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Mark Sheldon

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Kubler-Ross: An Unresolved Ethical Issue

Mark Sheldon, Ph.D.



A graduate of Shimer College, Professor Sheldon was a Sachar Fellow at Oxford University and received his doctorate from Brandeis University. He is an associate professor of philosophy at Indiana University-Purdue University at Fort Wayne.

There are few who would venture to question the importance of the work of Kubler-Ross concerning the stages of death,¹ and it is not fully my intention to do so in this paper. That is, I do not plan to meet her views directly with arguments opposing her clinical work. However, it is my intention to do two things. First, I do want to show that there are those who disagree with Kubler-Ross concerning the stage of death, their order, and the clear manner in which they can be distinguished. On this particular question, I will discuss Edwin S. Shneidman's views.² Second, I want to indicate that, even if one has a view of the stages of dying as Kubler-Ross delineates them, it does not mean that all ethical dilemmas are resolved. It would, of course, be emotionally and morally convenient if this were the case, but it is not. The choices, I will argue, remain very difficult — for some, agonizing.

Death, of course, is a concept which for centuries has troubled the imaginations of many. An especially excellent article which deals with this is "Various Ways in Which Human Beings Have Sought to Reconcile Themselves to the Fact of Death" by Arnold Toynbee.³ The author discusses the variety of ways in which human beings have attempted to reconcile themselves to the fact that, inevitably, they will die. Some ways, for instance, which Toynbee (1976) mentions are hedonism, pessimism, physical counter measures, the winning of fame, immortality of community, personal immortality, resurrection and heaven, in one form or another. While it is clear that human beings have dealt with death in a variety of ways, dying has remained essentially the same. And it is toward an understanding of this process which Kubler-Ross has made her primary and most influential contribution. (It is not the purpose of this paper to discuss or evaluate the ontological, religious or metaphysical significance of certain dying

experiences upon which she has concentrated much of her attention in the last several years.)

There is no question that Kubler-Ross has made contributions of immensely human importance to the care of the dying. Neglect and avoidance are, at least, minimally no longer the method of professionals in dealing with individuals in the final stages of a terminal illness. Her main contribution, however, has been toward a psychological understanding of the process of dying through which the terminally ill patient passes. This psychological understanding is not simply a theoretical exercise for her, but rather the basis for her approach to therapy, counseling and, most important, meaningful and ministrative support for persons moving through the loneliest experiences of human life. What she has taught us concerning the needs of the dying and their articulation of these needs is so important that I do not comfortably put forth the discussions in this paper, and the criticism that will follow is tentative.

According to Kubler-Ross, the terminally-ill patient passes through five stages in the process of dying: denial and isolation, anger, bargaining, depression and finally, acceptance. While it is true she admits that not all patients will pass through all the stages, nor will all the patients pass through the stages all in the same order, it is clear that she thinks all patients *ought* to pass through the stages and that the last stage, acceptance, has special significance. She also clearly regards each stage as having an appropriate "therapeutic" response. To all of this I shall return shortly.

Stage one, denial and isolation, gives the patient necessary time to gather and collect the self and mobilize other, less radical defenses. Kubler-Ross writes, "Denial is usually a temporary defense and will soon be replaced by partial acceptance. Maintained denial does not always bring increased distress if it holds out until the end, which I consider a rarity. Among our two hundred terminally ill patients, I have encountered only three who attempted to deny its approach until the very last" (1969, p. 40).

Stage two, anger, is the stage when patients are at their most difficult. They provoke, among the staff, rejection and fear at the precise time, ironically, when they most require help. Here Kubler-Ross writes, "They fight it to the end and often miss an opportunity for reaching a humble acceptance of death as a final outcome. They provoke rejection and anger, and are yet the most desperate of all" (1969, p. 56).

Bargaining is the third stage. The patient tries to make some kind of arrangement in an attempt to postpone death, at this point understood to be, ultimately, inevitable. Things in a material sense are offered and arrangements are made, in an exchange for time.

