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

Part I. Views of surviving spouse on effects of the service on the patient

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Summary

The surviving spouses of 34 patients who died of cancer at St Christopher's Hospice have been interviewed about 13 months after the patient's death. The information given is compared with that obtained from 34 spouses of patients dying from cancer in other hospitals and matched with the St Christopher's group.

Patients at St Christopher's were less often thought to have suffered severe pain and other distress than at other hospitals, but pain relief was not bought at the cost of drug-induced confusion and patients at St Christopher's remained more mobile than at other hospitals.

Hospice patients were more aware of chapel services and prayers than at other hospitals. None was said to have been upset by these and 66% were glad of them.

Despite the frequency of deaths in the Hospice, patients at St Christopher's were no more likely to be thought to have been 'upset' by such events than patients elsewhere or to have found their interactions with other patients anything but helpful.

Introduction

The term 'Hospice', originally a house of hospitality for pilgrims, has acquired a fresh meaning since the inception in 1968 of St Christopher's Hospice in Sydenham under its medical director, Dr Cicely Saunders. Essential components, in her view, are small autonomous units (maximum 50–70 beds) having a high nurse : patient ratio; a mixture of patients including some long-stay and some brief admissions for pain control as well as patients admitted for terminal care; a home-care programme serving patients at home; spiritual support for staff and patients but avoiding dogmatism and rigid answers; a tradition of flexibility and open communication between staff and staff, staff and patients and staff and families; minute attention to the relief of pain and other symptoms; full use of volunteers from the local community; willingness to teach and conduct research when and where possible, and support for the family before and, where necessary, after the patient's death.

This is a report of evaluations of the effects on the patient of in-patient care only. These were made by surviving spouses of patients who died at St Christopher's Hospice during 1967–71. They are compared with evaluations by spouses of a matched group of patients dying in other hospitals in the area. Effects of the in-patient service on the patient's spouse are reported in Part II. Evaluations of the home-care service and bereavement service will be published elsewhere.

Method

The families reported here are 2 subsamples of the 276 who were included in a survey of the patterns of terminal care in the south London boroughs of Lewisham and Bromley. They were located through the death registrations of patients under the age of 65 years who had died from cancer during the period of study. Surviving spouses were interviewed in their homes on average 13 months after bereavement and systematic information obtained regarding the patient's terminal illness and the reactions of patient and spouse to each phase of care. Further details of the sample, interview methods, reliability testing and findings of that study are published elsewhere (Parkes, 1978).

For the purposes of this study it was attempted to contact the spouses of 57 patients who had died at St Christopher's Hospice and to ask them to agree to a second interview. One could not be located and one other declined; 55 were re-interviewed. It was then attempted to match each of the re-interviewed St Christopher's patients with a patient who had died in another hospital. Matching criteria were age, sex, socio-economic status, duration of terminal period and severity of pain before the terminal period (for the purposes of this study the terminal period was the period from the end of active treatment to death). Second interviews with 34 matched pairs were eventually obtained.

Difficulty in matching resulted from the inclusion in the St Christopher's sample of a number of patients who had died within a few hours or days of admission. Only a few patients who had had similar brief

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periods of terminal care in other hospitals could be found.

The second interviews were semi-structured. That is to say the interviewer obtained answers to specific questions covering each aspect of the care provided during the terminal period in hospital or hospice but also encouraged the respondents to talk freely about this period of their lives and recorded their comments verbatim.

Results

Demographic characteristics of the matched pairs are shown in Table 1 along with comparable figures for the total sample from which they are drawn. It will be seen that in both settings and both samples there is a preponderance of male patients of mean age 55 years and with a normal distribution across social-class groupings. Matching for age, sex, social class, severity of pain before terminal period and mean duration of terminal period is quite good except for a rather larger proportion of patients said to have had severe pain before admission to St Christopher's. The matched groups resemble the full sample on most points, the main difference being the greater amount of pre-terminal pain said to have been suffered by 42% of the full sample of St Christopher's patients and 32% of the matched sample.

Further evidence of successful matching comes from analysis of the data from the first interview which refers to the period of care before the terminal illness. Among 31 different measures there were no significant differences between the matched groups.

The process of admission

Several questions concerned the process of admission and the view which the patient had of the hospital before admission. St Christopher's Hospice had not been open for very long in 1969–70, and was not widely known in the neighbourhood, in fact only 2 respondents said that they had heard of it before the patient's referral. By contrast, 27 (79%) of the respondents whose spouse had been admitted to another hosptial had previous experience of the hospital which was usually the same general hospital in which the initial diagnostic admission had taken place.

In 6 cases spouses of patients who were subsequently admitted to St Christopher's Hospice paid an initial visit. They reported that they had seen all they wished to see and been satisfied with the answers to their questions. None of the 26 whose spouse was admitted to the hospice without prior knowledge of the place answered 'Yes' to the question, 'If you had (visited the hospice) would you have changed your mind about admission?'

