Nursing management in palliative care

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Nurses, have from the very beginning, played a key role in the delivery of palliative care. In all settings of care; home, hospital, or hospice/specialist palliative care unit, nurses lead or participate in the care of patients with far-advanced illness. Two levels of specialist nurses exist, the first are nurses who have undergone post-qualification training in palliative care and who work in a variety of settings using skills gained from this. The second is a distinct role, that of 'the nurse specialist'.

The role of 'the nurse specialist' in palliative care developed in the UK from the early 1980's, and was designed to make expert palliative care more widely available. The goal for specialist nurses was to pass on good practice in the control of symptoms such as pain, and to increase the proportion of patients realising the wish to die at home. Since these early beginnings there has been a rapid expansion in the number of nurse specialists and in specialist palliative care services. For example, in the UK there are now some 2000 specialist nurses funded by the charity Macmillan Cancer Relief, and the government has made funding available to establish nurse specialists for patients with the most common cancers such as lung, breast and colorectal cancer.

The rapid expansion of nurse specialists in the UK has been excellent in allowing the provision of high quality services. Roles have largely been developed according to local needs and priorities, and in a somewhat ad hoc manner; there are, as a result, problems of role confusion, role overlap between similar posts, and the need for education, training and research into best practice. There is also a need for evidence from the range of existing service models about the particular contribution of nurses and evidence about outcomes for patients.

My intention here is not to review all the literature pertinent to the role of nurses in palliative care, rather, to selectively explore how nurses' input into patient management. Both levels of palliative care nursing are discussed, at times interchangeably and at other times I will refer more specifically to the work of 'the nurse specialist'. Nursing management in palliative care is explored under 2 themes:

1. The work of palliative care nurses.
2. The concept of nursing therapy and the contribution of nursing to the management of difficult symptoms.

The work of nurses in palliative care

Care of patients with far advanced illness such as cancer, and dealing with death and dying is an inescapable part of nurses' work in all settings. The degree to which nurses have skills in palliative and terminal care varies, as does nurses' confidence in dealing with issues such as talking openly about illness and dying, or in symptom management. Managing issues around death and dying is one of the most frequently cited sources of stress and difficulty for nurses and doctors in both acute and community settings. Recognition of the difficulties in caring for people who are dying led to the establishment of specialist palliative care nurses.

Palliative care as a speciality has evolved rapidly over the last 40 years. There are now an array of services and facilities that exist across the range of health care settings:

- specialist in-patient facilities,
- services in acute hospitals,
- services to support people in their own homes,
- intermediate care, such as day and respite care.

The two levels of specialist nursing can be observed in all of these settings, most nurses who work in specialist palliative care facilities have undertaken post qualification training. There also exist in all these settings more advanced and independent 'specialist nurses'. 'The nurse specialist' is an expert clinician who works with a caseload of patients and their families, offering consultancy over the management of a patients' problems, educating and supporting other staff involved in care of patients with advanced disease, and conducting research, or more importantly, implementing the findings from research. Often specialist nurses work solely with patients who have cancer since palliative care originated through the hospice movement which has primarily focused on meeting the needs of patients with cancer. Many now work with patients dying from a variety of conditions since there has been growing awareness of patients other than cancer patients, who otherwise may not have access to specialist palliative care [1].

Specialist nurses frequently work as members of interdisciplinary teams. However, many 'nurse specialist' services are nurse-led or comprise a team of nurses who do not have other health professionals as part of the team. Since palliative care avows interdisciplinary working as a core principle, there is debate as to whether care offered by a single discipline is ideal.

The question as to whether nurses offer a unique role within palliative care has been raised. In particular, this has focused on whether the skills needed to offer expert care and support to patients with advanced cancer and other illnesses, are ubiquitous and transferable between professionals. There is a growing community of academic nurses who are interested in such questions, and who are committed to developing the role of nurses in palliative care and through this contribute knowledge for the speciality as a whole. Understanding the particular contribution of nurses in the increasingly interdisciplinary field of palliative care, and where leadership roles are often assumed to be for the doctors, is important.

