ISSUES WITH DYING PATIENTS

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Doctors have the privilege of looking after patients from the moment of birth to the moment of death. Yet, the holistic approach to patients is interfered with by the doctor's role as a warrior against death, where death's everpresent claim on our lives, and its final victory, are ignored. This paper attempts to explore why doctors are in their current position, the mechanisms for ignoring death which are shared by doctors and patients, the nature of the fear of death, and practical implications for the treatment of dying patients. More and more patients die now in medical settings. It is incumbent on doctors to understand the dying process, if much unnecessary suffering is to be prevented.

HOSPITALS, like battlefields, are places where humans hope for a better future, but they are also places of death. In hospitals, it is the doctors who are the generals. On their white uniforms are many unseen medals for having conquered death, and they seem at home, confident, and powerful where the infantryman-patient feels weak and terrified.

When recovery is the outcome, the spin-offs from the doctor/general relationship are easy to see. The patients feel they have powerful and benevolent allies on whom they can call to restore their own powers. They show the doctors their gratitude. On the other hand, the doctors feel their powers have been confirmed, and respond warmly to their grateful patients. On a deeper level, both patients and doctors have proved that death is weak and that it can once again be ignored. Doctors and patients collude in denying death, and pretend that the magic of medicine can overcome its threat. In effect, they have used the defences of denial and omnipotence.

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DENIAL AND OMNIPOTENCE

These are universal defences which arise in childhood, and which defend against the fear generated by helplessness. In adults, these defences are subdued most of the time, but they become starkly visible at times of actual danger, be it on a battlefield or in a hospital.

Denial ignores an obvious danger, and omnipotence compensates for the feeling of helplessness by a fantasy of power. These defences may keep fear at bay in many circumstances, but they interfere with the dying process if they are used excessively, and, in extremes, can be quite antitherapeutic. Examples are the gravely ill patients who disconnect their intravenous infusion apparatuses and insist on going home. Yet, it is easier for them, by denial, to hasten their own deaths, than to face the anxiety of the truth of their helplessness.

Doctors have to understand these defences, and be wary of bolstering or shattering them beyond the patients' current needs. Doctors who have uncomfortable feelings about death may take arbitrary action such as telling all patients "the truth", or never telling patients that they are dying.

Unfortunately, doctors are too often themselves omnipotent deniers who set the pace of excessive use of defences in their patients. That this can be done has been shown by analysing interviews between doctors and dying patients.[1] Fewer overt references to anxiety were made by patients where the doctor was a denier, yet interview tapes showed that patients were giving subtle messages about concerns that outwardly they were denying. They denied, then, to please their uncomfortable caretakers. Conversely, patients of doctors who were not using denial were more ready to share their anxieties overtly with their doctors.

Denying doctors often use their work to bolster their defences. Their work is particularly suited for this. It is easy for them to accumulate work and patients who enhance their self-images as powerful healers and eternal survivors. As in their patients, however, this drive reflects at a deeper level the knowledge of final defeat. Busy doctors then are not so unlike the patients who disconnect their intravenous infusion apparatus. The doctors' own excessive use of their defences accelerate them towards their own deaths, but they, too, may find the alternative of facing their frailty too daunting a prospect.

Society approves of the hospital sickroom situation. It has switched its use of denial and omnipotence from religion to medicine to represent its illusion that death can be conquered. The miracles of the eradication of many killing diseases have encouraged this refocusing from old miracles. Furthermore, denial is given freer rein by the ubiquitous removal of the dying to institutions. Family experience of death is becoming rare.

The ministers of the medical religion reflect their own, and society's wishes. Humanistic aspects of medicine are felt to be irrelevant, because the final aim is not to accept the frailties of humanity, but to work towards a deathless life. Where a patient dies, it is felt to be a failure in the faith to be corrected, as in the past death was evidence of sin to be overcome. Doctors have fallen into the belief that they are fighting death, rather than disease.

THE NATURE OF THE FEAR OF DEATH

The irony is that, deep down, we are not even afraid of death, because on the emotional level, where it counts, we cannot conceive of our own death. Death, then, is not represented in the unconscious.[2] We have no engrams which represent death. This is like epileptics who are anxious about their illness, but who are not emotionally afraid of their fit because they cannot really conceive of it. Similarly, we do not fear sleep. Furthermore, it appears that people who believe that they are facing imminent death have little fear, pain, or suffering.[3,4] Hence, the contention that humans fear death because it is the great unknown has to be revised.