Despite their ignorance of the hospice, only one patient was said to have been relucant to be admitted. By comparison, 8 who entered other hospitals were reluctant or very reluctant.

In only 3 cases (2 St Christopher's and one other Hospital) was there said to have been difficulty in finding a bed and the mean delay before admission was 3·6 days at St Christopher's and 2·7 days at other hospitals (4 patients in each setting had waited for more than one week).

Ward unit

Three patients in each setting were cared for in single rooms. Of the remainder, those at St Christopher's were nursed in small partitioned units of 4–6

TABLE 1. Characteristics of matched pairs and full sample of cancer patients dying in hospital or hospice

	Matched pairs		Full sample	
	St Christopher's	Other hospital	St Christopher's	Other hospital
n	34	34	55	100
Sex				
Female	35%	35%	40%	34%
Male	65%	65%	60%	66%
Mean age (years) (respondent)	54·9	55·4	49·9	55·0
Socio-economic status				
Group I	12%	9%	11%	13%
Group II	9%	21%	13%	18%
Group III	50%	44%	47%	49%
Group IV	21%	24%	20%	16%
Group V	9%	3%	7%	5%
Severe or very severe pain before terminal period	32%	21%	42%	28%

beds, whereas those in other hospitals were in larger units (most often these contained 11–20 beds but in 24% the patient had been nursed on a ward of over 20 beds).

Severe pain during the terminal period was said to have been suffered by 48% of patients at other hospitals, and in 36% this was mostly unrelieved. At St Christopher's Hospice, however, the proportion who were said to have suffered severe pain was 18% ($P<0.05$) and in only 50% of these cases was this mostly unrelieved.

Reports of distress reflected those of pain but even when this was taken into account patients at St Christopher's were said to have suffered less distress than those at other hospitals. Thus, confining attention to 20 patients at St Christopher's and 11 at other hospitals who were said to have had little or no pain, 3 at St Christopher's (15%) and 6 at other hospitals (55%) had apparently suffered moderate to severe distress (Fisher's Test, $P<0.05$).

Lest it be thought that increased relief of pain and distress at St Christopher's Hospice is bought by 'knocking out' the patient with large doses of narcotic or tranquillizing drugs, assessments of the overall level of consciousness and mobility in the 2 settings were also compared. These are shown in Table 2 from which it is clear that consciousness is no more likely to be impaired at St Christopher's Hospice than at other hospitals and that patients are rather more likely than at other hospitals to be out of bed throughout the major part of their period in hospital.

TABLE 2. Reported pain, impairment of consciousness and mobility in the patient

	St Christopher's	Other hospital	P
Pain rated as severe or very severe	18%	48%	<0.05
Consciousness—			
Fully alert	33%	16%	n.s.
Some impairment	44%	61%	
Very confused or unconscious	23%	23%	
Mobility—			
Confined to bed	61%	87%	<0.05
Not bed-bound	39%	13%	

Awareness of prognosis

Respondents were asked to assess the extent to which the patient was aware of his diagnosis and prognosis. Figures for assessment of prognosis are given in Table 3. Assessment of awareness of diagnosis were very similar. In both settings about one third of the respondents said that the patient had never discussed his diagnosis or prognosis with them and that they had no idea how much he knew. Patients at St Christopher's were twice as likely as patients from other hospitals to be fully aware of diagnosis and prognosis but this proportion was still only a third of the total and the difference did not reach statistical significance.

TABLE 3. Patient's reported insight into prognosis

	St Christopher's	Other hospitals
Doubtful or not known	29%	38%
Unaware of prognosis	15%	18%
Partially aware	21%	27%
Fully aware of prognosis	36%	18%

Religious aspects

St Christopher's Hospice is 'a religious and medical foundation' and it is appropriate to consider how the religious component was perceived by the patients and their spouses.

There was no evidence that patients admitted to St Christopher's were selected or selected themselves for admission because of their faith. Thus only 4 were said by their spouse to have had a 'strong' faith in God compared with 7 admitted to other hospitals (not significant) and only 4 were regular weekly church attenders compared with 6 at other hospitals (not significant).

It is unusual for a hospital to lack a hospital chapel but only 7 respondents whose spouse had died at 'other hospitals' knew of the existence of such a chapel in their hospital and in no case had the patient attended a service in the chapel. By contrast, 32 of the 34 whose spouse had died at St Christopher's Hospice knew of the existence of a chapel ($P<0.001$) and in 9 cases (27%) the patient was known to have attended a service.