What is clear is that although in palliative care health professionals increasingly work as part of interdisciplinary teams, the roles of individual health professionals, while blurring somewhat at the edges of practice, have a distinct orientation. For example, for nurses, their work seems to be characterised by a deep interest in personal and interpersonal aspects of care for people who are dying, and although clearly this is not exclusive to nurses, working with emotional aspects of facing death has become a prominent part of the specialist nurses' work. This is not to say that specialist nurses have become 'counsellors', 'psychiatrists' or 'psychologists' in this setting, it is a question of orientation — what is prioritised in their work, and how this may differ from priorities set by other health professionals. In general, nurses have focused less on the treatment of patients' symptoms than have medical colleagues, or at least this seems to be an important, but less prominent aspect of their work.

Studies of nurses in palliative care reveal 5 core functions that seem to represent their work. These are shown in Fig. 1.

For example, drawing on the accounts of a palliative care nurse's work with 10 patients, Davies and Oberle [2] describe the work as having 6 dimensions:

1. 'Valuing' the person who is dying,
2. 'connecting or getting in touch' with the patient and family members, that are entering their experience,
3. 'empowering or enabling' the patient and family to do tasks for themselves that help meet their own or other's needs,

1. Providing emotional or interpersonal support - assistance with adjusting to knowledge of life limiting illness and its implications for the person who is ill and for family members.
2. Giving practical assistance with everyday tasks and roles, this may involve direct assistance with these or finding individuals or agencies that may assist.
3. Co-ordinating the range of health and social services, which may be needed by the person who is ill.
4. Facilitating packages of care, assessing when there is a need for a change in these as the illness progresses, and intervening where necessary to orchestrate change.
5. Leading symptom management – offering expertise to other health professionals, making initial and ongoing assessment of problems, co-ordinating optimal management.

Fig. 1. Core functions of specialist palliative care nurses.

4. 'doing things for' the patient such as controlling pain and symptoms, making arrangements or lending a hand with care when the family are having difficulty coping,
5. 'finding meaning' by focusing on living and acknowledging death and by helping patients and families to come to terms with dying,
6. 'preserving his/her own integrity' as a nurse by reflecting on one's work and self and acknowledging one's own reactions to patients'.

The dimensions identified by Davies and Oberle are powerfully directed at the emotional experience of dying, and the practical concerns of patients and carers.

More recent work by myself and a group of researchers from the Centre for Cancer and Palliative Care Studies at the Institute of Cancer Research in London, the Sheffield Palliative Care Studies Group and the London School of Hygiene and Tropical Medicine is a recently completed cost–outcome evaluation of UK Macmillan nursing services. The findings from this work, published elsewhere [3], reflect the orientation of specialist palliative care nurses. The study was undertaken in 12 services in Trent (in the north of England) and Thames (London and the south). Forty-four palliative care nurses were involved in the study. Services studied were in both the acute hospital setting and in the community, and were located in a mixture of urban and rural settings. The research team studied in detail the services offered by the nurses including all work undertaken with patients and families referred to the services over a period of 8 weeks (814 patient referrals were studied in total). Seventy-six patients referred to the services were followed intensively and were studied over a period of 28 days.

The most common reason for referral to a Macmillan specialist palliative care nurse was for emotional care either for patients or for a family caregiver. These accounted for almost two thirds of all referrals. Other reasons for referral included physical symptoms, emotional care for carers, advice and information, discharge planning, assessment for hospice admissions, practical help and physical care, although the latter represented less than 1% of cases. On average, each nurse was receiving just under 3 referrals each week, their work involved assessing the needs of these new referrals and developing packages of care for them, while also having a continuing input into the care of patients who are part of their existing caseload. The fact that referrals to specialist nurses reflect the orientation towards emotional care, suggests both a substantial need for this kind of care, but also that nurses are successfully imparting their work and skills to other health professionals in the areas such as symptom managers, thereby securing appropriate use of themselves as a resource.

By tracing the date of death of all patients referred to Macmillan nursing services, we observed that one third of patients died within 6 weeks of referral, one third died within 200 days, and one third were still alive beyond this time. These data indicate the range of needs that specialist palliative care nurses are addressing. Their work involves much care of patients in the last days and weeks of life, but also involves care and support of people who may have life-threatening illness, but who may not be dying imminently.

