

Dying from cancer in community hospitals or a hospice: closest lay carers' perceptions

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SUMMARY

Background. Despite there being around 400 community hospitals in the United Kingdom, there is little published research on the quality of service provided by these hospitals.

Aim. To compare the quality of terminal cancer care in community hospitals with a hospice as assessed by patients' closest lay carer (relative or friend).

Method. Structured interview (or questionnaire based on the interview proforma) with closest lay carers of all patients dying over one year in 12 community hospitals in east Devon and a purpose-built hospice in the city of Exeter.

Results. A total of 292 cases (176 in community hospitals and 116 in a hospice) were identified, resulting in 238 carers being eligible for interview or questionnaire survey. Overall, 106 successful interviews and 55 questionnaires were completed, giving a response rate of 67.6%. Carers gave a near unanimous vote of excellence for the total care given by the hospice, while around 40% of carers of patients in community hospitals considered that improvements were possible. Community hospitals attracted more negative comments than hospices, with criticism being directed at problems of communication, lack of nursing staff, and lack of support in bereavement. Carers of hospice patients were significantly more likely to be present at the time of death than those of community hospital patients [45/70 (64%) vs. 31/89 (35%); $\chi^2 = 13.6$, $P < 0.001$], an observation possibly because nursing staff in community hospitals are less experienced at dealing with terminally ill patients and such hospitals have fewer adequate facilities.

Conclusions. Lay carers indicated great satisfaction with care given in the hospice and less satisfaction with care given in the community hospitals. However, the community hospitals are non-specialist units with far lower levels of trained staff. Improvements in terms of the communication skills of doctors and nurses, specific training for nurses in palliative care, and structured bereavement care could be made without necessarily increasing staffing numbers.

Introduction

THE care received by patients dying of cancer in hospitals has attracted criticism,¹⁻³ while the introduction of hospice inpa-

tient care has been associated with increased satisfaction with terminal cancer care by both patients and carers.⁴⁻⁶ Although around 13% of people dying from cancer die in inpatient hospice beds,⁷ it has been estimated that community hospitals in the United Kingdom (UK) are the place of death for around 8% of cancer patients.⁸ No research as to the quality of care afforded by community hospitals for terminally ill cancer patients has been published. This study compared the perceptions of the closest lay carers of cancer patients dying in community hospitals in 10 towns in east Devon with the perceptions of the closest lay carers of cancer patients dying in a consultant-led inpatient hospice in the city of Exeter.

Method

The setting and technical limitations of the study are described in an accompanying paper.⁹ The hospice or community hospital medical records for each case identified from death certificate returns were examined, and the patient's general practitioner (GP) was contacted asking if there was a reason not to contact the closest lay carer of the patient. The closest lay carers were contacted 12-14 weeks after the death of the patient, told the purpose of the study, and asked if they would be willing to participate in an interview or to answer a questionnaire based strictly on the interview proforma. Carers not replying to the initial invitation after four weeks were sent a second invitation along with a reply-paid copy of the postal questionnaire. Those carers living more than 30 miles from Exeter were sent a postal questionnaire only. Interviews were conducted between four and six months after the death of the patient by a trained research nurse. The interview was structured, with some open-ended questions giving opportunity for comment, which was recorded verbatim where practical or summarized with the carer's agreement. Time was allowed at the end of the interview to answer specific questions, give relevant information regarding the normal course of bereavement, and explain events during the final illness. The postal questionnaire posed exactly the same questions as the interview proforma, with space provided for answers to the open-ended questions. In situations where excessive grief was expressed by the carer or confusion over the purpose of the interview arose, the interview was terminated and counted invalid.

Areas addressed in the interview included events leading up to the final admission, the facilities and care provided, issues of communication, bereavement aftercare, and a general appraisal of the service provided with its advantages and disadvantages. Statistical analysis employed the use of chi-squared tests and, where appropriate, Student's *t*-test statistic. For the semistructured comments, common themes were identified, grouped, and counted. Named nurses of patients were contacted for details of previous experience and training relevant to palliative care.

Results

There were 292 cases (176 in community hospitals and 116 in a hospice) over the year of the study. Medical notes were unavailable for five community hospital cases, giving 287 cases for study. Permission to contact a closest lay carer was refused by GPs in 18 cases and, in 31 cases, there was no apparent carer to contact. A total of 238 closest lay carers (136 for the community

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Table 1. Carers' perception of reasons for the final admission.

