

SPEECH-LANGUAGE PATHOLOGIST PARTICIPATION IN DECISION-MAKING
RELATED TO ARTIFICIAL NUTRITION AND HYDRATION AT THE END OF LIFE: A
SURVEY OF EXPERIENCES AND PERSPECTIVES

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ABSTRACT

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by Erica Raymond, RD, CNSC

Purpose: Speech-Language Pathologists (SLPs) have the unique ability to address the cognitive, communication, and swallowing difficulties that occur at the end of life (EOL). The purpose of this study is to identify factors that influence SLP participation in EOL decision-making related to Artificial Nutrition and Hydration (ANH).

Methods: Descriptive statistics, frequencies, and correlation tests were analyzed for 312 online survey responses provided by SLPs.

Results: The majority of SLPs indicated that their preference toward ANH would be dependent on the patient's wishes. SLPs' race/ethnicity correlated with the preference toward specific modalities of ANH, opinion on how complications of ANH are managed, and comfort with interpersonal communication. SLPs' marital status correlated with the preference toward specific modalities of ANH, comfort in discussing death and dying, and perceived influence of healthcare providers on the decision to forego ANH. SLPs' religious affiliation correlated with the choice to forego ANH. Institutional culture at the SLPs' place of employment correlated with how SLPs perceive their role in EOL decision-making and outcomes of ANH.

Conclusions: Understanding the opinions and perceptions of SLPs is essential in advancing education, training, and research in the area of death and dying, ethical aspects of EOL care, and decision-making for ANH.

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Introduction

End of life (EOL) care encompasses a combination of intensive, palliative, and hospice care provided to patients with conditions that cannot be reversed or cured. Patients at the EOL may be unable to maintain adequate oral food or fluid intake due to the progression of their underlying disease or as a part of the dying process.

Artificial nutrition and hydration (ANH) encompasses a variety of medical therapies that include enteral or parenteral administration of nutrients and fluid (Figure 1 and 2). ANH is a highly effective means of providing nutrition and hydration to patients who cannot take food or fluid orally (Fine, 2006; Ganzini, 2006; Mazzini et al., 1995; Miller, 2001; Scolapio et al., 1999) but may increase risk without benefiting patients with advanced dementia or other terminal illnesses (Callahan et al., 2000; Ciocon et al., 1988; Finucane et al., 1999; Gillick, 2000; Klein et al., 1994; Odom et al., 2003; Meier et al., 2001; Mitchell et al., 1998; Post, 2001; Sampson et al., 2009).

In dying patients, ANH has been associated with nausea, vomiting, abdominal discomfort, and aspiration, and the obligatory fluids provided to the patient during ANH delivery may cause or exacerbate pulmonary secretions, dyspnea, urinary frequency, edema, effusions, and ascites (Borracos et al., 2010; Casarett et al., 2005). The administration of ANH is associated with the need for increased medical intervention to maintain enteral/parenteral access, monitor the biochemical and physiologic response to nutrition therapy, manage the complications associated with ANH, and preserve patient comfort and dignity while receiving aggressive nutrition intervention (Borracos et al., 2010; Schwartz, 2013). In addition, ANH can disrupt the physical and physiological adaptations associated with dying that protect a patient from pain and discomfort (Casarett et al., 2005).

There is little evidence to indicate that providing ANH to terminally ill patients who are unable to maintain oral food and fluid intake at the EOL will benefit the patient in terms of survival time, mortality, quality of life (QOL), or physical function (Schwartz et al., 2013). Inability to maintain substantive oral food and fluid intake, weight loss, impaired physical function, and biochemical disturbances associated with death and dying will not be reversed with ANH alone (Cervo et al., 2006).

Despite the lack of benefit and potential risk of providing ANH to terminally ill patients, decisions are often made to initiate, continue, or advance ANH in patients due to a variety of individual and instructional variables associated with providing EOL care. Due to psychological and physiological association between nutrition, life, nourishment, and vitality, ANH is often perceived differently from other lifesaving treatments and medical interventions at the EOL, and the decisions to withhold, withdraw, or forgo ANH at the EOL often pose unique medical, ethical, legal, and emotional challenges to healthcare providers, patients, and caregivers. (Barrocas et al., 2010; O'Sullivan et al., 2013). The right of the patient or surrogate to make informed decisions about initiating, discontinuing, or forgoing life-sustaining treatment is widely accepted, though ethical dilemmas may arise when the patient wishes are not clearly understood, appropriately documented, or reliably enforced.

In facilitating discussion of the patient's conditions, communicating the patient's prognosis, and informing the patient and/or their healthcare proxy of the risk or benefits of ANH, the influence of healthcare providers' own beliefs, attitudes, and opinions on regarding ANH and EOL care should not be overlooked (Lambert, 2012).

Speech-Language Pathologists (SLPs) have the unique ability to address the cognition, communication, and swallowing difficulties that affect patient QOL and autonomy at the EOL.

However, little research is available to describe the breadth and depth of SLP involvement in, and contributions to, patient-centered EOL care and shared ethical decision-making (Lambert, 2012; Pollens, 2004). Like other allied health professionals, the role of the SLP in EOL decision-making is ill defined, and traditional education programs may lack intensive training in the area of palliative, hospice, or EOL care that would facilitate the integration of speech and communication therapies into these areas of practice.

Though SLPs may receive little education about enteral nutrition (EN) or parenteral nutrition (PN) in the course of their training, data shows that physician practice related to ANH is influenced by SLP recommendations (Shega et al., 2003). While the value of the SLP in palliative care is recognized and documented, few studies are available to outline the institutional impact and clinical outcomes associated with SLP involvement in decisions to withhold, withdraw, or forgo ANH in ethically complex situations at the EOL.

The purpose of this study is to identify factors that influence SLP participation in EOL decision-making related to ANH by assessing discipline-specific determinants of EOL care and the extent to which demographics, cultural/religious beliefs, understanding of ANH, and experience with ethical EOL issues influence EOL decisions made by SLPs. The goal of this survey is both to identify differences in perceptions among educators, caregivers, and healthcare providers in the field of speech-language pathology and to relate these differences to personal and institutional factors that influence SLP beliefs and attitudes related to ANH administration at the EOL. This study was a cross sectional, descriptive, observational inquiry, and no assumptions of causality were possible.

