Developing the Cambridge palliative audit schedule (CAMPAS): a palliative care audit for primary health care teams

M S ROGERS
S I G BARCLAY
C J TODD

SUMMARY
Background. Problems with the provision of palliative care have been reported. Audit is one means of improving care. Earlier audits of primary care palliative care have been initiated by general practitioners (GPs) and are predominantly retrospective record reviews. Widely applicable methods for the audit of primary care palliative care do not exist.

Aim. To develop relevant palliative care standards and to devise an audit schedule (the Cambridge palliative audit schedule, CAMPAS) suitable for monitoring palliative care in diverse primary care settings.

Method. Primary health care team (PHCT) members collaborated at all stages. Reasonable outcomes and acceptable interventions for PHCTs were identified and standards developed. Each standard was constructed to ensure uniform interpretation, and CAMPAS was structured to collect data necessary for determining whether the standards were met.

Results. Over 50% of PHCTs (n = 20) in the health district were recruited and trained to use CAMPAS. A total of 876 contacts with 29 patients was recorded by PHCTs using CAMPAS. Considerable inter- and intra-PHCT variation was found in the achievement of the standards.

Conclusions. The favourable participation rate suggests commitment to audit and improvement in patient care. Overall, the standards were reported to be suitable. Although 100% achievement of some standards may be unrealistic, the level of attainment for many suggests that it is possible. CAMPAS has been reported to be a useful structure for recording assessments and monitoring care, as well as a usable audit schedule. As an audit tool, it identified areas in need of improvement and facilitated feedback to participants. Future audit is required to determine whether improvements in care have been effected.

Keywords: palliative care; audit; primary health care team.

Introduction

Although palliative care is most recognizably provided by specialists, it is general practitioners (GPs) and district nursing teams (DNs) who provide most palliative care.1-3 Terminally ill patients reportedly prefer to remain at home,4,5 but many fail to achieve this.6-8 It appears that many carers are unhappy with this situation and would prefer to be able to support the patient at home until death.7-10

Problems regarding the provision of palliative care in the primary care setting have been reported. Inadequate control of difficult symptoms, particularly pain, nausea, vomiting, constipation, and dyspnoea, has been identified,2,7,11-15 and support is all too often inadequate to sustain care at home until the end of life.2,7,8,13,14,16-18

One means of improving patient care is through clinical audit.19-21 Audit has been described as 'systematic, critical analysis of the quality of medical care, including the procedures used for diagnosis and treatment, the use of resources and the resulting outcome for the patient'.22

Auditing palliative care

Palliative care has been summarized as the provision of active, total care at a time when the disease is not responsive to curative treatment. It involves the provision of relief of pain and other distressing symptoms while integrating the psychological and spiritual aspects of care.23 Active patient and family involvement in decision-making is a basic tenet of palliative care. Thus, it is important to adopt a comprehensive approach in the development of audit for palliative care rather than focusing on single symptoms.

Because of the challenges and constraints of the primary care setting, it is essential that any audit tools are easy to use and capable of providing immediate feedback. We, therefore, enlisted the collaboration of primary health care team (PHCT) members in the construction of the tools, and we chose a prospective data collection method.

Guidelines for good practice in palliative care have been derived from the expert opinions of specialists.24 For this reason, aspects of what has been agreed as good practice may not be transferable to primary care. Furthermore, available audit tools have been developed for use by hospice teams25 and do not appear to be appropriate for use by PHCTs.

As no audit tools suitable for specific use by PHCTs were available, the objectives of this project were to develop palliative care standards relevant to primary care and to devise an audit schedule suitable for monitoring palliative care provided by GPs and DNs. Therefore, the focus was on developing an audit methodology for PHCTs rather than on obtaining research data from a representative group of patients.

Method
Developing the audit tools

As the available literature concerned specialists rather than primary care services, it was not possible to identify a priori what were reasonable outcomes or acceptable interventions for PHCTs. Thus, the project entered the audit cycle at the point of 'observing practice',26 whereby GPs and DNs recorded their assessments and interventions for patients enrolled in the audit project.

A pilot version of the Cambridge palliative audit schedule (CAMPAS) was constructed on the basis of the literature, items from the support team assessment schedule,27 and the input of PHCT members. CAMPAS was used to record the severity of
Holistic care
Individualized care
Provision of information
Communication among professionals
Symptom control
Support for patient and carer

Box 1. Key concepts of palliative care.

