

Nurses' and patients' perceptions of expert palliative nursing care

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Aim. This paper reports a study of the perceptions of patients and nurses of palliative care and, in particular, the concept of the expert palliative nurse.

Background. Palliative care is a growing speciality and is practised globally. There is, however, limited information on patients' views about palliative care. While the idea of expertise in nursing is not new, few studies have explored the concept of the expert nurse in palliative care. Some evidence exists on palliative nurses' perceptions of their care, that it is supportive and involves maintaining therapeutic relationships with patients. Facing a terminal illness has been identified as a stressful and fearful experience that affects all aspects of life. It has also been revealed that dying patients may have unmet care needs, mainly in the areas of pain and symptom control, emotional support, and spending time alone.

Methods. A phenomenological study was carried out, using in-depth interviews and thematic content analysis. A convenience sample of 22 Registered Nurses and 22 dying patients was interviewed in 1996–1997.

Findings. Dying patients had a desire to maintain independence and remain in control. Palliative care nurses experienced both effective and ineffective interpersonal communication, the building of therapeutic relationships with dying patients and attempting to control patients' pain and distressing symptoms. Patients and nurses agreed that the two most important characteristics of an expert palliative nurse were interpersonal skills and qualities such as kindness, warmth, compassion and genuineness.

Conclusion. Although the study was conducted in the United Kingdom, the findings have relevance for palliative care practice globally in terms of dependence, issues of patient choice, nurses being interpersonally skilled and building therapeutic relationships with patients.

Keywords: dying patients, empirical research report, expert nursing, interviews, nursing, palliative care, phenomenology

Introduction

Palliative care is a growing speciality (Doyle *et al.* 2005). Although it was begun in the United Kingdom (UK),

palliative care has an international focus (Abu-Saad 2000, Bruera & Sweeney 2002). Despite being developed in different ways around the world, the key features of assessment, management of symptoms, multi-professional

care and making the patient and family the unit of care are common to the majority of palliative care programmes. Delivery of care can be adapted to different socio-economic conditions, cultural issues and private vs. public funding of health care, and levels of education amongst healthcare professionals will vary in different settings (Bruera & Sweeney 2002).

In the UK, there is increasing emphasis on its importance for patients with life-threatening illnesses [Department of Health 2000, NHS Quality Improvement Scotland (NHSQIS) 2002], including involving users in their care and seeking their opinions about that care (Department of Health 2000, Scottish Executive 2001, National Cancer Research Initiative 2004). Despite the growing body of empirical research into palliative care and an increasing evidence base in palliative care nursing (Wilkes 1998, Ingleton & Davies 2004), there is limited information on patients' views about this.

The World Health Organization (WHO) 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. (WHO 2003)

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients' illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (<http://www.who.int/cancer/palliative/definition/en/>).

Seymour (2004) argues that one of the clearest definitions of palliative nursing is that of Johnston (1999, p. 2):

All life-threatening illnesses – be they cancer, neurological, cardiac or respiratory disease – have implications for physical, social, psychological and spiritual health, for both the individual and their family. The role of palliative nursing is therefore to assess needs in each of these areas and to plan, implement and evaluate appropriate interventions. It aims to improve the quality of life and to enable a dignified death.

Background

An international search for research evidence (1989–2004) was undertaken using the following databases: CINAHL, Index to Theses of Great Britain and Ireland, Dissertation abstracts, Medline and PsycLIT and the keyword combinations: 'nurse–patient relationship', 'nursing role and palliative care', 'hospice care', 'terminal care', 'cancer'. 'perceptions and palliative care and hospice care', 'interviews and dying patients', 'good death', 'death and dying-psychosocial factors', 'process of dying', 'dying experience', 'palliative care-psychosocial factors' and 'pain and symptom control'. A hand search of key palliative care and nursing journals and reference lists of papers identified by the search were also used.

Current evidence reveals that there is lack of consensus between healthcare professionals and patients on what constitutes a good death, and the lack of studies on patients' views of a good death make it difficult to draw conclusions in this area. Nevertheless, the literature shows that healthcare professionals perceive a good death to be a physical and psychological process affecting a person's quality of life (Stephen 1991/1992, Hunt 1992, Wilkes 1993, McNamara *et al.* 1994). A high standard of care is necessary to achieve a good death, particularly in the areas of pain and symptom control (Hunt 1992). Indeed, a pervasive concept amongst healthcare professionals and patients was a 'pain free death' (Wilkes 1993, McNamara *et al.* 1994). Professionals also perceived that a good death involved a positive coping strategy and acceptance on the part of the patient (Hunt 1992, Wilkes 1993). Patients, on the other hand, perceived a good death as one for which they had prepared themselves psychologically, such as saying final farewells and being 'not afraid' (Kellehear 1990, Payne *et al.* 1996).

