General practitioners' beliefs and attitudes about how to respond to death and bereavement: qualitative study

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Abstract

Objectives To investigate the perceptions of general practitioners when they are notified or hear of a death or bereavement in their practice; to explore doctors' accounts of their relationships with their patients in the context of bereavement; and to explore the concerns of general practitioners in managing themselves and bereaved patients.
Design Semistructured interviews followed by qualitative content analysis.
Setting London borough of Redbridge.
Participants 25 general practitioners.
Results Almost all the doctors had felt guilty about issues relating to the death of patients. These feelings were based on their expectations of not making mistakes and diagnostic precision. They described a culture gap existing between hospital and general practice and a need to develop new models and methods to explain and manage the causes of illness presented to them. In the absence of useful teaching on bereavement, many devised strategies which relied more on their personal experiences. General practitioners used various methods to contact bereaved patients, especially if they had been involved in the terminal care or if the death was particularly shocking. The doctor was also bereaved by the death of well known patients and sometimes needed to grieve and express emotion.
Conclusion General practitioners may need support and learning methods to manage their own and their patients' bereavement.

Introduction

In 1941 Lindemann suggested that bereaved people need to separate from the memory of the deceased, readjust to the environment in which the deceased is missing, and form new relationships.[1] Bereavement carries appreciable morbidity and mortality.[2 3] Support for bereaved people had been proposed[4] as there is risk of depression,[5] prolonged distress,[6] and persistent or chronic grief.[7] Some studies have suggested that bereaved people benefit from involvement of family doctors.[8 9] Contact is at least appreciated.[10] Up to a quarter of patients have suffered unresolved grief before the onset of their medical problems.[11]

What are general practitioners doing about patients' bereavements? Death registers have been suggested[12] and, if organised by health authorities, would provide a more efficient system of notifying deaths to practices.[13] Charlton and Dolman recommended that practices appoint a key worker who would make contact with bereaved people to express sympathy and enable them to express emotion.[14] In South Thames region, two fifths of practices routinely offer contact with bereaved people.[15] However, there is a lack of research evidence about the efficacy of bereavement management and the role of the general practitioner. In addition, no definition exists of good practice, and there is a risk that general practitioners may medicalise a social experience to which they would then have to respond.[16–18]

We were interested in the beliefs and attitudes of general practitioners to death and bereavement among their practice populations, what they did, and how they explained their actions. The study set out to investigate general practitioners' perceptions when notified of a death in practice, to explore doctors' accounts of their relationships with their patients in the context of bereavement, and to explore areas of concern to general practitioners in managing themselves and bereaved patients.

Participants and methods

As this was uncharted territory, we decided to use qualitative methods to explore the ideas and experiences of the study population.[19 20] One of us (EMS), a general practitioner with an interest in bereavement, undertook six pilot interviews with general practitioners during 1996. Doctors' ideas and concerns about bereavement were identified. The main study was of general practitioners practising in the London borough of Redbridge. We used a semistructured questionnaire and recorded interviews on to audiotape for transcription. We analysed the interviews using a grounded theory approach[21] with Atlas Ti qualitative research software. The study was approved by Barking and Havering ethics committee.

We discussed themes as they emerged. EMS did most of the analysis. LR read the transcripts to identify themes, and differences were debated to find a consensus.

A list of general practitioners was provided by Redbridge and Waltham Forest family health services authority. General practitioners were chosen purposefully from a total of 118 in the area. A table was

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Common concerns of general practitioners regarding bereaved patients

- General practitioners' fears of making mistakes
- Different approaches in hospital and in general practice
- Effect of medical training versus personal experience of life
- Doctors' different approaches towards contacting the bereaved
- Doctors' own sense of loss

constructed of doctors stratified by sex, ethnic group, and whether single handed or in partnership. Doctors who agreed to be interviewed were subsequently visited at their home or practice.

Results

Of 45 general practitioners sent letters of invitation, 25 agreed to be interviewed, a response rate of 56%. Compared with the total population of general practitioners in Redbridge, there were more women in the sample (36% *v* 31%), fewer non-white doctors (48% *v* 55%), and fewer singlehanded practitioners (32% *v* 44%). The mean number of years in practice was 15.3 (SD 8) years. Twelve had had formal vocational training, and 14 completed their undergraduate training in the United Kingdom. Ten had membership of the Royal College of General Practitioners. The box gives the themes identified from the transcripts.

All but three doctors described fears of making mistakes and feelings of guilt and self blame when their expectations of the clinical course of illness differed from reality. One said:

> It was a classic: no history, a fit man (with) epigastric pain. Went off and had a heart attack a couple of days later, and I felt awful.

Some expressed the view that if there was a perceived error it was important to make contact in order to be seen to be taking responsibility. Some felt confession to be important as part of the empathic process. They also perceived the error as a learning experience. One doctor said:

> You feel better. They learn something from it, you learn something from it. The relatives feel better. You should tell junior doctors that it is better to front it out.

