The psychological care of patients with terminal illness*

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THE subject of death and dying has long been a taboo in medical literature; however, during recent years, more attention has been paid to the subject although, even now, the volume of medical writing on the matter is still slim. Much of what has been written is anecdotal, and this is to be expected since the methodological problems of research using controlled studies in this field are formidable, if not insurmountable. Indeed, the classic research paper in this area is probably that by Hinton (1963) who compared and contrasted two groups; in one, people dying mostly from carcinoma, and in the other, patients seriously, but not thought to be fatally, ill with diseases of comparable organs. In this controlled trial he showed very clearly the greater degree of anxiety and depression in the dying group, and especially in those under the age of 50 with young dependent children.

In spite of living in a world characterised by war and violence, brought in its immediacy by television into our living rooms, our modern funeral customs avoid the harsh reality of the event. Doctors in particular have been criticised for being especially unhelpful at this time of crisis, and it has often been suggested that the doctor must deny death as it represents therapeutic failure and impotence; and for some of us impotence may be a very significant threat.

Death and dying have different meanings for different people, and for the same people at different stages in their life according to personality, life experiences, social and cultural background. It is now well known and appreciated that the fear of dying is a matter different from the fact that we all must die, that is the anticipation of death. That much quoted English poet and preacher John Donne had this to say of the latter when he referred to the amniotic sac as a shroud. "We have a winding sheet in our mother's womb which groweth with us from our conception, and we come into the world wound in that winding sheet, for we come to seek a grave." There is no hint of fear in this elegant anticipation of death.

Our dying involves our personality as much as our living, and it is probably true to say that our attitudes towards death correspond to our attitudes towards life, and that in general how each person faces up to death is determined by how he or she has faced up to the problems of living.

General considerations

Weisman and Hackett in their notable 1961 paper published in the *Journal of Psychosomatic Medicine* looked at death from three viewpoints and considered *impersonal death*, *interpersonal death*, and *intrapersonal death.*

Impersonal death

In the first of these, the individual doctor or nurse stands in an 'I–it' relationship

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to a cadaver or specimen whose unique existence does not matter. Many of us adopt this defensive manoeuvre, and the patient who was 'the carcinoma of lung, third bed down on the left as you enter the ward' becomes an interesting autopsy problem. I can recall using this defence myself many years ago as a medical student when, in the pathology museum, I realised from the case history that the tibia with an acute osteomyelitis lesion in the pot had belonged to a young man whom I had known well on the sports field. The use of the 'I–it' relationship is probably a perfectly legitimate defensive ploy in some specialties. I have always considered, for example, that surgeons must, in order to make sound objective decisions involving great risk, be somewhat emotionally apart from their patients. For some doctors in whom emotional display is equated with loss of control, an 'I–it' relationship may be the only practical one, regrettable as this may be.

Interpersonal death

Interpersonal death objectifies the death of the other one; someone else is dead and it is their loss which upsets us. While grief is the usual and appropriate response, other less familiar syndromes do occur. A survivor may be jubilant and feel a sense of personal triumph, perhaps partly because of ambivalent attitudes towards the other dead person, but also in relief at being spared.

Occasionally a smug satisfaction is expressed by an elderly person commenting on the death of an old friend—'Fancy Mary going first, and she was always so healthy and four years younger than me.' Guilt may be felt at one's survival, and this occurrence was not uncommon in concentration camps and in Japanese prisoner-of-war camp survivors; such a survivor may feel no grief at the time, but years later, in the course of the loss of another relationship, the grief reaction becomes conscious and has to be worked through.

Intrapersonal death

Intrapersonal death, that is our own death, is the only one that really matters. 'When I am dead' has a double significance in that it applies to the fear of the process of dying, and to the fact of our own dissolution. The fear of the dying process, of one's personal stamina and courage lasting out the course, is more difficult for most to face than death itself. Condemned men have been known to attempt suicide in order to cut short the waiting period for execution, as have patients who have known or who have thought they had a fatal illness.

