

# Knowledge of Palliative Care and Advance Directives Among Speech–Language Pathology Students

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Palliative care is specialized medical care offered to persons with serious health conditions, with the goal to relieve or prevent pain and suffering, to manage burdensome symptoms, and to optimize as much as possible the quality of life of patients and their families (Institute of Medicine, 2015). Speech-language pathologists (SLPs) are not always recognized as key members of palliative care teams and speech-language pathology students seldom receive training in palliative care. Yet, SLPs often have an influential role in ensuring that patients with cognitive-communicative and swallowing impairments have the best possible communicative access and quality of life, regardless of the severity of their diagnosis. The purpose of this study is to report on 110 speech pathology students' awareness and knowledge about palliative care concepts and of the role of SLPs in palliative care. This study utilized a participatory design approach for survey development to study student awareness and knowledge of select palliative care topics. Study results revealed SLP students' high exposure to the construct of quality of life, with notably limited knowledge of and exposure to palliative care and advance directives. Furthermore, SLP students frequently reported being familiar with a concept or term and yet were unable to explain the concept accurately. These data were analyzed and offer critical insights into curriculum design for training SLP students about palliative care. **Key words:** *advance directives, awareness, hospice, knowledge, palliative care, quality of life, speech-language pathology*

**P**ALLIATIVE CARE is an interdisciplinary, specialized branch of medicine that aims to prevent and reduce suffering while supporting the best quality of life (QoL) possible for persons coping with serious, life-limiting,

or capacity-limiting health conditions (Institute of Medicine, 2015). Palliative care is considered as one of the fastest growing fields of health care in the United States (Center to Advance Palliative Care, 2018; Hughes & Smith, 2014). Globally, the World Health Organization (WHO) has estimated that approximately 40 million people worldwide need palliative care services, and a mere 14% of this significant number actually receive these services (WHO, 2018). The WHO championed the first global resolution on palliative care in 2014, the World Health Assembly resolution WHA67.19, which placed direct emphasis on improving worldwide access to palliative care across health care systems, and on including palliative care content in training for health care professionals. With this resolution, the WHO has explicitly recognized palliative care as part of the human right to health

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(see Mukherjea et al., 2020 [this issue, for a detailed discussion]).

Palliative care is a philosophy of both person-centered and family-centered care as well as a structured, integrated approach to delivering care, independent of patient prognosis or the need for ongoing curative treatment (Ferrell et al., 2018). Palliative care has been defined as the “multidisciplinary and holistic assessment and management of physical, cognitive, psychosocial and spiritual symptoms, with the goal of alleviating suffering” (WHO, 2019). Thus, palliative care emphasizes the quality, value, and meaning of life for patients and families; their physical, cognitive, emotional, and spiritual well-being; and respite, support, counseling, and bereavement services for family members. Palliative care has been described as helping people to live as well as possible for as long as possible, when facing a serious, acute, or chronic illness (American Cancer Society [ACS], 2019; Horowitz et al., 2014).

Given the rapidly growing numbers of older adults in the United States, and many more adults and children living longer with serious health conditions (e.g., cancer, cardiovascular disease, and neurological conditions), there has been an increasing demand for palliative care services. Furthermore, there has been grave concern about the rather high cost of care and poor QoL near the end of life for many Americans (Singer et al., 2016). In response to the growing demand for palliative care, there has been a rapid, continuing expansion in palliative care programs across hospitals in the United States in the last decade (Dumanovksy et al., 2016; Meier, 2011). Palliative care services are provided by an interprofessional team that includes physicians, nurses, social workers, chaplains, and other professionals. Such services can be offered to patients alongside life-prolonging treatments and are appropriate at any point in a serious illness, from the day of diagnosis through the end of life (National Hospice and Palliative Care Organization [NHPCO], 2019). Furthermore, in order to receive palliative care services,

there is no requirement that a person must have a terminal diagnosis, stop receiving, or stop benefiting from disease-curative treatments (ACS, 2019; Lynn, 2005; Smith, 2020).

