

Practical Psychiatry in Medicine

Part 6. The Dying Patient and His Family

In recent years the care of the dying patient and his family has received a great deal of attention in professional and lay circles. This has occurred largely because of remarkable advances in medical technology.

With the development of sophisticated life-support systems, cardiopulmonary resuscitation, chemotherapeutic intervention in heretofore life-shortening incidental infections, and advances in the various modes of treating cancer, the length of time between initial diagnosis of fatal illness and death has increased significantly. It is therefore inevitable that physicians, patients, and their families have become increasingly con-

cerned with learning how to help fatally ill and terminally ill patients. When looked at superficially this interest may seem to be in conflict with the role of the physician as one whose duty it is to combat death. This conflict of course is more apparent than real for in addition to his obligation to attempt to *cure* the patient of illness and thus to prevent death, the physician has always been presumed to be realistic in his expectations of therapeutic efficacy and to be concerned with the total *care* of the patient, including the alleviation of pain and the facilitation of comfort and peace.

Death and dying have a profound impact on physicians and nurses as well as patients and families. It is not rare in fact for the reactions of the staff to be of kinds that interfere seriously with caring for the dying patient or even interfere with developing a plan for the patient's care. In the following section, we will discuss some physician reactions that may interfere with management. Subsequently, we will describe the overall goals of management of the

dying patient, the stages of dying, and the period of bereavement that occurs in those close to the patient after the patient's death.

Physician Reactions to Death and Dying

In order to care effectively for the dying patient, it is necessary to think about him, to talk with him, to listen to him, and to maintain a relationship with him until death occurs. For some physicians this is feasible and for others it is extremely difficult. There are many possible factors that can enter into the development of interfering emotional reactions in the physician.⁴ As with all human behavior, the physician's response to the dying patient is determined in part

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The following chapter has been selected by the Publisher from its forthcoming book, *Practical Psychiatry in Medicine*, by John B. Imboden, MD and John Chapman Urbaitis, MD, in the hope that it will have immediate usefulness to our readers.

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by the sum of all the physician's past experiences in life and in part by the particular features of the situation in which he currently finds himself. From his own past experiences and personal development, the physician brings to the dying patient certain concepts, values, and expectations that he has concerning life, death, and himself as a person.

Denial of Death

In spite of their experiences with sickness and death, physicians are no more exempt from the tendency to avoid or deny death than are people in general. If in fact one customarily deals with the issue of physical death by not thinking about it and not accepting it as real and inevitable for oneself, then this defense (avoidance, denial) will be sharply challenged each time a dying patient is encountered. When this happens the physician may manifest the continuance of his own denial of death in a variety of behaviors: he may falsely reassure the patient (at a cost of later loss of the patient's confidence in him), he may overload the patient with too much information in one sitting in order to get the whole business done with, he may tend to withdraw from the patient, he may unwittingly participate in a "conspiracy of silence" thus contributing to the patient's isolation, or he may

simply fail to get across to the patient that he will stand by him to take care of such basic needs as the alleviation of pain and other discomfort.

What should the physician do if he suspects that his own denial of death is powerful and seriously interferes with his effectively relating to the dying patient?

For the short term, he may choose to obtain the participation of someone, perhaps another physician, a nurse, a clergyman, or a social worker, who is comfortable and experienced in working with dying patients. In such an event, the primary physician will usually decide to remain the responsible clinician though delegating part of the management to someone else.

For the longer term, the physician may choose to try to come to grips with the issue of death and of his avoidance of his own thoughts and feelings about his own death. This can be facilitated by having discussions with respected colleagues and friends. The development of an awareness and acceptance of death is not a gloomy, psychologically morbid process. Indeed, persons who achieve this awareness and acceptance report that they become more alive because they become liberated from the superficial expectations imposed upon them by society and are thus freer to pay heed to their own values and goals.

Death as a Rebuttal of Omnipotence

An illusion of omnipotence is a normal feature during infant and

child development. Fantasies of being omnipotent persist to some extent and with varying degrees of conscious awareness into adulthood. As was the case with the human tendency to deny death (which implies a feeling of being indestructible), physicians are by no means exempt from fantasies of omnipotence. Since a basic aim of medical care is to *cure* the patient, the dying patient may symbolize defeat of the physician. To the extent that the physician's own judgment of his professional performance is colored by fantasies of omnipotence, to that extent will he find it difficult to be realistic in his expectations of himself and to accept the inevitability of death without feeling inadequate, guilty, or frustrated. Failure to cope with such feelings by working through the underlying unrealistic expectations of himself can lead the physician to behave defensively when any aspect of the patient's case is discussed or questioned by a colleague or a relative of the patient. The physician also may deal with his own frustration by overtreating the patient, such as by taking extraordinary measures to prolong life in situations where this is inappropriate. It is natural for the dying patient to evoke a reaction of considerable ambivalence in the physician who feels helpless, frustrated, or defeated by the patient's illness. This ambivalence may be expressed in a number of ways, eg, the physician guiltily wishing that the dying patient would go ahead and die.

