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Understanding End of Life Practices: Perspectives on Communication, Religion and Culture

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Chandana Banerjee
Editor

Understanding End of Life Practices: Perspectives on Communication, Religion and Culture

Springer

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Preface

Death is that one thing that unites us across our faith, politics, religion, and culture. As mortals, we will one day part from this earth, leaving behind everyone and everything, material or personal. How death comes to welcome each one of us will be determined by many things including our destined fate combined with a stroke of luck or tragedy. Our journey is unique to each one of us no matter how simple or complicated our deaths might be.

Death and dying take both understanding and courage. Our understanding of each other's wishes, cultures, traditions, and perspectives on death is important in how we approach and help others during the end of life. Courage is instrumental in ensuring that whenever possible, death is peaceful, respectful, and acceptable. To find strength in the face of pain and suffering is the courage we all must find when talking about death and dying with our families, our patients, our friends and even with ourselves.

This book is an exploration, in the voices of the writers, of three domains important in understanding death and dying. These chapters seek to educate clinical and non-clinical providers so that they may have the tools and the knowledge on how to care for their patients at the end of life. The first section explores communication, cultural competency, decision making practices, grief and bereavement, end of life conversations in multiple settings, prognostication, and nursing practices as they apply to end of life. The second section takes us through a journey through various religions and how death and dying is viewed and practiced in each of them. The final section is an attempt to highlight the various innovations and modern-day practices surrounding death and dying, from Medical Aid in Dying, to Living Wakes and Death Doulas.

My hope is that you will read this book with curiosity and an open mind and embrace the differences and similarities we have as individuals and communities. I hope this book also serves to educate clinicians and non-clinicians to understand and accept the importance of end-of-life practices and the importance of communication around end-of-life care to provide empathetic, compassionate care for all those at the end of life.

Stay well, go well…

Duarte, USA — Chandana Banerjee, MD, FAAHPM

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Part I

Communication and Cultural Competency in End of Life Care

1 Redefining Cultural Competency: Practicing Cultural Humility

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1.1 Introduction

Cultural competence remains a cornerstone to our health care delivery system in the United States as our population becomes more diverse; requiring a unique understanding of individual cultural perspectives as they relate to personal health. The understanding of diverse health care needs across the care continuum proves essential to the patient's care experience. Traditionally, cultural competency is viewed as a concrete, linear, and measurable skill that facilitates provider and patient interactions in the health care setting (Prasad et al. 2016). It centers on other-based knowledge as its core guiding principle. The civil rights movements in the 1960s and 1970s drew greater attention to this concept, serving as a springboard for later integration into health care and other human services (Campina-Bacote 2018). As the current political and social climate continues to shift in the United States, the principles of diversity, equity, and inclusion persist in daily news feeds, the workplace, and in schools. This begs the question whether straight-line cultural competence proves adequate given the current needs.

Tervalon and Murray-García [1] initially coined the phrase cultural humility as an alternative and further encompassing paradigm to the existing concept of cultural competence. Viewed as an ongoing process, the concept of humility engenders a consistent commitment to self-reflection and re-evaluation within the health care setting. This constant self-dialogue renders a richer patient-clinician relationship and seeks to elevate the overall patient experience by extending beyond the technical tenets of cultural competence. The finality of cultural competence limits the facilitation of life-long learning and reflective practice, as one can never be fully competent in another culture (Greene-Morton and Minkler 2020). Additionally, cultural humility's emphasis on recognition and reflection on personal biases, better position clinicians, given the current social context, allowing for a more fluid approach to patient care. This chapter will examine cultural humility as a practice of self-awareness and self-reflection by owning one's own personal bias and leaning into being culturally confident. We will define what it takes to understand the practical application of cultural humility and sensitivity while learning how to role model cultural humility for others during the end of life and within the health care setting. We acknowledge that diversity is multifaceted and can include an individual's lived experiences, beliefs, values, language, gender, sexual orientation, intergenerational transmission of values and level of acculturation and much more. For the purpose of this chapter, we will focus on race within the cultural humility model.

1.2 Historical Context for Cultural Humility as a Core Element in Healthcare

To better understand the significance and the role culture plays within patient care, we must first understand the historical, social context and social contract in which medical care is subscribed to and whom it excludes. Racism categorizes people based on race, color, ethnicity, and culture, to differentially allocate societal goods and resources in a way that unfairly disadvantages some, while without merit, rewards others (AAFP 2010). As a system, racism has been institutionalized in a way that permits the establishment of patterns, procedures, practices, and policies within organizations that penalizes, and exploits people based on race, color, culture, or ethnic origin. Racism affects the attitudes, beliefs, and behaviors of one individual towards another (personally mediated), as well as how individuals perceive themselves (internalized) (AAFP 2010). The impact of institutionalized racism can be seen within health care and its direct effect on patient care.

Significant data strongly suggest most of the healthcare, public health personnel and researchers operate from a pro-white framing which includes normalized notions (e.g., stereotypes, images, narratives, ideologies) of biologically and culturally distinct racial groups. This is linked to discriminatory practices accounting for institutionalized inequalities in healthcare and health [2]. This systemic racism framework encompasses attitudes and behaviors of racist ideology which are emphasized in other theories of “race,” including array of biased emotions, visual images, sounds of accented language, interlinking interpretations and narratives, and inclinations to discriminate. The framework and practice of cultural humility inherently acknowledges the gap of inclusion and perceived racial and cultural inferiority within healthcare. It also allows space for individuals and institutions to reflect and reevaluate, when disparities are acknowledged; but the efforts put forth, do not result in the intended outcome. Cultural humility as a continuous practice, acts as a starting point to acknowledge disparities within healthcare and strives to provide culturally inclusive care. No population, race, or culture is monolithic. Every individual is different and has different beliefs, value systems and lived experiences. As we work with a diverse patient population and increasingly diverse providers and medical staff, practicing cultural humility is even more necessary. This is needed in an effort to earn trust, for all providers, even with same-ethnic identity, same-gender medical providers and patients, while collaborating to provide patient- centered care.

1.3 Cultural Humility and Behavior

Cultural Humility is a practice and framework that centers the patient in the center of their care. The term “competence” versus “humility” insinuates that an individual can be or become competent in another individual’s culture. The American Association of Colleges of Nursing (AACN) cites the California Endowment’s definition of cultural competence “as the attitudes, knowledge, and skills necessary for providing quality care to diverse populations.” In practice, cultural competence resides at the intersection of empathy and awareness—of both self and other—and in its broadest form, it encompasses knowing self and others when delivering care. Thus, cultural competency has been challenged for its failure to account for the structural forces that shape individuals’ experiences and opportunities. Culture continually evolves. It is a living, breathing aspect of one’s life that is layered and

Table 1.1 Cultural humility and behavior

Cultural humility can look and sound like:

1. Can you share what is most important for you to receive out of this treatment and partnership with your medical team?
2. What/ who are some key factors/ people that you take into consideration most when making decisions about your care?
3. Can you share if the plan we discussed is aligned/ can adapt to your home, family, or work life system? Would it be feasible financially?
4. Our appointment time is ending, is there anything else that is important to you that we have not addressed?

Note Questions developed by authors White, B., Gallo, M., Morales, A April 2021

steeped in an individual's values, beliefs, gender, age, geography, spirituality, and faith.

The concept of cultural humility accounts for the fluidity of culture and challenges of both individuals and institutions to address socio-economic and racial inequalities [3]. Cultural humility is a concept and awareness practiced by externalized behavior. This behavior requires a clinician to remain both open and curious minded when providing care to patients and families, and courageously leaning into what may feel uncomfortable. Additionally, it acknowledges that recommended interventions may not be feasible for patients, nor compatible with their values and wishes (Table 1.1).

1.4 The Practice of Cultural Humility and *Self-awareness*

To practice cultural humility requires clinicians to understand their own identities and have insight of their own internal biases, identity and lived experiences. This requires emotional regulation, awareness, and acknowledgement when clinicians interact with patients and families. This internal act encourages and illuminates a conscious recognition of the clinician's biases, stereotypes, and assumptions as they relate to the patient's and family's values. This practice of self-awareness allows the clinician to be mentally and emotionally present with patients and view them holistically throughout their care journey. When in practice, it influences a relationship of agreement and alignment between the patient and clinician resulting in the formation of a partnership rooted in cultural humility and developed with the needs and cultural values of the patient within the center of the partnership. Cultural humility is essential to creating a partnership that honors individualized and comprehensive care (Hughes et al. 2020).

Currently, the practice of providing individualized and comprehensive care, involves the application of culturally competent guidelines and accreditation standards that integrate the use of cultural assessments of patients' cultural beliefs, values, and practices [4]. While conducting a cultural assessment is important, the continuous awareness and practice of cultural humility ensures the clinician's continuous learning. Cultural assessments provide clinicians with valuable insight they can use to adapt interventions that honor both patients' culture and traditions, enabling patients and families to feel heard and understood. In contrast, the practice of cultural humility opens the door to improved communication through a fundamental demonstration of respect, while earning trust.

During discussions of treatment planning, clinicians identify what is most compatible, feasible and aligned with patient values and wishes. This acknowledges the components that make up a patient's values such as culture, family dynamics, economic status, beliefs, and spirituality can interplay within an individual's decision making. Therefore, it is essential that these components are acknowledged as an equally significant factor as clinician's partner with patients, in every phase of their care. The practice of cultural humility with patients and families has proven to develop mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations [1].

Cultural humility disrupts the historical power dynamic between a physician and/or clinician and the patient/family. This historical dynamic acknowledges the clinician as the expert, and solely identifies this as the most significant factor in determining patients' plan of care. In this dynamic, the clinician is the authoritative figure within the patient—physician relationship [5]. Cultural humility places the patient at the center of care and recognizes the patient is the expert of themselves with the right to self-determination in care planning. Cultural humility creates a space for the patients' wishes, values and other elements that shape their wishes and values, such as culture, spirituality, and life experiences to be acknowledged and considered when planning and providing care.

1.5 The Practice of Cultural Humility and *Self-reflection*

Cultural humility is a lifelong process of self-reflection and self-critique. The beginning of this approach requires clinicians to carefully consider their own assumptions, beliefs and goals of patient care first, rather than examining patients' belief systems. This exercise sensitizes clinicians to the special needs and vulnerabilities of different populations with the goal of providing accessible and appropriate care and services to all. This ultimately requires clinicians to step outside of themselves and be open to others' identities and lived experiences in a way that acknowledges the patient's authority over their own experience. In this model, the most serious barrier to culturally appropriate care is not a lack of knowledge of the details of any given cultural orientation, but the providers' failure to develop self-awareness and a respectful attitude toward diverse points of view and values (Fletcher 2007) (Table 1.2).

Table 1.2 Self-awareness and reflection exercise

1. What culture(s) do you identify with?
2. What are your own values and beliefs? Do they differ from your cultural or familial values and beliefs?
3. Are you aware of your personal biases and assumptions about people with different values than yours? What are they?
4. How may your biases show up verbally or in your body language when speaking with people with different values than yours? How do these behaviors come into play with patients while providing care?
5. Have you ever been given feedback that you may be biased? Has it impacted patient care?

Note Questions developed by authors White, B., Gallo, M., Morales, A April 2021

1.6 Cultural Challenges in Ethnic Minority End-Of-Life Care

A meta-analysis of ninety-four studies of ethnic minorities with cancer found that Latino cancer patients living in the United States noted unique challenges for end-of life care such as denial of disease progression or death, isolation due to holding prognosis in secrecy, and influence of a family-centered system for medical decision making [6]. Across diverse ethnicities, acculturation issues also give rise to a lack of understanding prognosis, planning for advanced care, increased medical mistrust, and a greater hold on specific religious practices and cultural beliefs that may impact end-of-life decision making [6]. The most difficult cultural challenge found when providers are having prognosis conversations with Latino patients is the refusal of accepting their diagnosis due to the cultural practice of not talking about death or grief to maintain hope. Furthermore, there is a belief that talking about a poor prognosis damages the alliance between the provider and patient, as it is perceived to take the focus away from hope and survival [6].

These realities pose questions such as “Does this mean some ethnic minorities such as Latinos prefer less or more information about their diagnosis and staging?” The answer to this question may vary across family dynamics, gender, age, religious beliefs, and identified language. In the United States, Latino cancer patients who are immigrants with limited English proficiency are more likely to be unaware of their cancer stage and prefer less information about their diagnosis and prognosis than non-Latino patients due to cultural taboos or influences [6]. These considerations can become challenging crossroads for clinicians, and it takes the practice of awareness, compassion, and a diligent manner of asking important questions that will inform culturally sensitive communication.

The practice of cultural humility is even more challenging when providing end-of-life care as it can be viewed as one of the most emotionally charged aspects of the care continuum. During this delicate time, ongoing, open, honest, and clear communication is essential amongst the medical team, patient, and family. In this phase of care and often poor prognosis (medically deemed to have six months or less to live), limited treatment options, recommendations for comfort care and/or recommendations for hospice are communicated to the patient and family. This

Table 1.3 Leaning with compassion and cultural humility at end of life

1. If you were nearing the end of life, what would you want your last moments to look like? Where would you want to be? Does this place have the space necessary to manage your medical needs?
2. How do you and or your family deal with death? Do your values at the end of life differ from your family's?
3. Are there any rituals and spiritual practices that you and or your loved ones would like to have performed?
4. Is there anyone in the family that may need help in freeing up their time so that he/she/they may be physically present with the patient? For instance, Paid Family Leave, or a letter of advocacy for their employer?
5. Logistically, this is what you can expect from our medical team, do you foresee any challenges in being able to carry out this agreed upon plan.?
6. Is there anything that is important to you, that I did not ask about?

Note Questions developed by authors White, B., Gallo, M., Morales, A. April 2021

information can induce an emotional reaction; it may create and or increase feelings of shock, fear, angst, anger, sadness, and grief. The display of these emotions or lack of display of emotions, can vary amongst individuals and cultures. Some cultures request providers not to use the word "death" or "cancer" as it is not aligned with some religions, belief system or their effort to protect the patient by not directly disclosing the imminence of end-of-life.

Cultural humility plays a key role within end-of-life care when discussing wishes and values and end of life planning with patients and families. It is essential to discuss the patient's preferences, last requests, special visits, etc., if they are nearing end of life. Some patients value being at home, surrounded by family, friends, and loved ones at the end of life. For some patients and families, they may subscribe to the belief that if someone dies at home, their soul will be trapped within the home and remain as a ghost. For these individuals, the preference is to remain at the hospital or in an alternative facility, other than their personal home. Arranging end of life care takes time, coordination, collaboration, and an interdisciplinary approach amongst the medical team. During this time, it is important to lean into compassionate curiosity to honor patients' wishes and values at end of life and allow them the time to carry out any end-of-life rituals and practices, plans or goals that hold cultural significance to them (Table 1.3).

1.7 Building Cultural Confidence: Get Comfortable with Being Uncomfortable

A patients' trust in the provider is activated by the clinicians' abilities to actively listen, use appropriate body language, know the patient's culturally influenced words to communicate, and be flexible and sensitive to the patient and their family's unique needs, beliefs, and practices [7]. The life-long practice of cultural humility can help build this trust by strengthening clinician's confidence in delivering culturally sensitive communication. A systematic literature review of

Table 1.4 Get comfortable with being uncomfortable

What does uncomfortable look like?	Non-verbal and verbal displays of feeling comfortable with the uncomfortable
1. How we position our bodies often displays our level of comfort (i.e., folding arms, dropping your head, keeping your eyes fixed on your computer or paperwork) 2. What verbal ques do you use to start your communication? (i.e., starting with a sigh or "um," not connecting with the patient first but leading with medical update, extensive use of medical terms without an awareness of the patient's level of health literacy) 3. Your body reactions can often display discomfort (i.e., folding of arms, eye-rolling, hands on your hips, hands on your head) 4. What are some behaviors that you display when you feel uncomfortable?	1. Find a time and place where you can sit at the same eye-level with the patient. Sitting down at a table may be a good option or pulling a chair to sit down in the patient's room. This can be a positive way to gesture your readiness to communicate and indicate dedicated time 2. Keeping a calm and present demeanor and tone 3. Demonstrate willingness to adjust your own behavior by being observant to follow the patient's lead- if the patient moves closer or looks you in the eyes, do the same 4. Be aware and practice creating your own practical style to demonstrate greater sensitivity 5. What are some of your own behaviors that demonstrate comfortability in an uncomfortable situation?

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thirty-seven relevant research papers from 1995–2017 revealed that the concept of cultural sensitivity first starts with "developing an understanding of one's own cultural beliefs, values, attitudes and practices and those of others" this awareness allows individuals to then learn about other cultures [7]. This finding reiterates the importance of cultural humility as the precursor to culturally sensitive communication. It is also important to recognize that cultural humility helps clinicians recognize if their lack of understanding of how to practice cultural humility is a factor associated with their perceived difficulty in having conversations about diagnosis, prognosis, and end-of-life (Table 1.4).

1.8 Implications of COVID-19 in Practicing Cultural Humility at End-Of-Life Care

The COVID-19 pandemic swept the world and significantly impacted every system within society, the economy, education, government, housing, and especially health care. Millions of people died, unexpectedly to the virus within the United States. Identified vulnerable populations, such as individuals who are immunocompromised and have preexisting illnesses (including cancer, and respiratory diseases) were deemed as high risk. This has left many cancer patients vulnerable and has greatly impacted treatment planning and collaboration with patients and families. Hospitals have had to review their safety measures and precautions, including limiting the number of visitors in their institutions. This resulted in some hospitals having either a no-visitor policy or having to limit the number of visitors the patient can have to accompany them within the hospital. This meant patients could not have their spouse, friend, or loved one physically with them, while undergoing treatment within the hospital.

1.8.1 Reflection

Could you imagine not feeling well, or feeling anxious about medical procedures, or lab results and not have the person of your choosing be able to physically be in the room with you to receive important updates? What are some feelings that would come up for you?

Clinicians have witnessed increased distress with patients, caregivers, families, and staff due to the implications of COVID within medical care and especially within end-of-life care. Logistically, as families and/or caregivers are not allowed to enter the hospital, providers are calling the identified caregivers/responsible parties and teleconferencing them to be involved in the appointment to provide additional support for patients. This is aligned with recognizing not all patients base their decision making for treatment on westernized notions, and that decisions are not always made individually, and yet, some rely on community, guidance, or the blessings from elders, their partners or family when making medical decisions regarding treatment. The inclusion and coordination of additional individuals have and can, add additional time to the encounter, for the medical team to ensure informed consent or informed refusal to care.

Providers and staff are now having to give updates multiple times to patients and family members. This can delay the decision-making process for some patients. There are increased complications in coping through hospitalizations for some patients. For patients who are in the hospital for extended periods of time, this has induced feelings of distress, angst, isolation, and restlessness in not being able to have physical contact with loved ones. Institutions have tried to remedy this circumstance by creating alternative means of connection and support for patients through the utilization of technology i.e., iPads, video conference calls, telemedicine, and other secure video platforms. However, access to this kind of technology is not a reality for all. This proved to be even more challenging for patients and families who are unfamiliar with this technology, do not have access to computers, smartphones or iPhones or households who do not have access to stable home internet nor the actual technology.

This economic barrier to access to technology exacerbates the challenges in communicating, to the patient's emergency contacts/ designated medical decision maker, the medical status, needs, and recommendations for a patient; if the patient themselves are altered mentally, cognitively disoriented, or sedated. Families could possibly go days to weeks without seeing or speaking to their loved one. Families have now become solely reliant on the communication of the physicians and hospital staff in receiving updates of their loved one's medical status and planning for treatment and end of life care, if needed. This has left families in increased distress and even disconnected in not being able to witness the patient's decline and limited functioning at end of life.

1.8.2 Case Scenario

A 66-year-old married, English and Spanish speaking, Afro Latina who immigrated from Panama, diagnosed with breast cancer, came into the emergency room for increased pain. Following an assessment, she was admitted to the hospital. Upon further testing, the patient was found to be positive for COVID-19 and her primary cancer had metastasized to her bones and lungs.

Within days, the patient became altered and disoriented and was medically deemed to be nearing end-of-life. The medical team did not recommend any further curative treatment, as it was believed that further care would prove to be futile. The medical team's ultimate recommendation was comfort care and transition to hospice. This patient was married to her husband of 48 years with 6 adult children, 13 grandchildren and 2 great grandchildren. She identified herself as a woman rooted strongly in her Christian faith and did not have a completed advanced directive on file.

Pause- Points to Consider: *What are some of the patient's values? How would you further explore the patient's values in the context of end of life? How could these be included when discussing disease progression and end of life care with the patient and her family?*

On her first day of admission, she stated that she wished to live for her family and consistently shared her wish to move forward with life extending treatments. These were the wishes and values her family has known her to uphold. As the patient declined, she became nonverbal and all medical updates and requests for decision making were communicated to the spouse via telephone. As the family tried to process the abrupt and significant change in the patient's medical status, they were flooded with feelings of shock and disbelief, along with feelings of grief and anger. The family actively engaged with the medical team, displayed a high level of attentiveness, and asked thoughtful and appropriate questions while carrying underlying feelings of mistrust towards the medical team. After multiple goals of care and end-of-life conversations, the medical team acknowledged that they could not provide absolute assurance that death was imminent. They also were uncertain if trying another treatment would provide additional comfort, improve the patient's orientation, or extend life. This left hope for the family. They made the decision on behalf of the patient to continue the goal of extending the patient's life.

With misalignment between the recommendations of the medical team and values of this patient and family, the medical team deemed and verbalized to their colleagues, their belief of the family to be aggressive, difficult, and in denial of the patient's possible recovery. Thus, the medical team decided to escalate the case to ethics for futile care considerations. The negative perception the medical team had of the family allowed little room for a more compassionate, empathetic, tolerable, and understanding response towards the family. The implicit bias the medical team had of this family, in their perception, validated their reasoning to take the case to the Ethics committee. They were prepared to override the families wishes of continued curative treatment and place the patient on comfort care. The medical team's implicit bias of this family, led to the initiation of escalated behavior toward the family that systematically disregarded their wishes through institutionalized policy. This heightened the family's feelings of disrespect, lack of support and mistrust toward the medical team. It was not until the patient was actively dying, that the family was amenable to moving forward with hospice care. This decision was made so that the family could physically surround the patient in her final moments with their presence and prayer.

Pause- Points to Consider*: What narratives and bias might the providers have of this family? Has it impacted how they provided care, communicated with the family, and influenced what systems are activated for this family? What systems of support could have been utilized for the providers, to ensure emotional regulation and consultation to partner effectively with this family?*

Once family members were reunited with the patient, they reported feelings of shock and needed time to process and adjust to the patient's physical presentation at the end of life. They reported this was a significant change in appearance and orientation of the patient over the span of six days since her initial admission to the hospital. Loved ones commented that physically seeing the patient during her hospitalization would have prompted a quicker decision to enroll onto hospice, which would have allowed the family more time with the patient in her final days. The patient died one day later after she was discharged onto hospice. The family shared that they were able to be at bedside with the patient and perform their familial and spiritual end of life rituals with the patient through prayer, community, and adornment of the body. During grief and bereavement follow up with this family, it was noted how implicit biases of the medical team, the activation of systems to act against the family's values, the lack of support and respect they felt they received from the medical team, and the racism they experienced, further complicated their grief after the patient died. Each immediate family member viewed the death of their loved one, compounded by the institutional racism, lack of cultural humility and disregard for their familial values, despite their advocacy, as one of the most traumatic events in their life.

Pause: Points to Consider*: What challenges in this case would you want addressed as a team internally? What work would you do to reflect and explore the implicit biases that came up for you and the behavior(s) that may have prevented you from practicing cultural humility effectively with this family? How would you request feedback from colleagues and other disciplines regarding opportunities of growth presented from this case?*

1.9 Conclusion

The practice of cultural humility is a commitment that supersedes the clinician's professional practice. The ability to recognize our own biases, culture, and values creates a foundation for more compassionate, empathetic, and honest relationships. In the patient, family and provider relationship, there are many factors that impact the kind of relationship we would want to create and role model for providers. Cultural humility opens the door to treating others as we would want ourselves and loved ones to be treated in the most difficult times. During times of crisis and high distress, cultural humility and specifically the behaviors of self-awareness, self-reflection and compassion, becomes even more important in partnering with patients and families to provide patient centered care; as timely decision making may be needed to honor the patient's values during their care journey. Planning end of life care requires each provider in the healthcare team to develop a foundational relationship of trust and compassion with the patient and family. The Covid pandemic further highlighted that the skill of cultural humility becomes even more paramount for an effective partnership with patients, families, and the medical team; especially when communication is challenged. This is essential to drive the deeply required honest communication needed to define the care and comfort patients and families need, during their most vulnerable times of need in their medical treatment.

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Cultural Competency Models at the End of Life

2

Noah Pujanes-Mantor and Sorin Buga

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2.1 Introduction

Ethnic and cultural differences greatly influence the way healthcare services are used. Research indicates that minority ethnic groups underutilize end-of-life services. It became evident that in order to serve the unique needs of patients, healthcare professionals needed to understand the importance of cultural differences by valuing, incorporating, and examining their own values and beliefs, as well as their healthcare organizations in providing support and respect [1].

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It is absolute that there is an increasing requirement for cultural competency concerning improving end-of-life practices. Healthcare providers must clearly understand the cultural influences that affect a patient's attitudes, behavior, and preferences surrounding end-of-life care. Cultural influences impact the way patients and families react to the dying process. Open conversations about death and dying are not acceptable in many cultures, some believe it to be bad luck. In some Asian cultures, the dying loved one is protected from knowing the prognosis with the extended family participating in goals of care discussions and decision-making. Managing symptoms such as pain is also an important part of end of life care; however, beliefs that pain is a sign of a test of one's faith or punishment may prevent request for pain relief. It is also important to consider the role of faith and spirituality in the perception of death and dying and partner with spiritual leaders according to the patient's wishes.

Although it is essential to be cognizant that a person of an ethnic group does not always mean the beliefs of the associated group are practiced, also keeping in mind how long they have been in the United States, levels of education, and experiences. Cultural competency is essential in obtaining a thorough assessment to identify unique needs and how to address them appropriately.

Cultural competency is an evolving commitment and active participation in the process of cultural awareness, cultural knowledge, cultural skills, cultural collaboration, and cultural encounter, providing the opportunity to deliver individualized care within the cultural context of the patient [2]. According to [3], the following key elements are required for healthcare providers to commit to ongoing learning to enhance services: ***cultural desire, cultural awareness, cultural knowledge, cultural skill, cultural collaboration, and cultural encounter.*** The desire of becoming culturally competent, aware, and sensitive to cultural beliefs and practices, learning and understanding the various ethnic groups and their values, partnering with the patient and family, and active engagement in culture are essential elements to consider during assessment [3]. With the knowledge that culture is a significant influence in behavior towards illness and the provision of healthcare, these considerations will allow providers to treat patients with dignity, respect, and quality care [2].

End-of-life services involve healthcare providers having difficult conversations with patients that can be challenging due to a number of variables, including the comfort level of providers, their tenure, training, and expertise. More importantly, the challenge often stems from cultural differences between the patient and the healthcare providers, particularly surrounding end-of-life care. With this knowledge, the need for cultural competency became imperative and clear in delivering exceptional care.

Cultural competency models fall under two categories: those designed to teach healthcare professionals, and those designed to utilize in assessment of cultural backgrounds of patients [2]. The following are examples of Cultural Competence Models that are currently used in healthcare.

2.2 The Sunshine Model

The Sunshine Model was developed by a nursing theorist, Madeleine Leininger. Leininger was an administrator, author, educator, researcher, and theorist, whose concept of transcultural nursing created an impact in how we provide care for patients with different cultures and backgrounds. Through experience, Leininger observed that the recurrent behavioral patterns were culturally based. It was then realized that the lack of cultural and care knowledge that is essential in supporting patient compliance, healing, and wellness prompted Madeleine Leininger to develop the Culture Care Theory.

The **Transcultural Nursing Theory** or **Culture Care Theory** is used to evaluate, integrate knowledge, and understand various cultures related to healthcare practices, beliefs, and values. The concept allows the opportunity to provide meaningful care to patients emphasizing on caring behaviors, health values, and cultural beliefs.

The model demonstrates the cultural care worldview that flows into cultural and social structure dimensions of individuals, families, groups, communities, and institutions in healthcare systems. This knowledge provides a perspective of varying factors that affect decisions about care and health. The aspects of culture considered include religion, financial, educational, social, political, legal, as well as philosophical dimensions. Awareness of patients' physical, spiritual, and cultural needs contributes to desired clinical outcomes.

Avoiding the stereotyping of patients is critical, and to accomplish important goals the Leininger Sunshine Model uses three major culture care concepts: maintenance/preservation, accommodation/negotiation, and repatterning/restructuring.

Maintenance/Cultural Care Preservation includes supporting actions and decisions that will help preserve the individual's care values in order to maintain their well-being, face illness or death. *Cultural Accommodation/Negotiation* includes actions and decisions that help patients adapt or negotiate satisfying health outcomes with providers. The *Culture Care Repatterning/Restructuring* includes actions and decisions that help patients modify their way of life for beneficial healthcare pattern, while respecting patients' cultural values and their beliefs [4]. The goal of the theory is to deliver culturally congruent care that will help patients face illness, dying, or death [4].

2.3 Transcultural Assessment Model—Giger and Davidhizar

The **Transcultural Assessment Model** emphasizes the significance of recognizing that every individual is unique. Giger and Davidhizar indicate that there are six common elements to every culture: communication, space, social organization, time, environmental control, and biological variation [5]. *Communication* is defined as the holistic process of how humans interact and conduct themselves and can be verbal, nonverbal, and written. Trust is essential in patient-provider relationships and can only be achieved through dialogue and action. Language can pose as a barrier to proper healthcare delivery due to a lack of transparency or unclear communication.

Personal space is the appropriate distance between individuals during interaction that differs according to each cultural background. It is essential to be mindful to avoid violating boundaries and causing unnecessary distress to the patient. *Social organization* is how individuals group themselves within their culture according to their family, beliefs, and duties. Acknowledgment that titles, coping management and sexual orientation are factors that influence behaviors towards healthcare. *Time* is subdivided into two: the clock-oriented group is fixated on time itself, mindful of appointments not being perceived as ill-mannered, while the socially oriented focuses on the present.

Environmental control suggests an individual's perception of society and factors such as beliefs and understanding of the pathophysiology of health conditions, its treatment, and management. Lastly, the sixth dimension, *biological orientation*, considers that certain races are prone to certain diseases. In addition, this model has a deeper understanding of nutrition preferences and pain tolerance which is essential to consider in end-of-life care.

2.4 Model for Cultural Competence—Purnell

The Purnell model focuses on creating a foundation for understanding the distinct characteristics of cultures, such as experiences and perception of healthcare and disabilities. There are twelve domains: overview of heritage, communication, family roles and organization, workforce issues, biocultural ecology, high-risk behaviors, nutrition, pregnancy, death rituals, spirituality, healthcare practices, and healthcare professionals [6].

The model shows a series of rings containing the development of cultural awareness and the continuous expansion from the family to global society. The first inner ring holds the person, the second holds the family, the third holds the community, and the outermost ring holds the global community. There are subsections within each ring that account for evolution within the individual's cultural competence including occupation, religion, education, politics, ethnicity and nationality, and gender.

All twelve domains are important considerations, though death rituals, spirituality, and healthcare practices are specific to end-of-life care. Each culture has a unique perception of death and what rituals are performed. Spiritually may include the use of prayer, religious practice, inner strength, the meaning of life, and how it relates to health. Healthcare practices include the responsibility for health as well as overcoming barriers to achieve successful outcomes. These practices may also include traditional practices, magical religious practices, treatment of chronic disease, mental health practices, and the roles of the sick.

The Purnell Model indicates that all subsections and rings continue until the individual accomplishes cultural competence. The model is flexible with fluency between domains, providing healthcare teams who are competent the ability to evaluate, plan and intervene hence improving the health of the person, family, and community.

2.5 The Process of Cultural Competence in the Delivery of Healthcare Services; A Model of Care

This model by Josepha Campinha-Bacote views competency as the evolving growth and development in which healthcare providers continuously work towards the ability to effectively work within the cultural context of those we serve by consistently integrating cultural awareness, knowledge, and skill in our practice. The ever-changing demographics and economics around the world and long-standing disparities in health status among ethnic and cultural backgrounds challenged providers to consider cultural competence as a priority. This model can be utilized by healthcare providers as a foundation for establishing and implementing culturally sensitive healthcare services. The model consists of five (5) constructs:

- Cultural Awareness
- Cultural Knowledge
- Cultural Skill
- Cultural Encounters
- Cultural Desire.

Assumptions of the Model.

1. Cultural competence is a process, not an event.
2. Cultural competence consists of five constructs: cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire.
3. There is more variation within ethnic groups than across ethnic groups (intra-ethnic variation).
4. There is a direct relationship between the level of competence of healthcare providers and their ability to provide culturally responsive healthcare services.
5. Cultural competence is an essential component in rendering effective and culturally responsive services to culturally and ethnically diverse clients.

The model considers cultural competence not as a consequence of certain factors but as a process. To achieve cultural competence, one must develop the capacity to deliver efficient and high-quality care using the five components. *Cultural awareness* is a process in which healthcare professionals consciously acknowledge their own cultural backgrounds, which helps them avoid biases toward other cultures. *Cultural knowledge*, is a process in which healthcare professionals open their minds to understand variations in cultural and ethnic traits related to patient attitudes toward illness and health. *Cultural Skill* is defined as obtaining the necessary information from patients via culturally appropriate conduct and physical assessment. *Cultural encounter* is when stereotyping is avoided during the interaction between healthcare professionals and members of different cultures. During this process, overreliance on conventional views is discouraged. *Cultural desire* is the driving force for becoming educated, skilled, competent, and aware of culture; it also presumes a willingness to have transcultural interactions.

2.6 Culturally Competent Care Model—Kim Godwin

Reference [7] suggests that providing culturally competent care in the community is a significant challenge to nurses as existing models do not provide specific guidelines. Moreover, these models do not address the effects on populations in community settings. There was a need for a comprehensive model specifically providing culturally competent care in the community-based setting to reduce racial and ethnic health disparities. Similar to the other culturally competent care models, cultural sensitivity, cultural knowledge, and cultural skills are considered in providing care. This model's focus is on the relationship between competency and health outcomes for culturally diverse communities.

2.7 Summary

Over the course of history, we strove to build an ever-evolving society that is diverse in culture and ethnicity. According to the Universal Declaration of Human Rights (United Nations, n.d.), *recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice, and peace in the world.* It is of utmost importance that our society embrace the changes arising with such a multiethnic and culturally diverse collective of people. Our nation is increasingly becoming more diverse and in order for healthcare providers to deliver appropriate care to patients, it is imperative that they understand the importance of cultural considerations. Culture is a significant influence in the way patients respond to illness, treatments, and preferences surrounding end-of life care. Research indicates that end-of-life services are underutilized due to the lack of understanding of patients' culture and beliefs related to death and dying. In order for providers to tend to the unique needs of this patient population, medical professionals need to consider the cultural differences by making it a priority to understand the different values and beliefs, embrace them, and incorporate these considerations in creating an environment that is sensitive to the patients' and family's needs.

Healthcare providers must be cognizant of their own biases, as well as their institutions, and seek and respect patient's and family's beliefs and preferences related to death and dying. Understanding and navigating the complex cultural needs can be challenging but can be accomplished through thorough assessments. Involvement of family members is crucial in this process and it is important to encourage clear communication of preferences and goals. The culturally competency models discussed in this chapter are used as teaching tools for healthcare providers as well as a guide for proper assessment of the unique needs in end-of-life care. The cultural practices can then be incorporated into the plan of care to ensure patients feel supported, valued, and dignified during the end of their life journey.

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A Mindset for Communication for End of Life Care

3

Tracy Lynch and Kristina De Corpo

Contents

Our collective story of death

Those dying remain one of the most underrepresented populations in our willingness to experience ourselves. Those providing care to those in End of Life have been influenced by the continuing wobble of our society that disallows death for the most part, because of its unknowingness.

There is a truth to the unknowingness of death, but there is also an inner knowingness to the death experience that this model uses as a foundation for both communication and perspective-taking for EOL providers.

To better equip ourselves with caring for those in the dying process, we as providers may be unconsciously categorizing death into realms of understanding. Death can often be considered either a mysterious experience or a living thief to our experience of being. This representation of death in our society can set us up for ongoing discomfort, as we face the challenges of serving those in the process

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of dying at the end of life. Discomfort with death is our collective story and the narrative we find ourselves in navigating the experience as EOL providers.

I am in my 23rd year of bearing witness and joining with those in their EOL experience.

Death is perceptible through felt senses through immediate experience and an innate process that is intrinsic to our human experience. I have found there is a readiness in each person prior to their death. This occurs sometimes at one's diagnosis after a long arc of complex illness, or for some, as they move closer to their moments preceding their last breath.

As a professional working as an EOL provider, I believe there is a gap in our perspectives of dying and what I know to be true through the witnessing and partnership of supporting EOL transition for more than two decades.

Why we need to embrace the concept of death as a part of a communication model

Death is an inevitability of our experience of being. It is inescapable and to find balance in our experience of being, death needs a support mechanism as a model to represent death as an intrinsic and universal experience of being.

In our ability to care for patients what perhaps is missing is a deep sense of connectedness to the process of dying. We need a communication model that meets the challenges of making the difficult conversations feel more effortless, in order to allow the patient to feel safe and supported in the process of dying.

Death is not outside our experience of being. It is who we are as a counterpoint to birth and death is purposeful. It serves a purpose to our own existence. It is when we as providers begin to identify that we are supporting the purpose of death in our shared experience, that the communication begins to unfold supported by this perception of death. This perspective includes death is not outside each one of us, and is universal to our shared experience of being.

Those in the transition of End of Life will want to receive something they can feel. A felt experience that moves past rational or logical processes and into the state of the immediate moment or flow. The challenge is to meet that need of flow in the present moment, in order to process the need for authentic connection of the shared experience of oneness in our shared experience of being.

Connection is relative in a felt experience, which exists in the relationship between the provider and patient in the wholeness of both the communication and perspective being shared. When the provider identifies with the shared experience of death, as purposeful to our shared existence of being, and is the counterpoint to each of our own births, there can be an open felt sense of oneness with the death experience. Which is universal to our state of being and creates the space for the inner knowingness of the death experience.

New language can be used to comfort and represent our shared connectedness to the death experience

What is the language of death? I realized in the very beginning of my EOL career, it didn't so much matter if I did not know what to say. Words were not as important as connecting to my patients. In order to attune to their thoughts and feelings and to feel present and whole, I began to try to release my "thinking" of whether their thoughts or a particular conversation was useful in the processing of their own death. I came to realize that it is the presence and acceptance of any information they are willing to share, combined with the communication of this model as an initial blueprint for opening communication, which allows my patients to have a more secure and empowered EOL experience and transition.

Once I became more masterful at holding the space for the process of dying to unfold, by maintaining presence and oneness with the patient's own unique thoughts, feelings, and emotions, I started to develop perspectives in my narrative that became the core foundation of my care as an EOL provider.

The communication model and the language I developed allows both the provider and the patient to feel integrated with the dying process, as an inner knowing that already exists within both the provider and the patient. This inner knowingness then becomes a blueprint for the unfolding of death, in a felt experience of oneness, as an empowered relationship between the provider and patient experiencing the process of dying, in shared moments of being, through open connection.

3.1 Blueprint for Intuitive Communication

- **There is a time for each of our own deaths and your body will do it perfectly in its own unique way.**

This conceptual thinking identifies that the provider is not outside the process in their own unique experience of being. This also allows the patient to own their own process and feel empowered in their own unique unfolding of the dying experience. I have found this communication can also help neutralize the seeming inequities of particular illnesses, ages, or "unmet" life plans.

- **Just like you are equipped to be born, you are born with inner resources to know how to die.**

This is a perception that both identifies and communicates there are fundamental inner resources to the birth process that are built into our shared human experience, and that those same inner resources that birth life are also equipped and adept at processing the unfolding and receiving of our own dying process.

I tell all those I serve, my wish for them is to be in a state of receiving. It is not just something that is happening to us, it is what we do. I share with them to trust their body and it will serve as a guide and we can trust the unfolding of it all.

- **You are your own purposeful experience of the wholeness of being you, in any experience of it.**

Birth is synonymous with death as an experience of self and I propose it is not a randomness of being, as a field of experience. As such, in a closed system, the energy can physically turn from one kind into another, but the total amount of energy does not change. There is a completeness and wholeness to our universal experience of being, in both the birthing and dying process, which needs to be identified within our perspectives, narratives and our communication as EOL providers. Which translates to our patients feeling both empowered and authentically supported in their EOL experience.

This blueprint meets the need to be understood in our full expression of self, in the stages of receiving self, in its completeness or wholeness. There is a *wholeness* to our experience of being that includes both birth and death. One cannot exist without the other. We cannot be of existence, without a birth and death experience.

I explain to my patients there is a common final pathway, a falling inward and a physical knowingness that is akin to ancient wisdom or the caterpillar to a butterfly. Because death is a truth to our experience of being, which we are not limited to in our ability to be able to process it as naturally as our own birth.

Focusing on the natural happening of the dying process, equal to the birthing process, allows the experience of oneself or fear of losing our life experience to subside more easily. This model of communication and perspectives empowers a series of feelings, shifts and allowances that serve to guide patients in their dying process. The patient is given a blueprint to see themselves in the oneness of this moment, in their own experience of wholeness, but in a shared and supported experience of being in open connection with the provider.

Connection can be received in many ways with patients receiving EOL care. Throughout this chapter I will share stories of my patients to bring a deeper understanding to the power of this model.

I was working with a poet named Sylvia, who attempted to cope with her illness with control. Understandably, control feels like a life preserver for some states of being where we have lost control and can be a particularly magnetizing way to cope for those in the end of life.

Sylvia feared sleep, for fear that death may more easily find her. She had insisted a bell be tied to her wrist, which she used to prop her head up to keep her from sleeping. The idea being, if she fell asleep her hand would move in a way that the bell would ring. Which would awaken her, thus evading death. Sylvia suffered from intense anxiety and almost total blindness and became angry with any attempts at soothing. I developed a conscious practice each time I parked my car prior to meeting with her. I was going to connect with her without any agenda or need to fix anything or create any shifts. My goal was to become an internalized soothing object. Similar to a transition object. A voice within her voice, that could remain in between visits. A practice that I adopted prior to each visit, and readily expanded and solidified because of Sylvia.

I abandoned any attempts at making her feel better and set the intention for the knowingness that Sylvia would have a dying experience she would feel ready for receiving. I set the intention of this knowingness as an active part of connection with her each time we were together.

After weeks of modeling this way of being in my care, Sylvia finally allowed her bed to be lowered and for the bell to sit next to her table. It was then she shared with me, “There is something that you have shown me, far more than anything that you have told me. It’s that you are not in distress at watching me die. You actually chose to be an expert or guide for me.” In her final weeks, Sylvia recited her poetry to me and allowed me to reflect some of her feelings felt within her words.

Through my intention and communication, Sylvia was able to experience more safety via her own inner resources and experienced increased security in her own surrendering to the process of dying.

Communication is challenging when we categorize death into narratives to be able to process it. In our own perceptions of the unknowingness of the death experience, if we disassociate from a conceptual inner knowingness of the death experience, we run the risk of disallowing a felt sense of oneness with the death experience in the connection to our patients.

We can ourselves, as providers, be ill-equipped for the beliefs or questions coming from our patients in our coping conversations with them, as we struggle to offer the words that console their fears and allow them to feel safe and supported. There is no group of words that can promote the calm needed for existential or total pain that we often feel in moments of thinking of our own dying. Unless an empowered blueprint for the shared experience of death is established.

We can then start to identify with the tangibility that death shares a purpose to our experience of self, equal to birth, which creates the connection for wholeness. Death is a universal experience that unfolds organically for each one of us, in its own unique way. Death is purposeful in our experience of being and we are each equipped with the inner resources to know how to die. This innate knowingness mostly belongs to the body, much as in birthing, and is a mindset that allows more stillness around the death experience once the blueprint of an empowered experience of death has been perceptually and intuitively communicated.

This I feel is our work. To be the transmitters of this knowledge. To hold it as primary in our awareness. To carefully discern this awareness from any platitude that limits our own knowingness there is a time for each of our own deaths, and everyone is equipped to receive their own dying experience, equal to their own birthing of self, as an infinite expression of being.

We are not birthed more and received less as a unique experience of being.

This is a mindset that I am proposing EOL providers adapt, which promotes innate safety and security, in the unfolding of the death and dying process. This communication and perceptual model of death allows a patient to be able to trust the team, to adapt and shift according to their own unique experience of dying, as the receiving of the experience of self, equal to birth.

It is critical we begin to support the understanding that just like birth is supported, each in its own way under varying conditions, death is equally supported by those providing EOL care.

Why death requires presence and a universal perspective for optimum communication

In EOL, one of the most principled concepts is active listening, which I would describe as relationship centered. It is true attunement. A tuning in and then reflecting back what the EOL provider is hearing, which translates as presence and a felt sense of oneness to the patient. It is in our own relationship to death that we can play a more active role in our relationship to our patients, as an empowered partner in the shared experience of being.

Life and death are a cycle of being in complete harmony and balance with life. Death is not the absence of itself. To be in wholeness of the experience and to truly identify with the feelings associated with death, we as providers must model presence with the purpose of dying. Dying is purposeful. It serves a purpose in the receiving of who we are in unity with our birthing of self. The self we have known, even if we do not believe that there is a continuation. Deep inside us all we can experience a self that has always been present in our life experience. We each have selves that we have identified as us, selves that remain intact, despite growing older.

There is an innate inner knowingness that becomes the blueprint for an empowered death when we identify with the understanding that death is equal to birth. One cannot exist without the other. They are interdependent of each other and just as there is a time for our birth, there is a time for each of our own deaths. It is in this felt sense of oneness within this universal experience of being that connection becomes relative based on the thoughts, feelings and emotions being experienced.

Research shows that when we are in a disconnected or stressed state, we release cortisol and adrenaline which amplify our beta waves, further reducing both our delta and theta waves. The research of Dawson Church Ph.d., illustrates how delta and theta waves allow us to stay in a deeper state of oneness in the present moment, through associating alpha waves, which link both our conscious and subconscious minds. The wave pattern then becomes a source of our own inner knowingness of oneness and deepens our presence with the now moment. As providers, we can miss sharing a profound inner experience of connection with the patient as an infinite field, if we have not established an empowered blueprint of the death experience.

If for even a tiny moment when we become balanced in the relationship, we release electrons in the same way that nature releases electrons, we can transmit a feeling of oneness through our shared connection with the patient. Nature has no resistance to balance as it always sees itself as whole. It is in that unity of felt presence the connection with a patient deepens and becomes open and whole in its felt sense of the relationship.

It is whether there is an open whole connection which allows the electromagnetic current to ripple and whether or not it attracts 50% of its electrons spinning in the reverse direction. This is the power of a mindset that does not disturb the equilibrium of the opposing force, by seeing itself as whole to remain in open connection and ripple the displacement of itself, as a standing harmonizing wave of vibration.

This allows neurons to fire in harmony as brain waves synchronize to share information efficiently in order to organize information in the present moment with a deep feeling and felt sense of oneness, over chaotically. Which then allows our alpha waves to associate information to allow our felt senses of oneness and presence to become coherent with incoming stimuli associated with our beta waves.

The outcome can be a patient that feels less stressed and openly connected and supported through their relationship to the provider through relating through felt senses. A patient can more easily attune to their own inner knowingness of the death experience as purposeful and the counterpoint to their own birth, in the receiving of their own dying process, as a state of whole connection in the shared experience of being with the provider.

To maintain connection to a patient receiving EOL care, providers can create possibilities in moments where the patient does not disconnect or separate their living from their dying, by becoming present in their relationship to the receiver or patient. This self-awareness helps create the flow for more open connection, which allows the patient to feel safe and supported in their dying process.

It is one experience in and of itself, as the birthing and receiving of our experience of being. Through this blueprint of perceptions and model of communication, a mindset is developed that allows a more empowered process to unfold through a felt sense of oneness between provider and patient, for the patient as a receiver of whole open connection.

3.2 Self-Reflection for Providers to Maintain Whole Open Connection

- **What matters most as providers, is what is my "now" perception. How am I feeling right now?**

Identify if you are feeling discomfort or are you grounded in the universal experience and attuned to death as it purposefully unfolds in the unique individual in your care?

- **How are they feeling right now?**

In the collective fear surrounding death in our shared experience, death is uncomfortable. What makes communication more effortless for providers is to stay present in the EOL care of their patients, no matter what types of feelings or emotions are being felt by the patient.

It is in the knowingness that each unique patient is having an experience of death, that they have the inner resources to know how to do, as it unfolds perfectly for them, each in its own unique way, which allows providers to become present with what is. Our power as providers is to provide presence with what is occurring for the patient, and to remain in open connection by identifying with the universal purpose of death, which is the receiving of self, equal to our own birth.

This creates the space to openly receive any feelings or conditions being processed by the patient, as part of the patient's own unique process of dying, which is a natural and intrinsic process to our state of being. It is in the open connection to the patient within the relationship, that the patient becomes more organized in their felt senses to tap into their own inner resources, to feel safe and secure in a coherent state. Which is more present and one with their own dying process, equal to their own birth.

- **Am I identifying / communicating with this shared experience as a purposeful experience of being?**

We, as providers, can identify with the purpose of death and stay present in the knowingness of our assistance of our shared experience of the story of being, as death unfolds.

When I provide EOL care, I imagine all the ways in which I can connect with another simply by holding the space for what is, in the process of dying, as its own wholeness of itself that I get to share and receive in the process of EOL care. I practice not bonding around the limitations of death, but in the purpose of it, as the receiving of an infinite self, equal to birth.

I choose to think that my work is to be a placeholder for all the conversations that are possible, which can lead to the very real metamorphosis of the mind, body, and spirit. It's during these conversations that I share my communication around death which has so many times been reflected back to me, as it strikes an inner chord of knowingness with patients. Aiming to be an internalized feeling, so when I am not physically present, my patients can recall the essence of my communication and assurance to better cope and self-soothe.

Neil had an atypical arc of ALS illness. It was just as extraordinary as he and unique as his middle name, Forrest. He loved the Herman Hess writing, 'What Trees Teach Us About Belonging and Life.' He would smile at the part, "Trees have always been the most penetrating preachers. I revere them when they stand alone. They are like lonely persons, not like hermits who have stolen away out of some weakness, but like great solitary men." He was so attuned with others but very out of balance with himself. His mother had mental illness and he was unconsciously trained to not have any needs, as to avoid overwhelming her, which he carried forth in his relationships. Neil could barely talk about himself. If he realized he was talking about himself, he would all at once avert all attention away and focus on me. As he began to lose function overall and had trouble talking and swallowing, due to choking, there would be moments when I could ask some questions to maintain the awareness of my presence and connection with him. "How is this experience affecting you? What is the hardest part?".

Often Neil would answer in some form of "I'm fine" or "I'm okay." Even if he was choking and coughing for an hour on and off. Through many months of dramatic changes of ALS, his coping was to deny any impact that the actual events were having on his well-being and at times even his overall functionality.

To me, it feels disconnecting to not be of the same organic experience as the receiver of care. Which is why I ask them to identify with the experience and am prepared to receive their “now moment” without any agenda other than to be present and one with the receiver in the shared experience of it.

Towards the end of our time together and closer to the unfolding of his death, Neil shared with me, “you told me from the very first visit that my body would know what to do. That my inner resources would always kick in through the changes of my dying. I believed you and that it is the greatest comfort. That very thing you told me on your first visit.”

This communication model gives patients a blueprint that supports their dying process in an empowered way, by identifying the patient as having their own inner resources, that equips them with the ability to trust their body knows how to die and will do it perfectly and organically in its own unique way.

It also gives a construct for connectedness between the patient and the provider, knowing the provider is not outside the death process, in their own experience of being. That dying is an innate and intrinsic process to our experience of being that we are all equipped to handle, each with our own inner resources, as a shared experience in the story of being.

Communication as Resonance

Tapping into the purposefulness of death allows EOL Providers to remain in whole resonance as they are communicating through language and felt sense to their patients. Meaning, as providers, our own personal categorization of the patient’s belief systems around death, which may or may not differ from our patient’s feelings and belief systems, and our own discomfort with death, no longer becomes an impediment to connection.

There is a conjoint experience of assistance with the purposefulness of the preparation and the release of the physical experience before death occurs, as a counterpoint to birth. It is an act of support in the oneness of our experience of human beings that we all share.

A resonance approach does not begin by asking, “what do I want to say?” But seeks to strike a responsive chord in people, not to get a message across, but to achieve a state of whole resonance with the person receiving the unfolding of the death experience. This communication is not for directing information into a patient, but to try to evoke stored information out of them in a patterned way, through connection, through holding the space for any thoughts, feelings, or questions in the present moment. As a felt state of oneness and presence, in the shared purpose of open connection receiving the patient’s own unique process of dying, in an organic state of wholeness.

If communication is one of our main treatments, it feels vital to not script “communication at end of life” other than a knowingness that permeates an open connection and whole resonance with the patient. The point of this model is to maintain a state of presence that communicates we can connect anywhere, in any conversation, in our shared experience of this universal experience that we are all equipped to handle, each in our own unique way.

If I am holding death as bad or sad or ill-timed or a medical failure, the patient cannot settle into a place of balance with their own unfolding of what is an innate and intrinsic process to our experience of being. My goal is not for people to just accept what I say in my communication around death. But to eventually align there, in the presence of the knowingness that death unfolds perfectly for each one of us, and we are each equipped with the inner resources to know how to die. That there is unison in death, not a randomness of being, in the return of an infinite self from an experience of being.

I am not proposing that we do not allow or include the necessary feeling states that accompany the unknown dying process in those we serve. Rather to recognize that we can model as a guide, the perspectives of a communication model that is aware death is a part of each of our own stories of being, and we are all equally equipped to know how to die and our bodies organically know what to do.

It is within our felt connection of oneness and presence of each other, in the relationship between the provider and patient, that this alignment allows a more empowered and supported experience of the dying process, through patterns of recognition of the felt sense of whole connection.

Maintaining Connection in the Presence of Trauma

Not all of us experience trauma in our life path. Perhaps it is fair to conclude we each store some pain moments in our experience of self. Whether we have experienced early trauma or not, most who are given a terminal illness experience and assimilate trauma initially, if not continually, as an ongoing crisis. Trauma can act like an invisible force in our lives, impacting us in powerful ways. The state of dying can trigger old trauma in addition to new crises, which in turn can activate implicit memory. Implicit memory is stored in the unconscious and the body memory and one feels as if the trauma is happening again in the present. Causing heightened reactivity as our present is continually “taken over” by the trauma of our past or our perceptions of the death experience.

If we can’t emotionally regulate, we fall into distress and often are under the influence of those implicit memories. Essentially, it feels as if those we serve are in an inner struggle and they can tend to disallow the emotional connection and safety of the support of their EOL experience. This shows up in versions others call; resistance, denial, non-compliant or “not ready”.

This stress amplifies a patient’s beta waves through the release of cortisol and adrenaline and inhibits other wave patterns associated with delta and theta waves which allow the receiver’s infinite field of awareness and resonance to maintain an open felt connection with the provider. Through the amplification of beta waves, delta and theta waves no longer allow alpha waves to link both conscious and subconscious information through felt patterns of recognition.

This whole connection is relative through coherent brain wave patterning that maintains either harmony or keeps the neurons firing in a chaotic state further reducing the openness of the pattern, as a field of resonance. Which naturally occurs in a state of balance as two resonant frequencies relate through their shared human experience of being, at their natural harmonic frequencies, as a repeat pattern establishing coherency of recognized patterns.

If beta waves are amplified due to stress of unfelt trauma, the cortisol and adrenaline break the patterns as the beta waves are amplified, which causes deconstructive wave interference, disturbing the displacement of the opposing weak force of the provider in open connection to the field of resonance of the patient which is dysregulated and chaotic. Our alpha waves can then disappear. The two fields in open resonance can no longer associate through patterning which allows the felt sense of presence and oneness to be shared in the unfolding of the dying process.

The role of the provider is to act in oneness, with presence to this shared experience of being, in order to allow the patient to process or to release trauma. The important action here, is to watch our reactivity. To be with them and to just hold the information for them for those moments. As providers, we have the ability to use our whole self, almost as a turning fork, to offer our whole connection of presence and oneness with the shared experience of dying, equal in equanimity and equilibrium with our patients, in our own experience of being.

One of the hardest parts of my job is to bear witness to so many moments of shame created by the natural occurrences of dying. Shame related to their appearance, their energy, their limitations, their fears and their feelings. Dying can be filled with intersections of feelings of being less than whole, which can feel traumatic. I have found relief in a model of communication that uses a blueprint which allows patients to view themselves and their treatment from a place of wholeness. A natural unfolding of a shared process innate to our shared story of being, which they have the inner resources to be equipped to handle.

This communication model seeks to empower one to cope with trauma by how the dying process is communicated. There is a time for each of our own deaths and death unfolds for everyone, each in their own unique way and your body knows how to handle it, organically. The process is synonymous with how you handled your own birth. It's not outside of each one of us. Birth cannot exist without death, which naturally unfolds in its own perfect way to become the *receiving* of your life experience, equal to your own birth.

As providers, we must keep the focus on the now, as we shift perspectives from the birth narrative, which can offer inner resources of relief, as we do not want to overlook what is happening in the present dying moments for those we serve. We must strike the balance of communicating this perception and not disallow our focus as providers of our own presence, to the felt feelings our patients can associate with death. Which can oftentimes be intense grief, despair, or pain. We do not want to disassociate ourselves from our connection to our patient, which disallows a safe and secure patterning of recognition, as a felt sense of oneness and presence, through associative alpha waves.

In other words, we want to avoid deconstructive wave interference and maintain the constructive amplitude of open whole connection to synchronize felt patterns of recognition, through the release of neurotransmitters. We want to avoid breaking the pattern of felt sense through the amplification of beta waves which release cortisol and adrenaline and disassociate synchronizing alpha waves linking our perceptual awareness of patterns of felt recognition.

Marilyn is an example of a patient that experienced severe trauma since birth and how the patterning of presence and oneness established a dramatic transformation in the process of her dying experience. She was born as a breech birth with broken hips. At the age of 4, her father tried to repeatedly kill her by encouraging her to walk into traffic. Both parents were highly critical of her, but Marilyn managed to achieve her dream of attending medical school.

At the age of 21, she suffered severe injuries from a car accident where she experienced cardiopulmonary arrest in the hospital three different times and had to have her arm sewn to her side for four months in the hospital to promote reattachment and growth. She had to learn to walk and talk again and in her own words, "was never able to fully actualize her generativity." Marilyn was so convinced that she would never be liked or cared for that she had a profound mistrust in all her relationships. At 68 years of age, she was not able to be truly present with any "now" moments that did not directly or indirectly collide with her trauma.

I set the blueprint of my communication of an empowered experience of dying by assuring Marilyn she would feel her own inner resources carry her through and her body would respond to her own inner knowingness and know what to do.

Through months of holding the space for any "now" moment of where Marilyn was in terms of being with herself, signs of some presence and oneness in her began to appear. In felt or communicated feelings, emotions, or stories, whether they seemed of value to her own processing of death, I saw evidence of soothing and comfort in Marilyn. Having avoided the "now" moments of her EOL, she had withdrawn into her own experience of the blueprint in her dying experience.

With the presence and support of a shared experience of oneness, with whatever Marilyn was feeling or processing as her own unique experience of the processing of her dying, without any agenda *except* holding the space for her process, Marilyn slowly began to open up and trust the team with her own dying, which can sometimes be recognized only as a felt sense of trust.

In my years of EOL care, I have realized that the felt sense of safety and support in a patient does not always draw from verbal communication. It is in the perspective that each patient has the inner resources and knowingness to equip them in the transition of their own death experience, which sets up the blueprint for them to begin processing their own empowered experience of the dying process.

Supporting one, in whatever feelings, emotions or stories appear to be the most critical, is more empowering to the patient, over an agenda of meeting a scripted communication. Which can often leave a patient isolated and unassured. I have found the assurance that there is a time for each of our own deaths and our bodies know how and what to do, as the receiving of self, equal to our own births, is what sets the patient up for the unfolding of an empowered experience of their own dying.

It is in the presence of oneness or wholeness in the shared experience of death, that is the necessary perspective. It is the shared presence and oneness of our living experience of self, that the assurance of death becomes a natural and intrinsic part of our shared story of being, in our EOL experience with our patients.

Marilyn's transformation came from both the blueprint and the perspectives of this model. She was able to connect within our relationship to feel safe and supported and to trust and surrender to the relationships around her to have an experience of death where she felt she could trust the care of her relationships. As well as the relationship she had with her dying self, who ultimately felt worthy of connection and felt secure and supported to "stop surviving" in order to surrender to being received.

Staying Present with What Is

Those we serve may never get to the point where they wish to speak on anything having to do with "trauma" of dying, and the patient must still feel connected to the provider. Those moments that feel disconnected can be the most important entry points into building the connection that allows for transformation in the patient. Transformation via the trust that the provider can trust a patient's death and serve as a guide in an empowered experience of death through a felt sense of oneness and presence with whatever the patient chooses or is willing to communicate.

One of my earliest teachers of this model was a patient named Ivory, at his end of life. We spent many months of weekly visits. He was very tall and one could feel in the way he carried himself there was a lot of pain he was carrying. I spent time with him during a time when providers could sign a waiver of liability and take people in EOL in their car. He liked to go to pet stores and IHOP for pancakes and steak. Ivory was very uncomfortable with interpersonal communication unless we were in an activity and seldom made eye contact. He was quiet more than he spoke.

When he was not able to leave his home due to overall decline and extreme weakness, he asked me if we could watch TV for our visit. It was then Ivory asked me, as he was gazing toward the TV, weeks from his death. "So where do you think elephants go when they die?" I felt paused by the depth and generosity of such a question. Which gave me time to thoughtfully consider, asking him the same question as my answer, "Where do you think elephants go when they die?".

He continued to stare at the TV and about 20 min later asked with a small smile in his voice, "So where do you think lions go when they die?" I smiled with my whole being and we made eye contact for a few seconds. He began to share that his current energy was very low, asking me if I could see that. I shared with him that we would honor the body and trust the energy system that was getting "tired."

Through patients like Ivory, I began to understand that although the world imagined that my job was to have conversations about dying all day long, my job was to be present for any moment of language that would appear, which never *reduces* but only enhances connection. Staying relational allows me to metabolize their dying and creates possibilities in moments where we do not disconnect or separate our living from dying. As a relationship, we exist together in a simultaneous state of being for whatever feelings, thoughts, or physical sensations are randomly occurring, in a state of open connectedness.

I realize now, through establishing the blueprint of this model organically in my practice, the blueprint created a felt sense of presence and oneness with people in my care, processing and shifting through moments of their own unique process of their death experience. It is through this perspective of not having any agenda other than to receive what is happening now, in all of its wholeness and completeness, and trusting the dying process in my patients, that I began to feel radical transformational shifts. As a sense of their own empowerment in their ability to handle the experience of dying, as the receiving of their own experience of being.

Eckhart Tolle identifies stored trauma in the body as our "pain-body" which is the accumulation of old emotional pain. He describes it as a "semiautonomous energy-form that lives within most human beings. It's made of emotions and has its own primitive intelligence that is directed at survival." His point is that the pain-body requires replenishment of its own frequency unless one moves beyond its activating force.

It is so critical to provide care that sets the patient up with a blueprint of an empowered experience of death and manages care in a felt sense of oneness and presence with the intention of holding the space for any thoughts, feelings, or conditions the patient is experiencing. By managing and identifying with the perception and inner knowing a patient has the inner resources to know how to receive their own dying in the purposeful experience of death.

In my years of EOL experience, I have found the transformation and shifts that occur in those I serve, happen when I connect to them right where they are in their now experience of felt feelings, emotions, and conditions. Going with the flow as providers, once an empowered perspective of death has been communicated in an open connection with the awareness that our death is the counterpoint to our birth, in our shared experience of being, is a developed mindset.

Death cannot exist without our birth and just as we are equipped to birth our own unique experience of being, we have the inner resources to know how to die. The communication of "there is a time for each of our own deaths and our bodies know how to do it" *includes* the provider in the shared "organic" experience of death, as a felt sense of the universal experience of the oneness of being.

EOL is a difficult field to sustain if we as providers are needing our patients to be having a different experience to feel we are proficient at meeting their needs in our care. Once an empowered blueprint has been expressed, communication and connection can feel more effortless and allows the provider to experience, maintain and even enjoy the connection, as well as experience more transformational outcomes in their patients.

Those in EOL and those who serve them can feel undernourished due to lack of expressed and non-felt exchanges. Almost all literature in our field takes a stance on "combating" the "emotional work" Truly, when I am maintaining connection to the model and to all who are in front of me, the connection is uplifting and at the end of sessions I can feel even more energized. Perhaps because of the open exchange we both feel and emit.

Embodying this mindset allows providers to feel a deep sense of wholeness with the patient, which allows those receiving EOL care to experience a felt sense of safety and support in their experience of EOL care. This mindset serves both the patient and provider because it makes way for meaningful connection that is purposeful and directed from the start, without needing any condition to change.

Awareness and Connection Graphic
Learning how to manage care in this way is a mindset. I have found the model of communication and perspective-taking allows patients to find balance in the receiving of their own unique dying process, as it unfolds for them as individuals.

It takes a willingness to decategorize our perceptions of death and embrace the shared experience in death's purpose, as our shared experience of being. Birth cannot exist without death. We are equally equipped to share this intrinsic and innate process in our collective story of the experience of being, each with our own inner resources of the knowingness of knowing how to die.

When a patient is in open connection with a provider, in a felt experience of oneness and wholeness of the death experience, there is less resistance to death's imminence. It is when both, the receiver and provider maintain a present state, with an empowered perspective of the dying process, through their relationship to each other, the natural unfolding of the death process becomes supported and feels intrinsic.

This model supports both receiver and provider in such a way where communication becomes more effortless, as the care is focused on being present with any thoughts, feelings, or conditions, which allows the patient to feel more safe and secure surrendering to their own unique EOL experience.

3.3 Awareness for Practitioners

Death serves a purpose.

Death is the counterpoint to birth.

Death is a universal experience to our shared experience of being.

3.4 Communication to Patients

There is a time for death and your body will do it in an organic way, in its own unique way.

You are equipped with the inner resources to know how to die.

You are in your own experience of your own sense of self, as it perfectly unfolds in unison with the experience of your own being.

3.5 Awareness of Presence

How am I feeling?

How are they feeling?

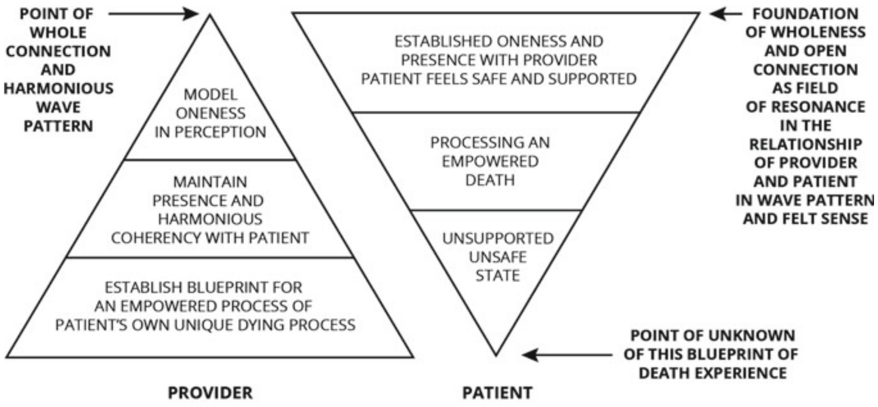
Where is my perspective right now?
What is my intention?

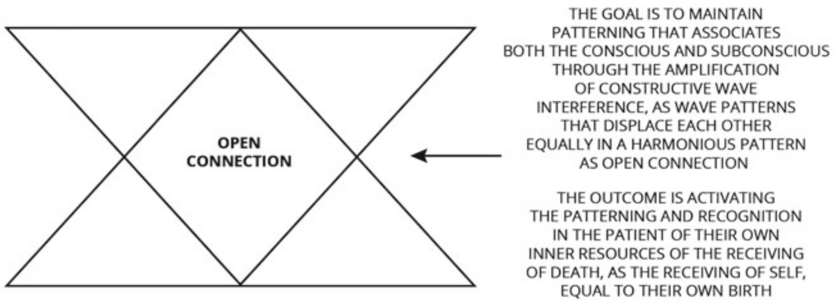
3.6 Intentions

I am here to actively listen and maintain open connection with my presence, to assist in the unfolding of a purposeful process, in this individual that is in my care, as a felt sense of a state of being.

I empower those I serve, in a shared experience of their own unique process of the death experience, which is being received equally to their own birth, in a state of unison with their unique experience of self, through my connection as a shared experience of being.

3.7 Model of Establishing a Blueprint for Open Connection as a Field of Resonance





Telemedicine in EOL care
Telemedicine is necessary and optimal in many EOL experiences. The goal of this communication model translates to the necessary focus that telemedicine requires because of its lack of human interaction, in the physical sense of a relationship. It is even more imperative that we communicate a blueprint for an empowered death, as we relate to receivers of EOL care through technology, over felt human connection through a physical experience of each other.

Dr Michael Fratkin has a pioneering platform for telemedicine called Resolution Care. They have received awards for the last 2 years for the continuing positive social impact they have on their rural community. He suggests that when using technology, we, "disappear the technology." "To let go of the device and "let it be a window." He has found, as have I too, there is something which promotes connection when as providers "are not invading their homes," as many of whom have not maintained their preference or standards of hygiene, home or self.

Almost every visit that I do, involves patients apologizing for their own appearance, level of energy or home. Some families even unconsciously participate, as they rush to grab old photographs and at times use language like," oh this is not my spouse, this is my spouse…before they got sick."

This mindset puts the provider in the shared experience of death, as having a time for their own death, equal to the patient. That the natural occurrences of our dying and the marked ways in which we cannot move about the world in the same way exist within the shared experience of it.

The people in EOL care are usually experiencing some degree of isolation and it's imperative that our communication as providers resonate a felt presence of whole connection, so that our patients can self-regulate in the pattern we are providing as a template for an empowered experience of their own dying process. Maintaining presence for the in-take of information to attune to their own unique feelings and condition in the understanding that we each are organically being received in a way our body is equipped to handle is critical for providers providing EOL telemedicine.

In my own experience of EOL telemedicine, I always check in with my own state of well-being before I begin my session with my patient. What is my state of being? Am I focused and ready to receive the feelings, distress or disconnection of another human being, in order to offer my whole connection? Am I prepared to resonate in oneness and presence of their own unique process in the purposeful experience of death?

It's in our own experience of self that we must focus, which determines the relativity of the connection to our patient. How we feel as providers becomes the patterns we demonstrate in our behavior, communication, and perceptions which impacts our patient's overall sense of safety and well-being in our care.

When we, as providers, transmit a blueprint of an empowered perspective of dying that we fundamentally relate to as providers in our own experience of being, neurons are firing in a harmonious pattern with them. As we are in a state of oneness and presence for our patient's unique process of their own EOL experience, as the open receiving of self, equal to birth.

Associative alpha waves are organizing patterns of felt sense and communication within our conscious and subconscious experiences which allow a patient's delta and theta waves to stay regulated in a harmonious wave pattern, within the relationship, in open whole connection. Over being cancelled out through amplified beta waves releasing cortisone and adrenaline when feelings of anxiousness and stress associated with death surface for either the receiver or the provider.

Telemedicine offers both access and continual care for many in EOL and is becoming a standard in its practice. It needs both intention and communication as a model to provide a foundation of care to maintain open whole connection, to provide harmonious patterning between providers and patients, as receivers.

The relationship between providers and those we serve is relative and it is in embracing that relativity that we offer a safe and supportive whole connection for others in our shared experience of being, through our communication and perspectives during EOL care. Which can sustain one through their own personal journey of their unique experience, both within care and when care is not present as a relationship, which allows them to feel more secure processing their own dying experience.

A Perceptual Shift of the Experience of Death

This communication model closes the gap in our perspectives of dying and how we can model oneness, in a state of presence during the moments preceding the organic release of the physical body into the purpose of death, as the receiving of self in its wholeness. A blueprint for communication and relating to the patient is modeled and handled in such a way that a patient feels safe and empowered in the unfolding of their own unique process of dying. Death becomes a receiving of self as an expression of having been birthed into our collective experience of being.

Death is a returning to self, as the complete experience of it. In my experience, there is a preparation for this truth that must be embraced. In my years of witnessing the death experience as an EOL provider, there is a readiness to surrender to the process in the moments leading up to our actual death experience, and our care as providers must support that truth.

Otherwise, as providers, we continue to categorically represent death into belief systems which do not represent the universal truth that death is purposeful and is the counterpoint to our birth, in the experience of being a unique self. Death is a shared human experience, in the receiving of it. It is in this recognition providers can provide care that is focused on the oneness of our universal experience in recognizing death is purposeful and there is a receiving of it, which we are each equipped to handle, equal to our own birth.

We do not have a proven theory of our fundamental experience of reality. There is no known theory which has yet to prove how the laws of nature work in our experience of reality. Scientists have intuitive guesses of what would work based on observing reality and studying the known particles that have been discovered. Which according to particle physicist Sabine Hossenfelder, are like a set of "pots and lids" that do not yet work as a model for how we fundamentally experience waves of exchanging information becoming our living experience of reality.

However, can we begin to recognize fundamentally that subatomic particles relate through patterns as electromagnetic fields? It becomes a question for us as multidimensional beings, in a non-dimensional experience of our infinite self, do thoughts, feelings and perspectives relate as felt experience through a field of resonance, as the unison of our unique self, not randomness, as the fundamental organic nature of our experience of being? In other words, in our shared experience of each other, do infinite fields establish patterns in a relative way through felt organized patterns of recognition?

This model seeks to communicate there is no physical separation as we organically relate through a felt sense, if a wave pattern ripples its own displacement equally. Death becomes the return to itself equally, from its own unique experience or resonance of a perceptual state of felt sense of being, with nothing less of itself being distributed, as itself.

In an infinite relationship, there exists the potential of balance and equilibrium as a system, distributing patterns which have the potential as whole resonance to ripple, as the equal displacement of each other, as an infinite expression of self, each as their own field of resonance, as a unique fundamental experience of being.

We have to widen the lens into the human condition in order to support our shared experience and perceptions of death, if we are to offer EOL care in the most empowered way, as both providers and human beings. We are each an infinite self, birthed and received equally, as an infinite experience of self.

This mindset is an intention which allows communication to be expressed and received in a more effortless way, by attuning the patient to a more harmonious and coherent pattern, securely supported in their own unique process of dying. As providers, we must make room for a sense of identity or self, extending beyond the individual or personal, to encompass wider aspects of our shared humanity and life.

This is what allows me as a provider to feel more effortless in my experience of practicing EOL care. I feel less physically and emotionally drained and I often feel more recharged after leaving a session than I do when I enter into a session with a patient. It is in the *receiving* of the open whole connection that resonates within my field of experience, as both a felt and physical experience of wholeness, where I feel reenergized in the purposes of caring for my EOL patients. I wish to highlight this experience, as I imagine if all medical professionals did not feel the contraction around being with death, it could minimize moral injury and burnout and even give an experience far beyond one would forecast. It feels so daunting to not feel “equipped” to approach end of life. Those stories begin to stack up in the being of the medical professional and can weigh one down to where they begin to not feel good about the care they provide or their potency in serving the total pain of the patient.

Death unfolds as the perfect experience of itself in its purpose of being received in its wholeness. There is a time for each of our own deaths and our bodies know what to do, and it is in the support of the provider providing a safe network through connection that the patient can embrace this truth. The connection and trust developed in this mindset between the patient and provider, allows the receiver of EOL care to surrender to their own unique process of dying more easily, in order for death to unfold in a more accepted and empowered way, through a felt sense of safety and support.

Death is a truth to our shared experience. It needs language and perception to support it in a more purposeful way with our presence and communication as providers that sees death for its universal purpose. We don't have the answers to how we experience fundamental reality which shapes our experience of reality through our relationships. But we do know death cannot exist without birth and it is the continuation of self into the knowingness of its own return to itself. There is an unknowingness to death, but there is also an intrinsic and innate knowingness to the experience of being that we can acknowledge as providers.

There are no proven laws of nature that can give us comfort in the unknowingness of death. Conceptual language around death that supports the empowerment of EOL patients in their partnership with providers is necessary to both model and embrace in our shared human experience of each other, as providers to other beings receiving EOL care.

4

Discussing Difficult News: Reframing Patient and Family Preferences Surrounding the Content and Style of Communication

Eric Goodlev

Contents

4.1 Scope of the Issue

Uncomfortable conversations transcend medicine across all sites of care and at all stages of a serious illness. From discussion of prognosis or prognostic uncertainty, to evaluation of competing treatment options, to disclosure of medical errors, to consideration of potentially toxic treatments, clinicians must approach such conversations with sensitivity to a patient's cognitive, emotional, spiritual, and cultural needs. Conversations small and large may be seen as "difficult" by a patient or their family, and there may be discordant views of the perceived "difficulty" of a

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conversation from the perspective of the medical team as compared to the patient or family.

