THE MEDICALIZATION OF END-OF-LIFE CARE: THE ROLE OF HEALTH PROFESSIONS EDUCATION

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ABSTRACT

In the past 100 years, the advances in medical science and technology have shaped the health care delivery system in remarkable ways. The side effect of these advances has been a tendency to dehumanize the dying process, and consequently it has led to the rise of a specialty focused merely on bridging this gap in care. The public's expectations of our legal, licensing, and medical education systems have also reflected this evolution in health care.

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It is not the end of the physical body that should worry us. Rather, our concern must be to *live* while we're alive—to release our inner selves from the spiritual death that comes with living behind a façade designed to conform to external definitions of who and what we are.[1]

I. INTRODUCTION AND DEFINING THE PROBLEM

In the preceding century, the causes and locations of death have changed drastically with an increased emphasis on the utilization of technology and adherence to the biomedical model of health care. Long gone are the days of expected death from incurable infectious diseases and public health or sanitation-related scourges. Now, one might expect to accumulate a variety of chronic diseases ultimately leading to a state of frailty and relative *homeostenosis*[2] that then renders the individual susceptible to life-threatening acute illness. Despite a recent decrease in hospital deaths,[3] there has been an increase in the use of hospitals and intensive care units.[4] Even more striking is the use of the intensive care unit in the last month of life despite the increased utilization of hospice services during the same time period.[5] Instead of dying at home surrounded by and cared for by friends and family, individuals are now patients of the medical system right up to the point of death, often in the medicalized setting of a hospital or hospice center.[6]

II. THE HEALTH CARE SYSTEM: HOW DID THIS COME TO PASS?

Numerous factors have converged in recent times to drastically change what human beings experience as "the dying process" in the United States. As mentioned previously, a major contributing factor is the development of

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1. ELISABETH KÜBLER-ROSS, DEATH: THE FINAL STAGE OF GROWTH 164 (1975).

2. Homeostenosis refers to the diminishing physiologic reserves available in a given individual to meet insults or challenges to one's homeostasis. George E. Taffett, *Physiology of Aging*, *in* GERIATRIC MEDICINE: AN EVIDENCE-BASED APPROACH 27, 27 (Christine K. Cassel et al. eds., 4th ed. 2003). This occurs in the period from maturity to senescence and "leads to the increased vulnerability to disease that occurs with aging." *Id.*

3. Jack E. Zimmerman et al., *Changes in Hospital Mortality for United States Intensive Care Unit Admissions from 1988 to 2012*, CRITICAL CARE, Apr. 27, 2013, at 1, 3.

4. *See* Neil A. Halpern & Stephen M. Pastores, *Critical Care Medicine in the United States 2000-2005: An Analysis of Bed Numbers, Occupancy Rates, Payer Mix, and Costs*, 38 CRITICAL CARE MED. 65, 66–67 (2010) ("More decedents in 2009 than in 2000 had an ICU stay in the last month of life."); *but cf.* Zimmerman et al., *supra* note 3 ("There was a relative decrease in mean hospital mortality of 35% from 1988/1989 to 2010/2012.").

5. *See* Joan M. Teno et al., *Change in End-of-Life Care for Medicare Beneficiaries*, 309 JAMA 470, 472 (2013).

6. *See* M. Agar et al., *Preference for Place of Care and Place of Death in Palliative Care: Are These Different Questions?*, 22 PALLIATIVE MED. 787, 791 (2008).

medical technology that allows physicians to support and even replace the function of certain organs. The development of artificial ventilation to support respiratory function, ventricular assist devices to support cardiac function, and hemodialysis to replace kidney function in the latter half of the twentieth century has allowed for new possibilities to extend physiologic function of the human body even as other body systems fail.[7] Previously, when illness or trauma led to cardiac and respiratory arrest ("the cessation of heart function and lung activity"), patients were pronounced dead.[8] But, these new technologies have allowed patients to survive the initial physical insult.[9] Sometimes, this has allowed for a full, or near full, recovery of the patient, as can be the case with various infections (e.g., pneumonia).[10] However, sometimes prolonged survival means that the patient risks becoming dependent on the technological replacement for the organ, such as long-term dialysis to replace the functions of the kidney.[11] An increased number of patients use these new technologies to extend the duration of their lives in a medicalized setting, such as in the hospital or thrice-weekly visits to a dialysis center.[12] Arguably, this has become the default approach in health care: if there is a technological support for a failing organ, of course it should be used.

