END-OF-LIFE CARE CONSIDERATIONS *for the* SPEECH-LANGUAGE PATHOLOGIST

Helen Sharp, PhD, CCC-SLP
Amanda Stead, PhD, CCC-SLP, CHSE

Plural Publishing
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PLURAL PUBLISHING
INC.

9177 Aero Drive, Suite B
San Diego, CA 92123

email: information@pluralpublishing.com
website: https://www.pluralpublishing.com

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Series Introduction

The Medical Speech-Language Pathology book series provides graduate students, clinicians, and clinical researchers with functional, comprehensive material to enhance practice in a medical setting. The books are designed to bolster transdisciplinary knowledge through infusion of information from neurology, pharmacology, radiology, otolaryngology, and other related disciplines. They capture our current understanding of complex clinical populations and offer expert guidance related to evaluation and management strategies. For each book, case studies are used to promote application and integration of the material, and are richly supplemented with figures/photographs and clinical resources. Each book in the series is authored by experienced professionals and content experts who are able to transform the research literature into clinically digestible information, allowing immediate application to everyday practice. This book series advances the medical speech-language pathology community by merging fundamental concepts, clinical strategies, and current theories with research evidence, with the goal of fostering outstanding clinical practice and clinical research.

The **first book** of the series set the stage regarding the environment of the medical SLP as an interprofessional team member, the clinical populations encountered by the SLP, and the foundational knowledge needed to understand and interpret neuroimaging, medication influences, and infection control precautions. The **second book** of the series is an invaluable resource on the frontotemporal dementias (FTDs), including primary progressive aphasia and apraxia of speech. It is a cutting-edge tutorial that encompasses differential diagnosis, clinical examinations, speech/language/cognitive assessments, neuroimaging findings, and treatment recommendations, with rich supplementary videos and images in the PluralPlus companion website. In the **third book** of the series, the authors harnessed their extensive clinical and research experience with people with dementia, and created a thought-provoking, practical resource. Centering their approach on dignity and empowerment, the authors reframe the traditional clinical approach, and use clinical cases to highlight the fusion of evidence-based practice with culturally responsive care. Clinical guidance is effectively enhanced by materials on the PluralPlus companion website, including photos, forms, and screening tools. The **fourth book** of the series is an innovative and masterful resource on tracheostomy and ventilator dependence. Using 38 real-world case examples across the lifespan, the authors expertly guide us through the complex clinical decision-making process. Case summaries are appropriately contextualized with foundational information and current evidence, and thoughtfully enriched with ample photographs, figures, and supplementary resources.

In this much-anticipated **fifth book** of the Medical SLP book series, Drs. Helen Sharp and Amanda Stead help speech-language pathologists navigate the complex and sensitive issues related to end-of-life care. Based on their extensive experience, the authors coach clinicians through assessment considerations, practical goal setting, and therapeutic options across communication, cognition, and swallowing. They provide expert guidance on ways to enhance positive outcomes while maintaining a focus on humility, and elevating the dignity and autonomy of the patient with a life-limiting diagnosis. With rich resources, including sample scripts, case examples, and clinical decision trees, they empower SLPs to serve as advocates for meaningful end-of-life care. Thoughtful discussions around interprofessional collaborations and practice standards inform the SLP about their roles and responsibilities in this journey with the family. This exceptional book will undoubtedly become a valuable resource for SLPs as well as students and course instructors. Through the lens of compassion, it serves as a thoughtful guide for SLPs to honor the choices of the pediatric and adult clients with life-limiting conditions.

Medical Speech-Language Pathology
Series Editors
Kristie A. Spencer, PhD, CCC-SLP
Jacqueline Daniels, MA, CCC-SLP, CBIS

Foreword

This long-needed compendium of information and advice about end-of-life care should give speech-language pathologists (SLPs) the confidence to offer skilled services to patients with terminal conditions who have difficulty communicating. As the recent COVID-19 pandemic painfully highlighted, the communication needs of individuals at the end of their life are more complex than having someone's hand to hold or seeing familiar faces on a computer screen. Many SLPs experienced frustration at being overlooked when the medical team was focused on patients' medical needs without full consideration of the importance of communication to patients' well-being. Our collective years of experience providing creative solutions to the communication challenges of adults with aphasia, ALS, and dementia and children with cystic fibrosis, cancer, and other disorders have armed us with a variety of tools to serve the unique needs of these populations. The contributors to this book have shared their insights and experiences about how to determine the conditions for optimum sensory input and the support needed for clear expression of thoughts and emotions. They provide specific examples of how to have difficult conversations, how to determine patient capacity for decision making, and how to write goals for meaningful interactions that promote the best possible quality of life during the dying process.

