

Dying Well-Informed: The Need for Better Clinical Education Surrounding Facilitating End-of-Life Conversations

Ryan Sutherland*

Yale School of Public Health, Yale University, New Haven, CT

The need for improved clinical education surrounding the way difficult news is delivered and how to initiate end-of-life (EOL†) discussions with seriously ill patients and their families is essential. Physicians and medical students often report feeling unprepared or uncomfortable with broaching the topic of death with their patients and families [1]. Early and honest conversations with patients concerning diagnoses and advance directives help patients and their families make well-informed decisions regarding future medical care, minimize pain and fears, and allow patients to experience a “peaceful death [1].” Moreover, end-of-life conversations frequently focus on resuscitation plans (advance directives), but should be broadened to include patients’ psychosocial, physical, and economic concerns. Transparent, realistic, and sensitive end-of-life conversations can help patients maintain autonomy and dignity in the dying process and increase their quality of life as they near death. Additionally, initiating these conversations can alleviate emotional stress and physical symptoms, prevent invasive, costly, unnecessary, and unwanted care, aid grieving families through the bereavement process, and increase patients’ satisfaction with end-of-life care provisions [2]. Overall, more attention and training must be delivered to physicians so that they are better prepared to initiate end-of-life discussions in a patient-centered way, focusing on patients’ values and priorities. Requiring a more in depth, developmentally appropriate, and standardized training in EOL and palliative care for physicians-in-training in all disciplines in medical education is necessary. Redesigning medical school EOL curriculum will ensure physicians are better prepared to discuss death and dying and to ensure that seriously ill patients are dying well-informed.

“I learned about a lot of things in medical school, but mortality wasn’t one of them... [o]ur textbooks had almost nothing on aging or frailty or death. How the process unfolds, how people experience the end of their lives, and how it affects those around them seemed beside the point. The way we saw it... the purpose of medical schooling was to teach us how to save lives, not how to tend to their demise [3].”
 – *Being Mortal: Medicine and What Matters in the End*, Atul Gawande

INTRODUCTION: THE IMPORTANCE OF END-OF-LIFE CONVERSATIONS

The need for improved medical education concerning the way difficult news is delivered and how to initiate end-of-life (EOL) discussions with seriously ill patients and their families is essential. Although initiatives such

*To whom all correspondence should be addressed: Ryan Sutherland, Email: ryan.sutherland@yale.edu.

†Abbreviations: EOL, end-of-life; IOM, Institute of Medicine; CMS, Centers for Medicare and Medicaid Services; OSCEs, Objective Structured Clinical Examinations.

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as the Serious Illness Conversation Guide scripted by Ariadne Labs have successfully outlined guidelines for clinical care providers' use, the uptake of these recommendations has been far from pervasive within medicine. Physicians and medical students often report feeling unprepared or uncomfortable with broaching the topic of death with their patients and families.

Physicians should not shy away from having difficult but important conversations about death because it is inevitable. But as Anna Beck of the Huntsman Cancer Institute points out, end-of-life conversations are frequently "too little, too late, and not great [4]." End-of-life conversations should not just focus on keeping patients alive, but about ensuring patients' wishes are respected in their final hours and that their quality of life is preserved in the dying process [5-7]. Physicians should recognize the ethical, emotional, and economic cost of aggressive care for dying patients and recommend against it where quality of life can be maintained.

However, according to the 2015 report, *Dying in America* from the Institute of Medicine (IOM), it is evident that poorer, younger, less-educated, and minority individuals are not having timely EOL conversations with their physicians, and as a result are dying in places and ways that do not reflect their wishes [8]. As custodians of health and wellbeing across the lifespan, physicians should be better trained on how to deliver difficult news to patients and their families about death and dying, particularly among vulnerable subgroups.

Unfortunately, research shows that although 86 percent of Medicare enrollees would prefer to die at home, 70 percent are hospitalized in their final 90 days, 29 percent are provided intensive care in their final month, and 25 to 39 percent die in acute care facilities [9-11]. Many experienced only short stays in hospice but endured frequent care transitions [10]. Aggressive care at the end-of-life results in lower quality of life for patients and higher incidences of psychological and physical distress [12,13], and results in lower satisfaction and higher rates of depression among caregivers [10,12]. Furthermore, most care provided at the end-of-life is often invasive, costly, unnecessary, and unwanted [14].

