

priorities between emergency and longer-term care. All too often, however, if only because of weight of numbers, the link leads to disregard of the long-term patients and a blind eye to problems that may arise after discharge from hospital. If geriatrics is to be linked with general medicine the same risk will arise. The right reason for any link along these lines is not because continuing care is professionally unsatisfying, but because disabled living is of fundamental importance to clinical practice.

In summary, medical training has to take serious account of the problems of disabled living, and in the process new types of initiative may be needed. The profession should make a more realistic contribution than has been usual and may have to rethink the allocation of responsibility among different specialties. Geriatric medicine has greater responsibility than most but disabled living is not confined to old people, and geriatrics has other important and legitimate concerns. Since in different ways disability is encountered by nearly every practitioner, the time to learn about it is during undergraduate education.

References

- ¹ Warren MW. Care of the chronic aged sick. *Lancet* 1946;ii:841-2.
- ² Howell TH. Geriatrics. *Br Med J* 1948;ii:762.

- ³ Sheldon JH. The role of the aged in modern society. *Br Med J* 1950;ii:319-23.
- ⁴ Thomson AP. Problems of aging and chronic sickness. *Br Med J* 1949;ii:243, 300.
- ⁵ Anderson F. The early detection and prevention of disease in the elderly. In: Isaacs B, ed. *Recent advances in geriatric medicine*. London: Churchill Livingstone, 1978.
- ⁶ Dubos R. *Mirage of health*. London: George Allen and Unwin, 1960.
- ⁷ Swales JD. Thoughts on the Reith Lectures. *Lancet* 1980;ii:1348-50.
- ⁸ Miller EJ, Gwynne GV. *A life apart*. London: Tavistock Publications, 1972.
- ⁹ Harris AI. *Handicapped and impaired in Great Britain*. London: HMSO, 1971.
- ¹⁰ Lefroy RB. Extended care: medical care of the elderly disabled. *Aust Fam Physician* 1978;7:259-65.
- ¹¹ Weir S. Our image of the disabled, and how ready we are to help. *New Society* 1981;55:7-10.
- ¹² Goffman E. *Asylums*. London: Penguin, 1968.
- ¹³ Arie T. Thoughts on rationing and responsibility. *Age and Ageing* 1977;6, suppl:104-7.
- ¹⁴ Sanford JRA. Tolerance of debility in elderly dependants by supporters at home. *Br Med J* 1975;iii:471-3.
- ¹⁵ Royal College of Physicians. Care of the elderly. *J R Coll Phys* 1977;10:276-85.
- ¹⁶ Townsend P. *The government's failure to plan for disablement in old age*. London: The Disability Alliance, 1979.

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Couples facing death

II—Unsatisfactory communication

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Abstract

Forty-one couples facing the prospect of separation by death were interviewed about how the nature and prognosis of their illness had been discussed with them by their general practitioner hospital staff, and the staff of the continuing care unit to which they were admitted. Communication between husband and wife and how they coped with telling their parents and their children was also assessed. Treatment was given when they were anxious or dissatisfied about the quality of communication in any of these areas.

The couples found hospital doctors least successful at communication. Almost all who were dissatisfied wanted more information, not less. The wish to protect dependent relatives conflicted with the wish to be open, making decisions very difficult. Considerable suffering is caused by poor communication, and much of this is avoidable.

Introduction

When a patient visits a doctor with a complaint that could be the first symptom of serious illness both begin negotiations about what to ask and what to tell. Concurrently decisions are made, either actively or by default, about who else shall be informed. This issue of communication is so important to

patient and family that a detailed study was made of it with the 41 couples described in the previous paper.¹ The sample comprised all married patients under 40 and a random selection of other married patients admitted to a continuing care unit over a period of 18 months. All but one had cancer.

Method

Patient and spouse were interviewed separately and asked to give a detailed account from the onset of what was said to them about the illness and how they felt. They were questioned separately about their general practitioner (and others helping in home care), hospital staff before admission to the unit, and staff in the unit. Overall satisfaction or dissatisfaction was recorded only if the attitude expressed could be substantiated by at least one example or incident illustrating why the interviewee felt as he did. Those who could not do this, or whose impressions were mixed, were rated as "uncertain/mixed."

