Survey of Nurses
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2008
End of life care

Survey of Nurses

contents                                            page
National Audit Office survey of nurses              1
Background                                           1
Demographics                                       3
Experience in providing end of life care           6
Confidence in providing end of life care           7
Post-graduate training                              12
Support to patients and families                   13
Barriers to delivering care                        15
Glossary                                           16
National Audit Office survey of nurses

1. With assistance from the Royal College of Nurses (RCN), we surveyed a sample of 181 nurses over the course of May 2008. The survey was advertised on the RCN website and was available for any RCN member to complete. In addition an email was sent to our main contact at each of the independent and NHS hospices which responded to our earlier census, asking them to circulate it amongst their staff, and to all nurses registered as working in palliative care with the RCN. The survey covered:

- Demographics of respondents.
- Experience in providing end of life care.
- Confidence in providing end of life care.
- Post-graduate training.
- Support to patients and families.
- Barriers to delivering care.

2. The survey formed one strand of the work for our report *End of life care* which was published in November 2008, the overall findings from the survey are presented here, and at points the results are compared to the findings from our survey of doctors.¹

Background

3. End of life care services aim to support people approaching the end of their life to live as well as possible until they die. End of life care is often delivered by a large number and wide variety of generalist staff including nurses, although the exact number of people involved in delivering this care is not known. Specialist palliative care is an aspect of end of life care delivered by health and social care staff with specific training in the management of pain and other symptoms and the provision of psychological, social and spiritual support. Around 5,500 staff work in specialist palliative care.

4. Given that end of life care will often by generalist staff for whom this is only one aspect of their role, and patients will come into contact with a range of clinicians during the last year of life, nearly all staff need to be able to deliver basic end of life care, and many will need to be able to discuss death and dying. There is however evidence that nurses’ training needs are not being met in this area. For example, in a 2008 survey of neurology nurses, who treat patients with conditions such as motor neurone disease and Parkinson’s disease, 68 per cent stated that they had palliative care training needs².

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5. A summary of the quantitative results from the survey is presented here. All percentages shown are the “valid percentages” i.e. they exclude blank and not applicable responses.
Demographics

6. Because the sampling method used was not entirely random (an article was put in the RCN newsletter and emails were also sent to all Independent and NHS hospices and all palliative care nurses registered with the RCN) the sample is dominated by palliative care nurses (44 per cent), and those who categorised their role as other (29 per cent). A large proportion of those who selected the other option stated they are community/district nurses. A good spread across all grades was achieved and the majority of respondents (91 per cent) were female (n=174\(^3\)).

Figure 1: Specialism of respondents

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\(^3\) In this report the ‘n’ value represents the number of respondents who provided an answer to the question. For example 174 of the 181 respondents stated what sex they are.
7. Responses were received from all geographical regions. A range of experience was captured with the majority of respondents having qualified over 20 years ago. No responses were received from nurses who had qualified in the last 2 years.
Experience of end of life care

8. Respondents were asked to estimate the proportion of patients whose care they had been involved in the last 12 months who would have been eligible for end of life care\(^4\) (n=180); and of these, how many they discussed their approaching death with (n=178).

\(^4\) For the purpose of this survey end-of-life care was defined as care that helps all those with advanced, progressive, incurable illness to live a well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

End of life care is underpinned by:
- An active and compassionate approach to care that ensures respect for and dignity of the patient and family
- Partnership in care between patient, family and health and social care professionals
- Regular and systematic assessment of patient/carer needs incorporating patient consent at all times
- Anticipation and management of deterioration in the patient’s state of health and well-being
- Advance care planning in accordance with patient preferences
- Patient choice about place of care and death

Effective coordination of care across all teams and providers of care (statutory, voluntary and independent sectors) who are involved in the care of patient and family
Figure 5: The proportion of patients whose care you were involved within the last 12 months who would have been eligible for end of life care

![Bar chart showing the proportion of patients eligible for end of life care.](image)

Figure 6: With how many patients at the end of life did you discuss the subject of their approaching death

![Bar chart showing the percentage of patients discussing end of life care.](image)

9. Given the predominance of palliative care nurses in the sample it is perhaps unsurprising that many respondents stated that a large proportion of patients they have cared for in the last year were at the end of their lives, although discussion of approaching death was less common.

