Terminal care: Evaluation of in-patient service at St Christopher's Hospice

Part II. Self-assessments of effects of the service on surviving spouses

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Summary

Self-assessments of 34 spouses of patients who had died from cancer at St Christopher's Hospice were compared with self-assessments of a matched group of spouses of patients who had died in other hospitals in the vicinity.

The spouses of St Christopher's patients differed significantly from the comparison group in spending more time at the hospital, talking to more members of staff, other patients and visitors, reporting less anxiety and psychosomatic accompaniments of anxiety before (but not after) the patient's death and being less worried about pain, others hurting or harming the patient or about revealing their own fears to the patient.

The institutional ideals of the Hospice were characterized as: 'The hospital is like a family', 'Nothing is too much trouble' and 'Don't worry'.

Introduction

One of the claims made for St Christopher's Hospice is that the family, which includes the patient, is the unit of care. That is to say the staff recognize that terminal illness often gives rise to severe stress on relatives as well as patients and that this stress needs to be understood if medical and nursing care is to be effective.

The self-assessments made by surviving spouses of their own reactions to the type of in-patient care provided to them and the patient at St Christopher's Hospice and at other hospitals in its vicinity are now reported.

Method

The details of the method of selecting and interviewing respondents for this study were given in Part I and in an earlier paper (Parkes, 1978a). Suffice it to say that 34 spouses of patients who had died at St Christopher's Hospice were carefully matched, case-for-case, with 34 spouses of patients who had died in other hospitals.

Information was obtained about various aspects of Hospice care using a standard interview schedule.

This included self-assessments by the widow or widower of the time which they had spent each day at the hospital, the activities which they carried out there, the numbers of various categories of staff members whom they met and their own emotional state during the time the patient was in hospital and after his death.

Emotional state while the patient was in hospital was assessed retrospectively using a check list of 6 common accompaniments of anxiety: loss of appetite, loss of weight, trembling, sleeplessness, tiredness and forgetfulness. In addition, a 'Worry Score' was obtained by making 5-point ratings of the intensity of 7 causes of anxiety commonly reported by spouses of patients in hospital. Post-bereavement adjustment was measured from a check-list of 21 symptoms and features of the emotional reaction to bereavement.

It is always difficult to characterize the 'atmosphere' of a hospital yet this word is often used of the overall impression given by a place and it is likely to reflect the institutional ideals more accurately than a more focused assessment of any part of the service. Pilot interviews with 7 matched pairs of respondents led to the formulation of 6 slogans which were then presented as a multiple choice question to the rest:

'Each institution has a different set of ideals. Which of these phrases do you think might be used by nurses to describe the institution where your husband or wife died? 'Efficiency comes first', 'The hospital is a family', 'We never give up', 'Don't worry', 'Leave it to us', 'Nothing is too much trouble'.

Results

The respondents comprised 22 widows and 12 widowers in each group. Mean age 55 years and from all social classes with nearly 50% from social class III (Registrar General) (skilled manual).

Ward visiting

In both St Christopher's Hospice and other hospitals the patient's husband or wife had been

permitted to visit daily and usually they had done so but there was a great difference between the settings in the length of time which they had spent at the hospital. This is shown in Table 1, from which it is clear that over 50% of the spouses of patients at St Christopher's Hospice said that they had spent 6 or more hours each day with the patient. This is probably as much time as they would have spent with him if he had been nursed at home. At other hospitals only 9% claimed to have spent this amount of time with the patient. Asked whether the patient had thought that the time they had spent at the hospital was too long, too short or the right amount of time, the great majority, in both settings, said that this was the right time. Exceptions were 4 patients at other hospitals whose spouse had spent one hr daily at the hospital and who had wished for them to stay longer (in only one case did the spouse share this view) and 2 patients at St Christopher's whose spouse had stayed 6 hr or more per day and who had wished they had not stayed so long (in one case the spouse agreed, in the other she wished she could have stayed even longer).

TABLE 1. Replies to question: 'How long did you spend with the patient each day (week)?'

