

Palliative care in heart failure: facts and numbers

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Abstract

Millions of people worldwide have heart failure. Despite enormous advances in care that have improved outcome, heart failure remains associated with a poor prognosis. Worldwide, there is poor short-term and long-term survival. The 1 year survival following a heart failure admission is in the range of 20–40% with between-country variation. For those living with heart failure, the symptom burden is high. Studies report that 55 to 95% of patients experience shortness of breath and 63 to 93% experience tiredness. These symptoms are associated with a high level of distress (43–89%). Fewer patients experience symptoms such as constipation (25–30%) or dry mouth (35–74%). However, when they do, such symptoms are associated with high levels of distress (constipation: 15–39%; dry mouth: 14–33%). Psychological symptoms also predominate with possibly as many as 50% experiencing depression. Palliative care services in heart failure are not widely available. Even in countries with well-developed services, only around 4% of patients are referred for specialist palliative care. Many patients and their families would benefit from receiving specialist palliative care support.

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Millions of people across the world are affected by heart failure. It accounts for a significant proportion of healthcare utilization and expenditure, particularly in Westernized societies. The global economic burden of heart failure includes direct healthcare costs as well as indirect societal costs in unreimbursed care, reduced productivity, and the effects of morbidity and premature death. Using data from 197 countries (and 99% of the world's population), this cost has been estimated at US\$108 billion annually.¹ Over the last 30 years, a better understanding of the pathophysiology of heart failure has enabled a range of pharmacological, device, and cardiac surgical therapies to improve the outlook for our patients, particularly those with heart failure with reduced ejection fraction. Many patients now live longer with heart failure but are still subject to a significant burden of physical and psychological symptoms and a relatively poor quality of life.^{2–5}

The heart failure disease trajectory is unique to each individual. Of those patients who survive their index presentation, many exhibit a period of relative stability following initial diagnosis and the establishment of evidence-based therapy. Thereafter, the clinical course is generally one of gradual decline, punctuated by episodes of acute decompensation, which usually increase in frequency and complexity as cardiac function deteriorates.⁶ There is an ever-present risk of sudden death, although this tends to be more common in the earlier phase of the disease and in those with underlying

coronary disease. The widespread use of implantable cardioverter defibrillators has mitigated this risk of sudden cardiac death to some extent. The mode of death for those surviving to develop advanced heart failure is through symptomatic congestion and multi-organ failure. About 5% of all heart failure patients are considered to have advanced disease with refractory symptoms.⁷ These patients merit consideration for support from specialist palliative care. Given the average age of patients with heart failure and their multiple comorbid conditions and frailty, this need for specialist palliative care services is likely to increase over subsequent years.

Palliative care

Palliative care is a relatively young clinical discipline. It originated about 30 years ago when it was primarily concerned with the care of those with cancer. The remit of this specialty has now been extended with the recognition that this level of care provision is no less applicable in supporting those affected by any chronic and/or life-threatening illness.⁸ Palliative care adopts a multi-disciplinary team approach to provide holistic care that addresses the physical, psychological, and spiritual needs of patients, as well as those close to them. Consequently, rather than concentrating on life

extending therapies, the treatment focus of palliative care lies more in maintaining or improving the quality of remaining life and best ensuring a comfortable and dignified death when that outcome becomes inevitable. Although palliative care is often perceived as synonymous with end-of-life care, the key concepts have been accepted as equally relevant throughout any chronic disease trajectory from the point of diagnosis until death (see Box 1).

Box 1. Goals of palliative care (adapted from World Health Organization, 2014. *Global Atlas of Palliative Care*)⁸

Palliative care is as follows:

- aims to provide relief from distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families that includes bereavement counselling;
- enhances quality of life and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life and includes investigations needed to understand and manage distressing clinical complications.

Despite modern advances in treatment, the diagnosis of heart failure confers a significant mortality risk. Data from national registries highlight poor short-term and long-term survival and suggest a within-hospital death rate of between 4 and 10%. Following a heart failure hospital admission, the 1 year death rates are reported in the range of 20 to 40%, with variation in these data between individual healthcare systems.^{9,10} In the UK, the National Heart Failure Audit collates and analyses data on patients admitted to national health service hospitals in England and Wales with new acute heart failure or decompensated chronic heart failure. Data between April 2013 and March 2014 on 54 654 episodes, representing 85% of all heart failure admissions over that period, demonstrate an overall in-hospital mortality of 9.5% rising to 12% for those aged >75 years. These trends remain largely unchanged over the previous 5 years.¹¹ The 1 year mortality of 27% and a 5 year mortality of 45% are similar to current American Heart Association statistics.¹²

Prognostication

Despite the overall relatively poor outlook for patients with heart failure, prognostication on an individual basis is difficult. Models to assess prognosis have been developed,¹³ yet each has specific limitations, particularly in the elderly patient population with multiple comorbidities and frailty where the 1 year mortality risk may be close to 50%.¹⁴ Given this prognostic ambiguity, health professionals remain unclear as to when to involve specialist palliative care or initiate end-of-life approaches. In spite of being subject to progressive physical disability, and having survived many clinical crises, patients frequently fail to appreciate the seriousness of their condition, and later, their families are often shocked by what they perceive as an unexpected death.

