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Title:

Quality of life and symptoms of depression in advanced heart failure patients and their partners

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### **Purpose of review**

To provide an overview of factors related to quality of life and symptoms of depression in heart failure patients and their partners. Furthermore, to give an overview of interventions that can be effective in improving their quality of life and decrease depressive symptoms.

### **Recent findings**

Quality of life of patients with heart failure and their partners is poor compared to their age-matched peers from the general population and also compared to patients suffering from other chronic diseases. Furthermore, a considerable amount of heart failure patients is depressed. Depressive symptoms of patients and of their partners seemed to be interrelated, making interventions complicated but needed.

Although the number of studies that specifically target improvement of quality of life and depression in heart failure patients and their partners is still small, several interventions are known to improve quality of life and these could be implemented in daily care.

### **Summary**

This review considers demographic and clinical factor that are related to quality of life and depressive symptoms and addresses interventions that can contribute to improvement of quality of life of heart failure patients and their partners and decrease depressive symptoms.

Education on self-care management and physical exercise are important to include in a disease management program. A multidisciplinary care approach including optimizing medical therapy and optimal symptom management is advised, focusing both on the patient and the caregiver. Treatment and care should not only focus on heart failure, but also address the consequences of co-morbidities and consequences of symptoms and therapies.

Key words: heart failure, depressive symptoms, quality of life, caregivers

## **Introduction**

Compared to the last decades, patients live longer with heart failure (HF), however their daily life is often marked by significant symptoms and side-effects of the treatment affecting not only the physical dimensions of life, but also social and psychological dimensions during the disease trajectory (1-3). A poor quality of life and depressive symptoms have been described to lead to an increased risk of hospital admissions and death (4,5). Quality of life is increasingly incorporated as an outcome (although mostly as secondary outcome) in clinical trials and improving quality of life is a major aim of treatment in HF patients in clinical practice (1). However, HF is a complex syndrome and many factors are related to the quality of life of the patients and their families.

## **Quality of life and symptoms of depression in heart failure *patients***

As can be expected in patients who suffer from a chronic disease, the quality of life of HF patients is more impaired than the quality of life of the general population (6) and than that of the healthy elderly population (7). However, HF seems to affect the quality of life patients dramatically, since their quality of life is described the lowest compared with patients with other chronic disorders (3,7).

Symptom burden, the disabling consequences of HF and the treatment regimen impact daily life of HF patients and contribute to a decreased quality of life. HF contributes to severe physical, role, social, and functional impairment as well as increased psychological distress. A high proportion of patients with advanced HF suffer from refractory symptoms such as breathlessness, persistent cough, fatigue, and limitation in physical activity. In addition, many patients suffer from pain, anxiety, depression, nausea and constipation (8-10). Sleeping problems are also common, almost 60% of the HF patients report trouble with sleeping which is related to a poor quality of life (11-13). More recently the prevalence of pain in HF patients has been addressed (14,15). Pain can have an effect on almost every aspect of life and the prevalence of pain in HF patients is a significant issue as 23% to 75% of patients report pain (14). The exact locations and causes of pain in HF patients are not always clear, but it is known that pain can influence the ability to maintain adequate self-management and can be both a precipitant for readmission of HF patients as well as a significantly increasing symptom at the end stage of HF (14). HF Patients often fear symptoms such as pain and suffocation at the end of life (16).

Depression is also common among HF patients and the prevalence varies between 9% to 60% (17), depending on type measurement approach. This rate is higher than compared to the normal population where the total prevalence of depressive disorders among adults in Europe approximately is 5-10% (18). Depression can lead to increased symptoms of HF, poorer functional performance, decreased quality of life and an increased risk for premature death (5,19, 20). Depressed HF patients also use more health care resources, which increases the economic burden on the health care system. (21)

