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End stage heart failure patients

Palliative care in general practice

Background

Chronic heart failure is common, particularly in older individuals, and comorbidities are frequent. Patients with end stage heart failure can be highly symptomatic and require careful monitoring and treatment adjustment to improve symptoms.

Objective

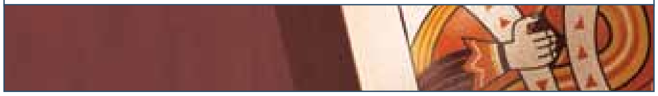
This article summarises the fundamentals of implementing palliative care in general practice and provides guidelines on caring for chronic heart failure patients at the end of life.

Discussion

The high mortality in chronic heart failure underscores the importance of effective communication, symptom management and advanced care planning. The unpredictability and uncertainty around the timing of death mean that individuals, and their families, may be less likely to have an understanding of their prognosis or have access to supportive and palliative care. Ideally, patients with symptomatic chronic heart failure should be managed in collaboration with a multidisciplinary heart failure program. Symptom management can be achieved by additive therapies and access to specialist palliative care services should be considered when the symptom burden is high.

Keywords: palliative care; heart failure; general practice

CPD



Chronic heart failure (CHF) is common, and more than half of patients diagnosed with CHF will die within 5 years.[1,2] Medical advances, particularly beta blocker therapy and implantable cardiac defibrillators,[3] mean that many individuals with CHF are living longer and cared for in the community. Patients with CHF experience a wide range of frequently distressing symptoms and in addition to breathlessness, pain, nausea and constipation, low mood is common and generally poorly controlled.[1,4–6] The symptom burden is of similar severity to patients with cancer,[7] therefore integrating supportive care into CHF treatment is important in both primary and secondary care settings.

Specific palliative care services, although originally cancer based, now also address the needs of individuals with nonmalignant conditions. The terms 'palliative' and 'supportive' care are often used interchangeably: both strive to improve the quality of life of patients who have serious or life threatening disease and to provide support for family members. Generally, this is best viewed as an approach to care rather than a discrete phase or setting of care.

The evidence base to guide the palliative and supportive aspects of care are less explicit than curative management[3] and further research is required. High rates of comorbidity, particularly renal and hepatic dysfunction, alter the potential risk-benefit profile of pharmacotherapy.[3]

Palliative care and CHF patients

Heart failure is a diverse and heterogeneous syndrome and patients will have variable disease trajectories and needs requiring tailored, targeted management.

Palliative and supportive strategies can add to the complexity of treatment. Palliative care can be challenging in primary care, particularly when after hours care is required. Supportive treatments, such as introducing opioid therapy for dyspnoea,[8] require close monitoring and titration. Therefore it is recommended that patients be referred to community based, interdisciplinary heart failure programs.These programs aim to promote self management in the community, optimise evidence based therapies, health related outcomes and decrease unnecessary admissions to hospital. Accessibility can be challenging, particularly for rural and remote patients, although there is an increasing focus on telemedicine strategies to decrease health inequities. The use of case conferencing item numbers may also facilitate communication across care settings, which is particularly useful in end of life care.[9]

Which CHF patients benefit?

Determining the end stage of disease can be difficult – typically functional decline and end organ damage signal that life is potentially limited. Complete assessment (including cardiology review) is required to ensure that reversible causes have been excluded, and treatment adherence (both patient and provider) considered before concluding a patient has end stage disease.[10]

End of life care discussions are important for all patients, however the following criteria are associated with poor prognosis, therefore palliative care is particularly important for such patients:

- New York Heart Association Class IV admission in past 12 months
- Decline in functional status and need for assistance in activities of daily living
- Persistent S3 gallop rhythm
- Serum creatinine ≥0.15 mmol/L
- Resting heart rate ≥100 bpm
- Age ≥70 years
- Serum haemoglobin ≤115 g/L without documented site of bleeding
- Serum sodium ≤135 mmol/L
- Serum albumin ≤33 g/L
- Daily dose of loop diuretic (eg. frusemide ≥160 mg)
- Documented ventricular fibrillation/ventricular tachycardia (VF/VT) arrest without an implantable cardiac defibrillator
- Unexplained weight loss of ≥5 kg over past 6 months (excluding index admission diuresis).[11,12]