1 Patient assessment is comprehensive.
2 Professional contact with patient is regularly planned.
3 Information is provided on a) disease progression and b) the dying process.
4 Available help is discussed.
5 Care is discussed and agreed with patient and family.
6 A severe symptom is reassessed within 24 hours.
7 DN visits are daily when patient is very sick and requires special care and support.
8 a) GP and b) DN visits are daily when patient is very sick and requires constant care and support.
9 Specialist advice is sought for severe physical symptom(s) persisting for 48 hours.
10 Patient or family anxiety assessed as severe is discussed with a PHCT colleague.
11 Specialist advice is sought for severe patient or family anxiety persisting for five days.
12 Patient is known to both GP and DN members of PHCT.
13 Patient and carer have the help and equipment to meet their needs.
14 Patient is to receive attendance allowance.

Box 2. Palliative care standards for primary care.

1 Normal activity; carers for self.
2 Activity/work restricted; cares for self.
3 Activity/work restricted; requires assistance with care.
4 Unable to care for self; requires special care and support.
5 Very sick; requires constant care and support.

Box 3. Disease Impact Scale.
symptoms and needs (outcome), and included a diary of interventions that was used by GPs and DNs to document care (process). This prototype CAMPAS was piloted by seven PHCTs over a four-month period on 13 patients, resulting in 157 patient contacts.

From the pilot study, it was clear that CAMPAS required major revision. Most importantly, fundamental components of domiciliary palliative care were identified (Box 1), and these permitted the elaboration of standards.

On the basis of the pilot work and the feedback from participating GPs and DNs, these key concepts and the related interventions were expressed as measurable standards. For example, the concept of individualized care was deemed essential. In order for care to be individualized, it must be negotiated with the patient and the carer. Hence, the standard that 'care is discussed and agreed with the patient and family' was adopted as an indicator of individualized care and made measurable in CAMPAS by the inclusion of just such an item to be rated. This process continued until 14 standards had been developed. A summary of these standards is reproduced in Box 2.

Amendments to the pilot version of CAMPAS were made as the definitions were developed. For half of the standards, these definitions include a time-frame and are based on the patient's functional status, as measured by the Disease Impact Scale (DIS) the structure of which is based on the revised Karnofsky scale, and/or the severity of one or more symptoms, as measured by the symptom and need scores included in CAMPAS (Boxes 3 and 4). The other standards were constructed so that a dichotomous (yes/no) response was appropriate. At an early stage, it became clear that standard 3 needed to be separated into two parts. As standard 13 is stated in outcome rather than process terms, it has been omitted from the present analysis.

The revised CAMPAS has two components. The first component is an assessment schedule based on a 0 to 4 scale to record patient and family outcomes. Included in the assessment schedule is a list of nine of the more commonly experienced problems amenable to intervention (pain, nausea/vomiting, constipation, diarrhoea, dyspnoea, patient anxiety, family anxiety, practical support needs, and equipment needs). The second component involves a list of yes/no questions concerning various intervention strategies (a copy of the CAMPAS schedule is available from the authors on request).

Testing the revised tools: a palliative care audit for PHCTs

Letters were sent to all 39 GP practices and the 43 district nursing sisters (DNS) in the former Cambridge Health District. Members of the PHCTs that had participated in the pilot phase were invited to continue using the revised tools. GPs and DNS who responded positively to this invitation were followed up by telephone. Those PHCTs in which the district nursing team and at least one GP agreed to collaborate were recruited (n = 20).

The audit facilitator visited these practices to introduce the standards and to train the PHCT members in the use of CAMPAS. PHCT members were asked to use CAMPAS while caring for adult patients in the palliative phase of any illness.

PHCTs collected data on patient and family outcomes and subsequent interventions. CAMPAS booklets were returned to the audit facilitator when completed or when the patient died.

After a six-month period, the audit facilitator and the GP member of the project group offered to visit each participating PHCT. There were four objectives for these visits: providing feedback on the local provision of palliative care; discussing the appropriateness and relevance of the standards; identifying areas of care in need of improvement; and discussing possible ways of implementing change.

Results

A total of 876 contacts with 29 patients were recorded by 12 PHCTs using the revised CAMPAS. A range of teams participated.

Table 1. Summary table: achievement rates of standards for total sample (number of applicable contacts or patients).

