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The First Steps Taken to Implement Palliative Care in Advanced Heart Disease

A Position Statement from Denmark

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SPECIAL REPORTS

The first steps taken to implement palliative care in advanced heart disease – a position paper from Denmark

(Prior abstract presentations should be described in a footnote to the title)

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Abstract

Background: According to WHO, palliative care must be available for everyone with life-threatening diseases. However, in daily practice the primary focus worldwide is on cancer patients.

Objectives: To generate a national position paper as the first step in implementing palliative care in severe heart disease with focus on advanced heart failure, including tools to identify the need for and timing of palliative care and how palliative care could be organized in Denmark.

Design and methods: A task force was formed in the Danish Society of Cardiology Heart Failure Working Group, and the position paper was prepared in collaboration with members from a broad group of specialties, including palliative medicine. Because of major gaps in evidence, the position paper was based on small and low quality studies and clinical practice statements.

Results: This position paper was aligned with the European Society of Cardiology recommendation, focusing on relieving suffering from the early disease stages parallel to standard care and supplementing life-prolonging treatment. The paper delivers practical guidance on clinical aspects and managing symptoms during the three stages of advanced heart disease. Further, the paper describes the importance of communication and topics to be broached, including deactivating implantable cardioverter defibrillators. The paper recommends a targeted effort on organizational strategies using high-quality assessment tools and emphasizes multidisciplinary and intersectoral collaboration.

Conclusion: Danish cardiologists supported by allied professionals acknowledge the importance of palliative care in advanced heart disease. This national position paper intended to inform and influence policy and practice can hopefully inspire other countries to take action towards implementing palliative care in advanced heart disease.

Keywords: palliative care; advanced heart disease; multidisciplinary; intersectoral; end-of-life

Introduction

Patients with advanced heart failure have a poorer prognosis than many patients with cancer (1). Further, they have severe physical symptoms and are often hospitalized (2, 3). Moreover, they often experience depression and struggle with social and spiritual issues (4, 5). Nevertheless, organization and knowledge of palliative care for patients with heart failure is still lacking in Denmark and in other countries (6) despite current recommendations from the Heart Failure Association of the European Society of Cardiology (7, 8).

In 2011, the Danish Health Authority developed recommendations for palliative care, calling on the professional societies treating patients with other diseases than cancer to develop guidelines in this area (9); these recommendations were updated in 2017 (10). In 2015, encouraged by the Danish Health Authority (9), the Heart Failure Working Group of the Danish Society of Cardiology initiated a task force to develop a position paper to facilitate and optimize the management of palliative care among patients with advanced heart failure as one of the first professional societies in Denmark involved in managing non-malignant diseases (11). The aim was to develop a position paper on palliative care and advanced heart disease intended to inform and influence policy and practice. This by focusing on heart failure, increase awareness of the need for palliative care among patients with non-malignant diseases and inspire the process of implementing and organizing palliative care in advanced heart disease both in Denmark and internationally.

Background

The care and treatment of patients with advanced heart disease are managed broadly depending on the original disease: ischemia, heart valve disease, cardiomyopathy, arrhythmia, congenital heart disease and pulmonary hypertension. Chronic heart failure is the common end stage for all these groups, with a mortality rate similar to severe cancer (12). Studies show that these patients have several symptoms and unmet physical, mental, social and spiritual palliative care needs (4, 13-17).

Further, studies suggest that patients with advanced heart failure and their relatives do not have adequate access to the palliative care they need (18, 19).

This applies especially to adult congenital heart disease. Although management of this disease is known to be non-curative, end-of-life discussions do not take place until the late palliative phase (20). One barrier is the great prognostic uncertainty for these patients (21). Most patients, however, want timely and proactive palliative care, including end-of-life discussions (22-25).

According to the World Health Organization and the Danish Health Authority, palliative care must be available for patients with life-threatening diseases, including heart failure (10, 26). In real life, however, attention is primarily given to patients with cancer, both in Denmark and in other countries (6). This article focuses on the process of developing a united position on palliative care and advanced heart disease related to the stages and prognostic challenges of the disease and recommendations on organization and management to promote palliative care in advanced heart disease in Denmark and in other countries.