What, then, is the source of this terror against which we fight so hard? Two lines of inquiry, the clinical and the psychoanalytical, have been used in attempts to answer this enigma. These will be summarized, and a psychobiological approach will be added for consideration, to supplement these two lines.

The Clinical Line of Inquiry

Much of the fear in old age is of abandonment, of the loss of faculties, of dependency, of a drawn-out painful illness, and of loss of dignity. Kübler-Ross[5,6] found in her interviews with hundreds of dying patients that it is these very anxieties, but now intensified, which preoccupy the dying.

Some of the feared events have now actually caught up with the patients. They may be helpless to a degree they have not experienced since early childhood. They are preoccupied again with bodily pain and discomforts, and depend for the relief of their distress on others. Even normal bodily care and functions are no longer solely personal concerns, and having to ask for help in their execution may be felt as an unwarranted loss of dignity and helplessness.

Thus, with the ripping away of adult props and veneers, patients regress to a physically childlike existence. A parallel emotional regression is a common clinical experience. Patients come to depend greatly on old contacts with those whom they love, and with their doctors and other caretakers whom they see as the new bases of their emotional security.

Thus, once the defences of denial and omnipotence are shaken, the anxieties that are felt resemble those of a child who feels helpless in danger, and dependent on others for basic physical and emotional security.

This is the background for the final journey described by Kübler-Ross[5,6]—from denial of death, through anger, prevarication and grief, to acceptance of death.

To recapitulate, the fears felt in the dying process will be influenced by the degree of physical helplessness, the degree of emotional helplessness, the stage of the dying process, and, finally, the type of person who enters the dying process. Patients' personalities, and styles of dealing with problems in life will influence their styles of dealing with problems in dying. These four facets need diagnosis for proper treatment of the dying patient.

The Psychoanalytical Line of Inquiry

This generally concurs with the previous line of inquiry in that fears in the dying are seen as reactivations of infantile fears. Thus Freud believed that the fear of death was equivalent to the primordial anxiety of being separated from, and being abandoned by, protective figures.[7,8] Analysis of neurotics who present with fears of death confirms that these fears can be traced to early anxiety of separation from such a figure. It is thought that fear of death, even in the dying, has a neurotic core.[3]

Psychoanalytical theory also helps us with the problem of the guilt which surrounds death, where the concepts of dying and killing are inextricably interwoven. Feelings among the grieving that they did not do enough to save the dead are commonplace. They not only reflect magical omnipotence, as though human wishes had impact on life and death, but they also indicate the ubiquitous aggressive feelings present in any close relationship. The guilt relates to the belief that these aggressive feelings had leaked out, and caused death. On the other hand, patients reciprocate these fantasies, with the difference that they believe that their state of abandonment and helplessness is a punishment for their own bad or aggressive thoughts. They also believe that, had they but done something or other correctly, rather than wrongly, they would not be in their current predicament. These fantasies are a reflection of the compound of the child's omnipotent feelings which negate his sense of powerlessness, along with a developing, primitive conscience, which says that being overpowered is punishment for being bad.[2]

Thus far, we see that the fear of death is at core the panic of helplessness and abandonment as felt by the infant. This feeling may be triggered off in the physical or emotional plane. Later, when magical thoughts, feelings of omnipotence, and feelings of conscience develop, humans feel guilt and rationalize their plight as punishment. They hope that by some prayer, good act, or belief in their faith they will be forgiven and returned to security.

In the clinical situation it is the doctors who survive, and they may have to assuage a nagging guilt that they may be inadvertently killing patients who die. A belief in their omnipotence and a belief that death is failure enhances their fantasies. They will rake up another test, another procedure, or another tube to show that they did "all that was possible". Their guilt may be heightened by their latent anger toward their frustrating patients who resist cure.

For their part, the patients will once again acquiesce in the doctors' defensive pacesetting, not only to please the doctor, but also because their hopes are being maintained that, by obeying and appeasing the powerful doctor, they will finally be forgiven and saved.

