

CHAPTER I

Constructing a “Good Death”

Historical and Social Frameworks

DAVID T. HELM AND SANDRA L. FRIEDMAN

The end of life is inevitable. The ability to control and participate in one’s own life-ending scenario is not. Longer lives, heightened awareness of impending death, and various planning strategies permit us to construct an all-things-being-equal plan for controlling our own “good death” scenario. That vision is certainly culturally prescribed and varies greatly from individual to individual or from family to family. It is, however, centrally connected to a sense of justice and fairness and to an ethically and competently administered and facilitated sequence. In hospice and palliative care settings, the definition of a “good death” refers to a process wherein the dying, their loved ones, and health care workers mutually accept the approaching death and share end-of-life decisions (Conway, 2007; McNamara, 1998). The goal of the chapters that follow is to help facilitate a process in which individuals with intellectual and developmental disabilities (IDD), their families, and loved ones can join with health care providers to reach that end. Unfortunately, the imagined as compared to the experienced end of life are often far removed.

The face of death has changed over the years. Death is rarely the family or community event it once was. The process of dying is now more often mediated by a bevy of health care providers, hospital administrators or regulators of some ilk, insurance overseers, and a host of other unrelated parties (Kellehear, 2007). This chapter looks at the connection between the individual’s social construction of a good death and the realities and responsibilities of those whose job it is to ensure that the individual’s or family’s wishes for end-of-life care are carried out with compassion, competence, and dignity to the best of everyone’s abilities.

It is well known that gains have been made in the areas of life expectancy, social and community inclusion, and participation in everyday activities for individuals with IDD. However, we have not yet realized all that can be done to improve the lives of people with disabilities, which includes end-of-life care. The end-of-life experiences and options for people with IDD should, and now more frequently do, mirror those of their peers without disabilities. Participation in the planning of one’s own death or end-of-life care needs to be carefully reviewed and orchestrated such that whatever the image may be, the “good death”

or “best way to die” can be thoughtful and carried out with dignity and caring for both the individuals and their families. Attention to the differing notions or constructions of what that may mean will vary across cultural contexts, but with planning, a “good death” can be realized. In the general population, this is occurring with increased frequency as more people demand control over their end-of-life decision making and care. It is only recently that individuals with IDD and their families started to demand those rights and procure those assurances. The process of recognizing that these rights also include individuals who have traditionally been excluded from equal rights or who have been devalued has been long and has often been fought in the courts and through legislation.

Death in this and other industrialized countries has become medicalized in most circumstances, with over 80% of individuals in the general population dying in hospital or institutional care (Klinenberg, 2001; Office of National Statistics, 2004). By comparison, it used to be that the death of an individual occurred within one’s home, was embraced by one’s community, and was a relatively short process supported by friends and neighbors. The epidemiological transition that has been occurring over the course of the century—that is, the transition from acute illnesses to chronic or degenerative illnesses as the primary cause of death and the consequently longer, more drawn-out dying process—has resulted in longer hospitalizations and institutional care. This propensity of a slow decline has naturally required an increase in medical treatments with the concurrent medicalization of the dying process. The resulting care, including management of pain and complex medical treatments, has too often prevented dying patients from being able to participate in, let alone control, their end-of-life care. The implementation of more palliative care processes has created the opportunity to rehumanize the process that had become dehumanized and detached from the family. Asserting control over one’s own death, to some degree, or one’s end-of-life care is becoming a new reality for many.

Death in earlier times was more normalized, visible, and part of everyday life. Modern medicine associated with caring for the dying, typically within a hospital setting, has made death and dying a hidden phenomenon, one controlled by experts and those often not related to the individuals or their culture. Death and the regulations surrounding the process are, at least partially, removed from the emotional and spiritual realm and focus more on the procedural. However, that being said, regulations do not necessarily foreclose the possibility of including the individual and their family from the process or planning for the end of life and operationalizing goals of care that take into account the individual’s and family’s wishes and cultural beliefs. These processes have been particularly difficult to realize if the individual has IDD or is removed from the setting of his or her family and is residing in an institutional setting. Historically these difficulties stem from a number of social and political ambiguities, including a lack of ethical clarity, the reliance on the growing influence of medical expertise to solve all problems, and the longstanding social devaluation of individuals with severe IDD. Some of these changing historical and sociological trends have had a profound impact on the current social, emotional, medical, and cultural landscapes that contribute to creating a “good death.”