Technological advancements in medicine such as the development of mechanical ventilators, dialysis, the widespread use of cardiopulmonary resuscitation, and minimally intrusive ways to insert feeding tubes have resulted in physicians being well armed to prolong life [15]. But a 2016 study revealed that approximately 33 to 38 percent of EOL patients received non-beneficial treatments that had little effect on prolonging their lives or improving their health. Ten percent of these EOL patients were admitted unnecessarily to the ICU where they received non-beneficial treatments (95% CI 0-33%) [16]. Thirty-three percent received chemotherapy (95% CI 24-

41%) in the last weeks of their lives, while an average of 30 percent received radiotherapy, dialysis, blood transfusions, or non-beneficial life support treatment, all of which is costly, unnecessary, often unwanted, and physically and psychologically taxing on patients and their families. Cardiovascular, gastrointestinal, endocrine treatments, and antibiotics were given with no effect to an average of 38 percent of dying patients. Thirty-three to 55 percent of patients with DNRs received non-beneficial treatments immediately preceding their deaths [16]. Overall, 25 percent of Medicare payments go toward treating patients in the last year of their life, and one-third of these payments are made for negligibly beneficial clinical services in the last month of patients' lives [14,17,18].

Presently, opinions about the clinical importance of palliative education vary. In one study, medical student participants mentioned that palliative patients provided limited opportunity for clinical instruction, citing that they "were not considered good teaching cases [19]." Additionally, the busy schedule of physicians, the frequency of care transitions, and — until recently — the lack of economic incentivization to lead EOL conversations might present further barriers to initiating, prioritizing, and coordinating these discussions. CMS (Centers for Medicare and Medicaid Services) reimbursement was not provided for end-of-life and advanced care planning conversations for physicians until 2016 (99497 ACP, 99498 ACP) [20]. As Kathy Kortes-Miller, author of *Talking About Death Won't Kill You: The Essential Guide to End-of-Life Conversations*, mentions, "if physicians can grow their capacity to have [end of life] conversations, they will increase their feeling of connection with some of the people they're serving. It will ultimately help their jobs be more rewarding and meaningful for them [21]." Increased guidance on how to have these conversations can potentially stave off compassion fatigue and burn out.

Physician competence and confidence in providing end-of-life care conversations can be increased through EOL medical education reform. Early and honest conversations with patients concerning diagnoses and advance directives help patients and their families make well-informed decisions regarding future medical care, minimize pain and fears, and allow patients to experience a "peaceful death [1]."

TOPICS

Barriers to Delivering Bad News: Reasons Why Physicians Shy Away From Discussing Death and Initiating EOL Conversations

Physicians need to be prepared to deliver bad news. So why are recommendations, such as those proposed by Ariadne Labs, not being adopted? Why do physicians

shy away from these discussions? Research has shown that physicians often are unsure how to initiate or proceed with these discussions, largely because medical education regarding EOL protocols is lacking. Medical education at different institutions varies widely and dealing with death is not uniformly considered a basic medical skill [22]. Inadequate funding, a lack of trained faculty, insufficient clinical supervision, an overcrowded curriculum that leaves little room for end-of-life care instruction, and discrepancies in the importance medical school administrators place on palliative care education affect the quality and prioritization of end-of-life and palliative care [22,23].

Studies by Sullivan *et al.* and others noted that providers lacked training, communication skills, and confidence regarding the initiation of end-of-life conversations [19,24,25]. According to a 2016 systematic review by Travers *et al.*, “recurrent themes within the literature related to a lack of education and training, difficulty in prognostication, cultural differences, and perceived reluctance of the patient or family [26].” Communication barriers that exist between physicians and patients in end-of-life discussions reflect the need for further cultural competency training. In a 2015 survey of over 1,000 physicians in PLoS One, 86 percent of physicians surveyed felt conversations related to end-of-life preparations with patients of different ethnicities were “quite a bit” or “a great deal” challenging [27].

