Caregiver Bereavement Outcome: Relationship With Hospice at Home, Satisfaction With Care, and Home Death

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Abstract / This study used a randomized controlled trial design to investigate the impact of hospice at home (HAH) on caregiver bereavement outcome. Secondary analyses considered the association between bereavement, place of death, and carers' assessment of support. Ninety-six informal carers of patients referred to HAH were surveyed six weeks post-bereavement about the quality of terminal care. Carers next completed measures of their own bereavement response and general health six months post-bereavement. There was no evidence that HAH had an impact on bereavement outcome. In contrast, perceptions of inadequate terminal support and high symptom severity were associated with worse carer bereavement response. However, it remains unclear whether carers' retrospective ratings constitute an accurate account of symptoms and care. Home deaths were associated with both better bereavement response and better physical health post-bereavement than were inpatient deaths. Further research is needed to investigate the implications of death at home for the carer.

Résumé / Cette étude contrôlée randomisée avait pour objectif de déterminer l'impact de service de soins palliatifs à la maison (SPM) sur le processus de deuil des soignants. Lors d'analyses secondaires on a examiné les liens entre la période de deuil, le lieu de la mort, et l'opinion des soignants sur le support dont ils avaient bénéficié. Ainsi, 96 soignants, dont un des leurs avait été orienté vers le service de SPM, ont été sondés sur la qualité des soins palliatifs six semaines après la mort de leur proche. Six mois plus tard, au cours de la période de deuil, les soignants ont à nouveau répondu à des questionnaires visant à savoir comment ils vivaient leur deuil et quel était leur état général de santé. Il n'y a aucune évidence à l'effet que la participation à un programme de SPM avait eu un impact sur le processus de deuil. Cependant les plus mauvais deuils ont été vécus là où les soignants étaient d'avis qu'ils n'avaient pu compter sur un support adéquat et que les symptômes du patient avaient été mal contrôlés. Par contre, on n'a pu déterminer si cette évaluation

rétrospective sur la qualité de soins est conforme à la réalité. Ainsi, on a noté que tout autant le processus de deuil que l'état général de santé des soignants était meilleur quand leur proche était mort à la maison plutôt qu'à l'hôpital. Il faudrait de plus amples recherches pour déterminer les nombreuses implications pour le soignant de service de soins palliatifs à la maison.

INTRODUCTION

The goal of palliative care is to achieve the best quality of life not only for patients, but also for their families (1). Enabling death at home, if this is the patient's wish, is often seen as part of ensuring the best possible quality of life. The considerable increase in palliative home care services in the U.K. over previous decades is, in part, a reflection of this (2,3). Good end-of-life support, in the location of choice, is in itself, an essential aim. However, an important question is to what extent such support also has an impact on carer bereavement outcome. It is possible that carers are helped in their bereavement if left with a feeling that everything was done for the patient, that all issues were resolved, and that the death was "a good death". However, not all aspects of support that are regarded as beneficial to the patient may benefit the carer. Enabling death at home, even if this is the patient's wish, if it considerably increases caregiver burden, may conceivably lead to worse bereavement outcomes.

The death of a loved one is one of the most stressful events in life (4). Bereavement is associated with increased risk of mental and physical disease (4), particularly if grief is traumatic (5). The bereaved are, furthermore, at higher risk of dying than nonbereaved comparison groups, with the risk being highest in the months closest

to the loss (6-8). Efforts to improve outcomes have mainly focused on post-bereavement care, and the identification and targeting of individuals at high risk of pathological grief. If normal distress can be affected by the quality of end-of-life care provision, however, how we manage such care may have an impact on the post-bereavement outcome for a broader population.

Participation in hospice programs prior to death has been found to be associated with less severe grief reactions (9). Parkes (10), however, found no difference in post-bereavement adjustment between carers of inpatient hospice and hospital patients. Cameron and Parkes (11) found that carers of patients who died in a hospital palliative care unit had fewer psychological symptoms, and less lasting grief and anger than carers of patients who died elsewhere in the hospital. However, this study also included post-bereavement support. Furthermore, the above were case control studies. Case-mix differences may have accounted for any differences in outcome, as those who receive palliative care are often systematically different from those who do not (12,13). Randomized controlled trials show mixed results. McCorkle et al. (14) report that carers of patients who were randomized to an oncology homecare group initially suffered less psychological distress than a control group, whilst differences disappeared after 25 months. In contrast, Ringdal et al. (15) found no difference in grief reactions between family carers of patients under a comprehensive palliative care program compared to conventional care. Similarly, Kane et al. (16), investigating hospital-based hospice care, found no difference between carers of control and intervention group patients in terms of anxiety, depression, health status, or health care utilization. The evidence that palliative care improves bereavement outcome is therefore by no means clear.

