THE DOCTOR AND THE TERMINALLY ILL

Khoo Oon Teik

Dying is not only a biological process but a psychological and social process which begins when death becomes predictable. It may take days, weeks or months before the terminal event of death. The real crisis of dying for the terminally ill patient is an awareness that life is threatened; that he may soon die; that he must face the meaning of his life now before death takes place (1). This crisis invariably has psychological and social implications which few patients can evade or deny. Death cannot be denied but its dignity can be by thoughtless, unfeeling and overscientific care. Death is probably the loneliest experience any of us will ever have to face. Those who are dying reach out for support and companionship to trusted advisers and to those they love most (2). Physical death represents the inescapable end of every human life for in the created order of nature, all living organisms decay and perish with time.

Our attitude towards dying and death is important because of social, psychological and religious implications. Since birth we are conditioned by our experiences and traditional practices. Not a few of us in the older generation can recall the dying of a loved one at home surrounded by family and friends. In constrast, today dying occurs more often than not in the ward surrounded not by the family but resuscitation equipment, monitors and especially in the intensive care ward by strangely clothed nurses, technicians and doctors. In Malaysia and Singapore, relatives when they sense the impending death of a loved one would request discharge to allow the person to die at home. However with more high rise flats where room is scarce and privacy difficult, more elderly patients are left to die in hospitals.

Attitudes to death depend not only on tradition, training and the times but also on the personality and beliefs of the dying person. In Bali, funeral rites are regarded as a festive celebration by the entire village. In Singapore, the death house is passing away as an institution. How each man relates to the fact that death is certain determines his basic personality constitution. Man has to come to terms with his own mortality one way or another. The inevitability of death could create an anxiety over non-being and other symptoms of personality disintegration. However each man if he is to live a productive and meaningful life free from unnecessary anxiety and self-pity must come to grips with the fact that he will one day die (3). Paul Tillich asks rightly, "And if one is not able to die, is he really able to live?" (4)

National Kidney Foundation
705 Serangoon Road
Singapore 1232

Khoo Oon Teik, AM, LMS, MD, MRCP (Edin), FRFPS (Glas), FRCP (Edin), FRACP, FRCP (Glas), FACC (USA)
Chairman

C D Kean has called this fear of death "Man's most universal anxiety" (5). Basically, man's fear of death springs from three sources (6), each of which poses a definite threat to his being, for all demand that he prepare himself for an event entirely foreign to his present thereby affording no opportunity for preparation for one cannot learn from his own death — he can but die (3).

The first source of fear regarding death is associated with the thought of physical pain and suffering which are commonly believed to accompany the dying process. While these morbid fears are generally true today because most people lapse into coma or are sedated in their terminal illness, it is still not uncommon to find that many endure long hours of agony prior to death. Bowen and colleagues have said, "Extinction itself is less feared than the process that brings about the progressive dissolution of the things that have been considered to be acts of living" (7).

The second main source of fear is the thought of leaving one's loved ones behind. This creates an almost unbearable anxiety as it threatens to cut off all of the meaningful relationship for which he derived security, happiness and inner stability. He fears that all that he has lived for in terms of family and friend and the love he has given and received will come to an abrupt end. If he finds no meaning in the life beyond that which he himself puts into it and what transitory relationship he obtains from it, the thought of death promises to destroy everything that ever mattered (7).

The third basic source of fear of death is the thought of entering an unknown realm of one sort or another. The nature of man fears that which he cannot comprehend and he cannot by any means conceive of himself in a state of nonbeing, although he knows this is inevitable. Therefore as a result, he tries to allay his anxiety by creating illusionary defences. Unless he obtains satisfactory and workable solutions to deal with the seeming meaningless of death, his anxiety becomes intolerable.

Accoording to Kubler Ross there are 5 stages through which a patient may progress before achieving acceptance of death — denial ('no, not me'), anger ('why me?'), bargaining ('yes, it is me but....'), depression ('it is me') and acceptance (8). Without the courage to face the possibility of death and without the face to retreat extreme reactions such as self-induced paralysis may be a way out (1). Psychiatrists term it conversion hysteria. Such interactions between the feelings of a person and his physical condition i.e. a psychosomatic interaction may take other varied forms such as fever, rigors, pain in various parts of the body, vomiting, nightmares, fainting episodes etc. They may occur in the patient or the relative(s) unable to realise their true feelings or accept their grief.

