FROM THE PROVIDER’S EYES: SPEECH-LANGUAGE PATHOLOGISTS’ PERCEPTIONS OF PALLIATIVE CARE

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A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

Communicative Sciences and Disorders – Master of Arts

2024

ABSTRACT

This study examined the role of speech-language pathologists (SLP) when working with patients facing life-limiting disease in the context of palliative care (PC), hospice (HC), and end-of life (EoL) care settings. A survey was distributed to SLPs in the United States through profession-specific listservs, social media, and professional contacts. The survey was constructed to collect information regarding roles of the SLP, PC team make-up, impact of COVID on providing PC, professional burnout of SLPs associated with PC, challenges faced by SLPs in PC, and desired attributes and skills of SLPs working in PC. Relevant demographic information was also collected. Sixty-seven participant surveys met the study inclusion criteria and were analyzed using descriptive statistics and qualitative analysis of open-ended questions about challenges and desired attributes and skills. There was a high percentage of respondents who agreed that the roles of an SLP in PC include providing consultations to patients, families, and care team members regarding communication, cognition, and/or swallowing to support a patient's quality of life. A wide range of professionals were reported to be part of PC teams, most notably social workers, PC specialists, and nursing teams. There was not consensus about the satisfaction of how SLPs are integrated into PC teams. Of the Big 9 service areas, swallowing was the most frequently addressed. The most common challenges reported were related to difficulties working with other healthcare professionals and directly with patients/families, and emotional and psychological burden from PC work. The skills needed to work in PC as identified by these SLPs included a variety of personal traits, empathy and compassion, and strong communication skills. Overall, results from this study help to establish a current baseline of the perceptions and experiences of SLPs working in PC settings.

ACKNOWLEDGEMENTS

My sincere appreciation goes to the entire MSU CSD staff and faculty for everyone’s time in providing me instruction and counsel these past few years. A special thank you to my thesis committee members, Dr. Thea Knowles and Ariana Farhad, for offering your support, time, and expertise to this thesis. Finally, I would like to express my deepest gratitude to my advisor, Dr. Jeff Searl, for his wisdom, guidance, and overall belief in me throughout my undergraduate and graduate education. Thank you for welcoming me, a freshman two months into her college career, into your research lab in 2018. The opportunities you have guided me to and through, including this project, have shaped me into the researcher I am today.

Thank you to my cohort for supporting me through this project. I have been so lucky to have met you, let alone go through this phase of life with you. I cannot wait to see all of the great opportunities you will seek. To my friends outside of speech-language pathology, thank you for your patience as I rambled to you in jargon you may never encounter outside of our connection.

Lastly, to my family: you have strongly instilled in me the importance of this opportunity. No number of words could describe the depth of love and appreciation I have for my parents and siblings. You have provided me the drive to finish this through, and I hope to have made you proud.

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LITERATURE REVIEW

Overview

The universal promise of life guarantees that everyone’s end will eventually come. Preparing for death, or determining if any preparation is needed, often is focal point that includes sacred traditions that vary across cultures and around the world. Death and dying are difficult concepts to contemplate for many people because of the emotional, physical, ethical, and legal challenges associated with the end of life. In the United States (US), dying is a taboo topic that many avoid. However, advocates for a more positive view of death and dying have attempted to shift perceptions to help people become more comfortable. Over several decades, a number of movements have emerged including the hospice movement, natural death advocacy, and more recently, the death positivity movement. The growth of the Internet over the past few decades has also contributed to the momentum of such movements by providing opportunities for information sharing as well as open conversations regarding the end of life.

It can be expected that many healthcare professionals are likely to work with individuals who are ill and nearing the end of their life at some point in their career. For those in allied healthcare fields, they may not feel prepared or supported when working with patients towards the end of life, even though their scope of practice covers the entire lifespan from birth to death. For fields like speech-language pathology (SLP) that are grounded in evidence-based practice, there is currently very little training and evidence to guide clinical practice. Without appropriate education and training, SLPs ultimately are not able to fully support patients or their families at the end of their life with the highest quality of care.

The focus of this thesis is to understand the ways in which SLPs are currently working with patients who have non-rehabilitative goals in palliative care (PC) and end-of-life care settings. Additionally, the study addresses issues such as perceptions of how well SLPs are integrated into PC teams, potential professional burnout from the work, the impact of COVID-19 on PC care, challenges that clinicians face in a PC setting, and perceptions of practicing clinicians about skills and attributes needed to be a successful SLP in PC work.

Defining Rehabilitation

The broadest definition of rehabilitation is any intervention that aims to allow a patient to be as independent as possible in their daily routine. The role of rehabilitative therapy in all settings is to attempt to maximize functional ability, estimate potential for recovery, and create a plan to meet that potential to the greatest extent possible (Frost, 2001). This traditional understanding of rehabilitation limits its services to those who have the potential to make progress, but some authors are attempting to broaden the understanding to include more patients. Eva and Payne (2014) state that rehabilitation helps support and improve a patient's "dignity, competence, resourcefulness, and resilience while at the same time adjusting to uncertainty and loss." In the most simplified terms, rehabilitative therapy is the "recovery of dignity", as Frost (2001) goes on to state, "systematically giving the patient his or her sense of self."

The continuum of care within rehabilitation typically falls on a spectrum with four overlapping categories, one of which is palliative care (PC). These categories are derived from Dietz's stages of cancer rehabilitation but hold relevance beyond cancer-related care and are commonly referenced in PC literature (Eva & Payne, 2014). The stages are as follows: 1) preventative, meaning to reduce severity of potential disability; 2) restorative, meaning there is the anticipation of returning to previous levels of function; 3) supportive, meaning to implement adaptations to meet functional needs; and 4) palliative, meaning to limit the impact of advancing, life-limiting diseases and acknowledging that death could be soon. Mahendra and Alonso (2020) cite this continuum of care in providing a rationale for rehabilitation to be considered for patients that historically have not been included in rehabilitative efforts, such as those who may be expected to make little functional progress or patients who have already reached a terminal stage of illness.

Although there are varying definitions and understandings of rehabilitation, rehabilitation's primary goal is to maintain and enhance a patient's quality of life post-onset of injury or diagnosis. Barawid and colleagues (2014) state that rehabilitation can take place anywhere on the continuum, but when done at later stages such as PC, services can assist in slowing down the degeneration of function, and thus prolonging a person's ability to engage in physical activity and maintain some level of independence.

In the US, there has been a 4.4% increase over the past 20 years in the number of people who are 65 years or older, with 3.8% of that increase being within the past decade (Blakeslee et al., 2023). The aging of the population will continue to place a heavy strain on the US healthcare system to accommodate their medical needs. Even with patients who have an otherwise healthy and typical aging process, medical issues and complications may still occur. Strain on the healthcare system is intensified by an increase in the diagnosis of chronic health conditions, especially when onset occurs at younger ages. Recent data from the NIH also shows that in 2020, 71.5 million people in the US were estimated to be living with at least one chronic illness, and by 2050, it is estimated to grow by 99.5% to 146.7 million people (Ansah, 2023). The number of people living with comorbidities is also expected to grow 91.16% from 7.8 million to 15.0 million people between 2020 and 2050 (Ansah, 2023).

Some of these medical issues among an aging population are amendable to restorative rehabilitation, but others are progressive or irreversible, requiring stages of ongoing care throughout the rest of their life. One of the stages of care that a patient may receive is PC.

Defining Palliative Care, Hospice, and End Of Life Care

The World Health Organization (WHO) defines PC as a human right to healthcare characterized by relieving pain and symptoms associate with a diagnosis, providing interventions and support that neither “hasten nor postpone death”, building a support system for patients to be active, building a support system for the family to support themselves and the patient throughout the continuum of their care, and incorporating psychological and spiritual factors into the care provided (Chahda et al., 2017). Six key components of PC are repeated in the literature: affirmation of life and death processes, emphasis that death is not hastened or postponed, provision of pain relief, integration of psychological and spiritual needs of the patient within the care process, provision of support systems, and provision of services to both the patient and the family (Pollens, 2004). The Center to Advance Palliative Care (CAPC), an organization that has spent the last 20 years developing PC education out of the Icahn School of Medicine at Mount Sinai, offers a simplified definition of PC stated as the medical specialty for people with severe illness to increase their quality of life (Meier, 2014). The CAPC emphasized that PC helps to reduce pain, fatigue, nausea, and insomnia, and can have radically positive impacts on mental factors such as depression and anxiety (Meier, 2014). With adequate and well-timed recommendations for PC, services could be better allocated throughout the continuum of care, overall reducing the stress on healthcare providers (Hughes & Smith, 2014).

Palliative care is one of the fastest growing healthcare specialties within the US, with estimates that 40 million people worldwide are in need of such services, but only 14% are getting them (Mahendra & Alonso, 2020). Healthcare organizations and professional bodies are familiar with this growing specialty area, and there are calls for additional resources to be created to support healthcare professionals working in this area (Chahda et al., 2017).

Once a patient is receiving PC, the continuum of care further breaks down to describe what happens once most curative treatments have been exhausted or ended by the patient. It is important to distinguish three other terms that are often confused or considered to be synonymous by many people when defining the continuum of care beyond the restorative and supportive stages of rehabilitation offered by Dietz: *palliative care, hospice care* and *end of life care*. These terms are often incorrectly used interchangeably in the literature, by healthcare providers, and by the general public. Toner and Shadden (2012), however, provide definitions that distinguish each as unique from the others:

1. *Palliative care (PC)* is any treatment that reduces pain and suffering. It is the most common option when no "curative options are available" (Toner & Shadden, 2012). Not all patients who receive PC have a terminal condition, and some may opt into "curative treatment" options if they are available. Others may be receiving this type of care due to pain from their primary treatment protocol. Toner and Shadden (2012) state that patients receiving PC do not necessarily have a short life-expectancy. Patients with a wide range of conditions may be in PC with some having the opportunity to recover from their disease altogether.
2. *Hospice care (HC)* is when *all* treatments have been exhausted and life expectancy is 6 months or less. It can be provided in many settings but is usually at a specialized center or within the patient's home. Patients receiving hospice care can still receive PC services, but typically with more intensive courses of pain management.
3. *End-of-life care (EoL)* is the term for patients within the last few days or weeks of their life. It is still included in the continuum of PC as these patients are usually

already within hospice care at this point. The effort begins to shift from the patient to even more emphasis on supporting the patient's surviving family and community in an attempt to reduce pressure and stress for all within the last days of life.

There is no consensus for when the PC continuum should begin in a patient's healthcare journey, but many clinicians agree that the onset of such care should be determined on an individualized basis per each patient's desires and needs (Collins, 2022).

Traditional healthcare has typically followed a medical model of patient care provision rather than a social model (Pollens, 2020). The medical model explores the relationship between function, impairment, and curative measures. In contrast, the social model focuses on supporting the patient and family to encourage participation in daily living (Pollens, 2012). Thus, the WHO-ICF model also follows a similar framework, where PC would be best situated within the participation-based models and outcomes, otherwise more similar to the social model over the medical model (Pollens, 2020).

Physiological Stages of Dying

Lambert (2012) reported that allied health professionals are not adequately trained and prepared to work with end-of-life decisions, such as recognizing the physiological stages of dying. As end-of-life care falls within the PC continuum, it is significant to understand the typical phases of dying. Blakelee et al. (2023) described the conversations about acknowledging death from the clinician's perspective in the PC continuum as "affirming life with regard to dying as a normal process." From the family's perspective, this would lead to the balancing of the life that the patient has left while preparing for the emotional, physical, and legal processes that can complicate grieving in the final days if not previously arranged. This topic will be further discussed in the *Advanced Directives* section below.

Using Toner and Shadden (2012) as a guide, dying is conceptualized as having two stages: pre-active and active dying:

1. The pre-active dying stage can last up to many months and is characterized by circulatory and body temperature changes associated with longer periods of inactivity. This also may include low motivation and fatigue in feeding, communicating, and participating in life. Families may begin to notice changes in their loved one including cognitive effects such as confusion, irritability, and anxiety as the brain starts to shut down. Dementia or dementia-like symptoms may also start to appear if they were not already present (e.g., "sundowning", where the patient experiences heightened anxiety and confusion near the end of the day).
2. The active dying stage begins within the final week preceding death and can progress rapidly from day-to-day. It is characterized by dramatic changes in the body such as low blood pressure, skin discoloration, incontinence, reduced strength, and a drop in body temperature. Patients are typically not able to feed themselves and will have little to no mobility or responsiveness. A distinct breath pattern known as the Cheyne-Stokes breathing sequence may begin, noted by a rapid series of short breaths with stridor from fluid build-up in lungs, followed by a prolonged period of a lack of breathing. Families' concerns may be related to the breath noises that they hear (stridor) which can be misinterpreted as an indication of pain. For this reason, it is important that healthcare providers give family ample counselling to remind them that these noises are normal and that the end of life may be nearing.

Prior to exhausting all treatment options, conversations about death and the dying processes should have already started with the patient and the family. Most patients receiving hospice services will pass away as an inpatient in hospitals or similar medical-like settings, with the second most common setting being nursing homes (Toner & Shadden, 2012). That being said, there is a rising number of patients who are choosing to die in their own home or that of a family. The reasons for this are almost entirely individualistic and may range from advancing technological treatments leading patients who are living longer to desire to be out of hospital's confinements, to distrust or fatigue from medical settings and wanting to be in a more personal and comfortable environment (Toner & Shadden, 2012). Some patients may also have become fatigued with how much treatment they had received, leading to a desire to discontinue treatments or services, thus leading them to pass away sooner without stable life-sustaining measures.

Palliative Care: Then and Now

History

Dame Cicely Saunders in the United Kingdom is recognized as the first person to develop and research modern hospice interventions used today, following her own experiences with chronic pain and terminally ill patients (Richmond 2005). She ignored her father's suggestions and attempted to become a nurse during World War II, however after experiencing her own troubles with chronic pain, she went on to become a social worker in the late 1940s. While working with a young, terminally ill patient early in her career, Saunders and this patient discussed the importance of the terminally ill being able to die with dignity within their final days. The death of this patient and her father in 1948 resulted in Saunders beginning her advocacy for better support of the terminally ill. Over the next few years, Saunders was met with opposition from the medical field, as the standard at the time was to abandon dying patients, but nonetheless she persisted when a surgeon recommended that she become a physician to gain credibility for this cause. While completing medical school, Saunders spent considerable time with the nuns at St. Joseph's Hospital defining better care conditions for terminally ill patients. In 1965, she received funding to develop the first inpatient hospice facility, and the first patient was accepted soon after in 1967. In 2005, after devoting her life and career to the development of hospice, Dame Cicely Saunders died in south London at St. Christopher's, within the walls and care that she inspired.

The history of PC originates from the United Kingdom's hospice movement, such as the life-long contributions made by Dame Cicely Saunders. Around the same time that Saunders advocated for better conditions, British researchers in the 1950's and 1960's were uncovering the grotesque conditions that elderly terminally ill patients were experiencing while living in nursing homes (Saunders, 2001). In 1960, Glyn Hughes with the Gulbenkien Foundation discovered insufficient conditions across 300 nursing homes, due to a lack of staffing and finances. Following this study, Hughes called out the United Kingdom's National Health Services for being unsuited to take care of the nation's elderly and terminally ill.

While hospice facilities were being built in the United Kingdom, researchers in the US were just getting started in recognizing the importance of end-of-life care considerations. In 1969, psychiatrist Dr. Elisabeth Kübler-Ross published *On Death and Dying*, a noteworthy publication that continues to be regularly referenced today in fields that work with grief. Dr. Kübler-Ross defined death as a normal stage of life and identified five stages of grief that one may experience when approaching death (denial, anger, bargaining, depression, and acceptance). Due to the apprehension that physicians had when treating psychological conditions in terminally ill and/or dying patients, this text was a point of contention in the medical community at that time (Loscalzo, 2008). However, Dr. Kubler-Ross continued to advocate for this patient population, and in 1972, testified in the initial hearings organized by the U.S. Senate Special Committee on Aging regarding protecting dignity in death (National Hospice and Palliative Care Organization [NHPCO], 2020).

In 1974, Florence Wald led an interdisciplinary team in founding the US' first hospice facility in Branford, Connecticut after inviting Dr. Cicely Saunders to give lectures to Yale nursing students (Connor, 2007). That same year, the first round of legislation calling for the federal funding of hospice care was introduced, but not enacted into Medicare until 1983 (NHPCO, 2020). By 1978, the National Hospice Organization (NHO) was founded (later becoming the National Hospice and Palliative Care Organization in 2000), with over 1000 attendees going to its first conference, and a year later the NHO formally adopted the "Standards of a Hospice Program of Care" (NHPCO, 2020). Throughout the next two decades, the hospice, and soon forthcoming PC initiatives, would be further developed under legislation, coinciding with the HIV/AIDS epidemic (NHPCO, 2020).

In 2005, following the controversial state and federal involvement in the removals of feeding tubes in persistent vegetative state patients like Terri Schiavo (Quill, 2006), the Committee on Health, Education, Labor, and Pensions at the US Senate met to discuss the hearing on "Health Care Provided to Non-ambulatory Persons" (NHPCO, 2020). Around this time, discussions arose regarding what is considered a life-prolonging treatment because up to this point, it was undetermined if providing alternative hydration and nutrition was beneficial for patients like Ms. Schiavo (Quill, 2006).

Historically, medicine has singularly focused on curative treatments, with such an emphasis on this leading to physicians either dramatically overtreating terminally ill patients or avoiding them altogether and not providing care (Stead at al., 2020). The implementation of hospice into medical school and other healthcare careers curricula is a recent event. Some medical schools started incorporating PC in their curricula in the 1990s, and although by 1997 it had been mostly implemented in didactic training, it still lacked critical clinical mentorship opportunities (Stead at al., 2020). In 2000, the Liaison Committee on Medical Education mandated that end-of-life care be incorporated in every accredited medical school, but by 2004, there still was not consistency in terms of the appropriate curriculum and guidelines (Stead et al., 2020).

Recruiting educators and clinical mentors has been difficult, and many students still to this day feel that they are unprepared to work with patients in PC. In 2011, a group of universities in the US worked in tandem to integrate several professions such as general medicine, nursing, and social work into interdisciplinary PC teams, yet this has continued to be a soft specialty in medical schools and facilities nationwide (Stead et al, 2020).

Recommendations are still being made regarding effective training of medical professionals to prepare them to work in PC settings. In 2019, Boland et al. released twelve clinical tips for universities to keep in mind when educating undergraduate pre-med students on the topic. These tips included themes related to access to field experience, educators having positive teaching attitudes with innovative approaches to encourage non-intended learning opportunities, increased institutional support, universal guidelines for educational objectives, specialist/current professionals submitting input, and forming collectives of passionate interdisciplinary PC professionals.

When undergraduates were surveyed, the aspect of PC that intimidated them the most was a misconception that once a patient begins PC, that the professional has failed to cure the patient and that the patient will die due to the professional’s failure (Boland et al., 2019). This prevalent misconception along with other longstanding negative attitudes surrounding death has made it difficult to motivate students to explore PC as an area of specialization resulting in a limited number of practitioners and a limited set of interested and qualified researchers.

Where the Palliative Care is Now

While healthcare educational curricula are in constant need of adaptation to relevant skillsets, PC in clinical practice has made a lot of growth within the past few decades. Dumanovsky et al's (2016) analysis on US' hospitals found that for the first time since the American Hospital Association's annual evaluation began, no state received an "F grade" (41% or below) on quality and access to PC within their facilities. Seven states, however, still had D grades and nine had C grades. A "D grade" translated to mean that in hospitals having 50 or more beds, only 21-40% of hospitals within the state had established PC programs; a grade of "C" indicated that 41-60% of hospitals in the state had such programs. Moreover, nationally, in hospitals with more than 50 beds, 33% did not have any established PC program. This type of analysis is essential in understanding where facilities stand in the ability to offer PC, and where the opportunities for growth remain.