Methods

Survey

Survey questions were developed using an interdisciplinary panel, including physicians, dietitians, nurses, pharmacists, and SLPs, and sequential, discipline-specific focus groups. Survey questions were refined with participant input and tested for internal and external validity. The online survey was created in Survey Monkey and was opened from January-December 2015 for the purpose of this study.

Design

All participants were required to give informed consent prior to participating in the survey; consent was given by pressing the “next” button on the first screen of the online survey. Survey questions were answered in a self-directed fashion and took 15-30 minutes to complete. All survey responses were anonymous, and all survey data were retained in a confidential manner. Approval for this project was obtained from the institution where the primary research was done. The research was verified to be exempt by Federal Statute number two of the Institutional Review Board (IRB) at that institution.

Participants

A direct mailing list was purchased from the American Speech-Language Hearing Association (ASHA). Direct mail was issued to a representative sample of ASHA members who were certified SLPs living in the United States. A letter mailed to ASHA members outlined the purpose of this project, the intended audience of direct mail, and a web address to access the online survey. A separate request was sent to administrators of Speech-Language Hearing Associations in all 50 states asking that survey information be posted or distributed to members who met inclusion criteria. Several of these organizations were able to invite SLPs to participate

in the survey via email, newsletter, or website. Other organizations were unable to relay survey information to its members.

Analysis

Data were cleaned, coded, and collapsed where necessary. All statistical tests were run in SPSS (IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp). Descriptive statistics were analyzed for continuous variables, and frequencies were run for nominal and ordinal variables. Bivariate correlations between survey responses were calculated using the Kendall's Tau B test. Two-tailed significance for all correlational tests was set at a $p < 0.05$. For variables that appeared to be influential to outcome, logistic regression models were built to ascertain the contribution of specific indices to distribution of variance.

Results

Demographic Variables

Responses from 312 SLPs were analyzed. The majority of survey participants identified as female (94.6%), white/Caucasian (90.4%), Christian (76.6%), and married (70.2%).

Additional demographic information is summarized in Table 1.

Opinions and Experiences

Of the 312 participants, 75 (24.0%) indicated that they would be in favor of providing food or fluids through the non-oral route to a person who was terminally ill and could no longer eat or drink safely by mouth. Thirty-four (10.9%) participants indicated that they would be opposed to providing ANH in this situation. There was no statistically significant correlation between demographic variables and favor or opposition to ANH. Only 110 (35.2%) participants indicated that they were in favor or opposed to ANH, while a greater number of participants

indicated that they did not know and that the decision to provide ANH would be dependent on other factors. More participants indicated that the decision to provide ANH would be dependent on patient wishes (n=229) than the family wishes (n=99) or patient's diagnosis (n=96). Only 15 (4.8%) participants indicated that the decision would be dependent on institutional factors (hospital policy or monetary costs), but all 15 of these participants indicated that the decision would also depend on the patients and family wishes. Only ten participants indicated that they were not able to answer the questions due to a lack of knowledge about ANH. Two participants did not answer the question because they felt that their personal or professional opinion was irrelevant to the decision. Two other participants indicated that the patient's current or predicted QOL should determine whether ANH is provided.

Of the participants in favor of ANH, 59 (18.9%), 25 (8.0%), 25 (8.0%), 103 (33.0%), and 49 (15.7%) indicated that they would be in favor of providing ANH via a nasogastric (NG) feeding tube, nasoduodenal (ND) feeding tube, nasojejunal (NJ) feeding tube, percutaneous endoscopic gastrostomy (PEG) tube, and percutaneous endoscopic gastrojejunostomy (PEG-J) tube for someone with a functional gastrointestinal tract, respectively. More participants (n=64 or 20.5%) indicated that they were in favor of providing EN by way of only long-term/permanent enteral access (PEG or PEG-J) compared to only temporary NG, ND, or NJ tubes (n=21 or 6.7%). Forty-one (13.1%) participants indicated that either a permanent or temporary feeding tube would be an appropriate technique for delivery of ANH to a terminally ill patient who cannot take food or fluids by mouth. Specializing in dysphagia or swallowing disorders was correlated with the preference toward temporary compared to long-term EN access (Kendall's $\tau = -0.171, p = 0.045$). Forty-one (13.1%) participants indicated that they would be in favor of providing PN to a terminally ill patient who cannot take food or fluids orally but has a functional

gastrointestinal tract. Of these 41 participants, 37 (11.9%) and 30 (9.6%) indicated that they would be in favor of providing central PN and peripheral PN, respectively.

Overall, 126 participants (40.4%) indicated that they would be in favor of providing EN. Of these 126 participants, 38 (12.2%) were in favor of providing either EN or PN. Only 3 (1%) respondents exclusively favored PN. Being married correlated with a participant's preference toward EN compared to PN (Kendall's Tau=0.251, $p=0.004$). In a logistic regression model, preference for PN was set against variables of age, marital status, and race. The results indicated that much of the variance was explained by the marital status category (Table 2).

Overall, 62 (19.9%), 20 (6.2%), and 47 (15.1%) favored long-term ANH, short-term ANH, or either long-term or short-term ANH, respectively. Participants who indicated that they were in favor of providing ANH by one or more of these techniques were asked to express the reason why in free text form. Of the participants in favor of providing ANH by one of more of these techniques, 12 indicated that their decision would be dependent on the wishes of the patient, family, or other healthcare providers. Respondents who indicated that all techniques would be appropriate said that it is the right of the patient to decide on which technique should be used (n=11). For those in favor of placing an endoscopic PEG or PEG-J tube, participants specified that they favored those techniques because: a) it would be more comfortable for the patient (n=11), b) they were more familiar PEG or PEG-J tubes (n=8), c) enteral access would be less noticeable (n=4), d) it is a more physiologic way to provide ANH (n=4), and e) it is safer for the recipient of EN (n=3).

When the 312 participants were queried about experiential influences, 42 (13.5%) indicated that they had seen or cared for a loved one receiving ANH, 32 (10.3%) indicated that they had seen or cared for a loved one receiving ANH at the EOL, and 123 (39.4%) had been

involved in the decision to initiate or discontinue ANH at the EOL. Only 2 (0.6%) of participants reported that they had received ANH themselves. A larger number of participants indicated they had cared for patients receiving ANH (n=220, 70.5%) or cared for patients receiving ANH at the EOL (n=162, 51.9%).