Historically, the skillset involved in discussion of these types of issues has been termed “breaking bad news.” Anthony Back and colleagues, in their seminal text “Mastering Communication with Seriously Ill Patients [1],” argue that in light of the increasing availability of medical information to the public, earlier diagnosis and intervention for serious illness, and an ongoing cultural transition towards shared decision-making in medicine, “talking about serious news” is a more appropriate term to define the task at hand, especially as it encourages a focus on adjusting to a new “functional and experimental normal,” rather than a one-way transmission of what the authors term “brokenness [1].” In sum, news should be defined as “difficult” not only based on what the medical team deems to be serious or “bad,” but also based on the cultural, spiritual, familial, and values-based concerns of a patient or family. All communication has the potential to be difficult for a patient or family to receive. Recognizing this challenge presents an opportunity for all high-stakes communication encounters to strengthen the clinician-patient relationship, build trust, deepen therapeutic presence, and encourage partnership along the journey of a serious illness.

In this chapter, we will review the core principles of transmitting difficult prognostic or diagnostic information to a patient, using well-known and validated communication paradigms as a guide. We will then discuss examples of discordance between perceived “difficult news” by the medical team and the patient or family, using a framework of curiosity and respect for diverse patient perspectives. Finally, we will propose actionable steps towards further improving communication surrounding disclosure of serious news, with an eye towards approaching every interaction as an opportunity to not only share information, but strengthen the clinician-patient bond in a patient- and family-centered manner.

4.2 Established Protocols for Discussing Difficult News

There are multiple protocols in the literature focused on providing a roadmap for discussing difficult news with a patient, each with the purpose of providing a conceptual framework to guide clinicians during the clinical encounter. Despite each model taking a slightly different approach, there are commonalities between models that are useful to highlight. Since every discussion surrounding serious news is unique, it is important for clinicians to be facile with different models and having intuitive understanding of common themes. This allows for communication that is fluid, yet anchored in key concepts.

Baile and colleagues published the *SPIKES* framework in 2000, initially targeted at oncologists faced with communicating difficult news, though the model can be used more broadly across all care settings. The model focuses on ***S****etting Up* (preparation of space and clinical preparation for the encounter); assessing a patient’s current ***P****erception* of the medical situation; requesting an ***I****nvitation* to discuss the news; sharing ***K****nowledge* by discussing the news specifically; expecting and receiving patient ***E****motion* with empathy and compassion; and transitioning to ***S****trategy* and ***S****ummary* in discussing a path forward [2]. More broadly, this model—and others like it—focus on preparation as a primary and essential tool, *prior to* initiation of the conversation, and proceeds to encourage clinicians to respond empathically to emotions, deliver news in a clear, patient-centered fashion, and allow time for synthesis and discussion of next steps.

There are several models that utilize a similar conceptual framework, with focus on the pre-work of understanding the clinical background and speaking with relevant specialists, setting up the physical (or in the case of telehealth, virtual) encounter space, effective and represents a different skillset, of news in layperson's terms, and openness to mediating strong emotional responses [3, 4]. Though understanding a patient's values is not explicitly included in the aforementioned models, the Serious Illness Conversation Guide [5] includes a reminder to explore key topics, such as fears, worries, tradeoffs, critical abilities, and sources of strength, allowing the clinician to align treatment plans with a patient's preferences.

4.3 Difficult News is in the Eye of the Beholder: Discordance Between Clinical Teams and Patients and Families

It is important to note that a diversity of "news items" shared in a clinical encounter may be perceived as difficult to hear by a patient or family member of a patient—even if thought to be innocuous to the clinician. Similarly, the medical team may worry about news being perceived as serious or upsetting, only to find that the patient and family have an unexpected emotional reaction. For example, sharing a new diagnosis of recurrent cancer may provide reassurance or relief to the patient with long-unexplained and difficult to treat bloating and nausea that has been either dismissed by the medical team or gone without diagnosis for a long period of time, despite its impact on prognosis. Conversely, seemingly "good" news might be perceived differently by a patient with values, cultural norms, life experiences, and fears that are discordant from those of the medical team. For this reason, the principles of effective communication of difficult news are important to keep in mind in every clinical encounter, particularly in the setting of serious illness.

This has been demonstrated clearly in the cancer literature. In one study, Back and colleagues performed structured interviews with patients living with gastrointestinal cancer, asking them to react in real-time to an audio recording of a physician breaking difficult news about cancer recurrence. The authors found that respondents valued when clinicians recognized the emotional impact of sharing this news, even after the news has been shared. Importantly, participants noted how important it is for clinicians to not empirically frame news in a particular negative emotional light, such as "horrible," and instead preferred a more neutral approach that allows the patient's emotional reaction to drive the discussion [6]. The authors go on to note that a clinician's ability to be responsive to a patient's perceived emotional state—in other words, to be willing to flex and address emotions and concerns before, during, and after a piece of news is shared—promotes an encounter that is therapeutic as well as informative.

One can imagine a situation when a clinician perceives news in a profoundly different way from a patient, and how this discordance might detract from the goal of aligning with a patient along their journey with serious illness. A patient, for example, who receives news that she needs a heart transplant after a protracted course of non-ischemic cardiomyopathy causing heart failure may be relieved that a definitive path forward is available, despite their fears of surgery and the uncertainty of awaiting a donor organ. In this situation, comments from the treating team overstating the perceived "difficulty" of this news might serve as counterproductive, as they distance the clinician from the patient's perspective. A better approach would ensure consistent attention to a patient's emotional state, their non-verbal communication patterns, and the text (and subtext) of their responses. Such an approach allows the clinician to respond to the patient's emotional state, rather than impose a preconceived notion of the "seriousness" of the news.

Across multiple cultural and ethnic groups, there is a diversity of clinical scenarios that might be perceived as difficult, highlighting the importance of being constantly attuned to potential difficult news in any clinical scenario. A recent study surveyed a sample of older adults (English and Spanish speaking and reflecting a broad range of cultural backgrounds) asked participants to recall medical decisions that they perceived to be difficult, serious, or important. Across multiple genders, ethnicities, and languages, participants reported finding discussions about cancer treatment or management of medical crises to be difficult. Importantly, they also described decisions surrounding management of chronic medical conditions, medication adherence, transitions of care, and decisions surrounding both emergent and elective surgery, to be difficult or serious [7]. In other words, there was a diversity of clinical topics and decisions that were deemed serious, though not all related to traditional definitions of "bad news." For this reason, clinicians must cultivate their sensitivity to patients' and families' responses to even seemingly innocuous clinical updates, and be ready to respond to emotion.

4.4 Patients, Families, and Providers Have Differing Preferences Surrounding Discussing Difficult News

Just as it is important to recognize that patients, families, and the medical team may have discordant views on what constitutes "difficult news," it is also crucial to recognize that there is a diversity of cultural and familial norms surrounding disclosure of serious diagnostic or prognostic information. Sensitivity to these differences and a curiosity surrounding a patient's cultural or familial preferences when discussing serious news is critical to maintaining therapeutic presence.

Cultural norms surrounding discissions of difficult news are nuanced, and there is no one-size-fits-all approach to predicting what a patient or family may find to be effective communication. For this reason, this discussion will avoid detailed discussion of specific communication needs of any particular group, recognizing that no written piece can capture the nuance of specific cultures or the dynamicity of preferences within a particular family. Rather, we will focus on broad themes that illustrate the diversity of preferences across patients from a wide variety of backgrounds, as well as a more general exploration of differing patient and provider preferences surrounding prognostic disclosure. As expectations surrounding difficult communication vary both *between* and *within* cultural groups and families, providers should approach all conversations with curiosity and humility and without preconceived notions of patient preferences.

4.4.1 Patient, Family, and Provider Perceptions Influence Communication

First, it is important to recognize that providers, patients, and families have varied comfort in delivering difficult news, independent of any cultural norms or practices. In a 2015 synthesis of qualitative research surrounding discussing bad news in an oncology practice, Bousquet and colleagues describe both physician-level and patient-level variables that influence the content discussed during a clinical encounter. The authors describe the precarious balance between hope and truth-telling, noting that oncologists may "balance" good news and bad news in an effort to preserve a patient's hope. Furthermore, the authors found that oncologists expressed hesitance to use words like "death," and at times noted that patient emotion, and even their own emotion, influenced the encounter. In addition, the authors noted that there are other systemic factors influencing discussion of difficult news, including time limitations, communication breakdown between different providers, or concerns about not being prepared to deliver difficult news [8].

The tension between hope and truth-telling extends to patients and their preferences, though the impact of prognostic or diagnostic disclosure on the quality of life and patient-reported outcomes is inconsistent. In a recent systematic review, investigators found that the impact of disclosing prognosis to a patient had variable impact on emotional and overall quality of life [9]. Recent data focused on patients with advanced breast cancer demonstrated that though patients initially desired to receive "all information" about their diagnosis, over time they expressed wanting only information deemed "useful;" the authors interpreted this as an effort to preserve hope and meaning in the face of incurable illness, recognizing that patients' preferences shift over time [10]. For these reasons, it is important to approach disclosure of difficult news with a sense of humility and an openness to understanding what a patient or family "wants to know." It is also crucial to remember that a patient may want to know more or less today than they did during previous visits. In some situations, providers may not fully recognize the impact of seemingly "appropriate" disclosures of difficult news on emotional or overall quality of life, highlighting the importance of asking a patient what they wish to discuss prior to information-sharing even if these discussions have happened before.

4.4.2 Impact of Communication Style on Patient and Family Experience

The manner in which difficult news is shared also influences patient and family experience. In one study, cancer patients shown videos of disclosure of a cancer diagnosis using “low” levels of patient-centered communication practices (not identifying emotion, etc.) exhibited increased anxiety and decreased trust in their physician as compared to patients shown a video of an identical diagnostic disclosure, but using “enhanced” patient-centered communication with increased attention to patient emotion [11]. In another study, patients expressed feeling most comfortable when difficult news was delivered in a way that emphasized the patient’s preferences, as opposed to focusing primarily on the disease or emotions [12]. In sum—there is not a one-size-fits-all approach, and when in doubt, it is best to check in with a patient about their communication needs.

4.5 Moving Beyond Existing Protocols—Some Actionable Steps

One might find the diversity of patient preferences overwhelming, and for good reason. The data reviewed above underscore how much the content and style of discussing a weighty diagnostic or prognostic “news item” can influence a patient’s physical, emotional, and existential well-being. Even patients that are well-known to a clinician may change their preferences surrounding receiving difficult news, further complicating longitudinal discussions of prognosis, values, and goals.

How is a provider to navigate this complex and dynamic area? Here we will suggest several adaptations to the communication maps outlined above, borrowing from different methods and inserting some unique approaches.

Assessing “perception” (SPIKES protocol) [2] *must include not only the patient’s perception of the clinical situation, but also the provider’s understanding of what the patient wants to know and is ready to hear.*

The above discussion highlights that there is variability in what patients want to know, how they want to receive information, and how they prefer that their families be included in discussions of difficult news. For this reason, it can be useful to ask a patient how they prefer to receive information (“big picture” versus “small details”), who they would like to be present (and who they would like to not be present), and how culture influences communication preferences.

4.5.1 Don’t Assume that the Information Shared is “Bad News”

In recognition of the variability of what constitutes “bad” news to a patient, it is important to approach information-sharing with an openness to differing interpretations of the news being shared. Remember that some patients may find news perceived as “bad” by the medical team to be reassuring, or news that is assumed to be “good” as distressing. A patient’s perception can be influenced by their preconceived notions of their disease state, their hopes for the future, and their fears or worries. Our natural desire to give a “warning shot” prior to discussing such news runs the risk of pre-judging the patient’s interpretation of the clinical information.

As an alternative, consider prefacing clinical news with a statement such as “I have some information to share with you, and I want to recognize that this may be a lot to take in (or surprising, or unexpected, or confusing, etc.).” In phrasing the “warning shot” in this fashion, the provider identifies the news as impactful, but not necessarily “good” or “bad.” This allows the patient to experience the news and their emotions without preconceived framing of their expected reaction. It may also be helpful to ask a patient whether the news was surprising to them, or if they were expecting this information. In this way the patient is able to set the emotional tone for the remainder of the encounter, and provide valuable emotional data to the provider to guide the conversation.

4.5.2 Re-assess, Even if You Know the Patient Well

Particularly over the course of a long-term doctor-patient relationship, there may be multiple opportunities to share medical information, prognosis, treatment options, or other “weighty” pieces of information. It is important to re-assess a patient’s communication preferences with each encounter, as well as the communication preferences of the family. In particular, when there is concern that a specific cultural belief may make it difficult for a patient or family member to speak up about their communication preferences, it is crucial for the provider to ask each person present how they would like to participate in communication surrounding new medical information. By setting this as the norm early in a therapeutic relationship, one can potentially empower all family members to fully participate in communication to the extent they feel comfortable.

4.6 Conclusions

In summary, there are multiple methods to disclose difficult or serious medical news. Most of these methods share common themes, including assessing a patient’s perception, allowing for and managing emotions, asking permission, adequate preparation, and assessing a patient or family’s take-aways from the discussion. However, given the diversity of patient preferences and family dynamics, there is not a one-size-fits-all approach. Above all, it is most important to remember that our definition of “bad news” and a patient or family’s definition may not align. Maintaining an openness to being surprised by a patient’s reaction, and being willing to ask how a news item “lands” for a patient, are valuable skills that not only maintain patient-centeredness, but also can deepen a therapeutic relationship.

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Demystifying Prognosis

5

Understanding the Science and Art of Prognostication

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Contents

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5.1 Introduction

Prognostication is a fundamental clinical competency, alongside diagnosis and treatment. It can be just as critical as providing a diagnosis for both the patient and the care team. Imagine you have been given a serious diagnosis, and it is easy to see how understanding what the future holds becomes of utmost importance. Historically, when humanity's ability to diagnose and treat disease was limited, being able to accurately form a prognosis was the cornerstone of high-level medical care. As medical technology advanced the ability to diagnose and treat, prognostication receded from the forefront of medicine, in some ways taking on mantle of mystery, as evidenced by the relative paucity of study in the field for most of the twentieth century [1]. Numerous studies highlight clinician hesitance and discomfort discussing prognosis despite being a necessary medical skill. In recent years, medical culture has shifted towards placing a greater emphasis on autonomy and the role of patient decision making as central to determining the plan of care [2]. There has been a growing body of scientific knowledge and evidence supporting prognostication as a clinical skill, prompted in part by this cultural evolution. Deriving an accurate prognosis and its effective communication has thus become more important than ever [3].

5.2 The History of Prognosis: Understanding the Past and Looking to the Future

Medical prognostication, particularly surrounding the prediction of survival from disease, has ancient roots. In the fifth century BCE, the work of Hippocrates helped build the foundation of medicine as an evidence-based science, and central to his philosophy of medical skill was the ability to prognosticate. Hippocrates' aphorisms in *The Book of Prognostics* are an early example observational evidence used to forecast death and have echoes in modern medicine. Instead of framing prognosis as a supernatural power, he notably emphasizes the role of using knowledge of the patient's own trajectory and clinical evidence to support the prognosis. This approach stood in contrast to a spiritual or religious stance in which forecasting the future, particularly regarding death, is something only known to a higher power, a difference which resonates in how prognosis is perceived today.

The temptation to ascribe mystical connotations to medical prognostication has persisted throughout history and is often tangled in the larger struggle between the secular and the spiritual. In Medieval Europe, medicine was intertwined with and held in the same esteem as the practice of divination and astrology. Much of the connection has to do with the skill of prognostication, a common theme across these disciplines [4]. While medicine has become scientifically grounded over time, particularly after the Renaissance, prognostication remained a clinical skill with an almost mystical aura.

Even today, clinicians and patients underestimate the evidence-based foundation of medical prognostication and can discredit its very concrete clinical importance when formulating a patient-centered medical plan of care. The focus of this chapter is the science behind contemporary medical prognostication. In this way, formulating and communicating prognosis should not be viewed by clinicians as an uncomfortable secret to be kept from patients, but rather as a clinical competency that can be taught, practiced, and integrated into the standard of patient-centered medical care.

5.3 What and Why We Prognosticate

The diagnosis of a serious illness often carries much uncertainty, and there are many things a clinician can prognosticate. For instance, if a person suffers a stroke, their family may wonder about the ability to live independently in the future. A patient with cancer may be interested in the possibility of a chemotherapy regimen resulting in severe side effects. In a 1981 paper, Fries and Ehrlich described five elements of serious illness that call for a prognosis: morbidity and symptom burden, mortality, disease progression, financial burden, and adverse effects of treatment [5]. These are all consequential factors in the complex medical decision making for patients and families. A clinician will likely be asked to weigh in on several of these aspects of life with a serious condition, however for the purpose of this chapter, the focus will be mainly on formulating and communicating a prognosis related to survival.

There are specific reasons why being able to estimate an individual's survival is important. Choosing a treatment plan is often dependent on time [6]. For some patients, accepting a very burdensome therapy like chemotherapy or a left ventricular assist device (LVAD) hinges on the prognosis with and without these interventions. Would the recovery time from a tumor debulking surgery be longer than the overall prognosis? Or is the prognosis such that going through a surgery would have a good chance of significant improvement in quality of life? [7] Prognostic awareness helps empower the patient to help guide their medical plan of care [8]. Similarly, for the clinician, prognosis is often a factor in the calculus of deciding a person's candidacy for a given treatment. For example, a plan of care may vary widely for someone with a prognosis of a few days versus several weeks, when considering the benefit and burden of intravenous fluids. These are very different circumstances, but both rely on an understanding of prognosis.

A thoughtful prognosis also makes early goals of care conversations possible. Having these conversations have been shown to lead to goal-concordant care. The SUPPORT Trial, a large prospective control study demonstrated prevalent miscommunication about desired medical care and a tendency towards aggressive measures at the end of life in patients admitted to the ICU. However, merely handing clinicians prognostic estimates and asking them to share it at the point of crisis was not shown to significantly affect patient outcomes [9]. The potential benefit of sharing prognostic information may be in the ongoing conversations with trusted clinicians along the disease trajectory. Goal-concordant care because of prognostic awareness is more likely when the patient is well enough to be involved [10]. To achieve this, developing prognostic skill is needed across the medical profession, so these conversations can be started further upstream and not merely at moments of crisis [11].

Prognosis also has practical implications for patients and their loved ones. Surveys of patients and families at the end of life suggests, in general, a strong preference for receiving information on how much time their loved one may have. Not only must we consider the numerous physical and logistical concerns that patients have near the end of life, but we must also recognize a patient's social, emotional, and psychological quality of life is impacted by an understanding of time. Being given the opportunity to find closure, say goodbye, take part in legacy building and arrange their affairs are important to patients during this stage [12]. Similarly, a clear understanding of survival time is important to caregivers of the patient, who desire this information to help mentally prepare for increased symptom management and care giving needs, as well as to help with the grieving process [11]. Having prognostic conversations with a trusted clinician in a thoughtful way can help to build trust, ease the distress of uncertainty, and support planning within the patient's personal life.

5.4 Conceptualizing Prognostication

When approaching prognostication, it may be helpful to break down the process into its different parts. Formulating, or "foreseeing", and communicating or "foretelling" are widely accepted as the two pillars of prognostication, and this will be the focus of this chapter [13]. It is important to remember, however, that this is not where the work of prognostication ends. As we will see later in this chapter, communicating prognosis is particularly rife with opportunities for miscommunication from both the clinician and the patient perspective. For this reason, naming uncertainty and assessing understanding should be considered a vital part of prognostication. Furthermore, providing support should be thought of as an indispensable part of prognostication to emphasize the importance of having the appropriate support systems available and adequate time to have a thoughtful and compassionate discussion following what may be the worst news an individual can receive. Finally, prognostication should be thought of as an active process. Complications, response to treatment and numerous other factors may change a patient's prognosis calling for revisiting and reformulation as time passes [1, 14] (Fig. 5.1).

The Phases of Prognostication

1. Formulating
2. Communicating
3. Naming Uncertainty
4. Assessing understanding
5. Providing support
6. Reformulating.

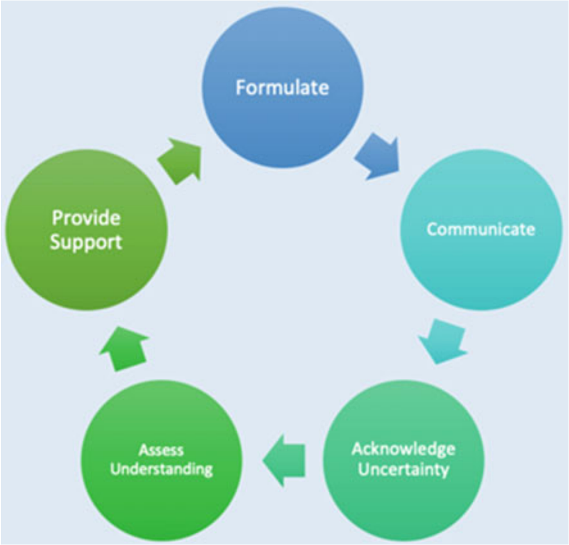

Fig. 5.1 Prognostication as a continuing conversation

5.5 The Science of Formulating Prognosis

Deriving a predicted survival time is the first step in prognostication. There are two types of approaches one may use, the subjective clinician prediction of survival or the objective actuarial (or modeled) prediction of survival. Often, some combination of the two methods is used in practice, though not in a standardized manner [14]. Though recent years have seen advancement in this area, there certainly remains ample room for growth and study. There can be inconsistent accuracy across different disease populations and at different stages in an individual's trajectory. Many of the studies that form the basis of these prognostication methods focus on advanced cancer in populations identified as "palliative", which is obviously difficult to standardize across studies, and therefore limit generalizability [13]. Another complexity in using studies in clinical practice is the inability to account for disease evolution with variables such as response to treatment and disease complications [6]. Nevertheless, with awareness of the potential pitfalls and the variety of validated tools and approaches available, a clinician can improve their ability to formulate an accurate prognosis for their patient using clinical judgement, actuarial predictions, or a combination of the two.

5.5.1 Clinical Judgement

Clinician prediction of survival (CPS) is the clinician's subjective formulation of prognosis based on the assessment of the individual patient in a clinical setting [8]. It is somewhat nebulous by definition, like any other clinical judgment, yet it is the most frequently used method of formulating prognosis. It happens in everyday clinical practice, even if it is not formally communicated. Attempts to discern what goes into CPS suggests a combination of clinical experience, statistical data, and knowledge of the individual's trajectory. CPS can be framed in three main ways [6].

- Temporal—Quantifying the expected time frame one expects the patient will live
- Probabilistic—Estimating the probability of the patient dying in a given time frame
- The "Surprise" Question—Reflecting on if it would be a surprise if the patient died in a given time frame.

Clinician predicted survival itself is an independent prognostic factor and correlates with survival, but accuracy is variable [15]. Using the temporal framing tends to result in an overestimation of survival and seems to be less accurate than using the surprise question or a probabilistic approach with cancer patients [6]. Regardless, CPS is important to understand, since it is what most clinicians use to formulate prognosis and it fundamental to services like the Medicare Hospice Benefit. A systematic review revealed that nearly all studies of CPS provided overly optimistic predictions of survival for patients with advanced cancer and was accurate up to 29% of the time [16]. Subsequent reviews support this tendency, adding that CPS is more than twice as likely to be overly optimistic than overly pessimistic [8]. Despite lack of precision, CPS has been shown to correlate well when compared to actual survival and is a good starting point, particularly when combined with performance status, biomarkers, and other prognostic tools [16, 17]. A 2015 multicenter study showed the CPS of palliative medicine physicians was significantly more accurate compared to other specialties' estimates, although the tendency to overestimate survival remained, and several other studies do not demonstrate a significant difference in skill across specialties [17, 18].

CPS accuracy also varies by the type of terminal illness and the timeline in question. The disease trajectory of organ failure such as heart failure or COPD is characterized by multiple exacerbations and recoveries, which makes coming up with accurate CPS particularly challenging, especially in the midst of an acute exacerbation. It can be difficult to tell where on the disease trajectory these patients are located. Even amongst cancer patients, there are conflicting findings on whether prognostication becomes more accurate as the patient approaches end of life. Some studies note a "horizon effect" in which short-term survival is more accurately predicted than long-term survival, but others have found the opposite [17, 19]. Even at a more basic level, the definition of "terminal" means differs from clinician to clinician, which understandably influences the content of these conversations [2].

5.5.2 Actuarial Judgement

Actuarial judgement, unlike clinical judgement, intends to remove “the human judge”. Instead, it relies on data to identify and weigh relationships to form predictive models [20]. When using actuarial judgement to formulate a patient’s prognosis one must keep in mind that actuarial judgement is implicitly not individualized, so clinicians still need to tailor the results to the specific patient and situation in question. Knowing in which setting the actuarial method has been validated and what variables were considered is important to ensure it is appropriate for a given scenario. Prognosticating survival often utilizes performance status, biomarkers, clinical findings, and symptoms, as these factors have demonstrated statistical relationships to survival time. When used thoughtfully, actuarial judgement based on these factors can provide illuminating and accurate information from which a prognosis is derived.

5.5.3 Performance Status

Performance status is an assessment of an individual’s capacity to carry out daily tasks and has been shown to be a key prognostic factor in both cancer and non-cancer diseases. Performance status has implications for eligibility to receive certain treatments, likelihood to benefit from treatment and overall predicted survival. The Karnofsky Performance Scale (KPS), Palliative Performance Scale (PPS), and Eastern Cooperative Oncology Group (ECOG) Scale are commonly used, validated tools. These tools have prognostic value, are accurate particularly for short term prognosis and can be used to easily communicate functional status as well as to formulate prognosis [15].

5.5.4 The Karnofsky Performance Scale

A 1983 study by Mor et al. initially demonstrated the relationship between KPS and survival in cancer patients. Lower KPS scores were more strongly predictive of short-term mortality. The converse- that a high score implied a long survival, was not necessarily found to be true, making it more useful for prediction of survival of patients with poor functional status. Additionally, this scale specifies hospitalization as part of determining a score, so it is not as universally applicable [21, 22].

5.5.5 Palliative Performance Scale

The PPS was developed in 1996 to relate functional status to survival more diverse settings such as home, clinic or hospice units [23]. In a study of patients with cancer and non-cancer terminal illnesses, it was found that PPS correlates with KPS and can be used interchangeably [24]. There is evidence to support that each gradation of PPS scores between 10 and 40% have significantly distinct Kaplan Meir survival curves for patients with advanced cancer, and thus can be used to formulate a survival time more accurately from initial assessment [25]. Additionally, a systematic review looking at PPS as a predictor of survival found that PPS can be used for both cancer and non-cancer diseases including heart failure, dementia, and COPD. A PPS of 10% accurately predicts a survival of 1–3 days for both cancer and non-cancer patients, though with higher PPS scores the range of survival became wider [26].

5.5.6 Eastern Cooperative Oncology Groupe Scale

ECOG is a widely used tool amongst oncologists, correlates with KPS and PPS but is specific to cancer patients [24]. It is used in combination with other clinical factors to help determine if a patient would tolerate chemotherapy or be a candidate for clinical trials. With a low ECOG there is a high likelihood that treatment toxicity would likely do more harm and not confer a survival benefit or improved quality of life. The American Society of Clinical Oncology recommends careful consideration of a patient’s ECOG score when offering palliative chemotherapy to maximize the potential benefit. There is also the prospect of causing harm with chemotherapy. A study of patients with refractory metastatic cancer who received palliative cytotoxic chemotherapy found that those with ECOG scores of 2–3 had no effect on survival or quality of life, while patients with an ECOG of 1 actually had decreased survival and worse quality of life [27]. It is important to note, however, that the same may not necessarily be true for all cancer directed therapies. A recent meta-analysis focusing on immunotherapy suggests that a poor ECOG was not linked to worse outcomes when receiving immunotherapy and should not weigh as heavily when determining candidacy for this type of treatment [28]. This illustrates the importance of understanding the individual situation and using clinical judgement in combination with this data to make medical decisions when prognosis is a key factor.

5.5.7 Symptoms, Clinical Findings, and Biomarkers

While performance status is widely regarded as one of the most significant determinants of survival, certain symptoms and clinical findings have been identified as independent predictors of survival.

Similarly, to performance status for advanced cancer, these indicators are more accurate for predicting survival when the prognosis is short. Where tumor characteristics may drive prognosis early the disease, patient factors become more predictive in advanced disease [8, 14]. A large multicenter study of cancer patients conducted by Ruben et al. noted dysphagia, anorexia/cachexia, and dyspnea as commonly experienced symptoms near the end of life [29]. Dyspnea and delirium are particularly strong indicators of poor short-term prognosis in advanced disease. A systematic review looking at studies of symptoms across all cancer types supports the idea of this complex of symptoms converging into a “terminal cancer syndrome” regardless of cancer site or pathology [15].

There are also particular signs and symptoms to consider when coming up with a prognosis in non-cancer diseases. For instance, survival for anoxic brain injury after cardiac arrest relies heavily on neurological exam findings. Even if CPR is successful in achieving return of spontaneous circulation after an in-hospital arrest, only about 20–30% of these patients will survive the hospitalization. Even if a patient survives to discharge from the hospital, morbidity and mortality remains extremely high. Of those who die, most deaths will be due to neurological damage sustained during resuscitation. A patient’s exam in the three days following arrest is heavily suggestive of their prognosis. Coma lasting greater than six hours after arrest is associated with severe neurological damage and indicates recovery to independent function in the ensuing year will be unlikely. Lack of pupillary or corneal reflex by day three carries a grim prognosis and most of these patients will not survive the hospitalization. The Full Outline of Unresponsiveness (FOUR) score incorporates brainstem reflexes, motor response, eye movement and respiratory status into a tool that can help determine prognosis by tracking scores on the first 3 to 5 days after the event [30].

Organ failure presents interesting challenges in prognostication given disease trajectory and the need to account for systemic consequences of this type of disease process. For patients with COPD, forced expiratory ventilation (FEV1) is used to quantify physiologic disease severity and is linked to mortality. This alone, however, provides an incomplete picture of patient’s clinical condition and of their prognosis. Risk of mortality is more complex due to the systemic effects of pulmonary dysfunction. A study published in the New England Journal of Medicine found that all-cause mortality for ambulatory patients was better predicted by considering the severity of dyspnea, BMI, and six-minute walk performance in addition to FEV1 [31]. Frequent hospitalization has also been shown to be an independent predictor of mortality, regardless of FEV1. Admission to the ICU in particular doubles 1 year mortality from 30% to around 60%. There is also some data suggesting that biomarkers associated with chronic inflammation, particularly leukocytosis and fibrinogen, are also associated with increased 3-year mortality [31–33]. Chronic hypercapnia portends a significantly worse 1-year mortality, but interestingly hypercapnia during an acute exacerbation is not associated with worse in-hospital mortality [33].

Heart failure is similarly complex. There is the problem of prognosticating in an acute exacerbation but there are also the added complexities of different types of heart failure, for instance preserved versus reduced ejection fraction, and various etiologies like ischemic versus nonischemic. A large, multicenter cohort study in 2006 helped to elucidate predictive factors for ambulatory patients with heart failure. It found that NYHA class symptoms, systolic blood pressure, hemoglobin, EF, sodium, and ischemic etiology were all independent predictors of poor outcome. This study was used to create the Seattle Heart Failure Model, which is widely used to predict 3-, 2- and 1-year mortality, as well as to assess the survival benefit of guideline directed therapy for individual patients [34]. Like COPD, simply being hospitalized is a poor prognostic factor, with a 30-day mortality of about 10%. For patients admitted with acute on chronic heart failure, biomarkers including elevated creatinine and BUN, low sodium, and physical findings such as tachycardia and low blood pressure all increased risk of in-hospital mortality [35, 36]. Risk stratifying these patients is key to guiding important medical decisions when it comes to advanced heart failure therapies and helps to guide prognostic awareness for patients and families who have likely experienced prior multiple admissions and recoveries.

5.5.8 Prognostic Tools

Prognostic tools have been developed to help incorporate functional status, symptoms, biomarkers, clinical findings, and in some cases, clinician predicted survival, with the goal of providing more accurate prognostication. These tools can be used in conjunction with clinician predicted survival to provide a more accurate estimation of prognosis. Care should be taken however to ensure that each tool is used in a cohort and setting that has been validated. As always, it remains important to be cognizant of the fact that for whatever prognosis is calculated, an individual's disease trajectory may differ for a multitude of patient and disease related factors.

5.5.9 Cancer

The Palliative Prognostic Score (PaP), and Palliative Prognostic Index (PPI) were developed to aid in the prognostication of survival in cancer. The PaP has clinician prediction of survival built into the score and was validated across several settings and stages of the disease [8]. The presence of delirium was later added to the PaP to create the D-PaP which was further able to discriminate prognostic cohorts. A multicenter prospective cohort study validated the PaP, D-PaP, PPI, and PiPs tools across variable settings, including patients receiving chemotherapy. These tools demonstrated an accuracy of 69% or greater in predicting both long- and short-term survival. This study did note that the practicality, particularly of PaP and D-PaP, made these tools less feasible for routine use when compared to the PPI [37].

5.5.10 Heart Failure

The Seattle Heart Failure Model (SHFM) is widely used to help predict 1-, 2-, and 3-year survival. It has been validated across a diverse range of heart failure models and can be used for both hospitalized patients with acute exacerbations of heart failure and ambulatory patients that are at their baseline. The SHFM is able to demonstrate the possible benefit from adding guideline directed medical therapy and can discriminate a patient's risk of death from decompensated heart failure versus from sudden cardiac death [34]. Patients hospitalized with heart failure have high short-term mortality rates. Separate tools including the Acute Decompensated Heart Failure National Registry (ADHERE) Model and Enhanced Feedback for Effective Cardiac Treatment (EFFECT) have been developed to predict 30-day mortality for this group [35].

5.5.11 Liver Disease

The Model for End-Stage Liver Disease (MELD) score is used to predict 3-month mortality in patients with end stage liver disease regardless of the etiology. It was created in 2000 initially to gauge the possible outcome undergoing transjugular intra hepatic portosystemic shunt procedure but was subsequently validated as a prognostic tool for liver disease in diverse settings [38]. The model, and its updated counterpart the MELD-Na, for patients with hyponatremia, use objective inputs such as INR, sodium, and BUN. In 2002, with increasing need for liver transplantation and studies showing that long wait time on the transplant list did not correlate to increased mortality, there was a shift to using MELD score as a way to allocate organs with the sickest patients gaining priority [39]. This adjustment did lead to a 12% decrease in mortality while on the list but concerns for certain populations being underrepresented by the MELD score perimeters [40].

5.5.12 COPD

Historically, FEV1 had been used to categorize COPD severity and as the main prognostic factor when determining mortality. This, however, did not account for the many systemic effects of COPD that contribute to overall mortality. A 2004 study proposed the BODE Index, multidimensional assessment that was found to have significantly better prognostic capability for four-year mortality than FEV1 alone. This scale combines BMI, FEV1, exertional capacity, patient reported dyspnea as gauged by the Medical Research Council Scale [31]. In addition to predicting death, the BODE Index is also useful to predict risk of exacerbations and hospitalizations [41]. Unlike the Seattle Heart Failure Model, the BODE Index does not incorporate the effects of initiating COPD directed treatments. For patients hospitalized with a COPD exacerbation, the DECAF score is a strong prognostic indicator in hospital mortality and is useful for risk stratifying patients on admission [42].

5.5.13 On the Issues of Race and Prognostication Models

In the late 2010s, clinicians and researchers began to question the role of race more actively in risk-prediction models, for example calculating glomerular filtration rate, which has implications for dialysis initiation and transplant eligibility [43]. The impacts of structural racism in health care access and care received is likely the primary driver of outcome differences, not any factors attributed solely to race This is an evolving area that has scientific, clinical, and cultural implications for the modern clinician. When considering any prognostic model, it is prudent to understand how race and racism could have impacted the modeling, validation, and application, and consider alternative models.

5.5.14 Prognostication in the Dying Process

Much of the study of prognostication focuses on a scale of months and years. This makes sense considering the utility of good prognostication along the disease trajectory to help guide the treatment plan and important medical decision making. Equally important, however, is prognostication for the imminently dying patient. Once a decision is made to transition to a comfort focused plan of care, it may seem that communicating a prognosis of hours versus days is a trivial thing, but in practice it is very significant for a patient's loved ones. Many times, asking about prognosis is amongst the first questions family will enquire after transitioning to comfort measures. An inquiry about time may hint at deep apprehensions or wishes that will inform the experience of their loved one's death. A husband asking, "So how long do you think this is going to take?" may be worried about prolonged suffering. A daughter asking if her father will be around until the end of the week may be hoping that a death doesn't occur at the same time as her child's birthday. Although prognostication of an imminently dying patient no longer deals with disease directed treatments, there are still important factors at play that warrant skilled prognostication.

Formulating a prognosis at the end of life calls for an assessment of the individuals' symptoms and interpretation of signs found on exam. A combination of physical signs, symptom burden and assessment of functional decline, particularly using the Palliative Performance Scale, seems to lead to the most accurate predictions [44]. A rapid deterioration of PPS score has been noted in the 1–2 months preceding death in cancer patients [45]. High symptom burden has been linked to mortality even amongst those with a relatively good functional status. In the last week of life, dyspnea, fatigue, dysphagia, and drowsiness becomes more severe [46]. An observational study of cancer patients admitted to palliative care units found seven physical signs including Cheyne-Stokes respirations, absence of radial artery pulse, and mandibular respirations, were specific predictors of imminent death within three days. Of note, these signs were not present in all patients who died within three days [47]. While much of what we know about imminent death is based on studies of patients with advanced cancer, a systematic review of symptoms at the end stages of various diseases including cancer, organ failure and AIDS, described a convergence of symptoms as person nears death, despite having experienced differing disease trajectories at earlier stages. These symptoms include weight loss, dyspnea, loss of appetite and fatigue [48].

Explaining and normalizing the process and prognosis of dying can be helpful for loved ones of the imminently dying person. Knowing what changes to expect, when to expect them and what this means in terms of prognosis help ease the discomfort of the unexpected.

5.6 Communicating Prognosis

Equally as important as formulating the prognosis is its effective communication. This may seem deceptively simple, but many studies have shown that it can be fraught with opportunities for misunderstanding. Confusion can flow from both the clinician and the patient perspectives. It is well documented that for patients, absorbing medical information, particularly when it pertains to bad news, is difficult and incomplete. At the same time, there is also a tendency for clinicians to equivocate and euphemize in these situations, thus further muddying the picture [3]. A study of advanced cancer patients and their oncologists showed a high rate of prognostic discordance, with 68% of patients rating their survival significantly different than what their oncologist had determined their survival to be. Patients and oncologists were not aware of this discordance in the majority of cases [49]. The obligation falls on the clinician to make the effort to understand how the patients perceive this information as well as their own bias in delivering prognosis. If this discussion is thoughtfully constructed, communicating prognosis can help build trust, decrease anxiety, and give patient's the tools they need to pursue goal concordant medical care [50].

5.6.1 The Clinician Perspective

Being mindful of one's own tendencies and biases as a clinician is an important first step in communicating prognosis. This is dependent on the individual's experience to some extent, but certain trends have been elucidated and are important to be aware of, as most physicians, regardless of specialty, will be faced with a situation in which they are asked to communicate prognosis [2].

There is a certain discomfort in delivering a prognosis that effects medical professionals broadly. Talking about death is still a taboo subject in many cultures and can seem even more so when one is asked to predict death. A large survey of internists found that most of the participants perceived delivering a prognosis distressing, and 90% of respondents felt that accurate prognostication was more difficult than diagnosis. Somewhat surprisingly, this high level of discomfort was felt across all specialties, including those asked to prognosticate frequently such has critical care physicians and oncologists [2]. Having more years of experience also did not add to a clinician's confidence with this skill. This study identified several possible explanations for this uneasiness. Clinical uncertainty regarding disease trajectory is often cited, as well as lack of training in how to formulate and deliver prognosis. Even implementation of society guidelines for having prognostic discussions does not change this. For instance, a separate survey reported similarly, feelings of uncertainty and inadequate training amongst cardiologists despite American Heart Society recommendations for yearly prognostic discussions as the standard of care for patients with advanced heart failure [51]. Clinicians also cite guilt about having to deliver bad news, as well as the perception that prognosis is not something that patients want to hear.

5.6.2 The Patient Perspective

Contrary to what clinicians perceive, patients and their caregivers tend to want prognostic information. A systematic review of prognostic communication by Parker et al. aimed to describe standards for communicating prognosis in a non-ICU setting for patients with a survival of less than 2 years. Notably, individuals may have different desires for information. Based on this review, about 60% of patients desired some information about survival at or around the time of diagnosis. The majority of patients and their caregivers also wanted information related to the dying process and to candidly discuss what this process would entail [11, 52]. Caregivers felt less anxiety with more information about what symptoms and changes to watch for as their loved one progressed in the disease trajectory. Patient and caregiver need for prognostic information was important to them across many domains of life.

5.6.3 Bridging the Gap: Frameworks for Communicating Prognosis

With any serious medical conversation, it helps to have a framework to help structure the discussion. Maltoni et al. proposed several recommendations to help improve accuracy with prognostication based on the limitations of clinician predicted survival found in a systematic review. The central recommendation for clinicians relying on CPS is to essentially be aware of the many opportunities for bias in formulation and communication of prognosis, and to take steps to help mitigate these biases. These recommendations include the following:

- Use clinician judgement in conjunction with another prognostic tool
- Consider asking for specialty input from more experienced colleagues
- Plan on reevaluating prognosis at fixed intervals.

After this initial "gut check" is done, the task then becomes contemplating the best way to present this information to the patient. Prior to delivering the prognosis, the clinician should consider the patient's preference for information, the setting in which this information is delivered, and with whom the information is shared [11, 52].

As discussed earlier in this chapter, patients and caregivers in general do desire prognostic information. With that in mind, it is important to recognize that individual patients may prefer different amounts of information, ranging from those that want specific details to those that want barely any specific information at all. Clinicians often cite lack of time during appointments as one of the reasons delivering prognosis is difficult. Care should be taken to ensure that a comfortable setting and adequate time exists in the appointment to have a thoughtful conversation, assess understanding and provide support. Finally, it is also prudent to consider who is with the patient during the prognostic conversation and ensure that it is ok to share with them.

The language used to convey the prognosis is significant. It should be clear in order to avoid confusion but needs to be thoughtful enough to encompass the nuances of prognostication. Some studies have indicated that presenting information as a probability or percentage can be confusing to patients, though some individuals will specifically desire numbers or statistics [53]. If asked to present this information, it is prudent to be aware of framing bias, in which individuals—both clinicians and patients—respond in different ways based on if information is framed as a gain versus a loss [52]. For instance, saying someone has a 20% chance of survival likely produces a more optimistic interpretation than saying they have an 80% chance of dying. One might consider presenting both the negative and positive framings to counter this effect. In general, when providing predicted survival, time frames should be given in ranges such as weeks to months, or months to years. Presenting prognosis as Typical-Best–Worst Case scenarios can also be helpful [55]. For instance, one might say "typically, patients in a similar situation may gain several months if the cancer responds to this treatment, with a survival of years being the best case. In the worst case, we see no response and survival is most likely weeks to months." Ultimately, it is up to the clinician to build a relationship with the patient and gain and understanding of the best way to communicate with the individual.

5.6.4 Cross-Cultural Communication and Prognosis

As with any patient encounter, it is important to take into consideration cultural differences when communicating prognosis. Central to cross cultural communication is acknowledging provider bias and understanding that patients with different cultural backgrounds may desire different information. Simultaneously, it is imperative to resist stereotyping or assuming what the patient and their family would want to know [55]. One should not assume a patient's perspective solely based on their cultural background. This becomes particularly essential when discussing something as difficult as prognosticating death, where maintaining patient-clinician trust is paramount. While it is important to educate oneself about diverse patient populations, many well intended providers may use limited knowledge in an inadvertently harmful and reductive manner. This results in treating patients of diverse backgrounds as monolithic groups rather than as individuals with complex personal experiences and influences and can cause miscommunication and distrust.

Approaching these encounters with a sense of cultural humility helps to avoid this pitfall. Cultural humility asks us to approach every patient interaction with the mindset of learning from that individual patient without assumptions and to engage in ongoing self-reflection [56]. When approaching any patient about prognostication, but particularly someone from a different cultural background, it is key to explore that individual's wishes and perspectives on prognosis with a sense of genuine curiosity. What information on prognosis is wanted or needed by the individual? How, when and with whom should this information be shared? What is the individual's idea of a good death? For instance, is this at home, in a hospital, or somewhere else? The answers to these questions vary from person to person. It is easy the provider to unintentionally impose our own bias and assumptions, but it is important to work to actively counteract this impulse. If you don't know, ask. As simple as this may seem it can be difficult to remember but is vital to communicating prognosis in a way that is patient centered.

5.7 Conclusion

Prognostication is a complex clinical proficiency that asks the clinician to meld objective and the subjective. It asks the clinician not to shy away from uncertainty but instead to acknowledge it and embrace it. The dual nature of medicine as a science and an art is apparent in the process of formulating and communicating a prognosis. Research, particularly in the last two decades continues to provide a more robust basis for understanding the science behind prognosis. Simultaneously, there has also been a trend towards more openness surrounding end of life communication and attention to patient and family experience of this phase of life. Understanding the data, using the available tools, and honing the skill of prognostication is an essential part of providing thoughtful patient-centered care to individuals facing serious illness. As you explore this book, the fundamentals of formulating a prognosis based on a clinician's judgement or a tool built on data will help enhance your clinical knowledge and practice but incorporating a sense of cultural humility and understanding may be the most meaningful way to better serve those under your care.

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Advance Care Planning Conversations: Laying the Foundation for Goal-Concordant Care at End of Life

6

Abigail Nathanson and Shirley Otis-Green

Contents

6.1 Overview

Advance care planning conversations lay the foundation for the delivery of person-centered, family-focused, culturally congruent quality care. Exploring the values, wishes and preferences of patients and their care partners enhances the probability of goal-concordant care and minimizes regret at the end of life for all involved. Advance care planning has been demonstrated to improve patient satisfaction and ease complications in bereavement. Yet few health professionals have received formal education regarding these nuanced conversations, nor have many had these conversations with their own families. This chapter will review the key components of quality advance care planning conversations and invite the reader to consider how to better integrate these important communication skills into their practice.

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6.2 Advance Care Planning Conversations

Advance care planning conversations are intended to guide decisions regarding a person's medical care if they are not in a position to speak for themselves. A primary component of palliative care is the promotion of interprofessional, person-centered, family-focused care from diagnosis through bereavement; advance care planning often forms the basis for a palliative care treatment plan [12]. Without specific information to guide care planning, the default standard of care presumes that intensive interventions would be desired. This often results in aggressive and costly medical interventions that may or may not be reflective of an individual's actual preferences, particularly as "end of life" for many has become an increasingly long and developmentally independent phase of life [3]. Families may be left questioning if the care received reflected the actual wishes of the patient and staff may feel moral distress when providing invasive services that seem unlikely to ultimately be "beneficial."

To address these challenges, legislation began being developed in the 1970s, marking a broader cultural shift from the physician as the primary decision-maker to a more patient-centered model. From living wills to durable powers of attorney for healthcare, conversations were being had around how best to ethically empower individuals and their medical teams to personalize care that was tailored to the preferences of those served. It was based on the idea that all treatment should be actively consented to, and formed the basis for ongoing legislative efforts at the local and international levels to clarify the relationship between patient wishes and treatment rendered [14].

Advance care planning conversations have evolved to include a discussion about a person's values, beliefs and preferences and the determination of a surrogate, or healthcare agent who would be able to relay these preferences to the medical team if the person was not able to speak for themselves. These conversations may then be formalized into a document called an Advance Directive. Advance Directives document a person's preferences and when properly completed and shared with one's healthcare team, can be used to inform medical decision-making, resulting in shared care planning.

Shared care planning is a formal attempt to regulate the relationship between medical care and one's own body. The importance of maintaining autonomy regarding what happens to one's body is a theme that plays out in many complex arenas such as sexual consent or abortion. In some of these areas, governments impact one's options, in other situations, individuals may exert more autonomy. The idea of putting legal paperwork in place in anticipation of future tragedy plays out along similar lines—a prenuptial agreement, for instance, gives individuals the right to dictate the outcome of a marital dissolution to override what governments would otherwise decide for them. Advance care planning has elements of these concerns in that there already exists ethical guidance regarding what care should be provided, and, there is an opportunity for an individual to exert some degree of autonomy over their bodies. A decision not to complete an Advance Directive becomes its own decision for a certain level of intensity in care. In the absence of a specific advance care plan, a person is likely to receive aggressive treatment as the default care plan, even in situations where the outcome is unlikely to be a return to an acceptable state of health.

Ideally, advance care planning conversations would organically occur throughout a person's life starting in early adulthood [3]. A shift in advance care planning culture means normalizing having this conversation as best practice, and not solely in response to urgent or disturbing developments in times of medical crisis. We can empower providers to address this cultural shift, by acknowledging both the reality of the human condition (normalizing our inherent mortality) and the messages patients may receive about these conversations.

For example, when a young person applies for a driver's license, in many states there is a question regarding organ donation. This might naturally invite a conversation about end-of-life wishes and an exploration regarding who they might want to be their medical decision-maker, if they were unable to speak for themselves. Ideally, when the person leaves home, gets married, or has a change in their health condition, decisions previously made would naturally be revisited and revised as circumstances change. As a person ages and relationships change, these conversations would continue to recur, with documents being updated as needs and decisions evolve. Once living with a serious illness, it is particularly important to review and update the Advance Directive to ensure its accuracy.

As health professionals, it is critical that we explain patients' medical conditions and prognosis as well as explore what types of future health states would be unacceptable. These preferences can guide care planning conversations with seriously ill patients and their surrogate decision makers. Informed decisions and the development of shared care planning with seriously ill patients require that the patient fully understands each option. This can be conveyed by exploring the best case/worst case/most likely case scenarios for each available choice. This conversation may lead to the decision to not attempt resuscitation (DNAR) of a hospitalized patient, and for patients for whom future hospitalizations and aggressive interventions are unwanted, the completion of a document indicating physician/medical orders for life sustaining treatment (POLST/MOLST—different states have different terms for these forms) may be warranted.

Engaging in a conversation to limit a particular treatment requires sophisticated and nuanced communication skills and is often best completed in the context of an interprofessional family meeting. Kindness and compassion are essential in explaining why a particular intervention is unlikely to be of benefit for this particular patient under this particular set of circumstances. Developing an ability to cultivate a patient's prognostic awareness takes time and expertise to do well. Seeking additional education to develop these skills and receiving mentorship from palliative care colleagues can be invaluable.

Summarizing your understanding of their thoughts and preferences for care at the end of life and their wishes for their body post-death will aid the surrogate decision maker during what will likely be an especially stressful period. Encouraging patients to consider proactively addressing non-medical issues that may arise (such as providing trusted agents with the information needed to manage finances, access social media accounts, or distribute possessions) can also be helpful. Yet, even for patients without a serious illness, having systems in place to normalize these conversations is beneficial, as approximately 25% of people who die in the United States each year are under the age of 65 [3].

The **Box** below offers a summary of the key steps for successful advance care planning.

Box: Key Steps in the Advance Care Planning Process

1. Reflect on your values, beliefs, preferences, focusing on *what gives your life meaning*. Some people find that their faith traditions offer guidance in this regard and benefit from speaking with others about these issues. As you reflect upon how your health may change over time, consider where you would want your care to be delivered and what trade-offs you might (and what you may consider to be a condition or fate "worse than death"), or might not, be willing to make in an attempt to extend life.
2. Determine who you would trust to speak for you if you were not able to make your own health decisions. Note: this person is ideally someone who is readily accessible and able to advocate on your behalf. You may also consider making a will and thinking about who you would trust to make financial decisions for you if you were incapacitated. Consider issues of guardianship and support for those who are dependent upon you (children, elders, pets, etc.).
3. Talk with this spokesperson (and others who would be impacted by your decisions) about your values and preferences and determine their comfort level in advocating for your wishes with the medical team.
4. Record a summary of your decisions and share that with all of those who may be impacted by your decisions. Clarifying your decisions and wishes minimizes family misunderstandings and regrets.
5. Complete an Advance Directive (see Resources) in accordance with your state's laws and regulations (and distribute copies to all who may be impacted by your decisions). Ensure that contact information is accurately recorded (and frequently updated).
6. Periodically discuss your preferences with your healthcare team. This may result in the completion of additional documents (such as a "Do Not Attempt Resuscitation" order or a "Physician/Medical Orders for Life Sustaining Treatments" form).
7. Regularly review and update your Advance Directive. This is especially important to do when your health condition changes (such as following a new diagnosis or a change in prognosis), or if there is a change in who will be your surrogate decision maker (such as due to a death or divorce), or if there is simply a change in contact information.

Health professionals reviewing the information above will note that it is focused on a holistic and non-medical perspective, as these decisions are fundamentally intensely personal and contextual, and may begin outside of a medical setting. Wishes and preferences naturally evolve over time, and ideally, so do these conversations. Yet there is a medical component to these decisions and thus, there is an important role for clinicians to routinely engage with their patients regarding these topics.

An advance care planning conversation might explore the following questions:

- *What do you feel would make you more comfortable as you approach the end of your life? Such as physical pain management prioritized over alertness, do you have privacy concerns if care is rendered by family or professionals?*
- *How important to you is maintaining your independence and being self-sufficient? What would it mean to you to lose these things? Is it to be expected, that at the close of life one is likely to require personal care, or is it seen as an unbearable loss of autonomy?*
- *What are your priorities when making decisions about your future medical care (for example, symptom management, length of life, quality of life)?*
- *What are the most important activities of daily living that will contribute to your quality of life (for example, being able to complete daily tasks, speak with family and friends or enjoy food)?*
- *How important is it to be in a home-like environment as your condition worsens, versus one where medical professionals are likely more readily accessible?*
- *What religious or spiritual considerations matter to you (for example, are there specific ceremonies or rituals that would be important to you if you were very ill)?*

To aid health professionals in these conversations, it might be useful to consider adapting the PLISSIT model as a communication guide. PLISSIT was originally developed by Jack Annon in response to another area that medical professionals had been reluctant to embrace—discussions about the impact of an illness or injury on a patient's sexuality [15]. Because of the sensitive nature of sexual concerns and the limited education that many providers had received regarding how best to address these concerns, many assumed that if the patient wanted to discuss these issues, they would bring them up themselves—not surprisingly, this left many patients with unaddressed sexual concerns.

PLISSIT as an acronym stands for Permission (giving permission/normalizing the concern), Limited Information (giving brief education or resources), Specific Suggestions (determining a specific concern amenable to specific strategies that might be helpful), and Intensive Therapy (identifying a concern best addressed by referring to those with specialized expertise). Annon postulated that all patients benefited from the normalization of these concerns ("P") and therefore, that all providers should be competent in permission-giving, while fewer patients would need the subsequent steps of the intervention, and fewer providers would need to have the expertise to address these.

Table 6.1 Adapted Ex-PLISSIT model to guide advance care planning conversations

Stage/Urgency	Possible interventions
Permission (Periodically for all patients)	Comprehensive biopsychosocial-spiritual assessment; Explore what advance care planning conversations have already occurred; If an Advance Directive has been completed—assess for applicability (is it current? Actionable? Contact information up to date?); Invite exploration of wishes, preferences and values to guide care planning; May occur organically in the community without medical guidance GOAL: Plant the seed for future conversations
Limited information (When there is a new diagnosis, or a change in setting)	Invite an advance care planning conversation: Provide education and anticipatory guidance regarding care planning; Introduce concept of an Advance Directive; Identify a surrogate; Facilitation of prognostic awareness; Normalize, clarify, explore, and address goals of care; Likely to occur in a medical setting prior to an urgent need GOAL: Understand the concerns of this particular patient at this particular time while educating them about the importance of an Advance Directive to guide future care planning
Specific suggestions (When there is a new diagnosis, a change in setting or a change in prognosis)	Complete (or review) advance directive (in accordance with your state's regulations and guidelines); Likely to occur in a medical setting—often when there is an anticipated need (such as a hospitalization) GOAL: Understand the concerns of this particular patient at this particular time while educating them about the importance of an Advance Directive to guide care planning
Intensive therapy (When there is a new diagnosis, a change in setting, a change in prognosis)	Complete (or review) a POLST/MOLST form (note that different states may have different names for these documents—ensure compliance with your state's regulations and guidelines); Likely to occur in a medical setting—often when there is the possibility of an urgent need GOAL: Understand the concerns of this particular patient at this particular time while educating them about the importance of an Advance Directive to guide immediate care planning

PLISSIT has since been modified to become Ex-PLISSIT, to emphasize the importance of *explicitly* normalizing concerns and giving permission to address the concern at *each* subsequent step of the intervention, to ensure that the intervention is as tailored as possible to the individual patient's specific needs [15].

Adapting this communication strategy for those who are providing care to patients with serious illness allows us to consider the following adaptation of Ex-PLISSIT to advance care planning conversations. In Table 6.1, we suggest how this framework might guide advance care planning conversations in a health setting. Note that we are recommending that the provider normalizes each step of the process. And just as PLISSIT recognizes that not all providers have the time or skills to complete each step, the steps below might be delegated to different providers who have different levels of time or expertise.

6.3 Challenges and Controversies

Despite the benefits of advance care planning, there have been those who have questioned the attention and resources that it has drawn. Morrison cites research showing that many of the well-intentioned efforts in patient self-determination (POLST/MOLST forms, e-MOLST forms, advance care planning billing codes) have not measurably increased goal-concordant care. While he notes that the complexities of the decisions on emotional, cultural and situational levels intersect with a profit-driven healthcare system to leave little planned-ahead impact on actual care rendered, he poses an intriguing question about what can be done within the existing system to further the goals of patient self-determination [11]. Commentary was generated on the challenge of quantifying a quality advance care planning conversation as so few professionals have been formally prepared to engage in these complex conversations, and so few institutions have supported the time and educational requirements needed to conduct them well [8]. Additionally, there are difficulties inherent in actually determining if the care provided was goal concordant, as there is no "gold standard" for how that elusive goal is best determined or how it might be widely measured.

Clearly, better measures are needed to evaluate the outcomes and effectiveness of many palliative care and ACP activities. Yet there seems little doubt in the inherent value of engaging in culturally nuanced conversations that explore patient's values, wishes and preferences. There are numerous anecdotal reports of ways in which ACP conversations "…support resilience, understanding, feelings of peace, and recovery from grief even in circumstances where this advance care planning doesn't change the care received…" [4]. A growing number of researchers are creating tools and exploring barriers to ACP from the perspective of the patient [1, 6] to improve the effectiveness of ACP conversations.

Yet, despite these efforts, there continue to be disparities in the completion of Advance Directives in racially and ethnically underrepresented groups [9], and many have worked to make them more amenable to a wider potential audience. As a field we have not routinely addressed the social determinants of health nor has healthcare always been trustworthy. We have an obligation to be as nuanced and compassionate as possible when engaging with patients to ensure that we understand the historic distrust that many have regarding our recommendations for what might be perceived as a limitation in care. Discussions about "discontinuing" a treatment can easily be interpreted as a cost saving strategy or be perceived as an indication that a particular patient's life is more "disposable" than others. Unintended biases continue to result in unequal care. More education is needed to ensure that health professionals recognize their role as advocates for social justice and the equitable delivery of quality care.

And even when Advance Directives are completed, there can be challenges in reliably (and quickly) retrieving the needed information. The various electronic medical record systems have not yet devised mechanisms to ensure ready accessibility of updated information needed to guide urgent conversations. This can result in delayed access to Advance Directives with some patients receiving unwanted interventions as a result.

While many healthcare professionals intellectually acknowledge the benefits of ACP, in practice, only 44% of hospice providers actually have them themselves

Table 6.2 Addressing barriers to implementation

Barrier to implementation	Possible responses
Provider: It will open a can of worms and take too much time	Uses less resources over time (provider time, inappropriate care); consider how social workers or chaplains might be enlisted to initiate advance care planning conversations
System: Forms not available, no witness, notary	Identify accountable person/position to meet legal demands for advance care planning availability
Provider: I am not confident I can have this conversation well	See resource list! There are many trainings available, and use the resources of your interprofessional team
System: EMR does not support	EMRs were originally developed to assist with billing, not as a care delivery system; identify IT people who can be authorized to create a work-around, most hospitals have created systems
Provider: If patients were ready they would bring it up	Unrealistic, people don't know what they don't know; patients rely upon providers to identify important topics for medical discussion
System: It won't impact the actual care implementation	Data shows that it does (see Resources: Respecting Choices); higher probability of people having care consistent with their goals when we know their goals
Provider: They will think there's something dire going on	Normalize that you have these conversations with all your patients
Provider: I will take away their hope	Hope evolves and changes over time

[10], just about 10% more than the general population [16]. What might account for this disconnect? People in healthcare understand how little control many of us may actually have when we are critically ill and how many of us will change our minds when faced with the reality of a situation. Yet, we have seen the relief of families and providers when care can be rendered according to previously stated wishes, and the sense of empowerment that comes from patients making choices for themselves, as well as the cost benefits of goal-concordant care. A cultural shift is needed, whereby health professionals recognize the value of engaging in these conversations in their own lives, so that they might more authentically have these nuanced conversations with others [2].

Table 6.2 lists common concerns and possible responses regarding the routine implementation of advance care planning conversations. Note the recommendation to utilize the interprofessional team in creating systems in place to support the occurrence of advance care planning. Palliative social workers are particularly well positioned to offer leadership in systemizing these services [13].

6.4 Summary

The likelihood of goal concordant care is enhanced when these nuanced conversations occur outside of the medical setting in a non-emergent situation [8]. To encourage these discussions, we have adapted the PLISSIT communication model that focuses upon normalizing these conversations. Providers may use the suggested interventions and ways to address implementation barriers, as well as the resources listed below, to improve their skills and comfort with this important work. The COVID-19 pandemic has highlighted the urgency for all of us to identify surrogate decision-makers who will be able to translate our wishes, values and preferences into an actionable guide for our medical care, should we find ourselves unexpectedly unable to speak for ourselves [7]. Health professionals have a responsibility to address social determinants of health and advocate for equitable access to care and to minimize disparities in the benefits of ACP.

Recommended Resources for Additional Information

Websites:

- ACP Decisions: https://acpdecisions.org/
- American Bar Association: https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning/
- American Society of Clinical Oncology (ASCO Answers: Advanced Cancer Care Planning): http://www.cancer.net/sites/cancer.net/files/advanced_cancer_care_planning.pdf
- Ariadne Labs (Serious Illness Conversation Guide): https://ariadnelabs.org/areas-of-work/serious-illness-care)
- Caring Connections: http://www.caringinfo.org/

- Center to Advance Palliative Care: https://capc.org/
- Coalition for Compassionate Care of California: https://coalitionccc.org/tools-resources/advance-care-planning-resources/
- The Conversation Project: http://theconversationproject.org/
- Leukemia & Lymphoma Society (*Advance Care Planning - Making decisions for your future*): https://www.lls.org/sites/default/files/National/USA/Pdf/Publications/PS94_Advance_Care_Planning2019_FINAL.pdf
- National Hospice and Palliative Care Organization (*Caring Connections*): http://caringinfo.org
- National POLST: https://polst.org/
- Patient Dignity Inventory: https://www.dignityincare.ca/wp-content/uploads/2010/05/The_Patient_Dignity_Inventory.pdf
- Palliative Care Network of Wisconsin (*Fast Facts*): https://mypcnow.org/fast-facts/
- Prepare For Your Care: https://www.prepareforyourcare.org/
- Respecting Choices: https://gundersenhealth.org/respecting-choices/
- Shiley Haynes Institute for Palliative Care: https://csupalliativecare.org/programs/advance-care-planning/
- Stanford Letter Project (*What Matters Most* and *Who Matters Most*): http://med.stanford.edu/letter
- Vital Talk: https://vitaltalk.org/

Books

- Altilio T, Otis-Green S, Cagle JG (eds) (in Press) Oxford textbook of palliative social work, 2nd ed. Oxford University Press
- Back A, Arnold R, Tulsky J (2009) Mastering communication with seriously Ill patients: balancing honesty with empathy and hope. Cambridge University Press.
- Denny AE (2013) My voice, my choice: a practical guide to writing a meaningful directive. Directives by Design.
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Conversation Aids

- The "Go Wish Game™" (www.gowish.org) is a card game that helps you to prioritize what will matter most to you during end-of-life care and then share those feelings with your family. You can purchase physical cards to play the game, or you can play for free online.
- The Institute for Healthcare Improvement Conversation Project's "Conversation Starter Kit" is free and can be downloaded at https://theconversationproject.org/starter-kits/
- "Five Wishes®" is a legal document (available for purchase at Aging with Dignity: www.fivewishes.org) that guides you through advance care planning before you are faced with a health crisis. This Web site provides a free guide on how to talk about healthcare choices and a conversation guide for individuals or families.
- "Voicing My Choices" is a discussion guide (available for purchase at https://fivewishes.org/shop/order/product/voicing-my-choices) that empowers young people who are struggling with a serious illness to communicate with family members, friends and caregivers about the type of care that they want now and in the future.
- "Heart to Heart" is a bilingual (Chinese/English) communication activity from the Chinese American Coalition for Compassionate Care (https://caccc-usa.org)
- "Hello/Hi!" Two interactive games that provide discussion prompts to help people discuss what matters most: https://commonpractice.com/pages/land-acp-for-everyone and https://commonpractice.com/pages/hi.

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Decision-Making Across Cultures

7

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7.1 Introduction: Cultural Competency, Cultural Humility, and Structural Competency

Medicine has seen a paradigm shift in its conceptualization of "culture" over recent decades. Whereas at one time culture was narrowly understood in terms of difference from some supposed norm, there is now widespread recognition that all patients are shaped by diverse cultural identities and that cultural factors are central to how every person experiences serious illness and decision-making. One outcome of this paradigm shift is that healthcare providers are now trained in "cultural competency" alongside traditional clinical competencies (see Chap. 2). In part because of the emphasis on whole-person care in palliative medicine, there is a rich scholarly literature on the role of culture in the care of seriously ill patients (see Chap. 3).

Sometimes, education in cultural competency inadvertently reinforces the very problem it is trying to address. Articles or book chapters may try to teach cultural competency by listing broad stereotypes about entire populations. This is not that kind of chapter. Such an approach is built on several erroneous assumptions: that cultures are homogeneous, that they are deviations from some cultureless norm (white people are seldom essentialized in these lists), and that there is a formulaic method for becoming "competent" in understanding them.

For these reasons, scholars have advanced alternative models for understanding the intersections of culture, illness, and health care. On the level of the clinician-patient encounter, the model of "cultural humility" is especially important [1]. Cultural humility is a process rather than an endpoint. It calls for the provider to examine his or her own cultural identity and associated biases, and how these affect his or her interactions with patients of different cultural identities. Because every clinician also belongs to a professional culture, some degree of cultural distance between clinician and patient always exists. Because of the power dynamic inherent in the clinical encounter, cultural differences can contribute to health care disparities due to unequal treatment through bias, stereotyping, and prejudice.

On the other hand, and on a more optimistic note, appropriate attentiveness to cultural dynamics in the care of seriously ill patients can help mitigate or redress broader societal patterns of injustice and racism. This can only happen if the clinician is equipped with the evidence-based communication skills to curiously and humbly elicit the values of each patient [2] and a commitment to advocate for those values to achieve goal-concordant care.

It is also crucial to broaden the focus from the individual patient encounter and to consider the dominant social and political forces, such as racism, that shape patients' trajectories of health and illness as well as their experience of health care. "Structural competency" is a field of study and pedagogy that has been developed to enable clinicians and clinical trainees to do exactly this. Structural competency includes a critical analysis of how attitudes or health conditions that are typically attributed to cultural differences or individual choices may be better understood as the downstream manifestations of societal ("structural") inequalities [3].

In the first section of this chapter, we adopt a framework of cultural humility for discussing the values that inform decision-making in serious illness. On the one hand, values are individual and dynamic: each patient has her own values, and they shift over time and across contexts. On the other hand, culture informs values: a patient forms her values through a process of negotiation between her individuality and her cultural, political, and social situatedness.

In the second section of this chapter, we adopt a structural competency lens. We review the scholarly literature to address one of the fraught questions in the area of culture and end-of-life care. The statistics are clear: racial and ethnic minorities, including but not only African Americans and Latinxs, receive fewer palliative care interventions and undergo more aggressive treatments at the end of life than white people. Should this be considered a health care disparity, and, if so, what are the barriers to equity? Or, is this pattern consistent with the values of specific racial and cultural groups? Is it therefore an expression of implicit bias and discrimination when clinicians exert pressure on dying patients and their families to go down the path of palliative rather than life-prolonging care?

In the third section of this chapter, we present two patient cases that illustrate the complex range of issues in culture and decision-making. Through the analysis of these two cases, we offer a set of practical communication strategies for achieving value-based, goal-concordant care.

7.2 Themes in Serious Illness Communication

7.2.1 Defining Culture

If there is one certainty in this world, it is that every person dies. Yet experiences at the end of life vary dramatically based on factors that include the culture of the patient (which is the focus of the present section) and how the patient's culture interacts with the culture of providers and the culture of medicine (which we will address in the following section).

For the purposes of this chapter, we define culture (following [4]) as a dynamic framework of identity that evolves and adapts through historical, political, and social forces. Cultural groups create systems of beliefs, values, and opportunities and often provide members a sense of safety and of meaning within their particular social, biologic, physical, and political niche. Different cultural groups have different levels of power and privilege, and this can also affect decision-making, especially during serious illness and end of life.

Before entering into cultural differences, it is worth emphasizing priorities at the end of life that tend to be shared across all cultural groups [5]. These include comfort and not being in pain; good communication between patient and doctors; maintaining hope; honoring spiritual beliefs; fixing relationships; making plans; and saying goodbye. These human values, however, are also colored by a wide array of inter- and intra-cultural variations.

Table 7.1 Addressing mnemonic for elements of culture (based on [6])

- Age and cohort effects
- Degree of physical ability
- Degree of cognitive ability
- Religion
- Ethnicity and race
- Socioeconomic status
- Sexual orientation and gender identity
- Individualistic life experiences (such as trauma or level of acculturation)
- National origin
- Gender role expectations

No overarching label for a cultural group will ever capture the diversity of experiences and viewpoints represented within that group. Consider the identity “Asian American.” This term encompasses numerous religious affiliations, including Hindu, Muslim, Christian, Buddhist, and Sikh, to name only a few. Every subgroup of Asian Americans has its own unique story and experience. For example, think of acculturated 4th- or 5th-generation Japanese Americans versus members of groups that immigrated to the United States after 1965, such as populations who were part of the brain drain as in healthcare (e.g., immigrants from India and the Philippines) or refugees from war and American foreign policy (e.g., Hmong migrants from Laos and subsets of Vietnamese immigrants). Similar analyses can be done for practically any conventional cultural label in the United States. Thus there is no such thing as a homogeneous Asian American (or, say, African American or Latinx or Jewish) approach to end-of-life decision-making. Culture *informs* decision-making but does not *determine* it.

We often think of culture as being primarily defined by race and ethnicity, national origin, or religion. But there are many additional axes of culture that also inform decision-making, for example, gender identity, gender roles in society, and sexual orientation. One framework for “addressing” the heterogeneity of culture is the ADDRESSING mnemonic (Table 7.1) [6]. This mnemonic can help clinicians attend to the many complexities of inter- and intra-group differences. It also reinforces the importance of cultural humility. Only the patient can tell you which sets of identities are most salient for him or her, and in what ways.

7.2.2 Cultural Values That Inform Decision-Making

But what are the specific ways in which specific cultural identities inform decision-making at the end of life? There are a number of recent review articles which address this question, presenting a gamut of cultural identities and suggesting general patterns of decision-making that clinicians tend to encounter in patients of different subgroups [4, 7]. However, because there is no one-to-one correspondence between cultural identity and decision-making style, here we will highlight the patterns of decision-making themselves. These are some of the main questions and possibilities to assess with each individual patient and family.

First: who makes the medical decisions? In western bioethics and legal systems, if a patient has mental capacity and legal competence to make medical decisions, that is their unassailable right. Yet patients of different cultures choose to involve family or community in their decision-making to a lesser or greater extent. Some patients wish to delegate some control over decision-making to others, be it a member of their family, their community, or their physicians. It is widely assumed in the scholarly literature that non-white racial and ethnic groups more often outsource their decision-making in this way. However, note that at least one well-designed study found no association between race and such "decision control preferences" [8]. In that study, older age was the sole demographic variable associated with the attitude of "Doctor, make my decisions." Indeed, in the same study, the large majority (82%) of participants across all demographic groups preferred an approach of shared decision-making.

Second: how much information should be disclosed to the patient? Once again, western bioethics and legal systems have one clear approach: it is the patient's right to know everything. Yet some patients will prefer *not* to know all of their diagnostic and prognostic information, and that is also their right. In some communities, there is a belief that bad news or discussing death will hasten death (e.g., see [9]). It has been hypothesized that orientation toward time in a given culture may affect openness to discussing advance directives [10].

Third: what are the health disparities and culturally-associated barriers to care? How can they be addressed? These are too numerous to list here. Some barriers may include the level of English proficiency, the level of comfort navigating health care bureaucracies, and explanatory models for illness and treatment that align or diverge from those endorsed by western biomedicine.

Fourth: what are the meanings ascribed to suffering, to dignity, and to death? How do these differing meanings translate into differing priorities for end-of-life treatments and trajectories? There is research to support the idea that certain cultures tend to value struggle over comfort at the end of life [11]. This tension is the basis of Sect. 7.3 of this chapter.

In sum, these domains of difference give a sense of the great heterogeneity both across and within cultures. The clinician must adopt an open and nonjudgmental approach in order to respond appropriately to the cultural nuances in the decision-making process.

A common challenge arises when the high value placed on individual rights in western medical ethics—the patient's right to know their prognosis and to make their own decisions—is misaligned with the patient's own value system. To reduce bias and stigma, we recommend incorporating standardized assessments of such preferences into the care of every patient, instead of attempting to guess when particular patients or families might have divergent perspectives. Whether it is a question of withholding versus disclosure of prognostic information, or a question

Table 7.2 Recommendations for addressing decision-making in serious illness

1. Adapt existing best practices around value-based, shared decision-making in order to mitigate bias and foster person-centered care.
    a. Resources: ACP videos (https://acpdecisions.org), Respecting Choices (https://respectingchoices.org), Vital Talk (https://vitaltalk.org).
    b. Techniques: Scripting, using in-person interpreters in settings of language non-concordance, drawing on cultural brokers within the health system or from the patient's community.
2. Clarify the different types of decision-making to the patient.
    a. Include the family members of choice to the degree that the patient desires.
3. Acknowledge mistrust and stigma in the healthcare system.
    a. Ask open-ended questions to determine whether the patient has experienced discrimination or breaches of trust from any past or current providers.
4. Evaluate, acknowledge, and make strategies to address social determinants of health and barriers to care, including but not limited to:
    a. Transportation options
    b. Insurance needs
    c. Documented vs. undocumented status

of how involved the family should be in decision-making, the clinician should endeavor to first meet privately with the patient and learn their preferences. Then, if the patient does not wish to receive prognostic information or wishes a family member to make medical decisions on their behalf, we must respect that. After all, the patient has the *right* to know and to decide, but not an obligation. Additional recommendations for practice are summarized in Table 7.2.

Lastly, when at all possible, advance care planning, including assessment of decision-making preferences should take place in the outpatient setting prior to acute crises. The long-term relationship of primary care provides the best setting for eliciting and documenting the patient's preferred approach to decision-making and to the communication of prognostic information. Any transition in care (e.g., hospital admission or discharge) should also remind the clinician to open such discussions. These conversations may have to unfold over several appointments. Due to structural constraints, such as time pressure and the low prioritization of preventive care within health care systems, advance care planning often gets postponed. As a result, complex end-of-life decisions too often have to be made when the patient has reached an advanced state of disease and may no longer be able to communicate his or her own preferences and values.

7.2.3 Trauma-Informed Care

Trauma-informed care is one orientation that providers should adopt in order to mitigate disparities and create a space of safety and support. "Trauma" is defined

Table 7.3 Five principles of trauma-informed care (based on SAMHSA [12])

1. **Safety** - Create spaces that are calm and comfortable by attending to the physical environment and to nonverbal communication.
2. **Trust** - Provide clear and honest information. Ask open-ended questions; seek to understand if medicine or society have breached the trust of this patient in the past; find out from the patient what they would want their providers to do differently.
3. **Choice** - Verbalize that the patient is the one who determines decision-making and treatment preferences; ask, "What matters to you?"; request permission to provide advice based on what you have learned about the patient's values.
4. **Collaboration** - Facilitate collaboration among your team members, the patient and family, and any wider community members the patient wishes to have involved (e.g., cultural broker, spiritual or religious advisor).
5. **Empowerment** - Notice and verbalize capabilities in an individual, with a focus on resilience); verbalize empathy (e.g., "I notice how you are coming together").

as events or circumstances that are "physically or emotionally harmful, or life-threatening, with lasting adverse effects" [12]. Histories of trauma, including adverse childhood events (ACEs), are strongly associated with future burden of physical and mental illness. Most adults in the United States have experienced at least one significant trauma in their lifetime [13]. There is increasing recognition that life-threatening illnesses and intensive medical interventions can themselves be traumatic experiences [14]. This means that past or present trauma may be an active factor in decision-making for any patient facing serious illness, and all the more so when serious illness is combined with social underprivilege.

