ARE SPEECH-LANGUAGE PATHOLOGISTS PREPARED TO WORK IN PALLIATIVE CARE SETTINGS BY UNIVERSITY CURRICULA?

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ABSTRACT

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There is an increasing recognition within the literature that speech-language pathologists have a role in providing care to palliative care clients. However, few studies have examined the preparedness of speech-language pathologists to provide such care. The purpose of this research was to examine whether speech-language pathologists working in palliative care settings in the United States felt as though they were adequately prepared by their university curricula to work in such a setting. Nine speech-language pathologists who were presently or had previously worked in palliative care settings were interviewed using a semi-structured interview schedule. The interviews were transcribed, and the data were analyzed and coded based on the themes that emerged. Participants revealed that they did not perceive themselves as prepared by their university curricula to work in palliative care settings and subsequently had to fill the gaps of knowledge left by their curricula using additional resources. Participants also discussed the various roles of speech-language pathologists working in palliative care settings such as improving quality of life at the end of life, educating and communicating with clients, families, and other professionals, and considering a variety of factors that can complicate how they provide care to palliative care clients. Additionally, participants revealed that working in palliative care settings has forced them to adopt resigned attitudes toward death and dying. Finally, participants recommended changes that could be made within university curricula to better prepare students to work in palliative care settings.

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INTRODUCTION

Speech-language pathologists (SLPs) provide treatment to clients in every stage of life. Often, this includes treating clients who are in the end stages of life and receiving palliative care. Although SLPs are expected to treat clients receiving palliative care, many believe they lack the education and training to do so. This research will examine whether SLPs providing palliative care believe they were adequately prepared to work in such a setting, how SLPs were able to fill gaps of knowledge that they possessed regarding palliative care, what information SLPs did not receive about palliative care in their undergraduate and graduate curricula, and what changes SLPs believe programs should make in order to better prepare their students to work in a palliative care setting.

CHAPTER I: LITERATURE REVIEW

Palliative Care

Sepúlveda et al. (2002) report the World Health Organization’s [WHO] definition for palliative care:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (p. 94)

Palliative care uses an interdisciplinary team (IDT) approach in order to care for clients who present with a variety of diagnoses including, but not limited to, cardiovascular diseases, cancer, chronic respiratory diseases, AIDS, and cancer (World Health Organization [WHO], 2018). One of the primary goals of palliative care is controlling symptoms and relieving pain and suffering in the absence of curative treatment options (Javier & Montagnini, 2011; Roe & Leslie, 2010; Toner & Shadden, 2012b). Annually, it is estimated that 40 million people are in need of palliative care services worldwide (WHO, 2018). It should be noted, however, that not every client who receives palliative care has a terminal diagnosis (Toner & Shadden, 2012b).

The Role of Speech-Language Pathologists in Palliative Care

Growing recognition that palliative care clients have specialized needs has led to the development of IDTs consisting of specialized practitioners, including SLPs (Eckman & Roe, 2005). Further, because many conditions that cause death can also cause swallowing or communication problems (Toner & Shadden, 2012a), an increasing number of SLPs have started working in palliative care settings in recent years (Eckman & Roe, 2005). Similar to SLPs who work in other areas, SLPs working in palliative care must use evidence-based practice by integrating the current research, their clinical expertise, and the client's values and opinions to make clinical decisions (Kelly et al., 2016). Unlike SLPs working in other areas, however, the SLP working in palliative care does not provide therapy using an impairment-based model (Kelly et al., 2016). Rather, SLPs providing palliative services use a social model that foregrounds the client's wishes when determining management options (Kelly et al., 2016). Since this approach requires the SLP to adapt to changes in the client's condition and level of function, the SLP must be knowledgeable about the progression of the client's disease, services that can be provided to clients at the end of life, and the dying process, including legal and ethical concerns (Kelly et al., 2016).

While SLP services may be recommended for clients with a broad range of diagnoses, SLPs most frequently work with clients who have cancer, Alzheimer's disease, or who survived a cerebral vascular accident (Toner & Shadden, 2012b). These clients can be treated in a variety of settings, including hospitals, nursing homes, hospice centers, and in the client's home (Toner & Shadden, 2012b).

While the majority of SLPs believe that they have a role in palliative care (O'Reilly & Walshe, 2015), many believe that this role is poorly defined and often not recognized by professionals in other fields (Hawksley et al., 2017; O'Reilly & Walshe, 2015; Pollens, 2012; Roe & Leslie, 2010; Wallace, 2013). Some researchers have attempted to define the role of the SLP in palliative care by conducting surveys with SLPs who work in the palliative care setting. In a survey conducted by Pascoe et al. (2018), participants reported that the role of the SLP in palliative care was to maximize the client's quality of life. Hawksley et al. (2017) also identified one of the key roles of SLPs in palliative care as working towards a good death for their clients.

Other researchers have further identified the roles of SLPs in the palliative care setting based upon the services that SLPs provide to their clients.

Consultation. An SLP working in the palliative care setting may be called upon by other members of the IDT to provide consultation regarding a client in a number of different areas. The IDT working in hospice care is made up of a number of diverse professionals including nurses, social workers, physicians, counselors, and nutritionists (Pollens, 2004). Other services that may be provided, but are not required, are physical therapy, occupational therapy, speech-language therapy, home health aide, pharmacy, and audiology (Pollens, 2004).

SLPs have various responsibilities that enable them to be productive and valuable members of the IDT. These responsibilities include providing information to the IDT about consultations and assessments, educating members of the IDT about client care strategies and the rationale for using them, and learning from other IDT members about the client's plan of care (Pollens, 2004). Some responsibilities of a consulting SLP may include giving clinical recommendations in the area of dysphagia and providing input regarding a client's ability to make decisions in light of communicative and cognitive deficits (Pollens, 2004). SLPs may also be called upon by members of the IDT to answer questions regarding nutrition and hydration or address concerns regarding communication due to an illness, tracheostomy placement, or the use of ventilation equipment (Lambert, 2012). Other members of the IDT may contribute information and inform choices related to the SLP's scope of practice (Pollens, 2012). O'Reilly and Walshe (2015) found that the majority of SLPs agree that the role of the SLP in palliative care includes collaborating with the IDT to contribute to client care and educating the IDT in the areas of communication and swallowing difficulties. Finally, SLPs performing consultations are expected to communicate with clients and their family members about preferences and concerns they may have.

Promoting Communication. One of the main functions of an SLP working in a palliative care setting is optimizing a client's ability to communicate (Eckman & Roe, 2005; Frost, 2001; Kelly et al., 2016; O'Reilly & Walshe, 2015; Pollens, 2004, 2012; Roe & Leslie, 2010; Salt et al., 1999; Toner & Shadden, 2012b). Setting communication goals in palliative care settings is important because clients' quality of life improves when they are able to communicate their needs, wishes, and feelings (Pollens, 2012).

When promoting communication in a client in palliative care, an SLP may have a number of responsibilities, including providing therapy, training the client's communication partners in how to facilitate communication, using alternative methods of communication (Eckman & Roe, 2005), helping the client express his or her various needs, concerns, or preferences related to care, and empowering the client to express different emotions and concerns related to dying (Pollens, 2004). SLPs may also play an important role in supporting communication between the client and family members and/or health care providers (Hawksley et al., 2017; Toner & Shadden, 2012b).

Managing Dysphagia. Another primary responsibility of SLPs who work in a palliative care setting is to manage dysphagia in clients who cannot swallow safely (Eckman & Roe, 2005; Frost, 2001; Hawksley et al., 2017; Kelly et al., 2016; O'Reilly & Walshe, 2015; Pollens, 2004, 2012; Roe & Leslie, 2010; Salt et al., 1999; Toner & Shadden, 2012b). The SLP treating dysphagia in clients receiving palliative care may have a wide range of responsibilities including assessment, client and family education, teaching safe swallowing strategies, and diet modification (Eckman & Roe, 2005; Pollens, 2012). In the traditional medical model, treatment from an SLP would focus on reducing the risk of aspiration, dehydration, or malnutrition (Pollens, 2004). However, in the palliative care setting, these goals often shift toward learning strategies that can help the client enjoy eating in as safe a way as possible (Pollens, 2004).

Cognition. It is important that SLPs working in palliative care evaluate a client's cognitive levels of competency (Wallace, 2013). While a general understanding of a client's cognitive ability is valuable to all members of the interdisciplinary team, it is especially beneficial to the professionals who work with the client to make end of life decisions and complete living wills (Wallace, 2013). In order for a client to have conversations on these serious issues and make well-informed decisions, other health care professionals must know what information to present and how it will be most effectively presented (Wallace, 2013).

Counseling. While working in palliative care, SLPs will undoubtedly encounter clients who are nearing the end of their lives. SLPs must be prepared to listen to their clients in order to understand their thoughts and feelings and make their clients feel supported (Spillers, 2007). When doing this, the SLP must be nonjudgmental and empathetic so the client feels accepted (Spillers, 2007). By listening and understanding a client's emotions, the SLP can better provide effective counseling and therapy services (Potter et al., 1979).

Effects of Working in Palliative Care

SLPs working in palliative care settings will often experience losing clients to fatal illnesses (Hawksley et al., 2017; Toner & Shadden, 2012b). When clinicians frequently lose clients with whom they have developed deep emotional bonds, they may be at risk for developing compassion fatigue in which they no longer feel empathy toward their clients (Toner & Shadden, 2012b). Keidel (2002) supports this theory when discussing how burnout and compassion fatigue affect hospice caregivers. According to Keidel (2002), burnout and compassion fatigue can impair the performance of hospice caregivers and foster negative attitudes and behaviors, including short attention span, short temper, and blaming behaviors.

