

Discussion

Current evidence-based research suggests that feeding tubes are not appropriate for older adults with advanced dementia. In spite of this, many people with advanced dementia receive nutritional support from a tube-feeding. The purpose of this study was to evaluate factors associated with whether RDs would recommend feeding tubes for their patients with advanced dementia.

RDs in this study were mostly Caucasian women, which is consistent with the larger population of RDs in the United States, which is 81% White/Caucasian, and 94% female (CDR, 2017). This gives evidence of external validity and generalizability of the results. RDs in the study had a mean age of 46.5 years and approximately 20 years of experience as an RD, on average.

The large majority of RDs (72%) responded that they were not likely to recommend a feeding tube for people with advanced dementia, a response that was consistent with evidence-based guidelines (American Geriatrics Society, 2014). Conversely, 28% of RDs responded that they were likely to recommend a feeding tube. These findings are important because the majority of RDs made recommendations that were consistent with evidence-based guidelines.

Prior studies with other members of the health care team showed opposite results. In an older study of physicians, 75% indicated that they would provide a feeding tube for a patient with a severe mental impairment such as Alzheimer's disease (Carmel, 1999). In two more recent studies of Speech-Language Pathologists, over 50% of clinicians in each study said that they would recommend feeding tubes for patients with advanced dementia (Sharp & Shega, 2009; Vitale, Berkman, Monteleoni, & Ahronheim, 2011). Thus, results from this study indicated that the majority of RDs made evidence-based recommendations, while the same cannot be said of the research from other health care practitioners.

After controlling for a number of variables, five variables remained significant in the multivariate regression model: Total Knowledge, Personal Values, Perceived Organization and Training, Perceived Policy, and Long-term Care or Hospice work settings. These results lend credibility to the survey tool, as the tool was developed based on the Social Ecological Model, and the factors that were significant in the regression model align with the constructs of the Social Ecological Model.

The regression analysis showed that for every 1 – point increase in the Total Knowledge score, the likelihood of making recommendations consistent with evidence-based guidelines increased by 40.4%. Similarly, for every 1 – point increase in the Personal Values score, the likelihood of making recommendations consistent with evidence-based guidelines increased by

30.4%. For every 1 – point increase in the Perceived Policy score, the likelihood of making evidence-based recommendations increased by 19.7%. RDs who worked in long-term care or hospice settings were 3.68 times more likely to follow evidence-based guidelines than those who worked in other settings.

The Perceived Organization and Training score had a significant, inverse relationship with the outcome variable, such that a greater score on this scale meant that RDs were less likely to make recommendations that were consistent with evidence-based guidelines. In other words, the perception that the organization encouraged alternatives to feeding tube use actually increased the likelihood of the RD recommending a tube.

Total Knowledge

Total Knowledge was significantly associated with the likelihood of recommending feeding tubes for people with advanced dementia, a finding that is consistent with the individual level of influence from the Social Ecological Model. This study demonstrated that RDs' knowledge regarding feeding tube use in advanced dementia was not always consistent with current guidelines. Out of 22 possible points on the Total Knowledge scale, the mean score overall was 15.41, or approximately 70%, indicating that knowledge deficits exist among RDs who work with older adults.

Responses to the knowledge items indicated that RDs in the current study were overwhelmingly correct in their knowledge of the responsibility of the multidisciplinary team regarding shared decision-making with family members and honoring the values of the patient. However, the majority of RDs provided incorrect answers to other knowledge items, as approximately 65% of RDs in this study were misinformed about the clinical outcomes and

complications associated with feeding tube use among patients with advanced dementia. Knowledge gaps exist among RDs, particularly in regards to adverse clinical outcomes associated with tube use in patients with dementia. These results provide valuable insight into future training needs for RDs who work with older adults.

Overall, these findings suggest that while RDs have knowledge gaps that need to be addressed through continuing professional education, they use their existing knowledge to make appropriate evidence-based recommendations. When compared to knowledge of other professionals on the topic, RDs in this study possessed more accurate information. For example, prior studies showed that only 6% of physicians (Shega et al., 2003) and 22% of Speech-Language Pathologists (Sharp & Shega, 2009) correctly identified that feeding tubes failed to improve nutritional status, compared to 33% of RDs in this study. Similarly, only 24% of physicians (Shega et al., 2003) and 37% of social services staff members (Lacey, 2006) correctly responded that feeding tubes failed to reduce the risk of aspiration pneumonia, compared to 84% of RDs in this study. Finally, 72% of RDs in this study correctly responded that feeding tubes failed to improve survival for patients with advanced dementia, compared to 57% of Speech-Language Pathologists (Sharp & Shega, 2009) and 39% of physicians (Shega et al., 2003). Thus, based on the research on other health care professionals, RDs in the present study displayed better performance regarding tube-feeding recommendations for this patient population, and their knowledge was the most consistent with evidence-based guidelines.

Personal Values

The Personal Values scale measured the extent to which the personal values of RDs impacted their clinical recommendations for their patients, with higher scores indicating that

RDs made recommendations based on evidence-based guidelines, and lower scores indicating that their recommendations were based more on their own personal values. The items in the Personal Values scale considered the RDs' personal feelings regarding quality of life versus prolonging life, and level of comfort with allowing a person with advanced dementia to go without a feeding tube. Studies have suggested that personal comfort with these issues varies between clinicians, and that this personal comfort may impact clinicians' feeding recommendations for their patients (Aita et al., 2007; Hinkka et al., 2002; Langdon et al., 2002). Not surprisingly, RDs in this study who responded that they were unlikely to recommend a feeding tube had significantly higher scores on the Personal Values scale. This indicated that RDs who relied less on their personal values when making clinical recommendations were more likely to make evidence-based recommendations. The significance of this variable is consistent with the individual level of the Social Ecological Model, and reaffirms the need for RDs to recognize their own values, but then focus on making evidence-based recommendations that are consistent with the needs and desires of the patient.

Long-term Care and Hospice Work Settings

This study found that the practice setting of the RDs was significantly associated with their feeding tube recommendations, such that RDs who worked in long-term care or hospice settings were significantly more likely to make evidence-based feeding recommendations when compared to RDs in other work settings. This suggests that RDs in long-term care, nursing home, assisted living, and hospice settings had additional knowledge, training, or experience that influenced their feeding recommendations for patients with dementia. This coincides with the organizational level of the Social Ecological Model. An important consideration is that those in

other settings were significantly more likely than those in the long-term care setting to recommend a feeding tube. Because feeding tubes are routinely placed during inpatient hospitalizations (Kuo et al., 2009), RDs in acute care settings need to be aware of evidence-based feeding guidelines, as they are likely to be involved in making feeding recommendations for patients in hospital settings.

Other studies have also noted differences in tube-feeding recommendations based on practice area. In a study of Italian physicians and nurses, those who had received specialty training in palliative care or those who practiced in geriatrics were less likely to agree with using a feeding tube for people with advanced dementia (Valentini et al., 2014). In an older study of Canadian dietitians' beliefs toward providing nutrition support for elderly patients at the end of life, those who worked in clinical dietetics were less likely than those working in other practice settings to agree with removing nutrition support among the terminally ill elderly patient (Taper & Hockin, 1996). On the other hand, those who had received training on ethics were more likely to be in favor of euthanasia for terminally ill elderly patients than those who had not received ethics training (Taper & Hockin, 1996). Langdon and colleagues (2002) found that RD opinions toward nutrition support at the end of life varied based on RD practice area, where those practicing in community settings were less likely than clinical dietitians to agree with removing nutrition support.