An assessment was made of how much each partner knew, how much they had shared, and whether they were content with the level of understanding they had reached together about the illness.

They were also asked about attitudes to telling parents, children, and other close relatives. In each instance where this issue was a source of anxiety or distress it was recorded as a problem and explored further in individual, conjoint, or family interviews as seemed appropriate.

Results

Tables I to IV show the views expressed about communication in the various areas by patients and their partners. Where husband and wife both held the same opinion this was noted in the third column headed "couple."

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Table V shows that couples varied in degree of satisfaction about the level of communication between them with regard to the illness. When either expressed dissatisfaction and wanted help, treatment was aimed at improving communication. Dissatisfaction with communication about the illness was not closely related to the general quality of the marriage. Some with poor marriages were nevertheless able to say all they thought necessary to each other—whereas some couples who had “always been close” found that they just could not put their feelings into words, though some wanted to. This confirms Hinton’s findings² that patients with average or poor marriages more often tell their spouse of their awareness of impending death.

Nine couples (22%) were not told the diagnosis at the same time. Table VI shows the varying lengths of time for which one partner alone knew the seriousness of the condition, and how this related to their satisfaction with communication about the illness.

TABLE I—Communication with general practitioner

Opinion	Patient	Spouse	Couple
Satisfied	26 (63%)	25 (61%)	22 (54%)
Dissatisfied .. .	8 (19%)	10 (24%)	7 (17%)
Uncertain mixed ..	7 (17%)	6 (15%)	—

TABLE II—Communication with hospital staff

Opinion	Patient	Spouse	Couple
Satisfied	21 (51%)	19 (46%)	16 (39%)
Dissatisfied .. .	13 (32%)	11 (27%)	7 (17%)
Uncertain mixed ..	7 (17%)	11 (27%)	—

TABLE III—Communication with unit staff

Opinion	Patient	Spouse	Couple
Satisfied	33 (80%)	35 (85%)	30 (73%)
Dissatisfied .. .	2 (5%)	2 (5%)	1 (2%)
Uncertain mixed ..	6 (15%)	4 (10%)	—

TABLE IV—Significance of preferences expressed (using the χ^2 test)

Preference	Patient	Spouse
General practitioners v hospital ..	NS (p: 0.1)	NS (p: 0.1)
Unit v general practitioner .. .	NS (p: 0.1)	p: 0.05
Unit v hospital	p: 0.01	p: 0.001

NS = Not significant.

TABLE V—Communication between husband and wife about the illness

Opinion	Patient	Spouse	Couple
Satisfied	34 (83%)	28 (68%)	26 (63%)
Dissatisfied .. .	2 (5%)	10 (24%)	2 (5%)
Uncertain mixed ..	5 (12%)	3 (7%)	—

Table VII shows the number of couples who felt that family members were dependent on them, and the number who found family members supportive. The fact that married patients under 40 were automatically referred accounts for the high proportion (46%) with children under 18. For this study such children were regarded as dependent, although parents often found some of them very understanding, especially if communication was open and the family was functioning as a unit. At the time of admission seven of the 19 couples with children under 18 had not begun to prepare them for the death of a parent. With regard to other relatives, those perceived as dependent were generally shielded from knowledge of the illness for as long as possible; those seen as supportive were told much earlier.

TABLE VI—Cases when patient and spouse were not told the diagnosis at the same time

Case No	Time in weeks between telling and death		Communication between husband and wife about the illness	
	Spouse	Patient	Spouse satisfied	Patient satisfied
3	21	1	+	+
13	65	13	+	+
14	2	Realised over several months	—	+
17	38	33	—	+
19	1	Never	+	+
24*	17	8	+	+
25	21	Never	—	?
27	10	2	+	+
36	22	13	—	+

*In this case the sons were told the diagnosis months before the wife, and she in turn concealed it from the patient.

TABLE VII—Relatives perceived as dependent or supportive

	Dependent	Supportive
No of couples with one or more:		
Children under 18	19	—
Older children	9	7
Parents	7	8
Other relatives	1	7

Discussion

Many factors influence the way a patient perceives and describes his treatment,³ and a study made in this way cannot be used alone to assess the quality of communication that took place. Its value lies in the accounts patients gave of what they found most helpful or most distressing.

