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# A SURVEY OF ETHICAL ISSUES EXPERIENCED BY NURSES CARING FOR TERMINALLY ILL ELDERLY PEOPLE

*S Patricia D Enes and Kay de Vries*

**Key words:** culture; elderly people; ethics; palliative care; terminally ill patients

This study examined the ethical issues experienced by nurses working in a small group of elderly persons' care settings in the UK, using a survey questionnaire previously used in other countries for examining the cultural aspects of ethical issues. However 'culture' relates not only to ethnicity but also the organizational culture in which care is delivered. Nurses working in elderly persons' care settings described a range of issues faced when caring for elderly terminally ill people, which illustrated the different needs of patients, relatives, professionals and society. These issues related to the unique needs of elderly people (such as dementia sufferers) and could have an impact on patients' quality of death.

## Background

Changes in health care have raised many ethical dilemmas. In palliative care, questions around the ethics of prolonging life, hastening death and disclosure have come particularly to the fore as society in the UK has become older and more multicultural.

Cultural influences on ethical decision making are well documented<sup>1,2</sup> with studies highlighting different philosophies in different countries around issues such as disclosure, consent and treatment decisions.<sup>3-7</sup>

A group of researchers carried out comparative questionnaire surveys of nurses from Japan and North America<sup>6,8-11</sup> on their experiences of ethical issues, particularly disclosure. Disclosure of information about a 'serious' diagnosis or prognosis to patients in Japan was not the norm, while North American nurses had the opposite experience. The main difference between these groups was the Japanese emphasis on the importance of the 'family bond' and the North American emphasis on the 'right to know'.<sup>8,9</sup> As a way of understanding how nurses from different countries experience ethical issues we were asked to carry

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out a study of a sample of nurses in the UK using the questionnaire developed by Davis and Konishi in 1998. Because of our palliative care background and particular interest in elderly people, we chose to explore the views of nurses working in elderly persons' care settings.

There is already some evidence that patients' age influences the ways in which nurses address ethical issues. May's study of nurses' experiences around disclosure of terminal prognoses in the hospital setting demonstrated how, although nurses preferred openness, they believed that certain patients should not be given information. This was particularly the case for very elderly or confused patients because of doubts about their ability to comprehend or retain information.<sup>12</sup> This type of belief was also evident in Costello's ethnographic study of three hospital wards for the care of elderly people, where it was described as exhibiting 'institutionalized nondisclosure' of information about death and dying. There was a cultural characteristic of families being given information that was withheld from the patients themselves.<sup>13</sup>

The ageing population, the increasing incidence of dementia and the greater number of nursing homes are likely to have a significant impact on palliative care.<sup>14</sup> However, as hospices move more towards shorter-term 'acute' palliative care, many patients are transferred to nursing homes to die,<sup>15</sup> creating greater overlap between hospice and nursing home services. Yet, little is known about the experiences of nurses caring for elderly terminally ill people in these settings and it is important to explore their views on the ethical issues they may face. The aims of this study were therefore:

- To examine nurses' experiences of disclosure in elderly persons' care settings;
- To determine other ethical issues that nurses experience when caring for elderly terminally ill patients in these settings;
- To examine these ethical issues with respect to the palliative care needs of elderly terminally ill people.

## **Method**

The researchers visited elderly persons' care units where consent to carry out the study had been obtained between February and April 2002 to give a short presentation, introducing the study to the nursing team. It was hoped that contact with the teams would help to increase the response rate.<sup>16</sup> Although the original studies accessed nurses through conferences, the researchers believed that the best way to reach a more representative sample of nurses in these settings was directly through their place of work. This meant a smaller sample, but one more likely to reflect the views of nurses who provide hands-on care.

A convenience sample of 135 registered nurses working in 13 elderly persons' care units (three community hospitals and 10 care homes) in southeast England was used. One questionnaire was provided for each member of each nursing team so that they could complete them anonymously at a convenient time. The questionnaires were semistructured, containing a range of closed, forced-choice and open questions that centred on nurses' work with dying patients. The closed questions were specifically about disclosure but open questions enabled participants

to write about other ethical issues related to their own work with terminally ill people and to the care of dying people in the UK in general. In view of the range of cultures represented by our sample, participants were asked to complete their questionnaires with reference only to working in the UK.

In order to maximize the response rate a self-addressed return envelope was provided with each questionnaire, together with an explanatory letter.<sup>16</sup> A poster outlining the presentation was also left at each unit for those nurses who could not attend. The matrons/managers of those units from which fewer than 50% of the questionnaires were returned were sent a letter asking them to remind the team to complete and return their questionnaires if they still wanted to participate.

