MEDICAL PRACTICE

Contemporary Themes

Talking with People about to Die

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Summary

Sixty patients receiving care for terminal cancer commented on their discussions with doctors and nurses. Of these, 40 had some awareness of dying and none disapproved of open discussion. Of the 21 reporting little or no truthful conversations with staff, nine were critical, but the other 12 were not dissatisfied, including some aware of the prognosis.

Introduction

What degree of truth is desirable when caring for the dying? Some people have simple principles which provide a certain answer, comforting dogmas which guide them and their patients. But no dogma is universally acceptable and the protagonists for truth may look askance at the ethics of those using evasions and lies, while they in turn may be criticized for unkindly destroying hope. Many doctors wish to avoid extremes, professing a flexible policy of discussion guided by individual circumstances. This may result in little more than an inconsistent ad hoc practice evolving from the early examples of their tutors followed by the accretion of troubled memories, avoided embarrassments, deferred decisions, and the encouragement of those who have "died well". Though such roots may be suspect, it does not preclude the policy being effective. Nevertheless, a practice apt to be biased by selective experience and the doctor's own personality does warrant examination. One way of assessing our practice is to gather the opinions of those who are dying. It cannot resolve all the ethical issues but assumes the principal that the views of dying patients count.

Views Expressed by 60 Dying People

Much information has been given to me by patients dying from cancer while receiving good care in either a home, a hospital, or a hospice. In trying to evaluate whether they approved or not of the way in which the staff had spoken to them of their illness, it was naturally relevant to take into account their own views on their prognosis. In the initial interview, five of the 60 volunteered that they were certain they were dying, eight thought it probable and 14 quite possible, while 13 spoke of its possibility but with more hopes or uncertainty. Only 20 made no spontaneous direct mention of fatal illness. This accorded with my previous experience. More significant is the close parallel of these findings with the recent wider survey of dying people in or out of hospital. Cartwright *et al.*, reported that in cases where their respondents could give information 47% of people indicated an awareness that they were unlikely to recover.

The frequent recognition by people that they may well be dying means that the question is not so much "Does the doctor tell?" but "How much do they discuss?" These patients with cancer often indicated what they wanted. Some said they wanted the whole truth or some explanation. Others wished to abdicate all knowledge and responsibility, or wanted re-assurance, perhaps stating that if the prospects were bad they did not want it said.

These 60 patients were asked if they were satisfied with the discussion they had had with the staff: 23 gave moderate answers indicating no serious dissatisfaction; while a further 28 indicated a more positive approval of their conversations with the staff about their condition; nine were dissatisfied. This 15% who criticized should be considered against the fact that it was rare for these same people to express dissatisfaction with either their physical treatment, their place of care, or the staff looking after them.² Sincere praise was frequently given for these aspects of care but less often for the opportunities to speak with staff about their condition.

As these patients saw their actual experiences of communication with doctors and nurses, their reports fitted into four categories (the Procrustean defects of this simple

fitting are referred to later). About a half had obtained reasonable but partial information; the remaining three roughly equal groups had either had the fatal outcome acknowledged, or it had been denied, or they received little or no information. The table links the figures with the associated expressions of satisfaction or criticism.

Views of 60 Patients with Terminal Cancer on their Discussions with Staff

Communication	Opinion	Awareness of Dying
Fatal outcome acknowledged	10 {satisfied 10 dissatisfied —	{aware 10 unaware —
Partial information	29 {satisfied 29 dissatisfied —	{aware 17 unaware 12
Little or no information	10 {satisfied 4 dissatisfied 6	{aware 1 unaware 3 aware 5 unaware 1
Fatal outcome denied	11 {satisfied 8 dissatisfied 3	{aware 6 unaware 2 aware 1 unaware 2

The results indicate that patients are likely to appreciate truthful information but may be dissatisfied with reticence (Fisher's exact test, $P < .002$). Those not acceptant of the silence, the untruths or the inadequate opportunities to talk seriously, made some telling and poignant comments. Nevertheless, contrary to the general trend, an important proportion of people (12/60) approved the policy of reticence and denial about their fatal illness.

A simple and logical explanation of this could have been that those who told me of their awareness preferred open communication with staff and some of those who did not speak to me of dying were consistent in preferring this silence. The right-hand column of the table shows *some* support for this hypothesis in that 27 of the 40 with some awareness of dying had either had frank discussion or apparently adequate information and they were satisfied. Similarly eight of the 20 who did not speak of their own awareness apparently had been told little of their condition and five of this eight approved of their doctors' avoidance. There was, however, an important, almost paradoxical, exception: six people who spoke spontaneously to me of dying, often with considerable certainty, also expressed satisfaction with those who denied that they would die.