	St Christopher's (n = 34)	Other hospital (n = 34)
1 hr/day or less	12%	41%
2-5 hr/day	32%	44%
6+ hr/day	53%	9%
Not known	3%	6%
$P < 0.001$.		

In both settings more than 50% of the spouses said that they did not help with the care of the patient in hospital (47% at St Christopher's and 29% elsewhere said they *had* helped but this difference did not reach statistical significance). Those who had not helped were asked if this was because there was nothing for them to do, because they did not wish to interfere with the nurses' work or because the patient did not want their help - nearly all (in both settings) said it was because there was nothing for them to do.

Most respondents had talked to a nurse and a ward sister whatever the type of hospital. They were likely to talk to a doctor at St Christopher's Hospice more frequently than at other hospitals. This is apparent from Table 2 in which it appears that 3 respondents at St Christopher's and 10 at other hospitals could not recall having talked to a doctor at all. Further confirmation of this finding came in response to the question, 'Do you know the doctors' names?' Sixty-eight per cent. could remember the

TABLE 2. 'How often did you talk to the doctor?'

	St Christopher's	Other hospitals
Not at all	3	10
'Occasionally' or 1-3 times	7	14
More frequently	17	5
Not known	7	5

$P < 0.01$.

name of one or more doctors at St Christopher's compared with only 24% at other hospitals ($P < 0.002$).

Those who had talked with ward staff were asked to assess them on 5 scales concerning their friendliness, approachability, helpfulness, efficiency and busyness. With few exceptions ward nurses, sisters and doctors were each seen as very friendly, very approachable, very helpful and very efficient. The only significant differences lay in assessments of their busyness. From these it is clear that nurses, ward sisters and doctors from St Christopher's were less likely to be seen as 'busy' than were those at other hospitals (Table 3).

TABLE 3. Assessments of ward staff busyness

	St Christopher's	Other hospitals	P^*
Ward Nurses			
Busy	18	26	< 0.01
Not busy	12	2	
Not known	4	6	
Ward Sister			
Busy	18	22	< 0.05
Not busy	12	2	
Not known	4	10	
Ward doctor			
Very busy†	8	15	< 0.01
Busy or less	22	2	
Not known	3	17	

* All significance levels based on Yates' χ^2 test after excluding 'not knowns'.

† The term 'very busy' was not included in the assessment scale for nurses and sisters.

Respondents were asked, 'How many other members of the institution staff did you get to talk to?' and a list was read out of 12 types of staff members whom they might have encountered. Sixty-eight per cent. at other hospitals said 'none' compared with only 15% at St Christopher's ($P < 0.002$). Particular staff members were: volunteers (19 St Christopher's, nil at other hospitals), receptionist (19 and 0), Matron (16 and 1), ward orderlies (11 and 3), porters or stewards (6 and 1) and social workers (2 and 4). The chaplain is not included in

this list because respondents were often unsure of the identity of any clergyman who had visited their spouse.

The patient's spouse during the period of terminal care in hospital

Whether the patient was in St Christopher's or other hospitals practically all respondents said that they felt less anxious with him in hospital than they had when he was at home. Even so it was unusual for a spouse to rate her overall level of anxiety as less than 'great' in either setting.

The check list of anxiety symptoms gave rise to mean scores of 0.38 from spouses of patients who died at St Christopher's and 0.68 from those at other hospitals ($Z=2.7$, $P<0.01$, Wilcoxon Test). The only individual score from the list which reached significance was 'loss of appetite' which was reported as 'great' or 'very great' by 36% of spouses of St Christopher's patients and 70% of those elsewhere ($P<0.05$).

Further confirmation and some explanation for these findings comes from the Worry Score which also distinguished the 2 groups (Wilcoxon Test, $Z=3.21$, $P<0.01$). The questions which make up this score are given in Table 4. This shows that spouses of patients at St Christopher's Hospice were less likely than spouses elsewhere to worry greatly about physical pain or its relief or about revealing their own fears to the patient. They were also less likely to express some worry that others might hurt or harm the patient. Other sources of anxiety do not distinguish the groups to a significant degree but all show trends favouring the St Christopher's group.