### **Quality of life and symptoms of depression *in partners* of heart failure patients**

Like in most chronic conditions the quality of life of the partners of a patient is affected by caring for the HF patient, which on one hand can be experienced as a burden, but on the other hand also can lead to increased life satisfaction (22,23). Although most partners seem to cope relatively well, the impact of HF on their lives can be profound. Some studies indicate that partners have a lower quality of life than the HF patients, however, these findings are still inconclusive (22,24). Partners caring for an individual with HF often have to endure and attend to a range of problems. The fact that partners have to perform caregiving tasks is also related to feelings of burden, especially when it concerns tasks regarding personal care such as assisting with washing and bathing and moving in and around the house (25). HF patients are often reliant on partners for assistance with instrumental activities of daily life (e.g., shopping, house keeping), activities of daily life (26,27) but also specifically assisting in health- and HF related activities, such as life style changes (e.g. dietary changes), clinic visits, activities related to providing medication and symptom monitoring. The most difficult care giving tasks are those dealing with a HF patients' behaviour or motivating patients to keep change life style (e.g. stop smoking)(27). Furthermore, partners often witness acute situations and this might lead to anxiety and stress in partners. By providing support to patients in their daily activities, partners often change their own daily schedule and have to adjust joint activities. They might have less time for activities with friends or not be able to fulfil their own life expectations (28). Regaining a new balance together is one of the challenges that dyads face when confronted with HF. Anxiety and depression of patients or the partners influenced their own quality of life but also each others quality of life. Patients whose partners had more depressive symptoms were more likely to indicate their own quality of life

as being poorer. Anxiety has similar actor and partner effects as depressive symptoms on quality of life (29).

### **Factors related to quality of life and symptoms of depression**

Several demographic, clinical and psychosocial and factors are related to quality of life of HF patients and their partners. The most prominent related demographic factors are related are age and gender, in which patients with younger age often report a poorer quality of life. In general the substantial impact of HF on quality of life is more pronounced in women: women with HF are more impaired in physical health, mental health, and well being than men with HF and report more depressive symptoms. (30,31). Clinical factors that are related to a lower quality of life are an increasing disease severity an increasing burden of co morbidity (30-32).

More recently, the relationship of anaemia and quality of life in HF patients is addressed. Anaemia is prevalent in HF patients (32) and is related to a poor prognosis, Additionally, anaemia can have clinical consequences such as fatigue or lethargy, depression, and impaired cognitive function which all might negatively affect quality of life (32-34).

Patients and partners influence each others quality of life. Important variables influencing quality of life of the partner are the partner's own mental health and the perceived physical health of both partners and HF patients (25).

Development of depression in patients with HF is associated to living alone, the economic burden associated with costs of medical care, alcohol abuse and poor rated health (35). HF patients who have sleep problems run a threefold risk of suffering from depression (31). Other factors associated with depression in HF patients are younger age, poor NYHA functional class, social conflicts and negative attitudes towards the loss of autonomy (36).

### **Interventions to improve quality of life and decrease depression in Heart Failure patients**

Although improvement of quality of life is pursued in several studies, there are a few randomized studies that particularly focus improving quality of life of HF patients and their partners. Additionally, data on the effectiveness of interventions to treat depression, specifically in HF is still scarce.

Until larger randomized studies are available an integrative approach to optimize quality of life including the following components might be advised.

### **1. Disease management program**

A multidisciplinary care approach in which care is coordinated along the continuum of HF and throughout the chain of care delivered by various services within the healthcare systems is advocated in HF care (1). Such an approach has demonstrated to improve outcomes such as a reduced hospitalization rate and a decreased mortality rate (1). Some studies have also shown improvement in quality of life as a result of such an intervention, however, the results are less conclusive.

Not all interventions are successful in improving quality of life on the long term (37,38), and even if short term improvements in quality of life are achieved, long term increase in quality of life of HF patients is difficult to sustain. However, since the natural course of HF patients show a decline in quality of life over time, a stable and not decreased quality of life, might also be considered as successful in these programs(38).

### **2. Optimize medical treatment and device therapy**

Both medication and devices positively influence symptoms and quality of life and it is therefore important to optimize treatment also in palliative and end-of life HF care (1,2). Evidence-based HF medications, including angiotensin-converting enzyme inhibitors and beta blockers decrease symptoms and improve quality of life in HF patients and should usually be continued in end-stage disease.

Also CRT and LVAD therapy have shown to positively influence symptoms and improve quality of life (1).

### **3. Optimal symptom management**

Optimal medical treatment can reduce symptoms of HF. The focus of the treatment of HF patients needs to incorporate constant comprehensive attention for symptom relief. Symptom burden associated with HF need to be assessed, acknowledging differences between patients', carers' and the health-care professionals' perceptions. Interventions aimed at alleviating symptoms should be directed at the patients' physiological and psychological symptoms, but also address their social and spiritual needs (2). Symptom control in end-stage HF poses specific challenges. Patients often

suffer from symptoms as severe breathlessness and fatigue, needing an approach focusing on palliation, focusing on the quality of life. Some HF patients give equal or more importance to quality of life as compared to length of life (39). In addition to optimal evidence based HF medication, other medication might be considered, such as morphine and tranquilizers. Evidence is mostly lacking on the application of symptom control interventions established in palliative (cancer) care to those suffering from HF.

