

End of Life

An Overview

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Speech-language pathologists (SLPs) provide services to patients confronting the end of life (EOL) in a variety of settings. Instead of targeting improvement of health or sustaining life, EOL services focus primarily on quality of life. Although SLPs may not consider themselves core members of the health care team providing EOL services, the ability to communicate during the final days of life can be as important as pain relief. Awareness both of the factors that influence individual and family responses to a terminal diagnosis and of the stages in the progression toward death helps the SLP make appropriate and realistic recommendations regarding communication and swallowing, counsel family members, and inform other health care professionals. **Key words:** *end of life, hospice care, palliative care, speech-language pathologist*

MOST PEOPLE, including speech-language pathologists (SLPs), know little about the end of life (EOL) until it becomes a personally relevant topic. At that time, people may seek information from countless online and print resources, but the information can be confusing and at times contradictory. This overview was written to clarify terms and basic facts about EOL, particularly as they are used throughout this issue of *Topics in Language Disorders*. Terminal illness and EOL affect all age groups, with unique professional and personal considerations for each population. This topical issue focuses on the adult population, and this introductory overview uses a *Frequently Asked Questions* format.

The nature of the services provided by SLPs lends itself to development of emotional

bonds between the professional and the patient. These bonds often provide significant rewards to the clinician and can result in a deep sense of loss when a patient dies. Speech-language pathologists employed in health care settings, such as acute care hospitals or long-term care settings, may confront patient death on a regular basis. It is reasonable to suggest that, under such circumstances, clinicians may develop symptoms of compassion fatigue similar to those experienced by other health care workers, resulting in a loss of ability to feel empathy with their patients (Joinson, 1992).

When compassion fatigue occurs, the interaction with patients may become less fulfilling. The feeling of making a difference in someone's life is one of the primary reasons cited by SLPs for entering and remaining in the profession (McLaughlin, Lincoln, & Adamson, 2008); therefore, those who no longer feel that reward may be more likely to experience burnout. It has been suggested that professionals who work with dying patients experience fewer negative effects if they are aware of factors that may create stress so they can develop appropriate coping strategies (Vachon, 1995). Although training, awareness, and experience can help professionals deal with the emotions, some SLPs may be unable to deal with the emotional issues and should avoid becoming involved in this area of practice.

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Although many universities offer courses in death and dying, these courses are typically associated with disciplines other than speech-language pathology. Few communication disorders programs offer specific coursework designed to prepare their graduates for dealing with the death of their patients. In one study, speech-language pathology and audiology students indicated that they felt such training would be beneficial but preferred to gain the information through experience or by consulting professional resources rather than additional coursework (Rivers, Perkins, & Carson, 2009). Although the actual experience of a patient's death may be necessary to truly comprehend the impact, basic understanding of the events surrounding the dying process may help ease the personal and professional toll. In particular, it may help SLPs to learn more about their roles as their patients progress from initial awareness of a terminal condition to the process of making health care decisions and perhaps to the stage of receiving palliative care.

Little research has been published regarding the role of SLPs at the end of life. This may be due in part to the perception that SLPs only deal with EOL issues when providing hospice care or that SLPs have a limited role when improvement of function is not expected. Many SLPs acknowledge that they play an important role in the quality of life for people with a diagnosis of a terminal disease, but they may not recognize their contribution to easing the process of dying. Although much of the information about EOL experiences is derived from hospice literature, as the next section indicates, most people facing end of life are not under hospice care.

WHERE DO SPEECH-LANGUAGE PATHOLOGISTS WORK WITH THE END-OF-LIFE PATIENTS?

According to data from the Division of Vital Statistics, National Center for Health Statistics (2005), the majority of people die in a hospital or medical center, with most dying as inpatients. Hospital deaths are followed in fre-

quency by deaths at home and then by deaths in nursing homes. A much smaller percentage of the population dies in facilities that provide care only to the dying. As medical care has advanced and the expected life span increased, it has become more common for people to experience a gradual deterioration of health due to a chronic illness, or an extended period of treatment for a terminal disease, rather than an unexpected death from acute illnesses and infections.

