COMMUNICATION IN END-OF-LIFE CARDIAC CARE 1: DIFFICULT ISSUES

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This is a two-part unit on communication issues in end-stage cardiac disease. Part 1 discusses the main communication problems relevant to end-stage heart failure. Patients may wish to discuss end-of-life issues but are denied the chance to do so as nursing staff often lack the skills or confidence in dealing with such issues.

INTRODUCTION
NICE (2003) guidance on chronic heart failure stated: ‘Issues of sudden death and living with uncertainty are pertinent to all patients with heart failure. The opportunity to discuss these issues should be available at all stages of care.’
The National Service Framework for Coronary Heart Disease (Department of Health, 2000a) recommended a palliative approach in managing end-stage heart failure. It also advised: ‘Open communication about disease outcomes should be offered to all patients suffering from heart failure,’ (see box below).

LEARNING OBJECTIVES
1. Identify the possible need for palliative care in patients with heart failure.
2. Explain the importance of effective communication in treating end-stage heart failure.

Despite these recommendations, the literature reports that clinical staff very rarely discuss with patients the likelihood of them dying. In most cases patients come to this conclusion themselves, with only the minority formally told (Gibbs et al, 2002; McCarthy et al, 1997). From the literature it is evident that cardiologists are comfortable discussing treatment options but less confident in asking patients open questions about terminal care. Wotton et al (2005) identified that open communication is rare among patients undergoing cardiac care and health professionals, leading to suboptimal palliative care and a failure to identify and honour patients’ wishes. Having access to clinical staff with the skills to address these issues is clearly important.

SPECIALIST STAFF
Many patients with heart failure have access to a specialist nurse, whose role in palliative care is to provide support and counselling, as well as monitoring the patient’s condition and providing good communication between patients and primary and acute care (Jolly, 2002). Often heart failure nurses monitor the patient’s condition, offer support, promote their needs and decisions and initiate end-of-life discussions.

Specialist palliative care is provided by health professionals with the skills and competence to deal with patients’ complex needs that generalists cannot deal with effectively. The role of the specialist palliative care team in end-stage heart failure is to assist the referring team in complex cases. This ensures that holistic care is provided, such as symptom management, psychological support and addressing difficult communication problems, for example end-of-life issues.

COMMUNICATION SKILLS
There may be times, such as during a severe exacerbation of illness, when patients may want to discuss difficult issues but may not have access to a heart failure nurse or specialist palliative care. Often nurses caring for patients are best placed to address their concerns but evidence suggests they lack the confidence or skills to do so. This has been recognised by The NHS Plan and The NHS Cancer Plan (DH, 2000b; 2000c) so communication skills training is now part of the national education curriculum for nurse and medical training, and competence in the area is a prerequisite for qualification. Courses are supported nationally.

This article aims to help nurses caring for patients with end-stage heart failure to manage difficult communication issues, whether referral to a heart failure/specialist palliative care team is possible or not. We aim to consider examples of difficult communication issues and then give guidance on how these may be resolved.

KEY POINTS ON PROVIDING PALLIATIVE CARE IN HEART FAILURE
- It can be difficult to recognise if or when a person with heart failure is near the end of their life but heart failure is often a malignant manifestation of CHD.
- Good symptom control, psychological support and open communication about disease outcomes should be offered to all patients with heart failure.
- When the aim of treatment is to control symptoms, a palliative approach can improve patients’ quality of life.
- A palliative approach recognises the importance of promoting physical, psychosocial and, often, spiritual well-being. It stresses quality of life, good symptom control, a whole-person approach, respect for patient autonomy and open and sensitive communication.

Source: Department of Health (2000a)

POTENTIAL ISSUES
Thoughts on dying
Patients with heart failure can have a protracted disease process with prolonged periods of relatively good health and quality
of life. During these periods patients rarely think about dying – they only tend to think about it during exacerbations and recoveries. This is not the case with patients diagnosed with cancer. Willems et al (2004) stated that most patients associate cancer with death and most reactions to a cancer diagnosis focus on mortality. Although ‘accepting’ and ‘living with’ cancer are terms often used to describe patients’ emotional reactions, it is difficult for patients to avoid its association with dying.

Advances in medical technology have enabled cardiologists to treat patients who would previously have died and rescue them from near-death situations. Although patients may recognise they are seriously unwell, they view this state of severe illness and recovery as a normal part of the disease process and do not always assume they are dying (Willems et al, 2004).

Discussions on dying become harder for nurses when they witness the recovery of patients who were thought to be on the brink of death. This makes it difficult to gauge when such discussions are appropriate (Wotton et al, 2005). Often patients feel they are dying but are denied the opportunity to verbalise such thoughts. Ellershaw and Ward (2003) suggested that in these situations nurses should initiate such discussions rather than give false hope.

Preparation for death
As discussed, most patients with heart failure think about death infrequently. In a study by McCarthy et al (1997), a quarter of patients surveyed expressed a wish to die sooner. Factors such as distressing symptoms and perceived poor quality of life were identified as predictors of expressing a wish to die. A sense of uselessness also appears to indicate a willingness to die. This may be stronger in patients with a disease that progresses slowly than in those with a more rapidly advancing disease such as cancer, because patients with heart failure feel ‘useless’ for a much longer period (Willems et al, 2004).

Identifying preferred place of death
DH initiatives on end-of-life care outline the importance of recognising and respecting patients’ wishes in dying in the environment of their choice (DH, 2003). Using good communication skills to discuss disease progression and patients’ concerns are vital in identifying their wishes regarding end-of-life care. However, evidence suggests a lack of discussion between clinical staff and patients and carers about such issues (Willems et al, 2004; Gibbs et al, 2002; McCarthy et al, 1997).

Often patients with heart failure appear keen to have timely and frank discussions about such issues but find doctors are reluctant to enter into such conversations (Rogers et al, 2000). This is often attributed to limited time during consultations and to staff feeling inadequately trained to deal with these difficult issues (Maguire and Pitceathly, 2003).

Dealing with loss
As with any terminal disease, patients have to deal with many losses and a decreasing range of abilities, as well as an increasing dependence on others for assistance. The difference in this respect for patients with heart failure compared with those with cancer is that cancer is often the main problem and dominates other difficulties.

However, for patients with end-stage heart failure, co-morbidity is equally important (Willems et al, 2006). Their symptoms and co-morbidity mean they have to deal with a complex range of illnesses and effects on their abilities. Patients with heart failure often report a sense of hope that they will recapture some of their former abilities and regain their ‘normal’ life. This can be as simple as summoning the energy they once had to enjoy life or just getting out of the house. As a consequence of continually decreasing abilities, it is common for patients to describe feelings of frustration, loss of self-esteem and confidence, and fear of being alone and isolated. These losses can leave them feeling hopeless, worthless and as if their lives are finished (Horne and Payne, 2004).

It is clear that the impact of loss can cause patients with end-stage heart failure significant emotional suffering. A palliative approach to care recognises the impact of such suffering and the importance of helping patients and carers to address their emotional needs. Nurses caring for these patients should use good communication skills to help patients recognise their losses and assist them in finding methods of coping.

Part 2 of this unit explores strategies nurses can develop to communicate with patients with end-stage heart failure and will be published in next week’s issue.

KEY REFERENCES


NICE (2003) Chronic Heart Failure: Management of Chronic Heart Failure in Adults in Primary and Secondary Care. London: NICE.


The full reference list for this unit is available in Portfolio Pages at nursingtimes.net