In 1991, the Commission on the Future Structure of Veterans Health Care formally recommended that veterans be eligible to receive hospice care in their benefit package, with the Department of Defense authorizing this coverage later the same year (NHPCO, 2020). Since then, the Veterans Administration Medical Center has become the largest US-integrated healthcare system that has a comprehensive PC program (Hughes & Smith, 2014). This means that almost every clinical provider in the facility is expected to know and be able to provide best-practice in PC. In addition to the VA's extensive training protocols, they also offer their patients "expanded-access hospice" for up to 2 years before expected death. Preliminary data conducted on the VA's PC integration program supports that early consultation with PC providers can reduce stress on providers and patients and can furthermore reduce the need for additional critical care services (Hughes & Smith, 2014).

The cost effectiveness of providing PC is an issue complicating accessibility to care, in part, because administrators have misconceptions about the goal of such services and whether there is value in providing care to people who are not expected to show progress from the services provided (Barawid et al. 2015). However, data shows that a comprehensive PC system throughout US healthcare facilities could amount to savings of upwards of $6 billion per year (Meier, 2014). Recognizing the misperception regarding costs, as well as understanding the accessibility barriers to PC, are essential in understanding why limited research is available. Furthermore, patients who could benefit most may be facing financial constraints when trying to receive therapy services while in palliative, hospice, and/or end of life care (Frost, 2001). Kelly et al. (2016) stated that allied health services are often considered as "optional extras" for patients with advancing life-limiting diseases. They go on to describe how these services are offered too late, and often at the last minute. When services are offered within the last months and weeks of expected life, outsiders often question what the purpose is, and they assume it creates strain on the healthcare system. Consequently, patients and families wanting to seek rehabilitative services may face roadblocks along the way.

Furthermore, many of the patients who receive PC and end of life services may be Medicare recipients (Meier, 2014). Although Medicare does cover allied health services in some situations, Medicare does not consider SLPs as a core member in end-of-life care teams (Wallace, 2013). Wallace (2013) mentions that some of these misconceptions are due to the cost effectiveness concerns as discussed above, but also include limited knowledge regarding the scope of practice of SLPs. However, change is happening. The 2013 Jimmo vs Seblius case ruled that Medicare guidelines must include the maintenance of skills not related to progression of recovery. This was preceded by the Joint Commission Roadmap for Hospitals in 2010 that stated patients with severe communicative impairments receiving end of life care must receive a consultation from an SLP as soon as possible (Pollens, 2022).

Before the COVID-19 pandemic, gradual deterioration from chronic conditions or extended treatment were more common patterns leading to death, compared to more rapid decline from acute infections or illnesses (Toner & Shadden, 2012). Long-term data on if and how this has changed due to the pandemic may not yet be available, especially when considering continuing long-COVID ailments. The pandemic emphasized a lot of strengths and weaknesses in the current structure of international healthcare collaboration, especially in examining the public's knowledge on end-of-life topics such as long-term ventilation use. In terms of weaknesses, staff shortages and lack of resources were abundant. Many authors of recent publications mentioned a heightened need for PC services following the pandemic, including a heightened need for professions to be prepared to step up services (Mahendra & Alonso, 2020; Pollens, 2020).

Palliative Care and Speech-Language Pathology

Some of the oldest available literature connecting the profession of SLP to the clinical needs related to death and dying is from Potter, Schneiderman, and Gibson (1979). They highlighted the growing aging population that will need care and the fact that SLPs have relevant clinical expertise that can meaningfully help individuals in the dying process. They also acknowledged that the taboo nature of death makes this type of clinical work difficult. Potter et al. (1979) further emphasized the need for clinicians to receive training in the area of counselling because patients who are dealing with serious conditions and the possibility of death often experience complex emotions.

From here, there is a significant gap in the PC literature specific to the field of SLP until the late 1990s. Studies such as Forbes in 1997 and Salt and Robertson in 1998 discussed the potential benefits that patients with cancer diagnoses could receive from proactive SLP consultations, mainly due to the variability of cancer progression and the possibility of treatment options having side effects including decreased breath support and control, inefficiencies in motor control, and mood dysregulations (Salt & Robertson, 1998). Early involvement of SLPs allows for the gradual introduction of supportive measures before a patient's communication and swallowing needs become more urgent. Additionally, establishing a therapeutic relationship earlier rather than later allows the SLP to have a clearer indication of the patient's "baseline" abilities and how they have changed over time. Forbes (1997) also emphasized this point by stating that without appropriate expertise, it is challenging to manage pain, symptoms, and psychosocial effects specific to communication concerns. These studies are significant in the history of SLP in PC because this was around the same time that medical institutions were mandating curricular coverage of the topic. However, there is very little early literature from the 1970s – 1990s regarding the SLP's role other than a few related to head and neck cancer. Over the past two decades, there has been an increase in research focusing on defining the SLP's role when working with patients who are facing serious illness, e.g., Kelly et al. (2017) and Stead et al. (2020). There are, however, still no universal educational or clinical guidelines for SLP students or practicing clinicians.

Role of Speech-Language Pathologist in Palliative Care

Overview of SLP Roles and Types of Patients Treated

In 2004, Pollens published a foundational piece that summarized four key roles of a SLP working in PC. These include to:

1. Deliver consultations to patients, families, and PC/hospice team members regarding scope of practice areas.
2. Acquire tactics relating to communication and decision making, sustaining relationships, and meeting other end of life and quality of care measures.
3. Minimize dysphagia symptoms by integrating strategies and techniques to improve comfort and pleasure associated with eating.
4. Work with the entire care team to make sure goals and care are being supported by other professions and vice versa.

For SLPs, their scope of practice includes a set of unique skills relevant to supporting patient comprehension, expression, cognition, and safe feeding and swallowing. In addition, clinicians can act as a mediator between patient's family and medical providers to ultimately advocate and protect the patient's dignity and autonomy (Mahendra & Alonso, 2020). Thus, therapy within PC populations would not differ from other traditional rehabilitative settings as it should still include common quality of life indicators that benefit both the patient and their family, such as further prevention of injury, removal of hazards, and pain relief provisions (Frost, 2001).

The SLP's scope of practice makes them uniquely qualified to work in PC settings due to the potential to improve a patient's overall quality of life; however, it has been difficult for researchers to define specific practices that clinicians utilize in the field because there is little guidance from professional bodies or the research literature (O'Reilly & Walshe, 2015). SLPs routinely provide rehabilitative services to patients who often may be appropriate for PC services as well. For example, Forbes (1997) reported that of patients receiving PC, 53% had communicative difficulties and 74% had dysphagia and other feeding complications.

The primary diagnoses of patients admitted to PC units include advanced dementia, cancer, and progressive/degenerative neurological illnesses, among others, which overlap considerably with common diagnoses on SLP caseloads (Pollens, 2020). In O'Reilly and Walshe's 2015 survey that was sent to SLPs internationally, they found among patients receiving PC on an SLP's caseload that 71% presented with advanced dementia, 78% had cancer, and 79% had a progressive/degenerative neurological condition (O'Reilly & Walshe, 2015).

Communication & Cognition

Communicative and cognitive concerns at the end of life are usually last-minute considerations, and often are not identified until it is too late to intervene with effective solutions (Pollens, 2020). Pollens (2021) wrote, "When patients facing a life-limiting illness are unable to communicate verbally, their right to inclusion in health care decisions and their specific views may be overlooked or misunderstood. Timely implementation of communication interventions may uphold the patient's autonomy, improve their perceived quality of life, and enable their participation in health care decision making" (p. 264). As in other areas of SLP practice, recommended interventions are tailored to a person's specific end of life needs and concerns (Chahda et al., 2017). Pollens (2020) specifically emphasized the individual supportive measures of a patient's communication to both maintain family and social relationships as well expressing needs and opinions for as long as possible.

Dementia is a common diagnosis found amongst patients receiving PC, but speech therapy services are not typically considered until debilitating symptoms start to arise. However, it is not recommended for patients with advanced dementia to be placed in a rehabilitative program at all if the aim is to restore function due to the progressive nature of the disease (Irwin 2006). Goals for patients with dementia need to be carefully considered in order to maintain autonomous function for as long as possible, but also must consider the reality that the patient will not recover communicative function to meet their prior levels. Irwin (2006) recommended that SLPs should consult with other team members and family members when making recommendations due to the complications that often arise.

Feeding and Swallowing

Dysphagia is one of the seven final symptoms that are commonly noticed within the last two days of life and is thus one of the primary deficits associated with end-of-life care within the SLP's scope of practice (Pollens, 2004). Dysphagia is present in 79% of head and neck cancer patients receiving hospice services (Frost, 2001). Schwarz et al. (2019) stated that a majority of the studies available discussing complex feeding decisions are related to dementia and end of life considerations. It is a prioritized area of concern as malnutrition and dehydration can result in other significant health complications and overall decline if left untreated (Chahda et al., 2017). Feeding is also a social activity, so communicative goals may overlap (Pollens, 2005).

Although swallowing difficulties are common in neurodegenerative diseases like advanced dementia, there are many issues that clinicians must consider before making recommendations. Schwarz et al. (2019) defines the situations associated with a complex feeding decision as having a high risk of aspiration, when quality of life is impacted, or when patient and family wishes deviate from professional recommendations. They further state that these contexts are complicated by legal and institutional policies and guidelines, and the competency of the patient to make informed decisions.

Berkman et al. (2019) surveyed over 700 SLPs in the US on the necessary circumstances that must be in place prior to the SLP deciding to recommend oral feeding in patients with advanced dementia. Six common themes emerged from their analysis. The most shared reason that SLPs would recommend an oral diet was that the patient's desires were clearly recorded, either through an advance directive or a surrogate decision maker for the patient. Other themes included quality of life considerations towards the end of life or in patients with poor prognosis, mitigation strategies for aspiration risk are able to be followed, the physician's preference after communicating with family, the SLP is knowledgeable on current evidence related to the decreased benefit of feeding tubes in patients with advanced dementia, and the family/patient clearly acknowledged the risk of aspiration and documented their decision for an oral diet (Berkman et al., 2019). They also discussed that the growing integration of patient-centered care and PC initiatives into the SLP profession are helping to promote the use of comfort feeding per patient preference, as it can help mitigate the clinician's moral distress and is overall less burdensome. Moral distress when working with dysphagia in this population was often linked to the mental conundrum of recommending an oral diet due to quality-of-life implications per patient/family preference while knowing that a considerable aspiration risk is present. Berkman et al. (2019) described that this is especially burdensome on the clinician because professional guidelines support both sides of the decision.

Preparation of Speech-Language Pathologists Regarding Palliative Care

In 2004, Pollens published one of the first articles that discussed the lack of PC preparation for SLPs. Some of Pollens proposed actions include more communication between professions, SLPs to be stronger advocates for working within this setting, stronger quality of care for both patients and families, and for students going into the field to have more opportunities to be educated and exposed to the end-of-life setting (Pollens, 2012).

When 332 speech-language pathologists were surveyed internationally, 92% of clinicians agreed with the WHO's definitions and goals for PC, and 96% firmly believed that SLPs have a valid claim in working with this population, even though clinicians also reported a lack of confidence in doing such work (O'Reilly & Walshe, 2015). O'Reilly and Walshe identified several themes in their 2015 survey from their SLP participants when asked about PC, such as protecting a patient's dignity and quality of life, providing individualized and interdisciplinary care, and ethical decision making regarding the amount of education and resources currently available. Several other studies emphasized the importance of individualized care from interdisciplinary teams (Barawid et al., 2015; Boland et al., 2015; Lambert, 2012; O'Reilly & Walshe, 2015; Pascoe, 2015; Pollens 2012; Stead et al., 2020)

One of the common misconceptions amongst medical administrations and the public at large is that SLPs do not have a role in palliative and end of life care because they only focus on achieving functional improvements in communication and/or swallowing (Chahda et al., 2017). Although it is likely true that a patient in PC is unlikely to restore functional deficits to match an earlier baseline, clinicians can still work on maintaining functional status for as long as possible for the skills that are most relevant in upholding a patient's dignity and autonomy. The WHO's definition states that death is neither hastened or postponed, and symptoms should be relieved (Chahda et al., 2017). This means that advancing death and inability to restore function should not restrict clinicians from providing the care necessary to support a patient's communication and/or swallowing during PC. Speech-language pathologists are considered lifespan professionals, meaning they should be educated and prepared to treat patients from infancy to death, even though in practice this is not the case.

There are currently no professional guidelines available regarding PC for SLP students and clinicians working within the US. The American Speech Language-Hearing Association (ASHA) does have a brief resource and reference document available online (“End of Life, n.d) to provide suggestions for SLPs in PC settings due to the prevalence of swallowing and feeding concerns in this patient population; however, this is one of the only published documents from ASHA relevant to American SLPs working in PC. Other professional organizations such as the Center to Advance Palliative Care (CAPC) have developed recommendations for clinical training, as well as continued education opportunities for practicing clinicians (CAPC, n.d.). Although guidelines are not yet available within the US, Ireland is ahead when considering SLPs to be critical members of PC teams and have thus been able to create and enact practical evidence-based guidelines for their clinicians (Collins, 2022; AIIHPC, 2023).

A secondary effect to the limited universal guidelines is the uncertainty that clinicians have in availability of resources, leading some clinicians to believe that they do not belong in this setting (O’Reilly & Walshe, 2015). Some SLPs have gone as far as to report that they feel like a burden and waste of time for their patients without a broader understanding of what their role is in this setting (O’Reilly & Walshe, 2015).

Curriculum Considerations

Disregarding the fact that guidelines for PC are lacking (at least in some parts of the world), other reasons why PC is not covered in curricula include an already crowded course program that is typically completed within two years, lack of available clinical specialists to provide training, and a lack of clinical placement opportunities (Pascoe et al., 2015). Stead. et al.

(2020) also emphasized the point that a lack of adequate preparedness among professionals likely results in inadequate care of patients in PC. Practicing SLPs also may avoid this type of clinical care because of the negative feelings they have about themselves and that such avoidance within the clinical practice further exacerbates the problem of being able to provide adequate course and clinical experiences for SLP graduate students (Stead et al., 2020).

Collins (2022) solicited input from Irish clinicians and students about their perceptions of working in PC. A striking quote from one of the student participants was ". . *.you're going to have to work in palliative care. . . so we better get comfortable*" (Collins, 2022). In contrast, clinicians from this same study reported that when they were students, they were often protected from being in palliative and end of life settings by their clinical supervisors, thus creating anxiety around this type of work. In essence, students felt that their instructors were reinforcing that it was "too challenging" for them to handle. Furthermore, the clinicians reported that students should have the opportunity for real-world PC experiences, but they also recommended that the introduction that clinical students have be gradual to limit shock or compassion fatigue (Collins, 2022)

The overarching recommendation from Collins (2022) included instituting confidence building measures for student clinicians. A critical part of confidence building is the feeling of being able to understand the terms associated with a topic and being able to confidently explain them to others. Mahendra and Alonso (2020) gathered data from undergraduate and graduate students within communicative sciences and disorders programs in the United States and found that 72% of students had heard of PC, but only 22% could accurately describe it. Additionally, just over half (55%) of the students surveyed were able to explain the concept of quality of life. Errors in student knowledge and perceptions that emerged included believing that PC was only for older patients with dysphagia and/or dementia, equating PC with hospice care, confusing PC with assisted suicide, and believing the SLPs should not be involved because the care is not rehabilitative in nature. Similar misunderstandings have also been reported from physical therapy and medical students (Mahendra & Alonso, 2020). Collins (2022) also enrolled students in coursework regarding PC to help address their erroneous knowledge and perceptions. Following the training, students reported being very interested in the education and potentially working within PC settings.

Advanced Directives and Waivers

People often do not even begin to think about what they want their care to look like at the end of life until it is too late. Once it becomes personally relevant, there can be countless additional stress factors to consider that can become overwhelming and confusing in the heightened state that follows onset of injury or diagnosis (Toner & Shadden, 2012). The lack of familiarity about end-of-life related implications is not just a weakness in speech-language pathology or in healthcare overall, but is a societal issue related to the sensitive and taboo nature of the topic that is often too uncomfortable to discuss.

Some of the common considerations that come up when working with end-of-life patients include life-sustaining measures, opinions on pain treatments, and power of attorney. When all of these decisions come together in a written document and are notarized, an advanced care directive is formed (Mahendra & Alonso, 2020). Many doctors are recommending that patients make these decisions earlier in their life before any considerable health issues arise that could complicate cognitive abilities (Lambert, 2012).

Speech-language pathologists thus have a unique role when patients do not have these affairs in order, but where complications have arisen. When patients are overwhelmed and cognition is impacted, SLPs are often consulted more than other allied health professions to assist in mitigating the communication needed for decision making (Lambert, 2015). Because of the importance of these decisions, clinicians should have a baseline knowledge set about advanced care directives and waivers. Common components in advanced care directives include opinions on resuscitation, ventilation, nonoral feeding and hydration, narcotic pain relief and its effects, dialysis, and modified diets (Lambert, 2015). Although SLPs may have some familiarity with these items, they may be less likely to appreciate the associated legal issues.

Discussions around advanced care directives are often left out of SLP curriculums due to a perceived lack of relevance. Mahendra and Alonso (2020) examined students' familiarity of various terms related to end-of-life care. They found that 46% of students recognized the term advanced directive, but only 22% could adequately explain what it was. This is concerning because they may work with patients who have advance directives that are in place and being implemented, even when patients are not in PC programs. However, knowledge about advance directives is especially critical when clinicians have to utilize such documents when making clinical recommendations. Berkman et al. (2019) stated that the most common reason that clinicians recommend an oral feeding approach for patients with advanced dementia was because the patient had included a preference to avoid alternative nutrition/hydration in their advance directive.

Another common issue arises when a patient does not have an advance directive, but they or their family decide that they do not want to follow the SLP's recommendations. Some facilities have a waiver system in place for this situation, where the patient or the patient's surrogate decision maker can decide to sign off on a form stating that they are aware of the risks if the patient does not follow the SLP's recommendations. However, there are many legal considerations here. Berkman et al. (2019) highlighted the most prominent one, namely, that waivers are enacted to protect institutions and clinicians, and by utilizing waivers, the ethical promises that healthcare providers make to keep the patient's best interests in mind are broken. Patients utilize healthcare institutions because they trust that the clinician is more knowledgeable than the patient and will thus make recommendations to meet the patient's best interest. This is juxtaposed with the idea that patients' opinions in their healthcare are equally valid, and they do not have to follow every recommendation. These situations occur, creating stress for clinicians as they can be pressured into following their institution's waiver guidelines but still want to practice a patient-centered approach (Berkman et al., 2019).

Clinician Burnout and Compassion Fatigue

People frequently exposed to end-of-life care may eventually experience symptoms of compassion fatigue and burnout. A common expression in human service fields is that 'you cannot fill another's cup if yours is empty.' Compassion fatigue occurs when a provider's metaphorical cup runs dry, and they have run out of empathy for patients and their families. For fields such as speech-language pathology that are empathy-driven, compassion fatigue and burnout can have a large impact on the services provided (Kelly et al., 2016). Many people enter the allied health professions because of their desire to make an impact on other people's lives, but when you are frequently around people who are dying and have the conception that you are failing to make progress with them, burnout is a significant risk (Toner and Shadden, 2012). However, professionals that are provided training on healthy coping strategies are less likely to report negative effects associated with professional burnout (Toner and Shadden, 2012). Effective training regarding the signs, symptoms, and prevention of compassion fatigue and other burnout signs can help future clinicians to be more mindful of themselves and the care they are able to provide. For current clinicians, mindfulness to self is critical for monitoring the signs and symptoms of burnout. Clinicians may also find benefit in understanding what grief is and how it can present differently in patients and families (Pascoe et al., 2015). In multiple studies, students have reported that they would feel much more confident and comfortable working in this setting if they were provided adequate training such as death and dying processes, grief stages, and coping strategies (Toner and Shadden, 2012).