The adage "with age comes wisdom" may resonate with many SLPs who have practiced for 20 to 30 years. We have learned through experience, and trial and error, how to address the challenges presented by our patients as we thought, "I never learned about this in school." As young clinicians, most of us were enthralled with the possibilities of helping our clients learn to communicate better and to reach their communication goals. It was not until we encountered patients who were terminally ill that we realized we might not know what to do to support their communication needs at the end of life.

My own "aha" moment came 15 years ago at my grandmother's funeral when the chaplain of her nursing home explained that we were about to experience a memorial service developed through conversations they had had with my grandmother in the last few months of her life. The prayers and songs of the service were my grandmother's favorites, but no one in the family would have known this. Many of our last conversations with her were to encourage her to "fight the good fight" and to "keep walking and eating to stay strong." It occurred to me that this chaplain had given my grandmother and our family a great gift—a meaningful way to say goodbye. She could do this because she was not family, fraught with emotion about our grandmother's imminent passing. The chaplain was able to be a neutral and empathetic person who could ask the difficult questions, offer support, and obtain objective responses.

I realized that SLPs could and should be the neutral person to discuss important topics with patients who are terminally ill. But without specific training in how to do this, it is unlikely that SLPs, especially those newest to clinical practice, would feel capable of expanding their scope of practice in this way. SLPs need to be prepared to help patients and their families communicate about important topics at the end of life. This textbook provides practical and useful guidance for effective practices that allow patients to embrace quality of life until the very end.

Michelle S. Bourgeois, PhD, CCC-SLP
Tampa, FL

Preface

One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.

—F. W. Peabody, 1927

The purpose of this book is to cultivate an understanding of the value of caring for patients with life-limiting conditions and for anyone facing their final weeks or days of life. For speech-language pathologists (SLPs), the idea of working with patients who do not have an expectation of recovery is too often perceived as fundamentally different from the (re)habilitation work an SLP usually does. However, the SLP's core knowledge and skills in speech, voice, language, cognition, communication modalities, eating, drinking, and swallowing places us as essential service providers for patients in decline. The fundamental shift for SLPs is to adopt a palliative care approach that holds quality of life, symptom management, and the patient's goals of care at the center (Pollens, 2012). Our goal in developing this book is to empower SLPs to serve as advocates who support the rights and needs of people with life-limiting conditions to eat and to communicate from the time of diagnosis through end of life.

Throughout the book we discuss *life-limiting conditions* to encompass any serious and incurable health condition. Decline in health is a process that may take years, months, or days. The *end-of-life* period generally reflects a likelihood of death within the foreseeable future, usually months, weeks, or days. Regardless of where a patient is on the trajectory toward death, at no time is it futile for a patient to communicate with their loved ones or to convey symptoms or other care needs to their health care providers.

Woven through the book is a core theme highlighting the essential role of humility for clinicians who work with patients with life-limiting conditions and those nearing the end of life. While each chapter presents common elements of care that emerge in clinical practice, the unique needs of each patient and family are of utmost importance. We use the term "humility" with deliberate acknowledgment of the work of Tervalon and Murray-Garcia (1998), who coined the term "cultural humility" to embody a commitment to lifelong learning and self-reflection, attention to the power imbalances between clinicians and patients, the importance of active listening, and true shared decision making with patients. Each of the components of cultural humility applies to every aspect of caring for patients in every context and is of utmost importance when we have the privilege of supporting people through their final days.

One example of a way in which clinicians can embody humility is to avoid assumptions about the patient's lived experience. An example of this is to avoid the use of the phrase "suffers from" in clinical notes or case examples. We often see notes that begin with a phrase such as "Joaquim suffers from multiple sclerosis. . . . " This phrase is not grounded in the patient's perspective, but rather assigns suffering to the patient from the perspective of the clinician. Instead, clinical writing can and should simply state "Joaquim is diagnosed with multiple sclerosis . . . " or " . . . has multiple sclerosis." If the individual clearly conveys suffering through what they say or how they respond, then the clinician should report this observation, ideally using the words of the patient in a direct quote.

