The Psychological Needs and Care of the Dying Patient

HAROLD COOPER, M.D., D.P.M., Department of Psychiatry, Groote Schuur Hospital and University of Cape Town

SUMMARY

Attention is drawn to the fact that the medical profession has failed in its obligation relating to the psychological care of the dying patient. Explanations are offered for this failure.

The importance of maintaining a supportive type of interpersonal communication between the doctor and the dying patient is discussed and evaluated.


A survey of the relevant literature points to the fact that it is only during the last 2 decades that any serious attention has been devoted to the problem of the psychological needs and care of the dying patient. There is no doubt that members of the medical profession, whether they be occupied in full-time hospital posts, or in private practice, with very few exceptions have not yet come round to facing up to this aspect of medical care and commitment.

The process of dying is part of the process of living, and the end of any process should not be regarded as less important than its beginning. Doctors are abandoning their patients at a time when they are faced with the greatest emotional crisis of their lives.

THE DOCTOR’S PROBLEM

The reason for this shortcoming in medical practice seems to me to be threefold.

Firstly, the doctor may be experiencing difficulty in coming to terms with his own death. In spite of knowing that we will all die some day, we hold on, in a strange, mystical way, to a kind of personal immortality. Cramond, an Australian psychiatrist, makes the point that only when a doctor can talk comfortably about death, and particularly about his own death, will he have a chance of communicating helpfully with his dying patient.

The second difficulty arises out of the fact that doctors become overwhelmed by a feeling of insecurity when their patients are dying, and this feeling stems from a threat to their conjured-up omnipotence. Doctors have been invested with the power to cure and they tend too readily to view this investment in terms of an all-powerful rôle, and the only rôle with which they must be seriously concerned. The doctor’s feeling towards the dying patient becomes confused. He feels exposed and threatened in his inability to cure the patient. His self-esteem suffers a severe setback, and his emotional reaction towards the patient tends to fluctuate between embarrassment and suppressed hostility. Such an inability on the part of the doctor to handle his own personal conflicts in relation to the situation makes it impossible for him to meet the emotional demands of the dying patient. Hinton comments on how difficult it seems to be for a doctor to consider death as ever being appropriate.

Weisman and Hackett found that imminent death is often faced with much more difficulty by the doctor than by the patient. He tells the story of a patient with a cancer of the tongue which made it impossible for him to talk. This patient, fully aware of his condition, became acutely conscious of the fact that his dejected doctor simply could find nothing to say to him when he visited his bedside. So one day the patient indicated a need for pencil and paper and wrote: ‘Don’t take it so hard, Doc.’

If the doctor is able to overcome his own anxiety and threatened status in relation to his dying patient, his third and final difficulty often lies in the fact that he simply does not know how to deal with this patient from the psychological point of view, or what to say to him.

Initially, there appeared in the medical literature a spate of articles on the theme, ‘Should cancer patients be told, and what should cancer patients be told?’ These articles had a very unrealistic approach and only during the last 15 years or so has very much more research-orientated, helpful information on the subject, emerged. An endeavour has been made to establish how dying patients really react to their plight, what they think about, what they fear, and what kind of communication and emotional support they desire and need. It has been recognized that only with a reasonable understanding of their fundamental psychological difficulties and needs, can one plan and provide adequate psychological care for these patients.

A most regrettable lack of communication still prevails between the doctor and his dying patient and there is a most urgent need for this situation to be corrected.

THE DYING PATIENT’S PROBLEM

Solzhenitsyn, the Russian novelist, in his book Cancer Ward, writes most understandably on this subject. He points out that ‘an unpleasant feature of all public hospitals is that nobody stops for a while to exchange a few words’.

He describes most graphically the psychological torment of his cancer ward patients in dealing with their
feeling of isolation and disruption from their former way of living, and the acute awareness of the limited expectations concerning what remains of their lives. The characters in the book are drawn from a heterogeneous group and the writer reveals how age, sex, intellectual endowment, personality make-up and station in life are all-important factors in determining what dying will mean for any one patient, and how his reaction will vary in accordance with his unique circumstances.