Increasingly, people diagnosed with terminal illnesses are dying at home and not as inpatients. Hempstead (2001) suggests that this trend may be interpreted in different ways. For patients with a rapidly progressing terminal illness, the trend may suggest improvement in EOL care allows them to choose where they die. Alternatively, for those dying of a slowly progressing, chronic illness, such as diabetes or heart disease, death at home may be interpreted as indicative of a lack of appropriate medical care, with at-risk patients being discharged from the hospital prematurely and without adequate counseling regarding the risks. Patients in both of these groups of patients may benefit from the services of an SLP.

Speech-language pathologists provide services to people who are dying in almost every setting, for example, hospitals, nursing homes, hospice centers, and at home. The degree and type of professional involvement depends on the diagnosis, associated disorders, and the patient's wishes.

WHAT ARE THE LEADING CAUSES OF DEATH?

The top causes of death in 2009 were heart disease, cancer, cerebral vascular disease, chronic lower respiratory disorders, injuries/accidents, Alzheimer's disease, and diabetes (Kochanek, Xu, Murphy, Miniño, & Kung, 2011). Almost any condition that causes death may result in communication and/or swallowing problems, but SLPs are probably most likely to be involved in the care of patients with a diagnosis of certain

types of cancer, cerebral vascular disease, and Alzheimer's disease. Speech-language pathologists also may work with patients with neurodegenerative disorders at some point in the disease trajectory, including conditions that affect cognitive/linguistic systems, motor systems, or both. Examples of these disorders include amyotrophic lateral sclerosis, Parkinson's disease, multiple system atrophy, Huntington's disease, and frontotemporal dementia. The timing of SLP involvement—whether it is close to or relatively removed from end of life—depends in part on the underlying disease. For instance, an SLP might be called in relatively soon after initial diagnosis if the disorder affects swallowing or speech functions. In contrast, a speech-language consult might occur later in the disease progression if questions about cognitive competence arise gradually over time.

WHEN DOES END OF LIFE BEGIN?

There is no generally agreed-upon definition of end of life or when the EOL experience begins. Perhaps, it is best defined on an individual basis. Although terminal illnesses are commonly defined as those that are fatal and have no cure, some patients may view such a diagnosis as the beginning of a fight for life. They do not consider themselves as being at the end of life until all options have been exhausted and decline is pronounced. Other patients might feel they are beginning the EOL experience when they receive the diagnosis of a terminal illness. Consideration of both the physical condition and psychological response of the patient may result in a better determination of the beginning stages of the end of life.

As professionals, we may identify the end of life or beginning of the death process as the point when patient care targets comfort and not improvement. Although terms such as “palliative care,” “hospice care,” and “end-of-life care” may be used interchangeably, these terms may also represent a continuum of care. *Palliative care* is the treatment that reduces pain, suffering, and stress, typically

when no curative treatment options are available. Not every patient receiving palliative care will have a terminal diagnosis; therefore, there may be no limit on the life expectancy of these patients and they may opt for curative treatment if one becomes available. In fact, some patients may receive palliative care services for relief of major distress caused by a treatment protocol.

In contrast, *hospice care* usually requires that the patient's life expectancy be limited to 6 months, and no further curative treatments will be provided. Essentially, palliative care is provided to hospice patients, but more extreme measures may be implemented in hospice care to reduce pain. Hospice care can be provided in any setting, and the patient may choose to be cared for in a hospice center or by hospice professionals in his home. Some people may be reluctant to enter hospice care, fearing that once they choose hospice, there is no return. In fact, hospice patients can choose to leave hospice care at any time to seek additional treatment and return at a later time. *End-of-life care* may be used to designate services provided in the last weeks of life. These services may be a continuation of palliative or hospice care, but the focus may shift. These services may target the family as much as the patient and are designed to ease the stress of the final days of life.

WHAT DOES A SPEECH-LANGUAGE PATHOLOGIST NEED TO KNOW ABOUT DYING?