Palliative Care Training

In an effort to educate professionals on providing services in palliative care settings, many health care programs have implemented palliative care training courses. These courses are crucial, as research demonstrates that professionals who work in palliative care settings are less likely to experience negative emotions if they can develop appropriate coping strategies to manage these emotions (Toner & Shadden, 2012b).

Nurses. Many studies have been conducted attempting to determine the effect that palliative care education courses have on nursing students. Generally, classes that are focused on treating clients in palliative care settings have received mostly favorable reviews from nursing students. 100% of students enrolled in a palliative care nursing class reported that the class had affected their perception of their ability to be more clinically competent when providing palliative care (Ballesteros et al., 2014). Furthermore, 50% of students reported that the class had influenced them to apply for a clinical position in a palliative care setting (Ballesteros et al., 2014). Although 16% of students reported that they did not want to work in a palliative care setting, they still spoke favorably about their experience in the class (Ballesteros et al., 2014). In a separate study by Bush and Shahwan-Akl (2012), nursing students who had taken a course on palliative care reported that they learned how to better communicate with and understand palliative care clients. Students enrolled in the course reported the importance of palliative care training in a nursing curriculum (Bush & Shahwan-Akl, 2012).

While palliative care classes have been shown to be effective in educating nursing students on palliative care, a study by Dickinson (2007) revealed that palliative care classes are not common in nursing schools. A course dedicated to palliative care exists in only 11% of nursing schools. It is more common that a palliative care curriculum is a module included in a larger course (32%) or only covered in one or two lectures (59%). A palliative care curriculum is not formally taught at any level in 12% of nursing schools (Dickinson, 2007).

Physical Therapists. Regarding the effectiveness of palliative care training programs for physical therapy students, Kumar et al. (2011) found that students reported positive changes in knowledge, attitudes, beliefs, and experiences toward palliative care at a statistically significant level. Morris and Leonard (2007) also reported that physical therapy students working on palliative care teams described having favorable experiences. Students enjoyed the support that they received from other members of the IDT and were able to learn about the roles of different health care professions in the palliative care setting (Morris & Leonard, 2007). Students also reported that they had a better understanding of the role of the physical therapist on a palliative care team and described their palliative care placement as a valuable learning experience (Morris & Leonard, 2007).

Speech-Language Pathologists. Researchers have acknowledged that palliative care clients require a different skill set than other clients that speech-language pathologists may encounter in their caseload (Hawksley et al., 2017; Kelly et al., 2016). In an attempt to address the lack of palliative care training for students of any health profession at the undergraduate level, the Palliative Care Curriculum for Undergraduates (PCC4U) Project was created (Mathisen et al., 2011). This organization then created a palliative care curriculum to be implemented in health care profession programs at the university level. Only one university, The University of Newcastle, implemented the curriculum in its speech-language pathology program. Of the speech-language pathology students who participated in this program, 59% rated the lecture format as helpful, 11% rated it as very helpful, and 30% rated it as somewhat helpful in regard to learning about palliative care (Mathisen et al., 2011). Clinicians working in palliative care settings who received palliative care training also reported feeling significantly more prepared to work in such a setting, compared to their SLP colleagues who did not receive palliative care training (Pascoe et al., 2018).

Preparation to Work in Palliative Care in University Settings

Although many universities offer classes on death and dying in a variety of disciplines, few of these courses are offered in the discipline of speech-language pathology to prepare clinicians to handle the death of clients and the unique caseload that comes with working in a palliative care setting (Roe & Leslie, 2010; Toner & Shadden, 2012b; Wallace, 2013). A study conducted by Pascoe et al. (2018) revealed that only 27% of SLPs working in a palliative care setting reported receiving palliative care training in their undergraduate or graduate speech pathology curriculum. In the absence of formal palliative care training at the university level, many clinicians begin practicing without understanding how the dying process affects clients and their families (Toner & Shadden, 2012a). It then becomes the SLP's responsibility to gain the necessary information about their roles and responsibilities when treating a client who is in the process of dying (Toner & Shadden, 2012a). However, Pascoe et al. (2018) report that 43% of professionals working in palliative care have not received palliative care professional development after graduating. SLPs who have not received palliative care training but have gone on to work in a palliative care setting have traditionally relied on their colleagues from other health care disciplines to provide their knowledge and support (Eckman & Roe, 2005). SLPs working in a palliative care setting have suggested that palliative care training programs cover topics such as counselling, communication skills, service delivery, dysphagia, and ethical and legal issues (Pascoe et al., 2018). Undergraduate and graduate students studying speech-language pathology have indicated that the preferred method for learning about palliative care would be through professional experience such as clinical placements rather than traditional classroom learning (Rivers et al., 2009).

Students' Perception of Preparedness to Work in Palliative Care

Pascoe et al. (2018) found that 69.9% of SLPs working in a palliative care setting did not feel prepared to work in a palliative care setting. In a separate study by Rivers et al. (2009), the majority of SLP student participants considered themselves to be somewhat knowledgeable about the death and dying process, although most did not perceive themselves to be experts. They also considered expertise about the death and dying process to be essential to providing care to clients and their families and expressed a need for additional professional preparation (Rivers et al., 2009). Many participants felt reasonably comfortable providing services to terminally ill clients but felt that their performance and personal feelings would be affected if they experienced the death of a client (Rivers et al., 2009).

Research Strategy

The experiences that SLPs had at their undergraduate and graduate universities regarding their preparation to work in a palliative care setting will be researched using a qualitative research design with an interpretative phenomenological analysis approach. The goal of qualitative research is to understand people's beliefs, experiences, and attitudes through non-numerical data (Damico et al., 1999; Kalra et al., 2013).

Interpretative Phenomenological Analysis (IPA)

Interpretative phenomenological analysis (IPA) attempts to determine the various ways in which different people perceive the world dependent on characteristics such as life experiences and personalities. While IPA is largely dependent upon the perspective of the participants, the perspective of the researcher, who is trying to interpret what the participants are saying, also plays an important role in attempting to understand the participants' experiences. The researcher is tasked with trying to find out what participants think and feel about the experiences that they are speaking of (Smith & Osborn, 2004).

Studies that use IPA generally use a small number of participants, as the goal is to understand the intimate experiences that each of the participants have had. Because the sample sizes in IPA studies are small, these studies typically do not obtain random samples that are representative of a diverse population. Rather, researchers typically attempt to establish a homogeneous sample. In doing so, similarities and differences in the data can be attributed to the experiences of individuals rather than variability in the characteristics of participants (Smith & Osborn, 2004).

Interpretative Phenomenological Analysis in Speech-Language Pathology

Autism. Huws and Jones (2010) used IPA to examine the attitudes, beliefs, and conceptions that the general public have about people with autism. Additionally, the same researchers also conducted another study using the same methodology in an attempt to explore the perceptions that young people with autism have of autism (Huws & Jones, 2015).

Aphasia. Klompas and Ross (2004) conducted semi-structured interviews in an attempt to determine how aphasia affected the quality of life of South African adults. Brown et al. (2011) used IPA to discover what family members of those with aphasia believe living successfully with aphasia means. Brown et al. (2010) also conducted a separate study in an attempt to discover what SLPs believe living successfully with aphasia means.

Dysphagia. Nund et al. (2014) conducted a qualitative, person-centered study in order to describe the experiences of people with dysphagia after being treated for head and neck cancer. LaDonna et al. (2016) conducted a study of caregivers of adults with myotonic dystrophy that presented with dysphagia in order to understand the experiences of providing care to this population. Research has also been conducted using IPA on the experiences of those living with dysphagia after suffering a stroke (Moloney & Walshe, 2017).

Parkinson's Disease. Habermann (1996) explored the day to day experiences of those living with Parkinson's disease in an attempt to understand those experiences. Further research was completed by Bramley and Eatough (2005) when they explored the social and personal aspects of living with Parkinson's disease. Giles and Miyasaki (2009) additionally explored the lived experiences of individuals and families of those with Parkinson's disease receiving palliative care at the end stages of life.

Stuttering. Trichon and Tetnowski (2011) conducted a study in order to determine if people who stutter perceive self-help conferences as being a useful strategy for stuttering management. Bricker-Katz et al. (2013) also used IPA to examine the experiences of people who stutter in the workplace.

Critical Gap

Multiple researchers have suggested a need for further research regarding the preparedness and training of speech-language pathologists in the domain of palliative care (Eckman & Roe, 2005; Pascoe et al., 2018). A limited number of research studies have already attempted to understand whether speech-language pathologists believe they were prepared by their university curricula to work in palliative care settings. A study conducted by Rivers et al. (2009) examined the perception of students who were currently studying speech-language pathology and had no hands-on experience with palliative care clients. Pascoe et al. (2018) examined the perception of clinicians working in a palliative care setting who completed their university training in Australia. However, there are currently no studies that examine the perceptions of preparation at the university level by speech-language pathologists working in palliative care settings in the United States. Studying the perceptions and experiences of speech-language pathologists who fit this demographic could provide insight into how prepared speech-language pathologists who study at universities in the United States are to work in palliative care settings. By identifying how well university curricula are preparing speech-language pathology students, speech-language pathology programs may gain insight into how they could better prepare their students to work in palliative care settings.

