

Piotr Sobański

Department of Cardiology, Regional Heart Failure Centre, II University Hospital in Bydgoszcz

Are patients with congestive heart failure entitled to receive palliative care?

Abstract

When, in 1963, J.M. Hinton published his article on the suffering that accompanies dying, by no means did he confine his observation to patients who suffered from oncological conditions. Quite the contrary, as in his essay we can find an explicit statement which says that the suffering of patients dying from cardiac or renal insufficiency is even greater than for patients in the terminal stages of cancer [1]. That article sparked off the development of charitable organizations in Great Britain which took care of oncological patients. This was the reason why palliative medicine was and still is associated with people dying from cancer. It has been more than 50 years since the publication of Hilton's work and from that we have rediscovered the forgotten part of the author's message and begun to realize that patients can ask for help not because of a particular disease, but because of the suffering that accompanies his dying. Modern palliative medicine has developed based on the care of oncological patients. For this reason, and despite the fact that the aim of this article is to draw attention to non-oncological patients, we cannot avoid referring to the problems of patients with cancer.

Key words: palliative care, heart failure, chronic disease

Adv. Pall. Med. 2008; 7: 119–122

Palliative care is directed to those patients coming close to the end of their lives. Each incurable and progressing chronic disease may cause suffering and, eventually, death. Patients diagnosed with heart failure are faced with a shortened life expectancy when compared to that of the general population. The yearly death rate for patients with heart failure depends on the disease advancement and fluctuates from 5% to 60% [2]. Diseases which result in the death of the patient are described by death trajectories, i.e. the expected scenario for the end of life. Patients suffering from heart failure die from the progression of dysfunction of the heart as a pump, from the mechanism of sudden cardiovas-

cular death or from non-cardiogenic reasons relating to coexisting diseases. The stage of heart failure advancement is translated into the distribution of the causes of death: the majority of patients with less advanced forms of the disease die more suddenly (around 60% of deaths) than patients in the more advanced stages (23% of deaths). A reverse relationship is found in proportion of deaths caused by the progression of heart insufficiency as a pump (28% of deaths in moderate stages of the disease, 44% in advanced stages) [3]. Dying from the heart's as a pump insufficiency is not necessarily the consequence of steady progressive deterioration of the heart function. Gradual disease progression is usu-

Address for correspondence: dr med. Piotr Sobański

Department of Cardiology, Regional Heart Failure Centre II University Hospital In Bydgoszcz

ul. Ujejskiego 75, 85–168 Bydgoszcz

e-mail: psoban@wp.pl

Advances in Palliative Medicine 2008, 7, 119–122

Copyright © 2008 Via Medica, ISSN 1898–3863



ally broken by periods of sudden exacerbations. It is hard to predict whether the present exacerbation is only temporary episode, or will put an end to the patient's life. So, the trajectory of the steady progression of heart insufficiency until the terminal stage is interrupted by periods of abrupt failure worsening and, sometimes, of an unexpected death. An analysis of the fates of patients with chronic congestive heart failure demonstrates that the course of their final period of life, the progression of the condition and the quality of life they experience, is difficult to predict and shows many individual variations. This is one of the key elements that make the process of qualifying cardiologists patients for symptomatic treatment so problematic [4].

The symptoms which accompany patients with congestive heart failure resemble those characteristic for people suffering from cancer. A small number of dissertations dedicated to patients with congestive heart failure demonstrate that such symptoms as pain, dyspnoea, sleeplessness, fatigue or depression are at least as frequent as the same symptoms present in the terminal stages of cancer (Table 1). Unfortunately, symptomatic treatment of the end stage heart failure today resembles the condition of health care for terminal cancer patients from before the era of palliative medicine. The symptoms in patients with heart failure who approach the end of life are treated with the help of ambulance crews, who are called to subsequent attacks of dyspnoea, syncope caused by a drop in arterial pressure, terminal pulmonary oedema or the patients' agony. As a result of emergency medical help, patients are sent to the intensive cardiac units, where they receive standard treatment for acute heart failure and