Effective communication and treatment goals

Perhaps the most important issue in addressing supportive care needs is ensuring the patient, family and health professionals are aware of the goals of treatment. Although health professionals dread this 'difficult conversation', in which treatment options and the likelihood of death are discussed, data suggests patients and their families welcome the opportunity for transparent and open discussion.[13] Ensuring all treatment providers are 'on the same page' is important to avoid ambiguity in treatment goals and futile, unwanted treatments.

Communication across healthcare teams, particularly primary and secondary care teams, is vital. Documenting patient preferences for the level and place of care at the end of life is important. Complex, difficult and value laden decisions, such as withdrawing and withholding treatment, should not be made as the patient is being placed in the back of the ambulance. Patients and their families should also be reassured that withholding specific treatments, such as cardiopulmonary resuscitation or ceasing certain medications, does not mean the end of all active care. In fact, often the patient and their family's needs are increased at the end of life. *Table 1* provides an example of how to approach this conversation. General practitioners are well placed to have these conversations as they understand their patients' conditions and social situation, which are both pivotal to assisting patients with CHF in advance care planning.

The importance of symptom management

The efficacy of supportive and palliative care is largely assessed by the quality of symptom management and the reduction of distress for patients and their family. It is important to remember that medications such as beta blockades, angiotensin converting enzyme inhibitors (ACEIs), angiotensin II inhibitors, and spironolactone improve symptoms in CHF.[3] Therefore these medications should not be withdrawn without careful consideration, even when it is clear that the patient is end stage. In some instances, hypotension, worsening renal function and electrolyte imbalance may require downward titration of medications. Generally, minimising the diuretic dose prevents hypotension and other CHF

Table 1. Approach for discussing prognosis and advanced care planning

- If there is suspicion of clinical depression, psychiatric evaluation and treatment is necessary before formulation of advanced care directives
- Choose a time and setting conducive to discussion
- Encourage participation of family members and/or caregivers
- Where possible involve all treating teams and primary care clinicians
- Assess the level of involvement that the patient wants in clinical decision making
- Assess the understanding of the patient concerning diagnosis and treatment
- Declare professional recommendations and empirical risks and benefits of treatments where available, eg. 'It appears that your kidney function is getting worse and therefore the risk that you will develop further complications is increasing'
- Introduce joint decision making processes and language, eg. 'We are going to work together'
- Use language which acknowledges patient autonomy, eg. 'We would like your opinion'
- Invite questions and comments and ask questions to ascertain understanding
- Be perceptive to body language reflecting withdrawal and/or distress
- Acknowledge the uncertainty of the prognosis
- Provide the option for delaying decisions, eg. 'You can tell us your decision at your next visit'
- Allow opportunity to discuss decisions with family and caregivers
- Offer ongoing decision support and contact details to clarify information
- Where possible follow up in the next few days to ascertain level of comfort with conversation.

medications can be continued.[14]

The principles of symptom control are the same irrespective of the patient's diagnosis. A clinical assessment is vital, including the patient's adherence to treatment recommendations and potentially reversible causes of decompensation, such as infection, anaemia or ischaemia. *Table 2* provides guidelines for undertaking a clinical assessment in end of life care.

