

## FOREWORD

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*It is difficult to accept death in this society because it is unfamiliar. In spite of the fact that it happens all the time, we never see it.*

– Elisabeth Kübler Ross<sup>1</sup>

Death became my professional acquaintance just after my twenty-second birthday. An eager student nurse working the night shift on New Year’s Eve, I was assigned to an actively dying patient for whom all curative interventions had been discontinued. He was utterly alone in the final moments. Death arrived before the new year. I stood in the room and watched his last breath—a scared, unprepared, and shame-filled trespasser at his death.

We didn’t cover this most basic and undeniable reality of hospital-based nursing care in school—as if death were an exceedingly rare and unexpected issue we were unlikely to encounter. Instead, I learned only by living through it. After he died, I gingerly washed away the evidence of his medical ordeal, scribbled his name on the paper tag and looped the string around his big toe. I hesitantly zipped up the body bag—the whole time feeling not quite alone and not quite in the presence of another person.

As staff voices faintly counted down to the new year, I pushed a suspiciously sheet-draped stretcher down the hallways as a co-worker ran ahead to close the doors to patient rooms. We were, by policy, required to do so: we were charged with protecting patients from the reality of death.

Over time, I would do better: I would learn to touch and sometimes talk to patients dying alone—be present for them (or at least for me) in the transition. I would also learn to support families—if support is really possible for someone experiencing one of the worst days of their lives. But that first time, I was simply a victim of the culture of death avoidance, which extends to the

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1. ELISABETH KÜBLER-ROSS FOUND., DEATH: THE FINAL STAGE OF GROWTH 5 (1975).

training of medical professionals, including doctors and nurses—the very people professionally charged with fighting, nudging, easing, pronouncing, cheating, and communicating about death.<sup>2</sup>

Over my time in nursing, especially in the intensive care unit (ICU), the systemic denial of death’s inevitability and the “full court press” of medical care was a regular source of frustration and distress. Then, as now: “the default position of medical practice in the United States is to use all available interventions to treat unless the intervention is judged by the physician responsible for the individual’s care to be medically unsound . . . or the individual has made his or her treatment preference known to medical providers.”<sup>3</sup>

Physicians Miguel Paniagua and Phil Fung raise serious concerns about the default medicalization of end of life care.<sup>4</sup> They describe the successes of medicine—the availability of cutting-edge therapies and the privileging of individual organ function over quality of life and patient wishes—as obscuring important deliberations about the appropriate use of technology at the end of life. According to the authors, “[d]eath is not anticipated or embraced as a part of human experience, but it is seen as an enemy to struggle against and hopefully defeat. This posture, tied in with a general optimism about medical science and research, also suggests that even death itself is only a temporary setback.”<sup>5</sup>

They advocate for valuing meaningful communication as much as technical skill by reorienting medical training to include communication about death and dying.<sup>6</sup> Paul Kalanithi shared their approach. In reflecting on his own work as a physician and his own impending death, he wrote, “the physician’s duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence.”<sup>7</sup>

In fact, regular and meaningful provider-patient-family communication about values and preferences at the end of life transforms the experience,

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2. I quickly adopted a position of adamant refusal to engage in euphemistic death speak—“expired” is what happened to milk and magazine subscriptions. “Passed away” was far too gentle a term for the many messy, painful, agonizing deaths I witnessed. I felt and still feel these terms further mask a reality unnecessarily and contribute to more avoidance.

3. Thomas D. Harter, *Is There a Moral Obligation for Health Care Organizations to Develop Robust Care Planning Programs?*, 10 ST. LOUIS U. J. HEALTH L. & POL’Y 45, 46 (2016).

4. Miguel Paniagua & Phil Fung, *The Medicalization of End-of-Life Care: The Role of Health Professions Education*, 10 ST. LOUIS U. J. HEALTH L. & POL’Y 9 (2016).

5. *Id.* at 12.

6. *Id.* at 18.

7. PAUL KALANITHI, *WHEN BREATH BECOMES AIR* 166 (2016).

improves patient care, and reduces the burden for families and loved ones.<sup>8</sup> Through interviews with family members, communications scholars April R. Trees and Jennifer E. Ohs describe the complex process of family and provider communication around end-of-life decisions.<sup>9</sup> They highlight the benefits and frequent limitations of current advance care planning (ACP) in practice, as well as the deep uncertainty and lasting pain for families when making decisions in the absence of clear patient wishes.<sup>10</sup> It is the quality of previous communications between patients and family members—even more than the presence or absence of a formal legal document—that determines the degree to which families are able to find meaning in their choices on behalf of their loved one.<sup>11</sup>

Our tacit societal agreement to avoid reflection on the proximity and quality of death ultimately harms patients, providers, and family members. Meaningful ACP in all stages of health care delivery requires ongoing communication between providers and patients, which in turn facilitates communication between patients and their family members about end-of-life values and preferences. The lack of ACP has consequences of both under and over treatment.

