

Management of the Dying Patient

Sometimes strong taboos and resistances are hidden behind the skirts of accepted axioms. Thus, in medicine it is 'axiomatic' that patients should be seen as persons with inter-related physical, emotional and personal problems; that patients have dignity irrespective of what illness or prognosis they have; and that the family is an integral part of the treatment milieu.

Yet we know that in everyday practice emotional factors tend to nullify these openly declared tenets, and perhaps nowhere more so than in the field of dying patients. Therefore, we should welcome restatements of values that are difficult to maintain, assimilate any new means offered to approximate these values, and learn why we resist putting these values into practice.

One of the most recent restatements of these values is that of Houghton [1]. She points out that there is a worldwide movement which is re-examining the position of dying patients as persons, who along with all other patients have the right to suffer as little as possible, and to conclude their lives with dignity. Patients may request this explicitly, as, for example, on a card carried on the person asking that, in case of unconsciousness, no heroic measures at resuscitation be undertaken.

Yet even without such a request, patients should not have their lives unduly prolonged when this really means only having their dying and suffering prolonged.

It is at this very point of time that the humanism of the 'axiomatic' values should come into their own. It is therefore paradoxical and tragic to note the frequent uncoupling of paths of doctors and patients when patients are dying. Thus, while patients are preoccupied with the highly individual problems related to their dying processes, and need to share these problems with their doctors, the doctors may be hiding behind pressure of work, tests, or trivia. In other words the death taboo is in full operation in the doctor and the 'axioms' are now meaningless window-dressing.

Knowledge can Broach Taboos

Yet taboos can be penetrated by knowledge, and medicine has broached a number of these in the past. Thus doctors have insisted that the human body is

not too sacred for investigation — whether the naked live body, or the corpse for dissection. Freud in this century showed that the human mind could be stripped, too, and examined. Masters and Johnson broached the taboo of observing human sexuality scientifically. Parkes observed the bereaved, and finally, Elisabeth Kübler-Ross observed the dying.

What is common to all these pioneer endeavours is that after broaching the taboo, it lost its terror. Instead, a mass of new information became available for clinical use. In the field of dying, Kübler-Ross broke ground which also produced much new information [2, 3]. She pointed out some salient facts about the concerns of dying patients, their reactions to the dying process, the stages they traverse in this process, and the reactions of those around the patients — their caretakers and families. Above all, she showed how it is careful listening which elicits information in individual patients, which then can be used for their benefit.

However, we should be warned from the history of some of the pioneer streams of medicine mentioned above. After the first breakthroughs comes the enthusiastic application of new knowledge. But then comes the dawning realisation of the new complex questions the breakthrough generated. For those outside the mainstream of the scientific endeavours, there is a tendency to simplify new discoveries, and graft some of the initial enthusiasm in the field to simple solutions, techniques, or new axioms.

Thus there is a danger that there will be attempts to abstract certain short cuts from Kübler-Ross' writings and that these simple solutions will be considered sufficient substitutes for sound clinical involvement with individual patients.

Two articles may be quoted to indicate that new awareness must also include awareness of new complexities, and that simple solutions are simply not good enough. The articles refer to potential catch-phrases like 'People should die at home' and 'No one need have pain dying.' Both statements have much potential merit, but unless they are applied to particular individuals in particular settings, they may cause unnecessary distress.

The Lancet [4] points out that lack of control of pain in the terminally ill can be due to many causes. But the main one is the lack of thorough assessment and reassessment of patients and their feelings. In the same vein, Parkes [5] concludes, after examining whether terminal patients suffer more pain in hospitals or at home, '...home can be the best place or the worst to die'. Awareness of the problem that too many patients die in impersonal institutional surroundings has now led to the more complex question of which patients should be helped in hospital or at home, when and for how long, in what way and by whom.

Blocks to Application of Humane Medical Values

Lastly, we must tackle the reasons why we resist putting our humane medical values into action.

In trying to deal with this question, Valent [6] examined the nature of the fear of death using clinical and psychoanalytic approaches. There seems to be a congruence of opinion that death is the final arbiter in the human struggle against helplessness, abandonment, vulnerability and smallness. The anxiety generated by the cognisance of death is the feeling of these very emotions, once felt as a child and defended against thereafter. The physical and emotional regression accompanying the winding down of life facilitates the return of these primitive fears in both patients and in the doctors tending them.

We may be closer now to understanding why doctors and patients are so often out of step. While patients may be forced to face the primitive fears, doctors may be at the zenith of their power, riding high on their fantasies of immortality, with full use of their defences of denial and omnipotence against these fears. Dying patients threaten these defences in doctors, and as often happens, defences are intensified under threat. Thus doctors may deny the patients who remind them that they will die. The patients may be forgotten, avoided, or allowed only superficial communication.

Yet, on the other hand, the fortified defence of omnipotence makes doctors feel that their patients are dying because of them. To counteract guilt arising from this doctors go out of their way to prove that 'everything possible is being done' — which includes tests and procedures which often prolong life unduly. A different reaction may be the withholding of helpful but dangerous drugs and procedures, because death consequent to their use would reinforce omnipotent fantasies that doctors are the instruments of life or death, and death is therefore their fault.

Valent tries to tie in the accepted values, new available concepts, and unconscious resistances into a pragmatic structured approach to treatment of the dying patient.

He suggests that a conscious antemortem diagnosis of the gravely ill patient be made. This should automatically mean discussion by the treating unit of the patient's problems, being aware that the caretakers themselves will have emotionally difficult feelings to contend with. These should be threshed out, with the more mature doctors helping their younger colleagues.

Next, the patient's state of defences are examined. Denial is not punctured, anger is not punished. Rather, patients are informed that the underlying anguish is understood. Next is diagnosis of Kübler-Ross' stages of dying, and patients are helped to progress into closer harmony between their emotional and their physiological states. When finally accepting, patients are not talked out of 'being morbid' and given more treatment.

Physical regression is diagnosed, and anxieties relating to it, e.g. pain and physical humiliations, are alleviated. Next, emotional regression is assessed. Guidance may be obtained here of visiting needs, or a particular person may be designated as a main listener.

Finally, the position of the family is elucidated and help is offered them to accept the situation along with the patient.

In conclusion, to be able to adhere to our values, we must keep them constantly in our minds. We must give sufficient time to patients to get to know them intimately. We must assimilate new knowledge relating to the dying. And to be able to provide sound empathic treatment, we also have to have the courage to share with our patients our common humanity.

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