However, none of these studies, and therefore current knowledge in this area, incorporated a multi-dimensional perspective (psychological, social, spiritual, physical and existential) of the process of dying, instead focusing on one or two of these aspects. Dying as a process, however, involves all these aspects, and to omit one or more elements is to ignore the holistic nature of the experience.

While the idea of expertise in nursing is not new (Benner 1984), only three studies have explored the concept of the expert nurse in palliative care. These studies were conducted in single institutions, were carried out in the United States of America (USA) and none approached patients for their views about expert palliative nurses (Degner *et al.* 1991, McClement & Degner 1995, Zerwekh 1995). The studies reported that expert nurses provided comfort and responded to patients' feelings (Degner *et al.* 1991, McClement & Degner 1995). The predominant factor in Zerwekh's (1995) study was truth-telling.

A few studies have explored palliative nurses' perceptions of their care, although they have tended to focus on their perceptions of the role. The pervasive elements were that the role was supportive (Davies & O'Berle 1990), and involved maintaining therapeutic relationships with patients (Steeves *et al.* 1994) and caring, loving and spiritual care (Larkin 1998).

The studies conducted into patients' experiences of hospice care have tended to be patient satisfaction research, asking structured questions set against predetermined criteria and evaluating care in only one setting (McDonnell 1989, Arblaster *et al.* 1990, Raudonis 1993). They revealed that patients want nurses to be responsive to their individual needs and to enable them to maintain their independence (Arblaster *et al.* 1990). Hospices were seen as peaceful places where patients' physical needs would be met (McDonnell 1989). The hospice nurse-patient relationship was perceived as important (Raudonis 1993).

Furthermore, living with a chronic illness was characterized by a lack of control and vulnerability (Gullickson 1993, Halldórsdóttir & Hamrin 1996).

Facing a terminal illness is, therefore, a stressful and fearful experience that affects all aspects of life. It has also been revealed that dying patients may have unmet care needs, mainly in the areas of pain and symptom control, emotional support, and spending time alone (Rasmussen & Sandmann 1998).

Overall, these studies show the importance of ascertaining patients' views of their care. Nevertheless, none compared patient and nurse views, and none used a combination of research methods or care settings.

In addition, lack of acknowledgement of patients' viewpoints seems to imply that researchers are afraid of upsetting dying patients by asking them about their experiences at a potentially distressing time (for a detailed explanation of this issue see Cartwright & Seale 1990). This fear of talking about death with dying patients appears to be an issue for professionals rather than patients themselves, as evidenced by the number of patients writing accounts of their dying in the media and popular literature.

The study

Aim

The aim of the study was to explore the perceptions of patients and nurses of palliative care and, in particular, the concept of the expert palliative nurse. The following research questions were formulated:

- What is palliative nursing care from the dying patient's perspective?
- What is palliative nursing care from the nurse's perspective?
- Are there differences between dying patients' and nurses' perceptions as to what constitutes expertise in palliative nursing care?

Design

A phenomenological approach was employed that focused on interpretation of patients' and nurses' lived experiences. In order to take on board the criticisms levied at nurse phenomenologists by authors such as Crotty (1996) and to move beyond the attempts to apply phenomenology within a purist Heideggerian, Husserlian or Gadamerian framework, it was decided to use an adapted phenomenological method, namely, nursing phenomenology. This approach involved:

- exploration of nurses' and patients' lived experience of palliative care;
- interpretation as described by Benner (1994) and Koch (1999) to guide the process of data collection and analysis;
- a process of data collection characterized by an interactive, participatory relationship between the researcher and the informants;
- use of Colaizzi's (1978) phenomenological framework to guide data analysis;
- use of a reflexive approach (Koch 1994, Carolan 2003) to guide the entire research process.

This was a 5-year study conducted in Scotland in two acute hospitals and two hospices. A pilot study involving 10 participants was conducted before the main study. Data were collected over an 18-month period, 1996–1997 via in-depth interviews (phase 1), with a second repertory grid interview seven to 14 days after the in-depth interview (phase 2). The nurse data were collected before the patient data. All patients and nurses completed the first interview, but 13 patients were unable to complete the repertory grid interview because of deteriorating health ($n = 6$), refusal ($n = 1$) or death ($n = 6$). Only phase 1 data are reported here (Johnston 2002).