The important variable may not be added professional help, *per se*, but rather the extent to which the support provided is considered satisfactory relative to need. Fakhoury et al. (17) found that carers' satisfaction with care delivered by community nurses and doctors was positively associated with carer self-rated health and psychological functioning post-bereavement. However, good adjustment to bereavement also appeared to be associated with less satisfaction with general practitioner care. A similar study found no association between carers' satisfaction with inpatient care and bereavement outcome (18). In both studies, satisfaction with care and post-bereavement outcome were measured at the same time. In this situation, carers' feel-

ings in bereavement may influence their perceptions of care, rather than vice versa.

The relationship between place of death and bereavement outcome is also unclear. Studies have found that, compared to carers of patients who died elsewhere, bereaved carers of patients who died at home were more psychologically distressed (19,20), more likely to miss or think about the deceased (9,19), and tended to have greater social isolation tendencies (9). They were, furthermore, less likely to have come to terms with bereavement, to look forward to things, and to feel that things were going well for them (19). However, carers have also been found to suffer less death anxiety (9), guilt (9,21), rumination, depersonalization (21), general anxiety and despair (22), and to have more positive feelings about the death (22) if the patient died at home compared to in hospital. Studies also show that bereaved carers are more likely to state that the place of death was "right" after a home death compared to a hospital death (23,24), although one study comparing home with inpatient care (hospital and hospice) found no such difference (25). Feeling that the place of death is "right" may not necessarily be directly associated with a better bereavement outcome. The association between place of death and outcome may depend on which outcomes are being measured, the basis for comparison with home care (hospice, for instance, may be viewed differently from hospital), the caregiver burden, and whether home was considered the most appropriate place of death or not.

The present study investigated how bereavement outcome was related both to an end-of-life palliative home care intervention (hospice at home), and to carers' satisfaction with end-of-life care. We also considered how outcome was related both to actual place of death and to carers' assessment of the appropriateness of the place of death. A measure specific to bereavement, and measures of general physical and psychological health were used.

The investigation into the impact of hospice at home formed part of a randomized controlled trial. Randomization should, therefore, ensure there were no case-mix differences between those who had the intervention and those who did not, and that differences in outcome could be attributed to hospice at home. When investigating the relationship between satisfaction with care, place of death, and bereavement outcome, similar experimental manipulation was clearly not possible. Measurement of satisfaction and place of death preceded outcome measurement, but we cannot discount the possibility that

outcome differences were due to case mix rather than to the independent variables investigated. Thus, these secondary analyses represent a weaker methodology. Nevertheless, the study sample was a relatively homogenous group, as all had been referred to the same palliative home care service. One would not, therefore, expect large case-mix differences to be present.

METHOD

Participants and Procedure

Participants were bereaved informal carers of terminally ill patients who took part in a randomized controlled trial of Cambridge Hospital at Home for palliative care (HAH) (26). HAH offers up to 24-hour experienced palliative nursing care in the home for a two-week period. Patients were randomly allocated to HAH or standard care upon referral to the service, at a ratio of 4:1 HAH to controls to ensure that HAH ran at full capacity at all times. Allocation was based on a random number table and was concealed in sequentially numbered, sealed, opaque envelopes. Upon referral, the HAH coordinator opened the next envelope in the sequence revealing the patient's allocation. It was not possible to blind recipients to the fact that HAH was provided.

The main informal carer for each patient was identified from HAH referral records. Carers were surveyed six weeks post-bereavement about the severity of symptoms and the adequacy of the support provided for the patient in his/her last two weeks of life. A reminder was sent one month after the first mailing. Identified carers were later contacted by letter six months post-bereavement and asked if they might be willing to participate in further research about the support for the patient towards the end of life. If they agreed, a researcher visited them, explained the research in more detail, and, with the carer's consent, conducted an interview. Carers were asked to complete measures of bereavement outcome and general health, in their own time, following the interview. The measures were mailed back to the researcher in a prepaid envelope. All procedures for contact, letters to carers, information sheets, and study protocols were approved by the Local Research Ethics Committee.

