EXTENDING THE BOUNDARIES OF LIFE: IMPLICATIONS FOR PRACTICE

MARCIA ABRAMSON and RITA BECK BLACK

Recent advances in medical technology are confounding traditional definitions of life and death and even of who is a person. This article considers the implications of these developments for social workers and presents a technique for helping clients make decisions in the face of ethical dilemmas created by new medical technologies.

Life-support systems, organ transplants, and other advances in medical technology have made it possible to prolong the life of the terminally ill and hopelessly injured and have blurred definitions of when life ends. For example, technology now allows the transplantation of various human tissues, including bone marrow, pancreas, liver, lungs, and heart, and it is possible to prolong life with machines that keep the body functioning even if the conscious mind has died. The availability of these life-support machines prompts this society to reexamine its definition of death.

Recent breakthroughs in treating the fetus also extend the definition of personhood at the beginning of life. For example, surgery performed on the fetus in utero can correct such conditions as hydrocephalus, a building of fluid in the fetal brain, and hydronephrosis, a blockage in the urinary tract. These capabilities raise questions about the status of the fetus. If the fetus can be treated, then is it a patient? If it is a patient, must it not be considered a person? And if it can be treated, is it immoral not to treat it? Is it too much, then, to imagine the federal government posting notices and establishing hotlines to ensure that hospitals do not withhold treatment from fetuses and the terminally ill, as was attempted recently for babies born with birth defects?

Professional Values and Ethics

Competing definitions of life and active versus passive euthanasia involve questions of ethics. Health professionals increasingly are coming to the realization that, as philosopher Joseph Fletcher says, “Every advance in medical capabilities is an increase in our moral responsibility.” Ethics is precisely the business of rational, critical reflection about the problems of the professional as a moral agent. The more options and opportunities, the more the professional needs a framework or system of virtues and moral values to guide decision making and relationships with others. Thus, “whether bioethics... should be an area of concern for the social work profession is a moot question, since many practitioners in health care are already confronted with such issues.”

It is generally accepted that social work
sees its major goal as the enhancement of social functioning. In keeping with this objective, the Code of Ethics of the National Association of Social Workers (NASW) tells the association’s members that their “primary responsibility is to clients,” that they “should make every effort to foster maximum self-determination on the part of the clients,” and that they “should promote the general welfare of society.” Although few would argue with these general principles, translating them into practical guidelines for practice is difficult. The dilemmas raised by the use of technology to intervene at the boundaries of life revolve around questions concerning the allocation of scarce resources, changing definitions of personhood, and decisions about when life ends. These questions will be explored in this article, which will also consider the implications that contemporary technological advances in the ability to extend the boundaries of life have for social work’s professional values and ethics. It also examines the practice implications for social workers assisting families and patients as they confront these new dilemmas and the importance of social work involvement in developing and influencing complex policy decisions related to modern medical advances.

Allocation of Resources

Dilemmas faced by those involved in providing heart transplants exemplify the questions of access and distributive justice raised by the new medical technologies. The chief clinical social worker at California’s Stanford University Medical Center has described the criteria used in deciding who gets a heart transplant. The criteria include the seriousness of the cardiac disability, freedom from disease in other organ systems, strong family support, financial resources, a maximum age of approximately 50, and the absence of a history of psychiatric illness or substance abuse.

One can question whether it is rational or fair to restrict transplantation to those who already have the advantages of financial, emotional, and family support. What about the Rawlsian concept of justice, which says that the least advantaged ought to be served first? The utilitarian criteria that base allocation on expected, positive outcomes have already resulted in an underrepresentation of women and minorities in the patient population. Furthermore, the chief social worker at Stanford who reported that facility’s criteria foresees major problems when transplants become more widely available and the number of potential recipients far exceeds the supply of donor hearts. On what theory of distributive justice will allocation decisions then be made?

It is interesting to note that Massachusetts General Hospital in Boston temporarily solved its allocation problem by refusing to initiate a transplant program, citing the extensive resources that would be needed, the impact such a diversion of resources would have on other patients and programs in the hospital, and the still experimental nature of the procedure. As numerous hospitals proceed with transplants, it is unlikely that many major hospitals will be able to stand on the sidelines for long.