Later, in the course of a terminal illness, this anxiety about the process of dying may diminish. That this is so may be due to a combination of drugs, toxic metabolites, or to the psychological defence of denial and by regression to a simpler level of ego functioning.

To look for a moment at subjective death, Weisman and Hackett find that this is impossible to imagine. In the phrase 'When I am dead' there is an element of psychological survival in which the 'I' continues to exercise some influence in one way or another. The aversion we have to the highly personal self becoming an impersonal 'it' in death expresses both a fear of passive dissolution and a projection in time of the fantasy in which a relic of the 'I' is buried or cremated as the 'it'.

Whatever our belief, that death is either the end of life as we know it or is the start of a new existence, it remains an important concern for all of us and one with which we require to come to terms at some point in our lives. This is particularly so for members of the helping professions who may, as part of their work, be required to help and support people in the dying process. People who do this sympathetically and well almost certainly have to come to terms with their own eventual death.

Telling the patient

It has often been said that something like 80 per cent of dying patients are aware that they are dying and would wish to discuss it, and 80 per cent of doctors believe the patient does not know and certainly should not be told the stark reality.

Those who believe the patient should be told argue that he or she has a right to know because affairs must be put in order, because the truth will come out anyway, or because in some mysterious way the person will be the better for it and will grow psychologically and spiritually.

The advocates of the 'not-telling' school, who may be those who have yet to come to terms with their own dying, argue that the idea of death is too much for the patient and may produce a rapid deterioration of both physical and mental health, and even precipitate suicide. Each side can produce anecdotes to support their views.

From my own experience, I regard the issue as a therapeutic exercise requiring the ability to listen and to observe what the patient is really telling you or asking you, and that this requires sensitivity and judgement; namely the timing of what and of how much to tell according to the patient's readiness to look at reality. I am quite certain that by our imposition of silence, denial, deception and isolation upon the dying person, we cause suffering and help to bring about a state of premortem bereavement, loneliness, and a sense of abandonment.

In addition, when we do not tell the patient, but inform the relatives with the injunction that the patient must not be told, we are really asking relatives to be more expert actors than the most brilliant stars on the West-end stage. Nor can we disguise our own feelings in facial expression or gesture. To quote Donne again, "I observe the physician with the same diligence as he the disease".

Open-ended approach

Doctors frequently express difficulty in knowing how to tell the patient the truth of his terminal illness or even whether the patient wishes to know, particularly if the patient does not ask in a direct manner. The technique therapeutically is to use what has been called the open-ended approach so that the patient's question is reflected back to him, and in this way the patient is allowed to comment further, thus revealing what is really on his mind or to drop the topic for the time being.

In either case, the doctor becomes better informed as to the patient's real attitudes. Such phrases as "Is it serious doctor?" can be answered by the statement "Well yes it is, but I wonder how you see it?" or "I would like to talk about this with you, but first how do you understand your own illness?"; or again the patient may say "I think I have cancer." Instead of a blunt "Yes" the way can be made easier by the comment "What makes you think that?" Comments like "I think I am pretty ill doctor" can be responded to by "Yes you are pretty ill and I guess you must be feeling very worried." This then allows the patient to take the matter a little further if he wishes. It is by using such techniques that the painful area is gently explored, and the doctor, listening carefully to the tone of voice and watching carefully the expression on a patient's face, becomes in a much better position to understand how best to meet the patient's queries.

Facing death

I have already noted that Hinton showed that anxiety and depression were more marked in those under 50 with dependents. In addition, those with tepid religious beliefs, the fence sitters, suffered more than those with stronger religious or with atheistic convictions. Aldrich (1963) agrees with this and suggests that it is particularly difficult for the strong, well-integrated personality to accept calmly the idea of his own death. Although such a person may hide depression and so perpetuate the idea that death is faced with acceptance, Aldrich claims that this is not the case. Death, he says, can be faced more readily if there is little to lose. Certainly we have all seen old people facing death with calmness since they feel it appropriate, that their race is run, that they have completed all their biological and social tasks. For the young person with a large circle of friends and relatives, each one is a loss and this adds up to a significant part of the total being; while for each friend or relative, the loss of the patient represents only one piece of his integrated self.