Forty-two (13.5%) of SLP respondents had both personal and professional experience with ANH, and whether a participant worked in a clinical or non-clinical sector was associated with having had experience with both a loved one and a patient on ANH (Kendall's Tau=-0.134, $p=0.034$). Sixty-one participants (19.6%) indicated that they had no experience with ANH.

Using Likert scales, 277 (88.8%) and 265 (84.9%) of participants indicated that patient's legal document or verbal statement opposing ANH would be most likely to prevent the inappropriate initiation of ANH, respectively. The majority of survey participants indicated that the patient's spouse or children, when voicing opposition to ANH, could prevent the start of ANH (n=255, 81.7% and n=239, 76.7%, respectively). The patient's attending physician, nurse, dietitian, and SLP were considered likely to prevent initiation of ANH by 244 (78.2%), 132 (42.3%), 150 (48.1%), and 182 (58.3%) of participants, respectively. Working in an institution where the SLP felt the culture could be classified as "Laissez Faire" was correlated with the belief that the patient's attending physician (Kendall's Tau=-0.144, $p=0.018$), nurse (Kendall's Tau=-0.138, $p=0.038$), dietitian (Kendall's Tau=-0.211, $p=0.002$), and SLP (Kendall's Tau=-0.254, $p<0.001$), would be unlikely or likely to prevent the inappropriate initiation of ANH (Table 3).

Scenario I

With regards to the first scenario outlined in Figure 3, 40.4% of participants indicated that they would be opposed to percutaneous feeding tube placement for initiation of EN, 53.8%

of participants indicated that they would be opposed to nasogastric feeding tube placement for initiation of EN, and 45.5% of participants indicated that they would be opposed to intravenous line placement for initiation of PN. A majority of participants indicated that they were also opposed to discontinuing ice chips and mouth lubrication (60.3%), fitting restraints to prevent pulling out EN/PN access (50.0%), and initiating sedating medication to prevent pulling out EN/PN access (52.2%). Participant race/ethnicity was correlated with being in favor or opposed to placement of an intravenous line (Kendall's Tau=0.187, $p=0.009$), fitting of restraints (Kendall's Tau=0.156, $p=0.028$), and initiating sedative medications (Kendall's Tau=0.146, $p=0.042$). Institutional culture was also correlated with favor or opposition to initiating sedatives (Kendall's Tau=0.191, $p=0.005$).

Participants were asked how they would expect the patient to respond to EN therapy should the PEG tube be placed and a high protein enteral formula containing adequate vitamins, minerals, and fluid be administered (Table 4). Institutional culture was associated with participant's perception of whether ANH would result in improvements in bedsores (Kendall's Tau=-0.147, $p=0.022$). Race/ethnicity was correlated with the view that ANH was likely or unlikely to improve QOL at Kendall's Tau=0.154 ($p=0.033$). Employment in a clinical versus non-clinical sector was correlated with the perception that ANH in this scenario was likely or unlikely to result in less emotional distress (Kendall's Tau=0.161, $p=0.030$) or longer survival (Kendall's Tau=0.227, $p=0.001$).

With regard to removal of a surgically placed feeding tube, 19 (6.1%) and 150 (48.1%) participants indicated that the patient in this scenario would or would not eventually have the tube removed, respectively. Seventy-seven (24.7%) participants indicated that they were unsure whether the patient's PEG tube could eventually be removed. Employment in a clinical or non-

clinical position was the only demographic variable correlated to the participant's view on whether or not the patient could eventually have the PEG tube removed in this scenario (Kendall's Tau=0.154, $p=0.013$).

Scenario II

Given a second scenario (Figure 3), participants indicated how not forcibly providing ANH would affect the patient and the staff responsible for his care. Those responses are summarized in Table 5. Whether participants identified the institutional culture at their primary place of employment as Laissez Faire was correlated with the participant's belief regarding whether the patient in this scenario would die sooner (Kendall's Tau=0.144 $p=0.038$), experience more pain (Kendall's Tau=0.184, $p=0.018$), and experience more discomfort (Kendall's Tau=0.174, $p=0.019$) if he was not forcibly provided ANH. The participant's education level was correlated with whether participants viewed the staff to be acting in an ethical manner (Kendall's Tau=-0.247, $p=0.001$). The participant's education level and a specialization in dysphagia were correlated with whether participants viewed the staff to be acting in the patient's best interest (Kendall's Tau=-0.223, $p=0.005$ and Kendall's Tau=0.197, $p=0.008$). The participant's education level was also correlated with the participant's view on whether staff would be providing the best care in the situation where ANH was not provided (Kendall's Tau=-0.238, $p=0.002$).

Participant beliefs regarding patient competence were assessed for the scenario regarding Voluntary Refusal of Foods and Fluids (VRFF). More than half ($n=165$, 52.9%) of participants indicated the terminally ill patient's VRFF in this situation was unlikely a demonstration of the patient being incompetent to make decisions for himself compared to 7.7% ($n=24$) of participants who indicated the patient's decision for VRFF was likely a demonstration of the patient being

incompetent. Whether the survey participant identified as Christian was correlated with this view on whether VRFF was unlikely or likely to indicate if the patient was competent (Kendall's Tau=-0.146, $p=0.045$). As it pertains to VRFF, 190 participants (60.9%) indicated that the patient should be allowed to determine the course of treatment even if conflicts with medical advice. Only 13 (4.2%) participants indicated that the patient should not be allowed to determine the course of treatment when it conflicts with medical advice.

When asked whether socioeconomic determinants are influential in EOL decision-making, 102 (32.7%) and 31 (9.9%) participants indicated that the choice for VRFF was unlikely versus likely to be overridden if the patient was wealthy and insured, respectively. Employment in the clinical or non-clinical sector and institutional culture at the participant's primary place of employment were correlated with the participant's view on whether being wealthy or insured would result in overriding VRFF at Kendall's Tau=0.224 ($p=0.010$) and Kendall's Tau=0.178 ($p=0.028$), respectively.

