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*Palliat Med* 2008; 22; 85

DOI: 10.1177/0269216307084612

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## Short report

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# Preferences for location of death of seriously ill hospitalized patients: perspectives from Canadian patients and their family caregivers

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Previous studies involving palliative patients suggest a preference for dying at home. The purpose of this paper is to examine, prospectively, patient and family caregiver preferences for, and congruence with, location of death for hospitalized patients with cancer and end-stage medical conditions. Questionnaires were administered to 440 eligible in-patients and 160 family caregivers in five hospitals across Canada. This paper reports results of 138 patient/family caregiver dyads who answered a question about preference for location of death. The results suggest that only half of all patients and family caregivers report a preference for a home death. Furthermore, half of the patient/family caregiver dyads disagree on preferred location of death. If one of the primary goals of end of life care is to enhance the quality of life of dying patients and their family caregivers, policies directed towards ensuring that patients die in their location of choice ought to be a priority and resources should be allocated to promote the development of excellent care, not only in the home, but also within our institutional settings. *Palliative Medicine* 2008; 22: 85–88

**Key words:** end of life; family caregivers; location of death; seriously ill-hospitalized patients

## Introduction

Population surveys have established that the majority of people would prefer to be cared for and die at home.<sup>1</sup> One consistently reported predictor of location of death is the availability of a family caregiver (FCG).<sup>2,3</sup> Frequently, it is the FCG who provides the majority of physical and emotional support to the dying patient at home.<sup>4,5</sup> Consequently, the FCG ought to be an active participant in deciding where patients should die.<sup>6</sup> Recent evidence suggests, however, that the FCG is not always involved in this decision, nor are their preferences for location of death equally considered to that of the patient.<sup>6,7</sup>

Little research has focused on FCG preferences for place of death of the patient. Congruence between patient and

FCG preferences has also received limited attention. Additionally, available studies focus almost exclusively on cancer patients and their FCGs, neglecting a larger portion of the population that dies with end stage medical conditions. This paper begins to address this gap through an examination of both patient and FCG preferences for location of death for patients with cancer and end stage medical conditions. The research questions guiding this inquiry were: (a) What are patient and FCG preferences for location of death?; (b) What is the relationship between patient and FCG preference for location of death? (c) Do preferences for location of death differ based on diagnosis (i.e., cancer and noncancer)?

## Methods

Data come from a cross-sectional study examining issues related to the quality of end-of-life care from both the patient and FCG perspective.<sup>8–10</sup> Five tertiary-care teaching hospitals across Canada participated in the study, which was conducted from 2001 to 2003. Eligible patients included those

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**Table 1** Patient and caregiver characteristics ( $n = 138$ )

	Patients <i>n</i> (%)	Caregivers <i>n</i> (%)
Median age (min–max)	72 (54–95)	59 (20–84)
Diagnosis		
Cancer	56 (40.5)	NA*
Congestive heart failure	43 (31.2)	NA
Chronic obstructive lung disease	31 (22.5)	NA
Cirrhosis	8 (5.8)	NA
Female		
Relationship		
Spouse	NA	63 (45.7)
Child	NA	62 (44.9)
Other	NA	13 (9.4)
Employed		
Overall quality of life		
Excellent	6 (4.3)	NA
Very good	16 (11.6)	NA
Good	27 (19.6)	NA
Fair	45 (32.6)	NA
Poor	44 (31.9)	NA
Preference for location of death		
Home	74 (53.6)	69 (50.0)
Hospital	38 (27.5)	55 (39.9)
Does not matter	26 (18.9)	14 (10.1)

\*Not applicable.

over 18 years of age who could understand English, who did not appear to have cognitive barriers and who had a minimum expected hospital stay of 72 h. Additionally, patients had one or more specified co-morbidities at an advanced stage (see Table 1). Details regarding patient eligibility are reported elsewhere.<sup>10</sup> All eligible patients who consented to participate were asked to identify a FCG (family member or close friend) who provided care at home. If a FCG was not identified, the patient was still recruited and only the patient questionnaire was administered. A face-to-face interview was administered to patients and FCGs by a trained research nurse. This paper reports results of 138 patient-FCG dyads who answered a question about preference for location of death.

Patients were asked: ‘Assume you could achieve the same high level of quality care at home as well as in the hospital. If your current condition deteriorated and you had only a few days or weeks to live, where would you prefer to die?’ This question was reworded for FCGs: ‘Assume you could achieve good quality care at home as well as in hospital. If your family member’s condition deteriorated until the point where s/he was dying, where would you like him/her to be cared for?’ Response categories for both patient and FCGs included: (a) home; (b) hospital and (c) does not matter.

Frequencies were used to examine preferences for location of death of patients and FCGs. The kappa statistic ( $k$ )<sup>11</sup> examined the relationship between patient and FCG preference for location of death. Chi-square tests were used to examine preference differences based on type of disease (cancer versus noncancer).

## Results

Table 1 presents demographic characteristics for patient and FCG participants. Frequencies for preference for location of death suggest that over half of all patients (53.6%) and half (50.0%) of all FCGs reported a preference for a home death. Nineteen percent of patients and 10% of FCGs reported that it did not matter to them where the patient died.