Pediatric Considerations

There is especially limited training and knowledge relative to pediatric PC interventions due to a lack of research (Mahendra & Alonso, 2020). Krikheli et al. (2020) published the first international survey of SLPs working in pediatric PC settings. Although their study had a limited response rate, the results provided "unique" and specific considerations for integrating the SLP role, PC, and pediatric populations. Some differences between pediatric and adult PC include developmental considerations, a child's dependence on their caregiver, the different types of conditions leading to PC, medication usage, and the clinical environments that care is provided (Krikheli et al., 2020). Although the participants had no specific treatment approach for pediatric populations, they shared five themes related to decision making. These themes were: not recommending instrumental dysphagia assessment in pediatric populations; including care management implications; patient's intolerance to the instrument or assessment procedures; instrumentation isn't relevant to quality of life or comfort feeding related goals; and the risks exceed the benefits (Krikheli et al., 2020). Results from this study indicated that SLPs perceived themselves to operate similarly on pediatric and adult PC teams. Although clinicians recognized a need for SLP to be integrated into the multidisciplinary PC team, they struggled in perceiving themselves as part of the team. Participants also mentioned a lack of training, with 98% stating they received little to no education during their degree granting program related to pediatric PC (Krikheli et al., 2020).

The Paradox within Rehabilitation

A common ethical conundrum that many clinicians face is that their idea of intervention goals may not always align with the patient’s wishes. The “goal of beneficence” relating to therapy activities leading to incremental progress towards recovery is not realistic in PC and can often cause clinicians to avoid working with this population (Chahda et al., 2017). Similar to the medical students feeling that they have failed when their patients are admitted to PC, SLPs may feel that the traditional goals and activities are a waste of time and resources because, in their mind, “*if the patient isn’t going to get better, why am I seeing them*?” Introducing the idea of facilitative goals, goals that are not intended for restoration of function but instead follow pre-existing frameworks of comfort care, early into curricula could help SLPs see the value of PC and their role in it (Chahda et al., 2017).

Statement of Purpose

A speech language-pathologist's knowledge and experience of providing care related to communication, cognition, and swallowing positions them as a strong advocate for patients receiving palliative care. Within the current framework of the healthcare system, SLP is one of the most ideal professions to be involved in the care of patients in PC. SLPs are often able to spend more time at bedside with their patients compared to physicians (Chahda et al., 2017; Mahendra & Alonso, 2020; Toner & Shadden, 2012). This increased time at bedside allows for more intimate and stronger relationships with patients, which can be crucial in supporting a patient’s communication and swallowing functions at an especially sensitive time in the patient’s life. Some countries outside of the US have already begun a more thorough integration of SLPs into palliative care settings. The progress made thus far can be used to learn from in order to further advance the practice in the US.

Chahda et al. (2017) called for clinicians to be actively involved in the development of norms and guidelines for working within this population. Establishing an evidence-base for PC in the US is in its infancy and one place to begin is to first examine what is currently being done on the front lines. From there, more thorough recommendations and guidelines can be established, and lines of research investigation can be established.

This thesis will document and analyze speech language pathologist's perspectives and experiences with palliative care and other end of life topics. This study will collect information from SLPs in the US regarding a variety of issues related to PC such as their current PC roles, clinical practices, educational experiences, professional burnout, impact of the COVID-19 pandemic on PC, challenges of working in PC as an SLP, and attributes that SLPs need to work in PC. The overall goal is to generate a baseline description of what current clinical practice looks like from the experiences of professionals that provide this type of care in the US.

METHODS

Participants

This project had a targeted recruitment of approximately 25-50 SLPs who have experience working with patients receiving palliative or end of life care. Inclusion criteria were: 1) experience working within the US for at least 3 years, 2) state license to practice as an SLP, 3) SLP clinical experience working in PC or with patients at the end of life during their CF or after, and 4) ASHA certification of clinical competence. Exclusion criteria were: 1) SLPs without at least one clinical experience in PC or with patients at the end of life, 2) without state licensure, or 3) SLPs who are not ASHA certified.

Survey Tool

A study-specific survey created by the author to address the aims of the study was generated through *Qualtrics Survey Tool*. The questions were formulated following an extensive review of the available literature. This review identified issues in PC from the perspective of practicing SLPs and other professionals. Two SLPs with recent clinical experience reviewed the survey in its entirety for face validity, as well as to identify any areas needing improvement in clarity and/or readability. Edits based on their suggestions were made prior to survey distribution. Demographic information was also gathered to allow for description of the participant pool.

The survey was constructed to gather the most prioritized information at the beginning of the survey. These initial questions focused on the experiences and perceptions of the SLPs about PC. The intention of soliciting this information at the start of the survey was to allow for some useful information from participants who might start the survey but quit for whatever reason prior to completing all questions. This survey was estimated to take about 15 to 20 minutes through Qualtrics Expert Review tool.

The survey consisted of eleven blocks of questions. Types of questions included multi-select, multiple choice, and fill-in-the-blank. All agreement/disagreement questions were set up in a multiple-choice format with a 5-point agreement scale arranged in a horizontal layout with the levels of agreement given as “strongly disagree”, “somewhat disagree”, “neither agree nor disagree”, “somewhat agree”, and “strongly agree” arranged from right to left. All frequency-based multiple-choice questions utilized the following choice options: “never”, “quarterly (at least one patient)”, “monthly (at least one patient)”, “weekly (at least one patient)”, “daily (at least one patient)”. See *Appendix A* for consent message and for survey questions and question options in its entirety.

1. The first block included the study’s consent form with information about the study and a yes/no question if the individual wished to participate. If the individual selected “yes”, the participant was moved to the next set of questions. If the individual stated “no”, the flow logic of the survey routed the participant to the end of the survey to thank them for their time and they saw no other questions and so they were not included in the analysis.
2. The second block of questions included two agreement/disagreement multiple choice questions for participants to rate their own level of agreement/disagreement to four definitions relevant to the study (rehabilitation, PC, hospice, and EoL). If the respondent indicated any level of disagreement to a definition (i.e., “strongly” or “somewhat”), they were prompted with a fill-in-the-blank question to provide additional context to why they disagreed. There were eight possible questions in total in this block that participants may have answered.

3. The third block of questions included two agreement/disagreement multiple choice questions about the role of an SLP in PC utilizing the four roles defined by Pollens (2004). Participants were also asked an agreement/disagreement multiple choice question about whether the roles of an SLP in PC differ compared to other settings.
4. The fourth block had eight questions about the clinical care that SLPs provide in PC settings. The first question was a multiple choice (“yes”, “no”, “I’m not sure”) asking if their facility had a dedicated PC team. If participant stated “yes”, they were routed to another question asking if SLP was included on this PC team. If participant stated “yes”, they were routed to multi-select question asking the participant to define their level of participation in their facility’s PC team (screening all patients, screening patients when requested, and/or providing consultative information to providers without meeting the patient). Following the completion of that logic flow, participants were then asked to rate their level of satisfaction with how SLPs were included in PC at their facility. Questions then transitioned into asking about the SLP’s caseload beginning with a frequency-based multiple-choice question asking participants to describe how often they were with patient’s facing a life-limiting disease. If never was selected, participants were routed to the next block of questions. If any other option was selected, participants were asked a multi-select question about the diagnoses of their patients receiving PC. Participants were then provided a multiple-choice question to describe the frequency of ASHA “Big 9” services to patients receiving PC. The last multi-select question in this block asked participants what other professions are on the PC team.
5. The fifth block of questions asked four questions regarding the participant’s experience with advanced directives, waivers of liability, telehealth, and counseling. The questions

about advanced directives, waivers of liability, and telehealth were frequency-based multiple-choice questions. Participants were also asked a multi-select question about the types of counseling they provide to patients receiving PC.

6. The sixth block asked three multiple choice questions and one fill-in-the-blank question about their experiences during COVID-19. The first question asked if they were a participant on a PC team during COVID-19. The next was an agreement/disagreement multiple choice question asking whether the pandemic made them more willing to work in a PC setting. Next, they were asked an agreement/disagreement multiple choice question if the pandemic changed how they provided PC. If participants indicated any level of agreement that the pandemic did change their PC care provision, they were then asked a fill-in-the-blank question for participants to provide any details to how the pandemic changed the care provided.
7. The seventh block asked five questions about the experiences of an SLP in PC. The first question was an agreement/disagreement multiple choice question about PC causing burnout. If any level of agreement was indicated, participants were provided a fill-in-the-blank question to provide additional details about their perception of professional burnout. Then, another agreement/disagreement multiple choice question was asked about whether they would recommend working in a PC setting to other SLPs. Participants were also provided two fill-in-the-blank questions, the first about challenges in providing SLP services in a PC setting and the second about attributes and skills a clinician needs to work in a PC setting.
8. The eighth block asked nine questions related to the SLP’s general career demographics. The survey collected the year of initial licensure through a fill-in-the-blank question,

states of licensure through a multi-select question, and past/current clinical settings through multi-select questions. Additionally, two multi-select questions were presented about the sources and topics of their PC-related CEU opportunities. A fill-in-the blank question was also provided for participants to further describe these opportunities. An agreement/disagreement multiple choice question was asked if participants felt these experiences prepared them to work in a PC setting. The last question in the block was a multiple-choice question with the option to fill-in-the-blank if they had any career outside of SLP.

9. The ninth block asked four questions related to participant's graduate education, including the year they graduated with their clinical degree (fill-in-the-blank question), topics related to PC covered in graduate school (multi-select question), other PC-related experiences during graduate school (fill-in-the-blank question), and their agreement/disagreement to graduate education preparing them for a PC setting (multiple choice question).
10. The tenth block asked five questions related to general demographics, including birth year (fill-in-the-blank), gender (multi-select), ethnicity (multi-select), Spanish/Hispanic/Latino origin (yes-no multiple choice), and other relevant identities (fill-in-the-blank).
11. The eleventh block asked one multi-select question about how the participant heard of the study.

Procedures

Purposive sampling was done via targeted emailing, social media posting, professional contacts, and messaging on relevant ASHA Special Interest Group listservs (SIGs 2, 3, 13, and

15) and Michigan Speech, Language, Hearing Association social media and listserv. The recruitment message encouraged SLPs to share the survey link and QR code with colleagues to encourage snowball sampling. See *Appendix B* for recruitment message. After the initial recruitment postings, in the number of surveys completed in Qualtrics was tracked weekly. After two weeks without any new responses, the recruitment postings were repeated. The survey was then closed after one more week without any new responses. In total, the survey was open during January and part of February 2024.

Analysis

For most survey items, descriptive statistics were completed. Nominal data from demographics and other survey questions were reported using frequency distributions, percentages, and modes. Questions with ordinal responses were analyzed using frequency distributions, percentages, median and mode, and range. Interval and ratio data were presented in terms of frequency distributions, means, standard deviations, and ranges.

For two open-ended questions, content analysis was conducted by the author following guidelines from Erlingsson and Brysiewicz (2017). The author began by reading the survey responses several times to familiarize themselves with the range of responses. While reading over the responses, notes were taken of common themes naturally emerging from this review. Next, the author began identifying and clustering identical (or nearly so) words and phrases. Words and phrases that were conceptually similar to other responses were grouped together. For longer responses (sentences), text was reduced while preserving the core meaning of the response (condensation stage). Condensed meaning units were coded and grouped into categories that naturally emerged or that had already emerged when clustering the single word/short phrase responses. A label was applied to each theme to summarize the unifying concept; in some cases, a theme had naturally occurring subcategories which were also given a label. These themes and subthemes, including the verbatim responses that were grouped within each, were then shared with another researcher (Jeff Searl, Ph.D., thesis advisor) for his review. He offered comments and suggestions regarding, highlighting when there was disagreement with categorization of specific words/phrases/sentences. The first researcher then worked with this input and some re-organization of the theme and sub-theme structure, and labeling occurred. The advisor then completed a second review to come to a consensus for the final content analysis results. Frequency counts of responses (words, phrases, sentences) that clustered within each theme/sub-theme are reported. All responses are presented verbatim in Appendix C and Appendix D.

RESULTS

Survey Respondent Characteristics

Demographics

A total of 98 responses were submitted. Of these, 67 participants met the inclusion criteria and had answered ≥90% of the survey items (each table below identifies how many respondents had answered that question, so denominators for percentages do differ). Not all participants were presented with all survey questions because of the conditional formatting of the survey wherein certain questions appear only if a respondent answers a preceding question in a certain way. For example, if a respondent reported disagreement with a statement presented in a survey question, they were subsequently asked to provide reasons for their disagreement. However, if they agreed with the statement, then they did not see the follow-up question asking for their reasoning.

Demographics regarding gender, race, and ethnicity are in Table 1. The group self-identified as predominately women, white, and non-Hispanic. Participants were also offered a write-in option to provide other identities that they wished to share that were not included in the multi-select options. Four respondents provided the following answers: (1) *Multilingual;* (2) *Member of the Long COVID community;* (3) *Caregiver of a person with a disability and an elderly parent. - These life experiences also give us some perspective in this area;* and (4) *Year of graduation…tells the story*. Descriptive statistics regarding age at survey completion and years since obtaining the ASHA Certificate of Clinical Competence are in Table 2. These data indicate a group of respondents who were relatively older and had held their CCCs longer compared to national data for SLPs in the US (2023 Member & Affiliate Profile Report: Annual Demographic and Employment Data).

Table 1. Gender, race, and ethnicity of survey respondents (n=67).

Demographic		Frequency	Percentage
Gender	Female	65	97%
	Prefer not to say	2	3%
Race	White	59	88%
	Asian	3	5%
	Black	1	2%
	Other	4	6%
Ethnicity	Non-Hispanic/ Non-Latino	62	93%
	Hispanic/Latino	5	8%

Table 2. Age at survey completion and years since obtaining Certificate of Clinical Competence (CCC) from the American Speech, Language, Hearing Association (ASHA) (n=67).

Statistic	Age (years) at survey completion	Years since obtaining ASHA CCC
Mean	49	21
Standard deviation	13	13
Minimum	29	3
1st quartile	39	10
3rd quartile	56	30
Maximum	80	50

Education

Topics relevant to clinical work in palliative, hospice, and EoL care that were covered in graduate school training (academic or clinical) are presented in Table 3. These data indicate that just over 50% of respondents reported that “geriatrics” was included as a topic in their formal education. Palliative care, hospice care, and EoL were reported by 15% - 18% of the SLPs while 43.0% indicated that none of the topics listed in Table 3 were addressed in graduate school. Respondents were given the opportunity to report additional learning opportunities outside of their coursework and clinical placements during graduate school in which they engaged those covered topics related to palliative and hospice care. Seven individuals provided responses that are also presented in Table 3. Lastly regarding education, 16% of the SLPs “somewhat” or “strongly” agreed that their graduate school training prepared them to work in a palliative care setting, while 74% “somewhat” or “strongly” disagreed with this statement (Table 4).

Table 3. Topics covered in coursework and/or clinical experiences during graduate school (n=67).

Topic	Frequency	Percentage
Geriatrics	35	52%
None of the above	29	43%
Advanced directives/other legal documentation	14	21%
End of life care	12	18%
Palliative care	10	15%
Hospice	10	15%
Physiological stages of death	9	13%
Healthcare worker burnout/self-care	4	6%

Write-in comments describing other coursework and/or clinical experiences during graduate school.

1. *Mentorship with clinical supervisor who covered some of these areas*
2. *I took a psych department course in dementia that included a module on end of life/dying*
3. *While doing my clinical rotations within a community hospital setting, my clinical instructor provided me opportunities to participate in end of life/advanced directives conversations and at times lead the conversation with family members. This was the most valuable learning opportunity I had in the area of palliative/hospice care, which I may have missed without that clinical placement.*
4. *No formal work- personally I had experience with serious rare illness in my 20s. This helped me appreciate the patient's perspective in many ways. While in HS I witnessed my grandfathers rapid decline and illness requiring him to be ventilated. His loss of communication and the SLP who helped him via low tech eye gaze in the hospital inspired my career decision.*
5. *Life experience only (with dying family members).*
6. *Life: Home health practice taught me more about palliative care than any other setting because of the engagement in a natural environment with all the key players (family, friends, caregivers) associated with the client. (IN advance of the question below, this was not a topic at the beginning of my career 45 years ago that was even explored, so that needs to be considered in your analyses.)*
7. *None. We came across patients in my full-time placement (at various SNFs) who might be nearing the hospice stage, but did not actively work with them. My first job after graduation did not have a formal palliative care team.*

Table 4. Ratings of agreement/disagreement with the statement, "*My graduate education prepared me to work in a palliative care setting*" (n=65).

Rating	Frequency	Percentage
1. Strongly disagree	32	49%
2. Somewhat disagree	16	25%
3. Neither agree nor disagree	7	11%
4. Somewhat agree	7	11%
5. Strongly agree	3	5%
No Response	2	3%
Mode	1. Strongly disagree	--
Median	2. Somewhat disagree	--

Work Setting and Continuing Education

The year in which the SLPs obtained their Certificate of Clinical Competence (CCC) spanned from 1973 to 2020 and were distributed as shown in Figure 1. Participants were from 27 states, as reflected in Figure 2. Nearly three quarters of the respondents indicated that they currently worked in a hospital setting in which they worked with adults although several other current work settings were also reported (Table 5). All but two of the respondents (97%) reported taking at least one continuing education (CE) opportunity related to EoL and PC topics. A wide range of sources for these CE opportunities were reported with online workshops and conferences (both paid and free) as the most frequent (Table 6). The CE topics covered varied with the most frequently reported being "palliative, hospice, and end-of-life," "geriatrics," and "counseling" (Table 7). Sixty-six percent of the respondents "somewhat" or "strongly" agreed that these additional CE opportunities prepared them to work in a PC setting (Table 8).

Figure 1. Distribution of year in which the SLPs obtained their Certificate of Clinical Competence (CCC) (n=67).

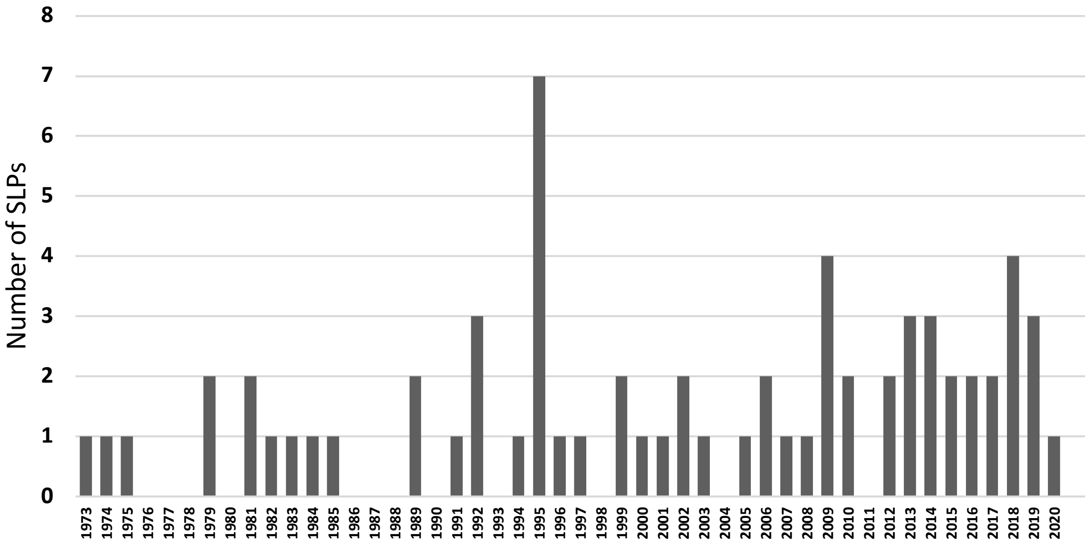


Figure 2. Map of United States indicating locations of licensure of participants (n=67).

