Collaborative working in end-of-life care: developing a guide for health and social care professionals

Anne Alsop

Abstract

This article describes a project to develop collaborative working between palliative care nurse specialists and community matrons for patients with a non-cancer diagnosis. Pathways to clarify decision-making in end-of-life care were created as part of the project and were subsequently developed into a guide for use by health or social care professionals caring for any patient, irrespective of diagnosis. The guide is designed to facilitate best practice in end-of-life care, by identifying the key questions which need to be addressed and the appropriate responses at different stages of the patient journey. The project was supported by the Help the Hospices' Care Beyond Cancer programme, funded by the St James's Place Foundation. The programme is designed to identify models of effective, replicable end-of-life care provision for patients with a non-cancer diagnosis, and to widen access to specialist palliative care.

Key words: ● Collaborative working ● Community matron ● Decision-making ● Equity of access ● Non-cancer diagnosis ● Palliative care nurse specialist ● Specialist palliative care

Anne Alsop is Education Facilitator (project manager for a Help the Hospices Care Beyond Cancer project), Dorothy House Hospice Care, Winsley, Bradford on Avon, United Kingdom

Correspondence: anne.alsop@dorothy-house-hospice.org.uk

Historically, most hospice and specialist palliative care patients have a cancer diagnosis, and only a small number of patients with other conditions receive this care (Department of Health (DH), 2008). The *End-of-life Care Strategy* states that the challenge for the NHS and social care services is to extend the quality of care provided for cancer patients to 'all people who are approaching the end of life' (DH, 2008: 28). There is now considerable evidence that patients with a non-cancer diagnosis have similar symptoms and palliative care needs to those experienced by patients with cancer (Addington-Hall et al, 1998; Edmonds et al, 2001; Murray et al, 2002; Solano and Higginson, 2006) but that 'palliative care may not be reaching all those who could benefit from it and access and referral to specialist palliative care is not equitable for all' (Ahmed et al, 2004: 525). Ahmed et al (2004) identify a number of barriers to access and referral to specialist palliative care. Some health professionals do not know which patients to refer or when, some may be resistant to handing over or sharing patients and there is a perception that specialist palliative care is only for cancer patients, thus excluding people with a non-cancer diagnosis. Patients and families themselves may also resist referral because of the perceived association between palliative care and imminent dying.

Frankland et al (2007) suggest that another barrier is a lack of clarity and understanding of the role of hospices and specialist palliative care. One reason for this lack of clarity may be that specialist palliative care providers themselves are apprehensive about widening access to their services (Addington-Hall, 1998). She suggests that they may have concerns about being overwhelmed by referrals and being committed to providing care for patients in the longer term when life expectancy is difficult to judge. She also identifies that there may be anxiety about resources and a fear that providing care for non-cancer patients will have an adverse effect on charitable fundraising.

The goal of equity of access to specialist palliative care on the basis of need, and not diagnosis, will only be achieved if these barriers are recognized and addressed. This will require health and social care professionals to be clear about their respective roles and responsibilities in the provision of end-of-life care, and the development of innovative approaches to partnership working. The project described here was conceived as an opportunity for a hospice to support community matrons in their care of patients at the end of life, through the creation of a new model of collaborative working.

The hospice employs a team of community palliative care nurse specialists whose role is to support patients and families at home and to offer advice and support to other health and social care professionals when needed. Community matrons had recently been recruited by two of the primary care trusts within the hospice's catchment area. The community matron role is relatively new within the primary health care team and it is central to the management of people

with long-term conditions and the prevention of unnecessary hospital admission (DH, 2004). They are experienced nurses who provide advanced nursing and clinical care in the patient's home, as well as effective, proactive case management for individuals with complex and intensive clinical needs (DH, 2006). They are expected to 'work in partnership with the individual, their carers and other relevant health and social care professionals to co-ordinate and manage their care' (DH, 2006: 04). They have a key role in coordinating care for people with long-term conditions as they approach the end of life (Bowler et al, 2009).