Data Collected

The support assessed by carers in the survey six weeks post-bereavement included night care, medical care, personal care, psychological support for the patient, support for the carer in

looking after the patient, help with household tasks, information, and psychological support for the carer. Carers were asked to rate whether they would have liked "a lot more", "a bit more", or "no more" support than they had received. The symptoms assessed included pain, nausea, constipation, diarrhea, breathlessness, anxiety, and depression. Carers were asked to assess whether each symptom had bothered the patient "not at all", "a little", "quite a bit", or "very much". Finally, they were asked to rate whether they felt the place of death had been the right place for the patient, using the categories "definitely yes", "probably yes", "probably not", or "definitely not".

Bereavement outcome six months post-bereavement was measured using the Texas Revised Inventory of Grief (TRIG) (27). The TRIG has two subscales: Scale 1 (eight items) asks carers to rate how the death affected their feelings, actions, and relationships immediately following death; Scale 2 (13 items) measures thoughts and feelings at the present time. A higher score indicates a worse outcome. Fascingbauer et al. (27) report coefficient alphas of 0.77 and 0.86, respectively, for the scales.

Physical and mental health at six months post-bereavement were measured using the SF-36 Health Survey (28). Two scales, the Physical Component Summary (PCS) and the Mental Component Summary (MCS), can be derived from the SF-36. Internal reliability for the PCS and MCS have been reported to range between 0.91 and 0.94 (28). Missing values for SF-36 subscales were replaced with the respondent's average value for the subscale if the number of missing values was 33% or less (29), and the PCS and MCS were computed from the resulting scores. For these scales, a higher score indicates a better outcome.

Information on place of death was collected from the Office of National Statistics and the local Health Authority. Patient demographic data were collected from HAH records and carer demographic data during the six-months-post-bereavement interview. Information on home nursing and inpatient care in the last year of life was collated from electronic health service databases. The method for this is reported elsewhere (30).

Analysis

The bereavement study sample was compared with the total RCT population by calculating confidence intervals for categorical data, and by using one-sample t-tests for interval data as appropriate. Background variables were compared

for intervention and control patients using χ^2 tests for nominal data, independent samples *t*-tests for normally distributed interval data (age), and Mann-Whitney *U* tests for skewed interval data (survival and service input) (31). Differences in TRIG, PSC, and MCS outcome scores between carer groups were analyzed using independent samples *t*-tests. The statistical software was SPSS for Windows 10.1.

RCT analysis of impact of HAH was intention to treat, i.e., carer outcome was compared for patients allocated to HAH versus standard care whether allocation resulted in actual HAH input or not. A second analysis compared carers of those who actually received input from HAH versus those who did not. Subsequent analyses compared outcomes for those who felt care was sufficient, or that symptoms were absent or minor, with outcomes for carers who were dissatisfied. Finally, outcome was compared for carers of patients who died at home and carers of those who died elsewhere. Only in the initial RCT intention-to-treat analysis can case-mix differences be discounted.

RESULTS

Participants

During the 15-month study period, 262 patients were referred to HAH. Thirteen patients were alive at the end of the study. Of the remainder, 186 patients had been randomized to HAH and 43 to the control condition. Twenty were excluded from the trial for having been referred as emergencies or when HAH was empty (26). A key informal carer could be identified for 198 (86%) trial patients. Identified carers were surveyed six weeks post-bereavement; of these, 143 (72%) returned the questionnaire. Six months post-bereavement, 196 carers were contacted for an interview (two of the original sample did not want further contact) and 115 (59%) agreed to participate, 95 of whom (82%) returned the SF-36 and 96 (83%) the TRIG. This represents 48% of the original sample of identified carers.

The present sample consists of the 96 carers who completed the TRIG and/or SF-36 six months post-bereavement. Eighty-five of these had also returned the six-weeks-post-bereavement questionnaire. Patients of carers in the bereavement sample were less likely to have lived alone (10%; 95% CI: 6%–18%) compared to patients in the RCT population from which it was drawn (21%). Otherwise the present sample was similar to the RCT population in terms of patient age, sex, diagnosis (cancer/non-cancer), survival from referral, inpatient days, hours of HAH

nursing, and all other recorded home nursing. Inpatient days included hospice, acute hospital, and continuing care beds. Other home nursing included both generic nursing (e.g., district nursing), and palliative care nursing (e.g., Marie Curie Cancer Care).

