

Facilitating Client Ability to Communicate in Palliative End-of-Life Care

Impact of Speech–Language Pathologists

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The client's ability to communicate is key to providing quality palliative end-of-life care. A speech–language pathologist (SLP) can facilitate the patient's ability to communicate concerns or preferences in order to (1) improve the health care team's ability to manage symptoms and engage in end-of-life discussions, and (2) support the patient and family's ability to maintain social connectivity. This article describes methods for implementing speech–language pathology communication consults in palliative or end-of-life care. The information is illustrated with patient vignettes and supported by literature resources. Specific participation goals and outcomes illustrate the impact of the SLP treatment on the interprofessional team palliative care outcomes. Approaches to advocating for speech–language pathology communication consults in palliative end-of-life care are highlighted. Ongoing research and advocacy may result in valuable skilled speech–language pathology services for patients with communication barriers in palliative or end-of-life care. **Key words:** *AAC, advance care planning, communication, end of life, hospice, interdisciplinary team, palliative care, patient–provider communication, speech and language therapy, speech–language pathologist*

THE WORDS *comfort* and *care* encapsulate the goal of palliative care services. The goal of palliative care services is to provide quality comfort and care for a person facing a life-limiting condition. A review of the literature pertaining to communication in palliative care yields many articles describing the need for physicians or other health care personnel to develop high-quality communi-

cation skills to use with patients and families when discussing difficult topics or to facilitate care planning.

However, what is not addressed in these articles is the effect of a patient's significant communication impairment on palliative care outcomes. Communication is very important for all patients facing a life-limiting illness. 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 (CareSearch Palliative Care Knowledge Network, 2019; Pollens, 2004; Speech–Language and Audiology Canada, 2016; Speech Pathology Australia, 2015). A speech–language pathology communication

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consult can provide the expertise to support the patient's ability to have "communication access" to express their palliative care decisions or concerns and to communicate with family at this critical time.

O'Reilly and Walshe (2015) surveyed 322 speech and language therapists (SLTs) working in palliative care in Republic of Ireland, the United Kingdom, the United States, Canada, Australia, and New Zealand to discover current international SLT practices in delivery of palliative care. The primary diagnoses of patients seen in palliative care included advanced dementia, cancer, and progressive neurological illness, all of which often result in significant communication impairments. In a survey by Kelly (2019) of 222 speech-language pathologists (SLPs) primarily in Australia (and a limited number from New Zealand, the Netherlands, Scotland, Singapore, Hong Kong, Malta, and Canada), responders reported additionally providing palliative care services for people with other diagnoses including liver or renal failure and chronic respiratory conditions.

Palliative care services are provided internationally with variations based on context (World Health Organization [WHO], 2014). The titles of the professionally trained communication specialists who work in settings with people receiving palliative end-of-life care vary across countries (Portland State University, 2019). In the United States, the professional is a "speech-language pathologist." In England, the title is "speech and language therapist," and in Belgium it is a "logopedist." The remainder of this article uses the title "SLP" to refer to this specialist, unless referencing a specific research outcome.

The terms *palliative*, *hospice*, and *end-of-life care* each describe an approach or time of care provision with an overlap in philosophy (Toner & Shadden, 2012). The discussions in this article apply to services along this continuum, with the overall focus on improving communicative access and quality of life for a patient and their family living with the challenges of a life-threatening illness (WHO, 2019a).

SUPPORTING COMMUNICATION ACCESS IN PALLIATIVE CARE

The WHO provides a definition of palliative care (WHO, 2019a) and delineates descriptors of palliative care. Four of these descriptors include the following: provides relief from pain and other distressing symptoms; offers a support system to help patients live as actively as possible until death; integrates the psychological and spiritual aspects of patient care; and offers a support system to help the family cope during the patient's illness and in their own bereavement.

However, a patient's communication impairment may be a significant barrier to the team's ability to effectively implement these palliative care goals. In this article, a series of case examples is offered to illustrate the range of communication interventions provided by SLPs and how the outcomes of these interventions correspond to the aforementioned WHO-specified palliative care goals.