THE GENERAL PRACTITIONER

The general practitioner was usually the first person to be consulted at the onset of the terminal illness. Many patients suspected the diagnosis from the beginning and were relieved when their general practitioner acknowledged their anxieties and discussed the possibilities with them, rather than giving premature reassurance. Some patients took the initiative in asking their doctors, saying that they preferred to know where they stood, and none complained of undue frankness. In five of the seven dissatisfied couples the diagnosis was made too late in the course of the disease for effective treatment to be given. Despite repeated consultations, they thought that the general practitioner had failed to take them seriously or had told them “it was all in the mind,” and they blamed him for the delay. Their opinion seemed partly justified, but the cases did present peculiar problems in diagnosis: two had pancreatic carcinomas, which are notoriously difficult, and the three others were hypochondriacal patients with long histories, where the presenting symptom of cancer was not recognised in the plethora of complaints.

Of the remaining two dissatisfied couples, one complained that despite their persistent requests their general practitioner had been exceedingly reluctant to give them information about the illness. The other couple wished their doctor had taken the initiative in telling them the diagnosis much sooner. Although the husband had been unwell for two years, they went ahead with a third pregnancy; they decided on abortion when told that he had motor neurone disease. The GP had waited too long for the opportune moment to talk.

In three instances where only one partner was satisfied there were marital problems, and it would have been almost impossible for the general practitioner to please both. In some instances

patients had probably displaced their feelings about the illness on to the person who first told them the diagnosis. One woman admitted that she was initially so angry with her general practitioner for telling her such awful news that she resolved to change to another doctor. He understood the likely reason for her apparent rejection of him and arranged to talk it over with her, whereupon they became "the best of friends" and she valued his support for the rest of her life.

The general practitioner can influence the quality of communication with the consultant by the way he writes his referral letter. What the patient already suspects and any factors that should be taken into account in deciding how much to say and to whom is more important than a detailed history of the illness.

HOSPITAL STAFF

Couples were less satisfied with hospital communication. Five who were dissatisfied with their general practitioner felt the same about the hospital and for similar reasons. Three couples in this group complained of the difficulty they had had in obtaining information. One couple complained that doctors told them more than they wanted to know—but this patient needed the defence of denial to cope with his anxiety.

Two patients were angry about thoughtlessness that led to them learning their diagnosis by accident. Both were shocked by what they learned and spent several anxious days and nights before they had the courage to ask the questions that had immediately occurred to them.

The couple coping with motor neurone disease suffered again, this time because too definite a prognosis was given. The wife was told (and the doctor concerned has confirmed this) that it was "most unlikely that her husband would live beyond Christmas." One of the patient's workmates became a close friend and support to the wife, and they let the relationship progress in a way they would have avoided or delayed (being caring and responsible people) had they known he would live on until the following summer. They felt unable to "turn the clock back"; the patient became aware of what was happening, and the result was much anger, guilt, and suffering that could have been avoided.

THE UNIT STAFF

In the unit patients were impressed by the fact that the staff seemed to have time to talk and listen, and usually did so on a one-to-one basis. They appreciated the willingness of staff to meet other family members and on occasion take the initiative in approaching them.

A ward round is not a good setting in which to ask "Am I going to die, doctor?" and most patients can put such a question only when a trusting relationship has been established. In the unit any staff member who felt confident to answer a patient's question did so, rather than adhering to the tradition that only doctors or sisters may impart serious news. Listening and talking were regarded as an integral part of patient care.

Everyone was expected to report back the outcome of conversations they had had about diagnosis and prognosis, in the same way that information about changes in physical condition and treatment would be passed on during nursing handover and doctors' rounds. Sisters and housemen were key figures in ensuring good continuity of communication.

Patients regarded general practitioners and hospital staff as erring on the side of saying far too little or else imparting information in an abrupt and blunt fashion. Unit staff aimed to correct this and usually succeeded, but one wife complained that she was told too much too soon, and a man began to have panic attacks after the home care sister answered his direct questions more explicitly than he could tolerate.

