

FACTORS ASSOCIATED WITH LOCATION OF DEATH (HOME OR HOSPITAL) OF PATIENTS REFERRED TO A PALLIATIVE CARE TEAM

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Objective: To identify factors associated with the location of death (home or hospital) of patients referred to a palliative care home support team.

Design: Retrospective case-control chart review.

Setting: Palliative care inpatient unit with a home support team in a large chronic care hospital.

Subjects: All 75 patients receiving services from the home support team who died at home between June 1988 and January 1990 and 75 randomly selected patients receiving the same services who died in hospital.

Outcome measures: Place of death (home or hospital).

Results: Of the 267 patients referred to the palliative care home support team during the study period 75 (28.1%) died at home. Factors significantly associated with dying at home were the patient's preference for dying at home recorded at the time of the initial assessment ($p < 0.001$), a family member other than the spouse involved in the patient's care ($p = 0.021$) and the use of private shift nursing ($p < 0.001$). The patients who died in hospital were more likely than the other patients to have had no home visits from the palliative care team after the initial assessment ($p = 0.04$). The patient's preference for dying at home was not met if the caregiver could not cope or if symptoms were uncontrolled. The patient's preference for dying in hospital was not met if his or her condition deteriorated rapidly or if the patient died suddenly.

Conclusions: Patients' preference as to place of death, level of caregiver support and entitlement to private shift nursing were significantly associated with patients' dying at home. The determination of these factors should be part of every palliative care assessment. Patients and their families should be informed about available home support services.

Objectif : Identifier les facteurs associés au lieu du décès (domicile ou hôpital) des patients confiés à une équipe de soutien à domicile en soins palliatifs.

Conception : Étude cas-témoins rétrospective des dossiers.

Contexte : Unité de soins palliatifs dotée d'une équipe de soutien à domicile d'un grand hôpital pour malades chroniques.

Patients : Les 75 patients recevant des services de l'équipe de soutien à domicile qui sont décédés à domicile entre juin 1988 et janvier 1990 et 75 patients choisis au hasard, recevant les mêmes services, qui sont décédés à l'hôpital.

Mesure de résultats : Lieu du décès (domicile ou hôpital).

Résultats : Des 267 patients confiés à l'équipe de soutien à domicile en soins palliatifs au cours de la période de référence, 75 (28,1 %) sont décédés à domicile. Les facteurs significatifs associés au décès à domicile étaient la préférence du patient à cet égard exprimée au moment de l'évaluation initiale ($p < 0,001$), le fait qu'un membre de la famille autre que le conjoint participe au soin du patient ($p = 0,021$) et le recours à des services infirmiers privés ($p < 0,001$). Les patients décédés à l'hôpital étaient plus susceptibles que les autres de ne pas avoir eu de visites à domicile de l'équipe de soins palliatifs après l'évaluation initiale ($p = 0,04$). On n'a pu respecter le souhait des patients préférant mourir à domicile quand le soignant n'était pas en mesure de faire face à la situation ou que les symptômes étaient incontrôlés. On n'a pu respecter le souhait des patients préférant mourir à l'hôpital quand leur état s'est détérioré rapidement ou qu'ils sont décédés subitement.

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Conclusions : La préférence des patients quant au lieu du décès, le niveau de soutien reçu des soignants et l'accès à des services infirmiers privés étaient des facteurs significatifs associés au décès du patient à domicile. Toutes les évaluations de soins palliatifs devraient tenir compte de ces facteurs. Les patients et leur famille devraient être mis au courant des services de soutien à domicile offerts.

Regardless of whether they die at home, patients with advanced progressive terminal illness usually spend most of their time there.^{1,2} As the proportion of elderly people in our population rises, and as the number of hospital beds is reduced, the time at home is likely to increase. In a study in Britain involving patients with cancer 28% stated a preference for dying at home.³ Palliative home care services in several countries have reported rates of death at home of 37% to 70%.³⁻⁸ An inpatient palliative care support service in Britain reported a rate of 26%;⁹ however, of the 56% of patients who expressed a preference as to place of death, 53% wished to die at home.