Developing collaborative working

The project manager, a palliative care nurse specialist based at the hospice, established a focus group of community matrons and nurse specialists to stimulate ideas and discussion about the development of the project. This group met regularly throughout the course of the project and was an essential element in checking that it was meeting its objectives. The project manager spent several days working with the community matrons to ensure a robust understanding of their role and responsibilities. She planned and coordinated a programme of study days for the community matrons and nurse specialists covering a range of topics, including the Gold Standards Framework (2009); advance care planning (NHS, 2008); the Liverpool Care Pathway (Marie Curie Palliative Care Institute Liverpool, 2007) and palliative care needs assessment. This also provided an opportunity for participants to network, to understand each others' roles in relation to end-of-life care, and to share knowledge and experience. This information was used to identify the key issues for the development of an effective model of collaborative working.

Box 1 provides the case study of Jane. The project manager visited Jane with one of the community matrons at an early stage of the project and her story illustrates some of the barriers to the provision of specialist palliative care for patients with a non-cancer diagnosis described earlier.

This case and other similar examples were used to explore the difficulties in referral and access to specialist palliative care, and to consider how these might be overcome. This process confirmed the view that there is an unfounded assumption that people share an understanding of the terminology and purpose of palliative care (Payne et al, 2008). The findings suggested that any model for collaborative working would need to clarify the definitions and terminology used in end-of-life care; to reflect the roles and responsibilities of the different services and to identify the decision-making processes involved in the provision of care. It became apparent that care pathways would be an effective way of meeting these requirements and providing a framework for decision-making and partnership working.

Developing pathways

The pathways were designed for use by health or social care professionals, caring for patients approaching the end of their lives, irrespective of diagnosis. This reflects the principle that assessment and referral for specialist palliative care and

Box 1. Case study

Jane was a 57-year-old lady with a history of chronic obstructive pulmonary disease. The community matron knew Jane well and had been helping her to manage increasing breathlessness and recurrent chest infections. During her last hospital admission, Jane was told that her prognosis was limited and the respiratory nurse specialist suggested that she should be referred to the hospice. The community matron made the referral but it was 'put on hold' because:

- The referral form was unclear about the aims of referral
- The day patient unit manager was hesitant about whether it was appropriate
- Jane's teenage son was distressed because he thought that it meant that his mother was dying

The community matron and the project manager visited Jane and discussed her limited life expectancy and concerns about dying. Her quality of life was deteriorating and she felt socially isolated, frightened and panicky. She frequently contacted the community matron, GP and out-of-hours medical service. She was concerned about her son, because she felt unable to talk to him about her death and his future. As a result of this visit, Jane was re-referred to the hospice and the palliative care nurse specialist agreed to visit and assess her need for specialist palliative care