Solzhenitsyn does not spare the reader the stark realities faced by some of these patients. He deals with the patient's choice between dying and being subjected to mutilating surgery, and the possible unpleasant effects of radiotherapy and powerful drugs. The pondering of one of his characters cannot be ignored: 'Should a man, to preserve his life, pay everything that gives life colour, scent and excitement? Can one accept a life of digestion, respiration, muscular and brain activity—and nothing more? Become a walking blueprint? Is this not an exorbitant price? Is it not a mockery? Should one pay?'

Herzberg, Aldrich, and others, have stressed the importance of regarding each patient as unique. The prospect of dying is inevitably going to prove more distressing to the younger patients. For them, they see the completely unanticipated abandonment of plans, ambitions, and people dear to them. A patient's degree of distress relating to impending death will tend to be proportionate to how much he sees himself losing by the premature curtailment of his life. The loss of loved ones is difficult to bear and the thought of leaving behind a spouse and small children is a severe blow. Other aspects of loss to these patients are multifarious, but do not require detailed elaboration.

It is generally agreed that the ordeal of dying tends to be seen by most individuals as a greater problem than the fear of death itself. Cicely Saunders has written particularly on the importance of adequate attention to the relief of pain in dying patients. The dying patient cannot avoid devoting many thinking hours to a review of his life story. If he is fortunate, he will find in it many happy memories but very often he will also find much that troubles him. In his introspection, perhaps he will encounter feelings of inadequacy, failure or resentment and a variety of as yet unresolved interpersonal problems and intrapsychic conflicts. There may be much that still requires psychological resolution before peace of mind can be attained.

Senescu, as well as Cramond, elaborate on the problem of the process of regression which arises in relation to a state of unremitting deterioration of bodily health. It is pointed out that the more helpless a patient feels, the greater will be his tendency to regress, and in so doing, seek a parent figure in his nursing environment. How responsive he will be towards such a parent figure will depend on his early parental situation. If in childhood this was a supportive one, his regression and dependency in hospital will be acceptable and helpful to him, but if not, his behaviour in hospital will tend to be resistive, suspicious and hostile. Whether a dying patient reacts to his incontinence with disgust, shame and guilt will also to a large extent be predetermined by his infantile toilet-training experience.

Recently Elisabeth Kübler-Ross, a psychiatrist working in Chicago, has established a psychotherapeutic relationship with over 400 dying patients, and reported her findings in a most helpful book entitled On Death and Dying.

Conceding that individuals will react differently when confronted with a fatal illness, she found that in general, patients suffering from malignant disease tend to pass through surprisingly clear-defined phases of psychological reaction. It appears to me that an adequate recognition of the validity of these phases is a fundamental requisite to the ultimate psychological management of dying patients.

The first stage is described as one of denial and isolation. This is a very common psychological defence mechanism, and understandably so. 'No, no, me, it cannot be true, leave me alone,' is the attitude. Some patients find it difficult to move beyond this stage.

The second stage is one of anger: 'Why me?' The patient is overcome by the unfairness of it all and feels that he has done nothing to deserve this fate. His anger and resentment tend to become projected against the medical and nursing staff, who become victims of this unreasonable, complaining, demanding behaviour. It is essential that those attending such a patient should not misinterpret his behaviour.

The third stage is viewed as a kind of bargaining with God. 'If I behave myself, grant me an extension of life, a postponement, and freedom of pain.' This bargaining process is best handled by a clergyman. A sense of great loss then gives rise to a stage of depression. It is important to recognize the normality of this phase and to regard it in terms of preparation for the final stage of acceptance of the impending death. With acceptance, the patient has overcome his anger and resentment. He has mourned his impending loss of all things and people who have been meaningful to him, and he is now prepared to await his death with a degree of quiet and peaceful expectation. It is towards such a stage that the doctor must direct his goal of psychological management.

THE ANSWER TO THE PROBLEM

The gradual accumulation of more precise facts relating to the emotional needs of dying patients has obviously contributed most valuably towards facilitating the task of their psychological care. Among the writers who have already been mentioned, together with others, there is a fairly general agreement concerning the principles involved in the psychological management of dying patients.

These patients have a desperate need to maintain a meaningful, trusting, freely communicative relationship with the doctor. They are terrified of being deserted by the doctor and it cannot be denied that this is precisely what is still far too frequently happening. Doctors will often rationalize their way out of this failing by maintaining that these patients tend to become withdrawn and appear to have no wish to talk about their fears, their illness and death.

