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ABSTRACT

The field of death and dying has become an important area for the development of both research and clinical technique. Psychologists in increasing numbers work in hospital and hospice settings, and therapists treat terminally ill patients and/or their families. Greater attention is being paid to the needs and rights of these patients and families, especially the rights of privacy, self-determination, and informed consent. This paper raises questions which must be faced in dealing with ethical dilemmas that arise over conflicting rights and needs in the area of informed consent. It also provides a decision-making model for working through such dilemmas. The model presented contains the five stages of recognizing the conflict, structuring the conflict, deciding on an action after considering all the alternatives and their implications, carrying out the decision or action, and assessing the results. The model is used in an analysis of the ethical dilemma involved in the dying patient's right to give informed consent. Procedures used by a hospice team are discussed as a sample of the decision-making process. (Thirty-five references are listed.) (Author/NB)

A Framework for Ethical Decision-Making with Dying Patients

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Abstract

The field of death and dying has become an important area for the development of both research and clinical technique. Psychologists in increasing numbers work in hospital and hospice settings, and therapist treat terminally ill patients and/or their families. Greater attention is being paid to the needs and rights of these patients and families, especially rights of privacy, self-determination, and informed consent. This paper raises questions which must be faced in dealing with ethical dilemmas that arise over conflicting rights and needs, in the area of informed consent. It also provides a decision making model for working through such dilemmas.

A Framework for Ethical Decision Making With Dying Patients

Many psychologists are faced with the problem of helping patients, families and/or medical institutions make decisions about living or dying. In this process, there are ethical issues which need to be addressed, such as the patient's right to privacy, right to receive accurate and complete information, the right to treatment and the right to refuse treatment, the right to give informed consent.

Respect for the integrity, privacy and autonomy of clients are basic tenets of the profession of psychology, as codified in APA's Ethical Principles (American Psychologist, 1981). Psychologists also implicitly subscribe to the principles of nonmaleficience (do no harm) and beneficience (do good) rooted in the medical profession (Fitting, 1984; Kitchner, 1984). However, situations in applied settings, such as terminal illness, are frequently ambiguous. In ambiguous circumstances, some of these principles may appear to conflict. Ethical problems can arise from (1) conflicting loyalties who is the client: the patient, the family, the institution, society? (2) lack of knowledge or skills needed for work with special populations (3) the intrusion of the psychologist's own attitudes and values into assessment and treatment (4) failure to provide clients with full and accurate information (5) failure to assume an activist stance to protect clients from abuse of authority (Goodyear & Sennett, 1984).

In exploring these problems in the context of terminal illness, it seems appropriate to turn to the Hospice movement. More than 1300 Hospice programs provide service to dying patients and their families (Guide to the Nation's Hospices, 1984). Several authors (Vanden Bos, G., DeLeon, P., and Pollak, M., 1982; Randolph, J., 1982; Butterfield-Picard, H. and Magno, J., 1982; Smyser, A., 1982; Aiken, L. and Marx, M., 1982) have already attested to the work of the Hospice movement. Each program is run by a team of professionals who offer physical, emotional, spiritual and practical help. The Hospice philosophy of care is based on assuming the role of patient advocate. That role often leads to conflict with hospital policies, with physician treatment plans and with family anxieties. Thus Hospice, as a movement, has much experience with resolving conflicts of interest to psychologists.

Moreover, psychologists are becoming increasingly involved as members of Hospice teams (Klipper & DeJoy, 1984). Liss-Levinson (1982) described the role of the psychologist on the team, while Klagsburn (1982) discussed the specialties that might be utilized, such as life span development, research in death and dying, family process, and clinical skills.

The present report focuses on decisions relevant to professional psychologists working on a Hospice team as well as the practitioner in private practice or in an institutional or agency setting. The paper will draw upon the experience of the first author, who worked as a member of a Hospice team for over 5 years and has helped staff members work through many ethical dilemmas.

A conceptual framework for ethical decision making will be provided. A typical dilemma will be presented, and the framework used to elaborate the dilemma.

