Right To Die
Terri D. Huntington

for
The Elizabeth N. Brehler Scholars Program
1993 Manuscript Competition Co-winner
Wayne State University
School of Social Work
What do the terms self-determination, self-advocacy, empowerment, and autonomy really mean beyond the protective boundaries of the university? In what ways and to what extent do we social workers actually promote these concepts when dealing with real human lives; sometimes vulnerable, desperate, and fragile human lives? After all the hours spent in Methods classes discussing values, the Code of Ethics, personal empowerment, and human dignity, how do I finally operationalize these concepts and give them meaning? I have learned so much about what it is to be human, to be a woman, a social worker, an entrusted vessel for others to turn to in their own search for validation and purpose. There is security in the classroom, a shared identity and opportunity to explore new territories of thought while exposing our weaknesses and vulnerabilities.

This candid outreach did not come quickly, nor was it easy. In fact, I must admit that it was not until I began recovering from a true crisis that it all came together. The difficult and grueling introspection necessary to assess my intrinsic belief systems, becoming an important member of a unique culture in its formative stages, and developing loving relationships with individuals who would ultimately and literally carry me through some of the darkest days of my life; this metamorphosis is only just now revealing itself to me. The long classroom sessions involving difficulties and adventures in field placements often seemed unimportant or redundant at the time, but as it all becomes processed, it takes the shape and dimension of one of the facets we grew to know as our “multifaceted problem solving approach.” In a sense, I guess I would give those facets the credibility and respect of a real diamond. I have so much for which I am deeply grateful and I do not even know where to begin in returning the love which has been shown to me. All this time I grieved that I did not have an extended family, yet I find that I have been adopted by a very special group of social workers, a physician, therapists, and others who have opened up their hearts for me to claim my space. This I discovered as I contemplated the inevitable conflicts of my own social work practice. I wanted to give serious consideration to the terms aforementioned in order to evaluate my true stance on them when it occurred to me that, in becoming self-determined myself, I also became more autonomous and empowered. Self-advocacy became critical for me when I hit a sizeable snag in my journey toward graduation and career development. I received what, in pre-school, we used to refer to as an object lesson. It involved trauma, disability, rejection, and numerous losses, yet it also included love I never knew existed, and patience and perseverance. I know I cannot hand empowerment to a client, or the inner strength to
see beyond his/her difficulty to his/her potential. In fact, as I promote self-determination I must remain cognizant that he/she may not even wish to reach his/her potential.

The strong and honorable social work principles to which I have solemnly acclimated will serve as a solid foundation in my practice, but I am quite aware that conflicts of all kind await the new energy and fresh approach I bring with me. Small, daily conflicts help to keep us sharp; they provide practice for critical thinking. Yet, some types of professional conflicts have the capacity to weigh heavily upon our hearts and to keep us awake at night as we try to determine which justice would be better served. I found myself in such a conflict this past year, and in search of its resolution I was compelled to study it further and seek advice and feedback from persons with varying opinions.

The seemingly unresolvable controversies over freedom of choice, such as the abortion issue and the intermittent movement to ban handguns, are examples of the difficulties we face in attempting to interpret what we believe to be in the best interest of the individual, of society at large and of future generations. There are usually good arguments on both sides of debates. Personal rights and how these rights impact others nearly always produce dilemmas between or among systems. Even the Supreme Court has expressed ambivalence when attempting to reach fair decisions in terms of personal rights such as self-determination (Gunther, 1991).

Throughout my own educational process my personal values have taken new directions. With diversified information, an increased knowledge base, a variety of experiences and the formation of magnificent mentor relationships, I feel much more confident in the development of new values than I did with many of those which I brought with me. A few years ago I believed that, because all of life is sacred and precious, no one had the right to end it under any circumstances. God created life and God alone had the right to take it back. With some of my more recent experiences, in and out of social work, I discovered the need to re-evaluate my very old and seasoned values. I was tripped and fell flat on my life. Shocked and outraged that some external force could step in to seize my life like that, I stood fast in my denial and forged ahead with my predetermined goals .... and fell again. Optimistically, this ordeal could be framed as an "opportunity for growth", but to be honest, I oftentimes viewed it as a frustrating inconvenience and painful disruption of my life. As most of us have come to realize, our greatest personal growth seems to occur during our worst tribulations. Some of my most unwelcome experiences of this past year will give me insights I could never have accumulated from books or classrooms. They
lend themselves to deeper consideration for persons with chronic or terminal illness along with the understanding of stigmatization and the ethical challenges to which they give birth. Although growth is adaptive, for some people, too many of these "opportunities" may begin to relay the message that life may not be such a blessing after all.