A common misconception is that palliative care is synonymous with hospice, or with end-of-life (EoL) care. Palliative care is appropriate at any age and at any stage in a serious health condition and is not limited to persons with a terminal diagnosis. Hospice care is one specific type of palliative care (Ferrell et al., 2018), focusing on care delivered to a person to manage symptoms or disease burden during the terminal phase of a person's serious illness (Centers for Medicare & Medicaid Services [CMS], 2019; NHPCO, 2019), defined by Medicare as when there is a life expectancy of 6 months or less (CMS, 2019). Hospice services are typically provided by a hospice program, making use of a written plan for care, established and periodically reviewed by a physician in consultation with an interdisciplinary team. End-of-life care broadly applies to services provided in the last weeks of a patient's life (Toner & Shadden, 2012). Other key concepts related to a thorough understanding of palliative care include awareness and knowledge of beliefs about death and dying, QoL, and of advance directives (ADs) or legal documentation of a person's treatment preferences in the event of a medical emergency.

## **ROLE OF SPEECH–LANGUAGE PATHOLOGISTS IN PALLIATIVE CARE**

Speech-language pathologists (SLPs) are the skilled providers who assess and treat impairments of communication, cognition, swallowing, and aerodigestive function. Frequently serving on interprofessional care teams, SLPs have a vital role in maximizing life participation and QoL by using evidence-based, culturally responsive, and patient-valued interventions. Also, SLPs routinely ensure that patients have communication supports, counsel patients and family, collaborate with other health professionals to address patient and family needs, plan

goals of care, and make referrals to other providers (Pollens, 2004, 2012). Specifically, an SLP's scope of practice (American Speech-Language-Hearing Association [ASHA], 2016) encompasses use of skilled interventions to enable patient comprehension and communicative expression (e.g., using augmentative and alternative communication devices), to facilitate patient-family and patient-provider communication, to ensure safe feeding and swallowing, to uphold patient dignity and autonomy, and to advocate for the rights of critically ill and vulnerable individuals. Furthermore, SLPs have a critical role in supporting patients on their caseloads with advanced illness to "let go" (Vescovich, 2015) of daily functions (e.g., eating, speaking, activities of daily living) and of life roles that exceed personal capacity when faced with serious illness.

At times, there is lack of clarity and also contention about the role of SLPs as key members of interprofessional palliative care teams. Given the researchers' clinical experience as medical SLPs and as academic and clinical educators with an interest in palliative care, it is our perspective that SLPs are valuable members of palliative care teams. This position is derived from a growing, global body of evidence on the role of SLPs in palliative care (Chahda et al., 2020; CMS, 2019; Pollens, 2012, 2020 [this issue]; Smith, 2020; Toner & Shadden, 2012; Voyzey, 2014). In 2004, Pollens described the paucity of articles detailing the role of SLPs in palliative care. She discussed four primary roles of SLPs in palliative care and hospice as including (a) consultation with patients, families, and interprofessional team members in communication, cognition, and swallowing, (b) developing communication skills to support a patient's inclusion in decision making, maintaining social closeness with family members, and fulfilling EoL goals, (c) dysphagia management to facilitate patient comfort, eating satisfaction, and pleasant feeding interactions for family members, and (d) communicating with the palliative care team to enhance patient care. Since then, there has

been heightened interest in this topic as also revealed in the work of multiple contributors to this issue.

Whereas physicians, nurses, social workers, and chaplains have well-established roles in palliative care service delivery to patients and families, it is increasingly recognized that rehabilitation clinicians (i.e., SLPs, physical therapists, occupational therapists) also play crucial roles in addressing patient well-being when dealing with serious illness (Barawid et al., 2015; Briggs, 2011; Hinson et al., 2014; Javier & Montagnini, 2011; Joint Commission on Accreditation of Healthcare Organizations [JCAHO], 2003; Krival, 2013; Medicare Hospice Benefit—Hospice 42 CFR§418, 2014; Pollens, 2020 [this issue]). Indeed, palliative care practices can be delivered by any clinician in any setting, per the national clinical practice guidelines for quality palliative care.

Based on growing published reports in the literature in the past decade, SLPs frequently have influential roles on palliative care teams, given their training and expertise in working with medically fragile adults and children (Chahda et al., 2017; Costello, 2009; Hanna & Joel, 2005; Krikheli et al., 2018; Krival, 2013; Mahendra et al., 2017; Pollens, 2012, 2020 [this issue]; Punttil-Sheltman, 2013; Roe & George, 2016; Smith, 2020; Stead & McDonnell, 2015; Stuart, 2004; Wagner, 2008). Yet, despite SLPs in medical settings frequently being on palliative care teams, SLPs anecdotally report and researchers have begun to document that graduate SLP students receive little to no instruction or training in providing services to patients who are terminally ill, deteriorating rapidly, or facing life-limiting conditions (Pascoe et al., 2018; Stead et al., 2020 [this issue]; Vescovich, 2015). This inadequate training for SLPs in palliative care was a motivator for this study. We wanted to assess the awareness and knowledge of palliative care and related concepts among undergraduate and graduate students majoring in speech-language pathology, with a view to using these data to design instructional modules