A large proportion of Macmillan specialist palliative care nurses work involves direct, face to face contact with patients; 89% of patients received face to face contact following referral, and the number of contacts made with the patient ranged from 0 to 13 over the course of care depending on the complexity of the case. These interactions were most commonly for emotional care or to give information, but they were also for interventions for physical symptoms, to give emotional care to a carer, and occasionally to give physical care. Around face to face contact there were many other interactions undertaken by nurses in relation to patient cases, for example interactions took place over the phone with the family caregiver or with other health professionals to organise care. Much patient management by specialist nurses was observed to go on 'behind the scenes' through offering advice and co-ordinating care packages and services. Sometimes this work is unknown to patients since this is not experienced by them directly.

Through an analysis of the experiences of care for the 76 patients and family members who were followed longitudinally, and from the specialist nurses' records, the work of nurses is revealed further. In particular, episodes of care were examined to discover where this had an impact that could be observed to be of benefit to the person who was ill, in particular, where this was recognised and valued by the person themselves, or by their family member who was the primary caregiver.

Aspects of care where there appeared to have been positive outcomes, revealed domains of specialist nurses' work that appear to be of benefit to patients. The Macmillan specialist nurses' *approach to care* was valued by patients and stood out from care by other health professionals, they seemed to have an effect on patients' sense of well-being. The *presence* of a specialist palliative care nurse especially at critical moments during patients' illness, for example, when difficult news about cancer was being given, was helpful. Specialist nurses were valued for helping to clarify issues or assisting patients to take decisions about their treatment or care. The nurse's presence in care was valued and was felt as therapeutic. He/she was someone who patients and carers felt they could 'bare their soul to', and was a supportive presence during times of difficulty or crisis. The specialist palliative care nurse was valued for *giving practical help*, for example, with social or financial matters.

Leading symptom relief was an important part of the role. Many instances were observed where symptoms were improved as a result of the actions of the nurse. While not responsible for symptom relief, nurses guided the actions of others, for example, ward nurses or doctors' prescriptions. Often this role was critical to the outcome of care since the specialist nurse could be seen to give advice or intervened in circumstances where other health professionals, such as general practitioners, had insufficient experience or knowledge of the problems of advanced cancer. A key role was *giving ongoing support to patients and carers*. The specialist nurse was often central in *managing complex cases* where there were multiple physical and psychological problems for the patient or complex family dynamics or conflict. Here the nurse worked to orchestrate the involvement of multiple agencies or worked to resolve family conflict. Finally, specialist palliative care nurses were used a *resource by other health professionals*.

Our study reflects earlier work by Cox et al. [4] who evaluated the work of specialist nurses using the critical incident technique. Patients were asked, during interviews, to describe positive and negative experiences of care by specialist palliative care nurses. Using this approach, a number of themes in relation to positive aspects of the role of nurse specialists in palliative care were identified. The most commonly cited aspects were: nurses' specialist knowledge of terminal cancer care, nurses' role in providing psychological and emotional care for patients and carers, and nurses' skills in liaison and knowledge of available services.

The orientation of nursing in palliative care towards emotional and practical support is an important one. The role of nurses has grown out of work undertaken from the 1960's highlighting the need to create a more open climate for people who are dying so that they may acknowledge and adjust to what is happening to them. Doctors have shifted from a policy of 'withholding' to a policy of 'revealing' to patients his or her terminal prognosis [5]. With this change, and since they have close and often sustained contact with patients, nurses have taken on an important role in both maintaining, and working with this new climate of openness. Nurses as a result have adopted the task of supporting people living with the repercussions of knowledge of life-limiting illness. However, this work is difficult and has consequences for nurses who may find it stressful, and also it may have consequences for the environment of care created through nurses' work and interrelations with people who are dying.

Copp [6] studied the experience of 12 patients dying in a hospice and the nurses caring for them, using interviews. From the accounts of patients and nurses she noted that nursing in this context was a 'fine balancing act'. Nurses' relationship with patients was characterised by a continual 'encountering' of how facing death was handled by the dying person, and was therefore not just a matter of 'what the patient had been told' about their prognosis, nurses' actions were also dictated by the patients own reactions and behaviours. Nurses were seen to watch and wait for the person to respond to their predicament. They acted to protect and control patients' physical and emotional state this was a complex and difficult task since patients' responses fluctuated from both open acknowledgement of what was happening to them to denial of it. Nurses' relationship with the dying person was balancing the need to hold and support them or assist them to let go. The ways in which nurses found themselves relating to patients were all part of complex strategies and interplay acted out by both the dying person and nurse as the continual losses arising from the process of dying were faced and dealt with.

