

Factors that Promote Success in Home Palliative Care: a Study of a Large Suburban Palliative Care Practice

VINCENT MAIDA, Centre for Palliative Care, William Osler Health Centre, University of Toronto, Ontario, Canada

Abstract / It has been repeatedly shown that most people would prefer to die in their own homes. However, many factors affect the feasibility of this choice. This study retrospectively examined the medical and nursing charts of 402 cancer patients who wished to die at home and had been referred to a palliative care service. Of those reviewed, 223 (55%) died at home, while 179 died in hospitals. The presence of more than one caregiver, an increased length of time between diagnosis and referral to a palliative care physician, an increased length of time under that physician's care, older age at referral, home ownership, and race were all significantly associated with home death, as were certain cancer diagnoses. The most compelling of these predictive factors have formed the basis for an evaluation tool, soon to be validated, to help palliative health professionals assess the viability of home-based palliative care culminating in a home death.

Résumé / Il a été dit et même répété que s'ils avaient le choix la plupart des gens préféreraient mourir à la maison. Cependant, plusieurs facteurs affectent la faisabilité de ce choix. Cette étude rétrospective examine les dossiers des soins médicaux et infirmiers de 402 patients atteints du cancer qui désiraient mourir à la maison et qui avaient été orientés vers des services de soins palliatifs. De ce groupe de 402 patients, 223 (55 %) sont décédés à la maison et 179 (45 %) sont morts à l'hôpital. Plusieurs facteurs favorisent de façon très significative la mort à la maison. Parmi ces facteurs mentionnés la présence de plus d'un soignant auprès du malade, le laps de temps écoulé entre le diagnostic et l'orientation du malade vers un spécialiste en soins palliatifs, la période de temps durant laquelle le malade a été sous les soins du même spécialiste, l'âge avancé du malade lors de la consultation, la propriété de sa résidence, la race de même que le type de cancer et son diagnostic. Les facteurs prédictifs les plus incontestables de notre étude sont ceux qui ont été à la base de l'instrument d'évaluation que nous avons conçu et qui sera prochainement validé. Il pourra aider les professionnels de la santé en soins palliatifs à évaluer la possibilité que les soins dispensés à un malade à domicile puissent culminer en sa mort chez lui.

INTRODUCTION

For our distant ancestors, death at home was the norm and often the only choice available. Over the past two centuries, however, hospitals have gradually taken over the role of the home as the appropriate place to die. Only in recent years has this trend begun to reverse as public interest in dying at home has increased. Stajduhar and Davies suggest that this resurgent interest is due to three factors: the perception of home death as more cost-effective than institutional death in an era of spiralling health care costs; concerns about institutional over-use of life-prolonging treatments at the cost of meeting social, spiritual, and psychosocial needs; and the belief that home death contributes to the overall quality of life of patients and families (1).

A number of studies have shown that, given the choice, most people would prefer to remain in their own homes to die (2-4). However, many challenges are associated with home death and many factors affect whether or not an individual is able to experience it successfully. This study examines some of these factors.

Previous studies in different populations have examined some of the factors associated with site of death and have found that patients most likely to die at home:

- are male (5)
- are of a higher social class and/or have greater financial resources (4,6-8)
- have cancer or AIDS (9)
- have a healthy full-time primary caregiver (4,10-13) or more than one caregiver (14,15)
- do not live alone (4,10,11)
- have personal needs that are manageable at home (10,11)
- have expressed a preference for dying at home (14,15)

This research was supported by a grant from Aventis Pharma Inc.

- have fully accepted and have a family that fully accepts the fact of impending death (4,7,10,11)
- have managed to avoid extreme fatigue in caregiver relatives (10,11).

Some studies have found that younger patients are more likely to die at home (4,6,16), while others have found that older patients have a higher probability of dying at home (3,17).

Patients who are less likely to die at home include those with prostate or brain tumours (4), chronic organ failure (18), a heavy and/or prolonged burden of care (4,19), and who lack full-time and/or healthy caregivers (19). Of course, a number of factors can lead a patient at home to choose to be admitted to hospital, including the need for symptom control, a lack of support or adequate space at home, personal preference, financial inability to afford drugs or home care, the presence of young children, superstition, religious reasons, a death-associated custom or belief system not compatible with home death, mistrust of the home care system, lack of acceptance of the death process, lack of insurance coverage, or lack of full-time physician coverage.