The doctor-patient relationship was also felt to potentially protect general practitioners:

> Because they know us better than hospital doctors this tends to negate the anger. The hospital is just the hospital. They have known us for years.

Approaches in hospital and general practice

Twenty of the 25 doctors described a difference they perceived between general practice and hospital medicine. One said:

> There is a need to teach medical students that in general practice things are often very fuzzy, and that the GP sees people over a very long time. In general practice you can have rows with someone yet still have a relationship with them.

They described their acquisition of a "hospital model" of serious disease, necessitating speediness in correct diagnosis; and a "general practice model" dealing with softer medical problems for which diagnostic certainty is generally less critical. They described their role as teasing out the physical from the psychological and social. But the initial training in the hospital model persisted and could be a source of guilt and self blame when serious illness was not diagnosed at the first attempt.

Influence of medical training and personal experience

Only three out of 25 doctors mentioned that vocational training had influenced their bereavement management. Most doctors felt that their attitudes and beliefs were based on personal rather than professional experience. Twenty three felt ill equipped by their medical school training:

> At medical school nobody tells you that you are not treating a disease. You are treating a person who has come to you with a problem.

In the absence of appropriate training, many based their response to bereavement on experience obtained from their family origin and culture. This approach was particularly acknowledged by Asian doctors and those who held religious beliefs. In all, 19 out of 25 doctors believed their previous personal experience to be important. One said:

> I was brought up in Tanzania, and there was a family doctor who was a real family doctor. He knew everyone in the town. That was it. I try to do the same.

Personal experience of bereavement also shaped the attitudes of some doctors. One commented:

> As you grow older, it is from the personal experience of bereavement that you begin to appreciate more of how people feel and what they need. When you are younger you behave as if you've got to help the relative deny that the deceased existed. That attitude changes as you mature.

Approaches towards contacting bereaved patients

Most doctors felt that general practitioners had a responsibility to make some sort of contact with bereaved patients, with 17 out of 25 doctors specifically discussing making a contact. All subjects related this to the doctor-patient relationship. If this was strong, then contact was more likely:

> If it was a patient I had been looking after for some time then I would follow up with a post-bereavement visit either immediately or within a couple of weeks after the death.

Some doctors reported that if the death was unexpected or particularly traumatic, they were even more likely to initiate a contact. If patients were not known to a doctor, however, responses varied widely, each case being considered on its merits. There was no consistent policy.

Contact was considered important. Most reported visiting the bereaved, sending a letter or card, and using the telephone. Visiting was used mainly for patients known to the doctor, but telephone contact was used too:

> We ring up sometimes . . . occasionally we write. That's about it, but if we've been involved with the death, we usually go round.

We asked the rationale for the general practitioners' approaches. All respondents expressed a desire to

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be empathetic, sympathetic, and compassionate. Being a human being as well as a doctor was considered an important rationale for this part of their work. One said:

I've been to their house many times, but this time I am not a medical man and my role as a medical man has finished. So I am just a human being and my feelings are those of a human being.

This aspect seemed to be an important ingredient in the doctor-patient relationship.

Doctors' own sense of loss

Occasionally a doctor reported experiencing personal grief at the loss of a patient because of a process of identification with the patient. One said:

I can see my own parents in some of my patients. I find myself attached to them trying to look after them the best I am able to in the last few weeks of their lives. I nurse them as I nursed my parents.

An intense, long term relationship may produce a sense of loss in the doctor when bereavement occurs. In such circumstances, grief was not vicarious but real. One said:

The longer I have been in practice the more painful the loss of my patients, particularly as I have known them for most of my professional life.

Discussion

This study explored the ideas and beliefs of general practitioners about death and bereavement in patients. The use of interviews allowed greater exploration of ideas and feelings than would have been possible by quantitative techniques. Interviewees' comments were taken at face value.

The study has the following weaknesses. The sample group was small, and some of the ideas may not be generalisable. In addition, the study population was selected purposely. It comprised only doctors who agreed to be interviewed and was not precisely representative of the total population of practitioners in Redbridge. Those who refused may have different opinions. The interviewer was a general practitioner and was able to establish good rapport with respondents. This may also have been a source of bias.