Objective

The objective of the present study is to gain additional insight into the degree of preparation that speech-language pathologists working in a palliative care setting in the United States believe they have received from their respective universities at the undergraduate and graduate level. This objective will be met by interviewing clinicians who currently work in palliative care settings using questions that pertain to the research questions listed below. Interpretative phenomenological analysis will then be used to analyze participant responses in an attempt to find common themes among participants. In a series of interviews with speech-language pathologists working in a palliative care setting, the present study asked the following research questions:

- Do clinicians believe they were adequately prepared by their undergraduate and graduate universities to work in the palliative care setting?

- How were clinicians able to fill any gaps of knowledge regarding palliative care once they started working in that field?
- What information have clinicians obtained by working in the palliative care setting that they did not receive at their undergraduate or graduate universities?
- What changes would clinicians suggest making to speech-language pathology curricula to better prepare students to work in palliative care settings?

Creators of speech-language pathology curricula at the university level may find the results of this study helpful when determining the best way to prepare students to work in palliative care settings.

CHAPTER II: METHODS

Participants

In order to be eligible to participate in this study, participants were required to have a master's degree in speech-language pathology and be a certified member of ASHA. Additionally, participants had to have worked in a setting where clinicians routinely provide palliative care, such as skilled nursing facilities, for a minimum of three years. Participants were required to report that they regularly treat people who are in the end stages of their lives.

Following Institutional Review Board approval, participants were recruited through contacts within the Department of Communication Sciences and Disorders at Bowling Green State University. I approached the clinical and academic faculty to ask if they had any connections with clinicians working in clinical practice who met the selection criteria. If the faculty were willing and able to furnish contact details, I contacted the prospective participants via email. If the prospective participants expressed interest in participating in the study, an in-person meeting was scheduled in order to obtain consent and conduct the interview. All participants in this study volunteered to participate in this study and completed the informed consent process. Participants were also asked if they knew of any other SLPs who work in palliative care who might be interested in participating in the study. These SLPs were then contacted via email.

In total, nine SLPs were interviewed for this study. On average, participants had been working in the palliative care setting for 12.2 years, with the minimum being 3 years and the maximum being 25 years. The participants interviewed worked in a variety of settings, including skilled nursing facilities, rehabilitation centers, transitional care units, federal medical prisons, hospitals, assisted living facilities, and home health. The participants represented six different undergraduate programs and four different graduate programs.

Table 1. Demographics of Participants.

Participant	**Time Working in Palliative Care**	**Undergraduate University**	**Graduate University**
SLP 1	16 years	University A	University A
SLP 2	6.5 years	University B	University B
SLP 3	15 years	University B	University B
SLP 4	3 years	University A	University A
SLP 5	5 years	University C	University D
SLP 6	14.5 years	University E	University F
SLP 7	25 years	University G	University A
SLP 8	14 years	University F	University B
SLP 9	11 years	University A	University A

University A, University B, University C, University E, and University F are four-year public doctoral universities with high research activity. University D is a four-year doctoral and professional university. University G is a four-year private not-for profit master's college and university.

Procedure

Prior to the interviews, each participant was given a copy of the interview questions in order to familiarize themselves with the questions being asked (Nund et al., 2014). Each participant was interviewed individually in a private setting of the participant's choice. Interviews were semi-structured, consisting of mostly open-ended questions (Brown et al., 2010, 2011; Habermann, 1996; Klompas & Ross, 2004; Nund et al., 2014). As a review of the literature indicated that there were no pre-existing interview schedules that met the needs of this study, original interview questions were formulated (Klompas & Ross, 2004). All participants were asked predetermined questions pertaining to relevant topics, but follow-up questions were asked to explore areas of interest based on the answers that participants gave (Brown et al., 2010, 2011; Klompas & Ross, 2004). Participants were asked to speak freely about their personal experiences (Nund et al., 2014). Interviews were recorded using an audio recording device with the participants' permission and were later transcribed verbatim for analysis (Nund et al., 2014). Participants were recruited until it was determined that saturation had been achieved.

Data Analysis

We took the following steps in order to analyze the data collected from participants:

1. We initially read through each interview transcript separately several times in an attempt to familiarize ourselves with the data (Bramley & Eatough, 2005; Bricker-Katz et al., 2013; Brown et al., 2010, 2011; Giles & Miyasaki, 2009; Habermann, 1996; Huws & Jones, 2010, 2015; LaDonna et al., 2016; Moloney & Walshe, 2017).
2. The data were coded separately based on themes that appeared using line by line open coding (Bricker-Katz et al., 2013; Brown et al., 2010, 2011; Huws & Jones, 2010, 2015; Moloney & Walshe, 2017).
3. Axial codes were then created separately based on the relationships between the open coding system previously used (Bricker-Katz et al., 2013; Huws & Jones, 2010).
4. We met to compare our open and axial codes in an attempt to combine them (LaDonna et al., 2016; Moloney & Walshe, 2017).

5. Schemas were then created to show the major themes, their dimensions, and the relationships between these themes (Bramley & Eatough, 2005; Bricker-Katz et al., 2013; Brown et al., 2010, 2011; Huws & Jones, 2010, 2015).
6. We re-reviewed the data to determine if the schemas were a grounded representation of the data (Bramley & Eatough, 2005; Huws & Jones, 2015).
7. The schemas were amended when necessary (Bramley & Eatough, 2005; Huws & Jones, 2015).
8. Memos were written on each of the themes and how they were described by the participants (Bramley & Eatough, 2005).
9. The transcripts were given to a qualified third party unrelated to the research who has experience in qualitative research and interpretative phenomenological analysis to confirm that the discovered themes were appropriately taken from the data. This third party has conducted and carried out multiple IPA studies and has published papers on IPA studies in peer-reviewed journals. This process is referred to as lamination (Bramley & Eatough, 2005; Huws & Jones, 2010, 2015; Simmons-Mackie & Damico, 1997; Trichon & Tetnowski, 2011).
10. Each participant was asked to confirm the findings from the analyses in a process referred to as member checking (Bramley & Eatough, 2005; Nund et al., 2014; Trichon & Tetnowski, 2011).
11. After lamination and member checking, we revised schemas based on the feedback that we had received.

12. Once all of the themes within the data were determined, verbatim quotes were chosen to support each theme (Bramley & Eatough, 2005; Brown et al., 2010, 2011; LaDonna et al., 2016).

CHAPTER III: RESULTS

Seven themes emerged from the interviews conducted with the participants. The themes identified include:

1. Clinicians are not adequately prepared by university curricula to work in palliative care settings.
2. Clinicians seek to fill in gaps from their university curricula with additional resources regarding palliative care.
3. Clinicians utilize client-centered approaches to try to improve quality of life at the end of life.
4. A key role of clinicians is to educate and communicate with clients, families, and other professionals.
5. Clinicians must consider a variety of factors that complicate how they function in end of life settings.
6. Clinicians have resigned attitudes toward death and dying.
7. Clinicians believe that changes could be made to university curricula to better prepare students to work in palliative care settings.

Theme 1 can be used to answer the first research question: “Do clinicians believe they were adequately prepared by their undergraduate and graduate universities to work in the palliative care setting?” Theme 2 addresses the second research question: “How were clinicians able to fill any gaps of knowledge regarding palliative care once they started working in that field?” Themes 3, 4, 5, and 6 provide findings related to the third research question: “What information have clinicians obtained by working in the palliative care setting that they did not receive at their undergraduate or graduate universities?” Theme 7 can be used to answer the fourth research question: “What changes would clinicians suggest making to speech-language pathology curricula to better prepare students to work in palliative care settings?” Each theme is discussed in further detail below.