The European Society of Cardiology (ESC) guidelines¹⁵ recognize this difficulty in deciding when patients require specialist palliative or end-of-life care. However, they provide some advice to help clinicians identify patients that should be considered for referral to a specialist palliative care or end-of-life service (Box 2).

Box 2. Suggested criteria for referral to specialist palliative care service

- Frequent readmission to hospital within past 12 months
- Frequent decompensation of chronic heart failure [Correction added after online publication on 23 January 2017: DE compensation changed to decompensation]
- New York Heart Association Class IV
- Progressive decline in quality of life

The patients' perspective of heart failure can be found in studies that have specifically sought their opinion, and these generally employ a qualitative research methodology. Whilst their study design does not set out to produce results that are statistically generalizable, key themes have emerged: That patients often experience barriers to open communication with healthcare professionals, including an inability to talk freely with clinicians and to ask questions about prognosis, together with a sense that information is being withheld.^{16–19} This may reflect an understandable reluctance of healthcare professionals to initiate discussion on end-of-life issues, either as a manifestation of their own attitudes to death or dying or anxiety about undermining patient's trust or hopes for the future.²⁰ In addition, patients describe professionally driven healthcare services that focus on delivering guideline-based medical treatment. This is sometimes burdensome in itself, and there is often poor co-ordination and a lack of continuity

of care.^{16,21,22} Heart failure management programmes have been developed in several countries to address many of these issues. Despite this, patients continue to experience an ongoing need for better communication and experience a high symptom prevalence and burden.

Needs assessment in heart failure

Multiple studies have described the symptom burden associated with heart failure and the impact on health status and quality of life. These studies illustrate how patients experience a high number of symptoms, many of which they also find highly distressing²⁻⁵ (Table 1). Here, we focus on physical and psychological symptoms.

More than two decades ago, large surveys reported a high burden of symptoms and concerns in patients with advanced heart failure.^{23,24} The most commonly reported symptom was pain, and this was also found to be very distressing in 50% of patients. Forty three per cent reported dyspnoea.

Emotional symptoms were also reported with low mood in 59% and high levels of anxiety in 45% of patients. Other symptoms, albeit less frequently reported, included urinary incontinence, constipation, and nausea. In those patients admitted to hospital, the management of these symptoms was optimized but brought little relief: 35% still experienced distressing pain, 31% constipation, 24% dyspnoea, and 24% nausea.²³ Data from the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT) of the last 6 months of life show that these symptoms increase in frequency close to death. In the final 3 days of life, as many as 63% reported extreme shortness of breath.²⁴ Whilst in recent years, the need to address symptom prevalence and relief in advanced heart failure has received a greater emphasis, many patients still experience a spectrum of refractory malaise.

More recently Blinderman and colleagues studied a sample of 103 patients in the USA.²⁰ The mean age was 67 years, 72% male, and all were in NYHA class III/IV. The most prevalent symptoms reported by more than half of this population were lack of energy, dry mouth, shortness of

Table 1 Goals of palliative care

	Lokker <i>et al.</i> ² n = 230		Blinderman <i>et al.</i> ³ n = 103		Zambroski <i>et al.</i> ⁴ n = 53		Wilson and McMillan ⁵ n = 40	
	Frequency (%)	High distress (%)	Frequency (%)	High distress (%)	Frequency (%)	High distress (%)	Frequency (%)	High distress (%)
Physical problems								Not Reported
Shortness of breath	95.2	89	56.3	43.1	85.2	60.5	65	
Feeling drowsy/tired	93.0	83	52.4	24.1	67.9	37.1	72.5	
Pain	91.3	76	37.9	54.1	57.4	51.7	52.5	
'I don't look like myself'	90.4	81	25.2	23.1				
Weight loss	84.8	51	19.4	25	32.1	18.8	52.5	
Lack of energy	82.2	67	66	44.8	84.9	63.6	70	
Swelling arms/legs	81.3	70	32	33.3	47.2	30.4	47.5	
Difficulty sleeping	77.0	64	44.1	44.4	64.2	60.6	52.5	
Tingling hands/feet	73.5	66	48.5	22	46.2	47.8	55	
Changes in way food tastes	73.0	61	15.5	18.5	18.9	44.4	50	
Lack of appetite	72.2	53	31.1	25.8	30.2	40	37.5	
Difficulty concentrating	67.4	30	33	29.4	50	44	40	
Problems with sexual interest/activity	52.6	8	26	46.2	46.3	50	17.5	
Cough	49.1	33	40.8	16.7	57.4	14.8	45	
Nausea	42.2	23			41.5	19	20	
Dizziness	41.3	19	27.2	32.1	51.9	38.5	45	
Feeling bloated	36.1	19	28.2	17.2	51.9	40	25	
Dry mouth	35.7	15	62.1	14.1	74.1	33.3	72.5	
Problems urinating	32.2	16	26.2	29.6	24.1	27.3	17.5	
Itching	28.3	8	34.3	22.9	43.4	47.4	40	
Constipation	26.1	15	25.2	38.5	26.4	30.8	30	
Vomiting	25.7	13			24.1	33.3	10	
Sweats	25.2	15	21.4	18.2	53.7	42.9	27.5	
Diarrhoea	12.2	18			22.2	10	17.5	
Psychological problems								
Worrying	94.3	30	43.7	33.3	61.5	53.3	50	
Feeling irritable	93.5	28	33	26.5	53.7	34.6	32.5	
Feeling sad	93	18	42.7	34.1	54.7	44	37.5	
Feeling nervous	92.2	50	35.9	38.9	53.7	38.5	30	

