

# End of life care: a discursive analysis of specialist palliative care nursing

Julie K. Skilbeck MMedSci BEd RN

Lecturer in Nursing, School of Nursing and Midwifery, University of Sheffield, Sheffield, UK

Sheila Payne BA PhD RN DipN CPsychol

Professor in Palliative Care, Palliative and End-of-Life Care Research Group, University of Sheffield, Sheffield, UK

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Correspondence:

Julie K. Skilbeck,  
School of Nursing and Midwifery,  
University of Sheffield,  
Manvers Campus,  
Sheffield S63 7ER,  
UK.  
E-mail: j.k.skilbeck@sheffield.ac.uk

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## End of life care: a discursive analysis of specialist palliative care nursing

**Aim.** The aim of this paper is to consider alternative approaches to service delivery for patients with chronic life-limiting illnesses other than cancer. It will also discuss the issues that arise when considering specialist palliative care services within a broader public health context in the United Kingdom.

**Background.** Contemporary specialist palliative care in the United Kingdom can be said to have two main client groups: the majority are people with a diagnosis of cancer, and a minority are those with a number of other chronic illnesses. From the evidence to date, patients dying from chronic, non-malignant disease experience a considerable number of unmet needs in terms of symptom control and psychosocial support. Although debates in the literature over the last decade have challenged the focus of specialist palliative care services on patients with a cancer diagnosis, only a minority of those with other chronic illnesses receive specialist palliative care services.

**Discussion.** Current models of specialist palliative care may not be the most appropriate for addressing the complex problems experienced by the many patients with a non-cancer diagnosis. We suggest that care should be structured around patient problems, viewing specialist palliative care as a service for those with complex end of life symptoms or problems. A role for innovative nurse-led care is proposed.

**Conclusion.** Reframing the approach to specialist palliative care in the United Kingdom will require great effort on the part of all health and social care professionals, not least nurses. Critical and creative thinking are prerequisites to the development of new models of working. We suggest that a more coherent approach to research and education is required, in particular strategies that explore how patients and nurses can work together in exploring experiences of illness in order to develop more proactive approaches to care.

**Keywords:** chronic illness, end of life care, nurse-led care, public health, specialist palliative care

## Introduction

Current estimates indicate that the world total number of people who may need palliative and end of life care each year could be about 300 million, or 3% of the world's population

(Singer & Bowman 2002). Thus, because of the large number of people involved, concerns about quality of care at the end of life are becoming a global public health issue (Foley 2003). In this paper, we will argue that current approaches to specialist palliative care services, mainly adopted from cancer

services, are not the most appropriate for addressing the complex problems experienced by the many patients with life-limiting illnesses. Indeed, the assumption that models of care developed for cancer patients are transferable to all patients, irrespective of diagnosis, is in our view deeply problematic.

In very broad terms, contemporary specialist palliative care in the United Kingdom (UK) can be said to have two main client groups: the majority are people with a diagnosis of cancer, and a minority are those with a number of other chronic illnesses. This second group is generally referred to in the palliative care literature as 'non-cancer', a term which in our view displays the emphasis in specialist palliative care services on cancer. Currently, nurses play a crucial role in the care of dying patients with chronic illnesses, whether that is in inpatient or community settings and irrespective of diagnosis. Changing patterns in the management of chronic illness mean that the number of older people is increasing, and so this role is likely to increase in the future; however, how the role is to be enacted requires careful consideration.

Debates within the UK literature over the last decade have challenged the focus of specialist palliative care services on patients with a cancer diagnosis (Field & Addington-Hall 1999, Addington-Hall & Higginson 2001). In turn, policies have driven the expansion/extension of specialist palliative care services to all patients with chronic and life-threatening illnesses (Addington-Hall *et al.* 1998a). In reality, this does not appear to be happening and in 2000–2002, 95% of patients receiving specialist palliative care had a cancer diagnosis (Hospice Information Service at St Christopher's Hospice 2002). Similarly, in a major evaluative study of specialist palliative care nursing services only 4% of new referrals were for patients with a diagnosis other than cancer (Skilbeck *et al.* 2002).