The author has no information regarding the frequency with which prayers are said on the wards of other hospitals. Four respondents reported that this was the case and 3 of them said the patient was glad of this. At St Christopher's Hospice, where ward prayers are said in the presence of the patients each day, 21 (62%) were aware of that fact, 13 said the patient was 'glad' or 'very glad', 8 'neutral', none thought he had regretted or been upset by the saying of prayers.

Twenty-one at St Christopher's and 13 at other hospitals were aware that the patient had been visited by a clergyman (not significant). One in each setting thought that such visits had been unhelpful. The rest were divided between those who had no opinion (11 St Christopher's and 6 other) and those who saw

the visit(s) as 'helpful' or 'very helpful' (9 St Christopher's and 6 others).

Asked 'Did the patient express any opinion about the emphasis or lack of emphasis on religious aspects in the hospital?' only 5 respondents, all spouses of patients who had died at St Christopher's Hospice, answered 'Yes'. Of these, all the opinions expressed were positive in tone.

Asked for their own opinion, 9 spouses of St Christopher's patients expressed a positive opinion, none negative and 14 neutral (leaving 11 'not known') whereas spouses of patients at other hospitals reported 2 positive comments, one negative and 14 neutral (leaving 13 'not known').

Other patients and families

In both St Christopher's and other hospitals patients were likely to get to know other patients (19 St Christopher's and 18 at other hospitals). On the whole interactions with others were likely to be seen as 'helpful' (15 and 10) rather than 'upsetting' (2 and 1).

Perhaps as a consequence of spending so much time at the Hospice, the respondents themselves were more likely to spend 'much' time talking with other patients and visitors at St Christopher's than at other hospitals: 12 at St Christopher's and one at other hospitals ($P < 0{\cdot}01$) said that they found this interaction helpful.

The proportion of all patients admitted who stay until they die at St Christopher's Hospice (*c.* 92%) is very much greater than at most other hospitals and the median length of stay is only 11 days. Even so, only 15 of the respondents (44%) were aware that a death had occurred on the ward during the patient's period in hospital and, as will be seen from Table 4, most were not, apparently, upset by this. Figures for other hospitals are remarkably similar, thus 11 respondents knew of a death on the ward but only 2 patients were said to have been 'very upset'. None of the differences shown in Table 4 approach statistical significance.

TABLE 4. Reactions to deaths on the ward

	St Christopher's	Other hospitals
'Did anyone in the ward die while (the patient) was there?'		
Yes	15	11
No	6	4
Not known	13	19
'How did he react?'		
Very upset	1	2
Upset	1	0
Some	2	0
Not upset	8	6
Helped or reassured	1	0
Not known	2	3

Discussion

The evaluation of any system of health care is difficult and no method is ideal. In focusing on information obtained from the patient's spouse some sources of error have been reduced but not others. Doctors and nurses, because they are part of the system, are likely to be biased in its favour, and patients themselves, while they are at the mercy of the system, can hardly be expected to be able to make an objective evaluation. By obtaining the information from surviving spouses 13 months after the patient's death it was hoped to eliminate some of this bias.

But it would be unrealistic to pretend that the husbands and wives of patients who have died in a particular hospital are completely unbiased in their attitude to that hospital. The fact that they are likely to have played a part in obtaining the admission in the first place plus their need to believe that everything possible was done to help their spouse may have distorted their judgements. Conversely the bitterness and resentment which is a common feature of grief may well have made some of them excessively critical.

It seems, then, that one must doubt the validity of the data, at least as it is expressed in absolute terms. Fortunately it is not with absolute levels that this study is mainly concerned but with a comparison of 2 systems of care in both of which it seems reasonable to assume that similar bias exists. It is a basic premise underlying the study that in the statistical analysis such biases will have cancelled each other out.

For this reason its was particularly important to ensure that the samples were well matched and some lengths were gone to to ensure that this was the case. The slight bias which crept in despite the attempts to match for 'pain before terminal admission' would tend to go against the hypothesis that patients at St Christopher's suffer less pain than patients elsewhere and need not, therefore, cause disquiet.

But the more rigorous the matching criteria the less likely it is that the matched subgroups are truly representative of the parent populations from which they are drawn. Table 1, however, indicates that the matched subsamples in this study were not much different from the full samples. The main discrepancies are found in the full sample of patients cared for at St Christopher's which differ from the matched subsample in containing more patients who had pain problems before admission and more who died within a few hours or days of admission. Despite this, the full sample was reported as having less pain in St Christopher's than the subsample. It seems likely, therefore, that the methods of pain relief in use at the hospice are likely to succeed even in patients

who have had severe pain before admission and in those who are only in the hospice for a short time.