Table 1 shows the background data for intervention and control patients in the bereavement sample. With the exception of the intervention itself (HAH), none of the differences were statistically significant.

HAH Input and Bereavement Outcome

There was no difference in bereavement outcome between carers of patients allocated to HAH and controls (Table 2). Not all patients allocated to HAH could eventually be admitted to the service. However, when comparing difference in outcome between carers of patients who were actually admitted and those not admitted to HAH (controls and intervention patients combined), there was still no difference in bereavement outcome (Table 2). There was, therefore, no indication that the HAH intervention had any impact on carers' bereavement.

Table 1 / BACKGROUND VARIABLES FOR PATIENTS RANDOMIZED TO CONTROL CONDITION OR HAH CARE

	Allocated to Standard Care (n=18) n (%)	Allocated to HAH (n=78) n (%)
Patient diagnosis		
Cancer	15 (83.3%)	65 (83.3%)
Non-cancer	3 (16.7%)	13 (16.7%)
Patient living circumstances		
Living alone	1 (5.6%)	9 (11.5%)
Living with someone	17 (94.4%)	69 (88.5%)
Patient sex		
Female	8 (44.4%)	39 (50%)
Male	10 (55.6%)	39 (50%)
Carer sex		
Female	11 (61.1%)	48 (61.5%)
Male	7 (38.9%)	30 (38.5%)
Carer relationship to patient		
Spouse	15 (83.3%)	54 (69.2%)
Other relative or friend	3 (16.7%)	24 (30.8%)
Place of death		
Home	11 (61.1%)	55 (70.5%)
Inpatient care*	7 (38.9%)	23 (29.5%)
	Mean (SD)	Mean (SD)
Patient age	69.9 (12.4)	72.4 (14.6)
Carer age	63.6 (8.3)	62.3 (13.0)
	Median (IQR)	Median (IQR)
Survival from referral (days)	7.5 (17.3)	12.0 (36.3)
Inpatient days	14.5 (29.6)	24.0 (41.0)
Hours of home nursing other than HAH	24.0 (46.6)	46.1 (83.8)
Hours of HAH nursing	0.0 (0.0)	18.0 (107.0)

*includes one patient who died in a nursing home
SD=standard deviation · IQR=interquartile range

Perceived Adequacy of Care and Bereavement Outcome

Carer ratings of adequacy of support at the end of life, made six weeks after death, were compared to TRIG scores measured six months after bereavement (Table 3). Perceived adequacy of care showed a significant relationship to how carers retrospectively rated their immediate response to bereavement (TRIG Scale 1), but not to how they rated their feelings about death six months following bereavement (Scale 2). Reported bereavement response immediately following death was worse if the carer had previously rated the medical or psychological support for the patient as insufficient. Reported early bereavement response was also worse if the

carers had previously rated practical home support, information, or psychological support for themselves as insufficient towards the end of the patient's life.

There were no significant differences in SF-36 PCS and MCS scores six months post-bereavement between those who had perceived care as adequate and those who had not.

Carers' assessments of the severity of patient symptoms showed a significant relationship with how carers rated both their immediate response to bereavement and their response six months after death (Table 4). Early bereavement response (Scale 1) was retrospectively reported as worse if the patient had previously been rated as suffering from considerable pain. Further-

Table 2 / TEXAS REVISED INVENTORY OF GRIEF (TRIG) AND SF-36 SCORES FOR RCT INTERVENTION AND CONTROL GROUPS, AND FOR PATIENTS ACTUALLY ADMITTED AND NOT ADMITTED TO HAH

	TRIG Scale 1 Mean (SD) n	TRIG Scale 2 Mean (SD) n	SF-36 PCS Mean (SD) n	SF-36 MCS Mean (SD) n
RCT allocation				
control group	20.1 (8.7) 16	46.8 (11.8) 15	43.6 (13.8) 16	49.2 (12.5) 16
intervention group	19.1 (6.9) 74	46.5 (12.9) 70	45.5 (13.4) 73	48.8 (11.0) 73
Admission to HAH				
not admitted	19.5 (7.1) 43	47.1 (11.1) 42	43.5 (14.7) 44	49.4 (10.2) 44
admitted	19.0 (7.4) 47	46.0 (14.1) 43	46.7 (12.0) 45	48.4 (12.1) 45

Scale 1: immediate bereavement response

Scale 2: present (six months) bereavement response

SD=standard deviation PCS=Physical Component Summary MCS=Mental Component Summary

