An evaluation of palliative care services in the community

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To develop palliative care services, it is imperative first to evaluate local services and identify any gaps in provision. A mapping exercise and a postal questionnaire were used in an attempt to canvass the views of patients and carers using a service in Gloucestershire. This article reports on the methodology and the findings of the questionnaire.

One of the most common reasons for patient admission to an acute hospital or a similar environment shortly before death is carer breakdown (Wiles et al, 1999). This frequently occurs because the patient’s family is no longer able to cope alone in addressing their complex needs. By providing appropriate care and support at a suitable time, crisis admissions can often be avoided, enabling the patient to remain in their own home for the final days of their life.

Out-of-hours services for those requiring palliative care in Gloucestershire are currently patchy, and many residents across the county have no access to support or advice outside normal working hours.

By evaluating local services through the use of a postal questionnaire, we intended to find out how well user needs were being met and to identify any gaps in the service. Some authors argue that questionnaires lack the richness of data provided by in-depth interviews, yet there is no actual consensus on the most appropriate research method for use with those receiving palliative care (Karim, 2000).

Conducting the survey via a postal questionnaire provided us with access to a wider spread of patients and carers. The potential problems associated with interview bias were also avoided. In addition, the information gathered, alongside that gained through a mapping exercise, provided the basis for developing the service and identifying good practice that could then be shared across the county.

Method
Identifying literature
Several electronic databases were searched for similar questionnaires to review. Keywords for the search included ‘patient questionnaire’, ‘palliative care services’, ‘research with palliative patients’ or ‘primary care questionnaire’. A number of palliative care journals were also searched manually.

The mapping exercise
We began by mapping all the specialties that provide any level of service to patients requiring palliative care in their own homes and in the community. There were two reasons for undertaking this in-depth exercise. First, the draft guidelines from the National Institute for Clinical Excellence (2003) highlight the importance of coordination and communication, and recommend the development of a services directory. Mapping all the services enabled us to compile a directory. Second, mapping the services identified the key stakeholders. This ensured that all service providers were included in the questionnaire and enabled any perceived gap in service provision to be identified.

Key stakeholders included, where possible, senior representatives from all voluntary and statutory providers. These were contacted either by telephone or e-mail, and invited to participate in a brief interview to discuss the services they provide. The questions for collecting data from providers of palliative care were drawn from a schedule of queries similar to those compiled by Wiles et al (1999). The length of interview time varied, and depended on the size of the service and how much the interviewee expanded on answers. All information was then collated using a basic Excel database.
Content
We modelled the survey questionnaire on one that was previously used by Gloucestershire Hospital NHS Trust looking at inpatient satisfaction. To ensure the questions were pertinent to our study group, several were altered or amended. The information gathered from the mapping exercise had helped us to identify all key stakeholders. The questionnaire set out to ask patients and carers about the services they were being offered, the services they had received and the value of the individual providers. Members of the research and development support unit provided guidance and advice on the content, format and structure of the survey. Advice and recommendations were also received from members of the specialist palliative care team.

The questionnaire addressed key issues such as:
● Current level of palliative care service;
● Availability;
● Equity;
● Difficulties;
● Suggestions for service improvement.

Once the initial design was finalised, the questionnaire was circulated for comment and feedback to some of those who had taken part in the mapping exercise and to a carer from the patients, families and professionals group. We invited comment on the relevance of asking the questions, the wording and how easily the questions could be interpreted.

Format
The questionnaire design was kept as simple as possible, as several other studies had recently been undertaken within the county and some stakeholders felt that patients might be reluctant to respond to another long questionnaire. Questions were kept short and we used a tick-box format.

The decision was made to keep free text to a minimum because we felt that this could be used to report specific difficulties or complaints and, due to the fact that the questionnaires were anonymous, we would be unable to take necessary action. It was also felt that comments would need to be transcribed, delaying the time plan. The decision to keep the overall length of the questionnaire to a minimum of three pages was also made.