In 2003, less than 18 percent of medical students and residents indicated that they had received formalized end-of-life care education, and almost 40 percent indicated that they felt unprepared to discuss patients’ fears in the dying process or to help their grieving families cope [28]. Moreover, 40 percent of medical residents surveyed felt unqualified to instruct end-of-life care [28]. In an article by Schmitt *et al.* in 2016, 88.1 percent of surveyed residents reported little to no in-class instruction on EOL care with most EOL conversations occurring unsupervised, while 54.3 percent reported little to no in-class instruction on EOL care during medical school years [29].

Lastly, physicians might be unsure whether they should be the ones to initiate end-of-life discussions with patients if they aren’t palliative care specialists. A study by Smeenk *et al.* found that physicians’ main concerns surrounding discussing death with patients revolved around when to inform patients that they were dying, the desire to shield patients from the truth of their diagnosis in order to maintain patients’ hope and emotional well-being in the dying process, and reservations surrounding who should inform patients of this information [24,30]. This might lead to delays in informing patients about their prognoses.

The “Rescue Fantasy”: Patient Death Shouldn’t be Viewed as Personal Failure, but as a Sometimes Unavoidable Consequence of Serious Illness

The misguided impression that doctors’ sole responsibility is to save lives is difficult to break free from — by nature of the discipline, treatment and interventions are provided to prolong life. The “rescue fantasy,” the idea that some patients might hold that modern medicine and heroic physicians can stave off death and save them from all ailments, might be at play. This mentality is often shared by physicians themselves and might make it difficult for them to initiate EOL conversations [31]. A 2018 report published by the Royal College of Physicians in the United Kingdom noted that physicians often shied away from these conversations because they believed in modern medicine’s ability to cure all illnesses and succumbed to this “rescue fantasy [32].” Consequently, many viewed patient death as a personal failure [32]. Junaid Nabi noted in an article appearing in STAT, something that many medical students report: “we train vigorously on how to delay the onset of death, and are judged on how well we do that, but many of us get little training on how to confront death [33].” Corroborating this assertion, Williams *et al.* cited a medical student who expressed this sentiment as follows: “I feel afraid that I will not have the knowledge I need in order to save the life of a patient.... I am afraid I will need to tell family members of the unexpected death of a loved one.... I am afraid of what my colleagues will think and I wonder will they continue to trust me as a doctor [19,34,35]?” This feeling of helplessness in the face of death isn’t just expressed by medical residents, but by veteran physicians. Physician, author, and Professor for the Theory and Practice of Medicine at Stanford University Medical School Abraham Vergehesse in *My Own Country* noted that “I had always felt inexpert when a patient was near death.... Give me a patient with massive gastric bleeding or ventricular fibrillation and I am a model of efficiency and purpose. Put me at a deathbed, a slow dying, and purpose is what I lack. I, who till then have been supportive, involved, can find myself mute, making my visits briefer, putting on an aura of great enterprise—false enterprise. I finger my printed patient list, study the lab results on the chart, which at this point have no meaning. For someone dealing so often with death, my ignorance felt shameful [36].” Patient death shouldn’t be viewed as personal failure, but as a sometimes unavoidable consequence of serious illness. Maintaining quality of life at the threshold of death is equally important as clinical attempts to cure illness and should be viewed as a vitally important medical skill.

STRUCTURING END-OF-LIFE CONVERSATIONS

EOL Conversations Should be Patient-Centered, Focusing on Patients' Values and Priorities

Conversations at the end of life should focus on patients' values and priorities and should frame the dying process using evidence-based discussions surrounding prognoses. Multiple studies indicate that patients with serious medical illnesses often do not inform their families or providers of their EOL preferences, or initiate these discussions in the last month of their lives [12,37]. Although 92 percent of people surveyed in one study believed that talking with family members about end-of-life care was important, only 32 percent of them actually had done so. Additionally, only 37 percent of people surveyed had written out their final wishes, although 97 percent had indicated that this was important [38,39]. Only 18 percent of people have had this conversation with a physician [38-40]. Physicians should indicate a willingness to discuss death and dying on patients' terms, but should not shy away from initiating these conversations. This opens avenues for communication and serves as an opportunity for trust building between physicians and patients. Discussing EOL care well in advance of death provides patients with knowledge of additional care options that they can pursue later, even if they choose not to follow physicians' EOL recommendations and opt for aggressive treatment instead of palliative care.

