

THE TERMINAL PATIENT'S RIGHT TO KNOW: PSYCHOLOGICAL, ETHICAL AND JUDAIC PERSPECTIVES

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Psychological assumptions about human behavior are central to . . . the question of disclosure to terminal patients by physicians, nurses, mental health professionals, philosophers, theologians and legal scholars. In addition to the clarification of theoretical aspects of the issues, further empirical research on the reaction of patients and other concerned parties to disclosure and to non-disclosure is necessary if we wish to make ethical choices and decisions that will be based upon more accurate knowledge of actual human behavior rather than upon speculative assumptions and generalizations about such behavior.

There are many ethical, psychological and religious issues relevant to the care and treatment of the terminally ill and the process of dying. Among these are the proper use of technology in prolonging life, the merits of hospice care, voluntary and involuntary euthanasia, rational suicide and the very definition of death.

This paper, however, confines itself to a series of questions that relate to one limited, though important aspect of the way in which to relate to individuals with terminal illness. Under what circumstances should a patient who has been diagnosed as having a terminal illness—in other words, an illness for which there is a prognosis of death within months or perhaps a year, with virtually no hope for recovery according to current medical knowledge—be informed of his objective medical condition and prognosis?

What considerations need to be taken into account by the physician, the family and other interested parties in deciding whether or not to inform the patient? Who should be involved in the decision as to whether, when and how to inform? Who should do the informing?

Is it possible to formulate any guidelines for deciding when to disclose and

when not to do so, that will hold as a general rule, allowing for isolated exceptions? Or should the only rule be that each individual case is unique and must be decided on an individual, situational basis without reference to or acceptance of any general rule?

SHIFT IN PHYSICIANS' ATTITUDES AND PRACTICE

Up until about twenty-five years ago most doctors felt that, generally speaking, terminal patients should not be informed of their condition, and this feeling guided prevailing medical practice. However, more recent empirical studies of physicians' attitudes and behavior indicate a dramatic shift in their approach to this issue.

Let us consider, for example, a summary of the findings of a study regarding disclosure in which forty-five physicians were asked the following series of questions.¹

1. Raymond G. Carey and Emil J. Posavac, "Attitudes of Physicians on Disclosing Information to and Maintaining Life for Terminal Patients," *Omega*, Vol. 9, No. 1 (1978-79), pp. 67-77.

1. If terminal patients request the information, do you feel they have an **unqualified** right to know the truth about their terminal conditions?

Yes 87%

2. Should a physician ever delegate the responsibility of informing the patient of his (her) terminal condition?

Never 49%
Rarely 51%
Frequently 0%

3. What factors should ordinarily determine whether or not a patient is told of his (her) terminal condition?

Percent responding "yes" to each item

Youth	44
Advanced Age	31
Length of life expectancy	29
Emotional stability	71
Depth of religious faith	13
Emotional support from family	33

4. As a general rule the physician should:

a. give complete and honest information regarding the terminal condition without waiting for the patient to ask.

29%

b. take the initiative in revealing the terminal condition, but then only answer very specific questions the terminal patient asks.

42%

c. answer completely and honestly the specific questions the terminal patient asks, but not take the initiative in revealing the terminal condition.

27%

d. answer the patient's questions only to the extent the physician feels it is appropriate.

2%

5. Should a physician ever tell a patient about his (her) terminal condition against the wishes of the patient's spouse?

Yes 84%

In this sample of physicians 71% would inform a patient of his/her terminal condition without being asked (4a and 4b.) and an additional 2.7% upon being asked by the patient would inform him. This study used a fairly small sample of physicians (45). However other relatively recent studies support the finding that in current medical practice the predominant physician attitude is in favor of disclosure.

Why have doctor's attitudes and behavior shifted so dramatically in the past three decades? At least five reasons could be suggested.

1. Physicians have come to accept the arguments in favor of disclosure as more compelling than the arguments against it.

2. Patient attitudes towards disclosure, in the direction of favoring it, have affected physician attitudes.

3. The general trend in medical care towards providing patients with more information about their treatment and increasing their rights has carried over to this issue.

4. Advances in medical intervention procedures that are life-prolonging and require patient consent for their use necessitates disclosure.

5. Fear of legal consequences of failure to disclose. If a patient is not fully informed regarding his condition, then his consent or lack of consent to certain procedures might not be considered by the law to be "informed consent."

What are the attitudes of patients and of healthy individuals on this question? Here the data are strikingly emphatic. Studies of both patient and non-patient populations indicate that the vast majority of both want to be informed if they have a fatal illness.