Participants

Convenience samples of 22 Registered Nurses (RNs) and 22 patients participated in the study (Table 1). As there were two hospices and two hospitals participating in the study, it was thought that 22 in each sample would ensure a reasonable number of participants from each site, would allow general and specialist palliative care to be represented, and allow for some sample attrition.

The patient eligibility criteria were

- being cared for in one of the four study sites;
- a diagnosis of a life-threatening illness e.g. cancer, motor neurone disease, multiple sclerosis;
- life expectancy of not >2 years but not <2 weeks;
- awareness of their diagnosis;
- ability to communicate in English verbally.

The criteria for nurse eligibility were

- Registered Nurse;
- postregistration experience of at least 2 years;
- postregistration qualification in palliative care.

All potential nurse participants ($n = 22$) approached about study involvement agreed to participate, as did all patients ($n = 22$) in phase 1. Participants were given at least 24 hours to reflect on participation before written informed consent was obtained. First, nurses were briefed on the study, informed consent was obtained and an in-depth interview held. At the end of the interview, each nurse was asked to identify a patient who met the study eligibility criteria. The nurse then approached that patient about potential study involvement. If the patient agreed, the nurse introduced the researcher (JB) to the patient. The researcher then described the study and obtained written consent. Some patients appeared to the researcher to be too ill to be interviewed, yet they still insisted on taking part.

Interviews

All interviews were held in a quiet room in the study sites at a date and time of the participants' choosing. Nurse interviews lasted 25–45 minutes while patient interviews lasted 45–90 minutes. All interviews were audio-taped with permission.

A reflective field journal was kept to provide an audit trail (Koch 1994).

Patient interviews focused on informants' experience of their care. The style of questioning maintained a focus on 'experience' in keeping with phenomenology, the principal tenet of which is that the ideal interview occurs when the interviewer's short, descriptive questions or clarifying statements provide an opening for informants' detailed descriptions. Each interview began with an open question such as, 'Can you take me back to the beginning of your illness and tell me what happened?' (Table 2) This was then followed up with general probes such as, 'Tell me more about that'. The nurse interviews were approached in a similar way, although the opening question was different. Specifically, nurses were asked to describe their understanding of effective palliative care, and to say how well they met their own criteria for an expert nurse in palliative care.

Ethical considerations

Ethics approval was gained before the pilot study. As the dying experience was the subject of the study, and given the sensitivity of the topic, it was thought that many ethical issues would arise, such as researcher bias, tape-recording, confidentiality, giving informed consent and 'gate-keeping'. All participants gave written and verbal consent to study participation which was re-validated before each interview. Assurances of confidentiality and anonymity were given. Although an experienced palliative care nurse, the researcher undertook a 10-week course in interviewing in order to increase data collection rigour.

Data analysis

All tapes were transcribed and checked for accuracy. Themes and categories emerged from the interview and journal data through an interpretive, reflective process using Colaizzi (1978) framework and in conjunction with Miles and Huberman's (1994) content analysis process. Guba and Lincoln's (1988) criteria of credibility, fittingness, auditability and confirmability were used to establish

Table 1 Description of sample

	Number of palliative care beds	Number of palliative care nurses (whole time equivalents)	Number of participating patients	Number of participating nurses
Hospice A	18	27	7	7
Hospice C	14	20	4	4
Hospital B	80	45	6	6
Hospital D	59	30	5	5

Table 2 Interview prompts

Patients	
	Can you take me back to the beginning of your illness and tell me what happened?
	Can you tell me about an incident that has happened to you, as far as your care was concerned, that you felt was particularly good for whatever reason?
	What was particularly significant about this incident?
	Can you now think of the opposite of that, an incident which you feel demonstrated ineffective care, for whatever reason?
	What was particularly significant about this incident?
	Can you describe to me the sort of person that you feel is a good nurse in palliative care?
Nurses	
	Can you start by telling me what you think effective or good palliative care is?
	Can you think of an event where you were directly involved which you feel epitomized effective palliative care?
	What was particularly significant about this incident?
	Can you now think of the opposite of that, an incident where you were directly involved, which you feel demonstrated ineffective palliative care for whatever reason?
	What was particularly significant about this incident?
	Can you describe to me the sort of person that you feel is a good palliative care nurse?
	How do you think you meet your description of a 'good nurse' in palliative care?

rigour and reflexivity guided the entire process (Koch 1994).

Findings

Eight themes and 29 categories were generated by patient and nurse interviews (Tables 3 and 4). For the data quotes below, the numbers are patient identifiers and the letter is the code for the location of the interview.