Although many SLPs find themselves working with individuals who do not have a pathway to recovery or cure, very few training programs address the role of the SLP in palliative and end-of-life care (Pascoe et al., 2018). This book is designed to introduce practicing SLPs and students who plan to become SLPs to the many ways in which their knowledge and skills can improve the lives of patients and their families as they face declining health and the trajectory toward death.

We recognize that training curricula are already dense with requirements, so we have designed this book so that individual chapters can be incorporated into existing coursework. We have also included teaching resources (Appendix A) to support faculty, instructors, and guest speakers with materials and examples to support the integration of palliative and end-of-life care in coursework. The activities and learning outcomes are designed to support a unit within a course such as aphasia, dysphagia, augmentative and alternative communication (AAC), counseling, interprofessional education, or professional issues. The book and instructional resources also provide a solid foundation on which to build a freestanding seminar or course in end-of-life care.

We are beyond grateful to the clinician–scholars who contributed their knowledge and experience to this book. Although social norms cast death and dying as "gloomy" topics to be avoided, in each chapter the authors have deftly captured the importance, joys, and fulfillment of clinical work with individuals who have life-limiting conditions. Each author concurrently recognizes the essential need for interprofessional team care for the benefit of patients and caregivers and as a mechanism for clinicians to manage the heaviness of this work. Every chapter includes practical tips, sample scripts, case examples, and practical advice grounded in the clinical experiences of the chapter authors. The authors collaborated, exchanged ideas, and brought the full depth of their knowledge and clinical experiences to this book with the hope that their words will inspire you to serve patients with life-limiting conditions.

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All names used in scripts and case examples are fictitious and all cases have been modified to protect patient privacy.

Contributors

Riwa Al Aridi, PharmD
Faculty of Pharmacy
Lebanese International University
Beirut, Lebanon
Licensed Pharmacist
Walgreens
The Villages, Florida
Chapter 1

Michelle S. Bourgeois, PhD, CCC-SLP
Professor, Retired
University of South Florida
National Aphasia Association
Primary Progressive Aphasia Task Force
Tampa, Florida
Foreword, Chapter 4, and Appendix B

John Costello, MA, CCC-SLP
Director
Augmentative Communication Program and Jay S. Fishman ALS Augmentative Communication Program
Boston Children's Hospital
Boston, Massachusetts
Chapter 6

Julieta Gilson, MD, FACP
Assistant Professor
University of Central Florida
Orlando, Florida
Palliative and Hospice Medicine
Naples Community Hospital
Naples, Florida
Chapter 1

Marnie Kershner, CScD, CCC-SLP, BCS-S, CBIS
Senior Inpatient Speech-Language Pathologist
MedStar National Rehabilitation Hospital
Washington, D.C.
Chapter 5

Paula Leslie, PhD, FRCSLT (U.K.), Reg HCPC (U.K.), CCC-SLP
Affiliated Faculty
Center for Bioethics & Health Law–Research Ethics & Society Initiative
University of Pittsburgh
Pittsburgh, Pennsylvania
Chapter 5

Robin Pollens, MS, CCC-SLP
Coordinator and Clinical Supervisor
Aphasia Communication Enhancement Program
Adjunct Professor
Department of Speech, Language, and Hearing Sciences
Western Michigan University
Kalamazoo, Michigan
Chapter 2

Rachel M. Santiago, MS, CCC-SLP
Clinical Coordinator and Speech-Language Pathologist
Inpatient Augmentative Communication Program
Boston Children's Hospital
Boston, Massachusetts
Chapter 6

Helen Sharp, PhD, CCC-SLP
Research Facilitator,
Interdisciplinary Research Lab in Palliative and End-of-Life Care
University of British Columbia Okanagan Kelowna, British Columbia
Chapters 2, 3, and Appendix C

Joseph W. Shega, MD
Executive Vice President and Chief Medical Officer
VITAS Healthcare

Associate Professor of Medicine
University of Central Florida
Gotha, Florida
Chapter 1

Amanda Stead, PhD, CCC-SLP, CHSE
Professor, School of Communication Sciences and Disorders
Pacific University
Forest Grove, Oregon
Chapters 2, 4, and Appendices A and B