Perceived Organization and Training

The Perceived Organization and Training score measured RDs' perceptions about the organizations where they worked, and the training they had received. Higher scores on this scale indicated that RDs perceived that their organization and the training they received supported

evidence-based feeding practices for older adults with advanced dementia. Conversely, lower scores indicated that the organization supported the use of feeding tubes. Interestingly, this variable was significantly associated with the likelihood of RDs recommending a feeding tube, such that those with higher scores were actually less likely to make recommendations that were consistent with evidence-based guidelines. RDs who perceived that their organization supported evidence-based guidelines were less likely to make recommendations that were consistent with those guidelines.

This finding is inconsistent with expected results, and several explanations may account for this inconsistency. The Diffusion of Innovations Theory may partially explain this finding, in that the theory posits that people adopt new innovations and ideas at different rates (Rogers, 2003). It is possible that some RDs perceived that their organization supported evidence-based guidelines, but they were not yet ready to integrate those guidelines into practice. According to this theory, these clinicians would fall into the categories of the ‘late majority’ and/or the ‘laggards’ (Rogers, 2003), meaning that they have simply taken longer to become comfortable with this change in the approach to providing nutritional care for people with advanced dementia. Another possible explanation for this finding is that, because this score incorporated items related to the training the RDs had received, RDs in this study may have viewed their training as lacking. Unfortunately, this scale was limited by a small number of items and minimally acceptable internal consistency, which may also explain these findings.

Perceived Policy

The Perceived Policy score measured RDs’ perceptions of public health policies, reimbursement structures, and regulatory compliance issues, as prior research indicated that

these factors may impact the use of feeding tubes for people with advanced dementia (Aita et al., 2007; Finucane et al., 2007; Lopez et al., 2010; Mitchell, 2003; Mitchell, Buchanan et al., 2003; Teno et al., 2008). Greater scores indicated perceptions that health policies were consistent with evidence-based guidelines, or avoiding feeding tube use for this patient population. Those who reported that they were unlikely to recommend a feeding tube in a case of advanced dementia had significantly higher Perceived Policy scores. Thus, RDs who perceived that public health policy encouraged alternatives to feeding tube use for people with advanced dementia were less likely to recommend a feeding tube.

The Perceived Policy variable clearly parallels the policy level of influence from the Social Ecological Model, making this finding very important. A hallmark of the Social Ecological Model is its focus on policy, which was not a focus in prior theoretical models in health (Schölmerich & Kawachi, 2016). Thus, the significance of this variable in the regression analysis further supports that the Social Ecological Model is an appropriate theoretical framework for this health issue, and affirms the role of health policy as an external influence on health care professionals. Health policy, reimbursement, and regulations are usually based on evidence-based guidelines, and these policies generally become integrated into organizational policies and procedures, which also impact RDs' recommendations. Thus, the policy level of influence may have a profound impact on clinical practice, as the effects of policies trickle down through the organization to the individual.

Limitations

While this study brings to light important factors associated with the clinical feeding recommendations of RDs who work with older adults with advanced dementia, it is not without

limitations. First, the researcher selected the four practice areas that she felt were most likely to represent RDs who work with older adults. Furthermore, RDs self-selected their practice areas during their most recent registration renewal period. Thus, it is possible that some RDs who work with older adults were not included in the sample frame because they selected a practice area that was not one of the four selected by the researcher. Additionally, it is possible that the responses from participants do not represent the RD population as a whole. Selection bias may be present, as those who agreed to participate may be somehow different from those who declined participation. This could be due to the use of an electronic survey, as not all RDs may be comfortable with the use of an online survey. Furthermore, electronic surveys tend to have lower response rates, representing another limitation. Social desirability bias may be present if participants failed to respond honestly, or if they provided responses that they thought the researcher desired. In order to minimize this threat, responses were kept anonymous so that no participant would risk their responses being disclosed.

Strengths

This study also has important strengths. In spite of a wealth of evidence and several recent position papers related to the use of feeding tubes for older adults with advanced dementia, no current research evaluated the knowledge of American RDs on this topic. This study shed light on the knowledge gaps of RDs, and it is the first of its kind to consider the clinical recommendations of RDs from a theory-based, ecological approach. This is especially important from the organizational- and policy-level perspective, as most prior research focused on the individual characteristics of RDs, but not the external influences that impacted their recommendations. The significance of multiple factors that impact RDs' recommendations

aligns ideally with the Social Ecological Model, and the near-perfect model fit yields considerable strength to the findings. Furthermore, the survey instrument was deemed valid and reliable, and the nationally-representative random sample further improved the generalizability of the results.

Conclusions

This study sought to identify factors associated with the likelihood of RDs recommending a feeding tube for a person with advanced dementia. Using a validated survey tool based on a well-known theoretical model, a random sample of RDs in the United States was surveyed to provide data for analysis. Overall, results were encouraging, as 72% of RDs responded according to evidence-based guidelines. The multivariate logistic regression analysis yielded a significant model, with five factors that influenced whether an RD would recommend a feeding tube for a patient with advanced dementia: Total Knowledge, Personal Values, Perceptions of Organization and Training, Perceptions of Policy, and employment in Long-term care or Hospice settings.

The knowledge variable, as measured by the Total Knowledge score, is important for several reasons. Total Knowledge was significantly associated with the likelihood of recommending a tube-feeding in the multivariate model, indicating that increasing RDs' knowledge of evidence-based practices may yield clinicians who are more likely to make evidence-based recommendations. In fact, several studies have shown that multidisciplinary education interventions can have an impact on practitioner knowledge and clinical recommendations regarding feeding tube use in advanced dementia (Campbell, Dove-Meadows, Walch, Sanna-Gouin, & Colomba, 2011; Monteleoni & Clark, 2004). Thus, interventions

targeting practitioner knowledge may be effective in correcting misinformation and keeping practitioners abreast of current evidence-based guidelines. According to the model, increasing practitioner knowledge would improve the likelihood of RDs making evidence-based recommendations regarding feeding older adults with advanced dementia.

However, addressing knowledge alone is not adequate to change RDs' recommendations, as evidenced by the other four significant variables in the regression analysis. The Social Ecological Model is based on the notion that individuals and their behaviors are influenced by multiple components of their environment (Bronfenbrenner, 1977). Therefore, changing behavior requires an ecological approach, where greater change can be achieved by addressing multiple levels within the environment (Economos et al., 2001; Stokols, 1992). This can be accomplished by utilizing interventions that target multiple influences within the environment, and that employ multiple intervention strategies (Golden & Earp, 2012; Green, Richard, & Potvin, 1996; Richard, Potvin, Kishchuk, & Prlic, 1996; Stokols, 1996). As such, interventions aimed at encouraging the use of evidence-based guidelines regarding feeding older adults with advanced dementia should incorporate components that address the knowledge and personal values of the clinician, along with organizational culture and public health policy. The combination of interventions that target multiple environmental influences using multiple intervention strategies is thought to yield a synergistic effect, whereby the results of the combined interventions may be greater than the sums of the individual interventions (Schölmerich & Kawachi, 2016).

Implications for Future Research

The current study provided valuable insights. Future research should focus on exploring specific factors in greater detail. Interventions to reduce the use of feeding tubes among older adults with advanced dementia should focus on incorporating the multiple influencing factors identified by the regression model. Not only should interventions seek to improve practitioner knowledge of evidence-based guidelines, but they should also include training on personal values and cultural competence, encouraging clinicians to acknowledge their personal values, but focus on making clinical recommendations that are consistent with the needs, goals, and values of the patient.