The development process

The Heart Failure Working Group of the Danish Society of Cardiology back in 2015 established a task force to prepare the position paper as a consensus paper in collaboration with the following relevant specialties: palliative medicine, health psychology, intensive care units, cardiac arrhythmia, congenital heart diseases, prevention and rehabilitation, general practice and nursing. Because of major gaps in evidence, the position paper is based on small and low quality studies (27-29), and published meta-analyses (30, 31) and clinical practice statements supplemented by knowledge on palliative care in cancer.

The objectives were:

- to establish a unified opinion on palliative care and heart failure;

- to improve the assessment of palliative needs and when they should be initiated; and
- to expand knowledge on organizing and managing palliative care to be interdisciplinary and intersectoral.

The position paper was published in Danish in 2016 (32) and is hereby presented in English in a reduced and updated version to reflect the most recent findings in palliative care research and the newly published position statement from the European Association for Palliative Care Task Force (33).

Stages in advanced heart disease and prognostic challenges

Symptoms develop gradually in chronic heart failure. In the beginning, there are no or modest symptoms, but with time, the disease stops responding to treatment. Accordingly, the typical patient experiences gradual worsening over time, with intermittent, acute decompensated heart failure that often requires hospitalization (34-36). During treatment, including the stable phase, patients have an increased risk of sudden death (malignant arrhythmia) (34, 35, 37, 38). Thus, the prognostic challenges of patients with heart disease differ from those of other life-threatening diseases (36). The unpredictability of the trajectory of the disease may explain the limited palliative care for patients with heart disease and the lack of evidence in this field (39, 40). Continuing optimism about treatment and prognostic paralysis may delay palliative care or result in no care at all for some patients with heart disease (41). The European Society of Cardiology recommends a model for palliative care that focuses systematically on relieving suffering physically, mentally, socially and spiritually beginning at the early stages of the disease parallel to standard care as a supplement to life-prolonging treatment (39), making palliative care an integrated part of the disease-specific treatment. Table 1 depicts the stages of heart failure and the associated recommended palliative care efforts.

Palliative care in advanced heart disease

Symptomatic assessment

Patients with advanced heart disease frequently have such symptoms as fatigue, dyspnea, nausea, pain, depression and anxiety, but there is minimal evidence on the treatment of these symptoms compared with other fields such as cancer (4, 13-17, 42, 43). Small studies suggest that focused palliative care for patients with advanced heart failure can achieve favorable effects (27, 28, 44-46), but this needs to be demonstrated on a larger scale in high-quality randomized controlled trials. Meanwhile, in clinical practice, no evidence indicates that the palliative symptoms experienced by patients with heart failure should be managed differently from those experienced by patients with cancer. Table 2 includes recommendations for managing the typical symptoms experienced by patients with advanced heart disease (47-49).

Discussions on future care and treatment

Patients with heart failure need information about the expected progression of their disease, prognosis, treatment and palliative care at all stages (Tables 1 and 2) (39, 47, 50-52). At regular intervals, open, honest and empathetic communication is needed. Several recommended models and tools are available. The SPIKES (Six-Step Protocol for Delivering Bad News) model has gained immense popularity for breaking bad news (53). Advanced care planning is concerned with, but not limited to, conversations about the level of treatment and wishes at the end of life (23-25, 54-56). Table 3 shows an overview of topics to discuss in consultation with the patient and relatives, including end-of-life preferences (57). Further, deprescribing of medication is an important topic to approach systematically (58). Nevertheless, further studies are needed in advanced heart failure to

guide decisions on pharmaceutical and medical device therapy, resuscitation and new therapies (59).

Psychological reactions and spiritual aspects

About 20% of the patients with heart disease experience anxiety and depression (5, 39, 60). Because the disease and how it is managed are complex, identifying anxiety and depression among these patients may be difficult. Accordingly, systematic screening using such scales as the Patient Health Questionnaire or the Hospital Anxiety and Depression Scale (61) may be the best solution, even though they have not been validated for patients with chronic heart failure. The symptoms not only influence the patients' quality of life negatively, but depression also reduces compliance and increases the risk of hospitalization and mortality independent of traditional risk factors (62). There are several other treatment options than prescribing psychotropic medication (Table 2), including cognitive behavioral therapy, sessions with psychologists (63, 64) and conversations with a religious counsellor. This has not been explored among patients with heart disease.