on this topic. Documenting SLP students' baseline knowledge about palliative care and learning about their perceptions about a complex area of practice offers an authentic approach to designing responsive curricula to better prepare SLPs for providing palliative care services. Developing a clearer understanding of learner awareness, knowledge, and dispositions before designing curriculum or significant learning experiences is widely regarded a principle of learner-centered design (Weimer, 2013) and a robust step to meeting learners where they are and being led by them in cocreating content and learning experiences (Fink, 2013; Taylor, 2014).

## STUDY PURPOSE

The purpose of this study was to investigate the baseline awareness and knowledge about select palliative care concepts in undergraduate and graduate majors in speech-language pathology at two university training programs located in the San Francisco Bay area in Northern California. Specifically, we wanted to document SLP students' knowledge of and familiarity with palliative care and related concepts of hospice, ADs and advance care planning, and QoL. We also wanted to identify the learning contexts and circumstances (academic or professional vs. personal experience) in which students had been exposed to these concepts.

## METHODS

This study was motivated by both researchers' experience as medical SLPs in acute care and long-term care settings, as well as direct observations and reflection that many SLPs had little to no training in palliative care and this limited their involvement and perceived self-efficacy as part of palliative care teams. Both researchers were also involved with The California State University Institute for Palliative Care (<https://csupalliativecare.org>), a national palliative care initiative, focused on improving access to education and training in palliative

care for educators across disciplines. Study participants were undergraduate and graduate speech-language pathology students recruited from two speech-language pathology programs, accredited by the Council on Academic Accreditation of the ASHA. Notably, both programs were located at universities, recognized nationally for their high percentages of racially and ethnically diverse and nontraditional (e.g., first generation) college students. Both institutions are federally classified as Hispanic-Serving Institutions and Asian American, Native American and Pacific Islander-Serving Institutions.

Initially, we conducted two focus groups with undergraduate and graduate SLP students from one program to explore student awareness and knowledge of basic palliative care concepts and their understanding of the role of SLPs on palliative care teams. The two focus groups comprised four graduate students and four undergraduate students from the same institution. Table 1 provides demographic characteristics of these focus group participants, who volunteered to participate. The intent behind conducting these focus groups was to use a participatory research design process (Cornwall & Jewkes, 1995; Levac et al., 2019) in which the primary stakeholders (students and future SLPs) were active participants in this research. Our longer term goal was to develop palliative care training modules for use in speech-language pathology courses and we wanted to design these modules by actively engaging students (and future SLPs), beginning with assessing their baseline awareness and understanding of palliative care.

Focus group participants actively shared their awareness and understanding of palliative care, discussed their learning needs (emphasized needing to know more about medical SLP and skills in counseling and having difficult conversations), and provided input into the final survey design and modes of dissemination. The goal of participatory research methodology is to allow a transfer of power or authority from researchers to research participants, giving

Table 1. Focus group participants—demographic data (*n* = 8)

Student Status	Gender	Race/Ethnicity	1st-Generation College	1st-Generation American	Bilingual	Reporting Chronic Health Condition in Self/Family	Reporting Serious Health Condition in Self/Family
SLP graduate students ( <i>n</i> = 4)	4 women	1 White, 1 Asian, 1 South Asian, and 1 Latinx	2 first-generation college students	1 first-generation American	2 participants	3 of 4 participants (conditions: diabetes, lupus, chronic pain, and PTSD)	3 of 4 participants (conditions: cancer and Alzheimer's disease)
SLP undergraduate students ( <i>n</i> = 4)	2 men 2 women	1 White, 2 Asian, and 1 Latinx	2 first-generation college students	2 first-generation Americans	1 participant	None reported	3 of 4 participants (conditions: cancer, Alzheimer's disease, and vegetative state)

Note. PTSD = posttraumatic stress disorder; SLP = speech-language pathologist.

the latter more control and decision making over the research process. Focus group participants were informed that they would be completing a pilot survey, followed by having discussion with researchers about palliative care topics, and their exposure to palliative care concepts in the speech-language pathology curriculum.