Other studies suggest that offering emotional support to people who are dying is difficult and nurses may themselves adopt strategies to avoid the emotional consequences of their work. Froggatt's [7] ethnographic account of nurses' work in a hospice suggests that nurses took on the role of supporting those 'venting' emotion, but also a role in containing it in case it became 'uncontrolled'. This is hard, draining work and nurses were observed to have developed distancing strategies to protect themselves from the emotional threats engendered by their work.

There is an emerging critique of the expectations of people who are dying and the nature of emotional care offered to them. One consequence of nurses adopting emotional care as a core activity is that it may add to the problem that nurses' work is undervalued, and that nurses as a result lack influence. James [8] has described the work of nurses in a hospice as 'emotional labour', a commodified form of women's work within the family, and as such, hidden, undervalued; subordinated as merely 'support work' beside the more highly valued activity of medical work.

Others reveal that a critical view of nurses in other aspects of care is needed. McNamara et al. [9], have identified that a routinised version of what constitutes 'good death' had become dominant in a hospice they studied, open acknowledgement and acceptance of death by the person who is dying, was expected in the interest of the hospice as an organisation. Those who did not conform could find themselves classified as being 'difficult'. Nurses were observed to be actively managing cases under this rigid view of what constitutes a 'good death', that is, one that conformed to the hospice 'ideal' and this may unknowingly have become an expectation of patients admitted to the hospice. This account accords with Seale's [10] description of the recent development of the social phenomenon 'heroic death', whereby in the context of palliative care, those people who are able to openly face and talk about their own death earn the right to 'accompaniment' by health professionals. This is a privilege not available to those who die suddenly or who suffer degenerative conditions such as senile dementia. It also accords with Lawton's [11] account of 'dirty dying' and the sequestration of difficult deaths into a hospice in which specialist care has unknowingly become a repository for 'socially unacceptable' dying and that within the hospice individuals who may have socially unacceptable problems such as foul smelling wounds or double incontinence, are avoided by nurses and other health professionals.

Thus, although the orientation of specialist nursing to emotional and supportive care is highly valued by patients, there is no room for complacency, nursing roles require continuing critical review.

The concept of nursing therapy and the contribution of nurses to the management of difficult symptoms

While a core function of nursing in palliative care is to offer emotional and practical support to people with life-limiting illness and to support family members and carers, leading and influencing symptom management is also an important activity. Symptom management, from a nursing viewpoint has a somewhat different orientation to that of medicine. Much of nurses' work in this area lies in influencing symptom management by others, for example by ensuring that acknowledged best practice in pain control is followed by general practitioners or medical colleagues working in acute hospital settings. Nurses are also beginning to undertake serious work of their own into the management of symptoms and this work is becoming influential across palliative care. Nurses, have not traditionally 'prescribed' treatment for symptoms, perhaps because of this they are interested in looking beyond traditional approaches such as pharmacological solutions to symptoms. Instead, nurses are interested in the problems and needs of people who have life-limiting illness, rather than the more narrowly disease focus that the term 'symptom' suggests [12]. Nurses are drawing on the concept of 'nursing therapy' for this work.

'Nursing as therapy' is a term used by MacMahon and Pearson [13] to describe a movement to reclaim nursing for nurses. They argue that the rise in medical knowledge and technology over the last century has led to the view that 'getting better' is largely dependent on intervention by doctors or paramedical therapists and that nurses simply carry out the orders of other professionals and attend to organisational matters. Nurses, it is suggested, have become analogous to flight attendants or cabin crew. Instead, they argue that "intelligent sensitive nursing does make a difference to consumers of health care".

MacMahon, using Meutzel's [14] model of the nurse-patient relationship, argues that partnership, intimacy and reciprocity are core elements of nursing practice. Nurses deliver therapeutic care by manipulating the environment, teaching, providing comfort, using physical interventions and complementary health practices. Other authors [15,16] add "reflection and evaluation of experience as an integral and ongoing process of practice and 'presence' in the psychotherapeutic sense of 'being there' and 'being with' clients". These elements of therapeutic work are clearly visible within the work of specialist palliative care nurses.

