Bereavement care in general practice: a survey in South Thames Health Region

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SUMMARY

Background. *Studies have shown that bereaved individuals suffer increased rates of physical and mental ill health. Bereavement support has recently been advocated as an area of prevention in primary care, with suggestions that general practitioners (GPs) should adopt protocols for the active follow-up of their bereaved patients, which relies on the early notification of deaths by hospitals and hospices. Little is known about the routine care currently provided by GPs and primary health care teams (PHCTs) to support their bereaved patients.*

Aims. *To explore GPs' perceptions of patient death notifications by hospitals and hospices. To describe practice policies relating to patient deaths and the provision of bereavement support.*

Method. *Postal questionnaires were sent to senior partners of a random sample of 500 general practices in South Thames Health Region.*

Results. *Three hundred and fifty-three practitioners responded (71%). Hospitals were perceived to be significantly slower than hospices in notifying deaths (P<0.0001). One hundred and ninety-six practices (56%) kept death registers, 230 (65%) discussed deaths together, and 142 (40%) identified bereaved relatives. One hundred and thirty-seven practices (39%) routinely offered bereaved relatives contact with a PHCT member; while 133 (38%) supported only those who asked for help. Routine support was significantly more likely to be provided by practices that kept a death register, discussed deaths together, identified bereaved relatives, and had a special interest in palliative care.*

Conclusions. *GPs perceive hospitals to be slower than hospices at notifying deaths, particularly in the first 24 hours. They are divided over whether bereavement support should be proactive or reactive. Keeping a practice death register, discussing deaths together, and identifying newly bereaved relatives are activities related to providing routine bereavement care.*

Keywords: bereavement support; hospitals, hospices; questionnaire survey; notification of death.

Introduction

ON average, 20 patients of a GP's list of 2000 will die each year.[1] Around two-thirds of these deaths occur in hospitals or hospices,[2,3] and the GP must rely on notification to initiate prompt bereavement support for relatives. Few studies have looked at hospital death notification to GPs, and the findings of those that have are conflicting. A study in six Dundee practices found that an immediate telephone call occurred in over half of cases.[3] However, a larger Tyneside study showed that GPs usually first heard of hospital deaths via the discharge summary; prompt hospital telephone calls were uncommon.[4]

Increased mortality[5,6] and higher rates of mental[7,8,9] and physical[6,10,11] ill health follow bereavement, with related increased use of alcohol, tobacco, and tranquilizers,[12,13] and increased hospital admission rates.[14] Interventions may improve outcomes, but the few well-controlled studies have been carried out on small samples. Parkes[15] and Windholz *et al*[16] concluded that counselling could reduce the risk of psychological problems after bereavement, especially for high-risk individuals. However, none of the studies were from primary care settings, even though practices are well placed to offer bereavement care, given their knowledge of the family and social situation. Recently, bereavement support has been advocated as an area of health promotion in primary care, with suggested protocols for the active follow-up of bereaved patients.[17] However, Woof and Carter highlight the possible dangers of over-medicalizing grief, and question the advisability of adopting such protocols unreservedly, without evidence from controlled evaluations that active follow-up affects outcome.[18,19]

Little is known about the range of routine bereavement care currently provided to patients in the primary care setting.[19] The only large study was by Cartwright,[20] completed in 1979, which found that 41% of GPs thought that a home visit should be offered when an elderly patient had been recently widowed, 8% felt they should make contact to see if they needed help, 36% said it would depend on the circumstances, and 15% thought they should respond only to direct requests for help. Changes to general practice since then, such as lower visiting rates, increasing demands on practitioners' time, a move towards larger practices, and fewer personal lists may have affected attitudes towards bereavement care provision.[21,22] More recent studies[23-25] have been mainly single practice based ones with limited generalizability, unable to examine the effect of practice characteristics and policies. Woof and Carter call for further research to inform the debate.[19]

We surveyed South Thames GPs to explore their perceptions of the communication of patient death information and to describe practice activities relating to patient deaths and bereavement support.

Method

A questionnaire was posted to the senior partners of a random sample of 500 general practices in South Thames Region. It asked about their experience of death notification from hospitals and hospices, their experiences of practice death registers, discussions about deaths, identification of newly bereaved relatives and support offered to them, and practice details. The sampling frame was collated from health authority lists. The questionnaire was piloted on 30 South Thames GPs, and ambiguous or difficult to answer questions were removed or modified. Merton, Sutton, and Wandsworth Research Ethics Committee granted ethical approval. Non-responders were remailed after two and three months. The full questionnaire is available on request.