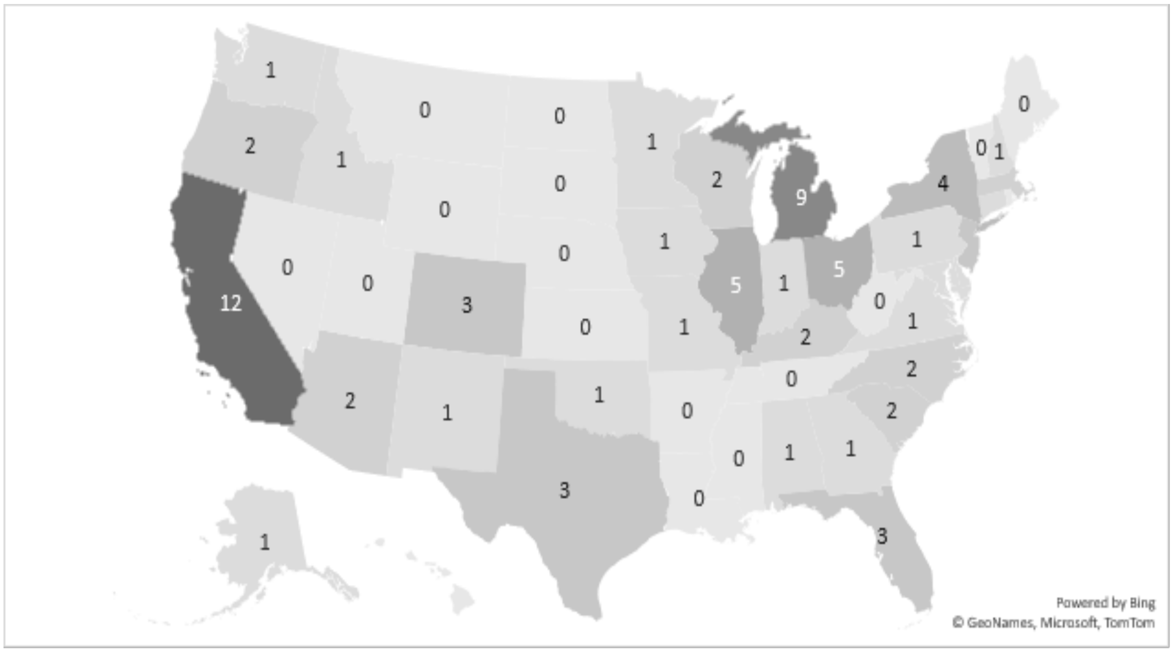


Table 5. Past and current settings of participants. Respondents could choose more than one work settings; therefore, the frequency count exceeds the number of survey respondents.

Setting	Current Work Setting(s) (n=63)		Past Work Setting(s) (n=58)	
	Frequency	Percentage	Frequency	Percentage
Early intervention, preschool, and/or K-12 schools	2	3%	19	33%
College/university	8	13%	15	26%
Hospital – pediatrics	7	11%	14	24%
Hospital - adults	46	73%	40	69%
Residential health care facility	14	22%	37	64%
Private practice	6	10%	22	38%
Corporate speech-language pathology	0	0%	2	3%
Local, state, and/or federal government agency	2	3%	5	9%
Public health department	0	0%	1	2%
Uniformed services	0	0%	1	2%
Home health	2	3%	4	7%
Other	3	5%	7	1%

Table 6. Sources of continuing education opportunities related to end-of-life and palliative care. (n=67).

Source	Frequency	Percentage
Paid resources online	42	62%
Online workshops and/or conferences	42	62%
Free resources online	38	57%
In-person workshops and/or conferences	33	49%
National professional associations	30	45%
State professional associations	19	28%
My employer provides CEU opportunities	18	27%
Other	7	10%
Write in comments		
"Podcasts"	1	-
"International professional conferences"	1	-
"Nonprofits"	1	-
"None"	2	-
"Experience"	1	-
"Few options"	1	-

Table 7. Continuing education topics (CEUs) that respondents completed (n=64).

Topic	Frequency	Percentage
Geriatrics	48	75%
Counselling	36	56%
Advanced directives and/or other relevant legal documentation	25	39%
Healthcare worker selfcare	19	30%
Healthcare worker burnout	18	28%
Physiological stages of death	17	27%
Grief	15	23%
Palliative care, hospice, and/or end of life care	56	9%
Respite services	4	6%
None of the above	0	0%

Table 8. Ratings of agreement/disagreement with the statement, "*These additional educational experiences (outside of graduate school) prepared me to work in a palliative care setting*" (n=59).

Rating	Frequency	Percentage
1. Strongly disagree	2	3%
2. Somewhat disagree	0	0%
3. Neither agree nor disagree	18	31%
4. Somewhat agree	30	51%
5. Strongly agree	9	15%
No Response (6)	8	14%
mode	4. Somewhat agree	--
median	4. Somewhat agree	--

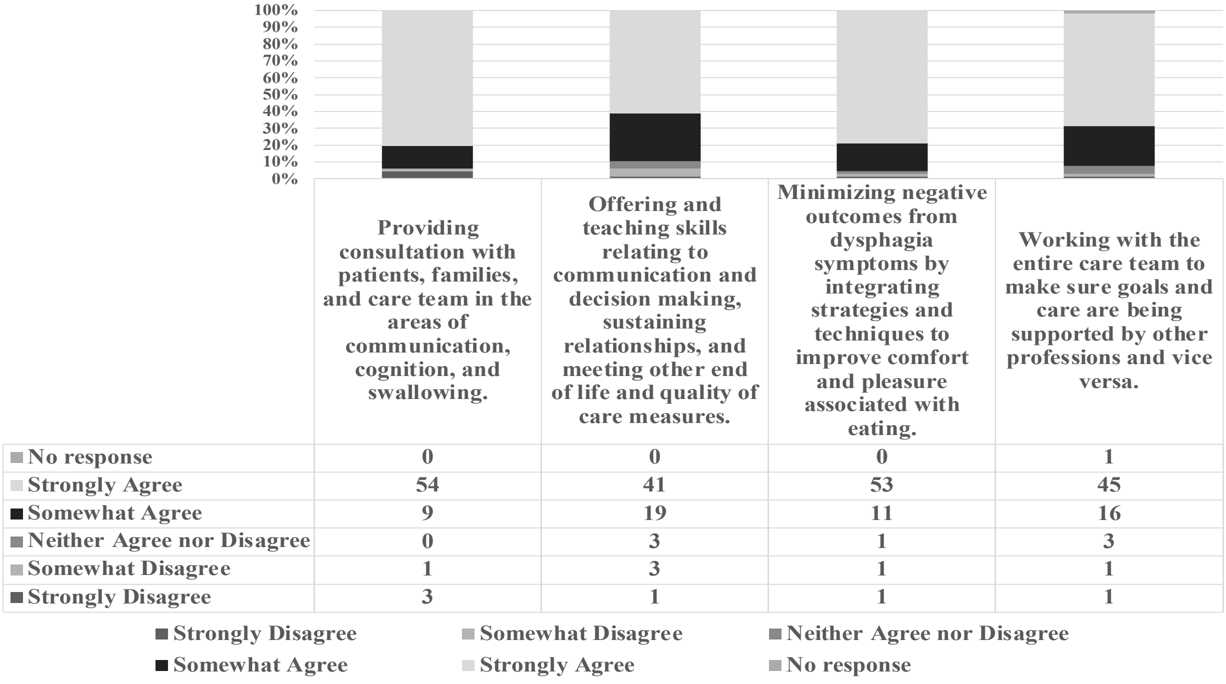
Agreement with Definitions of Rehabilitation, Palliative Care, Hospice, and End-of-life Care

Participants were prompted to rate their level of agreement or disagreement with definitions of rehabilitation, palliative care, hospice, and end of life care that were taken from the WHO and the National Institute on Aging (NIH; Table 9). Ratings of the respondent's agreement with each of the definitions are provided in Figure 3. More than 90% of the respondents "somewhat" or "strongly" agreed with each of the definitions. When a respondent "somewhat" or "strongly" disagreed with a definition, the survey display logic gave them an additional open-ended question asking them "What is it that you disagree with in this definition of (rehabilitation/PC/HC/EoL care)?" The verbatim responses to these open-ended questions are in Table 10.

Table 9. Definitions and their sources for rehabilitation, palliative care, hospice care, and end-of-life care provided in the survey.

Term	Definition	Source
Rehabilitation	includes interventions addressing the impact of a health condition on a person's everyday life by optimizing their functioning and reducing their experience of disability.	World Health Organization
Palliative Care	specialized medical care meant to enhance the quality of life for people living with a serious illness that may or may not be provided alongside curative treatment.	National Institute on Aging
Hospice Care	focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life.	National Institute on Aging
End-of-life Care	the term used to describe the specialized support and medical care given during the time surrounding death.	National Institute on Aging

Figure 3. Frequency counts (percentages) of ratings of agreement/disagreement with the provided definitions of rehabilitation, palliative care, hospice care, and end of life care (n=67).



	Providing consultation with patients, families, and care team in the areas of communication, cognition, and swallowing.	Offering and teaching skills relating to communication and decision making, sustaining relationships, and meeting other end of life and quality of care measures.	Minimizing negative outcomes from dysphagia symptoms by integrating strategies and techniques to improve comfort and pleasure associated with eating.	Working with the entire care team to make sure goals and care are being supported by other professions and vice versa.
■ No response	0	0	0	1
■ Strongly Agree	54	41	53	45
■ Somewhat Agree	9	19	11	16
■ Neither Agree nor Disagree	0	3	1	3
■ Somewhat Disagree	1	3	1	1
■ Strongly Disagree	3	1	1	1

Table 10. Open-ended responses in the follow-up question presented to those who indicated they disagreed "somewhat" or "strongly" with a definition (n=6). It should be noted that not all participants opted into providing additional context to their agreement/disagreement response.

Definition	Level of Disagreement	Response
Rehabilitation	Strongly disagree (n=1)	*It's about what is missing. It brings people back towards baseline.*
Palliative Care	Strongly disagree (n=3)	*It's about what is missing: not intended to improve performance.* *Curative treatment cannot be part of the plan* *It only mentions 'medical care' and not SLP or all the other care that is provided,*
Hospice Care	Strongly disagree (n=1)	*I agree but with the experience that some patients randomly get better and don't die*
End-of-life Care	Strongly disagree (n=1)	*My perspective is that "end of life" care is not necessarily associated with timing of death - as within days. It would begin for my practice w/ clients at the time of a 'terminal' diagnosis not just the final decline.*

Roles of an SLP in Palliative Care

Participant ratings of their levels of agreement or disagreement with the four roles in palliative care that were defined by Pollens (2004) are provided in Table 11. These ratings indicated that at least 89% of the respondents agreed (somewhat or strongly) with each of the roles that were presented. When asked if the SLP roles differ in PC compared to other settings, 76% agreed (somewhat or strongly) while 18% disagreed (somewhat or strongly). Participants were also asked to identify the level of participation that they had when working with their PC team (Table 12). Most (75.9%) of participants indicated that they did not have a standing position (i.e., screening all PC patients, and providing care when appropriate) within the care team but were instead only seeing PC patients on an as-needed basis. Of the remaining respondents, 30.2% indicated a standing-role and 10.3% indicated a consultative-role. Three respondents provided a response under “other” to provide context to their role (Table 12).

Table 11. Frequency counts (percentages) of ratings of agreement/disagreement with statements about the roles of a speech-language pathologist in palliative care (n=67, see "no response" column to indicate questions without full participation).

Rating	"The roles of an SLP in palliative care include ..."'				
	Providing consultation with patients, families, and care team in the areas of communication, cognition, and swallowing.	*Offering and teaching skills relating to communication and decision making, sustaining relationships, and meeting other end of life and quality of care measures.*	*Minimizing negative outcomes from dysphagia symptoms by integrating strategies and techniques to improve comfort and pleasure associated with eating.*	*Working with the entire care team to make sure goals and care are being supported by other professions and vice versa.*	*The roles of a speech-language pathologist (SLP) differ in palliative care settings compared to other settings in which SLPs work.*
1. Strongly disagree	3 (5%)	1 (2%)	1 (2%)	1 (2%)	5 (8%)
2. Somewhat disagree	1 (2%)	3 (5%)	1 (2%)	1 (2%)	7 (10%)
3. Neither agree nor disagree	0 (0%)	3 (5%)	1 (2%)	3 (5%)	3 (5%)
4. Somewhat agree	9 (13%)	19 (28%)	11 (16%)	16 (24%)	40 (60%)
5. Strongly agree	54 (81%)	41 (61%)	53 (79%)	45 (67%)	11 (16%)
No Response	0 (0%)	0 (0%)	0 (0%)	1 (2%)	1 (2%)
mode	5.Strongly agree	5.Strongly agree	5.Strongly agree	5.Strongly agree	4.Somewhat agree
median	5.Strongly agree	5.Strongly agree	5.Strongly agree	5.Strongly agree	4.Somewhat agree

Table 12. Self-identified level of participation speech-language pathologists (SLPs) have on their palliative care team (n=29) It should be noted that this question was a multiple-select question, so respondents could have indicated more than one level of participation.

Level of Participation	Frequency	Percentage
Referral for additional services/resources (e.g., respite services) where the SLP is referred to see palliative care patient on as-needed basis and works with care team to provide general recommendations.	22	76%
Standing position on the team where the SLP screens all admitted palliative care patients and provides treatment for those who are at risk for communication, cognition, or swallowing difficulties.	4	30%
Consultative where the SLP is asked for professional opinions but never provides direct services to the palliative care patient.	3	10%
Other	3	10%

Write-in comments provided under "Other"	*"Palliative services are often fully integrated into a curative plan for patients and so we find our services to be palliative at any point. The palliative team has indicated we are their greatest consult source, so we often are already on a case. Often the only time the team consultants would perhaps be to facilitate communication for a patient who seemingly can cognitively make decisions but has communication challenges, as in a high cervical complete SCI."* *"All three apply depending on medical condition. We have specialized Parkinson's and ALS clinics where I work, and I screen all those patients"* *"Palliative care team is following patients actively involved with speech for swallowing typically in acute care. Not sure if this is considered part of team. We interact frequently and they rely heavily on our input for swallowing safety"*

Palliative Care Service, Team Make-up and the Patients Served

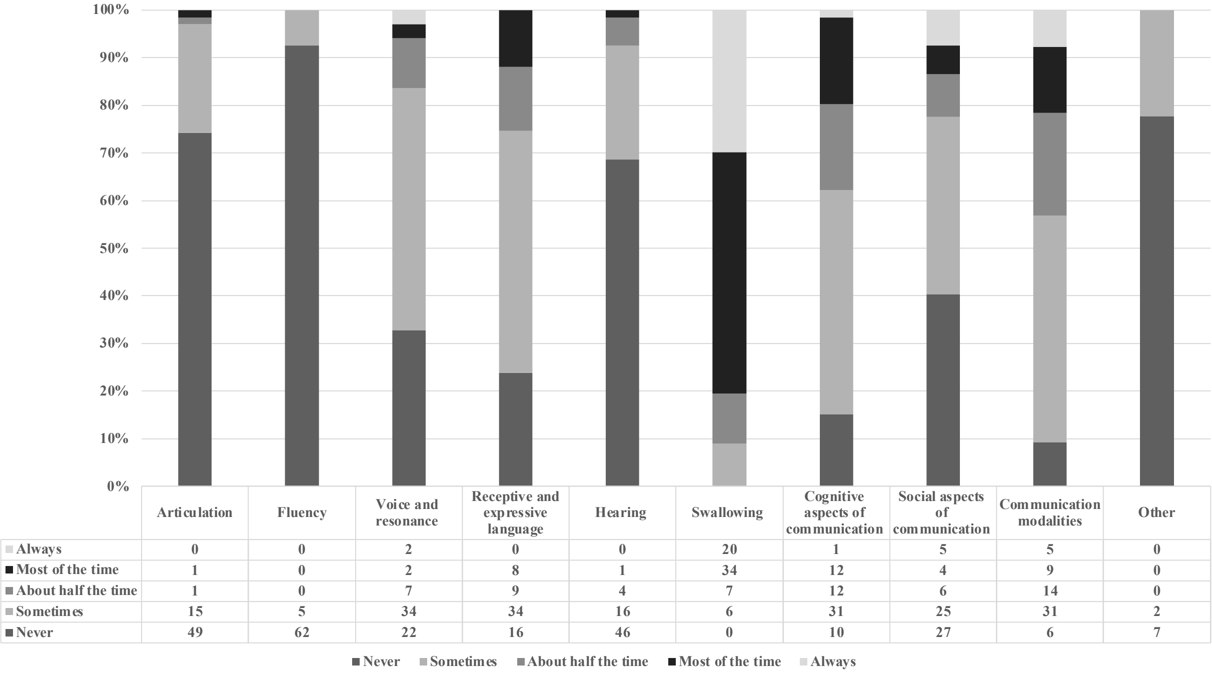
Twenty-two percent of respondents indicated that they see at least one patient with life-limiting disease daily, 30% weekly, 30% monthly, and 18% quarterly. Swallowing disorders was identified by the largest percentage of respondents as an area of focus (>80% identifying as "most of the time" or "always); conversely, fluency was observed to be the least common, with 92.5% of respondents indicating that they "never" work on fluency with these patients. All responses related to the frequency of ASHA "Big Nine" services are summarized in Figure 4.

Most (>80%) participants indicated that a social worker, palliative care specialist, and nurse were included on their PC team (Table 13). The least commonly reported discipline was audiology (2%). Participants were provided the options to write-in other disciplines that they commonly work with on their PC teams.

Over 90% of respondents indicated that the patients they most frequently treated in PC settings had a neurodegenerative disease, cancer, or dementia (Table 14). Several other medical diagnoses were also identified.

Participants were asked to rate their agreement/disagreement level with a statement related to how well speech-language pathology was integrated into their setting's PC team. There were varied opinions among these respondents with 48% "somewhat" or "strongly" agreeing that SLP was integrated into their PC team, but 35% "somewhat" or "strongly" disagreeing with this statement (Table 15).

Figure 4. Frequency (percentage) of speech-language pathologists who reported provided services in each of the American Speech and Hearing Association (ASHA) Big 9 areas with palliative care patients. Respondents could choose more than one service area; therefore, the frequency counts exceed the number of survey respondents.



	Articulation	Fluency	Voice and resonance	Receptive and expressive language	Hearing	Swallowing	Cognitive aspects of communication	Social aspects of communication	Communication modalities	Other
Always	0	0	2	0	0	20	1	5	5	0
Most of the time	1	0	2	8	1	34	12	4	9	0
About half the time	1	0	7	9	4	7	12	6	14	0
Sometimes	15	5	34	34	16	6	31	25	31	2
Never	49	62	22	16	46	0	10	27	6	7

Table 13. Professions that survey respondents reported were included on their palliative care teams (n=50). Respondents could choose more than one selection; therefore, the frequency exceeds the number of survey respondents.