When a person's treatment preferences are unknown to his or her medical providers, that person is at risk of receiving treatment not aligned with that person's goals of care—that is, the person may receive too much, or even in some cases, too little treatment for what the individual would have been otherwise willing to accept.<sup>12</sup>

A lasting consequence is to family members, who struggle to make sense of the experience when they make decisions in an informational void.

Our existing status quo is contrary to cultural shifts in medicine toward personalized and patient-centered care—a concept embraced without the broad inclusion of patient-centered dying.<sup>13</sup> The existing legal framework—what Thomas Harter calls *basic* ACP (as opposed to *robust* ACP)—has simply proven insufficient for meaningful communication and subsequent care guided by patient preferences.<sup>14</sup> Given less than successful efforts to improve the

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8. For simplicity, I will refer to patient family members, loved ones, and friends as family members or families for the remainder of this essay.

9. April R. Trees & Jennifer E. Ohs, *Making Sense of Family Communication About and at the End of Life: Family Communication Around End-of-Life Planning and Decision Making*, 10 ST. LOUIS U. J. HEALTH L. & POL'Y 19 (2016).

10. *Id.* at 22–25, 34–37.

11. *Id.* at 25–26.

12. Harter, *supra* note 3.

13. Admittedly, a few publications mention the term in passing. *See, e.g.*, Steve Paulson et al., *Prolonging Life: Legal, Ethical, and Social Dilemmas*, 1330 ANNALS N.Y. ACAD. SCI. 19, 37 (2014).

14. Harter, *supra* note 3, at 54–55 (emphasis added).

quality of dying through law and provider education, Harter suggests that the moral obligation for robust and meaningful care planning systems lay at the feet of health care organizations.<sup>15</sup> He provides a compelling and pragmatic argument that robust ACP programs situated at the systems level provide tangible benefits to patient, providers, and families alike.

Even robust care planning can fail when state laws interfere with the effectiveness of advance directives, an issue that Kathy L. Cerminara and Joseph R. Kadis explore.<sup>16</sup> In particular, they challenge state laws that condition the enforceability of basic, legally executed advance directives on a particular health status of the patient—such as the existence of a terminal condition as defined by state law.<sup>17</sup> They argue that the fundamental right to refuse even life-saving treatment should not be subject to such conditions when an individual has already clearly expressed their wishes through ACP.<sup>18</sup> They offer suggestions that would expand the utility of ACP documents and better honor patient autonomy and dignity.<sup>19</sup>

Too many times we failed to honor patients' dignity in the ICU by participating in the unreflective infliction of painful and costly procedures with no clear understanding of the patients' underlying treatment goals—this was most distressing when the patient had almost no chance of recovery.<sup>20</sup> In my experience, it almost always resulted from ineffective provider-patient-family communication entangled with unrealistic understandings about the limits of medicine and differing notions of the underlying goals of care.

Reliable information about the patient's values and wishes at the end of life are emotionally, morally, and financially significant to families and providers alike. Knowledge of patient preferences gives families the courage of their convictions to engage in meaningful discourse and even disagreement

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15. *Id.* at 66.

16. Kathy L. Cerminara & Joseph R. Kadis, *Give Me Liberty to Choose (a Better) Death: Respecting Autonomy More Fully in Advance Directive Statutes*, 10 ST. LOUIS U. J. HEALTH L. & POL'Y 67 (2016).

17. *Id.* at 71–73.

18. *Id.* at 92.

19. *Id.* at 73–75.

20. I only use the word “almost” to reflect the possibility that someone might recover. Certainly, highly technical lifesaving procedures can help many patients. I am, instead, referring to the use of technology on patients at the end of life for what clinicians and ethicists refer to as futile or non-beneficial care. Defining the terms carefully is, of course, important and the subject of numerous scholarly works. At the same time, I would suggest that non-novice ICU providers know when, in the euphemistic language of the ICU, a “flog” is occurring—an assertion consistent with many descriptions in the literature around futility. At that point, it was incredibly distressing to participate in the infliction of procedures without the prospect of benefit. It felt like an assault on the inherent dignity of the patient. In those situations, I never once saw a patient meaningfully recover. Not once. At best, a heartbeat would be restored for another day but death came in short order.

with physicians about the goals of care. More than once, I helped families successfully approach physicians and question the current treatment plan. The most contentious situations are often those in which family members insist upon continued, aggressive treatment that the providers judge non-beneficial.<sup>21</sup> These are typically situated in an environment of failed relationships and mistrust between providers and family members. “[M]ost of these medical futility disputes can be resolved through informal consensus-building approaches. Eventually, with intensive communication, negotiation, and mediation, the parties reach agreement.”<sup>22</sup>