Table 1. Definitions used in the end-of-life care pathways

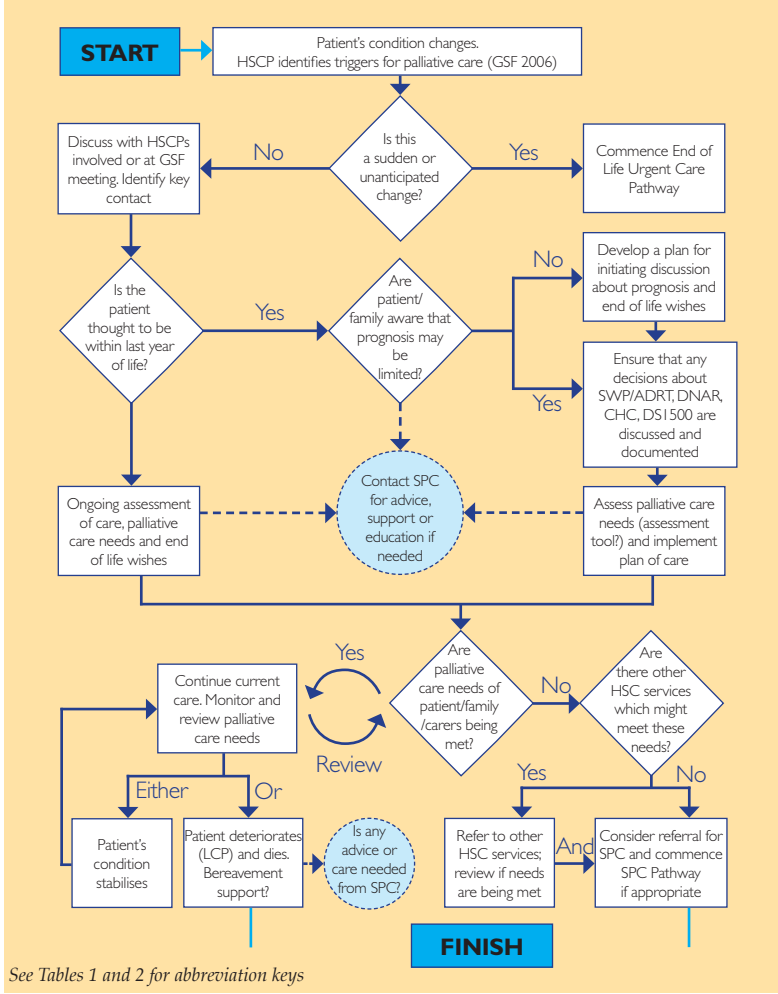
End-of-life care	Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. (Department of Health, 2008: 47)
Palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organization, 2002)
Specialist palliative care	Specialist palliative care services are provided for patients and their families with moderate to high complexity of palliative care need. They are defined in terms of their core service components, their functions and the composition of the multiprofessionalteams that are required to deliver them. (National Council for Hospice and Specialist Palliative Care Services, 2002: 3)

the level of response and intervention from specialist palliative care services should be the same for all patients. A decision was made to include social care as well as health professionals in the design of the pathways. This was in recognition of the active involvement in the coordination and/or implementation of end-of-life care that some social care professionals have e.g. residential care home managers, key workers for people with learning disabilities. For the purposes of the project, the community matrons and nurse specialists were used as a pilot group for the implementation and evaluation of the pathways. One of the key functions of the pathways is to provide clarity around concepts and principles, as well as roles, responsibilities and decision-making. The definitions and abbreviations used in the pathways can be found in *Tables 1 and 2*.

Table 2. Key to abbreviations in pathways

ACP	Advance care planning
ADRT	Advance decision to refuse treatment
CHC	Continuing health care
DNAR	Do not attempt resuscitation
GSF	Gold Standards Framework
HSCP	Health or social care professional
LCP	Liverpool Care Pathway for the Dying Patient
MCA	Mental Capacity Act, 2005
OOH	Out of hours medical service
SPC	Specialist palliative care
SWP	Statement of wishes and preferences

Figure 1. Palliative care pathway



See Tables 1 and 2 for abbreviation keys

The palliative care pathway (*Figure 1*) starts with a health or social care professional identifying a change in a patient's condition and recognizing the triggers for palliative care described in the Gold Standards Framework (2009). It prompts the practitioner to consider whether this change is sudden or unanticipated and to decide upon an appropriate response. If the multidisciplinary team agree that the change is deterioration owing to the natural process of dying, then it continues to follow the patient's journey through to an expected death. It refers to national end-of-life care tools, including the initiation of advance care planning conversations and the Liverpool Care Pathway for the Dying Patient (Marie Curie Palliative Care Institute Liverpool, 2007).

If the change is sudden or unanticipated then the professional is directed to the urgent care pathway (*Figure 2*) and asked to consider whether there are any potentially reversible causes of deterioration and what action should be taken in response. It reflects the NHS End-of-life Care Programme's guidance on advance care planning and prompts discussion of the patient's wishes in relation to treatment, resuscitation and place of care (NHS, 2008). It identifies the importance of communication between services, as this is essential if the patient is to be cared for in accordance with their wishes. It links back to the palliative care pathway when it is recognized that further treatment would be futile or not in the patient's best interests.