Discipline	Frequency	Percentage
Social Work	43	86%
Physician - palliative care specialist	40	80%
Nurse team	40	80%
Chaplain	33	66%
Dietetics/nutrition	29	58%
Patient's primary care physician	23	46%
Occupational therapy	21	42%
Physical Therapy	20	40%
Respiratory therapy	17	34%
Physician - not primary care	14	28%
Animal therapy	9	18%
Other	8	16%
Music therapy	5	10%
Audiology	1	2%
Write-in options from “Other”	Palliative Advance Practice Provider (n=1)	
	Recreational therapy (n=1)	
	Neuropsychology (n=2)	
	Behavioral health (n=1)	
	MD hospitalist (n=1)	

Table 14. Diagnoses of patients treated by their PC team (n=67). Respondents could choose more than one diagnosis; therefore, the frequency exceeds the number of survey respondents.

Diagnosis	Frequency	Percentage
Neurodegenerative disease	65	97%
Dementia	62	93%
Cancer	61	91%
Cerebral vascular accident (CVA)	48	72%
Heart/lung disease	46	69%
Kidney disease	38	57%
Traumatic brain injury (TBI)	29	43%
Other	13	19%
Write-in responses under "other"	*Liver disease (n=1)* *Old age (n=1)* *Rare genetic disorder (n=1)* *COVID (n=2)* *Depression (n=1)* *Infectious disease w/multi-system atrophy (n=1)*	

Table 15. Frequency counts (percentages) of ratings of agreement/disagreement with statement, *"I am satisfied with the extent to which speech-language pathologists are integrated into the palliative care team in my setting"* (n=66).

Rating	Frequency	Percentage
1. Strongly disagree	7	11%
2. Somewhat disagree	16	24%
3. Neither agree nor disagree	11	17%
4. Somewhat agree	18	27%
5. Strongly agree	14	21%
No Response (6)	1	2%
mode	4. Somewhat agree	--
median	3. Neither agree nor disagree	--

Table 16 provides summary statistics regarding SLP involvement with advanced directives, waivers of liability, and telehealth. For this survey, a "waiver of liability" was defined for the respondents as a “form that a patient or patient's medical decision maker signs to opt out of some, or all, recommendations made by the patient's care team.” Overall, most respondents indicated that they “never” or “rarely” are involved in the development of advance directives (80%) or that they utilize waivers of liability (77%). Telehealth was also “rarely” or “never” used in the PC setting (86%). The types of counselling and other methods of support that SLPs provide is summarized in Table 17. Of note, 100% (n=67) of respondents indicated conversing with family, and nearly all 99% (n=66) reported conversing directly with the patient when providing counseling services.

Table 16. Frequency of SLP helping to establish advance directives, use of waivers of reliability, and use of telehealth in the PC setting (n=66).

Topic	Advanced Directives		Waivers of Liability		Telehealth	
	Frequency	%	Frequency	%	Frequency	%
Unsure/unfamiliar with this term	0	0%	6	9%	0	0%
Never	34	52%	40	61%	51	77%
Rarely	19	29%	11	17%	6	9%
Sometimes	10	15%	6	9%	6	9%
Often	3	5%	2	3%	3	5%

Table 17. Types of counselling and/or other methods of support speech-language pathologists (SLPs) are providing in palliative care populations (n=67).

Counselling Type	Frequency	Percentage
Conversing with patient's family/community	67	100%
Conversing 1-on-1 with patient	66	99%
Providing online/printed resources	50	75%
Recommending participation in support groups	19	28%
Leading support groups	4	6%

SLP Palliative Care during the COVID-19 Pandemic

Participants were asked if they were practicing clinicians during the COVID-19 pandemic (spring 2020 to present). Of the 60 participants who responded to this question, 59 (98.3%) reported practicing as a clinician during this time frame. They were then asked if the COVID-19 pandemic changed their willingness to work with patients in PC and if the pandemic changed how they provide such services. The majority of respondents (71%) indicated that the pandemic did not make them either more or less willing to work in a PC setting (Table 18) while 17% agreed that it made them more willing and 12% were less willing. Sixty-seven responded to an agreement/disagreement statement regarding whether the pandemic changed how they provide PC services. A majority (54%) indicated that they neither agreed nor disagreed with this statement while 25% “somewhat” or “strongly” disagreed and 16% agreed (Table 19). Those who agreed that they had changed how they provided PC because of the COVID-19 pandemic were given the chance to describe the change(s). These responses are reported in Table 19.

Table 18. Frequency count and percentages of ratings of agreement/disagreement with the statement, "*The COVID-19 pandemic has made me more willing to work in the palliative care setting*" (n=61).

Rating	Frequency	Percentage
1. Strongly disagree	4	7%
2. Somewhat disagree	3	5%
3. Neither agree nor disagree	43	71%
4. Somewhat agree	7	12%
5. Strongly agree	4	7%
No Response	6	10%
Mode	3. Neither agree nor disagree	--
Median	3. Neither agree not disagree	--

Table 19. Frequency count and percentages of ratings of agreement/disagreement with the statement, "*The COVID-19 pandemic changed how I provide palliative care*" (n=67).

Rating	Frequency	Percentage
1. Strongly disagree	9	13%
2. Somewhat disagree	8	12%
3. Neither agree nor disagree	36	54%
4. Somewhat agree	9	13%
5. Strongly agree	5	8%
No Response	0	0%
Mode	3. Neither agree nor disagree	--
Median	3. Neither agree not disagree	--

Write-in responses:

Somehow the pandemic made the concept of palliative care more universally applicable to all families. There is now less of a barrier between provider and patient/family. We are all equally affected.

Homebound patients were able to start doing video consultations.

I became more involved in dealing with COVID related death because some people had serious lung issues that effected their ability to swallow.

65 of pts I had worked with in SNFs died over 18 months. I was actively involved with them, their families and worked to support optimum care. A SNF is a horrid place to die - Covid or not.

I realized that use of AAC and tools for supporting patient-provider communication with nonspeaking/ventilated patients are essential to end-of-life care.

It was really because of COVID that I had my first palliative care experience. And several since then were due to COVID.

During the pandemic, I was surprised by how many people that "made it" who appeared terminal to me. I have learned to be more judicious in my use of language and treat more deliberately toward what the patient has energy for and supporting opportunities to rally. I was likely doing this before, it's just now far more deliberate.

in acute care there were the people who were actively sick which led to frequent conversations regarding respiratory status and swallowing. Because of COVID, people didn't seek help for other medical conditions so now our patient's are sicker than ever, frequently with chronic conditions that are impacting swallow safety. I've become more comfortable with addressing how swallow function, communication abilities, and cognitive functioning are impacted by chronic conditions and will encourage the attendings to consult Palliative Care early when appropriate. We work closely with them and will have joint meetings with family when needed to help with decision making. Knowledge is powerful for a lot of these situations and we are the experts able to provide the education they need while navigating difficult decisions.

Burnout and Recommending Palliative Care as a Practice Area for Other SLPs

Participants were asked to rate their level of agreement or disagreement to the statement that working in PC had resulted in professional burnout. About 48% “somewhat” or “strongly” disagreed that working in PC settings had caused burnout, 18% “somewhat” or “strongly” agreed with this statement, and the remainder neither agreed nor disagreed (Table 20). Those who indicated that they had experienced burnout from this type of work were given the opportunity to provide any details they wished to share about their burnout with responses provided verbatim in Table 20. A follow-up question asked them to rate their agreement-disagreement about whether they would recommend working in a PC setting to other SLPs. Over 80% of respondents “somewhat” or “strongly” agreed that they would recommend working in this clinical area and 6% indicated that they would not (Table 21).

Table 20. Frequency count and percentages of ratings of agreement/disagreement statement: "*Working in palliative care has caused me to experience professional burnout*" (n=67).

Rating	Frequency	Percentage
1. Strongly disagree	20	30%
2. Somewhat disagree	12	18%
3. Neither agree nor disagree	23	34%
4. Somewhat agree	11	16%
5. Strongly agree	1	2%
No Response	0	0%
Mode	3. Neither agree nor disagree	--
Median	3. Neither agree not disagree	--

Write-in responses provided to explain SLPs experiences with professional burnout.

Risk if illness for myself and my family; limitations in PPE supplies. Burnout improved significantly after I was vaccinated and PPE supplies improved.

I find that our money greedy rehab world tends to discard people in need of palliative care and prefer the patients that bring in more money.

I worked for nearly 20 years in a large ALS clinic. I developed significant compassion fatigue and needed to step away from that patient population.

The palliative services that are provided don't contribute to my burnout, but families and patients electing for full medical management/not accepting palliative approach when patient has a very short life expectancy is taxing on me.

Not enough training to know how to communicate information in this population. I've since taken a course to help with this and read some articles that helped me to better navigate these conversations with patients, families, and physicians.

COVID really put a burden on our SLP team. We worked very long hours and in the early stages it seemed like we couldn't do too much – we didn't know a lot about COVID at that point.

Witness to egregious care and attention from administration through nursing.

I find institutional culture of communicating first and foremost with family/caregivers/proxies rather than directly with patients using tools/supports very demoralizing and exhausting. Providers don't have shared understanding of what communicative competence looks like and it affects patients' autonomy at end-of-life when they are not offered communication supports.

It was just exhausting to come to work each day during COVID. There were times that I really dreaded walking in the door to work. But I always rallied because families and patients were in rougher shape than I was.

It is pretty exhausting work. Also, I feel like I need a o always be available for that patient, basically 24 hours a day.

Table 21. Frequency count and percentages of ratings of agreement/disagreement with the statement, "*I would recommend working in palliative care to other speech-language pathologists*" (n=67).

Rating	Frequency	Percentage
1. Strongly disagree	1	2%
2. Somewhat disagree	3	5%
3. Neither agree nor disagree	9	13%
4. Somewhat agree	23	34%
5. Strongly agree	31	46%
No Response	0	0%
Mode	3. Neither agree nor disagree	--
Median	3. Neither agree not disagree	--

Challenges in Providing Speech-Language Pathology Services in a Palliative Care Setting

Respondents were provided an open-text question to share three to five key words or phrases to describe the challenges of working as an SLP in PC settings. From the content analysis, seven themes emerged, three of which had sub-themes (Table 22). The theme with the largest number of comments was "Challenges Working with Other Professionals", which also had three sub-themes as reflected in Table 22. This was followed by the theme "SLP Emotional and Psychological Challenges," "Practical Challenges" with three sub-themes, and "Challenges Working with Patients and Families" which also had three subthemes. The remaining three themes were "SLP Knowledge/Skill Limitation," "Lack of Health Literacy Among General Public," and "SLP Resource Limitations." There were 6 responses that were unable to be categorized due to ambiguity of the intended message. All responses are in *Appendix C.*

Table 22. Themes, sub-themes, and frequency counts summarizing key words/phrases that participants provided to describe challenges of speech-language pathology (SLP) in palliative care settings (n=55).

Theme (number)	Sub-theme (number)	Theme Frequency	Sub-theme Frequency
Challenges Working with Other Professionals (1)		41	
	Physicians/other professions not recognizing scope of SLP (1)		32
	Lack of referrals (2)		5
	Difficulties with administration (3)		4
SLP Emotional & Psychological Challenges (2)	---	29	--
Practical Challenges (3)		22	
	Time Pressures (1)		11
	Billing/reimbursement concerns (2)		8
	Lack of staffing (3)		3
Challenges Working with Patients & Families (4)		22	
	Difficulties working with families/patients		18
	Patient's wishes differing from family/SLP wishes		4
SLP Knowledge/skill Limitation (5)	---	20	--
Lack of Health Literacy Among the General Public (6)	---	15	--
SLP Resource Limitation (7)	---	6	--

Attributes and Skills a Speech-Language Pathologist Needs to Work in a Palliative Care Setting

An open-ended question asked respondents to provide three to five key words or phrases to describe the attributes and skills that a SLP needs to work successfully in PC settings. Four themes emerged with “Personal Traits,” which had seven sub-themes, having the highest frequency followed by “Care for Others” with three sub-themes, “Communication” with five subthemes, and “Clinical Skillset” with two sub-themes (Table 23). One comment was ambiguous and could not be placed within a theme. All comments can be found verbatim in *Appendix D*.

Table 23. Themes, sub-themes, and frequency counts summarizing key words/phrases that participants provided to describe the needed attributes and skills for a successful speech-language pathology (SLP) clinician in palliative care settings (n=58).

Themes (number)	Sub-themes (number)	Theme Frequency	Sub-theme Frequency
Personal Traits		77	
	Emotional strength and awareness		19
	Patience and flexible		18
	Other personality traits		14
	Humility		8
	Creativity		6
	Honesty		6
	Able to see "bigger pictures"		6
Care for Others		61	
	Compassion		30
	Empathy		22
	Acceptance of others		9
Communication		49	
	Counselling and education skills		16
	Interdisciplinary communication and collaboration		9
	Listening skills		9
	Broader communicative skills		9
	Advocacy skills		6
Clinical Skillset		40	
	Clinical knowledge and Skills		29
	Work-life boundaries and balance		11

DISCUSSION

The purpose of this study was to describe PC and EoL care from the SLP's perspective. The objective was to collect data from SLPs in the US regarding their current roles, clinical practices, and other relevant educational and career experiences when working with patients facing a life-limiting disease. The overall results from this study provide a comprehensive picture of PC and EoL care from practicing SLPs. The primary findings are the following: (1) most SLPs did not feel that graduate school prepared them for this clinical work, (2) they sought a wide range of sources on many topics relevant to PC through CE opportunities, (3) most saw PC as unique compared to other SLP areas of practice, (4) dysphagia was the most frequently addressed deficit and patients most frequently seen by SLPs in PC had diagnoses of neurodegenerative diseases, cancer, or dementia, (5) COVID-19 did not seem to influence the SLPs' willingness to work in PC or how they provided care, (6) about one out of five of the SLPs reported professional burnout related to this type of work, (7) working with other professionals was the most frequently reported challenge in PC, and (8) a number of personal traits and other attributes were identified as being needed for an SLP to be successful in PC settings. Further exploration of these findings is presented below.

As context for the discussion, it is important to note that the survey respondents were generally reflective of the make-up of the SLP profession as reported in the ASHA 2023 Member and Affiliate Profile. That is, the respondents were predominantly female, white, and non-Hispanic. However, the age distribution of the respondents suggests that the group may be skewed toward being older with a mean age of 50 years, whereas 56.7% of SLPs in the US are 44 years old or younger. It is unclear why the respondents are older and more experienced than anticipated. It may be that involvement in PC is something that becomes more appealing to more experienced SLPs although this only speculation. Lastly, a large majority of respondents indicated that they currently were working in hospitals (general or pediatric) and/or residential health care facilities. Given the focus of participant recruitment as well as the focus of the study on PC and EoL, SLPs in these settings logically might be oversampled compared to SLPs in schools and other settings.

Graduate School Preparation and Continuing Education

The results from this study indicated that less than 20% of the respondents felt that their graduate education adequately prepared them to work with palliative and EoL care patients. When specifically asked if they had topics such as EoL care, palliative care, and hospice, most SLPs reported that they did not receive any coursework or clinical experiences in these areas.

The fact that nearly three-quarters of the respondents expressed to some level that they did not feel prepared from their graduate education to work in a PC setting is consistent with several earlier studies. Irwin (2006) emphasized the lack of specialized education about PC provided to SLPs, specifically highlighting the need for training about clinical decision-making regarding feeding for patients with advanced dementia. Pascoe et al. (2015) identified the lack of education about PC and EoL care among Australian clinicians. They identified several potential reasons for this including the wide breadth of content that needs to be covered in graduate programs, the relatively short timeframe to cover all the content, little evidenced-based research to inform such instruction, and limited supervised practicum opportunities in PC for students. More recent studies have continued to find that SLP graduate students have little to no dedicated content coverage regarding working with patients at the end of their life (Mahendra and Alonso, 2020). The study results over the past 20 years regarding graduate level preparation of SLPs for PC work has remained consistent and indicates that limited progress has been made in this area.

In acknowledgement of the growing need of clinicians across several disciplines to work with patients in PC, the WHO has called for more thorough training of healthcare workers internationally (World Health Organization, 2020). At present, it is not clear that a strategy or guidance has emerged here in the US for how this will happen for SLPs.

Only 52% of respondents reported that geriatrics was covered during their graduate curriculum. This was the topic chosen most frequently by the respondents from a list of issues related to EoL This is not consistent with ASHA expectations regarding graduate programs providing education that covers communication and swallowing across the lifespan. The topic chosen with the second highest frequency was that of "none of the above," meaning 43% of respondents had no graduate school education on several topics relevant to EoL such as PC and hospice, among others.

One aspect of education that has been emphasized by Mahendra and Alonso (2020) is the importance of students understanding advanced directives and other relevant legal documentation relating to EoL situations. The majority of respondents (nearly 80%) in the current study reported that they had no graduate coursework covering this topic. Advanced directives are important for SLPs across several settings and patient populations that extend beyond PC. Advanced directives, for example, can include critical information about a person's wishes regarding resuscitation attempts and preferences related to nutrition. It may be that students acquire additional knowledge about these types of legal documents after they graduate (nearly 40% of respondents in this study reported they pursued this topic in CE activities post-graduation). However, if this knowledge is not taught or if it is learned too late, students and clinicians may be in situations where they could make critically wrong decisions about how to intervene with patients.

The write-in comments from SLPs were also informative about their graduate school education relative to PC and EoL. Specifically, some SLPs identified the impact that their clinical education opportunities related to EoL had on them and the value of the mentorship of clinical instructors when working in this space. Collins (2022) found something similar in which their participants reported that their clinical instructors played a large role in reinforcing attitudes related to treating patients in EoL settings. One respondent from the current study described such mentorship as "*the most valuable learning opportunity I had*." Although a few respondents in this study reported that strong mentorship regarding PC was a good experience, in a prior study students reported that their clinical instructor had guarded them from these clinically difficult experiences (Collins, 2022). That is, instead of fostering a meaningful learning experience working with patients in difficult situations, some students reported that their feelings of anxiety related to the PC setting were amplified. (Collins 2022).

Life experiences, such as a student dealing with their own or a family member's experience also were noted as being influential as part of the education regarding EoL clinical work. This is not something that was noted in the prior literature about preparation for EoL care, but it is reasonable to expect that one's own experiences can shape views and perspectives. Participants stated that their personal experiences with life limiting disease taught them invaluable skillsets. One participant specifically reported that their appreciation for the "*patient perspective*" of life-limiting disease was fostered because of their own serious health condition when they were young.

Overall, respondents from this study reported that they did not feel that their graduate education prepared them to work in PC. The findings in this study, in combination with prior literature, suggest that limited progress in PC preparation has been perceived by students and clinicians within the last two decades. The SLPs reported experiences in this study and in others indicate that there is a need for intentionally developing academic and clinical experiences for students in communicative sciences and disorders to introduce them to PC and EoL clinical practices and to begin training them in this area.

Looking beyond graduate school preparation, all but two respondents indicated that they had pursued CE opportunities related to PC and EoL. The fact that so many pursued such training indicates that the SLPs felt the need to bolster what, if any, education they had received during their graduate education. This could also suggest that once the participants were out of graduate school and practicing, they discovered more about their own knowledge gaps. In general, CE opportunities are intended to build and strengthen expertise and to remain current with new research and evidence-based practices. The survey presented respondents with several topics related to PC and EoL. The topics *Geriatrics* and *Counseling* were the most frequently identified topics of the CEs that they pursued with. Something that could contribute to these being the most frequently sought subjects is the fact that these topics have relevance across multiple settings, not just PC and EoL. *Counselling* in particular has been identified by Mahendra and Alonso (2020) as an important skillset for PC work. At the moment, it is not clear if SLPs will require specific education and training about counseling to best support their work in PC, or if more general counseling knowledge and skills are sufficient. Of note, a question was asked in this study seeking the respondents input about attributes a SLP needs to be successful to work in PC. Counselling and advocacy emerged as predominant themes (described below) suggesting the perceived importance of such skills (and perhaps a sense of needing to bolster their knowledge and skills in this area). The survey did not ask respondents to provide the reason(s) for pursuing specific CE content, so it is not possible to know for sure why these topics dominated.