Deactivation of implantable cardioverter defibrillators and left ventricular assist devices

In the terminal stage of life, having an active implantable cardioverter defibrillator may not be appropriate. Accordingly, discussing the possibility of deactivation with patients and their relatives is important (65). Patients with an implantable cardioverter defibrillator have indicated that discussions about deactivation should take place before implantation and in case of reduced life expectancy (66). Patients with an implantable cardioverter defibrillator were also asked about their preferences for or against deactivation, using a case vignette, and they had a favorable attitude towards deactivation and the wish for a dignified death (66). Table 4 highlights important issues to be discussed if the patient desires deactivation or if the health professional believes that the time for

deactivation has come. It is important to have a deactivation policy and processes in place at local health care institutions. Staff should be instructed in use of magnets if the ICD has not been deactivated towards end of life based on informed content (table 4). It should be stressed that deactivation with a magnet is only in urgent situations, until it is possible to deactivate with an ICD programming device. The small group of patients with left ventricular assist devices has special palliative care issues (67-70). These patients are in Denmark only managed in highly specialized units.

The last days of life in the terminal phase

When a patient is terminal and only has days or week to live, the following steps should be taken:

- reduce non-essential medication (discontinue vitamins, minerals, statins etc.) (58) and possibly change essential medication from oral to intravenous and subcutaneous administration;
- discontinue systematic monitoring of vital signs, blood tests, intravenous fluids etc. (50, 71, 72);
- ensure that the patient and his or her relatives are informed about the changes made because imminent death is expected; and
- ensure future prescriptions as needed, including recommendations for a basic symptom control box in end-stage heart failure (Table 5).

For the patients who want to die at home, palliative care should be optimized in close collaboration with the patient's general practitioner, primary care nurse and, if needed, a local outpatient palliative care unit before discharge.

Relatives - general and bereavement support

Care for relatives and bereaved family members is an essential part of palliative care in accordance with the WHO aim of improving the quality of life of patients and their families facing the problems associated with life-threatening illness (26). Identifying vulnerable families and offering support include facilitating common agenda and encouraging caring communication between caregivers and patients and informative communication between caregivers and health care providers, respectively. This does not only increase caregivers' efforts to provide care for patients but also increase patient adherence (73). Assessing caregiver burden and caregiver depression should also be considered, as caregivers have been shown to have long-term consequences of caregiving and after the loss of the patient i.e. Carer Support Needs Assessment Tool (CSNAT) (74). It has been associated with reduced patient perceived social support, patient confidence in heart failure and symptom management, and poor patient satisfaction with the relationship (75). In addition, instrumental support and care pathways for caregivers may be warranted, including a continuous needs assessment, as needs may change over time in the disease process and towards end of life (76). Finally, early bereavement support (right after initiating palliative care) can help alleviate consequences after loss and grief support in the aftermath of death can ameliorate grief-related complications such as depression or prolonged grief disorder.

Organization

Palliative care is thus characterized by being interdisciplinary and intersectoral, and coherent efforts require a high level of organization and coordination. The content and clinical practice for basic palliative care still needs to be clarified. The current organization of palliative care in Denmark is based on:

- general palliative care provided by the parts of the health care system that do not have palliative care as their main task, such as departments of cardiology, general practitioners and municipalities; and

- specialist palliative care provided by the parts of the health care system that have palliative care as their main task, such as palliative teams, palliative departments and hospices.

Recommendations for targeted services

With the purpose of targeted services based on individual needs assessment among patients with advanced heart disease, we recommend the following in accordance with the recommendations from the European Association for Palliative Care Task Force expert position statement (33):

- gathering department-specific palliative care services in one organizational unit, such as the outpatient clinic (the heart failure clinic);
- establishing an individual management team comprising the specialist physician responsible for treatment and the nurse and/or key people in the cardiac ward (77);
- establishing collaboration with other organizational units, including the primary sector, palliative teams and other relevant participants (such as psychologists, social workers, hospital priests, physiotherapists, occupational therapists and dietitians) depending on local conditions and accessibility;
- scheduling regular meetings to discuss specific patient cases, exchange experience and expand collaboration (multidisciplinary team conference);
- ensuring advance care planning support ;
- ensuring support including bereavement to caregivers and family members by health professionals; and
- focusing on educating health care professionals and developing their competencies.