Upon survey completion, focus group participants provided researchers feedback on survey items, ease of understanding, length of survey, and made suggestions for how the survey might be administered to their peers for maximal return and authentic responses. Subsequently, focus group participants were asked an identical set of key questions by the researchers about palliative care, the role of SLPs in palliative care, exposure to related concepts in their programs of study, any personal experiences with palliative care and ADs, and their perceptions about the best ways to introduce this content into their courses. Focus groups were not audio-recorded and yet interactions in both focus group sessions were documented carefully via live note-taking by trained research assistants. Focus group participants were instructed not to complete any additional surveys.

Based on the input of focus group participants, multiple changes were made to the pilot survey. First, the lead-in instructions to the survey were modified to inform student responders that the survey elicited sensitive information, included some personal questions (e.g., about demographics or health status), and they should attempt all items. Students also were told that the eventual goal is to develop learner-centered, curricular modules on palliative care. Some survey items were altered to clarify wording or to simplify questions. Focus group participants expressed strongly that an electronic survey would prompt students to look up information online, thus potentially resulting in spurious survey outcomes. Thus, a decision was made to administer the final survey only in hard copy. Furthermore, focus group members suggested that the best survey returns

might be accomplished if surveys were administered during a class, with students having the option to complete or not complete the survey.

Data gathered from the eight focus group participants revealed that all were familiar with the term “quality of life,” yet only two could accurately explain the term. The remaining six could partially explain QoL. Six out of eight participants had heard the term “palliative care”; only two of these six participants accurately explained the term. All eight participants reported having heard the terms hospice or “hospice care”; none were able to explain it accurately. Five of eight were incorrect in their understanding (e.g., describing hospice as intensive care, or as assistance with activities of daily living) and three were partially correct. When asked about ADs, six out of eight participants had never heard this term. Of the two participants who had heard the term, only one explained it correctly and the other was incorrect. When reporting familiarity and knowledge about a term, focus group members attributed their awareness to a combination of personal and academic experiences. For both undergraduate and graduate students in the focus groups, frequent dissociations were noted between recognition of a term or a concept and the ability to explain it accurately. All focus group participants expressed strong interest in learning more about palliative care. When provided an introduction to palliative care, clinical services that fall under palliative care, and examples of how SLPs work on palliative care teams, focus group members readily saw the fit with SLP curriculum. Focus group participants also provided keen insights about courses and instructional experiences (e.g., service learning, clinical practicum) in which palliative care training could be embedded.

Among the graduate student focus group participants, one had just completed a medical SLP externship and another was beginning such an externship. Graduate students in the focus group expressed interest in receiving resources and attending professional

development workshops on palliative care. Another insight shared by focus group members was that they reported limited to no opportunity to think about their own mortality, or their own wishes in the context of health care decision making. They expressed thoughtful concern that discussing EoL topics could be stressful and may elicit strong emotions from some students.

Based on the collective feedback from focus group participants, the final survey was a 27-item survey with 11 items pertaining to participant demographics (e.g., undergraduate or graduate status, age, gender, race, ethnicity, bilingual status, first-generation college student, first-generation American, and personal/family history of chronic or life-limiting health conditions). Another 16 items probed respondent knowledge about exposure to terms and definitions of palliative care, AD, hospice, QoL (see Table 2 for sample survey items), and in what contexts or courses (if any) they had learned these concepts, and whether these courses had been in the SLP department or other departments. Permission was obtained from instructors of select classes to administer surveys at the begin-

ning of class. Learners signed a short consent statement before completing the survey. No financial incentive was offered for completing the survey.

Following survey collection, a total of 110 SLP students completed surveys across two sites. Site 1 yielded 70 completed surveys (50 graduate students, 17 undergraduates, and three respondents who did not specify undergraduate or graduate status) and Site 2 yielded 40 completed surveys (all graduate students). Survey data were collected without identifying information from responders. Table 3 provides a demographic snapshot of survey respondents by site of data collection. These demographic data illustrate that our sample was diverse in race/ethnicity (41% of respondents who provided these data), language status (48% reported native bilingual fluency), status as a first-generation college student (27%), chronic health condition in self/family (43%), and life-limiting condition in self/family (17%). Table 4 shows how the four concepts of palliative care, hospice, ADs, and QoL were defined with examples of correct and incorrect descriptions from student surveys.