Several evidence-based approaches to trauma-informed care have been developed. An important element in all of these approaches is the initial screening for histories of trauma, which, ideally should be done as early as possible. Universal screening reduces the risk of providers making assumptions about burdens of trauma merely because of a patient's racial or ethnic identity. One method is to have the patient complete a questionnaire, such as a cumulative ACE survey, which also grants control to the patient to decide how much detail to provide.

In Table 7.3, we present the five principles of trauma-informed care as they are relevant to the context of decision-making at the end of life.

7.2.4 Recognizing Bias and Earning Trust

Trust is the cornerstone of a successful clinical relationship with a patient facing serious illness. Yet stigma and racism are ubiquitous within society as well as within medical institutions, both historically and continuing into the present. Racial discrimination perpetuates health disparities and contributes to worse health outcomes [15, 16].

For this reason, individuals from non-dominant cultural groups often have good reason to wonder whether their providers are genuinely trustworthy. The onus must

Table 7.4 Bias in end-of-life care (based on the SEEDS model from [22])

1. Similarity/difference bias
    a. Racial bias, implicit or explicit.
    b. Other forms of cultural bias (see "ADDRESSING" mnemonic in Table 1).
    c. Lavishing more attention on a patient who reminds you of a family member.
2. Expedience/confirmation bias
    a. A lack of openness to hearing from the patient something that goes against what you expect or what you already believe.
3. Experience bias
    a. Projecting your own assumptions about quality of life, especially for patients with disabilities (see Kripke 2017).
    b. Assuming that you know about the individual in front of you because of past interactions with ostensibly similar patients.
    c. Assuming that you are the expert (you should have the final say) because you are the clinician (you control access to treatments).
4. Distance bias
    a. Giving priority to what the most vocal family member is saying in the here and now vs. what is documented about the patient's longstanding values.
5. Safety bias
    a. Favoring choices based on risk aversion or sunk cost.
    b. Favoring choices based on a misleading way of framing (e.g., "Should we do everything for your loved one, or should we switch to comfort care?")

be on the provider to demonstrate trustworthiness and thereby earn the patient's trust [17, 18]. This process includes a commitment to openly explore sources of mistrust, to take the sources of mistrust seriously, and, when relevant, to be prepared to change one's own behavior and to advocate for change in one's institution [19].

As several scholars have recently emphasized, prejudice, implicit bias, and racism are universal human traits [20, 21]. The challenge for clinicians is to recognize the forms that these take—both on the individual and the institutional level—and to take active measures to mitigate their impact. Table 7.4 presents some of the most common manifestations and pitfalls of bias as relevant to end-of-life care.

7.3 Differences in Utilization of Palliative Care: Health Disparities or Differences in Values?

Clinicians work within broader systems of care and disciplines, and institutional cultures affect the behavior of every clinician. This may be especially true in end-of-life care, as demonstrated in one qualitative study of palliative care providers' perceptions of their biases. One attending physician expressed, "I do have a personal bias that, I think, because I chose palliative care, I believe in comfort care and allowing a natural death, and I really don't agree with a lot of intervention at the end of life" [23].

In contemporary end-of-life care, the high emphasis placed on palliative care measures, including hospice and even advance care planning, is a reflection of western ethical principles that are not universally shared [7]. These principles include patient autonomy, self-determination, truth telling, and an individualistic conception of dignity.

Patients of diverse cultural backgrounds have a wide spectrum of values concerning end-of-life care. Often, these values may be challenging to medical providers, who bring their own strong views about appropriate courses of action, informed by culture, by professional training, and by institutional constraints. Whereas in the mid-twentieth century, physicians tended to pressure patients to undergo heroic measures, the situation in the twenty-first century is the opposite: clinicians often pressure patients to accept that they are dying and to accept palliative rather than life-prolonging measures [24]. The patients who are resistant to such pressures disproportionately come from racial and ethnic minorities or other groups that similarly have less power and social capital within American society, such as people with disabilities [25, 26].

There are clear statistical trends in how the results of end-of-life decision-making differ across racial and ethnic groups in the United States. One indicator is Medicare hospice utilization. The Centers for Medicare and Medicaid Services compile data on the use of hospice by white people, African Americans, Hispanics, Asians and Pacific Islanders, and Native Americans. Of these groups, white people are the only ones who are overrepresented in hospice compared to their share in the Medicare population. All of the other groups receive hospice treatment at a rate much lower than their share of the population [27]. Numerous studies have found similar results for whites' and non-whites' engagement with palliative care in general, including advance care planning and the use of DNR or POLST orders [28].

These data do not speak for themselves. How should racial and other demographic differences in end-of-life trajectories be understood? Should the high usage of aggressive medical interventions at the end of life among African Americans (say) be considered a health care disparity, like the countless racial disparities in every domain of health care, from pregnancy to heart failure to chronic pain? Or should this phenomenon be regarded as a positive outcome? One could hypothesize that it is congruent with prevalent cultural values held by many African Americans, such as deep religious faith and a commitment to the struggle for rights—not to mention the struggle for life itself in a hostile society.

Some researchers have tried to answer these questions empirically. Kelley et al. [29, 30] offer evidence that the low use of hospice and the high use of end-of-life intensive interventions among Latinxs in the Los Angeles area should in fact be regarded as a disparity. In this study of 147 older Latinxs in the community, 84% of participants expressed that if they were seriously ill, they would prefer medical care focused on comfort rather than care focused on extending life. However, nearly half (47%) had never discussed this preference either with their family or with their physician, and over three-quarters (77%) had not completed an advance directive. Thus, there was a high risk that these individuals' wishes for their care would not be honored.

Another study similarly suggests that high rates of aggressive interventions and low rates of palliative care among African Americans and Latinx patients should be considered a health care disparity. Specifically, an analysis of all hospital discharges across 5 states in the year 1999 found that racial differences in terminal ICU use were largely accounted for by between-hospital factors (African Americans and Latinx patients were more often treated in hospitals that had a higher rate of ICU use overall) rather than within-hospital racial variation [31]. This study, however, did not address patient-level differences in preferences for treatment.

If 18% of African Americans and 15% of Latinxs would prefer to die in the hospital rather than forego any life-prolonging intervention, these percentages may seem small. But they are large in comparison with the 8% of white Americans who endorse the same preference, and there must be underlying reasons that explain such a large gap [32]. Yet there is a common assumption in clinical practice that dying patients who want "everything to be done" must be inadequately informed. These patients sometimes receive dismissive labels: they are "in denial," or they are "vitalists." After all, if death in hospice is self-evidently better than death in intensive care, as many clinicians believe, and if one feels that CPR with minimal chance of success is akin to torture, what well-informed patient would choose torture over comfort?

A related—and less condescending—hypothesis frames the question not as one of an intrinsic deficiency but rather as one of inadequate access to palliative care information and services [33, 34]. This view presumes that patients with access to palliative care will often change their minds about preexisting wishes for intensive treatment. There must be something to this hypothesis, because palliative care providers see this happen all the time.

Cultural competency requires clinicians to seek to understand the different viewpoints of different cultures around end-of-life experiences. But a clinician can understand others' views very well and still insist on imposing his or her own view on the patient.

Cultural humility and structural competency call for greater respect for patients' viewpoints. These frameworks lead us to challenge the widespread assumption that African Americans, Latinxs, and others ought to be persuaded to see eye-to-eye with white Americans—and the culture of medicine itself—on the value of palliative care. Hauschildt [25] relates the story of a critical care resident who reluctantly placed a central line (a large-bore IV that enters via the neck) for a patient who insisted on receiving any intervention that could extend his life, even if only by a day or two. At every step, the physician challenged the patient, "Are you sure?" This anecdote is a microcosm of the trend in medicine and scholarship to refuse to accept that a rational dying person might perfectly understand the difference between a comfortable death at home and a painful death in the ICU and still opt for the latter.

There are relatively few studies that seek to identify the underlying reasons for why members of particular cultural groups might wish to receive more aggressive care at the end of life more often that members of other cultural groups. Perhaps the best-studied group in this regard is African Americans. Johnson (2008) identified a complex of four traits as accounting for the differences in utilization of palliative care between African Americans and whites, namely: a desire not to discuss death, a desire for aggressive care at the end of life, spiritual beliefs which conflict with the goals of palliative care, and a perception that the medical system is not worthy of trust. (Mistrust, it has to be emphasized, is not an innate characteristic of African Americans. It is a product of the reality that the medical system has *breached* trust, both historically and in the present.) More recently, Sanders et al. [35] has suggested that the literature on advance care planning among African Americans may not accurately reflect the realities of individual experience. In particular, clinicians should not think of factors such as religion and spirituality as "barriers" to end-of-life care but rather as assets or sources of strength.

Let's return to the fraught question with which we opened this section. When racial and ethnic minorities in the United States confront serious illness and the end of life, on average, they receive more aggressive medical interventions and less palliative care. Is this a cultural difference or a health care disparity? The answer has to be "Both."

The sociological scholarship and the statistics paint a picture of non-alignment between clinicians and patients, especially non-white patients, in terms of the value placed on aggressive treatment versus palliative treatment at the end of life. The most common scenario in which patients receive care that is not goal-concordant is when patients—often non-white—desire more aggressive interventions than their clinicians are willing to provide.

We propose that clinical strategies can help avert this kind of clash between patients and clinicians, which results in the non-alignment of values with treatment. For example, in order to address patients' underlying fear that palliative care is equivalent to giving up, clinicians can acknowledge that fear and find ways to address its root cause. The answer is not necessarily to provide aggressive interventions merely because requested. Nevertheless, in many instances, a true commitment to value-based and goal-concordant care will require clinicians to respect and to follow the end-of-life wishes of patients even when those wishes run against the ethical system of the clinician or even the culture of the health system in which one works.

7.4 Value-Based, Goal-Concordant Care: Cases and Strategies

In this final section, we present two cases that illustrate the abstract themes discussed so far. We emphasize that any clinician, not just those in palliative care, can and should learn an approach to shared decision-making that is informed by cultural humility and structural competency.

Communication in serious illness and end-of-life care should be regarded as a procedure that improves with practice and a standardized, patient-centered approach. Studies show that patients wish to speak with clinicians frankly, to receive as much information as possible, and to feel that they have been heard as people rather than patients. Yet clinicians use medical jargon, fail to recognize that the patient or family is not following, miss cues that patients are experiencing emotions that affect information absorption, or block patient questions and concerns. The result is divergence in illness understanding between what physicians believe they have communicated and what patients believe they have heard [2, 36].

There are numerous evidence-based approaches to communicating with patients with serious illness in order to achieve goal-concordant care. In this section, we will refer to the SUPER3 model (acronym adapted from the framework proposed in [37], which was created by the Clinician Patient Communication and Life Care Planning group of the Southern California Permanente Medical Group (Table 7.5).

7.4.1 Case 1: A Decision Imposed on a Patient

Even when culturally sensitive shared decision-making occurs in an ideal manner, the results of decision-making have to be acted upon. The case summarized here is one of the institutional values ultimately overriding the values that had been elicited and documented from a dying patient.

Alang Tsaab was a 20 year-old Hmong man with primary mediastinal lymphoma. Even as his cancer progressed, he held on to hope that he would recover and even return to college and basketball. He ultimately enrolled in a clinical trial, but his symptoms eventually required hospitalization, and his providers knew this was likely to be a terminal hospitalization.

A series of goals-of-care family meetings proved frustrating to the clinicians caring for Alang. Both Alang and his mother Kaj, his designated decision-maker, were consistently adamant that he wished to remain full code; that they were not going to despair of recovery; and that the physicians should “not give up” and should do everything possible to “fix the cancer.”

Hospitals have their own culture and values, and Alang’s hospital prided itself in valuing patient autonomy, truth-telling to the patient about prognostic information, the documentation of goals via advance directives or POLST forms (Physician’s Orders for Life-Sustaining Treatment), and a preference for DNR (Do Not Resuscitate) status in cases of advanced disease.

In this case, the hospital’s preference for DNR status in advanced disease came into conflict with the hospital’s other values. Most of the teams caring for Alang were convinced that he should opt for palliative rather than life-prolonging measures and go home with hospice. Notably, one of the consulting teams disagreed: the palliative care team, which had built a trusting relationship with Alang and his mother over several weeks. They recommended the continuation of life-prolonging treatments in accordance with the patient’s clearly stated values.

Table 7.5 Sample scripting using the SUPER3 model

1. **Setup**
    a. Assess decision makers, awareness of clinical circumstance, evaluation of family:
        i. "Who is someone you trust to make decisions for you if you are very sick?"
        ii. "I'd like to talk about some decisions that people with your health conditions often face—is that OK?"
        iii. "How are healthcare decisions made in your family or support system?"
    b. Ensure shared understanding of the decision-maker role:
        i. A person who knows your values, wishes, and what is important to you.
        ii. A person who agrees to be your decision-maker.
        iii. A person who is able to make decisions in difficult situations
        iv. A person who agrees to follow your wishes even if different from their own
2. **Understanding**
    a. Assess patient's or decision-maker's understanding of the situation and address gaps:
        i. "What do you understand about his/her illness?"
        ii. "What have the doctors told you about that?"
        iii. "Do you feel that you have a good understanding of what to expect over time?"
3. **Past experiences**
    a. Assess prior hospitalizations, prior treatments, and context and experience with the condition (e.g., family members who went through a similar illness):
        i. "Do you know anyone else with this condition?"
        ii. "What did you learn from your last treatment? Last hospital stay?"
        iii. "Have you had experiences with family members who were very sick? Family members who were in the ICU? Who were on life support?"
4. **Elicit values**
    a. Assess personal goals, spiritual/religious affiliation, other cultural influences:
        i. "What abilities matter so much to you that you can't imagine living without them?"
        ii. What do you look forward to each day?"
        iii. "What does quality of life (living well) mean for you?"
        iv. "Do you have spiritual or religious beliefs that might inform your medical decisions?"
5. **Review/Recommend/Record (R3)**
    a. **Review** - recap the discussion to ensure agreement. You may need to provide additional information to bridge any misunderstanding.
        i. "It sounds like…"
        ii. "What I heard was…"
    b. **Recommend** - seek to align patient's goals and values with the treatment options being offered, asking permission to provide your own clinical recommendation:
        i. "Based on what we know about your health condition, and what I heard you say is important, I have some recommendations. Would that be OK?"
        ii. *If* the patient's values lead you to recommend DNR status:
            1. "I recommend a natural dying process. We'll make sure to prioritize your comfort and support your children. In medical language, this is a DNR order."
            2. "I wish intubation and tube feeding would cure the underlying ________."
        iii. "If you were to receive _______ what would you expect?"
        iv. "What concerns, if any, do you have about making this decision?"
    c. **Record** - make note of the information you have learned in the discussion somewhere it will be easily accessible later on. Especially document any changes in the course of treatment or code status
6. **Repeat** as many times as necessary, as the disease and the situation evolve.

Alang's respiratory status deteriorated, and he was transferred to the ICU and intubated. At the next family meeting, the primary physicians were still more adamant that Alang was dying despite anything that medicine could do for him, and they strongly recommended switching to DNR status and allowing Alang a natural death. For her part, Kaj remained calm and stood firm with the previous decisions. She expressed an understanding of the situation and what full code status would entail but expressed also that the family's religious faith was a source of tranquility and hope. She had no doubt that Alang would have wished to remain full code.

Yet, to the ICU providers who were caring for Alang and who would be the ones to attempt resuscitation, Kaj's decision seemed futile, even cruel and pointless. The same evening, they called for an urgent consultation with the hospital ethics committee. The ethics committee heard the arguments of the ICU providers to transition to comfort care and the arguments of Kaj to continue life-prolonging treatment. (The palliative care team had not been called.) Kaj later described this as a traumatic event, as she had to attempt to justify the values of her son without any support. The ethics committee ruled that Alang should be made DNR, informing Kaj that this was in Alang's best interest, that it was consistent with the ethical principle of "do no harm," and that they were merely following the hospital's policy of not providing "futile care."

Alang's heart stopped the following morning. Due to the decision of the ethics committee, he did not receive resuscitation, and he was pronounced dead in his ICU room.

7.4.1.1 Analysis of Case 1

Kaj later expressed to the palliative care social worker that this experience had tainted the family's views of health care in the United States, but that it was not inconsistent with her previous experiences of racial discrimination. She continues to ask why the hospital constantly insisted on knowing the patient's wishes if those wishes would ultimately be overridden.

In this case, there was a fragmentation of communication and of trust. The palliative care team had built a relationship of trust with Alang and Kaj, eliciting their values—cultural and religious and otherwise—and making recommendations consistent with those values. But other providers did not see eye-to-eye, and some even felt that the palliative care team had "too much empathy" to see matters clearly. In the end, the hospital ethics committee had the last word in an urgent session that was not about understanding the individuality of the patient but about focusing on the impersonal medical facts of the case and upholding the institutional values and policies.

7.4.2 Case 2: Serially Restaged and Dynamic Shared Decision-Making

What is the best course of action when a patient, informed by their cultural values, opts for a course of treatment that is felt to be unreasonable by medical providers? This, after all, is one of the way of interpreting the previous case. The ICU providers and the ethics committee may have felt that they were making a difficult but necessary decision. This is also the theme of Case 2, but the ending is different.

Chana Feld was a 95 year-old Holocaust survivor. She had several chronic diseases, including moderate dementia, but was still able to ambulate, feed herself, and enjoy time with her sons and her grandchildren. She contracted Covid-19 in late 2020 and survived the acute respiratory illness but developed encephalopathy, delirium, and dysphagia (difficulty eating).

To illustrate the technical nature of the family meeting as a communication procedure, and the sequential, dynamic nature of shared decision-making, we present three-time points in the course of Ms. Feld's experience of serious illness and medical treatment.

7.4.2.1 1st Family Meeting

The first meeting was brief. The hospital physicians tried to convey the severity of Ms. Feld's Covid-19 symptoms combined with her preexisting dementia. The family, however, resisted the medical recommendation for DNR status with no intubation. They said that withholding curative measures would be inconsistent with Ms. Feld's Jewish faith and longstanding values as a Holocaust survivor and refugee who rebuilt her life and family in a new country.

7.4.2.2 2nd Family Meeting

The family members opened the second meeting with their frustration that the initial team recommendations were so demoralizing. They felt that the clinicians had been making biased recommendations due to their assumptions about Ms. Feld's dementia and quality of life.

The clinicians heard this as important feedback and recognized that they had indeed made assumptions and allowed biases to dictate their approach in the previous family meeting.

They adopted the SUPER3 model to structure the conversation.

Setup (S)

This was largely accomplished in the previous meeting. It was established that Ms. Feld did not have decision-making capacity and that the family members would reach decisions through consensus, based on their understanding of what Ms. Feld would want for herself.

Understanding (U)

The clinicians learned that the family members had excellent understanding of the medical and ethical details of the case and were able to recount them.

Past Experiences (P)

Ms. Feld's prior hospitalizations were 2 years ago and 10 years ago. She received 24/7 help from caregivers at home for safety. In the course of the meeting, the son mentioned that his father had received a long-term tracheostomy and lived at a Long-Term Acute Care (LTAC) facility for the last years of his life. The family members felt that he had suffered unduly.

Eliciting Values (E)

The family was encouraged to share information about who Ms. Feld was as a person before this acute worsening of her illness, as well as information about her baseline physical and cognitive level of function. Her caregiver of 8 years, Kim, was also present and able to share information about Ms. Feld. The family and Kim described Ms. Feld ("Bubbe") as a matriarch, a person defined by resilience, "feisty," and opinionated. They emphasized that she was a survivor of unimaginable trauma as a girl and, later in life, had survived several episodes of illness that had also seemed hopeless at the time. Before this hospitalization, she had been looking forward to spending time with her grandchildren after Covid-19. She had run multiple businesses together with her husband, most recently a restaurant. She loved watching TV of all kinds and listening to music, especially her favorite song, "Que Sera Sera."

Recommendation (R1)

The physician leading the meeting: "Based on what I have been hearing from you about Ms. Feld's quality of life before the Covid-19 infection and the hopes that her cognition will improve and that she will be able to appreciate and listen to music like 'Que Sera Sera'—we would like to make some recommendations. Is that OK?"

The recommendation was framed in terms of the patient's underlying values. Ms. Feld might very well return to her previous baseline, but neither CPR nor mechanical ventilation could reverse the underlying conditions causing her health to deteriorate.

The family agreed not to pursue resuscitation or ventilation, but, citing their Jewish faith, they thought Ms. Feld should continue to receive food however possible. Given the medical circumstances, the only option for nutrition was via a nasogastric (NG) tube.

Review (R2) and Record (R3)

The decision was reviewed and recorded (with a POLST) that Ms. Feld would have DNR/DNI (Do Not Resuscitate/Do Not Intubate) status and receive a trial of nutrition through an NG tube. It was also established that these conversations would be continued. Ms. Feld returned home and had some improvement in her delirium.

7.4.2.3 3rd Family Meeting

One month later, Ms. Feld was readmitted to the hospital with acute shortness of breath, stridor, and vocal cord paralysis. This meant that she needed urgent respiratory support, which would be difficult in light of her NG tube feedings. The family members had already spoken with an ENT surgeon, and they believed that the best way forward would be tracheostomy and cordectomy.

The hospitalist physicians were alarmed by this suggestion and immediately mentioned that this would likely be a case for the ethics committee to decide. But the providers who had cared for Ms. Feld during the previous hospitalization were present at the time, and they urged further exploration before resorting to bureaucratic or antagonistic procedures.

At this family meeting, in addition to the medical teams and the assembled family, the family had invited Ms. Feld's trusted rabbi—Rabbi Levi—to be present, as the religious framework was an important element in their decision-making. The SUPER3 process was reinitiated.

Rabbi Levi explained to all present that Jewish law dictated certain approaches. Namely, that the patient's preferences should be respected, that heroic measures were not mandatory if they were to cause more suffering than benefit, and that the basics of human life (nutrition, hydration, oxygenation) should be pursued as long as this did not cause undue suffering. Furthermore, it was permissible to discontinue life-sustaining interventions (like tube feeding) as long as that withdrawal did not directly cause death within a certain time frame.

The clinicians reflected back to the family that they understood that the Jewish faith was guiding the decision-making process and that any decision to withdraw treatment was very difficult. They recommended, based on the information from the family and rabbi, that the goal should be to "continue providing basic necessities" (within the framework of Jewish values they had just learned about), not to hasten death, and to support the body and minimize suffering. Respiratory support (with a BIPAP machine) and IV fluids would be important; but NG tube feedings and any kind of surgery would be inconsistent with Ms. Feld's values.

The family wholeheartedly agreed with the summary and recommendations. Ms. Feld was discharged home on hospice, with BIPAP as needed and medications to treat her symptoms.

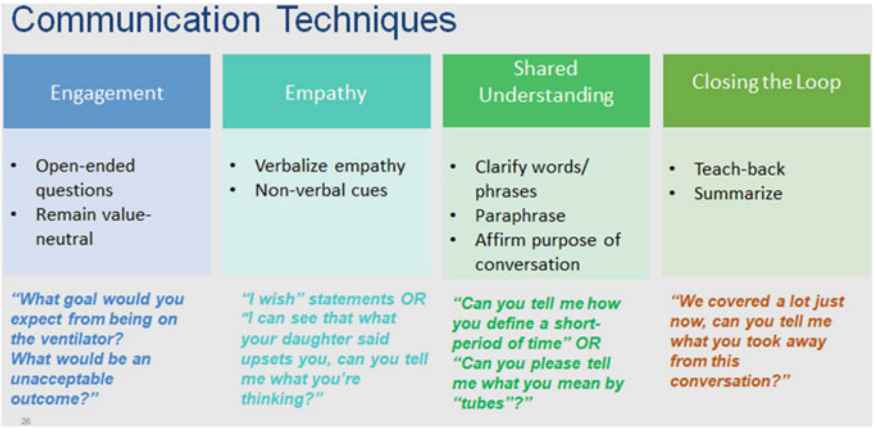
7.4.2.4 Analysis of Case 2

This case illustrates the nuances and importance of viewing communication like a procedure. Ms. Feld benefited from a continuity of providers, who were able to intervene during her final hospitalization when her new physicians (who did not know her) thought this would become an "ethics committee case." The providers who had gotten to know Ms. Feld through the multiple family meetings were able to adopt a lens of trauma-informed care and understand how her experience as a Holocaust survivor and her resilience were informing the interventions that she and her family wished.

Importantly, the providers did not reach a place of trust with this family right away. They initially made a serious misstep early on, when they made assumptions about Ms. Feld's quality of life based simply on the fact that her medical record included "moderate dementia." Through recognizing this bias, verbalizing that they had been wrong, and pursuing open discussions with the family decision-makers, the providers earned the trust of the family members. Still more importantly, the same providers were present at the crucial moment so they could advocate for Ms. Feld's values to be upheld—unlike what happened in Case 1.

To conclude, this case also illustrates how one might respond to a family request thought to be "unrealistic": the tracheostomy and cordectomy. One option is to assume an antagonistic stance and argue with the family about each specific intervention. However, bringing the case to the ethics committee would probably have alienated this family, damaged the trust that was built over time, and potentially compounded their grief. Instead, the matter was readily resolved through another round of staged shared decision-making. As the family had identified the Jewish religion as a key determinant of their decision-making, and none of the care team members had direct experience with Judaism, the presence of Rabbi Levi at the last family meeting as a cultural broker was essential for clarifying and validating the decisions made by the family.

We conclude this chapter here, presenting the following graphics by way of summarizing the clinical strategies we have presented for achieving value-based, goal-concordant care for patients with serious illness across the spectrum of cultural identities (Figs. 7.1 and 7.2).



Communication Techniques

Engagement	Empathy	Shared Understanding	Closing the Loop
• Open-ended questions • Remain value-neutral	• Verbalize empathy • Non-verbal cues	• Clarify words/phrases • Paraphrase • Affirm purpose of conversation	• Teach-back • Summarize
"What goal would you expect from being on the ventilator? What would be an unacceptable outcome?"	*"I wish" statements OR "I can see that what your daughter said upsets you, can you tell me what you're thinking?"*	*"Can you tell me how you define a short-period of time" OR "Can you please tell me what you mean by "tubes"?"*	*"We covered a lot just now, can you tell me what you took away from this conversation?"*

Fig. 7.1 General communication techniques in value-based shared decision-making. Original content developed by SCPMG (Southern California Permanente Medical Group) Life Care Planning and Clinician Patient Communication

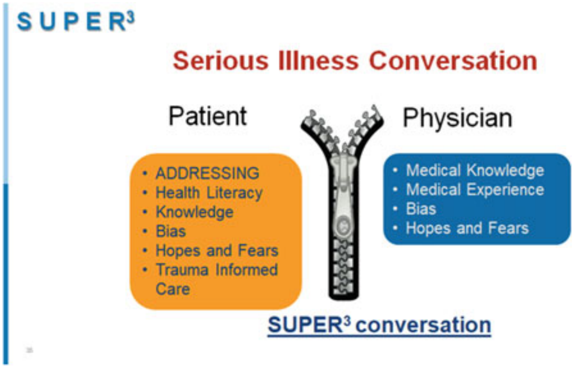


Fig. 7.2 Aligning patient and physician values (SUPER3). Original content developed by SCPMG (Southern California Permanente Medical Group) Life Care Planning

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8

Grief, Loss and Bereavement. Understanding Concepts, Clinical Manifestations and Cultural Considerations at End of Life

Kimberly Shapiro

> *There is no correct way or time to grieve.*
>
> *—Elisabeth Kübler-Ross and David Kessler*
>
> *On Grief and Grieving*

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Understanding Grief and Bereavement in the Context of Terminal Illness
The weight of grief is heavy on both patients with terminal illness, and their loved ones. We are now aware that grief is not limited to the time of death—grief reactions begin to occur at the time of diagnosis of terminal illness and evolve over time, impacting the patient and family unit in a variety of ways. Loss of what life "could have been" with better health, decline in physical functioning due to illness, and loss of identity and role within the family or community all play a part in the grieving process. It is important that caregivers and clinicians working with end-of-life patients understand the clinical, diagnostic, and cultural implications of grief and loss to care for the patient and their family in a more holistic, complete way.

8.1 How Grief Presents in Practice

8.1.1 Clarifying General Terms

Grief is considered to be the emotional response to a loss. This could be the death of a loved one, the loss of a relationship, a home, family, or even loss of a dream. In mainstream culture, it is often seen as interfering with life. However, as it is not realistic to go through life without any loss, grief is in fact intrinsic to the experience of living. Grief can be a long, emotional process, encompassing a variety of thoughts, feelings, and behaviors that are personal to each individual [1]. Factors affecting grief reactions include the relationship to the person who died, their age, the circumstances surrounding their death, and an individual's own personal experience, cultural beliefs, and coping mechanisms. It is important to recognize that Uncomplicated Grief is a normal process and is *not* a mental disorder [2].

Mourning is an outward expression of grief and loss. It is what is often visible to the public, and may include rituals, cultural customs, and religious beliefs. The rituals associated with mourning often provide meaning and structure to those who have experienced loss. These may include gathering with friends and family, planning a funeral, and burials.

Bereavement refers to a period-of-time, or state, in which grief is experienced and mourning occurs. It identifies the period of sadness after a loss. Eventually, there will be a shift in the bereaved person's state of emotional well-being, and the period will end. A person is in bereavement for as long as it takes them to process their grief.

8.2 Grief During End of Life

8.2.1 Anticipatory Grief

Anticipatory grief is experienced by all who know of an upcoming loss of a terminally ill patient. Patients and families experience an emotional response to the future loss, which can begin months to years before the actual death [3]. As in normal, uncomplicated grief, anticipatory grief has associated thoughts, feelings, and behaviors, yet is often experienced in a more silent manner than grief after a loss. Described as "grieving forwards," these emotions are distinct to the time period before the actual loss. Experiencing anticipatory grief is not protective for post-loss grief, and is not a reliable predictor of future outcomes. Even if grieving is already in process, it may continue or even worsen post-loss.

Symptoms associated with anticipatory grief include anger, anxiety, sadness, irritability, and dread. Furthermore, individuals may experience lack of motivation, desires to withdraw from social situations, and guilt. There is hope, however, during this period, as families have time to come together to say goodbye, spend quality time with the dying person, make peace, and make future plans. Clinicians would do acknowledge the challenges that patients and families are experiencing during this unique time, to provide support and referrals as indicated.

8.2.2 Grief Reactions Around Active Dying Phase

While a patient is actively dying or has immediately passed away, emotions run high, and grief reactions may be expressed passionately in the moment. They may be hard to manage or determine their "normalcy" in the early days after the loss. However normal uncomplicated grief gradually lessens into an acceptance of the reality of the loss. Distressing symptoms felt at the onset may decline over time, as the loss becomes more normalized and integrated into the life of the survivor. Symptoms may flare up at specific times that serve as a reminder of the deceased, such as birthdays and holidays. A hallmark of normal grieving is the ability not necessarily to move on, but to adapt to a new way of life without that person.

8.2.3 Prolonged Grief Disorder

While most bereaved people feel better with time and are able to adapt to new life circumstances without the deceased, approximately 10% of those experiencing grief have symptoms that do not improve.

Recently added the DSM-5-TR, Prolonged Grief Disorder captures these pathological grief responses in people who have lost a loved one within the past year. This person not only has lingering symptoms of grief, but these symptoms are intense and include preoccupation with or longing for the deceased that occurs almost daily for at least a month. The symptoms are distressing enough that they cause impairments in one's daily functioning, such as at work, in relationships with others, or taking care of themselves.

Other common symptoms include emotional numbness, feeling that life is meaningless, intense loneliness, an avoidance of reminders of the deceased, and continued emotional pain. Those with Prolonged Grief are at higher risk for medical co-morbidities and hospitalizations, additional mental health disorders and disability, and self-harm or suicide. If able to be evaluated, these patients can do very well with proper treatments.

8.2.4 COVID-19 Considerations

As COVID-19 has ravaged the planet, it has brought new challenges in end-of-life care. These include social distancing, isolation. People are unable to visit hospitalized patients, say goodbye to those dying, or perform usual rituals including funerals and burial. As a result, this has fundamentally changed how families cope and process grief during lockdowns and quarantining. COVID-19 has also disrupted traditional clinical practice, decreased access to social support for those dying, and decreased support for their surviving family [4].

8.3 Stages of Grief

Swiss-American Psychiatrist Elisabeth Kübler-Ross, in her groundbreaking 1969 book *On Death and Dying*, first postulated that those dying go through a series of stages of grief. She developed this Five Stage Model as a framework for how individuals learn to live with loss. Originally controversial due to its observational nature, over the years it has become widely acknowledged and adopted in medical practices, psychology, and end-of-life care. The stages of grief can affect both patient and family and are considered to be **Denial, Anger, Bargaining, Depression, and Acceptance** [5].

Denial is considered to be more disbelief than actual refusal to believe something is true. People tend to feel like "I can't believe this is happening" to me or my loved one. Avoidance, shock and, fear are commonly associated. Anger is often directed at the loved one for getting sick and leaving; at themselves for not taking better care or noticing that something was wrong with their loved one. Anger can also be placed on the diagnosing or treating physician [6], or on a Higher Power. Frustration, anxiety, and irritation are common symptoms of this stage. At the bargaining stage, people think of what they can "do" for their loved one to be spare. Thoughts such as "take me instead," and feelings of lack of control are common. This negotiation could be internal or spoken out loud and maybe medical, social or religious. Depression is the feeling of sadness that is an appropriate response to a significant loss. It is not to be confused with Major Depressive Disorder, a DSM-V-recognized disorder that includes depressed mood in addition to several other associated criteria that together create a syndrome/disorder [7]. And finally, acceptance is an acknowledgment of the reality that a loved one is dying, or gone. It does not mean that this person is alright or likes this reality, however they can learn to adapt and live with it [8].

The Stages of Grief are generalized, however the way each person experiences them is unique and individualized. Not every person goes through all stages, they can be experienced in a non-linear fashion, as people go back and forth between them on their way to healing and growth. People dealing with anticipatory grief go through the same five stages, More recently these have been expanded upon to include a sixth stage of grief, Meaning [9].

8.4 Treatment Options

While psychiatric or psychological treatment is not necessary for a normal grief reaction where a person is still functioning fairly well despite their loss, people do well in supportive psychotherapy due to the ability to vent and obtain feedback from an objective listener, or participate in group therapy or support groups to feel a sense of support and community [10].

For a patient experiencing prolonged grief, or perhaps major depression, both therapy and psychiatric evaluation may be useful. Treatment modalities include Cognitive Behavioral Therapy [21], Narrative Therapy, and Grief Counseling, and specific treatment for Prolonged Grief Disorder [11]. Support for Caregivers has been shown to improve symptoms, and medication support if indicated on a case-by-case basis [2].

8.5 The Impact of Culture on Bereavement Practices

While all humans are united by a sense of loss and a period of grief after the death of a loved one, the manner in which they mourn and experience this grief can be remarkably different depending on their upbringing. Culture, religion, and core values affect these practices. There is no right or wrong way to grieve [8], and religious or cultural beliefs impact experiences people have throughout end-of-life care. Clinicians working with terminally ill patients have an opportunity to help patients and their families process loss by understanding the cultural elements contributing to the dynamic.

Culture is a broad term, incorporating the behaviors and social norms of various human societies. It blends in beliefs, customs, laws, artistic expressions, traditions, and rituals of a group. Each culture has developed its own rituals and expressions of grief and loss [12]. Additionally, culture influences what is perceived as a loss or trauma, and therefore the manner and degree to which patients and their loved ones suffer losses. Many cultures are comforted by beliefs in life after death, or that the spirit of the deceased is watching over the living. Each group has its own beliefs about the meaning of life and afterlife, which can mitigate some grief responses. Participating in cultural or religious rituals surrounding death and dying helps people cope with loss, brings a sense of structure and control to a period of uncertainty, and provides comfort and community as patients and their loved ones prepare for loss [13].

We live in an increasingly diverse world where various cultures overlap, live in the same cities and communities, and families are often blends of different cultures and religions, creating their own unique rituals. This exposes clinicians to interactions with cultures and customs that they might not be familiar with. It would behoove those who work in end-of-life care to interact with patients in a culturally sensitive way, by acknowledging how these beliefs are affecting the patient experience at the end of life. Clinicians should be encouraged to research, ask questions and proceed with a culturally competent plan of care.

8.5.1 Cultural Rituals Surrounding Death and Dying

Rituals help people process loss, deal with the mystery surrounding death, and express grief in public and private. Communities unite over grieving rituals and come together to support those who have lost. These customs provide an organized, structured way to behave and help assign certain roles to a grieving family or community. They help inform a myriad of salient issues, including some of the following [7]:

- How grief is expressed—privately versus publicly, quietly versus vociferously.
- How patients are cared for/treated as they approach death—which ceremonies or prayers performed at the bedside, and which family, community members, or spiritual leaders are included.
- Where patients prefer to die.
- What happens to a person’s body after death—how is it handled, where is it located, comfort level of people with the physically deceased body, and whether to bury or cremate.
- Length of time family members grieve, if and when a spouse can remarry, and customs/dress during period of mourning.
- New family dynamics and roles—who takes on role as head of family, or takes on tasks that the deceased was previously responsible for.

8.5.2 Bereavement Practices of Specific Cultures

As America is truly a melting pot of races, cultures and religions, it would be difficult to include the grieving practices of all cultures. For the purposes of this chapter, it is acknowledged that this list is limited, and rather serves to show the variety of practices across a select few cultures—all of which have significant biological, geographic, religious and cultural diversity within them. Listed are the common practices after one is deceased for several cultures.

8.5.3 African-American Culture

- Gathering of family and friends at the home of the deceased
- A wake with music, hymns, singing; post-wake meal with grieving loved ones
- High church involvement, belief that deceased are going “home” to be with other deceased relatives and loved ones
- Funeral service followed most commonly by burial rather than cremation
- Public displays of emotion well-accepted
- Perhaps dressing in white to symbolize resurrection [7, 12, 13].

8.5.4 Asian-American Culture

- Emphasis on exquisite care for the physical body of deceased—dressed in warm clothes and particular caskets chosen to protect body
- Elders in the family will take over planning and ceremonial responsibilities
- Open casket
- Quiet expression of grief—often with controlled affect
- Importance placed on burial location, monument at burial site
- Community meal after funeral to pay respects to spirit of deceased and give thanks to those who came to mourn
- Small shrine at home with pictures and memorabilia [7, 12, 13].

8.5.5 Hispanic-American Culture

- Family and friends encouraged to participate
- Priest and church involvement
- Rosary Prayers are performed by surviving family/loved ones at the home of deceased; some families say the rosary every month for a year, and then again on each anniversary
- Funeral services include a Mass
- Public expressions of grief encouraged
- May include community financial contributions to cover funeral and burial costs [7, 12, 13].

8.5.6 European-American Culture

- Pubic expressions of grief encouraged
- Funeral proceedings are often subdued; traditionally mourners wear dark or black clothing

- Reliance on funeral director or religious leader to prepare services and plan burial
- Gathering of mourners at the home of deceased or close family member to grieve together
- Visitation or viewing at the funeral home, followed by religious or gravesite service [7, 12, 13].

8.6 Conclusions

Grief is a normal, human response to losses big and small experienced over the human lifespan. It is of vital importance that those working with patients and with terminal illness or their families, are aware of and understand the unique intricacies of grief reactions in end-of-life care. Keeping cultural differences at top of mind can help provide better holistic care, help ameliorate emotional pain of loss of health and life, and aid in appropriate diagnosis and treatment of mental health pathology.

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9

Primary Palliative Care in the Emergency Department and Acute Care Setting

Satheesh Gunaga and Jonathan Zygowiec

> *Cure sometimes, treat often, comfort always*
>
> *—Hippocrates*

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9.1 Introduction

Amidst a global COVID pandemic, the palliative care community and healthcare systems around the country continue to explore opportunities to improve early patient and family access to end-of-life care resources. They need not look any further than the Emergency Departments (ED) located on their campuses and around their communities for this chance. In 2018, there were over 130 million ED visits in America alone, resulting in over 16.2 million hospital and 2.3 million intensive care unit (ICU) admissions [1]. Patients 65 years and older had the highest ED and ICU utilization rates when compared to all other age groups with more than 75% of this demographic visiting the ED at least once in their last 6 months of life [1–3]. As advances in medical therapies continue to extend disease-specific life expectancies and as the American population continues to age, we will continue to see older adults with chronic medical illnesses visiting the ED in their final stages of life [3, 4]. If the ED is to continue to be the primary portal of hospital entry for patients requiring emergent care for acute and chronic terminal illnesses, then it stands to reason that it should also be equally prepared to provide the earliest access to palliative care and advance care planning resources for patients and families who may want and benefit from these services. This chapter will explore the unique horizon of opportunities that exist for emergency medicine and the palliative care specialty to fulfill this obligation.

9.2 History of Emergency Medicine and the "Resuscitation First" Paradigm

Emergency Medicine (EM) as a specialty is relatively young. Established informally by practice in the 1960s and then formally by residency training in the 1970s [5]. Board certification followed shortly thereafter in the 1980s [5]. The field of EM was born out of the need to provide care for a rapidly growing population of patients requiring immediate and unscheduled care for emergent medical conditions. With time, the ED became identified by many as the preferred health care venue to receive care for both acute medical emergencies as well as routine evaluation of non-emergent acute issues [1, 4]. The specialty of emergency medicine has grown immensely over the last six decades and now provides a large variety of complex multi-specialty care to patients with diverse medical conditions. These highly trained emergency medicine teams that provide treatment and stabilization to patients of any age, socioeconomic, ethnic, or cultural background represent the cornerstone and safety net of the American 9-1-1 and healthcare systems.

Historically EM has been centered around the science of resuscitation and a culture of initiating "heroic life-saving measures" in the most critically ill patients. The standard emergency medicine residency curriculum is typically focused on the identification, resuscitation, stabilization, and treatment of the sick and injured. In this historical EM paradigm, what occurs unintendedly to a group of seriously ill patients is the deleterious initiation of unwanted intensely resource-consuming care creating a significant delay in formal goal-directed end-of-life discussions and palliative care consultation. This culture of "resuscitation first, ask questions later" is flawed and can result in resource-consuming, goal-discordant end-of-life care.

9.3 The Evolution of Primary Palliative Care Services in the Emergency Department

Over the last 20 years, leaders within the EM and palliative care community have clearly recognized the importance of the ED as a unique window of opportunity to embrace palliative medicine [6–9]. It began in 2006, when Hospice and Palliative Medicine (HPM) became an officially recognized subspeciality of the American Board of Medical Specialties. By 2012, the American Board of Emergency Medicine (ABEM) created a clear pathway for EM physicians to be eligible for HPM fellowships and formal HPM boarding [9]. Since that time over 150 emergency medicine physicians have been dual boarded in EM/HPM and represent an important delegation of EM palliative leadership reforming EM culture [9, 10]. In 2012, the American College of Emergency Physicians (ACEP) recognized integrating palliative care into the ED as one of its top 5 Choosing Wisely best practices in EM [11]. The message from ACEP was powerful and specifically stated, "Don't delay engaging available palliative and hospice care services in the ED for patients likely to benefit." The College went on to say that "Emergency physicians should engage patients who present to the ED with chronic or terminal illnesses and their families, in conversations about palliative care and hospice services. Early referral from the ED to hospital and palliative care services can benefit select patients resulting in both improved quality and quantity of life" [11]. A message like this from the EM college began to set the stage for continued growth and movement away from the resuscitation first culture of EM.

In parallel, a consortium of emergency medicine and palliative care leaders began developing research, educational resources, tools, quality improvement collaboratives, and courses focused on the ED as an arena of delivery for primary palliative care services [12–17]. Primary palliative care is defined as "basic palliative care skills, including patient-centered communication, advance care planning, and refractory symptom management, that can be and are usually performed by a wide variety of clinicians including emergency physicians, nurses, emergency medical services (EMS), physician assistants, nurse practitioners, and social workers" [17]. The Education in Palliative and End-of-Life Care for Emergency Medicine (EPEC-EM) course and the quality improvement program generated from the Center to Advance Palliative Care's Improving Palliative Care in Emergency Medicine (IPAL-EM) are both outstanding pioneer resources that support healthcare professionals in learning the essential clinical competencies of primary palliative care and advocate for improved end-of-life care in acute care settings [15, 16]. Most recently in October of 2021, an expert multi-disciplinary panel of emergency medicine and palliative physicians, nurses, and social workers convened and published the Best Practice Guidelines for Primary Palliative Care in the Emergency Department [17]. This important paper reviewed two decades worth of EM and palliative care experience and literature and laid out very specific best practice guidelines for frontline ED providers. The authors' recommendations centered around core principles in screening, assessment, and management of palliative care needs in the ED, importance of goals of care conversations, and the coordination of early palliative care and hospice consults that can facilitate safe transitions of care from the ED.

9.4 Educational Initiatives and Resources

Opportunities abound as EM and palliative care teams beginning to partner and engage one another to bring awareness and enhance distribution of educational resources. Medical schools, specialties, and subspecialties in medicine have recognized that physicians and nurses in training should have at least an introduction to the field of hospice and palliative care [18–20]. This often comes in the form of both classroom lectures as well as clinical training scenarios or Objective Structured Clinical Exam (OSCE) as it is frequently termed. Outstanding primary palliative care resources from EPEC-EM [15], IPAL-EM [16], Wisconsin Fast Facts [21], and multiple other resources are available for physicians, nurses, and other palliative champions to access [22–24]. A variety of well-developed educational resources and tools developed to facilitate improved primary palliative care in the acute setting are available and listed in Table 9.1.

However, the raw emotion that is experienced in the moment, when the provider realizes their traditional approach of treatment is not working and then engages the family about end-of-life wishes, is something that cannot be taught but must be experienced. Clinical rotations with specialized palliative care teams and in the ICU are invaluable opportunities for growth for learners and should also be encouraged. Major educational initiatives are underway exploring core competencies for emergency medicine residents to advance their emergency primary palliative care skills [25–27]. These competencies have been developed and published as resources for EM residency leaders to incorporate into their training curriculums which are creating the next generation of EM physicians in this country [27].

Table 9.1 Excellent emergency medicine palliative care resources

EM palliative care resource	Internet address
Palliative Care Network of Wisconsin Fast Facts and Resources [21]	https://www.mypcnow.org/fast-facts/
Education in Palliative and End-of-Life Care for Emergency Medicine [15]	https://www.bioethics.northwestern.edu/programs/epec/
Integrating Palliative Care Practices in the Emergency Department [16]	https://www.capc.org/toolkits/integrating-palliative-care-practices-in-the-emergency-department/
Vital Talk [22]	https://www.vitaltalk.org/
End-of-Life-Nursing Education Consortium [23]	https://www.aacnnursing.org/ELNEC/About
Compassion and Choices: Dementia Values and Priority Tools [24]	https://compassionandchoices.org/end-of-life-planning/assess/dementia-values-priorities-tool

9.5 Initial ED Screening and Assessment of Palliative Care Needs

The starting point for reversing the “resuscitate first” culture that previously defined EM, is recentering the importance of early screening and assessment of a patient’s palliative care needs. This change begins by ED providers formally pausing during complex patient encounters and trying to assess whether a patient may benefit from some component of primary palliative care or advance care planning during this ED visit. A variety of factors go into this, including the assessment of a patient’s disease severity and trajectory, frequency of healthcare visits, and the outward physical and emotional distress they are presenting with. Some scenarios are obvious and include critically ill patients who are post-cardiac arrest, in respiratory failure or shock. In this group of patients, screening is transparent and mandates an early assessment of palliative care needs and focused goals of care conversations with patients and their families. Multiple prognostication tools exist to assist clinicians with the screening of patients that may benefit from early palliative care consultation and are described in detail in Chap. 7 of this textbook.

In the ED and acute care settings, one of the most effective screening tools studied was the “surprise question” [28]. This tool works by simply asking yourself the question, “Would I be surprised if the patient died within the next year?” If your answer is no, then this is a patient who may directly benefit from goals of care conversation exploring their understanding of their illness and better defining their wishes. The “surprise question” gains even more specificity and urgency by simply asking the same question but with shorter timelines, “Would I be surprised if the patient died within the next month or even during this hospital admission?” If the answer to these questions is no, then formal initiation of primary palliative resources from the ED is warranted as well as referrals to and consultations from specialized palliative care and hospice teams. Always remember that the patient’s decision to pursue palliative care services does not exclude continued evaluation and attempted curative management of disease processes and vice versa. Palliative care and traditional curative care are not mutually exclusive and are often most effective when used in combination to create an integrated goal concordant care plan for patients with severe illness.

9.6 Palliation of Refractory Symptoms in Acute and Chronic Illness

It is not uncommon for patients with severe end-stage diseases like cancer, dementia, congestive heart failure, chronic obstructive pulmonary disease, renal failure, and many other pathologies to visit the ED because of an exacerbation of their illness. These patients are often suffering and struggling at home but working with their primary care and palliative care teams to manage their symptoms in the outpatient setting. When they do present to the ED, they are often decompensated and may present for breakthrough pain, nausea, vomiting, dehydration, dyspnea, constipation, and fatigue. Beyond their medical symptoms, there may be a decline in function usually represented by a decrease in their ability to conduct activities of daily living (ADL). When this occurs, it often comes with great emotional stress, anxiety, and fear for patients as well as their families and caregivers. In many cases, the ED serves as the ideal venue for these patients to be evaluated. Immediate symptom palliation can be started while simultaneously initiating the diagnostic testing necessary to identify reversible causes of presentation. If the patient's symptoms can be managed and their fears and concerns addressed, then they may benefit from continued outpatient management with very close follow-up with primary care and palliative teams. If their primary complaints are not well addressed, then continued inpatient care with early palliative care consultation is always an option. Table 9.2 provides some basic guidance on how to pharmacologically manage some of the most common refractory symptoms encountered in the acute care setting [29].

9.7 Creating Meaningful and Skilled Goals of Care Conversations

The appeal to pursue emergency medicine for many is the unknown of what can come through the doors. Each shift can and often is drastically different from the next. Sadly, many of our patients did not wake up that morning knowing today would be their last day. Certainly, their family members and loved ones did not plan for what to do in that scenario. What makes the primary palliative care of emergency medicine so unique is that unlike someone with a progressive disease process, many of our patients have a sudden or drastic change in their health. This results in patients, families, and ED teams having unplanned, difficult, and urgent end-of-life discussions.

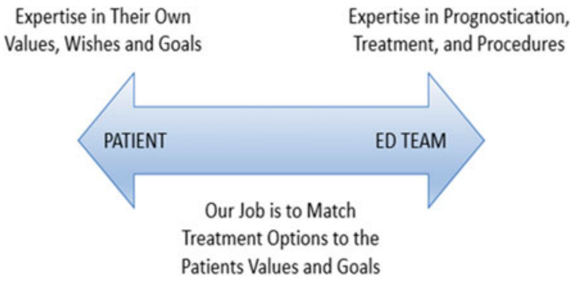
Table 9.2 Managing and palliating refractory symptoms in the ED

Symptom	Therapy to consider	Dose	Considerations and tips
Pain	Morphine	2–4 mg q4 h PRN	
	Fentanyl	25–100 mcq PRN	
	Dexamethasone	2–8 mg IV/PO q8 h	
Nausea and vomiting	Ondansetron	4–8 mg IV/PO	
	Haloperidol	0.5–10 mg q1 h PRN	
	Dexamethasone	2–8 mg IV/PO q8 h	
Dyspnea	Morphine	2–4 mg IV or 10 mg PO	
Delirium	Haloperidol	0.5–2 mg Q2 h IV or PO	
Secretions	Atropine sublingual	1% ophthalmic drops, 1–2 drops SL q1–2 h PRN	
	Glycopyrrolate	0.2–0.4 mg IV or SC every 4–8 h PRN	
Constipation	Senna	2 tablets daily	-Every time you prescribe a narcotic you should also prescribe a stool softener
	Colace	1–3 capsules daily	

Quill, Timothy E. *Primer of Palliative Care.* Glenview, IL: American Academy of Hospice and Palliative Medicine, 2010. Print [29]

The delivery of bad news while creating a meaningful goals-of-care conversation with an established patient and their family is challenging and requires a complicated skill set for clinicians to do properly. This task becomes uniquely more challenging in the acute care setting of the ED or the ICU because the physicians, nurses, and palliative care teams often have no prior relationship with that patient or their family. Beyond just giving bad news, the clinical teams in the ED need to quickly transition into assisting the patient and family in making decisions around an urgent progression or de-escalation of care. The following section will describe some tools, suggest language, and describe an organized approach for clinicians in the acute care setting to create meaningful and skilled end-of-life goals of care conversations. These conversations, if executed properly, can create a positive relationship between patient and clinical team and can clearly help guide the patient and family identify their wishes, options, and care goals, regardless of if they are curative, palliative or a combination of both.

Fig. 9.1 Facilitating shared informed decision making to deliver patient centered goal concordant care



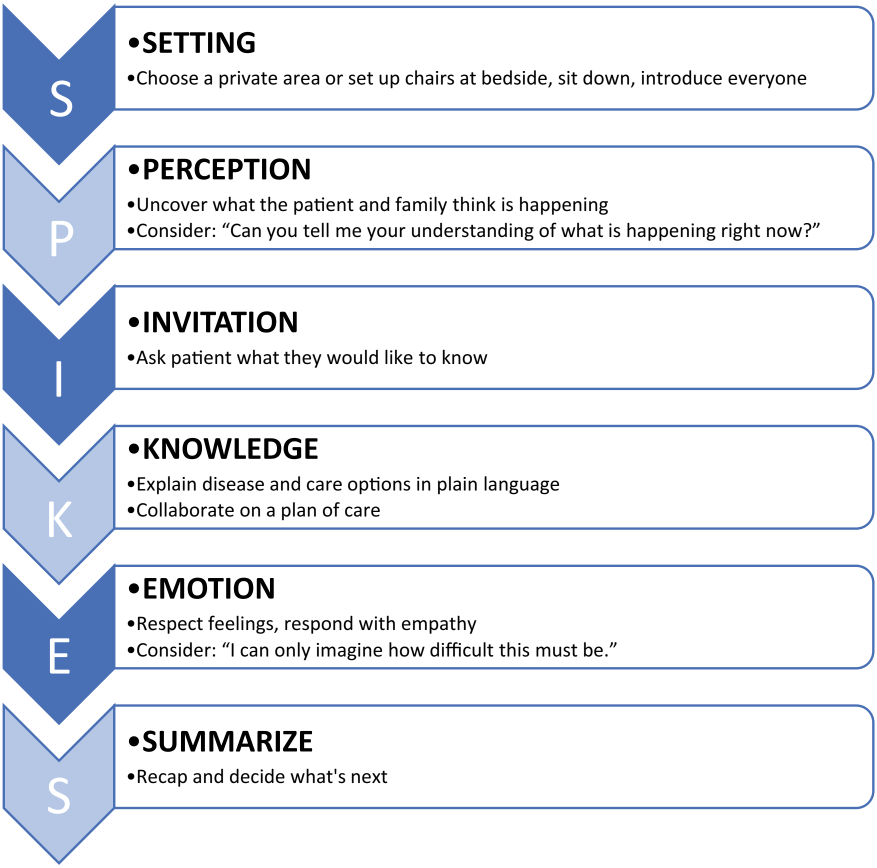
9.8 Importance of Shared Informed Decision Making

Shared decision-making is an essential component of patient-centered health care and the end-of-life discussion. In the palliative medicine arena, this process is focused on clinicians, patients, and their families. With them all working with one another to coordinate end-of-life care decisions and select advance care plans, that balance a patient's personal preferences and values. Both in the acute care setting and out-patient setting, this discussion is centered around thoughtful education and description of care options, which allows informed autonomous decision making by all parties.

There is no single way to approach the care of the critically or terminally ill patient. Every individual will have their preferences regarding treatment modalities, testing, and quality of life issues associated with these decisions. It is our role to serve as an educator and advocate for the patient and their wishes. To do this, clinicians must be ready to abandon the historical paternalistic physician- and patient relationship and move towards a shared decision-making model where the clinicians work with the patient to make decisions that best represent their wishes and goals. When done properly, patients will receive care that is goal concordant with their desires on how they want to live and how they want to die. Figure 9.1 illustrates our role to match treatment options to the patient's values and goals.

9.9 The SPIKES Model to Guide Goals of Care Conversation

The SPIKES model for "breaking bad news" is a straightforward and valuable framework to assist clinicians in engaging in and maximizing goals of care conversations. Coming into these encounters with an organized process has been shown to increase the confidence and effectiveness in a clinician's ability to disclose unfavorable information to patients and their families [30]. The SPIKES model uses this mnemonic to help assist clinicians focus on Setting, Perception, Invitation, Knowledge, Emotion, and Summarize, to guide these challenging conversations. Figure 9.2 highlights the SPIKE model and details suggested language and take away points from each step.



- **SETTING**
- Choose a private area or set up chairs at bedside, sit down, introduce everyone

- **PERCEPTION**
- Uncover what the patient and family think is happening
- Consider: "Can you tell me your understanding of what is happening right now?"

- **INVITATION**
- Ask patient what they would like to know

- **KNOWLEDGE**
- Explain disease and care options in plain language
- Collaborate on a plan of care

- **EMOTION**
- Respect feelings, respond with empathy
- Consider: "I can only imagine how difficult this must be."

- **SUMMARIZE**
- Recap and decide what's next

Fig. 9.2 Highlights how to use the SPIKE model and suggests language to help guide goals of care conversations

9.10 Proper and Organized Introductions

The first step in every patient and family encounter around delivering bad news in the ED is to assemble your team and get the family together in a quiet and private area. Historically this has been at the patient bedside, or in designated family room areas in the ED, but in the COVID era this has become more challenging. Setting is very important and should be prioritized around being private, quiet and with seating so that everyone can comfortably sit down to talk. Having a nurse, chaplain, or patient representative with you during these discussions can provide invaluable support. After family is gathered in the private area and your team is ready to go talk with them, it is an absolute priority that you verify the patient's name and then verify that the individuals in the room are truly the family of the patient you are discussing. Although rare, it is not uncommon to assemble the wrong family and then begin discussions that do not pertain to them. This is incredibly distressing to anyone involved and obviously embarrassing. Making sure you take a pause to review patient's name, any family listed in the chart, and gather contact information. Introduce yourself and your team and then ask, "who do we have in the room and what is your relationship to Mr. Joseph Smith?"

9.11 Advance Directives and Durable Power of Attorneys

It is important early in the discussion to identify who in the room is the Durable Power of Attorney or the de facto decision maker for the patient. Our hope is that this person has a clear understanding of the previously expressed wishes of the patient. Frequently when presented with an overwhelming and life-threatening condition, our default as humans who care for someone is wanting to essentially do anything and everything to keep that person we care about alive as long as possible. As skilled clinicians though, we must frame our goals of care discussions in simple, straight, and concise terms to provide a clear path. It is important not to overload the patient and family with information and options. The emergency department is the right place to initiate this conversation with the patient and power of attorney when presented with a life-altering diagnosis. Holding these conversations as early as possible and addressing the patient and families' questions, fears, and hopes can help assist future treatment teams as they present more data and options along the course of the hospitalization.

9.12 Really Listening to the Family

The art of listening is key during moments like this. Medical literature unfortunately describes physicians and clinicians as poor listeners who rarely can keep silent without interrupting patients and family for more than 11 seconds [31]. This must be one of those moments where we sit back and listen. Use open body language, affirmations like nodding your head, and looking people in their eyes when you are listening and speaking. To connect with a family or patient in moments like this, they must feel like they are being heard.

9.13 Asking Open Ended Questions

One challenge in the emergency room is that we are highly decision-oriented, looking for affirmation to continue or discontinue critical care resuscitation. Our instinct and training are to be direct and get right to the most important questions we need to be answered. In this situation, this instinct is likely a hinderance and will often create misguided conversations and decisions. Table 9.3 is a series of phrases that clinicians should avoid in the acute care setting when having goals of care discussions. Alternative phrases that allow for more meaningful open-ended discussion and sharing of patient and family wishes are listed for consideration [32].

Table 9.3 Reframing sentences

Reframing sentences	
"Do you want us to do everything?"	"Your mother/father is very sick right now, what would be most important for them right now?"
"Do you want us to resuscitate your mother/father?"	"It sounds like from how you're describing your mother/father, they would want a natural death"
"I'm sorry there's nothing more we can do"	I wish I could change what is happening here, but there is so much we can do moving forward to support her and you throughout this process

(Quill, JAMA 2000) [32]

9.14 How to Help Patients and Families Make Decisions to Progress Care

The ABCD approach outlined by the EPEC-EM curriculum is an excellent resource to help patients, families, and clinical teams stay focused when addressing goals of care conversations [15]. Keeping your discussion organized and simple allows the patient and family to feel more in control of the situation. The ABCD approach is outlined below:

A. Is there an **Advance** care plan regarding life-sustaining intervention wishes?
B. Can we make the patient feel **Better**?
C. Are there **Caregivers** to consider?
D. Does the patient have **Decision-making capacity** and, if not, has a surrogate been identified?

9.15 De-escalation of Care and the Terminal Wean

When patients and families decide not to advance care, it is our job in this situation to walk them through the hospice and palliative care options available to them. The first decision to consider includes maintaining the patient's current level of care with no further escalation. This choice essentially keeps all care that is actively occurring in place, but no additional escalation of care would occur, and very clear advance directives are defined around CPR, intubation, vasopressors, and other life support measures. Often patients and families will ask for withdrawal of care and an emphasis on comfort measures only. This too needs detailed advance directive charting and updates, but, in the ED or ICU may lead to withdrawal of care consistent with a terminal extubation or wean.

Terminal wean is a term that describes the withdrawal of advanced life support measures in critically ill patients. This often includes discontinuation of vasopressor or antiarrhythmic agents which are supporting blood pressures and preventing arrhythmia. This also can include the discontinuation of ventilatory support and extubation. These patients are often critically ill, and the discontinuation of this care will result in rapid decompensation and death. It is impossible to truly predict how long a patient will survive after withdrawal of care. If we tell the family minutes to hours the patient lives for days, if we say days they live only for minutes to hours. It is best, to advise the patient and family that after withdrawal of care the emphasis will be on comfort measures to avoid pain, anxiety, and prolonged suffering. This can be supported using low to moderate dose opiates like Fentanyl or Morphine as well as low dose sedatives like Versed or Ativan.

Terminal extubations should be carefully planned, families need to be advised that patients can die quickly without ventilatory support. Extubation should be performed without family at bedside, airway should be suctioned afterwards, and face cleaned. Applying a nasal cannula or non-rebreather mask as well as pre-dosing with morphine can help prevent some of the hypoxic respiratory distress that ensues and should be used as part of post-extubation comfort measures. The monitors and the alarms in the room should be turned off and observed from telemetry areas so families don't have to be distracted by these readings. Any opportunity to coordinate family, chaplains, or other important spiritual figures for the patient should be maximized.

It is OK if the patient and family are not ready to embrace palliative care discussions or advance care planning. Never take it personally.

You may encounter that the patient or family members are resistant to approaching the topic of initiating a palliative care or hospice consult during their hospitalization. This may be their third time being admitted for a COPD exacerbation and they have been experiencing significant functional decline since their first admission. Sometimes it is hard for us as clinicians to understand the why behind what the patient and/or family is resistant to discuss. Frequently, there are underlying stories as to why. They may be holding out for a special day such as a birthday, anniversary, or a wedding. Other times, it can be that they feel bad about not being the son, daughter, mother, father they thought they should be and hope in this time-restrained period that they can make up for it. Whatever the reasoning is, we need to merely plant the seeds of options available to them and be present at the moment to lend an ear. Just listening to stories about the patient and their life as the family member sits with them can be so meaningful and sometimes helps family come to the realization that not prolonging the inevitable is what their loved one would truly want.

While certainly, the flow of your emergency department is important to manage, pausing to ask, "Tell me about them", while you take a moment to sit in the room, will usually allow the patient and their family to know that you and your team genuinely care for them. Sometimes it's moments as simple as this that will turn conversations from life-sustaining treatments to discussions about how their loved ones lived, as well as the caregivers' own fears about their loved one suffering, or how their loved one's death may look. Non-verbal cues to show your interest in the patient can even be as simple as finding them an extra pillow or blanket and making the patient more comfortable without saying anything in the room.

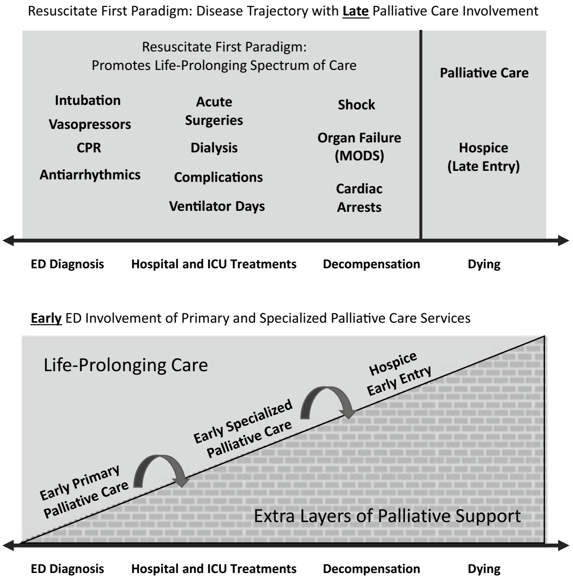
Both verbal and non-verbal interaction with the patient and family can help open conversation.

9.16 Moving Palliative Care Discussions and End-of-Life Care Options Earlier in the Continuum of Hospital Death. It needs to start in the ED

Some of the most significant innovations in critical care medicine over the last 30 years have involved proactively moving screening, assessment, and management earlier into a critically ill patient's clinical course. The evolution of sepsis care is one of the best examples. Historically definitive sepsis identification, resuscitation, and source control were coordinated in the ICU. In the early 2000s, it was proactively moved into the spectrum of emergency medicine. In this setting, ED teams were asked to provide earlier sepsis screening, identification, antibiotics, fluid resuscitation, and goal-directed resuscitation, which ultimately created dramatic improvements in patient outcomes [33–35]. Similar for admitted patients, the advent of hospital-based rapid response or medical emergency teams, changed the incidence of inpatient mortality [36]. The old paradigm would often manage decompensating patients on the floor, to the point of severe clinical demise, prior to activating necessary support resources needed to change the medical trajectory of a patient's illness. The presence of rapid response teams, empowered nurses, and other clinicians to screen for decompensation and ask for help earlier, which directly allowed patients to receive time-sensitive care more promptly to improve outcomes. In the same way, the specialized palliative medicine community needs to embrace EM leadership to continue to develop novel solutions on how to improve early engagement regarding end-of-life discussions and improve access to palliative care specialists earlier in the continuum of death.

Unfortunately, every ED across the nation has varying access to specialized palliative teams and primary palliative care education [11, 16, 37]. Some hospital systems have well-organized and intricate protocols and policies that facilitate early engagement of palliative care resources, many do not [11, 16, 37]. The variance of primary palliative care practices fluctuates within a single ED from shift to shift depending on who the clinical team is that day, and this variation obviously continues across our country's very diverse ED network. The challenge over the next 10 years will be to homogenize these resources and processes, transitioning EDs away from heterogenous and variable practice. Creating best practice guidelines as outlined by ACEP in 2021 is a great start [11]. EDs and health systems will need to identify and reward EM palliative champions who will serve to foster improved primary palliative care in their own departments locally. This will require direct and proactive collaboration with local specialized palliative care team members. Health systems need to mobilize much-needed, chaplain, social work and case manager support services to ED teams and their patients and families who may benefit from early palliative care referrals and home health care needs.

Fig. 9.3 Reconceptualizing palliative care as a continuum of support and emphasizing the benefit of early goal-directed end of life care (based on figure by Wang et al. [8])



EDs will continue to see a larger portion of patients dealing with terminal and chronic illness that may benefit from early evaluation of palliative care needs. Because of this, EM is positioned to take the lead on triaging these patients and then proactively becoming a palliative care hub helping patients link to the resources that would most benefit them. At the minimum, the ED can initiate skilled goals of care discussions with patients and their families, and fully address their advance directives, and some advance care planning needs. The ability of the ED to focus on the palliation of primary symptoms, and then proactively avoid hospitalizations, is another opportunity to reduce suffering and avoid unwanted hospital-based deaths. Early referral to palliative and hospice services will benefit patients, families, and health systems manage resources, and provide truly goal-concordant care for patients through their continuum of illness [8]. When primary palliative care resources are layered on top of traditional life-prolonging curative care, we see a significant increase in patients' receiving goal-concordant care, and the effects of this paradigm change are described in Fig. 9.3.

9.17 COVID-19 and Its Impact on Health Systems, ED, and Palliative Care

As we face sequential waves and new variants of COVID-19 in our nation, our healthcare system continues to be stretched to the very edge of its limits. Health care providers are facing significant physical, emotional, and spiritual strain as resources become more limited [38, 39]. On May 13th, 2022, one million Americans had died from COVID and over 6 million deaths worldwide [40]. The

American healthcare system, and the EDs specifically, are feeling significant pressures related to reduced ED and ICU capacity secondary to a severe national nursing and ancillary staffing crisis [41]. These deficiencies affect all staffing including technicians, respiratory therapists, social workers, and even other downstream palliative care teams [41]. Waiting room times in the ED are at an all-time high, with patients either leaving without completion of services or decompensating abruptly in the ED lobby waiting to be seen [42]. During such volatile times, we continue to see patient and family-directed aggression towards healthcare workers. The incidents of both physical and emotional injuries suffered by health care professionals during these encounters are sadly on the rise [38, 39].

As the pandemic spread and visitor restrictions started to be enacted across the nation, we found ourselves having to transition to phone or video conferencing. In fact, early in the pandemic, the majority of hospitals completely eliminated any visitors in the emergency departments as well as the ICUs, unless the patient was actively dying. Even during that period, the family often would only be able only to look into the room and were unable to hold their loved ones hands or be at their side. Though visitor restrictions have now been softened, families continue to have less access to patients in the ED and ICU than before the pandemic started. Our traditional in-person ways of communicating with and supporting patients and their families during this time have dramatically changed medicine. Being able to sit face-to-face with the patient and family was the cornerstone of the “goals of care conversation”. It allowed us to use non-verbal cues when discussing their care process. It allowed a more collaborative approach to the treatment plan and offered numerous chances to clarify the trajectory of care. This transition period has been and will continue to be, challenging for many. Clinicians will be required to focus on delivering clear and concise summations of what was happening during the ED stay, as well as next steps or interventions, and even potential pitfalls along the way. In the future ED teams will be frequently asked to make multiple phone calls to family members and will need to be proactive in keeping families involved in patient care.

9.18 Embracing the Future of Telemedicine in Palliative Care

Innovations often thrive in troubling times and the use of virtual telemedicine platforms and processes have grown exponentially since the onset of COVID [43]. We are seeing significant increases in patients using telemedicine with both primary care and specialty physicians for ED follow-up visits [43]. Behavioral health, too, as a specialty is utilizing virtual tele-psychiatry and mobilizing social workers virtually to reach more patients in need of care that were previously vulnerable due to lack of resources or geographic locations [44]. Across the country, we are seeing Emergency Medical Services (EMS) starting to utilize telemedicine in the form of well-developed mobile integrated health teams as well and community paramedicine programs [45]. A real opportunity exists for prehospital teams to join the many layers of available outpatient palliative support services and assist in the delivery of palliative care under physician guidance [45]. The Prehospital Providers Perspective on Palliative and Hospice Care Course is an innovative, free, three-hour educational program that is beginning to support and develop this opportunity and another example of innovation [46].

The palliative care and hospice specialty has already started to embrace these platforms. With palliative and hospice resources in some areas of the country being scarce, these virtual medical tools can help fill gaps where there is a deficit of trained workers to provide specialized palliative care [47]. Skilled palliative care specialists can now provide telemedicine services to other hospitals, skilled nursing facilities, Long-Term Acute Care Hospitals (LTACHs), as well as coordinate home visits. It is time to invest resources into coordinating systems that allow for urgent tele-medicine consultations between specialty palliative teams and the ED. The technology, platforms, patients, and need, are there for the ED and specialty palliative care to partner up to create a higher level of services than are currently being provided. Maximizing tele-medicine offers great potential to deliver both increased quantity and quality of palliative care services to patients who previously would not have been able to receive them.

9.19 Embracing Opportunities for Primary Palliative Care in the ED and Acute Care Setting

As EM continues to evolve, it is essential that the palliative care community and its leaders, continue to embrace and foster relationships with their ED partners. Working together, these two specialties can further develop much-needed awareness, education, processes, and protocols, that will foster primary and specialized palliative care services being initiated more often from the ED. When this happens, we will see a profound shift of unwanted and resource-consuming care, move away from acute critical care encounters. Instead, we will see more focused, goal-directed, and goal concordant end-of-life care being initiated earlier in the continuum of death. Bringing specialized medical and surgical services to the ED and patient bedside is not novel. Interventional cardiologists, trauma teams, and surgical specialists, are regularly activated to provide emergent care for cardiac, traumatic, and surgical emergencies. In collaboration, EM physicians and palliative care specialists, in combination, have an opportunity to fill a similar gap for the terminally ill. Patients and their families facing acute critical illness, and the looming possibility of a “goal-discordant death”, need the expertise of both a trained EM team, and palliative specialists. The ability to initiate essential goals of care discussions and then coordinate end-of-life care resources for patients much earlier in the continuum of terminal illness can play a dramatic role in improving both their quality and quantity of life (Table 9.4).

Table 9.4 Glossary of important primary palliative care terms

Primary palliative care	In the context of end-of-life care, a primary palliative care provider is the principal medical, nursing, or allied health professional, who undertakes the clinical management and care coordination including palliative assessment, triage, referral, and assisting patients and families to establish appropriate goals of care
Specialist palliative care	A *specialist palliative care provider* is a medical, nursing, or allied health professional, that have the specialist knowledge, skills, and expertise in the care of people living with an eventually fatal condition and their families Specialist palliative care services work in three key ways; providing direct care to referred patients with complex needs, providing consultation-based services to patients being cared for by primary care providers, providing support to end-of-life care services
Hospice	Hospice refers to a "program" that gives special care to people who are near the end of life, with an estimated prognosis of less than 6 months, and have stopped treatment to cure or control their disease. Hospice offers physical, emotional, social, and spiritual support for patients and their families. The main goal of hospice care is to control pain and other symptoms of illness so patients can be as comfortable and alert as possible. It is usually given at home, but may also be given in a hospice center, hospital, or nursing home
Illness trajectories	Distinct illness trajectories have been described at the end of life for frailty, dementia, cancer, and organ failure. These trajectories can provide a framework for addressing patient and family expectations of what will happen regarding their health
Advance care planning	A process to help the patient plan medical care in advance, so that if they become too unwell to make decisions, their wishes can still be respected by the healthcare team and the family. An important part of the plan is identifying a substitute decision maker, one who is able to adhere to the patient's values and wishes, in the event that the patient becomes unwell and is no longer able to speak or properly communicate their wishes

(continued)

Table 9.4 (continued)

Advance directives	A legal document that states a person's wishes about receiving medical care if that person is no longer able to make medical decisions because of a serious illness or injury. There are different types of advance directives, including a living will, durable power of attorney (DPA) for healthcare, and do not resuscitate (DNR) orders. In the United States, the laws for advance directives may be different for each state, and each state may allow only certain types of advance directives
Terminal wean	The gradual withdrawal of mechanical ventilation from a patient who is not expected to survive without respiratory support
Physician order for list sustaining treatment (POLST	POLST is a document that states a person's end-of-life wishes and may include a "Do Not Resuscitate" (DNR) order, instructions about artificial nutrition, antibiotics, and other medical interventions. While an advance care directive is usually meant for a hospital, POLST is designed to instruct emergency personnel on what actions to take while the patient is still at home

Definitions adapted from Pallipedia: https://pallipedia.org The Free Online Palliative Care Dictionary [48] and the National Cancer Institute's Dictionary of Cancer Terms: https://www.cancer.gov/publications/dictionaries/cancer-terms/ [49]

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Understanding End of Life Nursing Practices and End of Life Across Cultures

10

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10.1 Overview

Nurses are the largest group of health and social care professionals globally and they are central to the provision of palliative care. Over 28 million nurses [1] provide care in extremely varied settings, cultures, and under wide-ranging nursing practice models, yet they are united by shared values and a commitment to improved care for the seriously ill and dying [2, 3]. While there is diversity in the scope of practice and education across countries, there are many common areas of palliative nursing care. Nurses are involved in the assessment and management of symptoms, providing bereavement support to patients, caregivers, and communities, offering spiritual support, and managing transitions across settings of care [4]. Nurses are also the clinicians most frequently at the bedside at the time of death, offering critical support when it is most needed to ensure a peaceful death and a supportive, therapeutic presence for grieving families.

Palliative nursing began as a defined nursing specialty with the beginnings of hospice care at St. Christopher's Hospice in London. Access to hospice services has grown exponentially around the world and the development of palliative care has made clear the need to institute the principles of supportive care early in the course of serious illness rather than only at the end of life. The evolution of palliative care has increasingly underscored the critical role of nursing as palliative care extends across the trajectory of illness [5].

The global recognition of universal access to palliative care as an essential element of public health and human rights is reshaping health systems and agendas [4, 6–8]. Numerous factors including an aging society in many nations, pandemics, chronic illnesses, and overburdened health economies all lead to the reality that palliative care is critical for the future and must expand. The number of people who will die from serious illnesses is projected to increase by 87% by the year 2060 [9].

This chapter reviews the development of palliative nursing internationally including major organizational efforts, health policy advances, and developments in nursing education and certification.

