Palliative care 3: Using palliative nursing skills in clinical practice

Using palliative nursing skills in practice involves multiprofessional working, leadership, organisation and care planning, centred around patients’ wishes.

The pressures of staff shortages due to sickness, meeting targets and general workplace stress are no different here than they are anywhere else. What this tells us most emphatically is that it is eminently achievable for nurses to use the palliative care approach in an acute setting. The age-old excuse of not enough time simply reflects a lack of understanding of the true nature of palliative nursing and the means by which to organise and manage such care. The real world of clinical care will always demand of nurses that priorities be made depending on the resources available. That has never changed and it would be unrealistic to suggest otherwise. The challenge of using the palliative approach in a healthcare system dominated by the curative medical model will always be difficult (Fig 1). What nurses need, therefore, is some practical advice on how to use and integrate the palliative approach wherever they encounter dying people.

Organising and managing care

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INTRODUCTION

This extract illustrates the importance of humanity in palliative care. 'I felt sick, I got a tablet, I couldn’t breathe, I got another tablet. Now I can’t go to the toilet. I watched the doctor write out another prescription. I hoped it would help, but I was running out of faith. Along came Dawn. She asked me about everything and everything is now getting better’ (Becker and Gamlin, 2004).

This anecdote tells us much about the place in which care is being delivered and the staff there. It would be easy to criticise the doctor for not bothering to look at the effect of the prescriptions on the patient and for not noticing the patient’s concern. There are many busy acute settings where such events are commonplace but it does not necessarily mean that people fail to care. It is more about the culture and pressures of the job at that moment. The more interesting part of this story is what happens next. Dawn is the nurse who puts the humanity back into the care process, by using listening and attending skills, her competence at putting the patient at ease and skilled questioning technique.

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ORGANISING AND MANAGING CARE

Practice in depth

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Implementing a philosophy of care which emphasises quality of life, holism, futility and family involvement and sees death as a natural end of life is an enormous challenge for nurses in current complex healthcare environments. This article explores the practice-based reality of using the palliative approach in multiple settings and the challenges in such care.

PRACTICE POINTS

- A whole-person approach focused on open and sensitive communication, autonomy, choice and quality of life are the cornerstones of palliative nursing.
- End-of-life care management tools can offer an important contribution to support care, as long as they are used to complement a holistic palliative nursing approach and not to replace it.
- Palliative nursing can make a demonstrable and positive contribution to the welfare of dying people and their families.

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FIG 1. THE CHALLENGE OF USING THE PALLIATIVE APPROACH TO NURSING

CURATIVE CARE

Death = Failure of treatment
Emphasis = Quantity of life
Orientation = Physical body and disease process
Focus of care = The patient

PALLIATIVE CARE

Death = Natural end of life
Emphasis = Quality of life
Orientation = Holism
Focus of care = The patient and family

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Once decisions regarding medical care have been made, it is nurses who have the primary responsibility for delivering such palliative care, whether in care homes, acute wards or patients’ homes.

This is where tools such as the Liverpool Care Pathway (Ellershaw and Wilkinson, 2003), the Gold Standards Framework (Thomas, 2003) and Preferred Priorities for Care (formerly known as Preferred Place of Care (Storey et al, 2003) come to the fore. They provide multidisciplinary teams with documentation to underpin the comfort measures given while patients receive palliative care up to the point of death. They can also act as a useful checklist for teams to ensure all patients’ and relatives’ needs are fulfilled.

The idea is that a seamless service is provided as clinical areas liaise with other agencies to smooth care towards either discharge to a chosen care environment or a peaceful death. Essentially, they provide a template for patient-centred best practice and help to facilitate standards of record-keeping in line with NMC (2008) requirements.

However, such tools are only as good as their users’ competence and attitude towards delivering palliative care. At present, it is far too early to offer a full and objective opinion on their efficacy. Anecdotal evidence from around the UK indicates that, where they have been successfully adapted to suit local needs, the tools are beginning to make a difference. Uptake by trusts is optional, not mandatory; the tools are beginning to make a difference.

All members of the direct caring team should have up-to-date knowledge about a patient’s condition and should be prepared to share this if requested. Nurses express much anxiety about this area, but there is no code, rule or law that forbids them to give this information if in their judgement it is the right thing to do at the time. It is a matter for careful judgement in the context of the situation at the time, and accountability for such decisions is enshrined in the code of conduct (NMC, 2008).

However, nurses need to be sensitive to working relationships with colleagues and to their responsibility to patients to handle questions with the utmost care. Equally, they have a clear responsibility to advise non-professional and junior staff on how to deal with questions and when to seek help.

There are no easy answers to life’s most difficult questions but, in a palliative care context, there are some useful techniques that can help.