Table 3 / TRIG SCORES BY RATED ADEQUACY OF HELP PROVIDED

Area of Care	TRIG Scale 1 Wanted More Help		Help Sufficient		TRIG Scale 2 Wanted More Help		Help Sufficient	
	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n
night nursing	20.3 (6.9)	24	18.1 (7.3)	49	48.3 (11.3)	21	45.4 (12.5)	47
medical care	26.3 (5.9)*	6	17.9 (6.8)*	68	55.2 (7.5)	6	44.9 (12.4)	63
personal care	23.4 (7.2)	7	18.1 (6.9)	66	52.1 (10.3)	7	44.9 (12.5)	61
psychologicalsupport: patient	23.5 (7.3)**	10	17.9 (6.8)**	57	49.3 (12.8)	10	45.3 (12.5)	52
looking after patient	21.4 (7.2)	21	18.0 (7.1)	53	45.6 (13.0)	20	46.4 (11.7)	48
practical running of house	22.6 (6.7)***	14	17.9 (6.9)***	59	47.6 (14.6)	13	45.9 (11.5)	54
information	21.3 (7.2) [†]	19	17.3 (7.0) [†]	50	46.8 (11.8)	19	44.8 (13.2)	44
psychologicalsupport: carer	22.8 (6.5)**	16	17.3 (7.0)**	51	49.8 (11.0)	15	44.6 (12.7)	46

* $t=2.950$, $df=72$, $p=0.004$; ** $t=2.400$, $df=65$, $p=0.019$; *** $t=2.313$, $df=71$, $p=0.024$; [†] $t=2.115$, $df=67$, $p=0.036$; ** $t=2.824$, $df=65$, $p=0.006$

Table 4 / TRIG SCORES BY RATED SYMPTOM SEVERITY

Symptom	TRIG Scale 1 None or Little		Quite a Bit or Very Much		TRIG Scale 2 None or Little		Quite a Bit or Very Much	
	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n
pain	17.2 (6.8)*	40	21.4 (7.4)*	34	43.8 (12.7)	36	48.9 (10.5)	34
nausea	18.8 (7.3)	51	18.1 (7.4)	21	44.9 (13.2)	45	47.0 (11.5)	21
constipation	18.6 (7.6)	44	19.1 (7.4)	29	43.0 (12.8)**	41	50.6 (11.2)**	27
diarrhea	17.9 (7.5)	57	21.4 (6.2)	9	43.9 (13.0)	52	50.1 (10.5)	8
breathlessness	18.1 (7.0)	41	19.5 (7.6)	32	42.7 (13.0)***	37	49.3 (11.2)***	31
anxiety	17.8 (7.2)	39	20.6 (7.4)	32	44.8 (13.1)	36	47.3 (11.9)	30
depression	17.8 (7.3)	47	21.2 (7.5)	22	44.1 (13.3)	43	49.0 (11.2)	20

* $t=2.556$, $df=72$, $p=0.013$; ** $t=2.506$, $df=66$, $p=0.015$; *** $t=2.229$, $df=66$, $p=0.029$

Table 5 / TRIG SCORES AND SF-36 BY PLACE OF DEATH

Place of Death	TRIG Scale 1		TRIG Scale 2		SF-36 PCS		SF-36 MCS	
	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n
home	17.8 (6.8)*	65	44.8 (13.0)	59	47.0(12.6)**	63	50.1 (11.1)	63
inpatient care	23.1 (6.8)*	25	50.4 (11.2)	26	40.7(14.4)**	26	46.0 (11.0)	26

* $t=3.297$, $df=88$, $p=0.001$; ** $t=2.041$, $df=87$, $p=0.044$

more, bereavement response six months following death (Scale 2) was worse if the patient was felt to have suffered considerable constipation or breathlessness.

There were no differences in SF-36 PCS and MCS scores in relation to carer ratings of symptom severity.

Place of Death and Bereavement Outcome

Carers whose patients had died at home, compared to carers of those who had died as inpatients, reported a significantly better early bereavement response (Scale 1) as measured by the TRIG (Table 5). However, the difference in bereavement response six months following death (Scale 2) was not significant ($p=0.062$). Furthermore, carers whose patients had died at home had a significantly better PCS score than carers of those who died in inpatient care.