BIOETHICAL FOUNDATIONS

For centuries medical personnel have taken seriously the basic tenets of the Hippocratic oath, including the promise to do no harm as well as other guidelines that forswear

euthanasia, the seduction of patients, or the divulging of patients’ secrets. However, it is only since the 1960s that bioethics, the study of ethical issues pertaining to the biological sciences and health care, emerged as a distinct field and began to capture the public’s concern. This has had a strong impact on both research and clinical practice, which have a history replete with instances where vulnerable populations, including individuals with IDD, were treated in ways that would now be considered blatantly unethical.

Since its beginning in 1847, the American Medical Association (AMA) required its members to subscribe to its Code of Ethics. This code primarily pertained to medical etiquette rather than to what we might now consider to be bioethics. The genesis of much of our current foundation for ethical decision making stems from the Nuremberg Trials and the resultant Nuremberg Code (1948). These trials brought to light the extent to which human rights can be violated when left unchecked (Yan & Munir, 2004). The policies and practices that occurred in Germany and elsewhere at that time reflected a belief in eugenics. Some of these policies were also unfortunately enacted in the United States, although to a lesser extent (Lifton, 1986). The atrocities that occurred in Europe are now well known and widely reported as they came to light during the Nuremberg Trials. The decision of those trials formed the basis of the Nuremberg Code. The Code particularly highlighted that subjects must give informed consent with full understanding of potential risks and benefits before they participate in any research. For our purposes, it is of issue to note that this informed consent must come from the participants themselves, thus putting children or individuals with IDD at some continued risk.

The trials had received some publicity in the United States, but their immediate impact on medical practice in the United States was minimal (Rothman, 1991). As new technologies were developed and as health care costs continued to rise through the 1960s, new ethical questions began to be raised regarding the use of life-support systems for persons in a coma, access to new procedures such as kidney dialysis, and the development of organ transplant waiting lists. The spark that ignited the public debate was an article written by Henry Beecher in the *New England Journal of Medicine* in 1966. Here he described 22 research studies published in peer-reviewed journals that had used ethically questionable methods. He then looked at 100 consecutive research studies published in medical journals and found that researchers in 12 of the studies had not told their subjects the risks involved in participating in the research or, in some cases, that they were even involved in an experiment (Beecher, 1966; Weitz, 2001). Beecher’s work not only captured the attention of the professional and medical world but also awoke the public’s concern. The result of this revelation was the 1966 publication by the U.S. Public Health Service of a new and revamped guideline for protecting human subjects in medical research. The 1960s are often proclaimed as the birth of the bioethics movement (Fox, 1974; Rothman, 1991). Yet the 1970s would reveal that these ethical dilemmas had not disappeared.

The revelations discovered and made public in the Willowbrook hepatitis study, the Tuskegee syphilis study, and the Karen Quinlan case all stimulated more regulations and guidelines for medical practice. The Willowbrook hepatitis study reported on experiments on children with IDD who were either intentionally infected with hepatitis or knowingly not treated when diagnosed in order to study the natural course of the disease. The research began in 1956 and continued up until 1972. It was successfully

argued that the children were not properly informed (if at all) nor did their parents voluntarily provide consent for their children to participate (Ramsey, 1970). The debate and public outcry halted the research shortly thereafter. Similarly, the Tuskegee syphilis study, which began as early as 1932, was discovered to be ongoing as late as 1972. It was revealed that 399 poor and mostly illiterate African-American men who were infected with late-stage syphilis were left untreated in order to carry out medical research about the effects of the infection even though penicillin, discovered in the 1940s, was known to be an effective treatment. The study exposed medical research practices that preyed upon the disenfranchised, the uneducated, and others who were fundamentally powerless in society: namely, minority populations, including those who had IDD (Jones, 1993). The resulting legacy continues today with many African-American communities not trusting public health workers and the “medical-industrial complex” in general.

