

## MEDICINE AND SOCIETY

### How Do Medicalization and Rescue Fantasy Prevent Healthy Dying?

Peter T. Hetzler III and Lydia S. Dugdale, MD, MAR

#### Abstract

Before antibiotics, cardiopulmonary resuscitation (CPR), and life-sustaining technologies, humans had little choice about the timing and manner of their deaths. Today, the medicalization of death has enabled patients to delay death, prolonging their living and dying. New technology, the influence of the media, and medical professionals themselves have together transformed dying from a natural part of the human experience into a medical crisis from which a patient must be rescued, often through the aggressive extension of life or through its premature termination. In this paper, we examine problematic forms of rescue medicine and suggest the need to rethink medicalized dying within the context of medicine's orientation to health and wholeness.

*[O]n callow, lumpish, and selfish youth  
peril, sorrow, and the shadow of death  
can bestow dignity, and even sometimes wisdom.*

J.R.R. Tolkien, *On Fairy Stories*

#### Finding the Proper Place for Medicalized Dying

In J.R.R. Tolkien's famous lecture on the power of storytelling, "On Fairy Stories," he suggests that children's stories should not avoid the topic of death. Rather, they should explore "the shadow of death" to help children begin to understand death's inevitability. This is a lesson from which most adults also stand to benefit.

Today our societal avoidance of death has led, in part, to "medicalized" dying, by which we mean a dying process facilitated or prolonged by medical intervention. Dying has been removed from the home and community and transplanted in the hospital or institution in an attempt to rescue dying patients from death. Medicalization can violate the bodies of dying patients with tubes, restraints, mechanical hums, and beeps—all efforts to control what remains of life and to stave off death as long as possible. It has enabled patients, their families, and physicians to delay death without necessarily promoting the health and healing of patients.

Medicalized dying is not categorically bad. Most generally, the term could apply to anyone receiving any health care (eg, oral pain medications) during the dying process. But our critique concerns the [forms of medicalized dying](#)—aggressive extension or premature termination of life—that both exemplify and perpetuate the belief that dying is a medical crisis from which patients must be rescued. The patient with terminal lung cancer whose mechanical ventilation simply staves off death, for example, experiences this sort of medicalized dying. Such dying prompts the question: What is the proper place of medicalized dying within the context of the aims of medicine?

To answer this question, we will first explore medicalized dying as a crisis from which patients must be rescued. We will then consider current practices that attempt to rescue patients. Finally, we will examine the role for medicalized dying as rescue within the broader context of the goals of medicine.

### **The Crises of Unhealthy Approaches to Death and Dying**

In 2014, 37.3% of patients died in hospitals, approximately 23% died in nursing homes or long-term care facilities, and approximately 29% died at home.<sup>1</sup> In 2016, 48% of all Medicare patients received some hospice care, but roughly 28% of patients enrolled in hospice a mere 1 to 7 days.<sup>2</sup> Furthermore, in 2014, the national average for intensive care unit (ICU) mortality was 14.7%, with individual state averages reaching as high as 21.6%.<sup>3</sup> Taken together, these data suggest that the vast majority of patients experience highly medicalized dying and deaths, the antithesis of what most patients prefer. In fact, approximately 80% of Americans indicate that they would prefer to die at home.<sup>1</sup>

It is common to hear the public characterize the role of physicians as “saving lives.” It is no coincidence that this exalted depiction of the physician’s role exists, because the media routinely portray physicians as lifesavers or rescuers. Consider, for example, how cardiopulmonary resuscitation (CPR) has been romanticized. One study found that the immediate survival rate for television CPR was about 70%, which is much higher than the immediate survival rate of 37%–61% in reality.<sup>4</sup> Of adult patients who are revived with CPR, only about a quarter survive to hospital discharge.<sup>5</sup> Indeed, one study suggests that depictions of trauma patients in the television show *Grey’s Anatomy* might create false expectations among a general audience. The show typically depicts trauma patients either dying or being “fixed” and discharged from the hospital following a single surgery, which is far from reality.<sup>6</sup> These portrayals contribute to a misguided belief among the general public that medicine always has the ability to cure, fix, and save lives, regardless of the type of injury or illness—precisely the sort of medicine that makes for exciting television.

Medicine’s misrepresentation is not solely the fault of the media, however; the culture of the medical profession is to blame as well. Physicians can feel ill prepared to discuss dying and death.<sup>7</sup> As a result, patients, families, and physicians often address difficult

end-of-life decisions when it is too late—when patients are dying in the hospital and receiving useless interventions—in short, when death has become a medical crisis.<sup>8</sup> These circumstances lead to inferior end-of-life decision making and create a culture in which both physicians and patients are ill prepared for death. When physician and patient alike avoid goals-of-care conversations, death comes as a surprise, and patients can make health care decisions out of fear or confusion. By contrast, when the goals and values of patient and family are explored deliberately over the course of an illness, the patient is empowered to make informed health decisions as death approaches.