Personal Characteristics and Preferences

Based on their personal experiences (Table 6), participants indicated that they were comfortable with general interpersonal communication ($n=219$, 70.2%), discussing death and dying ($n=195$, 62.5%), and communicating bad news ($n=164$, 52.6%). Only six (1.9%), 24 (7.7%), and 44 (14.1%) participants indicated that they were uncomfortable with general interpersonal communication, discussing death and dying, and communicating bad news, respectively. In a binary logistic regression analysis using conditional forward entry of variables, little variance could be explained by factors such as age, marital status, or institutional culture when all of these variables were inserted into the model. This result was due to the vast

differences in numbers between categories leaving insufficient power for any single category to adjust the Beta.

The majority of participants indicated that they were comfortable in the concept of quality versus quantity of life (n=215, 68.9%) as well as the concept of that death is a natural part of life (n=215, 68.9%). Only 6 (1.9%) and 8 (2.6%) participants indicated that they are uncomfortable with these concepts, respectively. While 39.7% (n=124) of participants indicated that they were uncomfortable with the concept of saving lives at all costs, 18.6% (n=58) of participants indicated that they were comfortable with this concept, and 41.7% (n=130) indicated that they did not know or did not answer the question.

Based on their personal experiences (Table 6), the majority of participants indicated that they were comfortable speaking on behalf of others and on behalf of themselves (n=210, 67.3% and n=216, 69.2%, respectively). The majority of participants indicated that they were comfortable taking a stance on a controversial issue, advocating for an unpopular viewpoint, and advocating for those who cannot care for themselves (n=206, 66.0%; n=194, 62.2%; and n=214, 68.6%, respectively). One-hundred and forty (44.9%) participants indicated that they are comfortable with going against authority compared to 56 (17.9%) participants who indicated that they were uncomfortable. More survey participants indicated that they were comfortable dealing with interpersonal discord (n=153, 49.0%), emotional outbursts (n=172, 55.1%), and crisis situations (n=165, 52.9%) compared to those who indicated that they were uncomfortable (n=48, 15.4%; n=38, 12.2%; and n=33, 10.6%, respectively). More participants indicated that they were comfortable versus uncomfortable with dealing with ambiguity (n=143, 45.8% vs n=43, 13.8%), conflict of interest (n=155, 49.7% vs n=43, 13.8%), and ethical dilemmas (n=183, 58.7% vs n=26, 8.3%). Only 39.7% (n=124) of participants indicated that they were comfortable

advocating for the fiscally responsible provision of healthcare services while 10.9% (n=34) indicated that they were uncomfortable.

When asked to indicate their personal preferences regarding ANH in EOL care of a terminally ill patient unable to receive food and fluids by mouth, only 34.3% (n=107), 31.7% (n=99), and 25.6% (n=80) of participants indicated whether they would be in favor or opposed to ANH for themselves, a loved one, or their patients, respectively. Participants were more likely to indicate that their preference towards ANH at the EOL for themselves, their loved ones, or their patients would depend on the disease state (n=62, 19.9%; n=63, 20.2%; and n=64, 20.5%, respectively) compared to level or pain or the amount of time left.

Discussion

The majority of SLPs we surveyed indicated that their approval for or opposition to ANH would be dependent on the wishes of the patient or other unspecified circumstances related to the patient's condition or clinical status. While the right to patient autonomy and self-determination should be respected, it is essential that allied health professionals facilitate the level of communication necessary to support informed and shared decision-making between the patient or their surrogate, the provider, and other members of the multidisciplinary healthcare team. Although case studies and survey questions might not encompass the dynamic and complex nature of clinical situations, patients and families are often required to make decisions in emotionally heightened and emergency situations where there is a certain degree of ambiguity or uncertainty (Sharp et al., 2009; Vitale et al., 2011).

In our study, over 40% of SLPs indicated that they would be in favor of providing EN to terminally ill patients who are unable to take oral food/fluids but unlikely to benefit from ANH.

SLPs in favor of providing ANH were more likely to recommend a PEG tube over other methods of enteral access and were more likely to favor “permanent” enteral access (feeding tubes placed endoscopically or surgically) over temporary enteral access (nasogastric feeding tubes). Though only a small number of participants indicated that they did not have the knowledge or experience to choose which modality of feeding would be appropriate, more than 10% of SLPs indicated that they would be in favor of providing PN to a patient who does not have an evidence-based indication for IV nutrition therapy based on current practice recommendations (Worthington et al., 2017).

Given clinical scenarios, 59.3% of participants indicated that providing EN to a terminally patient would improve the patient’s nutritional status, and 46.8% indicated that EN was likely to improve survival time. More than a quarter of participants believed that providing EN would improve bedsores, lean body mass, dry mouth, risk of aspiration pneumonia, and general discomfort.

There is little evidence to indicate that providing ANH to terminally ill patients who are unable to maintain oral food and fluid intake at the EOL will benefit the patient in terms of survival time, mortality, QOL, or physical function (Schwartz et al., 2013). Our findings highlight a gap between the available evidence and opinions of SLPs, and these findings are similar to those published by other researchers. In a survey of clinical SLPs (n=326), Sharp and Shega (2009) determined that 56% of SLPs recommended PEG placement for a patient with advanced dementia who was unable to take adequate food or fluids. The authors found that SLPs believed that providing EN via PEG would improve nutritional status (78%), risk for aspiration pneumonia (46%), and survival time (43%) though few SLPs thought that PEG feedings would improve patient functional status (15%) or QOL (10%). Survey respondents were more likely to

recommend PEG placement for delivery of EN than any other mode of ANH or a combination of oral and artificial nutrition/hydration. The authors concluded that discrepancies exist between beliefs of SLPs and the evidence base that fails to prove that ANH would benefit patients with advanced dementia. They also determined that personal preferences towards ANH for oneself did not predict self-reported practice patterns in the patient care setting.

Similar findings were published by Vitale et al (2011). Results of their survey of ASHA members (n=731) found that only 22% of SLPs recognized that EN is unlikely to reduce the risk of aspiration pneumonia. A majority of the participants surveyed understood that EN is unlikely to prevent an uncomfortable death (50.2%), improve functional status (54.5%), or improve patient QOL (63.2%), and the authors concluded that misconceptions exist among SLPs about the role of EN in patients with advanced dementia. In analyzing responses related to SLP knowledge and comfort in addressing the feedings issues in this patient population, the authors determined that experience and exposure to alternative feedings in patients with advanced dementia would be more likely to impact knowledge than didactic coursework alone.