**Confidence in end of life care**

10. Respondents were asked to rate their confidence out of 10 (where 1 is not confident at all and 10 is extremely confident) in identifying the point at which end-of-life care should begin for a patient.

11. The mean score given by all respondents was 7.6 and the modal score was 9 (n=179). This compares to a mean score of 6.5 and a modal score of 7 for doctors (8.2 for palliative care specialists) although, as with all the results of this survey, care must be taken in making direct
comparisons due to the smaller sample size of nurses and the large number of palliative care specialists within that sample.

Figure 7: Nurses’ confidence rating in identifying the point at which end of life care should begin

![Nurses' Confidence Rating](image)

Figure 8: Clinicians’ confidence rating in identifying the point at which end of life care should begin

![Clinicians' Confidence Rating](image)

12. Grade, year of qualification or gender does not have a significant effect on nurses’ confidence in identifying the point at which end of life care should begin, perhaps due to the small number in each sub category.
13. Using the same rating scale respondents were asked to assess their confidence in delivering end of life care. Overall nurses gave this a mean rating of 8.1 and a mode of 9 (n=175) compared to 6.8 for all doctors and 8.8 for Palliative Care Specialists.

**Figure 9: Nurses’ confidence rating in delivering end of life care**

**Figure 10: Clinicians’ confidence rating in delivering end of life care**
14. Again there appears to no pattern or significant difference in the mean for the measure of confidence in delivering end of life care by grade, experience or gender.

15. The correlation between confidence in identifying the point at which end of life care begins and delivering care is reasonable ($r^2=0.57$) and is higher for the corresponding measure in our survey of Doctors ($r^2=0.41$).

16. Only 18 per cent of respondents stated that their pre-registration training covered the subject of delivering appropriate end of life care ($n=163$ CI 95% [12, 24])\(^5\). The corresponding value from the survey of doctors was 29 per cent ($n=901$ CI 95% [26, 32]). There is no obvious pattern in when training was undertaken and whether it covered delivery if end of life care (Figure 10). Those who received end of life care training rated it poorly, giving it a mean score of 4.8 out of 10 ($n=29$) for how well it prepared for them for delivering it (where 1 is not at all well prepared and 10 is extremely well prepared).

**Figure 11: Proportion of nurses trained in end of life care during pre-registration by experience**

<table>
<thead>
<tr>
<th>Years Qualified</th>
<th>Yes</th>
<th>No</th>
<th>Total (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than 25 Years</td>
<td>12%</td>
<td>88%</td>
<td>65</td>
</tr>
<tr>
<td>21-25 Years</td>
<td>32%</td>
<td>68%</td>
<td>28</td>
</tr>
<tr>
<td>16-20 Years</td>
<td>16%</td>
<td>84%</td>
<td>25</td>
</tr>
<tr>
<td>11-15 Years</td>
<td>22%</td>
<td>78%</td>
<td>27</td>
</tr>
<tr>
<td>6-10 Years</td>
<td>8%</td>
<td>92%</td>
<td>12</td>
</tr>
<tr>
<td>1-5 Year</td>
<td>33%</td>
<td>67%</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>18%</td>
<td>82%</td>
<td>163</td>
</tr>
</tbody>
</table>

17. Nurses gave a mean score to their confidence in discussing End of life care with patients of 7.8 ($n=177$). This compares to a mean score of 6.8 for all doctors and 8.8 for Palliative Care Specialists.

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\(^5\) The respondents to this survey are only a sample of the total ‘population’ of nurses. This means that we cannot be certain that the figures obtained are exactly those we would have if every nurse had responded (the ‘true’ values). We can, however, predict the variation between the sample results and the ‘true’ values from knowledge of the size of the sample on which the results are based and the number of times that a particular answer is given. The confidence with which we have chosen to make this prediction is 95% (i.e. the chances are 95 in 100 that the ‘true’ value will fall within the specified range). So in this example we are 95 per cent confident that the ‘true’ number of nurses who received pre registration training lies between 12 per cent and 24 per cent.
Figure 12: Nurses’ confidence rating of confidence in discussing end of life care

