Perceptions of the role of the hospital palliative care team

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Aim The aim of this study was to understand staff perceptions of the role of the hospital palliative care team and to identify knowledge and confidence levels of general staff caring for patients with palliative care needs.

Method A survey questionnaire tool was used with a response rate of 51 per cent. Participants included nurses, health care assistants and doctors.

Results The study highlighted several misconceptions about the role of the palliative care team, but demonstrated that the clinical staff surveyed were confident in their palliative care skills, with the exception of discharge planning, despite the fact that only 26 per cent of nurses reported having undergone training in palliative care. It identified that HCAs felt confident in caring for dying patients yet had little confidence in dealing with distressed relatives or speaking to patients and families about death. It was also interesting to note that trained nurses felt confident in their symptom control skills, and they rated training in this area as one of the top priorities.

Conclusion The findings have considerable implications for palliative care services. Professional education should continue to focus primarily on symptom control and communication skills training, but stress management training should be considered. Staff need to be clear about how to obtain advice and what support is available for cancer patients. Further research is required to understand the needs of HCAs and potential models for education and support.

Background More than one in three people in the UK will be diagnosed with some form of cancer during their lifetime, and one in four of these will die from the disease (Hopkinson et al, 2003). Since incidence of cancer increases with age, such predictions led the World Health Organization (WHO) to estimate that the need for palliative care services for the dying will increase markedly over the next 20 years as the number of older people increases (WHO, 2002).

The NHS Cancer Plan (DoH, 2000) identified a need to provide access for patients, families and carers to palliative care support from the time cancer is first suspected through to death and on into bereavement support. The National Institute of Clinical Excellence supportive and palliative care guidance (2004) promotes evidence-based service models that are most likely to lead to high-quality care for cancer patients. This applies to all patients with cancer and their carers, and includes issues such as coordination of care, communication, information, specialist and general palliative care and carer support services.

The guidance stresses that patients with cancer place most value on being treated with humanity, dignity and respect. They also value good communication between themselves and health care professionals and being given clear information about their condition, and want to receive the best possible symptom control and psychological support when they need it (NICE, 2004).

Background The WHO (2002) defines palliative care as: ‘...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’.

This definition provides a framework within which all palliative care can be delivered. Terminal care is only one of several areas of input. Palliative care now primarily begins at the point at which a patient is informed of an incurable diagnosis, and makes use of the knowledge, skills and attitudes developed in the care of dying people to improve the quality of care for terminally ill patients and those close to them.
Up to 54 per cent of people who die in England and Wales do so in hospital (Hopkinson et al., 2003). The challenge for health care professionals working in hospital is to ensure that all those who require palliative care at the time they need it. Palliative care teams play a key part in achieving this goal, providing specialist advice and treatment and educating non-specialist clinical staff in how to provide a basic level of palliative care and when to call for specialist support.

Sellick et al (1996) point out that hospitals do not always achieve their goals with regard to palliative care. Inadequately resourced palliative care services can be fragmented, leading to poor symptom control, lack of continuity and coordination of care, and ineffective education of staff. Costello (2003) finds that hospital staff do not have a good record of involving families in care of dying patients. McGowan (2001) suggests that nurses find death and dying stressful, while O’Gorman (1998) comments that professionals withdraw from the bedside because they are unable to cope with the process of death.

Health care assistants (HCAs) play a pivotal role in palliative care services. They provide personal care, observation and reporting of symptoms (Ersek, 2003). They also have a greater amount of patient contact than any other professional group – in care homes this can amount to between 80 per cent and 100 per cent of patient contact with care providers (Martinez, 2003).

There was limited literature acknowledging the role of unqualified staff within palliative care services, or their education needs. However, the literature did reveal useful information in terms of the education priorities for qualified staff. These included stress management for care givers, communication skills, pain management and symptom assessment (Sellick et al, 1996; Patterson et al, 1997; Ferrell et al, 1998).