An Ethical Decision Making Model

Several models of decision making have been proposed over the years (Dewey, 1933; Janis & Mann, 1977: Evans & Cody, 1969; Horan, 1979). In addition, models of ethical decision making have been developed (Aroskar, 1980; Ryden, 1978, Van Hoose & Kotler, 1982). Horan (1979) states that most stage theories of decision making are directly comparable, although there may be differences in emphasis and minor variations. The model used here has five stages which are: (1) Recognizing the conflict, i.e. asking what is the cause of the dilemma? What are my feelings about it? (2) Structuring the conflict which may involve gathering information, discussing the conflict and determining who is involved or affected by this dilemma (3) Deciding on an action after considering all the alternatives and their implications (4) Carrying out the decision or action, and (5) Assessing the results. The model emphasizes attention to the psychologist's personal feelings throughout the stages.

The following sections will analyze, in terms of this model, the ethical dilemma involved in the dying patient's right to give informed consent. In the past, the benefits vs. burdens framework (Gilmore, 1976) has been applied to medical decision making with terminal patients. However, it has become increasingly difficult to find agreement in the medical and psychological community as to what constitutes a benefit or a burden. This, in itself, has been a source of conflict. Therefore, while it may be a useful concept to keep in mind, the model presented here provides a more complete framework to apply to ethical decision making.

Recognizing the Conflict

Informed consent cannot be given without honest and complete information. A conflict often arises when a patient asks for information about his/her diagnosis, prognosis or treatment, and the family is opposed to the patient having that information. The physician, sometimes pressured by the family, does not tell the patient the potential risks, side effects, likelihood of benefit etc. because the patient might then decide not to give his/her 'informed' consent.

The psychologist, aware of this deception, may feel strong allegiance to the patient, the primary client, based on principles of trust, loyalty and client autonomy. Yet, considering one's desire to also promote client welfare, the question arises: Is the client best served by having all of the information? In addition, if the psychologist overrides the wishes of the family members, they may be forced to live with an unwanted decision long after the patient dies, complicating their bereavement. How can the needs of patient and family best be served?

Structuring the Conflict

In this part of the process, information is gathered, participants to the conflict noted, and discussion ensues in which positions are outlined. Since this report will deal mainly with the conflict in general rather than applied to a specific patient or family, the discussion here will be confined to delineating the dilemma.

In gathering information, it is helpful to look at religious, medical and legal issues surrounding this dilemma.

Until recently, most major western religions asserted that life was sacred and should be prolonged as long as possible by every means available. However, The Journal of Medical Ethics in 1981 reported that the Roman Catholic Church as well as the Church of England have stated that it is no longer necessary or proper to keep people alive if that requires extraordinary means. They defined 'extraordinary means' as "excessive expense, excessive pain, excessive difficulty and no reasonable or 'proportionate' hope of benefit to the patient" (Gillon, 1981, p. 55).

For physicians, a dilemma often results from competing values. The decision requires letting go of one value (e.g. the protection of human life) to realize another (e.g. the relief from human suffering). Other information may be part of the decision process. Sometimes cancer, even hopelessly advanced cancer, stops growing for no apparent reason. Shouldn't this patient have that chance? Only by working on impossible cases can medical advances sometimes be made. Could others benefit from this patient's suffering? Who should decide that? Each time the physician is unable to satisfy competing values in the necessary compromise, he/she has an ethical dilemma (Purtillo, 1980).

The doctrine of informed consent has a long history in the courts. Currently, the concept rests on a Washington D. C. case, Canterbury vs. Jones, of 1972, which requires that information be given to patients about the diagnosis, nature and purpose of a proposed treatment, risks and likely consequences, probability of success, reasonable treatment alternatives and the prognosis if no treatment is given at all (Cassileth & Cassileth, 1982, p. 173). Duty of disclosure is subject to two exceptions: (1) if the patient indicated a preference not to be informed or (2) if the provider believes, in the exercise of sound medical judgment, that the patient is so anxiety-prone or disturbed that the information would not be processed rationally or that it would probably cause significant psychological harm. However, the facts supporting this decision need to be carefully documented. The court very clearly stated that one could not evoke 'therapeutic privilege' merely because disclosure might lead the patient to refuse treatment (Cassileth & Cassileth, 1982, p. 174).

In applying this to the dying patient, the law is not clear. Only ten states have right-to-die laws, yet no court has interfered with the choice of competent adult patients to refuse 'heroic' measures, when death was imminent. No physician has ever been held liable for following the patients wishes to discontinue treatment. Moreover, when an adult patient is no longer competent, but has left clear instructions as to his/her intent not to be put on artificial life-support systems, courts have upheld that intent. This is particularly true when a document such as a Living Will has been signed (Concern for Dying Newsletter, 1979).

