

# Preferred Place of Death – A Local Study of Cancer Patients and their Relatives

A Lee, W S Pang

## ABSTRACT

**Background:** Knowing the preferred place of terminal care is helpful in the provision of services for the terminally ill. We carried out a survey of cancer in-patients and their relatives to determine the local preference for place of terminal care as well as the factors that affected their choice.

**Methods:** The study was conducted in the form of an interview survey on patients admitted to a general medical unit and a geriatric medicine unit. Relatives approached were the nearest kin (first degree relatives), or relatives living with the patients. Patients who were not aware of their diagnosis, who were unable to comprehend the questionnaire, or were too ill to participate were not interviewed.

**Results:** Fifty-two percent (23/44) of interviewed patients preferred to die at home if possible (compared to 34%, 15/44, who preferred the hospital). This is particularly so in the elderly and if there is assurance of domiciliary care. Relatives have an almost equal preference for the patient to be at home (45%, 35/77) or in the hospital (42%, 32/77) terminally. Given the support, more (37.5%, 12/32) of those who initially wanted their sick relatives to be in hospital would prefer them to spend their last days at home.

**Conclusion:** There is a greater preference in cancer patients for terminal care at home. This is especially so for the elderly and if there is assurance of domiciliary care. This is an impetus for greater support of home care services.

**Keywords:** terminal care, domiciliary care, neoplasm, attitude, hospice

## INTRODUCTION

Place and quality of terminal care are important components of care in the terminally ill cancer patient. Many programmes for palliative care of the cancer patient stress the importance of improving the quality of life by maximising time spent outside the hospital. Despite the higher prevalence of institutional deaths, studies done in predominant Anglo-Saxon populations have shown that most people prefer to die in their own homes<sup>(1-3)</sup>. Local statistics indicate that most cancer deaths occurred in acute care

hospitals. In 1994 and 1995, the proportion of cancer deaths occurring at home had been consistently at only 34%<sup>(4)</sup>.

A study was conducted on a group of patients and their relatives to ascertain their preferred place of death and to determine the factors that affected their choice.

## METHODOLOGY

The study was conducted in the form of a loosely structured interview survey on cancer patients admitted to a general medical unit or a geriatric unit. Relatives approached were the nearest kin (first degree relatives), or relatives living with the patients. Patients who were not aware of their diagnosis, who were unable to comprehend the questionnaire (a copy of which can be obtained from the authors), or were too ill to participate were not interviewed.

Patients were asked if they would participate in a simple survey to determine their attitudes. We stressed that the survey would have no influence on their management. They were given the choice to withdraw at any time from the survey if they so wished. We adopted the approach put forth by Townsend et al<sup>(1)</sup> when we spoke to them. The patients were asked a series of questions which we hoped would direct them to talk about their preferred place of terminal care given the present situation and if circumstances allowed for a choice. Leading questions included: "What do you think of your situation?" "Many people insisted on being discharged home when they knew that time was short. Some were admitted into hospital when they knew that their condition was deteriorating. Where would you like to be if that happened?" "If your symptoms were controlled, would you like to be cared for at home till you die?" "If we could provide support for you at home in the form of visits from nurses and doctors, would you like to be at home?" They were then asked to elaborate on the reason(s) for their preference. The relatives were also similarly interviewed whenever possible.

## RESULTS

The study was carried out from January 1994 to August 1994. Both patients and relatives who were approached assented to the interview. None of them withdrew from the interview. Eighty-three eligible

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**Table I – Patients' and relatives' preferred place of terminal care by patients' age, sex and presence of caregivers**

Patients' characteristic		RR (95% CI)	Patients' preferred place of terminal care (n = 44)		
			Hospital	Home	Unsure/No conclusion
Age	< 65 years (n = 28)	1.67	13	13	2
	≥ 65 years (n = 16)	(1.05 – 2.64)	2	10	4
Sex	Male (n = 22)	0.62	5	12	5
	Female (n = 22)	(0.26 – 1.46)	10	11	1
Presence of caregiver	Yes (n = 38)	4.13	10	22	6
	No (n = 6)	(0.68 – 25.1)	5	1	0