The population being assessed in this review represents a cross-section of cancer patients in a non-academic, suburban environment who were referred by their oncologists, surgeons, or family physicians to a palliative care service, and were, thereafter, under the care of a palliative care physician(s), 24 hours a day, seven days a week. All patients were the recipients of regularly scheduled RN visits. It was understood and agreed that the palliative physician would ultimately manage the patient's eventual end-of-life care. Since these patients were referred from another physician, they represented a more highly selected group than has been examined in other studies. These patients were aware of their terminal diagnosis, had already begun to think about place of death, and had expressed a desire to die at home to their health care professionals.

METHODS

This was a retrospective chart review of 402 sequential cancer patients referred over 24 months, between April 1, 1997, and April 8, 1999, to a combined community- and hospital-based palliative care service in a large metropolitan area. Both medical and nursing charts were reviewed. The patients resided in the Etobicoke, North York, Vaughan, Peel, and Toronto districts of metropolitan Toronto, Ontario, Canada, within a 20-kilometre radius of the base hospital. Non-cancer palliative patients were

excluded from the review, as many of these patients were still receiving active interventions of a non-palliative nature.

Referrals were made by oncologists, surgeons, and general practitioners. Patients were seen initially within 24 hours of referral. All patients had expressed a desire to die at home and all were given around-the-clock on-call coverage by the palliative care physicians. Information about the patients' demographics, medical histories, and preferences for place of death was documented during the course of history taking by the palliative care physician assigned to each case. This was supplemented, in some cases, by the patient's file from the referring physician, and/or the results of nursing assessments and psychosocial profiles carried out by social workers. Data about the number of caregivers and home ownership were gathered during the physician's first home visit. Estimated home valuation was determined by entering the patient's address into the Toronto Real Estate Board's interactive Web service.

All data were analysed with the Statistical Analysis System (SAS). 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.

Realizing that the distributions of some variables, such as the time period between initial cancer diagnosis and referral to the palliative care physician, would be skewed, the analyses were repeated using a logarithmic transformation and non-parametric analyses (e.g., Mann-Whitney). The *p*-values for these additional analyses were no different than the *p*-values from the parametric analyses. For reasons of consistency, only the parametric *p*-values are reported here.

RESULTS

Of the 402 patients in this retrospective review, 223 died at home, while 179 died in hospitals.

Table 1 / DEMOGRAPHIC CHARACTERISTICS OF PATIENTS REFERRED TO A PALLIATIVE CARE SERVICE BETWEEN APRIL 1, 1997 AND APRIL 8, 1999

	Home (n=223)	Hospital (n=179)
Mean age (s.e.)	68.5 (0.82)	65.3 (0.91)
Median age	69	68
Range	26-93	23-90
Male	119 (53.4%)	96 (53.6%)
Female	104 (46.4%)	83 (46.4%)
Caucasian	197 (88.7%)	144 (81.4%)
Non-Caucasian	25 (11.3%)	33 (18.6%)

3 patients were listed as neither Caucasian or non-Caucasian

Table 2 / CANCER DIAGNOSES OF PATIENTS VERSUS SITE OF DEATH (p=0.001)

Type of Cancer	Death at Home n (%)	Death in Hospital n (%)
Lung cancer	48 (55.8)	38 (44.2)
Colorectal cancer	35 (68.6)	16 (31.4)
Gynecologic cancers	18 (52.9)	16 (47.1)
Breast cancer	16 (50.0)	16 (50.0)
Esophagogastric cancer	12 (40.0)	18 (60.0)
Pancreatic cancer	14 (48.3)	15 (51.7)
Prostate cancer	17 (65.4)	9 (34.6)
Hepatobiliary cancer	9 (47.4)	10 (52.6)
Urologic cancers	13 (72.2)	5 (27.8)
Adenocarcinoma NYD	10 (62.5)	6 (37.5)
Head and neck cancers	11 (78.6)	3 (21.4)
Brain cancers	4 (30.8)	9 (69.2)
Lymphomas	7 (63.6)	4 (36.6)
Hematologic cancers	3 (30.0)	7 (70.0)
Sarcomas	5 (71.4)	2 (28.6)
Melanomas	1 (16.7)	5 (83.3)
Total	223/402 (55.5)	179/402 (44.5)

Table 1 shows the patients' demographic characteristics; their cancer diagnoses are shown in Table 2.

A number of factors were examined and were found to be unrelated to a patient's site of death (Table 3), including marital status, sex, home valuation, and number of comorbid medical conditions. However, analysis showed several factors to differ significantly according to place of death (Table 4): number of caregivers, length of time between diagnosis and referral to a palliative care physician, length of time under that physician's care, age at referral to the palliative care physician, home ownership status, and race. In addition, site of death was significantly correlated with type of cancer diagnosis (Table 2).