About two-thirds of the respondents agreed (and only 3% disagreed) that the CE opportunities they pursued did prepare them to work in PC. This is encouraging and suggests that the learning is helpful. However, about 30% of respondents were neutral on this issue. This may indicate the need for more high-quality CE options related to PC and EoL. Further exploration of what the SLPs found to be valuable and what was lacking in the types of CE courses could help in the development of the most beneficial post-graduate school training opportunities. It may be too high of an expectation that CE experiences on their own will prepare SLPs for PC settings, acknowledging that ongoing clinical experience, mentorship, and learning from other healthcare providers on a PC team probably play a major role in an SLPs perception of how well prepared they feel. It is possible, however, that some of the CE opportunities that the SLP respondents in this study attended have been lacking in terms of content focus, depth of coverage, practical advice, or in other ways such that some clinicians did not perceive them as particularly helpful. An overall lack of research about SLP practice in PC also must be considered relative to how SLP clinicians (and students) are trained. There can be great value in conveying expert SLP opinions about the necessary knowledge, skills, and best practices in PC. However, the education and skill building of SLPs would be greatly enhanced with a stronger research evidence base in PC. Finally, the author is not aware of any published guidelines in the peer-reviewed literature or from professional SLP organizations that give a recommended curriculum or set of trainings that SLPs should have to support their work in PC and EoL. This would be helpful in guiding the development of PC and EoL training opportunities. The data about content areas selected for CE training in this study suggest some of the areas that SLPs themselves feel they need, but it also could just reflect what types of CE opportunities have been most readily available or accessible to them.

Agreement with Definitions of Rehabilitation, Palliative Care, Hospice, and End-of-life Care

It is important for clinicians in any given profession to agree on the terms that they use. This helps clinicians communicate more efficiently and directly with one another. Agreement on definitions also implies some degree of unification of philosophy or approaches when it applies to terms such as rehabilitation, palliative care, hospice, and end-of-life care. There is very little that is published in the peer-reviewed literature about SLPs' agreement of the definitions of these terms, therefore this study sought to provide such data from practicing clinicians. In order to reduce bias, and to prevent respondents from simply looking up specific term definitions (although they could have searched for these), the source of the definitions used in the survey (i.e., WHO and National Institute of Aging) were withheld from respondents. Overall, most participants (93%) agreed to some extent (strongly or somewhat) with the provided definitions, compared to less than five percent of participants who disagreed to some extent. O'Reilly and Walshe (2015) also asked their participants to rate their levels of agreement/disagreement with the WHO definition of PC. They found that 96% of participants agreed with the WHO's terms and goals of care related to PC. The consistency across these two studies is positive in that it suggests some general agreement among SLPs about how to define PC.

Of the ten participants that reported a level of disagreement with a definition, six provided an explanation but these comments did not have a unifying theme. However, one specific comment deserves mention because it indicates a key misunderstanding of PC that has been mentioned in earlier research. One respondent disagreed that PC could include curative elements. Toner and Shadden (2012) identified this exact element as a key feature in PC, which separates it from hospice in the continuum of care. Pollens (2020) also highlighted the inclusion of curative treatments in the medical model of healthcare related to services provided by SLPs for palliative care patients.

In summary, most SLPs in this study agreed with the WHO and National Institute on Aging definitions. This is a positive result in the sense that if SLPs had different understanding of terms, then clinical care that is delivered could differ. For example, if a clinician does not believe that patients could receive curative interventions while receiving PC services, they may approach their clinical work and design interventions differently for a particular patient compared to another SLP who understands that curative interventions are still within the realm of PC. Additionally, as noted above, a common set of terms also should have a positive impact on professional peer-to-peer communications.

Roles of an SLP in Palliative Care

Over three-quarters of participants reported some level of agreement that SLPs have a different role when working with patients in PC, and moreover, different priorities compared to other clinical settings. Most respondents *strongly* agreed that the roles of an SLP in PC include providing consultation for relevant services, teaching skills within an SLP’s domain to ensure a patient’s quality of life, lessening dysphagia symptoms for comfort and pleasure eating, and working with the entire PC team to meet holistic goals. Similar roles for the SLP in PC were identified by Pollens (2004).

The results regarding the SLPs’ levels of participation on their PC team revealed that three-quarters of clinicians saw patients receiving PC on a referral-only basis. This means that most respondents are only consulted on an as-needed basis, and they work with the care team to provide general recommendations. This contrasts with teams where the SLP is a standing member who screens all admitted patients receiving PC, and then provides intervention for those at risk of or demonstrating communication and/or swallowing issues. Only 30% of the respondents indicated that they are on such teams. Due to the SLP's expertise in communication and/or swallowing deficits, and the increased likelihood of a patient encountering communication and/or swallowing deficits toward the end of life, SLPs are uniquely qualified to be integrated more fully into PC teams, going beyond a referral-only basis. Forbes (1997) reported that a large percentage of patients receiving PC had communication deficits, with even more reporting swallowing problems. Pollens (2004) also described that dysphagia symptoms typically worsen over the course of time leading up to the time of death, making dysphagia one of the seven consistent patient issues within the final two days of life. SLPs are uniquely qualified to help advocate for patients at the end of life to protect their quality of life, such as making recommendations that support comfort feeding. Medical administrations tend to assume SLPs can only target goals in an attempt to restore function, leading to a misunderstanding of the role that an SLP can and should have in PC settings (Chahda et al., 2017). Because of this, patients in PC may miss the opportunity of even a SLP screening and/or consult in a very critical period near the end of their life. A misunderstanding by administrators and other health professionals about the contributions an SLP can make is also highlighted in the current study wherein respondents identified this as one of the challenges for SLPs working in PC (see below in *Challenges in Providing Speech-Language Pathology Services in a Palliative Care Setting*). It is positive to see that in other countries such as Ireland that the SLP is being more deeply integrated into the evidence-based practice guidelines (Collins, 2022), further validating the value of the SLP in PC. However, continued work is still needed at all levels to advocate for standing positions on PC teams here in the US and in other countries.

Palliative Care Services, Team Make-up, and the Patients Served

Using the ASHA Big Nine clinical areas as a reference, swallowing services were part of SLPs' PC practice for 81% of respondents (either most of or all the time). This is not unexpected given that dysphagia is a primary deficit for patients in PC (Pollens, 2004). Forbes (1997) found that nearly 80% of patients on a PC caseload had swallowing issues. The alignment of these findings across studies and over time provide solid support for the participation of SLPs on PC teams given the high percentage of patients who have dysphagia.

Two other ASHA Big Nine areas were identified by many of the SLP respondents as being addressed most of or all the time in their PC work. Eighty-four percent reported working on "cognitive communication" issues and seventy-six percent reported working on "expressive and/or receptive" communication when working with a PC patient. Pollens (2020) highlighted that these are two issues within the domain of SLP that are commonly not identified as an area of need in a patient's plan of care until it is too late for effective solutions or remediations. However, Pollens (2004) stated that a primary goal for an SLP within hospice is the preservation of communication to maintain social relationship, as well as to support self-expression of wants, needs, opinions, and emotions. Additionally, some patients have spiritual and cultural practices that are important for them that they wish to partake in which may involve communicative and/or swallowing function. Therefore, it is not surprising that these two service areas are often addressed with patients in PC.

Overall, the findings in this study related to which Big 9 services are addressed most often with patients in PC are consistent with previous literature. Toner and Shadden (2012) make the point that anything that can cause death is likely to also impact communication, cognition, and/or swallowing.

The most common diagnoses of the patients that SLPs see in PC were neurodegenerative disease, dementia, and cancer. This is consistent with findings from O'Reilly and Walshe (2015), who reported these as major components of SLPs' PC caseloads. People with neurodegenerative diseases, dementia, and cancer (particularly head and neck cancer) are at elevated risk of cognitive and communication issues regardless of whether they are in PC, HC, or EoL.

Individuals who are receiving PC, HC and EoL care may encounter situations in which they have a difficult time communicating their wishes related to decisions regarding feeding, resuscitation, pain relief, etc., an SLP may be able to provide support in such situations so that patients can express themselves (Frost, 2001; Lambert 2012). Some patients may have never formally documented their wishes in an advanced directive, and for those who have, they have the right to change their mind at any time. SLPs may need to assist in helping patients express themselves given SLP's expertise in expressive/receptive language, cognitive communication issues, and use of various communication modalities. The results of the current study found that most of the SLPs are not involved in establishing advanced directives during PC with 20% indicating they sometimes or often are involved compared to 80% reporting that the rarely or never are involved. The study cannot speak to whether this an appropriate frequency of SLP engagement with this activity, but the data serve as a benchmark for such involvement that could be used as a point of comparison for any subsequent studies of SLPs in the PC environment in future years. It may be the case now that hospitals and healthcare systems are more diligent in asking patients and their families about whether an advance directive is in place and having that become part of the patients record. In this case, the number of discussions with patients needing to establish such documentation is low. A report done on behalf of the Center for Disease Control and Prevention (CDC) from Jones, et al. (2011) found that 88% of hospice care patients had at least one advance directive in place. However, patients have the right to change or revoke the directive(s) at any time. Patients with communication issues who are in EoL care may require the support of an SLP to help them best express their wishes in such circumstances. Establishing a mechanism for having such interactions in a timely manner is important because if the patient's condition progresses to a certain point, it may be too late for the conversations to be had. Future work could further explore whether, when, and in what circumstances SLPs should be more intentionally brought into such conversations, particularly given the high percentage of patients in PC who have communication issues (Pollens, 2004).

Not much has been described about how often SLPs utilize liability waivers. Berkman (2019) endorsed the utilization of waivers when a patient's wishes for their care differs from the SLP's recommendation(s). The waivers are typically work-place specific forms and coupled with extensive documentation to include what the SLP stated in their education session with that patient, as well as how the patient responded to demonstrate that they are fully cognizant of the risks. In the current survey, fewer than 15% of the SLPs reported using waivers either sometimes or often and a large majority (78%) reported using them rarely or never. The results indicate that SLPs do not use waivers very often. Additionally, 9% of respondents reported not being familiar with waivers of liability. The low usage of waivers of liability may be because some facilities might prohibit their use due to the fact that they are not legally binding agreements that would hold up in court. The results on waiver usage provide a picture at this moment in time about how often they are or are not used, and the proportion of SLPs who are unfamiliar with them.

Counselling is identified as a primary activity for SLPs in order to support the communication and swallowing needs of patients in PC (Mahendra and Alonso, 2020). To date, the means of counseling and education that SLPs engage in with this population had not been reported. In the current study, all but one SLP reported that they do converse directly with the patient's family and with the patient themselves. Lambert (2012) emphasized that clinical care needs to be individualized for all patients, but especially for PC and EoL patients. In order to build the optimal individualized care plan, SLPs need to engage in discussion with the patient and family (if available) to know how to best support their communication and swallowing. In addition to direct conversations, most SLPs also utilized online or printed resources when providing counseling for their patients. Future work is needed to better determine what resources are available, what specific items are used, and the accuracy and quality of those materials.

A large percentage of respondents (86%) reported that they rarely or never have utilized telehealth with patients receiving PC. There are no other studies of which the author is aware that have addressed the frequency of use of telehealth by SLPs when working with patients in PC. Prior to the pandemic, evidence was emerging that PC could be delivered virtually with positive outcomes in terms of symptom management, and positive reports from patients, families, and healthcare providers (Bonsignore et al., 2018) although specific data about SLPs providing PC is not available. Given the significant increase in uptake of telehealth more broadly by SLPs during the COVID-19 pandemic (Webb et al., 2021), it is somewhat surprising that telehealth for PC was only reported by 9 respondents as being used "sometimes" or "often." It may be that SLPs feel that providing high-quality PC requires (or is best) when done face-to-face. In fact, Bonsignore et al. (2018), while reporting positive outcomes from telehealth PC, also noted that patients, families, and clinicians indicated that virtual care could not replace the "depth of in person care" (p. 12).

There are many team members that comprise PC teams as evidenced by the fact that 18 different professions were reported by the survey respondents. Social workers, PC specialist physicians, and nurses were reported by at least 80% of respondents. This result may reveal the individuals who are commonly perceived as the core-PC team. The chaplain was also reported on these PC teams by 66% of participants, possibly emphasizing that holistic and spiritual care is needed by many patients. One of the goals of communication within hospice care that Pollens (2004) emphasized was maintaining the ability of patients to express themselves to obtain spiritual and emotional closure in their final days of life, which opens up the opportunity for interdisciplinary collaboration between the SLP and chaplain if this is a focus of care for an individual. Pollens (2004, 2012) also highlighted that a strong interdisciplinary team is necessary for the preservation of holistic care of HC patients, however there is room for further communication between team members. This current study did not go into depth regarding the extent that SLPs are communicating or intervening collaboratively with these disciplines. Future studies would be helpful in determining how and with whom SLPs tend to work interprofessionally on their PC teams.

Responses regarding satisfaction with the extent to which the SLP is integrated into the PC team were spread across the rating scale. Nearly half indicated that they agree somewhat or strongly that they were satisfied with the SLP integration while approximately one third disagreed somewhat or strongly. One interpretation of these results is that the amount of integration of the SLP simply varies across teams. The sizeable portion who are not satisfied with their involvement, however, is cause for concern. As Pollens (2004, 2012) has stated, it is important for SLPs to be active parts of PC teams given the high likelihood of patients having communication and/or swallowing issues. Although the survey did not ask for follow-up comments about their dissatisfaction, one possibility is that the large number of respondents who indicated that they are only consulted on an as-needed basis may reflect a less robust integration onto these teams.

SLP Palliative Care during the COVID-19 Pandemic

The COVID-19 pandemic changed the landscape of healthcare internationally. SLPs were not immune to the changes that there enacted through the peak periods of the pandemic. For the purposes of this survey, questions about COVID-19 referenced the pandemic as beginning in March 2020 and continuing through the time of the survey. Although not enough time has passed yet to determine all of the long-term changes to the SLP profession resulting from the pandemic, it seems likely that more will emerge. The inclusion of a few questions about the impact of COVID-19 on PC provided by SLPs was intended to add to what is known about the pandemic's impact.

Most respondents (71%) in this survey reported that the COVID-19 pandemic didn't make them any more or less willing to work in a PC setting. This may mean that although SLPs encountered an unfamiliar and possibly challenging work-setting during the pandemic, they were not deterred from PC. It has to be acknowledged that the individuals who were likely to respond to the survey invitation may have been those who are actively working in PC. As such, the survey may underrepresent the proportion of SLPs for whom the pandemic caused them to move away from PC. Although the percentage of SLPs who indicated the pandemic has made them less willing to work in PC was relatively small, this still represented one in ten SLP respondents who felt this way. Given the challenges of working in PC and the lack of PC training for SLP graduate students (as indicated by this study as well as Irwin, 2006; Pascoe et al., 2015; Mahendra and Alonso, 2020), it becomes problematic in terms of the coverage of PC patient care needs if even a small percentage of SLPs opt to not continue such work. Conversely, nearly one in five of the respondents indicated that the pandemic made them more willing to work in a PC setting. This could mean that some SLPs were more willing to work in PC because of the pandemic due to observing the increased need for the service within healthcare systems. Alternatively, it could mean that some SLPs saw the true value of what they could provide to patients at their EoL, possibly at a more intense rate than prior to the pandemic. It is also possible that some SLPs were required to become involved in EoL care even though they may not have wanted to do so. Further work is needed to explore how and why the pandemic has made some SLPs more likely and others less likely to work in PC.

The survey also asked the SLPs if the pandemic changed how they provided PC. For about half of the participants it did not change their clinical practices. Of the remainder, they were somewhat equally split with 25% disagreeing that the pandemic changed how they provided PC and 20% agreeing that it did. Eight participants provided additional context to their response. Three reported that the pandemic allowed them more access to patients receiving PC. Two respondents indicated that the nature of the severity of patients seen during the pandemic changed their perceptions of life-limiting disease. Two respondents reported changes related to their clinical practice, specifically regarding AAC for patients utilizing a ventilator and telehealth for homebound patients. The participants stating the increase in telehealth due to COVID-19 happened to report that they often utilize it for patients receiving PC.

Overall, the COVID-19 pandemic has impacted the willingness of some SLPs to work in PC and has caused some SLPs to change how they provide such care. However, the majority of the respondents reported that the pandemic did not change their willingness to or their provision of PC.

Burnout and Recommending Palliative Care as a Practice Area for Other SLPs

A large majority of the SLPs (82%) disagreed with or were neutral when asked if PC had resulted in professional burnout, in contrast to 18% who somewhat or strongly agreed that burnout had occurred from PC. Although no prior studies on this topic were found, Toner and Shadden (2012), Boland et al. (2019), and Stead et al. (2020) have explored how limited education opportunities related to PC topics and feelings of providing inadequate PC are related to SLP burnout. The fact that most of the SLPs in this current study reported they had not experienced burnout from PC does not minimize the occurrence for the remaining SLPs who had. The written comments in response to this question indicate how serious the issue can be. For example, a few respondents reported high levels of exhaustion and compassion fatigue, with one reporting that this resulted in them leaving their setting with this patient population. The loss of a clinician servicing this population is significant considering the widespread need for clinicians to be work with this patient population (World Health Organization, 2020).

Eighty percent of participants reported that they would recommend working in PC to other SLPs. It is not known if this indicates that the SLPs find great value and fulfillment in the work, or perhaps they see the need for more SLPs to help meet the clinical demand, or both. Combined with the finding that a relatively small proportion of these respondents reported experiencing burnout from PC, this may be a group that is largely very motivated and fulfilled by the work. The high number of SLPs who would recommend PC work to others is interesting to consider relative to prior literature that discusses SLP students' reduced interest in PC clinical activity due to feeling intimidated by this type of work (Collins 2022). Part of building a workforce of SLPs for PC must include improving how students learn about and first gain experience in PC. Gilman et al. (2015) completed an analysis examining Australian nursing preparation for work in oncology and PC settings. The authors concluded that students should be provided the following: strong peer groups, a curriculum highlighting work-life balance and self-care, continuing education on mental health, structured forums for debriefing, professional psychological counselling, and dedicated bereavement and processing time (Gilman et al. 2015). Many of these parameters may also be relevant for preparing students in any profession, including SLP.

Overall, the results regarding burnout are generally positive in that most of the SLP respondents reported they did not experience it from PC. However, intentional education should still be considered in order to best prepare SLPs to handle PC work.

Challenges in Providing Speech-Language Pathology Services in a Palliative Care Setting

The themes and sub-themes that emerged regarding challenges that SLPs faced when providing PC reflect findings that have emerged in prior studies of this topic. The challenges that the respondents identified related to working with other professionals, the emotional and psychological burden of the work, practical issues, difficulties working with patients and families, SLPs own knowledge and skills gaps, and reduced health literacy of the general public. Of these challenges, Pollens (2004) had identified several that overlap with the current study results, including inadequate existing support systems, difficulty servicing both families and patients, the need for stronger advocacy skills, and more opportunities for students to be exposed and educated on PC with guidance during graduate school.