10.2 The Urgent Need for Universal Access to Palliative Care

Although the need for palliative care has been recognized worldwide, many countries still lack access and most countries significantly underutilize the full potential of palliative care. In fact, only 20 of the world's 234 countries have successfully incorporated palliative care into their health care systems. Low and middle-income countries (LMICs), in particular, suffer from a lack of palliative care and these are countries who often need it most [10]. Compounding this inequity, these LMICs are faced with the greatest amount of disease and have the least amount of resources to deal with health crises [10]. Nurses play critical roles in all aspects of interdisciplinary professional practice to increase access to primary and specialist palliative care services and advocate policy changes that promote evidence-based symptom management and psychosocial support [3, 5, 11].

10.3 International Advances in Clinical Practice, Health Policy, Education, and Research

Numerous international efforts from the highest level of health care organizations have supported the need for access to palliative care. A key example has been the United Nations (UN) Sustainable Development Goals (SDGs). This 15-year agenda began in 2016 and recognized key actions needed across dimensions of health and society to strengthen nations [12]. For example, at the (UN) 2019 High-Level Meeting on Universal Health Coverage (UHC), palliative care was officially recognized as a crucial component of achieving UHC, as articulated by SDG 3.8 [6].

In addition to its recognition as an essential element of universal health care, palliative care must be accompanied by both primary and specialty training and this care must be aligned and available to the workforce in each region. There is significant diversity in the workforce across nations ranging from unlicensed nursing staff to doctorally-prepared nurses and in all countries, there is an opportunity to integrate palliative care within the workforce design of each country to reach communities at all junctures of serious illness care.

In 2011, Human Rights Watch recognized palliative care and access to pain relief as a human right [13, 14]. Similarly, WHO passed the Palliative Care Resolution in 2014 encouraging the incorporation of palliative care into national health care systems. The WHO has recognized the need for universal access to palliative care as an essential element of health care [8, 15]. WHO's vision as described in their Global Strategic Directions for Strengthening Nursing and Midwifery is "accessible, available, acceptable, quality and cost-effective nursing and midwifery care for all, based on population needs, in support of universal health coverage and the Sustainable Development Goals" [7, 8, 16].

The more recent Lancet Commission on Global Access to Palliative Care and Pain Relief sought to quantify the burden of serious health-related suffering worldwide and make explicit the role of palliative care in measurably alleviating it, particularly for the poorest and most at-risk populations [4]. The Commission's recommendations include access to an 'Essential Package' that included widespread access to essential medicines, including immediate-release oral and injectable morphine for healthcare workers in all nations to effectively treat moderate to severe pain and dyspnea at end-of-life. Furthermore, they emphasize the need to activate international collective action to address policies that prevent the full integration of palliative care into health systems as a component of comprehensive UHC.

The advancement of palliative nursing internationally has also been advanced by rapidly developing technology which has the capacity to provide networking between countries and foster sustained and mutually beneficial academic-practice partnerships. Emerging telehealth options, while still in low resource countries, has tremendous potential to expand the reach of palliative care [10, 17]. Some examples are E-hospice (https://ehospice.com.); Palliative Care Network (https://www.palliativecarenetwork.com/); Palliverse (https://palliverse.com/); and a range of international and regional palliative care organizations and the roles they play [10]. In addition, the freely available International Association for Hospice and Palliative Care advocacy training program provides pragmatic guidance to interdisciplinary professionals on how to advance palliative care advocacy at local, national, and global levels (https://hospicecare.com/what-we-do/programs/advocacy-program/).

In recognition of the WHO-designated 2020 Year of the Nurse and the Midwife, several initiatives were launched to honor the contributions of nursing historically, as well as to identify their roles in meeting the future demands of society. The WHO and the International Council of Nurses established the Nursing Now campaign (2017–2021) to raise the status and profile of nursing. This project and numerous others have called for greater involvement by nurses at all levels of health policy, the need for workforce development, and breaking down barriers that inhibit nurses from practicing to their full potential.

A key development in many nations has been the evolution of Advanced Practice Registered Nursing. Educational preparation, titles, and responsibilities vary by country but in most instances, the Advanced Practice Registered Nurse (APRN) role is focused on primary care delivery with expanded responsibilities in and patient assessment, prescribing of medications [18]. Palliative care APRNs provide leadership skills, advanced knowledge, expanded scopes of practice, and enhanced assessment and treatment competencies that can move palliative nursing forward in clinical practice, education, and policy settings [11].

Nurse midwives, who may be Registered Nurses (RNs) or APRNs depending on the country, have also been key providers of care, especially in countries with high infant morbidity and mortality. The COVID-19 pandemic has served as an example in which APRNs assumed major responsibilities for care across all settings of care from emergency departments, nursing homes, acute care settings, ICUs, and community-based care as the physician workforce was completely incapable of meeting the escalating needs, often in areas that were already vastly overburdened. The APRN role generally includes knowledge and clinical skills in areas such as clinical decision making, communication, ethical conflict resolution, and aggressive symptom management which are vital in a time of pandemic [18].

10.4 Educational Initiatives

Implementation of palliative care on a global scale has been hindered by a shortage of health care professionals trained to deliver it [4]. A phrase often used in describing the need for palliative care education is that nurses can’t practice what they do not know [19]. Expecting nurses to provide palliative care requires education and clinical experience that has unfortunately often been absent in many nursing education programs. Preparing nurses to be leading professionals in the delivery of palliative care demands education in the key domains of palliative care practice including pain and symptom management, communication skills, grief and bereavement of patients, families and staff, psychosocial and spiritual support, and ethical issues associated with serious illness and end of life.

Several global efforts were developed in response to COVID-19 to provide rapid training and resources to support professionals [13, 20, 21]. One example, the Global Palliative Education in the Time of COVID project [22], involves several US institutions, Uganda, and India. One notable aspect of this project is the "Resilience Inspiration Storytelling Empathy Project" which involves online sessions to share experiences of healthcare workers. The program's objectives include countering isolation, providing connection and community, promoting empathy and understanding, using listening as a form of healing, and increasing resilience and meaning making.

In current times, global issues are local issues as witnessed recently by the rapid transmission of COVID-19 and the resulting universal suffering in every corner of the globe [23–25]. Similarly, palliative nursing which addresses pain and suffering is a shared endeavor of nurses worldwide, as information and communication so easily transcend national boundaries. Cultural exchange, mentorship, training, and curricula made more readily available by technology allow nurses worldwide to learn from one another and share vital information and strategies that contribute to the advancement of palliative care.

10.5 Models of Palliative Nursing Care

The values and goals of palliative nursing care are based on a shared philosophy of nursing globally. Nursing, since its inception as a profession over 200 years ago, was founded on basic ethical principles such as the relief of suffering, whole-person care, and a focus on avoiding harm while providing benefits through attention to physical, psychosocial, and spiritual well-being. These shared values transcend boundaries and cultures and have been fundamental to the growing specialty of palliative nursing (Tables 10.1 and 10.2).

The End-of-Life Nursing Education Consortium (ELNEC) project is a national and international education initiative to improve palliative care. ELNEC is a collaboration between City of Hope, Duarte, CA, USA, and the American Association of Colleges of Nursing (AACN), Washington, DC. Since the year 2000, the project, administered by City of Hope, has provided undergraduate and graduate nursing faculty, CE providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics, and other nurses with training in palliative care so they can teach this essential information to nursing students, practicing nurses and other healthcare professionals.

While the initial ELNEC efforts, launched in 2000, were focused in the United States, many ELNEC trainers have had opportunities to travel internationally and provide this education to nurses and other healthcare providers throughout the world [26]. Currently, ELNEC trainers and faculty have traveled to six of the

Table 10.1 Nurses should work to increase accessibility to palliative care locally and throughout the world

- By working to train nurses and other healthcare professionals in palliative care
- By disseminating research and information on palliative care's ability to improve quality of life
- By adapting models of care that can meet the needs of underserved local communities as well as low-income countries throughout the world
- By forming global partnerships to exchange knowledge, skills, and models of care
- By rendering culturally sensitive, respectful, and inclusive care to all patients of all backgrounds
- By advocating for the palliative care nurse's importance to the interdisciplinary care team
- By advocating for palliative care's vital role in health organizations and systems throughout the country and around the globe
- By integrating palliative care education into nursing school curricula

seven continents, representing 101 countries. Many trainers have provided ELNEC educational courses, while others have gone as consultants to work with educators, health administrators, and community leaders to improve care of the seriously ill in their countries. Some are working on translating ELNEC into other languages and adapting it to increase the relevance to other cultures. As of 2020, ELNEC has been translated into 12 additional languages: Albanian, Armenian, Chinese, Czech, German, Hindi, Hungarian, Japanese, Korean, Romanian, Russian, and Spanish. Some examples of the international ELNEC efforts follow [27, 28].

10.5.1 Japan

The country of Japan was one of the earliest ELNEC collaborations and efforts here have developed into a strong network of ELNEC Trainers providing palliative care education throughout the country [29]. ELNEC JAPAN (https://www.jspm.ne.jp/jspm_eng/elnec.html) celebrated its 10th anniversary in 2019 with now over 3800 trainers who have taught over 44,400 others throughout Japan using the curriculum. Japan's success has been related to full translation of the curriculum, use of each of the specialty curriculum (Core, Pediatrics, Geriatrics, Critical Care) to have broad impact and their organizational structure as a part of the Japan Palliative Medicine Organization [29, 30].

10.5.2 Africa

ELNEC has collaborated with many countries in Africa and with leading organizations such as the African Palliative Care Association (APCA). Africa serves as an example of distinct needs, for example, a much higher level of childhood mortality necessity pediatric-specific content. Roles of nurses and education preparation have been areas of expansion to meet the needs in palliative care and African

Table 10.2 Resources to Support Palliative Nurses' Education, Practice, and Well-Being

Organization	Description	Website
• African Palliative Care Association	• Resources to guide palliative care practice in Africa and resource-constrained settings	• https://www.africanpalliativecare.org/articles/covid-19-resources/
• American Academy of Hospice and Palliative Medicine	• Tools, networks, and resources to guide self-care and patient education	• https://aahpm.org/education/covid-19-resources
• American Academy of Nursing	• Detailed timeline of policy advocacy to protect the public and nurses; links to multiple resources	• https://www.aannet.org/news/coronavirus
• American Association of Critical-Care Nurses	• Updates and resources for those in the critical care field, including technical information and content on moral distress in times of crisis	• https://www.aacn.org/clinical-resources/covid-19
• American Association of Nurse Practitioners	• Policy and practice updates for nurse practitioners working across settings	• https://www.aanp.org/advocacy/advocacy-resource/coronavirus-disease-2019-covid-19-policy-updates
• American Holistic Nurses Association	• Holistic self-care strategies including meditation, movement, nutrition, and other modalities	• https://www.ahna.org/Home/Resources/Coronavirus-COVID-19
• American Nurses Association	• Crisis standards of care; nurse preparedness for advocacy, policy, safety, and self, patient, family, and community education	• https://www.nursingworld.org/practice-policy/work-environment/health-safety/disaster-preparedness/coronavirus/
• American Organization for Nursing Leadership	• Resources to provide health system and hospital resources, webinars, and education	• https://www.aonl.org/updates-and-resources-novel-coronavirus-covid-19
• American Psychiatric Nurses Association	• Tips and resources to support all impacted by COVID-19 and strategies for self-coping	• https://www.apna.org/i4a/pages/index.cfm?Pageid=6686
• Ariadne Labs	• Serious illness care program COVID-19 response toolkit for communication and conversation needs	• https://www.ariadnelabs.org/coronavirus/clinical-resources/covid-conversations/

(continued)

Table 10.2 (continued)

Organization	Description	Website
• Center to Advance Palliative Care	• Response resources for symptom management, communication, telehealth, among others	• https://www.capc.org/toolkits/covid-19-response-resources/
• End-of-Life Nursing Education Consortium (ELNEC)	• ELNEC free resources including training modules, materials to support staff, and other links	• hhttps://www.aacnnursing.org/ELNEC
• European Association for Palliative Care	• Updates and resources on the European palliative care response to COVID-19 management	• https://www.eapcnet.eu/publications/coronavirus-and-the-palliative-care-response
• Coalition to Transform Advanced Care	• Resources for providers, patients, family caregivers, policy-makers, faith leaders, and foundations	• https://www.thectac.org/coronavirus/
• Hospice and Palliative Nurses Association	• Compilation of helpful resources to support both nurse and patient safety and well-being	• https://advancingexpertcare.org
• International Association for Hospice & Palliative Care	• Resources relevant for global palliative care in the context of COVID-19	• https://globalpalliativecare.org/covid-19/
• International Council of Nurses	• Global platform to share nurses' experiences, learnings, and advice from the frontlines	• https://www.2020yearofthenurse.org
• National Academy of Medicine	• Strategies to support the health and well-being of clinicians during COVID-19	• https://nam.edu/initiatives/clinician-resilience-and-well-being/clinician-well-being-strategies-during-covid-19/
• National Hospice and Palliative Care Organization	• Shared decision-making tool while considering likelihood of survival, preexisting conditions, and symptoms	• https://www.nhpco.org/wp-content/uploads/COVID-19-Shared-Decision-Making-Tool.pdf
• Robert Wood Johnson Foundation	• Updates, guidance, and information on ensuring health equity and supporting a culture of health throughout COVID-19	• https://www.rwjf.org

(continued)

Table 10.2 (continued)

Organization	Description	Website
• Sigma Theta Tau International Honor Society of Nursing	• Relevant free continuing education and series of free expert webinars	• https://www.sigmanursing.org/sigma-is-here-for-you
• VitalTalk	• Communication guide and playbook for difficult conversations during COVID-19	• https://www.vitaltalk.org/guides/covid-19-communication-skills/
• Worldwide Hospice Palliative Care Alliance	• Internationally based resources for the public, health care professionals, and those working in resource-constrained settings	• https://www.thewhpca.org/covid-19

countries are expanding the basic preparation of nurses in palliative care. Some African countries have expanded to scope of nursing to support nurses prescribing of morphine and several model hospice programs exist [19, 26, 31, 32], (www.africanpalliativecare.org).

10.5.3 Philippines

The Philippines has also served as a model for the development and wide dissemination of efforts throughout the country. As with many nations, initial attention began to the problem of untreated pain but early pain efforts were then extended to a much broader effort to all aspects of palliative care. This is also a country challenged by natural disasters such as tsunamis that have resulted in death in addition to the needs of the chronically ill [33].

10.5.4 Eastern Europe

Eastern Europe has served as a model of regional efforts with collaboration by several countries to make a major impact on nursing and palliative care in a region of the world. Lead by Romania, this has included widespread education throughout the region of nurses, physicians and other clinicians as well as national health policy changes and integration of palliative care in training programs [34, 35]. Several Eastern European countries have also emerged as leaders through the efforts lead by Romania including Albania, Hungary, and Armenia [34, 35].

10.5.5 India

ELNEC India has become a partner over the past 10 years with very important progress in extending palliative care education throughout the country (elnecindia.com). ELNEC INDIA has also used the model of preparing nurses to be ELNEC trainers who can then extend educational efforts. They have also impacted national policy to begin requiring palliative care as a component of basic nursing education. ELNEC India trainers have used technology to create videos for nurses on basic skills such as appropriate use of morphine [36].

Numerous other examples exist around the world depicting outstanding work by nurses to advance palliative care. Uganda has developed training to prepare nurses to prescribe morphine for the relief of suffering in a country with enormous needs [37]. Vietnam has made advances in incorporating training for nurses in palliative care as a component of basic education [5, 37]

10.6 Summary

These many efforts by international health organizations, nursing organizations, and individual countries have contributed substantial progress in palliative care over the past 40 years. The demand for palliative care has however far exceeded the progress in delivering the needed care to reduce human suffering throughout the world.

During this time there has also been rapid advancement as technology has supported research which has created an evidence base of knowledge regarding pain and symptom management as well as psychosocial and spiritual support of seriously ill patients and families. Much of the evidence base for the current field of palliative care has come from the contributions of nurses, working with their interdisciplinary colleagues [11, 38]. Expansion of nursing research will expand the knowledge base of practice yet there are many challenges including limited education or resources for nurse scientists in most countries. There is much that we share as nurses worldwide, but real progress must respect the vast differences across nations and the importance of defining goals for each unique country or region.

Palliative care for older adults, and the oldest old, is a key priority for many developed countries with large populations over the age of 80 and yet is low priority in nations whose mean age of survival remains in the 50s and who still experience very high childhood mortality. Some nations have focused on palliative care in the intensive care unit and protocols for withdrawal of ventilator support while other countries have none of these technologies or systems of care available. Many nations face the reality of war as a key cause of death and many nations continue to experience death from preventable causes and basic needs such as food and clean water. Other nations are challenged now with integrating palliative care into major advances in care which have made diseases such as cancer and heart disease chronic conditions in need of supportive care.

What divides us as nurses across wide geographic, cultural and language divides is so much less than what unites us. Palliative nursing care across all nations is based on fundamental ethical and moral codes of nursing and a commitment to serve people across ages, disease, and settings to relieve suffering.

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Part II

Religion and End of Life Practices

Buddhism

11

Teresa Khoo

Contents

After Christianity, Judaism, and Hinduism, Buddhism is the 4th major religion of the world. The Pew Research Center estimates that as of 2020, about 500 million people (or 6.6% of the world's population) practice Buddhism. China has the largest Buddhist population at 254 million, followed by Thailand at 66 million, and then Myanmar and Japan at about 41 million.

Buddhism was founded approximately 2,500 years ago at the end of the sixth century BC in Northern India by prince Siddhartha Gautama. He was unfulfilled by his wealthy lifestyle and came across a baby (birth), an old man (aging), an ill person (sickness), and a dead body (death) one day on a walk [1]. These four sights led him on a spiritual quest to understand the cause of suffering and find ways to stop it. In his search for the truth, he eventually reached Enlightenment (Nirvana)

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and became "Buddha" from that point on. During his lifetime, he taught his followers the Way and Path to overcome suffering. His teachings became known as the "Dharma," and his religious group became the "Sangha" [2].

There are three traditions of Buddhism—Theravada, Mahayana, and Vajrayana (Tibetan). Theravada is respected as the primary source of Buddha's teachings and the oldest form of Buddhism. It is followed by Southern Buddhism and is practiced in Myanmar, Thailand, Laos, Cambodia, and Sri Lanka. Mahayana is practiced by Eastern Buddhism, most prevalent in China, Taiwan, Japan, and Vietnam. Mahayana Buddhists believe that every practitioner can become a Buddha [3]. There are Bodhisattvas, people who have almost reached Nirvana, who wait to help assist people on their spiritual journey. Vajrayana is a derivative of Mahayana and is followed by Northern Buddhism and is practiced in Tibet, Nepal, and Mongolia [4, 5].

11.1 Samsara, Nirvana, and Karma

Samsara, Nirvana, and Karma are the main principles of Buddhism. Samsara is the cycle of existence—birth, death, and rebirth—understood as reincarnation. Nirvana is the goal of Buddhism, freeing a person from the continual cycles of rebirth and suffering. Karma is the natural consequences of action, the law of cause and effect. Good deeds and thoughts lead to good karma. Each cycle of rebirth is influenced by karma; good karma will bring a person closer to Nirvana [6].

11.2 The Four Noble Truths

Buddhism focuses on personal spiritual development in hopes of reaching Nirvana [7]. One of Buddha's first teachings provides a preface to help achieve Nirvana and end the cycle of samsara. These teachings are called the Four Noble Truths, and they are as follows:

1. The truth of suffering.
2. The truth of the origin of suffering.
3. The truth of the cessation of suffering
4. The truth of the path to cessation of suffering.

The Four Noble Truths are the basic tenets for Buddhism. It is believed that life is suffering, and this suffering is caused by the impermanence of life. Impermanence is the only permanent aspect of life [8]. As such, the goal of Buddhism is to end the cycle of suffering, the continual cycle of death and rebirths, to ultimately achieve Nirvana [9] through meditation, self-reflection, and practice as governed by the Eightfold Path.

11.3 The Noble Eightfold Path

The way to stop suffering is through the Noble Eightfold Path, which can be grouped into 3 categories:

1. Wisdom—right understanding and right thought
2. Ethical/Moral Conduct—right speech, right action, and right livelihood
3. Meditation—right effort, right mindfulness, and right concentration [10]

Right Understanding is having the knowledge of the Four Noble Truths—that all things are subject to suffering, impermanent, and selfless. With Right Understanding, a person develops *Right Thought*. There are three qualities to Right Thought—(1) A person should be selfless, detaching themselves from worldly pleasures, and think of others, (2) A person should be kind and benevolent to others, and (3) A person should act with compassion to all beings. As one progresses through their spiritual path, they become increasingly selfless, compassionate, kind, and benevolent [11].

Right Speech involves the respect for truth, avoiding lying, slander, or harsh speech. *Right Action* encompasses respect for life, property, and personal relationships. As such, there is no killing, stealing, or adultery. *Right Livelihood* refers to a person's job/occupation that respects the right speech and right action [12].

The last category of the Noble Eightfold Path includes *Right Effort, Right Mindfulness*, and *Right Concentration.* These factors allow a person to support their mind to allow them to continue to continue to practice with good intention. *Right Effort* is about having a positive attitude in all aspects of our life. *Right Mindfulness* is closely linked with the right effort. Mindfulness is essential to Buddhism regarding our actions, thoughts, and environment. The practice of mindfulness helps us achieve an end to suffering. *Right Concentration* is the practice of developing a person's mind on a single subject, which leads to mental and physical well-being and allows one to see things as they truly are.

The Noble Eightfold Path is "an integrated therapy designed to cure the disease of Samsara through the cultivation of moral speech and action, the development of the mind, and the complete transformation of one's level of understanding and quality of thought" [11].

11.4 Beliefs Around the End of Life

Although some key tenets of Buddhism focus on death and reincarnation, local culture and customs are more likely to influence a person's practice [13]. Thus, attitudes toward illness and death can vary widely among Chinese, Tibetan, Thai, Japanese, Western, and Indian Buddhist practitioners. Regardless of culture or custom, Buddhist people understand that death is natural and inescapable. It serves as a reminder to live well. As such, preparation for death is fundamental in Buddhism [14].

Death, for most people, falls within a cycle of samsara. Buddhist beliefs emphasize an understanding and preparation for death as a guiding force for actions during life that will bring about positive karma. While there is profound attention placed on the cycle of rebirth, there is little known about how Buddhists define death. Damien Keown suggests that Buddhists believe that death is “the irreversible loss of integrated organic functioning,” further defined as irreversible brain stem death.

The decision to continue medical treatment or life-sustaining treatment varies vastly. In some cultures, the patient does not make decisions regarding life-sustaining treatment. Oftentimes, this task may fall upon their family members or surrogate decision maker, who are more likely to want full life-sustaining treatment regardless of prognosis or overall course. This decision may be affected by filial piety and worry that suffering of death may help a person gain good karma in their rebirth [15]. For others, medical treatment may be declined if it will artificially prolong and increase the suffering of a patient or others (even the healthcare professional) [16]. Rather than treating various complications, some Buddhists look at the patient’s overall condition and prognosis. If a treatment will not affect a person’s prognosis, then it is okay to refuse or withdraw treatment [17]. In this situation, the push for continued medical treatment, and as such an attachment to life, is thought to be misguided.

Buddhists understand that death is inevitable given the cycles of rebirth and suffering required to reach Nirvana. Thus, many Buddhists are prepared to accept death. However, Buddhists would also not want to artificially hasten death. Although there is a moral issue with artificially hastening death, “withdrawal of treatment and letting a person die of natural causes would be acceptable in Buddhist doctrine, if the intention is to reduce further suffering and the actions taken do not interfere with the ability of the mind to complete its tasks at the time of death” [7].

In one study from Thailand, there are five core qualities that constitute a peaceful death: (1) knowing that death was impending, (2) preparing for a peaceful state of mind, (3) not suffering, (4) being with family members and not alone, and (5) family members were not mourning [18]. Knowing that death was close allowed the patient and families to prepare for their death. Mindfulness and mental clarity are important [19]. They believe a more peaceful death with a pure mind will lead to better rebirth. Buddhists believe that if the dying person’s mind was clear and focused on positive things, they would be reborn in a good and happy place [20, 21]. Crying loudly at the bedside or shedding a tear on a dying person’s body is not believed to promote a peaceful death. Similarly, in Tibetan Buddhism, a good death is defined as dying in the presence of family with a clear mind, symptoms well-managed, and encouragement from her family [22].

11.5 Preparations Around Time of Death

Local custom and traditions will have more influence on its interaction with healthcare than the Buddhist traditions [17]. Regardless of tradition or custom, the most important thing to take into account is the person's state of mind at the time of death as it influences his rebirth. The state of mind should be centered around peace. Some patients may wish to meditate, some may seek guidance from a Buddhist friend or monk. Chanting, assuring the patient not to worry and helping them focus on positive things, and inviting a monk to perform religious ceremonies can often be seen to help reach a state of peace [2, 6, 18]. Discussion around impending death is not typically avoided, but encouragement and positive thoughts are preferred over grief to encourage a better mindset for the next rebirth.

In symptom assessment, it is important to determine the patient's pain relief and level of sedation desired [23]. There can be a range of symptom control management. Buddhist traditions stress the importance of maintaining mental clarity. Thus, some patients may forego typical treatments of pain and other physical symptoms in order to maintain mindfulness and avoid decreased level of consciousness [24, 25]. When pain becomes more severe, they may be okay with taking opioids in hope of obtaining the best cognitive function to encourage meditative spiritual practices [1]. In one study, families felt that the dying person should not be in pain or have difficulty breathing. They should receive comfort care at the end of life [18]. Buddhists may approve such palliative treatments to show compassion for physical suffering. Some patients may find meditation or certain Buddhist chants to help with symptoms as well.

It is important for healthcare professionals to gain a better understanding of the patients' religious preferences and spiritual beliefs. End-of-life practices can vary based on a person's country of origin, culture, and family practices. It is critical to engage in discussion with patients and their families regarding their religious needs. Healthcare professionals can help create a calm and supportive environment for patients to perform Buddhist rituals (by providing religious photos and prayer beads, turning cell phones/pagers to silent or vibrate)—praying, practicing meditation, chanting, and quiet reflection [24]. In patients with terminal illnesses, compassionate care as a core theme of Buddhism can help healthcare professionals relieve patient suffering [26].

11.6 Funeral Practices and Burial

Some Buddhist traditions believe that the release of consciousness from a body occurs over a period of time. Oftentimes, this release may happen immediately after death. Buddhist texts are often read or chanted at death, and some patients may have a Buddhist monk officiate these rituals. There are instances where the body may be directed by the monk to remain undisturbed for up to 8 h until chanting or rituals have been performed [1, 27]. As such, post-mortem care of the body should be kept at a minimum. If possible, autopsies and organ or tissue donations are also delayed for three days.

Burial traditions may vary based on local customs. However, most Buddhist patients are cremated. Buddhists generally prefer cremation following a three-day waiting period [10].

Buddhists believe that once a person dies, they will be rebirthed based on their karma and their last thoughts and emotions. Thus, a calm and peaceful death has a positive impact on their rebirth [21].

11.7 Other Considerations

11.7.1 End of Life Options

In a survey of Chinese elderly in a day care in Singapore, more than half of them felt like end-of-life options should be allowed in special circumstances. However, about a third of these Buddhists would not pursue it even in futile situations [25]. Buddhists do not believe in unnaturally hastening death, feeling that it would have karmic repercussions to decrease the experience of suffering in this life, affecting their next rebirth [7].

11.7.2 Organ Donation

Buddhists differ in their views on organ transplantation. Keown believed that it was important to determine when death has occurred before proceeding with organ donation. It is important to distinguish between death and a “profound state of trance known as ‘attainment of cessation’”, which Buddha had been in. In the latter, most physiologic functions have stopped, but the “life-faculty or physical vitality” remains present. He reasoned that there is a difference between death of the higher brain and death of the whole brain, including the brainstem. The higher brain controls consciousness, and he equates higher brain death to injury of any other organ in the body. However, the brain stem controls vital autonomic functions like breathing and heart functioning [4]. Rinopoche believes that organ donation is an “extremely positive action,” stemming from compassionate wish to others and will accumulate in good karma [4, 28].

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The Message of the Beatitudes in End-of-Life Care for Catholics

12

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> *There is only Christ: He is everything, and He is in everything*. (Colossians 3:11, New American Bible)

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12.1 Introduction

Jesus professes the Beatitudes not only for an audience present during His sermon on the Galilean hillside but perpetually including the healthcare provider who is about to visit with their Catholic patient. The text of the Beatitudes is a message from the heart of the incarnate Word of God to the heart of every human being. The purpose of this divine teaching is to imbue every personal encounter with the hope of understanding what is meaningful and sacred. In health care settings, it grounds the provider and the patient in wisdom, empathy, and self-compassion.

The Beatitudes are the only liturgical texts of Holy Scriptures that are used in all forms of worship[1] by Catholics. This could be Sunday Mass, the Wedding Mass, or even the Funeral Mass, a reason why Pope Francis declares them to be the "Christian's identity card."[2] The purpose of familiarizing oneself with the Beatitudes is to understand that the members of a community of faith are in route toward sacredness in a distinct and practical way. This is a community transcending through their trials, guided by the power of the Holy Spirit and through God's revelation in Jesus, the Savior, and the "great physician."[3] Only grace and spiritual ties can connect and create such a community even among first-time or only one-time encounters. The extent to which we can recognize the reach of this community depends on the spiritual depth of everyone. The Catholic community is best described in the words of the one recognized as the first black woman Catholic theologian in the United States, Diane Hayes, to be made of "the borne, yet to be born, and those who have already passed over."[4] This applies not only in parish settings but vigorously in hospital settings. When suffering binds us to such a community, the deep relationship we sense allows us to experience the responsibility of supporting the well-being and healing for each other. This is true even when a physical cure is not probable.

The Beatitudes are a gateway to the source of strong emotions, producing the formation of character and securing hope for anyone facing challenges in life. Each of the nine Beatitudes transforms a negative experience into an opportunity. The richness of the kingdom will replace poverty, grief will be comforted, and the humble will be exalted while no hunger or thirst of any kind will define us. Further rewards are promised for the merciful, pure hearts, and peacemakers. Achieving the blessings mentioned in the Beatitudes, we grow in relationship with the man of suffering and the divine embodiment of compassion, Jesus Christ. He models the trajectory toward ultimate freedom and peace of a "kingdom of heaven" where no persecution can follow, and no evil or false accusation has a place. The following text from the Gospel of Mathew connects every soul with a legacy of vulnerability and powerlessness. The message consecrates transformation through faith, hope,

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[1] Pere A. M. Roquet, "Homilies for Funerals," (Chicago: Franciscan Herald Press, 1981), 91.

[2] Apostolic exhortation Gaudete et Exultate, paragraph 63.

[3] Mark 2: 17 - "Those who are well do not need a physician, but the sick do. I did not come to call the righteous but sinners." New American Bible.

[4] Diana L. Hayes, "Forged in the Fiery Furnace." (NY, Maryknoll, Orbis Books, 2012) page 142.

care, community, and shared wisdom of the ages from impoverished realities to the joy and richness of a great reward.

> Blessed are the poor in spirit, for theirs is the kingdom of heaven.
>
> Blessed are those who mourn, for they will be comforted.
>
> Blessed are the meek, for they will inherit the earth.
>
> Blessed are those who hunger and thirst for righteousness, for they will be filled.
>
> Blessed are the merciful, for they will receive mercy.
>
> Blessed are the pure in heart, for they will see God.
>
> Blessed are the peacemakers, for they will be called children of God.
>
> Blessed are those who are persecuted for righteousness' sake, for theirs is the kingdom of heaven.
>
> Blessed are you when people revile you and persecute you and utter all kinds of evil against you falsely on my account. Rejoice and be glad, for your reward is great in heaven…[5]

In their totality and also one by one, the Beatitudes bequeath blessings of guidance to people searching to attain the kingdom of heaven. Scarce and successive, the pragmatic words of Jesus in the Beatitudes start with the claim for the lost Paradise, without which we have been rendered destitute. The end of the Beatitudes points once more toward the joy of heaven, our eternal home. Coming from God and returning to God is thought in the Catechism of the Catholic Church to be a journey from our place of origin toward a hopeful return to our eternal destination. The Catechism of the Catholic Church speaks of the "Imago Dei,"[6] the divine image of God "present in every individual. It shines forth in the communion of persons, in the likeness of the unity of the divine persons among themselves."[7] The human being in every generation connects with God who created the first people, Adam and Eve. Through the Trinity, we relate to Christ the Redeemer as the new and "last Adam."[8] The Holy Spirit, the "Comforter",[9] is sent to us to be a helper in our time of need. This Spirit is the one who bestows graces and gifts as Saint Paul believed: "God's love has been poured into our hearts through the Holy Spirit who has been given to us."[10]

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[5] Matthew 5:1–12.

[6] Catechism of the Catholic Church—# 41.

[7] C.C.C.—# 1702.

[8] C.C.C.—# 359.

[9] John 14: 15 - 26.

[10] Romans 5:5.

12.2 Living the Beatitudes Through Catholic Social Teaching

The Beatitudes are traced through Jesus's teaching to the hopes of the prophets from the Old Testament. Additionally, they are connected to social justice through an awareness of human dignity, a belief equally primordial in its origins, captured as core Catholic Social Teaching (CST) principles. Pope Leo XIII marks a new awareness of those principles through his 1891 encyclical letter, *Rerum Novarum*,[11] which advocated economic distributism. After Pope Leo XIII, papal encyclicals continued to develop the Social Doctrine of the Church. Further roots of CST are traced to Catholic thinkers and theologians such as Saint Augustine and Saint Thomas Aquinas. Besides the Western representatives, CST combines concepts of ministry from the Eastern spirituality of the Church developed by Basil the Great and embodies the "holy physicians without the love of silver," Cosmas and Damian, who are strong representatives of the culture and piety of the early Church in the Near East.

As a central element of our faith, CST principles invite us to recognize Christ in the poorest and the vulnerable among us. Profoundly connected with the theological and social understanding of human life and human dignity, CST advocates for every human being from the evident perspective that we are created equal and made in the image and likeness of God. Catholics believe that human life and human dignity are inherently sacred from conception to life's end. In tandem with the Beatitudes, the Social Doctrine of the Catholic Church informs and supports a Catholic's way of expressing God's greatest commandment passed on to us through Jesus, "You shall love the Lord your God with all your heart, with all your soul, and with all your mind. You shall love your neighbor as yourself."[12]

Christian values and a long tradition of consideration for the other have informed CST principles over the years. Initially starting with the two basic concepts of human dignity and care for the poor, theologians identified several more apostolic beliefs to address the community's needs. Social Doctrine of the Church utilizes the twelve messages listed below to impact the social corollaries of every Catholic. These principles such as the calling to family and community, participation in the rights and responsibilities of citizenship, the dignity of work, and solidarity with each other as part of God's creation guide Catholics in integrating these into their life's purpose. Sister Juliana Casey IHM in her collection of texts entitled "Food for the Journey" explores these principles and the way they extend to all dimensions of health care within the mission of the Catholic Church. The following are her statements asserting how CST allows us to share the love and peace of Christ to all who are in the world:

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[11] Compendium of the Catholic Social Doctrine of the Church. United States Conference of Catholic Bishops, 2021 Washington D.C. page 39.

[12] Matthew 22: 37–39.

> The documents stress that the social reality is not separated from the religious dimensions of life; rather, it must be transformed in light of the Gospel.
>
> The dignity of the human person is a constant theme in all the documents.
>
> All human persons have inalienable rights which must be respected and protected by the institution of society.
>
> An emerging recognition of the growing gap between the rich and the poor leads to an insistence on a preferential option for the poor.
>
> Love of neighbor, a demand of the Gospel, implies action for justice.
>
> The promotion of the common good is of primary importance.
>
> The principle of subsidiarity (responsibility and decision-making at the level closest to local communities and institutions) should be respected.
>
> The teachings encourage participation in the political process of one's country as a means of achieving the common good.
>
> Economies' justice is vital since the economy exists for the people's betterment.
>
> The writing stress that the world's goods belong to all the world's people all must share the earth's resources.
>
> The documents call for a global solidarity.
>
> Social teachings also call for just peace among men and women.[13]

The above CST statements are a modern-day embodiment of the Beatitudes. The Church is the body of Christ; in that capacity, through its members, it manifests the truth of the Gospel and vision of Christ, not as an ideal but as living testimony in each culture and generation. Each of the Beatitudes has its own "action," inspired by the truth found in a corresponding social doctrine. In the Beatitudes, the task is communal and encompasses the presence of God. Similarly, once they gain traction within the communities whom they inspire, CST takes the form of a search and longing for God. The desire to do God's will cannot be satiated by anything else until it is addressed thoroughly, even when it requires sacrifice. The detriment of self is not limited to trivial approaches but witnessing to the presence of God calls for the practice of martyrdom.

Martyrdom is not to be understood only in the conventional way of shedding blood for a cause but in the powerful spiritual denial of self, to witness to the transcendent. The hospital setting provides a keen opportunity to see this acute level of martyrdom. As the Beatitudes state, there is an action of self-giving that allows one to become an earthy vessel of the Holy Spirit. The life of the Italian saint Gemma Galgani captures a narrative of such martyrdom as only a young soul of a mystic living for the sole purpose of uniting herself with Christ can express. An orphan from a young age, Gemma knew tremendous loss, including that of a sibling. After her father's death, poverty was paired with multiple life-threatening

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[13] Juliana Casey, IHM, Food for the Journey, Catholic Social Teaching and Healthcare of the Poor, (St. Louis, Eighth Printing, 2014) page 96.

health conditions, including tuberculosis. Gemma suffered greatly in her trials and was able to recover several times from her chronic condition. Toward the end of her life, her earthly calvary involved the experience of the stigmata. Without a known cause, the wounds of the one crucified marked her frail body as an evident connection to the passion of Christ. So intense was she living her last days in union with Jesus that often accounts of bloodstained tears and sweat were witnessed when she was subjected to blasphemies and hateful words by angry people in her underprivileged surroundings.

The last months of her life at the beginning of the twentieth century added the torments brought on by spiritual anguish. So tortured was Gemma by her physical and emotional suffering that one of the nursing sisters caring for her asserted, “We have cared for a great many sick people, but we have never seen anything like this.”[14] The inscription on her tomb conveys a complete message about her mystical life and her unwavering faith, “Gemma Galgani of Lucca, a most innocent virgin, while in her 25th year, consumed rather by the fire of Divine Love than by the violence of disease, flew into the arms of her Heavenly Spouse on Holy Saturday, the eleventh of April 1903. Peace be to Thee, O sweet soul, in company with the Angels.”[15] The narratives of such profound levels of sufferings inform the Catholic Church in including wholistic care and palliative care as necessities in the approaches of modern medicine to the end-of-life care.

Different kinds of “stigmata” are more familiar to us in the hospital space than the ones mentioned for Saint Gemma. They are caused by the prevalence of an aging population living with the effects of a chronic illness. The suffering brought on by the pathology of the disease leaves stigmata-like marks on our flesh. A neuropathic foot wound caused by damage due to diabetes. An unstageable pressure sore experienced by those whose blood supply to the tissue is cut off when bedridden. A side wound is caused when chest tubes are needed to drain blood, fluid, or air from around the lungs or heart. The crown of thorns can be associated with a shunt surgically placed. Modern medicine trying to prolong life leaves deep marks on the body of those who are compromised and started the journey to return to God.

Facing one’s suffering and potential demise while in reverence to the truth carried by the message of the Beatitudes is an experience that has become more crucial than ever. It is a time of witnessing beyond one’s faith and opening the potential for each of the protagonists in the tragedies of life to turn humbly toward Jesus, who came into this world to be like us in all aspects of humanity except for sin. In healthcare activities, one enters in dialogue with Christ Himself. Whenever we provide care to one of “the least of the brethren,”[16] we provide care to Him. A family conference to address treatment goals, complete one’s advance care planning, bedside rounds, collaborating with a spiritual care provider and including

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[14] “The Holy Death of St Gemma Galgani”. 2022. Stgemmagalgani.com. https://www.stgemmagalgani.com/2008/09/holy-death-of-st-gemma-galgani.html.

[15] Ibid.

[16] Matthew 25: 40.

local clergy in bioethical dilemmas are as integral to providing care as any direct treatment. Further, each one of these healthcare activities, when provided for a Catholic, carries the weight of the Beatitudes and Catholic Social Teaching all at once.

12.3 Blessed Are the Poor in Spirit, for Theirs is the Kingdom of Heaven

How does one relate to the kingdom of heaven? The answer is a balanced path through life driven by the hope to attain immediate joy and eternal happiness, driven by a spiritual desire to meet God face to face. The kingdom of heaven appears to take form for those looking beyond themselves or their comfort zone. Knowing the mission of Jesus who sent his apostles to all nations to preach[17] the good news of salvation allows us to understand the kingdom of heaven as starting with a relationship. The Gospel of Christ encourages a glance deep into the extent of our hearts to find where we locate our wellbeing in life. Some material comforts in life bring a false sense of security, as Pope Francis reminds us that "wealth ensures nothing."[18] If riches are poverty, no material wealth can transport us into the kingdom of heaven. What remains an actual value in life is the relationship with the other. As it is experienced in the story of the Good Samaritan, the kingdom of heaven starts with the care provided to a stranger who is in need. A day does not go by when working in a healthcare facility where we can escape meeting another human being who is downtrodden.

Recognizing another's poverty is empathy in motion externally but at the same time internally directed toward oneself. The vulnerability we feel when we are not running or hiding away from poverty, whenever and however we encounter it, becomes the richness that we share in the world where "moths and rust cannot destroy, and thieves do not break in and steal."[19] There is belongingness with the *Christ among us*[20] as enunciated by the title of the book written by Anthony Wilhelm in his own awareness of this fact. Acknowledging this affinity to the human family is extremely important in healthcare settings. It creates trust among people and goes so much farther than any transactional relationship. As we concede to self and the world, it becomes transformative that we are becoming poor in spirit, entering the realm of discomfort, exposed to frailty, suffering, and scandalized by the human condition. Thus, we are one with those we meet in our clinics and overwhelmed by illnesses in the hospital beds.

The inherent dignity of every human person, the core of the CST, connects significantly with this Beatitude as it captures the destiny of every person which is the kingdom of heaven. Along with the care of the body, the care of the soul has a

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[17] Mark 16:15.

[18] Apostolic exhortation Gaudete et Exultate, paragraph 68.

[19] Matthew 6: 20.

[20] Wilhelm, Anthony J. 2013. Christ Among Us. [United States]: HarperOne.

place of great importance in the hospital setting. Health care providers can assist the Catholic believer to receive sacramental ministry and sometimes to complete their sacramental formation before the end of life. A catechumen is a faithful Christian who was not baptized yet and who is actively seeking to be baptized and to enter the Catholic Church. With the intent of the Catholic Church, the Trinitarian formula, ("I baptize you in the name of the Father, and the Son, and the Holy Spirit"), and the use of clean water even a person of a different faith can validly baptize a Catholic in case of an emergency situation. This openness to the divine grace transforms human relationships. In this transformation, social reality ceases to be separate from the religious dimensions of life.

It is important to note that the religious identity of a Catholic extends over more than twenty rites from among whom the Roman Rite is the largest. Catholic faith supports a diverse practice of spiritualities like Latin, Byzantine, Arabic, or Syro-Malabar, to mention just a few. Each of those main spiritualities connected with the apostles' inculturation of the healing ministry of Christ further sustains local spiritualities. Saints developed them through religious practices, inspiring the world through beauty, strength, and wisdom. Within the Latin Rite of the Church, we find eremitic, Benedictine, or Dominican spiritualities from the first centuries of Christianity. Some spiritualities connect with the Middle Ages and saints like Ignatius of Loyola for the Jesuit spirituality or Teresa of Avila for the Carmelite spirituality. Contemporary times brought to us Taizé and Opus Dei, among other such spiritual developments that inspire a Catholic to live following the values of the Gospel. The light of the Gospel renews every heart that it encounters "for we walk by faith, not by sight."[21] This is an act of courage and of faith formation as the Scripture continues: "we are courageous, and we would rather leave the body and go home to the Lord."[22]

Additionally, the CST addressing the care of the poor also applies within this first Beatitude as it points to the growing gap between the rich and the impoverished, which leads to the declaration of the preferential option for the care of needy within the Church. This approach is informed by a physician–patient relationship based on listening deeply to what is before you. Mindful of the challenges faced by providers in offering this type of care, we must stay vigilant to the potential of only seeing a narrow perspective on suffering that is devoid of the full humanity of the patient. This Beatitude of human poverty when integrated into healthcare practices allows the building of enriching professional relationships through deep listening. The common pursuit of the kingdom of heaven honors the richness of the patient's religious identity despite the poverty imposed by illness.

To recognize that the foundation of our being is not in ourselves but in God is to know our ultimate dependence. This is absolute poverty, knowing we are ultimately dependent on God's graciousness. Poverty knows that we cannot go at it alone and that we have needs that can be fulfilled by unity only with the

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[21] 2 Corinthians 5: 7.

[22] 2 Corinthians 5: 8.

source of life. For any patient, chronic and terminal illness is an experience of true poverty, the ultimate letting go and final act of surrender. Dependency upon others is part of the human condition and is not an affront to human dignity. The example of Pope John Paul II offers a retrospective look to the life of a man who used his pontificate as an inspiration in all areas of public and private life. Devested of his former prominence by a cruel disease, the suffering induced by Parkinson took away from him any lasting vigor. He started his pontificate with a strong determination to persuade all Catholic clergy from direct participation in world politics. His intention was not to weaken the influence of Catholic Social Teaching globally but to unify the church around its moral authority. He hoped for the Catholic social doctrine to be delivered in all sectors of life with the foremost political authority of the Vatican, unaltered by any local and international politics.

In the early part of the 1980s, John Paul II survived a couple of attempts on his life. The most damaging was an assassination attempt by 23-year-old Mehmet Ali Agca, who shot him in the abdomen from a close distance, nearly killing him. The Pope later publicly forgave his aggressor who attempted to take his life on the feast day of the Virgin of Fátima. John Paul II expressed his gratitude to the Blessed Virgin Mary, the mother of Jesus who saved his life that day by protecting him from the damages of the gunshot to his vital organs. Years later, in May 2000, the Vatican officially announced a direct correlation between the mysterious third message the children's visionaries received from Mary at Fátima, Portugal, in 1917, as being a vision of the assassination attempt against the Polish Pope. The final years of his papacy were also crucial as the Pope strongly emphasized a message of nonviolence, reflecting a concern nurtured by his personal experiences of his homeland under Nazi and Soviet occupants. His repeated appeals for mercy on behalf of prisoners facing capital punishment were combined with a similar plead for solidarity in a world where confession and religion should never emanate sentiments of violence of any kind.

Toward the end of the twentieth century, the once robust John Paul II was visibly affected by his long battle with Parkinson's disease. Multiple medical procedures further diminished his vitality and rigorous schedule. With the entire world watching him, the Pope insisted on sharing how his perceived suffering was a part of his ministry of solidarity with those who were aging and forgotten by society. Faced with the option to resign, he chooses to respond to those who encouraged him to retire by retorting back, "Si crollo, crollo,"[23] meaning "If I collapse, I collapse." It was moving to follow his last years of life impacted by old age and disease. He continued to appear before enormous crowds gathered to worship and visit with him. During a last public Mass celebrated in his homeland in 2002, more than two million people gathered to participate in the holy mysteries of a shared faith in Christ. By 2003, his public appearances only captured him sitting. His last Easter in 2005, following a tracheotomy, he was limited to only sharing a gesture

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[23] "A Fitting And Fit Patron: Pope St. John Paul II". 2022. *Thomas Aquinas College*. https://www.thomasaquinas.edu/news/fitting-and-fit-patron-pope-st-john-paul-ii.

of blessing from his papal apartment window, not being able to speak any words to the crowds gathered. With the end of his life near, he remained in his Vatican residence in accordance with his expressed wishes of where he wanted to die.

John Paul II impacted Catholic bioethics not only through theology and Catholic morality but through his witness to the role of suffering. The use of pain medication at the end of life are connected to developing bioethics tenets through his experience and his teachings. He advocated for managing pain and strong palliative care availability that allows the person to prepare for death and maintain consciousness if possible. His example inspired in the Church the seeking for the balance between facing death free of pain, when possible, yet not with the primary goal of hastening the dying process. Thus, the deliberate administration of a lethal dose of pain medication is not morally permissible. The claim for mercy killing was met in the ideology of John Paul II with awareness of a failure to recognize that genuine compassion leads to sharing another's pain.

> Blessed are those who are convinced of their basic dependance on God, whose lives are emptied of all that does not matter, those for whom the riches of this world just isn't that important. The kingdom of heaven is theirs.
>
> (Source Unknown)

12.4 Blessed Are Those Who Mourn, for They Will Be Comforted

Grief is at the center of this Beatitude. No one enters stages of grief intentionally, and no one witnesses stages of grief without some way to retort. Often our experience of grief or response to it is unpredictable. The CST that offers guidance and connects with the wisdom of this Beatitude is solidarity. Christ came to Earth with the spirit of solidarity to experience the human condition firsthand. In doing so, He leads us through His passion, death, and resurrection and positively influences those facing death. Healthcare providers can connect in exploring the heavy emotions of grief with the help of scriptural text like the Psalms, first with the internal process of confronting their mortality and then as an outward expression of solidarity with the other. The stages of grief are responses to the finality of death. Each stage creates isolation around the person's individual story. The individual in the dying process and those accompanying the person often are left without emotional resources to continue that dialogue. The dialogue that breaks through this isolation is compassionate and relational, as noted with this Beatitude.

Thus, solidarity through empathy is a connector between the provider and the patient, extending beyond their relationship to include the family, loved ones, and community. This connection transcends generations, encompassing the entire Church and in communion with the saints. The communion of saints for Catholics holds a depth of connection that provides individuals a certitude that they are never alone. Thus, the litany of saints is a devotional offered at the end of life which can bring comfort and connection to these holy men and women.

> Blessed are those who wear compassion like a garment, those who have learned
> how to find themselves by losing themselves in another's sorrow.
> For they shall receive comfort. (Source Unknown)

12.5 Blessed Are the Meek, for They Will Inherit the Earth

This Beatitude connects with the CST principle stating that all human persons have inalienable rights which must be respected and protected by all the institutions of any society. Often our patients end up being known by room numbers, diagnosis, or labels like "frequent flyers" which denies the depth of their humanity. This diminishment of seeing the fullness of their personhood does not support their ability to show meekness. The inheritance of the Earth promised to the meek is a return to the bliss of paradise Adam and Eve inherited in their relational meekness toward God. Their simplicity relied on their intimate relationship with God for their sustenance. The provider's presence contains the hope for another hour or day of life or even for complete recovery. In supporting the rights of every patient, the healthcare environment, including every conversation between the patient and provider, becomes a sacred encounter. This encounter holds an opportunity for grace, "an amazing grace" that restores that inheritance. Patient advocacy becomes a crucial element in securing their inheritance. A provider leading by example demonstrates how to honor the patient's dignity and inalienable rights guiding others to do the same. Thus, the providers come to be champions of that meekness, utilizing their authority to protect and share in the sacred encounter. In knowing that harmony between us is essential, we continue our advocacy in the complex topic of racism and need for equity in the healthcare. Our combined well-being depends on building identical opportunities for everyone. If we are to surrender to the spirit of God in our modesty, we are to acknowledge the sin of racism inside and outside the walls where we heal. Racism is currently continuing to occur all around us. Without awareness of how it continues, we end up being engaged in it, witnessing it, or our work of healing is affected by it. The hierarchy of the Catholic Church addresses racism in the pastoral letters, "Brothers and Sisters to Us" and "Open Wide Our Hearts." Both documents of the United States Conference of Catholic Bishops outline the fact that racism is a sin, and the enduring call is to love and the fervent encouragement of continued dialogue among all people of God.

Known at birth as Joseph de Veuster, Saint Damien of Molokai was born in Belgium and died in 1889 in Molokai, Hawaii. Fr. Damien was a missionary priest and an icon of true mercy in action recognized today for how he devoted his life to the care of individuals in Hawaii suffering from leprosy. In 2009 he was recognized as a saint of the Catholic Church. His compassion during his work provided spiritual, physical, and emotional comfort to those suffering from the debilitating and incurable disease that exiled them to the Kalaupapa. He served as both pastor and physician to the colony, undertaking significant projects to better the conditions there. He improved water, food supplies, and housing arrangements for those left by the society to die in misery. For the children who were left without parents because of the ravages of disease, he founded two orphanages. He received assistance from other priests for only a few years of his total of sixteen years on Molokai. In 1884 he contracted leprosy and refused to leave those he cared for and subsequently died. He was buried at the colony as he requested, continuing to be a consoling presence to those he loved and cared for even from beyond the grave.

> Blessed are those who know that all they are is a gift from God; and so they can be content with their greatness and their smallness,
>
> Knowing themselves and being true to themselves for they
>
> Shall have the earth for their heritage.
>
> (Source Unknown)

12.6 Blessed Are Those Who Hunger and Thirst for Righteousness, for They Will Be Filled

In healthcare we are often confronted by the disparities and inequities of care. When the focus is on healing the body, we also know that illness can often be brought on by a lack of access to resources in our society. Though the scripture is filled with images of abundance at the table where all are welcome, the reality in our world is that people rarely experience that level of equality. Being mindful of these disparities promotes communion as a symbol of unity. Holy Communion is the pinnacle of this spiritual union. Mindful of this, every encounter is an opportunity to raise the awareness of that justice that brings us into unity. The unity is between peers and individuals, but also with God. A healthcare provider mindful of these inherited disparities or systemic inequalities would include a thirst for righteousness and unity in the plan of care.

Coming to the altar table to receive Holy Communion is the source that provides nourishment and encouragement for a life lived by grace for a Catholic. The hospital bed is another altar table of sorts. So important is this sacrament of the Eucharist that it is combined within the last three sacraments a Catholic would receive at the end of life. Traditionally known as the Last Rites, a priest confers to the dying Catholic the last Holy Communion they will receive on Earth, known as *Viaticum*, along with reconciliation (confession) and anointing of the sick. Often in contemporary hospital settings, it is rare when all three can be provided together at the end of life. For example, an individual on life support cannot make a valid confession or receive Holy Communion. Also, in times of emergency, it is not always possible to wait for a priest to arrive in time. Thus, a Deacon or an extraordinary minister of the Eucharist can provide Holy Communion for an alert and oriented patient without providing the other two sacraments. Regardless of the pressures of the moment, a healthcare provider could be mindful that, ideally, all three or any of these preparatory sacraments provide spiritual nourishment for the end-of-life journey. Creating space for this sacred ritual will quench the spiritual hunger and thirst for a patient who unites with the Divine through these transformative sacraments.

> Blessed are those who are hungry for goodness.
>
> Those who never get enough of God and truth
>
> And righteousness, for they shall be satisfied."
>
> (Source Unknown)

12.7 Blessed Are the Merciful, for They Will Receive Mercy

This Beatitude points to the wisdom that mercy is an investment. We are all called to show mercy; when it is combined with power, which can take many forms in healthcare, opportunities develop that can yield substantial systemic changes. At all levels of healthcare, including those with political reach, it is important to remember that power is not lasting. Thus, we have a limited time to guide our power through acts of mercy for the good of the other.

Life experience can teach us to show mercy, increasing the chances that when we bestow mercy the compassion we need will be reciprocated in our time of vulnerability. This text provides a foundation for viewing life through the virtues of love, faith, and charity. When integrated into life, these provide a lens of mercy that crosses generations. Often a provider is faced with two different approaches when delivering care for those who are suffering. One includes judgment, focusing on what the patient has done to cause this. The other asks the provider to look into the case through the lens of mercy, which leads to a new depth of understanding that can render even the best of us victim to humanity's limitations. In mercy, we make room to seek healing to childhood and secondary traumas, abuse, neglect at different stages of development and through all our relationships and the anxieties that they can produce.

The parable of the Good Samaritan[24] is central to the teachings of mercy. Jesus telling the story gives so many details of how far the path of mercy can reach. The Good Samaritan never wondered whose fault it was that left the man "half-dead," and remains removed from status or power. Mercy is a form of claiming freedom. It makes room for forgiveness and reconciliation while empowering even the victim and the oppressed to regain inherent dignity. The Good Samaritan uses

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[24] Luke 10: 25–37.

everything in his possession to continue that work of healing by giving his silver to the innkeeper and promising to pay the full cost of the treatment needed. Mercy is thus deeply rooted with the CST that implies an influence in the political and legislative process as a means of achieving the common good. Showing mercy is not limited to only citizens or paying patients, but to those who are undocumented and uninsured. Human dignity, hope for transformation, and an openness of the heart for the other support this understanding of mercy. Such feelings overcome limits imposed by the challenging circumstances of a hospital environment. The care provider moved by mercy seeks a renewed understanding of the patient that allows freedom and transformation to surface.

> Blessed are the merciful, those who remember
> how much has been forgiven them, and are able
> to extend this forgiveness into the lives of others
> for they too shall receive God's mercy.
>
> (Source Unknown)

12.8 Blessed Are the Pure in Heart, for They Will See God

Cleanliness is essential in the hospital environment. Beyond sanitation, purity can create a sterile environment conducive to eradicating harmful organisms. Purity of heart assures the advancement of medicine and the CST principle of subsidiarity. Following this principle, responsibility and decision-making remain at the closest level connected with the situation at hand. It benefits the immediate community and the institutions immediately involved. This principal respects parties engaged in decision making, requiring a single-heart approach. This Beatitude guarantees the opportunity to see God present to all of us when we put ourselves in the service of others and seek the greater good.

For a Catholic, there is no better example of purity of heart than Mary, the mother of Jesus. She is a close ally to every individual and a mother to all through Jesus. Many Catholics will relate to her comforting attributes and consider her an intercessor before her son. Many of Mary's devotions and liturgical practices are rooted in her messages given to the people where she appeared always near and identified with the simple and the vulnerable of the land. The diverse spiritualities she inspires through her apparitions transcend national and cultural boundaries, often surprising many through their diversity. Known as Our Lady, Mary brings healing through a profound understanding of God's love and concern for humanity. Water from Lourdes, France where she appeared to a young shepherd girl, the rosary beads, a miraculous medal or the scapular are all symbols of how a patient connects and benefits from the assistance of a powerful mediator of grace. Always a source of peace and comfort, Mary is present through liturgical art and devotions, icons, or rosary beads. Such spiritual items will often accompany a Catholic from the beginning of life into the next life. In a hospital room, they are visible symbols of one's faith and point to sources of hope and healing. The health care provider offers a Catholic an example of maternal and unconditional love and compassion when invoking the gentle presence of Mary through the Hail Mary prayer. This prayer ends with the sentence: "Holy Mary, Mother of God, pray for us sinners, now and the hour of our death."

> Blessed are those whose hearts are free and simple, those who
>
> have smashed all false images and are seeking honestly for truth,
>
> for they shall see God." (Source Unknown)

12.9 Blessed Are the Peacemakers, for They Will Be Called Children of God

Social teachings in the Catholic Church give primary importance to promoting the common good. Manifesting a global call to solidarity and justice for all, the Catholic Church looks at the impact of our economy on people's betterment and the communal sharing of goods. This Beatitude calls us to engage in work toward peace on a global scale. It is an effort attained not through war or conquering, but through justice and solidarity. It is a teaching that is grounded in our own internal peace and harmony. In the economy of salvation, the coherence between head, gut, and heart is needed before one can move with peace outward toward cohesion with another human being. This locus ensures attention is paid to understanding the other and toward gracious discernment, commitment to unity, and providing loving care among all people.

A peacemaker will not be satisfied with walls that rise because of desperation or from facing pain and potential death. Walls do not allow the establishment of connection from one heart to another. This isolation produces different negative emotions and facilitates the development of illness, promoting loneliness, fear, and misunderstandings. The Catholic Church's commitment to whole person care provides the antidote to this type of separation through the *Ethical and Religious Directives.* The United States Conference of Catholic Bishops wrote this document to safeguard the sacredness of life from birth to natural death. Spiritual obligations, clinical responsibilities, and pastoral guidelines provide a source of clarity through the 77 directives, which act as a connector between Catholic and non-Catholic and institutional and community partners. A shared understanding of dialogue supports the connection and secures freedom to ask questions that allow all parties to remain open to learning about each other. Where there is a stalemate, one must stay present to this tension until a peaceful solution is achieved.

The *Ethical Religious Directives* are an open invitation to nurture a professional encounter addressing Catholic moral dilemmas in hospital settings. Mindful of differences between what is casual for health care settings and what could become of grave moral importance, peace comes once an effort is made to recognize the Holy Spirit of God at work. An aspect of seeking peace could be a "holy indifference,"[25] which is a process of prayer and dialogue that places value on opinions contrary to ours or toward those we instinctually detest. Accepting one's treatment preferences and the provider's moral obligations even when we disagree is a form of serenely recognizing that we are all children of God. Considering the importance of life events through the prism of prayer is a common practice among Catholics. Saint Francis of Assisi left a timeless prayer for internal peace and calm. This invocation is well known, and it is widely practiced among Catholics and other than Catholics. The St. Francis prayer is used with the hope that will be an aid to restore peace in the tumultuous environment of health care.

The Peace Prayer of Saint Francis of Assisi:

Lord, make me an instrument of Thy peace;
Where there is hatred, let me sow charity;
Where there is injury, pardon;
Where there is error, truth;
Where there is doubt, faith;
Where there is despair, hope;
Where there is darkness, light; and where there is sadness, joy.
O, Divine Master,
Grant that I may not so much seek
to be consoled, as to console;
To be understood as to understand; To be loved as to love;
For it is in giving that we receive;
It is in pardoning that we are pardoned;
it is in dying to ourselves that we are born to eternal life.
Amen.

Blessed are the creators of peace, those who build roads that unite
rather than walls that divide, those who bless the world with the
healing power of their presence, for they shall be called children of God.

(Source Unknown)

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[25] "The Secret To Holy Indifference - Word On Fire". 2022. *Word On Fire*. https://www.wordonfire.org/articles/the-secret-to-holy-indifference.

> Blessed are those who are persecuted for righteousness' sake, for theirs is the kingdom of heaven.
>
> Blessed are you when people revile you and persecute you and utter all kinds of evil against you falsely on my account. rejoice and be glad, for your reward is great in heaven.

An anonymous proverb stating "hurt people hurt people" was later publicized by Dr. Sandra Wilson[26] in the book with the same title. The saying represents a sad truth often experienced firsthand in a place where hurt is predominant as in the case of hospital environment. Catholics recognize a sign of victory over hurt, suffering, and death in the cross of Jesus. Often present wherever Catholics experience suffering, the cross exists to bring hope. An image of a contemporary traumatic event is one of Fr. Michael Judge, Catholic priest and New York Fire Department chaplain designated as "Victim 0001" of the 9–11 attacks on the United States in 2001. Though not the first to be killed in the attacks, Fr. Judge was the first verified fatality in being the first body recovered and identified among the victims. Moments before the collapse of the first tower, he was aiding other victims. A healing image shared from the place where Fr. Judge and so many died that day is the Ground Zero Cross. This formation of steel beams found among the debris of the World Trade Center site in Manhattan continues to be exhibited since 2014 at the National September 11 Museum as a symbol of hope and resilience.

For Catholics, the cross is an altar, and its wood is a symbol of healing. It is a healing that is deeply rooted in ancient tradition; the wound was created by the fruit of the tree from which Adam and Eve ate, disobeying God's in the garden of paradise. As people who live inspired by the sign of the cross, Catholics are called to be instruments of God's grace in the world. It is the cross that we hold in our hand in times of suffering, one that blesses us in times of prayer or comforts us when it is placed on our loved one's coffin as we say our final farewell. In all these profound experiences and more, we are reminded of the victory of Christ over death and suffering.

We feel the pressures of discomfort when we are transgressing against the divine law. We are oppressed when the natural law of doing good and avoiding evil is not preserved in the world. We react when we are persecuted or reviled by fellow humans. Despite this pressure and discomfort, connecting with our human dignity blesses us. We are restored in Him who was crucified for our transgressions, and with Him and through Him we ascend peacefully over our trials and tribulations. The exchange that takes place when evil persecutes us or we are reviled by fellow humans, we feel blessed acknowledging that our human experience is united and restored by Jesus who died for our sins and rose again to ascend peacefully over our trials and tribulations. A constant theme in all the documents throughout Catholic Social Teaching, human dignity demands a level of respect calibrated according to how others honor or denigrate us. Facing the cross, we can accept hostility and anger without attempting to respond to hurt in kind. The last two

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[26] Wilson, Sandra D. 2015. Hurt People Hurt People. Grand Rapids, Mich.: Discovery House.

Beatitudes combined bring once again the notion of martyrdom to the surface, framed between the love for righteousness and the damages brought on by false accusations. Persecuted by the violence of illness, a Catholic can connect with the suffering Jesus endured without fault of his own, to give us strength when we have no other avenue but the path of acceptance.

The history of the Church demonstrates how the practice of holiness rises to the needs created by our situation through multiple accounts. Saint Kateri Tekakwitha, known by her affectionate name as the Lily of the Mohawks, brings her example to the litany of so many saints. A life of holiness reconciles the cross, anywhere where the human spirit embraces it. She was born from a Christian Algonquin mother who was taken captive by the Iroquois and made to be the wife to the chief of the Mohawk clan. Kateri came into the world among one of the boldest tribes belonging to the Five Nations. When she was only four, Tekakwitha lost her immediate family, parents, and little brother during a smallpox epidemic. The disease affected her greatly, leaving her disfigured and partially blind.

Kateri's continued contact with Christian principles shared with her by Jesuit missionaries moved her toward acceptance. One of her commitments through her baptism as a Catholic was refusing to work on Sunday. Kateri received no food that day. Through determination fueled by love, her life in grace flourished though she received consistent resistance from her own family. She shared with her spiritual father that she often meditated on the great dignity of being united with Christ through her baptism. Despite lack of education and constant humiliation and harassment, God's love for human beings impacted Kateri. Refusing to be married and returning to a life of solitude, she prayed in the wilderness for hours every day which instilled further in her heart the dignity of her people. Kateri adopted a practice of severe fasting as penance to persuade her nation to know the message of the Beatitudes. The Lily of the Mohawks died the afternoon before Holy Thursday at the age of 24 on April 17, 1680. A Jesuit priest who attended to her sacramental needs at the time of her death recounts how her emaciated face changed the minute after her passing. The serenity of her death transformed the ravages of a life of severe suffering and became "like the face of a healthy child." The deep lines of suffering, pockmark scars left by smallpox, disappeared as a touch of a serene smile remain upon her face.

> Blessed are those whose love has been tried like gold in the furnace,
>
> and found to be precious, genuine, and lasting, those who have lived
>
> their belief out loud No matter what the cost or pain.
>
> For theirs is the kingdom of heaven.
>
> (Source Unknown)

12.10 Conclusion

Diverse narratives from the last days on earth of venerated Catholic saints intertwined with Catholic Social Doctrine support the integration of the Beatitudes in daily life in the clinical settings of contemporary health care. The history of the Catholic identity proves to be inspired by the authenticity of the actions prescribed in the message of the Beatitudes. The potential is not entirely exhausted, remaining open through human connection to support our individual and communal dignity. It eradicates every form of poverty infringing on our potential to experience the gift of life to its fullness. The challenge remains before us and is not determined by legislation or political formalities. It is offered and attainable to all who approach life with humility, desiring for peace, seeking wisdom, and knowing that alone we are defeated by limitations. Caring for one another and our vocations, we pave the way for this earth to be like the "kingdom of heaven". In the process, we learn the meaning of compassion as it helps to restore and heal the ravages of illness and suffering.

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Christianity

13

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Contents

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13.1 Introduction to the Christian Faith

Christianity is the faith tradition based on belief in God the Heavenly Father as taught in the sacred writings found in both the Old Testament and New Testament of the Holy Bible. The truths about God within Christianity find their roots in the writings of the Old Testament. Furthermore, Christianity is the religious faith tradition that believes the God described in the Old Testament is fully revealed in the New Testament through the life and teachings of His one and only Son, Jesus of Nazareth.

The purpose of life for every Christian was given by Jesus Christ: "*Love the Lord your God with all your heart and with all your soul and with all your mind and with all your strength. The second is this: Love your neighbor as yourself*" (Mark 12:30–32) [1]. Jesus' words describe the two-fold essence of Christian living: First, love and serve God. Second, love your neighbor as yourself. For the Christian, this means living a life of service to God and service to others. "*For we are God's handiwork, created in Christ Jesus to do good works, which God prepared in advance for us to do*" (Ephesians 2:10) [1]. Therefore, the essential nature of Christian living is revealed in kind and generous actions reflective of a heart filled with love for God and compassionate concern for others.

Following closely along with Jesus' teaching about the Christian's dual life purpose is His teaching that has come to be known as *The Golden Rule: "So ineverything, do to others what you would have them do to you"* (Matthew 7:12) [1]. Christian living is also characterized by thoughtful living that emphasizes acting toward others in ways that Christians would want done to them.

In relationship to God, His Heavenly Father, Jesus taught: "*…the Father knows me and I know the Father…*" (John 10:15) [1]. "*I and the Father are one*" (John 10:30) [1]. "*…understand that the Father is in me and I am in the Father*" (John 10:38) [1]. "*Anyone who has seen me has seen the Father*" (John 14:9) [1]. Thus, Christians get to know who God as Heavenly Father is by getting to know and understand Jesus Christ and His teachings.

The inspired scriptures in the Old Testament and the New Testament form the foundation of faith and life. Witness to salvation and embracing the Christian faith is evidenced by participation in two sacred observances called sacraments: baptism and the Lord's Supper—also called Holy Communion or the Eucharist (from the Greek word meaning "giving of thanks").

Christians believe that although this life is a sacred gift given to us by God, this life is not all there is. They believe they will go to heaven to be with God when they die. "*…the gift of God is eternal life in Christ Jesus our Lord*" (Romans 6:23) [1]. "*Now we look forward with confidence to our heavenly bodies, realizing that every moment we spend in these earthly bodies is time spent away from our eternal home in heaven with Jesus... And we are not afraid but are quite content to die, for then we will be at home with the Lord*" (2 Corinthians 5:6, 8) [2].

This existence in earthly vessels is associated with a living, functioning human body. This body "*…is a single structure made up of billions of smaller structures of four major kinds: cells... tissues... organs... and systems*" [3].

The finite corporeal body of every human being has a terminal condition—an expiration date if you will—when the physical body will cease to function and die. "*... people are destined to die once...*" (Hebrews 9:27) [1]. King David, the second king of the nation of Israel, also addressed the fact that God watches over and cares for all of mankind with these words: "*... All the days ordained for me were written in your book before one of them came to be*" (Psalm 139:16) [1].

Beyond this physical body, the Christian faith recognizes that there is also an infinite dimension which God has designed within human beings. Jesus Christ calls this dimension eternal life. "*For God so loved the world that he gave his one and only Son, that whoever believes in him shall not perish but have eternal life*" (John 3:16) [1]. The path to eternal life is established by believing in God's Son, Jesus Christ, and receiving Him as personal Savior. "*Yet to all who did receive him, to those who believed in his name, he gave the right to become children of God*" (John 1:12) [1]. "*For my Father's will is that everyone who looks to the Son and believes in him shall have eternal life*" (John 6:40) [1]. "*Very truly I tell you, the one who believes has eternal life*" (John 6:47) [1]. "*The one who believes in me will live...*" (John 11:25) [1]. "*... God has given us eternal life, and this life is in his Son. Whoever has the Son has life...*" (1 John 5:11–12) [1].

Eternal life is possible because the Creator God has given Christians an undying, eternal spirit, "*and the spirit returns to God who gave it*" (Ecclesiastes 12:7b) [1] when their corporeal bodies die. The spirit aspect of our human existence is immortal. "The Apostle Paul asserts that Jesus Christ '*has destroyed death and has brought life and immortality to light through the gospel*'" [4]. Further, through Jesus Christ's sacrificial death for the sins of all mankind—past, present, and future—all may receive "*... the gift of God* [which] *is eternal life in Christ Jesus our Lord*" (Romans 6:23; bracketed word added for clarity) [1].

Christians view physical death as the moment their eternal spirit separates from their physical/material body—when the body ceases to function and dies—and their "*spirit returns to God who gave it*" (Ecclesiastes 12:7b) [1]. "The scriptures clearly imply that upon death the believer is immediately in the presence of the Lord." [4] The physical body is left behind while the believer's spirit goes immediately to be with the Lord.

Jesus often spoke to His followers about passing from death to life. An example of this teaching was the great comfort He offered Martha about spiritual life in the face of the recent death of her brother Lazarus: "*The one who believes in me will live* [spiritually], *even though they die* [physically]; *and whoever lives by believing in me will never die* [spiritually]" (John 11:25–26; bracketed words added for clarity) [1].

The Apostle Paul, one of the great church Apostles (leaders) of the first century of the Christian Era (C.E.), wrote about his struggle between continued ministry here on earth and leaving this world and his physical body (by dying) so he could be with Christ in heaven. "*For to me, to live is Christ and to die is gain. If I am to go on living in the body, this will mean fruitful labor for me. Yet what shall I choose? I do not know! I am torn between the two: I desire to depart and be with Christ, which is better by far*" (Philippians 1:21–23) [1].

13.2 Christian Beliefs About End of Life

Because of these foundational truths about eternal life, those who embrace the Christian faith have hope that transcends this life with its joys and sorrows, its laughter and tears, its pain and suffering, and the end-of-life decisions faced during dying and death. "Rather than desperately seek to control external circumstances, some persons have attitudes and viewpoints toward death and dying that make the need for such control less urgent. It is often religious faith and support from their spiritual community that gives these people greater internal control over the dying process" [5].

The hope of every Christian lies beyond this world's physical existence and looks to the great victory awaiting them in heaven. Again, the Apostle Paul describes this hope beautifully: "*For our earthly bodies, the ones we have now that can die, must be transformed into heavenly bodies that cannot perish but will live forever. When this happens, then at last this scripture will come true—'Death is swallowed up in victory'*" (1 Corinthians 15:53–54, the Apostle Paul quoting the Old Testament prophet Isaiah, Chap. 25, verse 8) [2].

Christian beliefs about the end of life may vary, depending on the Christian denomination's tenets or statements of faith. However, one principle basic to all of Christendom is established by these words from "*the Teacher*," [1] who is described as the "*son of David, king of Jerusalem*" [1] in the Old Testament book of Ecclesiastes, Chap. 1, verse 1. The Teacher writes these words about all of mankind: "*There is a time for everything, and a season for every activity under heaven: a time to be born and a time to die*" (Ecclesiastes 3:1–2) [1].

13.3 Christian Preparations Around the Time of Death

Believers acknowledge they are going to die—they just do not know when. "*…No one knows when their hour will come*" (Ecclesiastes 9:12) [1]. The time is coming when physical bodies are going to cease to function. What preparations do Christians make around the time of death?

It is hoped that preparations by the patient, with the support and cooperation of loved ones, resulted in the completion and signing of the following legal documents while the patient was competent and able to express personal wishes and desires:

1. A *Last Will and Testament* legally executed and in place.
2. An *Advance Health Care Directive* duly completed and executed, designating the patient's Primary Agent to make health care decisions when the patient is no longer capable of making such decisions. An Alternate Agent is also designated in case the Primary Agent is not willing, able, or reasonably available to serve. Health Care Instructions have been noted and this document is properly notarized and in place.

3. *Advance Health Care Directives* may include a "*My Health Care Choices*" section. This portion allows the patient to describe what he or she wants to know about their medical condition, what instructions they want their Agent to follow, end-of-life decisions they want made, information about their religious or spiritual preferences, after death decisions regarding matters such as organ donation, their preference for whole body burial or cremation, and whether the patient wants an autopsy. The website https://PREPAREforYourCare.org [6] offers a helpful, comprehensive database with free resources.

Chaplains and other spiritual care providers utilize two important skills to determine what rituals and end-of-life practices are most appropriate: active listening and ministry of presence.

Actively listening is being fully attuned to what the dying patient and family members are saying and doing, indications of spiritual or existential distress, conflicts, or peace. According to Drakeford, "listening is an intricate part of living, is highly needed and poorly practiced, if practiced at all." [7]. Listening carefully to the dying patient around the time of death is a primary need. For a Christian patient, as well as for those attending the patient, active listening to assess for unresolved spiritual issues with God or existential distress involving loved ones or close friends is one of the most important practices chaplains and spiritual caregivers provide.

The author visited a terminal patient and his spouse at their request to learn how he could attend to their spiritual care needs. After listening to the spouse for several minutes, the author reflected back one of her statements seeking greater understanding. With an amazed look on her face, she replied, "Wow! You actually listened to me!" Being heard is a precious and profoundly important gift every patient and loved one needs and deserves.

Chaplains are highly trained and skilled in knowing how to pick up verbal and non-verbal cues indicative of the dynamics in a patient's room. The chaplain's primary focus is the sick and dying patient, making sure all is well in the final hours. An excellent one item assessment tool to probe spiritual concerns to determine if the patient is experiencing spiritual distress or is at peace is described in an article titled Are You at Peace [8]?

Helping patients take care of spiritual business offers the freedom to let go of this life with a clear conscience and reach out to the eternal life awaiting them in heaven.