Mrs. A. was an 87-year-old woman with a progressive neurological illness. In 2000, an SLP was referred to see her in the home care setting. She had been evaluated at a tertiary medical center with consideration of bulbar amyotrophic lateral sclerosis (ALS), but the diagnosis was not confirmed. She had profound oropharyngeal dysphagia and was informed at this center that functionally she could not maintain nutrition orally and that her disease would progress. She had profound dysarthria that had progressed to unintelligible vocalization. She relied on writing lengthy messages, resulting in hand pain, as she had severe arthritis. She also had cardiac disease. She did not have a cognitive impairment and was the primary decision maker about her health care. She lived alone in a senior living facility with a series of hired aids providing daytime assistance in her apartment. Her family resided in other parts of the country.

The first palliative care goal pertains to providing relief from pain and other distressing symptoms. The SLP and the patient discussed tube feeding versus hospice with comfort feeding. The patient's views were clarified as she wrote out questions and opinions. The SLP *provided a summary of the patient's*

concerns to the team members (nurse, dietician) who would provide education. The patient declined tube feeding and chose hospice care. To reduce her need for repetitively writing her preferences, the SLP also *created a written guideline* of the patient's daily household care preferences, which was taped to the wall to inform new chore providers.

The second WHO palliative care goal focuses on offering a support system to help patients live as actively as possible until death. To meet this goal, the SLP *provided a Voicaid, a basic augmentative communication device* available at the time (Alper, 2015). The patient could push a button to activate a voiced response (yes, no, repeat, thank you). When facility staff phoned to list her soft foods choices for breakfast, she could communicate her preferences using this simple tool.

The third palliative care goal emphasizes that the psychological and spiritual aspects of care be integrated. As Mrs. A. declined in strength over the month, she became unable to write. The SLP *cocreated a low-tech communication board* with pictures and words of importance to Mrs. A. One of the items she chose to include noted: "I'm ready to be with God." This prompted her views to be explored further with the hospice chaplain.

The fourth palliative care goal is to offer a support system to help the family cope during the patient's illness and in their own bereavement. This patient's family traveled to see her shortly before she died. They informed the hospice bereavement counselor that it was comforting to read the aforementioned *communication board message*.

This case example highlighted a patient with a significant communication impairment and how she was supported by the SLP in communicating her concerns and her requests during end-of-life care. Skilled speech-language pathology services were important to assess communication and cognitive status as her disease progressed and to modify the communication modalities as she declined. To receive quality palliative care, the patient needed to be able to have access

to alternate modalities and multiple communication supports, some of which included environmental modification and staff training. Technology support options were more limited in the year 2000. Current-day technology advances such as text-to-speech software, semantic word prediction, electronic visual displays, and health-related apps could be supportive alternatives for a patient with this degree of verbal communication impairment with maintained language and cognitive function.

Communication consults with SLPs directly support clients, families, and health care team members. Speech-language pathologists can (1) ensure the patient's access to communicating needs and preferences, (2) enhance the medical team's ability to provide effective symptom management and to engage in end-of-life discussions with patients, and (3) support a family's ability to advocate for the patient's wishes and maintain social connectedness with their loved one. In the next section, these three aspects of speech-language pathology communication support are addressed, with case vignettes to illustrate key themes.

Communicative access for the patient

Communication barriers can reduce a person's ability to participate in decision making or advance care planning. Lambert (2012) describes the role of allied health professionals (AHPs) in advance care planning and provides a table describing areas that may be addressed, including resuscitation, ventilation, non-oral feeding, and pain control (p. 121). Tools have been developed to assist clients with communication impairments to communicate advance directive information or medical concerns and to educate team members on strategies to facilitate communication (Patient Provider Communication, 2019). Choosing the best resource requires clinical expertise to determine which type of support may best reduce patient barriers to communicating.

Hurtig and Slayman (2016) presented on resources used with people with ALS to express

care preferences through the use of communication templates for nutrition, spirituality, and other factors. Stead and McDonnell (2015) described using supported conversation strategies to assist a patient with aphasia to create advance directives.