Regional data on practice characteristics such as partnership size and training practice status were obtained from the General

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Medical Services statistics for England and Wales,[26] and data on fundholding status was obtained from the Regional Health Authority to allow comparison of sample responders with all South Thames practices.

Epi-Info[27] was used for data entry and analysis. Simple frequencies and chi-square analyses were calculated as appropriate, with Yates' correction for two-by-two tables. Matched data comparing GPs perceptions of death notification by hospitals and hospices were analysed by the sign test using Stata.[28] Associations were sought between five activities relating to patient deaths and bereavement care (keeping a death register, discussing deaths, identifying bereaved relatives, offering routine bereavement support, and having a practice counsellor) and six practice factors (partnership size, fundholding and training practice status, practice area, special interest in palliative care, and having an above average proportion of elderly patients). Associations were also sought between the provision of routine bereavement support and the other four activities related to patient deaths and bereavement care.

The free comments made by respondents were grouped into themes by one of the authors (TH) and the face validity of these themes checked by the other author (TK).

Results

Three hundred and fifty-three practitioners responded (71%). Table 1 shows their practice characteristics compared with the region overall. Responders were equally likely to be from fundholding or training practices, but were less likely to be from single-handed practices. Two hundred and forty-one (68%) described their practice area as urban; 139 (39%) said they had an above average number (more than 15%)[29] of over 65-year-old patients on their lists; and in 47 (13%) at least one partner had a special interest in palliative care.

Information on patient deaths from hospitals and hospices

Hospitals were perceived to be significantly slower than hospices in notifying deaths, particularly in the first 24 hours after death (Table 2). For deaths in hospital, nearly half the responders had experienced a problem with the *time* taken to receive information, and over a third with the *quality* of the information received. Specific comments were made by 114 responders about the time taken to receive information: 113 relating to hospitals. The most frequent complaints were of delays, sometimes of weeks or months (28), or of no information at all (21). Twenty-three responders reported sometimes hearing about the death from other sources, and 13 had been embarrassed on learning of a patient death from a relative.

Ninety-three comments concerned the quality of information received: 92 relating to hospitals. The most frequent complaints were that the cause of death was not given (40), or that letters were not detailed enough (38). Eight reported that they rarely received the coroner's report after a post mortem.

Practice activity relating to patient deaths

Death registers were kept by 196 practices (56%). In most cases this was held on computer, otherwise a noticeboard or death book was used. Those who kept a register were asked to state what they recorded and 175 gave further details (summarized in Appendix 1). Single-handed practices were less likely to keep a death register (29/75 [39%] versus 167/278 [60%]; $P = 0.04$), as were urban practices (122/241 [51%] versus 74/112 [66%]; $P = 0.009$). Those with an above average proportion of elderly patients on their list were more likely to keep a death register (87/139 [63%] versus 109/214 [51%]; $P = 0.04$).

Deaths were discussed within the practice by 230 (65%)

Table 1. Practice characteristics for sample responders and South Thames general practices overall.

Practice characteristics	Sample responders n = 353 n (%)	South Thames general practices n = 1278 n (%)
No of GPs in partnership		
1	75 (21.3)	424 (33.2)
2–4	185 (52.4)	597 (46.7)
5–7	82 (23.2)	229 (17.9)
8 or more	11 (3.1)	28 (2.2)
Training practice	103 (29.2)	431 (33.7)
Fundholding practice	155 (43.9)	556 (43.5)

Table 2. General practitioners' perceptions of death notification from hospitals and hospices.

	Information from hospitals n = 353 n (%)	Information from hospices n = 343[a] n (%)	P-value[b]
Usual time taken to receive patient death information			
<24 hours	89 (25.2)	168 (49.0)	P<0.0001
1–6 days	226 (64.0)	150 (43.7)	
1–4 weeks	27 (7.6)	7 (2.0)	
>1 month	5 (1.4)	2 (0.6)	
Don't know	6 (1.7)	16 (4.7)	
Problem with time to receive patient death information	159 (45.0)	30 (8.7)	
Problem with quality of patient death information	128 (36.3)	25 (7.3)	

[a]n = 343 for hospices, as 10 responders had no access to a hospice; [b]matched sample sign test.

responders. Table 3 shows the most common discussion was informal and between only the GPs. Single-handed practitioners were less likely to discuss deaths (39/75 [52%] versus 191/278 [69%]; *P* = 0.01).