In a British study a random sample of terminally ill cancer patients were interviewed at intervals.³ Initially, 58% said that they would prefer to die at home, but this changed to 49% as pressure on caregivers increased with advancing illness. However, when asked for their preference given ideal circumstances, the initial and final preferences for dying at home were given by 67% and 70% respectively. Of the 34 patients whose initial preference was for dying at home, 18 died at home, 15 in hospital and 2 in a hospice. Of the 24 who initially stated that they would prefer to die in hospital or hospice, only 1 died at home. The authors concluded that an increase in community care could enable more people to attain their preference for home death.

Factors associated with place of death were examined in a review of medical records of a US home hospice program.⁴ In the regression analysis death at home was significantly associated with a higher number of nursing visits, and death in hospital was associated with a longer period in the hospice program. In a population-based study in Genoa, Italy, multivariate analysis revealed that the provision of palliative home care was the strongest predictor of death at home and accounted for the trend toward an increase in deaths at home between 1986 and 1990.⁵ The authors suggested that an expansion of palliative home care services might enable 60% of cancer patients to die at home.

The growth of the hospice movement, the development of palliative care and the expansion of home care programs have provided different forms of institutional care for dying patients, as well as support for those wishing to die at home. Canadians now have more choice in these matters than they had before. There is little information, however, on what choices people are making and how successful they are in attaining their wishes.

The prerequisites for successful home care of dying patients have been described as (a) the patient's wishes and family support, (b) a team of professional caregivers and home support personnel, (c) a physician who is willing to

visit the patient at home, preferably on a scheduled rather than on an as needed basis and (d) 24-hour availability of support with a rapid response to crisis calls.¹⁰ Rapid response and strong support are especially important when the patient is close to death and the family is distressed by changing levels of consciousness, noisy breathing and other terminal symptoms. This may result in the family suddenly deciding to take the patient to the hospital, with all the potential consequences of death in the ambulance or emergency department and inappropriate attempts at resuscitation. For patients wishing to die in hospital, attainment of their wish depends on the availability of a bed when it is needed and good liaison between home care and inpatient services.

Between June 1988 and January 1990 the Palliative Care Home Support Team (PCHST) of the Palliative Care Inpatient Unit at Parkwood Hospital, a chronic care hospital in London, Ont., attended 75 patients who died at home and 192 who died in hospital. This patient population provided the opportunity to identify factors associated with place of death. Our hypotheses were that (a) the place of death would be associated with the patient's preference at the time of the initial assessment and (b) death at home would be associated with a higher level of family support in the home, a closer association with the PCHST and the presence of shift nursing during the terminal phase of illness.

PALLIATIVE CARE HOME SUPPORT TEAM

The PCHST, launched in 1988, provides support for family physicians and home care nurses caring for patients with advanced progressive disease and their families. The team consists of a nurse coordinator, two half-time nurse clinicians, a physician and a part-time social worker, all of whom are members of the Palliative Care Inpatient Unit. Most patients are referred to the team by their family physicians; some are referred by palliative care nurses in other hospitals and some by medical consultants. Virtually all patients receive care through the London-Middlesex Home Care Program, under the supervision of a case manager.

After the referral one of the team nurses does a full palliative care assessment in the home. Besides a review of symptoms, medications and functional status, there is an assessment of needs for personal and emotional support for both patient and family caregivers and of available resources. The patient and family are tactfully asked about their preferences as to place of death. The nurse's assessment and recommendations are discussed with the team physician, who also visits the home if the referring physi-

cian has requested a medical consultation. All new assessments and all active cases are discussed at the weekly team meeting.

The involvement of the team after the initial assessment depends on the wishes of the patient and family and on negotiation with the family physician and home care nurse. In a few cases no further contact is made with the patient or caregivers, in others progress is followed by telephone, and in some a close relationship develops and periodic visits are made to the home. One of the team nurses, with physician backup, is available 24 hours a day, and patients are given a number to call if their home care nurse or family physician cannot be reached. Although team members sometimes provide "hands-on" care when the home care nurse or family physician cannot meet the need, the team members never take over complete responsibility for care. In many instances, team members, home care nurses and family physicians know each other well, and mutual decisions about care are made on the basis of personal relationships.