I cannot imagine a more emotionally charged ethical dilemma than one currently emerging in American culture. We are a nation of people that refers often to our constitutional right to privacy, freedom of choice, and pursuit of happiness. Although we pride ourselves with the medical technology to prolong and sustain life, people are beginning to question the advantage or advisability of this type of existence. While health care technology offers many people a second chance for life, many others have been maintained in a comatose or vegetative state for months, or even years. This is highly traumatic, not only for the patient but for the loved ones as well, especially in an age when the cost of health care and insurance is skyrocketing and thousands of Americans cannot afford even minimal coverage. Several social forces appear to be converging which compel citizens to assess the value of remaining alive, even though permanently and totally physically and/or mentally incapacitated, only to eventually render their loved ones financially destitute.

On December 1, 1991, the Patient Self-determination Act went into effect that provides patients an opportunity to designate advanced directives should they become incapacitated. It was the first legalized expression, by Michigan's government and the health care profession, of an awareness that not everyone wishes to be kept alive when the quality and substance of life has deteriorated irreparably.

To pursue one's right to die is not an easy decision to make, nor is it an easy course to follow once the decision is made. Only the person actually facing a chronic or terminal illness fully understands the despair and devastation of realizing there is no future, and the fear of what will become of him/her as the dying process follows its course. Right to die issues cannot be taken lightly on either side of the argument. The social work practice is involved not only in counseling and advising individuals who elicit this type of information, it also has a responsibility to remain politically involved with mandates and policies which encompass these critical issues. As a social worker who plans to be involved in policy making and research, I feel gravitated toward becoming a legislative advocate in this area of concern. Though my position is not yet entirely defined, I have a clear sense that this is an area much in need of exploration.
Derek Humphry, founder of the Hemlock Society, educates interested persons on the methods of ingesting lethal drugs, sometimes with the assistance of another individual, for the purpose of committing suicide. He advocates for euthanasia as does a few other spin-off organizations around the country, such as the World Federation of Right to Die Societies (Humphry, 1986).

Dr. Jack Kevorkian made headlines when he assisted in the suicides of persons, even following a court order to cease his activities. People believed so intensely in his methods that some of them traveled across the country to obtain his assistance.

Assisted suicide/euthanasia involves the deliberate, premeditated taking of a human life, or the omission of specific steps taken in order to preserve it. Euthanasia is defined as the deliberate, painless killing of persons who suffer from a painful and incurable disease or condition, or who are aged or helpless. Categorically, there are four ways to accomplish this. 1) Active voluntary euthanasia is what Jean Humphry did when she asked her husband, Derek, to administer to her a poison "cocktail" should the pain from her terminal cancer finally become unbearable. She, the patient, made the decision early in the disease process while she was still mentally competent. 2) Active involuntary euthanasia occurs when someone hastens the death of an individual who is unable to participate in the decision, such as someone who is comatose. 3) Passive voluntary euthanasia is committed when a physician knowingly and deliberately neglects to administer treatment, by request of the patient, which might sustain life. A Do Not Resuscitate (DNR) order is one example. 4) Passive inactive euthanasia refers to the same situation as a DNR, but without prior consent of the patient. Is the right to die always wrong, always right, or is it situational? If it is situational, who should have the final say, and under what conditions?

Assisted suicide and euthanasia are debated on two basic premises: 1) God created life, and all of life, regardless of the tragedies contained within, is worth living. 2) The state has a vested interest in the outcome of this issue due to its responsibility to protect and preserve life. This commitment to the public must serve as the backdrop to all policies and laws passed.

In the 1970s, the Karen Quinlan case raised a very important question that is being revisited today: Is every life worth living? This should not be confused with: Does every life (person) have worth? In Karen's case, medical technology had reached the capacity to prolong
life, and in many situations this is a blessing. However, does that blessing cross the line and become a curse when the quality of life has been reduced to brain stem activity only? The entire nation watched as Karen's family and the judicial system struggled over Karen's "best interest." The decision as to whether or not to maintain life support would not only affect Karen and her family, it would set a precedent for subsequent similar cases (Colen, 1986).