Parallel to the development of the concept of nursing therapy, is the debate around how palliative care is evolving, and how nurses are actively contributing to this. One concern has been criticism surrounding the process of medicalisation of palliative care.

Medicalisation is a term first used to describe the influence of medicine on society's relationship with death. Over time, the expert at the bedside of the dying person ceased to be the priest and became the doctor; as this occurred care of dying people transformed from that of assisting individuals to identify meaning in his or her plight, to one of treatment, and the preservation of life at all costs by whatever means at the doctor's disposal [17]. The technical revolution in health care has increasingly meant that such care has taken place in hospitals away from home and family. The hospice, and more recently palliative care, sought to provide an alternative to this, in particular facilitating a home rather than institutional death.

The accusation of 'medicalisation' has been levelled at palliative care itself. Biswas [18] and Field [19] have argued that hospice and palliative care have now themselves become medicalised with a shift in emphasis away from care of dying persons to the rather more euphemistic endeavours of symptom control and 'palliation'. These terms may have allowed the denial of eventual death to become 'built in' to specialist care. Criticism also surrounds the increasing use of technical and invasive procedures in care and that this orientation towards care predominates (for a full discussion of these issues see Corner and Dunlop [20]).

Nurses working in palliative care are subject to these influences and are caught up in creating trends such as medicalisation, as well as resisting and offering critique of them. The work of specialist palliative care nurses reflect the nurses' wider position in health care, their work is part of biomedical health care delivery, but is also at the margins of it. Nurses are subject to tensions and difficulties in valuing working with a person-centred approach, while also needing to attend to biomedical and technical aspects such as symptom control. It is by using the ideas about nursing therapy and the desire to move beyond the 'medicalising' trend and contribute alternative, but complementary, approaches to symptom management that has led to an evolving programme of research into nursing interventions for symptoms in advanced cancer.

Development has been focused on the management of difficult symptoms such as breathlessness, fatigue or weight/appetite loss. Strategies employed in managing these symptoms have traditionally taken a biomedical approach. That is to say the focus has been on pathophysiology, although this is poorly understood. These difficult problems have in palliative care been seen as irreversible and therefore not amenable to cause-directed treatment. Research, where it exists, into these symptoms has largely been focused on pharmacological treatments. Nurses in palliative care are developing different approaches, based on the notion of 'nursing therapy'. For example in the management of breathlessness in advanced lung cancer, the nursing approach has encompassed the following features:

- An integrative model of care, in which the emotional experience of breathlessness is considered inseparable from the sensory experience or pathophysiological mechanisms. The model is rehabilitative in orientation and care is directed at assisting individuals to manage the problem of breathlessness for themselves.
- Therapy using this model involves listening to the patient's story of their illness and how breathlessness is experienced as part of this. Fear and stress in relation to breathlessness is shared and hopefully the person experiencing breathlessness finds such emotions become more manageable. Key to this is realising that breathlessness is not in itself life-threatening.
- Intervention employs techniques derived from respiratory rehabilitation such as breathing re-training, energy conservation, life adaptation, and for breathlessness in the more advanced stages of illness, relaxation and distraction. Breathing re-training is offered by nurses, a relaxed, controlled form of breathing is taught, and ways of using breathing control during activities such as walking, climbing stairs or dressing. Learning to adapt one's life and activities to the problems imposed by breathlessness is a central part of intervention (Fig. 2) [21].

This therapeutic approach to symptom management for breathlessness has been evaluated in a series of studies (Fig. 3). Evidence is beginning to accumulate to suggest that it is valuable. The approach to managing breathlessness is being taken up by nurses and other professionals and is being adopted as part of established symptom management in palliative care.

Similar approaches are being developed and evaluated for fatigue in advanced cancer, and for weight loss. Krishnasamy [22], a nurse researcher, studied 15 patients from a palliative care unit reporting being fatigued, tired or exhausted as part of advanced cancer using in depth interviews and material collected from case notes. Carers and health professionals were also interviewed. There appeared to be little obvious direct association between fatigue and mood or emotions such as anxiety or with depression. Evidence from case notes suggested that fatigue is hidden from view, few descriptors of fatigue, or records of interventions offered for the problem were evident in case notes, despite the problem being severe and distressing to patients. It was a complex, fluctuating and multidimensional problem where few obvious solutions seemed to be available. The opportunity to talk about the experience of fatigue and for such conversations to be valued and attended to, in itself appeared to be valuable and suggest an avenue for nursing therapy. These are to be evaluated in future work.