Connecting

'Connecting' was the key theme for patients. It illustrated the patients' views of palliative nursing, the importance of interpersonal skills and the value of the nurse-patient relationship in the context of the expert palliative care nurse. 'Connecting' was the central theme from which all other

theme categories emanated. Without good communication skills and an effective nurse-patient relationship, the other components of effective palliative care and characteristics of an expert palliative care nurse could not occur.

The major theme of 'connecting' comprised four categories: 'someone to talk to'; 'willing to listen'; 'getting to know me'; and 'avoiding me'.

'Someone to talk to' was, for the majority of patients, an essential component of their care and was characteristic of the expert palliative nurse. A good palliative care nurse was:

One that can sit down and talk to you, hold your hand and give you a wee bit of confidence...Someone like that cancer nurse who spoke to me in the hospital. I mean she was really good – but that is her job I suppose. (31/B)

Table 3 Themes and categories patients

Themes	Categories
Connecting	Someone to talk to
	Willing to listen
	Getting to know me
	Avoiding me
Being in control	Maintaining my independence
Meeting my needs	Fighting spirit
	Not helping me
Hospice as family	Providing comfort
	Being there for me
	Making me feel relaxed
	Feeling safe/secure

Table 4 Themes and categories nurses

Connecting	Willing to listen
	Facilitating communication
	Providing information
	Barriers to communication
	Building rapport
	Spending time with patients
Providing comfort	Supporting the patient and family
	Keeping patients comfortable
Working together	Controlling pain and symptoms
	Teamwork
Knows what they are doing	Acting as a go-between for the patient
	Professional knows best
	Learning about palliative care
	Professional experience
	Personal experience

'Willing to listen' was also central to how patients viewed the expert palliative nurse. When asked what makes an expert nurse, one replied:

Oh, a listener, a listener and somebody who will listen to you and doesn't talk. You want to talk to somebody and you don't want to have to listen to them. (2/A)

Nurses also saw effective listening as a core element of the expert nurse role:

I think a good nurse in the hospice is a nurse who listens more than anything else. She listens with perceptive ears and with thinking and with her mind. She's not just hearing words, she's hearing emotions. She's hearing the things that are not being said. (8/A)

'Getting to know me' involved nurses not just listening but also 'knowing' patients as described here by a patient:

Everybody gets to know you and they know your illness and they know how to treat you and take an interest in you personally. I just feel if I am coming here at least I know that they know what's wrong with me. If I take ill during the night, they know what to do here. (19/B)

'Avoiding me' occurred when communication was ineffective and a connection between nurse and patient failed to happen:

Well I was in hospital a fortnight after the tests and all that and I was informed it was terminal. I was just lying in the bed there. The other patients were getting seen to and I was not. There was nobody who came up to me. (44/C)

An aspect of interpersonal communication identified by nurses, but not patients, was providing information and facilitating communication:

We want to encourage open communication so nobody feels that you are hiding something from them. If patients have got specific questions you need the right information for them. (10/A)

Being in control

This theme illustrated the emphasis patients placed on being in control as a mechanism for maintaining their independence and therefore their quality of life, despite the fact they were dying. It was composed of two categories: 'maintaining my independence' and 'fighting spirit'.

'Maintaining my independence' was important. As a patient with spinal cord compression who died 4 days after this interview said:

I was in control totally up until maybe a week or two ago. Last week it seems that I was completely out of the game for three days or so.

But apart from that, I am now very weak but I am still in control... (43/C)

'Fighting spirit' was one way that some patients coped with terminal illness:

You see my wife has had fifteen years of cancer too. We are fighting cancer because, well it has to be because it's the only way to beat cancer. Cancer will not be done just sitting in a chair. You've got to be a patient who moves – keeps moving. (11/A)

Meeting my needs

This theme captured how patients wished palliative care nurses would care for them. It comprised five categories: not helping me; knowing about my illness; providing comfort; being there for me; and supporting me.

'Not helping me' could involve ineffective care:

I was in Ward X, a year past January. I was very bad with asthma. Anyway, I lay there for three days without a wash, without getting my nightie changed. She [ward nurse] had me crying...I could not even feed myself. I could not hold a glass in my hand. Nobody came in to give me a hand, nobody helped me. (19/B)

'Providing comfort' arose out of patients' descriptions of a good nurse:

The nurses at the hospice just generally make you feel that although there may be loads of other people, they are just dealing with you. They pay attention to every single wee detail. They just generally just seem to care beyond caring really. (40/C)

Nurses spoke passionately about the importance of providing comfort to patients. For instance:

There's one thing that epitomises effective palliative care for me. There is so much technology around now but at the end of the day it's the right kind of pillow or the right kind of bed that really counts. It's the small things when you're in hospital that really bug you, that you remember, that you get out of all perspective. (5/A)

'Being there for me' emanated from the importance the patients attached to the presence of the nurse, particularly when they were feeling low or upset. Several patients described how nurses spending time with them and even anticipating their needs made them feel comforted and supported:

I was alone of course after I had been told my diagnosis and it is not a very nice thing to be told that you have maybe months left to live. I was very touched that afterwards one of the nurses came and sat by me. (14/B)

The nurses were also concerned with this notion of 'being there'. Most believed that spending time with patients was central to building rapport, to supporting patients emotionally and to being an expert palliative nurse:

You need to put time aside so that patients get a chance to air any problems that they have no matter how rushed you are. Sometimes they're frightened to say anything because they see you're busy. (25/D)

The issue of symptom control was mentioned only by the nurses:

The patient's pain was very badly managed. It wasn't badly managed from the point of view that we weren't trying, we did try. We had actually asked advice...she actually died in agony. I felt, we all felt, we had failed her in some way. (28/D)

On the other hand, good symptom management was to be striven for:

There is one patient I remember in particular, she had cancer of her liver and was really quite poor when she was brought into hospital. She wanted to go back home again and we didn't think it was going to be possible. However, we got all her symptoms under control and we managed to get her home for a couple of weeks to achieve what she wanted. (25/B)

Nurses believed in the importance of effective teamwork in palliative care. Most felt when professionals worked as a team, the patient benefited:

To have effective palliative care, you need a team of people who believe in palliative care. I always think that that's quite difficult in the hospital setting that I work in. Sometimes I would say that patients are treated aggressively when really they should be palliative. I think if you've got a team who believe in palliative care then it makes all the difference. (24/D)

Hospice as family

'Hospice as family' was the fourth theme. It encapsulated the importance hospice patients attributed to the atmosphere, safety and sanctuary of the hospice environment. The patients were of the opinion that the hospice was very different from the hospital where they had been inpatients. This theme was formed from the following categories: 'making me feel relaxed' and 'feeling safe and secure'.

'Making me feel relaxed' referred to how much more informal and friendly the hospice was

This hospice here it helps to relax the patient. That is a big thing in itself – happy and relaxed and comfortable. I felt it immediately when I came in the door. (11/A)

'Feeling safe and secure' was the influence of the hospice felt by all the hospice patients regarding their well-being. While acknowledging that a major hospice role is that of sanctuary, nevertheless, for this patient group, the hospice meant more than sanctuary. The hospice was seen as a place of comfort, of security and of hope:

When I went into the hospice for the first time, it was so very restful, so comfortable and lovely to be in without being too ill. I felt really safe there. I had a rest and I felt so much better... (35/B)

Nurses referred to professional development and the need for personal and professional experience in order to work in palliative care:

I think a good nurse in palliative care is one that always strives to become well educated because the more knowledge they have, the more they can formulate ideas and opinions. (4/A)

Another reported:

I think it helps if you have had personal experience yourself. I've had a lot of personal death myself...I know it's different for everyone but I think I've got insight into what it's like to lose someone that you love so I can empathise with people and have some understanding into what people are going through. (24/D)

Discussion

Study limitations

Although the data were collected 10 years ago, no studies have been published since then that have explored the same specific questions. These patients' and nurses' views thus remain valid for them and relevant to palliative care nursing more generally. The possibility of researcher bias through the use of leading questions is acknowledged, but self-reflection, academic and personal supervision and sharing ideas and concerns with colleagues and at peer-reviewed conferences were used to understand and minimize that impact.

Multiple interviews might have enhanced rigour but, given the patients' fragile states of health, conducting additional interviews was likely to have proved unrealistic. The bias inherent in nurse selection of patients could have been lessened if patients had been approached first and had nominated their nurses, but this would have introduced other methodological issues.

It was difficult to separate perceptions of hospital and hospice patients as most patients had experienced both. Therefore, both experiences were referred to in interviews. This was not something foreseen, and it would have been

What is already known about this topic

- Palliative nursing involves a supportive and caring role.
- Communication skills are an important component of the palliative care nursing role.
- Expertise in nursing is about more than experience and qualifications.

What this paper adds

- Expertise in palliative care nursing was defined by patients and nurses as having relationships with patients, involving effective communication skills, providing comfort and knowledge.
- Psychological aspects of care, particularly interpersonal communication, are more important than physical aspects of palliative nursing.
- Dying patients can, and wish to, participate in research.

easier to differentiate if more patients with non-malignant disease had been recruited.