Our findings also corroborate those of O'Reilly and Walshe (2015) who surveyed SLPs (n=322) working with palliative care populations and determined that SLPs desire clarification on their role in caring for these patients. The authors found that SLPs believe involvement in palliative care is within their professional scope of practice, but highlighted the need for additional education, training, and research to inform, outline, and direct clinical practice.

In our study, race/ethnicity correlated with SLPs' preference toward or opposition to the choice of modality for providing ANH and how the potential complications of ANH are managed. Race/ethnicity were all also associated with SLPs comfort with interpersonal communication and comfort with saving the concept of saving lives at all costs. We found that

the participant's marital status correlated with the preference toward a specific modality of nutrition therapy, comfort in discussing death and dying, and the perceived influence that healthcare providers and administrators have on the decision to forego ANH at the EOL. We also found that participant's religious affiliation was associated with the choice to initiate or forgo nutrition therapy more than the expected outcomes associated of ANH.

These results emphasize the significant impact that sociocultural factors can have on beliefs, attitudes, and perceptions about death and dying, care provided to patients at the EOL, and decisions related to ANH. Research has shown that striking differences exists between racial/ethnic groups with regards to completing advanced care plans, communicating wishes/desires regarding EOL care, and choosing aggressive medical intervention at the EOL (Hopp et al., 2000; Wittenberg-Lyles et al., 2008). The perception of death/dying as well as the patient's role in decision-making about medical treatment and EOL care also differs between groups (Vincent, 2001). The emphasis on patient autonomy and self-determination emphasized in Western cultures should not overshadow the influence of family units or larger social networks important to other racial, ethnic, or cultural orientations (Kwak et al., 2005).

Religious doctrines differ in their views of life, attitudes toward death, approaches to EOL care, and extent to which they distinguish ANH, including EN and PN, from oral food and fluids (Heuberger, 2010). In addition to discussing the risks associated with providing ANH at the EOL and the expected outcomes of various modes of ANH therapy, healthcare providers should support the patient, family, and caregivers in seeking religious counsel and spiritual support where necessary during EOL care. Just as some racial, ethnic, religious, and cultural minorities may be underrepresented from the literature, the beliefs and attitudes of small or fundamentalist religious sects toward ANH or EOL decisions may be less widely understood.

Communication is essential in determining the needs and desires of the patient in making decisions regarding his/her EOL care.

Within group differences cannot be overlooked. Patients of the same race/ethnicity may come from a variety of educational, economic, and backgrounds; the understanding of and experience with ethical dilemmas, EOL issues, and ANH can vary significantly from patient to patient. Just as it is important for healthcare providers to recognize the potential differences in racial, ethnic, and cultural norms, it is imperative that the individual beliefs, desires, and expectations of each patient are considered. Allied health professionals, including SLPs and dietitians, should receive the appropriate education and training so that they are equipped and prepared to ask patients, surrogates, and caregivers about their preferences for interpersonal communication about condition and prognosis, goals and expectations for EOL care, and approach of decision-making related to ANH.

Social-cultural differences not only impact the EOL decisions made by patients or their surrogates but also the relationships and communication established between the patients/surrogates, providers, and other members of the multidisciplinary care team. In our study, institutional culture seemed to have a greater impact on how SLPs perceived their role in EOL decision-making and outcomes of ANH rather than influencing their opinion about a specific nutritional therapy. Policies put forth by the institutional can affect the dynamics of advance care planning, EOL discussions, and shared decision-making. How the roles and relationships of allied health professionals are defined at a particular facility can have a substantial impact on the patient and family's access to various services and support, including those provided by SLPs. An institution's approach to diversity, equity, and cultural competency, including employee awareness, education, and training, can either facilitate or impede

communication between patients, families, and the healthcare team at the EOL. Institutions are also responsible for identifying barriers to providing patients with the appropriate level of spiritual and emotional support as well as providing patients with access to those services.

Strengths, Limitations, and Biases

Our survey questions examined a wide range of measures to evaluate the beliefs and opinions of SLPs. Case studies provided context for questions regarding ethically and emotionally complex decisions related to forgoing ANH for a terminally ill patient at the EOL. The findings of this study are valuable in contributing to the body of evidence aimed at determining the knowledge, beliefs, and practices of SLPs in decisions related to ANH in EOL care.

The generalizability of these findings is limited because the nature by which participants were recruited and surveys were distributed did not generate a representative sample. Systematic selection biases were likely introduced in the study design as respondents participating in a survey about EOL care and decision-making may be more knowledgeable or experienced in the area of terminal illness, ANH, or palliative care. Participants in this survey could have been more comfortable in discussing death, dying, and ethically complex situations than those that did not participate. Responder and volunteer biases should also be considered; SLPs who completed the entire survey may have been more vested in this topic, more opinionated about the decisions and opinions being examined, or more interested in contributing to research in general.

It is unclear whether the beliefs and attitudes expressed in this survey are predictive of SLP practice. This survey did not examine how the attitudes and opinions of the survey participants impacted decision-making in actual patient cases or type, level, and degree to which these beliefs expressed in the real life situations. The analysis identified casual associations but

did not determine causality. Statistical analyses for correlations between demographic data and survey responses were limited due to the homogeneity of the data set. The length of this survey may have been a limiting factor in obtaining substantive free text explanations and in obtaining details about the degree of a participant's agreement or disagreement on specific issues.

Additional qualitative data are needed to understand the nuances in respondents' positions on ANH for terminally ill patients and their emotion toward the scenarios outlined in this survey.

Conclusion

SLPs possess unique knowledge, skills, and abilities that are vital to maintain high quality, patient-centered EOL care. SLPs have an integral role in facilitating communication between patients, families, and the healthcare team to promote shared decision-making regarding ANH. It is essential that SLPs, as a part of the multidisciplinary care team, have the training, experience, and perspective required to navigate through the decision-making process as well as their own opinions and emotions regarding patient care at the EOL. Understanding the opinions and perceptions of SLPs based on their personal characteristics and professional experiences is essential in advancing education, training, and research in the area of death and dying, ethical and legal aspects of EOL care, and decision-making for ANH.