Ministry of presence is a second skill practiced by chaplains, called "compassionate presence" in the medical field [9]. Chaplains are present to respond to patient and family needs, often practicing prayerful silence while attending the patient during the final hours. There is comfort and power in being present without filling the room with words. Drakeford calls this being "creatively silent" [7]. Chaplains provide ministry by simply offering a non-anxious presence, praying silently, and supporting the patient, loved ones, and others in the room.

13.4 Rituals and Practices Around the Time of Death

13.4.1 Scripture Reading

Christians find strength and guidance, comfort, and hope from numerous passages in both the Old and New Testaments of the Bible—God's Word—throughout life. Often, believers have life verses they have memorized and followed as guiding lights and life-affirming truths.

For the dying Christian, these verses offer comfort and hope in the final hours before this mortal vessel—the human body—is left behind and the faithful Christian crosses over into the Promised Land of heaven to meet their Lord and Savior Jesus Christ and God, their Heavenly Father.

In addition to passages family members know the dying patient loves, the following passages might be read in the waning hours prior to death:

The Shepherd's Psalm

> Because the Lord is my Shepherd, I have everything I need! He lets me rest in the meadow grass and leads me beside the quiet streams. He gives me new strength. He helps me do what honors him the most. Even when walking through the dark valley of death I will not be afraid, for you are close beside me, guarding, guiding all the way. You provide delicious food for me in the presence of my enemies. You have welcomed me as your guest; blessings overflow! Your goodness and unfailing kindness shall be with me all of my life, and afterwards I will live with you forever in your home. (Psalm 23) [2].

> A Psalm Promising the Lord's Help
>
> I lift up my eyes to the mountains—where does my help come from? My help comes from the LORD, the Maker of heaven and earth. He will not let your foot slip—he who watches over you will not slumber; indeed, he who watches over Israel will neither slumber nor sleep.
>
> The LORD watches over you—the LORD is your shade at your right hand; the sun will not harm you by day, nor the moon by night. The LORD will keep you from all harm—he will watch over your life; the LORD will watch over your coming and going both now and forevermore (Psalm 121) [1].

> Jesus Blesses the Children
>
> One day some mothers brought their babies to him to touch and bless. But the disciples told them to go away. Then Jesus called the children over to him and said to the disciples, 'Let the little children come to me! Never send them away! For the Kingdom of God belongs to men who have hearts as trusting as these little children's. And anyone who doesn't have their kind of faith will never get within the Kingdom's gates' (Luke 18:15–17) [2].

Jesus' Comfort for His Disciples

> 'Do not let your hearts be troubled. You believe in God; believe also in me. My Father's house has many rooms; if that were not so, would I have told you that I am going there to prepare a place for you? And if I go and prepare a place for you, I will come back and take you to be with me that you also may be where I am. You know the way to the place where I am going.' Thomas said to him, 'Lord, we don't know where you are going, so how can we know the way?' Jesus answered, 'I am the way and the truth and the life. No one comes to the Father except through me' (John 14:1–6) [1].

13.5 Discussion About Miracles

Patients and the families supporting them often have questions about the "m" word when it is apparent that time for their loved one is slipping away. The "m" word is "miracle." The New Testament Gospels of Matthew, Mark, Luke, and John, as well as the book of Acts—the first five books in the New Testament—recount numerous occurrences of God's healing grace, demonstrated through the life and miraculous work of Jesus Christ in the Gospels, and through miracles performed by Jesus' followers—Apostles—in Acts.

Here is a list of some of Jesus' miracles: raising the dead (Mark 5:40–43; John 11:38–44); restoring the sight of a man born blind (John 9:1–12); feeding 5,000 men, plus women and children from a boy's lunch of five barley loaves and two small fish (Matthew 14:13–21; Mark 6:32–44; Luke 9:10–17; John 6:5–13); feeding 4,000 men from seven loaves and a few small fish (Mark 8:1–9); turning water into wine (John 2:1–11); walking on the water (Matthew 14:22–32); calming the storm (Matthew 8:23–27; Mark 4:35–41; Luke 8:22–25); healing a man who had been unable to walk for 38 years (John 5:1–14). These are just a few of the people Jesus healed and the miracles He performed as recorded in the Gospels.

The book of Acts recounts numerous miraculous healings done by His Apostles: Peter healing a man crippled from birth (3:1–10)*;* the Apostles performing "*many signs and wonders among the people*" (5:12–16) [1]; Peter healing a paralyzed man bedridden for eight years (9:33–34); Paul raising a young man from the dead (20:9–11).

Christians through the ages have read these historical, biblical accounts of miracles and healings, knowing and believing that God has always been in the miraculous healing business. In modern times, Christians continue to experience and give accounts of documented miracles that are still occurring [10–13].

In healthcare, it is not uncommon for Christian patients to give witness to the medical treatment team, sharing their personal belief in the God of the Bible and His ability to miraculously heal and extend life [14]. When presented with the statement "I believe that God could perform a miracle in curing me of cancer" in a recent survey, nearly 50% of the participants chose the strongest response—"a great deal" [15].

Conversely, in a case study, a Christian patient and her family were followed as they relied on their Christian hope while the patient was treated for an aggressive lymphoma as she rapidly deteriorated to the point of dying. “The findings outline the transition from hope for a cure to hope for a good death and the role that the patient and family’s Christian hope played in this” [13]. The chaplain was “heavily involved in providing spiritual comfort throughout the patient’s stay and through the transition from active treatment to the patient’s death” [16].

It was not unusual for the author to be asked by family members, as their loved one lay in bed, often comatose at the end of life and hours from death: “Chaplain, do you think God could do a miracle in Dad’s life and heal him?” Each time that question was posed, the author’s answer was always the affirmative: “Yes! We believe in a God who can do anything. There is always hope for a miracle. “To respond otherwise would be to deny the patient’s and family’s faith in the miraculous healing power of God as their last hope.”

13.6 Anointing with Oil for Healing Ritual (James 5:13–16)

The New Testament contains clear instructions for how church leaders—called elders in the New Testament book of James—are to provide compassionate care for the sick. Praying and anointing the sick with oil has been the Christian practice since the first century C.E. and is still the practice in many Christian denominations today.

In hospital and hospice settings, chaplains are often called upon to anoint their Christian patients and pray for their healing. This practice is often done for patients at the end of life with family members surrounding the patient, placing their hands on their loved one, and joining the chaplain in the prayer for healing. Without question, this is one of the most moving and sacred moments in the life of the patient who is near death, those attending their loved one, and the chaplain doing the anointing.

Here is the biblical basis for this Christian practice from the New Testament book of James:

> Is anyone among you in trouble? Let them pray. Is anyone happy? Let them sing songs of praise. Is anyone among you sick? Let them call the elders of the church to pray over them and anoint them with oil in the name of the Lord. And the prayer offered in faith will make the sick person well; the Lord will raise them up. If they have sinned, they will be forgiven. Therefore confess your sins to each other and pray for each other so that you may be healed. The prayer of a righteous person is powerful and effective (James 5:13–16) [1].

Here is how the author leads the ritual of anointing with oil for healing.

The chaplain invites everyone in the room to gather around the patient’s bed and spends a few minutes talking with the patient (if conscious) and others, confirming the request has been made for the chaplain to anoint the patient with oil for healing.

A brief explanation is offered about this ritual, describing the New Testament foundation for this practice based on James chapter five, verses 13 through 16, which are then read. The chaplain may also affirm that there is nothing “magical” about the anointing oil.

The chaplain invites everyone surrounding the patient to lay hands on their loved one in a “Circle of Love” as he or she is anointed with oil. The chaplain makes the sign of the cross on the forehead with the oil and then leads in a brief prayer, asking for God’s healing according to His perfect will.

Of vital importance is acknowledging that our responsibility is to follow the admonitions in the Word of God to anoint with oil and pray for healing. It is the will of God that determines the outcome of this anointing ritual and the nature of His healing, as stated in verse 16: “*...pray for each other so that you may be healed*” [1]. In the original Greek language of the New Testament, the phrase “*may be healed*” refers to the possibility of healing. It is not an absolute promise or guarantee of healing.

The anointing and prayer of faith for God to heal our loved ones are done according to God’s will. We recognize it is God who determines His perfect will for the patient. Will He heal the patient “temporarily” for the here and now, or “ultimately” and allow this Christian patient to die and come home to Heaven?

13.7 Discussion About Death

The author was approached by a Clinical Social Worker and told that a Christian patient had asked her, “What happens when I die?” The Social Worker passed this especially important question along to the author, the patient’s chaplain.

Before visiting the patient, he put together a brief fact sheet with answers from the Bible. They were able to discuss her questions and she was greatly encouraged by his answers.

Here are the Bible facts they discussed:

1. “I tell you the truth, today you will be with me in paradise” (Luke 23:43) [1].
2. “If I am to go on living in the body, this will mean fruitful labor for me. Yet what shall I choose? I do not know! I am torn between the two: I desire to depart and be with Christ, which is better by far; but it is more necessary for you that I remain in the body” (Philippians 1:22–24).[1]
3. “Then I saw a new heaven and a new earth, for the first heaven and the first earth had passed away, and there was no longer any sea. I saw the Holy City, the new Jerusalem, coming down out of heaven from God, prepared as a bride beautifully dressed for her husband. And I heard a loud voice from the throne saying, ‘Look! God’s dwelling place is now among the people, and he will dwell with them. They will be his people, and God himself will be with them and be their God. He will wipe every tear from their eyes. There will be no more death or mourning or crying or pain, for the old order of things has passed away’” (Revelation 21:1–4).[1]
4. “Do not let your hearts be troubled. Trust in God; trust also in me. In my Father’s house are many rooms; if it were not so, I would have told you. I am

> going there to prepare a place for you. And if I go and prepare a place for you, I will come back and take you to be with me that you also may be where I am. You know the way to the place where I am going." Thomas said to him, "Lord, we don't know where you are going, so how can we know the way?" Jesus answered, "I am the way and the truth and the life. No one comes to the Father except through me" (John 14:1–6).[1]

The conversation provided the answers the patient sought, bringing her comfort and assurance. When she requested prayer her chaplain led in a brief prayer, providing additional encouragement and support.

13.8 Prayers

Within the Christian faith, no prayer is more well-known, more loved, and prayed more often than the one known as the "Lord's Prayer," which Jesus Christ taught His disciples.

One day when Jesus had finished praying, "*…one of his disciples said to him, 'Lord, teach us to pray…'*" (Luke 11:1) [1].

In response, Jesus taught His disciples this prayer:

> This, then, is how you should pray: 'Our Father in heaven, hallowed be your name, your kingdom come, your will be done, on earth as it is in heaven. Give us today our daily bread. And forgive us our debts, as we also have forgiven our debtors. And lead us not into temptation, but deliver us from the evil one' (Matthew 6:9–13) [1].

There are many other much-loved prayers recorded in the Old and New Testaments. Perhaps another of the most well-known and loved was penned by King David, the second King of the nation of Israel. It is based on his boyhood experiences when he was alone in the fields, watching over his father's sheep. Because of the depth of insight and understanding with which David wrote Psalm 23, frequently called "The Shepherd's Psalm," it is often used as a prayer.

Tamara Flinchum has taken this Psalm and used it very effectively as a comforting and compassionate part of her bedside ritual in the end-of-life moments for her Christian patients.

"Because so many people are familiar with Psalm 23, I really like to use it within a prayer before the patient dies. I begin with "Yea, though I walk through the valley of the shadow of death" and continue on through the rest of the psalm. I then pray specifically for the patient using the terminology from the psalm, that he/she would not be afraid but would know that the God of love and light accompanies him/her through this valley and know that loved ones are near. I feel that the familiarity of the psalm for so many people is a comforting thing at the time of death." [17]

Here is Psalm 23 in its entirety:

> The LORD is my shepherd, I lack nothing. He makes me lie down in green pastures, he leads me beside quiet waters, he refreshes my soul. He guides me along the right paths for his name's sake. Even though I walk through the darkest valley, I will fear no evil, for you are with me; your rod and your staff, they comfort me. You prepare a table before me in the presence of my enemies. You anoint my head with oil; my cup overflows. Surely your goodness and love will follow me all the days of my life, and I will dwell in the house of the LORD forever (Psalm 23:1–6) [1].

There are numerous approaches to prayer in the Christian faith. Some denominations employ written or scripted prayers within their worship liturgy, while others are more spontaneous, lifting unscripted prayers to the Lord during worship.

When supporting a patient at the end of life, a chaplain or other spiritual care provider will follow his or her training and faith practice when praying with and for the dying patient and others gathered around their loved one.

The author has used a powerfully effective and inclusive practice called a "Circle of Love" throughout his chaplaincy ministry when prayer is part of patient care, whether at the end of a patient visit or at the end of life. When prayer has been requested, he invites those in the room to gather around the patient's bed and join hands in a "Circle of Love," usually encouraging them to lay hands or touch their beloved family member. Joining this "Circle," he leads them in a brief, spontaneous prayer, lifting the patient by name to God, the Heavenly Father, asking Him to touch and bless this much-loved family member. He also prays for those gathered around the bed, for God to comfort and strengthen them during these difficult hours, concluding the prayer in the name of their Lord and Savior, Jesus Christ.

13.9 Sacred Music

Hymns and worship songs of praise are a significant part of the Christian faith. They are a musical celebration of the transformed life God has graciously given, the resulting peace through faith in Jesus Christ, and the promise of eternal life. Music is a vital part of the Christian worship experience. For the dying Christian, favorite hymns and songs of praise are often sung around the bed to offer comfort and assurance while the patient moves closer to death.

It was the author's experience to be at the ICU bedside of a dying pediatric patient as her favorite praise chorus was sung by those surrounding her bed and she peacefully slipped from this world and into the arms of her Lord and Savior Jesus Christ. It was one of the most moving and sacred moments in many years of chaplaincy as they sang, cried, and worshipped the Lord as this precious child of God moved on to her Eternal Home with God, her Heavenly Father.

Here are a few favorite hymns that are often sung:

"Amazing Grace" [18]

"Amazing grace how sweet the sound that saved a wretch like me! I once was lost, but now am found; was blind, but now I see.

When we've been there ten thousand years, bright shining as the sun, we've no less days to sing God's praise than when we've first begun."

"'Tis So Sweet To Trust In Jesus" [19]

"I'm so glad I learned to trust Thee, Precious Jesus, Savior, Friend; and I know that Thou art with me, wilt be with me to the end.

Jesus, Jesus, how I trust Him! How I've proved Him o'er and o'er! Jesus, Jesus, precious Jesus! O for grace to trust Him more!"

"It Is Well With My Soul" [20]

"When peace like a river attendeth my way, when sorrows like sea billows roll, whatever my lot, Thou hast taught me to say, 'It is well, It is well with my soul.'

And, Lord haste the day when the faith shall be sight, the clouds be rolled back as a scroll, the trump shall resound and the Lord shall descend. Even so—it is well with my soul.

It is well with my soul. It is well, it is well with my soul."

13.10 Sacraments of Baptism and the Lord's Supper

The sacraments of baptism and the Lord's Supper are identified as means of grace within Christianity. "A broad definition of the *means of grace* is that they are divinely appointed channels through which the influences of the Holy Spirit are communicated to the souls of men" [4]. They are the sacred rites or rituals reserved for those who have come to personal faith in Jesus Christ. These sacraments hold special meaning for the dying patient in the final hours of life.

Baptism: In the original Greek language of the New Testament, baptism literally means "dip, immerse." This sacrament is both a sign of having received Jesus Christ as personal Lord and Savior and a seal of that personal relationship. If the patient has recently become a Christian and requests to be baptized, the chaplain or spiritual care provider can perform this sacred ritual in the hospital, hospice, or even home setting by sprinkling or pouring water on the head as a powerful testimony, affirming the decision to follow Jesus.

The Lord's Supper: Also called Holy Communion or Eucharist, receiving the elements of bread and unfermented grape juice or wine—depending on denominational practice—at the end of life is the same ritual the patient would have observed many times during congregational worship services throughout his or her Christian journey. This is a tangible way to receive God's grace, following

Jesus' instructions to His 12 original disciples, "*Do this in remembrance of me*" (Luke 22:19) [1]. It is an affirmation of faith in Jesus Christ. It is likewise a link connecting the dying patient to fellow believers—those in the Body of Christ, the Church—one last time before leaving this world.

13.11 Discussions of Legacy or Life Review

It is natural for dying patients to cast a mental look backward over a lifetime as the end-of-life approaches, pondering what kind of impact their life has had. What kind of legacy remains [21–23]?

Questions like these, spoken or unspoken, are frequently in the mind of the patient: "I wonder if anyone will be sad when I am gone? Will I be missed? Did my life have meaning for anyone?" Such questions lend themselves to a life review or a discussion of legacy. What mark will the dying patient be able to say was left behind?

For example, the Christian husband or wife's legacy might include a summary statement beginning with a review of the promises made at a flower-lined altar on their wedding day: "To love, honor, and cherish until death us do part" could become a starting point of reference. The dying patient seeking perspective could be encouraged to reflect on his or her life based on this statement.

Another life review approach, tailored to fit the patient's life, could be introduced by a chaplain, spiritual care provider, or family caregiver with the following statement: "You have done well! You kept your promises to your spouse all these years. Together you brought children into this world, loved and protected them, raised them as a team, did your best to provide and care for them, and taught them to love and serve the Lord. You have been true and faithful to your vows, and you come to the end of your earthly journey leaving a wonderful legacy of love and faithfulness."

In addition to the patient's family legacy, other aspects of life to consider could include professional career, volunteer service to mankind, and ways the dying Christian allowed his or her love for God to be expressed in philanthropic ways.

Such a legacy or life review applies to all patients—those blessed with a long life and those who have lived far fewer years. Death is no respecter of person, and the desire to leave a legacy touches us all, regardless of age [24].

13.12 Preparations Around the Time of Death

Chaplain or parish pastor visits with the patient and family to provide comforting care and compassionate support. It is possible that discussions of unresolved family concerns might occur that the spiritual caregiver can address to help facilitate reconciliation, bringing the patient peace of mind in the final hours of life.

While the patient is alert and able to communicate, Five Wishes [25] can be an excellent tool providing the patient with a method for discussing vital topics with family such as "How I want people to treat me" and "What I want my loved ones to know." If the patient is aware, this document can be useful in addressing the patient's wishes. It is now available in more than 20 languages as well as Braille.

While serving as a hospice and hospital chaplain, the author answered numerous family members' questions about what they could expect as their loved ones approached death. Final Journey [26] is an excellent resource, providing easy to understand information about the body changes that happen as their loved one is dying.

Depending on the denomination (Anglican, Baptist, Nazarene, Presbyterian, Wesleyan, etc.), there may be slightly different traditions or rituals that are followed as the patient approaches death. Reaching out to a local parish pastor or the chaplain at the hospital or hospice for spiritual comfort and emotional support during these difficult times as loved ones approach death is a common practice.

13.13 Funeral and Memorial Service Practices

13.13.1 Funeral Service

Rituals such as a funeral play an important part in the healing process. In "The Mourner's Bill of Rights," [27] Wolfelt writes, "You have the right to make use of ritual. The funeral ritual does more than acknowledge the death of someone loved. It helps provide you with the support of caring people. More importantly, the funeral is a way for you to mourn. If others tell you the funeral or other healing rituals such as these are silly or unnecessary, don't listen" [27].

Within the Christian faith, there are numerous ways families choose to remember loved ones who have died. Having a plan for the ceremony helps determine how the loved one's life will be celebrated. Recognizing that each person is unique, the funeral will likewise be a unique representation of the one who has died. There is no single right way for a funeral to be done.

Many choose to have a time of visitation prior to the funeral. This is an arranged time at the church or funeral home when the body is present in an open or closed casket. It is an opportunity for loved ones and friends to support each other in their mutual grief. This gathering allows the family "... and others who loved the person who has died to acknowledge the reality of the death and to have the privilege of saying goodbye. Receiving friends through a visitation activates your support system and allows others to express their concern and love for you. They will remember you invited them and often stay more available to you in the months that follow the death. In other words, having a visitation encourages you to openly and honestly mourn the death." [28]

Death is often viewed as a heavenly Homegoing celebration for the Christian's life well-lived, so these services are frequently upbeat. The type of service a family chooses is not nearly as important as how it helps loved ones mourn their loss. Typically, this first aspect of bereavement, known as mourning, is a public and shared event. Family members, loved ones, and other friends who knew and loved the deceased attend this gathering focused on finding meaning and comfort as their bereavement begins.

Traditional Christian funerals include the presence of the body with either an open or closed casket. Viewing the body helps mourners begin to acknowledge the finality of death. “I have observed that keeping the dead person’s body present for the funeral ceremony often encourages more expressions of grief and authentic mourning. The body is the ‘ultimate death symbol’ and makes the unreal (‘How can they be dead?’) become real.” [28]

A member of the clergy, often the chaplain or pastor of the deceased, officiates at the service held a few days after the loved one’s death. During the funeral, there is typically music loved by the deceased, uplifting passages read from the Bible, a eulogy, and a Bible-based message remembering the departed and comforting those who remain.

13.13.2 Committal Service

This service is usually in addition to the funeral or memorial service. Following the service, there is a motorized procession to the cemetery gravesite where a brief committal or commitment service is also led by the chaplain or pastor before the body is buried, often alongside other family members already interred in nearby plots.

Depending on family wishes and arrangements, there may be final moments when attendees pass by the casket and lay flowers on top of the casket prior to it being lowered into the ground. Some services conclude with certain family members taking shovels or handfuls of dirt and tossing the dirt into the grave after the casket has been lowered to its final resting place.

Those leaving the graveyard may glance back one more time and will often see the chaplain or pastor still standing by the gravesite. This image offers a final picture of the steadfast comfort and faithful support provided by this spiritual caregiver to the mourners as they depart, having said their final goodbyes to their loved one’s mortal remains.

These celebrations and committal services are often followed by an informal buffet-style meal. Family and friends contribute their favorite dishes which are served potluck-style. The atmosphere is upbeat, providing everyone an opportunity to eat, mingle, talk, and further reminisce about the life of the one who has died.

The second part of bereavement, identified as grief, may either be a time of seeking solace alone or gathering privately with family members to remember the loved one.

It is important to understand that both aspects of bereavement—mourning and grief—are natural and healthy parts of healing and moving forward.

13.13.3 Memorial Service

A memorial service is a service without the body of the loved one present. The cremated remains in an urn or other container may or may not be present, depending on the disposition of the body. The service can take place weeks or even months after the death and may be held in any one of several locations: funeral home, church, outdoor setting, public facility, or a private venue chosen by the family.

Memorial services may be held in place of a funeral, or in addition to a funeral. The person may have grown up in a certain community but lived and died in a completely different locale where the funeral service was held. A memorial service "back home" might be held later for those who knew and loved the person, whether or not they were able to attend the distant funeral service.

These celebrations are often followed by the same kind of informal, buffet-style meal with those in attendance contributing their favorite dishes served potluck-style. The atmosphere is upbeat, providing everyone an opportunity to eat, mingle, talk, and further reminisce about the early years of the one who has died as he or she grew up in their community.

13.13.4 Additional Practices

The Christian faith is rich in other practices that add meaning to funeral, committal, and memorial services. Flowers sent by family or friends represent their love and are a beautiful reminder of the sender's heartfelt support. Candles illuminated during the service deepen the sense of sacredness. Memory DVDs providing a visual history of the deceased accompanied by comforting music offer moving tributes which add a wonderful dimension to the service. Many funeral homes offer memory DVDs or can direct the family to companies that are able to provide this service. Families often have someone with the technical skill to make such a Memory DVD.

13.13.5 Other Burial Practices

Earth burial. In addition to earth burial or interment of a body at a cemetery, which is the most traditional and common method for the final disposition of the body, [28] cremated ashes of the loved one may be buried in a cemetery and marked with a gravestone.

Here are other practices that are followed within the various Christian traditions:

Crypt burial in a mausoleum. A crypt is a location in a small building in a cemetery called a mausoleum. Much like an earth burial plot, only above-ground, the casket is entombed—placed inside the crypt—and the front is typically sealed with stone and marked with an engraved name plate.

Columbarium. Like a mausoleum, a columbarium is an above-ground structure for the final disposition of cremated remains. The urn is placed in an individual niche or placed inside family niches and marked with an engraved name plate.

Scattering site. If the deceased has been cremated, the ashes may be scattered in a variety of ways including at sea, or in a place sacred and special to this loved one.

13.13.6 Beliefs Regarding the Afterlife

Along with a discussion about death, it is only natural that some patients would be interested in discussing the afterlife awaiting them. The scriptures shared in response to the question, "What happens when I die?" may be followed by questions such as "What will happen after I die?" This is another important topic, since there is a great deal of mystery surrounding the unknown after our physical bodies cease to function and die.

The Word of God gives clear teachings about the afterlife—what happens after we die—such as Paul's words mentioned in the chapter's Introduction: "*And we are not afraid but are quite content to die, for then we will be at home with the Lord*" (2 Corinthians 5:8) [2].

The Psalmist King David made it clear he was looking forward to life eternal with God. In Psalm 17 he wrote, "*LORD, my plea is just; listen to my cry... As for me, I will... see your face; when I awake, I will be satisfied with seeing your likeness*" (Psalm 17:1, 15) [1].

In perhaps his most well-known Psalm, the 23rd, he concludes, "*Surely your goodness and love will follow me all the days of my life, and I will dwell in the house of the LORD forever*" (Psalm 23:6) [1].

What happens the moment the Christian takes that final breath and closes his or her eyes in death? Most Christians believe the spirit leaves the body and this world immediately and goes to heaven where it is forever united with God, Jesus Christ, and those Christians who have gone on before. These beliefs are based, in part, on the previously cited verses from Revelation 21 and John 14.

"Rather than trying to control everything, faith allows [Christians] to give up the need for control and instead to trust that God will control their circumstances based on God's love, wisdom, and unique knowledge about their situations. They say, 'It's all about letting go and letting God, not hanging on and holding tight to that which on this earthly plane is passing away.' These people are not trying to find a sense of home here on earth. Instead, they are looking forward to going back home, returning to their real home—to join loved ones who have already died and with the knowledge that loved ones still alive will soon join them. Dying is mainly about saying a temporary goodbye to loved ones and comforting them in their loss. It is a return to a place where they will no longer have pain or suffering, but rather have new bodies that will never become sick again. To those who believe, death is a time of true healing and wholeness like never before" [5] [word in brackets added for clarity].

The patient hovering near death finds comfort and reassurance in such answers, reaffirming their faith and looking forward to taking their last breath in this life on earth and awaking to the glorious majesty of heaven.

13.14 Practices After Death and Burial

Just as there is always a "before" leading up to the death of the patient, there is also an "after" following the death and burial, characterized by many potential actions within Christianity. These can include active projects like raising funds to create a lasting memorial to honor the loved one, designing a scrapbook or making a video. Planting a tree, a personal or community garden, or establishing a charitable foundation to fund research into the disease that took the loved one's life. Establishing a scholarship at a favorite college or university in the name of the deceased, naming a newborn after the deceased, designing an awareness campaign about a loved one's illness, or donating to the hospital where your loved one received compassionate medical care can also be positive, pro-active ways to remember him or her. These are great ways to honor the memory of the loved one.

On special occasions such as the deceased's birthday or the anniversary of the death, family members may choose to visit the grave, columbarium, or mausoleum, sometimes bringing children or grandchildren so they can experience a special story or memory. Some leave flowers or other objects that hold personal meaning for the visitor. If the deceased is a child, siblings who visit might leave a cherished stuffed animal or a drawing made for the occasion as an expression of their love. Such visits, with or without flowers or gifts, are signs of remembrance, respect, and love for the departed.

13.15 Bereavement Support

One of the most significant practices after the death and burial of a loved one is the self-care that comes when family members seek out bereavement support. Being part of a group with others who have also suffered the death of a loved one is vital to healthy grieving and the ability to heal and move forward in life [29–32].

"You have the right to move toward your grief and heal. Reconciling your grief will not happen quickly. Remember, grief is a process, not an event. Be patient and tolerant with yourself and avoid people who are impatient and intolerant with you. Neither you nor those around you must forget that the death of someone loved changes your life forever." [27]

13.15.1 "Myth" Understandings

The author grew up in a Christian context that left the unmistakable impression that one should never ask God "Why?" "Father, I don't understand why my baby sister got cancer and died. Why, Father, why?" No explanation was given for this prohibition; it was just an unspoken understanding.

As an adult, especially as a parish pastor for three decades, a grief counselor for 17 years, a hospice chaplain for nearly two years, and a hospital chaplain for more than a decade, the same idea was occasionally expressed by those to whom he provided spiritual care. It was phrased something like this: "Chaplain, I know I'm not supposed to ask God 'Why?' Why did our daughter get that brain tumor? I just don't understand." "Pastor, I know I'm not supposed to ask God 'Why?' But I just don't get it. Why did my wife die in that car accident?".

By this time, however, the words of Jesus Christ on the cross had impacted the author's life and understanding to such a degree that his thinking and his provision of compassionate spiritual care had been forever changed, forged by the crucible of Jesus' agonizing death. Childhood understanding was confronted by the example of the suffering Savior, the Son of the living God. When He cried out with a broken heart to His Heavenly Father in His hour of greatest need as He hung dying of a cross, Jesus experienced the worst pain, sorrow, and sense of abandonment ever known to a human being: "*My God, my God,* ***why*** *have you forsaken me?*" (Mark 15:34) [1] [Emphasis added.]

After coming to recognize that Jesus Christ cried out "why?" to His Heavenly Father before His death, the author's own understanding was transformed. So was his response to members of his congregations, as well as to patients and caregivers in the medical setting who were struggling with heartbreak and pain over approaching death. When a Christian spoke from a heart of brokenness and grief, "Chaplain, I know I'm not supposed to ask God 'why?' but I am really struggling and hurting right now," his response changed. With great compassion and gentleness, his reply became something like this: "Thank you for sharing your pain and struggle with me. I grew up thinking the very same thing. Then I realized that in His time of greatest need and suffering, while dying on a cross, Jesus Christ cried out to His Heavenly Father, 'My God, my God, why have you forsaken me?' In that moment, I came to understand that if our Savior and Lord could cry out in His brokenness, 'My God, my God, why?' then I think it's okay for us to cry out to our Heavenly Father in our times of brokenness and pain, 'My God, my God, why?'".

Not once has a parishioner, a patient, or a family member ever been disappointed by this response. If Jesus Christ could ask God "why?" so can we. Each hurting and suffering person came to see that God is listening, He loves us, and He cares. He feels our pain and understands what we are going through like no one else.

13.16 And Finally

The Christian life centers around faith in God, loving and serving Him, sharing His love with others, and trusting the teachings in His Word—the Holy Bible. The end of life is the critical time when the Christian's beliefs are put to the ultimate test of faith and trust. All the scriptures that have been read, all the prayers that have been said, and all the years of living and believing the truths recorded in the Old and New Testaments now face the final challenge: **ARE THEY TRUE?**

For the Christian who is about to step off into eternity, there is still great mystery connected with dying. Questions are asked: "When I take my last breath and close my eyes in death, will I open them and really see God in heaven the next moment?" "Will Jesus Christ be there to welcome me?" "Will patriarchs of the Old Testament like Abraham and Moses, the Apostles of the New Testament like Peter, James, John, and Paul, and my loved ones really be there waiting for me?".

All these questions are based on biblical truths every Christian has been taught. Dying one moment and being with Jesus Christ the next moment is based on Jesus Christ's own words which He spoke when He was hanging on a cross on a hillside called Golgotha outside Jerusalem on what has become known as "Good Friday."

A thief who was also being crucified next to Him said this: "*Jesus, remember me when you come into your kingdom*" (Luke 23:42) [1].

In reply, Jesus promised that thief, "*Truly I tell you, today you will be with me in paradise*" (Luke 23:43) [1].

"*For the Lord your God has arrived to live among you. He is a mighty Savior. He will give you victory*" (Zephaniah 3:17) [2]. "*Yet I* [God] *am always with you; you* [God] *hold me by my right hand. You* [God] *guide me with your counsel, and afterward you will take me into glory*" (Psalm 73:23–24) [1] [Words in brackets added for clarity].

The Old Testament prophet Zephaniah reminds us that God arrived to live among mankind, and He is a mighty Savior. Christians recognize God has given us victory through our personal relationship with Him, made possible by the sacrificial death of Jesus Christ, His Son. "*But thanks be to God! He gives us the victory through our Lord Jesus Christ*" (1 Corinthians 15:57) [1]. "*...Everyone born of God overcomes the world. This is the victory that has overcome the world, even our faith. Who is it that overcomes the world? Only the one who believes that Jesus is the Son of God*" (1 John 5:4–5) [1].

Christians resonate with the Psalmist David's words in Psalm 73—that God is constantly present, holding their hands, providing the comfort of His security, and guiding them with His counsel, even in the very last moments of life. And afterwards—after this life is over—taking them into Glory! This is exactly the Christian's perspective throughout life—reassurance of God's Presence and the glorious hope of heaven.

Within the Christian faith, death does not get the final word—life does—eternal life with God the Father through faith in His Son, the Lord Jesus Christ. That is the reason the Christian patient's final moments—the final breath at the end of this earthly life—gives way to indescribable joy, unfathomable hope, and the blessed assurance that in the next moment eternal life will begin in heaven with the unconditional, infinite, and eternal love of God, the Heavenly Father.

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14

Church of Jesus Christ of Latter-Day Saints (also Referred to as the Mormon Church)

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14.1 Introduction

Three-year-old Mary[1] arrived at the hospital by emergency life flight from a small community three hours away. It was clear she was suffering from liver failure, and without a transplant she would die within a matter of days. Although there was a compatible liver available from a healthy athlete who had just died in an accident, her father decided there would be no transplant.

Knowing that the father was a member of the Church of Jesus Christ of Latter-day Saints and held strong religious beliefs, the ICU staff called leaders from the local church congregation to come and “talk some sense into dad.” These leaders learned that the dad’s reticence was because of his experience with his own father, who had received a kidney transplant that did not go well and led to a slow, painful decline and death. He didn’t want to see his little girl go through that agony. “How much is too much?” he asked. The parents loved their daughter and cherished the privilege of having her as part of their family, but at that point, they were willing to let her go back to God rather than see her suffer like her grandfather had.

After listening and praying, the church elders laid their hands on each family member’s head and, through the power of the priesthood, spoke blessings on the father, mother and little Mary as they felt inspired by God. The elders encouraged the father to pursue all legitimate end-of-life medical procedures and to seek all the available blessings from heaven. After praying, receiving the blessing, and talking through his feelings about his own father, Mary’s father had a change of heart and consented to the liver transplant for his daughter. Within a day, her skin color returned to normal and she went on to recover.

This true story illustrates several important things about members of the Church of Jesus Christ. First, they accept modern medical science and believe in using it, along with calling on God for divine guidance and inspiration. At the same time, situations of life and death often throw people into stressful decisions they have never encountered before. These decisions present challenges to people across the faith spectrum, whether their beliefs are fragile or deeply held. Mary’s parents’ initial reaction is *not* a common parental response to a life-threatening event with a three-year-old, but it shows the spiritual anguish and uncertainty many people feel as they make life-and-death medical decisions. Through timely, sensitive spiritual care, this father received the inspiration and courage to face the situation by relying on both faith and medical expertise.

Latter-day Saints believe their theology answers life’s greatest questions, including “Where did I come from? Why am I here on earth? Where am I going after death?” They believe that all people lived with God as intelligent spirits before birth and desired to continue to progress by coming to earth, receiving a physical body and learning through life experiences as mortal beings. Death is the separation of a person’s physical body from their spirit, but not the end of existence. Church members believe that because of the death and resurrection of

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[1] Names have been changed to protect families’ and patients’ privacy.

Jesus Christ, all people will be resurrected, with their body and spirit reunited to a state of physical perfection, and live forever. They also believe that because of the Atonement of Jesus Christ, they can be forgiven of sins through Christ's mercy and grace and return to live in the presence of God. The afterlife is very much a part of their theology, which teaches that families can live together forever through ordinances performed on earth in holy temples. They look forward to an afterlife reunion with deceased loved ones who live and wait in a spirit world.

These beliefs manifest themselves in many medical situations. For example, ten-year-old Jacob sustained multiple serious injuries when he fell from a playground. He was in the hospital recovering for many months, and when one day a brain bleed developed, surgery was scheduled for the next morning. Jacob woke up early and asked for his mother, saying, "Did you see Grandpa Rob last night?" Grandpa Rob died when Jacob was two years old. "He was here with another man, both dressed in white. They put their hands on my head and said a prayer. And grandpa told me to tell you not to worry so much." Jacob didn't know that the admonition "not to worry so much" was a specific phrase Grandpa Rob had often said to Jacob's mother while he was alive.

Jacob's story also brings up the topic of medical miracles. His mother pleaded with the doctor to do an X-ray before brain surgery to confirm that it was necessary. Although the doctor initially protested, he relented and was incredulous when he saw the X-ray 40 min later. "Whatever we saw yesterday is not there now. The bleeding has subsided." A few weeks later, Jacob struggled but walked a few steps as he left the hospital.

Medical miracles often confirm the faith of people who pray for them, but what about families who do *not* receive the medical miracle they hoped and prayed for? Faith can help people find meaning and comfort in these situations, too.

David, age 84, and his family met with hospital staff to discuss hospice and palliative care. He easily qualified for hospice with advanced heart disease, end-stage renal disease and an array of other complications, but he and the family declined hospice, saying they wanted to "keep trying." His wife was very dependent on him and felt distressed at his absence from home. He continued to undergo procedures, rehab and home health physical therapy, and he was very motivated to "get well."

Over the course of the next few months, David and his wife decided to sell their home of 50-plus years and move to a lovely assisted living facility where David could have more support. The family supported their decision, the home sold quickly, and the children completed all the logistics. A week after moving to this new place, David died as he was being taken to the emergency department. Many clinicians had initially thought the family was in denial when they declined hospice, and David's death could have seemed like evidence of this. Yet the spiritual choice the family made felt right to the patient and his wife, and it carried his wife into a new, supportive environment where she felt she was meant to be. The healing that David's family hoped and prayed for did not happen, but they feel God blessed them through his death by providing for his wife in a way they had not anticipated.

Supporting and understanding the spiritual needs of families in end-of-life situations is truly a holy calling, and frontline healthcare workers play an important role in helping families prepare to release their loved ones into death and the afterlife. Walking alongside individuals by holding a non-judgmental space with empathy and equanimity is one of the greatest gifts medical staff provide.

As with people of any faith, each individual and family is unique, and faith can be fragile along life's journey. Latter-day Saints are not exempt from feeling fear, hopelessness, abandonment by God, or estrangement from family when facing trauma or a terminal diagnosis. A person's faith is not insurance against pain, but resource to deal with that pain when it comes. The dynamics of faith and emotions during a medical event can be overwhelming, even to those who believe, as well as to those who may have left their previous faith tradition.

We all—professionals, patients and families— benefit from genuine compassion, which can come from seeking to understand another person's culture and spirituality and paying attention in the moment without judgment. Using the core skills of being present, empathizing, listening and refraining from judgment blesses both the giver and the recipient, and has even been shown to decrease healthcare workers' emotional exhaustion.

In this chapter, we will examine the origin, beliefs and practices of The Church of Jesus Christ of Latter-day Saints to help give medical professionals a foundational understanding of what is important to members of the Church at the end of life. The Church also has an extensive website, ChurchOfJesusChrist.org with video and images, and this chapter includes several links that can assist in finding local contacts or additional information. Pages from this website will come up on searches that include the letters "LDS," such as "life help LDS."

The appendices to this chapter include a helpful "At a Glance" table summarizing relevant beliefs and practices for quick reference, along with official statements of Church doctrine to add context.

14.2 Origin of the Church

The Church of Jesus Christ of Latter-day Saints, founded in western New York in 1830, is a global church with nearly 17 million members worldwide as of 2021. Latter-day Saints view Joseph Smith, the church founder, as a prophet who received a vision of God the Father and His Son, Jesus Christ, and who was later led by an angel to an ancient record that he translated into English as "The Book of Mormon."

Along with the Bible (both Old and New Testaments), the Book of Mormon contains history and the teachings of ancient prophets, including a record of Jesus visiting and ministering to people in the Americas after his resurrection and ascension in Jerusalem. It also contains prophecies of Christ's Second Coming to earth in the future to establish His kingdom.

The term "Mormon Church" was originally a derogatory nickname, and church leaders have requested that the faith's official name be used by media, church members and the general public. Members of the Church are referred to as Latter-day Saints, saints or members. The term "saints" is used as it was in the Bible to refer to church members living in various locations, such as the saints in Ephesus or the saints in Corinth. It does not imply canonization or a level of religious commitment.

14.3 Organization

The Church of Jesus Christ of Latter-day Saints is led by a living prophet and apostles who have been called to leave their previous professions to serve as "special witnesses of Jesus Christ" and oversee the ministry worldwide. The President of the Church, The First Presidency and the Quorum of the Twelve Apostles head a hierarchical structure with various levels reaching down to local congregations known as stakes and wards. Each ward typically consists of 150–500 members and a stake is comprised of six to 12 wards within a specific geographical area. Occasionally, a smaller congregation, called a branch, might exist to serve a specific need, such as a medical facility or an ethnic group that speaks something other than the predominant language. These local congregations are organized geographically and led by unpaid lay clergy who are ordained bishops and elders. These volunteers serve as congregational leaders for three to five years while keeping their paid occupations. There is no paid ministry or staff in stakes, wards or branches.

The priesthood is viewed as the power and authority to act in the name of God for the blessing of humankind. Male church members eleven years and older may be ordained to various offices in the priesthood, provided they are living the teachings of the church. Women are not ordained to the priesthood but occupy leadership roles in church organizations at many levels. Church members serve their congregations by accepting callings or responsibilities that involve teaching, serving in child, youth, or adult programs, community outreach and administrative duties.

Most adults and youth also participate in the ministering program. Local leaders organize lists so that each household in the ward has two "ministering brothers" who are invited to serve and watch over them—which could involve anything from helping with yardwork to giving priesthood blessings, sharing gospel lessons, or just getting to know each other. Two "ministering sisters" are also designated to serve each adult woman, offering friendship, spiritual support and other help. Over time, ward members serve with different partners, serve different families and are served by different families, developing connections with one another. The relationships formed from this network of service provide care and encouragement to individuals and families throughout an entire congregation. During times of illness or crisis, it is often a family's ministering brothers and sisters who offer priesthood blessings, coordinate child care, bring meals and find out other needs that additional members of the congregation can come together to meet. The intricate design of the ministering program, which is implemented in every unit in the Church, is an integral part of the way Latter-day Saints follow the invitation of Jesus Christ to love their neighbors as themselves.

14.4 Beliefs

14.4.1 The Godhead: God the Eternal Father, His Son Jesus Christ and the Holy Spirit

Latter-day Saints differ from other Christian religions in their belief that each member of the Godhead is a separate being and that God and Jesus Christ have glorified, physical bodies of flesh and bones. Latter-day Saints pray to God the Father in the name of Jesus Christ. They acknowledge the Father as the ultimate object of their worship, the Son as Lord and Redeemer and the Holy Spirit as the messenger and revealer of the Father and the Son. These three beings make up the Godhead and are one in purpose and doctrine. They preside over this world and all of God's other creations.

14.4.2 Redemption Through Jesus Christ

Members of the Church believe that through Christ's death, grace and resurrection, all mankind will be saved in the afterlife. Because of the Fall of Adam and Eve, all people are subject to physical death, which is the separation of the spirit from the body. Christ took upon himself the sins of all mankind as he suffered in Gethsemane and upon the cross. Through the infinite Atonement of Jesus Christ, all people will be resurrected and redeemed from physical death. Resurrection is the reuniting of the spirit with the physical body in an immortal state, no longer subject to disease or death. Through grace and mercy, all will receive salvation if they desire.

14.4.3 The Plan of Salvation

Also known as The Plan of Happiness or the Plan of Redemption, the Plan of Salvation refers to the purpose of life and encompasses the existence of human spirits before, during and after life on earth. Latter-day Saints believe that prior to being born, all people who have ever lived dwelled with God as literal spirit children and chose to be born into this mortal experience. Receiving a physical body, human beings use their agency to actively choose between good and evil and grow in experience and knowledge. All people are the sons and daughters of God, and mistakes, sins and afflictions are covered by Jesus, who paid the price of justice and extends mercy and grace to all so they can become like Him if they repent and believe in His atoning sacrifice to forgive sins.

Family life is also an integral part of earth life. Illness and injury are parts of God's plan that provide opportunities for growth and refinement, although they may not be appreciated at the time of crisis, and may leave many asking "why?" Many challenges occur at random, some come from a person's choices or the choices of others, and others are allowed by God to refine individuals and turn them toward Him.

After death, a person's spirit leaves their body and moves on to the spirit world to wait for judgment and resurrection, which will occur after the millennium of 1,000 years of Christ's reign after his Second Coming to the earth. In the spirit world, those who did not have the chance to hear the gospel in life are taught and can choose whether to accept or decline the opportunity to believe. The plan teaches that eternal life includes three kingdoms of glory, or heavens, (the Celestial, Terrestrial and Telestial Kingdoms) where all men and women will be assigned after they are judged by God and their spirits are reunited with their then-immortal bodies. Since God is the ultimate judge of hearts, faith, works and earthly challenges, Latter-day Saints believe that all will be judged fairly and allowed into the kingdom where they will ultimately be the most happy. Families and loved ones of the faithful will be reunited. All three kingdoms are kingdoms of glory, and even the lowest, where people will live who do not desire or choose to live with God, is more glorious than any human can currently comprehend. "Hell," or outer darkness, is where Satan and his followers will dwell eternally, and it is separate from the three kingdoms.

14.4.4 The Purpose of Temples

Anyone, regardless of religion, may enter a Latter-day Saint meetinghouse and attend services. Temples, however, are different from meetinghouses, and because of the sacredness of temples as "houses of the Lord," only members of the Church who are observing the basic principles of the faith are allowed to enter.

Latter-day Saint temples are considered houses of God, places of holiness and peace separate from the preoccupations of the world. They provide a place where Church members make formal promises and commitments to God. They are also the place where the highest sacraments or ordinances of the faith occur—the marriage of men and women and the "sealing" together of families for eternity. They are also the only place on earth where ceremonies such as baptism and eternal marriage can be performed on behalf of those who have died—a practice that Latter-day Saints believe originated in New Testament times.

Temples point Latter-day Saints to Jesus Christ and their eventual life with Him, their Heavenly Father and their family members on the condition of faithfulness to Christ's teachings. There are more than 250 temples throughout the world either in operation, under construction or announced as of 2021.

On most temples, there is a golden statue of a man in flowing robes with a long horn pressed to his lips. The statue depicts the angel Moroni, an ancient prophet and a central figure in the Book of Mormon. The statue is symbolic of the preaching of the gospel of Jesus Christ to the world.

14.5 Practices

14.5.1 Priesthood Blessings

Priesthood blessings are important rituals in Latter-day Saint life. They are requested by church members when comfort, counsel or healing is needed or when life presents challenges. Blessings might be given when members start school or jobs, enter the military, get married or experience any challenging life circumstance—especially in times of illness, trauma or a life-threatening event.

Only ordained elders may give priesthood blessings. If possible, a father, close friend or family member who holds the priesthood administers blessings to afflicted members of the family. Often the ministering brother to the family is the first call to provide or assist in this rite. Normally, one elder will administer the anointing with consecrated olive oil by laying his hands on the patient's head, and then an additional elder will seal the anointing and give a more detailed blessing with words of comfort or advice. One person may perform both parts of the ordinance if two are not available. Blessings may be requested and given as often as needed. There is no expiration or recommended frequency.

Because the church is organized geographically, many medical facilities worldwide have a designated Latter-day Saint elder on call who can minister to a patient if family members or ministering brothers are not available. Contact information for local elders can be found on the church website by entering a location in the meetinghouse finder.

14.5.2 Worship

Weekly worship services, activities and classes take place in local church buildings, which often house two or three separate congregations. Worldwide, there are over 30,000 wards and branches as of 2020. The Sacrament (similar to Communion), in which members receive bread and water, is administered on Sundays in a weekly Sacrament Meeting that also includes sermons or testimonies from ward members. Separate class instruction is also held for men (priesthood quorums), women (Relief Society), teens and children. Church buildings are busy places with activities for all ages, often including baptisms for 8-year-old children or converts to the faith, funerals, classes, service projects, social gatherings, blood drives, youth activities and organized sports competitions. In recent years, the Church has also emphasized home worship, where families learn and discuss scripture together daily or weekly in their homes.

Twice a year, on the first Sunday in October and the first Sunday in April, there are no local church meetings. The church's semi-annual General Conference is broadcast all over the world, featuring sermons by the current Prophet of the Church, the Twelve Apostles and other men and women who have been called to serve as general church leaders. Music is by the Tabernacle Choir at Temple Square, formerly called the Mormon Tabernacle Choir. Members watch or listen to the broadcast from their homes and then review the sermons in subsequent personal study and during church meetings.

14.5.3 Prayer

All Latter-day Saints are taught to pray to God daily, to “hear Him,” and to have a personal relationship with Heavenly Father and Jesus Christ. Family prayer is also encouraged daily, as well as blessings on each meal.

Latter-day Saint prayer is a sincere, heartfelt talk with God. Even the youngest children are taught to pray and participate in personal and family prayers. Personal prayer does not follow any specific form, and can be a verbal or mental pouring out of the soul or a time of contemplation with no words, listening and seeking God. Church members often take time at the end of personal prayers to listen and “hear” or feel God’s response. Few answers come audibly, but are felt in the heart and mind as clarity or warmth or ideas that come from beyond oneself. Talking to God is called prayer, and God’s response is called revelation.

The Church has only a few set, formal prayers: the words used in the first part of priesthood blessings, the baptismal prayer, sacramental prayers over the bread and water and dedication of a grave.

A simple public prayer might follow four basic steps:

1. Address God as “Father in Heaven” or “Heavenly Father.”
2. Thank Him for blessings received.
3. Ask Him for what is desired or needed, such as wisdom, hope, comfort, direction, strength to deal with life or other specifics that are important.
4. Since Jesus is the mediator between people and Heavenly Father, prayers are closed with “In the name of Jesus Christ, Amen.”

Formal and respectful language is often used for public prayer, referring to God with words such as “Thee,” “Thy,” “Thine” and “Thou.”

14.5.4 Fasting

Members of the Church are invited to fast by skipping two meals on the first Sunday of each month. They are encouraged to donate the money they would have spent on food—a “fast offering”—to be used for those in need, along with any additional donation they wish to make. Those who are ill or whose health does not permit are not expected to fast. Fasting allows members to experience sacrifice and feel compassion for those who are suffering, and it invites them to turn from the concerns of the world toward caring for others, along with seeking inspiration for their own life challenges. Wards and families often fast together for people who are ill or dying or for a purpose such as relief from hunger or an international crisis. Individuals also fast whenever they feel a special need for inspiration or to feel close to God.

Fast offerings are used within the local congregation to provide for those in need or sent to church headquarters in Salt Lake City for world relief and humanitarian aid. The Church's welfare and humanitarian programs assist people and communities all over the world with food, clothing, clean water, emergency relief and medical supplies without respect to race or religion. There are 115 Bishop's storehouses containing food and other supplies in locations all around the world, and aid is often airlifted to remote areas.

14.5.5 Diet, Drinking and Drugs

The "Word of Wisdom" is a scriptural admonition about health that teaches abstinence from coffee, tea, alcohol, tobacco and non-medical drug use. It encourages eating nutritious food, regular exercise, proper hygiene, sufficient rest and being grateful. In addition, Church leaders have taught avoidance of substances that impair judgment or are harmful or highly addictive, whether legal or illegal. For example, vaping, misusing prescription drugs and the recreational use of marijuana are not in harmony with Church teachings.

14.5.6 Sacred Clothing

Like many people of faith around the world who wear special clothing as a reminder of sacred beliefs and commitments, adult members of the Church who have made covenants with God in the temples wear ceremonial clothing while in the temple and temple garments in their daily life. These garments are simple, white underclothes with a top similar to a T-shirt and a bottom similar to shorts. They are intended to serve as a personal reminder of covenants made with God to lead honorable, Christlike lives. Wearing the temple garment is an outward expression of an inward commitment to follow Christ. It can be removed for sports or hygiene, as well as during illness or medical procedures.

14.5.7 Miracles

Latter-day Saints believe in miracles and angels. The restoration of Christ's gospel through Joseph Smith, the faith's first prophet in modern times, is considered a miracle in itself. Miraculous stories abound in church history, as well as in the personal lives of members. Accounts of healing, rescue or deliverance from danger or death are often told and recorded to remember these instances of divine intervention and love.

Church members also speak of "tender mercies," which are small, personal "coincidences" that feel like very intimate, direct blessings from God that no one could have known were desired, or that "just happen" in unique ways. Unexpected connections or crossing paths with someone who relates information or brings an answer to prayer that they knew nothing about are examples of tender ways Latter-day Saints feel the love of God in their lives.

14.5.8 Accepting Medical Treatment

Church members actively seek modern medical treatment. Many members, including church leaders, work in healthcare professions. Latter-day Saints undergo surgery, take medications, get vaccinated and, when faced with a serious illness, rely on both faith and medical care and do all they can to facilitate healing. Church members also believe that they can be spiritually guided to a doctor or practitioner who is uniquely prepared to help them in that specific circumstance.

The Church does not mandate medical practices, and as in any religion, individuals make personal medical decisions based on their own situations and inspiration. Some may reject certain procedures or choose alternative practices.

14.5.9 End of Life

The Church teaches that human life is sacred, and it is therefore opposed to euthanasia, abortion (except in specific instances) or assisted suicide. Allowing a person to die from natural causes, removing a patient from artificial means of life support, or honoring a Do Not Resuscitate order are all seen as reasonable and merciful. Dying can be considered a blessing and a purposeful part of eternal existence, and church members are not obligated to prolong life by artificial means. Family members are encouraged to make decisions after receiving wise and competent medical advice and seeking divine guidance through fasting and prayer.

Because of their belief in miracles and divine intervention, families will often pray for miracles, invite priesthood blessings, hold congregational or extended family fasts and prayers, and do all they can to connect with heaven. Many times, miracles come. However, when hope for healing or extending life becomes unrealistic, the challenge turns to accepting God's will. Praying for comfort, for a peaceful death, or for reunion with loved ones who have died can bring a new kind of hope and purpose.

14.5.9.1 Dying

There is no formal rite required as death approaches, but priesthood blessings of comfort are often requested and given to the dying, as well as to other family members who might be in distress. (See previous topic "Priesthood Blessings" for details on how to request a blessing if family is not available.) It is not necessary for medical personnel to leave the room during a blessing, but it is appreciated for them to pause and recognize the sanctity of the occasion. Families will often gather to say their goodbyes and express their love to the dying and each other. As with people of all faiths, every effort that can be made to help the patient connect to family members who are not present is meaningful.

14.5.9.2 Organ and Blood Donation

The Church recognizes that the donation of organs and tissues is a selfless act that often results in great benefit. The decision to will or donate one's own body, organs or tissue for medical purposes, or the decision to authorize the transplant of organs or tissue from a deceased family member, is left to the individual or deceased person's family. The decision to donate or to receive a transplant is best made in consultation with medical professionals, family and prayer.

Church members are often asked to donate blood, and many congregations host blood drives.

14.5.9.3 Autopsy

Autopsy is acceptable with family consent or if required by law. It is recognized as a way of advancing medical knowledge and providing information that can be useful and comforting for families if they desire it.

14.5.9.4 Funeral Planning

The ward bishop or branch president will likely visit the family shortly after a death to assist in planning the funeral, which can be held at the local church, mortuary or place of their choice. Family members often give a eulogy, life history, musical performances and prayers. If the family is not connected to the deceased's local ward, the bishop's information can be found by entering the address of the patient's home on the church website and then clicking on the contact information for the nearest or most appropriate ward or branch.

14.5.9.5 Burial

Burial has been the norm but cremation is acceptable if the patient or family chooses. In many countries, cremation is required, and that is not a problem for Latter-day Saints. The person is buried or cremated in their ceremonial temple clothing if they have made temple covenants. The family or ward leaders can help dress the deceased if the local mortuary is not familiar with Latter-day Saint practices.

A specific ordinance to dedicate the grave at the cemetery is spoken in prayer by an elder who holds the priesthood, often a family member or close friend.

14.6 Conclusion

This chapter has explored the origins, beliefs and practices of members of the Church of Jesus Christ of Latter-day Saints and their acceptance of medical science and treatment along with divine guidance and inspiration. Understanding this perspective can empower medical professionals to provide culturally competent and compassionate care that will benefit not only patients and families but practitioners as well.

The following experience was related to a Latter-day Saint funeral. It captures the emotions that arise when facing end-of-life situations, how an extended family dealt with dying, and the hope and spiritual perspective they felt even though death occurred.

The funeral speaker said, "I'm reminded of our experience last year when our cousin Joseph was dying. So many of us went to our knees in great faith and desperation asking the Lord for a miracle on his behalf. As we fasted and prayed for him, the unequivocal answer came to us that the miracle had already happened—that 2,000 years ago the miracle occurred, and that regardless of anything that we are experiencing now, all has been made right and whole. Jesus *is* the great miracle. He has already mended and healed. He is full of compassion for us, His children, and all that He does is for our benefit. And so, we trust in Him completely."

Appendices

A. At a Glance: Quick Reference Guide to Beliefs and Practices
B. Links
   a. Official Church documents
   b. Full URLs of in-text hyperlinks from this chapter, in order of appearance.

Appendix 1

At a Glance:
Beliefs and practices of the Church of Jesus Christ of Latter-Day Saints that Directly Impact End-of-Life Care

The Godhead	God the Eternal Father, His Son Jesus Christ and the Holy Ghost are three separate beings that are one in purpose. Members pray to God or Heavenly Father in the name of Jesus Christ
Redemption through Jesus Christ	Through Christ's death, grace and resurrection, all mankind will be saved in the afterlife

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The plan of salvation	All people lived as intelligent spirits before birth and chose to be born on earth to receive a body and mind, and to learn through life experience. After death, all people will be saved through the mercy and grace of Jesus Christ and then live in various kingdoms of glory, or heavens, according to their faith and God's judgment. All will also experience a bodily resurrection, where body and spirit are reunited in a perfected state
Priesthood blessings	Blessings are an important ritual for Latter-day Saints requested when comfort, counsel or healing is needed and often given at the end of life to patient and family members. They are given only by ordained elders. Designated contacts can be found online or by calling a local branch or ward
Prayer	All members are taught to pray daily and to have a personal relationship with Heavenly Father and Jesus Christ. Prayer is a heartfelt talk with God. There are only a few set prayers in worship services
Accepting medical treatment	Latter-day Saints actively seek modern medical treatment and rely on both faith and medical care to facilitate healing
End of life	The Church teaches that life is sacred and is opposed to euthanasia, abortion (except in specific instances) or assisted suicide. Members are not obligated to prolong life by artificial means. Dying is a purposeful part of eternal existence
Dying	No formal rite is required as death approaches, but priesthood blessings of comfort are often requested and given to the dying as well as to other family members who might be in distress. Families often gather to say goodbyes and offer support to each other
Organ and blood donation	Becoming a donor or a recipient is left to each person and family to decide, based on consultation with medical professionals and prayer. Blood drives are common in Latter-day Saint congregations
Autopsy	Autopsies are recognized as advancing medical knowledge, and they are acceptable with family consent or if required by law
Funeral planning	Usually done with family and ward leaders. If the surviving family is not connected with local leaders, contact information can be found on the Church website
Burial	Burial is the norm, and cremation is acceptable if patient or family chooses. The deceased is buried or cremated in their ceremonial temple clothing if they have made temple covenants. The family or ward can help dress the person if the local mortuary is not familiar with Latter-day Saint practices

Appendix 2: Links

1. Three Official Declarations or Proclamations Issued Since 1995
    1. The Living Christ Proclamation. https://www.churchofjesuschrist.org/study/scriptures/the-living-christ-the-testimony-of-the-apostles/the-living-christ-the-testimony-of-the-apostles?lang=eng
    2. Proclamation on the Family. https://www.churchofjesuschrist.org/study/scriptures/the-family-a-proclamation-to-the-world/the-family-a-proclamation-to-the-world?lang=eng
    3. The Restoration Proclamation. https://newsroom.churchofjesuschrist.org/multimedia/file/restoration-proclamation-2020-april.pdf
2. The Articles of Faith, written by Joseph Smith in 1835 as a response to journalists' inquiries about Latter-day Saint beliefs. https://www.churchofjesuschrist.org/comeuntochrist/article/articles-of-faith
3. Full URLs of in-text hyperlinks from this chapter, in order of appearance. (**Search churchofjesuschrist.org if links have been moved, or for additional information.)**

Does Taking Time For Compassion Make Doctors Better At Their Jobs? (NPR).

https://www.npr.org/sections/health-shots/2019/04/26/717272708/does-taking-time-for-compassion-make-doctors-better-at-their-jobs

Doctrinal Study: Godhead (The Church of Jesus Christ of Latter-day Saints).

https://www.churchofjesuschrist.org/study/manual/gospel-topics/godhead?lang=eng

Doctrinal Study: Plan of Salvation (The Church of Jesus Christ of Latter-day Saints).

https://www.churchofjesuschrist.org/study/manual/gospel-topics/plan-of-salvation?lang=eng

Temples (The Church of Jesus Christ of Latter-day Saints).

https://newsroom.churchofjesuschrist.org/topic/temples

Find a Meetinghouse or Ward (The Church of Jesus Christ of Latter-day Saints).

https://ChurchofJesusChrist.org/maps/meetinghouses

Gospel Topics: Garments (The Church of Jesus Christ of Latter-day Saints).

https://www.churchofjesuschrist.org/study/manual/gospel-topics/garments?lang=eng

Euthanasia and Prolonging Life (The Church of Jesus Christ of Latter-day Saints).

https://newsroom.churchofjesuschrist.org/official-statement/euthanasia-and-prolonging-life

Find a Meetinghouse or Ward (The Church of Jesus Christ of Latter-day Saints).

https://ChurchofJesusChrist.org/maps/meetinghouses

Greek Orthodox

15

Heather N. Bitar

Contents

15.1 History and Origins of the Greek Orthodox Church

Historically, "Greek" in "Greek Orthodox" can refer to the heritage of the Byzantine Empire. Orthodox Greeks pride themselves on having a church of apostolic origins. The origins in Greece go back to the second missionary trip of the apostle Paul who accompanied by his disciples left Asia minor and set foot on European soil. Being under Roman rule at that time, the Christian religion was "imported" to Greece and Europe. Thus, Paul founded the first Christian communities in Greece leaving local disciples to continue his work [10].

The Great Schism of 1054 between the Greek Orthodox and Western Roman Catholic Church was an important event to mark the further development of Christianity. The separation came about through a gradual process of estrangement that

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spanned almost six centuries. During the 4th Century, Christianity revolved around five primary areas: Constantinople, Alexandria, Jerusalem, Antioch, and Rome. The Mediterranean world was turned upside down due to barbarian invasions in the West and the rise Islam in the East. Because of this, the primary focus of Christianity became Constantinople and Rome [12].

The dominant language of the West was Latin, while the dominant language of the East was Greek. Due, in large part, to the language barrier, the two halves of the church began to develop different rites and approaches to religious doctrines. Additionally, when a French bishop was elected as Pope Leo IX, he was intent on reforming the Papacy and the entire church. He claimed he held supreme authority over the entire church, including Constantinople.

After this, Greek churches were forced either to close or to conform to Latin practices. In retaliation, the patriarch of Constantinople, Michael Cerularius, attacked many of the practices and closed many of the Latin churches in Constantinople. Instructed by Pope Leo IX, the papal legate passed litigation to refuse Michael I the title of "Ecumenical Patriarch" and insist that he recognize the Pope's claim to be head of all the churches [2].

On Saturday, July 16, 1054, Cardinal Humbert walked into the Cathedral of Hagia and placed a parchment that declared the excommunication of Michael I on the main altar. This is the event that is credited for the complete schism between the Greek Orthodox and Roman Catholicism. Two attempts at reunion took place in 1274 (Second Council of Lyons) and 1438–1439 (Council of Florence), but neither was successful [8].

The Great Schism is a tremendous reminder of the need to properly abide by God's word (2 John 9). The Greek Orthodox church claims to hold God's word in the highest regard. They teach that one is not to add to what God has said. Man cannot sit where God belongs (2 Thess. 2:1–4). Paul warned the Thessalonians about apostasy. This would culminate with a man trying to sit where only God belongs. As long as humankind tries to rule, there will always be division (1 Cor. 1:10–13). Division proves that a group is no longer abiding in God's word. Jesus prayed for unity (John 17) which only happens when we are abiding by the same standard [8].

In 1864, before the Greeks arrived in masses to the United States, the first Greek Orthodox Church was established in New Orleans by a few wealthy merchants in the cotton trade. Mass immigration from Greece to the United States began in the late nineteenth century. About 400,000 Greeks had gone through Ellis Island by the 1920s. By the end of World War I, Greek Orthodoxy in America acquired a centralized administrative structure and governing body: the archdiocese. Composed of numerous self-governing ecclesiastical bodies, each geographically and nationally distinct but theologically and sacramentally unified. Each self-governing (autocephalous) body is shepherded by a Synod of bishops.

15.2 Overview of Greek Orthodox Beliefs

There are approximately 300 million members of the Greek Orthodox Church worldwide. It is the second largest Christian church. The church teaches that it is the one, holy, and apostolic church established by Jesus Christ and that its bishops are the successors of Christ's apostles. Orthodox churches, unlike the Catholic Church, have no single Supreme Pontiff or Bishop and hold the belief that Christ is the head of the Church. However, they are each governed by a committee of Bishops, called the Holy Synod, with one central Bishop holding the honorary title of "first among equals."

The Church holds a common doctrine and a usual form of worship, and they see themselves not as separate churches but as administrative units of one single Church. It maintains that it practices the original Christian faith, as passed down by holy tradition. They are notable for their extensive tradition for their veneration of the Virgin Mary, Mother of God, and the Saints and for their use of the Divine Liturgy on Sundays, which is a standardized worship service dating back to the fourth century A.D. in its current form. The Greek Orthodox Church recognizes seven major sacraments, of which the Eucharist is the principal one, celebrated liturgically. The church teaches that through consecration invoked by a priest, the sacrificial bread and wine become the body and blood of Christ. A person's communion with God expressed in love. Where there is no love, God is absent and there is no spiritual life. All are already saved (Christ's death and resurrection), are still being saved (through participation in the church) and will be saved in the future (second coming of Christ).

The Greek Orthodox view the Trinity as, three persons, one in essence and undivided. Christ is understood to be the Son of God, both fully divine and fully human, and the Holy Spirit enables humanity to apprehend God's presence in the world. The Father (God) is eternal and does not proceed from any, the Son is eternal and begotten of the Father, and the Holy Spirit is eternal and proceeds from the Father. The doctrine regarding the Trinity is summarized in the Nicene Creed [26]. In understanding the Trinity as "one God in three persons", "three persons" is not to be emphasized more than "one God." While the three persons are distinct, they are united in one divine essence. In the Bible, God has revealed Himself as living and present in his people. It is considered the "Word of God" though not considered literal.

According to the Greek Orthodox faith, at some point in the beginnings of human existence, humanity was faced with a choice: to learn the difference between good and evil through observation or through participation. The biblical story of Adam and Eve relates this choice by humankind to participate in evil, accomplished through disobedience to God's command. The result was the diminishment of human nature and its subjection to death and corruption, an event commonly referred to as the "fall of man." When Greek Orthodox Christians refer to fallen nature, they are not saying that human nature has become evil in and of itself. Human nature is still formed in the image of God; humans are still God's creation, and God has never created anything evil, but fallen nature remains open to evil intents and actions. It is sometimes said that humans are “inclined to sin”; that is, people find some sinful things attractive [13].

The Greek Orthodox Church teaches that through baptism into Christ’s death, and a person’s death unto sin in repentance, with God’s help humanity can also rise with Christ into heaven, healed of the breach of man’s fallen nature and restored to God’s grace. To Greek Orthodox Christians, this process is what is meant by “salvation,” which consists of the Christian life. The Church understands the death and resurrection of Jesus to be real historical events, as described in the gospels of the New Testament- but He, alone among humans, has two natures, one human, one divine, which are indivisible and inseparable from each other through the mystery of the incarnation. Not only this, but He opened the gates of Hades to all the righteous dead of past ages, rescuing them from their fallen human nature and restoring them to a nature of grace with God, bringing them back to life, this time in God’s heavenly kingdom [26]. Therefore, the Greek Orthodox proclaim each year at the time of Easter (Pascha), that Christ “trampled down death by death, and on those in the tombs bestowed life.”

The Church believes that Hell, though often described in metaphor as punishment inflicted by God, is in reality the soul’s rejection of God’s infinite love which is offered freely and abundantly to everyone. The Greek Orthodox believe that after the Final Judgment: All souls will be reunited with their resurrected bodies, all souls will fully experience their spiritual state, and having been perfected, the saints will forever progress toward a deeper and fuller love of God, which equates with eternal happiness [19].

The Greek Orthodox Christian life is a spiritual pilgrimage in which each person, through the imitation of Christ, cultivates the practice of unceasing prayer. It is then through God’s love in the action of the Holy Spirit that each member becomes more holy, more wholly unified with Christ, starting in this life and continuing in the next [4]. In Greek Orthodox services, the earthly members join with the heavenly members to worship God as one community in Christ, in a union that transcends time and space and joins heaven to earth. This unity of the Church is sometimes called the communion of the saints [7]. Therefore, the Church believes that the congregation of the church comprises both the living and the dead. All people currently in heaven are considered to be saints, whether their names are known or not. There are, however, those saints of distinction whom God has revealed as particularly good examples. Numerous saints are celebrated on each day of the year. They are shown profound respect and love but not worshipped, for worship is for God alone. In showing the saints this love and requesting their prayers, the Greek Orthodox manifest their belief that the saints thus assist in the process of salvation for others.

The most highly revered saint is the Virgin Mary (“Mother of God”). The Greek Orthodox believe that Christ, from the moment of his conception, was both fully God and fully human. Mary is thus called the “Theotokos” or “Bogoroditsa” as an affirmation of the divinity of the one to whom she gave birth. It is also believed that her virginity was not compromised in conceiving God-incarnate, that she was not harmed and that she remained forever a virgin. Due to her unique place in salvation history, Mary is honored above all other saints and especially venerated for the magnificent work that God accomplished through her [26].

Greek Orthodox Christians hold the belief that the Bible is a verbal icon of Christ, as proclaimed by the 7th ecumenical council. They refer to the Bible as holy scripture, meaning writings containing the foundational truths of the Christian faith as revealed by Christ and the Holy Spirit to its divinely inspired human authors. Holy scripture forms the primary and authoritative written witness of holy tradition and is essential as the basis for all Greek Orthodox teaching and belief [25]. The Bible provides the only texts held to be suitable for reading in worship services. Through the many scriptural quotations embedded in the worship service texts themselves, it is often said that the Greek Orthodox pray the Bible as well as read it.

Holy tradition does not change in the Greek Orthodox Church because it encompasses those things that do not change: the nature of the one God in Trinity, Father, Son, and Holy Spirit, the history of God's interactions with his peoples. Holy tradition is firm, even unyielding, but not rigid or legalistic; instead, it lives and breathes within the church. The continuity and stability of worship throughout the centuries is one means by which holy tradition expresses the unity of the whole church throughout time. The church strives to preserve holy tradition "unchanging" that it may express the one unchanging faith for all time to come.

15.3 Beliefs Around End-of-Life Practices

Followers of the Greek Orthodox religion believe in eternal life. Thus, the church strongly emphasizes a positive outcome in death—that the deceased is alive with God. While death is the separation of the soul (the spiritual dimension of each person) from the body (the physical dimension), the physical body will be reunited with the soul at the Last Judgment. Death is considered a special stage of human development and preparation for the resurrection and the last judgement [24].

The Greek Orthodox Church considers death not as a biological event but as a mystery with a sacred, spiritual character and as a great blessing. The church has no position on end-of-life decisions since the task of Christians is to pray and not to decide about life and death [1]. The beliefs of the Church suggested that death is an attainment of the deceased to pass on to eternity and away from the sins on earth. Death is viewed as a sacred event and marks the passing of the deceased's soul either to Heaven, or Hell [23]. Life and death are viewed as being totally "in God's hands" (Job 12:10).

The word "euthanasia" comes from the Greek for "good death," and the Greek Orthodox Church defines good death as "a peaceful death with dignity and without pain." On the contrary, the current international meaning of "active euthanasia" is perceived rather as "mercy killing" and is under no circumstances allowed [1]. It is viewed that we may medically intervene in the body for therapeutic reasons. Any act that favors and precipitates the body's decay is insulting to the soul and therefore is unethical. The decay process should be entirely natural and should never be forced [6].

15.4 Preparations Around the Time of Death

The Greek Orthodox religion is practiced today much as it was practiced hundreds of years ago and is highly ritualistic and symbolic. It is a tradition that a wake will be held in the house of the deceased among relatives and friends. It is believed that when someone dies in a household, the “evil spirit” has entered that house. For that reason, all the windows need to be open for the evil to be “washed out” with fresh air. The deceased’s body must be dressed up with new clothing which has not been washed, to be buried in grace, and all the mirrors in the house, as well as shiny surfaces, are covered with white towels or sheets, hence the bereaved are not diverting their interest into anything else but the reality of the deceased [3, 21].

During the wake, candles are burning by the head of the body, which is placed in a coffin and usually on a table. The candlelight is a means of saying “goodbye” to the person who has died, while the head of the deceased should face the front door of the house, as he/she is ready to leave. A Greek Orthodox priest administers the last anointing with holy oil on the forehead of the deceased.

The wake lasts for twenty-four hours, and during those hours family and friends are wailing, mourning, and expressing their feelings in an intense and demonstrative way. It is believed within the Greek culture that expressive ways of grieving show greater empathy to one’s loss [3, 9, 16]. Announcements are made in the community, prior to the wake, for whoever wants to have a chance of a last “goodbye.”

15.5 Funeral Practices

The coffin is most of the time left open unless the body has deteriorated too much due to an accident or an illness. With an open casket placed in front of the chancel, the first-degree relatives seated on the left side of it, and everybody else sitting or standing and holding a burning candle each, the ceremony begins. By the end of the chants and the priest’s compliments to the family and the deceased, the priest proceeds and kisses the deceased on the forehead. Kissing the dead symbolizes the farewell from this world [9, 16, 23]. After the priest, the family members will do the same, and the rest of the guests will follow.

Afterwards, the first-degree relatives of the person who passed stand (or sit if the grief is unbearable) by the exit of the Church and receive sympathy from the guests as a sign of respect for their presence. It is believed by the relatives that this will contribute to a passable trail of the dead in the Afterlife [21]. When everyone has shown his or her condolences and sympathy, they head back to the deceased’s house where the “coffee of comfort” is offered to everyone. During this time relatives and friends share experiences and memories for their loved one who has recently died. This ritual lasts from an hour to three or four hours, depending on how close the attendees were to the deceased.

Traditionally, a widow must wear black typically for one year, whereas men wear a black “weeper” around their left arm for forty days. If the widow does not wear black after the death of someone in the family disrespect is shown to the deceased. Additionally, after someone dies, a candle is lit for forty days in that household to remind everyone of the absence and the loss that has been experienced [17].

15.6 Burial

At the church, every person lights a candle as they enter, in memory of the deceased. The coffin is usually open, and an icon is placed on the body or the coffin. At the end of the service, everyone pays respect to the deceased and the icon, by passing the coffin. At the cemetery, the last funeral prayer is said, and the body is buried facing east, because when Christ was born the guiding star was in the East. The family has supplied a small bottle of wine mixed with oil and some wheat or bread, to the priest at the church. When the last prayer is finished, the priest pours the wine and oil mixture over the lowered coffin, making the sign of the cross three times, symbolizing the Holy Trinity and sustenance for the departing soul. The priest sprinkles earth into the grave, followed by family and friends.

In the Greek Orthodox religion, cremation is not permitted because it is believed that we are made from earth and that we shall return to earth. Additionally, it is believed that when Christ returns in the Last Judgement, the physical body will be reunited with the soul. Therefore, the body should be buried rather than cremated.

15.7 Afterlife

Greek Orthodox Christians believe that when a person dies the soul is temporarily separated from the body. Though it may linger for a brief period on earth, it is ultimately escorted either to paradise or the darkness of Hades, following the Temporary Judgment. The Greek Orthodox do not accept the doctrine of Purgatory, which is held by Catholicism. The soul's experience of either of these states is only a "foretaste"—being experienced only by the soul—until the Last and Final Judgment, when the soul and body will be reunited [20]. For this reason, the Church offers a special prayer for the dead on the third day, ninth day, fortieth day, and the one-year anniversary after the death.

The fortieth day is symbolic because it is believed that the soul roams on earth for forty days, as did Christ. The lighting of the candle during church service is symbolic in asking God for forgiveness on behalf of the deceased. Those rituals are commemorations, in which family and friends participate, and which are known as 'Mnemosyna' or memorial "Memory Eternal." After each mass, food is eaten in honor of the deceased's soul.

Special prayers are offered during a 'Mnemosyno' for the parting of the deceased from the world of the living. Furthermore, at those remembrances, boiled wheat is offered to the attendees. The wheat represents reciprocity and solidarity between the dead and the living. Since ancient times it is believed that this offering will remit the deceased's sins and that it has the meaning of renaissance [21, 27]. There are also several days throughout the year that are set aside for general commemoration of the departed, sometimes including nonbelievers.

