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Pastoral Care of Dying Patients and Their Families

Walter J. Smith, Ph.D.

The cultural values of American society do not allow people to confront and accept death realistically. They have been taught to cope with death by somehow disguising it, pretending that it is not a normal occurrence of every day life. Even those in the health professions, whose responsibility it is to care for the terminally ill, as well as for those who are expected to regain their health, are caught up in this attitude. Their whole education and training has prepared them to help make people well again and thus to extend their lives. When the curative measures are seen to be failing and the process of dying has begun, they tend to lose interest and to turn their attention to patients who can "profit more" from their ministrations.

Of course, the dying patient continues to be treated, but he usually is not regarded as meriting the amount of attention he would receive if his life could be expected to be extended considerably by medical and nursing care. Dying is thought of as a medical process rather than as a human experience. The human needs of the terminally ill patient, for companionship, for emotional support, and for human comfort, are not given sufficient attention.

The spiritual needs are turned over to the chaplain, if there is one, to a local clergyman, if the hospital has any on call, or ignored altogether.

Modern man has been taught to fear death, to regard it as a gruesome, lonely, impersonal process. Dying persons are often removed from the familiar surroundings of their own homes and sent to a hospital. Once there, they are frequently isolated by being placed in a private room, particularly if they are close to death, and shut off from all the activities around them.



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In addition, dying patients also have been taught to fear death, to regard it as an unnatural process, and not as a genuine part of human life. Many times they are left to go through it alone, or only with whatever non-professional and unskilled help relatives and friends, fearful of dying themselves, are able to provide. Frequently this is not much help at all.

Proper care of dying patients demands that they be given the support necessary for them to die peacefully and with that dignity which befits every human person. Relatives and friends are usually not able to provide for this. Thus it becomes the task of a skilled professional person, usually one of the clergy, to help the dying patient have a peaceful, hopeful, dignified death.

Before people can effectively help others through the experience of dying, however, they must have faced and dealt with the reality and meaning of death in their own lives. Only then will they be able to deal openly and honestly with dying patients and be of real assistance to them. The clergy, above all, are generally expected to have done this for themselves, and thus to have reached a position from which they can help others to an open and honest confrontation with the inevitable fact that some day they too must die.

Pastoral care of the sick, whether in their own homes or in a hospital, necessarily includes pastoral care of the dying. What

does this entail? The dying are cared for in a variety of ways by the different faith groups. Some, such as the Eastern Orthodox and the Roman Catholic, have very structured, sacramental means of ministering to the dying patient. Other faith groups have less formalized methods, but for effective pastoral care of the dying, clergy of all faith groups must provide a personal and interactive ministry to patients and their families in such a way that each knows what the other is thinking and feeling.

Provision for calling the clergy to conduct the appropriate religious ceremonies has become quite routine in most American hospitals. When the patient has a turn for the worse and is then regarded as critically ill, a chaplain or other clergy of the appropriate faith is called at the time when the family is notified.

The Need for Religious Rituals

This is very appropriate, for as Nolan¹ has pointed out, people in every culture have developed religious rituals to help them deal with life's crises. These provide support in times of loss or anticipated loss. They perform three functions: "(1) support in the expression of grief at the loss; (2) approval of the renunciation of what was lost; and (3) guidance in redefinition and reinvestment of self."

Religious rituals help to keep patients close to reality, since they deal with the situation as it actually is. They are designed to assist in maintaining emotional and spiritual strength to see pa-

tients through the crisis. Because rituals use words, symbolic actions, and materials with which people are familiar, they provide some sense of security in a situation characterized by very basic uncertainty.

For the Eastern Orthodox, Roman Catholics, and some Episcopalians, the Sacrament of the Sick serves these purposes. It is meant to ritualize the process of anticipatory grief in a therapeutic manner. If the patient's family, or friends, or some of the hospital personnel who have been caring for him or her are also present, they lend each other and the patient mutual support. Their feelings toward one another and about the illness can be expressed in a shared ceremony as the help of God is sought to give the patient emotional and spiritual strength to endure whatever hardship and suffering are entailed.

Feelings of guilt are relieved by the Sacrament of Reconciliation. When the bread of the Eucharist is shared, unity with the whole Christian community, from which the patient may feel some separation, is symbolized and maintained, and the hope of future life in union with God is expressed.

Other faiths make use of Scripture readings and prayers for these same purposes. Some which have been found to be very appropriate and consoling are: Isaiah 61:1-3; Lamentations 3:17-26; Romans 5:6-11; 8:14-17, 31-35, 36-39; Colossians 1:22-29; Matthew 11:25-30; and John 6:35-40. Some of the Psalms

make very appropriate prayers to offer at the bedside, particularly Psalms 4, 6, 13, 16, 23, 27, 34, 41, 57, 62, 63, 121, 130, and 146. In addition, spontaneous intercessory prayers, which take into consideration the actual condition of the patient and his or her needs and concerns, are most helpful in offering the patient both spiritual and emotional support.

It has been shown, however, that mere rituals and prayers, without faith on the part of the patient, give little assistance. In this instance, they become more of a distraction, which turns attention away from anticipatory grieving, rather than a helpful means of support through the process.²

Pastoral care provides emotional and spiritual support through this process of anticipatory grieving which is experienced by both dying patients and their relatives and friends. As Nolan (1974) has pointed out, "Grief can be a reaction to any significant loss. Indeed, the dying person himself grieves. As he consciously or unconsciously anticipates death, he fears separation from the significant persons and things in his world. The dying patient also experiences acute or gradual loss of various capacities and functions: cognitive skills, motor skills, and capacity for pleasure."