After the consultation period, the questionnaire was drafted under the titles of each of the three primary care trusts covering Gloucestershire and presented to Gloucestershire Research Ethics Committee for approval. Full approval was given after several small amendments had been made. A formal consent form was not required, as it was accepted practice that by returning the completed questionnaire the respondent was giving consent.

Distribution
We made sure that the questionnaire was an agenda item at district nurse sisters’ meetings throughout the county, and provided explanations on the format, content and method of administration. The nurses attending the meetings provided verbal consent, endorsing their role in the administration of the questionnaires.

Each practice was provided with five questionnaires and the district nurses were asked to distribute them to patients who matched the criteria, for example, people who were entering the last six months of life. The nurses were also advised that, should any patient wish to opt out of the study at any point, they should dispose of all relevant documentation.

It was suggested that 140 replies would be an acceptable response sample, as this would represent 10 per cent of deaths from cancer in the county a year.

Results
Initially, the response rate from some areas was disappointingly low. This increased slightly after a follow-up letter was sent to all the district nurses. In total, we received 61 responses. Anecdotally, many nurses felt reluctant to approach patients and discuss the questionnaire, which perhaps contributed to the low response rate. However, owing to the way we administered the study, we were unable to measure the actual percentage response rate.

Half the respondents were aged above 70 years.

FIG 2. DIFFICULTIES FACED BY RESPONDENTS IN OBTAINING HELP (n=37)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to speak to a doctor</td>
<td>4%</td>
</tr>
<tr>
<td>Unsure whom to contact</td>
<td>21%</td>
</tr>
<tr>
<td>Had to keep asking for help</td>
<td>4%</td>
</tr>
<tr>
<td>Unable to contact anyone at the weekend</td>
<td>21%</td>
</tr>
<tr>
<td>Services not flexible enough</td>
<td>21%</td>
</tr>
<tr>
<td>Found services confusing</td>
<td>21%</td>
</tr>
<tr>
<td>Not offered any help</td>
<td>8%</td>
</tr>
</tbody>
</table>

**REFERENCES**


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For related articles on this subject and links to relevant websites see www.nursingtimes.net
Meeting patient needs
In terms of how far the service met the needs of patients and carers, 59 per cent of patients and 42 per cent of carers stated that their needs had been met by all service providers. A further 35 per cent of patients stated that their needs had mostly been met. This was also reflected in a further question where respondents were asked to comment on difficulties encountered when attempting to obtain any type of help – 18 per cent reported some type of difficulty. At this point, it is worth noting that previous studies have found that health service user satisfaction generally tends to be high (Jacoby et al, 1999).

Equity of services
Home care and home nursing services are provided by a number of different organisations and charities across the county. Seventy-two per cent of respondents were offered the services available in their area. Marie Curie Cancer Care had a very low referral rate of four per cent. It has since been suggested that this may have been due to the fact that some requests for services had not been met in the past, and anxiety on the part of some district nurses not to raise carer and patient expectations. Macmillan nurses showed the greatest number of referrals, at 74 per cent. Forty-seven per cent of respondents found the service ‘very useful’ and a further 10 per cent found it ‘useful’. For example, comments included: ‘Very good service, especially Macmillan.’

Value of services
District nurses featured highly when patients were asked to comment on how useful they found the service, with 80 per cent stating they found the district nursing service ‘very useful’. The only, minor, criticism of the service related to not knowing the actual time the district nurse would visit.

Forty per cent of respondents found the home care and nursing services ‘very useful’, with a further nine per cent finding it ‘useful’. Sixty per cent indicated a high level of satisfaction with the service provided by GPs, with individual GPs mentioned by name in some cases.

Difficulty accessing services
The availability of certain services outside normal working hours (Monday to Friday, 9am to 5pm) is limited. In certain parts of the country there is no overnight district nursing service, while in other areas an on-call service is provided. Less than half the respondents, 40 per cent, had difficulty accessing the service. This may not reflect the demand for the service, as respondents may have been aware that there was no out-of-hours service, so did not list this as an issue.

In areas where there is no formal night nursing service, a district nurse often gives the carer or family their contact details should they encounter difficulties during the night. The Macmillan nursing service was noted as having the highest number of weekend access difficulties.