A key element of the palliative care pathway is to encourage the practitioner to assess the needs of the patient and family. At present there is no standardized screening measure to assess palliative care needs or to facilitate the referral process to specialist palliative care (Ahmed et al, 2004; Bestall et al, 2004). Some locally based referral criteria have been developed (Bennett et al, 2000) but these are not considered to be specific enough to identify which patients should be referred (Bestall et al, 2004), and eligibility criteria vary (Addington-Hall, 2008). The national Cancer

Action Team, following national guidance (National Institute for Health and Clinical Excellence (NICE), 2004), have recommended that cancer patients should receive ongoing, holistic assessment of their needs, with structured assessment at key points (Richardson et al, 2007). They acknowledge however, that there is no standard pro-forma or tool for conducting these assessments. In the absence of a standardized assessment tool, the pathway invites the practitioner to consider whether any support, education, advice or care from specialist palliative care is required.

The specialist palliative care pathway (*Figure 3*) begins with a practitioner identifying that the patient or family have unmet palliative care needs. It relates to the definition of specialist palliative care as being concerned with complexity of need and it illustrates the different levels of intervention which might be expected. Addington-Hall (1998) has suggested that there are three possible levels of specialist palliative care: consultancy, short-term intervention for specific goals, or the full range of services for patients and families with complex, ongoing needs. These ideas were incorporated into the pathway and an additional diagram (*Figure 4*) was created to clarify the role of specialist palliative care in meeting end-of-life needs. This reflects that direct involvement in the provision of care may only be necessary for a minority of patients but that specialist palliative care has a supportive role in the provision of education, training and advice for the professional carers of the majority of patients.

Discussion

The pathways were shared with the community matrons and nurse specialists and the impact of both the project and the pathways was evaluated. It was found that the project had provided an opportunity for community matrons and nurse specialists to develop their understanding of each other's roles and to forge the personal relationships which are so important for effective communication. The pathways in particular were reported to be helpful in highlighting the decisions which must be made to ensure that patients and families receive optimum care.

The following comments by two of the community matrons illustrate this point.

> **'The pathways are a really helpful guide to thinking through how to plan care with patients and their families and carers and have led on to discussions with other professionals.' (Community matron)**

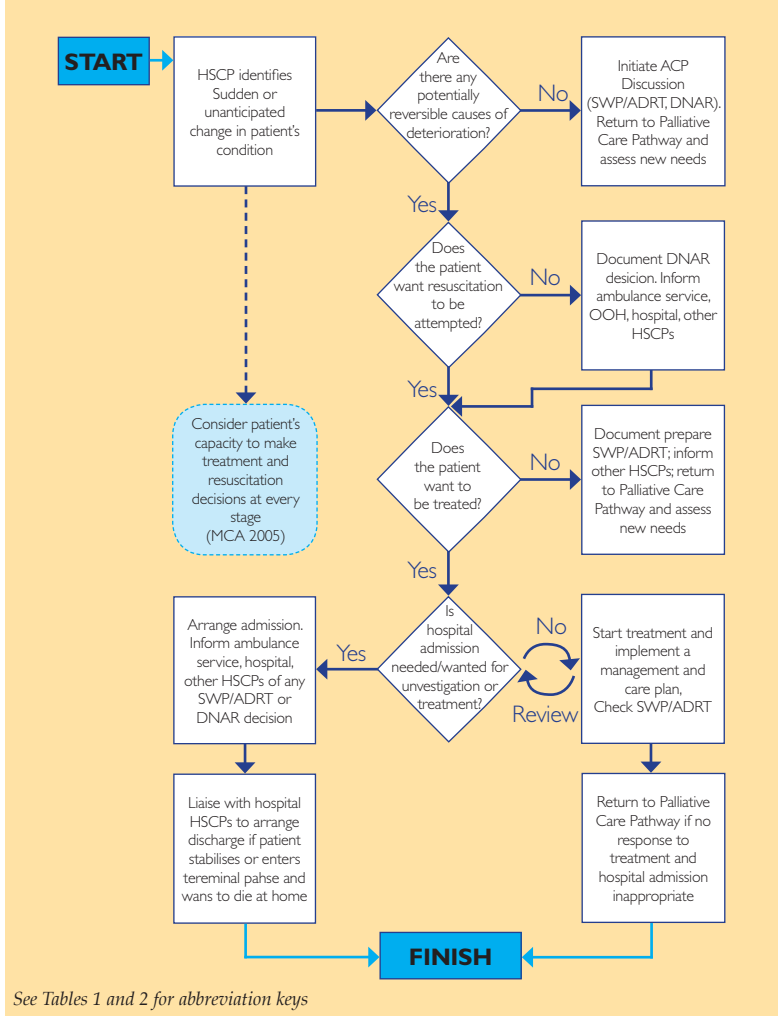
> **'... opened up the idea that non-cancer patients don't get referral to hospices or for specialist palliative care. I now wouldn't hesitate to refer if I felt I had a patient with an appropriate need.' (Community matron)**