The notion of *successful health care outcomes* has also been profoundly altered by access to life-sustaining technologies. There is a perception that effective care rests with improvement in physiologic parameters without immediate attention to the cognitive or functional parameters.[13] Specific goals, such as maintaining appropriate blood pressure and electrolyte levels, while attainable, became the primary goals of medical intervention once these advanced technologies were deployed.[14] These interventions are often continued into the very final hours of life because certain goals, such as the maintenance of blood pressure, are still seemingly attainable. Health care providers may or may not discuss other goals that the patient or her family may have and how medical treatment may help or hinder achieving those goals

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7. *See* Paul S. Mueller et al., *Ethical Analysis of Withdrawing Ventricular Assist Device Support*, 85 MAYO CLINIC PROCS. 791, 794 (2010).

8. *See* DANIEL CALLAHAN, THE ROOTS OF BIOETHICS 26 (2012).

9. *See id.*

10. *See* Luca M. Bigatello et al., *Outcome of Patients Undergoing Prolonged Mechanical Ventilation Process After Critical Illness*, 35 CRITICAL CARE MED. 2491, 2494 (2007).

11. Chiao-Ying Hsu et al., *Patient Able to Stay on Peritoneal Dialysis After Retroperitoneal-Approach Radical Nephrectomy*, 32 PERITONEAL DIALYSIS INT'L 104, 104 (2012).

12. U.S. RENAL DATA SYSTEM, 2015 USRDS ANNUAL DATA REPORT VOL. 2: ESRD IN THE U.S. 265, 266 (2015) (ebook).

13. Douglas P. Olson & Katalin E. Roth, *Diagnostic Tools and the Hands-On Physical Examination*, 9 AMA J. ETHICS 113, 114 (2007) ("[P]ractitioner[s] relying on the physical exam as the basis for diagnosis and treatment prevail[].").

14. *Monitoring Vital Signs*, EURONEWS (Apr. 2, 2014), http://www.euronews.com/2014/02/04/monitoring-vital-signs.

(e.g., the desire for intact cognition, functional independence, or making it to a relative's wedding next season).

Related to this is the conception of *death as failure*. A pervasive attitude exists in medicine as an institution (and it is stronger in certain medical or surgical specialties than others) that for a patient to die is for the physician to have failed.[15] If the definition of success is maintenance of blood pressure, kidney function, and other physiologic functions, then the cessation of these functions signifies failure. In other words, if these functions can be maintained, then failure has been averted. This attitude has even permeated the formation of young premedical students. The national premedical society, Alpha Epsilon Delta, states in their initiation ritual: "I am stationed under the skull, which represents our greatest enemy—death. More especially is death an enemy to us, for we have chosen to fight death not only for ourselves, but for others."[16]

Death is not anticipated or embraced as a part of the human experience, but it is seen as an enemy to struggle against and hopefully defeat.[17] This posture, tied in with a general optimism about medical science and research, also suggests that even death itself is only a temporary setback. With time, money, and effort, current physiologic limitations will be overcome through greater knowledge and more ingenious technologies.

Similarly, the *death as failure* mindset has also permeated what patients and their families now expect from modern medicine.[18] Because numerous technologies exist to support various body systems, many friends and family members assume that the technologies will be used to keep the patient alive.[19] This assumption is generally true and not necessarily undesirable in the short term (in various instances where meaningful recovery is defined and reasonably expected) as the medical team tries to correct whatever is making the patient ill. However, many times, there is little to no thought given to when these interventions would be stopped, even in the case of an invasive intervention as common as hemodialysis.[20] This default position towards interventions can be near miraculous for patients who come in critically ill

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15. Craig Bowron, *Our Unrealistic Views of Death, Through a Doctor's Eyes*, WASH. POST (Feb. 17, 2012), https://www.washingtonpost.com/opinions/our-unrealistic-views-of-death-through-a-doctors-eyes/2012/01/31/gIQAeaHpJR_story.html?utm_term=.ad3e48683a83.

