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Preferred place of death for patients referred to a specialist palliative care service

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ABSTRACT

Objectives Understanding patients' preferences for place of death and supporting patients to achieve their wishes has become a priority. This study aims to: (1) examine preferences of patients referred to a specialist palliative care service; (2) determine whether preferences of those who have been admitted as hospice inpatients differ from those who have not; (3) identify reasons why preferred place of death (PPD) is sometimes not recorded; and (iv) investigate whether nominating a PPD relates to actual place of death.

Method PPD information was collected as part of standard care for all patients referred to a specialist palliative care service. Case notes were reviewed retrospectively for 1127 patients who died under the care of the service.

Results Seventy-seven percent of the patients expressed a PPD, a further 21% of patients had documented reasons for PPD remaining unknown. Eighty percent of patients who had never been admitted to the hospice wanted to die at home. In contrast, 79% of those with at least one hospice inpatient admission wanted to die in the hospice. Patients who had an unknown PPD were three times more likely to die in hospital.

Conclusions Most patients in a specialist palliative care setting are willing to express a PPD. Preferences differ for patients who had never been admitted as hospice inpatients from those who have had at least one inpatient stay. Routine and ongoing assessment of PPD are recommended to support patients' wishes at the end of life.

INTRODUCTION

To have choice and control over where death occurs is considered central to a good death.[1 2] In recognition of this, most end-of-life care strategies promote the need to support people to die in their place of choice.[3 4] Current evidence suggests that, when asked, the majority of people would choose home as their preferred place of death (PPD), with very few choosing to die in hospital.[5] However, preferences of the general population are unrepresentative of those experiencing advanced progressive illness. Studies of patients with advanced disease show mixed findings.[6–13] The aim of the present study was to: (1) examine preferred place of death of patients referred to a specialist palliative care service; (2) determine whether preferences of those who have been admitted as hospice inpatients differ from those who have not; (3) identify reasons why PPD is sometimes not recorded; and (4) investigate whether nominating a PPD relates to actual place of death.

METHODS

Marie Curie Hospice Edinburgh (MCHE) provides specialist palliative care services (inpatient and outpatient) to a population of 500 000 in Lothian, Scotland. Hospice inpatient bed availability is 5.4/100 000 population. PPD information is recorded by specialist palliative healthcare professionals on an ongoing basis. The patient's preference, or reason why a preference is unknown, is recorded in a standard form held in the patient's notes.

For the present study, case notes were reviewed retrospectively for patients who died while under the care of MCHE in 2009 and 2010 (N=1127). The mean age of the patients was 70 years (SD=13 years). Half of all deceased patients were female. Ninety-four percent of patients had cancer as their primary diagnosis. NHS Research Ethics Committee approval was not required as the data used in this study were collected as part of standard patient care.

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RESULTS

Information on PPD assessment was documented in medical records for 97% of patients (n=1096). Seventy-seven percent of all patients nominated a PPD (n=863). For 21% of the patients (n=233), the reason(s) why a preference had not been recorded was documented. Only 3% had no record of PPD assessment (n=31). The median time between the last recorded PPD assessment and death was 6 days.

Of those patients who expressed a PPD (n=863), the hospice was the most popular place, followed by home (table 1). Hospital was the least frequently nominated location. Eighty-five percent of patients died in the place of their earlier expressed choice. The proportion of those who died in their PPD was highest for those wishing to die at the hospice and hospital, and lowest for those wishing to die at home. The results were similar for patients with both cancer and non-cancer diagnoses.

Eighty percent of patients who had never been admitted to the hospice wanted to die at home. In contrast, 79% of those with at least one hospice inpatient stay, or who were admitted to the hospice as they approached death, had a preference to die there.

A χ^2 test was conducted to explore the relationship between whether or not a PPD had been nominated and whether or not the patient died in hospital. There was a significant association between nominating a PPD and hospital death, $\chi^2(1)=37.21$, $p<0.001$. Six percent of patients for whom PPD was known died in hospital compared with 17% of patients whose PPD was unknown.