Several researchers have explored the ability of patients with moderate dementia to participate in advance care planning decisions. Chang (2015) determined that patients with moderate dementia demonstrated better decisional capacity regarding drug treatment and tube feeding decisions when supported by visual aids. Bourgeois et al. (2016) demonstrated that persons with dementia in skilled nursing facilities could more effectively communicate preferences related to quality of life with their nursing assistant using a sorting template with labeled pictures. Song et al. (2019) also determined that meaningful advance care planning was possible for those with moderate dementia by modifying intervention materials to reduce length, complexity of information, and reliance on short-term memory in order to respond.

Supporting the ability to communicate with family and care providers in palliative care not only is specific to working with adults but also pertains to children with life-limiting conditions. A scoping review of the literature related to SLP involvement in pediatric palliative care revealed a limited description of management approaches across the pediatric life stage (Krikheli et al., 2018).

Costello (2009) developed effective ways to incorporate the use of personalized voice banking (recording messages in the child's voice) prior to a child's anticipated loss of communication skills during end of life. He provided these messages on augmentative communication devices with multiple-message voice output for children with diagnoses such as astrocytoma of the cerebellum, juvenile Huntington's disease, or chronic respiratory distress secondary to cystic fibrosis. Stuart (2004) described her work developing augmentative and alternative communication (AAC) systems for children in palliative care in a hospital setting. She recommended ini-

tially designing components in the system that are fun and familiar and then adding more genuine needs and concerns. She also noted that SLPs need to have expertise in child development to do this work effectively. She provided a table on the developmental stages of children's understanding of death, spirituality, and grief responses.

Many referrals for speech-language pathology services in palliative care are in the treatment area of dysphagia (difficulty swallowing). The higher frequency of referrals to SLPs for dysphagia as compared with referrals for communication consults may not accurately reflect the clinical needs of patients in palliative care (Hawksley et al., 2017). For example, swallowing and communication deficits often co-occur in many progressive neurological diseases. Even if the SLP's initial referral is to address the area of dysphagia, a skilled SLP should be empowered to provide communication assessment and recommendations to ensure a client's right to communicate in a palliative care context. The following case describes the skilled SLP adapting her assessment of a patient in a skilled nursing facility.

An SLP received a referral for a swallowing assessment with an 80-year old man with Parkinson's disease. When the SLP arrived in the patient's room, his wife expressed tearfully that her husband's voice was so soft that she could not understand his words. The SLP trialed use of a personal sound amplifier and determined that the visual and motoric cue provided by talking into a microphone resulted in functional improvement in his volume and intelligibility. The wife was then observed conversing with her husband, comfortably hearing his words.

A patient's hearing acuity should also be considered an important factor for participation in end-of-life conversations. For example, a patient may want a conversation with a social worker or chaplain to remain confidential, and a voice amplifier may reduce the need for the health care provider to use an increased vocal volume (Wallace, 2013).

All members of the palliative care team may use their expertise to consider the psychospiritual needs of the patient.

Speech-language pathologists can use their skills to facilitate discussions and address specific communication needs. For example, a 32-year-old woman with an advanced glioblastoma and aphasia communicated to the SLP that she felt it was important to conclude her life's work by organizing her computer art files for her family to view after her death. The SLP's response was to create "aphasia-friendly" written guidelines (Stroke Association, 2012) to prompt her ability to follow the sequence of steps to navigate the computer task. A hospice volunteer then continued this ongoing meaningful project with the patient.

Facilitating the medical team's ability to provide effective care

In a survey of 322 SLPs who worked in palliative care, half identified that they worked primarily in acute settings (O'Reilly & Walshe, 2015). In the hospital setting, barriers to communication can directly impact medical outcomes and patient safety (Blackstone et al., 2011). Ideally, the medical team receives input from the patient for accurate assessment and decision making (Garrett et al., 2007).

In the intensive care unit (ICU), many individuals are unable to speak due to specific types of medical intervention (e.g., intubation) or illness severity. Although communication boards or devices may be present in a facility, SLPs have the skill to determine which type of support is optimal for a particular patient. The SLP may consider the patient's cognitive-linguistic status and additional factors such as motor movement access or patient preference. The SLP can (1) identify and train strategies to improve communication, (2) access resources that facilitate communication, and (3) educate others on effectively facilitating communication.