A practice policy for identifying newly bereaved relatives was reported by 142 (40%) of responders. Those with a special interest in palliative care were more likely to identify bereaved relatives (26/47 [55%] versus 116/306 [38%]; *P* = 0.04).

Type of bereavement care offered

Responders were asked which of three statements best described the care that their practice offered to the recently bereaved. One hundred and thirty-seven practices (39%) said they *routinely* offered contact with a primary health care team member, and 133 (38%) said they only supported bereaved relatives who approached them for help. Sixty-four (18%) reported different approaches by different partners in the practice, and in 19 (5%) practices none of these alternatives applied. Those practices with a special interest in palliative care were more likely to offer routine support after bereavement (28/47 [60%] versus 109/306 [36%]; *P* = 0.003); as were practices that kept a death register (89/196 [45%] versus 48/157 [31%]; *P* = 0.006); practices that discussed deaths together (104/230 [45%] versus 33/123 [27%]; *P* = 0.001); and practices that had a policy for identifying bereaved relatives (85/142 [60%] versus 52/211 [25%], *P*<0.001). Single-handed practices were *not* more likely to offer routine support (26/75 [35%] versus 111/278 [40%], *P* = 0.49). Those who reported they routinely offered contact with the primary health care team were asked for further details (Table 4). The most common situation was for the GP to offer a home visit to the bereaved spouse following any death.

Referrals for bereavement support

One hundred and twenty-nine (37%) responders reported that someone in the practice offered bereavement counselling. Of these, 95 (74%) were known to have had relevant training. Practices with a special interest in palliative care were more likely to offer bereavement counselling, (26/47 [55%] versus 103/306 [34%]; *P* = 0.007). The commonest job titles given for the counsellor were practice counsellor (70), community psychiatric nurse (21), GP (16), and practice nurse (11). Others included district nurse, health visitor, practice manager, and psychologist. Two hundred and twenty responders (62%) had referred patients to organizations outside the practice. Of these, by far the most common referral was to Cruse (125); 51 patients had been referred to local support groups, 30 to the community mental health team, 16 to hospice support groups, and others were to Compassionate Friends, the Samaritans, Macmillan counsellors, the Foundation for Sudden Infant Deaths, and the church.

Other comments

Sixty-one responders made comments and several clear themes emerged. These were the importance of the multidisciplinary nature of bereavement care (14 comments); time and workload restraints (9 comments); the importance of personal care, particularly commented on by single-handed and small practices (10 comments); the dilemma of whether to provide routine care (6 comments) or selective care (10 comments); and the danger of over-medicalizing the grief process (4 comments) (Appendix 2).

Discussion

The response rate of 71% was fair, and the proportions of fundholding and training practices were similar to South Thames practice overall. However, single-handed practices were under-represented, and our results may not generalize to all practices. Non-responders may have been less interested in bereavement care and we may be over-estimating the proportion of practices offering routine support to relatives. Our survey asked senior partners to respond on behalf of the practice, as they were thought most likely to be aware of any practice policies; however, their views may not be representative of younger partners' views.

The difference between practitioners' perceptions of hospitals' and hospices' notification of patient deaths has not, to our knowledge, been noted before. Hospitals were perceived to be worse at notification within 24 hours, with only 25% of GPs

Table 3. Practice discussions on patient deaths (percentages do not add up to 100 as several respondents made more than one comment).

Practices reporting discussion of patient deaths	n = 230 n (%)
With whom do you discuss deaths?	
Other general practitioners	161 (70.0)
Whole practice	60 (26.1)
District nurses	48 (20.9)
Practice nurses	36 (15.7)
Primary health care team	21 (9.1)
Practice manager	11 (4.8)
Relatives	6 (2.6)
In what forum?	
Informal meetings	148 (64.4)
Regular meetings	61 (26.5)
Which type of deaths?	
All deaths	142 (61.7)
Unexpected deaths	80 (34.8)
Potential for complaint	48 (20.9)
Following terminal care	32 (13.9)
Other	14 (6.1)

Table 4. Care provided by practices which routinely offer support to bereaved relatives (percentages do not add up to 100 as several respondents made more than one comment).