Even our political system has entered the arena of biomedical ethics. In 1983, President Reagan established the Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The commission consists of ethicists, lawyers, doctors, theologians, and academicians. The commission has argued that informed consent, and collaboration between patient and provider, are essential in promoting the best interests of the patient. Further, the commission suggests that the risk of wrongly cutting off the decision making process for many patients is worse than the risk of confronting some seriously ill patients with choices they might prefer not to face.

After reviewing the religious, medical, and legal aspects of this dilemma, it is pertinent to turn to the persons most closely involved, the patient and family, and ask three key questions. Does the patient really want to know? Is the patient capable of understanding and accepting the consequences of discontinuing treatment? What is the family afraid of?

In trying to determine whether or not the patient really wants to know, the psychologist may be influenced by decades of the medical policy which assumed that patients did not want to be told the truth (Gillon, 1982). However, recent research indicates that well over 90% of patients and the public at large say they want to be told the truth (Blumenfield, Levy & Kaufman, 1978; Carey & Posavac, 1978; Weingarten, 1981). Erickson, (1974) noted that in a group of studies conducted by Herman Feifel in 1963. 69-90% of the physicians favored not telling, while 77-89% of patients wanted to know. This seems to be an issue of paternalism vs. 'consumerism' (Ladd, 1980).

How can one tell if a particular individual patient does or does not want to know the truth? In judicious interviewing of patients, it may be possible to discern whether or not they really want more information (Hinton, 1974). If they are gently invited to obtain such information, and do not grasp the opportunity, or if they plainly state that they don't want to know any more, that choice must be respected. It is the right to choose that the psychologist should uphold. Research findings suggest that patients generally want honest information (Blumenfield, Levy, & Kaufman, 1978; Carey & Posavac, 1978; Weingarten, 1981; Erickson, 1974), but if there is evidence to the contrary, the psychologist should not force information on anyone.

Based on the first author's experience in working with dying patients, many patterns of response may occur once the patient has been fully informed. A desire to continue treatment may be expressed. Some patients hope for a miracle, others find every minute of life precious, still others view themselves as 'fighters' and must take action consonant with that self image. This desire to continue treatment is most often compatible with wishes of family members and physician, and proceeds unhindered. More often, a patient will ask that treatment be stopped or, in some cases, never begun. Such a patient usually claims that pain, suffering, incapacities and indignities are more burden than benefit. Rather than prolong such burdens, the patient wants just to be kept as comfortable as possible, amid familiar surroundings, until death.

The psychologist must carefully explore the choice to stop treatment. Does this wish represent a temporary depression in reaction to pain or another symptom that might be relieved if effectively treated? Is this a symbolic gesture on the part of the patient, i.e. a bid for control, for attention? Is this wish based on fears of treatment due to misperceptions or misinformation? Is the patient sure of this choice or is there some ambivalence to be explored? (Younger & Jackson, 1980). If adequate dialogue is not established, a caregiver, i.e. family member, physician, Hospice nurse, psychologist, etc., may not hear the patient's wishes but be responding to their own value system, or to countertransference issues. One must be sure that the patient's intent is clear.

And what if the patient can no longer make his/her wishes known? In a situation where a patient can no longer speak or otherwise convey intent, one must inquire about wishes expressed prior to illness. Did the patient talk to the physician or family about what he/she would want in such a situation? Did the patient sign a Living Will? (Concern for Dying Newsletter, 1979). If such intent has been previously expressed, it is possible to ascertain the wishes of a patient no longer conscious or otherwise capable. Otherwise, the closest family members, the next of kin, are asked to express the patient's intent. It is important to underscore that last phrase, for such family members are not asked to make a decision based on their own values or needs, but as representatives of the wishes of the patient (Concern for Dying Newsletter, 1979).

In January 1985, for example, the New Jersey Supreme Court, in a most far reaching decision, ruled that "all life sustaining medical treatment, including feeding tubes, can be withheld or withdrawn from incompetent as well as competent terminally ill patients provided that is what the patient wants or would want." (Sullivan, 1985, p. 1). In the case of incompetent patients, two tests need to be applied before treatment can be withdrawn. (1) An effort must be made to determine what the patient expressed about this issue while competent. (2) If no evidence is available, a benefits-burdens test should be applied by physician and family.