The supporting principles are:
- Encourage the expression of fears, doubts and questions;
- Use skills of active listening and empathy to communicate understanding;
- Try not to shy away from appropriate physical touch and reassurance;
- Learn to respect a silence and don’t always feel the need to fill it;
- Don’t give more information than patients ask for;
- If you are asked a direct question repeatedly then eventually you must answer it directly. Avoidance will create mistrust and suspicion;
- Don’t expect to have all the answers; there often are none to profound questions.

Box 1 outlines some helpful guidance on communication.

**Relief from pain and other symptoms**

All those suffering from life-limiting illnesses need expert care and support to manage the deterioration of their condition and sometimes pain and suffering. Nurses need experience, confidence and understanding of the trajectory of terminal illness and the dying process to deliver such care effectively.

The good news is that much can be done to relieve or help patients cope with pain and suffering. Nurses play a vital role in the art and science of assessing, planning, delivering and evaluating pain management.

The principles of good pain control include:
- Think holistically and observe patients carefully. Do not wait for them to say they have pain;
- Assess pain meticulously and repeatedly using recognised tools. Look for the nature of the pain, its site and duration;
- Communicate all pain-related findings to the team;
- Monitor the effectiveness of pain- and symptom-relieving measures and review at least every 24 hours until a stable regimen is established;
- Use individually titrated, regular analgesia and adjuvant drugs for symptom control so that the pain does not return and symptoms are minimised;
- Set realistic goals with patients if possible;
- Analgesic drugs alone will not relieve pain and suffering. Compassion, empathy, understanding and diversion are essential complementary measures.

**Good communication**

The appropriate use of communication skills to help build and establish a good working relationship with patients and families is the first stage in delivering quality care.

Much has been written about the specialist nature of such skills when used by advanced practitioners in clinical specialist posts (Skilbeck and Seymour, 2002). However, for practising nurses at the bedside, the range of competencies needed is generic in nature and highly effective when used well.

It is essential that information about diagnosis, treatment options and prognosis is communicated with honesty and sensitivity by nurses with the expertise to do so. Without this, it is much harder for people to take decisions about their care, leaving them disempowered by the advance of their illness.

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**The Practice of Palliative Nursing**

When dealing with people who need palliative nursing, a vast range of knowledge, skills and behaviours is required to help give good holistic support to patients and families. It is far beyond the remit of this article to go into such detail, but it offers a summary of the priorities for nurses in this sensitive area.

**THE PRACTICE OF PALLIATIVE NURSING**

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Respecting patients’ interpretation of their dignity

As patients’ physical condition deteriorates, they can experience a diminishing sense of control over their life. A patient-centred care approach aims to encourage greater choice and to treat patients as people rather than conditions. Let patients decide what their priorities are and work towards these. The government’s Dignity in Care campaign (Department of Health, 2006) is specifically designed to enhance such choice and dignity.

Nurses should avoid building a set of beliefs and values that unconsciously communicate that the death should represent an ideal. There is no right or wrong way to die. Many people die with unfinished business in relationships and personal difficulties that are impossible to influence or change; this does not negate or devalue the care given.

There is a need to recognise and accept that – despite the multiprofessional team’s best efforts – there will always be some people who choose to reject help. We must therefore learn to evaluate care based on what we know of the patient’s values and beliefs and not our own.

Considering patients’ choice about where they wish to be

Although many patients, when asked, express a wish to die at home, the reality is that few achieve that desire (DH, 2008).

With the majority of the population dying in some form of institution, attention to the environment can provide good psychological support by creating a milieu in which patients are comfortable. Some may prefer peace and quiet and wish to be in a side room. Others, however, like to be part of life on a ward and feel less isolated in a bay environment.

Such choice may not be available in nursing and residential homes, but the opportunity to personalise care within that environment is usually better due to greater continuity in staff and often more long-term relationships.

While those who die at home can have a wide variety of services to support them (depending on diagnosis), the psychological comfort of being in familiar surroundings is a powerful element.

The key word to consider is choice.

Understanding families’ needs

It is good practice to assign a member of staff to discover which family and friends are available, how they wish to be involved in care and what, if any, special needs they may have.

In hospitals or care homes, this is not only part of admission procedure but also a continuing responsibility, as relationships change and staff come and go. Although difficult to achieve in some clinical areas, the sense of continuity achieved by this approach is highly valued by both patients and relatives (Becker, 2007).

Support with the practicalities of dying

Guidance and support in accessing benefits and managing financial arrangements, wills and social care needs (including the loan of specialist equipment, for example) is vital and nurses need to know whom to contact within their locality to action this. They should seek out local policies and literature and keep a list of these available for all team members.

Many patients and family members will have internet access so it can be helpful to compile a list of websites that provide more useful information.

Recognising futility

One of the major challenges of palliative nursing in non-specialist environments is empowering staff to reach a decision regarding patients’ care orientation, that is, whether it is focused on curative, life-preserving measures, or towards more palliative, quality-of-life measures. Ideally, this should be done in conjunction with patients, relatives and all team members.

Much distress can be caused if efforts to initiate resuscitation or other procedures are fruitless when the quality of the remaining life is poor (BMA et al, 2007).