The progression toward death and the events surrounding the end of life vary depending on the cause of death and the care being provided. Some people die suddenly, literally “in their sleep,” following a gradual and predictable deterioration of functioning, or even without warning. Those with gradually progressing diseases, such as patients with Alzheimer's disease, may seem to just “fade away,” with a slow deterioration of function and responsiveness. Still others may follow cycles of improvement and decline in functioning before succumbing to death.

Although the actual experience differs for each individual, there may be some patterns that SLPs should know.

Much of the information regarding EOL experiences comes from organizations that provide hospice services. The most extensive information may be based on the treatment of cancer patients. The terms “preactive dying” and “active dying” often are used to describe events that occur in the final months, weeks, or days of life. The actual events experienced by the individual patient will be influenced by the medical condition leading to death. Some causes of death will extend the preactive and active periods of dying; others will shorten or eliminate them.

Preactive dying

The duration of preactive dying is frequently estimated to be 2 weeks, but it may last a month or more (Nguyen & Ash, 2002). During this time, several signs may indicate that the body functions are in a period of rapid decline. Circulatory changes reduce the ability to heal from infections or injuries. The body and extremities may swell (Hospice Patients Alliance, n.d.). Regulation of body temperature is affected. Long periods of inactivity or sleep become more common. At times, the dying person may become restless and unable to get comfortable. As the body shuts down, the dying person may be unmotivated to eat or drink (Nguyen & Ash, 2002). In fact, eating and drinking may increase discomfort or the energy required for eating and drinking may increase fatigue among people in a phase of preactive dying. As the body weakens, the person may experience difficulty swallowing. Respiratory changes may also appear, with the dying person showing long pauses in breathing. Periods of apnea lasting several seconds may be observed when asleep or awake (Hospice Patients Alliance, n.d.).

The physical declines associated with the dying process may affect social and emotional behaviors. Persons who previously enjoyed social activities and having visitors may now become increasingly fatigued by those interactions (Amitabha Hospice Service, n.d.).

Some may be able to enjoy visitors and lengthy conversations one day but be exhausted and withdrawn the next. At some point, such individuals may wish to limit their interactions to family members. As they expend their energy, they may become irritable, anxious, and confused (Hospice Patients Alliance, n.d.).

Cognitive changes appear as people continue to deteriorate across the phase of preactive dying as the brain loses function. They may show greater anxiety and experience more frequent periods of confusion or agitation (Hospice Patients Alliance, n.d.). Some may begin to report that they see people who are not present (Hospice Patients Alliance, n.d.). During this stage, cognitive symptoms may resemble the “sundowning” experience described in patients with dementia. Their fingers may involuntarily move in a picking motion (Amitabha Hospice Service, n.d.). Some will report awareness of the picking motion and wonder why it is happening. These cognitive changes may be particularly difficult for caregivers, family, and friends to understand and accept.

Active dying

The next stage in the death process is called *active dying*. Although the duration of active dying may vary, it is typically the last 2 or 3 days of life (Nguyen & Ash, 2002). The deterioration of all functions is often dramatic during the final days. The dying person’s blood pressure may drop dramatically, resulting in their extremities developing a blue tint and becoming cold and numb (Amitabha Hospice Service, n.d.). At this stage, the person may become unable to swallow food or drink. Bowel and bladder control may be lost in those who were not previously incontinent. Urine may be darkened with greatly reduced output (Hospice Patient Alliance, n.d.).

Dramatic respiratory changes are common. One pattern often associated with the last days of life is Cheyne-Stokes breathing, characterized by several rapid breaths followed by a prolonged period of no breaths (Hospice Patients Alliance, n.d.). Other disruptions in the pattern of breathing may

also appear. As fluids build up in the lungs, respiratory rales and rattles may be heard and coughing observed (Hospice Patients Alliance, n.d.). Because the person's swallowing ability is reduced, saliva may build up in the throat and cause additional sounds associated with breathing (Amitabha Hospice Service, n.d.). These respiratory sounds may alarm family members and caregivers, but they are usually not indicative of increased pain or discomfort.