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FIGURE 1: Definitions and Abbreviations.

Artificial Nutrition and Hydration (ANH): Nutrients and hydration provided to a patient via a nonoral route when oral intake is inadequate or unsafe.

Parenteral Nutrition (PN): Intravenous feeding.

Central Parenteral Nutrition (CPN): Intravenous nutrition provided via a catheter placed in a large, highblood flow central vein (usually the superior vena cava) to provide nutrients and fluids directly into the bloodstream bypassing the gastrointestinal tract completely. Also known as Total Parenteral Nutrition (TPN).

Peripheral Parenteral Nutrition (PPN): Intravenous nutrition provided via a catheter placed in a peripheral vein (usually in the forearm) to provide nutrients and fluids into the bloodstream bypassing the gastrointestinal tract completely. Due to the size of the peripheral veins, PPN formulas cannot be provided in sufficient quantities to meet all estimated nutritional needs.

Enteral Nutrition (EN): Enteral feeding provided via a tube placed into the gastrointestinal tract. Also known as “Tube Feeding.”

Nasogastric (NG): Feeding tube passed through the nose, down the esophagus, and into the stomach. Placement can be done at the bedside and confirmed by aspirating gastric contents or through radiographics. EN formulas are provided through the tube as bolus, intermittent, or continuous feedings.

Nasoduodenal (ND): Feeding tube passed through the nose, down the esophagus, through the stomach and pylorus, and into the duodenum (first part of the small intestine). Placement usually requires endoscopic, fluoroscopic, or computer guidance to ensure proper placement. EN formulas are provided through the tube as bolus, intermittent, or continuous feedings.

Nasojejunal (NJ): Feeding tube passed through the nose, down the esophagus, through the stomach and pylorus, past the duodenum, and into the jejunum (second part of the small intestine). Placement requires endoscopic, fluoroscopic, or computer guidance to ensure proper placement. EN formulas that do not require digestion by the stomach and duodenum are provided through the tube as bolus, intermittent, or continuous feedings.

Percutaneous Endoscopic Gastrostomy (PEG): Feeding tube placed using an endoscope and local anesthesia. The tube is guided through the mouth, down the esophagus, into the stomach, and then out through the abdominal wall providing direct access to the stomach. EN formulas are provided through the tube as bolus, intermittent, or continuous feedings.

Percutaneous Endoscopic Gastro-Jejunostomy (PEG-J): Feeding tube placed using an endoscope and local anesthesia. The tube is guided through the mouth, down the esophagus, through the stomach and pylorus, through the duodenum, into the jejunum (second part of the small intestine), and then out through the abdominal wall providing direct access to the jejunum. EN formulas that do not require digestion by the stomach and duodenum are provided through the tube as bolus, intermittent, or continuous feedings.

FIGURE 2: Drawing of Non-Oral Feeding Routes.

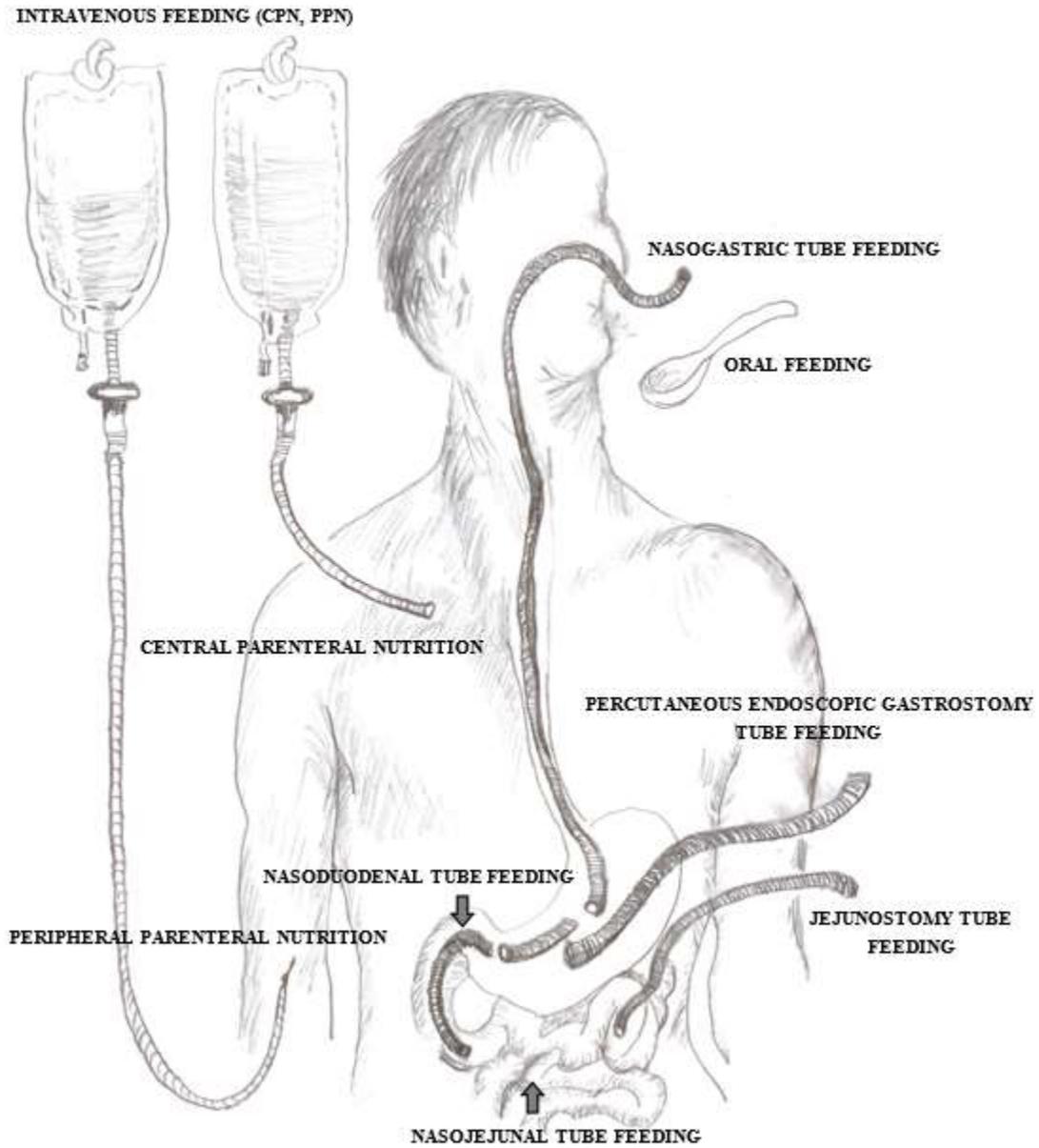


TABLE 1: Demographic Information.