Practices providing routine support	n =137 n (%)
Primary health care team member	
General practitioner	124 (90.5)
District nurse	35 (25.5)
Practice counsellor	26 (19.0)
Practice nurse	25 (18.2)
Health visitor	5 (3.6)
Other	7 (5.1)
Type of contact offered	
Home visit	108 (78.8)
Surgery appointment	66 (48.2)
Telephone call	58 (42.3)
Other	9 (6.6)
Following which patient deaths?	
All deaths	123 (89.8)
Unexpected deaths	15 (10.9)
Following terminal care	13 (9.5)
Which bereaved relatives?	
Spouse or partner	89 (65.0)
Any first degree relative	63 (46.0)
Other	13 (9.5)

receiving immediate notification (a finding between the 58% and 9% noted in previous studies),[3,4] but 315 practitioners (89%) reported usually receiving information from hospitals by one week. Our study looked at perceptions rather than exact timing for death notifications. There may have been recall bias, but we have no evidence that this bias favours hospices rather than hospitals. Reported problems with the timing of notification and quality of information were greater for hospitals than hospices. However, many more deaths occur in hospitals than hospices,[3] and comparisons should take this into account.

Over half the practices kept a death register, similar to previous findings among Tyneside practices.[4] Two-thirds discussed deaths within the practice and two-fifths had a policy for identifying newly bereaved relatives. Keeping a death register, discussing deaths, and identifying bereaved relatives may provide the link between receiving death notification and offering bereavement care, as all were associated with providing routine support.

We looked for associations between practice factors and practice activities relating to patient deaths and bereavement support, and made 34 statistical comparisons, of which eleven were statistically significant at the 5% level (and nine at the 1% level or less). By chance alone, only one or two would be expected to be significant at the 5% level, but caution is required in interpreting the importance of these associations, which should be regarded as hypothesis generating.

The multidisciplinary nature of bereavement support in primary care is illustrated by the range of PHCT members involved (Table 4), and by responders' comments. This survey looked at the GPs' perspective; other team members might differ.

Opinion is divided over whether bereavement support should be proactive or reactive: two-fifths routinely offer contact and two-fifths support only those relatives who ask for help. The comments reflect this difference of approach, some emphasizing the value of routine visits and others concerned about over-medicalizing the grief process and imposing care. Practices with a special interest in palliative care are more likely to be proactive in identifying bereaved relatives, in offering routine support, and in having bereavement counsellors in their practices.

Our study findings are not directly comparable to Cartwright's,[20] as her study focused on the elderly bereaved. However, our results are similar to her finding that half of GPs said they routinely offered either a home visit or other contact. This suggests that the changes that have occurred in general practice in the last two decades have not significantly lessened the contact that GPs are willing to offer bereaved patients. Bowling and Cartwright[30] found no association between practice size and provision of bereavement support; our results confirmed this finding.

Our study is limited by not including patients' views. Little is known about whether bereaved relatives prefer a proactive or reactive approach, but a single practice study found that the majority would have appreciated some acknowledgement from their GP at the time of the death, and most favoured a home visit.[24] Some bereaved relatives had difficulty seeking help as they felt they were not 'unwell' and perceived the doctor to be busy dealing with illness.[24]

Conclusions

Problems still exist with the immediate notification of hospital deaths to GPs. A wide range of activity relates to patient deaths and bereavement support in general practices across South Thames. GPs are fairly evenly split about offering routine proactive bereavement care, reflecting the lack of an evidence base for this type of service provision. Further research into this area is needed, with studies looking at patient needs and outcomes and economic costs of different approaches to bereavement care.

Appendix 1. Information usually recorded on practice death registers.

- Patient name
- Date of death
- Cause of death
- Age/date of birth
- Place of death
- Patient address
- Name of involved general practitioner
- Who is bereaved? Who needs to be informed?

Appendix 2. Illustrative comments.

Multidisciplinary nature of bereavement care
'I have a good idea of what my own patients will need, whether just myself, the district nurse, the hospice nurse or our own counsellor... Practice nurse, health visitor, practice manager or community psychiatric nurse may get involved.'

Time and workload restraints
'Not ideal, but then the pressure of general practice makes it impossible to "shine" in all areas... There is a long tradition of home visiting the newly bereaved, but it becomes increasingly difficult to keep it up.'

Personal care
'We still have individual lists, which is invaluable. I also attend a large percentage of my patients' own funerals... We are a small practice and are able to offer a high level of "personal" care.'

Routine versus selective care
'Initial contact after death is very important and appreciated… Individual partners contact relatives that we feel need support, but not routinely all relatives… Most bereaved relatives cope well with normal social support.'

Danger of over-medicalizing grief
'I normally find an acute visit for bereavement inappropriate. One must be allowed to grieve... We do not wish to impose bereavement care.'

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