Aldrich notes that the dying patient's reaction to grief is determined by three features; firstly, the extent and quality of the interpersonal relationships; secondly, the use made of denial; and thirdly, the extent of the regression and the restriction of ego boundaries secondary to the organic illness.

Therapeutic considerations

Perhaps we can understand something of the psychology of patients with terminal illness if we look at it from the standpoint of therapy with the dying patient. I use the preposition 'with' deliberately since the exercise is a mutual contract between the patient and the doctor, nurse, or minister of religion. We do not do therapy 'to' them or 'for' them, but in dialogue 'with' them.

Essentially we are dealing with the treatment of separation anxiety and with loss. We can therefore expect to be dealing with fear, sadness, anger, guilt, and with regression. As one of the important themes is that of separation, patients who as children had significant episodes of separation from parents through illness, death, or marital disruption, will be particularly sensitive having already been conditioned to the threat.

As with all psychotherapy, time must be made available, and if the therapist cannot make this time over a foreseeable future, he should not embark on the project as his disappearance is especially traumatic for the patient.

The total time spent need not be impossibly long; it is the quality of the contact that takes place, even in five minutes, that is important. Again, if the therapist feels he is unlikely to tolerate the intensity of the patient's feelings, or of his own future emotional loss of the patient, then it is probably better that he does not become involved, since the patient's perception of being abandoned is particularly painful. The number of visits will depend on the clinical situation and should be regularly irregular so that if a visit has to be omitted, the effect on the patient is negligible.

An awareness of the stages through which the dying person may pass psychologically, of the emotions that will be aroused, and of the defences that may be mobilised, is essential for all doctors, nurses and priests.

Denial

For example, to begin with the need to deny is paramount. We can avert our minds from unpleasant issues as well as we can avert our eyes, and some patients are quite consciously aware of this.

A young married woman with a young family described denial as being only able to look at a small piece of the problem at a time; once this was digested, and after a little while, she felt able to look realistically at a little bit more.

The ego defence of denial may always be retained by some patients. With them the defence should not be breached, but even so, good therapy can be done by supporting the defence and yet, at the same time, allowing relief to the patient by, for example, allowing them to retail dreams without therapeutic interpretation. The dream content is often about friends or relatives who are already dead, and talking about them enables the patient to loosen ties on life and to anticipate a meeting in the future.

Anger

It is important to understand how angry many of our patients feel towards us as doctors. Some of this anger may be realistic in that there was delay in reaching a diagnosis, for example, but much of the anger is due to displacement and to the patient's fantasies and needs to have an omnipotent parent figure. There is, in all of us, the child we once were, and our childhood experience of doctors invariably was that they were able to get us better so that, even for the elderly dying patient, there is the irrational belief which, being unfulfilled, leads to anger.

It is difficult for the patient to express this anger directly to the doctor upon whom he is dependent, for fear of retaliation, i.e. anger in the doctor leading perhaps in fantasy to rejection, i.e. loss of parental love. The anger is expressed indirectly as, for example, by criticising, in the strictest confidence of course, another doctor who failed the patient in some way.

Occasionally the doctor himself may become aware that he is becoming cross and irritated with the patient. This may be perplexing unless the doctor uses himself as an emotional thermometer as it were, and realises that his own irritation is a recognition of anger in the patient. It is much better at such a point to take the feelings out into the open. "I get a feeling that somehow or other you're disappointed with me." This comment gives the patient the opportunity to express his feelings. "Oh no doctor, I'm not disappointed with you." "Well, this is the feeling I am getting." "Well, perhaps, a little." "Would you like to tell me about it?" In this simple interchange the patient is given an opportunity to discharge feelings, to lower the head of steam as it were, and even if he does not take the opportunity, he knows that the doctor understands, can accept his negative feelings, tolerate and respect them, and will not reject or abandon him. This can make for a more honest and easier relationship. In some cases the expression of honest anger can reduce the experience of pain and distress with consequent effect on drug use.