are discharged without any real plan for further assistance. [5] The first step in improving the quality of treatment for patients with congestive heart failure would be to get better communication with such patients, then learn to respect their wishes ("learn about the needs of your patient, and then think if and how you can satisfy them"). The three principles that cardiologists should learn from palliative medicine professionals are listed below: 1. Active listening 2. The ability to convey bad news 3. Therapeutic dialogue. [6] The study that evaluated the quality of life in patients with heart failure in the last 48–72 hours of their life (based on accounts of bereaved families) demonstrated that 66% of patients suffered from severe dyspnoea, 45% from pain and 15% from mental disorientation. More than 40% of the patients in that condition underwent major medical interventions (feeding through a stomach tube, mechanical ventilation or resuscitation). Such a large number of interventions is especially alarming, if we consider that most of the patients declared that they wanted to die in peace instead of aggressively fighting for their lives. Only members of their families were aware of those wishes; the emergency teams of healthcare professionals were not [7].

The principles of palliative treatment have been worked out for oncological patients. Since the anti-cancer treatment itself is often the cause of symptoms and a decrease in quality of life, withdrawing from it may, therefore, bring relief to patients in the terminal stages of oncological diseases. Consequently, one cannot escape the thought that a similar reversal of therapy should also apply to patients with heart failure. In the meantime, the

Table 1. Frequency (in %) of symptom occurrence in the advanced stages of cancer and heart failure — moderate or severe (in brackets) [5, 13]

Patients' symptom	Oncological	Heart failure I/II and (III/IV) NYHA
Pain	78	41% (78)
Dyspnoea	61	83 (61)
Mental symptoms		
Mood deterioration	59	41 (59)
Sleeplessness	45	(45)
Fear	30	
Anorexia	43	21 (43)
Constipation	37	12 (37)
Nausea/vomiting	32	17 (32)
Fatigue		82
Difficulty in movement		65
Oedema		33

NYHA — New York Heart Association

currently applied treatment for patients with chronic heart failure, albeit bringing a positive effect to disease progression and/or distant prognosis, is often the source of a decrease in the intensity of cardiovascular system problems. Therefore, abandoning this type of treatment is neither necessary nor appropriate. The change in the priority of treatment, from improving distant prognosis and suppressing disease progression into short-term goals, i.e. improvement of the quality of life and reduction of symptoms, allows for the use of drugs which effectively reduce the symptoms of heart failure — even if they may affect life expectancy. This is the case with positive inotropic drugs (catecholamine and inhibitors of phosphodiesterases). Many randomized studies on the effects of these drugs on the progression of the disease have demonstrated that they increase the risk of death, although they effectively reduce the symptoms caused by heart failure. The key to accepting the use of these drugs in palliative cardiology is for the cardiologists to embrace the principle that the struggle for the prolongation of life in the final days may not be as important as the reduction of suffering. It is according to this principle that patients with extreme heart failure receive catecholamine infusions, even at home for symptoms control, but not for reaching of hemodynamic goals. Published results are still too few, but essays that evaluate the influence of these drugs on the symptoms of heart failure in the final period of life are promising and weigh in favour of introducing them in palliative cardiological treatment [8–11].

Implantable devices (pacemakers and resynchronizing pacemakers — CRT), as well as antiarrhythmic devices (automatic, implantable cardioverter-defibrillators — ICDs) have become so popular with patients with heart failure that attending dying patients who have such apparatus is slowly becoming a daily sight. Maintaining the ICD stimulation/activity during the period of dying has raised many doubts. Families of patients often inquire about the usefulness of prolonging stimulation or express their concern about unnecessary prolongation of agony by an active device. The deactivation of implantable automatic cardioverter-defibrillators has created even more controversy, as patients may suffer from the discharges of ICD. Such devices frequently intervene when patients are dying, which leads to uncontrolled movements of the body. It may cause great discomfort to the family and lead to fear of receive electric shock of caregivers. Although the debate concerning the functions of the devices in