One of the team's most important functions is acting as a liaison between the Palliative Care In-patient Unit and the home care service. This involves being alert for warning signs of family exhaustion, the planning of admission for family relief or symptom control and of discharge home again, and the planning of admission for terminal care. All services provided by team members, including telephone contacts with patients, family members, case managers, home care nurses and family physicians are recorded in the chart, which is maintained by the hospital's records department.

METHODS

The charts of all 75 patients who died at home between June 1988 and January 1990 were reviewed by one of us (I.R.M.), who was also physician for the team during most of the study period. The following items of information were abstracted from the charts and entered on recording forms: age, sex and marital status of the patient, type of residence (house or apartment), composition of household and family structure, diagnosis, dates of initial assessment, death and final admission to hospital, if applicable, number of visits to the home and of phone contacts with patient or family, home care nurse or case manager, and family physician, provision of shift nursing at time of final admission or death at home, and patient's preference as to place of death. On the basis of the nurse's initial assessment the preference was recorded in one of three categories:

1. Strong preference for remaining at home.
2. Preference for remaining at home conditional on family caregivers' ability to cope, or preference for remaining at home without strong support from family caregivers.
3. Strong preference for admission to hospital (no distinction was made between preferences for death in the

Palliative Care In-patient Unit and those for death in an acute care hospital).

The mother tongue of the patient was recorded as an indication of possible cultural influence on the choice. Notes were made about reasons for patients' choices not being fulfilled, about the circumstances surrounding the deaths at home and about the team's involvement in these deaths.

For comparison a list was compiled of all 192 patients who were attended by the PCHST during the study period and who died in hospital. The charts of 75 of these patients were randomly selected with the use of a random-number generator. The same items of information that were abstracted from the charts of patients who died at home were obtained from these charts.

A validity check of patients' preference ratings was conducted in a subsample of 10 patients (5 from each group) by the team nurses, each independently reviewing the other's assessments. Eight of the 10 patients were given the same rating by both the nurse and the investigator (kappa value 0.736). Only one of the discordant ratings was between the strong preference categories 1 and 3.

All data were entered and analysed with the use of Epi-Info software (version 5.0, US Centers for Disease Control and Prevention, Atlanta). The χ^2 test was used to compare categorical data, and *t*-tests were used to compare continuous data. A *p* value of less than 0.05 was considered to be significant.

RESULTS

In all, 75 (28.1%) of the 267 patients referred to the PCHST died at home during the study period. Of the 75 patients who died in hospital and whose charts were reviewed, 55 died in the Parkwood Hospital's Palliative Care In-patient Unit, 1 in another palliative care unit and 19 in acute care hospitals.

DEMOGRAPHIC CHARACTERISTICS AND DIAGNOSIS

Table 1 shows the demographic characteristics of the patients and their caregivers and the diagnoses in the two groups. The groups were similar in terms of mean age and diagnosis. The group of patients who died at home had more men and single people and fewer married people than the group who died in hospital; however, none of these differences was statistically significant. Ten patients who lived alone died at home, as compared with 14 living alone who died in hospital. More of the households of the patients who died at home than of those who died in hospital contained a daughter, son or person other than the patient's spouse (*p* = 0.021). Fewer of the patients who died at home than of those in the comparison group were cared for by their husbands, and more were cared for by a daughter or

son; none of these differences was statistically significant. A slightly higher, but not significantly different, proportion of patients who died at home than of those who died in hospital had a first language other than English.