In 1975, a few years after both studies, the case of Karen Ann Quinlan garnered much public attention. At the age of 21, Quinlan had fallen into a coma after ingesting a combination of drugs. She suffered extensive brain damage, and medical experts believed there was no chance of her regaining mental or physical functioning. The debate centered on the right to die and her parents’ request that she be removed from all life-sustaining machines. After a yearlong court battle, she was removed from the ventilator, although she remained alive for an additional 10 years as staff continued to provide her with artificial nutrition and hydration as well as antibiotics for acute infections. This case was widely debated in the public and raised the issue of the right to die. For the first time, it also posed problems related to too much, rather than too little, access to medical technology (Weitz, 2001). The legal system was now entering the health care decision-making process in full force.

In the 1980s and 1990s, new ethical dilemmas regarding the control of medical technology, or the rights to gain access to it, were confronted. How far can or should medical interventions go to disrupt or change the natural human process in life and death decisions? Reproductive technology came to the forefront when the “test-tube baby” hit the front pages of the news. Questions arose regarding who should have the ability to control human conception, what the parameters for human engineering would be, and how the future of medical technology was to be controlled. The issue of *in vitro* fertilization posed the initial ethical dilemma regarding modern medicine’s active role in human development outside of the traditional or natural processes. These debates continue in today’s world with issues raised from the human genome project, cloning technologies, and pre-natal testing protocols.

The result of these public revelations of morally debatable, and often reprehensible, events has been the development of ethics committees, institutional review boards, and professional standards. The impact on research, medical education, and clinical practice has been substantial, if at times controversial (Annas, 1991; Hafferty & Franks, 1994, Zussman, 1992). The public interest must be protected and researchers and clinicians are required to live up to reviewable standards and codes of ethical behavior. It is this background that sets the foundation for clinical behaviors relating to the clinical practice at the end of life.

MEDICALIZATION OF DEATH

As the population began to rely more heavily on medical interventions to ease pain, as the dominance of the biomedical model grew along with technology, and as dying became a more drawn-out experience, death became medicalized (Illich, 1976). We often now talk about the medicalization of society—the slow transformation of all human conditions into treatable disorders (Conrad, 2007). That is, conditions, circumstances, and behaviors have become defined and are treated as medical problems. This trend has been written about for years (Balard & Elston, 2005; Lock, 2001), and some have called it “one of the most potent transformations of the last half century in the West” (Clarke, Shim, Mamo, Fosket, & Fishman, 2003, p. 161). Many social factors have contributed to this trend and have set the context in which this transformation has flourished, including the increased faith in science to solve problems and possibly the decreased faith in religion to do the same. Similarly, technological progress and general humanitarian trends in Western civilization have promoted medical intervention. Thus, as opposed to individual medical or health care personnel attempting to control new conditions or circumstances, there have been a number of social trends pushing medicine to do so. Although many social scientists at least imply a critical overtone toward excessive involvement or too much control from medicine, some have called for collaboration between patient and doctor, differentiating between medicalization and medical dominance (Broom & Westward, 1996). Others argue that we are now in a demedicalization trend, moving toward holistic treatments and complementary and alternative medicine (CAM), and some prefer the term “biomedicalization,” which brings stronger connotations of technological and scientific findings and procedures (Clarke et al., 2003). Conrad argues that the influences of the ongoing trend of medicalization can be summarized as the coming together of biotechnology (pharmaceutical advancements and genetics), consumer demands and preferences, and managed care (Conrad, 2007, 2009).