For example, in the late 1970's, the Gallup Poll surveyed a national sample of 1,518 adults, eighteen or older, of which number 90% answered "yes" to the following question:

"If you had a fatal illness, would you want to be told about it or not?"²

ARGUMENTS AGAINST DISCLOSURE

One may well ask why it is important to understand the arguments against disclosure if now both physicians and patients favor it. Several reasons can be offered.

First—the arguments are of intrinsic interest, ethically, psychologically, medically and religiously.

Second—perhaps attitudes will shift once again, against disclosure, and it is important to understand what rationales might be presented to argue in favor of such a view.

Third—among physicians, patients and healthy individuals there presently exists a minority against disclosure and it is important and proper to appreciate their views.

Fourth—as we shall soon see, the position of Jewish tradition corresponds most closely with physicians' views of twenty-five years ago that patients should not be informed of a terminal diagnosis except in exceptional circumstances. Professionals working in Jewish sponsored hospitals or in Israel should be familiar with the rationale of the position taken by Jewish tradition whether or not they or their Jewish patients personally agree with that position.

The following are the major general arguments that have been presented against telling the truth to patients about a terminal diagnosis and prognosis.

1. The primary responsibility of the physician is to his individual patient (and not to the patient's family or others affected by his condition) and his duty is to do whatever he can to preserve life and to cause no harm to the patient. Any action that contributes to these two responsibilities of the physician supercedes the moral virtue of speaking the truth and not lying. Informing a patient of his terminal condition will generate several forms of psychological suffering, particularly depression, anxiety and loss of hope for recovery.

2. These psychological reactions can have somatic consequences that might accelerate death and thus are counter to the goals of prolongation of life and avoidance of harm.

3. The psychological reactions might induce suicide attempts.

4. Knowledge of the condition might induce the patient to refuse to cooperate in certain medical treatments that may extend his life somewhat.

5. No physician can be certain that an illness is terminal. There is always a possibility of and hope for recovery, particularly considering the vast research enterprise and rapid communication network of our society. Therefore, the very concept of a prognosis of "terminality" is not valid.

TRADITIONAL JEWISH ATTITUDES TOWARD DISCLOSURE

Jewish religious literature adds that loss of hope may result in the feeling that prayer is no longer worthwhile—that prayers for recovery are prayers in vain since they appeal to God to undo that which is naturally irrevocable. Although Jewish theology maintains that some prayers are indeed "vain" and hence improper, it does not consider this to be the case for the prayer for recovery of an individual whose known chances of recovery are almost nil. From the perspective of the religious tradition, prayer in this, as in general, is not

2. Michael Blumenfield, Norman B. Levy and Diane Kaufman, "The Wish to be Informed of a Fatal Illness," *Omega*, Vol. 9, No. 4 (1978-79), pp. 323-326.

only psychologically sustaining and consoling, but in some instances is efficacious as well. Therefore, nothing should be done to discourage it and disclosure of the truth might have such a discouraging effect.

According to a paper interpreting the Jewish traditional position, concern about hastening the death of a few patients overrides other interests of the majority of patients.

The five stages of dying, culminating in the ultimate acceptance of death without adverse physical effects, as described by Kubler-Ross, may well have been manifested by the subjects of those studies and by countless others as well. However, no universal generalization may be drawn with regard to the reactions of all patients. . .

The devastation experienced by some patients and their consequent loss of a desire to live is a repeatedly observed phenomenon. The physical effects of such psychological phenomena do not readily lend themselves to clinical analysis.

The possibility of adverse reaction is sufficient reason for eschewing a policy of full disclosure. Jewish law is concerned with the foreshortening of even a single human life. Accordingly, in this, as in other areas of *Halakhab* (Jewish Law), the possibility of hastening death in at least some patients must be the determining consideration.³

The stringency with which this position is maintained in contemporary Jewish legal literature is reflected in some of the specific directives summarized in an article that appeared in the Israeli journal *Assia* by Rabbi Shlomo Aviner.

1. Care should be taken not to inform any relative of the patient if the relative might break down and thus cause anguish to the patient.

2. Even where a father or mother explicitly commanded their child to inform them of the medical diagnosis and prog-

nosis, the child should not do so (in other words, the very significant religious obligation of honoring one's parents by obeying their requests is set aside in this case).

3. Even where the patient suspects that he has a terminal illness, it is forbidden to inform him.

4. The physician should assure the patient that he will live and prescribe treatments that will intensify the patient's belief in his eventual recovery.

5. One should not place one's trust in doctors but in God.

The only explicit exception to the policy of non-disclosure that Rabbi Aviner includes in his summary is that where a patient is suffering greatly and is hoping to die, it is permissible to tell him that he will soon die and be released from his pain.⁴

All of the above arguments against truth-telling are formulated explicitly by their proponents and are appeals to reason. It is of course, quite possible, that certain emotional or unconscious motives account for the opposition to disclosure by some physicians and rabbis.