The fourth stage is depression, two kinds of which Kubler-Ross actually distinguishes. The first is reactive depression. Kubler-Ross

writes, "When the terminally ill patient can no longer deny his illness . . . he cannot smile it off anymore. His numbness or stoicism, his anger and rage will soon be replaced with a sense of great loss" (1969, p. 85). Reactive depression sets in with the patient's recognition of past loss. The second kind of depression, preparatory depression, occurs as one begins to prepare for separation from the world. This is a critical stage, according to Kubler-Ross, and one in which the patient should not be given encouragement. Such empty optimism, Kubler-Ross suggests, reflects "our own needs, our own inability to tolerate a long face for any extended period of time" (1969, p. 87).

The final stage is acceptance. The patient is not happy and is devoid of feelings, as if the pain is gone, the struggle over. Kubler-Ross writes, "While the dying patient has found some peace and acceptance, his circle of interest diminishes. He wishes to be left alone or at least not be stirred up by news and problems of the outside world. Visitors are often not desired and if they come, the patient is no longer in a talkative mood" (1969, p. 113).

I intend to return to discuss a particularly significant question that may be involved in the stages I have just outlined, but I first want to discuss the views of one other individual concerning the dying process and the problem of designating and identifying the emotions that accompany it.

Schneidman's Writings

Edwin S. Schneidman, Ph.D. professor of thanatology and director of the Laboratory for Life-Threatening Behavior at the University of California at Los Angeles, writes as follows: "My own work has not led me to conclusions identical with those of Kubler-Ross. Indeed, while I have seen in dying persons isolation, envy, bargaining, depression and acceptance, I do not believe that these are necessary 'stages' of the dying process, and I am not all convinced that they are lived through in that order, or, for that matter, in any universal order" (1976, p. 446). He continues, "What I do see is a complicated clustering of intellectual and affective states, some fleeting, lasting for a moment or a day or a week, set, not unexpectedly, against the backdrop of that person's total personality, his 'philosophy of life' . . ." Then he asks: "What of that nexus of emotions manifested by the dying person?" He responds to his own question: "Rather than the five definite stages discussed above, my experience leads me to posit a hive of effect, in which there is constant coming and going. The emotional stages seem to include a constant interplay between disbelief and hope and, against these as background, a waxing and waning of anguish, terror, disinterest and ennui, pretense, taunting and daring and even yearning for death — all these in the context of bewilderment and pain" (1976, pp. 446-447). And then Schneidman concludes:

"One does not find a unidirectional movement through progressive stages so much as an alternation between acceptance and denial" (p. 447).

It is clear that Shneidman's views concerning the stages of dying are quite different from those of Kubler-Ross. In fact, from Shneidman's perspective, it is not clear that the dying experience takes place in "stages" at all. And the implication of this is that, in the clinical setting, the behavior, emotions, and responses of patients may not be effectively predicted. There may be real confusion, consternation, puzzlement and even error among those treating the dying. In fact, a good part of Shneidman's article concerns possible approaches to therapeutic assistance for those who do work with the dying. For instance, he writes, "The physician would do well . . . to interact intensively with a few, perhaps only one dying patient at a time . . . [since] a physician needs to take vacations from death. A gynecological oncologist, for example, should intersperse his practice with obstetrical cases, delivering babies as a balance for others of his patients who are dying. . . ." (1976, p. 450).

It is not my purpose to ask whether Kubler-Ross or Shneidman is correct in her or his assessment of the relevance of "stages to a description of the dying process for the terminally ill. I am not a psychologist, I have no clinical experience, but I wish to make the point that there may be no clinical basis for resolving the issue. In other words, it may not be a clinical or empirical issue, but a conceptual one. Kubler-Ross herself asks the question when, concerning the acceptance stage, she writes: "How, then, do we know when a patient is giving up 'too early,' when we feel that a little fight on his part combined with the help of the medical profession could give him a chance to live longer?" (1969, p. 114). Her answer is not explicit, but the implication appears to be that her whole book, detailing a significant amount of clinical experience, is the answer. Through her clinical experience, the stages emerge and they are recommended on this basis. Shneidman's clinical work, however, leads to the opposite view, that one should focus not on any stage-like, unidirectional process of dying, but on the individual patient, "treating that person as a paradigm of all . . . dying patients" (1976, p. 450). Even if one were to accept the book *On Death and Dying* as Kubler-Ross's answer to her own question concerning the accurate identification of the stages and ascription of emotion for the purpose of approaching the patient with the "right" therapy, it is possible to press the conceptual questions further. This seems to be especially necessary in light of Shneidman's views resulting from his clinical experience.