Fantasies

At times, one may come across the patient who wishes that someone else instead of him was in the bed dying. Such a fantasy may evoke feelings of shame, personal unworthiness and distress. As the patient weakens, regression to earlier and simpler types of behaviour appropriate to the child and even the baby appear. This, of course, is reinforced by the fact that, for the very weak patient, he may require to be fed, bathed, and toileted. He or she may at times be incontinent, and this evokes a shame of weakness, feelings of resentment, and we must be able to show the patient that we still value him or her, and regression must be handled with understanding, kindness and reassurance.

A case history

Perhaps the psychology of the patient with terminal illness might be made more clear by a brief account of one case, in order to bring out some of the insights that have just been discussed.

Hans was a Dutchman in his late twenties, a strong, muscular, professional fisherman who part-owned a tuna fishing boat. He had been diagnosed as suffering from a fatal illness characterised by remissions and relapses, and given some six months to live, At the time of the discovery of his illness he was in Australia and a psychiatric consultation was requested, not because he was mentally ill in any way, but because the physician in charge of his case was both puzzled and frustrated because Hans was refusing to return to Holland to his parents, but expressed the wish to end his days alone in Australia whither he had migrated some few years before. He was a bachelor with no relatives or emotional ties in the country.

The first session showed the patient was using the defensive mechanism of denial.

The original pain and bruising which had been the first symptoms of his fatal illness had gone, and he felt well in himself, was not depressed, nor unduly anxious, and had difficulty in believing that the information he had been given was true. He could accept it as an intellectual fact, but not emotionally.

He stated very bluntly that he had no intention of going back to Holland and was suspicious of the therapist whom he saw as someone who was supposed to make him change his mind. In the first interview no formal history was taken and he was encouraged to talk about the things that were important to him, his boat, the prospects of the fishing season, and this in turn led to some discussion about his family and his early life experiences.

Towards the end of the first hour it came out that the reason for neither returning home to Holland nor for informing his parents of his illness was that a female cousin had died of a similar illness and his aunt had had a significant depression following her daughter's death which had required hospitalization and active treatment. It therefore seemed that he was in his terms protecting his mother, and he was clearly relieved when the therapist accepted this and made no attempt to argue with him or to talk him into a personal decision that he did not feel right for himself.

The patient's right to decide

This reaction was in direct contrast to that of his physician who was pressing on him the advice that he should sell up in Australia and return at once to Holland. Here, an important principle may be noted. The physician was identifying with the patient and was trying to apply to the patient a solution that would have been right for him (the physician) in a similar situation, and was upset and genuinely bewildered when the patient would not accept what to him was perfectly sensible and valid advice; the psychiatric referral was made not on medical, but on social grounds in order to influence the patient in a certain direction.

As doctors we must accept that the patient, once he has all the facts clearly understood, has the right to his own unique decision which we must accept and support; this the physician, once he understood, willingly did.

In the ensuing weeks, the patient was frequently out of hospital and was able to carry out short fishing trips when the disease was in remission, but as time went on, hospital admissions grew more frequent and of longer duration, while his clinical condition was characterised by pain, fatigue and weakness.

Discussing feelings

At these times the patient presented with an air of sadness, and therapy consisted of encouraging him to speak about his feelings. He felt, in particular, the weakness as an affront to his virility and strength, and expressed frustration and resentment. At times, tears would be in his eyes and again this demonstration of feeling was encouraged, while the only therapeutic intervention was to reassure the patient that this was appropriate and not a sign of unmanliness. There were times when the therapist had choking feelings and a tear in his eye, and this unhidden and unbidden feeling seemed to help the patient.