16. *The Ritual of Alpha Epsilon Delta*, ALPHA EPSILON DELTA, http://www.aednational.tcu.edu/rituals.asp (last visited Oct. 25, 2016).

17. Marianne L. Matzo & Deborah Witt Sherman, *Palliative Care Nursing: Ensuring Competent Care at the End of Life*, 22 GERIATRIC NURSING 288, 289 (2001).

18. *Id.* at 289–90.

19. *See* Lee S. Wilkinson, *Legal Resolution of Denial of Access to Medical Technology*, 14 GOLDEN GATE U. L. REV. 203, 215 (1984) ("Patients and their families facing a potentially fatal disease are particularly susceptible to societal beliefs in the power of technology . . . .").

20. *See* Pooja Singh et al., *The Elderly Patient on Dialysis: Geriatric Considerations*, 29 NEPHROLOGY DIALYSIS TRANSPLANTATION 990, 992–94 (2014).

from an infection or a trauma, are then quickly treated or undergo surgery, and then improve dramatically. It is true that we are now able to save lives and return patients to a high level of function that would otherwise have been lost in the past.[21] However, the assumption that "because we can do certain interventions, we ought to" is troubling.

Medicine is a victim of its own success—in that the incredible technologies and knowledge available have actually made it more difficult to discuss how to choose which of these technologies ought to be used and for what purposes. Popular understanding of these technologies and interventions are largely informed by media, which show erroneously high survival rates and/or fail to show the complications or difficulties that accompany these interventions.[22] Because the popular misperception of the high success rate of many of these interventions, many patients' expectations do not align with known statistical medical probabilities when the patients are actually undergoing cardiopulmonary resuscitation (commonly referred to as CPR) or other aggressive life-sustaining interventions.[23] Many patients are only recently becoming empowered to ask questions about the larger overarching goals of medical interventions.

III. DYING AND THE MEDICAL EDUCATION SYSTEM

With the rise of medical technology, provider training has also shifted to depend more on technologies in the settings in which they are most commonly used—hospitals. In undergraduate medical education (UME) and even more so in graduate medical education (GME) or residency, training tends to focus primarily on the inpatient setting,[24] where trainees witness the medicalization of care firsthand during the most impressionable time in their training.[25] This reliance on inpatient-focused training is in part due to the funding system for GME, which is fully distributed and apportioned via Medicare to health care systems and hospitals (government-funded such as the Veterans Health

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21. ADVANCED MED. TECH. ASS'N, THE VALUE OF MEDTECH, http://www.lifechanginginno vation.org/sites/default/files/files/Fact%20Sheet_Medical%20Technology%20Saves%20and%20 Improves%20Lives%20-%20final.pdf (last visited Nov. 10, 2016).

22. *See* Susan J. Diem et al., *Cardiopulmonary Resuscitation on Television: Miracles and Misinformation*, 334 NEW ENG. J. MED. 1578, 1581 (1996).

23. Dhruv Kullar, *The CPR We Don't See on TV*, N.Y. TIMES: WELL BLOG (July 17, 2014, 11:00 AM), http://well.blogs.nytimes.com/2014/07/17/the-cpr-we-dont-see-on-tv/?_r=0.

24. James O. Woolliscroft & Thomas L. Schwenk, *Teaching and Learning in the Ambulatory Setting*, 64 ACAD. MED. 644, 644 (1989).

25. ROBERT A. LINDEN, THE RISE & FALL OF THE AMERICAN MEDICAL EMPIRE: A TRENCH DOCTOR'S VIEW OF THE PAST, PRESENT AND FUTURE OF THE U.S. HEALTHCARE SYSTEM 31 (2010).