Table 1: Demographic characteristics and diagnoses of patients referred to a palliative care team who died at home or in hospital between June 1988 and January 1990

Characteristic/diagnosis	Group; no. (and %) of patients*		p value
	Died at home (n = 75)	Died in hospital (n = 75)	
Mean age at death (and range), yr	68.5 (28-91)	68.2 (40-91)	0.865
Marital status			
Single	18 (24.0)	11 (14.7)	
Married or common law	47 (62.7)	58 (77.3)	
Widowed	6 (8.0)	2 (2.7)	0.183
Separated or divorced	4 (5.3)	4 (5.3)	
No. of men	42 (56.0)	35 (46.7)	0.252
Household composition			
Patient only	10 (13.3)	14 (18.7)†	
Patient and spouse	36 (48.0)	50 (66.7)	
Patient, spouse and son or daughter	12 (16.0)	4 (5.3)	0.021
Patient and son or daughter	10 (13.3)	3 (4.0)	
Patient and other	7 (9.3)	4 (5.3)	
Main caregiver			
Wife	33 (44.0)	31 (41.3)	
Husband	12 (16.0)	22 (29.3)	
Daughter	14 (18.7)	9 (12.0)	
Son	4 (5.3)	3 (4.0)	0.549
Other	9 (12.0)	8 (10.7)	
No identified caregiver	3 (4.0)	2 (2.7)‡	
First language			
English	60 (80.0)	67 (89.3)	
Other	15 (20.0)	7 (9.3)	0.116
Unknown	0	1 (1.3)	
Diagnosis			
Lung cancer	15 (20.0)	15 (20.0)	
Colon or rectal cancer	17 (22.7)	12 (16.0)	
Breast cancer	9 (12.0)	9 (12.0)	
Pancreas or stomach cancer	9 (12.0)	8 (10.7)	0.888
Other type of cancer	20 (26.7)	26 (34.7)	
AIDS	1 (1.3)	1 (1.3)	
Amyotrophic lateral sclerosis	1 (1.3)	2 (2.7)	
Other	3 (4.0)	2 (2.7)	

*Values are given as number (and %) of patients unless otherwise stated.

†Includes two patients in homes for the aged.

‡Includes one patient in a home for the aged.

DURATION AND FREQUENCY OF CONTACT WITH THE PALLIATIVE CARE TEAM

For the patients who died at home the duration of contact with the PCHST was from their initial assessment to the time of death. The mean duration of contact for this group was 63.3 days. For those who died in hospital the duration of contact with the team was from the time of their initial assessment to the time of final admission to hospital. The mean duration of contact for this group was 70.2 days. This difference was not statistically significant. Ten patients died within 2 days after admission, 37 died within 3 to 20 days after admission, and 28 were in hospital for 3 weeks or longer.

Even though their duration of contact with the team was shorter, the patients who died at home had more contacts with the PCHST nurses than did the patients who died in hospital (Table 2). The mean number of home visits by the team nurse was significantly greater in the group of patients who died at home than in the other group, both from the time of initial assessment ($p = 0.004$) and during the last week before death ($p < 0.001$).

For 18 of the deaths at home the PCHST nurses and physicians responded to distress calls from the family and often spent several hours in the home supporting the family and dealing with distressing terminal symptoms such as dyspnea and restlessness.

Significantly more of the patients who died in hospital than of those who died at home were not visited by the team after the initial assessment ($p = 0.04$) or were not visited in the last week before admission to hospital or death ($p < 0.005$) (Table 2). Although not a statistically significant difference ($p = 0.059$) the team nurses made more phone calls to home care nurses for the patients who eventually died at home (mean 2.01) than for those admitted to hospital (mean 1.57). The two groups did not differ significantly in their frequency of contact with the team physician. The patients who died at home had more private shift nursing than those who died in hospital ($p < 0.001$) (Table 2).

PREFERENCE FOR DYING AT HOME

Of the 150 patients in the study 58 (38.7%) expressed a strong preference for dying at home, and 24 (16.0%) a conditional preference. When this was extrapolated to the whole group of 267 patients referred to the PCHST, 47.2% had a preference, either strong or conditional, for dying at home. As we predicted, the patients who died at home had a much stronger preference for remaining at home than those who died in hospital ($p < 0.001$) (Table 2). In each group, however, there were patients whose preference was not met: 20 patients died at home despite their strong initial preference to be admitted to hospital, and 11 patients died in hospital even though they had ex-