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General Goals and Principles of Management

Stated in its broadest terms, the overall goal of management of the dying patient is essentially no different from that of any other patient. As Weisman has said, the objective is to help the patient to "live as well as possible for as long as possible."¹² Therefore, what Weisman has called an "appropriate death" takes into account the quality of life for the dying patient as well as the length of life.

The following goals are of paramount importance in the management of dying patients. They are not listed in order of importance since the choice of which to consider first will depend upon the individual patient and his needs at any particular moment in the course of his illness.^{2,3}

1. Alleviation of physical discomfort. It is important not only to provide current relief from pain or other discomfort to the extent that is practical, but also to instill a feeling of confidence on the patient's part that this aspect of his care will continue to receive consistent, careful attention. In part this message is conveyed nonverbally through the physician's manifest attentiveness and in part by frequent listening to what the patient has to say and tactfully inquiring into his state of comfort.

2. Prevention of unwarranted loneliness and isolation. To a considerable extent dying is an inherently lonely experience. Often, however, it becomes more lonely

and isolated than it has to be. This is the case when the patient, for whatever reason, is avoided by physicians, nurses, and relatives. Loneliness and isolation are also enhanced when no one is free to talk with the patient about what is happening to him even though everyone, including the patient, knows that he is dying. The alleviation or prevention (partial) of loneliness and isolation entails frequent, though often brief, visits with the patient and a willingness to converse with him in accordance with the patient's own level of awareness, interest, and concern at any particular point in time. Sometimes this may mean simply sitting with the patient, perhaps touching his hand, in silence for a few minutes. The physician will also assist the patient's relatives to cope with their own feelings in a way that will facilitate appropriate contacts between themselves and the patient.

3. Taking care of unfinished business. When a relationship characterized by trust and good communication has been established, the patient is in a position to reveal to the physician, nurse, or close relative certain personal matters that he wishes to take care of while there is still time. This may involve financial or business affairs, such as making a will, making sure the family knows where certain papers are kept, and so forth. The "unfinished business" however, may be of a more personal, emotional nature. The patient may need to talk about and work through residual psychologic conflicts that he finds disturbing. He may need to achieve a reconciliation with one or more persons with whom he has had a troubled relationship. The mother (or father) of young children may need to satisfy

herself regarding arrangements for their care after she has gone. Finally, the patient may wish to make his farewell to close relatives or friends.

One physician should be in charge of the patient's care and be prepared to carry through from the initial stage of informing the patient and family of the patient's serious illness to telling the family of the patient's death and being of assistance to them during the period of bereavement. Yet, this central physician need not, and probably should not, do all this alone. Other staff, including other physicians, nurses, social workers, and chaplains, can all contribute to the care of dying patients. The primary physician will work with some or all of those members of the staff who have continuing contact with the patient so that their approach to him is a consistent one. By this it is not meant that everyone should behave in exactly the same way to the patient, but that each person relates to the patient in his own individual way while taking into consideration the opinions and experiences of other members of the staff.

In the following section, specific issues of management that are associated with the various stages of dying will be discussed.

Stages of Dying

Kübler-Ross described the fol-

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lowing stages of dying: denial, anger, bargaining, depression, and acceptance. Not every patient will go through all five stages.⁷ Some will show evidence of more than one stage at the same time; others may go back to an earlier stage and then progress forward to the achievement of quiet acceptance and peace.

Informing the Patient: Denial

For purposes of discussion, the process of dying, when viewed from its psychologic aspect, will be considered as beginning at the time the physician informs the fatally ill patient (and family) that he has a serious illness. It is not advisable to tell the patient that there is no chance of recovery or that he has only a certain amount of time left. The patient does have a right to know that he has a serious illness, that treatment is available, and that all will be done for him that can be. The patient is thus given a message of grave import but is also given hope at the same time. Some patients will press for a specific diagnosis or for this or that detail regarding treatment and such information can be given to him, but in a way that does not remove hope or hold a fatal outcome to be a certainty. If the patient asks if the illness is necessarily fatal, the physician can reiterate that the illness is

a very serious one or even that one cannot be sure of the outcome at this time (which is true).