A small minority of these cases become intractable futility disputes. Useful resolution tools for futility disputes are critical—in their absence, families, patients, and providers suffer. Thaddeus M. Pope provides a thorough overview of existing tools of conflict resolution for intractable futility disputes, with a focus on the Texas Advance Directive Act (TADA).<sup>23</sup> He analyzes TADA through a lens of due process principles. While he concludes that TADA provides an efficient means of intractable futility dispute resolutions, it is deficient in attention to procedural fairness.<sup>24</sup> As such, he suggests TADA is a good but imperfect model for other jurisdictions.<sup>25</sup>

As disruptive as intractable futility disputes are to our ability to construct meaning around death, even more challenging are cases in which patients die by their own hands. One of the last patients I cared for in their transition to death was a woman barely out of her teens, Jane Doe—the only name we ever knew her by. Her skin was riddled with tell-tale signs of a long battle with intravenous drug use and her neck bore the distinct imprint of the rope she used to hang herself.

Although she was resuscitated at the scene, her lack of neurologic function betrayed the status of her oxygen-starved brain. After days of searching, no family or friend was discovered. The physician determined her brain damage was irreversible and consistent with brain death; the organ procurement organization could not use a single organ.

And so without any of the usual family rituals of mourning, I stood by Jane’s bed that evening with the background rhythmic hum of the ventilator and the glow of monitors and machines. I smoothed her sheets, silenced the alarms, and flipped the main switch on the back of the ventilator. The beginning of the abnormal and irregular heart rhythm that would slowly flutter

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21. Thad Pope describes this as the paradigmatic medical futility dispute. See Thaddeus Mason Pope, *Procedural Due Process and Intramural Hospital Dispute Resolution Mechanisms: The Texas Advance Directives Act*, 10 ST. LOUIS U. J. HEALTH L. & POL’Y 93, 94 (2016).

22. *Id.*

23. See generally *id.*

24. *Id.* at 147–48.

25. *Id.* at 107.

out to nothing began in the next few minutes while I held her hand and prayed she was at peace. It was impossible for me to find any meaning in Jane's death. I couldn't know anything other than what her track marks, lack of family members, and her suicide revealed: it all added up to tremendous suffering and a vacuum of love.

I wondered then as I do now if society could do more to prevent suicides. Far too often, I cared for people who nearly or eventually died from suicide. Jane just happened to be the last one I watched die. The Zulu language accounts for different types of deaths—expected or natural deaths are distinguished from untimely deaths, which are viewed as a “breaking off of life.”<sup>26</sup> Suicide deaths like Jane's break the lifeline in ways even other untimely deaths do not—leaving jagged edges immune to mending and meaning. This is the subject of Stacey A. Tovino's article on the alarming prevalence of suicidality among individuals with gambling disorders.<sup>27</sup> She illustrates the transformative effect that health insurance policy, including the Affordable Care Act, the Mental Health Parity Act, and the Mental Health Parity and Addiction Equity Act have had in this area.<sup>28</sup> In Nevada, her own state, many insurance providers will now be required to cover treatment for disordered gambling through the operation of these laws.<sup>29</sup>

Our collective willful blindness and inaction about death does palpable harm to patients, families, providers, and society. It hampers our ability to improve the quality of death for both the dying person and their family member; it also hampers efforts to address preventable untimely deaths. Nonetheless, the good work of so many clinicians and scholars continues to slowly chip away at the harms nourished by our general neglect of death. I am so pleased that we were able to bring together an interdisciplinary group of

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26. AXEL-IVAR BERGLUND, ZULU THOUGHT PATTERNS AND SYMBOLISM 78–81 (1976) as reprinted in THE ETHICS OF SUICIDE 613–14 (Margaret Pabst Battin ed. 2015).

There are essentially two concepts of death. Firstly, a timely death which presupposes a number of children and grandchildren who survive the deceased. Secondly, there is death which is untimely and is regarded as a serious interference in a human's life. The quality of such a death is included in the English idioms annihilation or extinction. A timely death is in the Zulu language expressed by terms such as ukugoduka, ukudlula, ukuhamba, and ukuqubeka, which all give notions of a passing on, a continuation. An untimely death is described as ukufa, ukubhubha, and ukugqibuka, which imply a breaking off of life.

*Id.* at 614.

27. Stacey A. Tovino, *Dying Fast: Suicide in Individuals with Gambling Disorders*, 10 ST. LOUIS U. J. HEALTH L. & POL'Y 159, 160 (2016) (noting, for example, that fifty percent of disordered gamblers have suicidal ideation, attempts, or deaths from suicide).

28. *Id.* at 165–171.

29. *Id.* at 172.

scholars at the 2016 Health Law Symposium<sup>30</sup> and to offer some of their works in this symposium edition of the journal.

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30. Video Recording: Dying Fast and Slow: Improving Quality of Dying and Preventing Untimely Deaths, ST. LOUIS U. CTR. FOR HEALTH L. STUDS. (Apr. 1, 2016), <http://law.slu.edu/HLsymposium2016>.