This is the picture by the deathbed, where the participants cannot accept that it is time to call it a day and let the curtain fall.

The Psychobiological Human

Living and dying is a total psychobiological experience. Let us now consider the biological underpinnings of the psychological processes so far in the dying process which have been discussed.

The Role of the Fear of Death

If the dying process replicates some aspects of childhood, and if the fear of death can be traced back to very early feeling states, we may expect that this anxiety has some function for the infant. Indeed, Bowlby[9,10] points out how anxiety is triggered for animals and human infants in situations of potential danger. The unpleasant signal then propels action which, through evolutionary adaptedness, ensures removal from danger. For the infant, this action is approach to the mother, who then takes further steps to protect the infant. Thus some of the fear during dying harks back to one of the life-preserving mechanisms of the human repertoire.

Some ramifications of this can be observed when infants (who have not learned to defend with denial yet) are forcibly removed from their mothers. They protest, search for the mother, and become angry. If mother returns, anger and clinging to her may be witnessed. If mother does not return, pining, grieving, and, eventually, detachment take place. Thus, while the infant does not accept that mother is lost, its reactions are such as to reestablish contact with the mother figure. Anger gives the driving force to overcome obstacles to reaching her, and anger and clinging to her on her return prevent her leaving again.

We recognize how these reactions of the abandoned child run parallel to Kübler-Ross's description of the progression of reactions in the dying. Anxious, dying patients will similarly protest, search, be angry, and cling before accepting that they are lost. Clinically, these reactions may be seen as noncompliance, "obtuseness", going from doctor to doctor, demandingness, excessive complaining, and unreasonable anger.

Understanding these reactions as basic attempts to allay anxiety by reestablishing lost security may prevent a too brusque retaliation on the apparently antisocial patient. The "antisocial" reactions in an abandoned child are easy to understand. Yet dying adults may react similarly, because they feel like abandoned children. Whether patients appear to us to be pleasant or to be unpleasant, they should be given a chance to have their anxieties understood.

Detachment in patients, as in children, is a later reaction to the deserting environment, and we should be wary of it because it may hide despair. Even denial and omnipotence, the defences against abandonment anxieties, may have adaptive underpinnings. Once flight from danger is impossible, fight without fear, with a conviction of superior power, may be the only viable alternative.

Ripeness and Acceptance

And yet, there is another face to the dying process which is different from the struggle against helplessness. Some dying patients are not filled with anxiety, nor do they defend themselves against anxiety. From the beginning of, or, more likely, during the dying process, they accept their situation. Their psyche seems to reflect, and be in harmony with, the winding-down processes of their bodies. They seem to be the ripe fruit ready to fall.

These are the heroes who have won the war against death by their very acceptance of it, and for this reason, in spite of their weakness, they evoke awe from those by their bedsides.

However, in clinical practice, the mind and the body are often in disharmony. There may not be time for biological and psychobiological ageing to synchronize, and the stages towards accepting death may have to be accelerated, or may not be able to be traversed at all. When this occurs, the life-preserving mechanisms described above hold sway for too long in the dying process.

In summary, all three lines of inquiry agree that dying patients react to a situation of diminishing security, according to the paradigm of a child exposed to abandonment. Their anxieties set in motion reactions designed to overcome the anxiety and the abandonment.

On the other hand, the more people have learned to truly stand alone in spite of recognizing their vulnerability, the more their maturity will enable them to accept reality in dying, as indeed in life.

DYING IN CHILDREN

The dying process in adults is closely paralleled in dying children.[11,12] In their unconscious communications and play, one sees the same anxieties, and same defences as in adults. Even the phases leading to acceptance are seen in children. The concept that children are "innocent" of the knowledge of death, and can be shielded from it, is erroneous.

However, children are more vulnerable, because they are more helpless in the face of adult misconceptions, and adult emotional needs. They are more reliant on their parents to liaise with their world, and are more susceptible to their parents' absence, or emotional disturbances. The anxieties of children are nearer the surface, especially in the younger ones, and their defences are not so solidified.

For these reasons it is especially important that dying children have parents who visit as much as possible, and that the caretakers be friendly, and visit reliably. Procedures should be carefully explained to them, to mitigate feelings that they are punishment, and anxieties should be given a sympathetic opportunity to be expressed, as with adults.