We acknowledge that the literature we discuss in this paper draws predominantly on evidence from the UK, but consider them to be relevant to nurses working with patients at the end of life in other industrialized countries, as many countries look to the UK as pioneers of modern specialist palliative care. Also, the paper is concerned with care for adults because specialist palliative care services for children are already predominantly concerned with those experiencing conditions other than cancer.

## Historical background

Historically in the UK specialist palliative care services have focussed virtually exclusively on the terminal care of patients with a diagnosis of cancer (James & Field 1992). This was perhaps for the very good reason that it was important to

start somewhere, and Cicely Saunders, who was the founder of the modern hospice movement in the UK in the 1960s, was predominantly concerned with the adequate control of cancer pain (Clark 2001). The subsequent decades have seen a shift from 'terminal care' to 'palliative care', based on a more comprehensive philosophy of care for individuals who have reached a point where curative care is no longer an option (Bliss *et al.* 2000). Subsequent developments have sought to extend the range of services in terms of both types and timing of interventions during the illness trajectory; for example, to include cancer patients at an earlier stage of the illness (Ahmedzai 1996). Changes in medical technology have also increased the range of interventions that may be offered (Clark & Seymour 1999, Doyle 2001), blurring the boundaries between curative and palliative treatment. More recently, 'supportive care' has been introduced as a framework for services that may be required to support people with cancer and their carers, of which palliative care is a component [National Institute for Clinical Excellence (NICE) 2004], thus adding to the conceptual confusion.

## Key concepts in palliative care

The key concepts that currently underpin palliative care services are shown in Table 1. Changing patterns in the management of chronic illness mean that people are now living longer. This will inevitably lead to an increase in the proportion of older people in the community, and these people will die from a range of diseases and will experience co-morbidities (Seymour *et al.* 2001a, 2001b).

Although the evidence is limited, there is a growing body of literature to suggest that patients with chronic illnesses other than cancer experience many symptoms and problems as they approach the end of life. For example, Skilbeck *et al.* (1997) identified that patients living with end-stage chronic obstructive pulmonary disease (COPD) report a high level of symptoms. As expected, the most distressing and debilitating was extreme breathlessness, experienced by 95% of these patients. The extent of other symptoms, such as pain, fatigue, difficulty in sleeping and thirst, was considerable. Patients also described reduced physical functioning, psychological morbidity and a low level of social functioning. Overall, they perceived their quality of life to be poor, and there was a positive relationship between poor quality of life and decrease in social life and low mood. Patients with dementia were the focus of an audit by Lloyd-Williams (1996), the aim of which was to determine the most prevalent symptoms in terminal dementia. The main symptoms experienced were pain and breathlessness. Similar findings have been reported in studies of patients with heart

**Table 1** Key concepts in palliative care*Terminal care*

Terminal care is concerned with 'the last few days or weeks or months of life from a point at which it becomes clear that the patient is in a progressive state of decline' [National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) 1995]

*Palliative care*

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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 2002a)

*General palliative care*

General palliative care is identified as 'palliative care provided by the patient and family's usual professional carers as a vital and integral part of their routine clinical practice. It is informed by knowledge and practice of palliative care principles'. It is 'provided for patients and their families with low to moderate complexity of palliative care need, whatever the illness or its stage, in all care settings' (NCHSPCS 2001, p. 3–4)

*Specialist palliative care*

Specialist palliative care is defined as 'palliative care provided by health and social care professionals who specialise in palliative care and work within a multi-professional specialist palliative care team. The service should be available in all care settings for patients with moderate to high complexity of need' (NCHSPCS 2001, p. 3–4)

*Supportive care*

Supportive care 'helps the patient and their family to cope with the illness and treatment of it – from prediagnosis, through the process of diagnosis and treatment to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment' (NCHSPCS 2004)

disease (McCarthy *et al.* 1996, Anderson *et al.* 2001, Horne & Payne 2004), stroke (Addington-Hall *et al.* 1997), motor neurone disease (Barby & Leigh 1995), and kidney failure (Cohen *et al.* 1995).