**Table 2.** Sample survey items

Type of Question	No. of Items	Sample Items
Demographic questions (multiple-choice or yes-no questions)	11	Are you fluent in a language besides English? Are you a first-generation college student, i.e., are you among the first in your family to attend college? Do you or does anyone close to you have a serious health condition?
Palliative care-specific questions	16	
Short-answer questions	7	Have you heard the term “palliative care”? Have you heard the term “advance directives”? Has the term “palliative care” been discussed in your speech-language pathology classes? Please explain what you understand by the term “hospice” or “hospice care.” Please explain what you understand by the term “quality of life.” In what context have you heard the term “advance directives”?
Narrative response questions	9	

Table 3. Speech-language pathologist student demographic data (*n* = 110)

Student Status	Gender	Race/Ethnicity	1st-Generation College	1st-Generation American	Bilingual	Reporting Chronic Health Condition in Self/Family	Reporting Life-Limiting or Serious Health Condition in Self/Family
Site 1							
50 graduate students	65 women	27 White, 8 Asian, 8 Latinx, 6 bi/multiracial, and 21 declined to state	19 first-generation college students	21 first-generation Americans	38 students	26 students	10 students
17 undergraduate students	5 men						
3 unknown							
Site 2							
40 graduate students	37 women 3 men	21 White, 9 Asian, 3 bi/multiracial, and 7 declined to state	11 first-generation college students	5 first-generation Americans	15 students	21 students	9 students

DATA ANALYSIS

Data from the surveys were entered using a data codebook developed by the researchers. Key components of terms being defined were established a priori and a scoring system used to categorize terms as correctly defined, partially correct, or incorrect. Survey data were analyzed to examine student familiarity with key terms (Table 5) and ability to explain terms accurately (Figure 1). Survey data revealed that QoL was the most familiar term to SLP students who completed the survey, with 55% of respondents being able to correctly explain the construct of QoL (Figure 1). Hospice or hospice care was the second most familiar term to SLP students, with 43% of respondents being able to correctly explain hospice care as related to a terminal phase of illness. Of our survey sample, palliative care was the term most frequently misunderstood. Whereas 72% had heard the term “palliative care,” only 22% of respondents could accurately explain the meaning or components of palliative care. The most common errors respondents made were in describing palliative care as pertinent only to older adults, related to dysphagia or dementia, or defining it as care provided only at the end of life. Across sites, SLP students were least exposed to an AD and its purpose, with 54% reporting that they had not heard the term. Of the remaining respondents who reported familiarity with ADs, only 27% were able to correctly explain what ADs were.

Initial data obtained from our focus group participants (*n* = 8) forecasted accurately that QoL was the most recognized or familiar concept, and ADs were the least familiar concept among survey respondents. Furthermore, focus group participants’ responses revealed a dissociation between reporting familiarity with a concept and being able to accurately explain the same concept. This finding was replicated with our larger survey sample. We probed the understanding of QoL as a construct because palliative care is aimed at improving as much as possible the QoL of a person with a life-limiting condition. Given the



Table 4. Defining concepts of interest<sup>a</sup>

Concept	Key Elements of Concept Definition
Palliative care	<ul style="list-style-type: none"><li>• Interdisciplinary care (led by MD), from point of diagnosis for persons with serious illness</li><li>• Holistic, person-centered care at any age, any stage of illness</li><li>• Emphasis on optimizing disease management, patient/family well-being, and QoL</li><li>• Offered alongside or independent of disease-curative care (<i>not essential to definition</i>)</li></ul> <p>Sample correct definition by student: “Long-term care by a team to help a person with a major medical condition have the best treatment yet also life participation and quality of life.”</p> <p>Sample incorrect definition: “Care for those who require assisted living supports.”</p>
Hospice	<ul style="list-style-type: none"><li>• Interdisciplinary care (led by MD) for terminally ill persons (&lt;6 months life expectancy)</li><li>• Emphasis on comfort care and pain management</li><li>• Initiate when burden of curative treatment outweighs benefits (<i>not essential to definition</i>)</li><li>• Services typically provided by hospice organizations (<i>not essential to definition</i>)</li></ul> <p>Sample correct definition: “Hospice is specialized care for persons who are terminally ill so that they are comfortable and suffering less.”</p> <p>Sample incorrect definition: “Hospice is when older adults can no longer care for themselves.”</p>
Advance directives	<ul style="list-style-type: none"><li>• Legal document that can be enacted by any adult</li><li>• Purpose of document is to provide guidance about types of preferred medical treatments a person wishes to receive in the event of a future medical emergency</li><li>• Process by which a person identifies a surrogate to make decisions about medical treatment if you could not speak for yourself</li></ul> <p>Sample correct definition: “Legal documentation of wishes in regard to medical care if someone is incapacitated—e.g., CPR or DNR.”</p> <p>Sample incorrect definition: “I think my grandma has one of these- not sure what it is.”</p>
Quality of life	<ul style="list-style-type: none"><li>• Broad concept (<i>not essential to definition</i>)</li><li>• Person’s perception of their overall wellness and position in life (contextualized by cultural and personal beliefs and values)</li><li>• QoL has multiple domains—physical, cognitive, social, spiritual, religious, and economic.</li></ul> <p>Sample correct definition: “QoL is a patient’s perspective of how they perceive their life after a diagnosis; QoL includes physical and mental health and other things.”</p> <p>Sample incorrect definition: “QoL is the amount of control over myself that I can live with.”</p>