Happ et al. (2010) studied ways to increase collaboration between nurses and SLPs to address communication needs for medically complex patients in the ICU. The SLP created "Communication Care Plan Wall Cards" to educate the team on a patient's communication needs. Bardach (2015) provided specific instructions to educate medical team members

or family members in use of augmentative communication systems, including alphabet boards, partner-assisted scanning, and e-tran boards.

Other patients receive palliative end-of-life or hospice services in their home. A team of interprofessional care workers visit the home to work with the patient and their family and SLPs provide services in this context. In the United States, some patients choose to enter the Medicare Hospice program (Centers for Medicare & Medicaid Services, 2019). The next three vignettes illustrate how home health speech-language pathology communication consults impacted the interprofessional medical team's ability to provide optimal care for patients and families in hospice.

Nurse: Clarifying the patient's choices about the care plan

The SLP was present as the admitting hospice nurse interviewed a patient with bulbar ALS who was unable to communicate verbally. She asked if he wanted to stay at home for his care. He hesitated and nodded "yes." The SLP provided a keyboard with text-to-speech capabilities. The patient then typed: "In general I want to be at home. But under certain circumstances I may need to be in a nursing facility." This nuanced response more clearly articulated his care plan concerns, and the nurse was able to probe with follow-up questions.

This speech-language pathology intervention supported a WHO palliative care parameter. The nurse was able to offer a support system to help the patient live as actively as possible until death.

Social worker: Engaging in key end-of-life discussions with the patient

A patient with ALS had progressed to being non-verbal with only minimal head movement capabilities and was seen by the medical social worker. The social worker asked the SLP for a communication consult. The SLP provided (1) a laser attached to a baseball cap with which the patient was instructed to point to large letters taped to the wall, (2) brief education for the wife and the social worker on effective ways to use this scanning/alphabet board to facilitate communication, and (3) a pictorial book that included sensitive topics for the social worker to explore (Kagan &

Shumway, 2003). Using these resources, the social worker determined that the patient's primary fear was how his wife was going to financially manage after his death. The social worker could then provide appropriate counseling (Pollens & Lynn, 2011).

This speech-language pathology intervention supported a WHO palliative care parameter. The social worker was able to integrate the psychological and spiritual aspects of patient care.

Physician: Understanding the patient's experience of physical symptoms

The medical team was having difficulty understanding a patient's speech attempts. He had dysarthria from a prior stroke, and he had become very weak with poor respiratory support as a result of his current end-stage disease. The SLP provided two skilled visits. She determined the best strategy was for the patient to produce two to three words per breath to maintain some phonation. The SLP educated the team to prompt the patient with this strategy. The physician was then better able to understand the patient's symptoms and provide comfort measures.

This speech-language pathology intervention supported a WHO palliative care parameter. The physician was able to provide relief from pain and other distressing symptoms.

In these three scenarios, the SLP directly impacted the team's ability to provide palliative care by supporting the patient's ability to communicate. Key to these three examples was respectful interprofessional interaction and communication among the members of the team. The SLP needed to know areas of concern, and the nurse, the social worker, and the physician were open to the possibility that the SLP could facilitate support. Writing SLP goals and outcomes from a palliative care context can facilitate this teamwork and is described later in this article.

Facilitating the family's ability to advocate and maintain social connectivity

The sudden onset of a significant communication impairment or deteriorating commu-

nication skills may result in a high level of patient and family stress. Leskuski (2009) and Pollens (2012) provided examples of significant challenges for a family when the patient exhibited a sudden onset or exacerbation of aphasia. The two brief vignettes also described supported conversation techniques (Kagan et al., 2001) modeled by SLPs to engage the patient and educate the family, including using written choices, establishing the overall topic, and confirming accuracy of the listener's understanding of the patient's communicative intent. These speech-language pathology interventions conducted over four to five treatment sessions resulted in a positive impact on the family during this critical time of care.

Significant communication impairments such as aphasia may not only impact the ability of the patient to comprehend and use language but also additionally affect the ability to maintain relationships and social roles (Lasker et al., 2007). The palliative care SLP can adapt the philosophy of the Life Participation Approach to Aphasia (Chapey et al., 2000) to focus treatment on the expressed needs of the patient and family in the palliative care context.

