

Palliative care provided by GPs: the carer's viewpoint

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SUMMARY

As most terminal and palliative care is in the community, general practitioners (GPs) have an important role to play. This study presents bereaved carers' views of the palliative care provided by GPs. It suggests that symptom control may not be optimal.

Keywords: terminal care; palliative care; carers.

Introduction

TERMINAL patients spend most of their last year of life at home and prefer to die there,¹ making palliative and terminal care an important part of general practice. Despite this, much previous research has focused on the specialist services. This study describes patients' experiences of palliative cancer care in general practice, using the views of carers as a proxy measure.

Method

We conducted a postal survey of people ('informants') who had registered a cancer death in a North Yorkshire district over a two-month period. With the approval of the informant's general practitioner (GP), an explanatory letter was sent offering the opportunity to opt out of the study or propose an alternative contact if they had not been a carer. VOICES, a validated postal survey, was sent out to United Kingdom addresses between four and six months after the bereavement.² No reminders were sent. The chairman of the local multicentre research ethics committee granted approval for the study.

Results

Three hundred and five people registered a cancer death in the district in the two-month period. Four could not be contacted, 17 were excluded on the advice of their GP, and 50 declined to participate. One hundred and thirty-nine of the remaining 234 (59%) returned the questionnaire: 55 (44%) were spouses of the deceased, 78 (56%) were relatives, and six (4%) were a friend or other contact. There were no significant sociodemographic differences between the patients cared for by responders and non-responders.

One hundred and one (96%) of the 105 patients who were reported to have had pain in their final illness had their pain treated by their GP. For 53 (52%), the pain was controlled. Thirty-three (67%) carers of the 49 patients who received help from their GP for anxiety or depression felt that it helped at least sometimes. Table 1 shows the rating of other symptom control by the GP compared with treatment provided by hospital and hospice doctors.

The service provided by the GP

Seventy per cent of the GPs (97/139) were perceived as having time to discuss problems and few carers reported difficulty with organising visits (9%) or surgery appointments (6%). Ninety-four of the 139 responders (68%, 95% CI = 61 to 77) rated GP care as excellent (64) or good (30) overall.

Forty-eight of the 56 patients who had expressed a preference wished to die at home. Twenty-four of these achieved this wish. There were no differences in the rating of GP care between those who died at home and elsewhere. However, carers of the 43 (31%) patients who died 'in their preferred place' were significantly more likely to rate GP care as good or excellent ($P < 0.005$).

Discussion

Satisfaction with palliative care provided by GPs in this study was high, despite the lack of optimal symptom control. Around half of the carers felt that pain control was not good and one-third that shortness of breath and difficulty sleeping had been treated poorly, or not at all, by the GP. Treatment of loss of appetite was poor in all three settings but for the other symptoms the GP was rated similarly to the hospital doctor and consistently worse than the hospice doctor. These results are comparable to other studies. When VOICES was used in inner London, satisfaction with GP care was lower than in our study but the rating of symptom control was similar.² In northern England, one-quarter of carers in a comparable survey felt that the GP could have done more to alleviate symptoms.³ Although carers may overestimate the severity of symptoms retrospectively,⁴ an audit of home deaths also supports the idea that treatment of symptoms by GPs could be improved⁵ and contrasts with GPs' favourable perceptions of their own symptom control.⁶

Offering subjects or their GPs the opportunity to opt out of the study may have introduced response bias but it is an important part of ethical study design. The modest response rate was typical of studies of this kind, though using death registration as a sampling frame increased the likelihood that our findings would be generalisable.

Overall, this study suggests that there is potential to improve palliative symptom control in primary care. The efforts of palliative care specialists should continue to focus on this area, supporting GPs who are providing an important service.

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Table 1. Control of symptoms.

Symptom and doctors' place of work	Number of patients with symptom	Percentage of symptom episodes with given rating (95% CI)			
		Good	Fair	Poor	Not treated
Vomiting					
Hospital	44	25 (13–40)	39 (24–55)	14 (5–27)	2 (0.1–12)
Hospice	19	53 (29–76)	37 (16–62)	5 (0.1–26)	5 (0.1–26)
General practice	75	25 (16–37)	40 (29–52)	12 (6–22)	7 (2.2–15)
Diarrhoea					
Hospital	28	14 (4–33)	36 (19–56)	14 (4–33)	7 (0.8–24)
Hospice	11	36 (11–69)	36 (11–69)	0	9 (0.2–41)
General practice	59	22 (12–35)	37 (25–51)	14 (6–24)	12 (5–23)
Constipation					
Hospital	36	19 (8–36)	33 (19–51)	14 (5–29)	3 (0.1–15)
Hospice	11	55 (23–83)	27 (6–61)	9 (2–41)	0
General practice	67	25 (16–37)	48 (35–60)	13 (6–24)	3 (0.4–10)
Shortness of breath					
Hospital	47	21 (11–36)	32 (19–47)	17 (8–31)	4 (1–15)
Hospice	15	40 (16–68)	40 (16–68)	7 (2–32)	7 (2–32)
General practice	72	19 (11–30)	32 (21–44)	15 (8–26)	15 (10–29)
Loss of appetite					
Hospital	71	3 (3–10)	21 (12–32)	23 (13–34)	14 (7–24)
Hospice	20	10 (1–32)	35 (15–59)	30 (12–54)	15 (3–58)
General practice	102	5 (2–11)	26 (18–36)	25 (17–35)	16 (9–24)
Difficulty sleeping					
Hospital	53	19 (9–32)	23 (12–36)	26 (15–40)	6 (1–16)
Hospice	14	57 (29–82)	14 (2–43)	14 (2–43)	7 (0.1–34)
General practice	84	15 (9–25)	32 (22–43)	25 (16–36)	6 (2–13)

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