<table>
<thead>
<tr>
<th>Standard</th>
<th>Achievement rate</th>
<th>Missing values treated as not meeting standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>29% (876)</td>
<td>NA</td>
</tr>
<tr>
<td>2</td>
<td>95% (872)</td>
<td>NA</td>
</tr>
<tr>
<td>3a</td>
<td>74% (141)</td>
<td>69% (150)</td>
</tr>
<tr>
<td>3b</td>
<td>36% (135)</td>
<td>32% (150)</td>
</tr>
<tr>
<td>4</td>
<td>85% (213)</td>
<td>79% (229)</td>
</tr>
<tr>
<td>5</td>
<td>92% (745)</td>
<td>79% (876)</td>
</tr>
<tr>
<td>6</td>
<td>78% (133)</td>
<td>NA</td>
</tr>
<tr>
<td>7</td>
<td>73% (138)</td>
<td>NA</td>
</tr>
<tr>
<td>8a</td>
<td>59% (22)</td>
<td>NA</td>
</tr>
<tr>
<td>8b</td>
<td>100% (16)</td>
<td>NA</td>
</tr>
<tr>
<td>9</td>
<td>36% (8)</td>
<td>20% (15)</td>
</tr>
<tr>
<td>10</td>
<td>94% (68)</td>
<td>67% (95)</td>
</tr>
<tr>
<td>11</td>
<td>80% (5)</td>
<td>57% (7)</td>
</tr>
<tr>
<td>12</td>
<td>93% (29 patients)</td>
<td>NA</td>
</tr>
<tr>
<td>14</td>
<td>83% (29 patients)</td>
<td>NA</td>
</tr>
</tbody>
</table>

NA, not applicable.
PHCTs were from both city and rural areas, had between two and seven partners, and included training and non-training practices. All patient contacts occurred at home; two-thirds by a DN, the remainder by GPs. The median number of contacts for each patient was 20 and, in general, patient care information was collected for three to six months. Five PHCTs contributed three or more patients to the audit, while seven enrolled one patient each. All patients had a primary diagnosis of cancer, although other diagnoses were not excluded.

**How well the standards were met**

The achievement of each standard across all PHCTs is summarized in Table 1. For example, for standard 1, in 29% of the 876 patient contacts, a score was entered for the DIS and all nine symptoms and needs, indicating comprehensive assessment. It should be noted that the achievement of individual standards varied across PHCTs. There was also considerable variation as to how well each PHCT achieved the different standards.

Standard 3b was achieved on just over one-third of all applicable occasions. Although it would appear that the achievement of standard 8a was at best fair, it was applicable to just six PHCTs; 86% of the failures to achieve this standard relate to a patient who had a high DIS score because of long-term disability rather than terminal illness. The achievement of standard 9 appears to be extremely poor; however, all but one applicable situation related to the same patient.

**Discussion**

**Initiating a primary care based palliative care audit**

Although there have been previous audits of primary care palliative care, explicit use of the audit cycle is unique to this project, and it appears to be the first to recruit GPs and DNs as teams. Earlier projects were initiated by GPs who involved their partners and undertook retrospective record reviews. Holden, however, encouraged GPs from more than one practice to audit their provision of palliative care.

Over 50% of PHCTs in the former Cambridge Health District volunteered for this project. Given that the focus of the project was developing an audit methodology rather than measuring patient outcomes, this compares favourably with the 6% participation rate reported by Holden. This level of participation suggests a commitment to audit and improving the quality of palliative care.

The level of participation may also be attributed to the availability of an audit facilitator. This was a dedicated post, and the facilitator had a background in research and community and palliative care nursing. Additionally, PHCT members reported that CAMPAS was a useful structure for recording assessments and monitoring care.

Involving PHCTs in the production of audit tools has several additional advantages. We were able to produce standards that were realistic and appropriate for PHCTs and to construct a data collection tool that appears to be usable and useful. Also, where professionals have collaborated, there is more likely to be a sense of ownership and commitment.

**How well the standards were met**

When the standards were under development, the expectation was that they should be achieved 100% of the time. The decision not to set targets under 100% or to identify exceptions was taken deliberately, as there is only 'one chance to get it right' in palliative care. Thus, it is unfortunate that so few standards were met near the 100% mark. The achievement of standards is even lower if missing values are considered to represent failure by the PHCT member to undertake the key intervention. This raises three possibilities: there is something wrong with the standards; the way the standards are measured is inaccurate; or there is considerable scope for improvement. Each of these will be considered in turn.