The most frequently reported challenge was that physicians and other professions failed to recognize the SLP’s scope of practice. That is, these other professions may not know what the SLP can do to assist patients in PC, and subsequently then, they do not refer patients for SLP services. A lack of referrals was another key challenge identified by respondents. Late or non-existent referrals are inconsistent with the Joint Commission on Accreditation of Healthcare Organizations guidelines from 2010 that recommend patients with severe communication impairments at the end of their life should be granted timely SLP consults (Pollens, 2020). Hughes and Smith (2014) also stated that well-timed referrals are required throughout a patient's continuum of PC as it benefits the patient and can reduce the stress on healthcare providers so that they are not having to come up with supportive care at the last minute. Furthermore, Mahendra and Alonso (2020) reported that only 14% of the world's population that would benefit from PC services are actually receiving them. Prior studies have also referenced concerns that physicians may be invalidating or minimizing the SLP role in PC. For example, Kelley et al.'s (2016) participants reported feeling like "optional extras." O'Reilly & Walshe's (2015) respondents reported feeling like a burden and that their services were a waste of time. Combating these concerns with advocacy at the national level (e.g., from ASHA) would help the field to be more unified in developing guidelines for SLP PC work and promoting the establishment of a stronger evidence-base for this work which, in turn, can be used to demonstrate the SLP's value to PC physicians. Such an approach has already been initiated in Ireland (Collins, 2022). Advocacy at the national level may also foster more efficient communication across interdisplinary healthcare professional organizations regarding each profession's scope of practice related to PC.

Many respondents also reported "Emotional and Psychological Challenges" associated with their PC work. These comments frequently included terms such as compassion fatigue and sadness. Some of the heavy emotions were also related to the difficulty of working as a mediator between families, patients, and other providers. Both Collins (2022) and Stead (2020) referenced SLPs reporting negative feelings about themselves, including compassion fatigue. While PC services are intended to reduce negative emotions and psychological strain for patients in PC to the extent possible (Meier, 2014; CAPC website), those providing PC appear to be at heightened risks to their own emotional and psychological state. Again, training healthcare providers regarding self-care and recognizing signs of burnout and compassion fatigue is important, as is putting in place support services for the PC team members.

Another challenge that emerged was a concern related to “Billing and Reimbursement” of services. It is the case that timely PC is not only the right approach, but also cost effective. Meier (2014) studied the cost saving that accompanies comprehensive PC integration into a patient’s plan of care, noting an estimated saving of six billion dollars or more annually. Unfortunately, denial of certain types of PC services such as SLP happen, most likely, because of the notion that patients must be appropriate for rehabilitation and have potential for progress. There is an ongoing need to educate billing staff in facilities and members of the health insurance industry about what should be covered for patients in PC.

Participants also reported inadequate access to resources and education that they feel would be helpful for their PC work. Related to this, another theme that emerged regarding challenges was a knowledge and skill gap for the SLPs. Other studies have emphasized how students are receiving little, if any, education on PC relevant topics and how this can create anxiety about working in PC when students enter the workforce (Collins, 2022). Stead et al. (2020) highlighted the relationship between feeling insufficiently prepared for PC and SLPs feeling that they have a knowledge and skill gap, potentially resulting in inadequate patient care. Professional guidelines from ASHA (or other relevant organizations) are also lacking. The availability of such guidelines could help researchers and clinicians determine where to devote their energies in developing and/or consuming resources to help themselves meet the professional guidelines. In the absence of SLP-specific PC resources, SLPs may need to rely on resources available through the CAPC or other organizations dedicated to educating healthcare workers on PC initiatives.

Another challenge in providing PC that was highlighted in this survey was a low level of health literacy in the general public about PC and the contributions an SLP can have. As far as the author is aware, there are no studies about this issue specific to the public's perception of SLPs in PC, however, the impact that health literacy has on patient care in PC has been studied. Noordman et al. (2019) completed a scoping review of the available literature highlighting communication strategies used by PC healthcare providers while educating patients about their choices. Their results emphasized that reduced health literacy is a recognized hurdle that impedes patients when making their own health decisions, but this hurdle could be reduced by having healthcare providers educate their patients in commonly understandable and digestible terms (Noordman et al., 2019). Ensuring patients understand the implications of the decisions they are making is at the core of providing patient-centered care. Again, SLPs are uniquely qualified to be part of this education process about the SLP role and, additionally, the SLP may be helpful anytime PC providers are trying to educate their patients when the patient has a communication or cognitive deficit.

Attributes and Skills a Speech-Language Pathologist Needs to Work in a Palliative Care Setting

Respondents provided key words and phrases related to skills and attributes that they believe clinicians working in PC settings should have. Four broad themes were identified which were: personal attributes encompassing a range of different traits; caring for others; communication; and clinical skill set. Within the theme personal traits, two in particular were frequently reported. The first was emotional strength. This likely reflects the inherent nature of PC work which can be quite challenging, thereby requiring emotional strength from the clinician.

The second common subtheme within the personal traits theme was patience and flexibility. Again, this likely reflects the nature of the work which may require interacting with patients and families who are dealing with many difficult and new situations that require the SLP to explain and support them, and perhaps having to do this several times.

The theme of “Care for Others” emerged because of many comments that were the specific, single words “compassion” and “empathy.” There were thirty responses that specifically mentioned the importance of compassion and similar themes related to a positive external reaction posed on another human due to their situation. Empathy, or the internal awareness of another's experience (Merriam-Webster, n.d.), was reported at nearly the same frequency and therefore emerged as a subtheme within the “Care for Others” theme. It seems natural for respondents to place emphasis on empathy and compassion, defined as the sympathy paired with action to help another person (Merriam-Webster, n.d.), given the fact they are working with another human being during a sensitive time in their life. Patients and their families deserve sympathetic concern for the difficult situation they are experiencing. Clinicians should have authentic acknowledgement of their patient’s emotional state in order to best support their patients. Having compassion and empathy should assist in the fostering of trust between patients and their PC team providers. Lambert (2012) described how SLPs and other allied health professions are at the patient’s bedside more than some other specialties on the PC team, such as the physician. Given this added time at bedside, SLPs may be likely to have lengthier and more intimate conversations about what the patient wants and needs in the PC process.

“Communication” was another main theme with nearly fifty responses that emphasized aspects of effective communication as an important skill. The emergence of “counseling and education” as a subtheme under “Communication” makes logical sense. It would be nearly impossible to engage in effective counseling if an SLP had poor communication skills. Likewise, good “Listening skills” (another subtheme) are required for strong counseling/education to occur. A third subtheme within the “Communication” theme referenced the need for clinicians to have strong “Interdisplinary Communication Skills.” This also makes sense in that providing good PC for patients requires a well-functioning PC team. Poor communication among team members would undermine the clinical care and adversely affect patients. This interdisciplinary communication could also include the SLP promoting their own services within PC.

The fourth theme was identified as “Clinical Skillset”. The theme itself emerged from comments about clinical knowledge and skills needed for PC and an additional set of comments about needing to have good work-life balance as a clinical skill. The first subtheme termed “Clinical Knowledge and Skill” included comments about specific pieces of content knowledge and approaches to clinical care that facilitate a clinician doing good work in the PC setting. The second set of comments specifically referenced that a strong clinical skill was being able to have separation between what occurs at work from the clinician’s home life. This also clearly has some relationship to other themes and subthemes such as the need for emotional and psychological strength.

Overall, this set of responses about the necessary skills/traits for an SLP to be successful in PC settings provides information that has not yet been explicitly reported. Previous authors, such as Lambert (2012), Pollens (2012, 2020), Chahda et al. (2017), Berkman et al. (2019), and Stead et al. (2020) have all emphasized the importance and application of counselling, interdisciplinary communication and collaboration, and active listening in an SLPs clinical skillset. Here, clinicians who are engaged in PC work provide their perspective on what is necessary for an SLP to succeed in a PC setting.

Limitations

There were several limitations to the study. Some of these relate to the representativeness of the SLPs who responded. The sample size was relatively small, and the geographic distribution was such that the states of Michigan and California had more representation in the data collected. It is unknown whether geographic location might somehow be related to how SLPs practice or perceive PC work. However, it is possible, for example, that one SLP in a given hospital or health system may have learned of the survey and then encouraged other SLPs in their facility or health system to also complete the study. In such a case, a small cluster of SLPs might be likely to respond similarly, at least to some questions such as PC team composition. Another issue related to representativeness of the SLPs relates to the age of respondents. As noted previously, this appeared to be a group who, on average, were older and had several years of clinical experience. This could be important for a few reasons. First, some questions required respondents to reflect on past experiences. Older respondents would have to think back further in their life, for example, to respond to questions about their graduate school training. Recall may be impacted compared to someone having to reflect back just a year or two. Secondly, those with more experience may have had time for evolution of their thoughts and perspectives that is not available to less experienced SLPs. Age or experience-based analysis could be important in future analyses once the sample size is increased.

The on-line and anonymous nature of the survey has some inherent limitations. To increase the likelihood of survey completion, many questions were multiple choice and multiselect format. While this makes it quicker to take the survey and easier to summarize the results descriptively, it does limit the depth and richness of the information obtained. For example, the survey did not allow respondents to explain their choices for most of the questions.

Such information would be helpful in interpreting and contextualizing the results. Future work that includes such questions or utilizes alternative designs such as focus groups or in-depth interviews could add substantially to the understanding of SLP PC practices. A second issue relates to the anonymity of respondents which does not allow the researcher to contact them to learn more about their reasoning or to track their perspectives over time.

The cross-sectional nature of the data collection also presents some limitations. As noted above, several questions require respondents to consider the past, and therefore accuracy of recall may be questioned. Additionally, the survey captures perceptions at a moment in time. Information is not available from the survey about how knowledge, skills, and perspectives have evolved over time.

The survey did not specifically address issues of PC with pediatric patients. This likely deserves specific investigation. It is also the case that the participant recruitment did not exclude SLPs whose experience was with pediatric PC. In fact, seven respondents reported a pediatric hospital as their current work setting and 14 others had it as past setting. The wording of the survey questions did not specifically focus on just adults to the exclusion of pediatric patients in PC. Because of this, some respondents may have been focusing their responses from the perspective of pediatric PC and most others from adult-focused PC. Combining responses may obscure unique aspects of one type of PC practice over the other. It is also possible that some respondents had experience with both adult and pediatric PC work. Future studies should address this issue and attempt to learn if pediatric PC work has its own unique challenges.

The survey was intentionally limited to SLPs in the US. However, this topic would benefit from including input from clinicians internationally. Gaining a worldview on PC has great value as those who are somewhat further ahead in integrating SLPs into PC could provide guidance to others. It is also possible that there are important differences in healthcare systems, training, culture, and other parameters that are influential on how PC is delivered.

CONCLUSION AND FUTURE DIRECTIONS

With the number of people living with chronic illness expected to increase over the next several decades, the number of people who need PC and EoL care will increase. Understanding how SLPs can best contribute to delivering high-quality PC is important because the patient populations likely to need PC are also at increased risk for having communication and swallowing issues. This study provides a relatively comprehensive picture of the perspectives of practicing SLPs in the PC setting. This data can serve a few purposes. First, the data can serve as a benchmark in time about how SLPs view PC care. If changes in training of SLPs regarding PC occur, future outcome studies related to that training could be compared to the work presented here to help track generally how the situation changes. The data also can serve as an impetus for change in how SLPs are trained and how they are integrated into PC teams, two main areas where the data indicate substantial changes are needed. On its own, the study is not likely to motivate wholesale changes in a given hospital or professional SLP organizations at the state or national level. However, building evidence about PC and the SLPs involvement is needed, and this study contributes to that growing body of research.

To keep up with the rising needs for this population, clinicians from across disciplines will need to strengthen their own skillset, beginning with their education, both in graduate school and beyond. Although clinicians are not solely responsible for how their learning experiences are generated during graduate school, advocacy from current clinicians may help motivate change within graduate programs to adapt to the changing landscape of healthcare which increasingly will include SLP involvement in PC. Future studies should address specific curricular needs. Professional advocacy about the value of SLP to PC is needed so that the profession has a strong role on PC teams. Having a growing research base regarding PC from the SLP perspective is imperative for the SLP field to have success in advocating for itself. This will take the efforts of individual researchers, educators, and clinicians, as well as the weight and guidance from professional state and national SLP organizations. If clinicians are unprepared to work with this population of patients, yet find themselves in settings interacting with these patients, it is likely that they may provide insufficient care. Additionally, further work may be needed to continue defining the clinical practice deviations between PC and other care population.

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APPENDIX A: SURVEY QUESTION BANK

Q1.1 **Welcome to the research study:** ***Speech-Language Pathologists' Perceptions of Palliative Care***
Principal Investigator: Jeff Searl, Ph.D.
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You are being asked to participate in a research study. The purpose of the study is to understand your perspective as a speech-language pathologist who provides palliative care. You will be asked questions regarding your levels of agreement/disagreement to statements related to definitions, the involvement of the field of speech-language pathology in providing palliative care, and your own experiences working in this area.

Your responses will be kept confidential. Your participation is voluntary. You can skip some of the questions you do not wish to answer or withdraw at any time simply by closing your web browser. However, some questions are designed to require an answer to continue the survey because they form the core of the study and will have a crucial role in drawing conclusions. Your participation in this study will take about 15 minutes, although it could be longer or shorter depending on how much information you choose to provide.

You must be 18 or older, currently licensed and certified as a speech-language pathologist, at least 9 months beyond the completion of your clinical fellowship, working in the United States, and have at least some experience providing palliative care. If you have questions or concerns about the study, you can contact the Principal Investigator, Jeff Searl, by email, phone, or US mail using the information at the top of this page.

You indicate that you voluntarily agree to participate in this research study by submitting the survey. (Multiple choice).

- Yes
- No

Q2.1 Rate your level of agreement or disagreement with this definition of rehabilitation. ***Rehabilitation includes interventions addressing the impact of a health condition on a person's everyday life by optimizing their functioning and reducing their experience of disability.*** (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q2.2 What is it within this definition of rehabilitation that you disagree with? ***Rehabilitation includes interventions addressing the impact of a health condition on a person's everyday life by optimizing their functioning and reducing their experience of disability.*** (Fill in the blank).

Q2.3 Rate your level of agreement or disagreement with this definition of palliative care. ***Palliative care is specialized medical care meant to enhance the quality of life for people living with a serious illness that may or may not be provided alongside curative treatment.*** (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q2.4 What is it that you disagree with in this definition of palliative care? ***Palliative care is specialized medical care meant to enhance the quality of life for people living with a serious illness that may or may not be provided alongside curative treatment.*** (Fill in the blank).

Q2.5 Rate your level of agreement or disagreement with the definition provided of hospice. ***Hospice care focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life.*** (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q2.6 What is it that you disagree with in this definition of hospice? ***Hospice care focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life.*** (Fill in the blank).

Q2.7 Rate your level of agreement or disagreement with the definition provided of end-of-life care. ***End-of-life care is the term used to describe the specialized support and medical care given during the time surrounding death.*** (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q2.8 What is it that you disagree with in this definition of end-of-life care? ***End-of-life care is the term used to describe the specialized support and medical care given during the time surrounding death.*** (Fill in the blank).

Q3.1 Rate your level of agreement or disagreement with each of the following statements. **The roles of an SLP in palliative care include...** (Multiple choice).

1. Providing consultation with patients, families, and care team in the areas of communication, cognition, and swallowing. (1)
    a. Strongly disagree
    b. Somewhat disagree
    c. Neither agree nor disagree
    d. Somewhat agree
    e. Strongly agree
2. Offering and teaching skills relating to communication and decision making, sustaining relationships, and meeting other end of life and quality of care measures. (2)
    a. Strongly disagree
    b. Somewhat disagree
    c. Neither agree nor disagree
    d. Somewhat agree
    e. Strongly agree
3. Minimizing negative outcomes from dysphagia symptoms by integrating strategies and techniques to improve comfort and pleasure associated with eating. (3)
    a. Strongly disagree
    b. Somewhat disagree
    c. Neither agree nor disagree
    d. Somewhat agree
    e. Strongly agree
4. Working with the entire care team to make sure goals and care are being supported by other professions and vice versa. (4)
    a. Strongly disagree
    b. Somewhat disagree
    c. Neither agree nor disagree
    d. Somewhat agree
    e. Strongly agree

Q4.1 Does your work setting have a dedicated palliative care, hospice, and/or end of life care team? (Multiple choice).

- Yes
- No
- I am not sure

Q4.2 Is speech-language pathology included in your facility's or organization's palliative, hospice, and/or end-of-life care team? (Multiple choice).

- Yes
- No
- I am not sure

Q4.3 Select the current role(s) that the SLP has on this palliative care team. (Select all that apply.) (Multi-select).

- Standing position on the team where the SLP screens all admitted palliative care patients and provides treatment for those who are at risk for communication, cognition, or swallowing difficulties (1)
- Referral for additional services/resources (e.g., respite services) where the SLP is referred to see palliative care patient on as-needed basis and works with care team to provide general recommendations (2)
- Consultative where the SLP is asked for professional opinions but never provides direct services to the palliative care patient (3)
- Other (4) (Fill in the blank)

Q4.4 Rate your level of agreement or disagreement with the following statement. ***I am satisfied with the extent to which speech-language pathologists are integrated into the palliative care team in my setting.*** (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q4.5 In the last year, how often did you work with patients facing life-limiting illness? A life-limiting illness is any condition that has no reasonable hope of cure and that is likely to shorten a person's life. (Multiple choice).

- Never
- Quarterly (at least one patient)
- Monthly (at least one patient)
- Weekly (at least one patient)
- Daily (at least one patient)

Q4.6 What are the diagnoses of the patients that you have seen for palliative care services? (Multi-select).

- Cancer
- Heart/lung disease
- Kidney disease
- Neurodegenerative disease (Alzheimer’s, Parkinson’s, Huntington’s, Amyotrophic Lateral Sclerosis (ALS), etc.)
- Dementia
- Cerebral vascular accident (CVA)
- Traumatic brain injury (TBI)
- Other (Fill in the blank)

Q4.7 How often do you provide services to patients receiving palliative care in each of the areas of SLP practice (ASHA 'Big 9')? If the service you provide is not listed, please select 'Other' and provide a description. (Multiple choice).

- Articulation
    - Strongly disagree
    - Somewhat disagree
    - Neither agree nor disagree
    - Somewhat agree
    - Strongly agree
- Fluency
    - Strongly disagree
    - Somewhat disagree
    - Neither agree nor disagree
    - Somewhat agree
    - Strongly agree
- Voice and resonance (including respiration and phonation)
    - Strongly disagree
    - Somewhat disagree
    - Neither agree nor disagree
    - Somewhat agree
    - Strongly agree
- Receptive and expressive language
    - Strongly disagree
    - Somewhat disagree
    - Neither agree nor disagree
    - Somewhat agree
    - Strongly agree
- Hearing (including the impact on speech and language)
    - Strongly disagree
    - Somewhat disagree
    - Neither agree nor disagree
    - Somewhat agree
    - Strongly agree
- Swallowing (oral, pharyngeal, esophageal, and related functions, including oral function

for feeding; orofacial myofunction)
  - Strongly disagree
  - Somewhat disagree
  - Neither agree nor disagree
  - Somewhat agree
  - Strongly agree
- Cognitive aspects of communication (attention, memory, sequencing, problem-solving, executive functioning)
  - Strongly disagree
  - Somewhat disagree
  - Neither agree nor disagree
  - Somewhat agree
  - Strongly agree
- Social aspects of communication (challenging behavior, ineffective social skills, lack of communication opportunities)
  - Strongly disagree
  - Somewhat disagree
  - Neither agree nor disagree
  - Somewhat agree
  - Strongly agree
- Communication modalities (including oral, manual, augmentative and alternative communication techniques, and assistive technologies)
  - Strongly disagree
  - Somewhat disagree
  - Neither agree nor disagree
  - Somewhat agree
  - Strongly agree
- Other (fill in the blank)
  - Strongly disagree
  - Somewhat disagree
  - Neither agree nor disagree
  - Somewhat agree
  - Strongly agree

Q4.8 What other health professions are on your palliative care team? (Select all that apply.) (Multi-select).