Where comparisons have been made between patients with a cancer diagnosis and other diagnoses, similarities in end of life experiences have been identified, and patients at the end of life have physical and psychosocial needs at least as severe as those with cancer (Skilbeck *et al.* 1998, Edmonds *et al.* 2001). Thus, there has been growing acknowledgement that the principles of palliative care may benefit patients with other life-limiting illnesses. This has been reflected in British policy documents, which state that irrespective of diagnosis all patients who require palliative care should have access to this service (Addington-Hall 1998b). The development of ethical arguments further supports the rights of all patients to access palliative care services if and when they require them,

providing a moral framework against which to examine current service provision (Wasson 2000, Seymour & Skilbeck 2002).

## Current service provision

In reality, current service provision in the UK for patients with life-limiting illness does not always appear appropriate to the problems identified. Those with advanced chronic disease are likely to receive increasingly fragmented care as they near the end of life, with minimal symptom control, and to access palliative care services in the terminal phase of the illness, if at all (Stuart 2003). Several studies have identified inadequate symptom control when compared with current accepted palliative care practice (Lloyd-Williams 1996, Skilbeck *et al.* 1997). Other studies have identified inadequacies in service configuration, with an emphasis on managing acute exacerbations of the condition. This results in patients experiencing high levels of symptoms most of the time, in the context of a fragmented service with gaps in community care (Skilbeck *et al.* 1998, Horne & Payne 2004). It is known that patients with chronic illnesses other than cancer are much more likely to die in hospital, and that access to specialist palliative care services and professionals is often minimal (Edmonds *et al.* 2001). In a recent study of clinical nurse specialists (CNSs) only 4% of new referrals were of patients with a diagnosis other than cancer (Skilbeck *et al.* 2002). It could be argued that this small number is not unexpected, taking into account that the focus of these particular clinical nurse specialists [also known as Macmillan Nurses (MNs) because they are funded by the Macmillan charitable organization in the UK] focus on improving care for people with cancer and their families (Webber 1997). Some of the nurses in this study, however, were working as members of a specialist palliative care team and it could be argued that this is too narrow a focus, given that in recent years the drive has been to extend palliative care to all patients irrespective of diagnosis (Addington-Hall 1998b). Similarly, referrals to specialist palliative care units and teams, hospices and home care services still appear to be dominated by patients with cancer (Cassel & Vladek 1996, Eve *et al.* 1997, Maddocks 1998). Furthermore, it is well-documented that equity of access for some socio-economic groups is poor. Examples include those from black and other minority ethnic groups (Koffman & Higginson 2001); older people (Seymour *et al.* 2001a, 2001b); residents in nursing homes (Froggatt 2001); and socially excluded groups, such as homeless people (Rousseau 1998).

From the limited evidence to date, patients dying from chronic, non-malignant illnesses experience a considerable

amount of unmet need in terms of symptom control and psychosocial support. That their palliative care needs require assessment to determine the services to be offered is now the current thinking for these patients. However, on the whole, current UK service provision does not appear to be meeting the identified needs. Certainly these patients are not generally accessing specialist palliative services, and the extent to which they receive general palliative care and supportive care services requires further exploration.

### **Extending service provision: what are the considerations?**

Based on current palliative care thinking, it is envisaged that for many patients the 'palliative care approach' would be sufficient to meet the identified needs (Addington-Hall & Higginson 2001). This approach would acknowledge the existing knowledge and expertise of nurses working in the field, and allow palliative care specialists to develop collaborative and supportive relationships within which the principles of palliative care are communicated and practised by those responsible for care giving. For those patients who need specialist palliative care, service configuration appears to be considered in the following ways (Addington-Hall & Higginson 2001). In some instances, patients with complex needs may require specialist palliative inpatient care where responsibility for care is assumed by a specialist palliative care team. For others, care could be based on the current UK model of supplementing and complementing existing services. Rather than taking over patient care, this would probably involve referral to a hospital or community multidisciplinary palliative care team, or specialist nursing service, such as those provided by MNs in the UK.

On the face of it, extending specialist palliative care services to patients with other chronic illnesses would appear to be straight forward. In the first instance, there is some evidence that professionals working within palliative care are addressing the needs of patients with non-cancer diagnoses and, second, there is a willingness on the part of other health care professionals to refer to specialist palliative care teams (Dharmasena & Forbes 2001).