	Community hospital (n = 91) n (%)	Hospice (n = 70) n (%)
Curative/active treatment ^a	4 (4.4)	1 (1.4)
Investigations ^a	13 (14.3)	4 (5.7)
Pain control ^a	11 (12.1)	24 (34.3)
Other difficult symptom control ^a	36 (39.6)	21 (30.0)
Social reasons ^a	9 (9.9)	4 (5.7)
Terminal nursing care ^a	15 (16.5)	15 (21.4)
Rehabilitation ^a	3 (3.3)	1 (1.4)
Pain control ^b	11 (12.1)	24 (34.3)
All other reasons ^b	80 (87.9)	46 (65.7)

^a $\chi^2 = 15.79$, $P = 0.015$. ^b $\chi^2 = 11.46$, $P < 0.001$.

hospital cases and 102 for the hospice cases) were contacted, and 55 agreed to answer a postal questionnaire (41/171 community hospital cases, with 13 carers residing outside the study area, and 14/116 hospice cases, no carers residing outside the study area). A total of 109 lay carers agreed to participate in an interview. Three of which (two community hospital cases and one hospice case) were terminated prematurely, resulting in 106 successful interviews (50/171 community hospital cases and 56/116 hospice cases). The overall response rate was 161 valid interviews or questionnaires from 238 eligible cases or 67.6%. Unless otherwise stated, there were no significant differences between the community hospital and hospice group responses.

The relationship of the closest lay carer to the patient was: spouse 82/143 (57.3%); son or daughter 36/143 (25.2%); brother or sister 11/143 (7.7%); other 14/143 (9.8%) (in 18 cases, the

relationship was not stated). The mean and median time from death to interview was 20 weeks.

The reasons for final admission as perceived by the closest lay carer are shown in Table 1. Admission for the primary reason of pain control was significantly more common for hospice cases than for community hospital cases, and pain and symptom control accounted for 50–64% of the primary reasons for admission to both settings. Symptoms suffered with equal frequency by community hospital and hospice patients at the time of and during the final admission were as follows: pain 116 (72.0%); shortness of breath 49 (30.4%); loss of appetite 95 (59.0%); insomnia 31 (19.3%); difficulty swallowing 31 (19.3%); cough 17 (10.6%); nausea 45 (28.0%); weakness 93 (57.8%); confusion 40 (24.8%); mouth problems 36 (22.4%); urinary incontinence 44 (27.3%); incontinence of faeces 18 (11.2%); constipation 48 (29.8%); bedsores 23 (14.3%), anxiety 36 (22.4%); fear 30 (18.6%); and depression 37 (23.0%). Vomiting was significantly more frequent among hospice admissions [hospice 26/70 (37.1%) vs. community hospital 17/91 (18.7%); $\chi^2 = 6.9$, $P = 0.009$].

Table 2 summarizes communication issues between patient, carer, and professional staff that were explored in the interviews or postal questionnaires.

Table 3 summarizes some practical points concerning accommodation, bereavement care, and perceptions of the appropriateness of the place of death and overall care received by the patient. Carers for patients dying in community hospitals were significantly less likely to be able to spend the night with the patient, have somewhere away from the patient to rest, or be present when the patient died compared with carers for patients dying in the hospice. Involvement in the care of patients was less likely to occur with community hospital patients, and the care given to carers immediately after death was significantly less

Table 2. Communication issues between patient, closest lay carer, and professional staff.

Question		Response			Significance (comparing community hospitals and hospice responses)
		Yes n (%)	No n (%)	Do not know n (%)	
Did the patient discuss the illness with					
You	CH n = 82 H n = 69	44 (53.7) 44 (63.8)	38 (46.3) 25 (36.2)	0 0	
Doctor	CH n = 77 H n = 64	47 (61.0) 38 (59.4)	18 (23.4) 16 (25)	12 (15.6) 10 (15.6)	
Primary nurse	CH n = 64 H n = 60	26 (40.6) 31 (51.7)	23 (35.9) 18 (30)	15 (23.4) 11 (18.3)	
Did you, the carer, discuss the illness with					
Doctor	CH n = 91 H n = 70	61 (67) 49 (70)	30 (33) 21 (30)	NA NA	
Primary nurse	CH n = 63 H n = 60	42 (66.7) 46 (76.7)	21 (33.3) 14 (23.3)	NA NA	
When you asked the professionals did they give adequate information?	CH n = 68 H n = 61	61 (89.7) 58 (95.1)	7 (10.3) 3 (4.9)	NA NA	
Did you find the professionals easy to talk to?	CH n = 81 H n = 68	76 (93.8) 68 (100)	5 (6.2) 0 (0)	NA NA	$\chi^2 = 4.3$ $P = 0.018$
Did you feel some of the professionals care for you?	CH n = 83 H n = 70	80 (96.4) 70 (100)	3 (3.6) 0 (0)	NA NA	
Did you get the impression that the staff were working as a team?	CH n = 84 H n = 70	74 (88.1) 68 (97.1)	4 (4.8) 0 (0)	6 (7.1) 2 (2.9)	

CH, community hospital responses; H, hospice responses.