<u>Variable</u>	<u>Percentage or M(SD)</u>	<u>Variable</u>	<u>Percentage</u>
Age	43.7(13.2)	Gender	
		Male	5.4%
Race/Ethnicity		Female	94.6%
Caucasian (White)	90.4%	Educational Attainment	
African American	5.1 %	Bachelor's Degree	11.9%
Hispanic	1.3 %	Master's Degree	83.3%
Asian	1.6 %	Doctoral Degree	4.8%
Native American	1.0 %	Specialization	
Two or More Racial Groups	0.6%	Speech Therapy	59.3%
Religious Affiliation		Communication Disorders	7.4%
Agnostic	5.4%	Speech Therapy and Communication Disorders	28.5%
Atheist	3.8%	Other	4.8%
Spiritual	6.7%	Employment	
Non-Denominational	8.0%	Clinical	67.8%
Catholic	28.2%	Non-Clinical	30.5%
Protestant	40.4%	Not Currently Working	1.6%
Jewish	3.2%	Institutional Culture at Place of Employment	
Muslim	0.3%	Laissez Faire Leadership	44.6%
Other	3.8%	Paternalistic Leadership	12.5%
Marital Status		Administrative or Autocratic Leadership	10.3%
Single	20.2%	Other	32.7%
Married	70.2%		
Divorced	5.1%		
Widowed	1.3%		
Cohabitant	3.2%		

TABLE 2: Binary Logistic Regression Model.

SLP preference (in favor or in opposition) to start PN for a terminally ill patient who can no longer take oral food/fluids but has a functional gastrointestinal tract.

Variable	B	S.E.	Wald	df	Sig.	Exp(B)
Age	-.026	.014	3.152	1	.076	.975
Marital Status			12.056	4	.017	
Single	1.071	.743	2.077	1	.150	2.917
Married	2.094	.720	8.460	1	.004	8.114
Divorced	1.118	.928	1.454	1	.228	3.060
Widowed	1.443	1.400	1.063	1	.303	4.234
Race			2.739	6	.841	
Caucasian	1.434	1.468	.954	1	.329	4.195
African American	2.627	1.782	2.174	1	.140	13.826
Hispanic	20.281	20019.48	.000	1	.999	6.42E+8
Asian	.664	1.852	.128	1	.720	1.942
Native American/ Alaskan Native	20.268	28419.41	.000	1	.999	6.34E+8
Pacific Islander/ Native Hawaiian	21.137	40192.97	.000	1	1.000	1.51E+9
Constant	-.112	1.661	.005	1	.946	.894

FIGURE 3: Scenarios.

Scenario I

The patient is an 89 year old, widowed, female. She is a devout Catholic. Her husband was her designated decision maker and no secondary was identified. She has two grown children and no legally documented preferences regarding how she wishes to be fed or hydrated. The patient has advanced dementia, is nonverbal, bedbound and is unable to eat or drink through oral routes. She is agitated and cries and moans as if in distress. Her children are fighting over how to proceed. A priest is called in and tells the family that based on his interpretation of the Catholic Directives on Artificial Nutrition and Hydration, the patient should receive artificial nutrition and hydration. The children agree.

In addition to advanced dementia, the patient has the following issues:

- Dysphagia (abnormal swallowing) with risk of choking and aspiration
- Sarcopenia (loss of muscle mass)
- Unintentional weight loss
- Dehydration
- Cracked lips, dry mouth, swollen gums
- Bruising
- Ascites (abnormal fluid accumulation in the peritoneal cavity)
- Myoclonus (muscle spasms)
- Stage III pressure ulcer (bedsore) on her buttocks
- Abnormal laboratory values indicative of protein energy malnutrition and dehydration
- Abnormal electrolyte levels with significant hypernatremia
- Several indicators of vitamin and mineral deficiencies
- Incontinence

Scenario II

The patient is a 43 year old, Caucasian male, single, no children, no other family, no religious affiliation and no insurance coverage. The patient has terminal cancer and is in a great deal of pain. The patient has stopped cancer treatment but continues to accept/receive morphine for pain and midazolam HCL for sedation. The patient has been deemed mentally competent and has legal documentation outlining his wishes for no aggressive or extraordinary measures. He has recently moved to another care facility and the staff know little about him. The patient is voluntarily refusing to eat or drink. He is becoming more dehydrated, weak and fatigued each day. His gastrointestinal tract is intact, functional and has not been directly affected by the cancer. The care team is discussing providing Artificial Nutrition and Hydration forcibly (against the patient's will).

TABLE 3: Correlation Table.

At times Artificial Nutrition and Hydration (ANH) is started for inappropriate patients. Which of the following parties or situations could prevent the start of ANH if they had voiced their opposition?