In view of the small sample size only descriptive information was used for quantitative data. Qualitative data from the open questions were content analysed.

## Results

Fifty-three nurses returned completed questionnaires, giving a response rate of 39.3%. The demographic details of those who took part can be seen in Table 1. Most of them worked in a clinical capacity (77.4%) and the time in their current position ranged from four months to 22 years.

### Care of terminally ill patients

All participants had some experience of nursing terminally ill patients. However, a quarter ( $n = 13$ ; 24.5%) stated that they were 'seldom' involved in ethical issues at work, generally because they thought that there were not many ethical problems.

The nurses were asked to state the types of ethical problems they encountered in their work. As Table 2 illustrates, problems centred on treatment issues, the use of life-prolonging treatments and the dilemma of balancing patient and family wishes.

### Disclosure

The majority of these nurses believed that most patients are told their diagnosis and prognosis ( $n = 45$ ; 84.9%), even in the case of terminal illness ( $n = 43$ ; 81.1%). However, around a fifth indicated that such information was given to families only ( $n = 12$ ; 22.6%). Decisions around disclosure were most commonly made by the doctor. The decision to disclose a serious prognosis, for example, was made by the doctor either alone ( $n = 24$ ; 45.3%) or with the family ( $n = 23$ ; 43.4%). Nurses were rarely involved in these decisions.

Questions about truth telling revealed that most of these nurses thought that professionals sometimes lie to patients. They believed that nurses ( $n = 34$ ; 64.2%) and doctors ( $n = 22$ ; 41.5%) sometimes lie to patients about their condition although fewer thought that this happened with relatives (17% and 24.5% respectively). Thirty-two per cent ( $n = 17$ ) indicated a belief that it may be ethical to tell

**Table 1** Demographic details of sample

	<i>n</i>	(%)
<i>Gender:</i>		
Female	48	(90.6)
Male	5	(9.4)
<i>Age (years):</i>		
≤35	3	(5.7)
36–45	17	(32.1)
46–55	19	(35.8)
56–65	14	(26.4)
<i>Place of birth:</i>		
UK	35	(66)
Ireland	1	(1.9)
Europe other	1	(1.9)
Africa	10	(18.9)
Asia	5	(9.4)
USA	1	(1.9)
<i>Length of experience in nursing (years):</i>		
≤10	2	(3.8)
11–20	17	(32.1)
21–30	20	(37.7)
<30	14	(26.4)
<i>Education:</i>		
RGN/SEN	37	(69.8)
RMN	3	(5.7)
Diploma <sup>a</sup>	5	(9.4)
BSc/BA <sup>a</sup>	6	(11.3)
Higher degree	2	(3.8)

<sup>a</sup>Includes some non-nursing subjects

the truth to families but lie to patients. Most nurses ( $n = 48$ ; 90.6%) believed that patients know when they are dying, even if they are not told.

The majority of the sample indicated that they themselves would want to be told if they had a serious diagnosis ( $n = 51$ ; 96.2%) or for a family member to be told ( $n = 48$ ; 90.6%). The participants were asked to explain the reasons for their beliefs, from which five themes emerged:

#### *The human right to know*

The nurses described how being told the truth about a diagnosis was 'fair' and 'a right': 'We must respect patients' rights. I do believe that every individual is entitled to know; in that case we are not taking their rights away from them.' They mentioned this 'right to know' more frequently when writing in reference to relatives ( $n = 14$ ; 26.4%) than to themselves ( $n = 5$ ; 9.4%).

**Table 2** Common ethical problems

	<i>n</i> (%) <sup>a</sup>
<i>Treatment issues:</i>	12 (22.6)
Medication (compliance/adequate analgesia for patient need)	
Life-prolonging treatment for elderly/sick/dying patients	
Living wills	
Percutaneous enterogastrostomy feeding	
Resuscitation	
<i>Placement/environment issues:</i>	4 (7.6)
Hospital (acute treatment) versus nursing home care	
Deciding best place of care for confused elderly patients	
<i>Family issues:</i>	7 (13.2)
Relatives can have unrealistic expectations of treatment available in nursing homes	
Relatives' expectations of the treatment that patients should undergo can be unrealistic	
Family versus patient's best interest	
<i>Professional issues:</i>	6 (11.3)
Communication within the team	
Conflict over management of patient care, treatment or medication	
Poor GP knowledge of symptom control	
<i>Patient issues:</i>	5 (9.4)
Right to die	
Choice/autonomy	
Need for advocacy	
Inability to make decisions	

<sup>a</sup>*n* = 32 nurses responded to this question (some nurses gave more than 1 response); percentages calculated using whole sample (*n* = 53)

### *Preparation*

The most common theme from the data was that of preparation. The nurses emphasized the importance of individuals being able to prepare for the future or for death. Preparation for death could take the form of practicalities such as finances, wills or funeral arrangements: 'Planning ahead, winding up finances, being in control of the funeral etc. would be important to me.'