Nurses should follow the simple ethical principle of ‘non-maleficence’ or, in other words, do no harm. The NMC (2008) code makes this explicit. The whole team should ask themselves whether IV infusions, parenteral feeding and subcutaneous fluids are useful and appropriate. The decision to withdraw such treatment is ethically, morally and legally defensible if the team agrees that it is in the patient’s best interest. The family’s views should be listened to and acknowledged, but are secondary in this instance.

It requires an assertive and knowledgeable nurse with a good understanding of accountability and confidence to challenge the status quo, where necessary, if the patient’s best interest is to be served.

Helpful guidance:

- Discuss the rationale for the current treatment regimen to ensure all staff understand the care priorities;
- Talk with patients to explore issues raised;
- Reassess the level of pain, symptom control or anxiety about their health status;
- Review management plans regularly;
- Remember the focus is on quality of life.

Spending time with dying patients

It is all too easy to avoid dying patients and their relatives. Sometimes they need to be left alone, but there are many times when they will need human contact, comfort and reassurance from healthcare staff (Mullard, 2005).

A number of authors acknowledge the caring concept of ‘being available’ and ‘presencing’. It is synonymous with Parse’s (1992) concept of ‘true presence’ and is one of the ‘carative’ factors used by Watson (1994). Benner and Wrubel (1989) noted that the ability to presence oneself, to be with a patient in a way that acknowledges shared humanity, is the basis of nursing as a caring practice.

There will always be a sense of powerlessness when confronted with death. No one can change this. The real skill is in learning to be comfortable with that powerlessness and using it to help patients and families. Nurses do this by the sensitive use of what is intuitive and felt as much as by what is learnt (Benner, 1984).

Other essential comfort measures

Diet/nutrition: The key things to remember are small well-presented meals that are high in calories to boost energy. Likes and dislikes should be noted and meals modified where possible to suit patients’ wishes. If feeding is needed, time should be allowed for this important and often neglected function.

Belongings: Making patients’ bed space personal to them is psychologically important in any caring environment away from the home. Encourage the use of photos, personal clothes and jewellery.

Visits: Find out from patients who the important people in their life are – do not always assume it is immediate family. Be aware they may tire easily with too many people around and be their advocate when necessary to limit time at the bedside. Find out about the visiting policy and remember issues such as parking, refreshments and chairs around the bed. Consider open visiting if families have to travel a long distance.

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Sleep and rest: Make sure there are quiet periods for patients, reduce intrusive noise such as television, radio, medication rounds and trolleys. Consider alternatives to sleep-inducing agents, for example Horlicks or Ovaltine, small amounts of alcohol where appropriate and earplugs.

Elimination: If diuretics are prescribed establish the timing. If a catheter is in situ, check for infections, blockages and observe the urine’s colour and consistency. If a patient has specifically requested that a catheter not be inserted when they become incapable, this should be respected.

Bowel care: Be aware that all opioids can cause constipation; a laxative should therefore be prescribed concurrently. Those that act as both bowel stimulants and softeners are often the most effective choice. Consider intervention every third day if the bowels have not opened. However, if death is imminent, mild constipation is not an issue and any such intrusion is neither comfortable nor desirable. Dignity is everything at this point.

Routine observations: It is not necessary to record temperature, pulse, respiratory rate or blood pressure for a patient who is clearly dying, except where instructed for clear medical reasons, for example when a procedure such as blood transfusion is in progress.

SUPPORT FOR NURSES AND COLLEAGUES
Being at the bedside of a dying person can have a profound impact on nurses. It is a formative learning experience and can shape professional values, attitudes and beliefs for the future.

For this reason, it is vital that nurses not only know how to find support for themselves at such a difficult time but also be aware of others’ needs in the team, who may be less experienced and encountering death for the first time in a professional context. See Box 2 for helpful guidance on seeking support.

CONCLUSION
Does palliative nursing care make a difference? Yes – there is clear evidence that good nursing care with a palliative emphasis has a positive and significant impact on patients’ quality of life (Barnard, 2006).

It is nurses who mostly bear the burden of care when medical treatments are delivered and thereafter, so nursing has a pivotal impact on overall treatment regimens (Hamilton and McDowell, 2004).

Nurses are also more likely to be present when someone dies than any other healthcare professionals and evidence indicates that families look to them for support, information and continuity in care (Smith, 2004).

The professional nursing skills and attributes necessary to support terminally ill people and those close to them are now much clearer. Equally, the organisational and resource reasons that limit nursing practice in this area are well known.

Current government initiatives, coupled with the vast experience of the hospice sector in the UK, have laid the groundwork for a more logical and systematic strategy for end-of-life care for the first time. The needs of dying people have never had such a high political and professional profile and nurses are central to the effective meeting of these needs. The imperative is now very much in the hands of the clinicians to make it work.

REFERENCES

RECOMMENDED FURTHER READING