

For Debate

Barriers to psychological care of the dying

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Abstract

Direct observation of doctors and nurses talking with real, simulated, or role played patients suffering from a terminal illness has shown that they consistently use distancing tactics. These prevent them getting close to their patients' psychological suffering and are used to try to ensure their own emotional survival. Since these tactics discourage patients from disclosing their psychological concerns they are a serious barrier to effective psychological care. If those concerned in terminal care are to risk relinquishing these distancing tactics they will need better selection, more appropriate training, regular psychological support, and real opportunities for taking time out.

Introduction

Most doctors and nurses concerned in terminal care have been alerted to the importance of giving psychological support and recognising and alleviating psychological distress.^{1,2} Yet they will not be able to do this unless they can first establish a dialogue with patients and identify their true concerns. But this is more difficult in practice than is generally acknowledged and serious barriers have to be overcome if communication is to be effective. The nature and basis of these barriers will be described and solutions discussed.

Distancing tactics

Direct observation by video or audiotape recording of interviews between doctors or nurses and real, simulated, and role played patients has shown that doctors and nurses often distance themselves from their patients' emotional suffering in several ways.

Doctors and nurses assume that patients who develop psychological problems will disclose them. So they rarely inquire directly about how dying patients are adjusting emotionally. Yet only a minority of patients disclose their key worries spontaneously.³

The doctors and nurses try to alleviate distress by explaining that it is understandable and experienced by everybody in that predicament. For example, a nurse working on a ward in a cancer hospital noted that a newly admitted patient was weeping. She commented, "Everybody feels upset when they first come in here, but you'll soon get used to it." This annoyed and frustrated the patient who realised correctly that her cancer had recurred and was not going to respond to treatment. She was fearful about dying and wanted to discuss this but also wished to be treated as a unique person.

When they observe patients' distress experienced doctors and nurses believe that they know why patients are upset and respond accordingly.

Hospice nurse: "You are bound to be upset with getting so much pain. We'll up your pain killers."

If this nurse had bothered to clarify why the patient was upset she would have discovered that it was unrelated to pain. The patient was dreading that her pet labrador, Sammy, would have to be put down when she died.

FALSE REASSURANCE

In their eagerness to comfort dying patients doctors and nurses make more positive statements than are warranted by the circumstances.

Doctor: "I gather from sister that you have not been feeling so good in the past few days."

Patient (a man dying of stomach cancer): "I can't seem to keep any food down. I feel sick all the time."

Doctor: "I'm sure your sickness will get better, we have good antiemetics these days."

Such false reassurance is commonly offered when pain is the main complaint.

Simulated patient (dying of prostatic cancer and suffering severe bone pain): "I hope you can do something about this pain. I'm not sure I can stand much more."

Nurse: "But that's why you have been referred to us. Pain is something we know about. I am sure we can relieve it."

Yet there was no certainty that his pain would be relieved and the patient was given no opportunity to express any worries.

When medical or nursing staff notice that patients look upset or despondent they try to "jolly" them out of it by saying, for example, "Come on Mr A, there's no need to look so glum. The sun is shining, it's a lovely day." Yet this 43 year old patient had good reason to be despondent. He knew that he was dying from lung cancer and was leaving a wife and three teenage children behind.

SELECTIVE ATTENTION

When a patient spontaneously mentions both physical and psychological difficulties the doctor or nurse follows up only the physical problems.

Surgeon: "Well, how are you today?"

Woman (dying of breast cancer): "I'm very worried about what is happening to me. I'm beginning to think I'm not going to get better this time. The pain in my hip is getting worse."

Surgeon: "Tell me more about this pain in your hip."

This preference for dealing with physical problems causes patients to believe that it is not legitimate to mention any psychological difficulties.

When patients confront a doctor or nurse with a psychological problem or difficult question this is dealt with by changing the topic.

Doctor: "How are you today?"

Patient (dying of lung cancer): "I am not so good. I can't understand why I'm continuing to lose so much weight."