Ethical and legal aspects

Shifting the treatment perspective from active treatment to palliative care may raise several ethical and legal aspects (78). Nevertheless, ethical dilemmas also exist when treatment continues beyond the patient's and the relatives' wishes.

Current action, future perspectives and contributions to the international scene

The European Association for Palliative Care Task Force expert position paper was newly published (33), emphasizing the importance of palliative care for people living with heart failure. The position paper from Denmark is the first step in acknowledging the importance at the national level to inform and influence policy and practice.

Palliative care should be part of the specialist training and continuing medical education of cardiologists. In addition, cardiac nurses and other health care professionals in contact with patients with heart disease should possess the appropriate skills to manage palliative care. The goal is to make evidence-based palliative care a natural part of cardiology care. Future trials are recommended to be primarily led from cardiology with access to Specialized Palliative Care (79).

The Heart Failure Working Group of the Danish Society of Cardiology started this process in collaboration with the Danish Society of Palliative Medicine. The two societies offered a supplementary course, including a workshop, to specialists in cardiology and palliative medicine with the aim of uniting these disciplines (80). The coming years will reveal how palliative care is implemented in the clinical care pathway for heart failure in Denmark.

This position paper extends the focus on setting up high-quality randomized clinical trials of the palliative care needs for patients with advanced heart disease. Parallel to establishing evidence-based knowledge, the focus should be on optimizing the implementation and organization of palliative care for patients with heart failure and their relatives and developing standards for systematically assessing palliative care needs at all stages of the disease. Further, the appropriate

services should be developed and implemented to support the specific needs of patients with heart disease and their relatives. We recommend quality assurance and evaluation of palliative care, such as through additional registration in existing databases.

Finally, we believe that this Danish position paper and the steps forward described to advance the field in Denmark are of general interest and applicable to other countries. Hence, the described working process and the final statement might inspire other countries to promote and endorse palliative care in heart failure to benefit the patients and relatives who need palliative care initiatives.

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Table 1. Characteristics of the stages in progressive heart disease, recommended palliative care and clinical indicators for stage II

Stage I: Management of chronic heart failure (NYHA I–III) – early palliative care

Active treatment with the aim of prolonging life and controlling symptoms

The patient and caregivers are educated on the condition, causes, treatment and prognosis, with the aim of improving the self-management of symptoms

Treatment is provided in accordance with the national guidelines and local protocols, including rehabilitation and exercise training

Stage II: Supportive and palliative treatment (NYHA III–IV) – late palliative care with focus on clinical indicators

The patient's symptoms become increasingly pronounced, with multiple hospitalizations and periods with decompensated heart failure despite optimal treatment in accordance with the guidelines

Old age and other comorbidities

Heart transplantation and mechanical circulatory support are ruled out

The patient can no longer tolerate decongestive treatment because of hypotension and/or progressive renal impairment

Delirium, change in mental status

Hyponatremia despite normal hydration

Signs of cardiac cachexia or low albumin

Repeated implantable cardioverter defibrillator shocks

Active treatment is reduced, and the aim moves towards sustaining optimal symptom control and quality of life

Identification of a key health professional is recommended to ensure optimal individualized continuity of care across multiple sectors and disciplines

A holistic, multidisciplinary assessment of the patient and his or her needs should be conducted continually in consultation with the patient and relatives: preferably with the same health professional and when the condition is clinically stable

Declaration of terminal care and financial support decisions should be considered

Stage III: Terminal treatment and palliative care

The patient will die imminently.

Heart failure treatment changes to alleviating symptoms only

A do not resuscitate order in case of cardiac arrest and waiver of intensive treatment needs should be discussed and documented

An integrated care plan should be devised, focusing on the psychosocial support needs of the patient and the family or caregivers

The preferred place of final care and death should be discussed

The care includes follow-up bereavement support as needed

Table 2. Possible interventions for common symptoms among patients with advanced heart disease