Because RDs in hospital/acute settings and other settings are more likely to recommend a feeding tube for a person with advanced dementia than RDs in long-term care and hospice settings, interventions should specifically target clinicians in acute care and other settings. Corporate culture, organizational norms, and health policy should also be addressed, such that organizational guidelines and health laws and regulations are consistent with evidence-based guidelines and research.

Future research should also consider additional variables, which have been significant in prior research with RDs and other health care professionals. For example, other studies have shown that race and gender impacted how health care professionals made end-of-life feeding recommendations (Hinkka et al., 2002; Mitchell, Teno et al., 2003; Modi et al., 2007), but those results were not found in this study due to the homogeneous nature of the RD population. Additionally, prior studies indicated that the age and years of experience of clinicians were associated with decision-making regarding end-of-life feeding (Hinkka et al., 2002; Langdon et

al., 2002; Taper & Hockin, 1996; Wall et al., 1991), but those results were not mirrored in this study. Therefore, these variables should be further explored in future research.

References

- Aita, K., Takahashi, M., Miyata, H., Kai, I., & Finucane, T. E. (2007). Physicians' attitudes about artificial feeding in older patients with severe cognitive impairment in Japan: A qualitative study. *BMC Geriatrics*, 7, 22. doi:1471-2318-7-22
- Alzheimer's Association. (2015). *Feeding issues in advanced dementia*. Retrieved from http://www.alz.org/documents_custom/statements/Feeding_Issues.pdf
- Alzheimer's Disease Facts and Figures. (2017). *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 13(4). 325-373. doi:10.1016/j.jalz.2017.02.001
- American Geriatrics Society Feeding tubes in advanced dementia position statement. (2014). *Journal of the American Geriatrics Society*, 62(8), 1590-1593. doi:10.1111/jgs.12924
- Asai, A., & Fukuhara, S. (1995). Attitudes of Japanese and Japanese-American physicians towards life-sustaining treatment. *Lancet*, 346(8971), 356-359.
- Attanasio, A., Bedin, M., Stocco, S., Negrin, V., Biancon, A., Cecchetto, G., & Tagliapietra, M. (2009). Clinical outcomes and complications of enteral nutrition among older adults. *Minerva Medica*, 100(2), 159-166.
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513-531. doi:10.1037/0003-066X.32.7.513
- Campbell, M., L., Dove-Medows, E., Walch, J., Sanna-Gouin, K., & Colomba, S. (2011). The impact of a multidisciplinary educational intervention to reduce PEG tube placement in patients with terminal-stage dementia: A translation of research into practice. *Journal of Palliative Medicine*, 14(9), 1017-1021. doi:10.1089/jpm.2011.0041
- Carmel, S. (1999). Life-sustaining treatments: What doctors do, what they want for themselves and what elderly persons want. *Social Science & Medicine*, 49(10), 1401-1408.
- Chung, A. M. (2012). Percutaneous gastrostomy feeding tubes in end stage dementia: Don't just do it'. *Journal of the Canadian Association of Radiologists*, 63(3), S5-S6.
- Cintra, M. T., de Rezende, N. A., de Moraes, E. N., Cunha, L. C., & da Gama Torres, H. O. (2014). A comparison of survival, pneumonia, and hospitalization in patients with advanced dementia and dysphagia receiving either oral or enteral nutrition. *The Journal of Nutrition, Health & Aging*, 18(10), 894-899. doi:10.1007/s12603-014-0487-3
- Commission on Dietetic Registration (CDR). (2017). *Registered dietitian (RD) and registered dietitian nutritionist (RDN) by demographics*. Retrieved May 1, 2017 from <https://www.cdrnet.org/registry-statistics?id=2092&actionxm=ByDemographics>

- Douglas, J. W., Turner, L. W., Knol, L. L., Ellis, A. C., Godfrey, A. C., & Lawrence, J. C. (2017). *Development and validation of a survey to evaluate factors associated with registered dietitians' tube-feeding recommendations for older adults with advanced dementia*. (In progress).
- Economos, C. D., Brownson, R. C., DeAngelis, M. A., Foerster, S. B., Foreman, C. T., Gregson, J., . . . Pate, R. R. (2001). What lessons have been learned from other attempts to guide social change? *Nutrition Reviews*, *59*(3), S40-S56.
- Finucane, T. E., Christmas, C., & Leff, B. A. (2007). Tube feeding in dementia: How incentives undermine health care quality and patient safety. *Journal of the American Medical Directors Association*, *8*(4), 205-208. doi:S1525-8610(07)00022-9
- Gay, L. R., & Airasian, P. W. (2003). *Educational research: Competencies for analysis and applications* (7th ed). Upper Saddle River, N.J.: Merrill/Prentice Hall.
- Golden, S. D., & Earp, J. A. L. (2012). Social ecological approaches to individuals and their contexts: Twenty years of health education & behavior health promotion interventions. *Health Education & Behavior*, *39*(3), 364-372. doi:10.1177/1090198111418634
- Green, L. W., Richard, L., & Potvin, L. (1996). Ecological foundations of health promotion. *American Journal of Health Promotion*, *10*(4), 270-281.
- Hinkka, H., Kosunen, E., Lammi, U., Metsänoja, R., Puustelli, A., & Kellokumpu-Lehtinen, P. (2002). Decision making in terminal care: A survey of Finnish doctors' treatment decisions in end-of-life scenarios involving a terminal cancer and a terminal dementia patient. *Palliative Medicine*, *16*(3), 195-204.
- Hosmer, D. W., & Lemeshow, S. (1980). Goodness of fit tests for the multiple logistic regression model. *Communications in Statistics: Theory & Methods*, *9*(10), 1043-1069.
- Kaw, M., & Sekas, G. (1994). Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing home patients. *Digestive Diseases and Sciences*, *39*(4), 738-743.
- Krejcie, R. V., & Morgan, D. W. (1970). Determining sample size for research activities. *Educational and Psychological Measurement*, *30*(3), 607-610.
- Kuo, S., Rhodes, R. L., Mitchell, S. L., Mor, V., & Teno, J. M. (2009). Natural history of feeding-tube use in nursing home residents with advanced dementia. *Journal of the American Medical Directors Association*, *10*(4), 264-270. doi:10.1016/j.jamda.2008.10.010
- Lacey, D. (2006). End-of-life decision making for nursing home residents with dementia: A survey of nursing home social services staff. *Health & Social Work*, *31*(3), 189-199.