Only four carers rated place of death as "definitely" or "probably inappropriate". One of these represented a home death, three an inpatient death. Numbers were therefore too small in the "inappropriate" category to analyze perceived appropriateness of place of death in relation to outcome.

DISCUSSION

In summary, this study's findings suggest that there was no effect of a HAH intervention on carers' bereavement outcome. Perceptions of inadequate end-of-life support and patient symptom suffering, however, were associated with a worse outcome. Furthermore, the outcome was worse for carers of patients who died in inpatient care.

The high number of statistical tests in the study increases the likelihood that some of the significant results could be attributable to chance, however all significant results were in the direction of insufficient support or severe symptoms being associated with poorer bereavement outcome. Thus, if any individual result may be questionable, the overall trend suggests that a negative perception of the patient's last weeks was associated with a worse outcome. The association between place of death

and early bereavement response was at $p=0.001$ and, hence, unlikely to be due to chance. Below, we consider what these results mean.

Impact of HAH

There was no indication that HAH input led to any difference in bereavement outcome for informal carers. Neither allocation to HAH nor actual HAH input was associated with a difference in outcome scores. Although study design and respondent attrition considerably reduced the statistical power of the trial, outcome scores did not suggest there was any real difference which lack of power prevented us from detecting. There was no indication that the control patients received more input of other care to compensate for lack of HAH intervention. Indeed, on the face of it, the HAH group appeared to have had more input of other care as well (Table 1), but there was such wide variation in level of input in both groups that no systematic, statistically significant differences were observed.

Previous data from the RCT of HAH suggest that the service did have an effect on quality of care and, in particular, that carers felt control of pain and nausea was better under HAH (32). The present data, however, suggest that care provision in itself had no impact on carer bereavement and that it may, rather, be perceived provision of care in relation to need that was associated with bereavement outcome. Whether perceived provision of care truly reflects actual provision in relation to need or is influenced by other factors is considered below.

Perceived Support, Symptoms, and Bereavement Outcome

Carers' perception of adequacy of end-of-life support was significantly associated with bereavement outcome as measured by the TRIG. Carers who, six weeks post-bereavement, felt the patient had had insufficient medical and psychological support, later rated their early response to bereavement as worse than their counterparts. Their early bereavement response was similarly worse if they felt there had been too little practical help, information, and psycho-

logical support for themselves. If the patient was felt to have suffered from considerable pain, early response to bereavement was also worse, whilst ratings of constipation and breathlessness were associated with worse bereavement outcome six months post-bereavement. Persistent constipation may, for instance, reflect failure to counter effects of opiate analgesia, or defective nursing care.

One should be careful about assuming that this demonstrates that insufficient care and severe symptoms lead to a worse bereavement outcome. Carers' retrospective assessments of care and symptoms may simply have reflected how they felt at the time of the assessment, rather than being an accurate account of their perceptions during the patient's final phase of life. Ratings of care and symptoms may, thus, correlate with early bereavement response because they both reflect how carers felt shortly after the death. Results for constipation and breathlessness do not, however, fit this pattern. Scores for bereavement at six months were worse for carers whose patients were perceived to have suffered from breathlessness and constipation, whilst early bereavement response scores did not differ.

Alternatively, carers' retrospective ratings may be a true reflection of their views before the patient's death. Yet it is possible that these views were more closely associated with carers' own distress than with the actual sufficiency of care, and that it was carer distress at the time of death that affected bereavement outcome. For instance, carers' ratings of patients' hope and distress have been found to relate more closely to carers' own feelings than to patients' feelings (33).

What is the evidence that carers' post-bereavement assessments of care reflect actual quality of care prior to death? Research by Higginson et al. (34) suggests that carers' assessments of symptoms and anxiety become polarized post-bereavement, compared to their assessments prior to the death. However, ratings of service support correspond better to prospective ratings. Hinton (35) found that carers rated pain as more severe post-bereavement than in their own and patients' prospective ratings. Nevertheless, more observable symptoms such as breathlessness and vomiting corresponded moderately well to patient and carer prospective descriptions. Carers' retrospective ratings of their own mood, anxiety, and fatigue showed moderate to fair agreement, and satisfaction with care showed moderate agreement with their prospective ratings.