While it is never too soon to initiate these conversations, putting off these conversations until days before patients' deaths is inhumane and distressing to the dying and their families. Earlier conversations facilitated by physicians would enhance goal-concordant care, increase patient satisfaction of care and quality of life, aid patients' families in the coping process, reduce suffering, and eliminate the need for invasive and costly care that provides patients with negligible clinical benefits and unnecessarily burden healthcare systems [13]. As Richard Balaban notes, "most patients, as they near death, contend with similar fears, needs, and desires. Dying patients experience fear of pain, fear of indignity, fear of abandonment, and fear of the unknown. Open and direct discussions can ease many of these fears [41]." Moreover, end-of-life conversations frequently focus on resuscitation plans (advance directives), but should be broadened to include patients' psychosocial, physical, and economic concerns.

Physicians Should Facilitate, not Lead Conversations about Death and the Dying Process

The role of the physician within the context of end-of-life trainings should not be one-sided: using scenario-based learning, medical professionals-in-training should remember that they must facilitate, not lead, the conversation. In these simulations, it is easy for physicians to adopt a one-sided approach in which they lead the

conversation according to a prescribed clinical checklist. Discussions in real life rarely go according to a script, and — while helpful — checklists should not be viewed as universal approaches to an individual patients' concerns in the dying process. While there are clinical checklists for diagnosing liver failure (MELD) or cervical spine injuries (NEXUS) along with countless other medical ailments, no standard protocol exists for discussing death at the bedside. Dying is an inherently individual process and medical educators should recognize that while there is no uniform way to discuss the dying process with patients or to deliver news of a patients' death to grieving families, these conversations must happen. Therefore, while medical education cannot provide a "one size fits all" script that physicians can deliver to dying patients, it should provide medical students with more educational opportunities to practice delivery of difficult news to different patient populations. So how do you teach physicians how to talk about this?

Physicians Should Use Substituted Judgement and Empathy When Discussing Death and Dying

Clinicians-in-training should not solely be asked to act out scenes of providing end-of-life diagnoses as *themselves*, paired with trained actors (standardized patients) who adopt the role of patients in preparation for the OSCEs (Objective Structured Clinical Examinations). Physicians should reflect deeply on the struggles faced by patients in the dying process. Considering the important empathetic nature of embodiment, medical training conversation guides should stress the need for substituted judgement — the process of putting oneself in the position of the dying person and thinking and acting as they would — and empathy. Trainings should emphasize the importance of letting patients lead these conversations in order to achieve better patient-centered care. In this way, physicians can not only experience what it is like to provide clinical care to dying patients, but can adequately understand what being on the receiving end of such news might feel like as patients. Only through this role reversal within educational roleplay can clinicians fully humanize this experience. Using the insights gained from these experiences, they can better intervene when conversations about dying are inadequate and to craft these discussions in an equitable, culturally-competent, trust-based, and patient-centered way that views patients as experts and partners in medicine. Physicians should be taught to pause, to allow patients to reflect and come to their own conclusions, to assume nothing, and to curate but not prescribe future care. Teaching physicians to listen deeply, to value reflective silence, and to give time for patients to process negative prognoses before jumping in is imperative. Doctors don't need to have all the answers. Silence is a tool — an over-eagerness to respond

and lead these conversations only perpetuates physicians' traditional paternalistic role in knowledge transmission. Patients should be in charge.