The majority of patients with end-stage HF have multiple medical conditions, such as diabetes, COPD or/and anaemia. Strategies to improve quality of life need to accommodate both cardiovascular and non-cardiovascular conditions.

#### **4. Treatment of depression and depressive symptoms**

Anti-depressive treatment can reduce depression and improve quality of life in HF patients (40). Additionally non-pharmacological interventions such as exercise therapy, stress-management and mindfulness therapy might be useful to reduce depression in patients with HF (41-43). However, these studies were all performed on a general HF population and not specifically on patients with depression. Patients with depressive symptoms also might need a more tailored disease management approach, since regular nurse-led HF clinics might not be optimally addressing their needs (44).

#### **5. Caregiver support**

The effect of caregiver interventions or family focussed interventions in HF are scarcely tested. It is not known that focussing specifically at family partnership can improve outcomes of patients and families., for example improving self management or decrease readmission. Some promising results were found from a family partnership intervention added to a family education program of HF patients and their partner. (45) Both interventions improved dietary sodium self-management in persons with HF, with a better effect of the family education + family partnership intervention (45). However, a telemonitoring intervention specially aimed at HF patients and their caregivers did not improve outcomes related to hospital readmission (46). An integrated intervention, (nurse-led counselling, a computer-based education and other written teaching materials) to assist dyads develop problem-solving skills was successful in improving perceived control in patients, but not in partners. However,

no significant differences were found as a result of this program with regard to dyads' quality of life and depressive symptoms, patients' self-care behaviors and partners' experiences of caregiver burden (47).

In general, HF partners do appreciate being involved in discharge planning and a planned discharge program can lead to higher satisfaction with care, feelings of preparedness and perception of care continuity and acceptance of the care giving role. (48)

## **6. Education on self-care management**

An important base for self-care management is relevant education on HF to the patient and their partners, families and/or caregivers. Patients and their families should have adequate knowledge about HF symptoms and the medical treatment, especially regarding effects, side effects, and how the medication should be taken and titrated (49). The webpage *heartfailurematters.org* is an internet tool provided by the Heart Failure Association of the European Society of Cardiology that permits patients, their next of kin and caregivers to obtain useful, practical information in a user-friendly format (1). Along with education a good communication about everyday life issues between the patient and his/her family and health care providers is crucial (49). It is difficult to draw definitive conclusions about the benefits of self-care on quality of life in patients with HF (50). However, a recent literature review including 22 studies reported a predominance of studies showing a benefit, especially in patients with more advanced HF, after interventions focusing at improving self-care (51).

## **7. Exercise:**

Exercise training can reduce HF-related hospitalizations and result in clinically important improvements in quality of life (52,53). The precise mechanism through which exercise-based interventions benefit HF patients remains unclear, but both a general cardiac rehabilitation programs or more HF specific training programs might be beneficial. Currently, the most evaluated programs concern exercise-only interventions. However, in addition to exercise training, patients might be provided with education and psychological interventions in a more comprehensive cardiac rehabilitation (54). In some cardiac rehabilitation for myocardial infarction patients relaxation techniques are included. This also might be beneficial for HF patients. In a

recent study relaxation techniques were found to be beneficial to the emotional and social health-related quality of life of Chinese patients with chronic heart failure (55).

### **Conclusion**

Heart Failure has serious consequences for patients and for their caregivers, often affecting physical dimensions of life but also social and psychological dimensions. Improving quality of life is recognized as one of the major treatment goals in HF and patient preferences are increasingly recognized as being highly important. Until now no clear risk profile consisting of demographic and clinical factors that would predict a low quality of life or a risk for depressive symptoms is established, but from current data it seems important to focus interventions to improve outcomes both on patients and caregivers. A multidisciplinary care approach including optimizing medical therapy and symptom management is advised, focusing both on the patient and the caregiver and addressing consequences of both HF and also co morbidities and depression. Furthermore, interventions including patient education, self management and exercise can improve outcomes and can be implemented in daily practice to improve quality of life and decrease depressive symptoms in HF patients and their partners.

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