  

Patients' characteristic		RR (95% CI)	Relative's preferred place of terminal care for patient (n = 77)		
			Hospital	Home	Up to patient
Age	< 65 years (n = 37)	1.15	16	15	6
	≥ 65 years (n = 40)	(0.72 – 1.83)	16	20	4
Sex	Male (n = 37)	0.92	16	16	5
	Female (n = 40)	(0.58 – 1.46)	16	19	5
Presence of caregiver	Yes (n = 67)	5.96	23	35	9
	No (n = 10)	(0.92 – 38.8)	9	0	1

**Table II – Main reasons for patients' preferred place of death (n = 38)**

Home	Frequency (%)	Hospital	Frequency (%)
Nearer relatives and loved ones	17 (45)	“Safer” environment	10 (26)
More convenient for family	2 (5)	Nobody at home	3 (8)
More “auspicious”	2 (5)	Less troublesome	1 (3)
Familiar environment	1 (3)	Do not want to “dirty” home	1 (3)
Save money	1 (3)		

patients and their relatives were approached for inclusion in the study. However, 6 relatives could not be interviewed because the patients died or were discharged before they were interviewed. Thirty-nine patients could not be interviewed because they were not aware of their diagnosis (25, 30%), were too ill to be interviewed (11, 13%) or they were uncertain of their illness<sup>(3)</sup>. Finally, a total of 44 patients and 77 relatives were interviewed. The mean age of patients interviewed was 55.8 years (range 24 to 84). There were 38 Chinese, 3 Malays, 2 Indians and one Eurasian. A total of 39 patients had metastatic disease, 4 had resectable tumours and one patient was newly-diagnosed with lymphoma.

If given the choice, the majority of patients (52%) preferred to be at home terminally rather than in hospital (Table I). This was especially so in those above 65 years of age (RR = 1.67, 95% CI = 1.05 – 2.64). Most of those who had a full-time care-giver (either a maid or a relative) at home also indicated their preference to be at home terminally though the results did not reach statistical significance (RR = 4.13, 95% CI = 0.68 – 25.1). Reasons cited for preferring to be at home terminally included being near their loved ones and friends and also the belief that it was more auspicious to die at home, greater ease and convenience for family members if they were to die at home and familiarity of the home environment as opposed to the foreign place of the hospital (Table II). One patient even cited substantial savings in hospitalisation cost if he were to die at home. Three patients (7%) were uncertain as to where they preferred to be terminally while 3 patients (7%) did not have any preference.

Of the 15 patients who preferred to be in hospital terminally, 10 (67%) felt that there was greater security in the hospital/institutional setting. However, should their symptoms be adequately controlled, 5 (33%) of them preferred to be at home. Six (40%) would like to be at home if there was provision for domiciliary support. The remainder would still rather be in hospital because of the security it provides.

The relatives interviewed expressed an almost equal preference of home (45%) and institution (42%) as a place of terminal care (Table I). Ten (13%) would go with the wishes of the patient whatever that may be. The reasons cited for preferring home as the place of death for their relatives were that they could offer better emotional and physical support or the belief that elderly patients would generally like to be at home when they die. Twenty-five relatives preferred their sick relatives to be in hospital because of the better facilities and availability of expert care. However, of these 25, 10 (40%) would like the patient to be at home if the symptoms were adequately controlled. Twelve (48%) of these relatives would also consider looking after the sick patient at home if there were home support teams.

There is a high degree of correlation between the patients' and their relatives' wishes. All relatives (100%) agreed with the patients who wished to be in the hospital terminally. Sixty-three percent of relatives concurred with the patients' desire to be at home terminally (Fishers' exact test p = 0.001).