When writing about their own death, preparation also meant preparing significant others and achieving closure or spiritual and traditional preparations: 'To enjoy the remaining time on earth with the family and friends and to prepare spiritually to meet God.'

The nurses wrote about the importance of preparation much more often when writing about themselves (*n* = 32; 60.4%) than about their relatives (*n* = 20; 37.7%).

### *Living well*

A third reason why the nurses believed in disclosure was the concept of 'living well', which was important for themselves ( $n = 24$ ; 45.3%) and for their relatives ( $n = 11$ ; 20.8%). The nurses wrote of the importance of knowing about a serious illness in order to try to overcome it: '... so that I could discuss treatment and decide how to live. Also to possibly investigate alternative therapies.'

They also described the importance of making the most of the time that is left, for example, doing things they had never managed to do, focusing on the important things in life or finishing unfinished business: 'I might feel depressed/sad but I can make the most of my time left to do or change what I didn't do before.'

### *Relationships*

A number of statements centred on the nurses' belief that a serious diagnosis should be disclosed to maintain and enhance relationships (18.9% when writing about their relatives' needs, 28.3% about their own). They wrote of the need to have open communication in order to be able to talk freely about treatment options as well as to promote trust and avoid deception: 'If information is withheld from any member of a family, this can lead to a breakdown of 'free' and relaxed communication, which is essential when someone is terminally ill.'

The nurses also described how disclosure gave the opportunity to say important things to loved ones before death and to concentrate the remaining time on relationships: 'To prepare them for what lies ahead, to allow them time to reflect, to have last wishes granted and to say to them things that perhaps have been left unsaid.'

### *Control and autonomy*

The final emergent theme was that of control and autonomy ( $n = 21$ ; 39.6% for themselves and  $n = 14$ ; 26.4% for their relatives). These nurses believed that knowing about a serious diagnosis gives people a sense of control: 'I believe that knowledge can alleviate fear.'

Disclosure was also stated to be important if people were to feel in control over their decisions, plans and choices:

It enables a person to understand what is happening to them and its importance. It enables them to readjust their lifestyle and future plans and to come to terms with changes that may come, before they happen, and seek support.

## **Current areas of ethical difficulty**

Open questions gave the nurses the opportunity to identify ethical problems, as they perceived them. Four themes emerged from their responses ( $n = 20$ ):

### *Quality of death*

The most prominent theme was quality of death ( $n = 19$ ). The nurses wrote of difficulties in deciding on the appropriateness of life-prolonging measures such as resuscitation and artificial feeding, as well as knowing when to stop treatment:

Many elderly patients are PEG [percutaneous enterogastrostomy] fed when there is no QOL [quality of life] which I think is a tragedy. People should be able to die with dignity. It is a huge subject that needs a lot of debate.

Some nurses mentioned euthanasia, mostly in general terms as an issue for debate. They also wrote about the way in which people die. They commented on poor symptom control and noted that poor resources or knowledge can mean that patients do not always die 'well':

When families are not present, dying patients do not get a carer to sit with them 'til they pass away because of the shortage of staff. This is very sad.

Pain relief is often still too little too late. People with terminal illness still die in pain. Hospices are good at this aspect. Nursing homes *are not*, as it is only a GP's decision; many elderly people die in pain, especially those without relatives to fuss about their condition.

In addition, there were problems associated with decision making, particularly for elderly patients suffering from confusion or dementia. There were problems not only in making decisions about treatment and quality of life issues but also in determining who should make such decisions:

If the patient has a mental health problem and is unable to express himself or herself the relatives are relied on for guidance. However, if there are no relatives it is problematic. At what point should active treatment be stopped for a dementia sufferer? Who decides how good their QOL [quality of life] is, and should major decisions like this be made on their behalf?

This is linked to the question of disclosure. Three nurses wrote of the difficulties associated with disclosing information to elderly patients with dementia, for example:

While information should be, and I think usually is, given to residents and their families, there are situations where this is not applicable, e.g. a very confused resident who has dementia and would not be able to understand. Reality about condition and prognosis would be incomprehensible to such a person and this would create further confusion and distress.