breath, and drowsiness. Less commonly reported symptoms included numbness or tingling in hands and feet, insomnia, cough, and anorexia. The patients also described various psychological symptoms: worrying, sadness, nervousness, difficulty concentrating, and feeling irritable. Alongside this high symptom prevalence, they described high levels of symptom intensity, frequency, and associated distress. High levels of distress were associated with symptoms of lack of energy, dry mouth, shortness of breath, and feeling drowsy and pain (*Table 1*)

Most studies of symptom prevalence in heart failure have been based on a typical elderly, predominantly male patient population, living with left ventricular dysfunction in the developed world. Whilst the prevalence of heart failure in developing countries is also high, a different aetiological background, including infectious and tropical diseases, more maternal ill health, and poorly controlled hypertension, leads to a younger demographic with a different gender bias. Despite these differences, a similar pattern of heart failure symptom and burden is emerging. A recent study of 230 patients with advanced heart failure attending a public hospital in South Africa reported on symptom prevalence and burden in younger patients.¹⁹ The mean age of the study population was 58 years, 127 (55%) female, and few patients had multiple comorbidities (mean two comorbidities). All were symptomatic on at least minimal exercise (NYHA class III, 90%; NYHA IV, 10%) and required considerable assistance to undertake the activities of daily life and were unable to work and required frequent medical care (Karnofsky Performance Status Score, mean score 50%). The patients reported a high prevalence of symptoms. Prominent physical symptoms included shortness of breath and feeling drowsy/tired and pain. In this younger population, urinary incontinence was also reported by 32% and constipation in 26%. Psychological symptoms with the highest prevalence included worrying, feeling irritable, and feeling sad. Symptoms of 'shortness of breath', 'numbness/tingling in hands or feet', and 'I do not look like myself' were described as most distressing¹⁹ (*Table 1*).

Alongside physical symptoms, there is a deleterious effect on psychological wellbeing. Depression is common in heart failure, likely applicable to at least a third of patients. Some depressive symptoms may overlap with symptoms of advanced heart failure, such as tiredness. However, even when taking such confounding factors into account and excluding these items from data analysis, studies still report high levels of depression in heart failure, possibly affecting as many as 50%.²⁵

Many patients experience multiple symptoms simultaneously which exacerbates their symptom burden. A recent survey of more than 700 patients with heart failure recruited from the USA, the Netherlands, Sweden, and Asia reported a cluster of physical symptoms that included dyspnoea, difficulty in walking or climbing, fatigue/increased need to rest, and fatigue/low energy. Worrying, feeling depressed, cognitive problems, and sleep difficulties formed an emotional

symptomatic cluster.²⁶ The authors report few cultural differences in the components of these symptom clusters. Whilst some of these clusters are interrelated, they do not necessarily share a common mechanism or trigger. Symptomatic clustering will no doubt influence the patient's ability to self manage their heart failure; maintain physical, mental, and social functioning; and increase the complexity of the intervention required to comprehensively deal with individual need. This all points to the need to consider a more nuanced approach to their care, taking into account these sometimes subtle but important differences, and facilitate provision of a personalized treatment plan consistent with their specific concerns.

