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Gawande, A. (2014). *Being Mortal: Medicine and What Matters in the End.* New York: Metropolitan Books. ISBN 978-0-8050-9515-9.

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As a surgeon who makes journalistic contributions to understanding medical practice in contemporary American society, Atul Gawande has been known to challenge the medical establishment. His 2009 New Yorker article "The Cost Conundrum" was particularly notable for raising the issue of inflationary health care costs in business environments dedicated to maximizing revenues at the expense of consumers. Gawande's work in that essay was so influential that it became part of the Obama administration's argument for health care reform. His latest book, *Being Mortal: Medicine and What Matters in the End,* is consistent with his earlier writing in that the medical establishment is again a primary subject of critique, but this book goes well beyond Gawande's previous focus on the economics of health care. Adopting a more philosophical approach, he is now addressing the medicalization of death and the dying process. He argues that "scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals" (6). The experience of death and dying has become an event that happens within the confines of the hospital and nursing home. Gawande refers to this fact as an "experiment of making mortality a medical experience" (9), and he is writing this book to expose how the experiment is failing.

Disability studies commentary typically adopts a structural critique when addressing the subject of medical interventions in the lives of the dying, with doctors cast as the agents of unwanted medical impositions. Thus it is somewhat surprising, and gratifying, to discover a member of that profession making a similar critique. In his very first paragraph, Gawande admits that, of the innumerable things he learned about in medical school, mortality was not seriously discussed. Corpses were dissected for the purpose of learning anatomy, and the "textbooks had almost nothing on aging or frailty or dying" (1). Gawande, his peers, and his professors did not seriously consider the experience of dying from the perspective of the patient because, in their view, "the purpose of medical schooling was to teach how to save lives, not how to tend to their demise" (1). Gawande argues that this remains a major problem in the medical profession today, as well as in the wider medicalized culture of the United States. Patients are just as likely to ignore the fact of their mortality, electing for invasive end-of-life procedures that are unlikely to result in maintaining, much less increasing, quality of life. The medical profession is structured in such a way that these procedures are the norm, and one of Gawande's intentions is to expose the fact that we are "putting our fates in the hands of people valued more for their technical prowess than for their understanding of human needs" (128).

A second line of critique, inextricably bound up with the medicalization of death, is the seeming inability of the general public to deal with the fact of their own mortality. Gawande argues that medical advancements and the consequent lengthening of lifespans has led to an unnatural emphasis on health as a sufficient criterion for well-being, which leads to embarrassment and a sense of failure when facing the inevitable decline in health at the end of life. "We're always trotting out some story of a ninety-seven-year-old who runs marathons, as if such cases were not miracles of biological luck but reasonable expectations for all. Then, when our bodies fail to live up to this fantasy, we feel as if we somehow have something to apologize for" (28). We can turn to the work of the late Tobin Siebers (2008) to clarify what Gawande is illustrating by this "fantasy" of the unreasonable longevity of health. Siebers argues that the fantasy derives from an ideological commitment to an abstract concept of ability that inculcates a "preference for able-bodiedness" (p. 12). In our contemporary society and culture, physical and cognitive ability are valued to such a degree that disability is rendered undesirable, and persons with disabilities are often marginalized and ignored. This is precisely what is happening to persons of advanced age facing the final stage of life, and Gawande writes extensively about the institutionalization of the elderly in hospitals and nursing homes where quality of life is mostly overlooked.

Institutionalized neglect is only one half of the problem, however, because the ideology of ability is also internalized in every person facing end-of-life decisions and the dying process. The arguments in *Being Mortal are* structured around personal narratives Gawande has gathered through interviews and first-hand experience. A consistent theme throughout is the gap between what a person values in life and how that person actually lives while dying, and it is an ideological commitment to ability that is responsible for this gap. For example, research studies consistently show that being subjected to invasive procedures for the sole purpose of prolonging life result in a diminished quality of life. As Gawande vividly describes, "You lie attached to a ventilator, your every organ shutting down, your mind teetering on delirium and permanently beyond realizing that you will never leave this borrowed, fluorescent place. The end comes with no chance for you to have said good-bye or 'It's okay' or 'I'm sorry' or 'I love you'" (155). From a disability studies perspective, this language could be considered problematic because it seems to reinforce the fears of a disabled state of existence upon which the ideology of ability is built. But Gawande is purposeful in these somewhat lurid illustrations that punctuate his book. He is using what we fear about dying to force recognition of the contradiction in how we want to die and how we actually die.