15.8 Considerations in the Medical Setting

Learning about traditional customs and rituals among different religions and cultures can provide unique expertise to practitioners such as social workers, psychologists, and health care professionals who work with such populations especially in the fields of Hospice and Palliative Medicine which are highly involved in death and dying. It is of paramount importance that these practitioners are aware of the cultural and religious differences on death and grief, and how those have an impact on the ways people would like to be treated as well as how they provide care.

In the Greek Orthodox religion, God is understood to be the "Divine Physician" and the, healer of our souls and bodies, which is facilitated through prayer and participation in the life of the Church. Traditional medical interventions are accepted. Greek Orthodox doctors generally do not withdraw treatment but instead usually withhold or set limits around treatment. Greek Orthodox doctors are less likely to discuss end-of-life decisions with patients and family. Although, acculturation may explain why doctors of the same religion have different practices in various locations [11].

Religion and cultural beliefs affect the decision and how to discuss end-of-life information with the patient's family if at all. About 55% percent of Greek Orthodox identifying physicians discussed the decision to withdrawal care with families in the Intensive Care Unit (ICU) setting ($P < 0.001$) [22]. Religious affiliation of the practitioner also affects the median time from ICU admission to the first limitation of care. The median time to overall first limitation of care was on average 3.2 days but varied according to the physician's religious affiliations. Greek Orthodox physicians first initiated or limited end-of-life treatment after a median of 7.6 days [22]. This does align with prior studies that show Greek Orthodox doctors are less likely to have withdrawal from care discussions and when they do tend to be later than physicians of other faiths.

The principle of "double effect" permits acting when an otherwise legitimate act may also cause an effect one would normally avoid, such as alleviating pain even if it unintentionally hastens death. The Greek Orthodox Church adamantly rejects intentional shortening of life by withdrawing therapy and would only allow alleviation of pain if it in no way leads to the patient's death. On the other hand, artificial support is justifiable only when it offers the prospect of continued life. Therefore, termination of ventilator therapy in a brain-dead person is allowed. Organ transplantation is permitted if the donor or his family has agreed knowingly and voluntarily [1]. It is viewed that the doctor is there to protect life (as indicated in the Hippocratic Oath) and the family is there to support the patient [6].

These views and beliefs can affect the ways in which a family meeting or goals of care conversation would be conducted. In Greek Orthodoxy, the patient and family make medical decisions together. At times, the family may request that the patient not be told about their prognosis as to minimize their loved one from “giving up hope.” The desire to sympathize with the dying person and the effort to delay the moment of death express the struggle of human nature against death as the consequence of original sin. The need for the patient to stay alive is sometimes greater for those standing by, even if the patient may not even be conscience anymore of his or her own existence [6]. The attempt to prolong life is viewed as ethically permissible as opposed to hastening death as in euthanasia.

On the other hand, quality of life should be compatible with survival. Advancements in medical technology allow patients to survive under conditions that are not always considered acceptable quality-wise as defined by patients and families. Thus, surviving and living become two different things [6]. It seems at times that technological survival can be worse than death due to the unbearable suffering and loss of dignity that it can bring. These technological advancements may create an environment in which human beings are unable to die in a natural way. Artificial life support is justifiable only when it offers a prospect of life and hope for meaningful recovery for the patient. Just as providers are not entitled to speed up death, the medical team is not to prolong its natural process. When the inevitable moment of death comes, it is believed that it should be humbly accepted and respected [5]. Therefore, timely advanced care planning and early goals of care conversations to help the medical team understand how the patient and family would define quality of life prior to a crisis or the patient losing capacity is critical. That way limitations around artificial life support can be better defined as to avoid situations where medical treatments are being withdrawn which can be viewed by Greek Orthodox families as hastening death.

It is also important to remember that there are various degrees of religiosity in which an individual may identify. Over time, especially in the United States, there may be varying degrees of assimilation toward or away from the Greek Orthodox faith. Therefore, the medical team should not assume that all patients of this faith will feel the same around end-of-life beliefs and practices. Additionally, further studies and analysis are needed to better understand the beliefs of other East Asian Orthodox churches such as the Syriac, Coptic, Armenian, Indian, and Ethiopian to name a few. The medical team must remember that as humans we all have unique perspectives on how we would like to receive medical and end-of-life care. It is important that providers take the time to learn each patient’s unique social, cultural, religious, and spiritual background to help guide them and their families on what to expect as they near the end of life. The individualized and culturally sensitive approach is what patients and their families will perceive as receiving the highest quality and personalized care.

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16

Hinduism

Purvi Patel

Let me not beg for the stilling of my pain but for the heart to conquer it.

Rabindranath Tagore

Contents

Death is a universal experience. Regardless of one's culture, religion, race or beliefs, we will all die. Hinduism views death very uniquely. Hindus simultaneously mourn and celebrate the loss of loved ones. While normal emotions are associated with loss, death is usually handled well. Any death in the Hindu religion is considered one of many deaths that a soul experiences as they move toward

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spiritual growth and enlightenment—it is the next step in the larger journey of life and is a natural experience.

For many people, whether they are spiritual or not, “healing is often more important than curing, yet most health care education is primarily focused on curative treatments, neglecting the importance of end-of-life needs [2].” “Religion and spirituality specifically influence how people view their own health, as well as the larger health care system, by helping patients and families to cope with illness [3].” For these reasons, it is imperative that individuals in the health care field have some level of understanding of religion and its impact on well-being, whether physical, mental, emotional or spiritual. This chapter will focus on Hinduism and end-of-life care and rituals.

16.1 Background

Hinduism is the third largest religion in the world and the oldest known religion still in practice [1]. Hinduism is the main religion of India [2]. Based on ancient Hindu scriptures, it is believed that Hinduism has been practiced for over 8000 years [1]. It is unique in that it has no founder, no beginning and no one Holy book [1]. The most sacred Hindu text is the Veda, which means wisdom. The Veda itself consists of 4 books.

There is one God (Brahman) with many forms [1]. Central to religion is the belief that God is within each living creature and object, and it is the journey and purpose of life to become aware of this divine essence. Spirituality is a way of life. Hinduism worships hundreds of deities, each representing their own core values and characteristics. The three major deities are Brahma (the creator), Vishnu (the preserver) and Shiva (the destroyer). Hindus choose which god or goddess they are devoted to.

Daily worship is done as a family and usually performed in the morning before everyone starts the day [1]. This morning worship is called “puja” and consists of lighting incense, reading prayers and meditation [1].

Family and community are highly valued by Hindus [1], so when caring for a patient who is Hindu, it is not uncommon to have many family members, and even close friends, visit the patient or crowd the room. Understanding this and having patience for this large involvement of people is important when caring for your Hindu patients. This is more pertinent for end-of-life care since this is a time when most family and friends will want to visit or be present.

16.2 Reincarnation and Karma

A central value to the Hindu faith is reincarnation. Reincarnation is the belief that when someone dies, their physical body is gone but their soul is reborn in a different form—transition to another life [2]. This cycle continues until the soul finds its true destiny. Each incarnation depends on the actions of that person in their previous life, also referred to as Karma (which is based on your words, thoughts and actions)—*a moral cause and effect of thoughts and actions* [1]. If you have lived a life of more good actions and thoughts than bad, and have devoted yourself to God, you will have a more fortunate rebirth. If you have not lived a good life, or have bad Karma, you are likely to be reborn to a less fortunate life, which is considered another chance to create good Karma.

Suffering is a key component of Karma since it represents thoughts or actions from the current life or a past life [1]. This journey can take many lifetimes and once enlightenment is reached it is known as Moksha—release from the cycle of death. While death is a sad time of mourning the loss of the individual, it is also a time to celebrate as the soul has either reached or is closer to reaching Moksha.

16.3 Body Preparation

The preparation of the body is a very important part of the entire process. The deceased is washed with ghee (clarified butter), honey, milk and yogurt. A thread is sometimes tied around the neck and wrist and the body is sprinkled with water from the Ganges (which is considered the holy river). A leaf from a sacred basil bush (this plant is called "Tulsi") is placed on the tongue. Essential oils can also be applied to the forehead in addition to turmeric, which is placed on females, and sandalwood which is placed on males. The palms are placed in a position of prayer and the big toes are tied together. The body is positioned so the head is facing south, symbolizing a return to Mother Earth. The family will pray around the body but avoid touching it since it is considered unclean. They will recite prayers, chants and hymns, with the goal of helping the person to keep a focus on Brahman. The body is dressed or draped in white clothing or a white cloth. If a woman dies before her husband, she will be dressed in all red. If she dies after her husband, she will wear all white clothing for the remainder of her life, as a sign of the lack of beauty and celebration that comes with being a widow. Lastly, a garland of flowers is draped around the neck.

16.4 Cremation

Hindus practice specific rituals during and after death, and they prefer to die at home. Once someone dies, cremation is the preferred funeral rite. This is done because after death the physical body serves no purpose and doesn't need to be preserved. This is also why Hindus do not use "RIP" or "rest in peace" to respect the passing of a loved one. After death that individual, or soul, is not thought to be eternally resting, but rather waiting to be reborn into the next life, Cremation is believed to be the quickest way to release the soul into the next life. Flames are also thought to represent Brahma.

The body should remain at home until the cremation is performed, which ideally occurs within 24 h of passing. The exception to cremation is with infants and young children, in which burial is acceptable after death. It is believed that they have not lived long enough to acquire bad karma and therefore do not need cremation to release their souls since they are still “pure” [1].

Funeral rites are performed in the form of chants or mantras and are overseen by either a Hindu priest or the eldest son of the bereaved. Family and friends may read religious texts or sing religious songs. It is customary for family and friends to visit the home of the bereaved to offer their condolences. During this time, any pictures of deities in the deceased’s home will be turned to face the wall.

16.5 Funeral and The Mourning Period

Hindu funerals are traditionally only attended by men, but modern funerals allow women to attend as well. After the funeral, the ashes are scattered over a sacred body of water, traditionally this would be the Ganges river, or a place of importance to the deceased.

When the funeral is over mourners wash and change their clothes before entering the house. This refers back to the belief that the deceased’s body is unclean. The time following someone’s death is considered impure and the time of this impurity can last days to a year, depending on the caste—the lower the caste, the longer the duration of impurity [1]. The mourning period can last 10–30 days. In this time families will often display a picture of their loved one in their homes, adorned with garlands of flowers. On day 13 after the death, the grieving family will hold a ceremony to help release the soul of the deceased for reincarnation. On the one-year anniversary of the death the family will hold another memorial event to honor the life of the loved one who passed away, which is known as Shradh. This event may occur on only the first anniversary of the death or can be done annually. During Shradh food is given to the poor in memory of the deceased. During this time the family of the deceased will not buy new clothes or new items, go to any parties or have any celebrations. Shradh lasts for one month.

Autopsies and organ donation are not traditionally performed, unless an autopsy is required by law. Autopsies are considered disruptive to the body, and in turn to the soul, inhibiting it from being released and moving forward to the next life [1]. Organ donation also disrupts the body and if a major organ is donated (heart, liver, kidney) then part of the body continues to live on, and this will interfere with reincarnation [1]. It is also thought that part of the organ donor’s karma will be transferred to the recipient [1].

16.6 Suffering

How we approach death and think about suffering varies greatly between religion and culture, and our spiritual beliefs formulate our ideas and perceptions about end-of-life [1].

Spiritual suffering happens at the end-of-life for Hindus when they feel their responsibilities have been left incomplete. In order to mitigate this, Hindus attempt to focus their attention and energy on thoughts of Brahman in order to facilitate the soul leaving the body in the highest possible state [1].

Some believe that enduring physical suffering can lead to more spiritual growth and in turn a more fortunate rebirth since spiritual suffering is connected to Karma. Suffering is an important part of life because it represents past actions and thoughts that were negative. By enduring suffering, you are paying the debt incurred for these past negative behaviors in previous lives [1].

Death should not be sought nor prolonged. There are varying views when it comes to Hinduism and physician aid in dying. Some believe that requesting to die prior to the body dying on its own will cause the soul and body to be separated at an unnatural time. This applies to both suicide and physician aid in dying. The Karma of both the patient and the doctor who agrees to the request will be affected. Others believe that by helping to end suffering you are performing a good deed and therefore fulfilling your moral obligation. It is also thought that artificially prolonging life, with mechanical ventilation or artificial nutrition and hydration, unless directly linked to improving quality of life, causes the soul to remain on earth past its natural time [1]. “Fasting near the end of life is considered a source of spiritual purification, so Hindus may also object to tube feeding for these reasons [3].”

Willfully ending life (i.e., suicide) is unfavored because it would result in a large karmic debt [1]. Death should come naturally at the appropriate time [1].

16.7 End of Life

The hospice philosophy emphasizes promoting the quality of end of life, and its care often focuses on pain and symptom management. In Hinduism, this is a concept that is often hard to accept because of their belief with suffering and the benefits that result because of it. It is important to remember that each patient has the right to make their own decisions, and the right to be as comfortable or uncomfortable as they want. Even under hospice care, we should be supportive of these decisions.

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Judaism

17

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17.1 Judaism: An Overview

Any attempt at a summary of Judaism must include some of its most cherished stories since it is a religion of stories. The following is one of many that are told and retold, as it speaks to the very core of the Jewish religion. A prospective convert comes to the house of the great rabbi, Shammai. He asks the rabbi to explain the whole *Torah* (Judaism's central religious text) to him as he stands on one foot. Understandably annoyed, Shammai shoos him away. The same convert next knocks on the great rabbi Hillel's door with the same request. Hillel replies: "That which is hateful to you, do not do to your neighbor. That is the whole Torah. The rest is commentary. Go learn" (Babylonian Talmud, Shabbat 31a).

Judaism is a religious tradition that has existed for approximately four thousand years. One of its core, enduring contributions is its unique articulation of monotheism, the belief in one God. Its central written law, the Torah, is traditionally believed to have been divinely given to the Jewish people at Mount Sinai, through the prophet Moses. A separate oral law, or interpretive tradition that expounds upon the Torah, was transmitted by word-of-mouth for generations until it was written down in the form of texts entitled the *Mishnah* (c. 200 CE), the *Talmud* (Palestinian c. 350 CE and Babylonian c. 500 CE), and subsequent legal codes. These sources, along with rabbinic responses to difficult questions that arise in their time, comprise the corpus of *halakhah* (literally, "the way"), or traditional Jewish law.

Judaism is not a monolith, but rather a rich, diverse tradition, which grows deeper the more it is explored. It contains a wide spectrum of ideologies, beliefs, practices, and ethnic backgrounds. Major movements in the U.S. include the Orthodox, Conservative, Reform, Reconstructionist, and Renewal groups, though this is not a comprehensive list. What most differentiates these denominations is their respective approaches to halakhah, and the delicate balance between tradition and change, which each addresses in its own way.

If we imagine an old-fashioned weight scale, then Orthodoxy is a scale that leans in favor of the "tradition" side. This does not mean that the "change" plate is empty. It simply means that greater deference is given to the received tradition, which is often interpreted along strict lines. The Conservative Movement might be visualized as a middle setting. The "burden of proof" still rests on those seeking to alter the tradition, but laws are generally interpreted less strictly in order to more actively accommodate modern concerns and lifestyles. While both of these denominations consider halakhah to be binding, the Reform Movement generally understands Jewish law to be wisdom and guidance that should be autonomously observed or rejected by each individual Jew. This scale leans toward "change," or "reform," emphasizing individual choice, but that does not mean that the "tradition" plate is empty.

Within each denomination and each person is a process of evolution. No one fits neatly into a box. It would be a mistake, therefore, to rely on generalizations when attempting to ascertain one's values, practices, and beliefs. These vary on a case-by-case basis and are best understood through a relationship with the particular person involved.

It should also be noted that many Jews are unaffiliated with a movement. Judaism sees itself as both a religion and a peoplehood, which means that one may claim Jewish identity regardless of personal belief or practice. In other words, an atheist Jew is just as much a Jew as anyone else. There are plenty of people who consider themselves to be "culturally Jewish," demonstrating that while Judaism is a religion, it is also a heritage and a culture with its own distinct foods, music, dance, and more.

The three largest Jewish ethnic groups in the U.S. are Ashkenazi (those originating from Germany, France, and Eastern Europe), Sephardi (those originating from Spain and Portugal), and Edot Mizrach (those originating from the Middle East and North Africa). Collectively, the Jewish people comprise less than two percent of the U.S. population and significantly less than one percent of the global population. Though small in number, Jews are found in vibrant communities around the world, each sharing key similarities and differences.

What are some of these core beliefs, and how, ultimately, do they inform end-of-life practices? In the opening chapter of Genesis, the first of five books of the Hebrew Bible (Torah), God creates human beings *b'tzelem Elohim*, meaning, "…in the image of God" (Genesis 1:27). Human beings are therefore inextricably linked to their Creator, each possessed of innate holiness and deserving of dignity and respect. This also suggests a fiduciary relationship to one's body, which is on loan from its divine source and not entirely at one's disposal, to do with as one pleases.

Another core, foundational, belief is that of *brit*, or "covenant." In Judaism's central biblical narrative, God delivers the enslaved children of Israel from servitude to freedom. The culminating moment of their desert wanderings is the giving of the Torah at Mount Sinai, as part of an eternal brit between the divine and the people. The laws it contains are all-encompassing, informing everything from large-scale societal issues, down to minute personal matters. They also delineate set times for rest, worship, and ritual observance. Because many of these laws have always required interpretation and adaptation to evolving social and historical contexts, the rabbinic enterprise makes central the need to mull over, comment upon, and hotly debate the received tradition, as deeper understanding is only achieved through questioning. Judaism strongly encourages thoughtful questions and arguments.

Its enthusiastic embrace of interpretation and debate comes with its own set of challenges. One cannot simply present end-of-life practices without inviting the reader to take an active part in the discussion. This is particularly true when considering two core Jewish values, namely *pikuah nefesh*, or "saving life," and the obligation to alleviate pain and suffering. The Jewish commitment to pikuah nefesh overrides almost any other commandment, demonstrating how sacred Judaism considers each and every life to be. In clinical settings, this must often be held up against Judaism's parallel commitment to safeguarding the dignity and comfort of terminally ill and dying individuals. The scale image again proves useful, this time in visualizing the delicate balance between saving life and alleviating suffering.

What follows is a survey of crucial bioethical concerns that health care practitioners frequently confront when caring for Jewish patients, as well as laws, rituals, traditions, customs, beliefs, and practices surrounding one's final days on earth and beyond. Considering the diverse nature and needs of this group, it is highly recommended that medical teams employ a holistic approach to healing, collaborating with hospital chaplains and the patient's rabbi, where applicable, who can consult on matters of halakhah when this is of concern to the patient. Jewish prayer begins each new day by praising God for the wondrous intricacies of the body, as well as for the transcendent nature of the soul. Ideal medical care for Jewish patients, and indeed for most patients regardless of faith tradition or lack thereof, ought to strive to meet one's physical and spiritual needs. This chapter is equally intended for non-clinicians who are interested in learning more about the subject. On one foot, it can all be summarized as "Love your neighbor as yourself" (Leviticus 19:18). The rest is commentary. So, let's "Go learn."

17.2 Palliative Interventions and Jewish Tradition

17.2.1 Life-Sustaining Treatments: General Principles

In the Torah, God instructs the people of Israel, "I set before you life and death, blessing and curse. Choose life…" (Deuteronomy 30:19). This might create the impression that Jewish law prioritizes preserving the life of the patient at all costs. While this is generally the case, to "Love your neighbor as yourself," carries with it an obligation to alleviate pain and suffering, concomitant with the concern for survival. Palliative care, therefore, which seeks to optimize the quality of life for patients dealing with serious illness, is not only acceptable, but also praiseworthy and encouraged (Weiner, 123).

According to halakhah, the general principle is that it is forbidden to hasten death (Mappah, Y.D. 339). Even when a patient is deemed a *goses*, meaning, an individual who is actively dying, it is not permitted for one to shut the eyes of this person (a customary act, showing respect for the dead), since doing so might possibly expedite the dying process even a single moment (Shulhan Arukh, Y.D. 339). That said, Judaism views death to be a natural part of life, given that there is "A time to be born and a time to die" (The Byrds, "Turn, Turn, Turn" Side 1: Track 1. Also, Ecclesiastes 3:2). It is not required, then, that one initiate medical interventions on a *treifah*, meaning, a terminally ill patient, if doing so would only briefly prolong a life of suffering and pain. On the contrary, impediments to the dying process may be removed to allow nature to take its course (Mappah, Y.D., 339; Sefer Hasidim, 234). The story of the death of Rabbi Yehudah ha-Nasi (Babylonia Talmud, Ketubbot 104a) is often cited to demonstrate this principle. It can be summarized as follows:

Rabbi Yehudah ha-Nasi is on his deathbed. His fellow rabbis decree a public fast and gather at his doorstep to pray that God keeps him alive. Meanwhile, his maidservant climbs up onto the roof and says, “The upper world (i.e. God) and the lower world (i.e. Earth) are both requesting Rabbi Yehudah ha-Nasi. May it be God’s will that the lower world imposes its will upon the upper world.” This all changes, however, when she sees the extent of the dying rabbi’s pain and suffering. She then reverses course, saying, “May it be God’s will that the upper world imposes its will on the lower world.” Seeing how the rabbis continue to pray fervently for his life, she takes a jug and throws it from the roof and onto the ground. Startled by the sound, the rabbis are distracted from their prayer for one moment, and Rabbi Yehudah ha-Nasi dies.

This story speaks volumes about some of the conflicting concerns a clinician, family member, or friend might experience when caring for a dying patient. Because the Talmud does not actually comment on whether the maidservant acted nobly or not, this passage also demonstrates how different interpretations of sacred text can breed opposing opinions on matters of practical palliative care. In other words, the same general principles may be interpreted along strict or lenient lines, even from within the same denomination.

For example, most Jewish opinions agree that if aggressive interventions hold more promise of pain than cure, they may be withheld from terminally ill patients. When it comes to basic needs like nutrition and hydration, however, stricter views hold that they may not be withheld, while more lenient positions argue that even they may be compassionately withheld. Regarding life-sustaining treatments, stricter opinions oppose withdrawing them once they have already been initiated, since that could then be considered hastening death. More lenient positions, however, allow for their withdrawal if they are not helping to improve the patient’s condition. Finally, since continuous forms of treatment, such as ventilators and pacemakers, are constantly at work, stricter interpretations generally oppose stopping them once they have been initiated. Cyclical/intermittent forms of treatment, such as chemotherapy and defibrillators, however, may be re-evaluated and stopped between cycles, since each new round can be considered to be like a new treatment. More lenient positions argue that even continuous forms of treatment may be stopped when this is carefully determined to be in the patient’s best interest. These general principles appear time and again when discussing specific bioethical concerns and clinical applications.

17.2.2 Artificial Nutrition and Hydration

Food and water are considered basic needs. In cases where patients are unable to ingest food and water orally, the administration of artificial nutrition and hydration can be considered to be required by Jewish law. If patients strongly refuse to be nourished in this way, however, one does not force or compel compliance

(Weiner, 125). Interestingly, American law provides that patients may refuse artificial nutrition. Why do Jewish sources resist this, and what accounts for the lack of consensus within the tradition?

The nature of this debate lies in whether or not artificial nutrition and hydration should be categorized like regular food and water, which is generally seen as mandatory, or if it should be classified as medicine, which is optional. Stricter stances go with the former, but compelling cases have been made to view it as medicine, [A Jewish Approach to End-Stage Medical Care by Rabbi Elliot Dorff, 100–106] which accords with American law. This takes into account the fact that patients nearing the end of life often lose their appetite, diminishing the need to mitigate the discomfort of hunger or thirst. For these individuals, the administration of nutrition, either orally or through tubes, might increase discomfort or present the risk of choking, aspiration, or infection. Jewish tradition strongly prioritizes the comfort and dignity of the dying, which is why less invasive forms of nutrition and hydration like menthol swabs, feeding for pleasure, or ice chips may also be used where helpful (Weiner, 125).

17.2.3 Intubation/Extubation and Mechanical Ventilation

Along with nutrition and hydration, oxygen is also considered to be a basic need. Intubation and mechanical ventilation are generally aggressive interventions and most Jewish sources agree that they may be withheld in certain cases. Regarding extubation, stricter positions oppose extubation if it is likely to result in the patient's subsequent decline and death, but allow weaning off when patients are expected to stabilize and regain the capacity to breathe on their own for a certain amount of time (Weiner, 140). More lenient opinions hold that extubation is allowed when continued intubation is no longer medically appropriate.

Some Jewish authorities also argue that palliative extubation is allowed when a patient is considered to be a goses (one who is dying imminently) (Weiner, 127). In this scenario, mechanical ventilation may actually be seen as impeding the person's natural transition from life to death, and would therefore be removable. The problem is, it can be very difficult to determine if death is imminent. Assuming this can be ascertained, comfort care measures are crucial in attempting to facilitate a compassionate death for the patient.

There is another notable option, which some Jewish authorities permit and has become accepted policy in Israel (Pan et al., 1263). Accordingly, ventilators may be set to a timer, automatically shutting off if not actively restarted. This allows the medical team to assess the patient's progress on the machine. If the patient is not benefiting from the intervention, then it can be passively discontinued. The timer ostensibly shifts the mechanical ventilator from being continuous treatment to being intermittent/cyclical, where each cycle is considered to be like a new treatment that may be compassionately withheld (Pan et al., 1263).

17.2.4 Dialysis

While dialysis is technically an intermittent treatment, it is actually an exception to the rule. Because it often serves as a regular part of a patient's medical routine, dialysis essentially becomes recategorized as continuous treatment. This means that, by strict standards, some are of the opinion that it should not be withheld between cycles (Weiner, 142). If, however, a patient is new to dialysis, receives a kidney transplant, or is not improving, suffering, and dying, then it may be discontinued between cycles.

17.2.5 Sedation and the "Double Effect"

The Jewish obligation to mitigate suffering runs deep. It is expected not only among human beings, but for animals, as well. There is a law in the Torah that if one sees a donkey lying under the weight of the burden that has been loaded onto it, one must help raise it back up again by removing some of the weight (Exodus 23:5). Similarly, Jewish law suggests that one must not look on the suffering of another person who is weighed down by the overwhelming burden of serious illness without seeking to mitigate some of this pain through appropriate intervention.

Ethical concerns arise, however, around the use of medications like morphine and other opioids that may be perceived to hasten death by contributing to respiratory depression. This is the concept of "double effect," given that the same treatment may have dual outcomes, where one is morally desirable and the other is not. Some hold that such medication may be administered only to the point that doctors are assured that it will not hasten death ["A Halakhic Ethic of Care for the Terminally Ill" by Rabbi Avram Reisner, 29]. Others hold that patients are permitted to receive opioid pain medication even if it might possibly hasten death so long as the intention for its use is relief of painful suffering, and not to end life ["A Jewish Approach to End-Stage Medical Care" by Rabbi Elliot Dorff, 82]. In this case, it would still be prohibited to knowingly administer a lethal dose of morphine.

17.2.6 Euthanasia and Aid in Dying

It is widely accepted that Jewish law strongly prohibits euthanasia (when a physician actively ends a patient's life according to the patient's wishes) and aid-in-dying (when a patient ends the patient's own life, with physician help). Even though a growing number of U.S. states have now enacted legislation that permits aid-in-dying, halakhah is clear that the body belongs to God and may not be intentionally injured or destroyed (Mishnah, Bava Kama 8:6–7). This principle is clearly demonstrated in the Talmudic account of the death of Rabbi Hananyah ben

Teradiyon (Babylonian Talmud, Avodah Zarah 18a), summarized here, with the warning that it is quite graphic:

Rabbi Hananyah ben Teradiyon is sentenced to death for teaching Torah in public, an illegal act under Roman law. As punishment, he is wrapped in a Torah scroll, and the two are set on fire. Not only that, tufts of wool soaked in water are also placed on his heart to slow the flames and increase the pain of burning. As the rabbi is being executed, his students advise him to open his mouth so that the flames may enter him and kill him sooner. Rabbi Hananyah ben Teradiyon answers, "It is better that the one who takes my life is the one who gave it to me (i.e. God), but a person should not harm one's self." The executioner, stirred to help, offers to remove the tufts of wool and increase the flames in order to reduce the pain. The rabbi accepts this intervention and is consumed by the flames.

It goes without saying that this story is an extreme example of torturous execution, which seems to have little to do with patients in a hospital setting. That does not stop generations of rabbis, however, from deriving laws from it that inform practical end-of-life decision-making. Rabbi Hananyah's refusal to harm himself, even when doing so would have spared him severe pain, can be interpreted as a prohibition against active euthanasia. His acceptance of the executioner's offer to remove the tufts of wool and to increase the flames can be interpreted as sanctioning "passive euthanasia," or the removal of impediments to the dying process in order to allow natural death to occur. It is further clear from this passage that the rabbis strongly oppose self-harm. Some Jewish authorities do make an exception for martyrdom, and the Talmud states that a person should choose death over being forced to commit murder, idol worship, or acts of licentiousness (Babylonian Talmud, Sanhedrin 74a), but euthanasia is not among these exceptions.

There are still a number of compassionate options that Jewish tradition offers suffering patients who wish to end their lives. First and foremost is the sincere, non-judgmental attempt by a holistic team to address the underlying needs and worries of a patient seeking death. These may include, among other concerns, the need for control, the financial burden of medical care and hospitalization, mental illness and depression, and unbearable physical or psychological pain. While aid-in-dying is not a conventionally accepted recourse, Jewish law stresses the importance of proper medical and spiritual care to provide as much comfort, support, and compassion as possible. This may take the form of pain and symptom management, mental health support, spiritual care, social work, and referral to palliative care or hospice programs (Weiner, 173). There are also times when it is considered permissible for a patient to decline certain life-sustaining treatments, or for unsuccessful interventions to be withdrawn (though this latter point is debated).

It has further been argued that aid-in-dying may actually be permitted exclusively in cases where terminally-ill patients are in uncontrollable pain ["Assisted Suicide/Aid in Dying Reconsidered," by Rabbi Elliot Dorff]. This position considers it unethical to watch a patient scream one's way to death, noting that since "God's compassion embraces all God's creations" (Psalms 145:9), a very narrow exception can be made. If a dying patient is experiencing intractable distress, Jewish arguments can be made for palliative sedation, even to unconsciousness, which would allow the patient to eventually undergo a natural death, or for compassionate aid-in-dying. This argument still acknowledges that in the vast majority of cases, both clinicians and patients have a sacred duty to alleviate pain and sustain life, not end it.

17.2.7 Advance Directives and DNR/DNAR/DNI Orders

Advance directives are crucial documents that protect one's autonomy in end-of-life medical decision-making. They help ensure that patients' values and wishes are honored in the event that they can no longer make these decisions themselves. In these cases, they also protect the interest of family members and dear ones, who would otherwise be put in the distressing position of having to make difficult decisions on the patient's behalf. With an advance directive, close ones can, instead, more confidently play their role in lovingly carrying out the patient's will.

There are two main types: a living will and a proxy/durable power of attorney for medical care (Kinzbrunner, 571). The former indicates a patient's preferences for end-of-life care, including interventions one does and does not want. The latter appoints one or multiple surrogates who are empowered to make these decisions for the patient if/when the patient loses the capacity to do so.

In some traditional circles, a living will is seen as controversial because it can prioritize individual autonomy over adherence to Jewish law. Along these lines, some Orthodox rabbis argue that a durable power of attorney for medical care is preferable since a competent rabbi may be appointed who can advocate for medical care that aligns with the patient's religious values. While this point remains valid, it is worth clarifying any misconception that a living will is at odds with Judaism. On the contrary, it is an important opportunity for a patient to communicate needs and values. The Conservative and Reform movements also offer their own versions of advanced directives, which can be very helpful. To mitigate any concerns about autonomy versus Jewish law, one can always complete one's living will with the help of one's rabbi.

DNR's (Do Not Resuscitate) and similar orders (Do Not Attempt Resuscitation, Do Not Intubate) have also been met with resistance by Jews who feel that these violate pikuah nefesh, the obligation to save life. As explored above, however, there are instances where life-saving interventions like intubation may be withheld. A patient can also decline the use of CPR, given low success rates in seriously ill patients and its potential to cause physical trauma like broken ribs, particularly for elderly patients ["A Jewish Approach to End-Stage Medical Care" by Rabbi Elliot Dorff]. In sum, halakhah permits the use of DNR orders for patients with incurable illnesses who are near death, suffering, and do not want to be resuscitated (Weiner, 122). Some opinions hold that DNR orders are also appropriate for patients when a "full measure of life" cannot possibly be restored ["A Halakhic Ethic of Care for the Terminally Ill" by Rabbi Avram Reisner].

The importance of thoughtful consideration as to the type of death one ultimately wants cannot be stressed highly enough. What are the values one wants to uphold when the time inevitably comes? How does one weigh quality versus quantity of life? Who are the key individuals one entrusts with such delicate matters if one cannot decide on one's own? It is never too early to complete advanced directives. Unfortunately, it can only ever be too late.

It is highly encouraged that patients also revisit their advanced directives every three to five years to reaffirm their wishes or to make any desired adjustments. This helps ensure that a directive aligns, as closely as possible, with the patient's most current, up-to-date values and goals.

17.2.8 Definition of Death

The definition of death is also debated in Jewish law, since the same source text can be read in different ways. The Talmud suggests that if a building collapses on *Shabbat*, the Jewish day of rest, and a person is buried beneath the rubble, one must break the laws of Shabbat by clearing away the debris up to the victim's nose in order to determine if the person is still breathing (Babylonian Talmud, Yoma 85a). This is because, as explained earlier, saving a life overrides almost all other commandments, including Shabbat.

One way to understand this story is that Judaism's technical definition of life is spontaneous respiration. This is supported by a Biblical verse in the story of Noah: "All in whose nostrils was the breath of the spirit of life" (Genesis 7:22). Advocates for this interpretation conclude that the careful medical determination of brain death sufficiently defines death, since the brain stem controls spontaneous respiration. Once this is no longer functioning, a person is considered to have passed.

The stricter position, however, is that death is the absence of both spontaneous respiration and cardiac function. That is to say, it is the complete cessation of bodily motion (Rosner, 43). Until that point, almost anything that can be done to maintain life must be done. This reading of the Talmudic story argues that uncovering the victim's nose is simply the quickest way to uncover a *sign* of life (i.e. breath), but that heartbeat and respiration together are the true metrics by which life is actually defined.

A third understanding points to another source, this time from the Mishnah, which indicates that decapitation is sufficient grounds for determining death (Mishnah, Oholot 1:6). A person who is decapitated is considered to be dead even if parts of the body continue to move, given that cells may continue to function for a period of time after a person dies. Though not an exact parallel, this line of reasoning is used to support the case for physiological decapitation, or the notion that brain death marks the end of life.

The position one takes in this debate has far-reaching implications. For instance, if a medical team determines a patient to be brain dead, but that patient's heart continues to beat and the flow of oxygen is maintained through a mechanical ventilator, how would Jewish values inform the care for this patient? Numerous ethical considerations arise, such as the emotional and financial burden of keeping a loved one alive in a vegetative state, concerns around the patient's dignity and quality of life, as well as the question of triage and keeping a hospital bed occupied that might otherwise be used to save another life. On the other hand, Judaism does not permit sacrificing one person's life in order to save another (Babylonian Talmud, Sanhedrin 72b), and there might be an equal, if not greater emotional burden for having "pulled the plug" on a loved one, who was still considered to be alive by many traditional authorities.

While there is much debate regarding how to define death in Judaism, it is worth noting that both American law and the Israeli Chief Rabbinate accept irreversible brain death as definitive (Weiner, 188). Given that cultural and religious understandings of death might differ from Western biomedical definitions of it, sensitivity and appreciation for nuance can only help Jewish patients and families cope with grief and loss.

17.2.9 Organ Donation

There is a misconception that Judaism forbids organ donation. This largely stems from concerns around hastening death, the Jewish obligation to bury the entire body and the prohibition against benefiting from or desecrating a corpse. Some also worry that they could not be resurrected in a body missing parts (see: **The Afterlife: Jewish Views and Beliefs** below).

Definitions of death play a large role in discussions around organ donation because certain organs only remain viable for transplantation when there is a continued heartbeat. If one accepts neurological criteria, then it would be permissible to donate organs from a patient after the cessation of brain function, even if that patient's heart is still beating. If, however, one defines death as the absence of both spontaneous respiration and cardiac function, then this kind of organ donation would be considered hastening death and therefore prohibited. Both definitions are supported in Judaism (see above), so a case can be made for and against extracting and accepting organs from patients meeting only neurological criteria for death.

In less controversial cases, when a body is ruled to be dead by all standards, Judaism largely supports organ donation. One common objection is that a body must be buried as soon as possible after death. One might think, then, that a Jew cannot donate organs, which should be quickly buried along with the corpse. This is not the case, however, since organs are actually thought of as "coming back to life" in a recipient's body, meaning, they are no longer in need of burial (Weiner, 213). Moreover, because transplantation must be done quickly after death, there is no delay in burying people who are organ donors. Even if there was, the obligation to save a life overrides rabbinic laws around speedy burials.

Another objection lies in the prohibition against benefiting from or desecrating a corpse. This type of benefit (i.e. the preservation of life), however, is certainly allowed, so long as the donor willfully consented. Further, the procedures required to extract these organs are not what is meant by "desecration," which more accurately refers to negative, senseless destruction (Weiner, 213).

In the case of healthy, living, individuals, organ donation is considered a righteous act, and saving a life is a *mitzvah* ("obligation"). Given the degree of risk involved, however, it is by no means required, and is even forbidden in cases where doing so would be life-threatening for the donor. While pikuah nefesh charges Jews with responsibility for the lives of others, it does not promote the sacrifice of one's own.

17.3 Jewish Practices and Rituals Surrounding Death

Much of Jewish practice and ritual marks time and transition. In the evening prayer service (*ma'ariv*), Jews praise God for "rolling light away from darkness and darkness away from light," as the sun sets and nightfall approaches. When Jews light candles on Friday evenings to usher in the Sabbath day of rest, they are marking a distinction between Shabbat and the surrounding weekdays. In traditional Jewish homes, even doorposts, which physically mark the transition between one room and the next, are imbued with ritual significance, since Jews traditionally affix *mezuzot* onto them (little boxes containing passages of scripture). It is no surprise, then, that Judaism has a whole host of rituals and practices surrounding death, which can be understood to be the time in one's life when the sun sets and nightfall approaches, when work stops and eternal rest begins, and when one transitions from the room of this world to whatever is next.

17.3.1 Preceding Death

Biqqur Holim, or "visiting the sick," is considered a *mitzvah*, or "obligation." One rabbinic source claims that the visitor relieves one-sixtieth of the patient's suffering (Midrash, Leviticus Rabbah 34). Judaism recognizes the crucial role any concerned person can play in alleviating the suffering of another. Along these lines, many synagogues organize biqqur holim committees in the hopes that none of its members should have to suffer alone.

It is worth mentioning here some of the things that a Jewish patient might find particularly helpful in a visit, whether that be by a professionally trained chaplain, a family member, or a friend. The recitation of psalms (liturgical poems found in the "Writings" section of the Hebrew Bible) might help bring comfort, as they contain themes that tend to resonate with patients' experiences. These include calling out to God in times of distress, divine protection, and healing. The Book of Job is a similarly salient text, as it explores the nature of suffering and faith.

Prayer is another way to offer support to Jewish patients, keeping in mind that beliefs and attitudes toward prayer vary from person to person. For those who want to pray, the *Mi Sheberah* blessing is particularly appropriate. It asks God to send complete healing of body and soul to the sick person, whose name may be inserted into the blessing. Interestingly, most Jews have far more experience (and thus, comfort) with fixed, ordered prayer than they do with spontaneous, personalized prayer. While inviting or helping to facilitate the latter might be most welcome, it is generally more common for Jews who are seeking prayer to turn to the traditional liturgy. Observant Jews might also want to pray three times a day, in accordance with *halakhah* (Jewish law). Chaplains or visitors can help these patients do so by ensuring that they have access to a *siddur* (Jewish daily prayer book), a *tallit* (ritual prayer shawl), and *tefillin* (phylacteries, or leather straps with boxes containing passages from scripture inside), though not everyone will want or request these items.

Jewish patients might also want to be given the means to celebrate Shabbat every Friday night and Saturday. Some hospitals offer Shabbat kits, which include the relevant ritual components like *challah* (braided egg bread), grape juice, and electric candles (since most hospitals forbid standard candles due to fire regulations). Finally, Jews who observe the traditional dietary laws of *kashrut* may be in need of certified kosher food, or, if offered, a kosher meal plan. This, however, goes a bit beyond the scope of visitation.

Hospital visits are difficult for many reasons. It can be very hard to find the "right words" to say to someone we care about, who is suffering. This is because there often are no "right words." Instead of demonstrating care by attempting to "fix" the unfixable, visitors are encouraged to offer a compassionate presence and a listening ear. This can be an effective way of signalling to patients enduring respect and a sincere desire to empathize with what they are going through. Some people may want to share with visitors the details of their hospitalization or medical condition, while others may want to discuss anything but that. Often, just talking to patients about the same topics one would if they were well can be a powerful way of affirming their humanity and bringing comfort.

Jewish tradition adds one forbidden topic of discussion. Visitors (in this case, generally family members) may not discuss funeral arrangements amongst themselves or any such plans in the presence of a dying patient, even if the patient is unconscious, since this can be seen as a form of hastening death. Some also avoid this topic because they believe that everything is in God's hands, so it is not one's place to presume when death will occur. While it is certainly true that families confront a sea of logistical concerns in the aftermath of a loss and may be tempted to get a "head start," traditional Judaism considers every moment of life to be precious and discourages such discussion in the presence of the dying.

It may be overwhelming to think in terms of visitation "do's" and "don'ts." At the end of the day, there are many meaningful ways to support Jewish patients. For the majority of people, it is simply the compassionate, empathetic presence of a friend or family member engaging in biqqur holim that accomplishes the most.

17.3.2 Death

There is one prayer that is traditionally reserved for the moment of death. This is the *Vidduy* ("confessional"), the core of which is the *Shema*, Judaism's central creed affirming the oneness of God. The purpose of Vidduy is to give dying patients the opportunity to reconcile with the divine and to cleanse themselves spiritually of sins. Patients are encouraged to pause between the prayers that comprise the Vidduy and offer their own words so that nothing may be left unsaid, whether that be to God or to the people around them. This can take the form of apologies, expressions of love, gratitude, and forgiveness, or anything else the patient wants to communicate, if able.

The tradition also encourages, where possible, that the words of the Shema be the last ones uttered with one's dying breath. In addition to affirming God's oneness, the creed also bespeaks the unity of all things, which aligns with the Vidduy's overarching theme of reconciliation (Diamant, 40). When patients are unable to pray the Vidduy themselves, but close ones know or suspect that this would have been desired, Jewish tradition considers it just as valid for the Vidduy to be recited by another party on the patient's behalf (Yoreh Deah, 338). Language should not be thought of as a barrier, as these prayers are equally acceptable in their translations. Prayer and ritual, however, should never be forced on patients, who may very well have no interest in them.

There are many practices that have historically been done at the moment of death. These include closing the eyes and mouth of the deceased (once death has been confirmed), straightening the limbs, laying the deceased on the floor with feet facing the door, opening windows, lighting a candle, and pouring out water. Many of these originated as superstitions and folkways aimed at protecting the soul and guiding it on its way (Diamant, 48). While some have lost traction in modern times or should not be performed in a hospital setting, others remain meaningful ways to uphold the dignity of the deceased or represent the loss symbolically. Another meaningful practice is to open the hands of the deceased to enact the following rabbinic insight: "A baby enters the world with closed hands. A person leaves the world with open hands. The first says 'The world is mine.' The second says, 'I can take nothing with me'" (Midrash, Ecclesiastes Rabbah).

There are two other, far more common, practices performed after death. The first is the recitation of *Tziduk ha-Din*. This prayer acknowledges God as the one true judge. Some people take comfort in the notion that everything is in God's hands. Others refuse to understand death, particularly when acutely tragic, as God's decree. Still, others embrace prayer as a way to draw close to the divine in a time of loss. The other practice is *kriyah*, or the rending of a garment or symbolic black ribbon (explained further below). This is an outward expression of grief that can be traced back to biblical times (Genesis 37:34). It also serves to represent the bereaved individual's broken heart (Diamant, 72). Different customs inform when to perform kriyah. Some tear their clothes as an immediate response to learning of the death, some do it at the cemetery, and some, like certain groups of Sephardi Jews, wait until returning home from the funeral (Wolfson, 154).

Like everything else, one should keep in mind that these practices run the gambit of being immensely significant to some, unimportant or rejected by others, and everything in between.

17.3.3 After Death

Following death, Judaism prioritizes *kevod ha-met*, meaning, “respect for the dead.” While the emotional needs of surviving friends and family must certainly be addressed, Judaism recognizes that this is an especially uncertain and overwhelming time, even in cases where death was expected. In the immediate aftermath, many people are not emotionally ready to receive words of comfort, no matter how sincerely given. Traditional Judaism therefore postpones the comforting stage until after the body is buried. From the moment of death up until the moment the funeral ends, the deceased’s family is in a stage called *anninut*, or “deep sorrow.” They are exempt from any obligation outside of honoring the dead. Ideally, this gives them the opportunity to begin to process their loss and focus on the flurry of logistical tasks that awaits them. Friends and community members are encouraged to help with these burdens to the extent that they can.

One way to help is by volunteering to fulfill the mitzvah of *shemirah*, or “guarding” the body. The remains of a departed soul is likened to a Torah scroll, which, even after retirement from use, is treated as sacred (Lamm, 3). In traditional Judaism, it is considered disrespectful to leave one’s remains unaccompanied. For this reason, synagogues often form what is called a *hevra keddisha*, or “sacred society” comprised of unpaid, anonymous volunteers who take it upon themselves to carry out ritual obligations of preparing the body for burial. Members of the hevra keddisha accompany the body to the mortuary and take shifts sitting inside or just outside the room, generally reciting psalms. Jewish funeral homes may also offer this as a paid service, however because they are generally staffed around-the-clock, some people do not feel the need to arrange for shemirah (Diamant, 55).

Another end-of-life practice typically performed by a Jewish mortuary or hevra kedisha is that of *taharah*, or the ritual purification of the body. This involves cleansing the body, dressing it, and placing it in a coffin. The notion that a dead body emits ritual impurity traces back to the Torah (Numbers 19:11), prompting the need to “purify” the deceased’s remains. This is performed with utmost respect for the dignity of the dead. Modesty and privacy are maintained by ensuring that the genital areas are covered by a sheet and that those performing taharah share the same sex as the deceased. Practices have also been updated to meet the needs of transgender and gender non-conforming individuals in this regard [Toward a Gender-Inclusive Hevra Kedisha” by Keshet]. Lastly, taharah is also significant in that, during life, many Jews visit a *mikveh*, or ritual bath, to cleanse themselves spiritually and to mark transitions in their lives. Taharah makes similar use of water to underscore this ultimate transition.

Jews are traditionally dressed in a *kittel* (simple white robe) or *takhrikhim* (plain white shrouds) for burial. They may also be laid to rest wearing *talitot* (prayer shawls) with cut fringes, indicating that they are no longer bound by the commandments (Diamant, 59). Modern Jews might prefer to be buried in a favorite suit or dress, but others embrace the socially equalizing effect of traditional shrouds with its powerful reminder that “I can take nothing with me.” The choice of shrouds dates back to the *Talmud* [Babylonian Talmud, Ketubbot 8b], or oral law, and attempts to avoid the scenario where one who cannot afford to bury a loved one in fancy clothing would endure embarrassment. It also recognizes that the pressure to bury a loved one ornately often adds to the already substantial financial burdens that come with death. This is also, in part, the reasoning behind the Jewish custom of burial in plain pine box coffins. Those with the means and desire to purchase more elegant coffins can certainly do so, but it is generally encouraged, instead, to select plain pine and donate *tzedakah* (charity) to a cause that was meaningful to the deceased.

The use of plain pine boxes also stems from the biblical verse: "For dust you are, and to dust you will return" (Genesis 3:19). This kind of coffin minimizes the separation between body and earth and encourages natural decay. Holes are bored into the bottom of the coffin to further increase this connection, and some Jews also follow the custom of placing dirt from the state of Israel inside. Plain pine coffins are also an environmentally responsible choice because they require less energy to make than metal caskets, and disintegrate in the ground. Burial in mausoleums is traditionally prohibited because it impedes this return to dust, but because there is a severe shortage of area for burial in large cities, increasing its cost significantly, many rabbis now permit such burial ["Alternative Kevura Methods," by Rabbi Jeremy Kalmanofsky]. Embalming and cremation are traditionally prohibited because they involve acts that are considered desecrations of the body. In light of the Holocaust, many Jews avoid cremation because it evokes the image of the crematoria used by Nazis in concentration camps. Concerns about bodily desecration also motivate Judaism's discouragement of autopsies, which scar, unless they are legally required or can be used in order to help others (Diamant, 60).

Judaism takes very seriously the obligation to honor the dead. In fact, respect for the dead is regarded as the ultimate act of loving-kindness because it is the only one that cannot possibly be reciprocated.

17.3.4 The Funeral

A Jewish funeral (or *levayah*, meaning, "accompaniment") resembles, in many ways, what most might expect from any other religious burial ceremony. There is a service that includes psalms and prayers. There is a eulogy recalling positive qualities of the deceased. Family members and close friends are invited to fill the space with memories and with tears. The body is interred. Closing remarks are made, as well as final prayers. In the end, guests are generally invited back to the mourner's home, where they come bearing food, comfort, love, and support.

Zooming in more closely, however, one finds certain features that make traditional Jewish funerals distinct. The most immediately apparent is how soon after death the funeral tends to occur. Prompt burials are understood to be biblically commanded by the verse: "You shall bury him the same day (…) His body should not remain all night" (Deut. 21:23). While various circumstances make same-day burials near impossible, and while funerals are halakhically forbidden on Shabbat and other holidays, Judaism remains committed to burying the body as soon after death as possible.

The use of cosmetics on the deceased is discouraged. It is also unnecessary in a traditional Jewish funeral, which discourages an open casket. Closed-casket ceremonies are preferable in that they avoid any risk of dishonoring the dead through the public display of the body after it has already begun to decay (a process that begins rather quickly after death).

The graveside proceedings are imbued with ritual. First, it is considered an honor to serve as a pallbearer and help carry the coffin to its eternal resting place. It is customary for pallbearers to stop in their tracks three or seven times between the hearse and the gravesite in order to display reticence to the act of burying a loved one. Even if the funeral itself occurs promptly, the act of burial should be carried out with awe and reluctance.

If the rending of garments and the recitation of the Tziduk ha-Din prayer (mentioned above) have not already been done, they are commonly performed at graveside or immediately after the funeral (Diamant, 72). These can be done with the help of officiating clergy. Historically, kriyah involved the tearing of one's physical garment. While this is still in practice today, many tear a symbolic black ribbon instead, which they wear throughout their mourning period.

It is actually a mitzvah for family members to bury their dead themselves. This is a notoriously painful experience, and many note that the dreadful sound of the dirt crashing down on the wood of the coffin is never forgotten. At the same time, this act often helps family and friends confront the reality of their loss and the finality of death. While no one should be forced to participate, especially when doing so would prove traumatic, Jewish tradition finds special meaning in personally burying loved ones. It is customary for each participant to remove the shovel from the soil themselves, without passing it from one to the other. Each member shovels dirt at least three times, the first time with the shovel inverted so that only the back of the blade is used. This mirrors the reluctance of the pallbearers and is another way to lovingly slow down the internment process, indicating no rush to carry out the duty.

Jewish tradition does not actually encourage leaving flowers at the grave of a loved one. Instead, it is common practice to set down small rocks and stones as a marker and sign of respect. Some may also follow the Iranian-Jewish custom of sprinkling rose water on the grave (Wolfson, 154). While flowers certainly offer beauty and a sense of continued life, it is once again encouraged to forgo lavish bouquets and to donate charity in their place, if able, in honor of the deceased.

Once the body has been buried, the bereaved formally transition from the anninut stage (explained above) to that of *aveilut*, or "mourning." It is the hope that at this juncture, after having fulfilled obligations owed the dead, the bereaved can finally begin to focus on the need to mourn. A few key moments at the end of the funeral formally mark this shift in stages. One is the recitation of the *Mourner's Kaddish.* This is a prayer that will be recited frequently in the days to come, but is said for the first time after burial. It is only recited in the presence of a *minyan* (quorum of ten Jewish adults), which is one of the ways in which Judaism encourages mourners to rely on the power of community to support them through their grief. By that same token, it is also one of the ways in which Judaism charges the community to stand with its mourners.

Another practice that marks this change in status from *onen* (one who is in anninut) to *avel* (one who is in aveilut) is hand-washing. This is typically done at the end of the funeral or upon returning home. Once again, as in taharah, water is used to symbolically cleanse and signify transition. One final marker of this shift is the recessional that concludes the funeral. Guests form two rows so that compassionate eyes and friendly faces meet the bereaved as they make their exit. They then offer Judaism's traditional words of consolation and comfort, which in English translates to: "May God comfort you among the mourners of Zion and Jerusalem." With this, the community officially undergoes a transition, as well. While everyone's priority up until this point has been honoring the dead, friends and neighbors now direct their full energies toward comforting the mourner.

17.3.5 Victims of Suicide

Evolving understandings of the nature of mental illness and suicide have heralded modern departures from what used to be practiced in the name of traditional Judaism. Because the body is seen as God's property and not one's own, Judaism strongly prohibits suicide. Those who clearly and intentionally took their own lives were historically buried at least six feet away from other graves or in a separate section of the cemetery (Lamm, 219) to shun the act and discourage its perpetuation. Meanwhile, the bereaved were always meant to be treated with empathy and support. As contemporary society has advanced its understanding that mental illness, like physical illness, is a medical condition that should not be stigmatized, it is clear that victims of suicide are deserving not of rebuke but of compassion. Most Jewish authorities now shun this discriminatory burial practice and discourage its perpetuation. Victims of suicide are to be afforded all of the same burial honors and respect given to anyone else (Wolfson, 155).

17.3.6 Mourning

It is impossible to prescribe a set amount of time for mourning that could ever be universally "sufficient." Each individual experiences grief differently, and it is safe to say that one never fully recovers from a loss. That said, traditional Judaism does set forth specific timetables for ritual mourning aimed at shepherding the bereaved through the "valley of the shadow of death" (Psalm 23) and back into the realm of the living.

The first of these stages is called *shiva*, which comes from the Hebrew word for "seven," since it lasts for one week. Shiva begins immediately following the funeral, and generally commences with a *seudat havra'ah*, or "meal of condolence," facilitated by friends and neighbors. This typically takes place at the home of the primary mourner. There is a rabbinic custom to serve circular foods at the meal like eggs or round cakes (Shulhan Arukh, Yoreh Deah 378:1), which invoke the cyclical nature of life (Diamant, 118).

Generally speaking, friends continue to visit every late afternoon/early evening to "sit shiva" with the mourners throughout the course of the week. These gatherings generally include eating, praying the afternoon and evening services (which gives the bereaved the opportunity to recite the Mourner's Kaddish), offering comfort, and filling the space with memories and stories of the deceased. Telling stories about the deceased not only honors the dead, but also serves the living, as it can help facilitate a much-needed cry, or even some much-needed laughter. It may also help one begin to separate oneself psychologically from the departed, as one starts processing the loss. Families observing shiva can always limit the number of guests and request alone time when needed.

There are a variety of mourning customs, each with its own unique symbolic and practical significance. Some, like covering mirrors and refraining from haircuts, shaving, and the use of cosmetics, effectively minimize vanity and promote inward reflection (Diamant, 116). Others are restrictions designed to remove distractions from, and impediments to, the grieving process. These include taking off work or school (if able), and abstaining from sexual intercourse, Torah study (considered one of life's great joys), watching television, shopping, and playing games (Diamant, 119). Still other practices are understood to be outward displays of grief and humility like sitting low to the ground (hence the phrase "sitting shiva") and not wearing leather shoes (historically seen as a sign of luxury). Some mourners light a seven-day memorial candle, symbolic of the divine spark, or soul, which has departed the world (Diamant, 117). All public mourning rituals are suspended on Shabbat.

Perhaps the most well-known custom is that of reciting the Mourner's Kaddish, or "kaddish" for short. Traditionally speaking, one recites the prayer as part of the morning service and then again during the afternoon and evening services held during shiva at home. Those who are unable to gather at least ten Jewish adults each morning and evening at their home may wish to attend morning and evening minyan ("quorum," or prayer service) at their synagogue. If they do not belong to one, they will be welcome at any synagogue where these services take place. Some Jewish circles ascribe to the mystical belief that all departed souls spend a certain amount of time in *Gehenna*, which can ostensibly be likened to purgatory (see more below). According to this belief, reciting kaddish shortens the amount of time a soul spends there (Diamant, 28), offering a compelling reason for the bereaved to recite it with disciplined regularity. A less mystical but similarly compelling reason why many Jews recite kaddish is that it plugs them into community and offers structure, routine, and support in a chaotic time. Interestingly, the actual words of the prayer praise God and make no mention of death. While there are many interpretations as to why that is, one is that the prayer seeks to foster connection between the mourner and the divine at the precise moment when this connection might be most vulnerable.

After one recites kaddish at morning minyan on the seventh day, it is customary for those assembled at minyan to walk the mourner around the block as a symbolic and literal return to the "world of the living." Community members may once again offer the traditional words of consolation: "May God comfort you among the mourners of Zion and Jerusalem." This concludes the formal shiva period. It bears repeating that there is no uniform Jewish mourning practice. Some observe three days or only one day of shiva. Others forgo it altogether. There is no "correct way" to grieve.

For purposes of mourning, Jewish law defines seven categories of people as close relatives: mother and father (parent), daughter and son (child), sister and brother (sibling), and spouse. If the deceased was any of such close relatives, then one's traditional mourning period and practices extend to a full month from the day of the funeral. This stage is called *shloshim*, or "thirty," referring to the days in a month. From the end of shiva and during the rest of shloshim, one may resume certain activities that were prohibited during shiva, such as returning to work or school, while other limitations remain in effect. The goal is for the bereaved to slowly transition back into the sphere of daily life. So, one may decide to attend a wedding ceremony during shloshim, but may choose to leave before the reception, since the festive spirit of a party clashes with the tone of bereavement.

One's mourning period extends to a full year (*shanah*) if the deceased is a parent. This means that children who wish to follow traditional halakhah recite Mourner's Kaddish every day for eleven or twelve months (depending on custom). In the strictest sense, this entails praying with a minyan for all three services daily. This may prove exceedingly difficult for such a considerable amount of time, especially for the many Jews who do not typically engage in communal prayer three times daily. Still others describe this experience as nothing short of transformative.

Traditional Judaism offers a timetable for mourning based on one's relationship to the deceased. While grief does not miraculously disappear after one week, one month, or even one year, Judaism attempts to balance one's need to mourn with one's eventual need to resume a productive life of meaning and joy. Recognizing that feelings of loss are permanent, Jewish tradition also prescribes annual rituals outside of the formal mourning period that commemorate the anniversary of a death, which is called a *yartzheit*. This date is typically observed by lighting a twenty-four-hour candle, reciting special prayers or psalms, giving charity, or visiting the gravesite. A Mizrachi custom (originating in the Middle East and North Africa), is to host an *Azkarah*, meaning "memorial," or a meal in honor of the departed, which generally includes Torah learning and speeches about the deceased. An Ashkenazi custom (originating in Germany, France, and Eastern Europe) is to add a special memorial service called *Yizkor* into the formal synagogue service four times a year, allowing individuals to recite prayers on behalf of the dead. In these ways and more, Jewish tradition designates sacred time and space to remember that which is never forgotten.

17.4 The Afterlife: Jewish Views and Beliefs

Judaism does not purport to know what happens after death. The Torah and rabbinic texts focus extensively on even the most minute details of life in this world, but when it comes to the afterlife, there simply is no consensus or definitive answer. Some may find this disappointing. Others may find it honest. Either way, traditional Judaism concerns itself more with living meaningfully and ethically in this world than it does with questions about what comes next.

That said, Judaism is by no means indifferent to the topic. On the contrary, the medieval philosopher and scholar, Maimonides, identified thirteen core principles of the Jewish faith and included belief in the resurrection of the dead among them. Jews who pray the traditional daily liturgy bless God “who gives life to the dead.” There is, therefore, a rich body of thought concerning the afterlife in traditional Judaism, with a whole spectrum of views and beliefs.

On one end is the conviction that life ends when the body does. This was the position of the Sadducees, a Jewish sect that was influential in the second century BCE, but which dissolved around 70 CE. The Sadducees rejected the notion of life after death, championing more of a “what you see is what you get” mentality. While seemingly morbid, this position can certainly motivate one to live life to the fullest, harboring no expectation of things to come.

By contrast, the Pharisees, a rival Jewish sect that endured and laid the groundwork for what has become modern rabbinic Judaism, affirmed the notion of a world to come, or “*olam ha-ba*.” While this is not synonymous with a Christian conception of “Heaven,” the world to come is also believed to be a place where the injustices of this world are corrected for and peace prevails.

This is closely connected to the concept of *Messiah*, which is deeply rooted in Judaism. The tradition is split, however, on what, exactly, Messiah means. One school holds that this refers to a heroic human figure, from the line of King David, who will be sent by God to herald an era of peace and a return to Zion**.** This can be contrasted with the Christian belief in Jesus as Messiah who brings a remission of sins, since Judaism does not ascribe divinity to this human figure. The other school holds that Messiah refers not to a person but to a time of peace, justice, and worship of God, which will be ushered in by righteous behavior.

While there is no Jewish conception of “Hell,” there are Biblical references to “*sheol*,” (Gen. 37:35, Num. 16:33, among others) which appears to be an underground pit where the dead go. Rabbinic literature also depicts *Gehenom*, an actual valley near Jerusalem, as a place of punishment for the dead (Wolfson, 301). These, however, lack any reference to eternal damnation or perennial suffering.

Resurrection of the dead is another facet of Jewish belief in an afterlife. One traditional view is that when the body dies, the soul returns to God, its divine source. At a later time, however, God will resurrect physical bodies, and restore these souls to their prior homes (Lamm, 228). Maimonides, however, rejects the notion of bodily resurrection and asserts that a person’s identity after death will be in a spiritual body, instead. Filling in details and offering alternative views, Jewish mystical traditions, like *Kabbalah*, offer further insights into the soul’s journey after life ends. This includes a belief in reincarnation, a topic that warrants deeper discussion beyond the scope of this summary.

On the far less mystical end of the spectrum is the belief that life after death means living on through the memories of loved ones and through the legacy one leaves behind. This may include meaningful projects and works, children, students, and anyone else upon whom one leaves a lasting impact. By saying Kaddish, lighting a yahrzeit candle, or living according to values that were important to the deceased, one plays an important role in symbolically giving life to the dead.

To return to the story that began this chapter, it is said that Jews follow the teachings of Rabbi Hillel in this world, but will follow the teachings of Rabbi Shammai in the world to come. Rabbi Hillel is a great scholar who embraces the prospective convert at his doorstep and is known for often interpreting the law more leniently, perhaps to better accommodate human imperfection. Rabbi Shammai, on the other hand, is the one who shoos away the short-cut-seeking student. This likely stems from Rabbi Shammai's proclivity for strict interpretation of the law, and perhaps higher demand of human behavior. This paints another picture of the world to come, wherein we are finally able to achieve Rabbi Shammai's impossible standard for us. Those who believe in an afterlife that resembles a celestial house of study or return to the Garden of Eden may take great comfort in the thought of departed loved ones probing the secrets of Torah, accessing that which was previously beyond reach.

Judaism offers much more of an array of views and beliefs about the afterlife than it does one clear picture. At the end of the day, there is just no way to know. When Jewish patients, nearing the end of life, engage a medical or spiritual professional on the topic of the afterlife, it might be most helpful to invite a discussion about the patient's own thoughts and beliefs on the subject. If a patient genuinely seeks an answer, "on one foot," it might suffice to say that Judaism recognizes life as a gift from the Creator. When life ends, there is certainly reason to believe that the divine spark in us reunites with its holy source.

Suggested Reading

Books

1. A time to mourn, a time to comfort by Dr. Ron Wolfson, LongHill Partners, Inc (2005)
2. Weiner RJ (2017) Jewish guide to practical medical decision-making. Urim Publications
3. Saying Kaddish: How to comfort the dying, bury the dead, and mourn as a jew by Anita Diamant, copyright © 1998 by Anita Diamant. Used by permission of Schocken Books, an imprint of the Knopf Doubleday Publishing Group, a division of Penguin Random House LLC. All rights reserved
4. The Jewish way in death and mourning by Rabbi Maurice Lamm, copyright 1969, 2000 by arrangement with Jonathan David Publishers, Inc. www.jdbooks.com

Articles

5. Reisner RA. A halakhic ethic of care for the terminally Ill
6. Dorff RE. A Jewish approach to end-stage medical care
7. Kalmanofsky RJ. Alternative kevura methods
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9. Cynthia X, Pan MD, FACP, AGSF et al (2020) Can Orthodox Jewish patients undergo palliative extubation? a challenging ethics case study. J Pain Symptom Manag 60(6):1263
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Islam

18

Mona Mojtahedzadeh and Hassan Qureshi

Contents

18.1 History of Islam

Islam is one of the religions of the book, others being Judaism, Christianity, and Sabianism. It is the second largest religion in the world, the first being Christianity. The followers of Islam are called Muslims, and they are the descendants of Abraham, known as prophet Ibrahim in Islam. Islam is a strictly monotheistic religion,

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C. Banerjee (ed.), *Understanding End of Life Practices: Perspectives on Communication, Religion and Culture*, Cancer Treatment and Research 187,
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meaning belief in one God (Allah). Prophet Ibrahim is the father of Arab people, and Islam originated in Arab countries. Prophet Ibrahim's sons, Isaac and Ishmael (Isma'il in Islam), are linked to Judaism and Islam, respectively [1].

Islam originated in Mecca and Medina, two Arab cities in the seventh century CE. According to Islamic beliefs, prophet Muhammad (PBUH) is the last prophet sent by God, and Muslims believe in all prophets sent before Prophet Muhammad (PBUH). However, their faith is different from previous religions preached by prophets in a way that Muslims believe that Allah completed the religions by sending Prophet Muhammad (PBUH) and Islam is a return to the original preaching of all prophets. Islam is the youngest religion of the religions of the book and the last one to be sent by Allah in the world for the guidance of humanity. The word Islam itself means "submission to the will of Allah" [2, 3].

Islam started in the seventh century CE when Prophet Muhammad (PBUH) who was born in the house of a respected figure of Quraysh tribe in Mecca. His paternal grandfather, Abd al-Muttalib, was one of the heads of Quraysh tribe. At that time, Quraysh tribe was living in Mecca and looking after Khana Kaaba, the house of Allah, and was highly respected. Prophet Muhammad (PBUH) was looked after by his paternal grandfather after birth because his (PBUH) father had died before the birth [4].

Prophet Muhammad (PBUH) was known for being truthful and honest in society. Impressed by his truthfulness and honesty, a successful Arab business women Khadijah bint Khuwaylid married him (PBUH) when she was 40 years old widow and Prophet Muhammad (PBUH) was 25 years old. This set an example of breaking stereotypes of marrying older and widowed women [4].

Prophet Muhammad (PBUH) was married to Khadijah when he (PBUH) had his first prophecy. He was meditating in the Cave of Hira when an angel, named Gabriel, came there in 610 A.D. when Muhammad was at the age of 40. The angel asked the prophet (PBUH) to say the words sent by Allah. *"Read. In the name of the Lord who created. Created man from Clot. It is the lord the most merciful/bountiful. Who taught by the pen. Taught man that which he knew not."* This was the first time and then the prophet (PBUH) kept getting revelation by Allah all his life over a period of 23 years through angels. These revelations were preached to the people in Mecca and were compiled in a book, the Holy Quran, that has a high religious significance for Muslims. It includes 114 Suras also known as chapters and 6616 Ayahs or verses, all preserved in original Arabic for the past 1400 years [4–6].

Islam progressively spread throughout most of the Arabia and beyond, as far west as Spain, as far north and east of China and Central Asia, and as far South as North Africa. Along with this came Islamic law and relevant health-related beliefs and practices. Caliphate system was followed in Islam and the caliphs were the leaders of Muslims after the death of Prophet (PBUH) at the age of 63 in Madinah. Around the year 661 CE, disagreements initiated over who would be the main caliph after Muhammad splitting off the followers into Shia and Sunni Muslims and later the Sufis based on their Calif. Islam has four main caliphs—Abu Bakr, Umar, Uthman, and Ali. Most Muslims today are Sunni (85%) believing Abu-Bakr, one of Mulammed's closest companions, as Calif. This is followed by Shia

(10–13%, represented mainly by Iran, Iraq, Pakistan, Lebanon), and Sufi. Based on the 2012 Pew Research Center, about 20% of Muslims indicate that they are simply "just Muslims" [7]. After these main caliphs, Islam had many prominent figures, meant to be elected by the people, that led Muslims all over the world and preached the teachings of Islam in all continents [8]. The core practice of Islam; however, is based on the laws of Islam as ruled in the Quran [6].

There are five pillars of Islam—believing in one God and Prophet Muhammad (PBUH) being the last prophet, offering prayers five times a day, giving money to needy people called Zakat in Islam, fasting in the name of Allah in the month of Ramadan, and performing Hajj which is a pilgrimage to Mecca that affording people are obligated to perform [9]. Islamic teachings are a complete way of life that guides Muslims in all aspects and situations. The main sources of knowledge are the Quran sent by Allah, the way of Prophet's life that is called Sunnah, and the knowledge shared by the Prophet (PBUH) himself that is called Hadith. Frequent remembrance of God, trust in God as the most powerful, endurance, forgiveness, unity, and the act of kindness with other fellow humans regardless of their faith, nationality, and occupation are some of the Islamic values [6].

Muslims believe in life hereafter. They have a strong belief that there would be a day of judgement and all humans will be judged based on their deeds on that day by Allah. People with good deeds will go to Jannah, while those with bad deeds will be punished. Therefore, they follow the code of life sent by Allah that allows them to be on the right path. All instructions about the code of life are clearly given to Muslims [10]. There is guidance available in every aspect related to social and personal life. Moreover, Islamic scholars are there to help find the answers. Islamic scholars also give rulings as per Islamic teachings and help implement Sharia. Sharia law is Islamic law that is implemented in many Muslim countries that ensures that people are adopting an Islamic lifestyle and have been given an opportunity to practice Islam in the best possible way.

18.2 Beliefs Around the End of Life

As mentioned before, Muslims believe that the end of this life is the start of the life hereafter. According to Islamic beliefs, this life is temporary, and its purpose is to test the servants of Allah. God has provided Muslims with Islam and following the religious teachings to please Allah is the purpose of this life. Anything that goes against the teachings of Islam can be a reason to displease Allah [11].

However, Muslims also have a strong belief that Allah is very kind and merciful and he forgives whenever someone asks for forgiveness. Therefore, it is appreciated to repent, ask for forgiveness and return to Allah whenever possible before the end of life. Some of the sins are unforgivable in Islam, such as Shirk, i.e., polytheism or worship of anyone except Allah.

In Islam, it is Allah who has the power to give and take life. This decision is solely Allah and humans cannot choose this for themselves. Once a person dies, his life after death begins. This life is called Akhirah [12]. Dead bodies are buried in the soil in Islam, and Muslims believe that the body stays in the grave till the day of judgement or Yawm al-din. According to Islamic beliefs, there are many signs that will appear before the day of judgement to warn people that the time is nearing. This will give them an opportunity to choose the right path before the day arrives. On the day of judgement, an angel named Israfil will blow a trumpet, and the bodies will be raised from their graves. All the humans who have ever existed in the world will gather in a ground. This ground is called the plain of Arafat or Maidan e Arafat. All humans who will be raised from their graves will be naked, so nothing can be hidden. Also, a book of their deeds will also be handed over to them that will have the details of their good and bad deeds. Everybody will be asked to read that book loudly one by one. The book of deeds can be given in the right or left hand. The ones who will be holding the book in the right hand will go to heaven, and those who will be holding the book in the left hand will go to hell. The life there is permanent. After this temporary life, all humans will live forever in the heaven or hell depending on their deeds. Muslims also have a belief that people who would have embraced Islam in their lives and repented will be eventually forgiven after completing a period of punishment in the hell and will eventually be sent to Jannah or heaven [13].

In Jannah, humans will be able to get whatever they desire. The beauty and luxury of Jannah is mentioned various times in the Quran. This gives Muslims a motivation to earn good deeds in their lives. Also, the doors of forgiveness will be closed on the day of judgement and no one will be forgiven after that. Therefore, Quran reminds to repent on the sins and come to the path of Allah multiple times [14, 15].

Moreover, the Prophet (PBUH) will be present on the day of judgement and will be backing his community, also known as Ummah in Islam. He (PBUH) will ask Allah to forgive his Ummah. Allah will not reject Prophet's request.

Muslims spend their lives according to the teachings of Islam to live in Jannah after this temporary life. They believe that the luxuries and comforts of this life are temporary, and they should not spoil their afterlife for the luxuries of this world. According to Islam, the luxuries of this life are a trap and a test for humans. Whoever will successfully pass the test by not indulging in the comforts and Haram (forbidden) in Islam will be rewarded for it. The Quran mentions many incentives for people who spend their time in this world as a servant of Allah.

18.3 Preparation Around the Time of Death

According to Islamic teachings, a Muslim should never forget death and should know that his life and death is in the hands of Allah. Allah can take his life whenever He decides. Therefore, a Muslim should always be prepared for death. For a Muslim who believes in afterlife, the fear of death is associated with his preparation for death. A well-prepared person who knows that he has pleased Allah in his life and has repented over his sins along with seeking Allah's forgiveness would not fear death. On the other hand, someone who has more wrongdoings would be fearful.

In Islam, a person can repent, seek forgiveness, and correct his wrongdoings until death. Therefore, the preparation around the time of death is considered very important for afterlife. Even if a person has not done anything right in his life but repents on his death bed, his sins will be forgiven as Allah is very merciful. According to Islamic beliefs, Allah loves humans 70 times more than a mother. This has been narrated in a hadith. Therefore, whenever a person asks for forgiveness with all his heart and true intention, Allah always listens.

The preparation of death goes on throughout the life. According to an Imam (leader) of Muslims, Imam 'Ali bin Abu Talib, the preparation of death is about completing one's obligations, staying away from Haram (forbidden), and being noble. However, the time around death is crucial and certain rituals are followed by Muslims when a person is on the death bed.

First of all, a person can make a will to distribute what he owns. One-third of it can be given to whoever a person wants, while two-thirds must be given to the children and heirs. Secondly, a person can make a list of all his obligations that he failed to complete but someone can complete them for him after death. These obligations include missed prayers, missed fasts, and Hajj or pilgrimage to Mecca [16].

When a person is going to die, he should lie on his back with his feet facing the Kaaba (called Qibla in Islam). If a person is bedridden or paralyzed, his family or people around him can do this for him.

Some Muslims also believe in giving Zamzam water at the time of death to ease the pain while Azrael, the angel of death, takes the soul away. Also, the person should recite Kalima for the declaration of faith. It carries a great value to recite Kalima before death as it signifies dying with faith in Allah and refreshing the faith. There is also a statement of faraj that can be recited around the time of death [16].

People sitting around the dying person are also advised to recite some Surah from the Quran to ease the pain of the dying person and to make his afterlife easy. There are many Quranic verses that are recited for this purpose. Moreover, the person can also be shifted to the place where he used to pray during his life. All of these things are recommended and according to Muslim beliefs, they help the dying person during the process of death and after it [16].

18.4 Funeral Practices and Burials

Once a person has died, some of the actions are recommended immediately. These include closing the eyes and mouth of the dead person and tying the jaw, straightening the arms by the side, straightening the legs, covering the dead body, keeping the room well-lit, making arrangements for the funeral immediately, and informing friends and family and other Muslims to attend the funeral prayer of the dead.

There are three major things that are done after a person dies. These are ghusl, kafan, and dafan. In Islam, ghusl means bathing the dead body, kafan means shrouding the dead body, and dafan means burying the dead body. These actions are obligatory.

Three ghusl (baths) are given to a Muslim dead body. The first one is with berry leaves mixed with water, the second one is with camphor mixed with water, and the third one is with pure water. The directions have also been given to select the right quantity of leaves and camphor. The quantity should not be too small to not be seen I the water or too much to get completely mixed with water [17].

In the first step of ghusl, all dirt and grease should be cleaned from the body to ensure that the water touches the skin of the dead. Also, dead body should be laid in such a way that the soles of feet are towards Qiblah. In step two, the person who has been designated to bathe the dead body should make an intention for the deed, known as Niyyat in Islam. In the first bath, the person should mention while making the intention that he is going to wash with berry leaves mixed with water. The same should be followed while washing with camphor mixed with water and pure water [18].

The persons who are designated for this task must be Muslims. Person or people giving the bath to the dead body are not allowed to look at the private part as it is Haram (forbidden), and private part should not be left uncovered. The bath should be started from head followed by neck, right side of the body and left side of the body. It is recommended to recite Quranic verses while giving bath. It is forbidden to perform this obligatory task for money. Once the ghusl is complete, camphor is applied to certain parts of the body including the forehead, palm, knees and toes. It is a basic method of performing ghusl of dead body in Islam. However, the details can differ among different sects [18].