On further analysis, however, this seems not to be the case. As we have highlighted, referrals of patients with non-cancer life-limiting conditions are not made, and there is limited evidence that specialist palliative care professionals support health and social care professionals in the care of patients dying with chronic and life-threatening illness, as well as taking on the patients' care themselves. Field and Addington-Hall (1999) have argued that there appears to be a general assumption that the knowledge and skills developed in the

field of cancer care are transferable, thus allowing specialist palliative care teams to manage care for patients with other diagnoses in different care settings. However, they go on to suggest that this is not necessarily the case. For example, there are elements of symptom control where even in 'expert' hands management is difficult, such as breathlessness (Ahmedzai 2001) and fatigue (Porock 1999). Furthermore, these patients are already receiving care from health and social care professionals with specialist knowledge and skills in their particular field (Addington-Hall & Higginson 2001). Indeed, there are now many CNSs managing care for a wide range of client groups, for example respiratory, cardiac and renal specialist nurses. Negotiating boundaries of care is of paramount importance, so as to avoid role confusion; in particular 'handing over' care to specialist palliative care teams, with the outcome that nurses already involved in a patient's care lose the opportunity to develop the skills required in managing problems for other patients at the end of their lives (Mytton & Adams 2003). The process of dying is in itself complex, and all nurses need to develop the knowledge and skills to be able to provide appropriate care and support at this time to patients and their families. In addressing complex problems, current thinking in the UK is that a system of shared care and responsibility may be a means of addressing the lack of disease-specific expertise within specialist palliative care teams (Dharmasena & Forbes 2001). How this is to be achieved requires further exploration.

It is also recognized that making decisions about which patients with chronic conditions require specialist palliative care is problematic (Field & Addington-Hall 1999). In the first instance, consideration must be given to the patient's illness trajectory and the appropriateness of palliative care interventions at any given time point. The reality is that for many patients curative interventions may continue to be appropriate. However, other approaches to care might be more suitable for others, for example, in the field of respiratory care broad-based pulmonary rehabilitation programmes are well-established (Morgan & Singh 1997). The difficulties experienced in predicting prognosis and life expectancy compound the situation (Christakis 1999). Thus, 'defining' the terminal phase of an illness is difficult, and may partly explain why patients with chronic conditions are not referred to specialist palliative care services because they are not considered suitable for these until they are thought to be in the 'terminal' phase. Also, they and their doctors may not recognize that they are 'dying' until very near the end, for example, in heart failure. It may, therefore, be difficult to know when to opt for palliative care. This becomes even more problematic for older people, who more often than not

experience a number of co-morbidities towards the end of life.

## New directions

Despite acknowledgement that patients with chronic life-limiting illness other than cancer experience high levels of distressing symptoms and require information about end of life care and the choices open to them, in reality access to palliative care services has been minimal.

As we have shown, there have been accumulating challenges to the notion that access to services should be merely on the basis of a primary diagnosis. We argue that this has arisen because of the dominance of medical classifications in the health care services. Currently, what seems to be happening in the UK is that the focus is being directed away from cancer, rightly in our view, but as a consequence other diagnostic labels are taking its place. In reality, the grouping of patients into these categories defined by medical specialties (e.g. oncology, dermatology, nephrology) may make little sense to patients themselves, especially older patients who frequently experience multiple pathology (Seymour *et al.* 2001a, 2001b). Moreover, these diagnostic labels may serve to disrupt care, as for example, a patient with breast cancer, diabetes and osteoarthritis may have to attend a number of different clinics, with different health care personnel, possibly at different hospitals, on different days. Over time, any one of these chronic conditions could be regarded as the 'primary' diagnosis. Yet there is evidence that nurses are heavily influenced by medical diagnostic labels and regard them as essential to delivering care (Payne *et al.* 2000).

In our view, diagnostic classification has become the dominant discourse, which in turn has framed the approach to service delivery. The extension/expansion debate, which has been a strong element in the drive for change, now appears to be preventing more radical approaches to patient care. Instead, we argue that a public health approach may offer different insights. It is now being acknowledged that palliative and end of life care share the characteristics of a public health priority: high burden, major impact, and potential for relieving the suffering associated with illness (Singer & Bowman 2002, Foley 2003). In developing its strategy for public health, the World Health Organization (WHO) has identified palliative care as one of the six major components of a chronic disease model of care (WHO 2002b). Rao *et al.* (2002) suggest that end of life care is a public health issue for a number of reasons. First, a large number of people are affected. Second, the end of life is associated with suffering for both patient and family, and thus the potential for improving quality of life is great.