### **Rescuing the Dying**

The miasma of fear, confusion, and uncertainty surrounding this unpreparedness for death forces patients and families to ask physicians to do everything possible to rescue the dying. When disaster strikes, victims look to be rescued, and the disaster of death offers no exception. The bioethicist Albert Jonsen calls this the “rule of rescue”:

Our moral response to the imminence of death demands that we rescue the doomed. We throw a rope to the drowning, rush into burning buildings to snatch the entrapped, dispatch teams to search for the snowbound. This rescue morality spills over into medical care, where our ropes are artificial hearts, our rush is the mobile critical care unit, our teams the transplant services.<sup>9</sup>

Jonsen suggests that the imperative to rescue becomes, in the face of death, a compulsion that overrides rationality. When death looms, the utilitarian ethic of doing the most good for the greatest number of people fails, and physicians adopt a deontological or duty-based ethic to save life no matter the cost.

More recently, the philosopher Nancy Jecker has claimed that the rule of rescue has no moral imperative and that it can in fact work in opposition to the principle of justice.<sup>9</sup> By attempting to rescue patients from situations in which the prospect of any benefit with treatment is minimal or poor, she writes that:

One is trying something, but it is not rescue. A more honest telling might be: harming the patient, wasting resources, feeding false hope, disregarding professional standards, failing to show courage, being seduced by technology, neglecting to focus on palliative care, being coopted by the family, refusing to acknowledge medicine’s limits, denying a patient’s impending death. Characterizing the use of futile interventions as rescue, or attempted rescue, clouds our moral perception, making it difficult to identify the morally egregious features of what we are doing.<sup>10</sup>

Jecker suggests that physicians should avoid such “dubious” and “farcical” rescue attempts.<sup>10</sup>

We agree with Jonsen and Jecker that the threat of death sometimes causes physicians to go to great lengths to avert it. But we want to push the notion of rescue further. It is true that sometimes rescuers throw ropes to the drowning, but it is equally true that

sometimes the more rational course is to abandon ship—to jump overboard hoping that some good might come of a bad situation. Jonsen and Jecker do not describe this sort of rescue morality, but we here suggest that an additional way that physicians rescue patients from medicalized dying is by helping them to abandon ship. Physicians do this by intentionally hastening death.

By “hastening death,” we mean a direct action with the aim of causing death. Although withdrawal of life support or withholding life-sustaining treatment can result in death, we do not define these acts as hastening death. The intent in these cases is not to make the patient dead but simply to remove or withhold treatments deemed to have more burdens than benefits. A number of cases, including Karen Ann Quinlan’s, demonstrate that removing life support does not necessarily lead to death. Quinlan lived a decade past removal of the ventilator.<sup>11</sup>

Perhaps the most controversial method of intentionally hastening death in the United States is through the practice of physician-assisted suicide, also called [physician aid in dying](#). According to the American Medical Association (AMA), “Physician-assisted suicide occurs when a physician facilitates a patient’s death by providing the necessary means and/or information to enable the patient to perform the life-ending act.”<sup>12</sup> The AMA does not currently support aid in dying,<sup>12</sup> and the practice is now legal in 6 states.<sup>13</sup> It will also become legal in Hawaii in 2019,<sup>14</sup> and it has been decriminalized in Montana through a 2009 state Supreme Court ruling.<sup>15</sup>

The physician-writer Haider Warraich offers physician aid in dying as a possible antidote to modern medicalized dying. After describing the “de facto mode of modern death” as an “acute escalation of medical interventions” for patients who are close to death, he notes that “a select few patients don’t want to go down this trodden path.”<sup>16</sup> Instead, he says, they choose death by “physician-assisted suicide.” Warraich suggests that because we physicians have complicated modern dying, we should not stand between patients and their wish to jump overboard to avoid the burdensome application of life-sustaining treatments. He acknowledges that many physicians oppose the practice of aid in dying and that only a minority of patients will request it. Still, he implies that physician aid in dying is, in fact, a deontological or duty-based ethic. Instead of a duty to save life, however, the duty shifts to respecting patient autonomy by facilitating patients’ choice to end their lives.