For too long we have thought of care of the dying as second rate medicine to be relegated a low priority in the health services and to be assigned to assistant nurses. Three main categories of people are involved in this service:

1) The health team, in particular the physician
2) The family, in particular the spouse
3) The pastoral team, in particular the minister

Obviously the first essential is good communication e.g. between the staff and patient over and above clinical experience which presumes the latest advances in medicine. The patient needs encouragement and education because his chief fear is isolation from those he knows and those he loves. Bad communication causes undue suffering. The dying patient feels totally alone and retreats more and more into himself. His fear of dying and death is real and relates to:

a) Separation from family, home or job
b) Being unable to complete some unfinished task or responsibility
c) The consequences for the dependants
d) Becoming dependant on others, of losing control of physical faculties, of being a nuisance
e) Mutilation or pain
f) Death itself — fear of what they may face after death in association with feelings of unpreparedness (2). Few patients talk to doctors about these fears but in fact they appreciate an opportunity to do so.

The experience of those working with terminal patient is that the pain associated with advanced cancer is chronic, constant in nature even if variable at times (9). Chronic pain is a situation rather than an event and normally gets worse rather than better and frequently expands to occupy the patient's whole attention. It is impossible to predict when it will end. It is therefore a meaningless experience which is exacerbated by other unrelieved symptoms such as fear, anxiety and depression. Pain requires a correct use of analgesic drugs. If his analgesic is given regularly in a dose carefully assessed to cover a little longer than the chosen period, pain need never intrude into the consciousness of the patient. The same dose can also be used effectively for many weeks or months. A four-hour interval between doses should be regarded as the norm though a shorter period is necessary. Chronic pain, whatever the aetiology, requires regular preventive therapy. The boggy of addiction should be nailed as negligent medicine in terminal cancer.

TOTAL TERMINAL CARE

"When does our care of a patient become care for the dying", asks Dr Cicely Saunders. She says, "Too often this moment comes when someone says, 'there is nothing more to be done', and then finds some way of withdrawing". The patient says, "No one seemed to want to look at me" — referring not only to hospital staff but also their family and friends. There is a need to create more hospitals for terminal care if at all to train personnel in total care for all the people affected by a death. Should the doctor tell? From experience, Cicely Saunders gives an astute but ethical approach. "Most patients know when they are dying but not everyone approaches us with a direct question about it. Neither do all who pose direct questions want direct answers. We have to learn when to speak directly and when to prevaricate. If a patient questions us, we should try to see the man behind the question. We must believe in his courage and then have the courage ourselves to impart as much of the truth as we believe will be helpful to him. We should not estrange him from reality and contact with others by false assurances but neither do we want to assault him with information for which he is not really. There are many aspects of truth in the situation and many different ways of imparting them but the real question is 'what do you let patients tell you?' Our work is to follow the patient's leading, to be available and approachable and to learn the truth that is so often in a relationship rather than in words" (10).

Communicating the truth to a dying person is more than flat statement. Hitherto the teaching has been to tell a lie, white or otherwise, when asked. Lord Denning, commenting on the statement by a leading member of the profession that it was not right to tell a man the truth when he was suffering from cancer, said that there was something wrong with the morality which proclaimed that it was right to tell a lie even for

a good cause (2). If the patient is to reach a state of acceptance of the inevitable, the lines of communication must be developed and maintained (2). The doctor should tell the patient what is wrong in words that he can understand and what medicine can do for him. Closer to the terminal event, the doctor should be sensitive to the patient's attitude and questions such as: 'And what's the next step, doctor?', I'm not getting any better, am I?', 'I know I am going to die', 'I know what I've got', I've got cancer, haven't I, doctor?'. The wise physician understands that the patient wants more information and could be ready to accept more of the truth even if it is not palatable. However, "the aim is to make dying a little easier, not to apply the dogma of always divulging the truth" (11).

Professional medical detachment is necessary if the physician is to do his job "while all about you are losing their heads and blaming it on you". However, there is some confusion between sentimentality and emotion that invariably surrounds the dying and the latter's need for empathy from the healing team. Many of us have experienced the tension of the death watch when the physician's or nurse's counsel, advice, gesture and even the slightest word is meticulously scrutinized by the patient and his family. The bedside manner of the physician is a reflection of his concern and sensitivity to human need and emotion. "The doctor's duty is clear — accurate diagnosis — a sound knowledge of his patient's clinical condition — all our effort to cure when he has equipped himself with the most up-to-date therapeutic information". Then if his patient's condition is irremediable, he must plan the therapy step by step, from day to day, with forethought and care. Here decisions must be taken firmly — the unnecessary operation must be avoided e.g. of tracheostomy in a person full of years, unconscious, with a massive cerebral haemorrhage. Patients coming to the end of their lives can be kept free from distressing symptoms such as thirst, pain and discomfort using appropriate medicines.