Rami Tarabay, MD
Associate Medical Director
VITAS Healthcare
Clermont, Florida
Chapter 1

Jordan R. Tinsley, MS, CCC-SLP
Clinical Assistant Professor
Communication Sciences and Disorders
Pacific University
Forest Grove, Oregon
Appendix A

CHAPTER 1

Introduction to End-of-Life Care for the SLP

Joseph W. Shega, Rami Tarabay, Riwa Al Aridi, and Julieta Gilson

> *"To cure sometimes, to relieve often, and to comfort always."*[1]

INTRODUCTION TO HOSPICE AND PALLIATIVE CARE

Palliative care and hospice represent a continuum of health care services for persons with serious illness from the time of diagnosis of a medical condition through death and bereavement care (Figure 1–1). Balfour Mount is credited with coining the term "palliative care," which is derived from the Latin root word "pallium," which refers to a cloak or outer garment. The term palliative reflects care that cloaks or covers the symptoms of serious illness. Palliative care has been defined in several ways over time, with more recent emphasis on caring for persons with serious illness. Kelley and Bollens-Lund (2018) defined serious illness as a "health condition that carries a high risk of mortality and either negatively impacts a person's daily functioning or quality of life or excessively strains his or her caregiver" (p. S-8). Table 1–1 summarizes the terminology incorporated into definitions of palliative care from leading organizations in palliative medicine and health care, including the American Academy of Hospice and Palliative Medicine (AAHPM), Center to Advance Palliative Care (CAPC), National Consensus Project (NCP), and the World Health Organization (WHO).

Palliative care emphasizes both patient and family, with a focus on improving quality of life through the assessment and management of pain and other symptoms, achievement of the patient's goals and preferences, and coordination of care across disciplines and settings. This comprehensive approach to care addresses physical, psychological, social, and spiritual domains through an interdisciplinary team that includes a speech-language pathologist (SLP). Palliative care can be incorporated

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[1] Source unknown but attribution in the literature includes Hippocrates, a 15th-century folk saying, Sir William Osler, Edward Livingston Trudeau, and others. Often used by the hospice movement to highlight the importance of the role of care, even when a cure cannot be achieved.

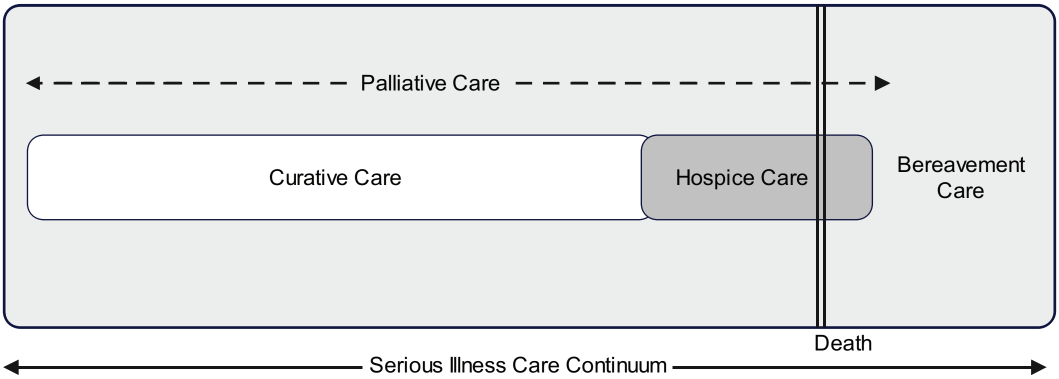

Figure 1–1. The continuum of care from time of diagnosis through death. Palliative care focuses on symptom management and quality of living with a serious illness. Hospice care is a type of palliative care offered to patients as they near the end of life. Hospice care encompasses care for the patient in the context of their family and close friends with services that extend beyond the patient's death.

at any time in the trajectory of illness, with earlier adoption as the standard of care.

Hospice is a type of palliative care and is implemented as patients approach the end of life (EoL). The term "hospice" is derived from the Latin word "hospis," meaning hosts and guests, the same root word that yields "hospital" and "hospitality." Hospice represents a service delivery system that incorporates the philosophies and approaches to palliative care with an emphasis on helping the patient transition from life to death and explicitly addresses the care of the family and other personal caregivers. A key component of hospice is to offer care in the community and in a location that the patient calls home, which can include a nursing home or assisted living.