**The standards.** The standards were developed in association with PHCT members and were accepted by them at the outset. GPs and DNs commented on how appropriate they were. For example, standards 6 (reassessment of severe symptoms within 24 hours) and 10 (severe patient or family anxiety is discussed with PHCT colleague) were created directly from observing practice.

While all standards were discussed by the 10 PHCTs who participated in the feedback sessions, only standards 3b (provision of information on the dying process) and 8a (daily GP visits when the patient is moribund) were to any degree contentious.

GPs' contrasting opinions of standard 3b appear to reflect a spectrum of communication strategies. Many DNs felt that it was the doctor's prerogative or responsibility to keep patients and family informed. These interprofessional differences have been highlighted elsewhere.

Although several GPs felt that it was essential for them to visit every day at the very end of life, others felt that daily DN visits were sufficient. Some GPs argued that patients would prefer to wait until their own GP was available, even if this meant waiting more than one day. A few GPs offer families the opportunity to contact them at home when they are absent from the practice.

Overall, the standards appear to be suitable, but standards 3b and 8a may require further explication. In the future development of CAMPAS, it will be necessary to ensure that adequate data are collected to distinguish between a high DIS score resulting from a chronic disabling illness and one that occurs as a function of progressing terminal illness.

**Measurement of achievement.** By creating measurable definitions for each of the standards, it was possible to ensure they were interpreted uniformly, and it was immediately apparent from the data whether they had or had not been met by each PHCT. It is therefore unlikely that the disparate results are attributable to faulty measurement; however, further work will need to be undertaken to determine the measurement properties of CAMPAS.

**The need for improvement.** When considering whether there is scope for improvement in care, it must be remembered that the realization of some standards depends on more than the PHCT members' interventions. At the very least, the patient and family had to be willing to allow interventions to happen. This would apply, for instance, to return visits to reassess severe symptoms (standard 6) or accepting attendance allowance (standard 14). In a less direct way, the role of specialists in palliative care affected the achievement of some standards. Difficulties in achieving standard 11 were reported by PHCT members as being largely caused by inability to obtain continuing nurse specialist support.

With these caveats in mind, we can now focus on participating PHCTs' accomplishments. The expectations contained within each standard were based on key concepts identified in the pilot data, and these concepts were sometimes addressed in more than
one standard.

The issue of holistic care was reflected in standards 1, 2, 7, 8a, 8b, and 14. As holistic care is considered paramount in palliative care, it is reasonable to expect a greater proportion meeting these standards.

We considered the concept of individualized care to be addressed in standard 5 as well as being incorporated within comprehensive assessment (standard 1) and those standards that included the provision of information (standards 3a, 3b, 4, and 14). Even though the achievement of standard 5 may be considered acceptable, the other standards were met much less frequently.

Standards 10 and 12, which relate to the fundamental component of good professional communication, were attained at a much more acceptable level. However, those that specified communication with specialists (standards 9 and 11) were not achieved uniformly, especially standard 9.

Although symptom control is the hallmark of good palliative care, those standards developed specifically to ensure this were not well met (standards 6, 9, 10, and 11). Standards 1, 7, 8a, and 8b relate indirectly to symptom management, but these were not well achieved either.

Support for the patient and family is considered essential in palliative care, yet only standard 2 was achieved at a reasonable level. Those standards relating to the provision of information, particularly standard 3b, and to visit patterns, particularly standard 8a, were poorly met. Finally, the achievement of standards 10 and 11, which relate to patient and family anxiety, leave room for improvement. This is particularly worrying, as high levels of severe patient and family anxiety were recorded during this audit.

While it was felt appropriate to set achievement at 100%, the expectation may have been unrealistic. This may be especially true for those standards where accomplishment is at least partially dependent on those other than PHCT members. Be that as it may, the level of attainment for many of the standards was not such as to make the expectation of 100% achievement completely unrealistic.

It appears that CAMPAS is acceptable and appropriate for PHCT audit of palliative care across a variety of primary care settings as well as as a clinical tool for monitoring care. Our results showed a diversity of practice in, albeit self-selected, PHCTs and a small number of patients. Future audit is necessary to determine whether improvements in care have taken place.

References
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Address for correspondence
M S Rogers, Unit of General Practice and Primary Care Research, Institute of Public Health, University of Cambridge, Robinson Way, Cambridge CB2 2SR.