Response	Kendall's Tau B Correlation Coefficient								
	Age	Gender	Race/ Ethnicity	Marital Status	Religious Affiliation	Education	Specialization	Employment	Institutional Culture
Patient's legal documentation	-0.035	-0.050	-0.047	0.005	0.106*	-0.137*	-0.085	-0.048	0.035
Patient's verbal statement	-0.100*	0.002	0.032	0.023	0.077	0.029	-0.029	-0.014	-0.012
Patient's spouse	-0.116*	-0.065	0.039	0.132*	0.030	-0.096	-0.072	-0.100	-0.088
Patient's children	- 0.154**	-0.074	0.024	0.113	0.067	-0.070	-0.047	-0.179**	-0.125*
Patient's other family or friends	-0.126*	-0.008	-0.026	0.118	-0.006	0.079	-0.055	-0.034	0.012
Attending physician	-0.111*	-0.017	-0.015	0.068	0.034	-0.071	-0.057	-0.144*	-0.144*
Nursing staff	-0.087	-0.031	0.035	0.045	0.046	-0.027	-0.071	-0.085	-0.138*
Dietitian	- 0.203**	-0.006	-0.029	0.094	0.039	-0.006	-0.022	-0.065	-0.211**
Speech therapist	- 0.203**	-0.018	0.008	0.140*	-0.066	-0.058	0.011	-0.170**	-0.254**
Pharmacist	-0.082	-0.121	0.000	-0.023	0.027	0.069	-0.027	-0.022	-0.119
Case manager or social worker	-0.012	-0.020	0.170*	0.039	-0.039	-0.067	-0.048	-0.029	-0.072
Clergy	-0.002	-0.083	0.109	0.093	0.047	-0.030	-0.068	0.014	0.022
Insurance carrier	-0.034	-0.015	0.002	0.167*	0.084	-0.085	0.070	-0.074	-0.021
Hospital administrator	-0.003	-0.063	0.090	0.203**	0.031	-0.064	0.015	-0.101	0.040
* Correlation is significant at the 0.05 level (2-tailed).									
** Correlation is significant at the 0.01 level (2-tailed).									

TABLE 4: Frequency Table for Responses to Scenario I.

This patient has a PEG tube placed and is being fed a high protein enteral formula with vitamins, minerals, and adequate fluids. Given the information, would you expect that the patient would show improvements in:

Response	Frequency (%)		
	Likely	Unlikely	Unsure/Don't Know
Bedsore	113 (36.2%)	96 (30.8%)	103 (33.0%)
Lean muscle mass	87 (27.9%)	106 (34.0%)	119 (38.1%)
Risk of aspiration pneumonia	80 (25.6%)	139 (44.6%)	93 (29.8%)
Dry mouth	82 (26.3%)	135 (43.3%)	95 (30.4%)
Nutritional status	185 (59.3%)	31 (9.9%)	96 (30.8%)
Electrolyte	192 (61.5%)	25 (8.0%)	95 (30.4%)
Agitation	61 (19.6%)	109 (34.9%)	142 (45.5%)
Quality of life	55 (17.6%)	139 (44.6%)	118 (37.8%)
General discomfort	92 (29.5%)	111 (35.6%)	109 (34.9%)
Physical pain	70 (22.4%)	124 (39.7%)	118 (37.8%)
Emotional distress	48 (15.4%)	136 (43.6%)	128 (41.0 %)
Survival time	146 (46.8%)	64 (20.5%)	102 (32.7%)

TABLE 5: Frequency Table for Responses to Scenario II.

Would you expect that if this patient were NOT forcibly provided with Artificial Nutritional and Hydration (ANH):

Response	Frequency (%)		
	Likely	Unlikely	Unsure/Don't Know
The patient would die sooner	162 (51.9%)	25 (8.0%)	125 (40.1%)
The patient would experience more pain	52 (16.7%)	97 (31.1%)	163 (52.2%)
The patient would experience greater discomfort	71 (22.8%)	91 (29.2%)	150 (48.1%)
The staff would be acting in an ethical manner	179 (57.4%)	17 (5.4%)	116 (37.2%)
The staff would be seen as "negligent"	35 (11.2%)	153 (49.0%)	124 (39.7%)
The staff would be seen as acting in the patient's best interest	162 (51.9%)	21 (6.7%)	129 (41.3%)
The staff would be providing the best possible care in a difficult situation	171 (54.8%)	18 (5.8%)	123 (39.4%)

TABLE 6: Correlation Table.

In terms of you own personal experiences, how comfortable are you with:

Response	Kendall's Tau B Correlation Coefficient								
	Age	Gender	Race/ Ethnicity	Marital Status	Religious Affiliation	Education	Specialization	Employment	Institutional Culture
General interpersonal communication	0.044	-0.034	-0.141*	0.073	-0.068	-0.064	-0.082	-0.071	0.090
Discussing death and dying	0.203**	-0.077	-0.051	0.154*	-0.015	-0.047	-0.074	-0.033	0.124
Communicating bad news	0.146*	-0.104	0.018	0.066	-0.009	-0.089	-0.056	-0.045	0.073
Use of technology to extend life	-0.015	-0.059	0.014	0.162*	-0.039	-0.084	-0.001	-0.003	0.072
Concept of quality versus quantity of life	0.100	-0.034	0.050	0.124	0.034	-0.065	-0.162*	0.050	0.064
Concept of death as a natural part of life	0.081	-0.040	0.060	0.057	0.075	-0.073	-0.019	0.023	0.134*
Concept of saving lives at all costs	-0.023	0.060	0.176*	0.006	-0.054	-0.048	0.039	0.055	0.082
Speaking up on behalf of others	0.035	-0.040	-0.097	0.000	0.000	-0.021	-0.047	-0.050	-0.002
Speaking up for yourself	0.041	-0.039	-0.106	0.013	-0.017	-0.074	-0.052	0.024	0.022
Taking a stance on a controversial issue	0.102	-0.054	0.020	0.060	-0.074	-0.047	-0.063	0.050	0.131*
Advocating for an unpopular viewpoint	0.136*	-0.074	0.016	0.043	-0.068	-0.056	-0.073	0.037	0.118
Going against authority	0.123*	-0.085	0.081	0.129	-0.065	-0.064	0.026	0.056	0.173*
Advocating for fiscal responsibility in healthcare	0.072	-0.121	0.101	-0.010	0.033	-0.004	0.099	0.185*	0.050
Ambiguity	0.009	-0.041	0.066	0.053	-0.096	-0.074	0.051	0.051	0.094
Emotional outbursts	0.000	0.023	0.105	0.027	0.023	-0.116	0.050	-0.057	0.075
Crisis situations	0.135*	-0.092	-0.013	0.093	0.052	0.013	-0.046	-0.043	0.102
Dealing with a conflict of interest	0.143*	-0.093	0.017	0.094	-0.053	0.067	-0.011	0.061	0.097
Dealing with ethical dilemmas	0.059	-0.080	-0.028	0.034	0.029	-0.063	0.034	0.026	0.101
Dealing with interpersonal discord	0.072	-0.106	0.079	0.024	-0.018	-0.118	0.111	0.018	0.091
* Correlation is significant at the 0.05 level (2-tailed).									
** Correlation is significant at the 0.01 level (2-tailed).									