Note. For a student to be scored correct at defining a concept, essential components of a concept had to be provided without added errors. QoL = quality of life.  
<sup>a</sup>From CMS (2019); Ferrell et al. (2018); Lynn (2005); NHPCO (2019); Smith (2020); and WHO (2001, 2018, 2019).

**Table 5.** Summary of survey results

	Palliative Care	Hospice	Advance Directives	QoL
Site 1				
Reported not having heard the term	14/40	2/40	20/40	0/40
Reported having heard the term	26/40	38/40	20/40	40/40
Explanation of concept	4/26: Correct 8/26: Partial 14/26: Incorrect	19/38: Correct 7/38: Partial 12/38: Incorrect	12/20: Correct 8/20: Partial 0: Incorrect	21/40: Correct 19/40: Partial 0: Incorrect
Site 2				
Reported not having heard the term	17/70	3/70 <sup>a</sup>	39/70	1/70
Reported having heard the term	53/70	66/70	31/70	69/70
Explanation of concept	20/53: Correct 8/53: Partial 25/53: Incorrect	28/66: Correct 0: Partial 38/66: Incorrect	17/31: Correct 0: Partial 14/31: Incorrect	39/69: Correct 28/69: Partial 2/39: Incorrect

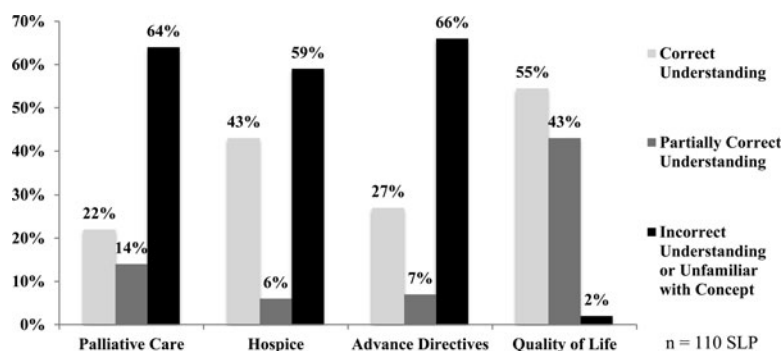
Note. QoL = quality of life.

<sup>a</sup>One person omitted this item.

importance placed on QoL in the SLP curriculum, in the World Health Organization's International Classification of Functioning, Disability and Health (WHO, 2001), the SLP Scope of Practice (ASHA, 2016), and in substantial research on QoL in persons with communication disorders (Autism Society, 2019; Chapey et al., 2000; Hilari & Byng, 2009; Martyr et al., 2018; Slavych et al., 2013), it was an expected finding that 55% of survey respondents accurately explained QoL, and another 43% of respondents partially explained the concept of QoL.

As an additional step in the analysis, we analyzed qualitatively the content of definitions provided by survey respondents. Definitions were analyzed for specific key words and key words being loosely categorized in main ideas (Boyatzis, 1998; Saldaña, 2009). In recognizing the lived experiences of survey respondents, we paid careful attention to personal experiences shared with chronic and life-limiting health conditions (Table 3). This analysis revealed that many respondents reported chronic health conditions for themselves or family members, with a smaller percentage (17%) of our sample reporting serious or life-limiting conditions. The most common chronic health conditions reported were diabetes, asthma, and mental health conditions (e.g., anxiety, depression). The most common life-limiting conditions reported by survey respondents were dementia, cancer (or cancer survivorship), and kidney disease.