A woman with a brain malignancy developed a decline in her ability to verbalize due to exacerbation of her aphasia. The husband was now cooking and providing all meals, which was a new role for him. The SLP worked collaboratively with this couple, creating a word and picture booklet with meal ideas and food preferences. The wife was able to provide input to support the husband in meal choices for the day. Over time, the patient declined in alertness and was unable to functionally use this booklet. The last communication intervention provided by the SLP was to provide a push button to be kept on the wife's chair. She could use it to alert her husband in the other room, as it activated an alert clipped on his belt (Pollens, 2004).

Speech-language pathologists may also help the family to view a broader perspective of "communication" to include nonverbal communication acts that support social closeness and emotional needs for families at end of life. Many examples of nonverbal acts

that express emotion have been observed: a husband in hospice placing his ring on his wife's hand, or a mother with dementia puckering her lips as if to kiss a daughter. Keeley (2007) noted the important role of nonverbal communication as an expression of connection and the value of paying attention to dying people's nonverbal communication.

A daughter tearfully told the SLP that she couldn't get her mom to eat. The SLP explained that her mother wasn't eating due to the disease of end-stage dementia. The SLP discussed other ways the daughter could provide nurturance to her mother. The daughter began to provide hand cream to her mother and talked with her gently. The patient opened her eyes and smiled at her daughter. This was a moment of communication.

For family members, having the opportunity to have some type of conversation with their loved one in end-of-life care may be valuable as they experience "anticipatory grief" of the future loss of the relationship (Keeley, 2007). Keeley's retrospective research affirms the meaning of end-of-life communication for the family members. She analyzed the recollection of final conversations that survivors had with loved ones in end-of-life care. Five themes emerged: love, identity, religion/spirituality, routine/everyday content, and difficult relationship issues. These conversational opportunities provided the survivor a sense of completion, an affirmation of their relationship with their dying loved one, reconciliation, or the gift of maintaining the relationship until the end.

STRATEGIES FOR IMPLEMENTING SKILLED COMMUNICATION CONSULTS IN PALLIATIVE CARE

Focusing on participation-based goals and outcomes

The overall goal of providing SLP communication treatment in palliative care is to support quality of life as defined by the patient and family rather than to cure a disorder. It may require a shift in thinking for SLPs who may be accustomed to creating rehabilita-

tion goals in other medical settings. Hawksley et al. (2017) suggested that speech pathologists engage in self-reflection and identify how their own attitudes and beliefs may impact the services they provide in palliative care.

One framework to draw upon when creating goals and outcomes in palliative care is the World Health Organization International Classification of Functioning, Disability and Health (WHO-ICF) model, which describes impairment-based or participation-based assessment and outcomes (WHO, 2019b). Participation-based goals more directly align with a palliative care approach than impairment-based goals (Pollens, 2012). Collis and Bloch (2012) surveyed SLPs in the United Kingdom and noted that although SLPs valued participation-focused care for patients with progressive dysarthria, the assessment continued to be primarily impairment-focused.

Table 1 compares the use of impairment-based versus participation-based written goals to describe an intervention and the resulting patient participation outcome. The participation goals include the communication context and state the value of the planned intervention. As noted by Yorkston and Baylor (2019), the roles that patients would like to participate in and the environmental context in which communication occurs may be important factors to consider in planning and reporting treatment outcomes.

Focusing on participation-based goals and outcomes may also clarify the effectiveness of the speech-language pathology interventions in palliative care. It may be a key factor in clearly communicating to the other members of the interprofessional team the value and impact of the SLP on the care of their patients. In some settings, weekly interprofessional team meetings are conducted to update on current patients' status. Concise participation-based outcomes orally read in this context may clarify the role of the SLP.