After the ghusl (bath) has been completed, the next step is kafan (shrouding). In shrouding, three pieces of cloth are mandatory. Some other pieces can also be used. Kafan is usually white and the fabric should not be too thin. After the body is completely shrouded, the skin should not be visible through the cloth [18].

Three obligatory pieces that are used to cover the body include a loin cloth, a shirt, and a sheet. The line cloth is used around the loin area like an apron. The second piece which is shirt-like covers from the shoulders till the knees. The third piece of cloth is a big sheet which is wrapped around the body and tied. Some additional pieces of clothes can also be used but these are not mandatory. A head scarf can be used for females and a turban can be used for males. A piece of cloth can also be used to cover the breasts in the females. Lastly, a big outer sheet can be used to cover the mandatory pieces of cloth. Quranic verses should also be recited while shrouding the dead body [18].

Once the process of bathing the dead body and shrouding is completed then the last step before burial is performed. This step is a prayer that is offered before burial, and it is called Salatul Mayyit or Namaz i Janaza in Islam. The prayer is offered in a congregation and only male Muslims take part in it. The dead body is placed on its back with the head towards right side and feet towards left side in front of the people who are going to say this prayer. People stand in rows in front of the body. The prayer leader (Imam in Islam) stands near abdomen of the male and chest of the female dead body, and leads the prayer [19].

After the prayer is complete, the process of burial starts. The body is carried to a graveyard. A Muslim dead body can only be buried in a Muslim graveyard. The body is laid in the grave turned towards right with its face towards Qibla. When the body of a female is laid in the grave, it is advised to cover it with a piece of cloth, so men who are not her close blood relations or husband cannot see her. Some verses called Talqin are also recited in the ear of dead body before closing the grave. After that, the grave is covered with the soil and shaped. Then family members sprinkle water over it and recite some Quranic verses and Surahs [19].

This is a basic and simple version of funeral practices and burial in Islam. The details can differ among different sects.

18.5 Islamic Beliefs, Afterlife, and Their Considerations in Medical Settings

Islamic beliefs about death and afterlife need to be considered in medical settings while the patient is a Muslim. In Islam, Halal (permissible) and Haram (forbidden) are clearly mentioned, and Muslims are supposed to follow this while getting a medical treatment.

For a medical practitioner, it is important to understand Islamic beliefs related to medical care in order to provide religiously appropriate treatment without hurting religious sentiments. Being the second largest religion in the world, the importance of understanding Islamic culture and beliefs is undeniable [20]. Being culturally and religiously competent is vital for a clinician while treating patients and specifically critically ill patients. In Quran, it is mentioned clearly that Allah does not burden a soul beyond its capacity. In Islam, suffering is considered a test of Allah and is not meant to punish a soul. Islam stresses on relieving pain and suffering. It is not permissible to suffer intentionally and Allah dislikes if someone intentionally chooses to suffer [21]. Therefore, medical treatment is highly important in Muslim faith to please Allah.

As mentioned in the sections before, afterlife carries a great value in Islam as they believe in the life hereafter and that their good deeds and wrongdoings can impact their life after death. A medical practitioner should understand how the medical treatment can go against the Islamic teachings and should try to stick to what is the best as it can have certain implications in Islam. It is obligatory in Islam to give life-saving treatments to a patient who can be saved [22].

18.6 Current Recommendations for CPR, Intubation, DNR, and DNI for Muslims

There are various life-saving treatments that are performed in a hospital setting on terminally ill patients. However, many cultural and religious beliefs can impact the choice of these treatments. As mentioned before, Halal (permissible) and Haram (forbidden) is clearly mentioned in Islam, and the guidance about all the Halal treatments is available. Also, there are many Muslim scholars that can help answer questions if there is any confusion regarding a treatment.

Cardiopulmonary resuscitation is a life-sustaining treatment (LST). In Islam, withdrawing any kind of life-saving treatment is Haram (forbidden), and that means performing CPR is completely permissible. However, not performing CPR when a patient's life can be saved is not allowed. It is obligatory for a clinician to perform CPR on a Muslim patient where required. Also, some Muslim scholars say that CPR should be performed even on the patients with brain death as they do not consider it a complete death [23].

Similarly, intubation is carried out to help the patient respire. In some patients, not performing intubation can lead to death. Therefore, intubation is also a life-saving and life-sustaining treatment. Intubation should be performed on a Muslim patient to save life, and it is permissible [23]. Intubation is carried out in all Muslim countries around the world.

Do not resuscitate (DNR) is one of the advanced directives in medicine. A patient can take the decision to not be resuscitated (DNR) or his clinician can decide this depending on the prognosis of cardiopulmonary resuscitation (CPR) in every given case of a seriously ill patient. Talking about the role of DNR in a Muslim patient, many fatwas are available that allow DNR orders in a terminally ill patient. For example, Fatwa no. 12086 in Saudi Arabia allows DNR and has been implemented in hospitals [23, 24]. Fatwa is a ruling issued by a cleric in Islam. This fatwa describes that "if three knowledgeable and trustworthy physicians agreed that the patient condition is hopeless; the life-supporting machines can be withheld or withdrawn. The family members' opinion is not included in decision-making as they are not qualified to make such decisions." Also, the fatwa describes six situations in which DNR is permissible. These situations include if the patient arrives dead at hospital, if DNR is already decided and mentioned on the file, if three clinicians reach the conclusion that DNR has no prognosis, if the patient is mentally and physically terminally ill with no prognosis and have had multiple cardiac arrests if the patient has an untreatable brain damage, and if cardiopulmonary resuscitation would not help patient and rather increase suffering. The Islamic Medical Association of North America (IMANA) states that if death cannot be avoided as declared by the clinicians who treat a terminally ill patient then no such life-saving procedures should be performed [23].

Do not intubate (DNI) is another advanced directive. It means that the patient can be resuscitated using chest compressions and life-saving drugs but should not be intubated to ventilate. Just as DNR, this decision can also be taken by the patient or clinicians. Islamic scholars state that life-saving treatments should not be performed if futile. Therefore, DNI is also permissible in Islam in certain situations where clinicians have determined that performing intubation would not change the outcome and would rather prolong the suffering of the patient [25].

Islam is a religion of peace, and it believes in easing the pain and suffering. Therefore, most life-saving treatments are allowed and in practice on Muslim patients. However, there are certain circumstances where the life-saving interventions are futile and can be a source of more suffering for an ailing patient. These certain situations are clearly described by Muslim scholars, and it is only permissible to withdraw such life-saving treatments in those situations.

18.7 Euthanasia in Islam

Euthanasia, also called mercy killing or assisted suicide in general terms, is a practice of helping a person die to ease their pain and suffering. This practice is legal in many regions in the world and is performed where suited. However, Islamic views are different about euthanasia.

In Islam, suicide is a Haram (forbidden) practice, and people who commit suicide will be punished for it in their afterlife. One Hadith says, “and do not kill yourselves. Allah is the most merciful to you.” Euthanasia is an act where you assist a person in committing suicide. Moreover, you are killing a person too for no reason which is not allowed in Islam. Quran says, “and kill not anyone whom God has forbidden, except for a just cause (according to Islamic law).” In a hadith, the Prophet (PBUH) said, “If anyone killed a person—not in retaliation of murder, or (and) to spread mischief in the land—it would be as if he killed all mankind, and if anyone saved a life, it would be as if he saved the life of all mankind.” Islam is a religion that encourage saving lives. It does not favor killing people. Therefore, euthanasia is Haram (forbidden) in Islam [25, 26]. Also, people who will be assisting in euthanasia like hospital staff are also considered murderers because in Islam, the people who stand by and let such a crime happen are also considered culprits [26].

According to Islamic beliefs, Allah tests humans by outing them in difficult situations and illness is one of them. Therefore, those who are ill should be patient. The Quran says, “Be sure that We shall test you with something of fear and hunger, some loss in goods or lives or the fruits of your toil but give glad tidings to those who patiently persevere.” Euthanasia is against Islamic beliefs and it equates to failing the test that Allah has put you in. Islam teaches that only Allah has the authority to give and take life. No human has that authority to take his life or assist someone in taking his life. Not a single day can be added or removed from someone’s life and it will end when Allah will want [26]. Euthanasia has no place in Islam and killing someone is a punishable crime according to Sharia law.

18.8 Total Parenteral Nutrition (TPN) and Tube Feedings in Islam

Total parenteral nutrition (TPN) is a process in which a patient who is unable to intake food via mouth are given nutritional products intravenously. In this method, the nutritional products enter the bloodstream directly rather than going to the stomach and gut and getting absorbed in the blood after digestion. Therefore, this type of nutrition is given to patients who are unable to tolerate oral diet or the gastrointestinal tract is not working properly. Tubing feed is another way of providing nutrition to patients who cannot take diet by their mouth. In this type of feeding, a tube is introduced in stomach or intestines via nose or abdomen in patients who cannot take diet orally but their gut is working properly [27, 28].

In Islam, it is clearly ordered to avoid any kind of activity that could harm the body. Also, it is clearly mentioned that a life should be saved, and efforts should never be stopped if they can help. Therefore, in patients who need hydration and nutrition to survive, it should never be withdrawn and should be given in other possible ways. In cases where oral feeding is not possible, total parenteral nutrition and tube feeding are Halal (permissible) in Islam. These methods are employed in all Muslim countries around the world to provide patients with hydration and nutrition to save their lives [29].

However, the benefits should always be weighed against the harms. Tube feeding or total parenteral nutrition (TPN) should never be withdrawn if the withdrawal can pose a threat to the patient’s life. But if this method of providing nutrition has more harm and can cause discomfort to patients rather than causing benefit then it should be reconsidered [29].

These methods of providing nutrition can come with various adverse effects and complications, such as aspiration, pneumonia, dyspepsia, and fluid overload, that can be bothersome for a patient. Therefore, in patients where TPN or tube feeding is not going to do any good and only increase suffering, it should be stopped. In Islam, where it has been directed to save a life as far as possible, it is also advised that futile efforts should not be made to delay death. So, in such cases, using tube feeding or TPN is not advisable [29]. This decision of withdrawing tube feeding and TPN in terminally ill patients with no benefits of nutrition is made with the input of the patient’s close relatives.

18.9 Comfort Extubation in Islam

In palliative care, comfort extubation or compassionate extubation (CE) is a process of removing endotracheal tube (ETT) attached to a mechanical ventilator in order to let a patient die naturally. It is considered a process to ease death and not an assisted suicide or euthanasia. The basic reason for comfort extubation is to shorten the patient’s suffering. It stops prolonging death and relieves pain or discomfort caused by ETT. This procedure is done after involving patients’ family and loved ones. Moreover, the process is made as comfortable as possible for the patient and his family to ensure a peaceful death [30].

In Islam, it is lawful to withdraw any treatment that is futile and only prolonging death without causing any benefit to the patient. Having said that, brain death is a recent concept in Islamic community, and it is unacceptable for most Muslims to withdraw treatment as it seems as interfering with the will of Allah. However, in 1986, on the occasion Third International Conference of Islamic Jurists, the brain death was declared as complete death [31].

While comfort extubation is carried out for the mere reason of alleviating any discomfort caused by ETT, it is not acceptable to carry it out in Islam. However, if the treatment is futile and not causing any benefit to the patient and rather causing harm then it can be carried out. Comfort extubation is done for the purpose of alleviating discomfort in most settings. Therefore, it is not acceptable in Islam. Moreover, there is no clear data available on comfort extubation and the topic has not been discussed exclusively. Based on general rulings about withdrawing a treatment, comfort extubation does not seem a good choice for Muslim patients and should not be carried out without discussing the religious aspect related to it with the family and close relatives of a Muslim.

18.9.1 Terminal Sedation and Terminal Extubation in Islam

Terminal sedation or palliative sedation is widely used in palliative medicine. Terminal sedation is given to terminally ill patients in the last days or hours of their lives in order to relieve pain, suffering, and anxiety. Terminal sedation allows a patient to die peacefully without any pain in the last few days or hours of his life [32]. Terminal extubation which is often wrongly mixed with comfort extubation is another practice in palliative medicine. In terminal extubation, the endotracheal tube (ETT) of a patient on ventilatory support is removed while removing all life-sustaining treatment while their use is considered futile [33].

Terminal sedation caused unconsciousness and therefore, there are concerns around it in Islam. Muslim scholars say that any kind of sedation that is given intentionally is Haram (forbidden) in Islam. There are many incidences of pious Muslims where they tolerated pain for Allah's reward in order to avoid intoxication and sedation caused by painkillers. Even for the pain management, opioid analgesic should be avoided at first for the sedation they cause. They should only be given if other painkillers fail to relieve intense pain [22].

However, if there is an absolute need for it, such as in surgery, only then a patient can be sedated. There are contradicting views around terminal sedation. It is like sedation carried out for surgery if it lasts for last few hours before death only. The major difference is that sedation for surgery is reversible and patient comes back to consciousness. But in terminal sedation, patient faces death. This permanent sedation can interfere with some religious aspects of death. For example, a patient who has been given terminal sedation would not be able to recite Kalima before death [22].

Some Islamic scholars say that terminal sedation is allowed in Islam under certain extreme circumstances. But terminal sedation is one of the topics that are in their initial stage of discussion, so available data is not vast [22].

Terminal extubation is also a relatively newer concept that is being discussed by Islamic scholars. However, brain-dead patients have been declared dead by some Muslim scholars in 1986 [28]. In a braindead patient, there is no chance of recovery and hence, all life-sustaining treatments are futile. Islam allows to withdraw a life-sustaining treatment in case of brain death or any other condition in which such efforts are futile and only prolong death and suffering of a patient. But the acceptance of terminal extubation is not very high among Muslim and it can contradict with their beliefs in most situations. Therefore, this decision is very sensitive and needs extensive discussion with the patient's close relatives in order to explore their religious concerns [34].

18.9.2 ESRD and Recommendations for Dialysis in Islam

End-stage renal disease (ESRD) is a condition in which kidneys cannot function and the decrease in function is as much that it can cause death in case dialysis or kidney transplant is not performed. It is a fairly common condition and affects 1500 people per million all over the world [35].

The condition is not uncommon among the Muslim population either. Therefore, a need for dialysis can arise. In case of a Muslim patient, the religious views should be explored before performing this procedure. According to Islamic views, a remedy should be sought for a suffering and a person should not do something that can harm him. Refusing dialysis can cause death in a patient of end-stage renal disease (ESRD). This is why refusing dialysis is equivalent to choosing death over remedy. In Islam, it is prohibited to not seek remedy when available [36]. It is Haram (forbidden) to choose to die over treatment, and he who does so will be punished. In Quran, it is mentioned in clear words: “Do not kill yourself, God is merciful to you. He who does so, we shall put him in hell. God shall do so”. Dialysis is widely carried out in all Muslim countries all over the world and is considered Halal (permissible).

18.9.3 History of Islam in Palliative Care Medicine

Hospice or palliative care medicine is an important branch of medicine that is getting more attention with time. The protocols of treating a terminally ill patients have changed over time. While there is a common code of practice in palliative medicine or hospice care, the religious consideration is vital. For a Muslim patient, a clinician should always consider Islamic laws and rulings in order to provide religiously appropriate remedies. In Islam, clear guidance is available on every matter. Some palliative procedures and activities are allowed in Islam while others are forbidden. In case of confusion, patient's attendants and relatives should be consulted and proper consent should be sought after counseling.

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Seventh-Day Adventists

19

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Contents

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19.1 Introduction

Seventh-day Adventists are Christians that accept the Bible as their only creed. Seventh-day Adventists are part of a movement resulting from the Protestant conviction of sola scriptura, which recognizes the Bible as the only standard of faith and practice for Christians [10]. The church founders emphasized evangelism, health, and religious and civil liberty. As a result, Seventh-day Adventists are among the fastest-growing denominations with about 22 million members worldwide, 1.2 million in North America alone. Seventh-day Adventists are one of the most racially and ethnically diverse American religious groups, consisting of 37% white, 32% black, 15% Hispanic, and 8% Asian congregants [6]. Seventh-day Adventists also have one of the largest healthcare systems and the largest hospital in North America [3].

Based on their interpretation of the Bible, Seventh-day Adventists hold several distinguishing beliefs. The Seventh-day Adventist name embeds two of their characteristic views. Seventh-day Adventists attend church on the Sabbath, the seventh day of the week, and they have eschatology surrounding the second advent of Jesus Christ. Seventh-day Adventists are premillennialists and believe that Jesus will physically return to the earth before the millennium described in the Bible. They use historicism to interpret Biblical prophecies, which associate symbols with persons, nations, and events.

William Miller, a Baptist preacher, is considered a substantial influence on Adventism. Miller became a farmer after serving in the War of 1812. The war events led him to an existential crisis, and he struggled with the idea of deism. When asked to read a sermon of an absent preacher, he had a conversion experience where he felt love from a personal Being.

This experience inspired Miller to study the Bible. He took particular interest in passages from the book of Daniel. From his study of Daniel 8:14, which reads, "…And he said unto me, unto two thousand and three hundred days; then shall the sanctuary be cleansed", Miller interpreted "the sanctuary be cleansed" to mean that the return of Christ to earth would occur on October 22, 1844. This non-event is described as "The Great Disappointment" and led to deep soul searching and loss of faith for many Millerites.

Following "The Great Disappointment," three small groups remained. One group believed there was no significance to the prophecy and that Jesus would come again soon but at an unknown time. Another group thought the prediction was correct but in a symbolic manner. The smallest third group believed the prophecy to be accurate, but the event was wrong, heralding not the return of Jesus Christ but that something else occurred on October 22, 1844. Seventh-day Adventists developed from this third group.

Hiram Edson, Joseph Bates, James and Ellen White, and J.N Andrews are considered the founders of the Seventh-day Adventist church. Hiram Edson, a Millerite New York farmer, responded to The Great Disappointment with prayer and extended Bible study. Through studying the books of Leviticus, Hebrews, and Revelation, Edson asserted that the Hebrew sanctuary services were symbolic of heavenly realities. Based on this understanding, Seventh-day Adventists believe that Jesus Christ has two phases of ministry. His life, death, and resurrection on earth serve as the only means of forgiveness of sins to those that accept Him by faith and offer a better understanding of God's love. His ministry as a High Priest in heaven serves the function of removing all sin and ultimate cleansing of sin. Edson's interpretation declares that Jesus' second phase of ministry, His work as High Priest, started on October 22, 1844, and will end with the soon return of Jesus and restoration of humanity to a world where sin will be no more.

Joseph Bates was a seaman and a revivalist minister. He converted while reading the Bible on one of his voyages. Bates was involved in various reforms, including temperance, and strongly supported abolition. Through prayer and Bible study, he concluded the Sabbath was instituted at creation as a memorial and will serve as a perpetual sign [1]. The Sabbath is observed as part of the Ten Commandments and described in Genesis and Exodus on the seventh day. Friday sunset to Saturday sunset is considered holy.

The Sabbath is time spent in reflection. Seventh-day Adventists engage in activities on the Sabbath, including congregational worship in church, gatherings of friends and family, and time spent in nature. Seventh-day Adventists see the Sabbath as an exercise in faith and a weekly rhythm for surrendering to God and restoration.

Ellen White was an influential leader and a prolific author, writing over 5000 articles and 40 books on topics ranging from theology and missions to education and nutrition. While there was much searching and defense around "The Great Disappointment," her central theological theme and focus were on God's Love. Ellen White's writings on Christian living shaped much of the Seventh-day Adventist lifestyle and culture. Many Seventh-day Adventists are vegetarian and abstain from alcohol and tobacco products. In response to her health reform messages, educational institutions and hospitals developed a form of medical evangelism. Loma Linda University, a prominent Seventh-day Adventist institution in Loma Linda, CA, is considered a "Blue Zone" with a large octogenarian concentration. Healthy eating and Sabbath-keeping are considered attributes to a long-life span [2].

While Seventh-day Adventists have distinctive beliefs, Seventh-day Adventists believe in these pillars:

1. God is Love, and there is only one God; the Father, the Son, and the Holy Spirit.
2. Salvation comes through faith alone, and this faith comes through the power of the Word and is a gift of God's grace. It is open and available to all and does not require membership in the church.
3. The Church's mission is to proclaim God's love to the world and the soon return of Jesus.
4. There is a promise for restoration in a fallen world.

19.2 Misunderstandings About Seventh-Day Adventists

People outside Seventh-day Adventism may see the church as non-Christian because of their characteristic beliefs. Sometimes people ask if Seventh-day Adventists are part of Judaism because of Sabbath observance. Conflating Seventh-day Adventism and Judaism is a misunderstanding because Seventh-day Adventists keep the Sabbath as it was instituted at creation before Judaism was distinguished. Furthermore, because behavior is part of Sabbath observance and included in the Ten Commandments, Seventh-day Adventists are misunderstood as legalistic.

Others may see Seventh-day Adventists as non-Christian because of the strong influence Ellen White had on developing the Seventh-day Adventist lifestyle and culture. While her writings are held in high regard today, none of her writings have contributed directly to church doctrine. Ellen White also took much time to emphasize that her writing was not to supersede the Bible or even equal to the Bible. She made clear that her writings should point to the Bible as the only source of truth.

19.3 Belief About Life

To understand how Seventh-day Adventists (SDA's) view death, we must first describe the SDA's belief about life. God formed man from the dust and breathed into him the breath of life forming a living soul. Dust + Breath = Living Soul (Life). Conversely, at the time of death, when the person ceases to breath, the breath of life returns to God and the body experiences death. "And the Lord God formed man of the dust of the ground and breathed into his nostrils the breath of life; and man became a living soul" (Genesis 2:7). "In the sweat of thy face shalt thou eat bread, till thou return unto the ground; for out of it was thou taken: for dust thou art, and unto dust shalt thou return" (Genesis 3:19).

19.4 Belief About Death

Because of this unique belief, SDA's differ from most Christian faiths in that they don't believe the human soul continues to exist outside the human body, either in heaven, hell or here on earth. Instead, the body is in a state of "sleep" waiting for Christ's second coming. The spirit will not ascend to heaven at the moment of death. "For the living know that they shall die: but the dead know not anything, neither have they any more a reward; for the memory of them is forgotten. Also, their love, and their hatred, and their envy, is now perished; neither have they any more a portion forever in anything that is done under the sun". (Ecclesiastes 9:5, 6) Adventists believe that death has been conquered by God. For this reason, Adventist Christians have hope they will be resurrected at the second coming. They are "hopeful, even confident, in the face of death, in spite of its ominous character. This is not because death itself is any less horrible than it first appears, but because something more powerful than death has conquered it [5].”

For this reason, SDA’s view of death is not something to be feared, but a celebration of their life, and ultimately looking forward to Jesus Christ’s return (Second coming). Once risen from the dead, they will meet with those who are alive in the clouds and return to heaven to live with God. “For this we say unto you by the Word of the Lord, that we which are alive and remain unto the coming of the Lord shall not prevent them which are asleep. For the Lord himself shall descend from heaven with a shout, with the voice of the archangel, and with the trump of God: and the dead in Christ shall rise first: Then we which are alive and remain shall be caught up together with them in the clouds. To meet the Lord in the air: and so shall we ever be with the Lord”. (1 Thessalonians 4:15–17).

19.5 Afterlife

Adventists do not believe that there is a life after death. People who die cease to exist physically, emotionally, and spiritually. They enter into nothingness. They are in a state of “sleep” until the second coming.

19.6 Considerations in the Medical Setting

“Seventh-day Adventists seek to address the ethical issues at the end of life in ways that demonstrate their faith in God as the Creator and Redeemer of life and that reveal how God’s grace has empowered them for acts of neighborly love. Seventh-day Adventists affirm God’s creation of human life, a wonderful gift worthy of being protected and sustained (Genesis 1–2). They also affirm God’s wonderful gift of redemption that provides eternal life for those who believe (John 3:15; 17:3). Thus, they support the use of modern medicine to extend human life in this world. However, this power should be used in compassionate ways that reveal God’s promise of eternal life in the earth made new, Christians need not cling anxiously to the last vestiges of life on this earth. Nor is it necessary to accept or offer all possible medical treatments that merely prolong the process of dying”. (A Statement Consensus on Care for the Dying. Seventh-day Adventist Church).

19.7 Death Determination

Seventh-Day Adventist medical institutions recognize and follow the legal standards of death determination; either irreversible cessation of cardiopulmonary function or complete, irreversible cessation of brain function.

19.8 Pain and Suffering

Comfort-focused care, relief of suffering/Withdrawal of life support.

"Christian love is practical and responsible. Such love does not deny faith nor obligate us to offer or to accept medical interventions whose burdens outweigh the probable benefits. For example, when medical care merely preserves bodily functions, without hope of returning a patient to mental awareness, it is futile and may, in good conscience, be withheld or withdrawn. Similarly, life-extending medical treatments may be omitted or stopped if they only add to the patient's suffering or needlessly prolong the process of dying. Any action taken should be in harmony with divine principles regarding the sanctity of life [7]."

Adventists believe in adequate relief of pain and suffering while avoiding active euthanasia. When it becomes evident that further life-sustaining medical interventions are non-beneficial and that continuation of such interventions would merely prolong the dying process, it is acceptable or even recommended to shift focus on comfort. This may include termination of ventilator support by compassionate extubation or removal of other medical devices that will not contribute to comfort of the patient. Adventist's support withholding or withdrawing medical interventions or life-sustaining measures that will only prolong suffering or the dying process. Adventist belief opposes active euthanasia. There is a clear moral distinction between allowing nature to take its course by forgoing artificial life-sustaining treatments and acting with an intention to actively terminate a person's life.

19.9 Withholding Nutrition

There is no stated belief regarding withholding nutrition. However, within Adventist medical institutions, withholding nutrition and hydration is generally acceptable when they do not sustain comfort, or they bring about more suffering at the end of life.

19.10 Decision Making Surrounding End-of-Life Care

"A person who is approaching the end of life, and is capable of understanding, deserves to know the truth about his or her condition, the treatment choices, and the possible outcomes. The truth should not be withheld but shared with Christian love and with sensitivity to the patient's personal and cultural circumstances (Instead, speaking the truth in love, we will grow to become in every respect the mature body of him who is the head, that is, Christ. Ephesians 4:15).

God has given human beings freedom of choice and asks them to use their freedom responsibly. Seventh-day Adventists believe that this freedom extends to decisions about medical care. After seeking divine guidance and considering the interests of those affected by the decision (For none of us lives for ourselves alone, and none of us dies for ourselves alone. Romans 14:7) as well as medical advice, a person who is capable of deciding should determine whether to accept or reject life-extending medical interventions. Such persons should not be forced to submit to medical treatment that they find unacceptable.

God's plan is for people to be nourished within a family and a faith community. Decisions about human life in the context of this statement are a personal matter and best made within the context of healthy family relationships after considering medical advice. When a dying person is unable to give consent or express preferences regarding medical intervention, such decisions should be made by someone chosen by the dying person. If no one has been chosen, someone close to the dying person should make the determination. Except in extraordinary circumstances, medical or legal professionals should defer decisions about medical interventions for a dying person to those closest to that individual. Wishes or decisions of the individual are best made in writing and should be in agreement with local legal standards regarding an advance medical directive or similar document [7].

19.11 Prior to Death—The Dying Process

There are no required practices at the time prior to death, however, for many SDA's it's a time of introspection and prayer. Although they believe God can perform miracles and heal the sick, the focus of prayer is on God's will and allowing His will to be done. During this time, SDA's will seek out their pastors and other clergy who will pray, sing hymns, meditate, anoint with oil, allow for confession, and read passages from the Bible. There is reassurance of God's love and how suffering was not God's initial plan. "Is any among you afflicted? Let him pray. Is there any merry? Let him sing psalms. Is any sick among you? Let him call for the elders of the church; and let them pray over him, anointing him with oil in the name of the Lord: And the prayer of faith shall save the sick, and the Lord shall raise him up; and if he has committed sins, they shall be forgiven him. Confess your faults one to another, and pray one for another, that ye may be healed. The effectual fervent prayer of a righteous man availeth much". (James 5:13–16).

19.12 End-of-Life Option

Seventh-day Adventists believe all human life is a gift from God and is considered sacred. God is the only one who takes life and gives it again (Deuteronomy 32:39). There is no published statement specifically regarding end-of-life option within the Seventh-day Adventist Church. Based on the biblical principles, generally, they do not support or participate in the act of active termination of life. However, should a person choose to end his/her life by pursuing the end-of-life option, church members should offer compassion and support for the dying.

19.13 Organ Donation

There is no church policy regarding organ donation. The decision is left up to the individual and or family.

19.14 Autopsy

There is no church policy regarding autopsy. It may be offered or accepted without objections.

19.15 Post-Mortem Care

There is no church policy for postmortem care. This is left up to the individual family. Seventh-day Adventists may hold viewing services, funerals, or memorial services at any time after their loved one dies. Adventists also have no specific beliefs about body preparation and may have whole-body burials or be cremated.

19.16 Funeral and Memorial Services

The focus is celebrating the life of the individual as they "sleep" awaiting the second coming of Jesus Christ and the resurrection. Many families look forward to reuniting with their loved ones and are reminded at the time of the services of God's promise to return and take us to heaven. "For God so loved the world, that he gave his only begotten Son, that whosoever believeth in him should not perish, but have everlasting life". (John 3:16) "And God shall wipe away all tears from their eyes; and there shall be no more death, neither sorrow, nor crying, neither shall there be any more pain: for the former things are passed away" (Revelation 21:4).

19.17 Bereavement

Adventists have no specific practices during bereavement. Despite the belief they will one day see their loved one again in the Second Coming, they may still experience expected grief of the loss of their loved one and may seek guidance and counseling from clergy and/or a counseling professional.

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Part III

Modern and Non-Traditional Approaches to End of Life

Spiritual Care

20

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Contents

20.1 Introduction and Definitions

Why is there a chapter entitled "Spiritual Care" in a book that is about cultural practices at the end of life? It would seem, on the one hand, that the entirety of this book is about this topic, and, on the other, that it would be impossible to capture the complexity of "spiritual care" in a single chapter. Thus far

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in this book, the reader has gained exposure to medical approaches to end-of-life care as well as a handful of *individual* cultural-religious practices. However, spirituality is broader than this. While religion is often institution-focused and carries a disciplined framework, spirituality is not necessarily institutionally-bound ([12], p. 1060). During a 2009 national consensus conference, Improving Quality Spiritual Care as a Domain of Palliative Care, the following definition emerged [24]:

> Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.

There are thousands of religions worldwide, and, as alluded to above, if we consider spirituality to encompass non-religious forms of expression, the possibilities are endless. The basis for this chapter's existence is simple: we live in a diverse and multicultural society; thus, the understanding of a handful of individual religions will not fully prepare an individual to appreciate and respond compassionately to that diversity of viewpoints.

The term "spiritual care" encompasses both care delivered within, and outside of, the framework of traditional religions. Thus, it can be delivered by individuals who do not represent any particular religious institution and delivered to patients who do not necessarily subscribe to any particular religion. Since much of this book is devoted to specific religious frameworks, we will not go into detail about these religions in our chapter. Instead, we will address spiritual care more broadly, as well as provide a more in-depth look at secular ways of approaching meaning. As such, we will primarily focus on modern spiritual care, and discuss historical trends and events to the extent that they have bearing on contemporary culture.

Spiritual care is regularly practiced not only by medical chaplains but by clinicians from every medical discipline. Furthermore, medical spiritual care at the end of life is only a piece of what spiritual care encompasses more broadly. Spiritual care is not always delivered within a medical context, and it can be delivered to individuals at all stages of life, not just at the end of life. This chapter will focus on the subset of spiritual care that is delivered to individuals within a medical context at the end of life. The medical specialty of Palliative Care is referenced several times throughout this chapter, and while some spiritual care practitioners will practice solidly within the bounds of this specialty, not all do.

The topic of spiritual distress and existential distress arises within this chapter. Though it should be recognized that this is not a chapter wholly about spiritual distress and that not all spiritual care at the end of life is delivered specifically to address suffering, exploring the topic of spiritual distress helps to frame conversations about what spiritual care *practically* accomplishes. Often, the presence of suffering represents the call for spiritual care, and in these situations, the intention of providing care is often to address this suffering.

For some readers, this chapter, this section, and the topics they comprise may uncomfortably stretch their personal understanding of spirituality, religion, and culture. Paying attention to this discomfort is productive, especially for the clinician-reader who may receive insight into his or her personal biases which can interfere with the delivery of compassionate, patient-oriented, and equitable care.

Finally, it should be said that this chapter is written from a Western and North American cultural perspective. With that said, the chapter is oriented toward a multi-cultural understanding of spirituality and attempts to acknowledge the vast influence that spirituality has not only on people belonging to specific religions but on many others as well.

20.2 Modern Chaplaincy

The concept of chaplains as spiritual representatives existing within secular organizations has existed for hundreds of years [11]. In the United States, although there is no central licensing body for medical chaplains, hiring organizations typically require a relevant degree (such as a master's degree) and the support of the religious organization to which the chaplain belongs (if any). In addition to this, there are clinical pastoral educational programs that encompass a 1600-h curriculum, 75% of which is direct clinical practice. Some hiring organizations require chaplaincy board certification, and there is also a specialty board certification available in hospice and palliative care. Modern chaplains receive training in how to provide spiritual screenings, take spiritual histories, formulate spiritual assessments, and offer tailored spiritual interventions. Models for spiritual assessments include the "SPIRIT" model and the "FICA" model ([12], p. 1062). The use of the term "chaplain" is being reconsidered in medical chaplaincy circles [35]; "spiritual care department" and "spiritual care provider" are more neutral terms, the use of which may improve access to spiritual care among non-religious individuals who are resistant to identification with traditional religion. Especially in secular organizations like non-religiously-affiliated hospitals, chaplains should be guided by ethical principles that promote equitable service to be provided to clients regardless of religious or cultural background and that prohibit proselytizing [11].

Modern chaplains serve a critical role within secular institutions that is distinct from that of spiritual authorities who exist more firmly within a specific traditional religious framework. Michelle Scheidt, a Senior Program Officer of the Fetzer Institute in Kalamazoo, Michigan, contends that as individuals become more disconnected from religion and unsure of where to turn with their spiritual questions, chaplains are well-equipped to address this need [10]. Even an individual who labels themselves as belonging to one particular religion or cultural tradition may benefit from exposure to an open approach to spirituality at the end of life, an approach that attempts to construct a unique and patient-centered spiritual support framework. Modern concepts of faith frequently acknowledge doubt of dogma as a normal and natural component of religious belief, as in the artist Barbara Kruger's assertion "Belief + Doubt = Sanity" [27]. Social science researcher Brené Brown, University of Houston Huffington Foundation Endowed Chair, discusses this concept in "The Gifts of Imperfection," stating "Faith is a place of mystery where we find the courage to believe in what we cannot see and the strength to let go of our fear of uncertainty" [8]. This may not be a uniquely modern concept, but the modern approach to this uncertainty can draw upon both traditional responses to doubt within faith, as well as secular and philosophical approaches, giving the practitioner a diversity of tools to address suffering that arises as a result of this. Chaplains may serve various roles in the context of a dying person's care, including offering philosophical and psychological support, bridging communication between family and loved ones, providing therapeutic presence for individuals and their loved ones during emotionally difficult times, and advocating for the dignity of the person throughout disability and at the point of death. With this said, for many individuals, the challenges to the individual's integrity posed by serious illness have spiritual meaning, and the service of a chaplain in this context may be symbolic and sacred rather than purely functional.

The Chaplaincy Innovation Lab at Brandeis University (https://chaplaincyinnovation.org/) and the Fetzer Institute (https://fetzer.org/) are organizations dedicated to developing chaplaincy as a cohesive profession and innovating the practice of spiritual care to meet the needs of modern individuals in a diverse society. Other resources include Transforming Chaplaincy (http://transformingchaplaincy.org/), which has sponsored the Hospice-Palliative Spiritual Care Research Network to promote research in this field [16–18].

20.3 Existentialism and Its Influence on Modern Bioethical Thinking and Spirituality

The "modern" age and all that it comprises, including modern spirituality, exists, in no small part, due to the Enlightenment. Our concepts of freedom and human rights, as well as the centrality to modern culture of individualism, autonomy, and rationality are rooted in this historical movement. It is partially through Enlightenment ideas and concepts that we can operate a diverse, multicultural, and complex modern society. While the Enlightenment emphasized the importance of these concepts, *Existentialism* was a philosophical movement that grappled with the personal distress that arose secondary to this newfound freedom. To be in charge of one's own life choices is both freeing and distressing. In the words of Søren Kierkegaard, one of the early existentialists, "anxiety is the dizziness of freedom." The frequency with which this quote is used to represent Kierkegaard and Existentialism exemplifies the habit of portraying existentialist philosophers as obsessed with "negative" aspects of human experience. Arguably, this has influenced how American medical culture has approached the concept of "existential distress." Often, the terms "spiritual distress" and "existential distress" are used interchangeably, and they are approached from a lens that focuses attention on the negativity engendered by these experiences, framing them as problems that can be "solved." But to the existentialists, though existential distress may be a problem of sorts, it is also central to what it means to be human. In a book chapter about the importance of Kierkegaard's philosophy to modern psychology's understanding of anxiety, Peter Slater explains that Kierkegaard believed that “anxiety informs us of the choices we have at hand” and represents an “opportunity for growth from a more self-centred [sic] need for immediacy to a more self-reflective, self-conscious state” [31].

What bearing does Existentialism have on modern spiritual care? In one vein, the complexity and diversity of existentialist thought can offer valuable insight to practitioners of spiritual care, especially when addressing the spiritual distress of atheists. This is because most of the existentialists spoke from a position that did not *presuppose* the existence of God(s) or the supernatural. In addition to this, the term “existential distress” would, at first glance, seem to directly refer to the type of distress with which existentialists were concerned. However, in common medical parlance, the term “existential distress” is often used to refer to distress regarding fear of dying, death itself, or non-existence, or it is used to refer to the sadness and loss that surrounds this. In many circumstances, “existential distress” in Palliative Care is used interchangeably with “spiritual distress,” and may specifically be used to refer to spiritual distress among atheists or other individuals who may not identify as spiritual. On the other hand, the “existential distress” that is central to Existentialism is of a different flavor.

As a contemporary historian of Existentialism, Sarah Bakewell has defined the philosophical movement thus: “[Existentialists] consider human existence different from the kind of being other things have…as a human I am whatever I choose to make of myself at every moment. I am free–and therefore I’m responsible for everything I do, a dizzying fact which causes–an anxiety inseparable from human existence itself…An existentialist who is also phenomenological provides no easy rules for dealing with this condition, but instead concentrates on describing lived experience as it presents itself. By describing experience well, he or she hopes to understand this existence and awaken us to ways of living more authentic lives” [3]. As Bakewell points out, many existentialists did not view this anxiety as a problem that could be eradicated—it is instead a function of our existence. This is an assertion which many may find difficult to accept: that humans are destined for a certain kind of existential anxiety. Lest this be written off as a necessarily depressing philosophical assertion, it is important to highlight the fact that existentialists, similar to Enlightenment thinkers before them, view free will as an essential and defining characteristic of humanity. Though this type of existential anxiety may not exclusively be linked to the experience of serious illness and dying, it certainly can manifest during this time in an individual’s life, especially in two specific ways: (1) the experience of anxiety regarding having to make medical choices or other important choices at the end of one’s life or a loved one’s life, and (2) the experience of regret or moral distress regarding past decisions made (sometimes decisions in the distant past) that turned out to have negative consequences for oneself or others. These examples of anxiety around what we might term “existential decisions” would appear to be exactly the type of distress to which Kierkegaard was referring.

Aside from this more common treatment of anxiety and distress in existentialist literature and philosophy, they also more directly discussed death at times. Jean-Paul Sartre viewed death as an inevitable and total destruction of that which he valued most: the experience of phenomena and the agency of free will. As Sartre wrote, “Death is an outrage that comes to me from outside and wipes out my projects” [29]. Simon de Beauvoir, Sartre’s longtime companion and an equally important existentialist voice, similarly viewed death as an affront to what she held dear [3]. Though some existentialists dealt with death differently (such as Martin Heidegger), it was life and *meaning* that they were most concerned with. One of the more pragmatic existentialist thinkers, Viktor Frankl, began to develop his “Logotherapy” psychotherapeutic technique in “Man’s Search for Meaning,” his book written based on observations from his experience in a Nazi death camp. While many of the most famous existentialist philosophers were not particularly concerned with trying to relieve human suffering per se, their philosophy can be argued to be essential to the development of modern psychology, which is *absolutely* focused on addressing human suffering. Psychotherapeutic techniques are critical within the context of spiritual care for dying individuals, highlighting the fact that the provision of spiritual care is not the exclusive purview of chaplains and spiritual authorities.

There is some inherent overlap between psychological distress and spiritual distress, and throughout the twentieth and twenty-first centuries, various psychotherapeutic schools and techniques have developed which focus around helping individuals explore the meaning of living. Frankl’s Logotherapy is one example, as are: meaning-centered psychotherapy, meaning-centered group therapy, life review therapy, and dignity therapy. These approaches address many of the same issues around meaning that traditional religions may address, but they do so within a framework that is ultimately secular. This continuum between traditional religion, philosophy, and psychology is important for the reader to recognize, as many modern individuals derive value from all three of these domains and may not internally differentiate between them.

As psychology and the study of human cognition become more sophisticated, the limits of autonomy and free choice are coming into clearer focus. The next section deals with the limits of autonomy, and how the ethical respect for autonomy must be balanced with that of other ethical principles.

20.4 The Intersection of Spirituality, Medical Decision-Making, and Bioethics: Why Spiritual Care is Foundational in the Treatment of Individuals with Serious Illness

Modern bioethics focuses around four primary ethical directives: beneficence (producing good), nonmaleficence (avoiding harm), autonomy (providing for freedom of choice), and justice (providing for equal opportunity) ([12], p. 325). This section, by taking a closer look at these directives, seeks to answer the question: what is the appropriate ethical stance of the spiritual care practitioner and the spiritual care community toward the suffering of dying people? End-of-life professionals will find themselves amidst profound suffering on a daily basis, and their personal and professional approach toward death, pain, compassion, and respect for individuality and dignity is constantly being tested.

Medical paternalism was the standard of practice through much of the twentieth century in communication between physicians and patients. Paternalism elevates beneficence and nonmaleficence above other ethical directives and excludes medical patients from the decision-making process. From the standpoint of modern bioethics, paternalism improperly ignores the important principle of autonomy in medical decision-making. In fact, respect for autonomy has taken on a leading role in medical culture for the past decades, to the extent that providers and systems may avoid supporting patients in their decision-making. This section makes four primary points: (1) that medical providers must be willing to discuss death with their patients in order to facilitate autonomous decision-making, (2) that advocating systematically for "dying well" can promote the interests of dying individuals without infringing on their autonomy, (3) that providers must attempt to address all forms of suffering, including existential and spiritual distress, both for its inherent beneficent value as well as to facilitate autonomy, and (4) that providers can *create* existential distress by abdicating the full weight of responsibility for choosing among medical treatments to the decision-maker in the name of "autonomy."

How people (or their legally recognized decision-makers) weigh treatment options is affected by their understanding of the medical circumstances. The fields of Geriatrics and Palliative Care have driven much of the recent research and innovation in communication with, and care for, these individuals in contemporary North American medical culture. In the formative years of the Palliative Care and Hospice movements, the majority of patients receiving palliative care were dying of malignancy. Type of illness has bearing on the physiological and functional trajectory ([12], p. 62), and individuals who die of cancer often have a long course of time between their diagnosis and the point at which they lose capacity to make complex medical decisions (in fact, many retain capacity until weeks or even days prior to their deaths). Illness type also affects how patients and their families experience anticipatory grief and bereavement. For example, the concept of "having cancer" implies a certain nearness of mortality. Thus, for years, palliative models of communication at the end of life were established through clinicians' interactions with individuals with cancer who had some implied sense that they were dying and who lived with this knowledge for an extended period of time, giving the clinicians more leeway in how directly to address mortality, and giving the clinicians more time to promote "prognostic awareness" which facilitates discussion of decision-making [19].

Palliative care research and practice continues to broaden its focus to individuals dying of other types of illness, such as neurological illness. As opposed to cancer, neurodegenerative conditions may render patients mentally incapacitated for years prior to death. Alternatively, accidental injury may render individuals severely neurologically compromised without any warning or preparation. Many chronic neurological illnesses, including dementia, are not known to the general public (and even many medical providers) to be terminal illnesses. The understanding of these different illness states affects how patients, their loved ones, and their health care team prepare for the future, as well as how they process grief. The spiritual care practitioner must be prepared to respond to both anticipatory grief prior to death as well as bereavement of a patient's loved ones after death. Additionally, *how* grief and spiritual suffering are addressed can impact how people make medical decisions. Some individuals are loath to have any discussions whatsoever that touch on the subject of their mortality. Compounding these communication difficulties is the fact that individuals, influenced by their circumstances and personal health literacy, can misinterpret information that is obscured by medical jargon. In the face of these challenges, in order to obtain informed consent, clinicians must ascertain whether the patient (or decision-maker) understands and appreciates their medical circumstances and the consequences of their decisions. This requires a discussion of mortality, prognosis, and values, in the context of having the patient's specific terminal illness. For the purpose of facilitating autonomy, our medical teams must address the issues that drive people away from talking about death, including spiritual pain.

In some circumstances, this kind of communication both relieves suffering and facilitates informed decision-making, thereby augmenting patients' autonomy. However, it is unrealistic to expect that a frank, full, and complete discussion of all of the issues surrounding mortality will be possible, let alone ethically advisable, with every single patient or their decision-maker. The resistance to discussing death for patients and family members can originate from a number of places, including religious edicts or concepts, denial, beliefs around what it means to "fight" for one's life versus "give up," values around loyalty to family/loved ones and non-abandonment, as well as anticipatory grief, fear of death, and spiritual pain. Some of these things are possible to address. Addressing spiritual distress may require discussion of both the fear and sadness surrounding death, as well as the gratitude for, and prioritization of, what is important for the individual in life (such as the goal-development strategy for which Karen Steinhauser and James Tulsky advocate) ([12], p. 82). The resistance of *some* patients to discussing death should not drive providers away from having these discussions with *other* patients who are open to such topics. As described by BJ Miller [34], some individuals may be averse to the discussion of and confrontation of death, but many *do* want to talk about this subject and benefit from this discussion. Thus, while we acknowledge the presence of variable levels of resistance to discussing death amongst *patients*, we do not condone resistance among *providers.*

Any discussion of beneficence at the end of life must consider the concept of a "good death." The qualitative experience of sickness and death matters: thus, it is only natural to discuss and qualify "good deaths" versus "bad deaths." The fact that this experience is qualitative, difficult to measure, and unique to each individual does not diminish its importance. Clearly, patients will define a good death in diverse ways, and spiritual care providers must orient themselves with respect to these differences. The Agency for Healthcare Research and Quality identifies patient-centered care as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" [30]. In order to respect autonomy, the definition of a good death must be patient-centered and thereby relative to an individual patient's value system. Though the clinical implications of using terminology that frames dying as "good" or "bad" is fraught with complexity ([12], p.81), this does not mean that the concept of a "good death" has no practical use. Both clinically, as well as in research and advocacy contexts, helping people "die well" is a way to operationalize the compassionate drive to alleviate suffering at the end of life.

As an analogy, consider the movement within medical research to focus on "patient-oriented outcomes," which underpin patient-centered care. While medical research has historically focused on studying outcomes that are considered to be important markers of health by researchers and clinicians, patient-oriented outcomes intend to represent what is important to patients themselves. Patient-oriented outcomes, especially in a research context, must be consensus-based, meaning that there is some agreement developed as to the outcomes that matter to patients and these are studied as "patient-oriented" outcomes. In this line of thinking, the assertion is not that all patients value one particular outcome, but simply that a large enough group of patients value an outcome to justify studying it. Thus, so too can the medical system and research community identify specific goals surrounding "dying well" for the *average* patient. People care about how they die: it is not paternalistic to advocate for interventions that facilitate *dying well* in the same way that it is not paternalistic to advocate for interventions that *improve quality of life* through the advancement of patient-oriented outcomes. Though individual patients may vary in their definition of a good death, system-wide advocacy for better dying is an appropriate application of the ethical principal of beneficence, and this broad approach for addressing suffering does not infringe on the autonomy of individuals to choose how they die within practical limitations.

Medical providers' concern about interfering with their patients' autonomy extends far beyond discussions around dying well. The fear of infringing on patient autonomy can interrupt the ability of providers to further the values of both beneficence *and autonomy* in their provision of medical treatments. Examples of this include (1) clinicians' failure to address spiritual distress when patients are ambivalent about whether they want help with their distress, and (2) clinicians' reluctance to make recommendations regarding medical treatments.

Regarding the first of these two issues, many patients experience heightened fear of death when they are aware of having a terminal illness. In order to enact the principle of beneficence, the clinician must at least attempt to address this fear (a form of suffering), while doing so in a manner that respects the patient's value system. Part of the art of providing spiritual care to a dying individual is knowing how to align with his or her values *in addition to* encouraging a healthy perspective. Likewise, it is the patient's prerogative to accept or decline any kind of assistance offered. Some patients will be extremely averse to discussing death and, ultimately, the clinician must respect a patient's autonomy to refuse any intervention offered.

However, there is an interplay between suffering and decision-making, and this relationship links the practice of beneficence to that of autonomy. The experience of suffering can significantly impact judgement, but patients who are suffering spiritually do not always ask for help and sometimes may express ambivalence about providers addressing spiritual issues. However, when successful, addressing these issues can be critical to facilitating truly autonomous decision-making by facilitating better judgement. The spiritual care practitioner, in paying attention to these issues, can have a profound effect on this process. As Allison Kestenbaum points out, chaplains, sometimes through their shear presence in a family meeting, can channel and bring to the surface many spiritual issues that interfere with decision-making [35]. Ultimately, the bond that clinicians and patients form through discussing and addressing their fears allows patients and their medical teams to develop a clearer perspective on how the patient's values can be best honored. In the guise of respecting autonomy, providers can sometimes risk neglecting their duty of beneficence toward relieving a patient's suffering and even complicate the very "autonomy" that they are trying to *respect*.

Finally, we consider the second form of reluctance alluded to above: clinicians resisting their duty to make recommendations about treatment decisions. One of the clearest examples of this is artificial life support, which, in the context of serious illness may delay death but will otherwise provide minimal benefit to the patient. Families or loved ones of patients on life support are caught in a situation that is foreign to everyday life, and they may be called upon to make decisions which they had never anticipated and never discussed directly with the patient. The modern medical system often leaves families and loved ones in difficult situations that increase spiritual distress, by initiating treatments like artificial life support, and then abdicating responsibility for decision-making to bewildered family and friends in the name of respecting autonomy. But these issues are not limited to decisions around life support. In one study of decision-making around treatments for advanced cancer, James Tulsky, Chair of the Department of Psychosocial Oncology and Palliative Care at the Dana-Farber Cancer Institute, observed, with the help of colleagues, communication between 70 triads of patients, caregivers, and oncologists [32]. Their findings indicated that only a minority of triads agreed on the goals of treatment, with oncologists tending to have a less optimistic judgement of whether the treatment may extend life. Tulsky concluded that "advanced cancer treatment decision-making occurs amid incomplete understanding among patients, caregivers, and oncologists."

Scott Halpern, the John M. Eisenberg Professor of Medicine, Epidemiology, and Medical Ethics and Health Policy at the University of Pennsylvania, similarly argues that placing such choices solely in the hands of decision-makers leaves them to make "existentially challenging decisions that will in many cases feel highly burdensome and leave them without sufficient guidance" [33]. Instead, he advocates for the role of "intentional mindful framing of choices around resuscitation or intubation preferences" and thus guiding patients and their surrogate decision-makers toward clinically-preferred medical choices. Scott Halpern and George Anesi provide a roadmap on how to execute this type of communication in an article on “choice architecture” or the concept of “nudging” decision-makers toward decisions that are more in-line with the average person’s values and goals [2]. Through primarily elevating the principle of autonomy without consideration for the limitations in individuals’ ability to appreciate complex medical information, medical professionals often provide non-beneficial care that harms patients, families, and clinicians, and consumes valuable resources that could be otherwise used in service of promoting efforts toward greater justice in health care (an important and often overlooked bioethical principle).

In conclusion, while patients and providers are not accustomed to openly discussing dying and death ([26], p. 126), patients must have information pertaining to their mortality in order to make decisions autonomously. Additionally, careful attending to values and goals is nearly impossible for patients who are overcome by spiritual pain. By addressing distress, the spiritual care provider can help patients more clearly advocate for what is important, exercise their autonomy, and ultimately, die well. In this way, addressing beneficence and autonomy provides synergistic benefits. Alternatively, providers who fully abdicate responsibility for decision-making to patients or their surrogate decision-makers can risk causing existential distress by presenting medical treatment options as choices. For surrogate decision makers, this could imply that they have the freedom to select a treatment pathway that would lead to the death of their loved one; this is not a choice that most people are willing or prepared to make. The critical flaw of Jean-Paul Sartre’s Existentialism is that individuals do not always possess the emotional and psychological resources to make existential choices without assistance. As providers and as a medical system, we must acknowledge the general limits of autonomy and work to identify these roadblocks to decision-making. In this way, the compassion that drives us to address suffering and promote beneficence can also allow for more authentically autonomous decision-making.

20.5 Alternative Cultural Approaches to “Finding” Meaning Within the Context of Serious Illness Care

Expressions of spirituality in modern North America are extremely diverse. Individuals from all backgrounds adapt principles from various traditional religious and cultural frameworks, sometimes mixing components. Prior to the advent of the concept of biomedicine, illness was often understood within the context of spirituality, rather than being wholly separate. Thus, even though the biomedical system carefully separates spirituality and medicine, for many patients, this dichotomy is more fluid or may simply not exist. This may contribute to the high utilization rates of alternative medical therapies around the world and within North America. In one systematic review of studies that surveyed utilization rates of complementary and alternative medical therapies among rich modernized societies in North America, Europe, Asia, and Australia, the average prevalence was found to be 32.2% [14]. The reviewed studies that contained follow-up data showed rates increasing over time. In most of these studies, higher levels of education and income were predictive of higher utilization rates, arguing against the idea among some medical professionals that education levels might reduce utilization of therapeutic methodologies that exist outside of the accepted “evidence-based” biomedical paradigm. In this way, belief in alternative therapies is an important aspect of how some people understand and address illness. The practitioners from which they seek these types of medical care come from diverse traditions, such as naturopathy, homeopathy, Reiki, Chinese Medicine, Ayurvedic Medicine, Yoga, and Qi Gong, among others.

These practices are approached in different ways. Some recipients view the practices as existing within the biomedical model, looking to controlled trials that may demonstrate efficacy in treatment. For example, Mindfulness-Based Cognitive Therapy and Mindfulness-Based Stress Reduction are psychological therapies that borrow from Buddhism but strip the techniques of their traditional ethical and religious context to bring their benefits to a non-Buddhist audience. Other practices may be recognized for their value purely because they seem to have a robust “placebo” effect, despite the acknowledgement that the practices may not have all of the advertised or intended benefits. Often, modalities are extracted, modified, and combined in different ways to suit a particular health need. The use of psychedelic substances for the therapeutic benefit of dying individuals provides an interesting case study demonstrating the complexity with which certain traditional culturally-specific spiritual and medical therapies interface with modern society and biomedicine.

20.6 Psychedelic Substances and Their Use in the Context of Serious Illness

Classic psychedelics became known to modern Western audiences and biomedicine in the mid-twentieth century. Predating this was the use of some of these substances within traditional cultures, including ayahuasca, psilocybin, and mescaline [26]. Psilocybin was used medicinally within Mexico predating Spanish colonization [25]. Interest in psychedelics in American culture expanded in the 1950s and 60s, including in the scientific community where they were examined for their efficacy in treating psychiatric illness and anxiety surrounding mortality [26]. The author Aldous Huxley was an early counter-cultural figure who wrote about his own use of psychedelics (a term for a class of hallucinogen that Huxley himself coined along with Humphry Osmond). Huxley died of laryngeal cancer in 1963 in his personal home in Beachwood Canyon, Los Angeles, and at the time of his death, he specifically requested for his wife, Laura Huxley, to administer lysergic acid diethylamide (LSD). This was an early and notable use of psychedelics at the end of life. To this day, his home remains a place of pilgrimage of sorts for advocates for medicinal psychedelic use [21]. Despite promising early scientific indications of success, the initial regulatory and cultural openness was followed by a backlash and their eventual addition to the Drug Enforcement Agency’s Schedule I classification for substances that the Agency considers to possess a high potential for abuse and “no currently accepted medical use” [13]. The complex socio-cultural reasons for this backlash have been considered and written about elsewhere [19, 21], and they persist to this day, as evidenced by continued legal prohibition and cultural skepticism that exceeds that of other psychoactive substances with clear evidence of risk of abuse potential and severe negative health effects (alcohol, tobacco) and even other types of hallucinogenic compounds (cannabis). In recent years, the study of these substances has been revived due to the increased availability of research licenses in the United States, as well as due to international work in this area. Ketamine, classified as a “dissociative” anesthetic but also having properties similar to psychedelics at certain doses, has been studied extensively and its esketamine enantiomer was approved by the FDA for treatment-resistant depression in intranasal spray form. The substance MDMA (3,4-Methylenedioxymethamphetamine), also with psychedelic properties, has been investigated in phase-3 trials for treatment of PTSD [37].

Most pertinent to our discussion here are the multiple properties of psychedelics that are relevant to care of individuals at the end of life, including: (1) they can have rapid effects on mood and anxiety (as opposed to traditional biomedical and psychological treatments which can take months to years to have full efficacy) [28], (2) many individuals describe deriving meaning from hallucinogenic experiences while under the influence of psychedelics, including profound effects on their relationships with loved ones, the material world, and their own mortality [26], and (3) these effects often persist well-beyond the serum half-life of these substances—one study showed persistent effects in over 80% of subjects at 6 months after a single dose [23, 28]. Though still early in the study of these compounds for specific use for spiritual distress at the end of life, the growing recognition of their rapid and prolonged efficacy in the treatment of a variety of psychological conditions may prove to be very useful within the context of terminal illness. Moreover, the way that individuals describe their experiences while under the influence of psychedelics goes beyond the emotional, and often includes references to spiritual and religious experiences [26]. In pilot studies of individuals with serious illness, psilocybin was found to have profound and lasting effects on distress surrounding anticipated mortality. One participant in a trial at New York University who was a self-described atheist reported that, during the trial, she felt “bathed in God’s love,” and despite remaining an atheist after the trial, she carried with her a sense of peace from this experience [15, 23, 28]. William A. Richards, a clinical psychologist at the Johns Hopkins Bayview Medical Center, one of the historical and contemporary centers for research on psychedelics, has documented his professional experience working with these agents in the context of care for dying individuals. He asserts that psychedelics can have a profound effect on physical and psychological pain: “The meaning of pain often shifts during psychedelic therapy from a threatening herald of death in the central focus of awareness to a sensation somewhere in the periphery of one’s field of consciousness…Repeatedly I have heard, ‘The pain is still there, but it doesn’t bother me like before’” ([26], page 135). Leaders within the medical specialty of Palliative Care have advocated for a fuller consideration of and study of these substances. Sunil Aggarwal, named a 2019 Emerging Leader of the American Academy of Hospice and Palliative Medicine (AAHPM), and Ira Byock, former president of the AAHPM and author of the seminal text "The Four Things that Matter Most" have both advocated for legally-sanctioned study of psychedelics for distress at the end of life [1, 9].

One of the important characteristics of psychological and spiritual pain is that they may not conform fully to the concept of *relief*. As existentialists argued, there are some kinds of distress that are an unavoidable part of being human. But the existentialists are not alone in this assertion. One important category of psychological and spiritual pain relevant to the experience of both dying individuals as well as to their loved ones is grief. Scholarship regarding grief has evolved over time from classifying it as something that has an endpoint, or a point of "closure," to something whose complexity frequently evades our attempts to "contain" it: as in grief researcher Pauline Boss' concept of "ambiguous grief" [4]. Boss writes, "While simplistic declarations of closure are comforting for bystanders, they are hurtful for the bereaved. If we have loved, we will want to remember" [6]. Boss' approach to addressing grief involves incorporating and subsuming it into a different understanding of our lives: the grief changes the individual and becomes a part of his or her life. Rather than the role of the spiritual care provider being the relief of grief, Alan Wolfelt, for example, advocates for a companionship approach to healing within the context of grief. In describing the compassionate response to the grieving of another, he asserts that "companioning is about being present to another person's pain,it is not about taking away the pain" [36]. Stephen Jenkinson, a preeminent counter-cultural voice in this arena, states, "Suffering, learning how to suffer, is how you make meaning from what seems random, chaotic, or pointless…Meaning comes from this kind of wrestling" [20]. Of all the psychologically, medicinally, and spiritually important properties of psychedelics, perhaps the most important is one that appears to be unique among psychotropic chemicals: psychedelics seem to be able to facilitate *catharsis* of certain kinds of distress without *erasing* the experience of distress itself. William A. Richards points out that "the confrontation of unresolved grief…is a common occurrence during the action of psychedelic substances," and that "claims of increased freedom and relaxation are often made following the catharsis of grief, not only for those who have lost loved ones in the past, but also prospectively for terminally ill people who also need to grieve the imminent loss of all they have known in life" [26]. The experience that psychedelics facilitate for the individual may allow him or her to reconstruct or reframe the understanding of the suffering, rendering it more meaningful and perhaps less painful.

20.7 The Meaning of Nature

Another important alternative source of meaning for individuals struggling with a feeling of powerlessness in the face of difficult life events, including death, is the experience of nature. The meaning of nature is very culturally specific. In the modern era, the term "sublime" has been used to describe certain natural landscapes. Modern use of the word "sublime" in English stems from a retranslation into English in 1712 of a second-century treatise "On the Sublime" attributed to the Greek author Longinus [7, 22]. Since this time, many an author has ascribed a kind of sacred, and often simultaneously non-religious, significance to natural landscapes that evoke an exhilarating awe in the individual experiencing them: vast deserts, jagged mountains, endless oceans. Connection with nature is often cited by atheists as an important source of spiritual meaning [12], but religions also highlight the meaning behind the sublime in nature. British essayist Alain de Botton has framed this phenomenon in both religious and secular terms [7]. Referencing the Book of Job, Botton raises the issue of Job's bewilderment as to why he has been made by God to suffer, citing God's response:

> Where wast thou when I laid the foundations of the earth? declare, if thou has understanding…
>
> By what way is the light parted, which scattereth the east wind upon the earth?
>
> Who hath divided a watercourse for the overflowing of waters, or a way for the lightning of thunder?.
>
> [5, 7]

While there are numerous interpretations of the book of Job, Botton highlights the manner in which God contrasts Job's limited viewpoint as an individual human being with the immensity and splendor of nature itself. Botton elaborates that, similar to the way that the Book of Job illustrates that "our lives are not the measure of all things" by pointing out the powerlessness of human agency in the face of natural phenomena, secular considerations of sublime natural places remind us that "we are the playthings of the forces that laid out the oceans and chiseled the mountains."

There is significant diversity in what individuals identify as meaningful and beautiful in nature. Botton's analysis is interesting in that it draws common threads of meaning through both traditional religious frameworks and secular frameworks, illustrating the fluidity with which concepts may traverse religious and secular realms. Stephen Jenkinson has also written about how shifting one's view of the sheer power of natural forces can offer a template for approaching one's own mortality:

"The sea…is malevolent and seems to have a taste for humans the moment there is a question of whether we will make it to the shore. But that idea…isn't what the sea means. The sea doesn't become any more itself when we go down in it, and its continuing ability to be the sea doesn't need humans awash, adrift, or at its bottom. We make that meaning when we fight the sea. A good seaman loves the sea at times, heeds its signs and its portends at other times, might even hate it when he loses his senses, and he comes to them later and realizes that it's something of himself that he's hating. He will always have a fine regard of its way of it being itself, no matter whether he approves of the current, the swell, or the squall of the moment" [20].

The sublimeness and immense power of natural phenomena can place human life in context. In Botton's words, "it is the vast spaces of nature that perhaps provide us with the finest, the most respectful reminder of all that exceeds us. If we spend time in them, they may help us to accept more graciously the great, unfathomable events that molest our lives and will inevitably return us to dust" [7].

20.8 Conclusion

Prescriptive and specific religious advice may not be welcome or helpful for modern individuals who do not strictly identify within a single religious tradition. Therefore, modern spiritual care must adapt a fluid and flexible form. Tools used by practitioners of modern spiritual care include facilitating connection with important people or places, helping individuals find resonance with rituals that provide meaning including alternative medical or spiritual therapies, psychological techniques that have been developed intentionally to address existential issues and anxiety at the end of life, as well as simple therapeutic presence. Compassionate care for dying individuals requires the sophisticated balancing of respect for autonomy with the beneficent drive to address and prevent suffering. Spiritual care is essential to this process.

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End-of-Life Doulas

21

Debbie Salgia and Sari Williams

Contents

21.1 What Is a Doula?

Doula is a Greek word meaning "experienced woman who helps other women" [4]. Historically the role was associated with birth and the people who assisted and accompanied women through this process in a non-medical way, both emotionally and physically. Doulas are involved in the birth plan and often in the post-natal period [4]. Due to their lack of formal medical training, a doula's care tends to be "invisible emotional labour and behind the scenes support" [4], and it is suggested that their companionship and *being* (as opposed to doing) result in safer and easier deliveries, savings on medical expenses and higher patient satisfaction. Because of doula's capacity for caregiving and companionship, one may consider the other end of life's spectrum and the need for an "end-of-life doula" (EOLD):

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a non-medical but professionally trained person that assists in the care of a terminally ill person physically, emotionally and spiritually, during the dying process. While a birth and death doula appear to be opposites, they share a common concern for some of the most vulnerable persons during milestone life events [4]. The role of an end-of-life doula has been described as complementary nursing care where one accompanies, mentors and advocates for the dying [3]. The attention towards end-of-life care comes at an interesting time with populations living longer, aging populations growing and the fact that funding and the social structure of society is changing. This attention is also likely in response to changing norms and desires about end-of-life concerns and care [5]. End-of-life doula care strives for balance in what is sometimes an unfortunate and excessive medicalization of end-of-life care [4] such that they provide non-medical care that focuses on quality versus quantity of life: the patient's social, emotional, practical and spiritual needs.

21.2 Doula Role Description

Similar to patient navigators, EOLD helps provide emotional support, promote information-sharing and assist the patient and family through complex health-related obstacles [6]. There is a theme of EOLD being a "unique care link" within a family in that they can assist with interpersonal relationships between the patient and spouse or other family members, have expertise through experience, provide emotional support, sustain relationships after the patient's death, and provide opportunity for family respite [2].

According to Rawlings et al. [6] and Krawczyk and Rush [5], most individuals identifying with an EOLD position are female and over half have health qualifications, mostly nursing, social work, or backgrounds in education. Other self-reported characteristics include having a broad range of life experiences specific to end-of-life, and a maturity fundamental to developing a flexible, compassionate and holistic relationship with clear boundaries and innate wisdom, conferring upon them an implicit knowledge [5]. A common motivator for becoming an EOLD was a personal experience of significant loss, and it was the experience of accompaniment itself that led them to pursue this role [5].

End-of-life doulas identify as companions, complementary to medical staff, and offer preventative care against loneliness in socially vulnerable patients [4]. They have called themselves death midwife, soul midwife, end of life consultant [5]. In a study of EOLDs conducted by Krawczyk and Rush [5], respondents described key characteristics of their scope including support, coordination, collaboration, navigation, mediation, guidance, and assessment and planning. Another valuable role was that of empowerment: increasing patient/family capacity to make end-of-life decisions, facilitating legacy projects, enriching community-based understanding of the dying process and the ability to reclaim dying in the home and enhancing death literacy in the community through death cafes, public speaking, free advanced care planning workshops. Rawlings et al. [6] described the role as "personalized care directly controlled by the dying person" that is intended to reduce the burden on family caregivers and provide individualized care.

An EOLDs role as defined by respondents in this survey was advocate, caregiver and companion entrusted with reducing fear and anxiety about the dying process, providing whole-person care and empowering individuals and families with information sufficient to make their own thoughtful decisions [5]. Others mentioned that they hold a compassionate space or offer unconditional positive regard [6]. There are many other terms for EOLDs including the Chinese term translating literally to "path of ease", the Japanese term end-of-life celebrants (mitorishi), end-of-life care assistants, terminal care guides [4], "stervensbegeleiding" (the Dutch word for dying guidance), death sitter and amicus mortis (friend in death) [6].

21.3 Why Doula Care?

The role of death doulas has developed as a response to the realization that medicine can only take a patient so far. It is also increasingly recognized that the subjective happiness and sense of security and confidence that are fundamental to one's quality of life are challenging to obtain through medical care alone [4]. Current healthcare systems lack the bandwidth to support healthcare providers who care for dying patients, as these providers are pulled between changes in the workforce, costs, increased census and emphasis on interventions [6]. Rawlings et al. [6] go on to say that death is a humanistic process rather than one that should be medicalized,it is a normal part of life's milestones and currently, healthcare systems are not meeting the needs of dying patients and their families. Challenges may be two-fold: a difficulty some patients have with being able to openly ask their providers questions or express wishes about end of life, or a provider's lack of time or inability to prioritize listening and conversations around end-of-life preferences [4]. This leaves what the authors mention as a "dearth of empathetic individualized care and allies able to advocate on the patient's behalf" [4]. Within a healthcare setting, palliative care professionals are involved sooner in disease trajectories and often identify patients for whom the risk of dying alone may be high. These are often patients with limited resources but can also include those who do not live near loved ones or whose family have other work/life demands.

In a systematic review done by Candy et al. [2], they discovered that in the adult palliative care setting, families who experienced greater volunteer involvement were significantly more satisfied with care, and that the most valued aspect of volunteer involvement was companionship. Volunteer services included clinical or clerical care, social support, and task-oriented activities such as serving meals [2]. Because of their presence and engagement with the patient and family, volunteers in these settings reduced service costs by 23% [2]. Families who had volunteer support ranked the following as most helpful: companionship, shopping, homemaking, visiting after the patient's death, allowing for family respite, independence, dependability, ability to listen, ability to meet the patient's needs, friendliness, willingness to do what was needed, sensitivity, and commitment.

Rather than replacing the role of the doctor or nurse, doulas are readily available to address any client need without providing medical care. Fukuzawa and Kondo [4] point out that death "is a process, always unknown and unique to each individual", and EOLD are prepared to help their dying patient find a good death. The goal of an EOLD is to alleviate physical and emotional suffering of those dying through any non-medicalized means available. Their function is to make patients and their families feel more comfortable and less stressed, reduce medical costs, provide sincere accompaniment based on intimate human relations, provide holistic care to the dying person, have the maturity necessary to meet death at the culmination of life, and decrease the burden on medical staff via their continuous support [4]. This recalls the definition of doula as an "experienced woman", suggesting that only those with the maturity, wisdom and the privilege of experience would be best suited or qualified for the role. Additionally, many doulas will continue to care past death and actively assist with funeral or service arrangements or with grief and bereavement care, as discussed in the next section.

21.4 Where/How Doulas Work

End-of-Life Doulas may serve dying patients and their loved ones at home, in a hospice facility, or wherever one finds persons nearing the end of their life. Those who are working in health care but also identify with the role of death doula recognize that in their dual capacity they are paid for their degree (RN, MD, etc.) but it is what they offer in their complementary capacity that provides the meaning and connection in that work. As the need for EOLDs increases, there are concerns regarding training and under what governance those providing the care fall. There are also questions regarding how to reimburse for services without getting absorbed into the medical model and being mindful of not blending roles if dual licensure exists.

End-of-life doulas are active in community educational events and workshops in an attempt to reclaim tradition and define their role and goal of improving end-of-life care by empowering individuals, creating compassionate communities and reducing healthcare system burdens [5]. They aim to do so by moving the death experience back into the home. Volunteer models of the EOLD role, while not common, are most often seen in hospice and palliative care programs when. Over the years the EOLD has been developing strongly as a community-based role [5], one that addresses how end-of-life care becomes everyone's concern [6].

There are three phases of doula services. The first typically involves planning and preparation for a patient with a terminal condition and getting their affairs in order. It includes answering questions regarding where someone would like to die, who should be present and what they would like to say to loved ones before they are gone. Typically, a patient may complete advance healthcare directives during this time, work on legacy projects, make calls, or write notes. During the second phase, the doula attends the last 4–5 days of a person's life with the family. More time is spent at the bedside, navigating the signs of continued decline, explaining the normal aspects of death and providing emotional support. The third phase of a doula's work comes after the death, and addresses grief: spending sacred time with a family, touching base with them and checking on their wellbeing in the weeks that follow the death. While some doulas are certified in grief counseling, a doula can also refer families to licensed grief counselors if needed. Post-mortem care includes washing the body and funeral planning, although that will depend on the regulations of the community they work in, as it could be considered practicing funeral directing without a license [5].

It is noteworthy to mention that EOLD are not there to impose their own agenda or become overly involved with the family in ways that may lead to dependency. And while EOLDs are advocates, they do not speak for the patient nor are they there to fix familial problems or make promises about a good death [5]. Finally, as mentioned before about creating distinct lines between roles, EOLDs do not offer services that would fall under the scope of another licensed professional, including offering medical or legal advice [5]. Deciding what care is a standard EOLD service versus an inappropriate practical or personal service should be part of the doula's contract. Maintaining role flexibility with an eye on boundary blurring is a challenging balancing act the doula takes on. There are some differences of opinion about after-life care falling under the EOLD purview, some report that they include that in their services and others do not. This is usually a negotiated part of the services when drafting a contract with the patient but may also depend on geographical differences in end-of-life care [5], including insurance coverage, assisted dying legislation and funeral service regulations.

In the United States, insurance policies include a mix of hybrid private and public funding models. End-of-life doulas have identified routes of reimbursement based on specific jurisdictions and molded by the professionalization of EOLD services (i.e. certification), integration into formal healthcare systems, and the development of billing codes or expansion of HSA fund use [5]. Unless EOLDs are in a voluntary role, a barrier to use is the ability to afford their end-of-life services [6]. This is not the intent of the EOLD movement whose aim is to make end-of-life care a community project, one that is widely accessible.

21.5 End-of-Life Doula Associations and Affiliated Organizations/Training

The EOLD presence has been rapidly growing in countries like Australia, Canada, the United Kingdom, and the United States, and this movement towards doula companionship has also come with an increase in training programs and associations whose aim is to develop core competencies, practice guidelines, and establish accreditation pathways [5]. This is particularly important as the EOLD role is still relatively new and is accompanied by uncertainty and confusion regarding services and scope of practice. The quality of education and training EOLDs receive and their relationship to palliative care services have been studied [6]. It appears that the work may lack clarity as it relates to the medical and social care systems, and that there is inconsistency in training, prior skills, knowledge and experience. For example, disparities in hands-on clinical hours during the doula training process could result in differences in skill levels. Accreditation and certification would ensure that the role and services remain consistent, that benefits are maximized, and risks are minimized.

Since the first end-of-life doula program launched in 2003 at a hospice in NYC by Henry Fersko-Weiss there are now about 40 certified death doula programs with approximately 3,000 trained doulas.

Training organizations include International End of Life Doula Association (INELDA), a nonprofit organization dedicated to advancing the end-of-life doula approach, through end-of-life specialist certification pioneered in 2003. INELDA's mission is to facilitate deeper meaning around death for the patient and loved ones and to offer great comfort. The National End-of-Life Doula Alliance (NEDA) is a non-profit membership organization that welcomes and supports all end-of-life doulas, trainers and interested parties, regardless of background or level of experience. There is also Doulas of North America International (DONA), Death Doulagivers End of Life Doula directory, The End of Life Doula Alliance, and the End-of-Life Doula Council through the National Hospice and Palliative Care Organization (NHPCO).

21.6 Conclusion

End-of-life doulas emerged out of the same philosophy as birth doulas and in the context of a medical providers' lack of time as being the biggest barrier to appropriate, individualized, and dignified end-of-life care. As [4] pointed out it is better to not hold medical healthcare providers responsible for focusing entirely on the dying patient due to their limited time, rather it is more valuable to recognize that the problem exists and find its solution. An end-of-life doula is a non-medical professional trained to care for a terminally ill person's physical, emotional and spiritual needs during the death process. A doula's role is to ease anxiety and suffering from grief through information sharing and compassionate presence, and to encourage a deep exploration of meaning through the entire continuum of death for the dying person as well as for those who succeed them. End-of-life doulas appear to be the missing piece and the solution to an absence of attentive and compassionate end-of-life care. They are seen and valued as having a complementary role with a focus on being with a dying patient [1]. As discussed by Krawczyk and Rush [5], the EOLD role is perhaps experiencing common developmental growing pains similar to what birth doulas have gone through. Granted, no solution can be borne without its problems, and doulas will continue to find they must finesse their role and relationship with medical personnel while overcoming the inherent barriers of status, hierarchy and subordination [4]. Within the practice itself, EOLDs report that fundamental to their work is not fixing or doing for [6] but rather, it is their presence, empowerment and provision of resources on three levels [5]. On the micro-level EOLD services perform holistic personalized care that empowers the patient and their family by enhancing the quality of life they have left and supporting them in making informed decisions. The meso-level of empowerment is provided via the community activist role in attempts to develop local and community-based end-of-life care services, ultimately making EOLD superfluous. Finally, the macro-level of care attempts to make a broader cultural shift to reclaim dying, putting EOLDs in the role of "ideological change agents" [5]. Achievement of these outcomes is met with the concern that provision of EOLD services may create a "new form of expertise and dependence, thereby recreating the very knowledge and care infrastructures seen to have directly led to the doula movement in the first place" [5]. Consider the proverb "Give a man a fish and he will eat for a day. Teach a man to fish and you feed him for a lifetime". As the end-of-life doula movement proceeds towards empowering and resourcing people in response to the complexities of death and dying, they can similarly teach communities how to make informed decisions about their end-of-life choices, and death and dying can be re-claimed by households to pro-naturalize and de-medicalize them. We can witness a re-birth of dying brought to you by the end-of-life doula.