Table 2. Assessment for end stage heart disease

Physical	Pain assessment[*] Dyspnoea[**] Nausea Anorexia Functional impairment[†] Bowel and bladder function – continence and constipation Oedema – consider presence of sacral edema due to immobility Assess for potential drug effects (eg. digoxin toxicity)
Social	Financial status Role change Capacity to self care[††] Adherence with lifestyle recommendations Fear for dependents Carer burden Place of death Current advance care directive
Emotional **Psychological**	Depression[#] Reflection on life and events Delirium[††] Confusion Fear and anxiety[††] Concerns for future Quality of life[#]
Cultural	Cultural significance of death and dying Cultural requirements for management of death
Spiritual **Existential**	Meaning of death Preparedness for death Religious beliefs and desires for burials

[*] The World Health Organization Three Step Analgesic Ladder approach is useful in assessment and management of pain and/or discomfort[36]

[**] A visual analogue scale is a valid and reliable strategy to monitor levels of dyspnoea[37]

[†] Consider using anchors or reference points such as walking to the bathroom to determine deterioration in functional status

[††] Where possible it is useful to use validated measures for patient reported outcomes such as depression, anxiety, stress, functional status, oedema, pain and quality of life. This not only facilitates empirical clinical decision making but also communication across healthcare sectors

[#] Sequential measurements of psychometric measures over time can be useful in monitoring prognosis and functional status[35]

Breathlessness

Breathlessness is a common and distressing symptom in CHF and a highly subjective sensation.[14] Therapy needs to improve the patient's subjective sensation rather than simply correct abnormal physiological parameters.[15] When evidence of fluid overload is present, increased doses of diuretics are warranted. Diuretic titration is an important part of care and the addition of thiazide diuretics to loop diuretics may overcome diuretic resistance.[16,17] Intravenous administration may be more effective than oral administration if diuretic resistance is probable and congestion is problematic.

Breathlessness is not always associated with fluid overload but can be attributed to other causes such as anaemia, fatigue and deconditioning.[18] Opioids have an important role in managing breathlessness in the palliative phase of illness.[19,20] Evidence supporting the use of oxygen in mildly hypoxaemic patients is sparse.[21] Benzodiazepines can be used to relieve the anxiety associated with breathlessness. Information regarding dosing can be accessed through the recently revised Therapeutic Guidelines: Palliative care.[22] As a general principle, start at low doses, observe responses, and slowly uptitrate. Opioids should be titrated to the level of symptoms and can be used without causing respiratory depression or excessive drowsiness.[23] Constipation should be anticipated and instructions regarding aperients should be provided.

In addition to pharmacological strategies, a range of nonpharmacological approaches can be useful and can also increase the sense of control for patients, and their families. Advice on posture, relaxation techniques and having a flow of air across the face, from a fan or an open window, is important. Airflow is believed to relieve breathlessness through inhibitory fibres from facial receptors.[24]

Sleep disordered breathing is common in CHF and should be assessed and managed appropriately.[25] The majority of people with sleep disordered breathing have central sleep apnoea and the minority, obstructive sleep apnoea.[26] The use of continuous positive airway pressure can provide symptomatic relief and improve breathlessness and fatigue.[27]

Given the difficulties in accessing polysomnography in Australia,[28] if sleep disordered breathing is considered a cause of symptoms, sleep evaluation needs to occur earlier in the illness trajectory rather then in the later stages of CHF.

Gastrointestinal symptoms

Gastrointestinal symptoms, such as nausea or vomiting, constipation and incontinence are important in the palliative phase of CHF. Antiemetics can be prescribed to relieve nausea. Constipation is common and aperients may be required, particularly if opioids are prescribed.[29] Anorexia is frequently a concern for family members, but is part of the end of life trajectory in many conditions, including CHF.[30] Cachexia should be managed with an unrestricted calorie intake and dietary supplements where appropriate.[31] Small frequent meals may be better tolerated. Reduced dietary intake may necessitate warfarin adjustment as the international normalised ratio (INR) can rise when anorexia and catabolism is present.[32]

Elimination

Strategies to manage incontinence should be implemented to promote patient comfort and avoid pressure areas and ulcers. Urinary incontinence may be managed by changing the timing of diuretic doses, or by the use of a urinary catheter, incontinence pads or noninvasive continence devices.