At this stage, the dying person may experience more agitation and confusion, perhaps mistaking the identity of loved ones (Hospice Patients Alliance, n.d.). Activity level declines, and the person may not move for long periods. Responsiveness continues to decline, and it becomes difficult to wake the person. The person may appear to be in a coma-like state and may become unresponsive to sounds, visual stimulation, and touch. It is at this stage that family members often wonder whether the dying person can "hear" them, and they may have questions regarding how they should talk to their loved one.

WHAT ROLE DOES CULTURE OR ETHNICITY PLAY IN END-OF-LIFE CARE?

Culture refers to those socially transmitted behavioral patterns, beliefs, and traditions that are associated with a particular group. Ethnicity is used to identify groups of people who are clustered together in terms of some common racial, national, religious, linguistic, or other unifying trait. Together, culture and ethnicity can influence attitudes toward dying and toward EOL care. Consequently, they can influence any conversations about such care, comfort with services, and decisions to follow or not to follow medical recommendations (Kagawa-Singer & Blackhall, 2001). Kobylarz, Hernandez, and Hurwitz (2008) and Hallenbeck, Goldstein, and Mebane (1996) provide helpful discussions of cultural considerations in EOL care.

When speaking about the need for culturally appropriate protocols in EOL care, Hernandez (quoted by Kobylarz et al., 2008, p. 1) states:

Our role as clinicians is to facilitate healing and ultimate outcomes, but on the basis of our patients' and their family members' definitions of these terms, and not on our own. We need to understand that in every culture, health, illness, death, caring, and healing are defined differently.

Often, what physicians describe as poor compliance is simply a product of values and concerns that emerge from a culture that differs from that of the physician's.

The same statements apply to SLPs working with terminally ill patients. It is important that SLPs understand their own cultural influences and avoid substituting their values for those of their patients. To this end, SLPs must first understand how members of patient culture view the process of dying and the dying individual, as well as the role of the family at the EOL. For example, in some Central and South American Latino cultures, the dominant values include denial of illness and secrecy about prognosis, combined with a closed family-centered care system. Needless to say, given such restrictions, it would be difficult to communicate about dying and to discuss planning for any changes that may occur in the future. Not surprisingly, hospice use is quite low for this ethnic group (Kreling, Selsky, Perret-Gentil, Huerta, & Mandelblatt, 2010). Other examples include reports that African Americans are less likely to discuss EOL care with clinicians than are White patients (Crawley et al., 2000). In fact, in some cultures, there are beliefs that talking about death actually brings it closer (Kagawa-Singer & Blackhall, 2001).

Although legal guidelines must be followed in establishing who must agree to recommendations regarding health care, SLPs should be aware of the potential effects of culture on beliefs about decision making and patient autonomy. In other words, where does the locus of control lie for decisions that are made at EOL? Is it with the physician? The health care team? The patient? There are also questions about family roles in decision making. If the patient is elderly, cultural beliefs about older adults come into play as well. Adult children may not feel their elderly parents are capable of making informed decisions about

their health care, for example, continuing to eat orally against medical advice or declining to participate in therapy to improve communication.

Cultural differences and beliefs can affect EOL care and the interaction between health care providers and the patient or family in countless other ways. No one health care provider can be an expert in EOL beliefs of all cultural and ethnic groups. However, SLPs must be sensitive to potential differences in perspectives on dying so that they can respond appropriately when loved ones and health care providers have conflicting views of care.

WHAT SERVICES DO SPEECH-LANGUAGE PATHOLOGISTS PROVIDE IN END-OF-LIFE CARE?

Speech-language pathologists can improve comfort for dying people by facilitating communication and swallowing and by counseling family members regarding expected changes in those functions. Many SLPs think of their primary role in provision of EOL services as identifying swallowing risks and determining the best and safest way to provide nutrition and hydration to dying patients. This usually requires counseling for caregivers and family members to help make feeding interactions as pleasurable and risk free as possible and to help them understand when oral feeding may increase stress and discomfort.

Although nutrition and hydration are obviously important, a means of communication may be more important. The National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care (National Institutes of Health, 2004) suggests that communication not only allows improved care but can also help reduce suffering. A means of communication allows the person to interact with friends and family, make health care decisions, and participate in EOL planning. Clinicians must be sensitive to the potential need for augmentative and alternative communication strategies toward the EOL. For those patients already using augmentative and alternative communication,

EOL communication needs must be addressed (Fried-Oken & Bardach, 2005).

