Original Article

PALLIATIVE MEDICINE

Palliative Medicine
25(4) 333–336

DOI: 10.1177/0269216310387459
pmj.sagepub.com
SAGE

Achieving the preferred place of care for hospitalized patients at the end of life

Ruth Gerrard *CNS in Palliative Care, 2nd floor Clare House, St George's Healthcare NHS Trust, London, UK*
Janet Campbell *Clinical Audit Officer, Knightsbridge Wing, St George's Healthcare NHS Trust, London, UK*
Ollie Minton *Cancer Research UK Clinical Research Training Fellow and Honorary Consultant in Palliative Medicine, St George's University of London, Division of Mental Health, 6th floor Hunter Wing, London, UK*
Berit Moback *CNS in Palliative Care, 2nd floor Clare House, St George's Healthcare NHS Trust, London, UK*
Charles Skinner *Consultant in Palliative Medicine, 2nd floor Clare House, St George's Healthcare NHS Trust, London, UK*
Catherine McGowan *Consultant in Palliative Medicine, 2nd floor Clare House, St George's Healthcare NHS Trust, London, UK*
Patrick Charles Stone *Macmillan Reader in Palliative Medicine, St George's University of London, Division of Mental Health, 6th floor Hunter Wing, London, UK*

Abstract

Background: The Department of Health end-of-life strategy contains a number of quality markers which include taking into account patients' wishes for their final place of care. There is a wide variation in how this information is recorded. Methods: An audit was conducted on discussion of preferred place of care (PPC) for all patients referred to the hospital palliative care team who died during the audit period. Barriers to achieving PPC and the efficacy of a fast track discharge service were also monitored. The audit was first done in 2007 and was repeated in 2009. Results: There was an increase in recording PPC. Overall PPC wishes were ascertained for 87% of the patients seen by the team. The PPC was achieved in 76% of cases. The number of patients wishing to die in hospital significantly increased over the audit cycle (from 10% to 30%). Approximately one-third of patients changed their minds regarding PPC. Conclusions: The data highlights the need to distinguish between preferred place of care and preferred place of death. Patients' wishes regarding PPC change as death approaches. A greater number of patients wished to die in hospital than was expected.

Keywords
Medical audit, palliative care

Introduction

The Department of Health end-of-life strategy was published in 2008.[1] The main aim was to promote high quality care for all adults at the end of life. Ten markers were included to monitor its introduction and future success. One of these outcomes was to ensure that individuals' preferences and choices for end-of-life care are documented, communicated and achieved where possible.

One of the reasons for this strategy was the wide variation in standards of care and place of death nationally.[2] The current evidence suggests that many people with advanced illness would choose to die at home[3] but that the majority die in hospital. In order to try to reduce the incidence of hospital deaths, discharges from hospital have been speeded up to allow for death at home. The use of these services, however, requires knowledge of a patient's wishes and a discussion about end-of-life care.

St George's Healthcare NHS Trust is a large London teaching hospital and forms a joint cancer centre with the Royal Marsden hospital. The hospital

---

Corresponding author:
Dr Patrick Stone, Macmillan Reader in Palliative Medicine, St George's University of London, Division of Mental Health, 6th floor Hunter Wing, Cranmer Terrace, London SW17 ORE, UK
Email: pstone@sgul.ac.uk

palliative care team provide an advisory service to more than 1000 patients per year. In keeping with the spirit of the 'End of life care strategy' we wanted to improve the proportion of St George's patients who achieved their wish to die in their preferred place of care. In order to evaluate our success in this regard we undertook a baseline and a re-audit of documentation of patient preferences and of actual place of death/discharge.

Methods

The audit was done initially in 2007 – based on proposals from the International Observatory on End of Life Care.[4] It was then updated in 2009. As this was an audit only no ethics approval was sought or required.