In the United States, hospice is a defined insurance-covered benefit for someone who has a prognosis of life expectancy of 6 months or less if the illness runs its normal course. Hospice care coverage mandates specific components as part of the care model and provides a fixed rate of reimbursement for each day of care (Greenstein et al., 2019). This fixed rate (or capitated payment) covers all care related to the patient's terminal prognosis and is not adjusted for acuity or complexity of the care provided. Under United States guidelines, hospice services must also provide bereavement services for the family after the death without additional reimbursement. To access hospice care, a patient or their proxy must elect to enroll and consent to a care plan that is palliative, not curative, with an emphasis on quality of life. At any time, a patient or family can revoke the hospice benefit and resume access to traditional medical care.

Hospice care is delivered by a core interdisciplinary team that includes a physician, nurse, social worker, chaplain, home health aide, bereavement counselors, and volunteers. Other disciplines are incorporated in the patient's care as needed to achieve the palliative care plan. Other skilled services may include dietary, pharmacy, physical and/or occupational therapy, and speech-language pathology. Home medical equipment and medications are covered by the hospice program.

Patients benefit from the availability of four levels of care—(1) routine, (2) inpatient, (3) continuous, and (4) respite—with each level of care designed to keep patients in their preferred location. Confusion often exists around continuous care, which is only

Table 1–1. Language Incorporated in Commonly Used Definitions of Palliative Care

Source	Focus	Goals	Domains	Time Frame	Other
American Academy of Hospice and Palliative Medicine	Patient Family	• Quality of life • Treat disease-related distress	• Physical • Intellectual • Emotional • Social • Spiritual	Any stage of illness	• Autonomy and choice • Preferred therapies • Appropriate anytime and location
Center to Advance Palliative Care (consumer definition)	Patient Family	• Relief from the symptoms and stress of an illness • Quality of life	• Not addressed	Based on need, not prognosis	• Any age or stage • Provided along with curative treatments • Extra layer of support: Physicians, nurses, and other specialists
National Consensus Project	Patient Family	• Assessment and management of pain and other symptoms • Support of caregiver needs • Coordination of care • Assess preferences and how to achieve them	• Physical • Functional • Psychological • Practical • Spiritual	Appropriate at any stage of illness, ideally early integration in care plan	• Interdisciplinary • Offered in all care settings
World Health Organization	Patient Family	• Quality of life patient and caregiver • Relieve suffering through assessment and management of pain and other problems	• Physical • Psychological • Social • Spiritual	Life-threatening illness	• Team approach • Bereavement counseling • Human right to health • Needs and preferences of the individual

employed when a patient develops uncontrollable symptoms from an exacerbation or disease progression and incorporates a nurse or home health aide to be in the home to support a patient and family up to 24 hours a day. However, hospice does not provide nonskilled or custodial in-home care. Routine custodial care is expected to be provided by family members or by assistants a family may choose to hire. Families may be eligible for respite care, which refers to short-term (5 consecutive days) inpatient support designed to support rest and recovery for family caregivers.

Hospice services and, to a lesser extent, palliative care services, have been demonstrated in multiple studies to improve the quality of patient care at a reduced cost (Aldridge et al., 2022; Kleinpell et al., 2019). Family caregivers for hospice recipients report better pain and symptom management, increased likelihood of emotional support, sense of respect through service delivery, and overall improved satisfaction with care when compared with reports from caregivers whose family members died without hospice services (Kleinpell et al., 2019; Teno et al., 2004). At the same time, hospice care substantially decreases the likelihood of hospitalization and emergency department use without adversely impacting life expectancy, with total cost of care also significantly lower for those who receive hospice services (Kelley et al., 2013).

THE ROLE OF REHABILITATION AND RESTORATIVE CARE IN PALLIATIVE CARE

In general, the overall goal of rehabilitation and restorative care is to help patients regain physical abilities with a focus on independence. Interventions are designed to optimize function and reduce disability from health conditions and their interaction with the environment (Balen et al., 2019; Dahl, 2002). Such interventions benefit from self-management skills, adaptive equipment, rehabilitation (self-care, mobility, and functional independence), and chronic disease management. Despite the most robust interventions, patients near the EoL typically fail to benefit from such an approach and may experience worse quality of life and other health care outcomes (e.g., increased hospitalizations, emergency room visits, and health care costs). Of significance to outcomes, when services focus on maximizing function, patients and families may lose the opportunity to complete other critical life tasks such as achieving a life goal, saying goodbye to loved ones, or managing personal affairs.