The patient's spouse after bereavement

Widows and widowers of patients who had died at St Christopher's Hospice scored a mean of 21 on the Postbereavement Adjustment score. This was identical with the score obtained at other hospitals.

At the time covered by this study no systematic attempt was being made to support bereaved families at St Christopher's Hospice and it was left to the

initiative of family members to ask for help if they needed it. Thirty-two per cent. of spouses of St Christopher's patients did recall being invited to 'keep in touch' (compared with none elsewhere) and 24% had in fact done so. But such contacts were sporadic and isolated, with little consistent help being given them.

Institutional ideals

Table 5 shows the slogans which were thought by respondents to have applied in each setting. Since respondents were permitted to indicate more than one slogan per hospital the totals add up to more than 100%.

TABLE 5. Respondent's view of institutional ideals

	St Christopher's	Other hospitals	P
'Efficiency comes first'	22%	37%	n.s.
'The hospital is a family'	78%	11%	<0.001
'We never give up'	22%	15%	n.s.
'Don't worry'	41%	11%	<0.05
'Leave it to us'	26%	33%	n.s.
'Nothing is too much trouble'	100%	59%	<0.002

Five respondents, all of whose spouses had died at other hospitals, said that none of the phrases could be said to apply. The phrase which best distinguished St Christopher's Hospice from other hospitals was 'The hospital is a family', which was checked by 78% of spouses of patients who had died at St Christopher's and only 11% from elsewhere ($P<0.001$). The most popular attribution in both settings was 'Nothing is too much trouble,' this was asserted by all respondents with respect to St Christopher's but by only 59% from elsewhere ($P<0.002$). Less commonly claimed was 'Don't worry', which was said to apply to 41% at St Christopher's and only 11% elsewhere ($P<0.05$).

Second favourite at other hospitals was 'Efficiency comes first,' but this was one of the least favoured

TABLE 4. Sources of anxiety reported by respondents

Were you worried about?:	Level	St Christopher's	Other hospital	P
1. Physical pain and its relief	Great or v. great	9%	36%	<0.05
2. Revealing fears to patient	Great or v. great	9%	33%	<0.05
3. Your own future	Great or v. great	13%	28%	n.s.
4. Being unable to go on	Mild-v. great	25%	43%	n.s.
5. Separation from your husband/wife if he/she had to be moved elsewhere	Mild-v. great	0%	11%	n.s.
6. Others hurting or harming husband/wife	Mild-v. great	7%	35%	<0.02
7. Future of children or other dependents	Mild-v. great	19%	31%	n.s.
Mean 'Worry Score'		5.26	8.65	<0.01

attributions for St Christopher's Hospice (37% and 22% – not significantly different). The other 2 phrases, 'Leave it to us,' and 'We never give up,' were favoured by less than 33% in each setting.

Discussion

There is good evidence from this study that spouses of patients at St Christopher's Hospice are likely to spend very much more time at the bedside than those at other hospitals. This is fostered by the lack of restrictions on visiting, by the provision of sitting room facilities and residential accommodation for families who need to stay over-night and by a staff policy of including the family within the unit of care. This, coupled with the provision of sufficient staff members to ensure that staff are not seen as too busy to communicate with the family, probably explains the greater tendency at St Christopher's for the patient's spouse to get to know more staff members and more patients and families than at other hospitals and to agree with the statement that 'the hospital is like a family'.

The question then arises, what do relatives do during the long periods of time which they spend with the patient? The answer would seem to be that they *do* very little. There is some interaction with fellow relatives and staff and 47% play some part in caring for the patient but much of the time at the bedside the family are likely to sit quietly conducting a vigil which will not end until the patient has died. The patients themselves usually seem to value the presence of their family very greatly but ask no more than that they should just 'be there' and few of them took the opportunity to talk about the implications of the illness. It is a reasonable assumption that the presence of a loved relative helps to allay fear, not because of the medical or nursing skills which they bring but because it is in the nature of attachment behaviour that their presence should do so. Attachment behaviour, the tendency to seek to maintain proximity to loved others, is evoked by any situation which threatens security and is most evident in mother/child interaction. But it is also clearly seen in the reluctance of patients and spouses to be separated from each other during the final phase of a terminal illness*.

