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Heart failure as a subject for palliative care

Abstract

Heart failure (HF) is a common end stage in any structural or functional cardiac disease advanced enough to impair the filling of the ventricles or blood ejection. If the degree of impairment makes the heart unable to cope with the actual demands of pumping blood, the diagnosis of heart failure is justified. The heart first disables the circulation during exercise and finally, in end-stage HF, even at rest. HF is a progressive process, usually only slowed by the treatment currently available. Thus from diagnosis, the disease will accompany patients for the rest of their lives, sometimes becoming the cause of death. A patient reaching end-stage heart failure should be considered for one of four treatment options: mechanical circulatory support; continuous intravenous positive inotropic therapy; a referral for cardiac transplantation; or hospice care. Before the patient is considered to have end-stage HF, all curable factors potentially causing a deterioration in cardiac function have to be actively explored and corrected. This paper focuses on patients for whom methods to improve prognosis and heart function have been exhausted. The number of such patients is increasing continuously. This is caused by the growing incidence of heart failure, improvement in the medical care prolonging survival, and progress in decreasing the number of sudden cardiac deaths in the early stages of the disease.

Key words: end-stage heart failure, palliative care

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Introduction

The prevalence of heart failure in the European Union is estimated at 2–3% of the general population [1]. In Poland 700,000–750,000 people are affected by heart failure (HF) [2, 3]. In a recent Polish study, the average age of patients admitted to hospital due to HF decompensation was about 70. Heart failure mostly affects elderly people: the mean age of HF patients in developed countries is about 75 years old. This explains the important influence of concomitant diseases on the quality of life, possible drug interactions and finally the cause of death. Ischaemic aetiology is mentioned

in over 60% of patients, often with hypertension as a concomitant disease [2]. The overall prognosis in HF, although improving, still remains very gloomy. About 50% of patients die within 4 years of diagnosis [1] and the average time elapsing between diagnosis and death is very short (1.7 years for men and 3.2 years for women) [4]. Statistical data clearly indicate that HF is associated with a bad prognosis and a decidedly lowered life expectancy but awareness in the clinical praxis is still not satisfactory. Modern clinical decision-making has to be supported by clinical trial results, whereas the primary end-point in those trials has been a reduction of cardiovascular mortality or all-cause

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mortality. Unfortunately, quality of life or a life span with satisfactory quality was almost never investigated. Current guidelines pay increasing attention to the need for supportive care in end-stage HF patients [5].

The natural history of heart failure

The current ACC/AHA classification of HF focuses on a stepwise progression from the presence of HF risk factors (Stage A), through structural heart abnormalities (Stage B) to heart failure (Stage C), and its end-stage phase (Stage D). The last two stages (C and D) are the subject of functional NYHA classification (I to IV). The development of structural cardiac abnormalities can have one of three outcomes: 1. the patient dies before developing any symptoms; 2. the patient develops HF symptoms which respond to treatment; and 3. the patient dies from progressive HF. Sudden death can interrupt this course at any time [1]. During the initial presentation, many patients experience symptoms corresponding to NYHA class III. After appropriate treatment is instituted, some of the patients improve, some stabilize at their current condition, and some deteriorate despite optimal therapy. Of the patients admitted to hospital for HF decompensation, 40% will die or be readmitted within one year [1].

Despite unchallenged progress in treatment, the prognosis for HF patients remains poor, often even worse than for many cancer patients. However, patients can potentially benefit from heart transplantation (there were only 325 transplantations in Poland during the years 2003–2007) or mechanical circulatory support but most patients with advanced heart failure enter the terminal phase and die [3]. The main mechanism of death in NYHA class IV is the progressive failure of the heart as a pump.