PROGNOSIS

Almost invariably the patient who accepts that he has terminal illness wants to know about prognosis. We have already seen what happened to one couple when too definite a prognosis was made. Because uncertainty is hard to bear, patients tend to select what they hear according to their needs and expectations, and may report that they have been given a firm prognosis when a doctor has taken particular care to be guarded. A statement like "You will probably have six months to a year" may be interpreted by the pessimist as "I have got six months" whereas the optimist may tell his family "The doctor said I might live for years." Patients often need help in bearing the uncertainty.

TELLING THE SPOUSE

As soon as malignant disease is diagnosed, decisions are made either actively or by default about communication to the patient and others. With regard to the spouse, the doctor's task is simplest when the couple attend together and they ask directly for information. Even in these circumstances a few reported that they had to press hard to get answers to their questions. With more reticent couples, and on the occasions when the patient comes alone, doctors are commonly guarded in talking to the patient and say more to the spouse later.

Table VI shows that nine couples (22%) did not learn the diagnosis simultaneously. Patient 14 gradually guessed, but concealed it from everyone for as long as she could, saying later that she did not want to see her husband upset. When she came for terminal care, only two weeks before her death, he was told and was very shocked. Two patients in the study died without any open acknowledgement that they knew what was happening. In one instance it was the husband's wish that it be so, and as the patient gave no indication that she wanted to talk about her illness, it was easy to respect his decision.

The other instance was painfully different. She was a woman of 39, mother of teenage daughters, who had a glioblastoma. Although he could only partially excise it, the neurosurgeon made a firm decision that she should be told only that she had a cyst, and that radiotherapy would cure it. The husband concurred, feeling he had to accept the neurosurgeon's judgment, although he really wanted them to cope with this problem together in the same way that they had shared difficulties before. His wife made a good partial recovery and became convinced that she would get well. Deterioration brought depression with suicidal feelings, and her husband thought she no longer had the resources to cope with the truth. By the time she came to the unit he had decided it would be best not to tell her at all, and the staff concurred. As his daughters became more fully aware, they were forced to join in the collusion, and all three found the tension almost unbearable. The patient died frightened, confused, and sometimes paranoid. At follow-up, her husband reiterated his wish that she had been told at the outset. He recognised that he might have been wrong, but he knew his wife better than the surgeon did.

Table VI includes information on how these nine couples felt about communication with each other with regard to the illness. Although all the patients expressed overall satisfaction (except the woman with the glioblastoma, who was in no position to say), several were angry with their spouse for keeping the secret but then recognised that it was done at considerable cost and was well meant.

"Please don't tell"

The question I am asked more often than any other is, "How do you respond when the spouse asks you to promise not to tell the patient the diagnosis?" In some instances the patient already knows, at least partly, and in others the doctor

senses that he wants to know and would benefit from being told. The spouse may be blind to this because of his or her own resistance to accepting the diagnosis. Couples conceal their knowledge from each other in a "conspiracy of silence," which is often the cause of tension between them, resulting in undue anxiety or depression. Each may be able to speak to the staff about it but not to each other. The reason for this is that conversations with comparative strangers about death or forthcoming bereavement are painful enough, but conversations with each other are about separation and loss, which hurts very much more. Yet in instances where blocked communication between husband and wife co-exists with severe depression or anxiety in the patient, these symptoms are often relieved when the pair can be helped to be more open with each other.

Requests not to tell should be discussed sympathetically, exploring with the spouse the fears he may have about the effect of breaking the news. These include the expectation that the patient will lose hope or break down. Both of these are unlikely to occur. If good rapport is established the spouse will usually agree that the doctor may tell the patient "if you are certain he wants to know." The unit staff will not give an undertaking to conceal the truth from a patient who insists on knowing. Where there has been a conspiracy of silence and it is agreed that the doctor should break the news, he should inform the spouse when he has done so, to avoid an awkward meeting at visiting time when the spouse does not know whether or not the vital conversation has taken place.

Many couples react after the initial emotion by turning to practicalities. Two wives in this study were worried that no will had been made and that they did not know their husbands' wishes in other respects also. They were glad when this was dealt with. As soon as the couple have accepted the diagnosis together they can openly mobilise the resources of the extended family—and this leads to further discussion about what shall be told and to whom.

