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PERSPECTIVES

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Holy Simplicity: The Physician's Role in End-of-Life Conversations

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Early initiation of end-of-life (EOL) conversations has been shown to improve patient agency in dying, increase early access to hospice care, and facilitate a dignified death. Despite the benefits of early initiation, EOL conversations do not occur as readily as physicians or patients wish. While medicine is commonly considered both a science and an art, increasing medicalization may narrow a clinician's focus towards procedures or specialized clinical frameworks rather than a patient's end-of-life wishes. Since physicians are ambassadors of clinical knowledge and are trusted patient advocates, it is important they facilitate EOL conversations early in the dying process. Patients desire their physicians to convene these conversations. However, physicians are often hesitant to do so. Notable theologians, philosophers, and physicians offer a broad framework outlining the importance of physician-led EOL conversations.

INTRODUCTION

Facing one's own mortality is an unavoidable aspect of the human experience. Too often, the realities of death are avoided due to fear, denial, or urgency. Dr. Timothy Keller, founding pastor of Redeemer Presbyterian Church in Manhattan, writes, "Death is an abstraction to us, something ethically true but unimaginable as a personal reality" [1]. In the same article Keller discusses facing his own mortality after receiving a pancreatic cancer diagnosis early in 2020. Despite providing countless hours of counseling to ill congregants and having expertise on the theology of death, Keller found himself in disbelief asking, "What was God doing to us?" [1].

Spirituality can broadly be understood as existentially contemplating one's meaning, purpose, and goals in life, and religion as an organized set of beliefs or rituals regarding the supernatural [2]. The perspective Keller shares suggests that religious faith alone does not provide solace. Belief in an afterlife does not therein-of itself provide comfort and strength. Dying well with dignity requires both intellectual and emotional engagement that Keller terms "*head work and heart work"* in reference to more familiar terms: reasoning and feeling [1]. Keller asserts that a rational conviction not only gives a framework to strengthen faith but prepares the dying for death as well [1].

Dr. David Kuhl, Associate Professor of Family Prac-

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Abbreviations: EOL, End-of-life; AAMC, American Association of Medical Colleges.

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tice at St. Paul's Hospital in Vancouver, British Columbia writes that patients have difficulty embracing life while preparing to die [3]. For many, death is a slow process that takes months or years, and for some it is swift without remorse. How an individual processes their death early on through conversation and personal reflection will determine the course of a person's final days and may even absolve loved ones of pain and guilt over medical decisions made on one's behalf. For better or worse, physicians have the responsibility of relaying the grim prognosis to patients and their families. Dr. Kuhl notes that misplaced words and actions in these conversations can cause pain and poison the dying process [3]. Unfortunately, end-of-life (EOL) conversations are too often poorly implemented by medical professionals and occur too late and infrequently [4]. Many physicians note feelings of inadequacy or lack of training. Others question whether they should initiate the conversation or refer to a palliative care specialist with more expertise [4]. Regardless of a physician's hesitancy to initiate EOL conversations, confronting the reality of death early is paramount, allowing patients time for *head work* and *heart work.* The role of a physician in the dying process is a uniquely challenging duty. Because of their knowledge and authority to speak into a patient's life, physicians are aptly equipped to catalyze EOL conversations.

INITIATING EOL CONVERSATIONS EARLY

Dr. Steven Radwany is a palliative medicine physician who has practiced for more than 30 years. In his American Medical Association opinion piece, *Our Best Judgement*, Dr. Radwany shares his expertise as he reflects on the narrative of his brother Les's COVID-19 diagnosis and subsequent death. In the beginnings of his piece Radwany struggles with Les's decision to decline a ventilator, should it become necessary. Unbeknownst to Radwany and Les at that time, this decision undoubtedly preserved Les's dignity into death. Les, like many Americans, had been dealing with chronic disease, and after seeing the protracted death of his friends, decided that he did not want life support, saying, "If I die, I die. I've had a great life." Les clearly outlined his EOL wishes early, years before the COVID-19 pandemic; he did not want to trade a "great life" for one fraught with suffering [5].