In both swallowing and communication, the SLP can help family members understand the changes that are taking place as the death process affects functioning. This helps the family to understand the behaviors and symptoms that appear and reduces their concern that they should be doing more. In addition to roles in direct services and family counseling, Pollens (2004, 2012) describes the importance of the SLP as a member of the EOL interdisciplinary team serving the dying, both in considering information provided by other professions and in providing the team with information about swallowing, communication, and cognition.

In the last weeks of a patient's life, the most important role of SLPs may involve counseling the family. When and how information is provided to the family often differs depending on the diagnosis and service delivery site. Immediately after a terminal diagnosis, patients and families may be given extensive written materials or suggestions for resources that describe what they can expect at different stages of the disease. The information may or may not address communication, cognition, and swallowing. The shock of the diagnosis may overwhelm families and patients and reduce their ability to process any information provided at this time.

For that reason, professionals involved in EOL care should be prepared to provide patients, caregivers, and family members with the information they need at a time when they are able to understand it and again when they need it. For example, information about preactive and active stages of dying may be reserved until the dying person is actually approaching his or her final days. As different symptoms appear, family members may be given additional information or referred to specific portions of previously provided materials.

Although the extent of direct involvement of the SLP at the EOL varies depending upon the disease, it is important that both professionals and family caregivers be given the best information about communication, cognition,

and swallowing as these functions deteriorate. Access to all types of medical services is limited in some rural areas of the country; therefore, not all dying people and their families have access to extensive professional hospice services in their community. They may rely on professionals who have provided care throughout the course of the illness or disorder for hospice care and information about the dying process. An SLP may have established a long-standing relationship with a dying patient and his or her family. That relationship can place the SLP in a position of trust and result in the family seeking input or a second opinion when swallowing difficulties or signs of cognitive deterioration appear. If the SLP is not well informed about the expected changes at the EOL, he or she may provide input and make referrals that will cause unnecessary alarm and stress.

CAN SPEECH–LANGUAGE PATHOLOGISTS BE REIMBURSED FOR END-OF-LIFE SERVICES?

Services provided by SLPs in an acute care hospital setting are typically reimbursed using diagnosis-related group codes. In that setting, SLPs are confident that their services to EOL patients will be reimbursed. Outside the acute care setting, there may be a concern that services provided in cases for which no improvement is expected will not be eligible for reimbursement. Medicare guidelines, however, support interdisciplinary hospice care and allow services provided by SLPs that facilitate the dying person's ability to maintain daily functions and quality of life as long as possible. End-of-life care teams do not always have an SLP member but can contract for those services as needed.

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SUMMARY

Although there is no single definition of EOL, it is clear that SLPs have many opportunities to play a role in EOL care. They work with many of the disorders that cause death and in all of the settings where people die. In some instances, SLPs may be involved in the care of a dying patient in the early stages of an illness; in other instances, they may be called to serve a patient who is closer to EOL. The appropriateness of the care they provide is recognized and reimbursed by Medicare.

Because adequate nutrition and hydration are basic to sustaining life, it may be common to focus on the role of SLPs in swallowing at the EOL. For many, it is at least as important for SLPs to facilitate communication and to counsel families about communication and cognition. During assessment and counseling, patients and families may ask questions about EOL, including very specific questions about available services and/or about the actual experience of dying. Speech–language pathologists should know enough about these aspects of the EOL experience to be able to either provide accurate information or make appropriate referrals to other health care providers who can.

Not all hospice or EOL care teams include SLPs or acknowledge any role for SLPs beyond swallowing management and related counseling. Because communication is so critical at the EOL, clinicians should be proactive in offering to participate in interdisciplinary EOL care and defining their roles and the ways in which SLPs coordinate with other team members. Hopefully, this issue of *Topics in Language Disorders* provides readers with some of the knowledge needed to be a productive EOL team member in a variety of settings.

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