Finally, on a societal level there are huge financial implications of chronic disease that have an impact on families and communities. Conceptualizing palliative and end of life care as a public health issues may offer a more appropriate framework for services for patients with end of life needs.

## Practical implementation

For patients currently requiring specialist palliative care services, we argue that care could be structured around the complexity and disruptiveness of patient problems, viewing specialist palliative care as a service for those with complex end of life symptoms or problems. It is not necessarily the aetiology of symptoms such as fatigue and breathlessness that should determine the application of clinical nursing interventions. Instead, access could be controlled by, for example, assessment of symptom severity or complexity rather than through diagnostic label. There is some evidence that in many inpatient specialist palliative care units the trend is for increased admissions for acute symptom control followed by discharge home, and for the management of particular types of difficult dying (Lawton 1998). We acknowledge that symptoms are at the heart of bio-medicine, where disease is often understood as facets of a biological state and disease symptoms (Krishnasamy *et al.* 2001); however, illness is only partly defined as a purely physiological response (Pellegrino 1982), and past service configurations have failed to address the impact that distressing symptoms have on patients' daily lives (Corner *et al.* 1995). We would argue that, although patients use the language of symptoms and problems, they do not simply focus on disease status. Rather, they attach personal meanings to their illness experiences and their problems. When individual meanings are not considered, there is a danger that care becomes directed at the problem, rather than the person experiencing the problem, and this is de-personalizing for them (Murphy 1990). Until patients are able to discuss their experiences of illness in shared language, using symptoms and problems remains a starting point for initiating discussions with them. Further exploration is needed of ways in which patients and health care professionals could work collaboratively to explore patients' experiences of illness at the end of life and how these could be communicated.

However, this means that some patients with cancer who are currently eligible to receive specialist palliative care might not be able to access the services if they do not have complex problems and symptoms requiring specialist care provision. This might prove unpopular with the general public and cancer charities. Similarly, certain types of patients and families, such as those requiring respite care, those with

prolonged dying trajectories and those without carers, could be disadvantaged by changes that redefined specialist palliative care services so that they only addressed complex symptoms or problems rather than particular diagnoses.

We suggest that there may be a role for innovative nurse-led care to meet these demands. Nurse-led care can be loosely described as encompassing roles at the interface between nursing and medicine (Griffiths 2002). Nurse-led clinics are one interpretation of this. Nurses working in this area of advanced practice are enabled to undertake holistic patient assessment, monitor treatment programmes, co-ordinate the care pathway, provide consistency of contact with other health and social care professionals and facilitate communication (Loftus & Weston 2001). In such clinics, there is also a real opportunity to work with patients and their families, in particular to understand the nature and impact of the problem from the perspective of the person experiencing it, so that effective therapy can be provided (Corner *et al.* 1995). There is a general consensus that nurse-led clinics have positive outcomes on many facets of care, for example, symptom assessment and management (Corner & O'Driscoll 1999). In fact, research evidence indicates that patients are often more satisfied with nurses carrying out procedures that are usually the domain of doctors (Steiner *et al.* 2001, Miles *et al.* 2003). Referrals could be made to such clinics according to patients' symptom severity or complexity. A role for nurse-led inpatient units (NLIU) is more problematic as currently there is conflicting evidence as to their effectiveness. Initial evaluative work in the UK supported the hypothesis that 'therapeutic nursing', delivered in a nurse-led unit, had a positive effect on patient outcomes compared with medically managed acute care (Pearson 1992, Griffiths & Evans 1995). However, later evaluations, also in the UK, have been unable to identify such an impact on patient outcomes (Griffiths *et al.* 2001, Steiner *et al.* 2001). In reality, most of this work has focused on patients requiring 'intermediate care', defined as 'a lack of need for acute medicine/surgical intervention or monitoring (Griffiths 2002, p. 2). Considering that, for many patients requiring end of life care, their trajectory is punctuated by acute episodes, how this could be enacted in practice needs further investigation. What seems clear is the need for effective multiprofessional working in NLUs; thus, the clinical leader requires not only clinical knowledge and skills, but also team leadership qualities in terms of recognized authority and management skills. Finally, we suggest there could be scope to extend the CNS role to one of leading patient care. A study of Macmillan nurses highlighted that a key component of their clinical work was 'behind the scenes work', in which brokering services provided by others was key. In fact, the majority of patient care seemed to be pursued

through liaison activities with others (Skilbeck & Seymour 2002). These approaches are alternative ways of conceptualizing the roles of specialist palliative care nurses and they challenge medical hegemony.