At least three come to mind immediately. For the physician there might be the difficulty of acknowledging his "failure" to heal or extend life. There is also the desire to avoid the pain of confronting the patient with the harsh reality and the unpleasant reactions it might evoke. And there is also the desire to avoid "unpleasant" scenes with members of the patient's family. For better or for worse, most doctors are not trained to be social workers, psychologists or hospital chaplains.

ARGUMENTS FOR DISCLOSURE

1. The duty of being truthful is unconditional. This is an ethical approach derived from Kantian ethics.

3. J. David Bleich, *Judaism and Healing: Halakhic Perspectives*. New York: Krav, 1981, pp. 27-33.

4. Shlomo Aviner, "Ha'amadat Holeh al Matzavo," *Assia*, January 1978, pp. 39-43.

2. There are negative consequences of not telling the truth that outweigh the positive consequences. This is an ethical approach derived from utilitarian ethics. At least five negative consequences have been suggested in the literature:

1. lack of knowledge about one's medical condition produces anxiety that may be greater than the anxiety engendered by knowing of one's terminal condition.

2. faithful participation in treatment which may extend life for several months will occur more readily when the patient is fully aware of the seriousness of the diagnosis and the prognosis.

Notice that both of these arguments are exactly the opposite of arguments that were put forth to defend non-disclosure. It is, of course, possible that both sides are partially correct. Individual and situational factors will determine patient reaction, and such reaction will vary across patients.

Empirical research that would generate more and more sophisticated data on factors determining patient reaction to disclosure and non-disclosure would be useful in guiding policy-making on this issue. To what extent Jewish legalists would be willing to modify their rather strict rulings on the basis of empirically derived psychological predictions of patient reaction, were they to contradict the psychological assumptions of Jewish law that are rooted in sacred, authoritative texts, is an open question.

3. lack of knowledge can do serious harm to the economic interests of the patient and of his family.

4. patients may want to prepare wills, effect reconciliations with family members or other people and take care of other matters of personal importance to them before they die. Since they generally won't do these things if they don't feel that death is impending, by not informing

them of their true condition, we are depriving them of an opportunity to do something that is of great importance to them.

Jewish tradition, aware of these two arguments, and of the importance to it of an individual's confessing his sins and effecting a reconciliation with God before his death, formulated a policy which attempts to encourage the patient to do the above but without informing him of his true condition. I am not aware of any data on how effective this policy actually was, historically, or is, today.

5. a policy of not telling the truth may have the long-range, negative impact of contributing to a state of mistrust between doctors and patients which in the long run is detrimental to both the medical profession and to patients. Patients won't believe the truth when they are told that their condition is not life-threatening.

In the long run this will produce more anxiety for more patients. As the ethicist Henry Sidgwick wrote many years ago:

Where deception is designed to benefit the person deceived, Common Sense seems to concede that it may sometimes be right: for example, most persons would not hesitate to speak falsely to an invalid, if this seemed the only way of concealing facts that might produce a dangerous shock. But if the lawfulness of benevolent deception in any case be admitted, I do not see how we can decide when and how far it is admissible, except by considerations of expediency; that is by weighing the gain of any particular deception against the imperilment of mutual confidence involved in all violations of truth.⁵

Three additional arguments have been put forward against a policy of non-disclosure.

6. failure to disclose forces unnatural behavior on physician, hospital staff and family, since they cannot relate to the pa-

5. Henry Sidgwick, *The Methods of Ethics*. New York: Dover, 1966, p. 319.

tient honestly, and openly express their true feelings for him or her.

7. to deprive people of information about their health is to deprive them of freedom to make responsible choices about their lives and to prevent them from exercising as much control over their lives as is feasible in their situation.

8. physicians are not particularly or uniquely adept at making psychological analyses and predictions about how patients will react to disclosure. Therefore, it is wrong for them to rely on their own, often erroneous, intuitive judgments. They should be bound by a general rule in favor of disclosure, based upon the previous arguments.

Given the generally heavy demands made on physicians' time and energy, it is reasonable to assume that many of them do not have the time, interest, information and skill to get to know their patients sufficiently intimately such that they can predict their reactions to disclosure with a high degree of accuracy.

A perceptive, sensitive and thoughtful book by two sociologists, Glaser and Strauss, titled *Awareness of Dying*, describes the following range of reactions to disclosure based upon their hospital observations.