- Langdon, D. S., Hunt, A., Pope, J., & Hackes, B. (2002). Perspectives in Practice: Nutrition support at the end of life: Opinions of Louisiana dietitians. *Journal of the American Dietetic Association, 102*(6), 837-840. doi:10.1016/S0002-8223(02)90186-0
- Lopez, R. P., Amella, E. J., Strumpf, N. E., Teno, J. M., & Mitchell, S. L. (2010). The influence of nursing home culture on the use of feeding tubes. *Archives of Internal Medicine, 170*(1), 83-88. doi:10.1001/archinternmed.2009.467
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly, 15*(4), 351-377. doi:10.1177/109019818801500401
- Mitchell, S. L. (2003). Financial incentives for placing feeding tubes in nursing home residents with advanced dementia. *Journal of the American Geriatrics Society, 51*(1), 129-131.
- Mitchell, S. L., Buchanan, J. L., Littlehale, S., & Hamel, M. B. (2003). Tube-feeding versus hand-feeding nursing home residents with advanced dementia: A cost comparison. *Journal of the American Medical Directors Association, 4*(1), 27-33.
- Mitchell, S. L., Teno, J. M., Roy, J., Kabumoto, G., & Mor, V. (2003). Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *Journal of the American Medical Association, 290*(1), 73-80.
- Modi, S. C., Whetstone, L. M., & Cummings, D. M. (2007). Influence of patient and physician characteristics on percutaneous endoscopic gastrostomy tube decision-making. *Journal of Palliative Medicine, 10*(2), 359-366. doi:10.1089/jpm.2006.0145
- Monteleoni, C., & Clark, E. (2004). Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: Before and after study. *BMJ (Clinical Research Ed.), 329*(7464), 491-494. doi:10.1136/bmj.329.7464.491
- Richard, L., Potvin, L., Kishchuk, N., & Prlic, H. (1996). Assessment of the integration of the ecological approach in health promotion programs. *American Journal of Health Promotion, 10*(4), 318-328. doi:10.4278/0890-1171-10.4.318
- Rogers, E. (2003). *Diffusion of innovations*. (5th ed). New York, NY: Free Press.
- Schölmerich, V. L. N., & Kawachi, I. (2016). Translating the socio-ecological perspective into multilevel interventions. *Health Education & Behavior, 43*(1), 17-20. doi:10.1177/1090198115605309
- Schwartz, D. B., Barrocas, A., Wesley, J. R., Klinger, G., Pontes-Arruda, A., Márquez, H. A., . . . DiTucci, A. (2014). Gastrostomy tube placement in patients with advanced dementia or near end of life. *Nutrition in Clinical Practice, 29*(6), 829-840. doi:10.1177/0884533614546890

- Sharp, H. M., & Shega, J. W. (2009). Feeding tube placement in patients with advanced dementia: The beliefs and practice patterns of speech-language pathologists. *American Journal of Speech-Language Pathology*, 18(3), 222-230. doi:10.1044/1058-0360(2008/08-0013)
- Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2003). Barriers to limiting the practice of feeding tube placement in advance dementia. *Journal of Palliative Medicine*, 6(6), 885-893.
- Stokols, D. (1992). Establishing and maintaining healthy environments: Toward a social ecology of health promotion. *The American Psychologist*, 47(1), 6-22. 10.1037/0003-066X.47.1.6
- Stokols, D. (1996). Translating social ecological theory into guidelines for community health promotion. *American Journal of Health Promotion*, 10(4), 282-298.
- Szeto, M. O. P., O'Sullivan Maillet, J., Brody, R., A., & Parrott, J., S. (2014). Registered dietitians' roles in decision-making processes for PEG placement in the elderly. *Canadian Journal of Dietetic Practice & Research*, 75(2), 78-83. doi:10.3148/75.2.2014.78
- Taper, L. J., & Hockin, D. (1996). Life sustaining nutrition support for the terminally ill elderly: Dietitians' ethical attitudes and beliefs. *Journal of the Canadian Dietetic Association*, 57(1), 19-24.
- Teno, J. M., Feng, Z., Mitchell, S. L., Kuo, S., Intrator, O., & Mor, V. (2008). Do financial incentives of introducing case mix reimbursement increase feeding tube use in nursing home residents? *Journal of the American Geriatrics Society*, 56(5), 887-890. doi:10.1111/j.1532-5415.2008.01647.x
- Teno, J. M., Gozalo, P., Mitchell, S. L., Kuo, S., Fulton, A. T., & Mor, V. (2012). Feeding tubes and the prevention or healing of pressure ulcers. *Archives of Internal Medicine*, 172(9), 697-701. doi:10.1001/archinternmed.2012.1200
- Teno, J., Meltzer, D. O., Mitchell, S. L., Fulton, A. T., Gozalo, P., & Mor, V. (2014). Type of attending physician influenced feeding tube insertions for hospitalized elderly people with severe dementia. *Health Affairs*, 33(4), 675-682. doi:10.1377/hlthaff.2013.1248
- Teno, J. M., Mitchell, S. L., Kuo, S. K., Gozalo, P. L., Rhodes, R. L., Lima, J. C., & Mor, V. (2011). Decision-making and outcomes of feeding tube insertion: A five-state study. *Journal of the American Geriatrics Society*, 59(5), 881-886. doi:10.1111/j.1532-5415.2011.03385.x
- Valentini, E., Giantin, V., Voci, A., Iasevoli, M., Zurlo, A., Pengo, V., . . . Manzato, E. (2014). Artificial nutrition and hydration in terminally ill patients with advanced dementia: Opinions and correlates among Italian physicians and nurses. *Journal of Palliative Medicine*, 17(10), 1143-1149. doi:10.1089/jpm.2013.0616

- Vitale, C. A., Berkman, C. S., Monteleoni, C., & Ahronheim, J. C. (2011). Tube feeding in patients with advanced dementia: Knowledge and practice of speech-language pathologists. *Journal of Pain and Symptom Management, 42*(3), 366-378. doi:10.1016/j.jpainsymman.2010.11.017
- Volkert, D., Chourdakis, M., Faxen-Irving, G., Frühwald, T., Landi, F., Suominen, M. H., . . . Schneider, S. M. (2015). ESPEN guidelines on nutrition in dementia. *Clinical Nutrition, 34*(6), 1052-1073. doi:10.1016/j.clnu.2015.09.004
- Wall, M. G., Wellman, N. S., Curry, K. R., & Johnson, P. M. (1991). Feeding the terminally ill: Dietitians' attitudes and beliefs. *Journal of the American Dietetic Association, 91*(5), 549-552.

CHAPTER 6

OVERALL CONCLUSIONS

The purpose of this study was to develop and validate a survey instrument to assess the knowledge, beliefs, attitudes, and perceptions of RDs regarding the use of feeding tubes for older adults with advanced dementia, and to utilize this survey to explore factors associated with the likelihood of RDs making evidence-based feeding recommendations. Using the Social Ecological Model as a theoretical framework, this study sought to identify internal and external factors influencing RDs' recommendations for nutritional care for those with advanced dementia. This chapter provides the overall conclusions of the study.

Survey Development and Validation

The survey instrument was developed and validated using a standardized process that included multiple rounds of review by experts in the field to address face and content validity. Prior to the efficacy study, pilot testing using a convenience sample of RDs provided evidence of adequate initial internal consistency and allowed for item reduction through item-to-total correlations. The efficacy survey response rate was consistent with another recent electronic survey of dietitians, and provided more than the minimum desired sample size. The Cronbach's alpha from the efficacy study indicated adequate internal consistency reliability. An analysis of test-retest reliability indicated that the instrument was adequately reliable. Thus, upon analyzing

results from the efficacy survey, the instrument was deemed valid and reliable for use among RDs who work with older adults in the United States.

Factor Analysis

Responses to the validated survey were subjected to exploratory factor analysis to provide evidence of construct validity, yielding the five following factors: I) Knowledge Self-Efficacy, II) Religion/Spirituality/Culture, III) Personal Values, IV) Perceived Organization and Training, and V) Perceived Policy. Existing literature supported the naming of each factor based on the nature of the items loading onto the factor. These five factors accounted for a substantial portion (59%) of the variance in the survey items analyzed. All factors had at least three items loading on them, and item loadings were at least .30, indicating adequate construct validity. Correlations between factors were weak to moderate, indicating that they were somewhat related, but still measured independent constructs. Scales were created for each factor, consisting of the items loading onto each factor. Analysis of each scale provided an acceptable Cronbach's alpha, indicating adequate internal consistency for each.

Regression Analysis

A multivariate logistic regression model was used to identify factors associated with the likelihood of RDs following evidence-based guidelines when recommending feeding tubes for patients with advanced dementia. The independent variables analyzed were selected based on the literature and subjected to univariate analyses, where only variables with univariate significance were entered into the multivariate model.

