

Community Palliative Care

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The Role of the Clinical Nurse Specialist

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Introduction

Community palliative care clinical nurse specialists (commonly known as Macmillan nurses) play an important role in specialist palliative care (Skilbeck et al. 2002). They spend time with patients and their families, helping them come to terms with an array of complex emotional and practical problems, facilitating communication, giving information and advice about treatments and also offering expertise in controlling pain and other distressing symptoms. These nurses are equipped with specialist skills to assess the complex palliative care needs of patients referred to the service. However, Bliss et al. (2000) found that referral to services is dependent upon the individual who initiates it and, although unintentional, may result in a form of gate-keeping with patients and carers not receiving services relevant to their needs.

The author is presently employed as a community palliative care clinical nurse specialist and in a recent study, as part of an MSc degree, set out to identify the triggers that motivate district nurses to refer patients to the service. The topic selected for the study resulted from observation within the author's clinical practice, where it was noted that district nurse referral patterns to the specialist nursing service were very inconsistent. Some district nurses refer regularly to the service, whilst others rarely refer. This raised the possibility that factors other than 'patient need' influenced referrals. The study incorporated semi-structured interviews with district nurses and the results of the research revealed a very apparent lack of knowledge regarding the role of the community palliative care clinical nurse specialist. A subsequent literature review also indicated that other authors had identified similar observations (Clark et al. 2002; Ahmed et al. 2004). As a consequence, the author has been afforded a valuable opportunity to produce a written text for community nurses, other members of the primary health care team and professionals involved in palliative care, on the role of the community palliative care clinical nurse specialist.

Palliative care is the active, total care of patients and their families by a multidisciplinary team; at a time when the patient's disease is no longer responsive to curative treatment and life expectancy is relatively

short (Twycross 2003). The aim of palliative care is to provide support and care for patients and their families so that they can live as fully and comfortably as possible. Whilst many nursing texts discuss the challenges of palliative care in the home, few examine the role of the community palliative care clinical nurse specialist. This book hopes to provide its readers with a clear understanding of that role and the potential benefits that their knowledge and specialist skills can bring to the primary health care team.

The book is divided into three sections: professionals, patients and carers. The first section discusses the roles and contributions made by other members of the primary health care team, in particular, the pivotal role of the district nurse in caring for patients with palliative care needs. The text then examines the role of the community palliative care clinical nurse specialist. This role not only incorporates care to patients and their families, but also provides a source of professional support to other members of the primary health care team.

The psychosocial support needed by patients receiving palliative care is the subject of the second section. The text explores the community palliative care clinical nurse specialist's role in relation to complex psychological as well as practical problems surrounding a life-limiting illness. For example, the diverse issues involved in dealing with treatments, information needs, emotional demands and facing death will be explored. The use of case studies allows the reader a further insight into the complex needs of patients and their families. The role of the community palliative care clinical nurse specialist includes assessment of pain and symptom control. This is an important aspect of the role and involves liaising and negotiating with the primary care team to ensure optimum patient comfort. However, the text does not discuss symptom management, as there are many nursing and medical books on that subject, but instead concentrates on the complex support and information needs of seriously ill patients and their families. The text encompasses not only the patient's journey, but also that of the family during the illness trajectory and into the bereavement period.

The final section looks at the needs of the family and carers and the support that the community palliative care clinical nurse specialist can offer to these individuals. Included in this segment are the complex issues faced by carers in relation to the changing roles within the family, their children and impending death and bereavement. The assessment of the family is viewed as important to the management of the patient with palliative care needs (Payne et al. 2004); however, the core members of the primary health care team may struggle to fulfil family and carer needs due to time constraints and other demands from within

primary care. It is therefore essential to utilise the expertise of other members of the primary health care team. The community palliative care clinical nurse specialist is in a unique position to be able to offer support to the patient with complex needs, and his or her family, not only during the patient's illness, but also into the bereavement period.

According to Bestall et al. (2004) the decision to refer a patient to specialist palliative care services relies upon the knowledge and expertise of the professional that the patient consults. It is therefore imperative that community nurses and others within the primary health care team are aware of the role of the community palliative care clinical nurse specialist. This book will help to inform and educate, to provide a stimulating resource for all professionals and students interested in palliative care and subsequently to improve the care of patients and their families in the community setting.