DISCUSSION

One result of this study confirms an observation seen in other study populations: that an in-

Table 3 / FACTORS NOT ASSOCIATED WITH PATIENT SITE OF DEATH

Factor	Death at home (n = 223)	Death in hospitals (n = 179)	p-value
Marital status			0.121
divorced	5 (2.2%)	7 (3.9%)	
married	156 (70.0%)	116 (64.8%)	
single	3 (1.3%)	9 (5.0%)	
widowed	59 (26.5%)	47 (26.3%)	
Sex			0.957
female	104 (46.6%)	83 (46.4%)	
male	119 (53.4%)	96 (53.6%)	
Mean Home Valuation (s.e.)	\$211,957 (6,267)	\$205,345 (5,309)	0.498
Mean number of medical comorbidities (s.e.)	0.7 (0.03)	0.6 (0.03)	0.205

Table 4 / FACTORS ASSOCIATED WITH PATIENT SITE OF DEATH

Factor	Death at home (n = 223)	Death in hospitals (n = 179)	p-value
Number of caregivers			<0.001
none	0 (0.0%)	14 (7.9%)	
<1	3 (1.3%)	72 (40.2%)	
1	82 (36.8%)	82 (45.8%)	
>1	138 (61.9%)	11 (6.1%)	
Mean number of months between diagnosis and referral to palliative MD (s.e.)	27.3 (2.34)	11.6 (2.61)	<0.001
Mean number of days under care of palliative MD (s.e.)	68.8 (5.89)	37.2 (6.57)	<0.001
Home Ownership			<0.001
own	191 (85.6%)	102 (57.0%)	
rent	28 (12.6%)	75 (41.9%)	
unknown	4 (1.8%)	2 (1.1%)	
Mean age at referral (s.e.)	68.5 (0.82)	65.3 (0.91)	0.01
Race			0.038
non-Caucasian	25 (11.3%)	33 (18.6%)	
Caucasian	197 (88.7%)	144 (81.4%)	

3 patients were listed as neither Caucasian or non-Caucasian

creased number of caregivers improve the likelihood that a patient will die at home. Age at referral and type of cancer were also associated with place of death in this study, and other studies have yielded similar results, especially when cancer diagnosis is correlated with its associated burden of care. The only characteristic found to be a predictor in other studies, but not this one, was financial/social status, if home valuation can be interpreted as a measure of this. However, home ownership status was a predictor in this study.

Two new characteristics were found to differ significantly according to place of death: length of time between initial cancer diagnosis and referral to a palliative care physician, and length of time under the palliative physician's care. Those study patients who died at home had a significantly greater period of time between their initial cancer diagnoses and referral to a palliative care physician, and had therefore been living with the knowledge and ramifications of their condition for longer than had the patients who died in institutions. It is postulated that this situation gave these patients the opportunity to develop a greater acceptance of their terminal prognosis. This group also went through more trials, tribulations, and treatment failures, and spent more time in institutions, overall, than the other groups. Perhaps these patients had a greater desire to return home finally to die.

Previous research has suggested that the involvement in a patient's care of full-time caregivers—family members, RNs, RPNs, and the like—promotes the likelihood of home death (3,14,20). Previous research has also suggested that the involvement of home visiting physicians enhances the likelihood of a home death (3,14,20). In this study, those patients who died at home were under the care of a palliative physician for significantly longer than were those who died in hospitals. We postulate that these patients benefited from the additional physician care in two ways: time and medical assistance allowed them to achieve better pain and symptom control; and they were able to foster a closer relationship with their physician. Both of these factors contributed to these patients' greater sense of confidence in their ability to have a successful home death.

The most compelling predictive factors from this study have been used as the basis for a concise evaluation tool, intended to assist palliative health care workers in determining the likelihood of a given patient having a successful home palliation and death. Early tests of EPPAT (Etobicoke Palliative Placement Assessment

Tool) have indicated that it has sensitivity of more than 60% and specificity of greater than 90%, although the tool has yet to be validated. This validation will be done shortly in a prospective study of 50 to 100 patients.

Cantwell et al. reported on the validity of a home death assessment tool (HDAT) incorporating four factors believed to be necessary for home death to occur:

- desire on the part of patient and caregivers for a home death
- skilled, full-time medical support
- more than one caregiver
- financial resources that allow caregiving to take place at home (21).

Of patients with three or more of these factors, 32 of 49 died at home (65% specificity), while of those with fewer than three factors, 22 of 24 died in institutions (92% sensitivity). EPPAT focuses on different predictive factors than does HDAT and may, therefore, be useful in different patient populations, although this has yet to be confirmed.