#### *Professionals' needs*

A small number of nurses ( $n = 5$ ) described ethical scenarios depicting professional problems. These focused on professionals' need for more knowledge:

Often GPs want subcut[aneous] fluids put up, which cause 'chestiness'. Recently I nursed a dying man with subcut[aneous] fluids which caused him a 'bubbly' chest, and the GP then prescribed IM [intramuscular] antibiotics for his chest. This would never happen at the hospice and is distressing to the nurse and sends out the wrong message to the family. He was also very distressed and this problem was not addressed. This is just one example of many. I feel that nurses are much more up to date and up front about the care of dying patients than GPs. Many of our doctors have very dated and poor attitudes.

In addition there were issues about the emotional needs associated with caring for dying people: 'Doctors feel they are failing their patients when they cannot "save" them . . . but some of my most rewarding nursing was when caring for terminally ill people.'

### *Relatives' needs*

Conflict between patients' and relatives' needs was also highlighted by a small number of nurses ( $n = 3$ ). This conflict was associated either with disclosure or with relatives' difficulties in accepting that the patient is dying:

Withholding information from patients because the family wants this done is a difficult issue when nurses are trying to build up good relationships of trust. However, if a patient asks a direct question then they have the right to an honest answer that also gives hope of quality of remaining life, adequate symptom control and a 'good death', and this approach needs to be explained to families.

The greatest problem we experience is with relatives of an elderly person who do not want to accept that their relative is dying. They often request that invasive procedures are carried out in the hope of a 'miracle' cure.

### *Society's needs*

Finally, two nurses in the survey described ethical problems in terms of society's needs. These were associated with the medicalization of death and its taboo nature: ' "Dying" is not seen as part of "life" any more but a more clinical and hospitalized procedure.'

### *No ethical problems*

Thus, ethical problems as perceived by this group of nurses working in care of elderly persons settings in the UK reflect the different needs of society, professionals and service users. However, some did not think that there were any ethical problems and, indeed, some emphasized the positive side of how ethical scenarios could be managed in these settings:

There are very few problems with nursing elderly people when they are terminally ill. Decisions regarding management are made with the GP, the family, the resident (when able) and nursing staff. Very few residents would want to leave the home at this stage to go to a hospice or anywhere else.

## **Discussion**

The original questionnaire has been used internationally in comparative studies of nurses' experiences of ethical situations in a range of clinical and nonclinical areas. Our sample was purely from the elderly persons' care setting within a small area of the UK and therefore cannot be truly compared with these samples. However, this study does raise some interesting points about nursing elderly terminally ill people in this country.

### **Disclosure in different cultures**

Differences in cultural, traditional and religious beliefs can have a profound influence on how ethical questions are managed. In Japan, for example, the individual is viewed as 'socially embedded'<sup>2</sup> so that groups (in particular the family) make decisions rather than the individual. This contrasts with a western emphasis on autonomy and the litigation-consciousness of US culture, which may influence

decisions concerning ethical issues such as disclosure of a terminal illness.<sup>17</sup> Overall, our sample's views came somewhere between the rather polarized positions of nurses in Japan and North America.<sup>8-11</sup>

The majority of the nurses in our sample believed that, even if they are not told, patients usually know they are dying. In the context of a multicultural society such as the UK the ideal of 'open awareness'<sup>18</sup> may not always be possible or appropriate. Field and Copp<sup>19</sup> describe a shift in the UK from closed awareness to open awareness and back to 'conditional openness' as disclosure has become more of a process that takes account of patients' changing emotional needs at different stages of their illness. In addition, open awareness may conflict with the traditions and beliefs of cultural groups.<sup>20</sup> It is important to understand, respect and work with different traditions and be aware of the influence that cultures may have on each other and how they may alter over time. In contrast with other countries such as Japan, the UK nursing workforce is multicultural and therefore nurses' perceptions of ethical issues may be influenced by those cultures from which they originate, live and work.