Results (Table 2) from the 138 patient-FCG dyads suggest that 49.3% of patients and FCGs agree on preference for location of death ( $k = 0.16$ ).

Table 3 reports patient and FCG preferences for location of death based on diagnosis. Preferences between cancer and noncancer FCGs are similar and not significantly different ( $\chi^2 = 2.40$ ,  $P = 0.30$ ), although slightly more FCGs of people with a noncancer diagnosis compared with those with a cancer diagnosis preferred a hospital death. Over half (57.1%) of cancer FCGs and just under half (45.1%) of noncancer FCGs prefer a home death. Preference for a hospital death is 32.1 and 45.1% for cancer and noncancer FCGs, respectively. As shown in Table 3, differences between cancer and noncancer patients follow a similar pattern ( $\chi^2 = 0.54$ ,  $P = 0.77$ ). Half (50.0%) of all cancer patients and 56.1% of noncancer patients prefer a home death, while 30.4 and 25.6% of cancer and noncancer patients, respectively prefer a hospital death.

## Discussion

Many health systems across Canada advocate home-based palliative care, noting that patients and FCGs prefer to be

**Table 2** Agreement between patient and caregiver preference for location of death ( $n = 138$ )

		Patients		
		Home <i>n</i> (%)	Hospital <i>n</i> (%)	Does not matter <i>n</i> (%)
Caregivers	Home	45 (32.6)	13 (9.4)	11 (8.0)
	Hospital	23 (16.7)	20 (14.5)	12 (8.7)
	Does not matter	6 (4.3)	5 (3.6)	3 (2.2)

**Table 3** Patient and FCG preference for location of death based on diagnosis

	Cancer ( $n = 56$ )		Noncancer ( $n = 82$ )	
	Patient <i>n</i> (%)	FCG <i>n</i> (%)	Patient <i>n</i> (%)	FCG <i>n</i> (%)
Home	28 (50.0)	32 (57.1)	46 (56.1)	37 (45.1)
Hospital	17 (30.4)	18 (32.1)	21 (25.6)	37 (45.1)
Does not matter	11 (19.6)	6 (10.8)	15 (18.2)	8 (9.8)

cared for and to die at home. In this study, a considerable number of patients and FCGs reported a preference for dying at home, but many also reported either the hospital as the preferred location of death or that location of death did not matter to them. The idea that home is the 'ideal location for care and death' has taken firm hold in the minds of many health service providers and policymakers,<sup>6,12</sup> and for many Canadian families, this is certainly the case. However, the findings reported here also suggest that this idea may not be reflective of what many patients and FCGs desire, indicating a need for an individualized approach to decisions regarding location of death.

That patients and their FCGs agreed only about half the time on where the patient should die is an important finding. A qualitative study examining variations in and factors influencing family members' decisions for palliative home care found that patients' and FCGs' wishes often did not coincide.<sup>7</sup> Though this previous research did not make the distinction between location of care and location of death, it lends support to the current investigation, highlighting that we cannot assume that patient and FCG preferences are the same. Although a patient's preference to die at home is undoubtedly important, the preferences of FCGs are clearly significant given their central role in allowing patients to die at home, and the documented risks to their own health of caregiving at home.<sup>13-15</sup> Thus, both patient and FCG preferences should be given consideration in the decision-making process and efforts to understand both patient and FCG perspectives should be made to ensure clear communication exists.

Finally, results from the across-disease comparisons suggest that FCGs of noncancer patients tend to prefer a hospital death more frequently than a home death. It is not clear why close to half of these FCGs preferred a hospital death. We speculate that it is possible that noncancer FCGs are more comfortable with the hospital than cancer FCGs because end-stage medical patients often have numerous hospitalizations to treat exacerbations over the course of their disease. Family caregivers of noncancer patients may also feel less confident in taking care of the patient at home than FCGs of cancer patients because they may perceive the home care situation to be as technologically complex as the care they observe in the hospital and the FCGs of noncancer patients may therefore feel they are unable to handle the care needed at home. On the other hand, these FCGs may not be aware of how comfort care to enable the patient to die at home would be different (technologically) than care in the hospital. The reasons for and implications of this high percentage of FCGs reporting hospital as the preferred location of death for noncancer patients should be further investigated to enhance our understanding of the end-of-life experience for noncancer patients and their FCGs, which in turn will allow us to provide the most appropriate care.

Although this study provides a beginning point for further investigations, there are a number of limitations. Since the progression of disease and passage of time have been found

to influence preference for location of death,<sup>1</sup> measuring length of time between interview and death would be informative. Longitudinal studies are also needed to examine if and why preferences change over time. Moreover, the wording of some of our questions could be improved. For instance, both patients and FCGs were asked to respond to a hypothetical question and the response categories used for the question focused on preference for location of death were limited and difficult to interpret. For example, the category 'does not matter' could suggest that the respondent does not have a preference for home or hospital or that they really have not given the question any thought. Future studies should consider categories such as home, hospital, nursing home, hospice, hospital palliative care unit, location does not matter and have not considered this question. Finally, only hospitalized patients and their FCGs were surveyed. Had home care patients and FCGs been surveyed in addition to hospitalized patients and their FCGs, the results might have been different.