Results of the regression analysis identified five variables that were significantly associated with RDs making evidence-based feeding recommendations. These included: Total Knowledge, Personal Values, Perceived Organization and Training, Perceived Policy, and employment in Long-term care or Hospice settings. This model predicted 53% of the variance in the likelihood of following evidence-based guidelines, and displayed good model fit.

Implications

The factors that emerged from the factor analysis were consistent with internal and external factors from the Social Ecological Model, indicating that the Social Ecological Model was a good theoretical framework for explaining the influences associated with RDs' recommendations for patients with advanced dementia. Both internal and external influences emerged from the factor analysis, as was expected. However, the Perceived Organization and Training and Perceived Policy factors displayed minimally acceptable internal consistency reliability and test-retest reliability. Future research should seek to explore these external factors more in-depth.

The results of the regression analysis also indicated that both internal and external factors were associated with whether RDs would make evidence-based feeding recommendations. Perhaps the most notable findings were the relationships between the outcome variable and Total Knowledge and working in long-term care or hospice settings. According to this model, increasing RD knowledge regarding evidence-based feeding guidelines for patients with advanced dementia has the potential to significantly impact RD recommendations. Therefore, interventions that seek to increase RD knowledge should be implemented. Additionally, the finding that RDs who work in long-term care or hospice settings are highly likely to follow

evidence-based guidelines when compared to RDs in other settings sheds light on the need for interventions to be developed for RDs in other work settings, particularly given the fact that most feeding tubes are placed during acute care hospitalizations. Thus, providing educational interventions for RDs in acute care settings may help to ensure that hospitalized patients with advanced dementia receive evidence-based nutritional care.

The Personal Values score was also associated with the likelihood of RDs making evidence-based feeding recommendations, such that RDs who avoided making recommendations based on their own personal values were more likely to make evidence-based recommendations. This highlights the need for training on ethics and cultural competence, encouraging RDs to acknowledge personal values, but make clinical recommendations that are consistent with the needs, goals, and values of the patient.

RDs' perceptions of health policy, reimbursement structures, and health care regulations are also an important consideration, such that RDs who perceived that health policy supported evidence-based guidelines were more likely to follow those guidelines. This suggests the need for RDs to clearly understand current health policy, and to advocate for policy changes that support current research.

Conclusions

This study achieved several different aims, including the development and validation of a survey instrument, the identification of factors through exploratory factor analysis, and the specification of a regression model to explain RDs' recommendations for the use of feeding tubes among older adults with advanced dementia. The Social Ecological Model was shown to be an appropriate theoretical framework for this health issue. Future research should focus on

developing theory-based interventions that target each level of the Social Ecological Model. More specifically, interventions should seek to increase RDs' knowledge of evidence-based guidelines, increase cultural competence, and encourage RDs to acknowledge their own personal values, but make clinical recommendations that are consistent with the desires of the patient. Additionally, interventions should be specifically aimed toward RDs who provide nutritional care to older adults with advanced dementia in settings other than long-term care and hospice. Organizational norms and public health policy need to be aligned with the provision of evidence-based care.

REFERENCES

- Administration on Aging. (2014). Aging Statistics. Retrieved October 7, 2014 from http://www.aoa.acl.gov/aging_statistics/
- Aita, K., Takahashi, M., Miyata, H., Kai, I., & Finucane, T. E. (2007). Physicians' attitudes about artificial feeding in older patients with severe cognitive impairment in Japan: A qualitative study. *BMC Geriatrics*, 7(22). doi:1471-2318-7-22
- Alvarez-Fernández, B., García-Ordoñez, M., Martínez-Manzanares, C., & Gómez-Huelgas, R. (2005). Survival of a cohort of elderly patients with advanced dementia: Nasogastric tube feeding as a risk factor for mortality. *International Journal of Geriatric Psychiatry*, 20(4), 363-370.
- Alzheimer's Association. (2015). Feeding issues in advanced dementia. Retrieved from http://www.alz.org/documents_custom/statements/Feeding_Issues.pdf
- Alzheimer's Disease Facts and Figures. (2017). *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 13(4). 325-373. doi:10.1016/j.jalz.2017.02.001
- American geriatrics society feeding tubes in advanced dementia position statement. (2014). *Journal of the American Geriatrics Society*, 62(8), 1590-1593. doi:10.1111/jgs.12924
- Asai, A., & Fukuhara, S. (1995). Attitudes of Japanese and Japanese-American physicians towards life-sustaining treatment. *Lancet*, 346(8971), 356-359.
- Attanasio, A., Bedin, M., Stocco, S., Negrin, V., Biancon, A., Cecchetto, G., & Tagliapietra, M. (2009). Clinical outcomes and complications of enteral nutrition among older adults. *Minerva Medica*, 100(2), 159-166.
- Ballarè, M., Del Piano, M., Micunco, C., & D'Andrea, F. (2012). Does PEG insertion really worsen short-term survival and complication rates in patients affected by advanced Alzheimer's dementia? *Nutritional Therapy & Metabolism*, 30(2), 99-101.
- Baranowski, T. (1989). Reciprocal determinism at the stages of behavior change: An integration of community, personal and behavioral perspectives. *The International Quarterly of Community Health Education*, 10(4), 297-327.

- Bell, C. L., Lee, A. S. W., & Tamura, B. K. (2015). Malnutrition in the nursing home. *Current Opinion in Clinical Nutrition & Metabolic Care*, 18(1), 17-23. doi:10.1097/MCO.0000000000000130
- Bonner, G. J., Wang, E., Wilkie, D. J., Ferrans, C. E., Dancy, B., & Watkins, Y. (2014). Advance care treatment plan (ACT-plan) for African-American family caregivers: A pilot study. *Dementia*, 13(1), 79-95. doi:10.1177/1471301212449408
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513-531. doi:10.1037/0003-066X.32.7.513
- Bryon, E., Dierckx de Casterlé, B., & Gastmans, C. (2012). 'Because we see them naked' - nurses' experiences in caring for hospitalized patients with dementia: Considering artificial nutrition or hydration (ANH). *Bioethics*, 26(6), 285-295. doi:10.1111/j.1467-8519.2010.01875.x
- Bryon, E., Gastmans, C., & Dierckx de Casterlé, B. (2010). Involvement of hospital nurses in care decisions related to administration of artificial nutrition or hydration (ANH) in patients with dementia: A qualitative study. *International Journal of Nursing Studies*, 47(9), 1105-1116. doi:10.1016/j.ijnurstu.2010.01.011
- Bryon, E., Gastmans, C., & Dierckx de Casterlé, B. (2012). Nurse-physician communication concerning artificial nutrition or hydration (ANH) in patients with dementia: A qualitative study. *Journal of Clinical Nursing*, 21(19-20), 2975-2984. doi:10.1111/j.1365-2702.2011.04029.x
- Buiting, H. M., Clayton, J. M., Butow, P. N., van Delden, J. J., & van der Heide, A. (2011). Artificial nutrition and hydration for patients with advanced dementia: Perspectives from medical practitioners in the Netherlands and Australia. *Palliative Medicine*, 25(1), 83-91. doi:10.1177/0269216310382589
- Cai, S., Gozalo, P. L., Mitchell, S. L., Kuo, S., Bynum, J. P., Mor, V., & Teno, J. M. (2013). Do patients with advanced cognitive impairment admitted to hospitals with higher rates of feeding tube insertion have improved survival? *Journal of Pain and Symptom Management*, 45(3), 524-533. doi:10.1016/j.jpainsymman.2012.02.007
- Carmel, S. (1999). Life-sustaining treatments: What doctors do, what they want for themselves and what elderly persons want. *Social Science & Medicine*, 49(10), 1401-1408.
- Carmines, E. G., & Zeller, R. A. (1979). *Reliability and validity assessment*. Beverly Hills, CA: Sage Publications.
- Centers for Medicare & Medicaid Services. (February 27, 2012). Long term care minimum data set. Retrieved from <https://www.cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/IdentifiableDataFiles/LongTermCareMinimumDataSetMDS.html>