Fatigue

Fatigue is common in CHF and the causes can be both physiological and psychological.[33] Both emotional and cognitive dimensions influence fatigue perception and energy conservation techniques are useful. Exercise is an important therapeutic strategy and prescription of both active and passive exercise, even in end stage disease, is important.[1] This also minimises dependent oedema and breathlessness and decreases the risk of decubitus ulcers and other complications related to immobility. Psychostimulants have been shown to decrease fatigue in cancer,[34] although there is no data on CHF. Anaemia is common in CHF and is an important source of fatigue and exercise intolerance. Erythropoietin and iron supplementation are promising for treating anaemia but are still largely experimental.[35]

Uraemia

In the palliative phase of CHF, progressive renal impairment is common and a marker of poor outcome.[36,37] Renal dysfunction may be due to vascular changes, congestion and medication effects. Nausea associated with uraemia can be treated with haloperidol or another anti-emetics.[14] Skin irritation due to uraemia may respond to topical steroids and agitated delirium may be treated with neuroleptic agents.[38] Morphine metabolite accumulation occurs in patients with severe renal impairment, resulting in clinical features of neuroexcitation such as agitated delirium and frequent myoclonus.[39]

Pain

Many studies identify pain as a symptom in CHF. The causes of this pain are unclear but can include musculoskeletal problems.[40] Management of pain should follow evidence based treatment strategies and it is important for clinicians to recognise that pain can be a problem.

The importance of cultural, psychological, social and spiritual care

Depression is a frequent comorbidity in CHF and should be screened for and treated appropriately. At the end of life, relationships and spiritual and existential care are of great importance. Social workers, volunteer organisations and pastoral care should be engaged where appropriate. Given that many individuals with CHF are elderly and live alone or with an aging partner, engaging social services is a high priority. Cultural beliefs are also an important consideration in approaching end of life care.[41] Family members should be provided with bereavement care and referred to services where appropriate.

Complementary and alternative therapies

Complementary and alternative therapies, such as relaxation, biofeedback and stress management, may relieve symptoms such as breathlessness and anxiety.[42] There is an increased trend in the use of complementary therapies in the community[17] and this may increase with deteriorating health, as people strive for alternative solutions. Creating an open environment encourages disclosure and may prevent adverse interactions. For example, some alternate therapies can potentiate the effects of warfarin and digoxin.[43]

Withdrawing and withholding treatments

Withdrawing and withholding treatments is perhaps one of the most challenging decisions faced by health professionals. Effective communication and appraisal of prognosis is important. Guidelines for turning off implantable cardiac defibrillators are available and can assist in clinical decision making.[44] The decision to deactivate should be undertaken in consultation with the patient, their family members and, where possible, a cardiologist. In special circumstances, industry representatives can be enlisted to visit the patient's home or hospice to assist in deactivation.

The decision to withdraw or withhold medication should be based on a comprehensive clinical assessment, including the capacity to swallow. Generally, the aim should to be maintain core CHF drugs, such as beta blockers, for as long as possible as they assist in decreasing symptom burden.[3] If a treatment goal is to reduce the number of tablets taken by the patient, then withdrawing/withholding medications, such as digoxin and cholesterol lowering drugs, should be considered. Warfarin therapy should be critically assessed in terms of risk and benefits. Diagnostic tests should be avoided unless there is a clear intent to act upon the results, particularly in the last weeks of life.[11]

Conclusion

A palliative care approach is relevant across the CHF trajectory, not only for those expected to die within days or weeks, although it is particularly relevant for those with end stage disease. Palliative care should be integrated as part of a team approach. At the end of life, symptom burden is the focus of care. General practitioners and primary care professionals play a crucial role in assisting patients and family to navigate this challenging and vulnerable phase. Engaging specialist heart failure and palliative care services may be appropriate when symptom burden remains high and is refractory to conventional methods.

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