Table 2: Factors associated with deaths at home or in hospital

Factor	Group; no. (and %) of patients*		p value
	Death at home (n = 75)	Death in hospital (n = 75)	
Patient preference			
To die at home	47 (62.7)	11 (14.7)	
To die at home conditional on family's ability to cope	7 (9.3)	17 (22.7)	< 0.001
To die in hospital	20 (26.7)	45 (60.0)	
Not clear	1 (1.3)	2 (2.7)	
Palliative care team			
No nurse visits†	20 (26.7)	33 (44.0)	0.04
No nurse visits in last week‡	27 (36.0)	45 (60.0)	< 0.005
Mean no. of nurse visits (and standard deviation [SD])	1.57 (1.21)	1.00 (1.12)	0.004
Mean no. of nurse visits in last week (and SD)	1.20 (1.15)	0.48 (0.64)	< 0.001
Mean no. of physician visits (and SD)	0.47 (1.01)	0.47 (0.79)	0.478
Shift nursing§			
No shift nursing	51 (68.0)	70 (93.3)	
< 9 hours per day	11 (14.7)	4 (5.3)	< 0.001
9–24 hours per day	13 (17.3)	1 (1.3)	

*Values are given as number (and %) of patients unless otherwise stated.

†Does not include initial assessment.

‡Last week before death or final admission to hospital.

§At time of death or last admission to hospital.

pressed a wish to remain at home. Of the 24 patients in the conditional category, 17 died in hospital. Of the 20 patients who wished to die in hospital but died at home 7 had a condition that deteriorated rapidly before admission could be arranged, 2 died suddenly, and 8 changed their minds about remaining at home; for the remaining patients, a bed was not available when needed for 1, and no reason was recorded for the other two. The reasons why the 11 patients who wished to remain at home died in hospital were as follows: uncontrolled symptoms (4), family discord (3), caregiver became ill (1), home conditions proved to be inadequate (1), and death occurred while in hospital for family relief (1); no reason was given for 1 patient. Of the 17 patients in the conditional group who died in hospital 4 were admitted because of the caregiver's death or illness, 8 were admitted because the caregiver was unable to manage, and 3 had uncontrolled pain; no reason was recorded for 2 patients.

DISCUSSION

Of the patients referred to the PCHST between June 1988 and January 1990, 47.2% had a preference for dying at home. The rate of deaths at home among these patients (28.1%) was similar to that among all cancer patients in Britain in 1987 (27%)³ and in Genoa, Italy, (33%)⁵ but lower than most rates reported by other palliative care home support services.^{3-5,7,8} The expectation that the patient's preference would be associated with place of death was strongly confirmed ($p < 0.001$). Failure to attain the stated preference was often due to the kind of sudden and unexpected developments that are associated with terminal illness: rapid deterioration, uncontrolled symptoms and sudden death. Of interest, eight patients decided to stay at home after initially stating a preference for dying in hospital. The conditional category included patients whose preference for dying at home was qualified by doubts about the family's ability or willingness to cope, and in 17 of these admission to hospital was necessary.

That 10 patients were able to remain at home even though they lived alone was surprising but can be easily explained: 3 had 24-hour nursing care, 1 had a 24-hour homemaker, and 3 died suddenly and unexpectedly; for the remaining 3, family members managed the care even though they did not reside in the home.

There were some significant differences between the two groups in composition of the patient's household. The household in the group who died at home was less likely to consist of patient and spouse alone and more likely to have a resident daughter or son. This supports the hypothesis that dying at home would be associated with a greater level of support in the home.