At times, ideas that he had achieved very little in life were expressed, as was the ambition to stay alive until the next spring, six months off, when the boat would be paid for completely. It is important to encourage patients to have such simple goals so that a ray of hope, no matter how faint, is never extinguished. Every effort was made to value the patient for what he had done with his short life and this began to include the effect that his quiet dignity and courage were having on the therapist and on the hospital staff. In such a way, patients can be reassured of their personal worth and humanity, and relationships be meaningful and satisfying right to the end.

Anger and fear were expressed from time to time as the relationship deepened, including on one occasion the encouragement of the expression of anger to the therapist who failed to return one day having promised to do so.

The technique was to allow the patient to decide what he wished to speak about and to do very little interpretation. Some visits were as short as five minutes and some as long as an hour, but about 20 minutes was the average, about two or three times a week when the patient was in hospital, becoming daily towards the end.

On occasions, when the patient was asleep, a note would be left at the bedside, or a paperback book that had perhaps been discussed at a previous interview. In this way, the patient's rest was not disturbed, but he knew he had not been forgotten or abandoned. The question of religion was touched upon, but was not considered appropriate by the patient, so that the help of the hospital chaplain was not required.

Transference

Patients in this situation very rapidly make a strong positive transference to people they see as helping, and this may be the doctor, but it may also be a junior nurse, and this intense, quickly developing displacement of deep feelings of love can be threatening to the therapist who has to accept the inevitable loss to himself of the patient with whom he has formed a deeply emotional bond. There is no doubt that, while the therapist may give a great deal to the dying patient, the exchange is not all in the one direction, and much can be given by the patient to the therapist.

After about two months, the picture was acutely complicated by the fact that a young and very pretty Dutch trainee nurse developed a strong positive counter transference to the patient. She fell in love with him and wished to make the rest of his life complete by marrying him. This situation caused the patient a great deal of conflictual distress since he himself wished to become immortal, as it were, by fathering a child so that he could go on in the life of another. Yet, at the same time, he realised on a rational level that this was impossible.

The nurse had no help, except criticism from her supervisors, on how to deal with this situation, and the therapist's initial reaction was one of anger that this had happened as it was causing the patient distress and upsetting the smooth planned course of therapy.

Once the therapist recovered from his irritation, he saw the nurse and had to help her with her feelings and to look at matters in a more realistic light; but it is true to say that both parties were able to give each other a tremendous amount in the couple of months that were left. Nevertheless, it is a situation that should be provided for by sympathetic supervision and support of young members of staff who may become involved in this type of situation.

Grandmother's death

The therapist had known the patient for about four months before Hans was able to speak of the death of his grandmother. The therapist had asked if the patient had known of any deaths in his family apart from his cousin's which had occurred after he had already migrated. It transpired that his grandmother had died when he was aged nine, and it was at this point he had first seen his father break down in tears and cry for most of a day. His father was also a fisherman, normally strong, rugged and self contained, so that this had made a very great impact on Hans and he saw his father as being weak in the face of death.

This was the key to the reason why he felt he could not return home to his parents to die since this would induce too much of a strain on them and they might not be strong enough to carry him through his own personal trial. He therefore had come to see the therapist as the 'good father' who would be strong enough, and it was significant that this quite conscious material was only produced after he had known and tested out the therapist for about four months. He had accepted that the therapist could stay the course.

Regression

In the last few weeks Hans suffered a great deal of pain, and his behaviour progressively regressed. Visits were often of ten or 15 minutes duration and were conducted in complete silence with perhaps the therapist's hand resting on his. Occasionally the therapist would play the maternal role of making the patient comfortable by rearranging the pillows or by holding up his head to give a cooling drink. This caring behaviour helped the patient to regress with dignity.

Eventually it was decided that no further medical treatment was indicated and the therapist, because of his relationship, was asked to convey this decision to the patient. This was done, and Hans' only reaction was to close his eyes and jerk his head away from the therapist, while retaining his hand, in a silent angry movement. The unspoken gesture was exactly that of a small child in a huff. It was a very good example of regression in action, while Hans knew that his anger would be accepted and that it would make no difference. He died about 24 hours later in a coma.