The physician thus attempts to tell the patient the news accurately and in small pieces, so to speak. He does not overwhelm the patient with a mass of details which the patient probably won't remember anyway, and he is careful to inform the patient of whatever treatment is available. In the first session in which the physician informs the patient he should allow plenty of time so that neither he nor the patient will feel rushed and so there is ample opportunity for questions and answers.

The responsible members of the family should also be told. The physician should give the family accurate information as he did the patient but may choose to provide more details. If the physician suspects that the patient has not yet grasped the seriousness of his situation, he should be sure the immediate family understands. It is usually wise to inform the family in stages rather than all at once, especially if the initial reaction is that of being shocked or stunned.

Frequently, the patient's reaction after he has been given the news of his illness is that of denial. Thus the patient may go about his business as if he had not been informed of his serious illness or he may show his disbelief by seeking the opinion of other physicians. It is as though the patient has said to himself, "no, not me, it can't be true!" and believed this.

The physician does not attempt to challenge or override the denial which the patient uses in this initial stage or, for that matter, in later stages of the illness unless the denial results in behavior which interferes with important treatment. In that event, the physician care-

fully reviews with the patient the fact of his illness, the diagnosis, and the advisability of treatment. When this is done, the physician continues to be careful to remain both truthful and hopeful, eg, explaining the probable usefulness of treatment but without indicating that it will result in permanent cure.

Gradually the patient struggles to comprehend the seriousness of his situation and, as time goes by, the message that he will die. During this phase of dying, it is important to be able to listen to the patient and to respond to him truthfully when he asks questions about his condition. The patient himself may tentatively venture the opinion or offer a hint that he is dying and if he does so he should not be contradicted or offered false reassurance.

Anger

As the truth of his dying dawns upon him the patient commonly reacts with anger. He may say to himself and to others: "Why did this happen to me? Why me!" He resents being singled out, chosen for death, and the seeming unfairness of it all is very difficult to bear. As anger develops, the patient becomes irritable, and demanding, and may take a hostile, reproachful attitude toward everyone with whom he comes into contact.

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Perhaps he is really angry at fate or God but is taking his anger out on the nearest available targets.

The physician who is aware of this stage of anger so frequently experienced by the dying patient is in a position not to react defensively or with angry rejection of the patient. The physician knows that it is not he or other staff or relatives toward whom the patient is really angry. The physician's understanding of the patient's anger enables him to listen to the patient, to allow the patient to ventilate his feelings, and to assist other staff and relatives in attaining a healthy measure of objectivity and tolerance. Patients for whom being in active control of all aspects of their lives has always been important may fear and resent the loss of control over their own destiny that dying brings. When this is the case it may be helpful to enlist the patient in active participation in his own care and in planning for future care to the extent that is feasible.

Bargaining

The patient may partially resolve his angry feelings and ward off depression for a while by engaging in what Kübler-Ross has called "bargaining." Bargaining entails a degree of denial combined with a

magical expectation of cure or of prolongation of life if the patient says or does certain things. The latter may involve being a good patient by doing everything the physicians and nurses ask of him or it may involve prayers or promises to be fulfilled if granted the time in which to fulfill them. Here too the physician listens to the patient, allows him to bargain, but does not confirm the patient's unrealistic expectations. Eventually the bargaining attempts fail (although medically unpredicted recoveries do occur) and the patient again becomes angry and/or depressed.

Depression

The patient recognizes the apparent inexorableness of his dying as though he has answered the question of "why me?" with "why not me," though these actual words may not be uttered. Depression comes as people prepare to die. There are several factors usually present which contribute to depression: the failure of bargaining, persistent or recurrent pain or other discomfort, and the multiple disappointments and losses which the process of dying and the prospect of death entail. The dying patient may feel that he has already lost his role as a useful, needed, or attractive person. Unrealized hopes and ambitions leave him feeling unfulfilled. He feels lonely and faces the prospect of giving up all his relationships with those whom he loves. At this stage the continued availability of the physician and others who are willing to listen

to the patient when he chooses to discuss his feelings or simply to sit quietly by him when he chooses to be silent is important in counteracting his isolation and in providing him with support. The physician can be extremely helpful to the patient at this stage by alleviating physical discomfort and by seeing if there are any personal affairs with which the patient needs help.