Following Les's hospital admission, Dr. Radwany received a phone call from Les's intensivist who delivered a poor prognosis. Les would not survive the next 24 hours. The intensivist and infectious disease consultant both insisted that further interventions would be inconsistent with Les's wishes and, based on what they had seen in similar cases, would prolong suffering. Their suggestion: "keep him comfortable" [5]. Les died within 24 hours of admission, but the family's grief was attenuated by the care and comfort measures given. Expectations were clearly disseminated to the family, and wishes for comfort care were respected. Les's wife and son were allowed to stay for the duration, and a chaplain was able to sit with and pray with Les while he was still conscious. Les was even able to partake of the Eucharist, a spiritual ritual of substantial personal importance to him. In his last hours, Les appeared peaceful, dying with hands held by both wife and son—an experience described by his family as "peaceful and spiritual" [5]. The outcome of the case study of Dr. Radwany's brother was possible because Les had outlined his EOL wishes early, and his physician clearly communicated strong recommendations that aligned with Les's wishes. The narrative of Les's death demonstrates that dying well starts with the art of living well, *ars moriendi,* Latin for the "art of dying," a concept discussed by Dr. Lydia Dugdale, in her book *The Lost Art of Dying: Reviving Forgotten Wisdom* [6]. Les was able to die with dignity because he was not willing to compromise his desired quality of life.

LACKING URGENT CONVERSATION: PHYSICIANS AND EOL CONVERSATIONS

Les was an outlier having had had these conversations at all. The Institute of Medicine published a report in 2014 that notes most people "particularly younger, poorer, minority, and less educated individuals," experience structural barriers that impact one's capacity to have EOL conversations with their physician [7]. Many individuals who receive invasive treatment at the end of life – a tracheostomy, endotracheal tube, or gastrointestinal tube – may, in retrospect, have wished to forgo treatment in order to experience a peaceful death. A California survey notes that 70% of state residents prefer to die at home, but, in 2009, only a third of California deaths did. Eighty two percent of Californians noted a desire to have EOL wishes in writing but only 23% of respondents have had their wishes documented. The same article notes that of 80% who have expressed a desire to talk with a physician regarding EOL care, only 7% have done so [8]. This data paints a clear picture that patients desire to have these conversations, yet they are not happening.

Dr. Atul Gawande discusses the case of 34-year-old Sara Monopoli in his book *Being Mortal*. Sara had been the recipient of an unfortunate cancer diagnosis, having failed two chemotherapeutic treatments and placed on a third despite unrealistic expectations regarding positive treatment outcomes [9]. Rather than acknowledge the low odds of successful treatment, Sara's physicians used promising language suggesting that a last-ditch experimental trial may have positive outcomes; such interventions seldom lengthen or improve quality of life. These phenomena has been described by Shim, Russ,

and Kaufman as *technological incrementalism*, a form of the *treatment imperative,* where momentum for subsequent treatments are easily rationalized through serial progressions or incremental increases in risk [10]. Sara and her family were placed in a position that many facing a medicalized death experience—emulsification in false hope. While physicians communicate treatment options and drug cocktails to patients, these conversations often lack direction [5,9,11]. Ill patients and their loved ones cling to optimism, interpreting optimistic outlier statistics as the norm. Such an interpretation is not only statistically unlikely but may cause undue suffering. Dr. Gawande asserts that "hope is not a plan," emphasizing the goal of physicians should not focus on providing a good death, but a good life until the very end [12]. However, patient-family reciprocal interdependence may complicate EOL care [13]. Dr. Susan D. Block, professor of Psychiatry and Medicine at Harvard Medical School, pulls from her clinical experience, noting that two-thirds of patients are willing to undergo treatments they would have initially refused if they believe family wish they do so [9]. Mrig and Spencer discuss that hope is often paired with aggressive treatments to "wage war" on cancer. Hope, when used to optimize dismal prognosis, may constrain hospice utilization, exemplifying biomedicalization [14]. Sara fell victim to this phenomenon and was admitted to the Emergency Department and subsequently to the ICU. Despite having ample time to communicate her desire to die at home to family and practitioners, Sara died in the ICU [9]. While many variables led to Sara's EOL wishes not being fulfilled, physician willingness to discuss EOL was a substantial contributor. As seen in the case of Les and absent in the case of Sara, patients need providers that will navigate the tough conversations to bring about *ars moriendi*.

SPIRITUALITY: EASING INTO EOL CONVERSATIONS

The American Association of Medical Colleges (AAMC) notes that there is enormous psychological resistance for doctors to initiate EOL conversations [15]. In some ways, these conversations are outside the expertise or comfort of physicians whose role is, traditionally, to ward off death with surgical and medical efforts. In some instances, death can be incorrectly viewed as a failure of the physician [16]. As a result, it is not an uncommon phenomenon for the physician's visits to dwindle as the prognosis becomes terminal.