Respondents were asked to comment on any specific difficulties they encountered when trying to obtain help for their illness. While 63 per cent reported no problems, 37 per cent identified some form of difficulty (Fig 2).

Preferred place of care
All respondents were asked to consider where they wished to be cared for should their condition deteriorate. Sixty-one per cent stated that they would choose to remain at home. Just over 15 per cent stated that a hospice would be their choice (Fig 3).

In spite of this clear preference, in reality far fewer are dying in their own homes. In the past 10 years, only 26 per cent of patients who have died of cancer in Gloucestershire have done so in their own homes (Fig 4). This suggests that we are not enabling patients to fulfil their last wishes to die at home.

Within this sample group, the largest number of respondents who identified a hospice as their chosen place of care came under the care of West Gloucestershire

### References


Primary Care Trust (8.2 per cent). In contrast, as few as three per cent who chose a hospice were under the care of Cotswold and Vale Primary Care Trust, with the remaining 3.8 per cent being in the care of Cheltenham and Tewkesbury Primary Care Trust.

Discussion
When setting a sample size, investigators should be aware of the limitations of the distribution methods (Noble et al, 2001). In this case, as a result of the researcher not directly administering the questionnaire to all staff but relying on other sources, some staff felt pressurised into doing something they were not comfortable with, and so did not distribute the questionnaires.

In spite of the small sample size, the study can still be seen as valid, as the results enabled service providers to gather valuable information. It is often difficult to gain access to the required sample size or maintain sample size due to patients’ deteriorating health or death (Kirkham and Abel, 1997; McWhinney et al, 1994). In future we may consider conducting a limited number of interviews with patients to obtain further information.

When working with this patient group, this method is considered to be one of the most valuable, and would enable more detailed data to be collected (Jordan et al, 2002; Heslop, 1995).

At present, palliative care provision varies across the county, yet a significant proportion of respondents expressed positive views. Despite being invited to suggest ways to improve the service, only 40 per cent took the opportunity to document anything and, of these, only 14 per cent made negative comments about the service, such as: ‘Would have appreciated having a shoulder to cry on at the time I was told.’

No suggestions were made on ways to improve the service. The remainder of respondents used the free text area to make positive statements such as:
- ‘Surprised how much help is available’;
- ‘My treatment couldn’t be better.’

A number of the gaps in services that were identified through this survey are being tackled, with the aim of developing a more equitable palliative care service. We were unable to identify any reasons that some patients were not referred to a particular service. Perhaps it was not appropriate or required at that time, or health care professionals were not aware of all the available services. In an attempt to resolve this issue, a service directory has been created. This is available on the Gloucestershire health community intranet site and has been circulated throughout the county.

A district nurse review is being undertaken in some parts of the county to examine ways of providing a more inclusive service for patients. In addition, following the recent allocation of funding for specialist palliative care, a larger NHS contribution is being made to some of the charitable organisations providing home palliative services in the county. The appointment of a third palliative care consultant in Gloucestershire has also been approved and there are plans to provide telephone advice at all times.

This questionnaire illustrates the importance of effective communication. In an attempt to address the difficulties, 34 practices within Gloucestershire have adopted the Gold Standards Framework in Community Palliative Care (Thomas, 2003). The framework promotes communication, coordination and proactive planning and suggests that each patient should have a key nurse and GP to ensure they or their carer know whom to contact.

Conclusion
This study provided an effective starting point for ascertaining patients’ and carers’ views of palliative care services in Gloucestershire. Gaps in the service identified by respondents were not unexpected. These included:
- Access to advice and support outside the normal working week;
- Lack of 24-hour nursing cover;
- Confusion about whom to contact;
- Inequity of services.

We must now, in collaboration with all service providers, use this information as a basis for a needs assessment to facilitate the ongoing development of palliative care services.

Methods of involving patients must be based on their terms and not ours. We must ensure that we are flexible, compassionate and realistic, and that we do not raise unrealistic expectations.