A retrospective case note review was carried out at two time points by one of the authors (RG). All patients referred to the team who died during the audit period were examined. The first time period was January to June 2007. In the 2007 audit data was only available from the notes review. If there was documentation of questions about PPC and/or preferred place of death (PPD) this was noted and recorded onto an Excel spreadsheet. This process was repeated between April and September 2009 using both notes review and new specific internal documentation. This repeat audit was part of the cycle to monitor performance against the agreed gold standard of the end-of-life strategy markers. For the purposes of this audit the last time the question of preferred place of care (PPC) was asked prior to discharge (or expected death) was assumed to be the PPD. Although these are two different questions there is considerable overlap in hospitalized patients, the rationale being that patients are often being asked to make explicit end-of-life plans about ongoing care in order to facilitate urgent discharge from hospital if that is their wish. While not synonymous we feel the PPC question asked at this time is a true reflection of PPD in the majority of cases where an answer to either question is given.

Results

The 2007 audit examined data on 236 recorded deaths. An analysis of demographic and clinical data showed that two thirds (66%) of the patients had cancer. Male ($n = 117$) and female ($n = 119$) numbers were approximately equal. The mean age was 78 years. The initial data showed some limitations of the service when it came to documenting PPC. In 37% cases PPC was not recorded and 48% of those that expressed a PPC did not die where they wished.

From the 2009 audit, data was available on 275 patients who had died. An analysis of demographic and clinical data showed that three-quarters (76%) of the patients had cancer. The majority of patients (58%) were male and 68% were White British. The mean age was 72 years.

The 2009 data demonstrated an increase in the rate of recording of PPC. It was possible to obtain PPC from the patient and/or carer in 87%. Additionally, in 76% of deaths recorded ($n = 209$) the preferred place of death (as expressed by the patient [75% of total] or the carer) was achieved. The 2009 data also shows that over one-third (37%) of patients changed their minds at least once over the course of a single admission with regard to PPC. This most frequently changed from home to either hospital or hospice in roughly equal measure. These figures do not include 49 patients (18% of total) who refused to discuss PPC in the first place.

A comparison of the two audits is shown in Table 1.

Table 1. A summary of PPC for both 2007 and 2009 data sets. This compares figures for both audits comparing the stated PPC and the actual place of death where it was possible to obtain the data. This data refers to stated patient preference only

	Number (%) of patients who nominated this location as their preferred place of care				Number (%) of patients who actually died in their nominated preferred place of care			
	2009		2007		2009		2007	
Location	*N*	%	*N*	%	*N*	%	*N*	%
Home	39	24	66	44	32	82	26	39
Hospice	63	38	52	36	49	78	29	56
Hospital	52	31	14	9	52	100	14	100
Nursing home	12	7	17	11	9	100	8	53
Total where preference known	166	100	149	100	142	85	77	54

Discussion

Overall it was possible to obtain complete data for PPC on only 87% of referrals. The reasons for missing data were mainly due to either an acute deterioration or that the patient was dying when the referral to the team was made.

A limitation of the data is the potential for observer bias in the recording of PPC. These data were recorded retrospectively and only one author reviewed the notes for relevant entries. Prior to the 2009 audit we also raised the issue in our multi-disciplinary meetings more frequently and tried to distinguish explicitly between where patients wished to be 'cared for' and where they wished to die.

Discussing 'preferred place of care' with patients is an easier communication issue than discussing 'preferred place of death'. Many patients and their families are unwilling or unable to contemplate the hour of their death. It is difficult for patients to anticipate how they will be feeling when they reach the final stage of their illness. For these reasons (and because health care professionals often find it stressful to talk directly about death) discussions frequently centre on location of care rather than place of death. This hypothesis is supported by data from a longitudinal study.[5] The authors found that preferences for both PPC and PPD changed over time. There was also limited agreement between carers and patients. However, this data was not recorded solely in hospital patients and was a secondary analysis of a larger trial. This means that a direct comparison of the datasets is limited. It may, however, explain why a significant percentage of patients in our audit changed their mind during the course of their illness as to where they wished to die. Our experience and data suggest that as someone becomes less well they are more amenable to a discussion about where they wish to die. This is, however, not a blanket rule and from our data only applies to one-quarter to one-third of patients. The majority still focus on PPC as a euphemistic term for PPD and this may explain (as in the Agar study[5]) why there is substantial missing data when direct questions about PPD are asked. These findings are, however, in keeping with results found in previous work of a longitudinal study of a hospital palliative care team.[6] The authors found changes in expressed PPC as their illness progressed with a shift away from dying at home. Future research should explicitly distinguish between PPC and PPD and record this over time. However, there is the risk of significant missing data and without stratifying for prognosis this data may be unhelpful in isolation. The explicit discussion around end-of-life care in hospital patients should be recorded to the agreed national standards and this audit is a record of our local approach. It will not reflect conversations and findings in a hospice or community setting.