Although fetal surgery has not yet developed to the extent that these hard questions of distributive justice arise, success in this new area is likely to lead to similar dilemmas. Although American scientists are continuing to develop technology that will make it increasingly possible to treat fetuses with abnormalities before they are born, this country continues to have one of the highest rates of infant mortality among Western industrialized nations. Will criteria for selecting fetal patients include such factors as family support or financial resources similar to those used in decisions about who should get artificial and transplanted hearts? Perhaps the most basic question, however, concerns the allocation of resources to those who are “defective.” As the technical capacity to intervene before birth develops, the increasing pressure to treat seriously damaged newborns might easily be applied to earlier stages of gestation. How then will decisions be made be-
between the treatable fetus, who nevertheless will remain seriously damaged, and the fetus with potential for “normal” functioning?

Definitions of Personhood

Basic to all values in social work is a belief in the “worth, dignity and uniqueness of all persons as well as their rights and opportunities.” Adherence to this fundamental belief provides a rationale for the very existence of the profession. But what is a person? In arguing for respect for the comatose, Rolston says that “life is present where there are ongoing spontaneous organic functions, even in the absence of mental functions, and such life ought to be given moral respect, although at a level that is reduced from our respect for the full human personality.” Fletcher listed 15 characteristics that define a human being, including minimal intelligence, self-awareness, self-control, a sense of time, a sense of futurity, a sense of the past, the capability to relate to others, concern for others, communication, control of existence, curiosity, change and changeability, balance of rationality and feeling, idiosyncrasy, and neocortical function. How many of us would agree with the inclusion of all 15 of these features? Yet which ones can be excluded, and how and by whom should such decisions be made?

Existing frameworks for defining the beginning of life are challenged by the newly emerging possibility that fetuses will be accorded the status of patients. It seems plausible that the failure to treat a less than perfect fetus might eventually come under existing laws concerning child abuse and neglect. At the other end of life, legal complications have arisen over the issue of brain death: definitions such as Rolston’s suggest that an individual with brain death who has normal vital signs should have all the rights of a person.

Both ethicists and health care professionals demonstrate increasing interest in the impact of new technologies on conceptions of what defines a person. This impact is dramatic. For example, a preliminary investigation suggested that parents who use ultrasound imaging to view the fetus before quickening establish a bond of loyalty toward the fetus that is as strong as the bond generally associated with a later stage of fetal development. As second trimester and even earlier ultrasound examinations become routine in diagnosing and monitoring high-risk pregnancies, parents may experience a shock of recognition that the fetus is a person closely connected to them. As one mother said after viewing the moving fetal form on the ultrasound screen, “I feel that it is human. It belongs to me. I couldn’t have an abortion now.” Contrary to the popular fear that medical intervention may dehumanize the fetal-maternal bond, ultrasound examination may actually increase the value of the fetus to parents who already desire a child.

Just as many centuries of cultural and biological evolution were required before childhood was viewed as a differentiated stage in life, ultrasound and other prenatal technologies may be ushering in the recognition of a new stage of prenatality. This reality is reflected in the following comments of the chief of maternal and fetal medicine at Boston Brigham and Women’s Hospital:

The monitoring of fetal well-being...[is] almost like going to nursery school to watch behavior of three-year olds. Eventually, we may be able to distinguish normative behavior for the fetus...That will help us to identify abnormal fetal development, perhaps early enough to correct the environment or treat the fetus in utero.

Definitions of personhood stand at the center of the current abortion debate in the United States. Questions focus on whether and at what stage a fetus is a person. Frustrated by their unsuccessful attempts to get Congress to adopt legislation that defines when life begins, groups opposed to abortion have created the new crime of “feticide” to push state legislatures to recognize the fetus as an individual. Under feticide laws, any interruption of pregnancy...
other than by legal abortion performed by a physician would be a crime. Many feticide bills are not limited to intentional homicide but cover manslaughter and negligent homicide as well. If negligent or reckless conduct leading to the death of a fetus can be prosecuted as homicide, then a pregnant woman who, for example, consumed too much alcohol, smoked too many cigarettes, or continued living or working around teratogenic chemicals against her doctor’s advice could be charged with manslaughter if the fetus died as a result. In 1973 Roe v. Wade held that, for purposes of Fourteenth Amendment protections against life, liberty, or property, a fetus is not a person. The feticide question obviously conflicts with this premise and asks instead whether abortion is murder.