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Section I

Professionals

Community Palliative Care: The Team



Introduction

The patient receiving palliative care at home may potentially be in contact with a wide variety of professionals and support services. This chapter explores the concept of palliative care and briefly examines the roles of health care professionals within the community setting. Particular attention is given to the pivotal work of the district nurse in caring for patients with palliative care needs at home. Specialist palliative care and its various functions within the community are introduced, highlighting the collaborative working between primary health care teams and the specialist services.

Palliative care

Palliative care is an important part of the every-day work of most health care professionals, whether they work in the hospital or community setting. The word 'palliative' originates from the Latin *pallium*, a cloak. In palliative care, symptoms are 'cloaked' with treatments whose primary aim is to promote comfort. The more modern definition in the Oxford mini-dictionary may prove easier to understand: *reducing bad effects*. But what is palliative care? The recognised World Health Organisation (1990) definition describes palliative care as '*the active total care of patients whose disease is not responsive to curative treatment*'. Palliative care is considered, in most definitions, to incorporate the physical, psychological, social and spiritual aspects of care and is orientated to patients who have a non-curative condition. Palliative care should not be confused

with terminal care, as many patients have palliative care needs from the time of their diagnosis and require ongoing palliative care for many months or years (Costello 2004). The aim of palliative care is to assist patients and their families through the physical and emotional traumas of life-threatening illness and to support them in that journey. Palliative care is not limited to cancer or even to the terminal stages of illness; it can last for years, and can be applied to any life-threatening disease, though it is most often associated with cancer. Palliative care is not an alternative to other care, but is a complementary and essential component of total patient care.

Developments in palliative care have been dramatic. Today, much of our understanding and knowledge of the subject has grown through the work of the hospice movement (Faull 1998). During the 1960s the first tentative steps were taken in the United Kingdom towards the growth of modern palliative care. The first hospice, incorporating research and teaching, was founded in 1967 by Cecily Saunders in London. The subsequent expansion of the hospice movement illustrated the value of 'care not cure'-focused institutions, with priority given to symptom control (Turton and Orr 1993). In due course, the 1980s saw the speciality of palliative medicine being formally recognised. This allowed for not only an improvement in care for patients with palliative needs, but also research into best practice and ongoing multidisciplinary education. Although modern hospices and 'palliative care' embody a relatively young concept, their effects have been enormous and as a result many patients have been enabled to maintain a good quality of life, to die peacefully, and to know that their families are supported after their deaths (Addington-Hall and Higginson 2001).

Since the beginning of the modern hospice movement, emphasis has been on care of the patient with cancer, but clinicians are realising that the principles of palliative care extend beyond malignant disease to the care of patients with diseases such as congestive cardiac failure, chronic obstructive pulmonary disease, stroke, motor neurone disease, etc. The illness trajectory for some non-malignant diseases may be many years and the patient and his/her family will require ongoing symptom control and support, comparable to the cancer patient. Therefore the provision of palliative care is now based on need and not diagnosis, ensuring that appropriate care is available to all and not just to cancer patients.

At the beginning of the 20th century, the majority of people died at home with the care being given by the family, but medicine has changed considerably over the last 100 years. Developments in medical science and new treatments moved the focus of care away from the patients' homes into the hospitals; correspondingly, the number of people dying

at home has fallen progressively. Figures reveal that the home death rate is now low (23% for patients with cancer, 19% for all deaths) and the hospital death rate is high (55% for patients with cancer, 66% of all deaths) (Thomas 2003). However, patients with cancer, for example, spend over 90% of their last year of life at home (Addington-Hall and McCarthy 1995) and irrespective of where a patient dies, the emphasis has to be on caring for that patient and family at home during the patient's illness. The main location of palliative care therefore remains in the community, under the direction of the primary health care team.

Community palliative care services

Caring for seriously ill patients within their own homes can prove difficult and challenging to the health professionals involved; especially when the illness is progressing and there are the added complexities of distressing symptoms, emotional issues to address and family members to support. However, given the choice and a supportive family, most patients would want to be nursed at home during their illness and to die at home (Palmer and Howarth 2005). The aim of palliative care in the home is to have a well-supported family and ensure the patient is comfortable and able to deal with his or her approaching death. The patient may require assistance to manage not only physical, psychological, social and spiritual needs, but also legal and financial issues that may have to be addressed (Abu-Saad and Courtens 2001). This requires the skills of many professionals working together as a team to achieve the desired outcome.