Administration, non-profit, and for-profit entities).[26] Another consequence is that the overwhelming majority of UME and GME residency trainees tend to do most patient care in these settings.[27] With few exceptions (namely, the Accreditation Council for Graduate Medical Education pilot programs[28]), trainees do not see people die at home or even in long-term health settings. Patients, who are often quite ill, are admitted to teaching hospitals and are cared for by various trainees during their admission.[29] Sometimes there is longitudinal experience following the same patients after they are discharged, but this is unfortunately less common.[30] Traditionally, longitudinal outpatient learning experiences have tended to be an afterthought, rather than a primary focus, of most medical training, even for primary care specialties such as pediatrics and internal medicine. The lack of focus on longitudinal outpatient learning makes trainees perceive that they are insufficiently trained to provide appropriate outpatient care, despite a growing emphasis on newer models of training that emphasize the importance of longitudinal and focused ambulatory experiences.[31] Due to the current model of training, trainees are most familiar with the hospital and the hospital system of care.

Because patients are predominantly cared for in the inpatient setting, almost all deaths that trainees actually observe are in the inpatient setting. Rarely does one have the chance to experience death in the home setting, in either a professional or private capacity. Additionally, multigenerational homes are rare in the United States now, which is a demographic change from the past.[32] The lack of exposure to home deaths has led to trainees taking a single view—often the only one that they have been exposed to—that medicalized

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26. INST. OF MED., GRADUATE MEDICAL EDUCATION THAT MEETS THE NATION'S HEALTH NEEDS 62 (Jill Eden et al. eds., 2014).

27. *Id.* at 74.

28. *Pursuing Excellence in Clinical Learning Environments*, ACCREDITATION COUNCIL FOR GRADUATE MED. EDUC., http://www.acgme.org/What-We-Do/Initiatives/Pursuing-Excellence/ Overview (last visited Sept. 12, 2016).

29. *See* Leah Smith & Catherine L. Hough, *Using Death Rounds to Improve End-of-Life Education for Internal Medicine Residents*, 14 J. PALLIATIVE MED. 55, 55 (2011) (noting that "interns provide much of the care for patients dying in the hospital setting").

30. Aliyah Baruchin, *Having the Talk: When Treatment Becomes End-of-Life Care*, AAMC REP., July–Aug. 2015, *reprinted in* AAMCNEWS (Oct. 24, 2016), https://news.aamc.org/patient-care/article/having-talk-when-treatment-becomes-end-life-care/.

31. *See, e.g.*, Fred R. Buckhold et al., *An Evaluation of Continuity Clinic Redesign*, 28 J. GEN. INTERNAL MED. 1556, 1556 (2013).

32. *See* PAUL TAYLOR ET AL., THE RETURN OF THE MULTI-GENERATIONAL FAMILY HOUSEHOLD 4 (Mar. 18, 2010), http://www.pewsocialtrends.org/2010/03/18/the-return-of-the-multi-generational-family-household/ (stating that while there has been a recent uptick in multi-generational households, the overall rate has gone down significantly since the 1940s).

death is preferable, either in the hospital or under the auspices of hospice care.[33]

IV. THE MEDICAL EDUCATION SYSTEM OF ASSESSMENT

In recent times, emphasis on competencies outside of mere medical knowledge to ensure safe practitioners has increased. However, high-stakes examinations that primarily assess knowledge (and the application of knowledge) are the standard by which licensing, promotions, and even job placements (GME or residency placement) are made.[34] These so-called "soft competencies" remain just that, in part due to the inability to reliably and consistently assess trainees' competence in these areas. To ask a series of multiple choice questions to test one's communication skills, professionalism, or bedside manner is simply non-congruent. Yet, since the implementation of the Step 2 Clinical Skills (CS) portion of the United States Medical Licensing Examination in 2004, there has been constant pushback from both medical school faculty and examinees.[35] For many years, three-digit scores have been provided for the clinical knowledge portions of the medical licensing examinations; the first of which is widely used to stratify residency applicants and assist in their placement into training programs.[36] The Step 2 CS examination tests both patient-focused communication and clinical problem-solving skills.[37] Due to the complexity in case creation, validity, and reliability, the examination does not provide numerical scoring (only pass/fail reporting) or feedback to examinees.[38] Despite evidence that Step 2 CS has validity in predicting subsequent performance in history taking and physical examination skills for trainees in supervised practice,[39] in the eyes of its detractors, the cost

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33. *See generally* Thomas J. Nasca et al., *The Next GME Accreditation System — Rationale and Benefits*, 366 NEW ENG. J. MED. 1051 (2012) (discussing the rationale for the new accreditation system for medical education and its role in exposing trainees to new learning experiences).