In contrast, prochoice advocates emphasize the rights of the pregnant woman to make decisions about her own body. The new options of fetal therapy and monitoring only heighten the question of the mother’s autonomy because these are gynecological procedures, and the pregnant woman is a principal party to any therapeutic program physicians wish to pursue. Operating on the fetus also means operating on the woman. Yet surgeons already regard the fetus with a correctable congenital defect as a patient. As ultrasound imaging further strengthens parents’ and health care professionals’ perceptions of the fetus as a person, the possibility of conflict between maternal rights and fetal rights increases.

**Decisions about When Life Ends**

The other side of the question of what defines a person is the question of when life ends. Except perhaps in a religious sense, this issue did not concern people until relatively recently. People’s lives ended when they died, that is, when they stopped breathing and their hearts stopped beating. Life and death were ultimate, self-evident opposites.

With the advent of many new technologies in medicine, however, the distinctions between these opposites have begun to blur. For example, technology now makes it possible to maintain respiration and circulation artificially in persons who are considered “dead” so that their organs can be removed and used to save someone else’s life. Pregnant women considered dead have recently been kept alive long enough to be delivered of live babies. This situation may be summarized by the following observation:

> For almost any life-threatening condition, some intervention can now delay the moment of death... Matters once the province of fate have now become a matter of human choice, a development that has profound ethical and legal implications.

Furthermore, medical technology can enable physicians who believe their responsibility is to sustain life at all costs to do so, irrespective of the patient’s wishes. Even for mentally competent persons, relatives, physicians, hospital administrators, lawyers, and courts often play active and contradictory roles in making treatment decisions that affect the quality of the end of life. As a result, the past several years have seen an attempt to clarify both the definition of death and the rights, duties, and obligations of all those involved in the decision-making process.

Beginning in the mid-1960s, cases of unethical experiments on human subjects in this country provoked public outcry and, eventually, professional and official responses. This led to the creation in 1974 of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. When this commission’s charter expired in 1978, Congress established the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research to study a wider range of bioethical problems in health care. One of the first tasks of this commission was to try to establish a uniform definition of death. In July 1981 the commission reported its conclusion and recommended the adoption of the Uniform Determination of Death Act, which was devel-
oped in collaboration with the American Bar Association, the American Medical Association, and the National Conference of Commissioners on Uniform State Laws. These guidelines provide some structure for decision making, but many problems remain.

Optimal decisions about when death occurs are made when prognoses are certain and accepted by all concerned parties, patients' current or premorbid preferences and their views of the quality of life they wish for have been expressed, and families are in agreement with the patients and health care providers. However, as illustrated by three recent cases reported in the national press, this ideal often is not attained.

In the first case, the physicians and family concurred that continued treatment would be futile, and the incompetent patient previously had made known his preference not to be made into another "Karen Ann Quinlan." He had, however, expressed this wish verbally and not in writing. Because others in the health care system disagreed with the decision of his physicians to stop treatment, the physicians involved in the case were indicted for murder, although the charges were later dropped. In the second situation the patient's wishes were not known, and the institution involved refused the family's request that treatment be withheld. An appellate court's initial upholding of the family's request was later reversed by a higher court. In the third case a hospital refused to discontinue dialysis treatment of a fully competent man who, with his relatives' concurrence, asked that treatment be stopped. Even after two psychiatrists found this patient competent, the hospital went to court to obtain an order requiring him to continue dialysis. After two court hearings at the bedside, treatment was discontinued with an inexplicable urgency that denied his family the opportunity to be present when he died, as both he and they had requested. These dramatic cases made the newspapers, but many like them are occurring all over the country without attendant publicity.

Impact on Social Work Practice

The cases described and the questions they raise pose significant dilemmas for social work. The question of how to "promote the general welfare" in the face of scarce resources is not a new one for social work, but it takes on a new and challenging dimension when it is applied to the gray areas of life itself—to definitions of personhood and decisions about when life ends. These issues strike at the core of the value judgments that must be made in applying the new medical technologies. The NASW Code of Ethics states that the social worker's "primary responsibility is to clients." But who is the client? If society cannot agree on definitions of life, how are social workers to decide to whom their clinical responsibility should be directed?