Attachment is essentially concerned with security and we should not be surprised to find that wives and husbands who are together during much of the day are less anxious and have fewer psychosomatic accompaniments of anxiety than those who are separated from each other. But there are other possible reasons for the lower levels of anxiety reported by the spouses of patients at St Christopher's Hospice.

* For a fuller discussion of the nature and function of attachment behaviour see Bowlby's important work *Attachment and Loss*.

As was demonstrated in Part I, the respondents reported that patients suffered less pain at St Christopher's and this, in itself, accounts for the fact that they were less worried about pain relief and less fearful that others would hurt or harm the patient than in other hospitals.

Of particular interest is the finding that spouses at St Christopher's were less worried than elsewhere by the need to conceal their own fears from the patient. One might think that the amount of time spent at the bedside would have made concealment more rather than less difficult. It appears, however, that family members at St Christopher's feel less fearful and consequently have less fear to conceal. But no amount of emotional support will alter the fact that the patient is approaching death and it is this that relatives seem most anxious to conceal. It would seem to follow that some part of the fear of death itself is mitigated by the circumstances of care at St Christopher's Hospice and it is suspected that the most important reason for this is the acceptance of the dying patient and his family by the staff themselves. Remarks such as, 'There was never anyone around', or 'They were rushed off their feet' or 'Understaffed' which were made of some of the other hospitals were never directed at St Christopher's and the situation was summed up by the wife of one patient who said of the nurses, 'They were gracious and sweet, floating about anticipating everyone's needs . . . oiled wheels all the time'. And of the doctors 'They were all very charming, very helpful'.

One might have expected that, even before the introduction of a bereavement support service, the spouses of patients who had died at St Christopher's Hospice would be better prepared for bereavement and would have suffered less after the patient's death than spouses from other hospitals. This is not confirmed by our evidence although a later investigation did demonstrate the beneficial effects of introducing systematic bereavement support for those families thought to be in need of it (Parkes, 1978b).

It may be that the spouses of patients dying at St Christopher's are more vulnerable than those of patients dying elsewhere; the Hospice accepts many patients for admission because there are psychological or social reasons which make it hard for their spouse to cope with them at home and some of these spouses are mentally unstable. Since no attempt was made to control this selective factor in matching respondents from the 2 settings it may be that any reduction in risk which resulted from the support given to families before bereavement did no more than offset the increased risk which already existed.

The replies to the question on institutional ideals throws an interesting side light on the qualities

which people refer to as 'the atmosphere of the place'. St Christopher's is not seen as particularly efficient (few thought that 'efficiency comes first') nor is it seen as a place where the staff will take over all responsibility from the family ('leave it to us') or as engaging in determined attempts to prolong life at all costs ('we never give up'). On the other hand it is perceived as a place in which 'nothing is too much trouble,' and the staff achieve the kind of relationship with patients and relatives which cause three-quarters of the respondents to characterize it as 'like a family'.

The findings of this research confirm the hopes of the staff that the service provided at St Christopher's Hospice for dying patients and their families was superior in many respects to that provided in other hospitals. Since the study was carried out many of the approaches espoused by the Hospice staff have been adopted elsewhere and staff have played

a part in training health care professionals in their own district. A replication study is now being undertaken to assess whether these activities have resulted in changes in terminal care in the area.

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References

- BOWLBY, J. (1969) *Attachment and Loss*. Hogarth, London.
PARKES, C. MURRAY (1978a) Home or hospital? Terminal care as seen by surviving spouses. *Journal of the Royal College of General Practitioners*, **28**, 19.
PARKES, C. MURRAY (1978b) Evaluation of a bereavement service (submitted for publication).