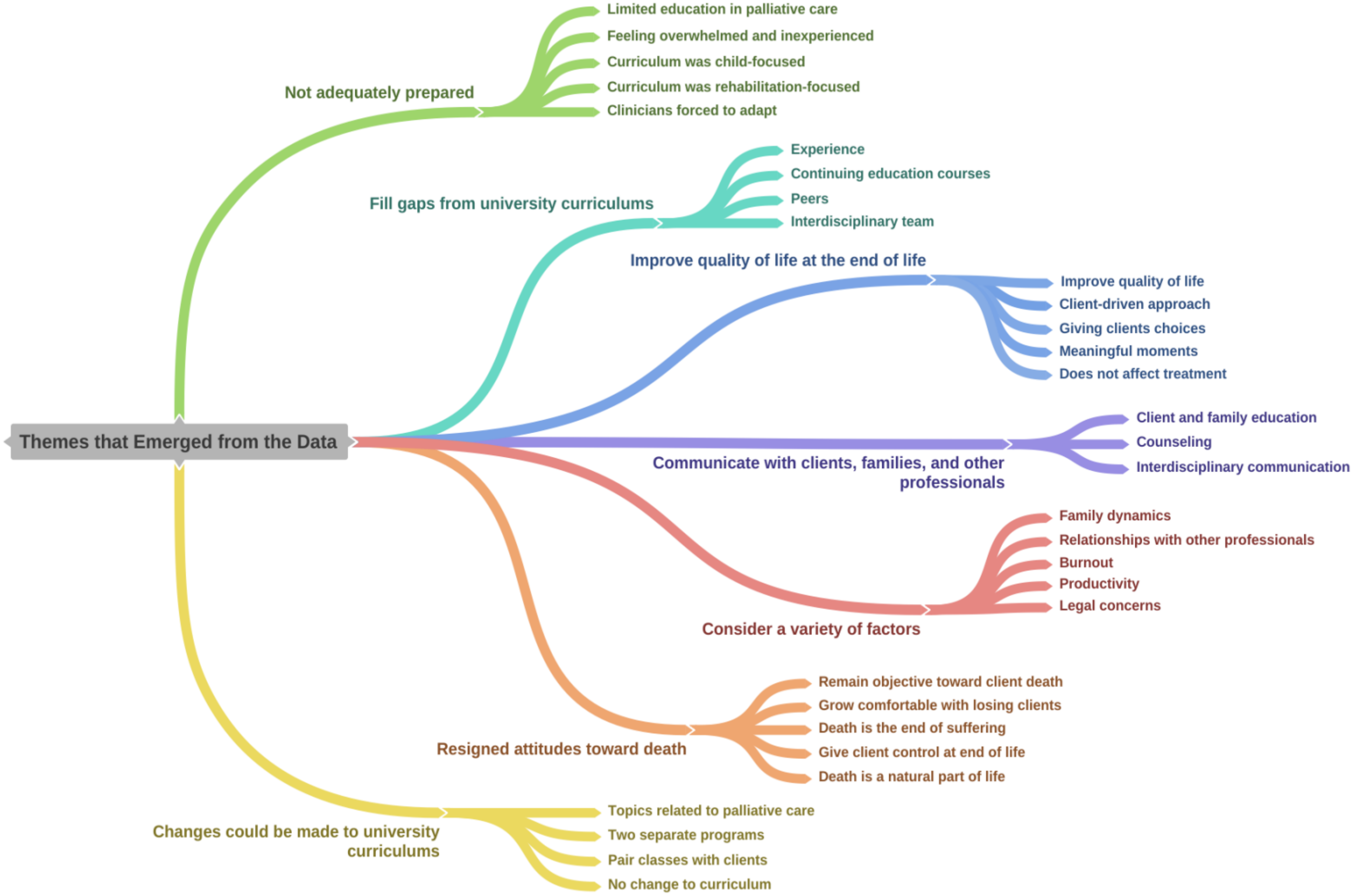

Figure 1. *Themes That Emerged from the Data.*

Theme 1: Clinicians Are Not Adequately Prepared by University Curricula to Work in Palliative Care Settings

Limited Education in Palliative Care. All of the participants reported receiving either very limited or no education on palliative care from their university curricula. One participant recalled that palliative care had not been mentioned in her university curriculum:

> *"I don't think that they prepared… You know, we did voice disorders, we did types of strokes, we did childhood disorders. We did, you know, it was more types of disorders and treatment than it was anything to do with palliative care."*
>
> *SLP 7*

Another participant reported that she didn't learn about palliative care until she was employed in a hospital setting:

> *"I work with palliative care, but as a speech therapist… You don't learn much about palliative care. I learned about palliative care in the hospital. I didn't know what it was. I didn't know it was comfort care until I was working for a while."*
>
> *SLP 4*

While some participants reported that they did not receive any sort of palliative care education in their university curricula, others reported that they did remember brief discussions on the topic. However, as one participant explained, she had not yet had any experience to apply this discussion to:

> *"I think the only place we touched on palliative care services was probably in my dysphagia course, and it was very brief. I remember one professor coming in for a day and discussing dementia, discussing diet management, disease management, and different things to make food more palatable for the patient. But at that point, I had nothing to apply it to as far as visualizing it or seeing it."*
>
> *SLP 5*

Another participant recalled a course in which, although palliative care was not explicitly mentioned, clinicians were encouraged to include quality of life as a variable in treatment:

> *"Yeah, I will say that we learned a little bit about quality of life and end of life when we were in therapy. Not a ton, but I do remember talking about it and*

> *keeping it in mind. I remember our professor telling us to keep in mind quality of life and to keep in mind comfort care and things like that."*
>
> *SLP 4*

Feeling Overwhelmed and Inexperienced. Participants also discussed how the lack of preparation to work in palliative care settings at the university level left them feeling overwhelmed and inexperienced. One participant wished she had more experience working with adults in her graduate program:

> *"In all honesty, I don't know if I felt prepared in any of the topic areas I faced. I felt that I had knowledge and I learned from them, but I wasn't ready. If my externship would've been at an adult setting, I think I would've graduated with a better grasp of adult. But I barely got my adult hours in, so I didn't feel like I had that knowledge."*
>
> *SLP 9*

Another participant remembered starting her first job and feeling overwhelmed and underprepared:

> *"My first job was in a hospital, and I was the only speech pathologist there, and I was totally overwhelmed, and I had no idea what to do… But I was running a hospital, and I had no idea what I was doing."*
>
> *SLP 1*

The same participant reported that she has also supervised graduate student clinicians that seemed overwhelmed when working with adults:

> *"Interns that I get seem incredibly clueless to me. I've probably had fifty students. And that's not even talking CFYs… They're so overwhelmed."*
>
> *SLP 1*

Curriculum was Child-Focused. Many of the participants interviewed reported that their university curricula were more focused on children rather than adults. Several participants discussed how the majority of the classes in their curricula were child-oriented, while adult-oriented classes were neglected:

> *"I hate to say it, but we were kind of fed to the wolves on the adult spectrum. The biggest saturation when I was in college was on pediatrics and EI. A lot of early*

> *intervention, pediatrics, and stuff like that. There was a lot of neglect on the adult side which was unfortunate for my program and my class because 90% of us were going into geriatrics or adults."*
>
> *SLP 4*

Another participant agreed, stating that she reviewed her coursework prior to the interview and found a shortage of classes that prepared students to work with adult populations:

> *"I felt very underprepared for my undergraduate university, but I didn't want that to be untrue, so I tried to look at my coursework. Low and behold, I didn't even get a lot of coursework in adult populations… But I feel like I got most of my training with phonology and articulation, child language acquisition… But there was nothing that was very heavy on adult populations…Not well prepared."*
>
> *SLP 5*

One participant recalled that the lack of education regarding adult populations made her fearful of hurting a client:

> *"I mean, it's very child-focused… So, I went into swallowing feeling like I'm going to kill somebody because I didn't have a full grasp of all of it."*
>
> *SLP 9*

Curriculum was Rehabilitation-Focused. Participants also recalled that the adult-oriented classes that they did take were often solely focused on rehabilitation. However, some participants discussed how, in palliative care settings, rehabilitation is not always a viable goal for clients:

> *"So, with Parkinson's is a good example. With Parkinson's, we talked in our neuro class, and this was years ago, but we talked about voicing. And with Parkinson's, voicing tends to be an issue. People aren't as loud. They don't vocalize well. Their articulation is poor. So, we would talk about how to deal with that, how to treat that, how to work with a patient to do that. At the end of life, you don't have someone who's capable of doing those things. Those are very metacognitive skills. I can't teach somebody who can't remember what I said five seconds ago. And for some of these patients at end of life, you're not managing their voice. You're trying to find other ways for them to communicate. For them to point to something. For them to use their eye gaze to show you something if they can do that. And teaching staff and families how to read those nonverbals or that body language to figure that stuff out."*
>
> *SLP 2*

Another participant also discussed how the focus on remediation left her feeling unprepared to treat clients for whom those types of goals were inappropriate:

> *"Yeah, they were remediating… And dementia isn't like that. It's not like that. And that was a whole different way of thinking… You're not going to have 100% accuracy. And that was hard because every goal we wrote at the clinic was for that. I mean, that's what we were doing."*
>
> *SLP 3*

Lack of Education Forced Clinicians to Adapt. Some participants discussed how their lack of education on palliative care forced them to adapt on the job. One clinician spoke on how, although she did not feel prepared to provide treatment, she knew where to look to find necessary information:

> *"I would say that once I started out of grad school, I knew where to look and I knew the basics. I knew where to look to get information on treatment, but I don't think that I would've… Once you finally get into it and hopefully have a good enough supervisor that can kind of help you."*
>
> *SLP 8*

A lack of experience forced another participant to think on her feet:

> *"And you won't know until you practice. You're like, 'God, I wish I knew this. I wish I would've had some experience with this.' But you don't. So, you just adapt. You just become somebody who can think on their feet and adapt and then go home and look it up or go to the office and look it up if you're not sure."*
>
> *SLP 3*

Theme 2: Clinicians Seek to Fill in Gaps from Their University Curricula with Additional Resources Regarding Palliative Care

Experience. All of the participants referenced experience as the primary method for filling in gaps from their university curricula. One participant described how having a variety of different experiences results in growth as clinicians:

> *"Initially, in the beginning, you're still kind of fresh off the boat there so to say. Looking at things maybe a little more narrow-minded. But when you go through certain experiences, whether it's with patients or diagnoses, the severity levels,*

> *you definitely have a broader perspective of how to approach things even though it's still individualized for each person."*
>
> *SLP 6*

Another participant emphasized that having a number of the same experiences was a crucial part of her learning process:

> *"That was key to filling in those gaps. You've got to experience it. You've got to be exposed to it. And not just one time. You've got to see it a handful of times to really grasp it, and you've got to be willing to do it with somebody and by yourself."*
>
> *SLP 4*

Participants also mentioned that clinicians' individual experiences allowed them to become unique therapists with individual approaches to therapy:

> *"There's nothing better than learning on the job either. And developing your skill set with each patient. I mean, if I look at myself as a therapist eleven years ago compared to where I am now, it's going to be a very different mindset and therapy style and belief practices too."*
>
> *SLP 9*