These ethical dilemmas have important implications for practice. Even as the debate over fundamental assumptions and values rages on, the clinical practitioner must face the current reality of assisting patients and families who are confronted with new and ambiguous choices. If the treatable fetus or the brain-dead individual is defined as a patient, a person, and, therefore, as a client, who then advocates for the needs and rights of the mother or the family as a whole? This is an old practice problem in a new context—balancing the needs of the many individuals involved in a given situation. In the future, strict legal guidelines may dictate whether medical intervention is to be used or withheld and whose rights are to be given priority. For the present, however, parents, spouses, and other family members frequently share these difficult decisions with health professionals.

Unlike the professional who will move on to the next "case," families must consider what it will be like for them if their loved one or their unborn child should live. For example, some patients who emerge from a coma survive with a brain that is very different from before. There may be severe and lasting emotional problems, including an impaired capacity to empathize or self-
reflect, to control one’s emotions, or to plan and organize one’s life. Similarly, those confronted with fetal surgery are faced with the possibility of a damaged child and must decide whether it is better to have a less than perfect child or no child at all. The decisions families must make in these situations are ethical and emotional decisions that will affect them and the patient for the rest of their lives.

The difficulties of such decision making cannot be overemphasized. The recent findings of psychologists who are studying coping and decision making under conditions of uncertainty confirm social workers’ long-standing clinical knowledge of the complex emotional and psychological processes involved in clarifying values and making decisions. Research indicates that decision making in the midst of uncertainty is a highly subjective, complex process and that it is vulnerable to both cognitive and emotional biases. The quality of the procedures used by the decision maker are crucial in determining a satisfactory decision. Janis and Mann described seven procedural criteria that increase the likelihood decision makers will reach conclusions best for them in the long run. These involve the following steps:

1. thoroughly canvassing a wide range of alternative courses of action;
2. surveying the full range of objectives to be fulfilled and the values implicated by the choice;
3. carefully weighing whatever is known about the costs and risks of negative consequences as well as of positive consequences that could flow from each alternative;
4. intensively searching for new information relevant to further evaluation of the alternatives;
5. correctly assimilating and taking account of any new information or expert judgment available, even when the information or judgment does not support the course of action initially preferred;
6. reexamining the positive and negative consequences of all known alternatives, including those originally regarded as unacceptable, before making a final choice;
7. making detailed provisions for implementing or executing the chosen course of action, with special attention to contingency plans that might be required if various known risks were to materialize.

Social workers can utilize these seven criteria as part of a framework. With it, they can assess whether clients are engaging in careful and thoughtful decision making about the ethical dilemmas involved in their situation.

Decision-Making Strategies

Preliminary evidence further suggests that clients who are helped to use clear, specific strategies in arriving at decisions are more likely to reach conclusions that fit their personal values and objectives. Particularly helpful to clinicians have been guidelines for a “decisional balance sheet” approach, which social workers already use for clients involved in genetic decision making and in counseling for unplanned pregnancies. The decisional balance sheet offers a technique for helping clients to consider simultaneously the full range of practical, social, and ethical aspects of their choices. Using this approach, the social worker asks the client to list all the pros and cons of the decision in four main categories:

- **Utilitarian Gains and Losses for Self.** What implications does each option have for personal, utilitarian objectives? The client needs to consider financial cost, the drain on emotional and physical energies, and the loss of time from professional and social activities.
- **Utilitarian Gains and Losses for Significant Others.** What will be the impact on other persons in the client’s social network, particularly other family members? For example, children may be deprived of privacy, face added economic constraints, and have to manage with less of their parents’ time if a new baby or ill parent survives with serious health problems or disabil-
ities that demand specialized medical care. Approval or Disapproval by Significant Others. A question for the client is, “Will my friends and loved ones feel that I made the right choice?” Negative social feedback, including criticism and ridicule, can be powerful sources of postdecisional regret because the influence of reference groups and reference persons is often strong. Unanticipated disapproval by close friends or relatives may even precipitate hasty and ill-considered reversals of earlier decisions.

Approval or Disapproval of Self. Under this category the client brings into direct view those internalized moral standards, ego ideals, and components of self-image that constitute the ethical aspects of the decision. Because individuals often translate values and ethical principles into personal issues of self-esteem and morality, the social worker can help the client consider such questions as, “Will I feel proud or ashamed of myself if I make this choice? Will I be living up to my ideals? Will this decision enable me to become the kind of person I want to be?” Equally important, clients must also be helped to consider if and how their moral principles are influenced by their answers to questions about utilitarian gains and losses and social approval.