The particular sort of case that illustrates what ultimately seems to be a conceptual dilemma is as follows: a woman, from the interpretive perspective of the physician, has been judged to have passed from denial, to anger, to bargaining, to depression, and is now, according to

Kubler-Ross, in that very critical stage of moving from reactive depression to preparatory depression. The physician informs the woman's husband of this, and also strongly advises him that it is very important that he now leave her undisturbed, in order to let this stage develop fully. He should not encourage her to continue the struggle against dying.

Two Possible Problems

At this point, it seems to me, there are at least two possible problems. The first is that, if Shneidman is correct, then identifying what stage the woman is in, predicting what stage will follow, and advising an "appropriate" response, are all problematic. It may be that this particular woman needs to know that someone cares and needs and wants the encouragement that her husband can give her. And it may be that fighting the dying process in this instance will meaningfully prolong the life of the woman. This is the difficult problem of ascribing a particular emotion to a particular patient, as well as of predicting pattern and process of emotional change in particular circumstances.

The second problem is more general but relates directly to the problem of ascribing emotion in any single instance. All will agree that it would be extremely helpful were it truly possible to understand fully the psychology of the dying, if we could predict with confidence the emotions, the feelings of those passing through the physical stages of terminal illness. It would make it so much more possible for us to respond with confidence that what we are doing is, without any doubt whatsoever, the right response. This would be a wonderful way to feel, emotionally beneficial to ourselves, as well as to the patient and the patient's family. But no matter how much we may wish that we could have this knowledge, to be able to establish without question the presence of a particular emotion in a patient, indicating how we should respond (whether it be to encourage or to withdraw), there does not seem to be any final way to demonstrate this. One, I think, must admit the difficulty in establishing sufficient and necessary evidence to support the judgment that there is present in a particular patient the emotion of preparatory depression which would give an individual permission *not* to encourage such a patient. In other words, because of this conceptual difficulty, the moral dilemma is not alleviated. This painstaking and well-intentioned attempt to provide a psychological map of the emotions of the dying does not afford us the certainty that our actions are correct. It is still, ultimately, a matter of choice, and the situation is extremely difficult. The husband, no matter what the physician advises, will have doubts about his choice. The possibilities for guilt, remorse or regret are enormous. What is the moral status of the act in the husband's mind at this point? Allowing

to die? Killing? Abandonment? What is the moral status of the act in reality? Has the physician interpreted the situation correctly? How certain are the results and conclusions of Kubler-Ross's investigations? These are agonizing questions that do not have, it appears, simple, clinically established answers. The physician must ask himself or herself, how does one ultimately distinguish between working the patient helpfully and carefully through the stages of dying and possibly, but not intentionally, *manipulating* the patient through the stages of dying?

It may be that these are problems which have special significance primarily within the setting of the institution. It may be observed outside the hospital or hospice, and in the home where the patient is on his or her own ground, that the patient will pass not so predictably through the "stages." In the home there is obviously not the same "institutional" concern for the convenience of having a "good" patient, one who does not pose difficult demands on the limited time of the staff, however dedicated it may be (and this is not at all the question). If this is the case, it would follow that, within the institution, special care and attention ought to be directed toward determining that there is no coercion, however slight, no pressure, however subtle, and no manipulation, however well-intentioned. It is probably true that aside from possibly and even unconsciously wanting a manageable patient, the staff would also like to have a patient who accepts that for which it is preparing him or her. Such acceptance would mean, from the perspective of Kubler-Ross, that the staff has done its work well. This would be more emotionally satisfying, and of course no one would want to deny the staff this small satisfaction which is so important in the area in which it works, where success is measured by the sort of death the patient has, and never by recovery. However, in a particular case acceptance may not occur, and a patient may remain angry or depressed. This, I think one must agree, is the patient's right, and this right must be respected.

To conclude, there may be no solution for the dilemma I have discussed. However, the dilemma may resolve itself as attention is directed toward a softening of the institution's demands, giving patients the increased freedom and encouragement to express themselves.

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