In current practice in the United States, many health care facilities are utilizing electronic medical records (EMRs). One of the

Table 1. Comparing impairment-based and participation-based communication goals

Impairment-Based Goal	Participation-Based Goal	Participation Outcome
The patient will type sentences with accurate spelling.	The patient will independently use text-to-speech tablet software to communicate care decisions.	The patient was able to state his preferences regarding home or skilled nursing facility placement using augmentative communication.
The patient will point to correct word from array of 20 words on the communication board.	The patient will use the augmentative communication board to effectively express end-of-life concerns.	The patient successfully communicated two end-of-life concerns with the social worker, using supported communication strategies.

goals of implementing EMRs was to enhance communication between health care providers, and documentation templates are often used to reflect the services provided (American Health Information Management Association Work Group, 2013). Ideally, the intervention templates for the SLP in palliative or end-of-life care would reflect participation-based goals. For example:

- The SLP will provide strategies for the patient to communicate needs, symptoms, and choices for care;
- The SLP will provide the patient with communication strategies to maintain social closeness with family; and
- The SLP will provide communication strategies for end-of-life emotional or spiritual conversation with the team.

Choosing brief, timely interventions

There are few documented studies of the content of verbal communication immediately prior to death (M. Erard, personal communication, December 4, 2019). However, verbal output usually significantly declines as the patient approaches actively dying. “Final words” is not the time to initiate a referral to an SLP for communication support. An SLP referral should be initiated when a member of the care team, the patient, or a family member is concerned that a patient’s communication ability limits the patient’s capacity to provide input to the medical team, participate in care decisions or meaningful life activities, or engage in social interaction. In an interview about SLPs on palliative care teams, SLP Laura Chahda stated:

We don’t get called in enough and when we do, we often get called in far too late Months or even weeks before I could have created a plan that would have affected the quality of their life at the end-of-life. (Wiseman, 2016)

The skilled SLP’s intention should be to focus on brief interventions appropriate to the diagnosis, setting, and level of severity of the communication impairment and overall physical status. In the hospital setting, a patient’s agitation and anxiety can be increased

by their frustration and fear at not being able to communicate (Garrett et al., 2007) and timely initiation of communication support is optimal. In hospice, the SLP may not be part of the core team and often is called in only on a referral basis (Centers for Medicare & Medicaid Services, 2015). Working efficiently with clients and families and communicating outcomes may prompt further referrals by the hospice team.

Speech-language pathologists in palliative care also need to anticipate change so that goals can be adjusted accordingly (Roe & Leslie, 2010). Yorkston and Beukelman (2007) provided “early-, middle-, and late-” phase communication interventions in patients with the progressive conditions of multiple sclerosis, Parkinson’s disease, and Huntington’s disease. Brownlee and Bruening (2012) conducted a 4-year survey of caregivers of persons with ALS and reported communication strategies utilized at three time intervals: 2–6 months before death, 4 weeks before death, and the last 1–2 days of the person’s life. Strategy use clearly changed over time. At the first time interval, 16.5% of persons with ALS were using electronic AAC systems to communicate, but by the third time interval, only 5% used devices to communicate.

Speech-language pathologists often need to focus treatment on preparing patients and families for the likely occurrence of significant decline in communication, as in the case of persons with primary progressive aphasia (PPA; see Mahendra & Tadokoro, 2020). Individuals with PPA need an SLP to provide brief treatment episodes at intermittent points of the disease progression to provide communication partner training and family education related to these changes (Khayum et al., 2015).

Formal communication assessment is rarely implemented in the context of palliative end-of-life care (Kelly, 2019). Experienced SLPs may evaluate patients informally and consider the context of the patient’s communication needs. Speech-language pathologists may also need to be creative in de-

veloping materials that can be implemented quickly.

An SLP visited the home of a family that was caring for their mother with a rotation of care aides and church visitors. The patient had limited communication due to her history of dementia and a recent stroke. The SLP collaborated with the family to determine key sentences related to the woman’s life history and the family provided pictures to illustrate it. The SLP educated the family how this booklet could facilitate visitors’ ability to interact with this patient. Following the patient’s death, the SLP read the obituary and discovered that many of these sentences were included.

Being present

Professionals working in palliative or end-of-life care often develop sensitivity and responsiveness to the feelings or experiences of their patients and families. Relationship-centered care is an approach to health care that recognizes that emotion is an important component of care and that care is provided in relationship with the patient (Beach et al., 2006). Goldberg (2006) provided perspective as an SLP who became a hospice volunteer and suggested talking gently with patients at end of life and becoming a compassionate listener. Bernstein (2019) advised attending to what is happening “now” with the patient without being distracted by other concerns, and caring with dignity for the patient. The SLP may come into a session with a treatment plan in mind—while also being open in the moment to what may be needed or what is being expressed. This is important in order to align the clinician’s own expectations for that session with the realities of the patient’s or family’s experience. It involves the use of a clinical mind and intuitive skills. These are valuable skills for all types of speech-language pathology intervention, but SLPs who work in palliative or end-of-life care may find the need to draw upon this strength even more. The SLP’s presence as a responsive listener may result in the patient or family expressing their concerns.