Essentially, quality of life can only be determined by the individual and there are those who believe that life's meaning has been completely eroded due to chronic or terminal illness. From a Hastings Center Report, Reverend Richard McCormick, asserted, "One can and, I believe, should say that the person is always an incalculable value, but that at some point continuance in physical life offers the person no benefit. Indeed, to keep "life" going, can easily be an assault on the person and his or her dignity" (Lyon, 1985). McCormick is a Jesuit and professor of Christian ethics at Kennedy Institute, Georgetown University.

The right to die is loaded with legal, moral, religious, and ethical complications, especially for social workers, since we are the helpers, the mediators, and most importantly, the advocates. Over the last twenty years our society has gradually adapted to the anticipatory conflicts between physicians, courts, and families regarding whether or not to administer life saving measures for patients whose potential for recovery is deemed extremely poor. No doubt, social workers have been intricately involved in those crucial life-determining decisions as they advocated for and counseled family members. The right to die is deeply embedded within our concept of self-determination, yet so many of the variables are virtually non-definable. We wish to educate and empower those who place their trust in us, but we must have a clear picture in our mind of what self-determination really means when a client asserts him/herself and informs us that life must now end and assistance is needed. This same client might have children or other loved ones who oppose this provocative decision and they might also be our clients. We certainly have legal, professional, and personal responsibilities, but they may be in direct conflict with each other, particularly with this ambiguous issue.

On the forefront of the nineties is the question of assisted suicide and euthanasia, which takes a giant step outside the parameters of the emergency room. Within the past few years this ethical dilemma has intermittently become the focus of Michigan's politics, and by way of Dr. Kevorkian's behavior, the nation is watching to see how we handle this. Kevorkian has implicitly expressed his belief in patient self-determination through his methods and techniques of aiding
people with terminal or chronic illness in the hastening of their death. As a physician, he has the knowledge and means to perform these acts, but has his professional role been violated in terms of the Hippocratic Oath? Physicians have taken this oath which, until 1948, stated that, "I will neither give a deadly drug to anybody, if asked for, nor will I make a suggestion to this effect." The General Assembly of the World Medical Association in Geneva in 1948 modified the oath by removing this phrase, not in order to promote mercy killing, but to allow a pro or con position regarding death by choice. Another portion of the oath is contradictory to its probable intent. It promises to relieve suffering and to prolong and protect life. There are many incidents where to prolong life is to prolong suffering and death (Maguire). This aspect of the Hippocratic Oath is often brought into question by proponents of the right to die.

As social workers, one of our founding principles, self-determination, has been challenged in the social and political struggle to legally determine an individual's right to die, should he/she decide that life is indeed not worth living. A few years ago I had no doubt that this was morally, ethically, and spiritually wrong, and I was perfectly comfortable with my position. Then, in my quest to promote self-determination I was prepared to advocate for the legalization of assisted suicide. However, with further research and listening to the concerns of those who fear becoming victimized by its legalization, and having been touched by it on a deeply personal level, my position is somewhat more cautious in terms of possible repercussions to vulnerable populations. Within the last 16 months, I have witnessed the quintessence of life and love but also its greatest tragedy. If there is a right to die, it must be evaluated on an individual basis, as is quality of life, but who makes that ultimate decision?

In the fall of 1991, I watched the miracle of a double transplant while I stood on a crate at the shoulder of a very generous surgeon. As a mother donated a kidney to her young son, I was allowed to witness the affirmation of love and a unique form of familial bonding, and how one life can literally continue on through another.

Unfortunately, not all of life is as exhilarating and self-renewing, and not everyone wishes to go on living. Barely one year ago, a dear friend of mine watched quite helplessly as her ten year old son weakened against the ravages of an infection, secondary to a bone marrow transplant; his final battle against leukemia. His major organs had irreversibly shut down, he was on 100% oxygen, and he was bloated beyond recognition with the fluids that had collected throughout his innocent little body. Among several other medical complications, such as prostate cancer, this
young boy was conscious and in constant pain which his daily doses of morphine no longer alleviated. Each day the doctor greeted his mother or father with additional news of his slow deterioration, but he continued to maintain agonizing consciousness. Finally, these grieving parents had to decide if they owed it to their young son to await a miracle or to ask the physicians to disconnect the life support systems that prolonged this little boy's life (death?). When my friend phoned me that last evening to discuss what she felt compelled to do I was stunned but not surprised, and I sensed the tremendous grief and desperation clinging to this final decision she and her son's father felt they must make. Early the next morning I was there with them and a few other family members while the machines were slowly turned down in order to reduce the likelihood of convulsions. Within thirty minutes this young child, in his loving parent's arms and in the presence of his two older brothers and friends, quietly passed from this life to another.