Discussion of findings

The patients perceived that expert palliative nursing care consisted of effective interpersonal skills and caring skills, and that the nurse should meet their needs by helping them, 'being there' for them, providing them with emotional support, being someone to talk to, providing comfort and, most importantly, spending time with them. The importance of these skills in nursing is not new (Wilkinson 1991, Booth *et al.* 1996, Heaven & Maguire 1996). Nurses are sometimes given the chance to explain their actions and give their views (Wilkinson 1991), but patients are rarely given this opportunity. Only Bailey and Wilkinson's (1998) study actually asked patients for their views on nurse-patient interaction. Yet, implicit in the studies of nurses' skills is the notion that patients want to tell nurses their concerns and will do so provided the nurse encourages, and does not block, them.

Effective communication is a particularly important issue in palliative care. Patients are likely to require a practitioner who can sensitively assess their needs and provide appropriate support when it is required. Hence, although this finding is not unique, it has a particular meaningfulness for palliative nursing care.

The nurses considered that palliative nursing care required a cohesive multi-disciplinary team to function effectively. This finding is endorsed by the UK palliative care literature (Doyle *et al.* 2005), although rarely identified in research.

Nurses also attributed importance to having knowledge and personal and professional experience. There is much debate on the link between expertise and experience (see English 1993, Darbyshire 1994, Cash 1995, Macleod 1996, Paley 1996). As far as the nurses in this study were concerned, they are inextricably linked.

Nurses in the study also proposed that nurses could not provide effective care without providing comfort, requiring the ability to relieve pain and control distressing symptoms. Although this is an assumed component of good nursing in palliative care (Webber 1993), there is a little evidence to support the importance of knowledge related to pain and symptom control. Indeed, no studies were found relating to how nurses perceive this aspect of their role.

Differences in the way patients and nurses perceived expert palliative nursing care were identified in the interviews. Patients discussed the need to maintain their independence, as well as adopting a fighting spirit as a way of coping with their terminal illness. This finding is novel: issues of dependency and maintaining independence in palliative patients have rarely been investigated. However, Seale and Addington-Hall (1994) suggested that patients who are in the last year of life fear dependency more than pain, potentially causing patients to request euthanasia, and Flanagan and Holmes (1999) considered that a person with a life-threatening illness must be able to engage in self-care activities. Their ability to do this is determined by symptom burden, illness trajectory and the desire to engage in self-care.

In addition, those who had been hospice patients identified the importance that the hospice, as opposed to the hospital, had in their lives as a place of sanctuary and in making them feel safe and secure. Somewhat surprisingly, given that the original function of a hospice was as a place of rest for travellers (Saunders 1999), there is very a little literature to endorse these points (McDonnell 1989, Seale & Kelly 1997). McDonnell (1989) found that the hospice enabled the patients to be 'peaceful', 'calm' and 'comfortable' and patients commented on the 'relaxed atmosphere' of the hospice. Seale and Kelly (1997) also found that the hospice was much more likely to be viewed as being more 'like a family' than the hospital.

The lived experience of a palliative patient is different from the experience of a qualified nurse caring for that patient. The patient lives their experience without respite, and with all the fears that a person with a poor prognosis faces. Patients come with their unique perceptions and are probably less likely to have a firm view of what their journey will be like. Nurses should be able to see the totality of the experience, may have definitive views on what good quality of life and good death look like, and are influenced by professional education and

experience. The differing perspectives are, therefore, important for palliative nursing practice and endorse the need to practise from a more patient-centred perspective.

Overall our findings demonstrate that important characteristics for expert palliative nurses are

- interpersonal skills;
- willingness to listen;
- being someone the patient feels able to talk to;
- demonstrating interest in knowing patients as people;
- recognizing that some patients may need to feel in control even when it would appear that their state of health does not allow for this.

Conclusion

This study was original in that it explored palliative nursing from the perspective of patients and nurses working in both hospices and hospitals. Rarely have palliative care patients been asked about their opinions of their care and never before about their perceptions of an 'expert palliative care nurse'.

The findings suggest that interpersonal skills training should be mandatory for nurses who work in palliative care, either as part of a postgraduate programme in palliative care or as stand-alone courses for those who already have a specialist practice qualification. In addition, education about pain and symptom control should be matched with emphasis on the psychosocial aspects of palliative care and the critical role of effective communication and caring characteristics. Future research should be carried out to observe whether expert nurses actually practise in the way they and palliative patients say they should.

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Author contributions

BJ and LS were responsible for the study conception and design and drafting of the manuscript. BJ performed the data collection and data analysis and provided administrative support. LS made critical revisions to the paper. LS supervised the study.

