

Palliative Care Journal Club

Presented by: By Richard Delisle Family Medicine Resident, April 3rd, 2008.

Reference: Elli I Stajduhar, Diane E Allan, S Robin Cohen, Daren K Heyland; *Preferences for location of death of seriously ill hospitalized patients: perspectives from Canadian patients and their family caregivers*; *Palliative Medicine* 2008; 22: 85-88

Background

Previous studies have demonstrated, in palliative patients, a preference for dying at home. This paper attempted to focus, not only on the patient's preferences, but also on the family caregiver's preferences regarding the location of death. It also paid special attention to the congruence between the patient and the family caregiver's preferences. Cancer patients, as well as patients with end-stage medical conditions, were included.

Methods

A cross-sectional study, published in 2005, examined issues pertaining to end-of-life care from the perspective of both the patient and the family caregiver. It did so by administering a questionnaire to 440 eligible in-patients as well as 160 family caregivers. The data was collected between 2001 and 2003 across five Canadian tertiary care teaching hospitals. Amongst eligibility criteria, patients included in the study were over 18 years of age, understood English, had no apparent cognitive barriers and were expected to stay in hospital for a minimum of 72 hours.

Abstract:

This paper reports results from 138 patient-family caregiver dyads who answered, from the original questionnaire, a question regarding their preference for location of death. Other details regarding patient eligibility in the original study were not reported in this paper. The exact question, for patients, was: "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?". Family caregivers were asked: "Assume you could achieve good quality care at home as well as in the 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?" In both cases, answer options were: (a) home; (b) hospital and (c) does not matter.

Results

Table 1 Patient and caregiver characteristics (n = 138)

	Patients n (%)	Caregivers n (%)
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.

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

		Patients		
		Home n (%)	Hospital n (%)	Does not matter n (%)
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 n (%)	FCG n (%)	Patient n (%)	FCG n (%)
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)

Of the patients, 53.6% preferred home death, compared with 50.0% of family caregivers while 19% and 10% respectively reported that it did not matter. Interestingly, only 49.3% of patient-family caregiver dyads agreed on preference for location of death. Also of interest, although preferences between cancer and non-cancer patients and caregivers were fairly similar, slightly more family caregivers of non-cancer patients, compared to caregivers of cancer patients, preferred hospital death.

Discussion

A few interesting conclusions can be drawn from this study, but the most important finding, in my opinion, is the frequent discordance between the patients wishes and the family caregivers preferences. Although the patient's preference is certainly important, the family caregiver's opinion should also weigh heavy in the decision.

Given the caregiver's invaluable role in allowing a home death, and knowing the health risks that they face, their preferences should be considered equally important. Efforts should be made to understand both party's perspectives and consideration given to each.

Another interesting fact noted in this study is that family caregivers of non-cancer patients tend to prefer a hospital death. It isn't clear as to the exact reason for this discrepancy, but one can only speculate that end-stage medical patients may appear more complex than the cancer patient counterpart. This may be due to the more frequent hospital admissions resulting from multiple exacerbations.

Overall, despite a few flaws and biases in this study, the results point out an important situation that needs to be addressed regardless of actual percentages. The main strengths and weaknesses noted in this study are listed below.

Strengths

- Canadian study – similar population;
- Cancer and non-cancer patients;
- Multi-centre study (n = 138).

Weaknesses

- Subgroup study of a larger study;
- Patient selection and eligibility criteria are unclear;
- Hospitalized patients only;
- Only includes patient-caregiver dyads who answered this specific questions;
- The question was poorly worded (limited answer options, hypothetical scenarios).

Conclusion

Home as often been thought to be the preferred location of death for most patients and this study appears to agree to some extent. There is, however, a significant population indicating the hospital as their preferred location for dying. This indicates the need for an individualized approach to the end-of-life care. Furthermore, patients and family caregivers only agree half the time on the preferred location of death. This can be a challenge since palliative care treats, not only the patient, but deals with all family dynamics. It is part of our duties, as palliative care team members, to try and understand the differences in opinions and bridge the gaps.

Finally, since quality of life of dying patients is a primary goal for palliative care, every effort should be made to assist both patients and family caregivers to die in the location of their choice. Policies should reflect these needs and resources should be allocated appropriately.