Doctor: "Have you had any pain?"

Patient: "I'm not going to get out of here am I?"

Doctor: "Have you had your bowels open since yesterday?"

This leaves a crucial question unanswered.

Difficult questions like "How long have I got?" or "Will this treatment make any real difference?" are dealt with by advising the patient to ask the ward sister, consultant, or general practitioner. Psychological problems are often dealt with in a similar way.

Role played patient (with advanced large bowel cancer): "I can't stop thinking the worst. I'm so worried."

Stoma nurse: "Then I'll ask the social worker to come and talk to you."

Doctors and nurses tend to spend less time with patients who are dying and may avoid them altogether. This is especially likely when patients dying on general wards are moved into side rooms. Ward rounds may then pass them by and contact is maintained only through junior medical and nursing staff.

Reasons for distancing tactics

Although these various distancing tactics are obvious to an observer, doctors and nurses are usually unaware that they are using them. But these tactics are used so consistently that they must have an important function. Interviews with doctors,⁴ and discussion with doctors and nurses who have participated in workshops on counselling cancer patients have shown cogent reasons.

Most doctors and nurses work under considerable pressure. To seek psychological problems by active inquiry might overload them. It is safer to assume that patients who develop problems will disclose them.

If doctors and nurses encourage a proper dialogue they could be faced with problems with which they will not be able to cope. They could be asked awkward questions, "Is it cancer," "Am I going to get better?" "How long have I got?" or "Why isn't the treatment working?" These are difficult enough to answer without the added hindrance of being instructed by a doctor or relative that the patient must not be told the truth. Few doctors or nurses knew how to deal with such collusion and feared that attempts to talk with the patient would cause more harm than good and get them into trouble with their seniors.

Many doctors and nurses feared that if they clarified how a dying patient was feeling they could unleash strong emotions like despair and anger that they could not contain. This would take up too much time and they might be accused of upsetting the patient. They were uncertain about how to distinguish between worry and an anxiety state and between sadness and a depressive illness. So it was prudent to avoid asking open questions like "How are you feeling in yourself."

FEAR OF GETTING TOO CLOSE

If the carers established a proper dialogue with each patient they would be confronted with the enormity of the suffering and the consequences of the impending loss. This would make them feel sad and angry because the death seemed unjust, untimely, and senseless. Such feelings could be overwhelming if they had come to like the patient or the patient reminded them of someone they loved or had lost. They also worried that "getting emotionally involved" would make it much harder for them to accept that they could not always guarantee a peaceful death for their patients.

How often can the carers risk getting this close to patients and provoking such feelings in themselves before they feel drained emotionally? If they do tune in to their patients' suffering what do they do with their own feelings? If they disclose how they feel to colleagues they might be viewed as unsuited to terminal care. If they take their feelings home it might impair close personal relationships. Their consequent emphasis on pain control and symptom relief could, they acknowledge, be the most effective distancing tactic of all.

Those who wish to improve psychological care of the dying face a dilemma. How can they provide effective care without jeopardising their own emotional survival, for it has been found that getting close too often can exact a toll and cause "burn out"?⁵

Cost of caring

In the early stages of "burn out" the carer feels increasingly exhausted and becomes prone to colds, aches, pains, and insomnia. He or she becomes more irritable, particularly in the home, and begins to withdraw socially. The carer now has too little in reserve to cope with any additional emotional

demands and responds with resentment and indecisiveness. Yet he or she is now also less willing to heed colleagues' views about management and becomes cynical, rigid, obstinate, resistant to change, and takes refuge in gallows humour. Eventually, self disgust may cause the doctor or nurse to opt out of terminal care.

Those who are extremely dedicated, have no other major interests or outlets, lack personal support outside their work, have high ideals and standards, keep problems to themselves, are ambitious, and identify closely with their patients are most likely to "burn out" within a few years of beginning work with the terminally ill. Consideration needs to be given, therefore, to ways of ensuring effective psychological care of the dying while minimising the risks to the carer.