Figure 13: Clinicians’ confidence rating in discussing end of life care

<table>
<thead>
<tr>
<th>Specialism</th>
<th>Mean Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Care Doctors (n=40)</td>
<td>8.5</td>
</tr>
<tr>
<td>Doctors (overall n=901)</td>
<td>6.9</td>
</tr>
<tr>
<td>Nurses (Overall n=175)</td>
<td>7.4</td>
</tr>
<tr>
<td>Other (n=50)</td>
<td>6.5</td>
</tr>
<tr>
<td>Mental Health (n=4)</td>
<td>5.7</td>
</tr>
<tr>
<td>Learning Disabilities (n=9)</td>
<td>4.7</td>
</tr>
<tr>
<td>Palliative care (n=77)</td>
<td>8.7</td>
</tr>
<tr>
<td>Emergency / intensive care (n=10)</td>
<td>7.1</td>
</tr>
<tr>
<td>Cardiology (n=7)</td>
<td>7.3</td>
</tr>
<tr>
<td>Respiratory (n=5)</td>
<td>6.8</td>
</tr>
<tr>
<td>Cancer Care (n=8)</td>
<td>7.2</td>
</tr>
<tr>
<td>Care of Older People (n=12)</td>
<td>7.0</td>
</tr>
<tr>
<td>General Practice (n=7)</td>
<td>6.5</td>
</tr>
</tbody>
</table>
18. Only 15 per cent of nurses stated that their pre registration covered communicating with patients at the end of their lives (n=163 CI 95% [10, 20]). This compares to 39 per cent of doctors (n=901 CI 95% [36 42]) who reported their undergraduate training covered this.

19. Again there is no obvious association between when training was undertaken and the likelihood of it covering communication with patients at the end of their lives, indicating that this has not been a major component of nurse training for some time.

**Figure 14: Proportion of nurses trained in communicating with patients at the end of their life during pre-registration by experience**

<table>
<thead>
<tr>
<th>Years Qualified</th>
<th>Yes</th>
<th>No</th>
<th>Total (number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than 25 Years</td>
<td>11.3%</td>
<td>88.7%</td>
<td>65</td>
</tr>
<tr>
<td>21-25 Years</td>
<td>14.3%</td>
<td>85.7%</td>
<td>28</td>
</tr>
<tr>
<td>16-20 Years</td>
<td>12.0%</td>
<td>88.0%</td>
<td>25</td>
</tr>
<tr>
<td>11-15 Years</td>
<td>23.1%</td>
<td>76.9%</td>
<td>27</td>
</tr>
<tr>
<td>6-10 Years</td>
<td>21.4%</td>
<td>78.6%</td>
<td>12</td>
</tr>
<tr>
<td>1-5 Year</td>
<td>16.7%</td>
<td>83.3%</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>14.9%</td>
<td>85.1%</td>
<td>163</td>
</tr>
</tbody>
</table>

20. Those nurses who did receive training on communication gave the training a mean rating of 4.9 of how well it prepared them to discuss death with patients and their families (n=24).

**Post Graduate Training**

21. The number and proportion of nurses who reported that they had undertaken post graduate training in the main end of life care tools are detailed below.

**Figure 15: Proportion of nurses trained in the main end of life care tools**

<table>
<thead>
<tr>
<th>Tool</th>
<th>n</th>
<th>Proportion (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liverpool Care Pathway</td>
<td>122</td>
<td>72.2</td>
</tr>
<tr>
<td>Gold Standards Framework</td>
<td>90</td>
<td>58.1</td>
</tr>
<tr>
<td>Preferred Priorities of Care</td>
<td>79</td>
<td>53.4</td>
</tr>
<tr>
<td>Other</td>
<td>114</td>
<td>73.1</td>
</tr>
</tbody>
</table>

22. Nurses were asked to rate the improvement in their confidence in communicating about and delivering end of life care as a result of being trained in the main approaches to end of life care (where 1 is no improvement and 10 is a significant improvement).