Integrating palliative care into heart failure care

Given the poor survival rates from heart failure and the high prevalence of symptoms, the need to integrate a palliative care approach into the overall heart failure patient pathway is clear. Palliative care is recognized in international heart failure guidelines.^{11,27} The Heart Failure Association (HFA) of the ESC issued a position statement in 2009,²⁸ and the most recent ESC heart failure guidelines of 2016 acknowledge the value of including palliative care but stop short of providing a recommendation with a level of evidence.¹¹ In contrast, the 2013 heart failure guidelines from the American Heart Association and American College of Cardiology recommend palliative care to improve quality of life in symptomatic patients based on perceived patient benefit. They advise that this should be incorporated in discharge planning (Class 1; level of evidence B).²⁷

Despite this recognition, few patients are referred to specialist palliative care services. Turning again to data from the UK, the National Heart Failure Audit data from 2013 to 2014 report that only 4% of patients with heart failure were referred to specialist palliative care services, a proportion which has been relatively constant over several years.⁷ Whilst not significantly different from the earlier reported 5% threshold of need,³ this low referral rate to specialist palliative care services likely represents an under provision of support for these acute heart failure patients who may have particularly complex needs. However, heart failure nurses in the UK provide comprehensive disease management and view the provision of general palliative care as a major component of their role. Following an educational initiative from the British Heart Foundation and fostering links with specialist palliative care through a multi-disciplinary team approach, their delivery of general palliative care has increased in recent years.²⁹ Limited access to similar collaborative heart failure disease management programmes and variation in team roles and responsibilities across Europe may result in some

patients and their families being denied this much needed level of support.

Implanted electronic and mechanical assist devices

Dilemmas related to the handling of implanted device therapy in the face of progressive heart failure or the occurrence of another life limiting disease are worthy of special mention in relation to palliative and end-of-life care. There has been an exponential increase in the rates of use of implantable cardioverter defibrillators, and cardiac resynchronization therapy with defibrillators as evidence for benefit has accrued. At the point of implantation, discussion tends to be framed around the protection conferred by having the device. To the patient, the decision is often binary in accepting the device or anticipating an avoidable death. The possibility of later device deactivation in the face of clinical decline towards the end of life is rarely broached.³⁰ Similarly, the informed consent process tends to concentrate on peri-procedural and short-term risk rather than considering events, sometimes perceived as hypothetical, later in the course of life. Evidence suggests that patients and families sometimes anticipate later adverse clinical scenarios and show a willingness to confront these issues at the time of implantation.^{30,31} Guidelines issued by the European Heart Rhythm Association suggest that end-of-life issues should be incorporated in pre-implant discussions and revisited at intervals along the heart failure disease trajectory.³² Many studies have demonstrated that discussion of device deactivation, if it takes place at all, may occur very close to the point of death.³³ Advance care planning might obviate some of these problems but has been little espoused by heart failure patients. When these instruments are used, they tend to be generic with little attention to device-specific preferences.³⁴ Decisions on device deactivation should be undertaken at times when there is access to the equipment and personnel with the required expertise to facilitate this process. Many reports describe patient and family distress as shocks are administered during the active dying phase, even when a 'do not resuscitate' order is in place.³⁵

For those with left ventricular assist devices, implanted either as a bridge to transplantation or as destination therapy, liaison with palliative care is appropriate.³⁴ Inter-professional discussion is relevant pre-implantation, and palliative care involvement is certainly critical when withdrawing therapy.

Challenges to integrating palliative care and heart failure

The need to increase the emphasis on palliative and end-of-life care has been identified as a policy recommendation that is necessary to improve care to patients with heart failure: a document endorsed by the HFA alongside 49 national heart failure working groups.⁶ However, this will require several challenges to be overcome.

Integrating heart failure and palliative care remains difficult, with insufficient evidence to allow us to currently recommend any specific model. Examples of good practice do exist and describe the provision of heart failure palliative care based on local service configuration. One service adopted a shared care approach by a cardiologist and palliative care physician, with the heart failure nurse specialist acting as a key worker and liaising among local medical care, hospital specialists, and hospice services.³⁶ A small pilot study of integrated palliative advanced home care and heart failure care study in Sweden (PREFER study) randomized 72 patients with advanced heart failure to usual care or care provided by palliative and heart failure specialists (physicians and nurses). The intervention included patient education around heart failure self care, advanced care planning, and frequent needs assessment that included physical, psychological, social, and spiritual issue needs. Needs assessment focused on heart failure and other comorbidities.³⁷ The patients randomized to receive the intervention experienced a significant reduction in nausea ($P = 0.02$), better quality of life ($P = 0.05$), fewer hospitalizations ($P = 0.009$), and fewer days in hospital (103 vs. 305). Symptom relief was aided by the administration of intravenous diuretics at home but was fairly labour intensive, some patients requiring several home visits each day. Additional studies on similar initiatives are currently underway.³⁸ When reported in full, they should add to our knowledge and help to inform guidance on how best to integrate palliative and heart failure care.

Providing palliative care alongside optimal heart failure management is difficult, and sometimes, the ethos of palliative care and cardiology seem to be at odds. Rather than working in silos, a multi-disciplinary approach is applicable, garnering and synergizing the skills of both specialties so that patient care is optimized throughout the course of the illness.

Conflict of interest

None declared.

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