Solutions

Doctors and nurses appointed to work with the terminally ill should be selected carefully. Those who are flexible and willing to heed the views of others, are willing to share any problems, have good emotional support, and other interests outside work, and are optimistic but realistic about what can be achieved in terminal care are likely to function well and survive.

TRAINING

If staff are to feel confident in opening up and maintaining an effective dialogue they must be trained in the relevant interviewing, assessment, and counselling skills. Such training should include demonstrations on television of how to talk with dying patients and handle difficult problems.⁶ It should include practice with real, simulated, or role played patients so that each doctor and nurse is given constructive advice about their skills. Feedback should also identify any distancing tactics they use. Yet few courses that train nurses to care for the terminally ill include this feedback training. Nor does undergraduate or postgraduate training of doctors give much attention to these skills or problems of talking with dying patients and their relatives.

The use of short training courses for those already in post could help to remedy this deficiency. Workshops that include doctors and nurses and use feedback methods seem effective. Doctors' rules about communication and nurses' willingness to hide behind or reluctance to challenge them can be examined jointly and common difficulties acknowledged and worked through.

STRUCTURING THE WORK

Properly selected and trained staff will get close to their patients' concerns and suffering. Is it fair or wise to expect any doctor or nurse to do this full time? Should they not be limited to three or five year contracts? Doctors might function more effectively if they divided their time between care of the terminally ill and other clinical specialties, such as radiotherapy or anaesthesia. For, as one anaesthetist expressed it, "I move between two extremes. At the sharp end (terminal care) are those patients suffering terrible pain and facing death. At the other (general anaesthesia) I just put them to sleep."

Nurses who specialise full time in terminal care are unlikely to have been trained to conduct research or to teach. So it might be difficult for them to spend time on different tasks, particularly if they are the only specialist nurse in a given geographical area. It might be preferable to employ part time nurses or include the job in a rotation between hospice, continuing care unit, or domiciliary care team and general hospital work or other duties in the community. This would have the advantage that nurses would transfer what they had learnt in terminal care to other settings and raise standards.

Since working with dying patients is so demanding when done properly, time out is essential. Attendance at study days or workshops is one way of achieving this. Yet few medical or nursing managers see this as a priority. They may be especially reluctant to grant leave if the doctor or nurse is the only resource in terminal care available to them. So more than one specialist worker should be appointed in each area.

Doctors and nurses are more likely to survive when their roles are made explicit, they respect each other's difficulties, the doctor accepts the nurse acting as the patient's advocate and gives her permission to enter into dialogue with his patients.

If they are to function effectively those working in terminal care should have a regular opportunity to talk about any patients or staff who are causing them difficulties. This may be achieved through the establishment of support groups held fortnightly and attended by doctors, nurses, and social workers. They should be led by a person who understands group dynamics and helps staff to face key issues without turning the support group into a "therapy" group.

Conclusion

Too few doctors and nurses concerned in terminal care have had adequate training in key communication skills or are receiving

adequate support. Unless these deficiencies are remedied they will continue to employ distancing tactics and psychological care will be neglected. Alternatively, they will risk getting close but could be harmed by their experience.

References

- 1 Hinton JM. The physical and mental distress of the dying. *Q J Med* 1963;32:1.
- 2 Stedeford A. *Facing death*. London: William Heinemann, 1984.
- 3 Cartwright A, Hockey L, Anderson JL. *Life before death*. London: Routledge and Kegan Paul, 1973.
- 4 Rosser JE, Maguire P. Dilemmas in general practice: the care of the cancer patient. *Soc Sci Med* 1982;16:315.
- 5 McElroy AM. Burnout—a review of the literature with application to cancer nursing. *Cancer Nursing* 1982;6:211.
- 6 Maguire P. Communication and patient care. In: Steptoe A, Matthews A, eds. *Health and human behaviour*. London: Academic Press, 1984:153-73.