Care plans that focus on palliation and quality of life frequently derive substantial benefit from therapy services that traditionally focus on rehabilitation. For example, physical therapy may be able to restore sufficient mobility to optimize ease of transfers from chair to bed or to achieve safe and efficient ways to turn a loved one to avoid painful pressure sores and to change bed linens. Similarly, speech-language pathology services can contribute substantively to a palliative and EoL care plan in a variety of impactful ways. For example, compensatory strategies that help patients maintain oral intake for as long as possible or access to alternative communication strategies enable a patient to express their needs more effectively and to participate in goals of care conversations with physicians and other team members. With these impacts in mind, hospice programs in the United States are required to provide access to therapy services that include physical, occupational, and speech-language pathology services.

Persons with serious illness often have distinct yet overlapping goals that at times may seem to conflict with one another. For example, a patient may simultaneously want to live as long as possible, be as strong as possible, be at home, and optimize quality of life despite a progressive illness with a life expectancy of weeks. While medical care teams strive to achieve all patient goals, in some cases tradeoffs must occur and are delineated through the process of shared decision making to reach agreed-upon goals of care. Such conversations help identify the type and intensity of health care services a given patient may opt to receive. Clear goal-setting is particularly important as many services may be available simultaneously but focus on and cover very different care plans.

Differentiating Therapy Services by Setting

Three commonly available services for persons with serious illness in the United States include skilled nursing facility care (surrounding a hospitalization), home health, and hospice services. Some of the key differences in characteristics are shown in Table 1–2. Skilled nursing facility services and home health may incorporate palliative care outside of an insurance or Medicare hospice benefit, but these services are not typically as comprehensive or structured to meet the specific, complex, and rapidly evolving needs of patients who are dying. Although there is certainly overlap, in general, skilled nursing facility services and home health generally focus on restorative care, whereas hospice focuses on supportive services with treatment decisions tailored and limited to those that enhance the patient's quality of life.

FACTS AND FIGURES: PALLIATIVE CARE AND HOSPICE SERVICES IN THE UNITED STATES

America's Care of Serious Illness 2019 State-by-State Report Card reported that at least 12 million adults and 400,000 children have a serious illness such as cancer, heart disease, renal disease, or dementia (Morrison & Meier, 2019). It is expected that the majority of the large "baby boomer" population (those born between 1946 and 1964) will experience a chronic illness over the next decade.

To help meet the need for palliative care, the number of hospital-based palliative care teams continues to increase. Among hospitals with 50 or more beds, 72% report a palliative care team in 2019, which is a sizeable increase from 67% in 2015 and 7% in 2001. The larger the hospital, the more likely a palliative care team exists, with 94% of hospitals with more than 300 beds reporting a palliative care team, in contrast to 62% of hospitals with 50 to 299 beds (Morrison & Meier, 2019). Rural hospitals are substantially less likely have access to palliative care, with just 17% versus 90% of urban areas with 50 or more beds (Morrison & Meier, 2019). Outpatient and community-based palliative care programs continue to increase in number but are generally limited in access due to barriers to insurance coverage and scalability.

In comparison, access to hospice care is almost universal for adults in the United States because it is a defined benefit covered by most insurers and approximately 80% to 90% of those enrolled through Medicare. According to National Hospice and Palliative Care Organization (NHPCO) statistics, 1.61 million Medicare beneficiaries who died in 2019, or 51.6% of all Medicare decedents, were enrolled in hospice care for 1 day or more (NHPCO, 2021). In general, referral to hospice occurs relatively late in the course of disease and hospice lengths of stay tend to be short. A Medicare hospice benefit defined as a prognosis of 6 months or less has an 18-day median length of service and mean length of hospice of 93 days (NHPCO, 2021).