Guilt, blame, and diagnosis of serious disease

General practice carries a high risk of mental illness for doctors.[22] All but three doctors in this study had felt guilty about issues relating to the death of patients. Such feelings of guilt seemed to be based on the expectation of not making a mistake. Medical school education, with its emphasis on the biomedical model and appearing to "get it right," left some general practitioners with a feeling of inadequacy. There is ample evidence of stress among general practitioners, and this is one of the likely causes.[23]

A culture gap seems to exist between general practice and hospital medicine. The professional socialisation of doctors within medical school and hospital seems inadequate for general practice, which needs new models and methods to explain and manage illness in the community. Diagnosis seemed to be more difficult in general practice because of the evolving nature of medical problems.[24]

Key messages

- Most general practitioners fear making mistakes because they have a model of diagnostic precision based on their initial professional medical socialisation
- Doctors differ in their approaches to bereavement management
- The techniques developed by doctors to manage the immediate phase of bereavement stem from personal experience rather than medical training
- General practitioners may need to express their own grief at the loss of a patient and a relationship
- General practice needs to develop its own models to reduce the stress felt by practitioners

Contact

If general practitioners were intensely involved with the dying patient, they considered a home visit, telephone contact, or some other contact with bereaved relatives appropriate. When the relationship was less intense, or if the death occurred outside the borders of general practice, contact was less likely. Visiting, telephone, cards, and letters were all used. Although professional expressions of sympathy and condolence were offered, there could also be a personal element from the doctor. The doctor was also one of the bereaved, having lost a patient and a relationship, and some needed to grieve and express emotion.

We thank the participating general practitioners in Redbridge who gave so freely of their time to make this research possible. This study was presented by EMS in partial requirement for the master of science in general practice at UMDS Guy's and St Thomas's Medical School, University of London.

Contributors: ES conceived the original idea, developed the questionnaire, organised the sample, undertook the interviews and analysis and developed a dissertation from which this paper arose. LR supervised the research, helped to clarify ideas and procedures, contributed to the analysis, and gave helpful criticism in the preparation of this paper. The paper was written jointly by both. ES is the guarantor.

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Commentary: Use of personal experience should be legitimised

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Saunderson and Ridsdale are correct in saying that conclusions about general practitioners' attitudes to bereavement can be obtained only by qualitative techniques. Even if the ideas are not generalisable, the study carries validity in terms of the true feelings of the interviewed doctors. It also echoes two familiar truths of general practice. On one hand, personal care can not only bring unquantifiable benefits to patients and their families but also give deep and long lasting satisfaction to the doctor. On the other hand, equally familiar is the guilt of doctors who feel they are not practising the "proper medicine" that goes on in hospitals. It is surprising and sad to discover that this canard still persists.

The authors conclude that doctors rely more on their own experience than on formal teaching from medical school when dealing with death and bereavement. It would be tempting to conclude that here is a subject crying out for inclusion in the undergraduate medical curriculum. Thank goodness, in today's reformed educational world[1] more thoughtful counsels will prevail. To regular readers of the *BMJ*'s Personal View column this finding is also not a surprise. Every few weeks a personal account of illness in themselves or a close relative describes doctors learning from the experience of suffering. Yet my own contact with students suggests that most of them come to university already equipped with this understanding of suffering, based on the experience of friends or close relatives.

Our lived experience, or that of close friends and relatives, is probably one of the most valuable resources, helping us to a more immediate understanding of human illness than any medical textbooks, or even a study of narrative, can do. Perhaps undergraduates in the first years of study know this instinctively, or perhaps they simply have nothing else to guide them. However, what traditional courses teach them, if only implicitly, is that this knowledge is not to be trusted. As Platt put it so eloquently, "The first staggering fact about medical education is that after two and a half years of being taught on the assumption that everyone is the same the student has to find out for himself that everyone is different, which is what his experience has taught him since infancy."[2]

What is needed is a rigorous approach to using life experience. We should start by legitimising it as a valid source of information. We need then to explore the pitfalls—how and when it misleads. Like every drug, operation, intervention, technique, instrument, etc, it carries risks as well as benefits. So while we are making its use explicit we may be able to help doctors learn the limits of its usefulness. The message to students and doctors needs to be not only "trust your experience" but also "know when to trust it and when not to," and even, most difficult "be confident about synthesising what you know from experience with your knowledge of biomedical science." What we want are graduates who, as the participants in a similar study in 20 years' time, will reply confidently: "One of the things I learnt in medical school was to rely on my own experience with these kind of problems."

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A memorable consultation

STD outreach by taxi

My taxi driver was extremely buoyant and excited. The newest London taxis now have a microphone system allowing the driver to talk into your ear. No longer the chance to close the glass screen and read your papers. His excitement centred around his last fare: "A gorgeous bird from Lithuania with long blonde hair, black boots, and a short skirt. I got her address and she's going to introduce me and my friends to some other Lithuanian birds." At this point he dropped me outside my clinic. I couldn't resist asking him if he knew what happened inside Mortimer Market. Yes, he did, and "aren't you the guy who's always talking about AIDS?" I explained that we had recently seen a substantial rise in HIV and syphilis imported from eastern Europe and that many Lithuanian women were being lured to London to find that the exciting job they had been offered turned out to be prostitution. He seemed saddened and deflated by the news, driving off swiftly only to screech to a halt after 20 yards, leaning out of his cab to shout, "Thanks Guv, you've saved my life." I congratulated myself on a successful first foray into STD outreach by taxi.

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