**Figure 16: Nurses’ rating of the improvement in confidence as result of training in the main end of life care approaches**
November 2008

Improvement in confidence in delivering end of life care as a result of training

<table>
<thead>
<tr>
<th>Tool</th>
<th>Mean Improvement Score (excluding Negative Impact and N/A)</th>
<th>Negative Impact (number)</th>
<th>Mean Improvement Score (excluding Negative Impact and N/A)</th>
<th>Negative Impact (number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liverpool Care Pathway</td>
<td>7.5</td>
<td>1.8% (3)</td>
<td>7.8</td>
<td>0</td>
</tr>
<tr>
<td>Gold Standards Framework</td>
<td>7.4</td>
<td>2.2% (4)</td>
<td>7.3</td>
<td>0.6% (1)</td>
</tr>
<tr>
<td>Preferred Priorities of Care</td>
<td>7.2</td>
<td>1.1% (2)</td>
<td>7.4</td>
<td>1.3% (2)</td>
</tr>
<tr>
<td>Other</td>
<td>8.1</td>
<td>0.6% (1)</td>
<td>8.1</td>
<td>0.7% (1)</td>
</tr>
</tbody>
</table>

Support to Patients and Families

23. There was more agreement than disagreement with the statement ‘people at the end of life and their families generally are sufficiently and appropriately involved in decisions about their care.’ This may be a reflection of the environment and areas of care that the majority of respondents work in (n=173).

Figure 17: Nurses' level of agreement with the statement people at the end of life and their families generally are sufficiently and appropriately involved in decisions about their care

24. Respondents were asked to rate out of 10 how poorly or well the NHS and the voluntary sector meet the needs below for people at the end of their lives (where 1 is not at all well and 10 is extremely well).
25. In line with our survey of doctors, nurses rated voluntary services as better at meeting the needs of people at the end of their lives than NHS services (Doctors rated all voluntary services more highly except pain management which got the same mean rating as NHS services).

26. Nurses tended to give a higher average rating to voluntary services and a lower average rating to NHS services than doctors did. Again this may reflect the fact that a high proportion of our respondents work in palliative care and are therefore likely to be employed by a third sector provider.

27. Respondents were asked to rate services on how well they support carers (where 1 is not at all well and 10 is extremely well). Nurses rated services less highly than doctors.

Figure 19: Nurses views of how well NHS and Social services meet the needs of carers of patients at the end of life (where 1 is not at all well and 10 is extremely well).
Barriers to delivering care

28. Respondents were asked to identify the first, second and third largest barriers to the delivery of high quality end of life care services in the area. The largest barrier selected overall was ‘Lack of education and training of generalist staff’, which was selected by 34 per cent of respondents as the first, second or third largest barrier. This was followed by ‘Poor co-ordination across health and social care’ (selected by 27 per cent of respondents) and Lack of 24/7 District Nursing (26 per cent of respondents).

29. The three most commonly selected barriers by doctors overall, ‘poor co-ordination across health and social care’ (29 per cent of respondents), ‘lack of provision of hospice at home’ (25 per cent), followed by ‘lack of education and training of generalist staff’ (22 per cent).
Glossary

End of life care
Services to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive and end of life care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This support is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.

The Gold Standards Framework
A primary care based approach for identifying end of life care patients, assessing their needs, and coordinating their care. It provides prompts to a healthcare professional that discussions about the end of life should be initiated, if they have not already taken place, and enables GPs to identify patients for inclusion on a palliative care register.

The Liverpool Care Pathway
Developed for use in hospitals, but can be used in primary care, care homes, or hospices. It empowers generalist clinicians to care for the dying and manage pain and other symptoms in the last days and hours of life by providing guidance on comfort measures; anticipatory prescribing of medicines; discontinuation of inappropriate interventions; psychological and spiritual care; and care of the family (both before and after death).

Palliative care
The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. Most palliative care is provided non-specialist staff such as GPs, hospital doctors, ward nurses, and staff in care homes.

Preferred Priorities for Care
A patient held record documenting care on an ongoing basis which helps staff follow patient’s expressed wishes. This record enables patients and carers to express preferences over the care they wish to receive, including where they wish to be cared for as they approach the end of life.

Specialist palliative care
See palliative care. Specialist palliative is provided by multi-disciplinary teams that might include consultants in palliative medicine, nurse specialists, specialist social workers and experts in psychological care. Such staff are specifically trained to advise on symptom control and pain relief.