Listening to the patient's or family's concerns

Listening to a patient's concerns is a primary way to address meaningful, contextually based participation goals. A person with ALS expressed frustration that his friends still visited him but he was not able to participate in the conversation. The SLP provided him with a headset microphone and a small speaker with a long cord. When a group of friends came to visit, they could now hear him express his ideas.

Listening to a family member's concern is also a crucial way to address meaningful goals on behalf of the patient and the care provider. A patient's husband sadly expressed his daily difficulties in caring for his wife with dementia. In the following session, the SLP provided (1) a whiteboard for him to write down key plans for the day to reduce his wife's agitation and (2) resource information for a call button that his wife could push to alert him when he was outside.

These treatment outcomes directly responded to the patient or family member's immediate communication concerns. Developing a professional relationship in which the SLP attends to the family or patient as they express feelings or challenges can enable the SLP to work collaboratively toward goals that are meaningful and valuable.

It is also important to recognize when the SLP's services are not helpful or should be discontinued. An SLP went to greet a patient with dementia lying in bed. The patient became agitated, saying "Who are you?" Shortly after, the patient's daily care provider entered the patient's room. The patient clearly stated to her, "Is Jesus ready for me?" The SLP recognized that the care of this familiar provider was paramount for the patient in this moment, and the SLP did not return to the room.

ADVOCATING FOR SPEECH-LANGUAGE PATHOLOGY COMMUNICATION CONSULTS IN PALLIATIVE END-OF-LIFE CARE

At times, it is family members who may request a speech-language pathology consult

to support their ability to communicate with and care for their family member.

A patient with an end-stage disease was admitted to an acute care hospital and had a sudden brain bleed, resulting in severe aphasia. The care team recommended that the patient be discharged home to hospice. Although a family member inquired about speech pathology services, none were recommended. The family member was overwhelmed with the sudden change in their spouse's ability to communicate. The family member did not know how to manage the communication breakdowns, nor how to enlist any strategies that might have reduced the frustration and fear during their final conversations. The spouse reported feeling "helpless" as a communication partner. (AB, personal communication, 2019)

What is the consequence of having a family member come home without the tools to support their final conversations? Listening to the direct perspectives of family members in this situation can inform our understanding as SLPs. One woman stated,

The frustration and anger that this aphasia caused in my husband impaired our family's ability to cope with all the rest of our problems. It made me resent him at the very time I wanted to be loving him until the end of his life. (CD, personal communication, 2019)

Brownlee and Bruening (2012) stated that the loss of communication "can be like the loss of humanity" and provided a poignant quote from a daughter.

My Mom could deal with the loss of the ability to walk and use her hands, but she was not able to deal with the loss of communication—it would simply make her cry; this represented her biggest loss in life. (p. 178)

Position statements have been published internationally in support of access to speech-language pathology services in palliative care. Presenting this information might help the family member or SLP to advocate for services.

In the United States, Centers for Medicare & Medicaid Services (2015) guideline 418.72 states that speech-language pathology services must be available and offered in a manner consistent with accepted standards of practice. The Joint Commission (2010, p. 26)

Roadmap for Hospitals states that if a patient develops a more severe communication impairment during end-of-life care, the speech-language pathology department should be contacted.

The National Health Services England (2016, p. 8) states that multidisciplinary palliative care teams should have formal access to input by SLTs. Speech Pathology Australia (2015) advocated for information for consumers on the role of an SLP and resources for end-of-life conversations. Speech-Language and Audiology Canada (2016) developed a position paper advocating for SLPs to provide communication support for shared closeness with loved ones in end-of-life care.