Any doctor confronted with the problem of hopeless and incurable suffering must have thought seriously about the subject of euthanasia. In its proper meaning, euthanasia means gentle and easy death. This is something all health care practitioners desire for their patients and for themselves. It may mean that further elaborate investigation is omitted and the substitution of less burdensome therapy to ease the individual for any distress or pain in the last days or hour before death. "Such a decision is best left to the mature and experienced doctor — the person in whom the patient especially the elderly patient has complete trust and confidence. The doctor is the friend of the weary and must not betray the trust" (12). A distinction should be made between taking a life and letting one die. Killing involves taking a life whereas natural dying does not, it is merely letting one die. "A man is responsible for the former, but God is responsible for the latter", writes Norman Gersler (13). When a doctor takes a decisive purposeful action to cause to die a person who has placed trust, faith and confidence in his hands, it is quite clearly an act of medicated manslaughter. Some would argue that if one has the right to live, one has the right to die. The case for voluntary euthanasia has been overtaken by events because we live today at a time when it is possible to ease pain, abolish worry and dissociate the patient from his day to day concern by means of new drugs which have revolutionised the care of the dying. Voluntary euthanasia also conjures up the spectre of a section of the medical profession trained to kill e.g. indulge in medicated manslaughter. This is entirely different from mercifully permitting the sufferer to die. Precipitating his death can never be morally right. On the other hand, the obligation of man to preserve life does not mean that the doctor should not feel morally obligated to resuscitate a monster or human vegetable. The mere preservation of biological life devoid of all manifestation of the human spirit is not the highest good. Under such circumstances it is ethically justifiable to obtain merciful release (or antidysthanasia) through the withdrawal of extraordinary means of treatment eg. the respirator. The prohibition of administering any treatment to begin with and the use of a massive dose of pain-killer that in the process of relieving pain causes the death of the patient are really indulging in benign form of manslaughter. Proponents call euthanasia "giving death" rather than "taking life". "Euthanasis as medicated manslaughter is the disposal of the unwanted and cannot be regarded as a substitute for improving greatly the care of the dying", says Prof Ferguson Anderson (12).

It is often forgotten that it is not the patient who faces the greatest ordeal in dying. For those who live the terminal setting could be more disruptive and frustrating. Families have been torn apart both physically and spiritually by their confrontation with death. There are feelings of profound loss and often hopeless despair and ambivalent feelings of guilt. Many family members in repressing a fear of being contaminated by the dying, experience and anticipating grief reaction prior to the death of their loved one, which serves to cancel out the patient as 'dead' before he actually dies (3). While not all families react to the crisis of dying in the same manner, there emerges a fairly consistent pattern of attitudes, needs and behaviour. One of the first problems faced by the family and especially the spouse is that of readjusting their thinking so that it is in line with the reality of the situation. This is difficult because the contemporary outlook is to cover the reality of death and make it into a illusionary villain that strikes only those outside the family unit. The family's general reaction is denial of the seriouness of the situation in order that only their own security but also that of the family unit may be maintained. The second stage is realisation that the death of the loved one is not only a possibility but a certainty. With it comes a sense of impending emptiness and loneliness — a feeling that part of their own lives is about to be taken from them. This is natural because to deny that they are losing part of themselves in the death of their loved one is in essence to deny that they ever really loved. "Grief is natural; grief is also evitably self-centred. We are sorry for ourselves at the loss of a loved one", observes Stephen Bayne (14).

The third stage is characterised by feelings of contradictory emotion felt by the family in regard to the dying one. Many may resent their dying relative for putting them through such stress and effort, perhaps due in no small way to weariness and exhaustion and partly to practical matters of money, anxiety of funeral arrangements.

The fourth stage represents the family's feeling of guilt. Perhaps the most distressing thought for a family member is a feeling of relief that it is someone else who is dying and not himself. "There but for the grace of God go I", is a subconscious thought. In any long protracted illness, the dying patient may become unreasonable in his demands, non-communicative, even exasperatingly noble. Those who care for them cannot help feeling some resentment at the time. When death occurs, the survivors remember these resentments and feel unhappy at this.