Aims

Members of the hospital palliative care team at the Princess Royal University Hospital were keen to identify what level knowledge about the palliative care service existed among clinical staff. They also wanted to understand clinical staff’s own perceptions of their palliative care educational needs, particularly in relation to communication and symptom control.

The study reported here had two main aims:

- To gain an understanding of staff perceptions of the role of the hospital palliative care team;
- To identify knowledge and confidence levels of general staff caring for patients with palliative care needs.

It was anticipated that the information generated from the study would assist the palliative care team in identifying and prioritising areas for education and support. Further, by separating out the responses of medical staff, nurses and HCAs, it was hoped that the specific needs of each group in terms of palliative care education and support would be identified.

Overall, it was anticipated that action taken as a result of the findings would improve patient care by enabling general staff to provide basic palliative care support on a 24-hour basis. The research team wanted staff to feel confident about when to call in the palliative care team for specialist advice and support.

Method

A steering group was created, consisting of the director of nursing, members of the palliative care team, a pharmacist and senior nurses.

The literature review found no suitable audit tools and only a limited body of evidence regarding health care professionals’ perceptions of the role of palliative care teams or their own knowledge and confidence levels with regard to palliative care.

A tool was therefore developed and brought to the palliative care steering group for refinement. Separate questionnaires were developed for qualified staff and HCAs. The qualified staff questionnaire focused on their confidence in caring for patients requiring palliative care, their understanding of the role and contact details of the palliative care team, and their perception of their own educational needs. The questionnaire targeted at HCAs focused on their levels of confidence and training needs.

The questionnaires were then piloted with 10 staff within the gynaecology department. Issues identified during the pilot regarded the wording of some questions so these were rephrased to make them clearer. The palliative care steering group then reviewed the tool and a final version was agreed. The clinical audit facilitator used the staff database to randomly select the staff to whom the questionnaire would be distributed.

Sample

The participants were qualified and unqualified staff spread evenly across medicine and surgery units. The unqualified group consisted of 100 HCAs while the other of 210 qualified staff consisted of the following professional groups:

- Registered nurses of any grade (40);
- Consultants (40);
- Associate specialists (13);
- Registrars/staff grade/specialist registrars (43);
- Senior house officers/trust doctors (58);
- House officers (16).

KeywORdS Palliative care Education Staff perceptions

REFERENCES


This article has been double-blind peer-reviewed.

For related articles on this subject and links to relevant websites see www.nursingtimes.net
**Results**

Data was inputted into a simple Microsoft Excel pivot table. This allowed the level and type of response from the different staff groups to be established.

Collating incorrect answers regarding the palliative care team’s role enabled the research team to identify common misunderstandings. A comprehensive analysis was carried out on self-identified confidence, which respondents rated on a four-point scale. A comparison of levels of confidence with educational priorities was made.

A total of 161 questionnaires were returned, giving an overall response rate of 51 per cent. Respondents included the following:

- Registered nurses (26);
- Doctors (76);
- HCAs (59).

**Role of the palliative care team**

Overall, nurses and doctors did have a good general understanding of the role of the palliative care team. They recognised that the team provided specialist advice and support on pain and symptom control, liaison, support, counselling and education. Misunderstandings occurred where respondents thought that members of the palliative care team were responsible for setting up syringe drivers (nurses n=6; doctors n=12) and filling out palliative care referral forms (nurses n=1; doctors n=13). The biggest misconception occurred where 34 per cent of the sample (nurses n=8; doctors n=26) thought that the role of the team was to organise discharge planning. In addition both groups appeared to lack knowledge about who is available to support patients with cancer and their families.

**Contacting the palliative care team**

The majority of qualified staff knew how to contact the palliative care team for routine (63 per cent) and urgent (73 per cent) enquiries during the normal working day. However, only 13 per cent knew how to obtain palliative care assistance during evenings and weekends.

**Education**

Just under half of the qualified respondents were aware of the availability of informal training in the hospital’s clinical areas and formal training in its education department. Table 1 shows the training undertaken by qualified staff within the previous five years. Qualified staff were also asked to select two areas in which they would like to receive training (Table 2).