Considering the fact that most people approaching death are concerned with "avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden on others, and achieving a sense that their life is complete" (155), death in the ICU can only be explained as ideological. A primary function of ideology, according to Siebers (2008), is the "smoothing over" of contradictions in a belief system. We do this because "the ideology of ability makes us fear disability, requiring that we imagine our bodies are of no consequence while dreaming at the same time that we might perfect them" (p. 13). Almost every personal narrative in *Being Mortal* exhibits this behavior: failing to prepare for the inevitability of the dying process because it is a fearful prospect, and assuming that the medical establishment can fix whatever goes wrong with one's body. Gawande points out that "[p]eople naturally prefer to avoid the subject of their decrepitude" (35), turning instead to the mass market bestsellers on aging that perpetuate the lie that old age is a continuation of youth. As a consequence of this obsession with the youthful, healthy body, "[w]e put off dealing with the adaptations that we need to make as a society. And we [miss] the opportunities that exist to change the individual experience of aging for the better" (35).

While there is much in Being *Mortal* that aligns well with the concerns and arguments of disability studies scholars, Gawande leaves some presumptions about old age unchallenged. For the most part, he is consistent in allowing his interviewee to characterize his or her own life experience, but sometimes these descriptions are provided by someone else, which inevitably leads to "burden" language. Such is the case for Lou Sanders, an 88-year-old man from Boston who is facing end-of-life decisions. Some of the material for this narrative comes directly from Lou, but Gawande relies most on the experience of his daughter on whom he relies for care. Too much of this narrative is dedicated to the "trials" of the daughter, who has to "look after her dear but frighteningly frail and dependent father" (84). The description of life with Lou focuses on the many "large and small" burdens he presents to his daughter, such as not eating the food she prepares for the family, playing his TV at high volumes, and not consistently taking medications. Gawande does turn a critical gaze on the daughter later in the narrative when questioning her decision to place Lou in a particular nursing home that values Lou's safety over his quality of life. He is also remarkably consistent in providing historical, social, and cultural explanations for the experience of the dying process. But Gawande could be more aware of his reliance on third-person descriptions of old age and the way in which they reinforce, rather than contest, the ideology of ability.

Despite this weakness, Gawande's ideological critique, coupled with his emphasis on human decrepitude and the sometimes gory details of the dying process, raises a crucial issue for disability studies scholars. The preference for able-bodiness is much easier to critique when the feared disability in question does not necessarily diminish one's quality of life. For example, disability studies scholars have thoroughly discredited the commonly expressed belief that death is preferable to being paralyzed because this belief is based on false assumptions about the kind of life a person with paralysis can lead. In most circumstances, this critique holds true, but how does the argument change when applied to a dying person? *Being Mortal* concludes with a powerful narrative about Gawande's father who died from a tumor in his spinal column. The author recounts how his father, devastated by increasing paralysis as a result of the tumor, admits he fears quadriplegia more than death. In most circumstances, the typical disability studies critique is appropriate, but this situation comes with the complication that death is not hypothetical but soon to occur. Moreover, if Gawande is to accomplish his purpose of improving quality of life for the dying, it is hard to imagine how he could do so more effectively than to confront his readers with the often fearful details of the dying process in order to urge us to think more about how we want to die. But in doing so, does he paradoxically reinforce the fear of mortality upon which the ideology of ability is built? This remains an open question, and these unsettled issues make *Being Mortal* a thought-provoking and challenging book to disability studies scholars interested in the ideological dimension of dying.

Works Cited

Siebers, T. (2008). *Disability Theory*. Ann Arbor: University of Michigan Press.