The third key question to be explored is: What is the family afraid of? In order to answer this the psychologist needs to learn about the family's previous pattern of coping with adversity, as well as its degree of flexibility. Cassileth & Cassileth (1982, p. 121) ask: What support systems exist? What is each family member's relationship with the patient? How does each family member conceptualize the patient's impending death? How will family roles change when the patient dies? How has the family resolved conflict in the past? How do family members deal with anger, aggression, hostility? The psychologist's can assess the meaning of the patient's death to the family system in light of these questions. Through such exploration, it may be possible to allay the family's fears.

Weingarten (1981) surveyed 48 normal, healthy adults about how information should be communicated when a terminal illness is first diagnosed. The overwhelming majority thought a patient should be told, but one-half were reluctant to do the telling. Of these, 98% gave as the reason for their unwillingness, a belief that psychological factors can influence or even cause death. This implied a fear that they might hasten or even cause the death of their loved one being the bearer of bad news. Of those who believed a patient should not be told, 88% were from families in which death was not openly discussed. Thus, early experience of closed communication in families of origin might contribute to an individual's anxiety about speaking openly about the illness.

Many who say 'Don't tell my wife, she couldn't take it' are really feeling underneath those words, 'Don't tell my wife, I couldn't take it.' Family members may be afraid that if they openly discuss the diagnosis or prognosis with a loved one, they will break down and lose self control. In addition, admitting to the patient that the illness is terminal means that they must first admit it to themselves. Denial is a very powerful coping mechanism, for family as well as for patient, and as such may be used to distance from the patient and from the pain of having to lose such an important person (Lebow, 1976).

The family must also be assessed for alliances, communication styles and concurrent problems. Is there a lack of communication between the family and the patient which reinforces the denial and isolation of either or both? Are they acting out of guilt for perceived past misdeeds or present neglect? Can family members distinguish their own needs from those of the patient? Are they avoiding other problems by concentrating on taking care of this dying patient? Can they be helped to 'let go'?

If the psychologist can help the family to work through some of these concerns and anxieties, the issue may be resolved amicably. If the dialogue is completed, and the patient's refusal to give informed consent to further treatment remains firm, there is always time to withdraw life supports or other active treatment.

Implications and consequences of each alternative could be positive or negative with respect to the first choice, helping the patient's wishes to prevail, the possible positive outcomes are (1) the patient will feel more in control of his/her own destiny, (2) the patient will be relieved of further prolonged pain and suffering, (3) the family will be saved huge medical bills from additional active treatment, (4) the family will be grateful for the move, relieved that the decision was made, even when not by them, (5) patient and family can emerge from the web of lies that isolated each from the other, and perhaps enjoy intimate sharing in the days that remain, (6) the family will emerge emotionally stronger for having learned to 'let go' and having dealt more realistically with the impending death, (7) the family will feel better that they gave their loved one the death she/he wanted, (8) business affairs can be settled. A lack of accurate information often leads to postponing the settlement of legal and financial matters, which can bring disastrous consequences, (9) the psychologist may feel personal integrity in following his/her own values and acting as patient advocate.

Possible negative consequences might be (1) the patient will become very depressed upon learning that further treatment is useless and never 'snap out of it'. While certainly a possibility, this is by no means the inevitable result feared by anxious family members. (2) the family may feel guilty about not exhausting all treatment possibilities. They may need further professional help to cope with their bereavement. (3) the family and/or physician may resent what they view as outside interference, and publicly criticize or refuse to refer again to Hospice, the agency or the psychologist. Thus, the agency or professional may suffer in terms of reputation and/or economics.

As for the second alternative, saying nothing, potential positive outcomes might be (1) the patient will remain hopeful until death, and have a better quality of life (2) the family will feel satisfied that they left no stone unturned in trying to save the patient (3) the physician will continue to treat and there is a remote possibility that the patient will get better (4) there will be a spontaneous remission and the patient will have weeks or months more of good quality life. Possible negative consequences could include (1) the patient will suffer longer physically, not only from the illness itself, but also from the side effects of the treatment, (2). the patient will feel more anguish and anger at being kept alive and in some cases, deceived about his/her prognosis (3) the patient will feel more isolated having to keep up a hopeful front for the family (4) the family will incur extra medical bills that may take years to pay (5) the family will not do any anticipatory grieving because their own denial is so strong, and thus have a harder time afterwards

(6) the psychologist will feel frustrated and ineffective when incapable of acting on professional values and serving as patient advocate.