Acceptance

As the dying patient mourns the profound losses of all which he has and loves he begins to divest himself of emotional attachments, eventually even to those who are dearest to him. In the process of this progressive "letting go," the patient may or may not talk about or review some aspects of his past life. In this phase the patient frequently achieves a quiet and peaceful acceptance of the approaching end. At this stage it is not unusual for the patient to wish to be alone or, if someone is with him, to be silent. Kübler-Ross has commented on the dignity and apparent equanimity of the dying patient who has worked through the depression and mourning of his losses and has achieved acceptance of his state.⁶

The stages listed above are a useful description but it is worth reemphasizing that they are not to be interpreted too literally, espe-

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cially the notion of one stage following another in orderly progression. Denial in various forms and degrees may repeatedly appear and disappear prior to final acceptance and one may see varying admixtures of denial, anger, bargaining, and depression at more or less the same time.

It must also be noted that the physician may observe developments in patient or family that lead him to request psychiatric consultation. The psychiatrist who has had experience in consultations on medical and surgical services is apt also to have had experience with dying patients and bereaved families. The excessive and interfering use of denial by patient or relatives and the development of suicidal risk are among the problems for which psychiatric consultation may be helpful.

Prolongation of Life

There has been much discussion about the extent to which physicians should go in prolonging the life of hopelessly ill patients. We have found the work reported from the Massachusetts General Hospital and Beth Israel Hospital in Boston to be informative and useful in developing an approach to this difficult problem.^{1,9,10}

The plan for care of any criti-

cally ill patient should include an attempt to assess the probability of his survival as a neurologically intact person. This probability may need to be reassessed daily. If plans for therapy, based on this prediction, include a less than maximum effort to preserve life, the patient and his family must participate in this decision, although they should never be forced to make it themselves, without support of the primary physician. After discussions of the sort described earlier, patient and family will be well enough informed, and acquainted enough with the primary physician, that they can have a vital share in decisions about how, and for how long, to continue therapy aimed at delaying death.

The patient may be able to participate in this decision at the time of his illness or he may have already expressed his choice in the form of a living will. The latter may include a statement such as "If my death is near and cannot be avoided, and if I have lost the ability to interact with others and have no reasonable chance of regaining this ability, or if my suffering is intense and irreversible, I do not want to have my life prolonged. I would wish, rather, to have care which gives comfort and support, which facilitates my interaction with others to the extent that this is possible, and which brings peace."¹

This statement offers a starting point for the individual choice which the patient and family must make. The principle of this is that the patient and/or family express a preference, and the physician is responsible for judging whether or how to best carry out the preference. Laws are being drafted and passed in various states which may make clearer both the respon-

sibilities and the immunities for the physician attending the dying patient.

The Place of Dying

Not all patients die in the hospital. Another organized form of care for the dying is provided by the hospice, based upon traditional and religious practices of care for the seriously ill. In England, Dr. Cicely Saunders has founded modern hospices, offering sound medical care for terminal cancer patients. Features include judicious and unobtrusive use of analgesics, warm attention by trained and emotionally secure staff, and generally unlimited visiting. Patients offer support to each other as well. These specialized hospices are also appearing in this country.⁵

Patients may choose to spend their final days at home, and in many instances this can be a help in allowing the family to participate more and in lessening the isolation of the dying patient. Some families can do this; others, whether at home or in the hospital, need to be supported in refraining from a prolonged bedside vigil which can drain them. Physicians and nurses need to care for the families as they care for the patients.

Especially at home, but in any

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instance of a patient's dying, the question arises of the family's being at the bedside at death. With patients who have been made comfortable, this seems very possible and indeed desirable. The patient and family can offer support to each other and the family can know personally how things were at the moment of death.

The Bereaved Family

Although there is considerable variation among individuals, it is possible to make some generalizations about the process of grief. Among the important variables that influence the reactions of those who have lost a loved one is the length of time between first learning of the serious or fatal nature of illness and the death of the loved one. When the dying has been a relatively slow process, the spouse or other close relative is apt to go through various emotional stages (which may or may not be coordinated with those of the dying patient) similar to those of the dying patient. When dying has occurred slowly and has been accompanied by considerable physical discomfort and progressive emaciation, the bereaved relative may understandably accept the death of

the patient as not only inevitable and natural but also as a welcome release. In such instances, grief has begun prior to actual death although even here the utter finality of death is not usually completely comprehended until the event has occurred.