A PPD was not specified by 233 patients. The most frequently given reason for PPD being unknown was that the healthcare professional deemed it inappropriate to ask, either due to not knowing the patient long enough to have the discussion (31%) or concern about causing the patient too much distress (19%). Twenty-one percent of patients were undecided or the place was unimportant, while 12% of patients did not express a PPD due to either cognitive impairment, an inability to communicate or a combination of reasons. One percent of patients were considered too early in their disease to have this discussion. Only 34 out of 233 patients who did not specify a PPD were unwilling to have this discussion (15%).

DISCUSSION

The majority of patients referred to a specialist palliative care service were willing to express a preference for place of death. This reflects recent findings based on both hospital-based and community-based specialist palliative care services,[8 13] and suggests that most patients receiving specialist palliative care are open to discussions exploring preferences for place of death.

Most patients chose hospice as their PPD, reflecting the results of a recent audit of a hospital specialist palliative care service.[8] However, patients who had never been admitted to the hospice were more likely to have expressed a preference to die at home. These two groups are likely to have different characteristics. Hospice inpatients may have more complex symptom control issues, and/or less social support compared with those never admitted, which may make the hospice a more favourable location than home for some patients. Familiarity with the hospice environment and staff may also make it easier for patients and families to view the hospice as an appropriate final place of care.

Very few patients expressed a wish to die in hospital (<1%). This supports the findings reported in a number of studies.[7 10 12 13] Patients who did not nominate a PPD were more likely to die in hospital compared with those who had a documented preference. Patients with an unknown PPD may have been ambivalent about dying, more reluctant to have end-of-life discussions and less willing to fully engage with hospice services, thus affecting their actual place of death. Alternatively, if there were potentially reversible causes for a patient's deterioration, then hospital admission may have been considered more appropriate.

The vast majority of patients who nominated the hospice as their PPD actually died there (93%). However, only 72% of the patients who expressed a preference to die at home were able to achieve this. This finding is similar to that of a Welsh community

Table 1 Summary of place of death (PPD) and actual place of death for patients who died in 2009 and 2010 (N=863)

	Patients who nominated this location as their preferred place of death		Patients who died in their nominated preferred place of death		Patients who did not die in their nominated preferred place of death	
	N	%	N	%	N	%
Location						
Hospice	517	60	482	93	35	7
Home	319	37	229	72	90	28
Care home	21	2.4	19	90	2	10
Hospital	6	0.7	6	100	0	0
Total where preference is known	863	100	736	85	127	15

Note: Sums do not always amount to 100% because of rounding.

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palliative care service, where 69% of the patients, who expressed a preference to die at home, were able to do so.[13]

While PPD discussion may not always be appropriate, the data here suggest that the vast majority of patients receiving specialist palliative care services are open to it, if handled sensitively. Discussing end-of-life preferences can be difficult for healthcare professionals as well as patients; they may fear offering choices that are impossible to deliver or that raising the issue will cause distress to both themselves and their patients.[10 14] However, the potential benefit of discussion is that professionals have a better understanding of how to support patients in their choices.

Key strengths of this service evaluation are the size and completeness of the dataset. Our data relate to the patient's last recorded PPD, which was less than a week before they died for at least half of all patients. A limitation is that for a small number of patients, PPD was sometimes reported by the next of kin/carers in situations where the patient had become too unwell to report PPD directly.

CONCLUSION

It is possible to discuss PPD with most patients referred to a specialist palliative care service. Being a hospice inpatient is related to patient preferences. In this study, patients who had never been admitted were more likely to choose home as their PPD, whereas those who had been admitted were more likely to choose the hospice. Hospital is the least PPD for all patients; and patients who could not nominate a PPD were nearly three times more likely to die there compared with those with a known preference. Routine and ongoing assessment of PPD of patients receiving specialist palliative care is recommended to support patients' wishes at the end of life.

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Competing interests None.

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