Each component of these social trends has increased the demand for medical intervention to enhance human comfort and thus prolong a good life. It is clear that biotechnology, often in the form of pharmaceutical advancements, is seen everywhere, in all phases of life from birth to death. Drugs are viewed as the cure-all, the least invasive medical treatment used to prevent problems (e.g., lowering cholesterol and risk for heart attack) and solve problems (e.g., depression, hyperactivity). This appeal has been taken directly to the consumer since the U.S. Food and Drug Administration passed the Modernization Act in 1997, allowing for wider and more direct promotion of products, most evident on television. Patients have demanded more access to drugs, and the pharmaceutical companies have taken hold of that demand to satisfy the outcry and, at times, to create new markets (Conrad & Potter, 2004; Koerner, 2002). This consumer demand has strengthened the medicalization movement in all facets of health and illness, including end-of-life care.

Consumers themselves have demanded medical intervention and treatment not only for “classic” medical maladies such as heart disease and cancer but also for the “correction” of human variation through selective surgery (Sullivan, 2001) and medication for mood disorders or personality variations of all kinds (Barsky & Boros, 1995; Shaw & Woodward, 2004). Thus, medical treatment of human problems has become the rule rather than the exception.

It is beyond the scope of this chapter to fully discuss these social trends and resulting influences on medicalization; however, a third element that must be discussed is the oversight of this pharmaceutical explosion and consumer demand by managed care systems. The delivery of health care in the United States is clearly dominated by managed care organizations with various bureaucratic gatekeepers actively involved throughout the process. This is a complex relationship that both encourages and limits medicalization (Conrad, 2009). Thus, for instance, managed care may reduce coverage for psychotherapy for individuals with mental and emotional problems (Shore & Beigal, 1996) but may be more open to paying for psychiatric medications (Goode, 2002). These social forces come together to begin to transform human differences into pathological conditions, all with a medical remedy or intervention. Unfortunately, “the great danger here is that transforming all differences into pathology diminishes our tolerance for and appreciation of the diversity of human life” (Conrad, 2007, p. 148).

The results of medicalization have generally been positive, with new hope generated for cure, treatment, and care of a host of human maladies. Similarly, “blame,” or acceptance of responsibility for an individual’s condition, is mitigated when a medical diagnosis is attached: one is typically not held accountable for one’s behavior or actions if it is deemed to be caused by a medical condition beyond the control of the individual. We must remember, however, that the positive aspects of the trend toward medicalization of behaviors or conditions may also be accompanied by social risk, negative outcomes, and pockets of resistance. That is, medicine can now often be seen as the definer of what is “normal,” and thus medicalization creates an insidious stigma for those who are deemed different. This has generated resistance to a number of facets of the medicalization of life, especially in disability communities or elsewhere where differences can be and are celebrated. The disability rights movement is particularly wary of too much adherence to and acceptance of the medical model as opposed to celebration of human differences and variations.

DISABILITY RIGHTS MOVEMENT

As an extension of the civil rights movement, the disability rights movement has been increasingly active and growing for decades (Batavia & Schriener, 2001; Fleischer & Zamers, 2001; Shapiro, 1993, 1994) as the voices of individuals with disabilities, their family members, and supporters have been addressing classic rights for access to employment, housing, education, and community inclusion in general. The success of this movement is well known and includes many legislative advances, epitomized by the American with Disabilities Act (ADA) in 1990 and the American with Disabilities Act Amendments Act of 2008 (ADA-AA). The rights of individuals with IDD have been advancing in all facets of social life, including in the relationships between individuals and the medical world and the attitudes within the medical world.

Throughout history, medical views on individuals with IDD have not been altogether favorable, nor have medical attitudes been particularly welcoming (see chapters in this volume by Botsford & King, and Levy & van Stone). Individuals who are different, or who have conditions that create functional limitations or shortened life expectancies, have often been looked at as inferior and substandard. Only a brief reminder of the eugenics movements will bring this to light all too quickly (Pfeiffer, 1994). Those ideological stances have

been successfully defeated for the most part, although remnants of that era reappear from time to time. The lasting social or attitudinal remnant that is often unintentionally sustained by the medicalization movement is that individuals with disabilities are still devalued in all sorts of obvious and covert ways (see chapter by Luftiyya & Schwartz). This, then, can play a role in the end-of-life care expected by or given to individuals with IDD.