Critics of the provision of special in-patient units for the terminally ill point to 3 supposed disadvantages of such places: (1) The 'death-house' image. It is suggested that such places are likely to get a reputation as places where 'nobody gets out alive' and that this will deter people who need their services from accepting admission. (2) The 'depressing' environment. It is suggested that any ward which contains more than a few dying patients will become gloomy and that patients will communicate to each other feelings of depression and doom. (3) The 'upsetting' effect of deaths on the ward. It is suggested that patients in a unit with a high death rate are much more likely to become aware of the death of other patients than at other hospitals and that this will produce unnecessary fear and distress.

These are important criticisms which deserve to be taken seriously. The first cannot be answered from the present data since the author has no information from people who may have refused admission. The fact that some patients do improve sufficiently well to return home and that 'open days' at the hospice are held with the aim of reducing horrific fantasies may go some way to eliminate the danger. None of the relatives of patients in this study who knew nothing of the hospital before admission subsequently regretted having agreed to the patient's admission and the policy of encouraging patients and family members to visit the hospice in advance may have helped to reassure some of those who had doubts (but again, the author has no data concerning any who might have been 'put off' by such a visit).

As to the second point. The data reported here certainly dispel the notion that patients at St Christopher's suffer more distress than patients elsewhere or that interaction between patients are likely to be seen as unhelpful rather than helpful. Relatives too, as will be shown in Part II, report feeling less worry and distress than at other hospitals so that the picture of the terminal unit as a 'slough of despond' certainly does not apply in this setting.

Despite the high death rate at St Christopher's Hospice over 50% of the respondents seem to have been unaware of the death of another patient while their husbands and wives were in the ward. At first sight this seems remarkable until one recalls the small size of the ward units (4–6 beds) in which the patients at St Christopher's Hospice are nursed. Clearly, the chances of knowing what happens to the other patients is much greater in a ward of 20–40 beds than it is when the only people you get to know well are your neighbours in a 4–6 bed unit. It is not possible to know for sure how many patients succeeded in concealing from their spouse the fact that they were upset by the death of another patient but in view of the amount of contact which they had with other patients and their families it seems unlikely to have been a large proportion. Since the death of one or more other patients was known in 15 cases at St Christopher's and 11 cases elsewhere why were patients not more often said to be 'upset' by this? A possible explanation was given by one widow who thought that her husband had been reassured by the occurrence of deaths on the ward . . . 'Because it all seemed so simple and caused no upset'.

The new approaches to the relief of chronic pain adopted by Dr Saunders have been described above but little systematic evidence for their effectiveness has previously been published. The assessments of pain made by the respondents in this study are obviously subject to retrospective error but independent interviewers did, at least, agree quite well and there is no reason to believe that any bias which had crept in affected the assessments of pain at St Christopher's any more than those at other hospitals. There seems to be good reason to accept the overall assertion that patients under care at St Christopher's Hospice suffered less severe pain than patients at other hospitals and that this result was achieved without 'slugging' the patients with huge doses of drugs so that they were more likely to be rendered immobile or unconscious than patients elsewhere.

How much of the improvement in pain relief is attributable to drugs and how much to the relief of psychological distress is hard to say. Pain is a psychobiological phenomenon and, whatever physical causes may be behind it, it is very likely to be aggravated by fear, tension and anxiety. Relieve the anxiety, and the pain improves, relieve the pain, and the patient grows less anxious. With so many interacting factors it is not possible to know how much weight to attach to any one of them.

Traditionally the church has had a recognized role in providing a context of meaning for death, a set of rituals which are assumed to provide support to the dying and the bereaved, and a community of clergy and others who see it as their role to comfort them. In present Western society, however, it can no longer be taken for granted that beliefs, rituals or guidance from the 'religious' community will be offered or, if offered, will be acceptable.

The present data certainly confirm the small part played by religion in the 'other hospitals' to which patients were admitted. At St Christopher's Hospice most respondents were at least aware that chapel services and ward prayers took place and that most patients were visited by clergy. It was rare for them to have regarded any of these practices as harmful or intrusive and about 33% felt that they had been helpful or very helpful. Among those who took a positive view were several who had not previously

expressed much interest in religion. This conforms to general experience at the hospice where the aim is not seen as a militant attempt to produce 'death-bed conversions' and where confirmations and baptisms are rare. Nevertheless most staff members have religious convictions of their own which they see as giving meaning to their work and as enabling them to become vehicles for the expression of God's love for the dying and the bereaved.

St Christopher's Hospice is often spoken of as a 'community', a network of concerned persons who, through personal interaction with each other and with the patients and family members who seek their help, support each other in facing the fears and griefs which often accompany death and bereavement. To evaluate this component of Hospice care it is necessary to examine the way in which it was experienced by the husbands and wives of the patients. This will be reported in Part II.

Reference

PARKES, C. MURRAY (1978) Home or hospital? Terminal care as seen by surviving spouses. *Journal of the Royal College of General Practitioners*, **28**, 19.