

# Improving management of bereavement in general practice based on a survey of recently bereaved subjects in a single general practice

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## SUMMARY

**Background.** Previous studies of bereavement in primary care have tended to concentrate on the attitudes of general practitioners (GPs) to bereavement support and little has been documented on the views of patients.

**Aim.** To establish the role, content, and value of a protocol designed to help the newly bereaved by examining the experiences and expectations of a group of bereaved patients within a single general practice, with a view to developing patient care within this area.

**Method.** A qualitative approach was adopted using a semi-structured questionnaire, data collection, and analysis consistent with the principles of grounded theory. Patients were approached by letter and those who agreed to take part in the study were interviewed at home.

**Results.** Many of those interviewed expected some form of contact from their GP after bereavement, although the nature of the contact they would have liked varied. The majority would have appreciated a letter of sympathy and none would have objected to it. Over half expressed some form of dissatisfaction either with their GP or with the hospital. Quality of information giving and communication affected bereavement outcomes for some. The role of the GP was examined and patients responded positively to practical suggestions to improve bereavement care.

**Conclusions.** Bereavement support was seen to be an important part of the GP role by the majority of those interviewed. As a result recommendations have been made for a protocol to support the newly bereaved.

**Keywords:** bereavement; grief reaction; bereavement support; GP attitudes.

## Introduction

NOWADAYS most people die in institutions such as hospitals and residential and nursing homes, and so families and relatives are not prepared to deal with the death of a relative in the same way that their grandparents were.<sup>1</sup>

Expectations of modern medicine can make the reality of death a subject with which most people feel uncomfortable. Thus Costello<sup>1</sup> suggests that this can result in a stigma being attached to the subject and preparation for bereavement has become a subject which people avoid. However, Steen<sup>2</sup> believes that the death of a loved one is one of the most stressful experiences of life, describing it as a personal natural disaster affecting both health and social circumstances. Writers<sup>3-5</sup> have emphasised the normative component of grief reactions. One of the earliest theories

was put forward by Freud<sup>3</sup> in his work *Mourning and Melancholia*. He believed that grief was a normal process involving withdrawal of ties to the deceased. Other authors<sup>4-6</sup> have since developed models that are derived from this work. However, some people deviate from the norm, leading to the concept of abnormal grieving. Parkes<sup>7</sup> describes the circumstances under which abnormal grief reactions can occur.

Symptoms that might indicate an abnormal grief reaction have been documented by various authors and summarised by Woof and Carter<sup>8</sup> in their literature review. If bereavement can have a detrimental effect on health, it should be of relevance to the health professional. While some would warn against the medicalisation of grief<sup>9,10</sup> others consider that grief should be regarded as a medical problem as it can be associated with illness,<sup>11</sup> social isolation, and loneliness.<sup>12</sup> Charlton and Dolman<sup>11</sup> believe that bereavement care is a neglected area of health promotion and that general practice is the ideal place to help and support bereaved people, providing preventive care where problems are likely to occur.

The aim of the study was to improve the management of bereavement, to examine bereaved patients' views of bereavement support within a general practice, and to develop a protocol for helping the newly bereaved as no formal bereavement support policy currently exists.

## Method

A qualitative rather than quantitative approach was adopted using the principles of grounded theory<sup>13</sup> where data are collected and analysed concurrently. Early data are coded with words that describe emerging themes. These themes will determine what information will be sought next and interview questions may evolve or change as the ongoing analysis refines the focus of the study.<sup>14</sup> Approval for the study was obtained from the Local Research Ethics Committee.

## Sample

As no form of death register existed in the surgery, the identification of patients within the practice who had been bereaved was difficult. The only method available was to use the practice computer to compile a list of patient deaths in the previous two years and check the family registers of those patients for relatives or partners still living at the same address. By this method a list of patients registered in the practice and who had suffered a bereavement were identified (after excluding for ethical reasons the recently bereaved and those with known bereavement-associated problems). For ethical reasons the following were excluded from the study: anyone under the age of 18 years, those who had been bereaved within the previous six months, and anyone whose practice records included entries relating to health problems associated with their bereavement.