Nurses have expertise which they can contribute to patient care, but there also needs to be recognition that patients and their families have their own 'lived' experience of chronic illness and skills in self-management. New models of working with patients and families as 'experts' in managing their chronic diseases are starting to emerge in the field of gerontology (Nolan *et al.* 1996, Costain Schou & Hewison 1997, Department of Health 2001). These regard patients and carers as 'experts' in their own care, suggesting that care should be negotiated between health and social care providers and their clients. Negotiated care involves supporting patients to negotiate the requirements of a therapeutic regime in their personal situation (Sloan 1999). Nurses could be in a pivotal position to facilitate this, performing an 'in-between' role (Bishop & Scudder 1990, p. 171) and mediating between the professional management of care and the experiences and expectations of patients for their own care at the end of life.

### Palliative care and prevention

Little attention has been paid previously to palliative care as a method of prevention. Foley (2003) suggests that there is a need for a public health research initiative in palliative care to develop the evidence base of its role in prevention, particularly in relation to self-management programmes. Health promotion, one element of a broader approach to public health, may have a role to play. In reality, terminally ill patients are a group consistently omitted from the health promotion discourse. Promotion of health appears to follow the older, mechanistic notions of health as the absence of illness, rather than the now widely-accepted idea of health as a situation in which a sense of well-being is maximized. Seriously ill people can and should have periods of positive well-being and these should be enhanced (Kellehear 1999), but the question of how this could be achieved is not yet resolved.

In the first instance, attention needs to be paid to promoting palliative care as part of broader public health developments (Kellehear 1999). This would involve actively seeking to dispel the idea that death and dying are not important unless the patient has a cancer diagnosis. Kickbush (1989) suggests that what death might mean to people at different times and places in their lives needs to be explored, as it can have great implications on what may be expected from health and from health promotion. A key to health promotion in end of life care is developing a better

understanding of preferences for such care and enhancing public understanding of care options. However, many previous initiatives to improve end of life care have focused on the communication skills and knowledge of health care professionals rather than those of potential care recipients (Seymour *et al.* 2002a). In a recent study, Seymour *et al.* (2001a, 2001b) identified that older people drawn from community groups were keen to participate in discussions about the application of 'life prolonging' and 'comfort care' technologies during serious illness management and impending death. The older people who participated valued the opportunity to discuss these sensitive issues with their peers, and reported that the discussions were useful as a way to introduce end of life care issues. As a result of that study a model of peer education has been developed. Peer education, in which trained volunteers teach their peers in a relaxed atmosphere, is a potentially valuable means of assisting people to discuss and learn about health-related issues (Buonocore & Sussman-Skalka 2002). It appears to be most successful where it is linked to an area of interest within a community group. This approach could be undertaken with many self-interest groups, for example, older people, young people with life-limiting illness and carer groups.

Another challenge in relation to health promotion would be to explore the perceptions and understandings of death and dying of people currently experiencing life-limiting illness, particularly in relation to their own illness trajectory. In the United States of America (USA), advance care planning protocols implemented in the community with patients with life-limiting conditions, and their families, have been associated with improved palliative care outcomes (Schwartz *et al.* 2003). In particular, they had the potential to help people plan for their end of life care and assist in preventing 'unplanned' and 'crisis' admissions to hospital during the last year of life (Farber *et al.* 2003, Fried & Bradley 2003). It might be argued that people would not want to talk about these issues, and that there is a danger that clinical actions that are linked to an advance care plan may be akin to euthanasia. Seymour *et al.* (2001a, 2001b) identified that it is important to build a trusting relationship between clinicians and patients in order to create an environment in which discussions necessary to underpin advance care planning can take place. In the context of nurse-led care, it is possible to envisage situations in which nurses in general and specialist palliative care settings would be able to work with patients in opening up discussions about end of life care, and facilitate communication across the health and social care team.