Multidisciplinary team working lies at the heart of palliative care and involves many individuals working together with a common goal. Functioning as a team, the professionals can provide continuous and integrated supportive care. Today's patients and their families have increasingly high expectations of the health care services and what professionals should offer. Therefore, when the needs of the patient and family require ongoing visits from a number of disciplines, optimal care is given when the health care providers collaborate as a coordinated team. As such, the palliative care team requires excellent communication skills, an understanding of each other's abilities and an acceptance of 'blurred' role boundaries. This approach will support most patients and their families with a sense of security, consistency and comfort (Ingham and Coyle 1997).

Providing support for the family is an important role for the team, as carer fatigue is often the main factor in the hospitalisation of patients

towards the end of their life. In order to sustain a patient at home, it is essential to consider the family carer as a member of the team, and consideration should be given to the carer's views and opinions, as well as to the patient. There is no 'typical' team in community palliative care; the composition is dependent on 'patient need' and the skills available to meet those needs. The patient receiving palliative care at home may potentially be in contact with a wide variety of professionals. For example, as well as the general practitioner and district nurse (who will be discussed later), the patient may need the services of the physiotherapist, occupational therapist, social services, dietician and Marie Curie nurses.

Physiotherapist

The role of the physiotherapist in palliative care is different from the therapist in a rehabilitation team; rather than attempting to improve function, the aim will be to maximise the patient's weakening resources, through problem solving and emotional support (Doyle et al. 1998). The community physiotherapist plays a significant role in the non-pharmacological relief of symptoms, improving patient mobility and as a specialist resource in the management of lymphoedema. The therapist may have contact with the patient in the home, at a symptom control clinic or in the day care setting. Physiotherapists have a particularly important part to play in managing the patient with breathlessness (Doyle and Jeffrey 2000); they can teach relaxation, breathing techniques and give assistance to those having difficulty expectorating. They also give advice to patients and their carers on lifting and transferring, or recommend appropriate walking aids to maximise mobility. As mentioned earlier, in many instances, they have specialist knowledge of the management of lymphoedema, which can be a debilitating and distressing condition. They can advise on massage or appropriate stockings or sleeves for limbs affected by lymphoedema and act as a resource for community nursing colleagues. In palliative care, physiotherapy includes the setting of achievable goals and aims to improve quality of life and encourage independence.

Occupational therapist

The role and contribution of community occupational therapists in palliative care is both varied and challenging. They play a vital role

in providing adaptive equipment for the home. They approach the patient's problems as they arise and assist in the provision of equipment as appropriate (Cooper 1998). This can enable patients receiving palliative care to not only maintain a safer environment, but also retain independence for as long as possible. The ability to carry out normal daily living activities is often the main objective for patients with a life-threatening illness (Kealey and McIntyre 2005); occupational therapists can assess patients to determine their abilities for independent living and provide equipment and adaptations as necessary. They can advise on the provision of aids such as rails, ramps, commodes and raised toilet seats. Giving practical advice and support to families and carers is also an important aspect of their role and can be invaluable in helping families to adjust to the ever-changing needs of the patient.

Social services

The aim of social work in palliative care is to help patients and their families with the social and personal problems of illness, disability and impending death (Doyle et al. 1998). Social workers are usually responsible for co-ordinating the package of social care at home to meet the needs of the patient and family. Social services provide for individuals with palliative care needs through social workers, home carers, meals on wheels, emergency alarm systems, etc. The primary health care team work very closely with the social work department and increasingly rely on them for providing assistance with personal care, meal provision, medication prompting, financial assessment and carer support. The social worker can also advise on child care issues and housing difficulties. The aim of social services is to allow patients to remain as independent as possible, within a supportive environment with their own families.

Dietician

The dietician's knowledge and skills can make a valuable contribution to the team caring for patients with palliative care needs. The inability to eat and enjoy food is just one of the losses for a patient dealing with a life-threatening illness. Effective management of nutrition-related problems can improve quality of life; significant weight loss may lead to weakness and lethargy (Hill and Hart 2001). The dietician can assess patients and give advice to patients and their families on diet and

nutritional supplements. The carers may also benefit from explanation and guidance to allay fears and concerns regarding the dietary intake of the seriously ill patient.

Marie Curie nurses

The Marie Curie nursing service was established in the United Kingdom in 1958 to care for patients in their own homes (Higginson and Wilkinson 2002). The service provides direct nursing care and support to patients and carers by providing overnight care and also day 'sits' to allow exhausted family members respite. Marie Curie nurses are experienced registered nurses and healthcare assistants who receive induction training before working with patients. The nurses are not specialists in palliative care, but deliver essential nursing care to the patients usually in accordance with the district nursing care plan. They can monitor symptoms, give medication, provide support and allow carers much needed respite. Referral to the service is through the primary health care team, usually the district nurse. They are organised and funded by the nationwide charity Marie Curie Cancer Care, in partnership with the NHS.