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Celebrations of Death

22

Charles Pohl and Lynne Le Holsclaw

Contents

22.1 Introduction

Across the world, societies have developed different customs, traditions, and practices to memorialize the death of a loved one. Commemorations vary greatly between cultures, and may incorporate different intensities of grieving and celebration. We have selected six unique cultural observances for the deceased which have found beauty and celebration in death.

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22.2 Hungry Ghost Festival

Observed by Buddhists and Taoists in China and East Asia on the fifteenth night of the seventh Lunar month (often July, August, or September in the Western calendar), the Hungry Ghost Festival incorporates practices and rituals dedicated to souls of the deceased [1]. On this day, it is believed that the realms of Heaven and Hell, as well as the realm of the living, are open. Following this opening, ancestors are thought to visit the homes of their relatives for offerings of food, luxuries, and entertainment [2]. For those ghosts without descendants, collective festivities in the city center or marketplace provide offerings and appeasement [2]. Celebrations, therefore, take place both in the household and in the community.

Veneration of the dead is central to the celebration. Extravagant meals are prepared and delivered to empty seats at the table, conducting the repast as if the dead were alive and present. Paper money and paper offerings representing items of value are burned in venerance to gods, ghosts, and ancestors. This sacrifice is undertaken with the intention of acting as an offering for peace. Religious rituals held by Buddhists and Taoists relieve the ghosts' suffering, incorporating altars built for the deceased and throwing rice and food into the air for the benefit of the ghosts. Release of lanterns and paper boats onto water provides guidance to the spirits of the forgotten deceased to the afterlife.

Entertainment and live performances are held, with the first row of seats empty for admittance of the ghosts. Performances traditionally include opera, but concerts and dramas have become prevalent over recent years. Believed to entice and engage the ghosts, these shows are performed at night and at high volume.

The Hungry Ghost Festival is characterized by celebration of the deceased and communal unity. Many comparisons are made between the Hungry Ghost Festival in the Far East and Dia De Los Muertos in North and South America. While many similarities exist, there are rich differences between the two observances.

22.3 Dia De Los Muertos

Bright flares of magenta and marigolds, hundreds of candles, and gravesites and ofrendas beautifully decorated during Dia De Los Muertos vibrantly contrasts with the traditional Western archetype of death being dark, quiet, and dim. Dia de los Muertos is one of the most well-known celebrations of the dead. It originated in central Mexico from the indigenous Nahua people and predates the pre-Columbian Mesoamerica period of the Aztecs [3].

Dia de los Muertos is celebrated from October 31 to November 2. During this holiday, spirits of the dead can reunite with the living. Humans are thought to be the bridge between heaven and earth from which the souls travel. Families leave offerings of tools and food to facilitate the spirit's journey through Mictlan or land of the dead [3]. It is believed that this quest consists of 9 levels, including crossing razor blade mountains, flesh-scraping winds, the realm of raining arrows, dark rivers, and giant jaguars. The long arduous journey takes roughly 4 years for the souls to reach Mictlan (the final resting place) [4].

The celebration was brought to the New World by Spanish conquistadors. In recent years, it has become popularized through mainstream culture. The Disney animated feature, “Coco,” tells the story of a young boy who travels to the land of the dead. On this journey, he learns that one’s identity is enriched by the history and traditions of our culture and ancestors that preceded us.

22.4 Ghana

Believing that life transcends death, Ghanaians have developed rituals and celebrations to represent the passage from life to the spiritual realm. Ghanaian funerals are most notable for the inclusion of “fantasy” coffins. These caskets represent the deceased’s passions, values, or careers, and serve as a social event for the community to mourn and celebrate the life of the departed [5]. Ghana funerals are often extravagant in cost and scale and heavily steeped in symbolism and social convention [5].

Funerals may cost nearly as much as weddings and celebrations may include hundreds of guests [5]. Larger gatherings directly correlate to how influential, charitable, or sociable the deceased was in life. Dressed in black or red, mourners may travel great distances to honor the deceased. In return, the expectation is that the bereaved family will provide food, drinks, and entertainment for the guests.

The event maintains an expected decorum of the hosts and attendees. Specific seating arrangements are predetermined, appropriate clothing is adorned, music and activities are performed, and orchestrated presentations are designed to satisfy the expectations of mourners. Prominent members of the community are announced and given recognition for their attendance. Guests will publicly announce their donations to the bereaved which assist with the cost of the celebration. Eventually, dancing, drinking, and additional announcements of gifts to the deceased and bereaved will complete the celebration. These funerals can last anywhere from two to eight hours before burying the body [6].

Possibly one of the most stunning and ostentatious customs of Ghanaian funerals, which has captivated Western audiences, is the *adebuu adekai*, better known as fantasy coffins [7]. The tradition originated with the Ga people in southern Ghana in the 1960s but has been adopted by the Ewe, Asante, Adangbe, and Fanti [7]. These vessels are designed to transition the deceased into the afterlife [8]. Ghanaians believe that the departed will continue their profession in the afterlife, and these coffins are designed to represent their careers and passions while alive. Caskets may resemble ships, buildings, animals, cars, or planes, and are decided on by the family of the deceased. Depending on the materials, details, and craftsmen, a fantasy coffin may cost between $5,000 to $15,000 [8]. These intricate creations have been exhibited globally, introducing the remarkable Ghanaian funeral celebration and its fantasy coffins to the world.

22.5 Aboriginals

Despite the rapidly changing environment and industrialization of Australia, the central and northern Australian Aboriginal peoples have retained a strict adherence to their traditional mourning rituals and celebrations of death [9]. Their ceremonies are honored by the participants, and take precedence over other pursuits. These commemorations incorporate practices such as the smoking ceremony, marking the house of the deceased, and the death ceremony [9].

The purpose of the smoking ceremony is to drive away the deceased's spirit [9]. This is most often performed within one to two weeks of a death, and most frequently occurs in the house of the deceased. However, any living space previously occupied by the departed may be substituted. Specific rooms, their car, or a place personally special to the deceased can be "smoked." Special coals and fires are brought into the designated location with the intention of filling the air with smoke [9]. There are many regional differences between Aboriginal customs, but it is not uncommon for the family of the deceased to leave the home temporarily before returning.

While the interior of the selected living space is smoked to advance the spirit, the exterior of the living space is painted with a red ochre which serves a similar purpose [9]. Similar to smoking, the red ochre will be painted on any place where the deceased spent significant amounts of time. The intention of this practice is to help release the spirit of the dead to join the spirit world [9]. Additionally, marking the home or vehicle informs the community of the place of the deceased. Regional variations in practice determine how long the ochre stays up, and if the practice is followed at all. Cultures that favor traditional practices are more likely to mark the home of the deceased.

Finally, the body is laid to rest at a formal death ceremony. The celebration may last between several days to over five weeks depending on how far the mourners travel. Initial preparations can take several weeks and include decorating the inside of the house with flowers, perfume, and incense to make the house a beautiful haven for the body to rest before being placed into the ground [9]. Following the beautification of the home, the burial ceremony is conducted. This involves painting the bodies of the mourners, chilling the body of the deceased, and dancing. Mourners from multiple communities travel to the event, and camp next to the road in pitched tents. They celebrate by dancing, singing, and sharing food. Dancing occurs throughout the day and for many days. On the last day of the ceremony, a church service is held for several hours, followed by more dancing. After the church service is completed and the sun begins to set, the coffin with the body is laid in the ground to rest.

22.6 Nordic

References to Nordic death traditions in Western culture often inspire depictions of Viking funerals with thousands of arrows setting ablaze a boat carrying the body of the deceased, lavishly adorned in gold coins and other valuables. However, these elaborate send-offs were most often reserved only for royalty, the wealthy, or warriors who died during combat. In these rituals, fire represented the soul transitioning to the afterlife, while boats symbolized safe passage [10]. Typical Nordic funeral also included cremation, ground burial, or a hybrid where small burial mounds contained cremated ashes [10]. The funeral tradition was followed by a feast on the 7th day after the person's death called Sjaund, accompanied by singing, chanting, and drinking funeral ale in honor of the deceased [11].

A great importance was placed on grave goods, which are often objects that the deceased had valued while alive, or objects to help prepare the deceased through their journey in the afterlife. These goods served as a symbol of status [11]. To guarantee that their status was maintained in the afterlife, Nordic societies practiced forms of human sacrifice to ensure that the privileged members of society were accompanied by their servants or spouse in the afterlife [12].

Perhaps the most famous Nordic boat funeral was excavated in 1904–1905 by Swedish archeologist Gabrail Gustafson in Tonsberg, Norway [13]. Christened the Oseberg, the massive vessel was 970 sq ft with a 33 ft mass and held the remains of 2 women [14]. One of these women was believed to be Queen Asa of the Yngling clan located in Agder, Norway (Kruger). Additionally, there were remains of 15 horses, 2 cows, and 6 dogs, as well as luxurious textiles, household items, and agricultural tools [15].

Honoring the deceased was particularly important because of the trepidation that inadequate burials would lead to hauntings by the undead, referred to as Draugr [11]. Fear of the Draugr was so profound that Nords would refuse to answer a knock at the door when someone had died, believing the undead would be let into their homes unintentionally [11]. Conversely, three knocks symbolized the holy trinity, and admittance was granted [11]. Due to these superstitions, talismans and crosses were frequently worn for protection from the supernatural [11].

Furthermore, spirits distinct from the Draugr, known as Haugbui, resided at burial sites that were disturbed by the living. These creatures haunted the living when the deceased were unsatisfied. Concern for incurring the wrath of the Haugbui or Draugr was so overwhelming that some Nordic societies practiced blind folding the deceased or carrying them feet first to prevent them from being able to find their way back to the living [11].

Once a soul passed on to the afterlife, it arrived at different locations depending on circumstances surrounding their death and social status. The four most notable destinations were Valhalla, Folkvanger, Ran, and Hel. Valhalla and Folkvanger were ruled by gods Odin and Freyja, respectively, and were for the passage of kings and warriors who died in combat "honorable deaths". Ran was the residence of those who died due to drowning. Finally, Hel held the overwhelming majority of souls, most of whom had passed due to a "natural death or old age" [11].

Nordic death culture was highly complex, glorifying death while simultaneously fearing the possibility of supernatural hauntings. The fashion in which a body was prepared and the residence of the soul in the afterlife served as a reflection of the deceased’s social status in life, in addition to the circumstances of their death.

22.7 Jazz Funeral

New Orleans is defined by the sound of brass instruments, Jazz music, and celebratory dancing on Bourbon street during Mardis Gras. More obscure is the juxtaposition of Jazz music in local culture. Music joyfully celebrates life but also serves as a prominent component of death commemorations. Jazz funerals were first established in the nineteenth century during the civil war as a way of honoring lost African American soldiers [16]. It was thought to be a blend of Christianity and West African culture of rejoicing at death through music [17]. Initially, they were referred to as musical funerals. Only in the 1950s, during the rise in popularity of Jazz music, was the term Jazz funeral christened.

A Jazz funeral starts with a marching band called the “first line” at the home, church, or funeral, and concludes at the cemetery. First, the procession begins with a slow and somber hymn. This line was led by a grand marshal adorned with a black top hat and followed by band members dressed in white and black. These musicians accompanied the horse-drawn hearse cavalcade. Arriving at the cemetery, the body of the deceased was buried or “cut loose,” a term symbolizing freedom. These funerals are sometimes funded by the Benevolent Society as a way to support the African American community that was often deprived of social services during the Civil war.

Once the body is “cut loose,” the celebration becomes energetic and enlivened. The music changes to upbeat melodies, including favorites such as “The Saints Go Marching In.” This change represents the commencement of the “second line,” designed to celebrate the life of the deceased and facilitate their journey to heaven. It is also believed that the music would please the spirits who protect the dead. As the procession returns home, the cortege marches with a forward strut, handkerchiefs, and parasols twirling. Passersby are encouraged to join the second line [17].

While the tradition of Jazz funerals emerged from a dark period, it remains an important part of American history and symbolizes the inequality that many African American men faced during the nineteenth century. More recently, Jazz funerals have been primarily held for musicians and celebrities more frequently than for the general public, especially with the practice becoming less popular due to the extravagant cost.

In conclusion, many different cultures celebrate death in various ways that are highly complex and are incredibly unique. While some are fear-based, others are about honoring the legacy of the deceased. The common theme though is that death is not the end. The deceased are never forgotten as their memories are immortalized through the living. This notion that the living and the dead are two sides of the same coin is what connects us.

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The Living Wake

23

Stefanie N. Mooney

Contents

> "The minister related a touching incident in the lives of the departed… which illustrated their sweet, generous natures, and the people could easily see, now, how noble and beautiful those episodes were, and remembered with grief that at the time they occurred they had seemed rank rascalities… Almost with one impulse the congregation rose and stared while the three dead boys came marching up the aisle, Tom in the lead, Joe next, and Huck… They had been hid in the unused gallery listening to their own funeral sermon! Aunt Polly, Mary, and the Harpers threw themselves upon their restored ones, smothered them with kisses and poured out thanksgivings…Tom Sawyer the pirate looked around the envying juveniles about him and confessed in his heart that this was the proudest moment of his life [1]."

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23.1 Introduction to the Living Wake

Funerals have been described as a ritual to “physically sever the bonds of the living with the deceased and place them in social memory” [2]. The additional power of the funeral is to “symbolically conquer” Death by allowing society to demonstrate their perseverance in spite of the loss of an individual, as well as assist with the grieving of those who were close to the deceased [3]. How much more, then, can Death be defeated by the commitment to celebrate and commemorate in advance of impending departure?

In *The Adventures of Tom Sawyer*, Mark Twain fictionalizes a troublesome youth who has the opportunity to witness the lovely things people say about him at his funeral shortly before they realize he is not in fact dead. While darkly humorous, it raises the point that what is said during a funeral would provide greater benefit to the deceased individual if they could have heard it prior to death. This concept is not unique to fiction and is additionally well stated in the bestselling memoir *Tuesdays with Morrie*, in which Mitch Albom narrates his time spent learning life lessons from sociology professor Morrie Schwartz, his mentor ailing from Amyotrophic Lateral Sclerosis: “When a colleague…died suddenly of a heart attack, Morrie went to his funeral. He came home depressed. ‘What a waste,’ he said. ‘All those people saying all those wonderful things, and Irv never got to hear any of it.’ Morrie had a better idea… he was joined in his home by a small group of friends and family for a ‘living funeral.’…And all the heartfelt things we never get to say to those we love, Morrie said that day. His ‘living funeral’ was a rousing success [4].”

23.2 Evolving Traditions

The concept of a living wake, also called a living funeral, pre-death funeral or celebration, or pre-funeral, represents one stage in the evolution of thanatological tradition. In pre-modern society, it was common for several generations to live together under one roof, and death typically occurred at home with family by the bedside. Funerals were often organized by the community and inspired by religious practices [2]. However, by the mid-twentieth century, death had become institutionalized as more people died in hospitals observed by medical teams rather than loved ones, and the average person was less likely to be exposed to the dying process. Additionally, as the process of caring for and disposing of bodies became more complex, funerals were outsourced to professionals. It was not until the 1970s as the hospice movement gained momentum in the United States that the pendulum began to swing back and allowed people the support to again pass away in their homes surrounded by kin [5]. This allowed for a greater sense of personalization in the dying process, and pre-death rituals and funerals similarly grew more individualized, and at times with less attention to religious significance. This secularization and individualization coincide with other modern departures from tradition, such as having a “birth plan” for childbirth, or a wedding in which a friend rather than a religious figure officiates and the vows are hand-written [6]. Life celebration funeral events are another example of evolving customized traditions and have become increasingly popular since the start of the twenty-first century, which allow family and friends to focus and commemorate the *life* of the deceased, rather than the death. The living wake then takes one more logical step in the pursuit of unconventionality by emphasizing that we are in fact alive until the moment of death and highlights the need to celebrate a life while it is still being lived.

23.3 Foresight of Death as a Prerequisite to the Living Wake

Understandably, the concept of a living wake is most likely to be relevant for those with ongoing life-threatening illness, as some foresight of death is required for planning purposes. This was true of Morrie, suffering from a progressive neurologic condition, but there are several other common examples as well. An article in the *Journal of Palliative Medicine* describes a patient on long-term dialysis who made the decision to discontinue dialysis as his overall health deteriorated. Given the eventual expected outcome was his death, it allowed his community the opportunity to visit with him and "communicate with him directly, rather than leave their sentiments for a funeral oration," and assisted with the sense of "completion" that is thought to be an important factor in a "good death," along with being "pain-free, peaceful, and brief" [7]. The AIDS epidemic of the 1980s also allowed patients suffering from the illness a unique understanding of their imminent demise. Many of the afflicted were already treated as outcasts of society; holding a living wake allowed for a yearned-for divergence from tradition and a way to celebrate a life dramatically cut short [8]. In current times, patients suffering from cancer, which is oft described as a journey rather than a destination, are additionally logical candidates for a living wake since the disease trajectory can often be anticipated. The increasing legalization of Medical Aid in Dying, which allows terminally ill patients some choice in the timing of their death, can also afford people the opportunity to formally schedule a time to celebrate life and say goodbye.

23.4 The Value of the Living Wake

There are many reasons why someone may pursue a living wake, some practical, some more emotional. From a practical perspective, living wakes have been seen as a way to relieve family of the "burden" of death and to allow the soon-to-be-deceased the option of remaining pivotal in the determination of how their death is approached. In other words, by planning for a pre-death celebration, a patient may remove the responsibility of death planning from others as well as preserve a semblance of control over the memories that are left behind [9]. *Seizenso*, which translates to "funeral-while-alive" [6] epitomizes these sentiments and was popularized in Japan during the 1990s as a way for elders to preserve dignity while simultaneously removing both financial and cultural burden from their children [5]. Japanese anthropologist Dr. Satsuki Kawano states, "By designing, conducting, and consuming their own pre-funerals, older persons playfully construct an age-specific ideal of independence against a treasured, mainstream value of mutual dependence [10]." In regards to financial burden, the impact of death can be a challenge to many families—the average cost of a traditional funeral in the United States is upwards of $5000, which does not even account for the cost of medical bills prior to death [11]. When a living wake is selected in lieu of a traditional funeral, the cost is often much less, and additionally more convenient: without a dead body, there is no need for special permits, sanitation, or need for a specific location like a funeral home, which allows for increased flexibility in planning [6].

From an emotional perspective, while critics might perceive a living wake as a vain attempt to flaunt one's own achievements, others see it as a chance not to simply honor successes, but also to reflect on past and current relationships, both positive and negative [10]. It provides someone nearing end of life the opportunity to thank family and friends for how they have contributed to their life, the chance to reconcile with someone estranged, and the ability to plan for death. A study of occupational therapists' perceptions on what matters to patients with terminal illness concluded the importance of focusing on living, and once death becomes more imminent, preparation for dying. The former may include a desire to maintain a sense of normalcy and routine, as well as an opportunity to contribute to their environment and leave a legacy for family. The latter involves practical concerns such as writing a will, making burial preparations, and activities such as holding a living wake, which can additionally help facilitate closure through the opportunity to say goodbye [12]. In a modern culture that is typically "death denying," the opportunity to say goodbye should not be understated [13]. Qualitative research suggests that the benefit of after-death rituals for the bereaved is dependent on their ability to say goodbye in a meaningful way and the perception of social support [14], both of which may be accomplished more readily during a living wake since it allows direct interaction with their loved one prior to their passing. Beyond the chance to say goodbye, a living wake may additionally benefit the soon-to-be bereaved by serving as a prophylactic salve for grief. In *Parting Ways,* Denise Carson describes a variety of contemporary death rituals including her own mother's experience with incurable cancer and subsequent living wake: "That day, we eclipsed her imminent death by bonding together to celebrate her life. The social gathering turned out to be preventative medicine for all the 'survivors' left behind [8]."

Perhaps the most straightforward reason to hold a living wake is simply to celebrate. In response to the first broadcast of a living wake in 1993, honoring Japanese actress/singer/producer Takiko Mizunoe, a retired instructor of protocol for the Emperor and head of Takano Elder's Club Mr. Hamada noted, "Funerals that cost so much are meaningless unless the deceased can see and enjoy them. The funeral should be for me, not for family members or others. Why do I need lots of flowers, food, and letters after I am dead and senseless? [15]." During an interview prior to her living funeral, a 93-year-old named Ethel Leather similarly told the author of a *Metro News* article "I'm not missing out on my party. I didn't want them to enjoy themselves without me [16]."

23.5 Preparation for the Living Wake

Perhaps the most challenging decision about the living wake is the timing. For someone who is critically ill, it should ideally occur before the disease progresses too far to meaningfully participate, and yet not so far in advance that the intent of the event is overshadowed [6]. At times it may coincide with another celebration, such as a birthday or anniversary. Since fatigue is a common side effect of progressive disease, the event should be scheduled during a time of day when the person's energy tends to be highest. Given that many people have never attended a living wake, an invitation may be useful to explain the concept and set the tone for the guests. Depending on the amount of advance notice available, this may be done using formal hand-written invitations, or more casually through email or telephone, especially if prognosis is thought to be short. Guests may choose to include only close family members and friends, or to have a grander event that additionally involves people from school, career, and other paths of life. The event should be individualized to the desires and needs of the soon-to-be deceased, or "honored guest," and may be formal or informal, but most often is designed as a time to celebrate rather than a time to mourn.

Another decision is the location. Because the lack of a body limits "taboo" and sanitary needs, the living wake does not need to be held in a typical location like a funeral home, and instead is usually held somewhere with personal significance [6]. Oftentimes it is held in the home of the honored guest, or that of a family member or friend. However, public venues can also be used, such as a community center or banquet hall, a church, a favorite restaurant or bar, or perhaps more uniquely, a park, stadium, or amusement park [6]. In recent times of pandemic, these have also been held virtually, though a virtual component may also be useful outside of global health crises as a way for guests living out of the area to more easily participate. The most important factor in choosing a location, however, is the comfort of the honored guest. Regardless of the site, there should be ample opportunity for the honored guest to sit, which may involve use of a comfortable chair stationed in the middle of the venue, or a wheelchair for improved mobility while visiting with guests. A more frail person may even need a bed or place to recline. A space to privately rest may allow the honored guest to spend more time at the party by taking intermittent breaks as needed to regain their strength. Other comforts such as protection from the elements for an outdoor celebration, or premedicating with pain medications as indicated, may help the honored guest enjoy their time more thoroughly with fewer distractions.

23.6 The Party

Food plays a significant role in all cultures and is frequently made and shared as an expression of love, making it an important contribution to the living wake. Whether homemade or store bought, favorite food items of the honored guest are often central to the menu [13], such as fresh-baked apple pie at the living wake of the previously mentioned Mr. Hamada [15]. Catering by a preferred restaurant can be ideal for those seeking ease of preparation, while hosting a potluck is a way to lower expenses while also allowing guests to participate and share their own culinary manifestation of love to the family. Although a menu is often prepared for attendees, a key consideration for the honored guest is whether their illness will actually allow them to participate in eating. Not uncommonly, nausea, pain, anorexia (loss of appetite), and dysphagia (difficulty swallowing) afflict patients nearing end of life. At times just the sight or smell of food, even food previously loved, may make them feel ill. In this case, pre-medicating with nausea medications and positioning the food away from the honored guest may help improve comfort.

Music is another key component to any party, including a living wake. Historically, music has added to the ritual effect of a funeral, and can serve various functions such as promoting inclusion, form, and enhancing connectivity to God or the spiritual realm. In more contemporary and secular settings, music may be utilized to evoke an emotional response or a sense of connection to the deceased, often through the use of favorite songs or songs that otherwise encourage remembrance [17]. For a living wake, allowing the honored guest to select music in advance can be a bonding experience with loved ones, as it is likely to call to mind memories they have shared. During the celebration, a professional DJ or volunteer can play recorded music, or live music may be played by a musician or band. It is not uncommon for the theme of the music to shift throughout the course of the event as well, depending on whether it is being used as background music to speeches, eating, or the focal point of the moment. In some instances, creative strategies such as karaoke have been utilized [16], allowing for the honored guest and their company to play a more interactive role in the entertainment.

Other ways to further personalize a living wake involve strategies to make new memories or “pay it forward.” The event may be coupled with a fundraiser or request for donations to a favorite charity in lieu of gifts, or have a symbolic component such as planting a tree to signify that the life of the honored guest will live on in new ways after they are physically gone [6]. Similar to a wedding, a guestbook or letter box will allow guests to share their thoughts in a way that can be saved as a memento. A photo booth can give guests the opportunity to take pictures with the honored guest as a token of remembrance and may help humanize their memory of the end of life [18].

23.7 Tributes

Depending on the life and preferences of the honored guest, there are many forms of tribute that may be paid during a living wake. Physical tributes such as photo displays, photo albums, and slide shows are often central to the atmosphere of a living wake and can help illustrate the entirety of the honored guest's life and career. Photographs may help family "feel connected to their loved ones and may have the ability to collapse space and time between individuals by transporting the viewer back to the moment captured [18]." Other types of physical displays may evoke important features of the honored guest's life dependent on their interests, such as an exhibition of personal artwork, a gathering of items collected out of hobby, or treasured items such as jewelry or other heirlooms. This additionally may allow a formal opportunity to bequeath some of these objects to a loved one at a time when the honored guest is able to experience their appreciation and enjoyment.

For those of a spiritual nature, tributes such as prayer, reading passages from a sacred text, or other religious practices may provide a sense of comfort and peace, as well as provide reassurance that there is more than just the physical life, which therefore aids in the conquering of Death. These may additionally provide the opportunity to praise and express gratitude to a higher power, or conversely, to explore some of the complicated existential questions and emotions that can arise at end of life. As an example, the previously mentioned Japanese actress/singer/producer Takiko Mizunoe's living wake involved traditional aspects of a death ritual like the burning of incense and sutra chanting [15]. At others, this might include a recitation of the biblical Psalms or the lighting of candles.

Although some living wakes are officiated by a religious figure, as is done for many traditional funerals, or by a professional master of ceremonies, it is perhaps more common for a friend or family member who knows the honored guest well to host the event [6]. This allows for a much more personalized atmosphere, as well as a more authentic description of the honored guest's character and life, which they might put forth by way of a eulogy. A eulogy is an opportunity to "state a case in defiance of the fact of death" and to "convey the possibility of living more strongly having borne the suffering of loss [3]." The eulogy also offers the ability to present a summary of personal and societal contributions at a time that allows the honored guest to learn how they have impacted others. On some occasions, the honored guest might actually give their own eulogy, or otherwise make a speech giving their thanks to how others have contributed to their life.

Sharing stories may be one of the most meaningful ways to pay tribute during a living wake, as it allows loved ones to highlight the memories that they hold most dear. Stories may be serious and reveal depth of character, or be anecdotes of humorous times spent together. In *Parting Ways* Denise Carson remarks on her mother's living funeral: "My mother… basked in the spotlight on a bed surrounded by not mourners, but revelers as the ambiance in our home turned from quiet pain to a quickening pulse of celebration. Friends regaled her with stories of old. Her laughter, rising in cadence, egged them on. I'd never felt so proud of her than at that moment. She radiated a picture of dignity and grace in motion [8]."

23.8 Last Thoughts

While music, prayers, stories, and even favorite poems can all provide meaning and value to a living wake, what is most important to say at a living wake? While each celebration will hold a unique tilt, all living wakes afford the time to say "The Four Things that Matter Most," as written by Dr. Ira Byock: "Please forgive me. I forgive you. Thank you. I love you. [19]." Participants can provide peace to the honored guest by letting them know they will not be forgotten, and that their loved ones will endure after their physical presence has moved on. They can give permission to let go. They can shake hands and hug goodbye. They can laugh together and perhaps cry together as well but know that ultimately, they are not alone. While there is no single right way to prepare for death, the Living Wake is one way to continue living life to the fullest in the time that is left.

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An Exploration of Green Burial in the Natural Death Care Movement

24

Sarah Janelle Hernandez

Death is natural, the ritual should be natural. Death care plays a fundamental role in our acceptance of susceptibility to inevitable death and decay. According to the *Tibetan Book of Living and Dying*, death is certain, it is uncertain when or how we will die. We can find meaning in our lives by making every moment an "opportunity to change and to prepare–wholeheartedly, precisely, and with peace of mind–for death and eternity" [1]. Life care fluidly transcends into end-of-life and death care. Exploration of death care planning should be integrated into discussion of advance care planning, further promoting advocacy of death positivity. Just as advance care planning is fundamental in expressing goals and values so that we may have a dignified death and relieve some of the burden from grieving friends and families, writing out death care instructions expresses to our loved ones what we want to be done to our bodies once we have passed and gives others permission to honor and celebrate the deceased.

Per the *Tenets of the Death Positive Movement* by Caitlin Doughty, everyone "should be empowered (should they wish to be) to be involved in care for their own dead," as well as be ensured the governing laws of death and end of life care honor the wishes of persons, regardless of sexual gender, racial or religious identity [2]. Elizabeth Fournier, in the *Green Burial Guidebook*, shares that a death care directive should address our vision of what would be satisfying and feel right. Fournier recommends taking a couple of hours to think about your death. After death, how do you want your body to be handled? Would you like it washed,

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dressed, and handled with love and kindness by a loved one or handed over to a funeral home? What type of shroud would you want? Where would you want your loved ones to gather to honor your life and death? How do you want your funeral to look and feel like for those who will gather in honor [3]. Modern burial and cremation are the most common practices of death care, which is why we must first explore a brief history of these practices as well as their toxic effects to humans and the environment so that we move toward sustainable, socioculturally, spiritual, and environmentally conscientious death care.

As a society, it is imperative to address the environmental impact of annual corpse disposal as the world's population has an expected increase in death rate from an aging population. According to the World Health Organization and the Center for Disease Control, [4] over the course of 1 year, there were 3 million deaths from the COVID-19 pandemic worldwide. Half a million of those deaths were in the United States [5]. These corpses inundated hospitals, morgues, and subsequently funeral homes. An average estimate of a modern funeral and burial in the United States is anywhere from $6,000 to $10,000, depending on the level of service add-ons [3]. If half a million people in the United States who died from COVID-19 received a traditional funeral and burial, an approximate 3–6 million dollars contributed to the multibillion dollar funeral industry in 1 year alone. The impact of COVID-19 has been exceptionally devastating to vulnerable underserved communities. The US Census reports that in 2019, there were 34.0 million people in poverty, with 10.5% of the US population living under the poverty line. CNBC reports that 63% of Americans say they are living paycheck to paycheck since the Covid-19 pandemic hit the U.S [4]. How can families experiencing healthcare and racial disparities afford to bury their dead? The tremendous death impact of the COVID-19 pandemic reaffirms the need for advocacy and implementation of laws governing death care that is more economic and ecologically friendly, laws that ensure that a person's wishes are honored at the end of life.

As more and more families are experiencing funeral poverty, the rising popularity of cremation has reduced some of the economic impact of death care. After the 1963 publication of *The American Way of Death*, cremation grew in popularity as it was considered a more ecological and economic alternative. Elizabeth Fournier shares there are several reasons for the popularity of cremation: (1) cremation is about 50% cheaper than modern burial; (2) there is minimal planning pre-and post-mortem; (3) the feasibility of transporting and storing cremains so that they may be placed in meaningful places. According to the National Cremation Institute, direct cremation is the least expensive option for end-of-life services, eliminating funerals and embalming. Standard direct cremation costs approximately $2,000. The cost of a casket may be reduced by using a simple container or an eco-friendly biodegradable urn, instead [3]. However, cremation poses risks through the release of contaminants such as carbon dioxide and mercury into the atmosphere. In Katrina Spade's *How Your Death Affects Climate Change*, we learn "the average cremation uses 28 gallons of fuel to burn a single body, emitting about 540 pounds of carbon dioxide into the atmosphere. That's about 250,000 tons of CO_2 each year" [6]. In *Till Death Do We Pollute*, the authors explore how the emission of these greenhouse gases negatively contributes to climate change. U.S. Crematoriums use filtering systems, such as after-chambers that burn and neutralize pollutants like mercury emissions from dental fillings, however the carbon emissions are not filtered [7]. In 2019, the European Environment Agency estimates that crematoriums contribute up to 0.2 percent of the annual global emission of greenhouse gases [8]. On January 17, 2021, Los Angeles County's South Coast Air Quality Management District issued an Emergency Order to temporarily suspend certain permit conditions for crematories to assist with the backlog caused by the COVID-19 pandemic [9]. There is more research needed to investigate the ecological impact of over half a million corpses being created from the deadly COVID-19 pandemic. Due to the dramatic health and ecological effects of climate change, a major challenge currently facing societies is reducing carbon emissions, thus it is important to note cremation as a potential source for reduction. It is also important to consider that cremation ashes are not fertilizer—they contain the byproduct of mostly former bones, tricalcium phosphate. Calcium phosphate is created by the heat of furnaces vaporizing corpses at temperatures of around 760–1150 °C [10]. The Green Burial Council notes, "cremated remains on their own are not capable of further decomposing without enzyme reduction, and cannot support plant life on their own, as calcium phosphate is not conducive to healthy plant life" [4].

There are eco-friendly options to incorporate into crematory death care. According to the Green Burial Council and *The Green Burial Guidebook*, some cemeteries, natural burial grounds, and conservation areas allow burying or scattering of cremation ashes. There are numerous biodegradable urns made of sustainable materials available that will help to reduce the carbon footprint, as well as urns that support plant growth by mixing cremains with organic content. Some urn companies provide parks and green spaces for planting trees [3]. For an additional cost of $150 to $500 more than traditional cremation, alkaline hydrolysis is a form of death care that may reduce carbon footprint and is safe without harmful chemical or microbial contaminants. The Cremation Association of North America describes alkaline hydrolysis (also known as water resomation, bio-cremation) as a process that uses "water, alkaline chemicals, heat to accelerate natural decomposition, leaving bone fragments and a neutral liquid called effluent." "The effluent is sterile, and contains salts, sugars, amino acids and peptides. There is no tissue and no DNA left after the process completes. This effluent is discharged with all other wastewater, and is a welcome addition to the water systems" [11]. According to U.S. News World and Report in [4], there are 20 states wherein alkaline hydrolysis is legalized, including, California, Colorado, Florida, Utah, and Illinois [12]. In California, the UCLA Donated Body Program uses alkaline hydrolysis. According to their website, "the sterile process prevents the release of emissions into the atmosphere and helps protect the earth's natural resource…The remaining sterile ash is scattered in the ocean" [13].

According to the academic paper *Till Death Do We Pollute*, "many cultures and religions embrace burial as the desired method for disposal… The idea of returning bodies to the earth, recycling them to the biota that supports life is the basis for burial in many cultures and religions." The history of lawn park cemeteries has transcended over two centuries because of increased economic wealth in urban areas. Their eternally manicured appearance eventually transformed into a retreat place of socio-cultural and spiritual significance [7]. Cemeteries play an important role in the grieving process, a place of connection and remembrance for the dead. Through corpse and funeral artefact decomposition, modern burial and cemeteries introduce chemical and biological pollutants into the surrounding earth, water, and air. In the 2018 research article *Natural Burial as a Land Conservation Tool,* the U.S. practice of burying embalmed cadavers in a lawn park cemetery is not environmentally sustainable. It consumes significant resources for caskets and vaults, and introduces a host of toxins into the environment—from the embalming fluids used to preserve bodies to the petrochemicals needed to maintain manicured landscapes [14]. *The Green Burial Guidebook* and the Green Burial Council add that each year in the U.S., conventional funeral and burial practices utilize 4.3 million gallons of embalming fluid for corpse preservation, 1.6 million tons of concrete for vaults, 20 million board feet of hardwood and 2,700 tons of copper and bronze for caskets. These statistics, originally developed by science writer Mary Woodsen, expose the voluminous, unsustainable utilization of resources by traditional funeral homes and cemeteries [3]. According to the World Health Organization, the quantity of decay products from buried people and wood, fabrics and plastics used in coffins is directly influenced by the age and number of human corpses decaying in the cemetery at any one time. Imagine the ecological impact of burying 3 million bodies worldwide in 1 year [15]. Of note, funeral industry professionals have a statistically significant increased risk for mortality from myeloid leukemia with prolonged duration of embalming practice and related formaldehyde exposures [16].

Now that we know that cremation and traditional funeral and burial have a health and environmental impact, we can continue moving forward, revolutionizing the future of death care. Elizabeth Fournier shares in *The Green Burial Guidebook*, the number of people seeking intimate and human connection is increasing [3]. Suzanne Kelly shares that humans are "meaning-making beings, so if we don't find ways of meaning then meaning itself will find a way to elude us altogether." This is a fundamental explanation for why "rituals fortify who we are, what we believed, and how we are to live, they essentially weave the substance of our living" [17]. In *Face to Face: Meet the Death Positive Movement*, Sarah Chavez Troop endorses our "unhealthy and unsatisfying relations with all aspects of death, dying, aging, and grief. People are seeking alternatives and choices for themselves and their loved ones, and along the way, we are discovering that cultivating a relationship with death can lead to a happier, more fulfilling life. Being conscious that our lives are finite can help us to value our time and relationships more and engage in more meaningful actions" [18]. From Buddhist teachings we learn that if we are prepared, there is tremendous hope, both in life and death [1]. In 2011, Caitlin Doughty founded The Order of the Good Death–a collaboration of funeral care professionals, academics, and artists, who advocate for acceptance of death as natural, breaking down barriers to access of a "good death." Advocates of death positivity are inherently part of a social justice movement promoting end of life and death care that aligns with an individual's goals and values [19]. Mediums of green burial such as home funerals, natural burial, and reformation have transcended into the Death Positive Movement.

Green burial offers alternative options of reformation and natural burial with environmental, sociocultural, and spiritual benefits. It is a form of death care that creates a culture of restoring the death and dying process as a natural ritual of love, peace, and community. Ed Bixby, one of the original advocates for the Green Burial Movement and owner of Steelman Town National Cemetery, shares his journey to the inside of the Green Burial Movement. Bixby felt driven to own the unkept, vandalized cemetery where his infant brother was buried. Mr. Bixby naturally originated the movement in 2007 after protesting the modernized funeral standard. He felt environmentally and spiritually appealing alternative funeral rights needed to be offered, not asked for. His experience was informed by his own understanding of the meaning families were seeking. Bixby adds in his *An Outsider's Journey to the Inside of the Green Burial Movement,* that families came to him, hoping for a different experience, where they could feel empowered and connected to one another through the simple age-old rituals of walking to the gravesite, of taking turns shoveling solid back into the grave." On the business side, Mr. Bixby invested the burial cost in conserving the land so that families will receive peace of mind for generations [20]. Green burial encompasses the opening of our minds, bodies, and souls to the ritual of returning our bodies back to the earth, with an eco-friendly, socially responsible, and humble process, to be buried in a place where nature and mourning meet.

In the 2013 documentary *Dying Green* by Ellen Trippler, we learn how the revolutionary idea of using natural burial can fund land conservation and create wildlife preserves. Dr. Billy Campbell, a family medicine physician, and his wife Kimberley Cambell share their passion as founders of one of the first natural burial grounds, Ramsey Creek Preserve in Westminster, South Carolina. Dr. Campbell believes conservation burial as a death ritual is the "right thing to do". It offers bereaved family and friends the ritual of being directly involved in the process, lowering the body in the ground, covering the grave. He adds there is nothing natural about the traditional funeral process wherein nature is kept at bay. Alternatively, the Campbells advocate that natural burial ritualizes a transformation from "dust to dust" to life again, meanwhile conserving land. Conservation burial encompasses a higher purpose as a range of eco-responsible burial rituals to the creation of memorial landscapes and natural areas of high ecological quality and social value [21]. In *Dying Green*, we see how a bereaved widow shares her and her husband's story of electing natural burial just prior to the unexpected death of her husband. They elected an environmentally responsible burial option that reflects their values. Her husband's burial site is along a creek, a place to meditate, to grieve, a space to aid in her healing. There is a sense of beautiful peace, a connection to earth as she shares her enjoyment in coming to walk, sit, watch the stream, listen to the water, be part of a natural ceremony in the Ramsey Creek Preserve.

There are over 300 green burial sites in the US and in Canada—nearly half are in existing conventional cemeteries and the rest are separate green cemeteries. These cemeteries and burial grounds have been reported to provide "natural burial options, including conservation preserves, natural burial grounds, hybrid cemeteries that allow some space for burial without a vault, and even a handful of known municipal cemeteries that simply do not require vaults that do not intentionally identify themselves as green." An updated list of green burial sites in the US and Canada may be found at the New Hampshire Funeral Resources, Education, and Advocacy website: https://www.nhfuneral.org/green-burial-cemeteries-in-the-us-and-canada.html. In general, a green burial ground encourages nature to flourish—a haven for native flora, birds, and other wildlife [21].

The Green Burial Council is the only independent environmental certification organization setting standards in North America. In Lee Webster's *What Every Funeral Director Needs to Know about Green Funerals*, she distinguishes three types of green burial grounds:

- Hybrid Burial Grounds: conventional cemeteries offering the option for burial without a vault, concrete or liner. They shall not require embalming and must allow for eco-friendly burial containers, including shrouds.
- Natural Burial Grounds: adopt practices of no embalming fluids, biodegradable casket, no vault energy conservation, minimizing waste production, and prohibiting the use of toxic chemicals. It also must incorporate Integrated Pest Management as well as incorporate a natural landscape based on native plans and materials compatible with regional ecosystems.
- Conservation Burial Grounds: Meets all the requirements of the natural burial ground as well as perpetuate land conservation [22, 23].

According to the 2018 research article *Natural Burial as a Land Conservation Tool in the US,* natural burial cemeteries are expected to grow as a more sustainable eco-friendly alternative to traditional cemeteries. Natural burial conserves resources and is more economic. Certified natural and conservation burial grounds forego few legal barriers in their protection by deed restrictions and conservation easements. Additionally, there is no shortage of land in need of restoration/conservation that may be utilized for burial. Conservational burial preserves also have the potential to serve as multifunctional greenspaces [14]. Natural burial offers the opportunity for the dead to blend into the natural landscape, to provide a point of connection through natural space and spiritual practices, to leave a space of emotional vulnerability where nature and mourning connect, where we see beauty in the natural return to Earth.

In 2019, Washington became the first state in the US to legalize human composting, also known as natural organic reduction, which turns bodies into soil within approximately 30 days. 33Katrina Spade, founder and CEO of Recompose in Washington, shares she first developed human composting while studying architecture at the University of Massachusetts, Amherst. She describes a light bulb going off when discussing composting of farm animals with a colleague. Spade further researched human composting at Washington State University's crop and soil sciences department. The cost of human composting is about $5,000, between the cost of cremation and traditional funeral burial. 33According to Recompose, this includes the transformation of a person's body into soil, the option to participate in a streamed laying-in facilitated by our staff, the filing of the death certificate, and full support throughout the death care journey. It also includes the opportunity for a virtual ceremony facilitated by staff during what Recompose calls the "laying-in," the practice of placing the body into the vessel. This marks the initiation of the body's transformation into soil. Spade's idea is founded in her interest to develop a more conscious reality of death in our society, wherein we have a fundamental role in the natural cycle of life. The process is a form of composting where you need to have the right mix of carbon-based materials and nitrogen, and the microbes in the process have enough oxygen to decompose. The body is laid on top of a barrel-shaped vessel filled with a carbon and nitrogen mixture of wood chips, alfalfa and straw, then covered with the same mixture and enclosed in the vessel. A fan system is set up to ensure the microbes are oxygenated, promoting decomposition of the body into two wheelbarrows of soil within a month. [6]. Lynn Carpenter-Boggs is a soil scientist at Washington State University and research advisor at Recompose, she describes the process of human compositing as beautiful: "to lay them on fresh plant materials, to cover them with fresh plant materials, to know that it is trillions of microorganisms having a great time, then convert that material that something is something completely different looking, a pleasant material to smell and touch…a soil that can improve the land." Lynn Carpenter-Boggs says during human decomposition, the oxygen-fueled bacteria begin breaking down the cadaver cell by cell into molecules released by the chemical process. She describes the soil material yielded as fine, nonmalodorous, larger diameter potting soil [4]. Human composting provides a viable alternative to eco-toxic traditional burial or the carbon footprint of cremation by alleviating the problem of burial space. Families have created a space to grieve and celebrate their loved ones at Recompose, they are provided a vessel to take as much of the soil created as they wish [24]. Some of the people who volunteered during the study desired to give back whatever nutrients they have in their bodies when they die, to nurture the earth that gave them life rather than burn that nutrient up through cremation or bury it in a vault [4]. In 2020, at the height of the COVID-19 pandemic, California Assembly member Cristina Garcia introduced legislation to give California residents the legal option to have their bodies composted [25].

When talking about the natural death care movement, we innately discuss home funeral and burial rituals. By virtue of rejection of invasive embalming practices and support of ecologically conscientious burial rituals, home burial has resurged as part of the Natural Death Care Movement. In Philip Olson's *Home Funerals as a Social Movement*, he shares the following funeral narrative from the 1998 backyard burial described in *Grave Matters* by Mark Harris.

> When Sharyn died in her home, her nurse and a local midwife laid out her body by candle light, washing it, dressing it in a white gown that a friend made specially for her funeral,

> and rubbing Sharyn's hands and face with lotion. After the women finished making arrangements for the following day's burial, they left Sharyn's body with her cousin, Michael, who kept vigil through the night. The next morning, a hired laborer dug a grave on Sharyn's property while a family friend prepared a board on which to carry the body to the grave. Mourners gathered at Sharyn's house, and the women in attendance wrapped the body in a sheet. The men placed her body on the board, carried it to the gravesite, and lowered it into the grave with rope. The attending mourners prayed and sang before filling the grave with dirt and returning home.

The preceding narrative echoes the death ritual of what we may have experienced almost a century and a half ago. Prior to the U.S. Civil War, families and the community gathered to care for and honor the deceased. What is appreciated by this narrative, is how Sharyn's family and friends were empowered to assume the intimate and meaningful funeral and burial ritual. The story of Sharyn's and others who elect for home funerals and green burials resonate with my own dissatisfaction of seeing my family members, friends, and patient's experiences of institutional and industrialized end-of-life and death care practices. Olson adds, politically, home funeral guides and home birth advocates are applying a countercultural response to authority over the bodies of the dead [26]. According to the Natural Home Funeral Alliance website, the primary goal is to empower families to care for their own dead. "Home funerals invite family, friends, and community into an authentic and healing after-death care experience in a safe and familiar place, with care performed by loving hands" [27]. Home funerals are legal across the United States. When planning a home funeral, one must plan to store and keep the corpse cool with cooling techniques such as ice, transport the deceased to the place of burial or cremation, filing the death certificate and obtain burial permits, provide a suitable container for body storage, transportation of the corpse. Of note, legalization of home burial is under the jurisdiction of local, regional, and state law [3].

We see how the Green Burial Movement is part of a growing complex ecological, sociocultural, and spiritual movement of Natural Death Care, advocating for collaboration by the government, funeral industry, and the public. The Natural Death Care Movement is recreating a new culture of death care, echoing the hunger for more meaningful and communal understanding of end-of-life and death care rituals. Because of recognizing the environmental and human health risks of modern funeral and burial practices, the movement is making bold moves towards an earth-based, sustainable end-of-life option where there is appreciation and value in the ritual of integral death and decay. By virtue, the Natural Death Care Movement is empowering a growing number of people to care for their dead, providing educational resources and outreach that serve the public, rejecting the authority of industrialized funeral and invasive burial practices. Ashes to ashes, cell by cell, molecule by molecule, may we transform into something beautiful in our natural return to earth, which all living things ultimately return.

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Memorial Spaceflights and Extraterrestrial Burial

25

Eric D. Mecusker

Contents

25.1 Space Burial in Popular Culture

> *He would have his body shot into space enclosed in a rocket to become a satellite of the earth as long as the earth continued to exist. He reasoned logically. Any material substance, whether of organic or inorganic origin, cast into the depths of space would exist indefinitely. He had visualized his dead body enclosed in a rocket flying off into the illimitable maw of space.*
>
> *Neil R. Jones, "The Jameson Satellite", Amazing Stories, July 1931* [1]

Mankind's fascination with space, borne of the innately human desire to explore the universe around us, has inspired authors and screenwriters to consider how people will live and die as we reach out into the final frontier. Like the sailing vessels of the Age of Exploration, the spaceship is an island in a void both inhospitable and often violent as over a century of science fiction would attest. Jules Verne understood the dangers of the vacuum in his novel *From the Earth to the*

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Moon first published in 1865, "[…] for in spite of your diver's dress, swollen by the expansion of air within you, you would have burst like a shell" [2]. Images of starship funerals evoke the naval traditions of burial at sea in popular science fiction films and television. This was notably exemplified in 1982's *Star Trek II: The Wrath of Khan*. In the film Mr. Spock sacrifices himself to save his crewmates from deadly radiation after the film's climatic space battle. To honor his commitment to, "the needs of the many," he is interred in a torpedo casing and launched from the United Starship *Enterprise* towardere of a new planet as Chief Engineer Scott plays *Amazing Grace* on the bagpipes [3]. For many people, a deep symbolism is present in their dedication of some part of themselves to the vast unknown, be it the sea or outer space. Wende Doohan, wife of James Doohan who played Engineer Scott in several *Star Trek* television shows and films, said at his memorial service,

> *It's a unique experience because memorials are for the living and you're mourning the loss of someone, someone that you cared about a great deal. And yet, when the rocket goes up, as much as you miss them, as much as you loved them, you are so excited, and so happy, and so joyful that you get to experience what they really wanted. And you just know that they are somewhere yelling, 'Yahoo!' because they finally made it […] It's an unbelievable experience* [4].

Jon McBride, an American astronaut, said at a service dedicated to families present at a memorial flight launch, "I am […] flooded by emotions of what I see and hear, to be with you, and think of the wonderful thing you chose to do for your loved ones. They truly 'slipped the surly bonds of earth, and touch the face of God [5].'"

25.1.1 Memorial Spaceflights

The modern practice of "space burial" is limited by presently available technology, cost, and international treaties governing the peaceful use of space [6–8]. At the time of this writing only two privately owned companies in the United States have the clearance and resources necessary to perform memorial spaceflights [9, 10]. Counter to the vision of Mr. Jones, whose quote opening this chapter represents one of the first printed examples of interment in space, no organization or business can send a whole body to space. Instead, most extraterrestrial memorials are performed with a "symbolic portion of cremated remains," about 1 g in mass [11]. There are two flight types currently offered: sub-orbital and orbital. A sub-orbital flight path allows for an intact return to Earth by recovery of the capsules from the reusable rocket stage after reaching a maximum altitude of about 70 km [12]. An orbital flight path attaches the capsules to rocket stages or satellites intended to remain in orbit. In accordance with regulations, these spacecrafts are expected to re-enter Earth's atmosphere and disintegrate, "like a shooting star," as their orbits decay [13]. Future flights are planned for deep space missions into solar orbit and beyond [14].

25.2 Lunar Burials and Solar Orbits

A portion of the remains of Eugene Shoemaker, who co-discovered the comet Shoemaker-Levy 9 that dramatically impacted Jupiter in July 1994, were included in the payload of the National Aeronautics and Space Administration (NASA) *Lunar Prospector* mission. Carolyn C. Porco, planetary scientist at the University of Arizona, wrote in her article *Destination Moon,* "[…] I read in the morning newspaper that Gene's body would be cremated. The love he engendered in all who knew him, his inspirational life, and how badly he had wanted to get to the moon all flashed through my mind with the speed of a cosmic impact. Let's send Gene to the moon, I thought. This is his last chance." [15] His remains are the only to have been placed on a celestial body outside of Earth, though additional lunar missions are scheduled to include payloads of human remains. To date no remains have been permitted to leave Earth orbit on a commercial spaceflight. A mission for solar orbit is scheduled for 2022, though this was delayed due to the COVID-19 pandemic [10, 16].

25.3 International Law for the Commercial Use of Space

The use of outer space is regulated by five international treaties and other principles established by joint resolutions of the United Nations Organization. The initial treaty, The Outer Space Treaty was first proposed in 1966 and ratified in October 1967. The treaty serves primarily to limit military use of space, including the ban on placement of weapons of mass destruction on or in orbit of any celestial body. However, there are three key principles present in this treaty relevant to the commercial use of space by member States of the United Nations:

- States shall be responsible for national space activities whether carried out by governmental or non-governmental entities.
- States shall be liable for damage caused by their space objects.
- States shall avoid harmful contamination of space and celestial bodies [6].

In accordance with these provisions, all memorial spaceflights originating in the United States must be approved by the Office of Commercial Space Transportation of the Federal Aviation Administration. To comply with regulations more easily, all flights from the two commercial entities providing these services do not release any material from a spacecraft. Functionally, all memorial spaceflights are conducted as additional cargo on missions designed for other purposes. Most missions designate cremains as a "secondary payload" to distinguish the material from a "primary payload" which may be intended for placement in orbit [7]

25.4 A Brief History and Future Plans

The first memorial spaceflight was conducted in 1992 in secret by a member of the crew of the Space Shuttle *Columbia.* Majel Barret Roddenberry loaned a portion of her husband Gene's ashes so that he was, "[…] able, just once, to go into that great galaxy he dreamed about, where so few men have gone before […]" Mr. Roddenberry would also be part of the first commercial memorial spaceflight, Founders Flight, from Celestis, Inc., launched as a secondary payload to Spain's MINISAT 01 mission on April 21, 1997. It was launched by a Pegasus rocket from an Orbital Sciences Corporation Stargazer aircraft. The satellite orbited the Earth every 96 min until it reentered the atmosphere on May 20, 2002. Other notable individuals on board Founders Flight included physicist Gerard O'Neill, rocket scientists Beauford Franklin and Krafft Ehricke, and psychologist Timothy Leary. The remains of 20 other people were included in the first flight [17].

From 1997 to 2019, Celestis, Inc. has conducted 16 memorial flights, including serving as the private sponsor for including Mr. Shoemaker's remains on *Lunar Prospector*. Three of these missions carried the remains of *Star Trek* actor James Doohan and NASA astronaut Gordon Cooper. The most recent of these flights, New Frontier, also carried portions of the remains of 306 other people [18].

Another corporation, Elysium Space, intends to offer a service where the remains are contained within a separate "CubeSat" intended to be jettisoned from the launch vehicle and allowed to orbit freely before eventually re-entering the atmosphere and burning up. Elysium also plans to create "lunar mausoleums" using lunar lander technology from Astrobotic [16].

As of 2021, flights with Celestis, Inc. may be reserved across four unique services. The sub-orbital "Earth Rise" package is priced starting at $2,495 USD and includes the return of the decedent's cremains or DNA sample. The Earth orbit service starts at $4,995. Planned Lunar orbital or surface missions as well as Deep Space launches are priced at $12,500. All services include invitations to launch events, memorial services, a commemorative certificate, and a mission completion guarantee that promises a complementary second mission if the first attempt is not successful. Celestis also offers multiple capsule sizes that permit one, two, or three participants in a single launch for an additional fee [11].

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Medical Aid in Dying

26

Kim Callinan, David Grube, and Victoria Ramirez

Contents

26.1 Introduction: Why Medical Aid in Dying?

> Modern scientific capability has profoundly altered the course of human life. People live longer and better than at any other time in history. But scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals. And we in the medical world have proved alarmingly unprepared for it."—ATUL GAWANDE MD

As the nation's 75 million baby boomers enter into a new phase of their life, care for their aging parents, and contemplate their own mortality, many have come to realize that our end-of-life care system is hamstrung by outmoded views of dying. It is a system that reflexively values quantity of life over quality. Sometimes the

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treatment causes more suffering than the disease or condition from which an individual is dying. Such treatments also have the potential to significantly decrease your quality of life, and even reduce the length of time that you live.

So, the conflict is often not about living or dying; rather, it's often between how one dies and how much suffering is endured. For those who reach the point of exhausting all available treatments, the question is quite simply how they will live their remaining days. While palliative and hospice care have evolved and advanced significantly in the United States, they often cannot control all pain and suffering for patients at life's end. In fact, the decline can be quite debilitating, as evidenced by many suffering with end-stage cancer.

Chris Davis was just 29 years old when he faced the late stages of bladder cancer—which was ravaging his body. Despite hospice and palliative care, Chris suffered tremendously at life's end. His swollen skin was bursting from the pressure of edema. His pain was excruciating. He died exactly how he had feared: With tubes draining various bodily fluids that protruded from his stomach, kidneys, and chest. For Chris, a peaceful death was preferable to prolonged suffering. He wanted the option of medical aid in dying; however, it was not available to him.

Medical aid in dying

refers to a practice in which a mentally capable, terminally ill adult may request a prescription from their medical provider for a medication that they can self-ingest to die peacefully if their suffering becomes unbearable.

The majority of people who use medical aid in dying are also receiving hospice and palliative care. Terminally ill people who request medical aid in dying do not request it because hospice or palliative care has failed to provide the best symptom control available. Rather, people want the option for multiple reasons all at once: pain and other symptoms such as breathlessness and nausea, loss of autonomy, impaired quality of life, and loss of dignity [1]. It is not any one reason, but rather it is the totality of what happens to one's body at the very end of life.

That said, pain control is an issue for some. The evidence from scientific studies confirms that despite the wide availability of hospice, palliative care, and pain management, up to 51% of patients experience pain at the end of life [2]. The prevalence of pain has been noted to increase significantly in the last four months of life, reaching as high as 60% in the last month of life [3]. Additionally, breakthrough pain—severe pain that erupts despite receiving a long-acting painkiller—remains a harrowing experience for some patients. It has been estimated that between 65 and 85% of patients with cancer—by far the most common disease among people who request medical aid in dying—experience significant pain [4].

For others, the side effects of pain medication (sedation, nausea, obstructed bowels) are just as difficult to endure as the pain resulting from the disease. In some cases, these adverse effects can be controlled or relieved only through continuous deep sedation. Even then, patients may moan and grimace, suggesting significant pain may still be present. Conversely, many patients value their consciousness so highly that they bear extraordinary pain in exchange for a state of alertness during their final days.

Still others want the option of medical aid in dying because they want to try that one last, long-shot treatment with the peace of mind of knowing that if it results in unbearable pain, they have an option to peacefully end their suffering. While as a country we should improve hospice and palliative care, it is not an either or: some patients will still want the option of medical aid in dying.

Personal Story–Kim Callinan

In 1970, when my mother delivered me, she had no say in her childbirth experience: she was strapped down to her bed, medication was automatically administered, and my father was relegated to the waiting room. Fast forward 30 years to when I delivered my son. I had an 8-page birth plan. I chose limited interventions. My medical team used my birth plan to guide care decisions. And my husband was right by my side every step of the way.

Over that 30-year period, an enlightened generation of women became adamant about shaping a much different experience—one of options, with partners heavily involved—and a collaborative relationship with doctors around every aspect of pregnancy. The pressure from women and their partners was so intense that the system yielded. There was a seismic shift from a paternalistic health system that completely discounted the preferences of pregnant women and fathers to a patient-driven system that recognized a patient’s values should guide medical decisions.

This is the exact shift that is taking place in end of life care, and the authorization and implementation of medical aid in dying is paving the way for this transformation.

The option of medical aid in dying puts the decision-making power where it belongs: with the dying person. And it paves the way for the same type of seismic shift that took place at the beginning of life with the childbirth movement to take place at the end of life.

26.2 Where Is Medical Aid in Dying Available in the United States?

The option of medical aid in dying was first authorized in the United States in 1994 in Oregon when the voters in the state, by a citizen initiative, approved the Death with Dignity Act [5]. Today, more than one in five people, 22%, live in

Table 26.1 States or territories where medical aid in dying is authorized

State	Name of act	Authorization date	Method	Effective date
Oregon	Oregon death with dignity act	11/8/1994	Ballot	10/27/1997
Washington	Washington death with dignity act	11/4/2008	Ballot	3/5/2009
Montana	Baxter V. Montana	12/31/2009	Courts	12/31/2009
Vermont	Vermont patient choice and control at the end of life act	5/20/2013	Legislature	5/20/2013
California	California end of life option act	10/5/2015	Legislature	6/9/2016
Colorado	Colorado end-of-life options act	11/8/2016	Ballot	12/16/2016
Washington DC	DC death with dignity act	12/19/2016	Legislature	2/18/2017
Hawaii	Hawaii our care, our choice act	4/5/2018	Legislature	1/1/2019
New Jersey	New jersey medical aid in dying for the terminally Ill act	4/12/2019	Legislature	8/1/2019
Maine	Maine death with dignity act	6/12/2019	Legislature	9/10/2019
New Mexico	New Mexico Elizabeth whitefield end-of-life options act	4/8/2021	Legislature	6/18/2021

a jurisdiction where medical aid in dying is authorized, either through statute or court decision (Table 26.1).

The majority of Americans have supported medical aid in dying since the 1970s. The option has gained growing acceptance since October 2014 when Compassion & Choices partnered with Brittany Maynard, a 29-year-old woman suffering from terminal brain cancer, and her husband, Dan Diaz, to share her story [6]. Brittany and Dan moved from California to Oregon in order to access that state's Death with Dignity law. Since Brittany shared her story in 2015, six states and Washington DC have authorized this option. Prior to that, four states authorized the medical practice in a 20-year period.

26.2.1 Cultural Perspectives

Dozens of public opinion surveys demonstrate that the overwhelming majority of Americans support the option of medical aid in dying. A 2020 Gallup survey found that nearly three out of four U.S. residents (74%) agree that: "When a person has a disease that cannot be cured…doctors should be allowed by law to end the patient's life by some painless means if the patient and his or her family request it [6]." In 2016, LifeWay Research released a survey that included a more in-depth look at racial and ethnic groups and found majority support among the surveyed populations, including white Americans (71%), Hispanic Americans (69%), and more than half of black, non-Hispanic Americans (53%) [7]. Data from other racial and ethnic groups were not reported.

While there is widespread support that the option should be available, there are considerable differences among demographic groups regarding utilization of the practice. Currently, public health departments in nine authorized jurisdictions have issued reports regarding the use of medical aid-in-dying laws: Oregon, Washington, Vermont, California, Colorado, Hawai'i, the District of Columbia, Maine, and New Jersey.

Differences in data collection and reporting complicate comparisons across states, however, we are able to make some generalizations. The data suggests that users of medical aid in dying tend to be 65 or older (72%), educated (72% have at least some college), and enrolled in hospice care (85%). The state reports also demonstrate clear patterns in utilization of medical aid in dying among different races and ethnicities. Overwhelmingly, the majority of people (94%) who request a prescription for medical aid in dying are white. Asian Americans and Hispanics/Latinx each represent approximately 2% of medical aid in dying participants. The remaining races listed on state annual reports—indigenous American/Alaska Native, Native Hawaiian/Pacific Islander, and multi-race—all comprise less than 1% of medical aid in dying participants [8].

Currently, data does not exist to confirm why racial and ethnic minorities are less likely to access medical aid in dying. However, racial and ethnic minorities are also less likely to engage in advance planning or access other end-of-life care options like hospice and palliative care [9]. The literature suggests a range of reasons for these disparities:

- Differences in spiritual or cultural beliefs [10]
- Lack of trust in the healthcare system based on disparate negative treatment [11]
- Lack of awareness about medical aid in dying as an option [12]
- Less provider and patient communication about end-of-life care including the option of medical aid in dying [13]
- Less comfort in discussing death among certain populations [14]
- Lack of ability to find providers who will support their desire [15]
- Provider racial bias [16, 17].

Additional research is needed to understand why diverse populations are not choosing to access the option of medical aid in dying. If the low utilization rates of such populations result from spiritual beliefs or personal values, this is okay. However, if underserved populations are not choosing to access the option because of lack of information, mistrust of the healthcare system, a discomfort with raising the issue with their doctor or a lack of availability of supportive healthcare providers, these disparities must be addressed.

Personal Story-Victoria Ramirez

I have been an oncology social worker for over six years, and a social worker for EOLOA (The End of Life Option Act, California's medical aid in dying statute) for the last four years. Another possible area to explore and its effect on representation of diverse populations may be awareness about the aid in dying law. Physicians are not required to speak with their patients about medical aid in dying as an option and may not be aware that their state or institution participates. This may leave the patient to be their own advocate and there may be a lack of information in their community. It is helpful to have a navigator for patients to assist with guidance. Some institutions have a social worker who is able to partner with a patient that has expressed interest in medical aid in dying.

Patients have also expressed worry about how their physician will react if they ask about this option and a middle person contact that can provide guidance may be helpful in removing such barriers. During my time as an EOLOA social worker, I have received few requests from Hispanic patients; this is surprising considering the high percentage of Hispanics in Southern California, where our cancer center is located. I will never forget one patient: a Spanish-speaking woman, coping with metastatic cervical cancer. As she evaluated her end-of-life options, she spent a lot of time discussing EOLOA with her family in detail; eventually, she decided to start the process for the aid-in-dying medication. Unfortunately, one day, during an inpatient stay, a physician doing rounds questioned her decision-making and commented that as a Catholic, this option is not supported by the Catholic church. This physician had never met the patient before, but because the patient was a monolingual Spanish-speaker, assumptions were made about her ethnic identity and her religious preferences. After that encounter, the patient no longer wished to proceed with EOLOA. She never mentioned the topic again, despite reassurance from others, including her family, that she may choose this option without any judgment.

Many other patients I supported through this process have been Chinese, some monolingual Mandarin or Cantonese speaking. The common difficulty this population has identified is the desire to die outside of their home, for fear of bringing bad luck or further burdening their family with the sale of the home and the belief that a death in the home will impact ability to sell.

26.3 The Nuts and Bolts: How It Works

The medical aid in dying legislation in nine of the 10 authorized states is very similar. (Montana is legal as a result of a Supreme Court ruling and as such, does not have aid in dying legislation.) The states modeled their laws after the Oregon Death with Dignity Act, which is carefully crafted to protect patients. A fundamental principle of the legislation is that it is entirely optional—for both the provider and the patient.

When a patient requests medical aid in dying, it is imperative that all members of the health care team explore the reasons for the request. It is not uncommon that fears or lack of knowledge are driving the request, and often these can be addressed and resolved. Simply having the conversation about all end-of-life options, including medical aid in dying, is palliative in and of itself. Fully one-third of patients who complete the process of medical aid in dying do not ingest their prescription [8].

The legislation includes strict eligibility criteria. A person must be:

- An adult (18 or older)
- Mentally capable / volitional
- Terminally ill (less than six months to live).

Individuals are not eligible for medical aid in dying because of age or disability.

The patient must also be able to self-administer the medication. Medical aid-in-dying laws in the United States do not allow physicians, family members, or anyone else, including the dying person, to administer medical aid-in-dying medication by intravenous (IV) injection or infusion.

The law also has additional regulatory requirements which vary by state. Generally, they include:

- Two providers, licensed in the state of residence of the patient must certify the person meets the eligibility requirements (New Mexico only requires one if the person is already enrolled in hospice care)
- Requests must be made by the patient, orally and in writing
- Two witnesses must certify the patient is not being coerced. One of these witnesses may not be related to the patient, and neither may be the patient's physician/nurse
- There is a mandatory mental health evaluation if either healthcare provider has concerns about the patient's capacity and volition to make an informed health care decision (with the exception of Hawaii where the evaluation is mandatory in all instances)
- Waiting periods (vary by state).

These regulations are in addition to the education, training, and oversight that govern the practice of medicine for any medical procedure. In addition, the attending/prescribing provider, in counseling the patient, must offer all end-of-life alternatives (continued care, reduced care, hospice, and palliative care); should recommend that the patient informs next of kin/loved ones; recommend that the patient not be in a public place such as a park when ingestion occurs; and ensure that any prescribed medication be safely and securely stored.

The current Oregon model, which laid the foundation for all of the other authorized jurisdictions, requires a lengthy, multi-step process. While on paper it appears that a person can get through the process relatively quickly, in reality it takes a dying person several weeks to several months to get through all the steps, if they are able to complete it and obtain the prescription at all.

The evidence and data from a combined 40 years across six jurisdictions (California, Colorado, Montana, Oregon, Vermont, and Washington) [8] show that many individuals die with needless suffering while attempting to navigate an unnecessarily burdensome process. For example, a study by Kaiser Permanente Southern California [18] showed that one-third of patients who requested the option of medical aid in dying were unable to complete the process and obtain a prescription before they died. It's worth noting that Kaiser is a health system supportive of patient preferences, with dedicated patient navigators to assist individuals through the process. The percentage of patients who die suffering because they start the process in a health system that forbids their doctors from participating is considerably higher.

Oregon lawmakers acknowledged the need to remove unnecessary regulatory roadblocks in July 2019, when its Governor signed a law to revise its Death with Dignity Act to allow doctors to waive the mandatory 15-day waiting period for medical aid in dying if a doctor does not believe the terminally ill person will live through the period. The 2020 annual report issued by the Oregon Health Authority showed that within the first year of the updated provision, 20% of patients required a physician exemption in order to make it through the process [19].

Lawmakers across the country are working to improve their aid-in-dying laws or create new ones that find a more appropriate balance between necessary safeguards and excessive regulatory roadblocks. New Mexico's bill, the latest state to authorize medical aid in dying as of this writing, has advanced the most innovative solution—reducing the waiting period to 48 h with a physician waiver for patients imminently dying, allowing patients to seek just one certification from a provider if enrolled in hospice, and allowing nurse practitioners and physician assistants to serve as one of the providers.

26.4 Provider Knowledge, Practices, and Behavior—The Evolution

As noted above, the Oregon Death with Dignity Act, a citizens' initiative, was first passed by Oregon voters in 1994. Implementation of the Act, however, was delayed by several lawsuits, including a petition that was denied by the United States Supreme Court. The Ninth Circuit Court of Appeals lifted an injunction on October 27, 1997, making medical aid in dying a legal option for terminally ill patients. In November 1997, a statewide Measure authorized by the Oregon House of Representatives asked citizens to repeal the Death with Dignity Act (DWDA). Voters chose to retain the Act by a margin of nearly 20% (59.9 to 40%) [20].

The lawsuits and referendum had the effect of stifling utilization and the integration of medical aid in dying into standard medical care. Finally, in March of 1998, the first medical aid-in-dying prescription in the country was written by

Peter Reagan, M.D., a Portland family physician [21]. Utilization of the practice grew slowly. In the first year of the DWDA, 23 Oregonians received prescriptions, 15 of which ingested them (prescribed by 14 different physicians) [20]. In the subsequent years, there has been growing acceptance of medical aid in dying, as noted in annual reports of the Oregon Health Authority [20]. By 2020, a total of 142 physicians wrote 370 prescriptions for medical aid in dying [22].

There has also been a growing comfort level with the practice among U.S. physicians. A 2020 Medscape poll of 5,130 U.S. physicians from 30 specialties demonstrated a significant increase in support for medical aid in dying from 2010 [23]. Today, of physicians surveyed, endorse the idea of medical aid in dying, agreeing that "Physician assisted death should be allowed for terminally ill patients" whereas in 2010 only 46% supported the option [24].

With each new state authorizing medical aid in dying, national associations and organizations removed oppositional policies, including the American Academy of Hospice and Palliative Medicine [25], the American Academy of Family Physicians [26], and the American Nurses Association [27]. Frye and Youngner, in an article in the Annals of Internal Medicine, argue that "beyond their current endorsement of palliative care, professional organizations should adopt a position of engaged neutrality in which they take responsibility to help minimize or avoid the potential harms" of medical aid in dying [28].

While there has been a growing acceptance among providers, more work needs to be done to ensure patients can access medical aid in dying as a part of routine end-of-life care. Because providers can "opt out" of providing medical aid in dying services, it's not uncommon for dying patients to have a difficult time finding one who will support them. We encourage providers who want to learn more about the practice to take the Medscape continuing medical education (CME) activity—*Medical Aid in Dying: My Clinical Guide and Practice Points* (available for one credit) [29]. Other resources include City of Hope's *How Medical Aid in Dying Really Works in Authorized States* [30] and Compassion & Choices Doc to Doc program, CompassionAndChoices.org/d2d or Call Doc2Doc: 800.247.7421 or email Doc2Doc at doc2doc@CompassionAndChoices.org.

Personal Story–Dr. David Grube

Early in my career as a rural family physician, a neighbor's son had called me to tell me that "something is wrong with my dad." His mother was not home. His father, I knew, had end stage renal cancer and was in hospice. I was able to go to their home immediately and found his father sitting in a chair in the back bedroom with a shotgun between his legs. He had taken his life. The shock of finding him, calling the police, finding his wife, and cleaning up the terrible physical result has had a deep and lasting negative impact upon me. I promised myself that I could never let this happen to another patient ever again.

A first patient asked me, in 1999, about utilizing Oregon's Death with Dignity Act (the medical aid in dying law in the state). He was a former smoker, a tenured university professor who presented with a cough. Imaging studies revealed metastatic lung cancer, surgery was not an option and subsequent radiation and chemotherapy were ineffective. He rapidly deteriorated, and he was clearly suffering in ways that hospice and palliative care could not assuage.

His plea to me, death with dignity, was just that; a patient-centered, nonviolent and compassionate end of life option. However, although I knew that I would help my cancer patient, because this was my first experience with medical aid in dying, I needed a mentor. I contacted the medical director of my local hospice, and he sat down with me and helped me with the process. He also became the Consulting Physician. Together with the patient, we went through the necessary steps (waiting periods, written request, and, at that time, a mental health referral) and I ultimately prescribed medication to the professor. While I offered to attend his planned death, he preferred to be alone with his wife and children. His wife later reported to me that his death was peaceful and gentle, and she thanked me not only then, but for years after, for respecting my patient's wishes, and providing comfort and care to him and their family.

When I think back on these two events—the violent suicide and the peaceful passing of the professor—it is clear to me that medical aid in dying is a valid and vital option at end of life. Seeking counsel from an experienced physician, as we do in all arenas of medicine, was critical and immensely helpful.

26.5 Impact of Medical Aid in Dying on End-of-Life Care

The growing support for medical aid in dying is attributable, in part, to the fact that it is a compassionate and time-tested end-of-life care option. Researchers and legal scholars have confirmed that the experience across the authorized jurisdictions "puts to rest most of the arguments that opponents of authorization have made—or at least those that can be settled by empirical data. The most relevant data—namely, those relating to the traditional and more contemporary concerns that opponents of legalization have expressed—do not support and, in fact, dispel the concerns of opponents [31]." A brief summary of the evidence finds:

- **There have been no documented or substantiated incidents of abuse or coercion** across the authorized jurisdictions since Oregon implemented the first medical aid-in-dying law on Oct. 27, 1997. In 2008, the Journal of Medical Ethics concluded that: "Rates of assisted dying in Oregon … showed no evidence of heightened risk for the elderly, women, the uninsured … people with low educational status, the poor, the physically disabled or chronically ill … people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations [32].” In fact, Disability Rights Oregon has never “received a complaint that a person with disabilities was coerced or being coerced to make use of the Act [33].”

- **Relatively Few Will Use Medical Aid in Dying, But Many Benefit From These Laws.** Based on data from the jurisdictions that have authorized medical aid in dying and subsequently published statistical reports, less than 1% of people who die annually in an authorized jurisdiction will decide to use the law, but large numbers will benefit from simply knowing the law exists [8]. Awareness of the law has a palliative effect, relieving worry about end-of-life suffering. About one-third of terminally ill adults who receive an aid-in-dying prescription in Oregon never even take the medication. However, they report experiencing enormous relief from the moment they obtained the prescription because it alleviated their fears of suffering [34]. Quite simply, medical aid in dying is a prescription for comfort and peace of mind.
- **The implementation of medical aid in dying improves end-of-life care generally.** As an example, a 2015 Journal of Palliative Medicine study found that in addition to having one of the highest rates of hospice use, Oregon had the lowest rate of inappropriate hospice use [35]. “Inappropriate hospice use” is defined as very short enrollment, very long enrollment or disenrollment. This same study suggested the medical aid-in-dying law may have contributed to more open conversations between doctors and patients about end-of-life care options, which led to more appropriate hospice use. Hospice programs across Oregon did, in fact, report an increase in referrals following passage of the Oregon Death With Dignity Act [36]. Over 20 years later, more than 90% of individuals who used medical aid in dying were receiving hospice services at the time of their death [37].

26.6 Conclusion

It’s not uncommon for progress to reveal new challenges and that is exactly what has happened with our end-of-life care system. Incredible advances in medicine have prolonged life. At the same time, in some instances, it has also prolonged suffering and delayed death beyond the point of meaningful life. As the baby boomers see this travesty first hand, they are seeking to chart a different path forward, one that provides them with a greater ability to chart their own journey and less suffering.

We have seen this story before in the childbirth movement, and perhaps that serves as a window into where we are headed. Imagine if we could have that same type of transformation for the end of life that we had in the childbirth movement? What if a person could write their own plan, decide when and where they die, decide who they want with them when they die and what they want their last sound to be? What if they could determine how much pain they're willing to endure, even if that means accelerating their time of death? Imagine if the default standard of care for end of life was for doctors to assume the patient's values are paramount. That future is possible. In fact, we are in the midst of this transformation.

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