Table 3. Practical issues concerning accommodation, bereavement care, and other closest lay carers' perceptions.

Question		Response			Significance (comparing community hospital and hospice responses)			
		Yes <i>n</i> (%)	No <i>n</i> (%)	Do not know <i>n</i> (%)				
1. Was the patient able to have a single room if required?	CH <i>n</i> = 74 H <i>n</i> = 58	59 (79.7) 52 (89.7)	15 (20.3) 6 (10.3)	0 0				
2. Did you have somewhere to sit or rest away from the patient?	CH <i>n</i> = 82 H <i>n</i> = 70	52 (63.4) 65 (92.9)	20 (24.4) 1 (1.4)	10 (12.2) 4 (5.7)	$\chi^2 = 20.4$ $P < 0.001$			
3. Were you able to spend the night with the patient?	CH <i>n</i> = 81 H <i>n</i> = 67	36 (44.4) 44 (65.7)	9 (11.1) 1 (1.5)	36 (44.4) 22 (32.8)	$\chi^2 = 9.3$ $P < 0.001$			
4. Were you present when the patient died?	CH <i>n</i> = 89 H <i>n</i> = 70	31 (34.8) 45 (64.3)	58 (65.2) 25 (35.7)	0 0	$\chi^2 = 13.6$ $P < 0.001$			
5. Have you been back to the unit since the death?	CH <i>n</i> = 83 H <i>n</i> = 70	46 (55.4) 43 (61.4)	37 (44.6) 27 (38.6)	0 0				
6. If yes to question 5, was it a helpful experience?	CH <i>n</i> = 28 H <i>n</i> = 37	16 (57.1) 31 (83.8)	12 (42.9) 6 (16.2)	0 0	$\chi^2 = 5.6$ $P = 0.018$			
7. Did the nurses involve you in the care of the patient?		Yes	Yes	Yes	No	N/A	Significance	
		Thoroughly <i>n</i> (%)	Many times <i>n</i> (%)	Sometimes <i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)		
CH <i>n</i> = 80 H <i>n</i> = 69		7 (8.8) 9 (13.0)	2 (2.5) 12 (17.4)	13 (16.3) 15 (21.7)	45 (56.3) 24 (34.8)	13 (16.3) 9 (13.0)	$\chi^2 = 13.9$ $P = 0.008$	
8. Do you feel the practical help given by the staff immediately after death was:		Very helpful	Quite helpful	Not very helpful	Not at all helpful			
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)			
CH <i>n</i> = 74 H <i>n</i> = 70		45 (60.8) 67 (95.7)	22 (29.7) 3 (4.3)	3 (4.1) 0	4 (5.4) 0		$\chi^2 = 25.7$ $P < 0.001$	
9. On the whole would you say that over the last admission the patient was:		Very content	Content	Not too happy, reasonably content	Unhappy	Very unhappy	Close to suicide	
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
CH <i>n</i> = 84 H <i>n</i> = 65		32 (38.1) 34 (52.3)	18 (21.4) 14 (21.5)	20 (23.8) 12 (18.5)	7 (8.3) 2 (3.1)	7 (8.3) 3 (4.6)	0 (0) 0 (0)	
10. During the last admission were you on the whole:		Very content	Content	Not too happy, reasonably content	Unhappy	Very unhappy	Close to suicide	Significance
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
CH <i>n</i> = 88 H <i>n</i> = 68		38 (43.2) 44 (64.7)	14 (15.9) 10 (14.7)	17 (19.3) 7 (10.3)	7 (8.0) 6 (8.8)	11 (12.5) 0 (0)	1 (1.1) 1 (1.5)	$\chi^2 = 14$ $P = 0.008$
11. Overall do you think it was the most appropriate place for the patient to die:		Definitely yes	Probably yes	Do not know	Probably no	Definitely no		Significance
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)		
CH <i>n</i> = 88 H <i>n</i> = 70		52 (59.1) 59 (84.3)	25 (28.4) 9 (12.9)	3 (3.4) 0	7 (8.0) 0	1 (1.1) 2 (2.9)		$\chi^2 = 16.4$ $P = 0.003$
12. Do you feel that the total care received by the patient and yourself during the final illness was:		Excellent	Good	Moderate	Poor	Bad		Significance
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)		
CH <i>n</i> = 88 H <i>n</i> = 69		53 (60.2) 67 (97.1)	27 (30.7) 2 (2.9)	7 (8.0) 0	1 (1.1) 0	0 0		$\chi^2 = 29.3$ $P < 0.001$