Communication skills and bereavement education were most commonly reported, training having been undertaken by up to half of both nurses and doctors. The top two training priorities for qualified staff were symptom control and communication skills.

Only 25 per cent of HCAs had received training in the previous year on how to talk to patients and families who are upset and angry. Just under half of the doctors and only a quarter of the nursing group reported having received training in symptom control. Training in the use of syringe drivers had, as expected, been undertaken by more nurses than doctors. Finally, nurses and doctors had received little education about discharge planning over the previous five years. However, this was not seen as a priority for them.

**Table 1. Training received by nurses and doctors within last five years**

<table>
<thead>
<tr>
<th>Training area</th>
<th>Nurses (n=26)</th>
<th>Doctors (n=76)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom control</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Communication skills</td>
<td>11</td>
<td>44</td>
</tr>
<tr>
<td>Bereavement</td>
<td>12</td>
<td>32</td>
</tr>
<tr>
<td>Use of syringe drivers</td>
<td>16</td>
<td>25</td>
</tr>
<tr>
<td>Discharge planning</td>
<td>7</td>
<td>13</td>
</tr>
</tbody>
</table>

**Table 2. Educational priorities for nurses and doctors**

<table>
<thead>
<tr>
<th>Training area</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom control</td>
<td>77</td>
</tr>
<tr>
<td>Communication skills/breaking bad news</td>
<td>50</td>
</tr>
<tr>
<td>Issues of loss/bereavement</td>
<td>25</td>
</tr>
<tr>
<td>Use of syringe drivers</td>
<td>23</td>
</tr>
<tr>
<td>Discharge planning</td>
<td>18</td>
</tr>
</tbody>
</table>

**References**


Confidence
Respondents were asked to rate their confidence levels with regard to certain aspects of palliative care on a four-point scale (Tables 3 and 4). Qualified staff felt confident in all aspects of caring for dying patients except discharge planning, while HCAs felt confident in caring for dying patients but had little confidence in dealing with distressed relatives or speaking to patients and families about death. Comments from HCAs indicated that they find these conversations difficult and included a need for: ‘more training’, ‘support for staff for dealing with emotional problems’, ‘support groups for staff somewhere we can debrief’.

Discussion
The staff who were surveyed had a good overall understanding of the role of the palliative care team. However, there were some misconceptions about the role of the team, which highlighted possible issues regarding clarity and ownership of care by general staff. Interestingly, qualified staff do not appear to have undergone training or feel confident in discharge planning. However, this area is not a high educational priority for them. This possibly reflects a perception that training is not the issue here, rather that the process of discharge planning requires streamlining.

It was also interesting to note that, although nurses felt confident in their symptom control skills and rated training in this area as a top priority, only 26 per cent reported having undergone such training. It is possible that the symptom control advice given by the palliative care team is not recognised as training.

The high number of qualified staff who rated training in communication and symptom control

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### TABLE 3. AREAS OF LITTLE TO NO CONFIDENCE

<table>
<thead>
<tr>
<th>Area</th>
<th>Qualified staff (n=102)</th>
<th>Health care assistants (n=59)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dealing with distressed relatives</td>
<td>n/a</td>
<td>41</td>
</tr>
<tr>
<td>Discharge planning</td>
<td>45</td>
<td>44%</td>
</tr>
<tr>
<td>Knowing who is available to support patients and their families</td>
<td>45</td>
<td>44%</td>
</tr>
<tr>
<td>Speaking to patients and families about the fact the patient is dying</td>
<td>n/a</td>
<td>41</td>
</tr>
</tbody>
</table>

### TABLE 4. AREAS OF MODERATE TO HIGH CONFIDENCE

<table>
<thead>
<tr>
<th>Area</th>
<th>Qualified staff (n=102)</th>
<th>Health care assistants (n=59)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring for a dying patient</td>
<td>83</td>
<td>81%</td>
</tr>
<tr>
<td>Dealing with distressed relatives</td>
<td>84</td>
<td>82%</td>
</tr>
<tr>
<td>Managing symptoms</td>
<td>86</td>
<td>84%</td>
</tr>
<tr>
<td>Caring for patients with cancer during evenings and weekends</td>
<td>71</td>
<td>70%</td>
</tr>
<tr>
<td>Caring for patients with cancer 9am–5pm</td>
<td>81</td>
<td>80%</td>
</tr>
<tr>
<td>Speaking to patients and families about the fact the patient is dying</td>
<td>78</td>
<td>76%</td>
</tr>
</tbody>
</table>