Nighswonger³ has indicated that studies conducted in the "Death and Dying Program" at the hospitals and clinics of the University of Chicago have shown the necessity of a combined

approach, whereby both the patient's and the family's anticipatory grief processes are dealt with concurrently. When this is done, the dying patient is much better able to cope with death, and to die in a peaceful and dignified manner. The family also is enabled to accept the death of the patient with greater equanimity.

Some patients wish to talk about their impending deaths, and many find that physicians and nurses either have not the time to spend with them, or else are made so uncomfortable by the thought of death that they shy away from this prospect. The clergy can help here, not only by listening to the patient, but in addition by helping the family and the professional staff to be able to do so also.

It is well not to give too much assistance to patients, but to let them experience the therapeutic value of doing everything they can for themselves. It is good to be near to lend a hand when necessary, and to aid in the grieving, allowing and encouraging the open expression of the emotions being felt. No one ought to be apologetic about the emotions they feel either during religious experiences or in grief. It is much better to express them than to try to shut them off and thus pen them up inside with the likelihood that they will harm later adjustment.

Pastoral Care During the Stages of Dying

Care for the dying patient entails a willingness to deal openly

and honestly with them. Hence when the patient denies that he is dying, good pastoral care does not attempt to break down this denial. It is seen for what it is: usually only a passing stage.

When the denying can no longer be sustained, the patient will be likely to be angry and to express hostility. This also should be understood in its context, as one of the normal stages through which dying patients are likely to pass. It is only natural that they be angry when they are about to experience such a great loss — life itself.

When the patient is in a period of depression, this should be acknowledged and empathy should be shown, but no effort ought to be made to cheer up the dying person. This would not only be unrealistic, since the patient has very good reason to be depressed, but would interfere with the normal process of grieving. It will help, however, if someone is able to stand by and give assurance, quietly and confidently, that this unpleasant mood will eventually pass.

It should be realized that facing the reality of inevitable and impending death is not the same as despair. The dying patient may actually welcome death as a relief from pain and suffering. This may well be in harmony also with deeply held religious convictions and values, with confidence that death will be merely a passage to a better world.

Sometimes dying patients are in greater pain than the medical and nursing staff realize, and are not receiving sufficient medication even to keep them moderately comfortable. Appeals may then be made to the clergy for help, either by patients themselves or by their families. As neutral persons, the clergy may then be able to initiate a conference of doctor, nurse, patient and family to arrange a schedule for sedation which will be more satisfactory for all concerned.

When patients get close to death, they need even more support from the companionship and concern of their families and the staff. The clergy also should be in attendance at this time. Even though the patient is seemingly unconscious, there still may be some awareness covered over by an inability to respond. Prayers for the dying are comforting to all at this time, particularly since they assist in dealing with the grief of the impending separation.

In most hospitals it is typical that the physician and the nurse spend a little time with the family. In a brief informational conversation, they support the family's expectations of death with an appropriate rationale. But usually that is all. Whatever help the family receives from that point on will usually come from other hospital staff, most likely social workers or chaplains. This arrangement lightens the work load of both the physicians and the nurses and enables them to fulfil their obligations to other pa-

tients. But if no one at the hospital is available to come to the aid of families, they are treated as if they did not exist.

The clergy then become counselors who help the relatives to accept the reality of the patient's impending death, and to work through the process of grieving about the coming separation. Families usually want to talk to someone about the loss they are about to encounter. For the most part, what they need is a sympathetic ear; the counselor's job entails little more than listening with patience and understanding, while they recount their concerns about past, present, and future. It may be found helpful at times to take the family to the hospital chapel, if there is one, and pray with them there about their own apprehensions and anxieties and those of the patient.

Should the Patient Be Told?

Thus far it has been assumed that both the patient and the family know about the seriousness of the patient's condition and of the likelihood of his early demise. Often the very imparting of this knowledge to the patient and the family is a problem in and of itself. There is a tendency for both the physician and the family to conceal the truth in order to protect the dying person. John Hinton's⁴ study of dying patients has shown that this ploy seldom succeeds. He visited patients periodically during the course of their illnesses and paid particular attention to the comments they

made regarding their expectations of recovery. Some patients had terminal illnesses and others did not. He found that regardless of what they had been told, most patients with terminal illnesses knew that they were going to die before too long. He also noticed that they welcomed the opportunity to talk about the disturbing and fearful prospect of their impending death. This has been the experience of most chaplains also.

It is usually assumed that someone in the family must be told that the patient has a terminal illness. The questions are: "Who should do the telling?", "Who should be told?", "When should the information be given?", and "How should this be done?"

The customary time at which all this takes place is when the patient is placed by his physician on the list of critically ill. The family is then notified of this fact and asked to come to the hospital. This immediately arouses suspicion in the minds of the relatives that all is not going very well, and by the time they arrive at the hospital they are somewhat prepared to receive disturbing news. Upon arrival they are taken to some place where they can have some privacy and are told as gently as possible by the doctor that unless there is some unlikely turn for the better, the patient is not going to recover. The physician then answers any questions they may have. Other staff members may also be present: a nurse, a social worker, a chaplain. One or

all of these give whatever support may be necessary to avert an emotional breakdown, or at least to minimize it and offer some comfort.

But, should the patient be told? And if so, when and how? Mutual pretense keeps patient and family at a distance from one another, and both feel this isolation as a disturbance to their caring relationship. Patients usually feel it more than the family, and sometimes ask a chaplain to intervene so that there is a coming together in mutual knowledge. Only then can there be acceptance on both sides of the unpleasant and inevitable outcome.

When all the hospital staff, as well as the patient and family, are united in mutual knowledge and acceptance of the prospective death of the patient, everyone is in a better position to cope with the suffering and grief. As a result the patient has a greater chance of concluding his or her life with dignity and in peace.

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