- Chambaere, K., Loodts, I., Deliëns, L., & Cohen, J. (2014). Forgoing artificial nutrition or hydration at the end of life: A large cross-sectional survey in Belgium. *Journal of Medical Ethics, 40*(7), 501-504.
- Chung, A. M. (2012). Percutaneous gastrostomy feeding tubes in end stage dementia: Don't 'just do it'. *Journal of the Canadian Association of Radiologists, 63*(3), S5-S6.
- Cintra, M. T., de Rezende, N. A., de Moraes, E. N., Cunha, L. C., & da Gama Torres, H. O. (2014). A comparison of survival, pneumonia, and hospitalization in patients with advanced dementia and dysphagia receiving either oral or enteral nutrition. *The Journal of Nutrition, Health & Aging, 18*(10), 894-899. doi:10.1007/s12603-014-0487-3
- Commission on Dietetic Registration (CDR). (2017). Registered dietitian (RD) and registered dietitian nutritionist (RDN) by demographics. Retrieved May 1, 2017 from <https://www.cdrnet.org/registry-statistics?id=2092&actionxm=ByDemographics>
- Cordell, C. B., Borson, S., Boustani, M., Chodosh, J., Reuben, D., Verghese, J., . . . Fried, L. B. (2013). Alzheimer's association recommendations for operationalizing the detection of cognitive impairment during the Medicare annual wellness visit in a primary care setting. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 9*(2), 141-150. doi:10.1016/j.jalz.2012.09.011
- Cronk, B. C. (1999). *How to use SPSS : A step-by-step guide to analysis and interpretation*. Los Angeles, CA: Pyrczak Publishing.
- DiIorio, C. K. (2005). *Measurement in health behavior: Methods for research and education*. San Francisco, CA: Jossey-Bass.
- Douglas, J. W., & Lawrence, J. C. (2015). Environmental considerations for improving nutritional status in older adults with dementia: A narrative review. *Journal of the Academy of Nutrition & Dietetics, 115*(11), 1815-1831. doi:10.1016/j.jand.2015.06.376
- Dunne, A. (2010). Nutrition and dementia. *Nursing & Residential Care, 12*(3), 112-116.
- Economos, C. D., Brownson, R. C., DeAngelis, M. A., Foerster, S. B., Foreman, C. T., Gregson, J., . . . Pate, R. R. (2001). What lessons have been learned from other attempts to guide social change? *Nutrition Reviews, 59*(3), S40-S56.
- Engel, S. E., Kiely, D. K., & Mitchell, S. L. (2006). Satisfaction with end-of-life care for nursing home residents with advanced dementia. *Journal of the American Geriatrics Society, 54*(10), 1567-1572. doi:JGS900
- Enrione, E. B., & Chutkan, S. (2007). Research: Preferences of registered dietitians and nurses recommending artificial nutrition and hydration for elderly patients. *Journal of the American Dietetic Association, 107*, 416-421. doi:10.1016/j.jada.2006.12.008

- Finucane, T. E., Christmas, C., & Leff, B. A. (2007). Tube feeding in dementia: How incentives undermine health care quality and patient safety. *Journal of the American Medical Directors Association, 8*(4), 205-208. doi:S1525-8610(07)00022-9
- Fitzgerald, N., & Spaccarotella, K. (2009). Barriers to a healthy lifestyle: From individuals to public policy – an ecological perspective. *Journal of Extension, 47*(1).
- Gay, L. R., & Airasian, P. W. (2003). *Educational research: Competencies for analysis and applications* Upper Saddle River, N.J. : Merrill/Prentice Hall, 7th ed.
- Gessert, C. E., Haller, I. V., Kane, R. L., & Degenholtz, H. (2006). Rural-urban differences in medical care for nursing home residents with severe dementia at the end of life. *Journal of the American Geriatrics Society, 54*(8), 1199-1205. doi:JGS824
- Givens, J. L., Selby, K., Goldfeld, K. S., & Mitchell, S. L. (2012). Hospital transfers of nursing home residents with advanced dementia. *Journal of the American Geriatrics Society, 60*(5), 905-909. doi:10.1111/j.1532-5415.2012.03919.x
- Golden, S. D., & Earp, J. A. L. (2012). Social ecological approaches to individuals and their contexts: Twenty years of health education & behavior health promotion interventions. *Health Education & Behavior, 39*(3), 364-372. doi:10.1177/1090198111418634
- Green, L. W., Richard, L., & Potvin, L. (1996). Ecological foundations of health promotion. *American Journal of Health Promotion, 10*(4), 270-281.
- Hanson, L. C., Carey, T. S., Caprio, A. J., Lee, T. J., Ersek, M., Garrett, J., . . . Mitchell, S. L. (2011). Improving decision-making for feeding options in advanced dementia: A randomized, controlled trial. *Journal of the American Geriatrics Society, 59*(11), 2009-2016. doi:10.1111/j.1532-5415.2011.03629.x
- Hasan, M., Meara, R. J., Bhowmick, B. K., & Woodhouse, K. (1995). Percutaneous endoscopic gastrostomy in geriatric patients: Attitudes of health care professionals. *Gerontology, 41*(6), 326-331.
- Healy, S., & McNamara, E. (2002). Tube feeding controversial patients: What do dietitians think? *Journal of Human Nutrition & Dietetics, 15*(6), 445-453.
- Henderson, C. T., Trumbore, L. S., Mobarhan, S., Benya, R., & Miles, T. P. (1992). Prolonged tube feeding in long-term care: Nutritional status and clinical outcomes. *Journal of the American College of Nutrition, 11*(3), 309-325.
- Hinkka, H., Kosunen, E., Lammi, U., Metsänoja, R., Puustelli, A., & Kellokumpu-Lehtinen, P. (2002). Decision making in terminal care: A survey of Finnish doctors' treatment decisions in end-of-life scenarios involving a terminal cancer and a terminal dementia patient. *Palliative Medicine, 16*(3), 195-204.