A total of 36 patients who were identified in this way were contacted by letter and asked to participate in the study. Of these, 23 (six men and 17 women) agreed to be interviewed. All participants were over the age of 60 years. The participants were interviewed at home by the author. Data were collected using a

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### 1. Satisfaction with GP

#### (i) Completely satisfied:

- No contact with surgery
- GP contacted patient
- Patient contacted GP

#### (ii) Not satisfied:

- No contact from surgery
- No acknowledgement during consultation
- Felt ill-informed about seriousness of illness
- Support disappeared following bereavement
- GP forgot cause of death

#### (iii) Nature of dissatisfaction:

- Felt let down by the surgery
- Hurt by apparent lack of awareness
- Angry following an unexpected death
- Bitter because given misleading diagnosis

### 2. Quality of information given (hospital and GP)

#### (i) Prior to death (excluded are those previously well or who died suddenly):

- Felt fully informed
- Felt inadequately informed
- Were unaware of seriousness of illness

#### (ii) After death (excluded are those who felt fully informed). Of the remaining 13:

- GP/hospital explained cause of death to their satisfaction
- Some subjects gave more than one reason
- GP/hospital still unable to offer adequate explanation

### 3. Adequacy of communication

- Some reported that they way information was given to them affected how they felt

### 4. Differing expectations of the GP service

#### (i) Contact with surgery/GP following bereavement in any form:

- Some form of communication/contact should be made
- Contact with the surgery/GP not necessary

#### (ii) Acknowledgement of bereavement during routine consultation:

- Important and should happen
- Possibly, but wary of trivialising physical symptoms
- Not necessary

### 5. Development of the service

These are positive responses to suggestions put to the subjects by the researcher:

- A letter offering sympathy/support would be appreciated
- A visit by GP/nurse should happen
- A specific bereavement consultation should be offered
- Notes should be tagged to allow GP/nurse to be 'bereavement aware' during consultation
- Record of deaths kept to allow members of staff to offer sympathy when appropriate

**Box 1.** Themes arising from interviews with bereaved patients.

semi-structured interview schedule. Areas of enquiry were:

- individual experience of bereavement;
- the intervention of the health care services at the time;
- expectations of the health care services regardless of their actual experiences; and
- their reaction to several suggestions for possible improvement.

Participants were encouraged to talk about their own experiences from their own point of view. This unstructured form of interview is described as a 'conversation with a purpose'.<sup>15</sup> The interviews were not tape recorded. Field notes were made at the time by the author and a written record of the interview made as soon as possible afterwards with actual comments and opinions

recorded. As the interviews progressed emerging themes were noted and subsequent interviews focused on them. The ongoing analysis of the data allowed themes and issues not considered before the start of the study to be pursued and developed. Issues surrounding hospital care emerged and have been included in the study. Widening the search to increase the number of participants was considered. However, as no new themes were emerging during the final interviews, this was not felt by the author to be necessary.

## Results

After all the interviews had been completed, themes or categories were identified. These are set out in Box 1.

### *Satisfaction with the service*

Ten subjects who expressed complete satisfaction with the service they received all had relatives who had been ill for some time. Those who had had contact with the surgery appreciated it. Those who were satisfied but had no contact with the surgery felt that the general practice was not required in this situation. Thirteen subjects voiced some dissatisfaction with the service they had received. Those who mentioned that there had been no contact with the surgery felt that this was an important job of the general practitioner (GP) or a member of his team. Contact in any form would have been appreciated and they had expected it to happen. Some felt they had not been made aware of the seriousness of the illness. One felt the hospital had understated how ill her husband was 12 hours before his death, while another felt abandoned by her GP after her husband died.

### *Quality of information given (GP and hospital)*

*Prior to death.* Those who felt fully informed at every stage of their relative's illness told of the 'kindness' of hospital staff, the 'marvellous' GPs, and the 'excellent' care their relatives received both in the community and during hospital admissions. Others, however, felt they had not been fully informed. Several subjects said they were unaware their relative had reached the end of what in most cases had been a long illness and missed the chance to share final memories. Another felt that no-one told him what was going on. Some seemed apparently unaware that their relative had a life-threatening illness.