### **Disclosure and truth telling in the elderly persons' care setting**

In elderly persons' care settings such as nursing or residential homes, disclosure issues may be less commonplace than in other more acute settings, as was indicated by the responses of nurses in this study. Nevertheless, if disclosure did become an issue it was sometimes made even more challenging because of the unique needs of this patient group, such as those of people suffering from dementia. The repeated disclosure of bad news to those who are unable to retain information, or to those with a limited capacity to comprehend, was highlighted in May's study<sup>12</sup> as a potential source of stress for nurses and as an influence on decisions over whether or not to disclose a terminal diagnosis in the hospital setting. This may explain why some respondents in our sample revealed that lying may be a feature of caring for people with 'serious' diagnoses and prognoses. This mirrors both Japanese and North American nurses' experiences, although lying was more common in Japan.<sup>9</sup> While lying can undermine trust, it may be morally acceptable to avoid disclosing the entire truth.<sup>21,22</sup> In this study some participants stated that professionals would in some cases be 'economical with the truth'. Nondisclosure and truth telling centre on attempts to do good and avoid harm,<sup>23</sup> but what constitutes 'good' or 'harm' and how different harms are weighed up against each other may be perceived differently by individual people or cultures. Japan may place more emphasis on preventing the harm of negative emotion associated with truth telling, while North America may be more concerned with preventing social isolation from nondisclosure.<sup>17</sup> Similarly, harms within the culture of an elderly persons' care home may be perceived differently when compared with more acute care settings.

### **Conflict of needs in ethical decision making**

Although the majority of Japanese nurses would have wanted to be told if they had a serious diagnosis (92.7%) a smaller proportion would want such informa-

tion revealed to a family member (62.4%). The North American group was unanimous in wanting open disclosure in both scenarios.<sup>8,9</sup> Our sample reflected the North American standpoint and their reasons for disclosure illustrate the complex multiple needs of people who may be facing death: the need to know, to prepare, to live well, to have relationships and to have control. These are human needs and the fact that the themes that emerged in our study were also reflected to some degree in the original studies<sup>9</sup> implies that they may be shared across cultures. The difference may be what is stressed as most important. In Japan the theme of 'family bond' ('relationship') was very much emphasized, while the North American nurses stressed the 'human right' to know.<sup>8</sup> Nevertheless, across all three cultures the greatest emphasis was placed upon the need to prepare for death and for control over decisions.

Most of the nurses in our sample stated that they would want to know about their own diagnosis and similarly for those close to them. The most commonly stated reason they gave for wanting to be told themselves was to 'prepare', although they placed less emphasis on dying patients' needs to prepare, focusing instead on their 'rights'. Maguire *et al.*'s study<sup>24</sup> of family attitudes towards disclosure of a diagnosis of Alzheimer's disease illustrates the discrepancy between what individuals want for themselves and for others. Eighty-three per cent of the family members of patients with Alzheimer's disease said that patients should not be told their diagnosis, but 71% would want to be told themselves should they develop the disease. The participants believed they had a right to know (36%) but did not seem to apply this in the same way to the patients (5%).<sup>24</sup> Although the nurses in our study generally expressed similarities between what they wanted for themselves and for their families and patients, a small number had reservations, illustrating some element of inconsistency in what may be considered as ethical.

The wish to prevent disclosure of potentially distressing information reflects human needs, the need to protect others from upset, to protect ourselves from emotional pain, or to maintain some sense of control. These needs are also important for patients. One study of patients with cancer showed that they clearly did not want their families to influence the information they received.<sup>25</sup> Although they approved of open disclosure, these patients emphasized the need for their views to take precedence over those of their families. Thus there is a need to balance patients' need to know, relatives' need to protect, and the medical need to act in a model of openness.<sup>20</sup>

## Quality of death and dying in the elderly persons' care setting

### *Medicalization of death*

The main sources of ethical difficulty represented by the sample of nurses centred not so much on disclosure but on some of the struggles that exist in UK health care and society. Conflicts were associated with the difficulties that relatives can have in 'letting go' and the medicalization of death, which can affect patients' quality of death through the use of inappropriate treatments, transfer to hospital, or the use of 'life-prolonging' measures. A number of nurses described interventions such as artificial feeding as an 'inappropriate' or ethically questionable decision for elderly people who are terminally ill.

The ethical difficulties described in Japan and North America did have some contrasts.<sup>11</sup> In Japan the main problems related to disclosure, the question of who makes decisions about treatment, staff shortages, the inappropriateness and heroic nature of treatment, and a lack of choice regarding the place of death. In North America the question of who makes decisions was also raised but there were additional issues of euthanasia, organ donation, advance directives and the question of deciding when to stop treatment.<sup>11</sup>

#### *Challenge and conflict in decision making*

Elderly patients who are very ill or have dementia may be unable to make informed decisions about their care; these may therefore fall to their relatives or professional carers. How to make decisions about another person's treatment when that person is unable to decide for himself or herself remains an area of ethical difficulty. Families may be asked to make substituted judgements as a way of protecting patients' autonomy but such decision making may be open to abuse and is subject to a range of problems.<sup>26</sup> Surrogate decision makers are better at predicting patients' wishes for more invasive procedures,<sup>27</sup> which may have implications for those in elderly persons' care settings who have to make decisions about less invasive treatments such as the use of antibiotics. In addition, although surrogates may aim to make decisions that reflect the patient's 'self', this may be made more difficult in the case of dementia when the patient's 'self' may be altered by the condition.<sup>28</sup>