In examining the context of where respondents had learned about these concepts, multiple sources were identified. Undergraduate students comprised only 17 respondents in our sample; 12 of these 17 reported some exposure to concepts related to palliative care in speech-language pathology classes. Again, QoL was most frequently reported as being taught, five of 17 mentioned being introduced to hospice, and four reporting explanation of palliative care. Undergraduate students did not report familiarity with or exposure to ADs. Outside SLP courses, these respondents identified other courses and departments where these topics were



**Figure 1.** Speech-language pathology student understanding of palliative care, hospice, advance directives, and quality of life. SLP = Speech-language pathologist.

occasionally discussed, including courses on medical anthropology, ethics, health and wellness, history of nursing, and psychology of grief. Among the graduate students, 42 of 50 graduate students from Site 1 and 22 of 40 at Site 2 reported limited content related to palliative care in SLP courses on adult disorders—this most often included QoL. Overall, graduate students reported minimal exposure to palliative care and virtually no exposure to ADs, pediatric palliative care, or the precise roles of SLPs on palliative care teams.

Beyond courses for academic credit, student respondents revealed additional sources of information that had influenced their understanding of palliative care and related concepts. These included medical television shows (e.g., *Grey's Anatomy*), mainstream movies (e.g., *The Descendants*—featuring an extended discussion of ADs), recent books by physicians (e.g., *The Conversation*—Volandes, 2015, *Being Mortal*—Gawande, 2014), YouTube videos (e.g., *The Last Chapter*, lectures by geriatrician and palliative care advocate, Dr. Atul Gawande), personal experience (e.g., most often involving a grandparent or older parent), and medical internship experiences (for graduate students who had completed these). These data about sources of learning for survey respondents also revealed that QoL was the concept they reported as discussed most often, followed by hospice care. Palliative care and ADs were rarely identified as having been discussed or

taught about in SLP courses, nor details provided about the role of SLPs in palliative care.

## DISCUSSION

There is an undeniable, increasing demand for palliative care training among health professionals, across health care practice settings (Meier, 2011; WHO, 2019). This has implications for curriculum change and consideration of pedagogical approaches most suited to teach for acquiring the complex clinical competencies associated with palliative care service delivery. Significant progress has been made to improve palliative care education in medical school curricula for physicians-in-training (Fitzpatrick et al., 2017) and for nursing students (O'Shea & Mager, 2019). These advances have implications for SLPs who are not being well trained in palliative care, yet frequently find themselves on palliative care teams with rising numbers of patients on their caseloads having life-limiting conditions. An evidence base has been steadily building for growing SLP involvement in palliative care (Chahda et al., 2017; Costello, 2009; Kelly et al., 2016; Krikheli et al., 2017; Pollens, 2004, 2012, 2020 [this issue]; Radford et al., 2020), the need to better train SLPs in palliative care (Mahendra et al., 2017; Pascoe et al., 2018), and how to train future practitioners (Mathisen et al., 2011; Stead et al., 2020 [this issue]). Based on the results of this study, undergraduate and graduate SLP students lacked accurate and complete understanding of

palliative care concepts and yet had high interest in learning more about palliative care.

Quality of life was the most familiar concept for students (Figure 1), one that was accurately or partially explained more than any other concept (Table 5), and most frequently reported by students as being taught explicitly in SLP curricula. All students offered at least two distinct components of QoL in their definitions (e.g., patient satisfaction, physical/mental health), and more than half consistently listed more than two specific components of QoL (e.g., discussing WHO's ICF model or contextual factors, life participation, health status, patient-reported outcome measures, managing negative effects, family well-being, and the human right to high QoL). These results suggest that the concept of QoL, and by extension, that of optimal life participation with a serious health condition, could be a robust instructional hook for introducing palliative care in speech-language pathology. Expanding instruction in palliative care could easily include the right to maximal QoL for persons with serious, life-limiting, or progressive conditions in adults (e.g., Alzheimer's disease, primary progressive aphasia, head and neck cancer) and children (e.g., muscular dystrophy, cancers) and how QoL is contextualized in the work of SLPs when treating communicative, cognitive, swallowing, and aerodigestive concerns. Across students from both participating academic programs, erroneous definitions were most often provided for the terms "palliative care" and "advance directives" (Figure 1), confirming that these terms are poorly understood among SLP graduate students and require more explicit, thoughtful instruction.