There are several potentially reversible causes of HF that should be ruled out prior to acknowledging HF as being end stage and irreversible. The development of specialized outpatient clinics would allow competent discrimination between potentially curable and true end-stage forms of HF. The interdisciplinary teams would ensure optimal tailoring of therapy and support for patients and their families. This means not only prompt use of reasonable modalities and devices but also abandonment of redundant procedures (e.g. implantation of ICD for people with a short life expectancy). A life expectancy shorter than one year due to HF, the patient's general condition or concomitant diseases (often seen in elderly people), should dictate the avoidance of

invasive procedures (e.g. ICD, CRT or cardiovascular surgery). Refusal to use such interventions can be seen as a way of keeping quality of life at the best possible level.

Heart failure as a terminal disease

There are a few conditions which have to be fulfilled for treating patients with end-stage HF properly with regard to the advancement of the disease. First of all is the awareness of medical caregivers of the bad prognosis. The statistical facts are usually well known but remain without influence on clinical praxis. HF is still treated as a relatively benign disease causing breathlessness and oedema. Consequently, communication with patients and their families is often far from ideal. However, the tools for predicting the outcome and the time taken for the course of the disease, even if very sophisticated, are imperfect [6, 7]. In a recent study it was shown that nurses' observations anticipated, with the highest accuracy, the probability of death within 6 months [8]. The prognostication about life span in HF is more difficult than for other chronic diseases. The stable, stepwise deterioration trajectory of chronic HF is sometimes broken abruptly by an unpredicted worsening [9]. This worsening can be of only temporary exacerbation but it can also be the last episode, finishing life [1]. Studies investigating the quality of life of patients with HF have shown that they suffer, to at least a comparable degree, as much as patients dying from cancer, but for many months longer before death. Approximately 40% of patients are unable to get out of bed or a chair for the 12 months prior to death [10], which is why the time for scheduling palliative care should be determined by the symptoms or degree of disability, not the predicted live span. If a patient suffers from marked symptoms despite optimal medical therapy, the symptomatic approach should outweigh the causative [5]. The goals and steps in the palliative approach to HF have been given in current guidelines for the diagnosis and treatment of acute and chronic heart failure by the European Society of Cardiology (Table 1) [1].

Elements of a palliative approach to a patient with heart failure

Education

The patient and family should be informed about the prognosis, treatment options, possible function-

Table 1. Goals and steps in the process of providing palliative care in patients with heart failure (HF) [1]

Patient features	1 episode of decompensation/6 months despite optimal tolerated therapy Need for frequent or continual IV support Chronic poor quality of life with NYHA IV symptoms Signs of cardiac cachexia Clinically judges to be close to the end of life
Confirm diagnosis	Essential to ensure optimal treatment
Patient education	Principles of self-care maintenance and management of HF
Establish an advanced care plan	Designed with the patient and family member. Reviewed regularly and includes the patient's preferences for future treatment options
Service should be organized	The patients' care within the multidisciplinary team, to ensure optimal pharmacological treatment, self-care management and to facilitate access to supportive services
Symptom management	Requires frequent assessment of patients' physical, psychological, social and spiritual needs. Patients frequently have multiple co-morbidities that need to be identified
Identifying end-stage HF	Confirmation of end-stage HF is advisable to ensure that all appropriate treatment options have been explored a plan for terminal stage of illness should be agreed upon
Breaking bad news to the patient and family	Explaining disease progression and a change in treatment emphasis is a sensitive issue and must be approached with care
Establishing new goals of care	End-of-life care should include avoidance of circumstances which may detract from a peaceful death. All current pharmacological treatment and device programmes should be considered. Resuscitation orders should be clear

NYHA — New York Heart Associations

al deterioration and life expectancy [5]. An early start to this process is preferable in order to prepare the patient and family for settling important end-of-life questions. It is easier to accept the need for asking questions about treatment strategies or the abandonment of resuscitation in case of cardiac arrest when the patient is in a stable condition than in more urgent circumstances. Even if patients change their mind, it seems more comfortable for them to return to a discussion that has already been started. A lower-than-expected percentage of patients admitted for HF decompensation declare the wish not to be resuscitated in the event of cardiac arrest (23%). This number decreases by 40% after discharge [11], which probably reflects the hope that the next exacerbation of symptoms will only be a similarly temporary event and, after treatment, it will be possible to return to the condition preceding decompensation.