There may also be challenges for health care professionals. Norberg *et al.*<sup>29</sup> examined the different ways in which professional groups caring for older patients address such decisions. Doctors were concerned with fairness and appropriate levels of care, while registered nurses placed more emphasis on patients' quality of life. The nurses in our study indicated how such decisions in the elderly persons' care setting remain a struggle, not only because of the question of how such decisions are made, but also because decisions were often perceived as 'wrong'. Incidents involving artificial feeding, transferring patients to hospital for active treatment, or the use of antibiotics were all cited as examples where nurses did not always agree with their medical colleagues' decisions.

Conflict and the nurse-doctor relationship has been illustrated in studies in different settings.<sup>8,13,29,30</sup> With ethical questions, conflict may arise because of the professional hierarchy and the different perspectives that doctors and nurses have of their roles,<sup>17,30</sup> and there are sometimes power relationship difficulties when deciding on symptom management, disclosure and resuscitation.<sup>13</sup> Nurses often believe that they have a minor role in decision making when caring for terminally ill people in hospital,<sup>3,12,13</sup> yet they do not always openly challenge medical decisions.<sup>13</sup> If there is to be more effective discourse regarding ethical issues across disciplines,<sup>30</sup> nurses may need to place more emphasis on their role as advocates for terminally ill elderly patients, if necessary challenging decisions they believe to be detrimental to their holistic care. A greater emphasis on the multiprofessional team, as illustrated in the palliative care approach,<sup>31</sup> may mean that ethical decisions are determined by patient need and the ethos of care rather than by the professional stance of any single group. Lloyd-Williams and Payne,<sup>32</sup> for example, demonstrated how multiprofessional guidelines could improve palliative care in

a long-term psychogeriatric setting, aiding decision making when there was an ethical dimension to a patient's problem.

### *Ethical palliative care for elderly terminally ill people*

It is interesting that our sample described poor symptom control as an ethical problem when caring for elderly terminally ill people. Nurses described how poor levels of education in symptom control (largely attributed to GPs) and communication skills, as well as low staffing levels could impact on patients' quality of death and consequently the ethical provision of care. The importance of incorporating the palliative care approach when caring for terminally ill patients in hospital has been well documented,<sup>33</sup> but there is also a recognized need for a better understanding of these principles by those caring for elderly people, by means of education, support and resources,<sup>34-37</sup> including GPs who provide medical cover for nursing and residential homes.<sup>15,35</sup> Contact with specialist palliative care teams can help staff working in these settings to become more aware of the contribution that symptom control and emotional support make.<sup>37</sup> However, although many palliative care teams do work at elderly persons' care homes their involvement is often infrequent, reactive and minor in terms of education and training,<sup>38</sup> and there is a need for more formal educational initiatives. Froggatt<sup>36</sup> has demonstrated how one education package tailored to the needs of nursing homes had a positive impact on the care of residents, particularly on pain control and communication, which were two areas cited by our sample as being poor at times yet having a significant effect on the quality of a person's death.

In addition to education, improving palliative care in nursing homes requires a better understanding of the culture of care found in these settings.<sup>15</sup> The needs of elderly terminally ill people may differ from the current palliative care population.<sup>36,39-41</sup> Only a small proportion of residents die of cancer,<sup>42</sup> yet specialist teams covering these settings care primarily for people with malignant disease<sup>38</sup> and so patients with other conditions such as end-stage dementia can have unmet needs for symptom control.<sup>32,35</sup> The provision of ethically adequate palliative care to this patient population may therefore require expertise in the needs of people dying of diseases other than cancer, of people experiencing dementia-type conditions, and of elderly people of a 'certain generation' with its own specific culture. Perhaps there is a need for a cultural change. Taking account of the expertise they already have,<sup>15</sup> elderly persons' care units need to take a more active role in recognizing the palliative care needs of those in their care and work more collaboratively with other specialists in the palliative care of elderly people.<sup>36</sup>

## **Limitations of the study**

Although the questionnaire has been used in other studies, it is not a validated tool. It was designed originally for Japanese nurses, a group likely to represent a single culture. Therefore, although it has been used in countries such as North America, its applicability to a multicultural sample is unclear. The questionnaire's focus on disclosure may mean that broader ethical issues were not explored in enough detail. However, many of the nurses did respond to open questions about

other ethical issues, often writing extensively. In addition, the fact that the researchers were based in a palliative care setting and intended to explore ethical issues from this standpoint may have had some influence on the nurses' responses and increased their focus on palliative care issues.