Euthanasia?

I did a field placement as a nephrology social worker last year. Roughly half of our patients were individuals with diabetes and were consequently suffering a multitude of secondary health problems such as blindness, amputations, and heart disease. End stage renal disease is permanent, so dialysis in one form or another is also permanent. The procedure contains an element of risk since blood and other fluids are pulled from the body with a force that puts strain on the heart. Dialysis must be administered 3-4 days per week for 3-4 hours each. Not only is the individual forced to deal with chronic illness and a life-time commitment to dialysis treatments, he/she must also cope with the psychological adjustments related to the subsequent losses; loss of body image, self-worth, a career, sexuality, autonomy, physical independence, and financial stability among numerous others. These losses are deemed insurmountable by some people and, coupled with the sense of being a permanent burden to loved ones, it is not so unusual for a person to choose the natural course of death over being connected to machines several times a week for the duration of life. It may be perceived that an acceptable quality of life has been permanently surrendered.

Upon intake, the different treatment modalities are presented. Although most patients opt for dialysis and/or transplant, it was my experience that occasionally a person would consider all of the options then decide on none of them. Since dialysis is a life-sustaining treatment, refusal generally means death within only a few days. In order to promote self-determination, the nephrology social worker is obliged to advocate on the patient's behalf if he or she refuses
treatment once all of the options have been carefully explored. Supportive counseling and a referral to hospice usually follows this type of decision. Assisted suicide?

Within the context of my own situation I can speak for sudden disability and chronic pain. Even though everyone experiences pain from time to time, only a chronic pain patient fully understands the sense of hopelessness of living out a life consumed in pain. It was challenging enough to suddenly realize that I might never again enjoy the physical freedom and comfort of a healthy working body, but the fact that in fifteen months, I have not experienced a pain-free day gives every aspect of life a new look. I learned pain management, which was essential in order to continue with life at a semblance of my prior level of productivity. It is definitely a quality of life issue and it is likely the most misunderstood reason for a person giving up on life since chronic pain individuals can look perfectly normal to the rest of the world. The benefit in this is the strong foundation I have achieved for understanding and empathizing with chronic pain persons and those with disabilities. I can understand how a person might finally reach the point where he/she perceives a need to put an end to the pain. It is certainly not evidence of a weak person, but rather an exhausted one; one whose energy is seriously depleted and whose spirit has diminished. I heard much criticism from the media and people around me regarding the woman with multiple sclerosis whose death Dr. Kevorkian assisted. Her situation was minimized because she did not suffer from cancer, because MS is not a terminal illness. It is a progressively painful, degenerative disease and this woman deserved compassion not criticism. There is more to human suffering than whether or not a disease is terminal. No one knows the degree of agony the woman endured, the pain she suffered, or the possible lack of emotional or financial support she was provided. Also, some people simply do not wish to become a tremendous financial burden to their families when they learn they have a disease which will eventually result in death and possibly leave the family in financial ruin.

On the other side of this ethical dilemma, however, are the major and legitimate concerns expressed by elderly citizens and those who are disabled, either mentally, physically, or developmentally. There are elderly and disabled persons who fear the potential long-term consequences of the legalization of the right to die. They have already been devalued by mainstream society, and stigmatized for their perceived "deficiencies" and lack of "productivity." This vulnerable population is often viewed as the useless portion of society which costs taxpayers exorbitant amounts of money for their specialized care. Social attitudes are currently rejecting of the elderly and intolerant of persons with disabilities. As we know, it took an act of Congress to
ensure civil rights for disabled persons, and at another time, to provide handicapped access to public buildings. If we awarded dignity and respect to all people, we would not require legal mandates to accommodate people with special needs.