The group of patients who died at home had significantly more visits from the PCHST nurses; the patients who died in hospital were more likely to have no home visits after the initial assessment. The PCHST nurses had

more contacts with home care nurses and case managers for patients who died at home than for those who died in hospital, an association also reported by Bass, Pestello and Garland.⁴ Although the results indicate a closer association with the PCHST in the group of patients who died at home, it cannot be assumed that the team's support enabled the patient to remain at home. Close association with the PCHST could have been a result of the patient's wish to remain at home as well as a factor enabling the patient to attain this wish. On the other hand, there is evidence that for some patients the PCHST, by responding to distress calls, was instrumental in enabling the patient to remain at home in the last stages of illness. Since 10 patients died within 48 hours after admission to hospital, intervention by the PCHST might have enabled more people to attain their preference for dying at home. In the Genoa study, an increase of 5% in the rate of deaths at home between 1986 and 1990 was attributed to the activity of a home palliative care service.⁵

The use of shift nursing in the home was strongly associated with dying at home ($p < 0.001$). In nearly all cases this was paid for by an employee's or retiree's benefit plan. Often, the patient and family were unaware that they were entitled to this benefit, and questions about entitlements were a routine part of the PCHST's assessment. The use of these benefits could have been the result of the patient's decision to die at home rather than a factor enabling the patient to remain at home. It was the team's observation, however, that patients dying in hospital rarely had entitlements to private shift nursing. The availability of additional resources therefore seems to be an important factor in enabling patients to remain at home during their final days. Since the insurance policies usually stipulated that only services by nurses would be covered, nearly all the shift nursing was provided by RNs. In some cases the services of a nursing assistant or night attendant would have been sufficient. Since shift nursing had such a strong association with dying at home in our study, and since one-to-one professional nursing is expensive, further research should be done into the levels of care needed for patients dying at home.

Retrospective studies have a number of limitations. Since criteria for the interpretation of the material have not been established in advance, the interpretation depends on the judgement of the investigators more so than in prospective studies. Although the use of a randomly selected control group enables associations between factors to be identified, without randomization it is not possible to make strong causal inferences. Collection and interpretation of the data by a member of the clinical team who had prior knowledge of the main outcome (place of death) raises the possibility of bias. In our study the investigator's judgement of patients' preferences as to place of death was subjected to a validity check. Significant associations were found despite some disagreement about classification. Other recorded items required only simple calculations, such as numbers of visits or telephone calls, with minimal interpretation.

Wherever patients choose to die, our health services should try to help them attain their wish. In our study, when strong support services were available most patients who stated a preference for dying at home had their wish fulfilled; some who initially wished to go to hospital changed their mind when they saw how well supported they could be at home. As pressure on hospital beds increases, it may become more difficult to meet patient's desires for admission to hospital. If patients and their families knew more about the support available to them at home, more of them might choose to remain at home. At present we know little about the factors influencing patients' choices. Further research could help us to counsel patients and their families in the later stages of illness.

To explore patients' choices further we believe that a series of interviews should be conducted with patients and their family caregivers when they have come to the point of thinking about the care they would prefer in the last stages of illness. In a prospective study the criteria for assessing preferences could be established in advance, although room would have to be left for interviewers to vary their approach to such a sensitive subject. Subsequent interviews could explore the factors that supported or interfered with the patient's choice or that led to a change of mind. One of these factors would be the availability of different levels of shift nursing, homemaking and night sitting in the last stages of illness. To assess the strength of this factor, all levels of care would need to be available for all patients in the study, irrespective of their entitlements. An economic assessment of this factor would be important. Preferably, the study should use a population sample, which would thus avoid the risk of selection bias inherent in a sample of patients referred to a palliative care support team. The use of a population sample would also make it possible to assess the strength of the PCHST as a factor in enabling patients to attain their wishes.

In addition, causal relations between these interventions and place of death could be examined in controlled trials. However, our experience has been that the use of controlled trials to assess palliative care services, especially if randomization is involved, poses unique methodologic and ethical problems.¹¹

For patients who choose to die at home and their families, the final days are a crucial testing time. If strong support is not readily available some caregivers will be unable to bear the strain, and the patient and family will go through the trauma of an unplanned admission in the last hours. These crises can be avoided if physicians and nurses prepare families for this ordeal, visit the home frequently and make themselves instantly available for distress calls. Whenever possible, shift nursing, or at least the services of a night attendant, should be offered during the final days so that the family caregiver can get some rest. The patient's

and family caregiver's preferences as to place of death, the support available in the household and the patient's entitlement to private nursing are important elements in predicting the place of death and should form part of every home assessment.

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