Modification of current medication

Basic HF medication improves not only prognosis and disease progression, but also helps to control the signs and symptoms of cardiac insufficiency. Thus the basic treatment should also be continued in end-stage HF. The discontinuation of treatment can provoke symptom exacerbation. Lowering the dose of ACEI, seldom discontinuation, in cases of hypotension is justified only if it is symptomatic. The main reason warranting the abrupt discontinuation of ACEI is angioneurotic oedema. Abrupt withdrawal of treatment with an ACEI can

lead to a deterioration of the patient's state and should be avoided if possible. Beta-blockers, used as standard treatment, should preferably not be stopped, even in the case of HF exacerbation. Instead, decreasing the dose temporarily is suggested [5]. However, drugs prescribed for improving the long-term prognosis can be revised (e.g. lipid-lowering agents). Some controversy has arisen over the potential harm of aspirin in advanced HF. A few of the older studies have suggested that aspirin can enhance the risk of rehospitalization due to the worsening of heart failure [12]. As such, perhaps, long after myocardial infarction in patients without coronary stents, the discontinuation of acetylsalicylic acid would be reasonable if they are prone to hypervolaemia.

The introduction of symptomatic medication

The general rules of symptomatic treatment, until eventual studies addressing HF patients indicate otherwise, are similar to end-of-life treatment used in palliative care. However, it has to be remembered that those treatment strategies have been established for patients dying from cancer. Neuroleptics, anxiolytics, non-opioid analgesics and opioids, co-analgesics and oxygen are usually prescribed for symptom relief. In addition, the armamentarium for the treatment of HF patients embraces drugs which influence the cardiovascular system: positive inotropic drugs and intravenous diuretics [5]. It is important in the context of palliative care to underline the reason that the administration of drugs is for

symptomatic reasons and the improvement of the quality of life, not the prolongation of life. Even if inotropes are accused of having a negative influence on survival, they are acceptable in end-of-life treatment when decreasing suffering becomes the priority.

The restriction of device therapy

Implantable cardioverter-defibrillators (ICD), with or without cardiac resynchronization therapy (CRT), are recommended for patients in a stable condition with NYHA class II or III, with at least 3-6 months of optimal therapy and a life expectancy with a good functional status of longer than one year. Pacemakers with atrial or ventricular pacing (without CRT or ICD) may be observed in patients who have evolved further in living with heart failure after a device has been implanted. When the patient enters the end-stage phase of heart failure and death is approaching, it is reasonable to consider deactivating the device or some of its functions. The main issue is the deactivation of defibrillating capacity [5]. The decision concerning the lack of ICD intervention in cases of ventricular fibrillation is consistent with a non-resuscitation decision. If death seems to be imminent, as a consequence of advanced and progressive disease leading to irreversible damage of the organ or system function, there is no indication to resuscitate. Automatic interventions by the implanted device, attempting to interrupt the process of dying, are useless in these circumstances and can potentially even worsen suffering. The decision about ICD deactivation should be discussed much earlier with the patient, his or her family and GP. Pacing capacity can usually be kept unchanged because this does not cause suffering and, in addition, can prevent symptoms triggered by arrhythmia (e.g. syncope). However, people sometimes have concerns about the potential possibility of pacemakers prolonging agony. This issue is in fact more complex and controversial than ICD deactivation.

Conclusions

The development of a palliative approach to patients with HF is an important area of treatment which breaks down the barriers between specialties. The person who is suffering becomes the subject of holistic medicine. People who care about others complying for symptoms caused by different diseases try to solve their problems, to allow them to spend left life time in best accessible quality, in

comfort and in quiet surroundings. To achieve this ideal picture, a great deal has to be done. One of the most important issues is the question of who should be the carer: the cardiologist, palliative medicine specialist or a GP supported by other practitioners. It seems reasonable that patients should remain under the supervision of the doctor who has accompanied them during their illness. Such a solution, however difficult to organize, would give the dying person continuity of care between the inpatient and outpatient settings.

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