Table 4. Spontaneous comments by carers.

	Hospice			Community hospital		
	Postal	Interviewer	Total	Postal	Interviewer	Total
Positive statements	11/14	52/56	63/70	32/41	34/50	66/91
Warm/caring staff	6/14	16/56	22/70	13/41	20/50	33/91
Holistic care	4/14	22/56	26/70	11/41	5/50	16/91
Good communication	1/14	4/56	5/70	1/41	1/50	2/91
Personal knowledge of staff	0/14	0/56	0/70	3/41	5/50	8/91
Proximity of unit to home	0/14	0/56	0/70	0/41	2/50	2/91
Good bereavement aftercare	3/14	5/56	8/70	0/41	0/50	0/91
Peaceful/relaxed atmosphere	0/14	6/56	6/70	3/41	0/50	3/91
Good facilities/food/ease of visiting	1/14	9/56	10/70	4/41	2/50	6/91
Death with dignity promoted	1/14	0/56	1/70	2/41	0/50	2/91
Negative statements	0/14	5/56	5/70	6/41	19/50	25/91
Poor communication	0/14	0/56	0/70	3/41	8/50	11/91
Poor bereavement/aftercare support	0/14	1/56	1/70	1/41	4/50	5/91
Poorly equipped unit	0/14	0/56	0/70	0/41	3/50	3/91
Inadequate nursing care						
(level, standard and organization)	0/14	0/56	0/70	2/41	8/50	10/91
Social/community services inadequate	0/14	2/56	2/70	0/41	0/50	0/91

NB. Only one negative comment each regarding: symptom control (hospice), inadequate medical care (community hospital), diet of patient (community hospital).

helpful for community hospital patients than for hospice patients. The hospice was more often seen as the appropriate place of death than the community hospital, and the perception of total care was less favourable for community hospital patients than for hospice patients.

Spontaneous comments by carers summarized into common themes are shown in Table 4. Positive accounts centred mainly on the warmth and caring nature of the unit staff and the concept of holistic care offered to patient, carer, and family alike. Hospice bereavement care attracted positive comment, whereas community hospitals did not. Negative comments were more common for community hospitals, with the main problems being poor communication, inadequate nursing care (covering issues of the nursing staff numbers, standard of nursing, and organization of nursing activity), and lack of bereavement care.

There were frequent positive statements concerning both hospice and community hospital care. Some negative comments regarding community hospital care illustrate the problems with communication: 'I would have liked my husband's illness explained to me. I had no idea at all what was wrong with him or what to expect...'; 'Friendly but slightly chaotic atmosphere did not altogether inspire confidence. There was a distinct lapse of organization and some misinformation about (the patient's) actual condition'; 'I came across a lot of uncaring and unfeeling attitudes from the GP and other professionals. Father was a stubborn man not willing to accept any help and preferred to have a glass of whisky rather than take medications'. A comment concerning the hospice serves to re-emphasize the underlying ethos of palliative care 'the hospice is not just a building — it is the care that is so important'.

Nursing care for the 12 hospice beds was provided by 13 whole-time equivalent (WTE) trained nursing staff (RGN, SRN, or SEN) or 1.1 WTE per bed and, for the 350 community hospital medical beds, by 135 WTE trained staff or 0.4 WTE per bed.

The mean number of years since qualification for named nurses was 16 (community hospitals) and 14 (hospice) (no significant difference), with 27/75 (36.0%) community hospital nurses and 9/23 (39.1%) hospice nurses having trained in a specialty relevant to cancer care (hospice nursing, oncology, haematology, and radiotherapy were the most frequently mentioned); 11/78 (14.1%) community hospital nurses and 10/23 (43.5%) hospice nurses had the ENB 931 (care of the dying patient and family)

qualification ($\chi^2 = 9.3$, $P = 0.0023$). One community hospital nurse and one hospice nurse had the more advanced ENB 285 (continuing care of the dying) qualification.