Beck et al. allegorically discusses the physician EOL care experience through the case of Margie, a breast cancer patient, whose "optimistic, up-tempo" oncologist, Dr. T, was absent near the end. Margie's ex-husband gave Dr. T the benefit of the doubt, noting that he retreated to bolster up energy for those that he could save [11]. However, according to Dr. Alan C. Mermann, physician and former Yale School of Medicine Chaplain, Dr. T missed an opportunity to rise to the occasion and acknowledge the spiritual and existential needs of the patient, which can ease the dying process and alleviate physician burnout [11,16,17]. Dying, in a general sense, can be a spiritual event; patients, family members, and clinicians have noted that including spirituality is an important dimension of EOL care [18]. Concluding his article *Spiritual Aspects of Death and Dying*, Dr. Mermann writes, "When the personal need of the dying patient is greatest, and the need for technical expertise is lessening, the defining attributes of the good physician can be displayed at their finest" [16]. Mermann asserts that the clinician's role to nurture the patient does not end when preservation of life ceases but at the banks of death itself.

A national US survey published in 2017 surveying physician opinions on engaging patients' spiritual concerns found that a majority of physicians believe that it is good practice to discuss spiritual concerns at the end of life [19]. However, a 2016 systematic review consisting of 61 papers and over 20,000 physician reports notes that religion and spirituality are infrequently discussed by physicians [20]. While the number of end-of-life discussions increases among patients with terminal illness, many physicians note a preference to defer to chaplains for religious and spiritual conversations [20]. However, some research has shown that there are benefits for both patient and physicians in administering EOL conversations [17,21,22]. A decreasing number of spiritual care providers and social workers in medical environments affirms the importance for physician's being skilled at initiating EOL conversations [3]. Patients have been noted to express greater appreciation and satisfaction of care after receiving spiritual or religious conversations from physicians [17]. Burnout has also been noted to decrease among physicians who initiate spiritual or religious EOL conversations with patients [17]. Importantly, patients who had received spiritual conversation with physicians had improvements in quality of life, compared to those who received usual care; non-religious patients did not experience distress as a result of these conversations [17]. Furthermore, 41% of hospitalized patients in a large urban medical center desired to have discussion on religious and spiritual concerns with their healthcare provider [19]. Physicians have expressed similar patient expectations and disclosed that engaging patients in spiritual practices such as prayer enhances the patient-physician relationship and helps patients cope will illness [19]. Individuals who receive high spiritual support from medical providers are more likely to use hospice, less likely to receive aggressive treatments at EOL, and less frequently die in ICU settings [19].

RELIGIOUS BELIEF OF PHYSICIANS IN THE US

Evidently, the desire to have EOL conversations is prevalent and acknowledged by both physicians and patients. There are measurable benefits to EOL conversations. However, since EOL conversations are inherently spiritual, critics may suggest that religious identity preclude the feasibility of EOL conversations by physicians. Many studies have focused on the religious perspectives and beliefs of patients; few have broached how physicians' religious background impacts their decision-making. When entering EOL discussions, a provider's personal perspective may bias EOL decisions. The AAMC encourages medical education to teach students to be self-aware of their spirituality and to incorporate these beliefs and practices in to the care of patients. They warn that beliefs, practices, and individual spirituality may interfere with patient care [23]. A 2005 national survey investigating Religious Characteristics of US Physicians by researchers at the University of Chicago note that 55% of physicians surveyed agree that their religious beliefs influence their practice of medicine [24]. While physicians and the general population in the US are similarly likely to adhere to a religious affiliation, physicians are more likely to belong to underrepresented traditions, attend religious services less often, and are less likely to consciously apply their beliefs to other areas of life [24]. It is important to note that the general population more readily relies on God as a means of coping with major illness and more readily look to God for strength, support and guidance than physicians who attempt to rationalize meaning independent of God [24].

EMPLOYING A HEALER MINDSET

Even among physicians who hold a faith construct, physicians approach death from the perspective of a scientific healer rather than that of a humanistic healer. Dr. Gawande notes countless times that patients, became more centric in their approach to life when death is imminent [9]. Patients speak of relationships, whom they love and who loves them. They consider existential questions and how they want to be remembered near the end [3,6].

Dr. Keller concludes his article noting, "The less we attempt to make this world into heaven the more we are able to enjoy it. No longer are we burdening it with demands impossible for it to fulfill . . . the simplest pleasures of this world have become sources of daily happiness" [1]. Keller continues, noting that the practice of *head work* and *heart work* have given him perspective that has made him more *heavenly minded* [1]. Grappling with existential questions, desires, and needs early provides patients with a healthier perspective to their dying process; the physician is aptly equipped to nurture environments and facilitate such conversations. Therefore, the role of the physician at the end of life does not stop at providing a selection or description of treatment options to choose from. The physician by definition is a healer, an individual that meets the needs of the sick so that they can flourish. As such, the physician should feel empowered and honored to aid patients on the journey towards a dignified death: *ars moriendi*.

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