But the fault here usually lies with the doctor and not the patient. A dying patient will be reluctant to talk...
to a doctor who has obviously lost interest in him, nor will he wish to talk to a doctor who proves to be unresponsive, uneasy or frankly anxious and floundering for an adequate response. Paradoxically enough, the dying patient becomes concerned about his doctor and will tend to avoid discussion that he knows the doctor will be unable to tolerate. This withdrawal is accounted for on the basis that he does not feel free to communicate.

Here it is worth drawing attention to the fact that a very similar situation tends to develop between the dying patient and his immediate relatives. He may wish to share his feelings and thoughts with them but often fails to do so because they reveal an attitude which makes it impossible for him to enter into such communication. In attending to the dying patient, the psychological aid required by the relatives from the doctor must not be neglected.

The question of what to tell these patients, which is the one so often posed, is not really the essential issue. The doctor's role is that of an individual who shows himself willing and able to listen, rather than talk, and one whose aim it is to understand and support the patient's point of view, rather than express his own. Most dying patients will talk to those who are prepared to listen and who do not display any obvious fear of this type of communication. Essentially, the patient must be allowed to choose what he wants to talk about, but the doctor's responses must be guided by the content and course of the patient's conversation. Having established a satisfactory communicating relationship with a dying patient, a most important medical responsibility has been attained, but it is also a responsibility to which the doctor must remain obligated until the patient's death.

Kübler-Ross does not believe in telling a patient that he is dying. Her view is that he will tell you when you dare to listen and when you are able to hear it. Her research, which has been supported by several other investigators, has shown that a surprisingly high percentage of patients know when they are dying. But what if that dreaded question, 'Am I dying, doctor?' does arise? Generalizations cannot be made and each case will have to be assessed and handled individually, but deception should always be reduced to a minimum. The patient can be told that he is suffering from a serious illness and in appropriate cases, the word cancer can even be used. The only emphatic rule is that the patient must never be completely deprived of hope.

Ruth Abrams, a psychiatric social worker, issues a warning in respect of attempts at reassurance. She quotes a patient who said, 'I was glad the doctor told me after the removal of my breast that I had cancer, but I was frightened when he added that it had not spread. I never thought of that.'

Denial is an important and most valuable defence mechanism used by many of these patients, more especially in the relatively early stages of their illness. In most cases, it is unwise for the doctor to make any attempt to oppose this denial, and it is suggested that the patient should be allowed to abandon his denial in his own good time. On the other hand, it has become clear to investigators in this field that a patient who would otherwise have reached a point where he is able to abandon his denial, is unable to do so because of the attitude of those attending him. This might apply both to his relatives as well as to his doctor. Often these individuals fear that the patient will abandon the mechanism of denial to confront the reality of the implications of his illness, and in so doing they retard the patient's progress towards the necessary abandonment of denial. As with all aspects of the management of the dying patient, when it comes to the question of denial, the doctor and relatives must be firmly supportive towards the patient's wishes and needs, and not allow their personal feelings in the matter to intervene.

It is also essential that the depressive phase of dying patients should not be misunderstood. Kübler-Ross describes this depression as an essential tool for dealing with the impending loss of loved objects, as a step towards facilitating the final stage of acceptance. Reassurance at this stage in such terms as 'it's not so bad, try to look on the bright side', is extremely upsetting for the patient. The depression must be viewed as appropriate, demanding not interference but understanding. The prescribing of antidepressive medication is probably only justified if the depression assumes extreme proportions.

Concerning the final stage of acceptance, Kübler-Ross feels that it is important that a patient should not be forced to strive for life when he is ready to die. It is often especially the relatives who require the doctor's aid to enable them to accept rather than resist the inevitable end. A conflict between a patient's readiness to die and the relatives' expectation and demand for the prolongation of life can be a source of terrible grief and turmoil for the unfortunate patient.

Ideally, there should come a time when the dying patient finds peace of mind. If he does, he has little need for further communication, but at the same time, he should not be abandoned.

CONCLUSION

In conclusion, it might be said that the essence of the psychological care of the dying patient lies in the preservation of his identity and dignity. Weissman and Hackett have expressed the view that every doctor is committed to help his patient achieve an appropriate emotional world in which to die. Perhaps there is an even greater truth in the idea that every doctor is committed to help his dying patient achieve an appropriate emotional world while he still lives.

REFERENCES