Discussion

No simple answer has emerged from this inquiry except perhaps one, which is that no patient voiced criticism of being told unpalatable truths. Any censure on such disclosures came from relatives who have their own understandable problems.

The absence of a straightforward answer might be due to defects in the investigation. The wrong questions may have been asked. The information could be considered unreliable in that the patients' statements contained apparent inconsistencies; the same individual could also give different views on different occasions. The methods of categorizing the information have tended to oversimplify and, perhaps, distort. These faults must be admitted. There is inherent evidence, however, to indicate that it is a complex problem which does not have a simple sufficient answer.

The patients' statements frequently contained several messages at once. Their words could hold ambiguities and contradictions which were significant because they reflected intermingled truths, uncertainties, desires, fears, and needs. What they have said provides both evidence and highly valid discussion. In an attempt to convey this, there follow many quotations providing a sentence or two from most of these 60 people. To give a pattern to this collage their views have

been linked by a few themes; but theirs are the words which count.

Some abdicated the problem to the staff: "I've not wanted to ask questions. Doctors tell me all I want to know." "Dr. just tells me what treatment they plan. I don't want to dwell on my illness." "I don't want to know all the details about it. If they've done their job that's all I need to know. The surgeon said he'd come back—he never did—but that was O.K." "I just leave it with them—but I never go right into the matter. I never actually ask what is actually wrong. I leave myself in their hands."

There was collusion in not knowing: "I might want to talk to someone—I'd like it to be a man. I don't really want to know anything when you get down to it." "You don't ask your doctor do you? It's not the done thing. I wouldn't mind talking more but I haven't asked." "Doctors don't have much time, they're so busy. It's their job. If they've got anything to tell you, they'll tell you—I think so." "Doctors, they can't talk it over—just wait and see. They don't want to talk. Sometimes I don't know whether I want them to really. I wouldn't mind—I'd want them to tell me if it's good—but I'm not sure if I want them to say if it's not."

Ignorance was partially imposed by doctors: "I haven't pressed for information . . . but after all it's my body. I'd like to know what's going on." "It would be a bit better if they came into the open a bit more. A patient's idea is just to get better—the more a doctor reassures a patient—you can feel very lost. . . ." "I have got a cancer, haven't I? I've never used that word before. I would have liked to have talked a bit more—but they're so busy."

Knowledge was flirted with: "I've asked if I'm going to get better and they say yes, rather glibly. I'd like them to say more—but I don't want them to say I won't." "If they say it's getting on all right I leave it to them. I'm one of those believers."

Some wanted reassurance: "If only I could have something to hang on to. If someone senior could say there was a hopeful sign." "I've spoken to sister and staff nurse and they say 'You'll be all right'." "I talked to them at the hospital as much as they'll say—they say you're getting on all right. They can't say too much—as long as they tell me I'm getting on that's all I need to know."

Others suppressed or repressed the problem: "I haven't spoken to doctors much. I didn't go to doctor for a year with the lump in the breast." "They reckon there's no reason why I shouldn't go back to work—a lighter job. Don't really want to know any more." "I don't want to talk about it—I leave it to the doctors. The breast was removed when I was 50; it healed up so quickly. I didn't want to talk of it."

OPEN DISCUSSION OF DYING

Dying could be openly discussed, as had occurred with the next two people, and then "forgotten": "They answer all I ask—but I tend to forget what they say. They haven't kept any secrets and that's the way I want it." "You know what doctors are like—you don't seem to get an answer. Not like that now—I've talked to Dr. A., taken it as far as I could—can't really say what we've talked about. Don't feel need to talk more of it."

Uncertainty could trouble: "Doctor said I had a shadow on the lung; no one's really said, they keep it hush-hush. If you know too much you start worrying." "They've said it's cervical spondylitis—what it is I don't know." "Doctor said it was bronchitis. They don't explain why I don't get clearance of it." "My doctor's doing all she can to help me. We have little chats—I don't ask. Do you think I've got a chance?"

But fatalistic attitudes were not uncommon: "What's to be will be, that's why I don't ask doctors."