- Animal therapy
- Audiology
- Chaplain
- Dietetics/nutrition
- Music therapy
- Nurse team
- Occupational therapy
- Physical therapy
- Patient’s primary care physician
- Physician - palliative care specialist
- Physician – non-palliative care specialist
- Respiratory therapy
- Social work
- Other (fill in the blank)

Q5.1 How often are you involved in helping to establish a patient’s advanced directive? (Multiple choice).

- Unsure/unfamiliar with this item
- Never
- Rarely
- Sometimes
- Often
- Always

Q5.2 How often does your current setting use waivers of liability when a patient does not consent to services? (A "*waiver of liability*" refers to a form that a patient or patient's medical decision maker signs to opt out of some, or all, recommendations made by the patient's care team). (Multiple choice).

- Unsure/unfamiliar with this item
- Never
- Rarely
- Sometimes
- Often
- Always

Q5.3 How often do you use telehealth with your palliative care patients? (Multiple choice).

- Never
- Rarely
- Sometimes
- Often
- Always

Q5.4 What types of counseling or other support do you provide to your palliative care patients? (Select all that apply.) (Multi-select).

- Conversing 1-on-1 with patient
- Conversing with patient's family/community
- Recommending participation in support groups
- Leading support groups
- Providing online/printed resources
- Other (fill in the blank)

Q6.1 Were you a practicing clinician at any time during the COVID-19 pandemic (spring of 2020 up to the present)? (Multiple choice).

- Yes
- No

Q6.2 Rate your level of agreement or disagreement with the following statement. ***The COVID-19 pandemic has made me more willing to work in the palliative care setting.*** (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q6.3 Rate your level of agreement or disagreement with the following statement. ***The COVID-19 pandemic changed how I provide palliative care.*** (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q6.4 If you are comfortable, please share any details or context about how the COVID-19 pandemic changed the palliative care that you provided. (Fill in the blank).

Q7.1 Rate your agreement or disagreement with the following statement. ***Working in <u>palliative care</u> has caused me to experience professional burnout.*** (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q7.2 If you are comfortable, please share any details or context that you believe are associated with your experience(s) of professional burnout while working in palliative care. (Fill in the blank).

Q7.3 Rate your agreement or disagreement with the following statement.
I would recommend working in palliative care to other speech-language pathologists. (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q7.4 Provide up to 5 key words/short phrases that describe the challenges in providing speech-language pathology care within a palliative care setting. (Fill in the blank).

Q7.5 Provide up to 5 key words/short phrases that describe the attributes and skills that a clinician needs to work within a palliative care setting. (Fill in the blank).

Q8.1 Provide the year that your ASHA Certificate of Clinical Competence (CCC) was initially obtained. (Fill in the blank).

Q8.2 Select which state(s) and/or US territories you are currently licensed in. (Multi-select).

- *All states and US territories were listed*

Q8.3 Please select the <u>current</u> setting(s) that you are working in. *See https://www.asha.org/students/employment-settings-for-slps/ for definitions of each.* (Multi-select).

- Early intervention, preschool, and/or K-12 schools
- College/university
- Hospital – pediatrics
- Hospital – adults
- Residential health care facility
- Private practice
- Corporate speech-language pathology
- Local, state, and/or federal government agency
- Public health department
- Uniformed services
- Other (fill in the blank)

Q8.4 Please select any past setting(s) you have worked in.
See https://www.asha.org/students/employment-settings-for-slps/ for definitions of each. (Multi-select).

- Early intervention, preschool, and/or K-12 schools
- College/university
- Hospital – pediatrics
- Hospital – adults
- Residential health care facility
- Private practice
- Corporate speech-language pathology
- Local, state, and/or federal government agency
- Public health department
- Uniformed services
- Other (fill in the blank)

Q8.5 Please select from the provided options and/or submit under "other" to describe where you find continuing education (CE) opportunities regarding palliative, hospice, or end-of-life care. (Multi-select).

- Free resources online
- Paid resources online
- My employer provides CEU opportunities
- In-person workshops and/or conferences
- Online workshops and/or conferences
- State professional associations
- National professional associations
- Other (fill in the blank)

Q8.6 After completing your graduate school training, for which of the following topics have you sought more knowledge and training through courses, workshops, conferences, or other learning opportunities? Select all that apply. (Multi-select).

- Palliative care, hospice, and/or end of life care
- Respite care
- Counseling
- Geriatrics
- Advanced directives and/or other relevant legal documentation
- Grief
- Physiological stages of death
- Healthcare worker burnout
- Healthcare worker selfcare
- No – I have not participated in a learning opportunity related to any of the above topics

Q8.7 Briefly describe the course(s), workshop(s), conference(s), or other learning opportunity(s). (Fill in the blank).

Q8.8 Rate your agreement or disagreement with the following statement.
These additional educational experiences prepared me to work in a palliative care setting. (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q8.9 Have you held any professional career outside of speech-language pathology? (If yes, please describe.) (Multiple choice).

- Yes (fill in the blank)
- No

Q9.1 What year did you graduate with your clinical speech-language pathology degree? (Fill in the blank).

Q9.2 Which of the following topics were covered through coursework or clinical placements/internships in graduate school? (Multi-select).

- Palliative care
- Hospice
- End of life care
- Geriatrics
- Advanced directives and/or other relevant legal documentation
- Physiological stages of death
- Healthcare worker burnout/ self-care
- None of the above

Q9.3 What other experiences or learning opportunities outside of coursework/clinical placements did you have (workshop, conference, etc.) covering palliative care/hospice while in graduate school? (Fill in the blank).

Q9.4 *Rate your agreement or disagreement with the following statement.* ***My <u>graduate</u> education prepared me to work in a palliative care setting.*** (Multiple choice).

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Q10.1 Birth year (Fill in the blank).

Q10.2 Gender (please select all that apply). (Multi-select).
- Man
- Woman
- Transgender
- Non-binary / non-conforming gender
- Prefer not to say

Q10.3 Ethnicity (please select all that apply). (Multi-select).
- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other

Q10.4 Are you of Spanish, Hispanic, or Latino origin? (Multiple choice).
- Yes
- No

Q10.5 Please provide any other identities that you wish to share that are not included above. (Fill in the blank).

Q11.1 Where did you learn about this study? (Multi-select).
- ASHA SIG 2: Neurogenic Communication Disorders
- ASHA SIG 3: Voice and Upper Airway Disorders
- ASHA SIG 13: Swallowing and Swallowing Disorders (Dysphagia)
- ASHA SIG 15: Gerontology
- Social Medica
- Colleagues
- Other (fill in th blank)

APPENDIX B: RECRUITMENT MESSAGE

Research Study Opportunity!

Speech Language Pathologists' Perceptions of Palliative Care

The purpose of the study is to understand your perspective as a speech-language pathologist about palliative care. You will be asked questions regarding your levels of agreement/disagreement to statements related to definitions, the involvement of the field of speech-language pathology in providing palliative care, and your own experiences working in this area.

TO PARTICIPATE: You must be 18 or older, currently licensed and certified as a speech-language pathologist, at least 9 months beyond the completion of your clinical fellowship, working in the United States, and have some experience providing palliative care, even if it is not a primary focus for you.

- **WHAT DO YOU HAVE TO DO:** Take an online survey. The survey is expected to take about 15 minutes but could take longer or shorter, depending on how much information you decide to provide.

- **QUESTIONS**? Contact Jeff Searl at searljef@msu.edu or by phone at 517-884-6724.

CLICK LINK TO START SURVEY:
https://msu.co1.qualtrics.com/jfe/form/SV_eQ001Hba0Us6s9E

APPENDIX C: CHALLENGES IN PROVIDING SPEECH-LANGUAGE PATHOLOGY SERVICES IN A PALLIATIVE CARE SETTING

Practice Challenges

Time Pressures

- Time
- Priorities
- Not enough time for sessions
- Lack of early discussions from medical providers about eventual death with certain conditions (Parkinson's dementia etc.)
- Lack of time
- Not enough time in our schedules to give patients and families the time they need for these hard conversations
- Scheduling conflicts with other medical providers
- Frequent unavailability due to illness or medical decline
- Long hours
- Long hours
- I work in acute care goals of shorter hospital stay

Billing/reimbursement concerns

- Money
- Insurance coverage
- Reimbursement issues in long-term care setting
- Billing
- Limitations and misunderstandings by insurances
- Insurance
- Reimbursement issues
- Not always reimbursable by insurance

Lack of staffing

- Lack of staffing
- Staffing issues.
- Number of Palliative care practitioners.

Challenges Working with Other Professionals

Physicians/other professions not recognizing scope of SLP

- Lack of recognition that we can help
- Follow-through
- Lack of understanding from other disciplines about what we do and can offer to patients and family
- Helping other PC team members understand that mbss is not just pass/fail
- Buy-in from colleagues
- Educating referral sources
- Lack of team structure
- Convincing other team members that we have a role
- Lack of understanding by the primary team on what we are doing with this population

- Doctors
- Physician refusal to ask for Palliative Care
- Only being consulted for diet recommendations
- Team
- Team compliance with patient wishes
- Lack of medical team support
- Lack of direct communication from Primary medical team to Pt and families
- How medical changing the number of medications that patient use to elect to die affect dysphagic patients
- Team buy-in
- Consistent use of AAC/communication strategies across providers
- Lack of communication with SLP on team
- Lack of Advance Directive
- Physicians/providers who are resistant to bringing in the palliative team
- Lack of understanding benefits of palliative by other healthcare workers
- Physician knowledge
- Health care providers' AAC competence
- Seen as "not as important" by the rest of the clinical team
- Lack of knowledge of SLP contributions
- Acceptance/Inclusion from other professionals
- Wonderful colleagues but don't always appreciate what I can bring to the table
- Working with other providers who are jaded
- Others' lacking expertise
- Limited understanding of palliative services by many professionals as it is not well taught in schools

Lack of referrals

- Getting referrals
- I have palliative care pts in skilled and ICF with swallow disorder who would benefit from slp services and can not get referrals
- Caseload In the acute care setting can be prohibitive
- Primary care Physician support and referral
- Lack of referrals

Difficulties with administration

- Desire (of company/building)
- Administration
- Value of service from administration
- Inflexible administrators

Challenges Working with Patients & Families

Difficulties working with families/patients

- Beliefs
- Using medical vernacular that pt/families understand
- Family denial

- Lack of acceptance of patient’s decline from family/caregivers
- Lack of caregiver support
- Family fears of "killing" their loved one (allowing them to continue to aspirate)
- Unreasonable family expectations
- Dealing with patient and family anxiety
- Managing patient/family/your emotions
- Challenging family dynamics
- Lack of pt/caregiver knowledge
- Family education
- Slp area of practice may not be at top of patient or family’s list of priorities
- Seeing patients and families struggle to come to terms with disease
- Close relationships
- Patient mental health
- One needs to be willing to relinquish a level of control in decision-making
- Unrealistic expectations for recovery

Patient’s wishes differing from family/SLP wishes

- Pt wishes/family wishes differ
- Shared understanding of jco standards for patient communication
- Permitting the client to make choices (good or bad)
- Provide support regardless of differing philosophies between clinician and pt/family.

Lack of Health Literacy Among the General Public

- Comfort is not choking all the time.
- Overcoming the idea that therapy (whatever method) is curative
- It’s not “all or nothing”
- Lack of health literacy
- The idea that there are palliative care “settings”
- Health literacy
- Public Distrust of health system
- Lack of public knowledge about what swallowing entails
- Poor medical literacy
- Low medical literacy
- Societal misperceptions that our US healthcare can fix all medical ailments.
- Health literacy
- Health care emphasis on intervention over understanding patients' actual wishes with communication
- "Speech therapy is not needed"
- Thought to be ‘rehabilitative’ instead of ‘palliative’

SLP Emotional & Psychological Challenges

- Sadness
- Depression
- Depressing
- Emotional distress

- Depression
- Teary
- Being able to compartmentalize the care as it can be depressing
- It takes a special person to want to care for the extremely ill that likely won’t get better.
- Emotional barriers
- Wide range of emotions
- Emotional
- Fear
- Sad
- Difficult for me to let go
- Stress of chronic illness
- Emotionally charged
- Dealing with denial
- Difficult
- Frustrating
- Emotionally draining
- Exhausting
- Desperate
- Frustration - lack of access to patients I could help
- Stressful
- Tiring
- Unpredictable
- Fear related to working with death
- Having hard conversations
- Frustration with others lack of compassion

SLP Resource limitation

- Resources
- Very few resources
- Lack of resources
- No real EBP to work from
- Accessibility to services or technology for telehealth

SLP Knowledge/skill limitation

- Not feeling competent
- Providing comfort
- Allowing comfort feeds
- Dealing with sialorrhea
- Dealing with thick secretions
- The challenge is that most slps are trained to improve function not help maintain or work with the goals of the care of patients/families to improve quality of life even in the smallest ways
- Providing helpful insights about g-tubes
- Slps who are not comfortable having serious illness conversation

- Slps who are not comfortable discussing advance directives
- Being comfortable with "sticky" conversations about end-of-life
- Sibtle shift in mindset for goal-setting
- Lack of knowledge
- Slp training
- Identifying how our services fit into the big picture
- Eliminate restrictive approach to po intake
- Maintain maximize functionality of speech language swallow respiration
- They can eat anything
- Pts are seen in slp services and we usually recommend palliative care consult for pts/families that refuse npo recs or anh/feeding tubes related to aspiration and dehydration/malnutrition risks
- Identifying when a patient would benefit from palliative care
- Unclear goals of care

Uncategorized responses

- Meaningful
- Support
- Lack of patient education
- Lack of compliance
- Reduce unnecessary interventions which do not accomplish above
- Limited support
- Fears of dying

APPENDIX D: ATTRIBUTES AND SKILLS A SPEECH-LANGUAGE PATHOLOGIST NEEDS TO WORK IN A PALLIATIVE CARE SETTING

Communication

Counselling and education skills

- The SLP needs to understand the goals of care or discuss with the patient in regards to our scope of communication and swallowing
- Serious illness conversation skills
- Being comfortable communicating about difficult topics
- Ability to build relationships
- Counseling skills
- Counseling (in our scope)
- Ability to hold your shape during uncomfortable conversations
- Rapport with pt/family
- Education of patient and family re: end of life preferences
- Ability to help clarify goals which are not opposed
- Good educator
- Connect with maturity and grace: Establish a relationship that will be remembered.
- Counseling skills
- The ability to be present for the patient and family

Interdisciplinary communication and collaboration

- Interdisciplinary teamwork
- Connected to team
- Collaborator
- Awareness/knowledge of what other Palliative Care team members have already covered with pt/family members
- Good rapport with team mates
- Inter professional mindset
- Interpersonal communication skills
- Communication skills within interdisciplinary team
- Collaboration

Listening skills

- Great listening skills
- Excellent listener
- Listener
- Listens more and talks less
- Listening
- Processing: Develop active listening skills
- Excellent listener
- Good listener
- Good listener

Broader communicative skills

- Strong conversational skills
- Communicator

- Effective communicator
- Skilled communicator
- Effective communication
- Concise
- Direct communication
- Strong communication skills
- Direct communication

Advocacy skills

- Advocacy
- Willingness to report your employer
- Committed to patient autonomy/rights
- Advocate for pt and families.
- Advocacy
- Advocacy skills

Clinical Skillset

Clinical knowledge and skills

- End of life knowledge
- Understanding of EOL
- To know that curative and palliative can occur at the same time
- The same skills we need for all care from birth to death
- Health literacy
- Just let the patient eat and drink It isn't black and white
- Dysphagia
- Knowledge of the process of death
- Objectivity
- The SLP also often needs to be skilled in AAC (speech generating devices) especially if it’s a condition like ALS.
- Social determinants of care
- Ability to balance concerns for safety vs comfort and patient preference
- To know that you do not have to always recommend what is “safe”
- Clinical knowledge
- Competent
- Specific Pt/family directed goals
- Knowledge.
- To know that when we recommend what WE think is safe may not be of benefit to a patient and may actually cause harm
- Experience and insight into human behaviors
- Understanding of definitions
- Understanding that EOL is a natural part of life.
- Aspiration risk and patient comfort
- Expertise
- Focused on quality of life
- Commitment to quality of life

- To know that sometimes you can take your curative hat off completely
- Essential Intervention: Cut to the chase and do what is essential and helpful
- Different mindset regarding goal of intervention
- Sound clinical judgement

Work-life boundaries and balance

- Self-care
- Compartmentalized
- Centered
- An ability to avoid becoming too caught up in patient issues
- Ability to move on
- Willing to set boundaries
- Boundaries
- Balancing empathy and professional distance
- Numbness
- Ability to let go at end of day to provide self respite
- Have thought about your own internalized/religious/intellectual beliefs about death

Care for Others

Compassion

- Compassion
- Compassionate
- Compassion
- Compassion
- Compassionate
- Compassion
- Compassion
- Compassionate
- Compassion
- Compassion
- Compassion
- Compassion
- Respect
- Professional
- Compassion
- Compassion
- Compassion
- Compassion
- Compassionate
- Insight- I can suggest small tweaks to environment/presentation that can support quality of life
- Caring
- Respect
- Compassion
- Compassion

- Caring.
- Compassion
- Caring
- Compassionate
- Compassion
- Compassion.

Empathy

- Empathy
- Empathy
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- Empathetic
- Empathy
- Empathy
- Empathy
- Empathy
- Empathy
- Empathy
- Sympathy or empathy
- Understanding - of where patient's are in readiness for EOL
- Thoughtfulness
- Empathy
- Empathy

Acceptance of others

- Ability to manage multiple perspectives
- Willingness to respect other's believes
- Acceptance of end of life
- Acceptance
- Comfortable with religion or spirituality
- Spiritual support
- Cultural humility
- Non-judgmental
- Confidence in patient choice and rights

Personal Skills

Emotional strength and awareness

- Mature
- Strong
- Internal strength

- Grit
- Strong
- Resiliency
- Resilience
- Inner peace
- Strong
- Emotional intelligence
- A strong support system -internal or external- for yourself
- Ability to not internalize other people's sadness
- Emotionally stable
- Grit
- Emotional intelligence
- Emotionally fit
- Ok with sorrow
- Self-awareness
- Determination

Patience and flexible

- Patience
- Patience
- Flexibility
- Patience
- Patience
- Flexibility
- Patience - I can't expect the patient/family to be clear on their expectations
- Patience
- Flexibility
- Patience
- Patience
- Patience
- Patience
- Patience
- Patience
- Patience
- Patient
- Patience

Other personality traits

- Calm affect
- Insight: Know what you are after and what you are getting read the stakeholders
- Justice
- Calm
- Sense of humor (yes
- Organized
- Critical thinking
- Trust worthy

- Realistic
- Realistic
- Leadership
- Engaging
- Know when to bow out when you’re not wanted.

Humility

- Humility
- Humble
- Humble
- Humility
- Unselfish
- No ego.
- Humility
- Accept we can’t fix everything

Creativity

- Thinking outside the box
- Creative
- Creative
- Out of the box thinker/problem solver
- Resourceful
- Resourcefulness

Honesty

- Honest
- Honesty
- Integrity
- Honesty
- Honesty
- Honesty

Able to see "bigger pictures"

- Vision
- Open mind/no preconceptions
- Big-picture thinker
- Knowledge of the big picture
- Holistic patient care
- The ability to look at the whole patient.

Uncategorized

- Time