The other finding is the increase over time in the desire to die in hospital. This differs from the results of a systematic review of patient preferences for PPC.[7] The authors of this review suggested that home is the most common PPC. Our data suggests that the minority of patients who expressed a view wished to die at home. However, it is likely that the observed increase in the proportion of patients choosing to die in hospital between these two audits is an artefact arising as a consequence of a greater focus being placed on distinguishing between where patients wished to be 'cared' for (usually 'at home') and where they wished to die. It is likely that in the first audit (when the distinction between place of care and place of death was not made explicit) a significant proportion of patients who reported that their PPC was at home did not actually wish to die at home – but were simply expressing a wish to be discharged from hospital before they died.

Our figures only relate to a proportion of patients with advanced illness dying in one hospital. It reflects our local experience and is not necessarily generalizable nationally. However, these figures do contradict previous findings and may reflect changes in attitudes as service provision improves in hospitals.[8]

It should be noted that the greatest percentage (38%) of patients in our audit wanted to die in a hospice. This has implications for both bed availability and transfer time to a hospice if these figures were representative.

In an effort to achieve the PPC for a greater proportion of those patients who chose to die at home we introduced a 'fast-track' service. The purpose of this service was to identify patients in the last few days or weeks of life who wish to die at home and who would not be discharged in a timely fashion without intensive intervention from the team. For 'fast-track' patients one of the team acts as a discharge facilitator. Their role is to collate the documentation for continuing care funding, to liaise with community services and to escort the patient home.

The service has been successful and continues to allow patients to get home to die. Since the audit has been completed 81 patients underwent fast-track discharge (to April 2010) with only three readmissions and subsequent deaths in hospital. This is potentially one model that could be used to meet expressed PPC.

These audits have highlighted an unexpected consequence of the focus on achieving patient choice. Although large numbers of hospitalized patients may initially report that their preferred place of care is at home, caution must be exercised to ensure that this also reflects their preferred place of death. In our own practice a greater attention to distinguishing between these two concepts has identified a significant proportion of patients who prefer to stay in hospital when they enter the terminal phase. While every effort should continue to be made to facilitate the desire of patients to die at home, care must be taken not to neglect the wishes of patients who prefer to die in hospital.

Funding

This work was supported by a Cancer Research UK Psycho-oncology Fellowship (to OM). No external source of funding was obtained in the conduct of this work.

References

1. DOH. End-of-life strategy from Department of Health. http://www.dh.gov.uk/en/Healthcare/IntegratedCare/Endoflifecare/index.htm (2008, consulted 22 April 2010).
2. Gomes B and Higginson IJ. Where people die (1974–2030): past trends, future projections and implications for care. *Palliat Med* 2008; 22: 33–41.
3. Gomes B and Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006; 332: 515–521.
4. Storey L, Wood J and Clark D. Developing an evaluation strategy for 'Preferred Place of Care'. *Prog Palliat Care* 2006; 14: 120–123.
5. Agar M, Currow DC, Shelby-James TM, Plummer J, Sanderson C and Abernethy AP. Preference for place of care and place of death in palliative care: are these different questions? *Palliat Med* 2008; 22: 787–795.
6. Townsend J, Frank AO, Fermont D, et al. Terminal cancer care and patients' preference for place of death: a prospective study. *BMJ* 1990; 301: 415–417.
7. Higginson IJ and Sen-Gupta GJA. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 2000; 3: 287–300.
8. NICE. Guidance on palliative and supportive care available from: http://guidance.nice.org.uk/CSGSP/Guidance/pdf/English (2004, consulted 28 April 2010).