CONCLUSION

In the Greater Toronto Area, as elsewhere in Canada, we face a looming crisis in the delivery of all aspects of palliative care, due to hospital closures, a shrinking pool of health care personnel skilled in providing palliative care, increased numbers of cancer cases, increasing life expectancy, and an aging population.

A decade ago in Toronto, 75% of all terminal cancer patients died in hospitals (22), despite the many advantages to home palliation and death discussed in this article. Caregivers as well as the Canadian health care system would benefit from a way to predict which patients would most successfully achieve home palliation, culminating in a home death, and which would be more appropriately managed in a hospital or hospice.

This study has shown that important predictors of the success of home palliation include the patient's number of caregivers, the time interval between the initial cancer diagnosis and referral to a palliative care physician, the age at referral, the length of time under the care of a palliative care physician, and the type of cancer. It is hoped that knowledge of these predictive factors will aid palliative care personnel in accurately identifying, among patients desiring a home death, those for whom home palliation and death are most appropriate. In this manner, home-based palliative care resources may be more used more equitably.

Date received, October 6, 2000; date accepted, January 18, 2001.

ACKNOWLEDGEMENTS

The author would like to acknowledge the assistance of Carol Thomas in the preparation of this manuscript for publication. The author would also like to acknowledge the assistance of John Stewart for his database and statistical expertise.

REFERENCES

1. Stajduhar KI, Davies B. Death at home: challenges for families and directions for the future. *J Palliat Care* 1998; 14(3): 8-14.
2. Townsend J, Frank AO, Fermond D, Dyer S, Karran O, Walgrave A, Piper M. Terminal cancer care and patients' preference for place of death. *Br Med J* 1990; 301: 415-417.
3. Costantini M, Camoirano E, Madeddu L, Bruzzi P, Verganelli E, Henriquet F. Palliative home care and place of death among cancer patients: a population-based study. *Palliat Med* 1993; 7(4): 323-331.
4. Gilbar O, Steiner M. When death comes: where should patients die? *Hosp J* 1996; 11(1): 31-48.
5. Higginson IJ, Astin P, Dolan S. Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. *Palliat Med* 1998; 12: 353-363.
6. Komesaroff PA, Moss CK, Fox RM. Patients' socioeconomic background: influence on selection of inpatient or domiciliary hospice terminal-care programmes. *Med J Aust* 1989; 151(4): 196, 199-201.
7. Seale C, Addington-Hall J, McCarthy M. Awareness of dying: prevalence, causes and consequences. *Soc Sci Med* 1997; 45(3): 477-484.
8. Higginson IJ, Jarman B, Astin P, Dolan S. Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England. *J Public Health Med* 1999; 21(1): 22-28.
9. Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. *N Engl J Med* 1996; 335(3): 172-178.
10. Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliat Med* 1994; 8(3): 183-196.
11. Hinton J. Which patients with terminal cancer are admitted from home care? *Palliat Med* 1994; 8(3): 197-210.
12. Miller PJ, Mike PB. The Medicare Hospice Benefit: ten years of federal policy for the terminally ill. *Death Stud* 1995; 19(6): 531-542.
13. Cleary JF, Carbone PP. Palliative medicine in the elderly. *Cancer* 1997; 80(7): 1335-1347.
14. McWhinney IR, Bass MJ, Orr V. Factors associated with location of death (home or hospital) of patients referred to a palliative care team. *CMAJ* 1995; 152(3): 361-367.
15. Cantwell P, Turco S, Brenneis C, Hanson J, Neumann CM, Bruera E. Predictors of home death in palliative care cancer patients. *J Palliat Care* 2000; 16(1): 23-28.
16. Clifford CA, Jolley DJ, Giles GG. Where people die in Victoria. *Med J Aust* 1991; 155(7): 446-451, 456.
17. Rhymes JA. Home hospice care. *Clin Geriatr Med* 1991; 7(4): 803-816.
18. Lynn J, Wilkinson AM. Quality end of life care: the case for a MediCaring demonstration. *Hosp J* 1998; 13(1-2): 151-163.
19. Bradshaw PJ. Characteristics of clients referred to home, hospice and hospital palliative care services in Western Australia. *Palliat Med* 1993; 7(2): 101-107.
20. Beck-Friis B, Strang P. The organization of hospital-based home care for terminally ill cancer patients: the Motalan model. *Palliat Med* 1993; 7: 93-100.
21. Cantwell P, Turco S, Bruera E, Kneisler P, Hanson J. Home Death Assessment Tool: a prospective study. *J Palliat Care* 1998; 14(3): 104-105.
22. Metropolitan Toronto District Health Council. Report of the Task Force on Palliative Care. *Palliative Care: an initial planning report on services for the terminally ill in Metropolitan Toronto*. July 1993.