34. Catherine E. Lewis et al., *Numerical Versus Pass/Fail Scoring on the USMLE: What Do Medical Students and Residents Want and Why?*, 3 J. GRADUATE MED. EDUC. 59, 60 (2011).

35. Peter Gliatto et al., *Scylla and Charybdis: The MCAT, USMLE, and Degrees of Freedom in Undergraduate Medical Education*, 91 ACAD. MED. 1498, 1499 (2016); *see also generally* Matthew D. Alvin, *The USMLE Step 2 CS: Time for a Change*, 38 MED. TCHR. 854 (2016) (noting that major arguments for eliminating the Step 2 CS exam include testing costs, travel inconvenience for medical students, and limited value in assessing student abilities).

36. Gerard F. Dillon et al., *The Role of USMLE Scores in Selecting Residents*, 86 ACAD. MED. 793, 793 (2011).

37. Alvin, *supra* note 35.

38. *Id.*

39. Monica M. Cuddy et al., *Evaluating Validity Evidence for USMLE Step 2 Clinical Skills Data Gathering and Data Interpretation Scores: Does Performance Predict History-Taking and Physical Examination Ratings for First-Year Internal Medicine Residents?*, 91 ACAD. MED. 133, 136 (2016).

of the examination does not seem to justify its use as a step to licensure. As the Step 2 CS assessment evolves, further competencies important to the care of the dying patient (in addition to communication skills) will be assessed.

V. THE RISE OF PALLIATIVE CARE

Some see the increased utilization of hospice care as the reversal of the medicalization trend, but end-of-life care remains under the umbrella of medicine with the rise of a specific medical specialty known as hospice and palliative medicine. This specialty has gained popularity lately as physician writers such as Atul Gawande have written about the care provided at the end of life.[40] This specialty has made immensely important contributions to the care of patients as they approach death, including, but not limited to, pain and symptom control as various diseases progress and organ function declines.[41] The specialty has certainly made a difference in the lives of patients and their families, but it also firmly places the dying process under the purview of the medical establishment. Some would say that this is worthwhile to have this multidisciplinary specialty entrenched in medicine if it means that patients are able to get the pain relief and support that they need.[42] Others argue that this is merely an extension of the perspective that the body is a collection of physiologic mechanisms and processes to be managed.[43] In response to the notion that the biomedical model predominates in the field, many hospice and palliative medicine specialists make it clear that they are part of a multidisciplinary team that can include social workers, clergy, mental health professionals, and more.[44] This multidisciplinary approach is a well-meaning attempt to place the patient in their real context, where the team hopefully gets to know the patient as a person, so that they can engage in this process together in a partnership. However, even well-intentioned collaboration is being subsumed under a medicalized model, where efficacy must be proven in terms of dollars saved or higher patient satisfaction ratings. A recent study showed that among patients with advanced lung cancer, early palliative care improved quality of life and mood, and it even prolonged survival.[45]

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40. *See generally* ATUL GAWANDE, BEING MORTAL: MEDICINE AND WHAT MATTERS IN THE END (2014).

41. *See id.* at 249–58 (describing the story about the end of life of the author's father).

42. *See* Daren K. Heyland et al., *What Matters Most in End-of-Life Care: Perceptions of Seriously Ill Patients and Their Family Members*, 174 CANADIAN MED. ASS'N J. 627, 630–31 (2006).

43. JEFFREY P. BISHOP, THE ANTICIPATORY CORPSE: MEDICINE, POWER, AND THE CARE OF THE DYING 19–22 (David Solomon ed., 2011).

44. Irene J. Higginson et al., *Do Hospital-Based Palliative Teams Improve Care for Patients or Families at the End of Life?*, 23 J. PAIN & SYMPTOM MGMT. 96, 97 (2002).

45. J.S. Temel et al., *Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer*, 363 NEW ENG. J. MED. 733, 739 (2010).

As mentioned previously, physicians now approach death within a medicalized framework, which is a remarkable change from prior centuries when people regularly faced death at home, usually with family and clergy at their bedside. The medical team is now an ersatz Charon, escorting the patient across the River Styx. The dying process has been stripped of meaning and context, aside from the numbers of a few physiologic functions and medications.