As the above demonstrates, in order to meet the diverse needs of patients, it is necessary to utilise a range of disciplines. The roles discussed are by no means the complete list of professionals that a patient may encounter in the community, but merely those more commonly involved in palliative care. In reality, however, only a few individuals will be providing the majority of the care. The key professionals within the primary health care team caring for the patient at home are the general practitioner and the district nurse. According to Hull et al. (1989), when a patient is very ill, the first need is for expert nursing care and the second need is for an understanding doctor, skilled in communication and symptom control. Palliative care is at its very best when the skills of the different professionals are combined.

General practitioner

Ultimate responsibility for the overall medical care of patients in the community rests with the general practitioner (Jatsch 2002). The majority of general practitioners now work in multi-partner practices, allowing for greater flexibility, but potentially less continuity for patients (Barnett 2002). With the changes in the organisation of primary care and

the use of out-of-hours cooperatives, there is less emphasis on home visiting and continuity becomes even more difficult to provide (Doyle and Jeffrey 2000). The general practitioner is, however, in a unique position, as he/she may have considerable previous knowledge about the patient and his or her family and therefore may understand the dynamics within the patient's home to a greater extent than any other professional within primary care. Indeed, many families regard the general practitioner as the professional who has cared for them over many years and with whom they have built a relationship of trust. In today's health service, however, this relationship may be more difficult for general practitioners to establish and maintain due to the ever-increasing workload demands within primary care.

Taking into account this increasing workload and the time and resources required caring for a patient at home with palliative care needs, do general practitioners today envisage their role as incorporating palliative care? In a study of London general practitioners by Burt et al. (2006), the majority of general practitioners (72%) who participated agreed that palliative care was a central part of their role. Within the primary health care team, the general practitioner is usually seen to have a key role (in conjunction with the district nurse) in coordinating palliative care and appropriately referring onto other services when needs arise. According to Costello (2004) the quality of care provided by the general practitioner and other members of the primary health care team determines the ability of the family to cope at home during this traumatic time. Though individual general practitioners rarely have more than a handful of patients requiring palliative care at one time, their role in supportive care and accessing other services cannot be overstated (Brennan 2004). They must be prepared to take time to foresee and alleviate potential problems and be adept in communicating with patients and their families. General practitioners require a good knowledge of symptom control, but it is also essential for them to understand their limitations in terms of both palliative skills and time constraints (Jatsch 2002). Their role is to enable the patient with palliative care needs to carry on living, at times for many months or years, and, where appropriate, provide medication to ensure relief of symptoms, thereby maintaining quality of life until the patient dies (Charlton 2002).

District nurse

District nurses are the largest group of community nurses in the United Kingdom (Bryans and McIntosh 2000; Kennedy 2002) and responsibility

for assessing and planning how patients' and families' needs are met in the home constitutes a basic component of their role (Kennedy 2002). They can trace their roots back to the mid 19th century, when William Rathbone provided the first fully trained hospital nurse, Mrs Robinson, to care for the sick poor in their own homes in Liverpool. At that time, district nurses had to contend with welfare issues such as poor sanitation, unemployment and overcrowding: their concerns were not only for the patient, but also for the health of the family. Through the decades, district nursing services have been continually developing in response to the changing needs of the community (Boran and Clarridge 2005), and the traditional work of district nurses has been redefined and their remit has now expanded to include, for example, nurse prescribing and the assessment and management of patients with long-term conditions. Today's district nurse provides a modern service which is accessible, meets the needs of patients and carers and is delivered within the patient's own home.

District nurses are registered nurses who have undertaken additional post registration education, now at both degree and post graduate level, in order to gain a recognised district nurse qualification. They are highly skilled nurses and lead teams of community staff nurses and nursing assistants, coordinating nursing care for those patients within a geographical area or within a practice population. Practical nursing at home is not the same as in a hospital setting. The situations district nurses often encounter within the community can be complex and nursing activity is therefore likely to be influenced by a number of factors including social circumstances, the environment, resources available and the expectations of the patient and family. The district nurse provides nursing care to patients through direct access from self referral and also receives referrals from other members of the primary health care team and secondary care. Early referral to the district nursing service of patients with a life-threatening illness permits the nurse to assess the needs of the patient and carer and allow time to 'get to know' the family. This early contact is important for establishing relationships with patients and their carers before the time when intimate care is needed and death approaches (Griffiths et al. 2007).