Hospice use increases with age, and by age 85 and older almost 63% of Medicare decedents are enrolled under the hospice benefit. Despite increased use rates, significant health

Table 1–2. Care Options Available Near the End of Life in the United States

Characteristic	Skilled Nursing Facility	Home Health	Hospice
Eligibility	Qualifying hospital stay 3 consecutive midnights Skilled need: therapy services or nursing 24-hour nursing care in a facility	Face-to-face physician visit within 90 days to establish need with certification every 60 days Skilled need: therapy services or nursing Homebound except for short durations of time	Physician-certified prognosis <6 months, if disease runs normal course Palliative not curative care plan Not required to be homebound
Duration of services	1–20 days full coverage; 21–100 days partial coverage with coinsurance; >100 days no coverage Must meet the skilled need and make progress toward a goal	Limited number of visits based upon diagnosis Must document progress within the length of service allowed	Unlimited number of visits based on patient need and care plan
Location	Inpatient	Community	Community, assisted living, long-term care
Payment	Medicare Part A	Medicare Part A	Medicare Part A
PT/OT/Speech	Restorative	Restorative/functional	Functional/palliative
Palliative care	Infrequent	Infrequent	Always
Medications	Yes	No	Yes
Equipment	Yes	No	Yes
After-hours staff availability	Yes	No	Yes
Physician available	Yes	No	Yes
Bereavement	No	No	Yes

disparities are evident in hospice utilization statistics, with 54% of White Medicare beneficiaries, 43% of Hispanic Medicare beneficiaries, 41% of Black Medicare beneficiaries, and 38% of Asian American and American Indian/Alaska Native Medicare beneficiaries who died while enrolled in hospice (NHPCO, 2021).

ESTABLISHING GOALS OF CARE

The field of medicine generally focuses on the diagnosis and management of diseases, with little incorporation of patient preferences or priority-aligned decision making that considers individualized goals of care. This is particularly relevant in palliative care and hospice, as serious illness studies document that the health care patients experience is often not consistent with their values (Khandelwal et al., 2017). Patients' health status influences the intensity and focus of health care, with the relative emphasis on patients' wishes and values increasing as life expectancy decreases and as the focus of care shifts from hospital-based cure or restorative goals to quality of life or palliative goals of care. Research with patients nearing the EoL finds that patient's goals include individual preferences for care (e.g., being at home), pain and symptom management, emotional well-being, being treated with dignity, clinical adherence to treatment preferences, and time with loved ones (Meier et al., 2016). Engaging in care goal conversations over time facilitates a patient-centric approach that integrates the patient's values, wishes, and priorities in the context of medically appropriate treatment through shared decision making (see also Chapter 3).

Differentiating Goals of Care From Advance Care Planning

One common area of confusion is the difference between "goals of care" conversations that focus on current and ongoing medical decisions and "advance care planning" that serves as the care plan should the patient not be able to make decisions for themselves. For example, advance care planning can lead to the creation of an advance directive that outlines the care one would want when diagnosed with a life-limiting condition and the inability to communicate one's wishes (e.g., living will), the appointment of a health care power of attorney to make health care decisions should one become unable, and wishes related to cardiopulmonary resuscitation. Although goals of care conversations may focus on advance care planning, the primary goal of goals of care discussions are to clarify what patients and their families value most and to facilitate the creation of a care plan to support those goals.

A goals of care conversation aims to support informed decisions based on the patient's values and preferences. Goals of care may focus on the benefits and risks of any of the following areas of decision making:

- the approach of care, such as skilled care with intensive rehabilitation versus hospice with palliative-driven interventions
- the location of service delivery (role of hospitalization or intensive care unit [ICU] care versus care delivery at home with hospice support)
- decision making about whether to continue current nonpalliative therapies such as a ventilator, chemotherapy, or any other treatment or medication regimen
- decision making about prospective or proposed assessments and treatments, such as a new chemotherapy or initiating dialysis

As the care team discusses the patient's preferences and undesired side effects or other burdens of treatment, it is critical to provide clear guidance that if certain treatments are stopped (or not started), the intensity that surrounds *care* is never stopped.

A patient and family may express multiple goals that they want to be met concurrently but are not possible to achieve simultaneously. Such apparent conflicts may create uncertainty for clinicians about how to incorporate the patient's goals into a feasible care plan. In these circumstances, clinicians provide ongoing support and clear communication to help the patient identify their priorities. Through counseling and discussion, clinicians work to support patient understanding that certain goals may need to be sacrificed to meet other goals with a higher priority.