Further studies focused on understanding the nuances of patient and FCG preferences and the factors that influence these preferences are also needed to provide a more complete understanding of preference issues. As Thomas *et al.*<sup>16</sup> point out, preferences for place of death are rarely stated categorically, but rather, are often discussed in relation to factors such as the relationship between the patient and FCG, interactions with service providers, and support from the health care system. Both quantitative and qualitative examinations would assist in crystallizing not only the 'what' but also the 'why'<sup>16</sup> of patient and FCG preferences.

## Conclusion

Home has often been cited as the location in which most patients prefer to die and, indeed, much of the evidence supports this contention. However, there appears to be lack of agreement between patients and FCGs on a preferred location of death. If one of the primary goals of palliative and end of life care is to enhance the quality of life of dying patients and their FCGs, policies directed towards assisting patients die in their location of choice, if this choice is supported by the FCG, ought to be the priority and resources should be allocated to promote the development of excellent care, not only in the home, but also within our institutional settings.

## Acknowledgements

This research was partially funded by the National Health Research and Development Program. Dr Stajduhar is supported by a New Investigator Award from the Canadian Institutes for Health Research and a Scholar Award from the Michael Smith Foundation for Health Research. Diane Allan is currently supported by a Ph.D. fellowship from the

Michael Smith Foundation for Health Research. The authors also would like to thank the many individuals who agreed to participate in this study thereby providing us with a valuable resource in which to examine this important research question. We wish to acknowledge Deb Pichora for her assistance with co-ordinating this study and finally, we wish to acknowledge the following site investigators who played an integral role in the collection of the data used in this paper.

- Graeme Rocker DM, MHSc, FRCPC, Department of Medicine, Queen Elizabeth II Health Sciences Centre and Dalhousie University, Halifax, Nova Scotia
- Peter Dodek MD, MHSc, FRCPC, Program in Critical Care Medicine and Centre for Health Evaluation and Outcome Sciences, St. Paul's Hospital and University of British Columbia, Vancouver, B.C.
- Neil Lazar MD, FRCPC, Department of Medicine, University Health Network and University of Toronto, Toronto, Ontario
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## References

- 1 Higginson IJ, Sen-Gupta GJA. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 2000; **3**(3): 287–300.
- 2 Pritchard RS, Fisher ES, Teno JM *et al.* Influences of patient preferences and local health system characteristics on the place of death. *J Am Geriatr Soc* 1998; **46**: 1242–50.
- 3 Tang ST. Determinants of hospice home care use among terminally ill cancer patients. *Nurs Res* 2003; **52**(4): 217–25.
- 4 Dudgeon D, Kristjanson L. Home vs. hospital death: assessment of preferences and clinical challenges. *CMAJ* 1995; **152**: 337–40.
- 5 Harding R, Higginson I. Working with ambivalence: informal caregivers of patients at the end of life. *Support Care Cancer* 2001; **9**(8): 642–5.
- 6 Stajduhar KI. Examining the perspectives of family members involved in the delivery of palliative care at home. *J Palliat Care* 2003; **19**: 27–35.
- 7 Stajduhar KI, Davies B. Variations and factors influencing family members' decisions for palliative home care. *Palliat Med* 2005; **19**(1): 21–32.
- 8 Heyland DK, Dodek P, Rucker G *et al.* for the Canadian Researchers at the End of Life Network (CARENET). What matters the most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* 2006; **174**: 627–33.
- 9 Heyland DK, Frank C, Groll *et al.* for the Canadian Researchers at the End of Life Network (CARENET). Understanding cardiopulmonary resuscitation decision making: perspectives of seriously ill hospitalized patients and family members. *Chest* 2006; **130**(2): 419–28.
- 10 Heyland DK, Groll D, Rucker G *et al.* for the Canadian Researchers at the End of Life Network (CARENET). End of life care in acute care hospitals in Canada. A quality finish? *J Palliat Care* 2005; **21**(3): 142–50.
- 11 Cohen J. Weighted kappa: nominal scale agreement with provision for scaled disagreement or partial credit. *Psychol Bull* 1968; **70**(4): 213–20.
- 12 Seale C, Addington-Hall J, McCarthy M. Awareness of dying: prevalence, causes and consequences. *Soc Sci Med* 1997; **45**(3): 477–84.
- 13 Aoun SM, Kristjanson LJ, Currow D, Hudson P. Caregiving for the terminally ill: at what cost? *Palliat Med* 2005; **19**: 551–5.
- 14 Haley WE, LaMonde LA, Han B, Narramore S, Schonwetter R. Family caregiving in hospice: effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. *Hosp J* 2001; **15**(4): 1–18.
- 15 McCorkle R, Pasacreta JV. Enhancing caregiver outcomes in palliative care. *Cancer Control* 2001; **8**(1): 36–45.
- 16 Thomas C, Morris SM, Clark D. Place of death: preferences among cancer patients and their carers. *Soc Sci Med* 2004; **58**: 2431–44.