question has become heated, it is beyond any doubt that the patient, and most likely his or her family, has the right to demand deactivation of them. Patients have an undisputed right to decide about their treatment. They may not, therefore, agree to start a new therapy but they can also ask to abandon a treatment that has already been in progress. The deactivation of a ICD is an example of such a decision [12]. Nobody has the right to question this wish if the patient has the full mental capacity to ask for the deactivation of this device. It may, however, be considered which moment is the most appropriate to discuss the issue of deactivating the ICD in case when the patient is approaching death. It seems that the most logical solution is to inform the patient about the possibility of deactivating the ICD device before it is implanted. The most important element in the interpretation of the decision to abandon therapeutic activities (especially ICD) at the end of life is to understand that the cause of death is the end stage of disease, not a specific medical intervention. The essence of such action is, therefore, not to cause death but to prevent the suffering from increasing [12]. The decision to deactivate an ICD can be compared to the decision not to resuscitate. In the case of natural death caused by extremely advanced and incurable diseases, resuscitation is not only illogical but may also become a reason for questioning the ability to assess the situation in a professional manner. Unfortunately, everyday clinical practice demonstrates that the wishes of patients are not respected, be it from fear of ethical qualification of such behaviour, lack of confidence that the apparently inevitable deterioration of a patient's condition can be reversed or the intention to inform the bereaved family (or, most likely, to reassure the doctors themselves) that everything possible was done to save the life of the patient.

Death is the natural end of life. The diagnosis of an incurable and progressive disease determines the time and manner of approaching it. Doctors, marvelling at the effectiveness of modern medicine, often forget that incurable disease eventually reaches the stage at which death becomes inevitable. They see their mission as eliminating the disease, not curing the patient (treating is not a synonym for curing!). In the meantime, a significant part of the medical profession equates the dying of patients with failure of the treatment. The feeling of failure, so often present with doctors, makes them avoid talking to patients and their families about the issue. Consequently, patients cannot understand their

disease and doctors are not aware of the patients' needs. The knowledge of the course of a disease enables doctors to take note of the moment when further heroic struggles for the prolongation of a patient's life may diminish the comfort of his or her last days. Mature support of patients who suffer from fatal diseases should, therefore, consist of a skilful change to the treatment objective, from lengthening the prognosis to improving the quality of life, and eventually to providing as much comfort in dying as possible.

References

1. Hinton J.M. The physical and mental distress of the dying. *Q. J. Med.* 1963; 32: 1–21.
2. Rose E.A. et al. The REMATCH trial: rationale, design, and endpoints. *Ann. Thorac. Surg.* 1999; 67: 723–730.
3. Carson P. et al. Mode of Death in Advanced Heart Failure: The Comparison of Medical, Pacing, and Defibrillation Therapies in Heart Failure (COMPANION) Trial. *J. Am. Coll. Cardiol.* 2005; 46: 2329–2334.
4. Gott M., Barnes S., Parker C. et al. Dying trajectories in heart failure. *Palliat. Med.* 2007; 21: 95–99.
5. Nordgren L., Sorensen S. Symptoms experienced in the last six months of life in patients with end-stage heart failure. *Eur. J. Cardiovasc. Nurs.* 2003; 2: 213–217.
6. Ward C. The need for palliative care in the management of heart failure. *Heart* 2002; 87: 294–298.
7. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA* 1995; 274: 1591–1598.
8. Erlemeier H.H., Kupper W., Bleifeld W. Intermittent infusion of dobutamine in the therapy of severe congestive heart failure — long-term effects and lack of tolerance. *Cardiovasc. Drugs Ther.* 1992; 6: 391–398.
9. Marius-Nunez A.L., Heaney L., Fernandez R.N. Intermittent inotropic therapy in an outpatient setting: a cost-effective therapeutic modality in patients with refractory heart failure. *Am. Heart J.* 1996; 132: 805–808.
10. Young J.B., Moen E.K. Outpatient parenteral inotropic therapy for advanced heart failure. *J. Heart Lung Transplant.* 2000; 19 (8 Suppl.): S49–57.
11. Sindone A.P., Keogh A.M., Macdonald P.S., McCosker C.J., Kaan A.F. Continuous home ambulatory intravenous inotropic drug therapy in severe heart failure: safety and cost efficacy. *Am. Heart J.* 1997; 134: 889–900.
12. Mueller P.S., Hook C.C., Hayes D.L. Ethical analysis of withdrawal of pacemaker or implantable cardioverter-defibrillator support at the end of life. *Mayo Clin. Proc.* 2003; 78: 959–963.
13. Anderson H., Ward C., Eardley A. The concerns of patients under palliative care and a heart failure clinic are not being met. *Palliat. Med.* 2001; 15: 279–286.