Individuals with disabilities routinely look warily toward the broad social view that focuses on the narrower medical realm that designates them as sick, a realm that often assumes or forces them to take on the sick role when in fact they are not ill. The lack of distinction between a medical model and a disability model can be traced to the root of social discrimination and exclusion and can thus play a role in end-of-life care and related social expectations as well as policy (Turnbull & Stowe, 2001). That is, when a medical definition or norm becomes the basis of what society regards as normal for bodily functions, intellectual capacity, articulation, or possibly hearing, for example, then those who do not meet such standards are deemed less worthy and possibly stigmatized as “subhuman.” The deaf community certainly has stood up to such characterizations, as have many in the disability rights movement (Conrad, 2007; Fleischer & Zamers, 2001). It is the notion of the medical sense of “normal” that can confront or compromise the end-of-life care provided individuals with IDD.

In the broader social and policy arena, such organizations as ADAPT (Johnson & Shaw, 2001) and Not Dead Yet (<http://www.notdeadyet.org/docs/about.html>) have been particularly vocal in dissent and resistance to the right-to-die movement that had been epitomized in the Dr. Kevorkian and, later, the Teri Schiavo situations. Both organizations call for more public discussion about who controls end-of-life scenarios and how policy and public opinion will play a role in individual choices surrounding this issue. Professional caregivers play critical roles in working with and assisting individuals to make these difficult yet important decisions.

A backdrop to increasing end-of-life care options for individuals with IDD is the broader patient rights movement. Within this movement there is a segment of the patient population that gained momentum from Kubler-Ross’s (1969) publication of *On Death and Dying*, which called attention to the dehumanizing aspects of modern medical treatment for the dying, including any individual who had been given a terminal diagnosis, which is typically accompanied by chronic or degenerative conditions where life expectancies are severely limited and death is imminent. In this case, ethical dilemmas of control and caring within the circumstances of the individual’s end-of-life care become paramount. The relationship between care providers and consumers “is fraught with ethical issues relating to power” (Friedman, Helm, & Marrone, 1999, p. 349). It is how this power is utilized that makes end-of-life care comforting or not.

Role relationships between providers and patients have a long history in sociological literature beginning in the 1950s and continuing today (Anderson & Helm, 1979; Love, Mainour, Talvet, & Hager, 2000; Parsons, 1951; Szasz & Hollander, 1957), and who is in the best position to make decisions in life-and-death situations has likewise been a topic for study and debate (Hackler & Hiller, 1990; Nursey, Rohde, & Farmer, 1990). The relationship challenge, however, still lies in being able to provide the best and most comprehensive care to an individual with IDD while working closely with the family and other caregivers

(Friedman, Helm, & Marrone, 1999). The disability rights movement, as do all similar political movements, essentially boils down to respecting all individuals equally, thus providing them with person-centered and culturally competent care that fosters their autonomy and independence and therefore their right to make their own decisions.

CONCLUSIONS

The merging of the social consequences of an increasingly more defined bioethical stance toward patients' rights both in research and in clinical work, the recognition of the consequences of the medicalization of the dying process, and the increased influence of the disability rights movement have resulted in a more humanistic and respectful process in end-of-life care. These historical and social trends create the backdrop on which this book focuses.

The remaining chapters of the book provide information on children and adults with IDD and some of the risks they face that may bring on premature death. How to anticipate upcoming needs of patients and how to secure resources to assist them is crucial for successful planning at the end of life. Providers and families can maximize end-of-life care that is compassionate and competent, dignified and respectful. Although the end of life is inevitable for all individuals, it is becoming increasingly possible that children and adults with IDD can participate in constructing their own end-of-life scenario to obtain a "good death," or at least one that is as good as a well-planned ending can be.

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