*After death.* Some subjects who had expressed some dissatisfaction at not feeling fully informed prior to the death were happy that the GP/hospital explained to their satisfaction the reasons for the death of their relative afterwards. Others were unhappy because, even up to three years later in some cases, they did not fully understand the cause of death or the circumstances surrounding it. Three said that they still did not understand why certain things had been written on the death certificate. On being told of advanced arthritis as a secondary cause of death one subject claimed that 'no-one told me she had arthritis, and suddenly it's advanced!' Most of this group felt that the reason they had not been given a full explanation was because there was no contact from the health services after the death.

### *Adequacy of communication (GP and hospital)*

The majority of patients reported no problems in this area. Most could not actually remember what had been said to them, but only recalled that the manner of health service staff had been comforting and supportive. However, those who reported problems in communication could recall exact remarks made at the time and were still upset about them.

### *Differing expectations of the GP service*

At the end of the interview some subjects still had no expectations of their GP following a bereavement. However, the majority felt that contact and communication with people who had recently been bereaved was important and something that ought to happen. Some were visibly upset during the interview: 'I can't understand it at all ... Why did no-one contact me after? ... we had been with the practice all our married lives.'

The need for the GP to be aware of bereavement and to acknowledge it during routine consultations was thought to be important by some subjects. Several were upset when their bereavement was not mentioned as they had questions they wanted to ask but felt unable to raise the subject as the GP had not mentioned it. Those who were normally fit and well and who rarely attended surgery said that had they needed to see their GP and would have expected acknowledgement of their bereavement. The majority of those whose bereavement had been acknowledged by their GP appreciated it and felt it proper that it had been. Three subjects were worried that genuine physical symptoms might be trivialised or assumed to be part of a bereavement reaction.

### *Development of the service — several specific suggestions were put to the subjects to seek their views*

*A letter of sympathy.* The majority said 'yes'. One felt that it would have given her 'permission' to ask for help, another expressed the view that while most people do not need professional help, it was easy for those who did need help not to receive it and a letter from the surgery would be valued: 'I don't think you'd be inundated with weeping people.' Another said: 'I think that about 50% of people would benefit, but 100% would appreciate it.'

*Visit from GP/nurse.* A few believed it to be necessary, although most would have appreciated it. One simply asked for 'five or ten minutes to explain what had happened and why', while another was more distressed: 'His death has left me desolate and until I have answers to my questions, I'm finding it so difficult to come to terms.'

*Tagging of notes.* A practical way of ensuring bereavement awareness is by 'tagging' or marking the notes of the bereaved person in some way and this was also put to the subjects. Not surprisingly, those who expected awareness and acknowledgement reacted enthusiastically to this suggestion, while the few who had reservations were those concerned about the trivialisation of physical symptoms.

*Record of deaths.* The final suggestion was that there should be a record of deaths within the practice. This would allow surgery staff to offer sympathy to those who had been bereaved if appropriate. This was generally well received. Box 2 contains some additional quotes from the subjects.

## **Discussion**

The decision not to tape record was taken because of the very sensitive nature of the interview and it was felt that subjects might feel threatened by the fact that their conversation was being recorded and taken away by the author. Some subjects came with their own agendas and talked at length about very distressing experiences. Others were very critical of both hospital services and their GP and were aware that the author was the practice nurse employed by their GP. For some, it was the first time they had spoken openly about these matters to anyone out-

### *No contact with GP*

#### (i) Satisfied:

- 'What could he (the GP) have done? It wouldn't have changed anything.'
- 'That's not their job.'
- 'They're too busy to perform this social role.'

#### (ii) Dissatisfied:

- 'The GP should visit personally. I should not be expected to go to the surgery.'
- 'A simple acknowledgement of bereavement is often all that is required it would not strain the service in terms of time or resources.'
- 'A telephone call would do.'

### *Unaware of seriousness of illness*

- 'They [the hospital] told me he wasn't very well and could stay another week if he wanted — he died that night.'
- 'Not very well is a huge step away from being so ill he died within 12 hours.'
- 'Lots of people have asthma and they don't die.'