When dying has been rapid, or death has occurred suddenly, or when the relative has not been able to get past the stage of denial during the patient's dying, little or no anticipatory grief has occurred and therefore the grief process takes place mainly or entirely after the death of the patient.

Parkes has described three stages of grief: numbness, yearning and protest, and disorganization.⁸ Parkes' conclusions are based in part on a study of 22 London widows under age 65 who were periodically interviewed during the 13 months following the death of their husbands. As one would expect, there is much in common between Parkes' stages of grief and Kübler-Ross' stages of dying although they are not identical. In contrast with Parkes' study, one gets the impression that much of Kübler-Ross' experiences with the family concerned the period prior to death. It is useful for the family physician to supplement his own personal and professional experiences with the observations made by others in order to develop an appropriate notion of what to expect when a patient or relative has lost a loved one. This knowledge may assist him in understanding and supporting a person who is undergoing grief as well as enabling him more readily to recognize significant deviations from the more usual patterns.

The initial stage of numbness begins after being informed of the death and may last from one day to

a week or longer. The person may describe himself as not feeling anything, or feeling as if he were in a dream, or as if he simply could not comprehend the reality, could not let it sink in. Marked tearfulness may occur prior to numbness and may be interspersed during this stage when denial or disbelief momentarily break down and the person is overwhelmed with distress.

The stage of "yearning and protest" is characterized by intense pangs of grief in which the bereaved person pines for the lost one and refusal (often not entirely conscious) to accept completely the fact that the deceased is gone. During this period the person feels sad, tearful, and may have symptoms of anxiety, poor appetite, and insomnia. There may be feelings of anger directed at the deceased person for having left or at the physicians for not having saved the loved one's life. The bereaved person may blame himself for not having done more. Parkes has described the bereaved person in this period as "searching" for the deceased. This may take the form of mentally visualizing the deceased, focusing attention upon his possessions, visiting the grave, mistaking someone on the street for him, or thinking one has felt his presence or heard his voice. Such experiences, including illusions and hallucinations, during this stage are not indicative of impending psychosis. The bereaved person may begin unconsciously to imitate or adopt traits or even symptoms of the de-

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ceased, which represents a psychologic attempt to keep the lost one by making him part of one's self.

In most persons, the second stage of grief reaches its peak about two months after the death and subsequently begins to subside. However, many months and sometimes even years after the loss there may occur waves of sadness and pining, often precipitated by some fresh reminder such as a birthday, holiday, anniversary of the death, hearing a certain melody, or visiting a formerly favorite vacation spot.

The third phase of grief, "disorganization," becomes evident as yearning and protest diminish and is characterized by apathy, aimlessness, and disinclination to look to the future or to establish goals and plans. This stage is apt to be less evident and prolonged if the widow's or widower's situation is one in which there are clear expectations and responsibilities such as taking care of the children or earning a living.

There is no clear or readily perceived end-point to the process of grief. Parkes states that two thirds of the widows he studied were still in the stage of disorganization at the end of their first year of bereavement. Although we know that people never completely get over grieving in the sense of forgetting about their loss, they do eventually renew their interests in social activities and work and make emotional investments in one or more

new interpersonal relationships. To do this, to heal the hurt and empty feelings, to find new ways of living without a spouse or parent or child, many people may need assistance.

This can come from several sources. Friends and neighbors offer considerable support in most communities. During the first days of bereavement, in the numb stage, the person needs simple and direct assistance, someone to help him arrange for the funeral and associated activities. Later, in the stage of yearning, when the pangs of grieving come, the person needs unintrusive companionship, in which the person's need for support and for periods of privacy are understood.

Still later, the bereaved person will need to find ways of resuming accustomed patterns and perhaps of starting new endeavors. Neighbors, family, and friends can be important here in providing encouragement. In recent times a movement has developed in which widows work together in self-help groups. On the principle that a person who has successfully coped with a crisis can provide both comfort and guidance to another in the same kind of crisis, these groups have made sizable contributions to many widows' recovery and reentry into active life.¹¹

The family physician is in a good position to know when people may need some outside help in dealing with their grief, since he knows the customary habits and patterns of health of his patients. He can offer some direct assistance, support, or advice, or can remind people of other resources and agencies that may help.

He may also detect early signs of complicated or atypical grieving. When a patient shows either no signs of grieving, or exaggerated

features such as excessive or prolonged social isolation, unmoderated guilt or anger, or panic attacks, the physician should consider the possibility that the patient is developing a depression which warrants treatment by the family physician or a psychiatrist.

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