Symptom	Possible intervention
Shortness of breath	Re-evaluate medication (diuretics) Oxygen (or room air) during meals or permanently, fan, breathing training Nebulized bronchodilators Nitrates Opioids Benzodiazepines Anemia: consider intravenous iron therapy Walking aids Exercise training
Swelling and edema	Loop diuretics Vasodilators Diuretic resistance: combine with thiazides and/or consider inotropes or hemofiltration Fluid restriction Salt restriction Increased rest and bed rest and reduction of physical activity
Dizziness	Re-evaluate medication Treat arrhythmia, if present Anemia: consider intravenous iron therapy
Weight loss	Exercise training Dietary guidance, nutritional supplements Consider thyroid dysfunction
Nausea, loss of appetite	Re-evaluate medication Consider kidney and/or liver dysfunction Dietary guidance Consider haloperidol, metoclopramide, lorazepam, olanzepine or domperidone Appetite stimulants (small amounts of alcohol, steroids)
Depression	Avoid tricyclic antidepressants (risk of prolonged QTc interval) Selective serotonin-reuptake inhibitors, sertraline Physical activity, psychological evaluation
Pain	Opioids Anginal pain: antianginal medication and/or revascularization
Lack of energy, fatigue	Identify and treat secondary causes (anemia, infection, sleep apnea etc.) Exercise training

Table 3. Topics that can be used in dialogue with the patient about future care and treatment depending on the patient's disease stage

- The severity and incurability of the disease
- Possible progression of the disease (slow deterioration or sudden death)
- Options and opportunities for support during the process both for patients and their relatives
- Need to assign a primary nurse
- Need to establish open admission (unlimited hospital stays)
- Possibility to have a contact physician and contact nurse at the ward
- Continued affiliation with the heart failure clinic
- The role of the general practitioner
- Need for referral to the palliative care team
- Advance health care directive
- Treatment level in the event of acute deterioration
- Do not resuscitate order
- Deactivating the patient's implantable cardioverter defibrillator
- Application for socio-medical case management (terminal declaration pursuant to Section 122 of the Consolidated Act on Social Services)
- Application for subsidy for drugs towards end-of-life care from the Danish Medicines Agency (pursuant to Section 148 of the Health Care Act)
- Discontinuation of drugs
- Possibility of care leave for significant others
- Need for hospice care
- End-of-life preferences (where does the patient prefer to be towards the end of life or to die?)

Table 4. Topics that can be used in dialogue with the patient and relatives if the patient wants the implantable cardioverter defibrillator antitachycardia pacing (shock therapy) function to be deactivated towards the end of life or if health care professionals deem that it is time to deactivate the implantable cardioverter defibrillator

- The severity and incurability of the disease
- Examine whether the patient and relatives are aware of the possibility of deactivating the implantable cardioverter defibrillator
- Dialogue about deactivating the implantable cardioverter defibrillator:
 - Deactivation will not lead to death
 - Deactivating the shock function of the implantable cardioverter defibrillator will not deactivate the pacing function if the patient has a pacemaker
 - Deactivation is not painful and will not make death more painful
 - Implantable cardioverter defibrillator shocks towards the end of life can be ineffective, painful and lead to anxiety among both patients and relatives
 - Deactivation can help to ensure a peaceful death and to avoid unnecessary shocks
 - If the patient's circumstances change, the implantable cardioverter defibrillator can be reactivated
- Ensure that the patient and relatives understand what deactivating the implantable cardioverter defibrillator means and the consequences
- Ask about the preferences of patients and relatives
- Decision to deactivate the implantable cardioverter defibrillator and when it should take place:
 - Informed consent from patient (with the presence of any relatives if relevant)
 - Note the decision in the patient's electronic health record
 - Inform the patient's general practitioner about the decision

Table 5. Content of the basic symptom control box and standard dosage suggestions: the box contains medicine for terminal patients who can no longer take oral medicine

Injectable morphine 20 mg/ml, 2.5–5 mg intravenous or subcutaneous as needed, without maximum, for pain and dyspnea

(Morphine is prescribed after calculating the patient's current dosage for the past 24 hours)

Injectable midazolam 1 mg/ml, 1–3 mg intravenous or subcutaneous as needed, without maximum, for anxiety, unease and sleeplessness

Injectable haloperidol 5 mg/ml, 0.5–1 mg intravenous or subcutaneous as needed, maximum six times in 24 hours, for nausea, delusion and incipient delirium

Injectable furosemide 10 mg/ml, 10–40 mg intravenous or subcutaneous as needed, without maximum, for pulmonary edema

Injectable hyoscine butylbromide 20 mg/ml, 20 mg intravenous or subcutaneous as needed, maximum 120 mg per 24 hours, for death rattle