### *Poorly informed*

- 'I have looked after him so intimately, over so many years, the end was so important for me to have him home where I could have some time for us to face it together.'
- 'The consultant didn't like talking to relatives.'
- 'I still don't know whether he died at home, in the ambulance or in the hospital.'

### *Poor communication*

- 'The specialist made a joke of it saying her heart was as strong as a bull's.'
- 'He was crying out and I asked the auxiliary to help. I've only got one pair of hands she said.'

### *Importance of family and friends*

- 'I've been very lucky with family and friends, but there must be lots of people out there on their own who need help.'

**Box 2.** Quotes from the subjects interviewed.

side their family. The fact that the interviews were not recorded might seem to limit the study in terms of sound measurable research methods. However, it was felt by the author on hindsight that the rich data that was actually collected was owing to the fact that some subjects felt they could express their thoughts and feelings in a confidential manner and that this justified the decision not to tape record.

The issues that emerged are not new. Poor communication and inadequate information caused distress to a number of subjects, sometimes resulting in bereavement difficulties. Seale's<sup>16</sup> view that those patients who suffered from cancer and their relatives were more likely to understand the implications of the diagnosis was confirmed in this study, whereas some relatives seemed to have been unaware of the seriousness of the illness that had resulted in the death of their relative. Those whose relatives had died from cancer understood that death was inevitable, although in some cases the timing was unexpected. Several subjects reported the upset that offhand remarks had caused. They described the guilt that they now felt after tactless remarks by health service staff. Davis *et al*<sup>17</sup> documents this finding also.

While a few subjects did not expect any contact from their GP following bereavement, none would have objected to a message of sympathy. Many bereaved persons adapt to their loss with little help from health professionals<sup>18</sup> and this was characterised by comments such as 'you just have to pick up your knapsack and carry on'. Others looked at what they still had and have moved on with the help of family and friends. 'I wept because I had no shoes, then I met a man with no feet.'

As a result of this study a series of suggestions have been made (Box 1, Item 5) based on the findings of this study and the documented literature. With regard to improving management of



bereavement, the suggestions that were put to the participants were generally received positively and are reflected in the literature. The development of a death register has been discussed by several authors<sup>11,19,20</sup> and an evaluation of such registers by Stacy *et al*<sup>21</sup> concludes that they are a valuable source of information used for, among other things, bereavement follow-up and care.

Most of the subjects felt that while some acknowledgement of their bereavement should be made, a visit was not necessary. This concurs with the results of Blyth<sup>22</sup> and Cartwright<sup>23</sup> but not with Gunnell.<sup>24</sup> Charlton and Dolman<sup>11</sup> suggest that if personal contact is not made then a suitably worded letter may be sent.

Robinson and Stacy's<sup>25</sup> guidelines for the management of the dying and bereaved include the recording of the death in the notes of close family members. Charlton and Dolman<sup>11</sup> also encourage the marking of case notes and only a few of the study subjects voiced an objection to this. Haines and Booroff's<sup>26</sup> survey of GPs found that half of their responders thought that terminal care was an important part of their work and believed that training in bereavement counselling would be helpful. However, a study of GPs in South Thames Health Region<sup>27</sup> found that only 39% of GPs who responded to their questionnaire routinely offered contact to their bereaved patients. The degree to which bereavement support is proactive or reactive seems to depend on the individual GPs interests, beliefs, and knowledge of individual patients. This has been demonstrated in this study also where bereavement support has been shown to be patchy and inconsistent. However, this study has identified from the bereaved person's point of view the practical steps that could be taken to improve bereavement care in general practice. This study has demonstrated that the bereaved do feel that some input from their GP is not only helpful but, for the majority, very important in helping them deal with their loss.

The study was limited in size, in that it was carried out within a single practice and thus reflects only the views of that practice population. It is also acknowledged that the sampling method did not identify all patients in the practice who had been bereaved, as it was not possible to find those patients who had been bereaved following the death of a person in another practice. However, the findings confirm previous research and therefore the author feels that they reflect a true picture.

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