The fifth stage consists of the family attempt to deal therapeutically with their complex problems in order to find peace and security to move beyond and through the terminal crisis in an open fashion thereby giving the dying one the supportive love and understanding he

needs. This adjustive insight is difficult because the relatives may have developed the 'anticipatory grief reaction' where they may so much anticipate the death of a loved one in their minds that they have already buried him or her before he or she actually dies. They go through the grief process before death and observers may report a tearless grief reaction (15). As a result the dying person ceases to be viewed as such and becomes simply the 'one' or 'it' who is visited and so he passes his last days in a lonely vacuum.

By working through with family members, their feelings of guilt ambivalence and impending loss in conjunction with the pastor and patient, the family may come to have insight in their inmost feelings and be enabled in the process better to give the dying relative the support he needs. The goal of the anticipatory grief therapy is to creat a genuine spirit of openness wherein both patient and family can express their internal feelings of doubt, hostility and apprehension and thereby enter the road of becoming a 'whole person' even in the face of death. Good grief then is a gift with the human situation and its value lies in the way in which each individual uses it i.e. he can sorrow as one who possesses a confident hope that death is but a door through which one passes into a larger life of God's service (3).

To counsel the dying, the counselling doctor, priest or pastor requires to have a psychological stability in addition to a securely grounded faith. His people depend on him for strength in the facing of death but they will use him as an object to transfer their own feelings of inadequacy, doubt, guilt, hostility and resentment. It can break a doctor or a priest who has not come to terms with his own inner feelings, needs, motivation and attitudes or dedicated himself fully to his high calling. The greatest problem for him in dealing with the crisis event of dying or death is himself for as Buxham wrote, "Every death, every sufferer, every sickness reminds us that we too must some day face these things". So the doctor or priest has to rise above his own personal inadequacies to become an 'incarnate' instrument of God's love to his people as they pass through the valley of the shadow of death. In doing so, he may have to walk an 'extra mile' down the road of death, submit himself to a high degree of anxiety, building up enough strength and courage to walk into the room of death and make a face to face encounter. If he unwittingly confuses the values of his calling with the values of the culture in which he ministers, he could feel threatened and helpless because of his inability to produce visible results, especially if the patient grills him with questions concerning heaven, hell, God's judgement to which he cannot find appropriate and intelligble answers.

Finally the management of the dying is a team concern. The team includes the dying patient, his immediate family, his children, his friends, his doctor, the lawyer, the chaplain, the nurses, the medical social worker and other ancillary staff. As death approaches, continuity of management forms an important part of the total care. Terminal illness should not be regarded as an intrusion into life; it is a part of life and can be a time of increasing maturity and deepening spiritual experience for all concerned. It is our job as doctors to help it be so (2).

REFERENCES

1. Perry S: The way we let them die. Australia Dove Communication.
2. Twycross RG: The dying patient. Christian Medical Fellowship, London.
3. Carlozz CG: Death and contemporary man: The crisis of terminal illness. Eermans, Michigan.
4. Paul Tillich. The eternal now: The meaning of death. Ed. Feifel (New York, McGraw Hill, 1959): 32.
5. Kean CD: Christian faith and pastoral care. (Greenwich, Connecticut, Seabury, 1961): 110.
6. Marti-Ibanez: A doctor looks at death. Reader's Digest, March 1964.
7. Bowen MK, et al: Counselling the dying. New York, Nelson: 2.
8. Kulber Ross, E: On death and dying, New York, Macmillan, 1970.
9. Day E: The patient with cancer and the family. New Engl J Med 1966; 274: 883-6.
10. Saunders C: Caring for the dying in the hour of our death. A record of the conference on the care of the dying, London, Chapman, 1974, Lack, Sylvia.
11. Hinton J: Dying. Harmonsworth, Penguin Books, 1977.
12. Ferguson AW: The elderly at the end of life. Nursing Times 1973; 69: 193-4.
13. Gersler N: Mercy dying vs mercy killings. Eternity, February, 1976: 13.
14. Bayne SF: Christian living. New York, Seabury, 1957: 158.
15. Backman CC: Ministering to the grief sufferer. Eaglewood Cliffs, New Jersey, Prentice Hall, 1964: 23-4.