Although our advanced technology extends life so that we might look forward to living longer, we have sent a clear message to senior citizens that we do not want them around. We put them in nursing homes, send them off to retirement villages, or abandon them in impoverished neighborhoods while they live out their lives in loneliness and near starvation. These groups of people feel betrayed as it is, and now many of them fear being pressured into suicide by weary or selfish relatives, or because they require costly medical care (Detroit Free Press, 4/20/92). Could assisted suicide become a convenient alternative utilized by the system if it is seen as cost effective?

Advocates for neonatal care share some of these same concerns in terms of physicians deciding which infants they will try to save and which ones will be allowed to die, particularly infants with disabilities. There is sufficient documentation referring to euthanasia or infanticide in hospitals around the country. In the Sonoma Conference on Ethical Issues (1974), twenty experts representing the disciplines of medicine, nursing, law, ethics, economics, journalism, social work, and anthropology assembled to consider the serious problems confronted in the neonatal intensive care units. Of the 20 experts, 17 indicated they would actively and deliberately intervene to terminate the life of an infant "whose prognosis was a lingering painful death" (Lyon, 1985). What deeply concerns some of the opponents of infant euthanasia is the potentiality of physicians placing more concern over the sense of burden these babies might impose on their families or society, rather than the actual suffering experienced by the infants (Lyon, 1985). There is also the fear that should parents alone be allowed to determine life or death on behalf of their newborn, they, too, could be deliberately or inadvertently self-serving in their decisions due to finances, anxiety, or social embarrassment (Lyon, 1985).

Within the last 20 years, the courts have struggled over countless conflicts between physicians, parents, ethicists, pro-life/pro-choice groups, and theologians in determining quality vs. sanctity of life debates. The ethics, legalities, and morality of withholding medical treatment for handicapped newborns become all the more difficult to ascertain as health care technology improves its methods of sustaining life. Nowhere is the relevancy of "quality of life" harder to grasp than when dealing with an infant with multiple defects. The question of quality requires a subjective
accounting of what constitutes an acceptable life, while sanctity objectifies life to the extent that infants would be saved regardless of infirmity. Saving such an infant merely because the technology has the capacity to do so might be perceived to be cruel in the most severe cases (Lyon, 1989).

Since we are a society that values perfect health and perfect babies, one of the greatest and most effective arguments used by abortion proponents has been the capacity to prevent or reduce birth defects by terminating pregnancy. On the surface, it appears to be a valid argument, but many persons with defects and/or disabilities have taken offense to this line of reasoning on the basis that their own lives would have been prevented had abortion been legal during their gestation periods. They wonder why there is not more concern about an infant's happiness and moral character than whether or not it will be formed perfectly. There are great numbers of disabled persons who lead active, productive, and fulfilled lives, and some of them anticipate the act of neonatal euthanasia being abused should it become legalized (Gill, 1992).

The right to die is an ethical dilemma for society and for social workers. I am a strong advocate for self-determination, but while this issue brings comfort to some people, it brings only fear and frustration to others, any of whom might need and request my assistance at some point in the future. As I have uncovered so many varied opinions regarding the right to die, I feel certain that I must not take an inflexible or unwavering position on this issue. While the right to die is advantageous to some people, it carries the potential for abuse. Is it worth that kind of risk, that kind of tragedy? Should a person be forced to maintain life if the quality has been irreversibly diminished and pain is all he or she has to look forward to? Will the legalization of euthanasia give permission to doctors to withhold critical treatment from babies with disabilities, with or without the parent's knowledge or permission?

I believe that social workers, regardless of their personal stance on this issue, would be wise to give serious consideration to a plan of advocacy should someone solicit their assistance in a right to die situation. The Michigan Chapter of the NASW has recently come out with its guidelines for social workers regarding assisted suicides. As stated in the NASW NEWS, March 1993 (p.14), social workers have the right to decide whether or not to participate in assisted suicide matters, although not in the act itself. The right to practice social work with autonomy brings with it a tremendous responsibility to ourselves, to our peers, and to those entrusted to us. Ethical dilemmas such as this one warrants serious research and introspection in order to
determine the most effective way to foster self-determination in our clients. I am entering this profession at an exciting time and I believe my personal experiences have enhanced my understanding of the need for positive activism and advocacy.
REFERENCES


Excerpts from *The Hastings Center Report,* Jan/Feb. 1992