Asking people to list the pros and cons under each of the four categories is especially helpful in generating possibilities that might otherwise be overlooked. The completed balance sheet provides the social worker and client with a starting point for examining potential sources of postdecisional regret and weighing the importance of practical, social, and ethical concerns.

Practitioners now have available to them the work of increasing numbers of social work authors who have begun to articulate the dimensions and practice implications of various types of ethical dilemmas and value conflicts. The work of Reamer is significant in this regard because it considers systems of ethical decision making and their use in resolving fundamental issues in the profession. Lewis has demonstrated how the principles that structure programs and justify practice are derived from both knowledge and values. Abramson has explored the frameworks developed in philosophy and in other health care professions to explicate the values addressed by social work's practice principles. These authors and others are beginning to develop a body of literature that should help practitioners clarify for themselves and their clients the value dilemmas generated by advances in medical technology.

Helping families reach decisions that will be best for them is a significant role for social workers involved with difficult questions of extending the boundaries of life. The practice challenges are great. Some families take the utilitarian approach and base their decisions on expected outcomes and consequences. Others base their decisions on firmly held moral principles that are rooted in religious and cultural beliefs. Social workers must be as skilled in assessing these underlying religious and emotional values on which families base decisions as they are in understanding the social, emotional, and environmental situations in which such values exist. Workers need to know how to probe into underlying values, beliefs, and expectations and yet remain sensitive to families’ needs for privacy and self-determination. They must also be adept at sharing the complexities and subtleties of these value systems with other members of treatment teams while maintaining privacy and confidentiality. In sum, social workers have an ethical obligation to provide families with the information and other assistance they need to participate...
most effectively in decisions that involve their practical concerns and ethical values.

Policy Considerations

The present is a time when major policy decisions are being made about the beginning and the end of life. As Congress is attempting to settle the abortion issue with a human life amendment to the Constitution and states struggle with statutes concerning brain death, scientists continue to develop new ways to extend life. Social work has a responsibility to take part in the ongoing debates and to present a point of view that advocates for patients and families. To do so, however, social workers must be clearer as professionals about their own views concerning the allocation of resources and, particularly, issues of access and distributive justice. Should the least advantaged be given priority, or should scarce resources be distributed equally? Social work's values and Code of Ethics demand the equal participation of social workers and others in developing definitions of personhood. If the primary obligation of social workers is to the client, it is essential that workers themselves participate in defining who that client is.

At the local level, social workers can exert their influence by organizing and actively participating in hospital committees designed to develop overall hospital policy concerning ethical issues and in committees that carry responsibility for making recommendations on particular cases. A growing number of teaching hospitals are using philosophers in their day-to-day operations to help their staffs make more informed and ethically sound decisions in situations that affect the life and death of patients. Social workers should be actively involved in communicating with these specialists to influence and be influenced by them. Bioethicists have much to contribute to the conceptualization of ethical dilemmas and the value assumptions that underlie choices. Social workers bring much expertise in assessing which clients are most likely to experience difficulties in making decisions and are experienced in helping clients reach the best personal solutions to difficult dilemmas.

The issues identified in this article clearly represent only a starting point for consideration. Medical technology's rapid advances have placed before society powerful tools for extending the limits of life. As these and other developments emerge, social work faces the challenge of applying its values, knowledge, and skills in careful analyses of the personal and societal implications of these advances, in the development of relevant policies to safeguard the rights and dignity of individuals and families, and in the provision of services to assist people who confront the growing range of difficult choices made possible by these advances. Future research should be directed to developing frameworks for structuring and clarifying the ethical dilemmas evoked by medical technology and to refining practice strategies for addressing these challenges.

About the Authors

Marcia Abramson, Ph.D., is Assistant Professor, School of Social Welfare, Health Sciences Center, State University of New York at Stony Brook. Rita Beck Black, DSW, is Assistant Professor, School of Social Work, Columbia University, New York, New York. An earlier version of this article was presented at the Social Work Section of the Annual Meeting of the American Public Health Association, November 15, 1982, Montreal, Quebec, Canada.

Notes and References

EXTENDING THE BOUNDARIES OF LIFE

173