However, there is not always consistent implementation of official agency positions in health care. In a summary document on aphasia services in North America, Simmons-Mackie (2018) states: "Communication access is recommended or mandated by government and national or international organizations; yet, few health care systems have incorporated communication access policies or measures" (p. 124).

According to Chahda et al.'s (2017) survey, SLPs believe that members of palliative care multidisciplinary teams do not recognize when referrals to SLPs for communication support could be helpful. They described a "self-perpetuating cycle" in which a few number of referrals limited the opportunity for the team to learn about the role of SLP with communication consults. Alan Dow, professor of medicine and director of interprofessional education, was interviewed in *The ASHA Leader* and stated: "Some health professions aren't clear as to the exact role of SLPs and how they can help people" (Volkers, 2019, p. 46).

Researchers are exploring strategies to address this. Happ et al. (2010) described a project in which the SLP led a weekly "communication case conference" with medical personnel to illustrate and reinforce communication strategies with existing ICU patients. The creation of practice guidelines for SLPs in palliative care has been recommended to de-

velop a clearer understanding of our role both for SLPs and for other health care providers (Chahda et al., 2017).

In Kelly's (2019) survey, most SLP participants did not work in a dedicated "palliative care position" and spent 1 day per week or less providing service with palliative care patients. Very few indicated there was specific funding for SLP palliative care services. In the United States, hospice is mandated by Medicare regulations to include a multidisciplinary team. An SLP is not a core participant but rather referred for services as needed. In practical terms, this means that it requires additional funds by the agency to consult with an SLP. The exact impact of this on referral patterns to SLPs is unknown.

Eva and Payne (2014) published an editorial stating that a culture in palliative care needs to develop in which rehabilitation is valued. One mandate was to strengthen connections between AHPs with research skills and those providing clinical palliative care. They also stated: "AHPs need to make the effort to participate fully in multi-disciplinary national and international palliative care conferences. At the present time, the proportion of AHPs attending such events is woefully low" (Eva & Payne, 2014, p. 311).

Establishing a liaison or working relationship with certain members of a palliative care team may result in the initiation of referrals to the SLP. This author has presented brief presentations to multidisciplinary teams at two local hospice organizations. Following the presentations, chaplains and social workers recalled patients who may have benefited from a speech-language pathology communication consult. These two fields often utilize direct interactive verbal communication to fulfill their professional goals on behalf of the clients and recognize the benefit of communication support (Pollens & Lynn, 2011; Wallace, 2013).

Other SLPs have reported offering their services on palliative care teams in hospitals. Successful models of SLPs increasing their participation in palliative care could be a valuable topic of future research, that is, how an

SLP's presence or educational efforts changed referral patterns in their palliative care setting, especially in regard to communication impairments.

Fried-Oken and Bardach (2005) recommended advancing communication research in end-of-life care by using within-subjects research designs to "define success" (p. 19) and Chahda et al. (2017) also recommended documenting successful outcomes of the SLP in palliative care. Writing palliative care goals and outcomes in relationship to the communication context may support the effort to measure "within-subject success."

This current article does not represent a defined retrospective or prospective cohort of speech-language pathology palliative care interventions. However, this article provides many case examples highlighting specific applications of the SLP's expertise for providing services to patients in palliative care and the resulting impact on outcomes.

CONCLUSION

A referral for a speech-language pathology communication consult should be initiated when a member of the medical care team, the patient, or a family member is concerned

that a patient's communication ability limits the patient's capacity to provide input to the medical team, participate in care decisions or meaningful life activities, or engage in social interaction. Most interventions by an SLP in a palliative end-of-life care context are of short duration and may be modified in response to the patient's decline in status. Experienced SLPs evaluate patients informally, determine the context of the patient's communication needs, and develop materials or strategies that can be functionally implemented. Developing a compassionate presence in which the SLP attends to the family or patient's expressed challenges can enable the SLP to work collaboratively toward goals that are meaningful and valuable. A focus on communication participation-based goals and outcomes may (1) support the patient's individualized needs, (2) address key aspects of quality palliative care, and (3) inform the palliative care team of the SLP's expertise and relevancy in communication facilitation. Ongoing research, education, and advocacy on behalf of patients who have communication barriers in palliative or end-of-life care may hopefully result in valuable skilled speech-language pathology services provided to these patients.

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