Extending palliative care beyond merely those with cancer will require great effort on the part of all health and social care professionals involved, not least of all nurses. First, good

working relationships and communication networks with clinicians with existing expertise in the care of these patients need to be established. This will facilitate the development and application of collaborative care strategies that acknowledge the strengths and limits of existing knowledge and skills of both teams, as well as exploring how knowledge developed in the field of cancer can be useful to other patient groups.

In terms of education, alternative approaches to conceptualizing specialist palliative care need to be developed, in particular the relevance of a public health perspective. This, in turn, necessitates the development of specific expertise in applying specialist palliative care to patients with all life-limiting and chronic illnesses. The level of palliative care knowledge of nurses and others working with these patients needs to be addressed in pre- and postregistration education. Moreover, advanced nursing practice skills courses in palliative care should not just be about end of life care for those with cancer. In particular, educational approaches are needed that explore the conceptual confusion that appears to have developed about the nursing care of dying patients in general hospitals, which in turn limits more proactive approaches (Holmes *et al.* 1997). This particularly relates to how nurses perceive a 'dying' patient in a hospital context, and how interventions are subsequently planned to provide comfort, protection and the taking over of tasks. Whilst these are acknowledged to be important components of care, there is the potential to exclude interventions which may enable the patient to live a full life and meet limited goals.

There is still a role for clinical nurse specialists in palliative care in terms of offering education about their specialist work for both hospital and community professional carers. Specific areas include postbasic skills development, as well as more considered assessment of what may be considered to be complex problems. Developing the knowledge of health and social care professionals might then facilitate appropriate referrals to specialist teams. However, the resources, organizational structure and managerial support with which to develop the educational role of CNSs need to be addressed (Seymour *et al.* 2002b).

Further, little attention has been given to the effectiveness of specialist palliative care nursing interventions for different patients in different care contexts. More research is needed on what models of care work best in what conditions, for whom and under what circumstances (Bosanquet & Salisbury 1999), and in particular for older people. Interventions that explore how patients interpret their illness experiences and the resulting issues, in particular the emotional experiences, need to be developed. The work of Krishnasamy *et al.* (2001) is a good example of how the totality of the problem of breathlessness as perceived by patients was used to develop a

### What is already known about this topic

- Patients with chronic illnesses other than cancer are likely to benefit from specialist palliative care services.
- There is an assumption that models of specialist palliative care developed for cancer patients are suitable for other patient groups.

### What this paper adds

- Care should be structured around patient problems, viewing specialist palliative care as a service for those with complex end of life symptoms or problems.
- Models of nurse-led care could offer alternative ways in which to conceptualize the delivery of specialist palliative care and challenge biomedical hegemony.
- A public health approach to care could facilitate wider discussions about palliative and end of life care.

non-pharmacological, nurse-led intervention in primary lung cancer. Positive outcomes of this intervention were improvements in breathlessness, performance status, and physical and emotional states relative to control patients.

Finally, it is also important to obtain the views of patients and their families to ensure that services are responsive and acceptable to differing cultural, social and age groups. Prospective, longitudinal and collaborative work is needed to map illness trajectories and determine obstacles to access and uptake of services.

### Conclusion

In this paper, we have discussed some of the issues faced when contemplating specialist palliative care for patients dying from chronic illnesses other than cancer. We have suggested that current approaches to specialist palliative care services, mainly adopted from cancer services, are not best placed to address the complex problems experienced by the many patients with life-limiting illness. We argue that conceptualizing specialist palliative care within a public health framework could offer alternative approaches to delivery. Insight to the many challenges that are faced has been given, so that nurses working in both general and specialist palliative care are aware of the many hurdles they face in finding creative solutions to the issues raised. These need to be engaged in collaboratively with other health and social care professionals, be evidence-based and cost-effective, and recognize the 'expertise' and wishes of patients and their families.

### Author contributions

JS and SP were involved in the study conception and design, drafting of manuscript and performed critical revisions of the paper. JS provided administrative support.

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