Survey results also indicated that graduate SLP students have many misconceptions about palliative care, similar to results reported among medical students (Balon et al., 2015; Pandey et al., 2015) and physical therapists (Briggs, 2011). The most common misconceptions included student beliefs that (1) palliative care services are only for older adults, (2) palliative care services are provided after a person has exhausted or opts out of curative treatment options, (3) palliative

care and hospice are synonymous, (4) receiving palliative care services may somehow hasten death, (5) confusion of palliative care with assisted suicide, and (6) palliative care services are not being viewed as an area in which rehabilitation disciplines or SLPs have involvement. These misconceptions revealed that SLP students were unaware that palliative care is a critical part of care planning for all persons with serious conditions, or that palliative care services often improve patient symptoms and satisfaction, patient and family well-being, and QoL (Hughes & Smith, 2014), while decreasing caregiver burden and treatment costs by reducing unnecessary hospitalizations (Meier, 2011; WHO, 2018). Furthermore, palliative care services are reported to confer a survival advantage for patients (Bakitas et al., 2012; Meier, 2011; Saito et al., 2011; Temel et al., 2010).

Our findings from this study resonate strongly with those shared by Stead et al. (2020, in this issue), as well as by other researchers (Chahda et al., 2017, 2020; Toner & Shadden, 2012) and confirm that graduate SLP students are not being prepared for their roles in providing palliative care services to adult and pediatric clients with serious health conditions and related communication/swallowing/cognitive disorders. This lack of awareness and knowledge about palliative care and the connection with an SLP's professional roles and responsibilities is a problem. Being unprepared in this area likely reduces SLPs' perceived self-efficacy and potentially limits actions clinicians might take to further develop their knowledge and skills in palliative care. This, in turn, likely restricts their involvement as clinicians in providing competent services to clients with life-limiting conditions (e.g., cancer, dementia, amyotrophic lateral sclerosis) and can contribute to the erroneous conflation of palliative care with only EoL care for a terminally ill person. Furthermore, an incomplete or inaccurate understanding of the importance of SLPs' roles in adult and pediatric palliative care also limits research on best practices for teaching about palliative care and delivering palliative services.

Given our highly diverse student sample and their cumulative lack of awareness of palliative care concepts, we also reflect on the racial and ethnic disparities in access to and utilization of palliative care services (Mukherjea et al., 2020, this issue). Mukherjea et al. report that one formidable barrier to providing equitable palliative care services is the lack of adequately trained and prepared clinicians who also are informed about diverse patient and family cultures. Thus, whereas more and better training is needed for all prospective SLPs for their roles in palliative care service delivery, we present that it is even more urgent to train diverse students and clinicians who can then be agents of change and further inspire the design and delivery of culturally responsive palliative care services.

In thinking about developing palliative care content modules for practitioners, Horowitz et al. (2014) have cautioned that palliative care competencies are complex and require clear definition and integration into health care curricula, lest they be abandoned because of content overload. This caution is highly applicable to developing palliative care content for inclusion in the speech-language pathology curriculum, so that this important content can be folded in thoughtfully and include content on adult and pediatric palliative care in courses on dysphagia, medical speech-language pathology, neurogenic communication disorders, counseling, augmentative alternative communication, contemporary professional issues, or seminars in ethics. In implementing this type of curricular change, clinicians and educators need to join forces so that SLPs may deliver services that fully encompass their scope of practice. Finally, when considering ADs, SLP students

in this study had little to no information about what an AD is, how it is used, and the reasons a person would consider having an AD. Such lack of knowledge about ADs is not merely an issue of clinical service delivery but a critical topic pertaining to the right of any person, with or without a serious health condition, to make decisions about their own future health care.

The increasing need for palliative care services is reflected in growing advocacy and urgency for improving training for health care professionals in this area. As a signature example, recently, the landmark Palliative Care and Hospice Education and Training Act (PCHETA, 2019) legislation passed the United States House (H.R. 647) and is being introduced in the U.S. Senate. Furthermore, there has been a heightened need for palliative services as health care systems experience extraordinary strain due to the seriousness and high mortality associated with the COVID 19 pandemic (Armour, 2020). This seems to be an important juncture when speech-language pathology professional organizations and educators should step up to include palliative care knowledge and skills in their curriculum and better prepare future SLPs for this important area of practice. In forthcoming work informed by this study's results, we will report on the efficacy of instructional strategies to teach SLPs about palliative care, how to learn about client beliefs about death and dying, and how to engage clients with communication disorders in advance care planning conversations. We hope that information shared in this article will empower readers to embrace the responsibility to provide education and training about palliative care in academic and clinical settings.

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