But implicit in Warraich’s assertion lies what the bioethicist Howard Brody calls a “rescue fantasy.” Building on Jonsen’s thesis, Brody asserts, “The rescue fantasy is a power trip: it envisions the physician having the power to snatch the patient from the jaws of death.”<sup>17</sup> This rescue fantasy is not just held by physicians; patients likewise subscribe to the image of a “powerful physician” who can save them from “the harm that threatens.”<sup>17</sup> The harm that threatens here is a prolonged, medicalized, “unhealthy”

dying process.<sup>18,19</sup> Thus, by offering aid in dying, the physician can “snatch the patient from the jaws” of an undesirable, highly medicalized death.

Most often physicians realize the rescue fantasy when they overestimate how medicine might help a dying patient and apply all available medical technology to thwart death—precisely the problem with medicalized dying. Brody insists, however, that physicians can also err by *underestimating* what medicine can do to relieve patients’ disquieting symptoms and to support them until death. He explores this assertion by addressing the subject of voluntary active euthanasia, illegal in the United States,<sup>17</sup> which occurs when a physician administers a lethal agent directly to the patient. Brody wonders whether euthanasia is not simply taking the easy way out. He notes that physicians have the ability to relieve almost any distressing symptom experienced by the dying and thus should be able to decline administering euthanasia. “But to do this the physician has to be willing to listen carefully to the patient’s view of his predicament and indeed to share in the patient’s anguish.”<sup>17</sup> This is an enormous undertaking—as much work as patching a sinking ship. Although Brody discusses the temptation to take the easy way out with regard to euthanasia, it can be applied to the practice of aid in dying. It is far easier for physicians to help patients “jump” to their deaths than it is to sit with them, listen, and coordinate the help of ancillary staff like social workers and chaplains to address patients’ concerns—existential, spiritual, familial, personal—at the end of life.

### **Medicalized Dying and the Goals of Medicine**

Perhaps medicalized dying and the rescue fantasy would be compatible with medicine if medicine were oriented solely toward the control of death and the indefinite extension of life. But it is not. Death control and delay are not medicine’s ends; they are subject to its broader aim.

What, then, is the aim of medicine? In a classic essay, the bioethicist Leon Kass suggests that the goal of medicine is promoting health, which he describes as “wholeness.” He writes, “The English word health literally means ‘wholeness,’ and to heal means ‘to make whole..... To be whole is to be healthy, and to be healthy is to be whole.’”<sup>20</sup> Health is not simply physical health, however. The psychiatrist George Engel declared in the 1970s that a reductionist, strictly biomedical view of the patient was insufficient. He proposed instead a new model—the biopsychosocial model—to replace the disease model of illness.<sup>21</sup> Since then, other scholars have expanded the model further, calling for a biopsychosociospiritual approach to medicine.<sup>22</sup>

A medicine that aims at health or wholeness, then, is a medicine that strives toward robust, biopsychosociospiritual care of the patient. It attends not merely to the physical but also to the psychological, spiritual, and communal. It often entails a multidisciplinary team. This robust sort of care can be thwarted by the application of aggressive life support to hopelessly dying patients. In such instances, technology becomes an excuse

not to work toward a patient's health or wholeness and can prevent deep engagement with the patient by the physician, chaplain, or family. Rescue technology prevents the possibility of a patient's intimacy with loved ones, and it prevents the patient's dying at home. In the case of physician aid in dying, facilitating a patient's death by lethal ingestion also thwarts efforts at biopsychosocialspiritual care, but, in such instances, it does so by elimination of the one who suffers.

### Conclusion

The rule of rescue is a pervasive, insidious force that has drawn physicians toward highly medicalized dying practices: aggressive life-sustaining treatment in futile cases and physician aid in dying. By uncovering and addressing the rescue fantasy, however, physicians can begin to improve health by promoting wholeness, even at the end of life. They, with the cooperative help of social workers and chaplains, can address each component of the patient's experience near life's end—biological, psychological, social, spiritual. By actively engaging with patients about the "peril, sorrow, and the shadow of death," physicians could help "bestow dignity, and even sometimes wisdom," on patients who are approaching the end.

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**Peter T. Hetzler III** is an MD/MHS candidate with a concentration in ethics at the Yale School of Medicine in New Haven, Connecticut. His research interests include end-of-life care ethics, especially the topics of physician-assisted suicide and do-not-resuscitate orders during the perioperative period.

**Lydia S. Dugdale, MD, MAR** is an associate professor and the associate director of the Program for Biomedical Ethics at Yale School of Medicine in New Haven, Connecticut. She is editor of the volume, *Dying in the Twenty-First Century: Toward a New Ethical Framework for the Art of Dying Well* (MIT Press, 2015).

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