In addition to citing clinical experience, some participants also mentioned the role that life experience played in promoting professional growth. One participant described how her previous work experience enabled her to manage difficult client behaviors:

> *"When you graduate from high school, you can get a certificate to be a substitute in a special needs classroom as an aid. I did those things, so I had a lot of that behavior management from being around special needs. And then transferred that over. It wasn't something like I took a class on special needs in grad school. It wasn't that."*
>
> *SLP 2*

Another participant discussed how experiencing the deaths of loved ones allowed her to take the perspective of her clients and their families:

> *"I think for me, it was personal experience. It was my grandma first, then my mother… And my father in law. So no, it was me incorporating being on the other side of it and then… It gives you such good insight because you think about what kind of things would you have wanted to hear? What kind of approach would you*

> *have wanted? And every time I interact, I try to be the person I would've wanted to see coming in the room when I'm sitting there."*
>
> *SLP 3*

Continuing Education Courses. Many participants referenced taking advantage of continuing education courses in order to fill gaps left by university curricula. One participant described how she continued to seek out relevant courses even after she became a trainer for one of the courses:

> *"So, I would seek out courses to help me build that knowledge. And then, because we're a specialty facility, we offer courses too. So, I would take the course that we offered and then eventually I became a trainer for that course and still seeking out things like that"*
>
> *SLP 2*

Another participant mentioned taking advantage of ASHA's resources and the continuing education courses her facility offers:

> *"I would say anything from, different things, like going onto ASHA's website. Maybe continuing classes [facility] offered… They will sometimes offer continuing ed where, whether it's a palliative team or a doctor… It may not be specific directly to speech, but just as a whole, the life continuum."*
>
> *SLP 6*

Peers. Many participants revealed that they were able to learn from their SLP peers in order to fill in the gaps in university curricula. One participant described how she continues to reach out to SLPs that she's previously worked with in order to ask questions:

> *"My peers… And then in the hospital setting, if you're lucky enough to work there, there are a lot of speech paths around and they're accessible… So, contacting them. And I still text people from that original job and ask questions."*
>
> *SLP 5*

Another participant explained that it was advantageous to maintain contact with peers because they may be able to offer a fresh perspective:

> *"You'll find people when you're practicing that are like you… You want to call with issues, bounce questions off of them… I can't really underscore how*

> *important that is to have just someone else because you're seeing the same thing every day. You miss the forest through the trees."*
>
> *SLP 3*

Interdisciplinary Team. In addition to communicating with other SLPs, some participants discussed the importance of learning from other members of the interdisciplinary team. One participant described her unique opportunity to learn from a geriatrician:

> *"So, I consulted with physicians. In particular, the physician at my current facility is a geriatrician... So, I've consulted with him on swallow study results, NPO recommendations, where they want to put a PEG in a person… He provided me the education about the PEG tube… He helps me a lot with the end of life decision making, so he's a nice resource."*
>
> *SLP 5*

Theme 3: Clinicians Utilize Client-Centered Approaches to Try to Improve Quality of Life at the End of Life

Improve Quality of Life. The majority of participants revealed that improving quality of life is their primary goal when treating clients who are receiving palliative care. Palliative care, as described by one participant, is about prioritizing quality of life above extending life:

> *"Quality of life is huge to me, it's huge to the patients, it's huge to my facility… That's because we're able to do things knowing it might shorten the length of your life, but it's going to add the quality to your life. Quality of life is huge with palliative care. It's really the purpose of it, is not getting poked and prodded and all this stuff that you don't want, just the stuff you do want towards the end of your life."*
>
> *SLP 1*

One participant explained how she may potentially provide treatment to a client who was receiving palliative care:

> *"But a pleasure diet to me means if that person wants cake or a candy bar or they want a cup of coffee or whatever they want that makes them feel happy, and everyone is in agreement, they can choose to have it… Now I do a lot of education on quality of life. You know, one of our most comforting things that we do is eating, and it's a huge pleasure until people don't eat any longer. So, keeping that ability to have that pleasure."*
>
> *SLP 7*

Another participant differentiated the mindset of SLPs who provide palliative care from those who aim to rehabilitate:

> *"It's really about their quality of life at the end of life, and I think being in that setting changes that perspective because you think about acute therapists. And they're more, 'Make them better, fix them…' When you're in that palliative setting, there's no putting them back together. Dementia doesn't get better. Dementia only gets worse… What can you do to make it as good as it can be when you know it's only going to be worse going forward?"*
>
> *SLP 2*

Client-Driven Approach. Many of the participants described the client-driven approach as one of the central tenets of palliative care. One participant discussed the importance of taking both clinical judgement and the client's wishes into account:

> *"Because a lot of times, you go in and you're evaluating a patient. 'This is what I want you to do.' But then you're looking at, again, always involving them in the care plan and then looking at the big picture. Maybe the patient does want to eat, but they're aspirating. Which, they understand they're aspirating, and they are fine taking that risk… What is their goal? What is their true goal? What is their intent? What are their wishes?"*
>
> *SLP 6*

The shift from the doctor-driven model to the client-driven model was described by another participant:

> *"It used to be very doctor-driven. Now they've really changed it to a more patient-driven model where families weigh in and it's much more interactive than it ever was."*
>
> *SLP 1*

Giving Clients Choices. Many participants emphasized the importance of providing clients with choices when providing palliative care. One participant highlighted the importance of providing options even when the clients may not take advantage of them:

> *"I've already talked to the kitchen. 'These are the foods they want. These are their desired foods. I want you to serve them on every tray.' 'Oh, they're not eating them.' 'I don't care if they're not eating them. I want them to have the option of eating them.'"*

SLP 3

Another participant revealed that, ideally, none of her clients would be on altered diets:

> *"Depending on their cognitive state, even if I get someone that's confused, I do communicate with them and give them choices and give them options. I don't want anybody to be on pureed food. I don't want anybody to be on thickened liquids. Steaks and martinis all around. Everybody gets steaks and martinis."*
>
> *SLP 1*

Palliative Care Provides Clients with Meaningful Moments. Many participants were able to provide specific examples of when clients receiving palliative care were able to have meaningful moments that they would've been unable to have otherwise. One therapist described how drinking soda created special moments for a client and her husband:

> *"We got to a point where she was still NPO and she got no nutrition, but she was a Coca-Cola addict. She loved soda. She wanted a sip of pop, and every day [her husband] would bring her a soda, and we'd give him a sippy cup and thicken it for him, and she would have a few sips of that. They would just laugh in that room. That was the only joy that they got. That I was able to allow her to be able to have this coke a couple times a day when he would come over. So, I know that doesn't sound like a lot, but think about how meaningful it was for them."*
>
> *SLP 1*

Another participant recalled how she was able to make a client happy by customizing her diet:

> *"Recently, I customized a person's diet. They need to be on puree. It's the most efficient and safest thing for them. But she had been caught eating mechanical soft snacks... I said, 'Let me go ahead and assess her. Let's see if maybe in isolation she can do the snacks and during the meals she can do the puree and keep her happy. And if she's safe to do it, let's look at it.' So, we assessed and determined she could do that. She just can't eat mechanical soft for a full meal for thirty minutes, you know what I mean? So, for her, that quality of life, just so she could have her Little Debbie fudge rounds a couple times a day between meals is what makes her happy."*
>
> *SLP 5*

Adding pleasure to the end of a client's life caused another participant to experience happiness:

> *"I had a lady tell me all she wanted to do was be able to have a cup of coffee. You know, she couldn't hold a cup of coffee, so we worked on adaptive equipment one time until she could have her cup of coffee and raise it to her lips...When people feel good and any pleasure is added to end of life, I'm happy."*
>
> *SLP 7*

Palliative Care Does Not Affect Treatment. While many of the participants discussed how palliative care affects the way that clients receive treatment, one participant explained that palliative care does not affect the way she provides treatment:

> *"But a lot of the palliative care I've dealt with has no effect on my caseload or what I do for therapy. It's mostly medication management. Allowing them certain medications to keep them comfortable and refraining from other medications for the same reasons. I've dealt with it. I've been educated and witnessed it from a nursing end. I have not seen it affect PT or OT either. Until it gets to hospice, that's when it affects you."*
>
> *SLP 4*

Theme 4: A Key Role of Clinicians is to Educate and Communicate with Clients, Families, and Other Professionals

Client and Family Education. One of the most crucial roles for an SLP providing palliative care, according to many participants, is educating clients and their families on different aspects of end of life care. One participant revealed that she is often the first person to have that conversation with clients and their families:

> *"So, talking to families about those things is hard... A lot of times, it's so tied into the cognition or the swallowing that I end up being the one to have that conversation."*
>
> *SLP 2*

Another participant agreed, describing the topics that often arise when educating clients and families on the end of life:

> *"They've got such emotion wrapped up seeing their loved one decline. Or with the dysphagia, with the choking and not wanting to eat. And that's very scary for families. So, I do a lot of education on what the normal aging process is and that what they're seeing is fairly consistent with the norm. Then I do a lot of education on what we could do to help intake and hydration…I can explain the process of*

> *when somebody completely stops eating, what the process looks like with that type of death."*
>
> *SLP 7*

Other participants revealed that they often have to provide education on misconceptions that clients and families may have. One participant spoke on how she often has to educate families on what palliative care is:

> *"Educating family on what palliative care really is. I feel like there's always the misconception that it means hospice. It means that you're signing the waiver or the death warrant type of deal when that's not what's happening."*
>
> *SLP 5*

Another misconception that participants commonly encountered was what families believed to be the role of SLPs:

> *"Not many people know about speech therapy… You say, 'I'm a speech therapist,' and they say, 'Well, my speech is fine.' Well, I'm not here to hear you talk, necessarily... Can you swallow? Can you recall things? Are you good at problem solving? They don't think about that under our umbrella"*
>
> *SLP 9*

Counseling. The majority of participants additionally described counseling clients and families as one of the main responsibilities of SLPs providing palliative care. According to one participant, she is often mistaken for her facility's psychologist, as she provides counseling to so many of her clients and their families:

> *"And so much of what we do is counseling. I'm telling you. People often mistake me for the psychologist in the building… They don't know because so much of what we do bleeds into other areas."*
>
> *SLP 3*

Another participant described the various types of counseling that she often provides:

> *"So, there's a lot of counseling the patient, then counseling family, then counseling together to try to help guide them. And usually, some of it I do individually, some of it I've done with a whole team, with a nurse, with a palliative care nurse that comes in, myself, and then the family and the patient."*
>
> *SLP 5*

Interdisciplinary Communication. In addition to communicating with clients and their families, communicating with professionals from other disciplines is a main responsibility of an SLP that provides palliative care. There are numerous other disciplines that SLPs need to communicate with, as described by one participant:

> *"But I think as a whole, as a team member… is making sure that we're in communication with the doctor, the main nurse who's really doing a lot of the conversation, the dietitian, and the social worker. PT and OT may be involved, you know, that's possible. But making sure that we're communicating what the initial evaluation outcomes are, impressions, and what our goals are versus what their goals are. Make sure that everybody kind of understands that handoff."*
>
> *SLP 6*

Conversations with the interdisciplinary team are often where potential recommendations for palliative care first emerge for some clients:

> *"And that's where we, a lot of times as a team, will say physically he's not doing well. Nursing is not doing well. Swallowing is not doing well. We need to talk to the doctor about other options and we need to talk to the family about what that means."*
>
> *SLP 2*

Another participant echoed this sentiment, describing instances in which she had suggested palliative care may be appropriate for certain clients to her interdisciplinary team:

> *"So, I will say that I do remember instances where I suggested to my therapy program manager as well as PT and OT about palliative care… There were cases where I recommended or suggested to an interdisciplinary team that maybe palliative is appropriate for this patient, or even hospice at that point."*
>
> *SLP 4*

Theme 5: Clinicians Must Consider a Variety of Factors That Complicate How They Function in End of Life Settings

Consider Multiple Variables When Providing End of Life Care. All of the participants discussed a variety of factors that affected how they provide care in palliative care settings. One participant summarized all of the factors that she considers when providing care to her clients:

> *"I consider, obviously, age of the patient, progression of disease, current intake. So, how much they're already eating. Because if they're already not eating a lot of whatever I've got them on, there's a good chance that if I make it less palatable, they're going to eat even less. I consult a lot of times with the doctor because he can tell me what are we concerned about? Dehydration with this patient in particular. Most of them, they are concerned about it, so taking that into consideration. Quality of life, I obviously take that into consideration. But having conversations with family about what the patient enjoys most in life and what they like. And some patients are fueled by what they eat, literally and figuratively. They really like to eat, or they have a specific thing that they really love. Trying to manage it as best I can. I'm trying to think of other things. I mean, current respiratory status. If they confirmed it's aspiration pneumonia or really weak respiratory system, I still might be a little bit more conservative and that kind of thing."*
>
> *SLP 5*

The factors that participants commonly cited as affecting the way they function in palliative care settings are discussed in further detail below.

Family Dynamics. The majority of participants cited having to navigate family dynamics as one of the major obstacles they face when providing palliative care. SLPs may feel villainized by families who feel obligated to fight for their loved one's life, no matter the circumstances:

> *"You do see this, it's hard I understand, but for the patient's sake it's tough as well where the family is continuing to fight for the patient just because they're supposed to… And as a speech therapist, and your PTs and OTs will tell you this too, as a speech therapist in those situations, you are the bad cop. And it's very hard. That can be very difficult. Everything is your fault."*
>
> *SLP 4*

Other participants discussed how clinicians must navigate situations in which family members disagree amongst themselves on the best way to care for their loved one:

> *"Probably one of the best things that I've been able to learn is maybe how to handle family dynamics. I've probably only met, in my career, two families of children that actually could come to a consensus about their mom or dad. The rest of them, this whole process can break up a relationship with friends or family… So, you have to be very respectful on how you think people are taking it*

> *or feeling. And you have to somehow let them know, not that you're in agreement with them, but that maybe you understand some of what they're going through."*
>
> *SLP 7*

Another participant shared similar experiences. She described the importance of educating the entire family and providing them with the same information:

> *"Family dynamics are always fun because you will always have one patient who has four children and none of them agree on what to do for mom… Especially when they share power of attorney because then you have to get them on the same page for them to make a decision. Some families, there's kids that don't talk and you still have to educate all of them the same and try to get them in the same room so that they're all hearing it the same and there isn't, 'Well they said this to me and they said this to me,' and it's not the same."*
>
> *SLP 2*

The same participant expressed the importance that culture plays on some family dynamics:

> *"There are some families that just, no matter how much you talk, you can talk until you're blue in the face, don't want to hear what you're saying. Don't believe what you're saying and don't trust the health care system. And some of that is cultural… There are a lot of cultures that don't believe in letting someone die. Hispanic cultures, African American cultures are very much full code. Do everything you can to save them. You'll come across exceptions to that, it's not an absolute. But as you read literature and you learn those things, they value different things."*
>
> *SLP 2*

Relationships with Other Professionals. Interdisciplinary teams are comprised of many different professions with many different approaches to providing treatment. Building rapport with physicians can be a crucial element in implementing a client's plan of care. One participant described the various dispositions she's encountered when working with physicians:

> "*I asked him for orders one time… And he goes, 'Do what you need to do, I'll sign it... He had faith and we worked together long enough that he's like, 'You don't need to come to me to get an order for a cognition evaluation. If you think it's necessary, then do it, and I'll sign off on it.' Some doctors are like that. Some doctors you have to establish that rapport first. And some doctors are like, 'Nope, don't care what you say, don't care how long you went to school, you're not a doctor.'"*

SLP 2

Another participant discussed how it's important to learn to work with other members of the interdisciplinary team who may have different views on providing treatment:

> *"You have to be able to also work with staff with different opinions. Nurses and therapists are very different. Nurses take care of people and they want to do for people. Therapists want you to get your independence back. So, there's always that little bit of give and take between the nursing field and the therapy field... And you might present a totally different mindset and different ideas to them, you know."*
>
> *SLP 7*

Having a good relationship with other therapy disciplines can also be beneficial when providing treatment, as one participant describes:

> *"I had a really good relationship with the occupational therapist at my skilled nursing facility, and we would co-evaluate a lot. He would always support the educational part for me, too. Because you might be able to do this, but you're not doing it safely... So, I had a great placement where I could actually provide a hands-on service with, you know, an actual therapist who was able to do that. I wouldn't transfer a patient by myself, but if he was there, then I was able to break it down more and explain the importance of all of it and consequences and other safety options they could do."*
>
> *SLP 9*

Burnout. Many participants described feeling burnout after working in the palliative care setting for some amount of time. Each participant attributed their feelings of burnout to a variety of factors. One participant partially attributed her feelings of burnout to watching her clients progressively get sicker over time:

> *"So, I often joke about I wonder how many years of my life have been scraped off because of that pressure. There's an internal pressure every day of my life that I work. So, you compound the sadness factor, the factor of it's not always roses and sunshine. People are going to die. People are not going to get better... I guess that's what I mean when I say it's not for the faint of heart."*
>
> *SLP 3*

Another participant who works part time in skilled nursing facilities revealed that she didn't think she would've been able to work full time for the duration of her career:

> *"I think it's a difficult field to work in, and I feel like I couldn't have done it full time for this many years. I think I would've been burned out a long time ago… Just with all the components I talked about like the staff at the nursing home. And you get to a certain point, and nobody seems to care that much or listen to your recommendations, and it just gets draining."*
>
> *SLP 8*

Productivity. One participant mentioned the pressure of meeting her facility's productivity standard. She revealed that the consistent demand to meet her productivity standard contributed to feelings of being burnt out:

> *"I don't know if you know about productivity, but that is a nightmare. And that, I think, is probably why I'm feeling a skosh bit burned out. Because my entire life for fifteen years has been the second I get in, I'm on the clock and I need to generate revenue. So, every minute is accounted for. And so, every conversation that happens that isn't billable, in my head when I'm talking, I'm thinking, 'Oh my god, how am I going to make up this time?' Because if it goes so long, I can't work enough in a day to still bill enough to have my productivity to be 85%."*
>
> *SLP 3*

Legal Concerns. The same participant also discussed being mindful about the legal implications of working with clients who are at the end of life. She explained that she always documents thoroughly to ensure that she has taken her due diligence:

> *"You have to educate to the nth degree and document as well. Because they can say, 'We know the risks.' But then she chokes, they could also sue. Then I'm going to get deposed. So, I need to make sure that I… and I'm very psychotic about my documentation. And all my CFYs have been. Because I'm like, 'Imagine that being read in a court room.'"*
>
> *SLP 3*

Theme 6: Clinicians Have Resigned Attitudes Toward Death and Dying

Remain Objective Toward Client Death. Many participants described an effort to remain objective when facing the death of a client. One participant described her effort to maintain the balance between caring for her clients and keeping a professional distance emotionally:

> *"I try to remain as objective as you can given their situations. Because if you're a family member and your husband dies, you're going to take off, you're going to go home, and you're going to plan the funeral, and you're going to be in mourning. If that patient dies, I still have seven more people that I need to see during the course of the day, and you can't fall apart. You have to be caring, but you also have to have professional objection… Once they pass away, there's nothing more I can do for them. There's something more I can do for the person sitting in front of me, so I just move on. I know that sounds really cold, but I'm here to help and I can no longer help this person, but I can help the next person coming in."*
>
> *SLP 1*

Another participant recounted the loss of a client that taught her the necessity of remaining objective:

> *"That was based on a lady that I knew many, many, many years ago. Every time I'd come into the facility, I'd go in and talk to her. It was the first thing I ever did. I'd go in and say hi and talk to her. And then I'd go check in and… I was the director of the program at that time and I liked her so much… And I came in one morning, and she'd died. And it taught me to be supportive, but not get too close. That was a big lesson. So, I can be really friendly and loving, and I'm all of that with my patients. But I know that since her, there is a barrier."*
>
> *SLP 7*

Grow Increasingly Comfortable with Losing Clients. Participants also frequently discussed how they have grown more comfortable with clients' deaths over time. However, one participant noted that you're never truly prepared to experience that loss:

> *"Are you really ever ready for that? No. Do you get more comfortable with it? I think so. I think being around death and dying is different now… You just get more comfortable with it, I think. You don't ever… you're never okay with it. You're never really prepared with it, but you get more comfortable with it.*
>
> *SLP 2*

Another participant reinforced the necessity of emotional separation:

> *"Recently, it doesn't affect me as heavily unless I had been with a patient for a long time because you find a way to kind of keep yourself separated a little bit emotionally… You definitely, over the years, you get a little more… You have to find a way to separate, I think."*
>
> *SLP 5*

Death is the End of Suffering. Some participants expressed that the knowledge that their clients are done suffering once they pass helps them cope with the loss. The loss is described as bittersweet by one participant:

> *"I always think about the suffering ending. That's my big thing. I don't want anybody to suffer. And you see immense suffering a lot of times in nursing homes. And so, I always kind of look at it like at least they're not suffering anymore."*
>
> *SLP 3*

Another clinician reinforced the desire for her clients' suffering to end:

> *"You want them to die. And that's not in a mean way. You want them to be done suffering… But I never found a profound sadness for it because we're all going to go at some point, and I already knew that starting out."*
>
> *SLP 9*

Give Client Control at End of Life. Allowing clients to die with dignity by giving them choices related to the end of their life is a crucial component of palliative care, some participants report. One participant revealed that having open conversations with her clients about the end of life can remove some of the stigma of dying:

> *"I think that's the biggest piece of it is when you can just talk openly and honestly and take that stigma of dying away and just be like, 'How do you want this to…' Putting it in their control. 'How do you want this to be? How do you want to do this with dignity? How do you want to take your final bow and have it be good quality of life?' I think that's one of the most important jobs in the world, honestly. Truly."*
>
> *SLP 3*

Allowing clients to make choices towards the end of their lives can relieve some of the anxiety that they may be feeling:

> *"I think that they're more at peace because somebody else isn't running the show. They have some control over their situation. Talk about anxiety. If you're put in this place where you have no control at all even to die. I'm sure that produces tons of anxiety and with the families as well. So, if you're in a more peaceful situation, I think that's hopeful for the families to cope and the patients to cope, and I think they're a little more present knowing that this is going to be a finite situation. This isn't going to go on forever."*
>
> *SLP 1*

Death is a Natural Part of Life. A few participants attributed their resigned attitudes toward death and dying to their views on death being a natural part of life. One participant explained that her pragmatic views on death were a result of her early childhood experiences:

> *"I think it started actually very young. My dad was a physical therapist, my mom was a surgical nurse, and our family's thought process on death and dying and life, that death is just a part of life. So, I think early on I saw my family not take death too tragically ever, and it was just a part of the whole thing. So, I think that was probably the key to my ability to educate on palliative care and treat people with care and kindness in that point in their lives and family members."*
>
> *SLP 7*

Additionally, preventing the dying process can be a very invasive process, as one participant describes:

> *"I actually had a really good friend who is a hospice nurse, and we would talk all the time about the dying process. And once they've started the dying process, really, it's a heroic effort to take them out of it. And people just don't die usually. Usually it is a process, so we're interfering frequently with that process. Do we want to put a tube feed in somebody who's already started that dying process? They're going to die anyway. If it's not their swallowing, it's going to be their other systems shut down."*
>
> *SLP 1*

Theme 7: Clinicians Believe That Changes Could Be Made to University Curricula to Better Prepare Students to Work in Palliative Care Settings

Including Topics Related to Palliative Care in University Curricula. Most participants felt that there was a need to include topics related to palliative care in university curricula. There were a variety of ideas regarding which topics should be covered in the curriculum. One participant included the topics that she had to learn on her own:

> *"Way more classes on hospice and palliative care. Way more classes on trachs and vents. And way more classes, just medical classes as far as disease processes. I mean, I had to learn all of that on my own, so it was just touch and go."*
>
> *SLP 1*

Death and dying were other topics that were frequently requested by participants:

> *"I think a course on dementia, a course on end of life, death and dying. You know, they usually teach you a little bit about counseling, but I think dementia and death and dying is important. We are involved in that. And when you're talking about swallowing, sometimes you're talking about death and dying. So, I think those would be valuable courses."*
>
> *SLP 2*

Some participants suggested integrating these topics into pre-existing classes, as they understood that it would be difficult to add new classes to an already full class schedule:

> *"So, making sure that students get that in-depth look at things. Offering some of those courses on the adult populations that would include the palliative conversations a little bit earlier on… But integrating into the classes you already have. So maybe making sure in your aphasia course, cover the fact that in the late stages of dementia, they also often develop aphasia… Or in your dysphagia class, make sure there's a really good, long unit on diet management and disease progression with the diet. It's not all rehabilitation with dysphagia."*
>
> *SLP 5*

Two Separate Programs for Child-Based SLPs and Adult-Based SLPs. Many of the participants acknowledged the differences between child-based SLPs and adult-based SLPs and subsequently suggested having two separate programs for each. One participant likened the prospective split to the separation of SLPs and audiologists prior to graduate school:

> *"To be perfectly honest with you, school speech pathologists and medical speech pathologists are two totally different careers. I'd like to see two totally different graduate school programs. Just like how audiology and speech pathology share the same undergrad, then they go off. I'd like to see that break apart."*
>
> *SLP 1*

While some participants suggested completely separate tracks, others suggested that all students take the same classes in their first year of graduate school, and then split in their second year to specialize in their desired population:

> *"I really think that they should do separate tracks. I think you should be exposed to both. I think with the education I've had through the whole course, my two years, should have been the first year to get you familiarized with what you like. Obviously, it's really hard to say if you like peds. But maybe doing a combination of geriatrics and peds. Just general, the first year between the two semesters. And*

> *then, over the course of the summer, doing a six-week stint at each place, kind of figuring out what you like. Then deciding your second year if you want to go the geriatric track or if you want to go the peds track."*
>
> *SLP 4*

However, one participant acknowledged that it may be difficult for some students to choose a program, as they may be unsure which population they prefer treating:

> *"I don't know if this is possible, but I think ideally, once you get into it, if there was maybe basics for everybody and maybe a track for working within palliative care, and maybe a track for working in a hospital, and maybe a track for working with children… But, I mean, a lot of people don't know what they're going to do, so they wouldn't know maybe which one to do. So, I don't know if it would be possible to get personal experience in each of the main areas and then that would help. I know that helped me a lot."*
>
> *SLP 8*

Pair Classes with Clients. A few participants suggested having students treat clients with the disorders that they are learning about in class at the time. One participant expressed that it would be valuable for students to learn about these disorders while obtaining simultaneous experience in treating them:

> *"I mean, if there was a possible way to have an aphasia class and an aphasia patient. If you have a dysphagia class and a dysphagia patient at the same time. That would be amazing, so you're learning and you're seeing at the same time."*
>
> *SLP 1*

Another participant agreed, reinforcing the idea that it would be beneficial for students to apply their knowledge with hands-on experience:

> *"I think it would be more beneficial to take the courses while you're taking the internships. If you're taking your dysphagia courses, that's when you should be in your hospitals. Do one stint in a hospital, then your next semester, do your next stint in a SNF or a long-term care or wherever else. So, you can learn those things and you can apply your knowledge there. I think that would be the best thing to be honest with you. I wish I had that."*
>
> *SLP 4*

No Change to Curriculum. Although the majority of participants did suggest that university curricula should be changed in some way, one participant expressed that it would be difficult for universities to prepare students more than they already are. She cited experience and motivation to learn as the primary factors for preparedness:

> *"I came out with information and still had the willingness to learn. I just learn best on the job and through my supervisor and I turned out okay. So, I don't feel like there was anything they could've done necessarily different… Like I said, our field is so wide that I don't think any university is going to be able to give you all of that information and make you feel proficient in it to be able to do that carryover. I just don't think that's going to be possible."*
>
> *SLP 9*

CHAPTER IV: DISCUSSION

The purpose of this study was to assess whether SLPs working in palliative care settings believe they were adequately prepared by their university curricula to work in such a setting, how SLPs filled any gaps of knowledge regarding palliative care that they possessed, what information about palliative care that SLPs did not receive through their university curricula, and what changes SLPs would make to university curricula to better prepare students to work in palliative care settings. While the literature clearly documents that SLPs have a role in providing palliative care (Eckman & Roe, 2005; Hawksley et al., 2017; O'Reilly & Walshe, 2015; Pascoe et al., 2018; Pollens, 2004, 2012; Spillers, 2007; Toner & Shadden, 2012b; Wallace, 2013), there is currently a lack of research regarding the preparedness of SLPs to work in palliative care settings. As there are an estimated 40 million people worldwide that are in need of palliative care services (WHO, 2018), it is imperative that SLPs are adequately prepared to provide treatment to this population. The present study is one of few to examine how well SLPs are prepared by their university curricula to work in palliative care settings and, subsequently, what changes they would make to university curricula to better prepare students to work in these settings. The results of this research should be considered by speech-language pathology programs when determining how they can better prepare their students to work in palliative care settings.