References

Abu-Saad H.H. (2000) Palliative care: an international view. *Patient Education and Counselling* **41**, 15–22.

- Arblaster G., Brooks D., Hudson R. & Petty R. (1990) Terminally ill patients' expectations of nurses. *The Australian Journal of Advanced Nursing* **7**, 34–43.
- Bailey K. & Wilkinson S. (1998) Patients' views on nurses' communication skills: a pilot study. *International Journal of Palliative Nursing* **4**, 300–305.
- Benner P. (1984) *From Novice to Expert*. Addison Wesley Publishing Co., Menlo Park, CA.
- Benner P. (ed.) (1994) *Interpretive Phenomenology Embodiment Caring and Ethics in Health and Illness*. Sage Publications, Thousand Oaks, CA.
- Booth K., Maguire P.M., Butterworth T. & Hillier V.F. (1996) Perceived professional support and the use of blocking behaviours by hospice nurses. *Journal of Advanced Nursing* **24**, 522–527.
- Bruera E. & Sweeney C. (2002) Palliative care models: international perspective. *Journal of Palliative Medicine* **5**, 319–327.
- Carolan M. (2003) Reflexivity: a personal journey through data collection. *Nurse Researcher* **10**, 7–14.
- Cartwright A. & Seale C. (1990) *The Natural History of a Survey*. Kings Fund Publishing Office, London.
- Cash K. (1995) Benner and expertise in nursing: a critique. *International Journal of Nursing Studies* **32**, 527–534.
- Colaizzi P.F. (1978) Psychological research as the phenomenologist views it. In *Existential Phenomenological Alternatives for Psychology* (Valle R. & King M., eds), Oxford University Press, Oxford, pp. 48–71.
- Crotty M. (1996) *Phenomenology and Nursing Research*. Churchill Livingstone, Melbourne, Australia.
- Darbyshire P. (1994) Skilled expert practice: is it 'all in the mind'? a response to English's critique of Benner's novice to expert model. *Journal of Advanced Nursing* **19**, 755–761.
- Davies B. & O'Berle K. (1990) Dimensions of the supportive role of the nurse in palliative care. *Oncology Nurses Forum* **17**, 87–94.
- Degner L.F., Gow C.M. & Thompson L.A. (1991) Critical nursing behaviours in care for the dying. *Cancer Nursing* **14**, 246–253.
- Department of Health (2000) *The NHS Cancer Plan*. Retrieved from <http://www.dh.gov.uk/assetRoot/04/01/45/13/04014513.pdf> on 24 April 2006.
- Doyle D., Hanks G., Cherny N. & Calman K. (eds) (2005) *Oxford Textbook of Palliative Medicine*, 3rd edn. Oxford Medical Publications, Oxford.
- English I. (1993) Intuition as a function of the expert nurse: a critique of Benner's novice to expert model. *Journal of Advanced Nursing* **18**, 387–393.
- Flanagan J. & Holmes S. (1999) Facing the issue of dependence: some implications from the literature for the hospice and hospice nurses. *Journal of Advanced Nursing* **29**, 592–599.
- Guba E.G. & Lincoln Y.S. (1988) *Effective Evaluation: Improving the Usefulness of Evaluation Results Through Responsive and Naturalistic Approaches*. Jossey-Bass Publishers, San Francisco, CA.
- Gullickson C. (1993) My death nearing its future: a Heideggerian hermeneutical analysis of the lived experience of persons with chronic illness. *Journal of Advanced Nursing* **18**, 1386–1392.
- Halldórsdóttir S. & Hamrin E. (1996) Experiencing existential changes: the lived experience of having cancer. *Cancer Nursing* **19**, 29–36.
- Heaven C.M. & Maguire P. (1996) Training hospice nurses to elicit patient concerns. *Journal of Advanced Nursing* **23**, 280–286.