Some wanted more defined knowledge: "I've wanted to know what the next stage is. At first no one said what was wrong. Then my G.P. said it was a tumour of the pancreas and they could treat it—so I felt better once I knew." "I've wondered for my daughter's sake. If anything's going to happen I want to be prepared for it—well when it's cancer you always wonder. I spoke to Dr. B. and he wouldn't say how long. He said they would do what they could and see how it went. It helped that he just didn't say it would be all right—I wanted to know." "I think people should know about cancer and how it can be dealt with. If anything ever happened I'd want the cornea to be used for others." "The doctors have told me what I wanted to know—about the breast and that—I wanted to know that I had cancer. I asked the doctor who told me; I guessed it anyhow; I'm glad to know, I can cope."

Evasion and lies could be resented: "I must know the truth—I want to see the x-rays and so on. If they don't tell me I'll think the worst and I won't trust the doctors. I watch their expressions." "You're left guessing. When doctor says we're going to cure you—you wonder when. . . . I've often wondered if I'd wake up next morning. You feel like this and want to talk about it, but you can't. They said they'd manage without surgery—how will I manage without surgery. They don't say." "If they'd told me the truth I'd have gone abroad for two months." "You can't speak to these people, they're so important. I don't think I could talk sense to any one now. Matron tries to brighten me up. I ask my husband; Am I going to die; if I'm going to die, why don't they let me die?"

White lies might do little but establish the nature of the doctor's attitude to the patient: "The first surgeon told me I'd be all right but said to my husband it would only be twelve months." "The first time they said it wasn't anything but wouldn't let me go. But then they told my husband and he told me it was a form of cancer, but a form they could treat. Apart from my husband and mother no-one will talk about it. It seems funny to me."

Knowledge, although painful, usually became acceptable: "Doctor's said it's in God's hands. It's natural to keep hoping, though. I asked my doctor, I wanted to know and she

told me it was in the liver." "They were doing a lot of hedging and I didn't like it. I asked the doctor here and she said it was a cancer and really I felt better. I'd got the ideas you see, and I wanted it straight out. Now I can talk about it to people; before they whispered and you knew what they were whispering about." "The breast operation and then trouble. A great shock when I was jaundiced. So I said that's it. Mr. G was so good, so determined—told me the honest truth." "I told doctor it was cancer; it shook him. You have to face up to these things. I said to my daughter: I shall have to go one day. I know it's coming and I keep my courage up. How it'll be when it actually comes I don't know."

It is apparent how much is owed to those, no longer alive, who gave such generous co-operation. I also wish to thank the relatives and the staff at the three places of care for their willing assistance.

References

- ¹ Cartwright, A., Hockey, L., and Anderson, J. L., *Life Before Death*. London, Routledge & Kegan Paul, 1973.
- ² Hinton, J., *Proceedings of the Royal Society of Medicine*, 1973, 66, 10.

Hospital Topics

A More Efficient Use of Hospital Beds?

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Summary

Faced with a shortage of trained nursing staff and a high wastage rate among learners the management of a district general hospital decided to close some of its acute beds. A beds committee attempted to minimize the effects of these closures by introducing a bed bureau, "pooling," and a simple system for forecasting waiting list admissions.

The figures for recruitment and wastage of nurses improved, and a very high turnover per available bed was achieved. This increased efficiency in numerical terms was not mirrored by an improvement in the morale of the doctors and nurses working on the wards, who were subjected to new pressures and considered that at times the standard of patient care deteriorated.

Introduction

Northampton is an expanding town in a county with the fastest population growth rate in England and Wales. It was already

considered to be short of acute beds by management and medical staff yet it was still deemed advisable to close acute beds owing to a shortage of nursing staff. This decision made us take a more critical look at the use of the remaining beds, and we believe our approach to the difficulties resulting from closure might interest others in a similar position.

Nursing Shortage

During 1972 the hospital experienced a shortage of trained nursing staff, and in 1971 it had the high wastage rate of 58% a year for student nurses (national average 28%). Committees to survey nursing problems were set up to look into these difficulties and to recommend steps to improve nursing services. The following reasons emerged for this high wastage rate among learners: (a) inadequate cover by trained staff, particularly at night; (b) insufficient teaching in the wards, which in any case was often contrary to what was taught in the school of nursing; (c) an unduly heavy work load at the district general hospital as a considerable amount of minor and intermediate surgery was undertaken at satellite hospitals. Similarly, pre-convalescent beds were at satellite hospitals; (d) The much increased extent and complexity of medical and surgical treatment, particularly of the elderly; (e) the hospital geography and architecture. Wards and departments were scattered over a large site and some buildings were pre-1905 including the main acute medical and surgical wards which are of the Nightingale pattern and still contained "centre" beds. The more commonly quoted reasons for the national shortage of nurses, particularly inadequate pay and unsocial working hours, also applied.

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