With regard to the third alternative, withdrawing from the case, all potential outcomes listed under the second alternative apply. Other potential negative outcomes would be that (1) the family and patient might feel abandoned by the psychologist and/or Hospice (2) they would no longer have the support services badly needed to ease the dying process (3) the physician might react negatively to the withdrawal of service, and there could be political and/or financial repercussions.

In the hospice setting, the team explores the implications of all these alternatives at a staff meeting. Each member of the team who has seen the patient and/or family presents his/her observations and feelings. In the experience of the first author, the decision of the Hospice team has been almost always to choose the first alternative, supporting the patient's choice, occasionally the second allowing family wishes to prevail and almost never, the third withdrawing from the case. In the end, Hospice stands on the principle of patient autonomy and the preservation of its own integrity, essential to preventing burnout in a highly stressful field.

Psychologists making these decisions on their own, will need to weigh all three alternatives in terms of ethical priorities, prior experiences and the current circumstances of the individual case. If the third alternative, withdrawal, is chosen, appropriate referrals should be made to other health care professionals and community resources, such as Hospice.

Carrying out the Action

Several members of the team are often involved in carrying out this decision in the hospice setting. The nurse will often explain the patient's rights to both patient and family, questioning the benefits of treatment taken thus far. The nurse may also contact the physician and question him/her closely on the same benefits vs. burdens theme. The psychologist has the main role in assessing the family's coping and communication patterns, and in trying to ease their anxiety and allow the patient to make the decision. In the end, professionals can only offer information and support to both patient and family, who will decide whether the patient should continue or stop treatment, probably in much the same way that decisions are usually made in that family system. In the experience of the Hospice team, the most powerful person prevails.

Assessment of the Decision

Supporting the patient has worked out well in the overwhelming majority of cases decided by a Hospice team, in the experience of the first author. The patient gets his/her wish; the family is ultimately relieved. The patient who has refused consent to treatment almost always means business, and doesn't get depressed at the cessation of treatment. More often, she/he is relieved in situations where Hospice team members have told the patient without the family's permission, or coached the patient to ask for more information from their family and physician, there have been surprisingly few repercussions. Perhaps this is because on some level family members know that deception is futile, and somehow, when this is brought to the surface, it gives them permission to acknowledge, and sometimes even accept, the inevitable result. In some cases, a chaplain has been useful to the patient and/or family concerned about religious interdictions against cessation of treatment. A sensitive chaplain may be able to absolve guilt and bring spiritual peace and should be considered an appropriate resource for the psychologist working with such families.

This decision making process has been informed by the experience of the first author in one Hospice setting. Hospice in

America is about 10 years old and there has been little hard data to support the ideas of personal experience presented here. It is difficult to conduct empirical research with the dying. What constitutes patient satisfaction or a family member's healthy mourning is both hard to define and difficult to ascertain without adding to the burden of a family already under stress.

Conclusion

Helping patients and their families through the dying process requires sensitivity and honesty. The aim is to get everyone together to determine the patient's wishes. This is a difficult undertaking when a family is devastated. The skills of the psychologist are crucial. Dialogue takes place and the truth emerges.

This paper has explored facts of the decision making process with respect to the right of informed consent to treatment for terminally ill patients. A conceptual model for decision making has been presented. Emphasis has been placed on awareness of ethical dilemmas and key questions to be asked in structuring the conflict. Procedures utilized by a Hospice Team have been offered as a sample of the process.

The setting for decision making is crucial. In Hospice programs, team support and joint decision-making, operating under the philosophy of patient advocacy, make it possible for the psychologist to maintain personal integrity and live with the consequences of ethical choices. Psychologists in other settings must develop a support network from among supervisors and colleagues, and professionals in other areas. Referring to questions such as those raised in this paper may provide a helpful framework for resolving ethical conflicts.

For all health care professionals, serving the dying and protecting their rights will continue to be a complex and challenging task.

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