## Conclusion

Although it is difficult to draw conclusions from this small study in a single area of the UK, it does raise some issues. The cultural influences that come into play in ethical decision making may not relate simply to ethnicity but also to the prevailing professional and organizational cultures where care is delivered. These nurses described a range of ethical questions faced by UK society, many of which can affect the quality of a person's death. Some nurses questioned the ethics of poor symptom control for elderly terminally ill people. Although some stressed that the palliative care provided in their setting was of a good standard, others indicated some room for improvement. Elderly patients dying in these settings, like any other patient group, deserve quality palliative care. These organizations, as well as providers of specialist palliative care, therefore have an ethical obligation to work increasingly towards achieving this.

## Recommendations

- Nurses working in these settings face a number of ethical dilemmas when caring for elderly terminally ill people and may benefit from more support from outside agencies, including specialist palliative care teams.
- As other authors have emphasized, there continues to be a need for education on the principles of palliative care for both doctors and nurses caring for elderly terminally ill patients in these settings.
- Nurses as a group may need to do more to raise their profile as patient advocates, particularly when caring for such vulnerable groups.
- Further research into the perceptions of groups such as care assistants (who often have the most contact with patients<sup>37</sup>) and GPs would improve understanding of the roles and experiences of different professional groups in ethical decision making in this type of setting.

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## References

- <sup>1</sup> Davidson B, Vander Laan R, Davis A *et al.* Ethical reasoning associated with the feeding of terminally ill elderly cancer patients: an international perspective. *Cancer Nurs* 1990; **13**: 286–92.
- <sup>2</sup> Davis AJ, Konishi E. End-of-life ethical issues in Japan. *Geriatr Nurs* 2000; **21**(2): 89–91.
- <sup>3</sup> Kuuppelomäki M. Ethical decision making on starting terminal care in different health-care units. *J Adv Nurs* 1993; **18**: 276–80.
- <sup>4</sup> Gonçalves JF, Castro S. Diagnosis disclosure in a Portuguese oncological centre. *Palliat Med* 2001; **15**: 35–41.