The nurse specialists also reported that the project had been useful in clarifying roles and enhancing collaborative working, as the following comments demonstrate.

> **'... because the pathways were so succinct and clear we built on these and have produced two of our own pathways that have simplified about 10 pages of A4 text ... It helped us focus on our role as community palliative care nurse specialists.' (Nurse specialist)**

> **'It's helped to have a better understanding of each other's roles and to have someone to work with who really knows about chronic disease.' (Nurse specialist)**

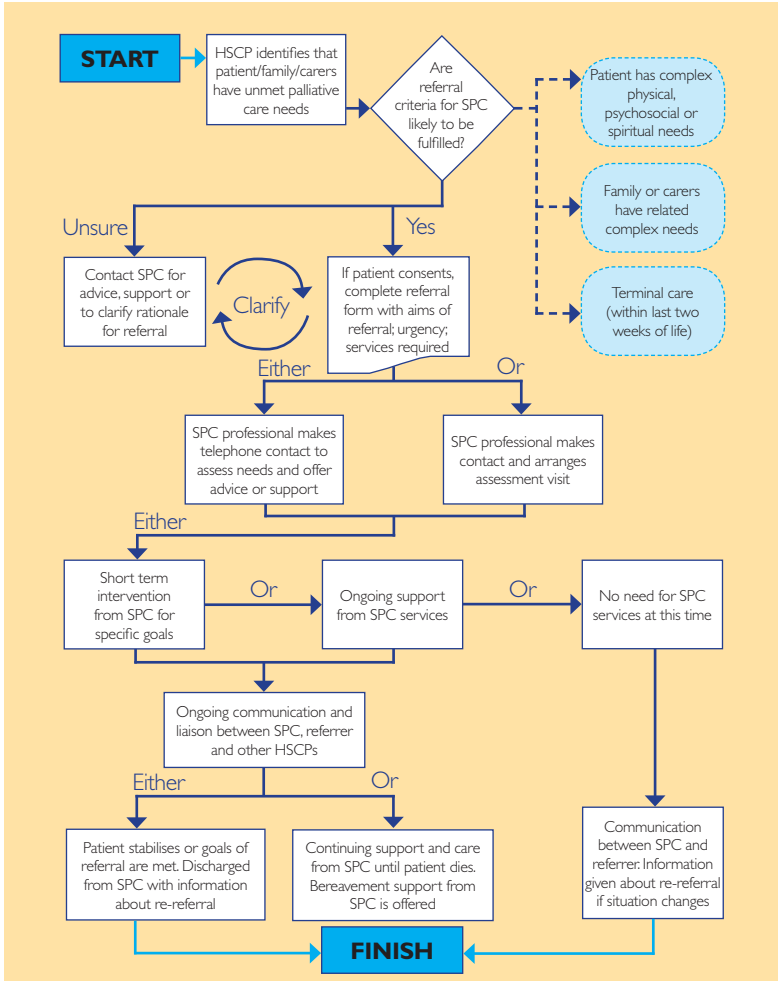
Figure 2. Urgent care pathway



See Tables 1 and 2 for abbreviation keys

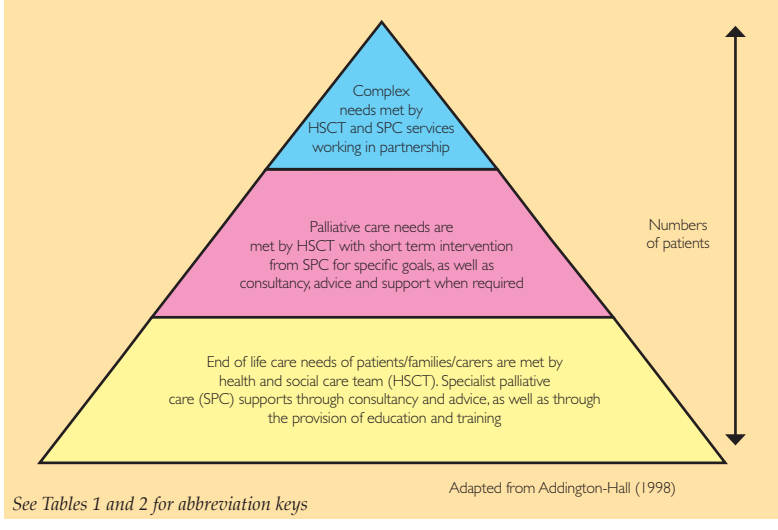
The project and pathways helped to clarify the role of specialist palliative care in end-of-life care for all patients and to highlight the decisions that are necessary to ensure that the patient receives the right care, from the right person, at the right time. They also contributed to the internal debate within the hospice about the challenges of increasing access to specialist palliative care for patients with a non-cancer diagnosis. The hospice is working to address these challenges through clarifying the role of specialist palliative care and explaining the different levels of intervention that are possible. It has also developed a programme of study days about non-malignant conditions, including end-stage neurological, respiratory and heart disease, to consider how secondary, primary and specialist palliative care can work together to improve end-of-life care. It is hoped that this will result in the route to specialist palliative care and the expectation of what it might provide being easier for patients like Jane.

Figure 3. Specialist palliative care



See Tables 1 and 2 for abbreviation keys

Figure 4. Levels of provision of specialist palliative care