Glaser and Strauss's own conclusion regarding disclosure is:

Once again, the benefits and liabilities of unawareness (nondisclosure), as opposed to

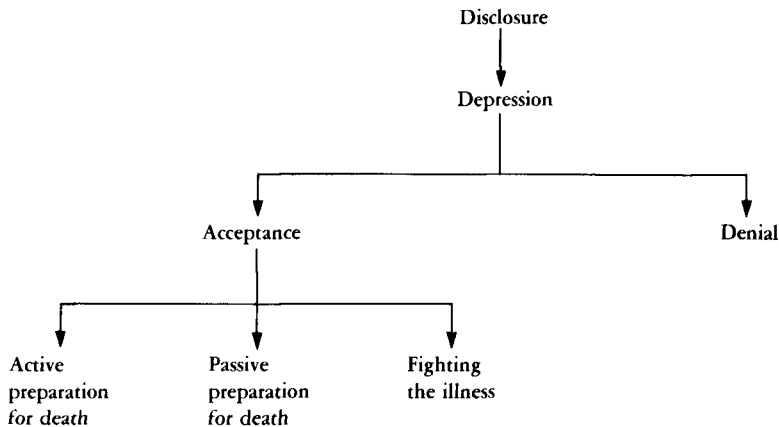
disclosure and its possibilities for acceptance or denial, depend on the nature of the individual case. But on the whole, there is much to recommend giving the patient an opportunity actively to manage his own dying.

As a strong controlling factor, staff members who interact with the patient could consciously soften the disclosure, handle the depression so as to encourage acceptance, and guide the patient into active preparations for death . . . readily ascertainable and unambiguous general criteria are needed for deciding when to disclose terminality and when to keep the patient unaware of it. Criteria that require "intimate knowledge of each patient" offer no better a solution to the doctor's dilemma than does a universally applied rule of telling or not telling.⁶

With respect to the question of who should decide whether or not to inform a patient of his condition, the Christian ethicist Arthur Dyck reports the following incident and comments on it:

Consider the following case: a man is seriously ill, so ill there is a high probability that he may die. The physician does not convey this to the patient nor does he inform the man's minister of this diagnosis. A nurse, however, connected with the case takes it upon herself to tell the man's

6. Barney G. Glaser and Anselm L. Strauss, *Awareness of Dying*. Hawthorne, New York: Aldine, 1965, p. 319.



minister before he sees the patient of precisely how serious the man's illness is judged to be. The minister, with some trepidation, but with firm resolve, decides to share this information with the patient.

When this incident was reported to a class of graduate students in religion, some of whom were training for the ministry and some of whom were obtaining higher degrees specializing in ethics, there was considerable criticism of the minister's action.

Many felt that the minister should not have taken this upon himself without consultation with the doctor. Indeed some felt strongly that the minister must have the attending physician's consent to talk to the patient about dying.

The minister in this instance disagreed sharply. He viewed the man who was in danger of dying as one who was not only paying the physician to carry out whatever duties were incumbent upon him as a physician, but as one who was also paying the minister to carry out his duties. . . . A lawyer or a friend or a relative concerned about whether a proper will has been made out, a minister concerned about whether persons have achieved a proper attitude toward their own limited powers as human beings, a nurse concerned with the anxieties of patients who want to know, all raise important considerations about what is beneficial for patients.

If physicians are the only ones who know that a given person is dying, the power of what is best for the patient in the light of what fact resides totally with him or her. Is this the way it ought to be?

Finally, with respect to the question of who should be the one to inform a patient of his terminal condition, given that a decision to inform had been made, Robert

Kavanaugh, a psychologist and a former priest, sensitively expresses his view:

Who is the best person to inform the patient about a terminal condition? The doctor in charge of total patient care has the moral and professional responsibility to see that his patient knows. Many people are better equipped than the doctor for the actual telling. . . .

The physician in charge may be new to the case and believe the family physician a better choice. He may be a timid soul and need the support of a relative, a nurse or a chaplain. . . .

A son or a wife or a kindly nurse or a respected crony [may be better equipped for the telling]. There is no proper person, only one brave and humble enough to try to bring the maximum of graciousness to a forbidding task.⁸

Dealt with in this article are issues in which medicine, psychology, ethics and religious values intersect. Psychological **assumptions** about human behavior are central to the various positions that have been taken on the question of disclosure to terminal patients by physicians, nurses, mental health professionals, philosophers, theologians and legal scholars.

In addition to the clarification of theoretical aspects of the issues, further empirical research on the reaction of patients and other concerned parties to disclosure and to non-disclosure is necessary if we wish to make ethical choices and decisions that will be based upon more accurate knowledge of actual human behavior rather than upon speculative assumptions and generalizations about such behavior.

7. Arthur Dyck, "Ethics and Medicine," *Linacre Quarterly*, August 1973, pp. 182-200.

8. Robert E. Kavanaugh, *Facing Death*. Baltimore: Penguin, 1972, pp. 68-69.