Avoidance of Cryptic Language and the Importance of Clarity: Saying the "d-word"

An additional barrier is the lack of awareness of what language to use when broaching this subject with patients and their families. Using cryptic, euphemistic language to discuss death or avoiding the "d-word" entirely might create misunderstandings. Being highly specific about prognoses and treatment plans, providing realistic timelines, and informing patients of the trajectory of illnesses is important. Honesty is the best medicine. Making statements such as "there is nothing else we can do," saying that patients "have failed all possible treatments," and substituting phrases to avoid saying the word "death" or "dying" outright (such as "your health is declining...") isn't helpful, and in fact, this lack of specificity is problematic [42]. Being cognizant of this and focusing on diagnostic clarity when delivering this news is most important to avoid patient misunderstandings or feelings that providers aren't doing enough during these conversations. Obviously, physicians cannot unfailingly predict patient health outcomes, but sensitively providing patients and their families with consistent and clear information about serious illness is necessary.

Maintaining Patient Autonomy, Dignity, and Quality of Life in the Dying Process

Care staff of seriously ill patients should coordinate realistic palliative conversations that are consistent, honest about prognostic information, and aligned with patients' goals and advance directives. And physicians should recognize that their job is not done when the list of clinical interventions has been exhausted. As Jay Katz discussed in his formative work *The Silent World of the Doctor and Patient*, physicians should involve patients actively in the decision making process to preserve their autonomy and dignity [43]. Having a continuous dialogue with patients and their families about clinical limitations and providing a warm handoff to care staff — such as social workers and chaplains — who might be better equipped to handle patient needs at the end of life is both professional and humane. "Poor communication is not the only obstacle to a peaceful death," an article in the *American Journal of Nursing* pointed out. "Some patients are overtreated, receiving aggressive care until their last breath. Others are undertreated, so much so that their final moments are steeped in physical pain. Still others receive conflicting advice from doctors and nurses on the best course of action, leaving them confused and unprepared for death [44]." Physicians should not conclude their involvement

in patient care when death is eminent or when it occurs — this can be viewed as abandonment. Although perhaps nothing further medically can be done, efforts to maintain patients' quality of life in the dying process are just as important as coordinating medical interventions. As Benjamin Bensadon asserts, "there may not be anything left to do medically, but there is always something left to do for the patient [45]."

The Need for Transparent, Early, and Repeated Communication Throughout the Dying Process

Transparent, early, and repeated communication throughout the dying process has been shown to decrease patients' and their families' anxiety, increases their sense of agency and control over medical decision making, and maintains their sense of hope [46]. It is therefore imperative that all physicians of all disciplines have more formal and in depth training in how to discuss it. While well-intentioned, shielding patients from information to maintain hope may affect future care planning which might cause more stress — emotionally, financially, mentally, etc. — for patients and their families in the dying process in the long-term. In cases where conversations are inadequate or avoided, death might come as a surprise to families. Death and dying need not be taboo subjects, and conversations about the dying process shouldn't be held off until the last moment. President of the Canadian Society of Palliative Care Physicians, Leonie Herx, noted that conversations about death and dying can "happen at the same time as maintaining hope for cure or control of disease... [and] can be a normal part of helping a patient and family understand and prepare for all of the possibilities [21]." Only through dialogue can patients and their families prepare appropriately. And the sooner physicians initiate these conversations, the better the outcome.

THE SHORTCOMINGS OF END-OF-LIFE CLINICAL EDUCATION AND THE URGENT NEED FOR MEDICAL EDUCATION REFORM

EOL Education is Variable in Quality and Quantity: The Importance of Curricular Reform and Standardization

While the United States Medical Licensing Examination includes questions on palliative care, death, and dying on licensing examinations, and the Liaison Committee of Medical Education (LCME) directs medical schools to include end-of-life care in medical school curricula, EOL education is variable in quality and quantity. While you cannot standardize EOL conversations — every patient's values and needs are different in the dying process — the systematization of developmentally appropriate and supervised end-of-life education that in-

cludes palliative care best practices is necessary in modern medical education. According to Norton and Thacker (2004), “a significant amount of learning can occur when and end-of-life experience takes place under the direction of a faculty member. Faculty members can function as role models and facilitators who help students understand their feelings about the dying experience [47].” In other words, medical schools should place higher curricular importance on teaching trainees how to deal with death and provide the appropriate supervision when students deliver difficult news to patients. Trainings should be developmentally appropriate and consistent with student knowledge at various stages of their medical education.