- Hunt M. (1992) Scripts for dying at home—displayed in nurses' patients' and relatives' talk. *Journal of Advanced Nursing* 17, 1297–1302.
- Ingleton C. & Davies S. (2004) Research and scholarship in palliative care nursing. In *Palliative Care Nursing: Principles and Evidence for Practice* (Payne S., Seymour J. & Ingleton C., eds), Open University Press, Maidenhead, pp. 676–696.
- Johnston B. (1999) Overview of nursing developments in palliative care. In *Palliative Care: The Nurses Role* (Lugton J. & Kindlen M., eds), Churchill Livingstone, Edinburgh, pp. 2–30.
- Johnston B. (2002) Perceptions of Palliative Nursing. Unpublished PhD thesis, University of Glasgow, Glasgow.
- Kellehear A. (1990) *Dying of Cancer: The Final Year of Life*. Harwood Academic Publishers, Berkshire.
- Koch T. (1994) Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing* 19, 976–986.
- Koch T. (1999) Phenomenology revisited an interpretative research process: revisiting phenomenological and hermeneutical approaches. *Nurse Researcher* 6, 20–34.
- Larkin P. (1998) The lived experience of Irish palliative care nurses. *International Journal of Palliative Nursing* 4, 120–126.
- Macleod M. (1996) *Practising Nursing – Becoming Experienced*. Churchill Livingstone, New York.
- McClement S.E. & Degner L.F. (1995) Expert nursing behaviours in the care of the dying adult in the intensive care unit. *Heart and Lung Journal of Critical Care* 24, 408–419.
- McDonnell M.M. (1989) Patients' perceptions of their care at Our Lady's Hospice Dublin. *Palliative Medicine* 3, 47–53.
- McNamara B., Waddell C. & Colvin M. (1994) The institutionalisation of the good death. *Social Science and Medicine* 39, 1501–1508.
- Miles M.B. & Huberman A.M. (1994) *Qualitative Data Analysis an Expanded Sourcebook*, 2nd edn. Sage Publications, Thousand Oaks, CA.
- National Cancer Research Initiative (2004) *NCRI Supportive and Palliative Care Research in the UK*. Retrieved from http://www.ncri.org.uk/documents/publications/reportdocs/NCRI_supportive_and_palliative_report_web.pdf on 5 January 2005.
- NHS Quality Improvement Scotland (NHSQIS) (2002) *Specialist Palliative Care*. Retrieved from <http://www.nhshealthquality.org/nhsqis/files/SPC.pdf> on 25 November 2006.
- Paley J. (1996) Intuition and expertise: comments on the Benner debate. *Journal of Advanced Nursing* 23, 665–671.
- Payne S.A., Langley-Evans A. & Hillier R. (1996) Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. *Palliative Medicine* 10, 307–312.
- Rasmussen B.H. & Sandmann P.O. (1998) How patients spend their time in a hospice and in an oncological unit. *Journal of Advanced Nursing* 28, 818–828.
- Raudonis B.M. (1993) The meaning and impact of empathic relationships in hospice nursing. *Cancer Nursing* 16, 304–309.
- Saunders C. (1999) Foreword. In *Oxford Textbook of Palliative Medicine*, 2nd edn (Doyle D., Hanks G.W.C. & Macdonald N., eds), Oxford Medical Publications, Oxford, pp. v–viii.
- Scottish Executive (2001) *Cancer in Scotland: Action for Change*. Retrieved from <http://www.scotland.gov.uk/library3/health/csac-00.asp> on 25 November 2006.
- Seale C. & Addington-Hall J. (1994) Euthanasia: why people want to die earlier. *Social Science and Medicine* 39, 647–654.
- Seale C. & Kelly M. (1997) A comparison of hospice and hospital care for people who die: views of the surviving spouse. *Palliative Medicine* 11, 93–100.
- Seymour J. (2004) What's in a name? In *Palliative Care Nursing: Principles and Evidence for Practice* (Payne S., Seymour J. & Ingleton C., eds), Open University Press, Maidenhead, pp. 55–74.
- Steeves R., Cohen M.Z. & Wise C.T. (1994) An analysis of critical incidents describing the essence of oncology nursing. *Oncology Nursing Forum* 21(Suppl. 8), 19–25.
- Stephen D.L. (1991/1992) A discussion of Avery Weisman's Notion of appropriate death. *Omega* 24, 301–308.
- Webber J. (1993) *The evolving role of the Macmillan Nurse*. Cancer Relief Macmillan Fund (unpublished), London.
- Wilkes L.M. (1993) Nurses descriptions of death scenes. *Journal of Cancer Care* 2, 11–16.
- Wilkes L. (1998) Palliative care nursing research: trends from 1987–1996. *International Journal of Palliative Nursing* 4, 128–134.
- Wilkinson S. (1991) Factors which influence how nurses communicate with cancer patients. *Journal of Advanced Nursing* 16, 677–688.
- World Health Organization (2003) *WHO Definition of Palliative Care*. Retrieved from <http://www.who.int/cancer/palliative/definition/en/> on 25 November 2006.
- Zerwekh J.V. (1995) A family caregiving model for hospice nursing. *Hospice Journal-Physical Psychosocial and Pastoral Care of the Dying* 10, 27–44.

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