- Jack, C. R. J., Albert, M. S., Knopman, D. S., McKhann, G. M., Sperling, R. A., Carrillo, M. C., . . . Phelps, C. H. (2011). Introduction to the recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 7(3), 257-262. doi:10.1016/j.jalz.2011.03.004
- Kane, J. P. M., Richardson, S., Allan, L., & Thomas, A. (2016). Diagnosing dementia. *British Journal of Hospital Medicine (17508460)*, 77(2), C22-C25. doi:10.12968/hmed.2016.77.2.C22
- Kaw, M., & Sekas, G. (1994). Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing home patients. *Digestive Diseases and Sciences*, 39(4), 738-743.
- Komiya, K., Ishii, H., Teramoto, S., Yasuda, T., Sato, S., Yamamoto, H., . . . Kadota, J. (2012). Medical professionals' attitudes toward tube feeding for themselves or their families: A multicenter survey in Japan. *Journal of Palliative Medicine*, 15(5), 561-566. doi:10.1089/jpm.2011.0496
- Krejcie, R. V., & Morgan, D. W. (1970). Determining sample size for research activities. *Educational and Psychological Measurement*, 30(3), 607-610.
- Kuo, S., Rhodes, R. L., Mitchell, S. L., Mor, V., & Teno, J. M. (2009). Natural history of feeding-tube use in nursing home residents with advanced dementia. *Journal of the American Medical Directors Association*, 10(4), 264-270. doi:10.1016/j.jamda.2008.10.010
- Kuraoka, Y., & Nakayama, K. (2014). A decision aid regarding long-term tube feeding targeting substitute decision makers for cognitively impaired older persons in Japan: A small-scale before-and-after study. *BMC Geriatrics*, 14, 16-2318-14-16. doi:10.1186/1471-2318-14-16
- Kwok, T., Twinn, S., & Yan, E. (2007). The attitudes of Chinese family caregivers of older people with dementia towards life sustaining treatments. *Journal of Advanced Nursing*, 58(3), 256-262. doi:JAN4230
- Kwon, R. S., Banerjee, S., Desilets, D., Diehl, D. L., Farraye, F. A., Kaul, V., . . . Tierney, W. M. (2010). Enteral nutrition access devices. *Gastrointestinal Endoscopy*, 72(2), 236-248. doi:10.1016/j.gie.2010.02.008
- Lacey, D. (2005). Tube feeding, antibiotics, and hospitalization of nursing home residents with end-stage dementia: Perceptions of key medical decision-makers. *American Journal of Alzheimer's Disease and Other Dementias*, 20(4), 211-219.
- Lacey, D. (2006). End-of-life decision making for nursing home residents with dementia: A survey of nursing home social services staff. *Health & Social Work*, 31(3), 189-99.

- Langdon, D. S., Hunt, A., Pope, J., & Hackes, B. (2002). Nutrition support at the end of life: Opinions of Louisiana dietitians. *Journal of the American Dietetic Association, 102*, 837-840. doi:10.1016/S0002-8223(02)90186-0
- Lopez, R. P., Amella, E. J., Mitchell, S. L., & Strumpf, N. E. (2010). Nurses' perspectives on feeding decisions for nursing home residents with advanced dementia. *Journal of Clinical Nursing, 19*(5-6), 632-638. doi:10.1111/j.1365-2702.2009.03108.x
- Lopez, R. P., Amella, E. J., Strumpf, N. E., Teno, J. M., & Mitchell, S. L. (2010). The influence of nursing home culture on the use of feeding tubes. *Archives of Internal Medicine, 170*(1), 83-88. doi:10.1001/archinternmed.2009.467
- Lubart, E., Leibovitz, A., & Habot, B. (2004). Attitudes of relatives and nursing staff toward tube-feeding in severely demented patients. *American Journal of Alzheimer's Disease & Other Dementias, 19*(1), 31-34.
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly, 15*(4), 351-377. doi:10.1177/109019818801500401
- Mitchell, S. L. (2003). Financial incentives for placing feeding tubes in nursing home residents with advanced dementia. *Journal of the American Geriatrics Society, 51*(1), 129-131.
- Mitchell, S. L., Buchanan, J. L., Littlehale, S., & Hamel, M. B. (2003). Tube-feeding versus hand-feeding nursing home residents with advanced dementia: A cost comparison. *Journal-American Medical Directors Association, 4*, 27-33.
- Mitchell, S. L., Kiely, D. K., & Gillick, M. R. (2003). Nursing home characteristics associated with tube feeding in advanced cognitive impairment. *Journal of the American Geriatrics Society, 51*(1), 75-79.
- Mitchell, S. L., Teno, J. M., Roy, J., Kabumoto, G., & Mor, V. (2003). Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *Journal of the American Medical Association, 290*(1), 73-80.
- Modi, S., Velde, B., & Gessert, C. E. (2010). Perspectives of community members regarding tube feeding in patients with end-stage dementia: Findings from African-American and Caucasian focus groups. *Omega, 62*(1), 77-91.
- Modi, S. C., Whetstone, L. M., & Cummings, D. M. (2007). Influence of patient and physician characteristics on percutaneous endoscopic gastrostomy tube decision-making. *Journal of Palliative Medicine, 10*(2), 359-366. doi:10.1089/jpm.2006.0145
- Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory* New York: McGraw-Hill, 3rd ed.

- Ogita, M., Utsunomiya, H., Akishita, M., & Arai, H. (2012). Indications and practice for tube feeding in Japanese geriatricians: Implications of multidisciplinary team approach. *Geriatrics & Gerontology International*, *12*(4), 643-651. doi:10.1111/j.1447-0594.2011.00831.x [doi]
- O'Sullivan Maillet, J., Schwartz, D., & Posthauer, M. E. (2013). From the academy: Position of the academy of nutrition and dietetics: Ethical and legal issues in feeding and hydration. *Journal of the Academy of Nutrition and Dietetics*, *113*(6), 828-833. doi:10.1016/j.jand.2013.03.020
- Pallant, J. (2005). *SPSS survival manual: A step by step guide to data analysis using SPSS for windows*. Berkshire, England: Open Press University, 2nd ed.
- Pallant, J. (2007). *SPSS survival manual: A step by step guide to data analysis using SPSS for windows*. Maidenhead: Open University Press, 3rd ed.
- Reisberg, B., Jamil, I. A., Khan, S., Monteiro, I., Torossian, C., Ferris, S., . . . Wegiel, J. (2010). Staging dementia. *Principles and practice of geriatric psychiatry* (p. 162-169) John Wiley & Sons, Ltd. doi:10.1002/9780470669600.ch31
- Richard, L., Potvin, L., Kishchuk, N., & Prlic, H. (1996). Assessment of the integration of the ecological approach in health promotion programs. *American Journal of Health Promotion*, *10*(4), 318-328. doi:10.4278/0890-1171-10.4.318
- Sanders, D. S., Carter, M. J., D'Silva, J., James, G., Bolton, R. P., & Bardhan, K. D. (2000). Original contributions: Survival analysis in percutaneous endoscopic gastrostomy feeding: A worse outcome in patients with dementia. *The American Journal of Gastroenterology*, *95*, 1472-1475. doi:10.1016/S0002-9270(00)00871-6
- Sanders, D. S., Leeds, J. S., & Drew, K. (2008). The role of percutaneous endoscopic gastrostomy in patients with dementia. *British Journal of Nursing*, *17*(9), 588-594.
- Schölmerich, V. L. N., & Kawachi, I. (2016). Translating the socio-ecological perspective into multilevel interventions. *Health Education & Behavior*, *43*(1), 17-20. doi:10.1177/1090198115605309
- Schwartz, D. B., Barrocas, A., Wesley, J. R., Klinger, G., Pontes-Arruda, A., Márquez, H. A., . . . DiTucci, A. (2014). Gastrostomy tube placement in patients with advanced dementia or near end of life. *Nutrition in Clinical Practice*, *29*(6), 829-840. doi:10.1177/0884533614546890
- Sharma, M., & Petosa, R. L. (2014). *Measurement and evaluation for health educators*. Burlington, MA: Jones & Bartlett Learning, 1st ed.
- Sharp, H. M., & Shega, J. W. (2009). Feeding tube placement in patients with advanced dementia: The beliefs and practice patterns of speech-language pathologists. *American*

Journal of Speech-Language Pathology, 18(3), 222-230. doi:10.1044/1058-0360(2008/08-0013)

- Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2003). Barriers to limiting the practice of feeding tube placement in advance dementia. *Journal of Palliative Medicine*, 6(6), 885-893.
- Snyder, E. A., Caprio, A. J., Wessell, K., Lin, F. C., & Hanson, L. C. (2013). Impact of a decision aid on surrogate decision-makers' perceptions of feeding options for patients with dementia. *Journal of the American Medical Directors Association*, 14(2), 114-118. doi:10.1016/j.jamda.2012.10.011
- Sorrell, J. M. (2010). Use of feeding tubes in patients with advanced dementia: Are we doing harm? *Journal of Psychosocial Nursing and Mental Health Services*, 48(5), 15-18. doi:10.3928/02793695-20100331-02 [doi]
- Stanner, S. (2007). Older people with dementia: Eating and drinking healthily. *Nursing & Residential Care*, 9(1), 18-21.
- Stokols, D. (1992). Establishing and maintaining healthy environments: Toward a social ecology of health promotion. *The American Psychologist*, (1), 6-22.
- Stokols, D. (1996). Translating social ecological theory into guidelines for community health promotion. *American Journal of Health Promotion*, 10(4), 282-298.
- Szeto, M. O. P., O'Sullivan Maillet, J., Brody, R., A., & Parrott, J., S. (2014). Registered dietitians' roles in decision-making processes for PEG placement in the elderly. *Canadian Journal of Dietetic Practice & Research*, 75(2), 78-83. doi:10.3148/75.2.2014.78
- Tabachnick, B. G., & Fidell, L. S. (2007). *Using multivariate statistics* Boston: Pearson/Allyn & Bacon, 5th ed.
- Taper, L. J., & Hockin, D. (1996). Life sustaining nutrition support for the terminally ill elderly: Dietitians' ethical attitudes and beliefs. *Journal of the Canadian Dietetic Association*, 57(1), 19-24.
- Teno, J. M., Feng, Z., Mitchell, S. L., Kuo, S., Intrator, O., & Mor, V. (2008). Do financial incentives of introducing case mix reimbursement increase feeding tube use in nursing home residents? *Journal of the American Geriatrics Society*, 56(5), 887-890. doi:10.1111/j.1532-5415.2008.01647.x
- Teno, J. M., Gozalo, P., Mitchell, S. L., Kuo, S., Fulton, A. T., & Mor, V. (2012). Feeding tubes and the prevention or healing of pressure ulcers. *Archives of Internal Medicine*, 172(9), 697-701. doi:10.1001/archinternmed.2012.1200

- Teno, J. M., Gozalo, P. L., Mitchell, S. L., Kuo, S., Rhodes, R. L., Bynum, J. P. W., & Mor, V. (2012). Does feeding tube insertion and its timing improve survival? *Journal of the American Geriatrics Society*, *60*(10), 1918-1921. doi:10.1111/j.1532-5415.2012.04148.x
- Teno, J. M., Mitchell, S. L., Gozalo, P. L., Dosa, D., Hsu, A., Intrator, O., & Mor, V. (2010). Hospital characteristics associated with feeding tube placement in nursing home residents with advanced cognitive impairment. *Journal of the American Medical Association*, *303*(6), 544-550. doi:10.1001/jama.2010.79
- Teno, J. M., Mitchell, S. L., Kuo, S. K., Gozalo, P. L., Rhodes, R. L., Lima, J. C., & Mor, V. (2011). Decision-making and outcomes of feeding tube insertion: A five-state study. *Journal of the American Geriatrics Society*, *59*(5), 881-886. doi:10.1111/j.1532-5415.2011.03385.x
- Teno, J. M., Mitchell, S. L., Skinner, J., Kuo, S., Fisher, E., Intrator, O., . . . Mor, V. (2009). Churning: The association between health care transitions and feeding tube insertion for nursing home residents with advanced cognitive impairment. *Journal of Palliative Medicine*, *12*(4), 359-362. doi:10.1089/jpm.2008.0168
- Teno, J., Meltzer, D. O., Mitchell, S. L., Fulton, A. T., Gozalo, P., & Mor, V. (2014). Type of attending physician influenced feeding tube insertions for hospitalized elderly people with severe dementia. *Health Affairs*, *33*(4), 675-682. doi:10.1377/hlthaff.2013.1248
- The Academy of Nutrition and Dietetics. (2017). What is a registered dietitian nutritionist? Retrieved May 17, 2017 from <http://www.eatrightpro.org/resources/about-us/what-is-an-rdn-and-dtr/what-is-a-registered-dietitian-nutritionist>
- U.S. National Library of Medicine. (2017). Medline plus medical dictionary. Retrieved from <https://www.nlm.nih.gov/medlineplus/mplusdictionary.html>
- Valentini, E., Giantin, V., Voci, A., Iasevoli, M., Zurlo, A., Pengo, V., . . . Manzato, E. (2014). Artificial nutrition and hydration in terminally ill patients with advanced dementia: Opinions and correlates among Italian physicians and nurses. *Journal of Palliative Medicine*, *17*(10), 1143-1149. doi:10.1089/jpm.2013.0616
- Vassilyadi, F., Panteliadou, A., & Panteliadis, C. (2013). Hallmarks in the history of enteral and parenteral nutrition: From antiquity to the 20th century. *Nutrition in Clinical Practice*, *28*(2), 209-217. doi:10.1177/0884533612468602
- Vitale, C. A., Berkman, C. S., Monteleoni, C., & Ahronheim, J. C. (2011). Tube feeding in patients with advanced dementia: Knowledge and practice of speech-language pathologists. *Journal of Pain and Symptom Management*, *42*(3), 366-378. doi:10.1016/j.jpainsymman.2010.11.017
- Vitale, C. A., Hiner, T., Ury, W. A., Berkman, C. S., & Ahronheim, J. C. (2006). Tube feeding in advanced dementia: An exploratory survey of physician knowledge. *Care Management*

Journals: Journal of Case Management; the Journal of Long Term Home Health Care, 7(2), 79-85.

- Volkert, D., Chourdakis, M., Faxen-Irving, G., Frühwald, T., Landi, F., Suominen, M. H., . . . Schneider, S. M. (2015). ESPEN guidelines on nutrition in dementia. *Clinical Nutrition*, 34(6), 1052-1073. doi:10.1016/j.clnu.2015.09.004
- Wall, M. G., Wellman, N. S., Curry, K. R., & Johnson, P. M. (1991). Feeding the terminally ill: Dietitians' attitudes and beliefs. *Journal of the American Dietetic Association*, (5), 549-552.
- Watkins, Y. J., Bonner, G. J., Wang, E., Wilkie, D. J., Ferrans, C. E., & Dancy, B. (2012). Relationship among trust in physicians, demographics, and end-of-life treatment decisions made by African-American dementia caregivers. *Journal of Hospice and Palliative Nursing*, 14(3), 238-243.
- Winett, R. A. (1995). A framework for health promotion and disease prevention programs. *The American Psychologist*, (5), 341-350.
- Xu, J., Murphy, S. L., Kochanek, K. D., & Arias, E. (2016). Mortality in the United States, 2015. *NCHS Data Brief*, (267), 1-8.
- Yeh, L., Fetzer, S. J., Chen, S. Y., Lu, F. H., Chuang, C. H., & Chen, C. H. (2013). Percutaneous endoscopic gastrostomy placement: Caregiver decision making in Taiwan. *Journal of the Formosan Medical Association*, 112(2), 99-104. doi:10.1016/j.jfma.2012.04.002
- Yeh, L., Lo, L., Fetzer, S., & Chen, C. (2010). Limited PEG tube use: The experience of long-term care directions. *Journal of Clinical Nursing*, 19(19), 2897-2906. doi:10.1111/j.1365-2702.2009.03157.x
- Yildiz, D., Büyükkoyuncu Pekel, N., Kiliç, A. K., Tolgay, E. N., & Tufan, F. (2015). Malnutrition is associated with dementia severity and geriatric syndromes in patients with Alzheimer disease. *Turkish Journal of Medical Sciences*, 45(5), 1078-1081.