Improving Palliative Care and End-Of-Life Trainings in Medical Education

Expressing the need for improvements in palliative care trainings in the medical curriculum, Robert Truog, co-founder of the Institute for Professionalism and Ethical Practice (IPEP) at Boston Children’s Hospital and director of the Center for Bioethics at Harvard Medical School states that “there aren’t enough palliative care experts to go around. We need to raise competency across all providers [47].” The Accreditation Council for Graduate Medical Education (ACGME) “Toolbox of Assessment Methods” includes an evaluation of emergency medical resident trainees’ ability to provide an “effective and empathic death disclosure [48].” But what about in other disciplines? And what about conversations that occur during the dying process, not just in the instance of death? While the Association of American Medical Colleges (AAMC) released version 1.0 of the Entrustable Professional Activities in 2014, recommending that students be able to “clarify patient’s goals of care upon recognition of deterioration (*e.g.*, do not resuscitate, do not intubate, comfort care)” and can exhibit “bidirectional communication with health care team and family regarding goals of care and treatment plan that leads to shared decision making” when entering residency, EOL programming across medical school curricula remains unstandardized [22,49].

Normalizing End-of-Life Conversations: Destigmatizing Death and Dying

No one is more vulnerable than when they are on the threshold of death. In *When Breath Becomes Air*, Paul Kalanithi writes “doctors invade the body in every way imaginable. They see people at their most vulnerable, their most sacred, their most private [50].” While honoring the Hippocratic Oath requires physicians to demonstrate understanding, warmth, and sympathy, medical education often values knowledge in the basic and clinical sciences over instructing students about empathy [51]. Death, as

one of the most vulnerable moments patients and families experience, should be guided by patients’ wishes and informed by empathy. Conversations surrounding death should be destigmatized and reframed to be part and parcel of medical education. These conversations shouldn’t be viewed as awkward, but instead should be normalized. And they should happen over time whenever possible, not just once, and not just in the moments preceding eminent death.

CONCLUSIONS AND OUTLOOK

While medical education related to death and dying, pain management, and palliative care have improved, much remains to be done to improve the quality of these conversations and better prepare physicians for delivering this news [8]. The Palliative Care and Hospice Education and Training Act (PCHETA, H.R. 1676) of 2017 includes amendments to the Public Health Service Act to improve palliative care by supporting end-of-life trainings for providers. Additionally, more resources such as the Serious Illness Conversation Guide, The Conversation Project and Stanford’s Letter Project have become available to help physicians and those who are nearing death and their families to outline end-of-life priorities.

Talking about death and dying are important medical skills and these conversations should not be avoided. Discussions of death and dying should be destigmatized and normalized in medical education. According to Richard Balaban, physicians should initiate timely conversations about death and the dying process, provide clear, consistent prognoses, identify patients’ end-of-life values, goals, and priorities, and formulate a plan for treatment. Patients should guide these conversations. Furthermore, physicians should have honest and straightforward conversations about death, should demonstrate a willingness to discuss death with patients, should deliver bad news sensitively, should listen deeply to patient needs and desires in the dying process, should encourage patient questioning, and should allow patients to lead these conversations and determine when they are ready to discuss death [52]. Having high quality, honest, and sensitive end-of-life conversations can help patients maintain autonomy and dignity, increase their quality of life, and make better informed future care decisions. Furthermore, high quality end-of-life conversations can alleviate patients’ emotional stress and physical symptoms, avert invasive, costly, unnecessary, and unwanted care, aid grieving families through the bereavement process, and increase patients’ satisfaction with end-of-life care provisions [7].

Overall, more attention and training must be delivered to clinicians so that they are better prepared to initiate these discussions and to view patient death not as a result of a personal failure to deliver quality care,

but as a sometimes unavoidable consequence of serious illness. Requiring an in depth, developmentally appropriate, standardized training in EOL and palliative care for physicians-in-training in all disciplines in medical education — in medical school and residency — is necessary. Standardized training will ensure physicians are better prepared to discuss end-of-life priorities and the dying process with patients living with serious illnesses, to inform patients' families of their deaths, and to insure patients are well-informed at the end of life.

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