Research Question 1: Do Clinicians Believe They Were Adequately Prepared by Their Undergraduate and Graduate Universities to Work in the Palliative Care Setting?

All participants revealed that they received limited education regarding palliative care. Some participants reported that they received no palliative care education, while others recalled having brief discussions on the topic. Other studies have corroborated these findings, as they also found that clinicians reported being inadequately prepared to work in palliative care settings

(Pascoe et al., 2018; Rivers et al., 2009). The participants discussed how their curricula were either focused on providing treatment to children or rehabilitating adults in order to restore function rather than discussing how to provide services to adults with whom restoring function may not be practical. The lack of palliative care education that these participants received reportedly caused them to feel overwhelmed and inexperienced once they began working in palliative care settings and forced them to adapt on the job.

Research Question 2: How Were Clinicians Able to Fill Any Gaps of Knowledge Regarding Palliative Care Once They Started Working in That Field?

Participants discussed using a myriad of methods to fill the gaps of knowledge about palliative care left by their university curricula. The primary method that participants cited in filling these gaps was experience. While some participants discussed using clinical experience as their primary method of obtaining knowledge, others reported reflecting on personal experiences. Some participants also consulted with other professionals, including SLPs and other members from the interdisciplinary team. This aligns with the findings from other research in which it was reported that SLPs who did not receive palliative care training often relied on other professionals from the interdisciplinary team to provide knowledge (Eckman & Roe, 2005). Additionally, participants referenced seeking out continuing education courses.

Research Question 3: What Information Have Clinicians Obtained by Working in the Palliative Care Setting That They Did Not Receive at Their Undergraduate or Graduate Universities?

The central tenet of palliative care is improving quality of life at the end of life, as reported by the majority of participants. Other research has corroborated this finding, as Pascoe et al. (2018) found that their participants reported that the SLP's role in providing palliative care is maximizing the client's quality of life. The participants revealed that they had to learn how to adopt a client-driven approach in which clients are given choices when provided with palliative care. Many participants were also able to provide examples of meaningful moments that their clients were able to have because of palliative care. While the majority of participants described how palliative care clients require approaches to treatment that differ from those employed when rehabilitation is a possible outcome, one participant reported that her treatment is not affected by whether or not a client is receiving palliative care.

The importance of educating and communicating with clients, families, and other members of the interdisciplinary team was a point that all of the participants stressed that they had to learn independently. Participants described educating families on different matters including end of life processes, the role of the speech-language pathologist, and what palliative care is. Counseling clients and their families was an additional skill that participants reported having to learn. The importance of SLPs counseling clients and their families aligns with other research that has emphasized counseling as a responsibility of SLPs working in palliative care settings (Potter et al., 1979; Spillers, 2007). In addition to learning how to educate and communicate with clients and families, participants also discussed having to learn how to communicate with other members of the interdisciplinary team. Many articles have reinforced the idea that the SLPs working in palliative care settings must consult with other professionals on the interdisciplinary team (Lambert, 2012; O'Reilly & Walshe, 2015; Pollens, 2004, 2012).

All of the participants described different factors that they have to balance against one another when working in palliative care settings that they did not feel prepared to handle from their university curricula. Intra-family relationships were frequently cited by participants as influencing service delivery. Additionally, participants also discussed the importance of learning how to develop and maintain professional relationships with other members of the interdisciplinary team. Some participants disclosed feeling burnout attributed to a variety of factors after working in palliative care settings after some period of time. Other factors that participants reported having to take into account included meeting a facility's productivity standard and being mindful of the potential legal aspects of providing care to a client at the end of life.

The participants also revealed that working in the palliative care setting forced them to adopt resigned attitudes toward death and dying. Participants discussed how they were able to grow increasingly comfortable with the death of a client after having to experience that loss repeatedly over time. Many participants reported that they are now able to remain objective toward the death of a client. Other participants described how they do not necessarily grieve clients' deaths, as they view death as a natural part of life and the end of suffering. They also stressed that part of the importance of palliative care is being able to give clients choices at the end of their lives and allowing them to die with dignity. Hawksley et al. (2017) echoed these sentiments, as they reported that a crucial role of the SLP working in palliative care settings is working toward a good death for their clients.

Research Question 4: What Changes Would Clinicians Suggest Making to Speech-Language Pathology Curricula to Better Prepare Students to Work in Palliative Care Settings?

Participants made several suggestions regarding ways that university curricula could be changed in order to better prepare students to work in palliative care settings. Many participants proposed including topics related to palliative care into the university curricula. While some participants suggested adding new classes dedicated to material related to palliative care, others advised integrating this information into pre-existing coursework. Clinicians have also expressed a need for palliative care training programs in previous research (Pascoe et al., 2018). Some participants also suggested revisions be made to students' clinical experiences. These participants thought it would be beneficial for students to experience clinical placements related to the material that they are learning about at the time. This sentiment aligns with previous research that found that professional experience was the preferred method for learning about palliative care rather than classroom learning (Rivers et al., 2009). Other participants proposed splitting the curriculum into two separate programs: one for child-based SLPs and another for adult-based SLPs. One participant acknowledged that university programs are doing their best to prepare students to work in a multitude of settings and maintained it would be difficult to prepare students better than they currently are.

Limitations and Future Directions

There are two notable limitations of the present study. The first is that the experiences and information shared by the participants relied on them being able to recall information retrospectively. As the participants were many years removed from the durations of time that they spent at their undergraduate and graduate universities, they may not have been able to accurately remember all of the content or experiences included in their university curricula. The second is that the participants represented a limited number of undergraduate and graduate speech-language pathology programs throughout the country. The participants were only representative of six undergraduate programs and four graduate programs. In total, seven universities were represented in the data. The extent to which the experiences of these nine participants is representative of the preparedness that all SLPs working in palliative care settings felt from their university curricula is unknown.

Further research should include a larger sample size that is representative of more undergraduate and graduate programs. This may provide a more comprehensive representation of whether SLPs in the United States believe they were adequately prepared by their university curricula to work in palliative care settings. Additionally, while there are a small number of studies that have examined the benefits of including palliative care training in speech-language pathology curricula (Mathisen et al., 2011; Pascoe et al., 2018), future research should further assess how speech-language pathology students who have undergone palliative care training perceive their ability to be more clinically competent when working in palliative care settings.

Practical Implications

The results of this study contribute to the small body of literature surrounding speech-language pathologists working in palliative care settings. In order to ensure that clinicians are providing quality care for clients receiving palliative care, it is necessary to ask clinicians to reflect on their perceptions of whether they believe that they were adequately prepared to provide such care. This study reinforces the findings from other research that speech-language pathologists are not adequately prepared by their university curricula to work in palliative care settings (Pascoe et al., 2018). Additionally, the results of this research provide insight into the types of changes that clinicians believe could be made to curricula in order to better prepare speech-language pathology students. Coordinators of speech-language pathology programs should be mindful of these results when determining whether they adequately prepare their students to work in palliative care settings and ways that the curriculum could be revised to prepare their students better.

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APPENDIX A: INTERVIEW SCHEDULE

1. How many years have you been working in a setting in which you provide palliative care?
2. What type of settings have you provided palliative care in (ex. skilled nursing facilities, hospitals, etc.)?
3. What types of clients have you encountered in the palliative care setting (ex. dysphagia, dementia, etc.)?
4. What university did you receive your undergraduate degree from?
5. What university did you receive your graduate degree from?
6. How did you become interested in working with the palliative care population?
7. What are your responsibilities as an SLP that provides palliative care?
8. Can you tell me about the preparation you received to work in palliative care from your undergraduate university?
9. In what areas do you feel that you were or were not adequately prepared by your undergraduate university to work in a palliative care setting?
10. Can you tell me about the preparation you received to work in palliative care from your graduate university?
11. In what areas do you feel that you were or were not adequately prepared by your graduate university to work in a palliative care setting?
12. What information have you obtained working in the palliative care setting that you did not receive at your undergraduate or graduate university?
13. How were you able to fill any gaps of knowledge regarding palliative care once you started working in this field?
14. Can you give an example of a client in palliative care that you treated in which the treatment went well? Please describe that experience.
15. Can you give an example of a client in palliative care that you treated in which the treatment didn’t go well? Please describe that experience.
16. What has changed in the way you treated clients receiving palliative care early in your career vs. the way you treat clients receiving palliative care now.
17. How did you react the first time a client passed away? Did you feel prepared to experience the loss of a client?
18. Are there any changes you would suggest making to speech-language pathology curricula?
19. Is there anything else you would like to add or think would be valuable for the purposes of this study?