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### REFERENCES


as important and stated that they were confident in these areas reflects the correct focus of the palliative care education and support programme for qualified staff. However, the uptake of training was not high – although this is not uncommon in palliative care; time and funding are frequently cited as the main reasons for lack of education in this area (Sellick et al, 1996).

It is a matter for concern that, although HCAs felt confident in caring for dying patients, this confidence appears to relate only to the provision of physical care. The most significant finding was that HCAs did not have confidence in dealing with the associated emotional needs of these patients and their families, and that they appeared to have particular problems with regard to difficult conversations.

This has resulted in a follow-on research project further exploring these issues and suitable supportive education packages for this vulnerable group of staff.

Perhaps this finding should not have been surprising as HCAs are often those working closest with dying patients and their families. They therefore tend to develop close relationships with patients and carers and their valuable contribution to the multidisciplinary team can go unrecognised (Winchester, 2003).

There are also concerns about the levels of stress that are experienced by HCAs in their everyday work and their own support needs. The literature that examines the situation of HCAs working with dying patients is scant and relates mainly to nursing homes.

Authors from the UK and Canada state that a lack of communication skills training for unqualified staff has left them unable to deal with difficult questions regarding end-of-life issues (Dowding and Homer, 2000; Winchester, 2003). They find such conversations difficult and may often take concerns home with them (Dowding and Homer, 2000).

Caudill and Patrick (1989) state that unqualified staff are often not prepared to deal with physical, psychosocial and spiritual needs of patients and families at end of life. Only one study has looked specifically at their education needs and identified a need for improved communication skills training (Ersek et al, 1999).

Winchester (2003) considers that communication skills training should be part of basic training for HCAs. Education programmes have been developed in Sweden and the US (Ersek, 2003; Martinez, 2003).

In the UK, Dowding and Homer (2000) have developed a programme to teach palliative care principles to care assistants working in nursing homes, which has been positively evaluated by those undertaking it. Among the topics covered in the course are physical, emotional, social, sexual (relationships) and spiritual care.

Limitations

Limitations of this study include the response rate of 51 per cent, which could mean that those who responded may not be representative of the population sampled. Also, staff may not recognise that they have received training if this has been delivered informally as a result of contacting the palliative care team for advice. Specific issues of stress management for staff or student nurses, who may have similar concerns to the HCAs, were not looked at.

Finally, we did not test respondents’ knowledge, but asked for their perceptions of their own needs and confidence in working with patients requiring palliative care. These perceptions may not always reflect the reality of competence of individual respondents. In a national survey undertaken in the US, Glajchen and Bookbinder (2001) found that nurses did not have good knowledge levels about pain control and that, in some cases, they over- or underestimated their knowledge.

Recommendations

We recommend the following to similar services:

- Qualified staff – education should continue to focus primarily on symptom control and communication skills. Stress management training should be considered and general staff need to be clear about the support available for patients with cancer and the role of the palliative care team. Qualified staff should also be very clear about how to obtain palliative care advice out of hours and a symptom control guide should be available in all clinical areas.

- HCAs – further research is required to understand the needs of HCAs and potential models for education and support. We know that the focus for training should be on developing communication skills and that a form of supervision/support is required for HCAs. Stress management training for HCAs may also be beneficial.

Conclusion

Palliative care services should be highly developed, well coordinated and always available to patients in hospitals, care homes and their own homes (NICE, 2004). Our findings have considerable implications for palliative care services. General staff need to understand and feel confident and supported in their role in order to provide a basic level of palliative care. This will improve care when the palliative care team is unavailable and will also free up the team to provide specialist services.