## DISCUSSION

We found that the majority of the patients preferred to be at home terminally. A significant proportion of their relatives also preferred to care for them at home. This is especially for those with full-time care givers at home. The reason cited most commonly by patients and relatives in preferring to be at home terminally was the desire to be close to their loved ones. Hospital environments are generally not conducive in

**Table III – Cancer deaths by ethnic group and place of occurrence, 1995**

Ethnic group	Total (n = 3898)	Residence (%)	Hospital (%)	Nursing home* (%)	Other locations
Chinese	3388	1059 (31.3)	1925 (56.8)	403 (11.9)	1
Malay	319	191 (59.9)	125 (39.2)	2 (0.6)	1
Indian	130	42 (32.3)	82 (63.1)	6 (4.6)	-
Others	61	16 (26.2)	27 (44.3)	17 (27.9)	1

\* Includes hospices

supporting a dying patient. The facilities for family members keeping vigil over the sick are poor, the number of relatives and friends allowed to visit the sick are generally limited in an open ward, many wards often restrict attendance to visiting hours (unless in a private room) and relatives may not be advised on the imminence of death. Not surprisingly, for patients without full-time caregivers at home, both the patients themselves and their relatives preferred death to occur in hospital. These patients could be considered for in-patient hospice care where the environment is more conducive for the holistic care of patients and family members. A study carried out in St Christopher's Hospice in UK showed that the hospice environment is significantly more likely to be viewed as being more "like a family" compared to the hospital, which has a busy public atmosphere<sup>(5)</sup>.

Hospital care is often associated with more active treatment and life-sustaining measures. The study by Hinton found that those who chose to die at home had probably accepted the terminal nature of their disease<sup>(6)</sup>. This might explain in part the higher proportion of elderly patients preferring to be at home terminally compared to younger patients, as the elderly and their relatives tend to be more accepting of the terminal nature of their illness.

There were two patients who felt that it was more auspicious to die at home. However, they could not explain their inclination. We suspect that it was due to their religious beliefs. Some Chinese believe that it is easier for the spirit of the deceased to return to their homes if they died there. In the course of our work, we have also encountered relatives who did not want the deceased to be put into cold storage upon death. However this apprehension, if present, was not voiced by those interviewed.

Other than the Chinese, the other ethnic groups were not well represented in the study population and hence it was not possible to make any meaningful comparison between the different racial groups. However, it is the personal experience of the authors that the Malays have a better social support system and generally prefer to be at home terminally. Data from the National Registration Board<sup>(4)</sup> shows that more Malays compared to other races died at home (Table III, Malays vs non-Malays, RR = 1.92, 95% CI = 1.74 – 2.13).

Thirty-six percent preferred institutional care because of the greater security that it offered. However, if there was provision for domiciliary care, 40% of these patients would actually prefer to be at home. A third of them would also like to be at home if their

symptoms were well-controlled. This is an impetus to support domiciliary services and develop hospital palliative care teams to help with symptom control as well as improve liaison with community services<sup>(7,8)</sup>. In Genoa, the trend towards increasing home deaths in cancer patients have been attributed to home care teams<sup>(9)</sup>.

The survey provided opportunities to talk about revelation of diagnosis to patients who did not know, and discussion of therapeutic options, prognosis and support services available in the community to both the patients and their relatives. We did not encounter any hostility or resistance with the survey. Due to the emotionally sensitive nature of the topic studied, we could not do a cross-sectional survey and hence, our study may have been biased because of this.

## CONCLUSION

Most patients preferred to be at home terminally. This was especially so for elderly patients, given the presence of a full-time care-giver at home and if there was an assurance of domiciliary support and symptom control. This is an impetus to improve and support home care services for the terminally ill patients. The fact that all relatives and patients (those who knew they had cancer) who were approached consented to the interview suggests that people are willing to discuss the issue of terminal care. This should encourage healthcare workers to be more open in their discussions with patients and their relatives.

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