- 5 Osuna E, Pérez-Cárceles MD, Esteban MA, Luna A. The right to information for the terminally ill patient. *J Med Ethics* 1998; **24**: 106–109.
- 6 Konishi E, Davis AJ. Japanese nurses' perceptions about disclosure of information at the patients' end of life. *Nurs Health Sci* 1999; **1**: 179–87.
- 7 Richter J, Eisemann MR. Attitudinal patterns determining decision making in severely ill elderly patients: a cross-cultural comparison between nurses from Sweden and Germany. *Int J Nurs Studies* 2001; **38**: 381–88.
- 8 Konishi E, Davis AJ, Ota K, Soyano A, Suzuki M. Ethical issues at the patient's end-of-life; Japanese nurses' perception. *Proceedings of the 12th World Congress on Medical Law*; 1998 Aug 3; Siofok, Hungary.
- 9 Konishi E, Davis AJ, Soyano A, Suzuki M, Ota K. Ethical issues at the patient's end-of-life: international and Japanese nurses' perceptions (2): nurses' attitudes about information disclosure. *Proceedings of the 4th World Congress of Bioethics*; 1998 Nov 6; Tokyo, Japan.
- 10 Ota K, Davis AJ, Konishi E, Suzuki M, Soyano A. Ethical issues at the patient's end-of-life: international nurses' perception. *Proceedings of the 3rd International Nursing Research Conference, Tokyo International Forum*; 1998 Sept 18; Tokyo, Japan.
- 11 Soyano A, Konishi E, Davis AJ, Suzuki M, Ota K. Ethical issues at the patient's end-of-life: international and Japanese nurses' perceptions (1). *Proceedings of the 4th World Congress of Bioethics*; 1998 Nov 6; Tokyo, Japan.
- 12 May C. Disclosure of terminal prognosis in a general hospital: the nurse's view. *J Adv Nurs* 1993; **18**: 1362–68.
- 13 Costello J. Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *J Adv Nurs* 2001; **35**: 59–68.
- 14 Doyle D. *Dilemmas and directions: the future of specialist palliative care*. (National Council for Hospice and Specialist Palliative Care Services: Occasional paper 11.) London: NCHSPCS, 1997.
- 15 Froggatt KA. Palliative care in nursing homes: where next? *Palliat Med* 2001; **15**: 42–48.
- 16 Edwards P, Roberts I, Clarke M *et al*. Increasing response rates to postal questionnaires: systematic review. *BMJ* 2002; **324**: 1183–85.
- 17 Costello J. Truth telling and the dying patient: a conspiracy of silence? *Int J Palliat Nurs* 2000; **6**: 398–405.
- 18 Glaser BG, Strauss AL. *Awareness of dying*. New York: Aldine, 1965.
- 19 Field D, Copp G. Communication and awareness about dying in the 1990s. *Palliat Med* 1999; **13**: 459–68.
- 20 Firth S. *Wider horizons: care of the dying in a multicultural society*. London: National Council for Hospice and Specialist Palliative Care Services, 2001.
- 21 Hinton J. *Dying*. Harmondsworth: Penguin, 1967.
- 22 Jackson J. Truth-telling In: Crompton S ed. *Vital judgements: ethical decision-making at the end of life*. London: National Council for Hospice and Specialist Palliative Care Services, 2002: 10–11.
- 23 Randall F, Downie RS. *Palliative care ethics: a companion for all specialties*, second edition. Oxford: Oxford University Press, 1999.
- 24 Maguire CP, Kirby M, Coen R, Coakley D, Lawlor BA, O'Neill D. Family members' attitudes toward telling the patient with Alzheimer's disease their diagnosis. *BMJ* 1996; **313**: 529–30.
- 25 Benson J, Britten N. Respecting the autonomy of cancer patients when talking with their families: qualitative analysis of semistructured interviews with patients. *BMJ* 1996; **313**: 729–31.
- 26 Bailey S. Decision making in health care: limitations of the substituted judgement principle. *Nurs Ethics* 2002; **9**: 483–93.
- 27 Sulmasy DP, Terry PB, Weisman CS *et al*. The accuracy of substituted judgements in patients with terminal diagnoses. *Ann Intern Med* 1998; **128**: 621–29.
- 28 Koppelman ER. Dementia and dignity: towards a new method of surrogate decision making. *J Med Philos* 2002; **27**: 65–85.
- 29 Norberg A, Udén G, Andrén S. Physicians', registered nurses' and enrolled nurses' stories about ethically difficult episodes in the care of older patients. *Europ Nurs* 1998; **3**: 3–13.
- 30 Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *J Adv Nurs* 2001; **33**: 707–15.

- <sup>31</sup> National Council for Hospice and Specialist Palliative Care Services. *Specialist palliative care: a statement of definitions*. (Occasional paper 8.) London: NCHSPCS, 1995.
- <sup>32</sup> Lloyd-Williams M, Payne S. Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia? *Int J Palliat Nurs* 2002; **8**: 370–75.
- <sup>33</sup> Glickman M. *Palliative care in the hospital setting*. (National Council for Hospice and Specialist Palliative Care Services; Occasional paper 10.) London: NCHSPCS, 1996.
- <sup>34</sup> Lloyd-Williams M. An audit of palliative care in dementia. *Europ J Cancer Care* 1996; **5**: 53–55.
- <sup>35</sup> Addington-Hall J. *Positive partnerships: palliative care for adults with severe mental health problems*. (National Council for Hospice and Specialist Palliative Care Services; Occasional paper 17.) London: NCHSPCS, 2000.
- <sup>36</sup> Froggatt K. *Palliative care education in homes*. London: Macmillan Cancer Relief, 2000.
- <sup>37</sup> Komaromy C, Sidell M, Katz JT. The quality of terminal care in residential and nursing homes. *Int J Palliat Nurs* 2000; **6**: 192–200.
- <sup>38</sup> Froggatt KA, Poole K, Hoult L. The provision of palliative care in nursing homes and residential care homes: a survey of clinical nurse specialist work. *Palliat Med* 2002; **16**: 481–87.
- <sup>39</sup> Field D, James N. Where and how people die. In: Clarke D ed. *The future for palliative care*. Buckingham: Open University Press, 1993: 6–29.
- <sup>40</sup> George R, Sykes J. Beyond cancer. In: Ahmedzai S, Clarke D, Hockley J eds. *New themes in palliative care*. Buckingham: Open University Press, 1997: 239–54.
- <sup>41</sup> de Vries K. Palliative care for people with dementia. In: Adams T, Manthorpe J eds. *Dementia care*. London: Arnold, 2003: 114–35.
- <sup>42</sup> Sidell M, Katz J, Komaromy C. *Death and dying in residential and nursing homes for older people: examining the case for palliative care*. London: Department of Health, 1997.