VI. LAW AND DEATH

Death is currently defined by the law, albeit with minor variations between states. The most notable aspect of the law is the two different criteria typically included. For Missouri:

> For all legal purposes, the occurrence of human death shall be determined in accordance with the usual and customary standards of medical practice, provided that death shall not be determined to have occurred unless the following minimal conditions have been met:
>
> (1) When respiration and circulation are not artificially maintained, there is an irreversible cessation of spontaneous respiration and circulation; or
>
> (2) When respiration and circulation are artificially maintained, and there is a total and irreversible cessation of all brain function, including the brain stem and that such determination is made by a licensed physician.[46]

With the advent of the technologies mentioned above, the prior definition of death was found to be inadequate, as medicine discovered it had the ability to maintain respiration and circulation in almost any situation.[47] This discovery led to the "brain death" definition, first established by the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death.[48] The newer definition of death squarely places the very power to declare someone dead in the hands of the physician. The patient is not dead until "such determination is made by a licensed physician."[49] Everything else about the patient may remain the same: her heart may still be beating, her lungs may still be exchanging gases, and other internal organs such as the intestines and kidneys may all be more or less functional. However, with the right neurologic conditions, death becomes a possibility—but one that is gated by physicians.

46. MO. REV. STAT. § 194.005 (2016).

47. *See* Henry K. Beecher et al., *A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death*, 205 JAMA 337, 337 (1968) (discussing the need for a revised definition of death to include the "irreversible coma" that sometimes occurs due to "[i]mprovements in resuscitative and support measures").

48. AD HOC COMM. OF THE HARVARD MED. SCH., *A Definition of Irreversible Coma*, 205 JAMA 337, 340 (1968).

49. MO. § 194.005.2.

There are groups that do not accept brain death criteria as being "true" death[50] and, therefore, do not accept the physician's authority to declare the patient dead in this situation, but they are few. The law and the vast majority of patients and their families have practically agreed that the legal authority to declare someone dead lies with physicians.[51]

Even with the rise of the empowered patient who may seek to reclaim power by pursuing other options such as euthanasia (in certain European countries[52]) or medical aid in dying (in a few states[53]), physicians remain the gatekeepers. When a patient's mental competency is in question, he or she must undergo psychiatric evaluation to ensure that his or her choices are not coerced or unduly influenced by other factors.[54] Prescriptions for medical aid in dying must still come from physicians.[55] The patient may choose the time of his death, but the pathway to death is now clearly delineated by the legal system, with the cooperation of medical professionals. Death is being controlled.

VII. CONCLUSION

And, in the end, we will all die. How we choose to do so is as much a product of our own desires, culture, fears, and the health care system in which we participate. Perhaps it is feasible for the dying process to create possibilities with guidance instead of only funneling people into narrowly controlled pathways. Culture can help shape law as social mores change, but law can also shape culture, in terms of allowing things to become more acceptable when not illegal. Perhaps the legal system also plays a different role in guiding patient-centered dying and the expectations of providers in the care of the public. Additionally, there is an expectation that "if we test it, they will teach it, and if we test it, they will learn it." This implies we must be compelled to work toward higher standards and expectations of our trainees beyond mere medical knowledge and its application to clinical scenarios. Compassionate care and in-depth communication with people facing serious illness are skills as important as any in medicine. We should expect our providers to aspire for excellence in acquiring these skills to apply to end-of-life care as much as they aspire to acquire their clinical knowledge.

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50. *See, e.g.*, John M. Luce, *The Uncommon Case of Jahi McMath*, 147 CHEST 1144, 1150 (2015).

51. *Id.* at 1144.

52. *See, e.g.*, Nicole Steck et al., *Euthanasia and Assisted Suicide in Selected European Countries and US States*, 51 MED. CARE 938, 939 (2013).

53. *Id.*

54. Shara M. Johnson et al., *The Role of and Challenges for Psychologists in Physician Assisted Suicide*, 38 DEATH STUDIES 582, 583 (2014).

55. Steck et al., *supra* note 52.