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The outcome of Jane's re-referral was that it was agreed that she was likely to benefit from specialist palliative care. She started to attend the day patient unit regularly; she participated in a breathlessness management programme; she received a course of complementary therapies and she benefited from two booked, respite admissions. She stated that she felt better equipped to manage her breathlessness and panic and that she was supported in talking to her son about her death. The community matron reported that she felt less isolated in caring for a patient with such complex needs and that it was helpful to work with the nurse specialist and to be able to access advice and support from the wider hospice team.

The decision to design the pathways so that they can be used by any professional caring for any patient at the end of life, created an opportunity to use them more widely for the promotion of best practice. They have been produced in leaflet form as a guide for end-of-life care and are being used in both formal and informal teaching with other health and social care professionals. They have also been adopted by the two primary care trusts as a framework for mapping existing end-of-life care provision and for identifying the systems and processes which need to be in place in order to ensure that every patient receives optimum care.

Conclusion

The challenges of providing the best care for every patient and family at the end of life remain considerable but not insurmountable. Success will only be possible, however, if services and practitioners understand each others' roles and establish ways of working collaboratively. The project and the pathways in particular have contributed to a greater understanding of the role of specialist

palliative care in supporting patients and families at the end of life. It is anticipated that the ideas generated through this project and incorporated into the pathways will continue to be used to improve partnership working and equity of access to specialist palliative care. IJPN

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