Discussion

This study used the closest lay carers' opinions as proxy for patients dying in community hospitals and the hospice and as a reflection of the overall quality of palliative care offered to the patients' families. This approach has been examined previously and found to be a valid source of information,¹⁰ taking into account the extreme difficulty in recruiting patients dying from cancer and obtaining meaningful data as to the process of their care.¹¹ It may be considered that the use of both interview data and questionnaire data may not be strictly comparable. However, care was taken to ensure uniformity of the question format and presentation of the questions by the interviewer. The choice of interview or questionnaire was clearly appreciated by carers, many of whom expressed a preference for being able to take their own time over answering a questionnaire and not having to make time for an interview. For many interviewees, the interview was clearly therapeutic, allowing them the opportunity to 'tell their story', express suppressed grief and anger, and to ask questions, as has been described before.¹² The greater proportion of postal questionnaire responses for carers of community hospital cases is partly the result of one third of the carers residing outside the study area and not having the choice of an interview. Carers of hospice cases may have opted for interviews to express their thanks in person to the interviewer.

Carers perceived the primary reasons for admission to community hospitals and the hospice as being pain and other difficult symptom control in 51–64% of cases, which is in accordance with the accepted role of palliative care in patient units.

There were no significant differences detected in the structured questions concerning communication between patient, main carer, and professional staff, apart from a perception that hospice staff were easier to talk to. However, in the spontaneous comments, poor communication was mentioned frequently by carers of patients dying in community hospitals, with no such comments from the hospice group. Negative comments were

freely expressed regarding the level of nursing, standards of care and organization of nursing care in community hospitals. Closest lay carers were significantly less likely to be involved in the care of the patients in the community hospital context, and practical help given immediately after the patient's death by the ward and administrative staff was perceived as being less helpful in the community hospitals. Interestingly, around two thirds of the closest lay carers for hospice patients were present at the time of death compared with only one third of carers of community hospital patients, a figure that compares with a previous study of cancer deaths in hospitals.² Whether this observation relates to the experience gained by hospice staff in determining when a patient is likely to die or whether the relative lack of overnight facilities and rest areas away from the patient in community hospitals is in part responsible is hard to decide. However, from comments received in the interviews and questionnaires, it was apparent that not being present at the death was often deeply regretted and upsetting.

Positive comments regarding hospice provision described warm and caring staff, holistic care of patient and family, and good facilities, food, and ease of visiting, mirrored to a lesser degree in comments on community hospital provision. Personal knowledge of community hospital staff was mentioned in eight instances, with no similar comment for hospice staff. This is to be expected in the context of community hospitals frequently employing staff living locally and serving a relatively small local population.

No significant difference was perceived by the carer as to the degree of contentment of the patient during the final admission. However, the carers' own perception of contentment differed significantly, with around 20% of patients in community hospital feeling unhappy, very unhappy, or suicidal compared with around 10% of hospice patients. As to the appropriate place of death for the patient, significantly more carers felt the hospice to be definitely or probably appropriate compared with the community hospital group. Community hospitals were, nonetheless, seen to be definitely or probably the most appropriate place of death for 87% of patients. In terms of the overall total care received, the carers of patients dying in the hospice gave an almost unanimous vote of excellence. Community hospitals received a more reserved judgement, with around 40% considering improvements possible, as borne out in the spontaneous comments.

This study bears out the high standards for terminal cancer care provided by inpatient hospices, as perceived by carers of patients in other studies.^{4,5,13} The hospice staff and facilities were highly praised, with appreciation of the holistic approach to caring extending beyond the death of the patient being expressed frequently. Against such a standard, it is perhaps not surprising that community hospitals with their mixed caseload, a much lower trained nurse/bed ratio, nurses with fewer relevant qualifications, and fewer purpose-built buildings should receive a poorer appraisal. Some improvements to community hospital care might be gained at little extra expense in resource terms, for example GPs improving communications about the patient and their illness to the nearest lay carers, involving lay carers more in the care of patients in hospital, doctors and nurses making a positive gesture to try to be easier to talk to, agreeing a protocol for trying to get carers to the bedside at the time of death, and instituting organized bereavement follow-up (in co-operation with the wider primary health care teams). Some improvements that might be gained at some extra cost would be the training of doctors and nurses in palliative care, communication skills, and bereavement care. It would seem to be possible to improve community hospital care without necessarily increasing staffing levels.

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