Whether family members are told or not seems to be related to whether they are perceived as dependent or supportive; the latter being told much earlier while the former are "protected."

TELLING PARENTS

Couples who have good relations with their parents usually want the support that comes from confiding in them, but they may also want to shield them, particularly if they are aged or in poor health. The elderly are especially grieved by the death of a son or daughter, feeling that this sequence of events is unnatural. Their sorrow is mitigated a little if they can give practical help, particularly in the care of grandchildren.

When relations were not good, telling parents sometimes stirred up conflict, especially if the parents of the patient became possessive and tended to exclude the spouse.

Seven couples had at least one parent who was dependent on them. The acute anxiety that they were experiencing with regard to the illness tended to prevent them from thinking clearly about who could be called on to help. Some couples were independent or isolated, feeling they should continue to cope on their own, and were amazed at the willingness of neighbours and others to rally round. Others from divided families were unwilling to disclose their predicament because it would mean confronting relatives from whom they were estranged.

Couples in their 30s and 40s who have children and parents both dependent on them are especially prone to anxiety and guilt. Specific inquiries should be made about their needs, as they are often reluctant to ask but are greatly relieved when appropriate support is given.

TELLING CHILDREN

Of the 19 couples with children under 18, a few took the initiative in talking about the illness quite early, but most

waited until they sensed that their children were beginning to be anxious or asked questions. By the time of admission seven couples had not begun to prepare their children for the death of a parent, thinking the children were not aware of the position or were unworried by it. Often there was independent evidence to the contrary. Children sense that something is happening that is too painful to speak about, and they may show their distress in their behaviour or confide in a neighbour or in another child. Some children understood their parents' wish to shield them, but especially at follow-up several were angry that they had been denied the opportunity to be close to the parent.

Even quite small children are sometimes capable of deciding for themselves how much they can take, such as a little girl of 6 who said, "When my daddy really starts dying I want to go to granny's." If they want to be with a dying parent it is important that they should do so. If possible they should be supported by another relative or friend so that the grieving parent is not overwhelmed and in conflict, wanting to care for the dying spouse and a needy child simultaneously.

Some parents protect adult children as if they have never recognised that they have grown up. Others find it hard to accept the role reversal implicit in receiving care from their children, and they need reassurance that there is nothing shameful in this. In cases where parents refrain from confiding in their children until late in the illness, they may cause them more suffering, not less. At follow-up, such sons and daughters said repeatedly "If only I had known. . . ."

The work with these couples, and other dying patients also, leads me to believe that poor communication causes more suffering than any other problem except unrelieved pain. It is also the easiest problem (in terms of therapist's time and skill) to treat. The patient benefits in terms of relief of depression and anxiety and sometimes better control of physical symptoms. The couple or family who talk together, and who are able to take leave of each other, seem to cope with bereavement better. Blocked communication is often our fault, and we owe it to our patients to help them to remedy it as often as we can.

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References

- 1 Stedeford A. Couples facing death. I. Psychosocial aspects. *Br Med J* 1981;283:1033-6.
- 2 Hinton J. Whom do dying patients tell? *Br Med J* 1980;281:1328-30.
- 3 Hinton J. Assessing the views of the dying. *Soc Sci Med* 1971;5:37-43.

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A baby given BCG in a maternity hospital appeared to have had an inoculation in both arms. Extensive investigation indicates that it cannot have been given twice. Is there a possibility that a sympathetic reaction could cause an apparent lesion to appear on the right arm?

I have never seen a sympathetic reaction in the opposite arm after BCG vaccination, and I assume that the possibility that BCG had been given in both arms can be utterly excluded. Presumably the BCG was given at the usual site, in the region of the deltoid insertion, and the reactions in question were those that might usually be expected a few weeks after BCG. Conceivably the mother or other attendant could have transferred leaking BCG, at the time of vaccination, to the opposite arm, though this too seems very unlikely. The questioner does not indicate whether efforts were made to culture organisms from both sites. It still seems most likely that the contralateral reaction resulted from a coincidental and unrelated skin lesion. One learns in medicine that surprising reactions do occur and skin lesions sometimes choose specific sites, but the occurrence of a sympathetic reaction of this type seems highly improbable.