Impact on staff

This young man had a tremendous impact on staff attitudes and emotions, and by his courage, good humour and qualities of character, it is true to say, without mawkish sentiment, that the feeling after he died was not of sorrow, but of having shared in a victory. One is reminded of Axel Munthe's comment about the plague in Naples in the 1800s that the figure of Death on the other side of the patient's bed is very often that of a therapeutic friend and helper.

As a postscript, it is worth recording that it was later learned that Hans' father died about three months after being told of his son's death; so perhaps Hans was right to try to protect his parents.

Conclusion

We cannot usually deal with the dying person in isolation, so no discussion of these matters would be complete without reference to the bereaved. There have been a number of studies now, notably by Maddison (1968) and Parkes (1970) which show clearly that, as a result of conjugal bereavement, widows run a greater morbidity and mortality risk than women of comparable age and social class who are not bereaved after one year.

The pattern of grief is now well defined. First there is a phase of almost total denial or numbness through a phase of bitter anguish and frustrated searching for the lost one. This is often associated with a sense of personal mutilation. Rees (1971) has recently shown that at least half of his series of 256 widows had hallucinated the deceased spouse.

This phase is succeeded by depression and apathy when hope of recovering the dead person is finally abandoned; next there is a final stage of reorganisation when new plans and assumptions about the world and the self are built up. Fear of further losses are described by the bereaved.

Crisis intervention, both with the dying and with the bereaved, must be of brief duration—about ten hours in all. For the dying, the therapy is directed to: the expression of and ventilation of the appropriate affects; permitting regression without shame or a sense of inadequacy; discussion of those who have gone before; and the expression of valuing the dying person as someone who has given life something useful.

For the bereaved, therapy encourages expression again of appropriate affect, discussion of the perceived unhelpfulness of others, and also suggests that the widow might like to talk over her life with her husband. If she has a continuing problem with her mother, this too is allowed to be expressed and the widow helped to work towards a realistic acceptance of the relationship.

Should there appear to be family factors, e.g. a pathological reaction in a child, adding further difficulty, then further family involvement is required. If there is a concurrent crisis situation, e.g. about housing, she is encouraged to deal with the effects and problems associated with this as well. In the absence of a sufficient social support system, the widow must be directly acquainted with the availability of supporting groups in the community, and her ability to use these followed up at later interviews.

In these sessions with the dying, and again with the recently bereaved, no attempt is made to take a detailed psychiatric history, no diagnostic formulation is made, and the material brought forth by the patient is dealt with only in the setting of its relationship to the current crisis.

Now if we are to apply crisis intervention to the dying when required, and to the recently bereaved, and in particular widows, how are we to do this logistically? Very few psychiatrists ever see dying or recently bereaved people. They are seen by family doctors, social workers, ministers of religion, funeral parlour directors, by police and by nurses, so we as psychiatrists have to apply techniques of mental health consultation.

For the dying, Cramond (1970) suggested brief training courses followed by supervised sessions for hospital personnel. In this way the service psychiatrist can use his time most effectively. With community groups, the psychiatrist must be ready, if invited, to perform the same role, for this is preventive psychiatry in action. Ulcerative colitis, peptic ulcer, asthma, rheumatoid arthritis, eczema, and coronary thrombosis amongst other illnesses have been reported as occurring unduly often after a bereavement.

Kraus and Lilienfeld (1959) showed in an epidemiological study that the mortality of the widowed is much higher than that of the married, even in the age group 20–34 years. In a study of general practice, Rees and Lutkins (1967) found that the death rate of the close relatives of a deceased person was raised for at least one year, the rise being greatest when the person had died unexpectedly.

From these and other studies with similar findings, it is clear that when we deal with the patient in the terminal stages of an illness, we deal with the close survivors of the patient. Informed crisis intervention might promote better mental and physical health; there are certainly ample opportunities for research.

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CANCER DEATHS

More than one death in five in England and Wales in the years 1962–67 was due to malignant disease. The Registrar General reports about 145,000 new cases a year being registered.