Clearly, we should be careful in interpreting carers' ratings post-bereavement as an accurate account of symptoms and care prior to death. Assessments in the present study were obtained

closer to death and, hence, may have been more accurate than those obtained by Hinton (35) and Higginson et al. (34), whose measures were obtained four and seven months post-bereavement, respectively. Hinton found that carer ratings made concurrently with the patient's ratings were, on the whole, considerably more accurate than retrospective ratings (35). Furthermore, if carer ratings become polarized post-bereavement, this should not indicate a complete change in assessment, only that existing views become more extreme.

Nevertheless, we need to be aware that carers' accounts are unlikely to be accurate for patient feelings and less observable symptoms (35-37), and may be more accurate for more easily observable symptoms, support, and, possibly, their own feelings. Thus, we may place more trust in results relating to ratings of breathlessness and constipation than in results relating to pain. We should, perhaps, also place more trust in results relating to practical support and, possibly, medical care than in results relating to adequacy of psychological support.

The present study suggests that worse bereavement outcomes were associated with a perceived lack of support, or at least practical support, and perceived severity of symptoms, or at least observable ones, towards the end of life. This was mainly related to early bereavement response, which may reflect that the impact of bereavement lessens over time (15), although it may also simply reflect that the TRIG scales that measured early and late bereavement response were different.

As long as we are unable to fully ascertain whether assessments of care really reflect adequacy of care, however, the association between adequacy of care and bereavement outcome remains a hypothesis for further testing. This emphasizes the need for prospective measurements of symptoms and support, where possible. However, in reality, retrospective assessments will often be the only practical solution. In this study, considerable effort was invested in attempts to obtain prospective measures before accepting that this was not feasible. Given the realities of palliative care research, we need to know more about when and how retrospective accounts are likely to correspond with prospective ratings, or find other ways of measuring adequacy of care prospectively which do not tax patient and carer resources.

Place of Death and Bereavement Outcome

Death at home compared to inpatient care was associated with better bereavement scores

immediately following death. This difference failed to reach significance for later bereavement scores. Physical health was better at six months post-bereavement for carers of patients who died at home.

The time sequence means there is good reason to believe there is a causal relationship between place of death and outcome. Still, we need to consider the nature of this relationship. Several studies have found that home death was associated with worse bereavement outcomes (9,19,20). Our sample, however, was carers of patients who were referred to HAH. This means that there was a wish for the patient to remain at home and probably also to die at home. Death in inpatient care may therefore be associated with a poor outcome because this was against the patients' and carers' original wishes.

An alternative and not entirely mutually exclusive explanation is that it was those carers who could no longer cope with home care whose patients died in inpatient care. Inpatient death may, thus, be associated with poor bereavement outcomes because it represents those carers who were least able to cope physically or mentally, and/or became most exhausted. This may explain why they had poorer physical health scores six months post-bereavement, and it may also explain why so few were willing to rate the place of death as inappropriate, even if bereavement outcome was worse for inpatient deaths. Carers may have felt everything that could be done had been done, and that inpatient death was the only sensible option.

The two explanations cannot be disentangled here. It is plausible that a failure to fulfill the patient's and one's own wishes about location of death would lead to a worse bereavement outcome. A positive rating of appropriateness of place of death in this context may be a wish to convince oneself, with hindsight, that it all worked out for the best. It is also plausible that any excessive strain placed on the carer during home care would have a negative effect on later response to bereavement. If so, we need to ask to what extent home support, if sufficiently provided, can help prevent such strain.

CONCLUSION

The present study found that provision of HAH had no effect on carers' bereavement. This implies that adding hours of care in itself does not affect bereavement outcome.

In contrast, perceived quality of care was associated with bereavement response. This may be because the discrepancy between actual care provision and need, rather than level of care in

itself, has a negative impact on bereavement. Findings may also reflect that carers' negative assessments of care are derived from their own distress, and that this is what is associated with bereavement outcome. These explanations have different implications. If the actual quality of end-of-life care affects bereavement outcome, this adds further impetus to ongoing efforts to improve such support. However, if poor bereavement outcome stems, in part, from distress or misperceptions of patients' suffering, we may improve bereavement outcomes by addressing carers' distress, or by helping them attain a more accurate perception of patients' pain and distress in situations where these are typically overestimated.

Death at home was associated with better early bereavement response and better physical health six months post-bereavement. This may mean that death at home, if desired by the patient and carer, improves bereavement outcome, and preference for place of death should be considered in future research. Further research also needs to consider the relationship between home care, caregiver burden, and bereavement. In situations where caregiver burden exhausts the carer's resources, home care may become detrimental to bereavement outcome.

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