PRACTICAL APPLICATIONS

We see that death is not a negation of all we aspire to in medicine, but rather a state which needs full diagnosis, avoidance of aggravation, and treatment to allow the patient to have as "healthy" a death as possible.

First, it is as well for the treating unit to make the physical diagnosis of the gravely ill patient, or the dying one. It will then be known that one will be up against difficult emotional problems in the patient and in oneself. The team should discuss the patient's management, and should also be self-supportive.

Second it is often the most inexperienced staff members who have to confront life and death issues. In group meetings their anxieties can be aired, and the more mature can support the young resident or nurse. The acknowledgement that the staff members have similar anxieties and defences about death to those of the patient can initiate some healthy self-questioning. For instance, is the doctor trying to be omnipotent by fighting death rather than disease? Is the tendency to isolate, or avoid, the patient a denial of what the patient represents? Are the tests, procedures, tubes, and injections going to improve the patient's life, or only make the doctor feel he is doing "all he can"? Are the doctors or staff members antagonized by the patient's means of coping? Such self-diagnosis with regard to denial, omnipotence, guilt, anger, and sadness helps to prevent attitudes which, far from allaying it, even cause anguish to the patient.

Once we are comfortable in ourselves, we turn to diagnose our patients. First, we observe their defences. We do not puncture their denials and expressions of omnipotent feelings. Rather we let them know that we understand that they are scared underneath their bravado, and we feed them with the realities of their situation at the rate at which they can digest them.

Next, we diagnose their physical regression and help alleviate the anxieties which attend it. We make sure that pain is adequately controlled, without concern for addiction. Helplessness should not be in excess of necessity. For instance, bedridden patients can be mobile in a wheelchair. Humiliation can be forestalled for instance, by leaving a bottle to prevent bedwetting. Respect for the patients as dignified human beings is maintained.

We then diagnose the extent of our patients' emotional regression, the degree to which they feel like abandoned, helpless children. Here we understand how our own person is an allayer of anxiety. While doctors may (needlessly) fear that patients regard them as a symbol of medical failure and betrayal, patients still see doctors as the "home base", in the sense that the mother figure is still essential to the child, even if she cannot change fate.

Our regular visits are therefore very important, as also is our mien. Humans can experience symbolic separation when they sense disapproval, and their fantasies of being bad and of being punished are heightened. That is why patients appreciate a congenial, open, and trustworthy attitude in their doctors.

Unnecessary regression is prevented by not talking down to patients, by not seeing them as cases, and by not approaching them with an omnipotent attitude. They should not be made to feel more powerless than they are.

We should diagnose the type of people patients are. From their past personalities we understand the colouration of their present reactions. Getting to know patients may require time, but possibly time spent with them in this direction is better spent than on many physical proccdures.

We are now ready to gauge where they stand with regard to Kübler-Ross's stages of dying.[5,6] Their anger and grief are allowed to take their course, and their "antisocial" reactions are discussed with the patients rather than counteracted by unwonted reactions of staff members, or treated with tranquillizers and antidepressants.

On the other side of the coin, we try to assess patients' acceptance of their situation, and we try to help synchronize their psyches with their bodies. It is important not to interfere with their natural involution by foisting treatment, false hope, and unwanted visits. Patients should be allowed to come to terms with death at their own pace, and with persons of their choice.

Finally, we diagnose the family's position in their grief and help them harmonize with reality as well as with the patient's needs from them.

CONCLUSION

Death, like life, will always be painful, but facing reality can at least remove some ugliness, and unnecessary suffering. Doctors have often been in the vanguard in broaching taboos, and humanity has benefited thereby. This is starting to happen now in the field of dying.

But the dying can benefit the living, too. Death is a necessary counterpoint to life, and, if we ignore death, we impoverish our lives.[13,14] The dying can teach us to accept death in our own lives. This is our gratification in treating the dying patient, in contrast to the gratification with the patient where infirmity is conquered.

It is as well for all of us doctors/generals to try to empathize with our infant(ry) man patients. Their dilemmas are our own. If we can accept their battles with wider and deeper vision, we may live without fighting hopeless and damaging wars in which they face defeat today, but we do so tomorrow.

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