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Medicine and the Media

IN NOVEMBER 1983 James Cutler of Yorkshire Television drew attention to high rates of childhood leukaemia in the neighbourhood of the Sellafield nuclear reprocessing plant. That programme led to an independent inquiry, chaired by Sir Douglas Black, and stimulated a spate of epidemiological research, which as yet has failed to provide clear cut evidence for or against the allegation that radioactive discharges from the plant are responsible for the local excess of cancer in children.

In their pursuit of radiation hazards Mr Cutler and his team have now turned their attention to the occupational and environmental risks arising from Britain's nuclear deterrent (*Inside Britain's Bomb*, ITV 3 December). Their main theme is an apparently increased incidence of cancer, in particular leukaemia, among young people living close to nuclear weapons establishments. The format of the report was familiar. An array of damning statistics was interspersed with sad case histories and emotive interviews with bereaved families. An earnest but harassed minister put the case for the government but on several occasions was made to look foolish by the editing process. The story was spiced with horrific tales of nuclear near accidents and evidence of overexposure to radiation among employees in defence institutions. To complete the picture we were informed of a cluster of cleft palates in children born to the wives of nuclear submariners. Several experts agreed that the findings of the investigation gave cause for concern.

The overall impression was of questions that need to be answered, although the true merits of the case were difficult to evaluate from the facts presented. Some of the statistics concerned only leukaemia, others reticuloendothelial cancer, and yet others all cancers combined. Figures were not given consistently for the same age groups, and the time periods studied were often unspecified or appeared arbitrary. Nor was it clear on what basis the areas of study around the nuclear installations were defined, and why data were not presented for all of the establishments mentioned in the programme. One was left with the suspicion that the study populations had been chosen to maximise the impact of the observations. Moreover, there was no description of the methods by which cases were ascertained or of the biases that can arise in the comparison of disease rates derived from different sources.

Perhaps it is unreasonable to expect detail of this kind in a programme for general consumption. The aim of the presentation was to provoke further inquiry not to provide a balanced overview of the problem. One can only hope that the investigation was carried out responsibly and that fears have not been generated inappro-

priately. To his credit the presenter, Jonathon Dimpleby, stated clearly in his conclusion that the link between radiation and the reported excesses of cancer is not proved, but whether this message got through to his audience is another matter.

No doubt the research that has been called for will materialise, although it may never provide satisfactory answers to the questions posed. When only small numbers of cases are available for study it is almost inevitable that substantial uncertainties will remain. If nothing else, reports such as this have the merit of keeping epidemiologists and statisticians in work. Whether they lead to the most efficient use of resources for research is, however, open to question. Perhaps one day there will be an exposé of the exposés.—
DAVID COGGON, epidemiologist, Southampton.

IN A BRASH FRONT cover, laid out as a tabloid front page, comes *The Report*, and inside the working party "tells all." The South East Thames Regional Health Promotion Group working party's enthusiasm for its remit—to consider "closer and more fruitful collaboration between the mass media and health educators"—is evident in its recommendations for incentive and direction to come from the top. Chairmen, general managers, and community physicians are all part of "a planning framework embodying a rolling programme." The report assures us that it is only lethargy and lack of motivation that lead to poor media campaign results. The recommendations under "keys to progress" move relentlessly on, and just in case anyone is tempted to duck out, pleading lack of experience, recommendation 8 refers to training in media communications skills.

The working party recognises that training is vital if the messages, information, and ideas health professionals want to convey are to be read, seen, or heard in the way and with the results they intend. The section on training is well presented, making recommendations to help both health professionals who may come into contact with the media only rarely and those whose jobs should mean frequent contact.

A special survey of 20 magazine editors, covering women's weeklies, teenage publications, and fitness publications, showed they did not regard the NHS as a source of information or ideas. Clearly the working party is vindicated in believing health educators must do more to promote positive health messages. How should health educators go about this difficult task? Here the report lacks