The district nursing work-load has changed considerably in recent years as a result of changes in community care legislation and they are now providing less personal hygiene care, with more emphasis on assessment and skilled nursing, such as palliative care (Barclay 2001). The district nurse is indeed the palliative care linchpin of the primary care team (Barnett 2002) and can be considered the 'key' person in the provision of palliative care in the home (McIlpatrick and

Curran 2000). The district nurse spends a considerable amount of time caring for patients, not only with cancer, but also with other chronic illnesses, and her knowledge and expertise can ensure that all individuals with a life-threatening illness, irrespective of diagnosis, receive effective palliative care. Dunne et al. (2005) report that although research examining the role of district nurses in palliative care is sparse, they are identified as providing practical nursing care, symptom management and emotional support for patients and their families. Their nursing support is particularly important to families, both for reassurance and to alleviate the physical burden of caring.

District nurses view themselves as having a central and valued role in palliative care, where the focus of their work will be the nursing assessment of the patient, meeting basic nursing needs, control of symptoms and support to the family. However, Simpson (2003) states that district nurses often lack the confidence to support patients and their families at home due to insufficient training, whilst a study by Wright (2002) has highlighted concerns that they may not have the necessary skills to provide such care effectively. She examined the district nurses' perspective in caring for patients receiving palliative care and found nurses lacking the skills to communicate with patients about emotional issues such as death and dying. Dunne et al. (2005) also found district nurses feeling inadequate and helpless in dealing particularly with children and young people in the family and as a result tending to exclude them from conversations. This may lead to the district nurse using 'blocking' strategies to avoid certain difficult topics. The difficulties that district nurses have in communicating with some patients receiving palliative care suggest that there is a gap in their knowledge and skills. This deficit in their patient care indicates that referral onto other services would be appropriate, in particular, the community palliative care clinical nurse specialist. It is important for district nurses to be aware of their own limitations and refer patients to the most appropriate service as needs arise, or the situation in the home changes. This requires a clear understanding of the services available within their own community, regarding not only skills and knowledge, but also access to these services (Bliss et al. 2000).

As mentioned previously, a small-scale research study undertaken by the author (Aitken 2006) cast some doubt on the district nurses' role in referring onto other services when difficulties arose. The study set out to identify the triggers that motivate district nurses to refer patients to the community palliative care clinical nurse specialist: the topic selected resulted from observation within the researcher's clinical practice, when it was noted that referral patterns to the community

palliative care clinical nurse specialist were very inconsistent. Other authors, namely Beaver et al. (2000) and Hughes (2004), had noted that cancer patients in particular had contact primarily with the district nurses and that they may potentially act as gate-keepers to other services. In order to provide effective palliative care in the home, the district nurses require an awareness of services available to patients and their families, but it became apparent in the author's research that there was a lack of knowledge amongst the district nurses regarding the role of the community palliative care clinical nurse specialist. This lack of knowledge relating to these specialist nurses has been affirmed previously by several authors (Graves and Nash 1993; Clark et al. 2002; Ahmed et al. 2004). Skilbeck and Seymour (2002) report that some staff respond to palliative care in a reactive manner, calling the community palliative care clinical nurse specialist to sort out a crisis. Indeed it was acknowledged by several of the district nurses in the author's study that they contact the specialist nurse when 'they were out of their depth' or 'when struggling with the patient'. This late intervention cannot be compatible with good palliative care. Palliative home care is a team effort (Wong et al. 2004) and district nurses need to utilise other services to meet the complex needs of their patients and their families.

Despite the findings of some authors questioning the knowledge and skills of the district nurses, or the perceived reluctance to refer onto other services, the district nursing team members carry out a valued and central role in the management of patients with palliative care needs. They visit patients in their own homes, carry out nursing assessments, produce care plans in conjunction with the patient and family and provide much of the day-to-day nursing care required. This individualised patient-centred approach is vital in order to plan and deliver care that is structured to the needs of the patient and family (Henry 2001). This allows patients the choice of where they want to be nursed and eventually die, knowing that their family will also be supported by the skilled district nursing team.

Specialist palliative care services

Palliative care now encompasses a wide range of specialist services and has made great strides forward since Dame Cicely Saunders opened St Christopher's hospice in London. Over the past four decades the hospice movement has been at the forefront of specialist palliative care provision in the United Kingdom, with the number of hospices and specialist palliative care teams having increased considerably in