A further area of investigation is weight loss and reduced food intake in the context of advanced cancer. Here work is at an early stage, a comprehensive

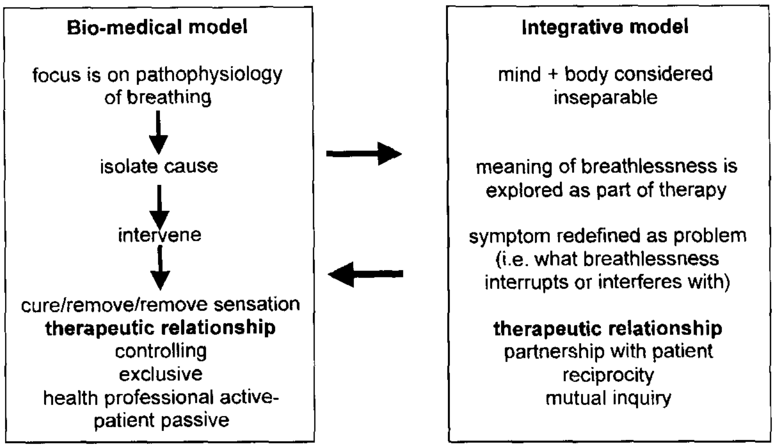

Fig. 2. Parallel models of breathlessness management.

Study 1	**Pilot study** Randomised controlled trial of nursing intervention in the context of a nursing clinic vs control Outcomes measured: - Breathlessness using visual analogue scale - Ability to perform activities of daily living - Functional ability - Anxiety and depression Detailed record of assessment, dialogue, intervention with patients n=34 randomised, 20 patients were evaluable (Corner et al. 1996)
Study 2	**Analysis of notes taken in clinic** (n=52) - The experience of breathlessnes (O'Driscoll et al. 1999)
Study 3	**Interview study of nurse research practitioners** - To elucidate the nature of therapeutic practice (Bailey 1995)
Study 4	**Multicentre replication study** - n=119 in 6 centres - outcomes study - detailed descriptive data of breathlessness in lung cancer - collaborative research model with Macmillan and Specialist nurses who were taught to use the approach to nursing intervention and helped to establish nursing clinics and work with the Macmillan Practice Development Unit to conduct the multicentre study (Bailey 1996, Bredin et al. 1999)
Study 5	**Interview study with participating nurse specialists** (Plant and Bredin, in press)
Study 6	**Development of assessment tool for clinical settings** (Corner and O'Driscoll 1999)
Study 7	**Dissemination study** establishment of resource and demonstration centres design and methods for this study, yet to be determined

Fig. 3. A programme of studies to develop new approaches to managing breathlessness in lung cancer.

review of literature on the subject again suggests there are few possibilities for reversing severe weight loss or food intake problems in advanced cancer, since these are inevitably a part of the dying process. However, little is known about problems with food intake or weight loss or how they are experienced by patients or carers, or what support might be needed to assist with them. Again a nursing approach to the problem is being developed and will start by seeking to develop understanding about how weight loss and problems with food intake are experienced. These experiences may offer ideas about strategies for support and more effective coping that nurses may offer more widely. This approach to developing therapeutic intervention contrasts directly with the biomedical approach since the view here would be that weight loss in advanced cancer is a physical manifestation of disease and should be managed as such.

Nursing in palliative care encompasses a wide range of activities and responsibilities. Through studies conducted in recent years it is possible to observe that nursing has evolved a distinct orientation. Nurses have prioritised emotional and supportive care within their work; this is highly valued by patients and families. Offering emotional support is also stressful and demanding, and as with the work of other health professionals is in danger of becoming routinised and defended if it is not adequately supported. Nurses are also developing their own research into the management of difficult symptoms and an emergent programme of research is visible. Work in progress established by nurses has a distinct and complementary orientation to medical research. It is hoped that this work may in future bring benefits to patients.

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