



Chronic Heart Failure Patients' Perceptions on their Palliative Care Needs

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KEYWORDS

Chronic heart failure;
Palliative care

Abstract

Objective: The aim of this study was to investigate the perceptions of patients with chronic heart failure regarding palliative care needs.

Method: The study used a qualitative design. Five patients with chronic heart failure (New York Heart Association functional classes III or IV) were interviewed in inpatient unit at the main referral government hospital in Indonesia. Data was analyzed using content analysis.

Results: Patients reported dyspnea and fatigue as the most common signs and symptoms of chronic heart failure. Psychologically, patients experience fear and believe that the disease is the most serious illness. Declining body functions and quality of life are the reasons chronic heart failure patients need palliative care. Professional treatment, end-of-life care, information, support, and motivation are identified as the needs of patients in palliative care.

Conclusions: The findings provide valuable information for health care professionals about the needs of patients with chronic heart failure in relation to palliative care.

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Introduction

Heart failure is a complication that often occurs in various types of heart disease, either congenital or acquired, and is the final stage of heart disease. Go et al (2014) in the American Heart Association data reported that around 5.1 million Americans experienced heart failure in the period 2007-2010, with approximately 825,000 new cases every year, and one in nine deaths was the result of heart failure. In Indonesia, Data and Information from Health Communicable Diseases (2012) showed that heart failure was the third most common cause of non-communicable disease resulting in death while in hospital (11.97%) in 2010, which increased from the previous year (10.21%), and was the second most

common (2.36%) reason for outpatient hospital visits in 2009-2010.

The high number of deaths due to heart failure and the increasing number of new cases of heart failure are correlated with poor disease prognosis. A cohort study by Levy et al (2006) reported that the estimated life expectancy of patients with heart failure ranges from 73.4%-90.9% in the first year and from 56.7%-83.3% in the second year. The study explained that patients with heart failure require significant physical, psychosocial, emotional, and spiritual attention from health care professionals during treatment. Several studies have evaluated the experiences of patients with heart failure and reported that patients experience a variety of symptoms, such as shortness of breath, pain, nau-

sea, and weakness; receive insufficient information about the disease and its management; and have problems communicating with health workers, especially in relation to their prognosis and treatment plan (Barnes et al, 2006; Cortis and Williams, 2007; Gibbs et al, 2002). Bekelman et al (2009), Goebel et al (2009), and O'Leary et al (2009) state that patients with heart failure suffer physically and emotionally and have a low quality of life compared with the general population and with people with other chronic conditions (Juenger et al, 2002).

The integration of palliative care that focuses on reducing symptoms, enhancing the function and role of the individual, and improving quality of life is highly recommended for patients with chronic heart failure (Hauptman and Havranek, 2005). A meta-analysis of 10 studies showed that palliative care in hospitals can improve patients' quality of life and symptoms and is associated with a reduced number of days in hospital (Higginson et al, 2002). A systematic review of 43 studies revealed that there has been improvement in symptom control, quality of life, and satisfaction with palliative care (Finlay et al, 2002).

In Indonesia, a 2007 decree by the Ministry of Health instituted palliative care services for patients with chronic diseases. However, the implementation is still more focused on cancer patients, although some studies have reported that palliative care is also effective in improving the quality of life of patients with chronic diseases such as heart failure (Coelho et al, 2005; Lorenz et al, 2008; Rabow et al, 2004). Because of the limited studies focused on palliative care in patients with chronic heart failure. The need of palliative care in patients with heart failure in Indonesia is important to be explored. Therefore, the purpose of this research was to explore patients' perceptions about palliative care needs related to chronic heart failure.

Method

Setting and sample

A qualitative study with semi-structured interviews was conducted at the main referral government hospital in Indonesia to explore the perceptions of patients with chronic heart failure regarding palliative care needs. The data was collected from August to November 2015. Five participants were recruited using the purposive sampling method. The number of participants was achieved based on saturated data. The patients recruited for this study were defined as having chronic heart failure of functional class III or IV (New York Heart Association), had undergone treatment in hospital, and were willing to be research participants.

Prior to the study, ethical approval to conduct the research was obtained from the Faculty of Medicine, Universitas Indonesia and Cipto Mangunkusumo Hospital. Participants were recruited from the inpatient unit, and the data collection procedure was as follows. First, patients eligible for the study were screened by the researcher in the inpatient unit and their eligibility was confirmed using their medical records. The researcher approached the patients and explained the research process and procedure before requesting their participation. Those who agreed to participate gave informed consent, after which the researcher

explained the research instrument and proceeded with the semi-structured interviews. Following are some examples of the questions: What do you know about your disease? Can you tell us how you get the disease? How do you feel when staying in the hospital? Is there any limitation when doing your daily activities? Can you explain the signs and symptoms of the disease that you feel the most? Have you ever heard about palliative care? Do you know what palliative care is? How do you feel knowing you have this disease? Does this disease affect your social or spiritual life? For ethical reasons, the confidentiality of the subjects' data was strictly guarded by the researcher.

Content analysis was used to analyze the data, the data was transcribed, and each sentence was grouped into meaning units. Furthermore, the transcript was translated from bahasa Indonesia to English. The researcher also clarified some unsure data to participants to ensure the data was properly understood and interpreted. Investigator triangulation was also conducted to minimize potential bias (Shenton, 2004).

Results

This study aimed to explore the perceptions of patients with chronic heart failure regarding palliative care needs. The study involved five participants, the youngest of whom was 35 years old, and the oldest 67. Three participants are female and work as housewives. All participants are Muslim. The average respondent had one comorbidity, and two of the five participants had been diagnosed with chronic heart failure more than three years ago. You may want to highlight what themes emerging from the study here?

Need of palliative care

Identifying the palliative care needs of patients with chronic heart failure was based on decreased body function, repeated symptoms, and low quality of life.

Decreased body function

The decreased body function that occurs in patients with chronic heart failure is illustrated in the following statement:

"[...] I try to organize my life, step by step, I adjust it, if usually I can do walking for 5 to 6 hours, now in 1 hour I've stopped [...]" (P1).

"[...] yes of course, before I can walk in 5 steps, now only one." (P5).

Repeated symptoms

Palliative care needs were also identified based on the repeated symptoms of patients. The health condition of patients improved after receiving health care in the hospital:

"[...] it could be repeated if there is more thought [...] I felt confused why it is difficult to sleep, I have consumed the drug from doctor, but I still like this [...]" (P3).

Decreased quality of life

Quality of life can be viewed from various aspects—physical, psychological, social, and spiritual.

Physical

Signs and symptoms often felt by all the participants were dyspnea, fatigue, coughing, insomnia, edema, and nausea, as illustrated in the following respondent's statement:

"[...] the dyspnea was worsen day by day, usually it happened once a day but now it can be more than three times a day [...]" (P4).

Psychological

Most of the participants complained of stress and felt fear without a definite cause. The participants said that heart disease is the most serious and dangerous disease:

"[...] I feel that I am scared but I do not know why [...]" (P3).

"[...] I feel so stressed, why I can get a heart attack. Sick even so, how could get a heart attack, because of that, I don't want to be alone, I want somebody or my friend who become a friend to share with [...]" (P2).

Social

All participants reported that having received the diagnosis of chronic heart failure grade III or IV, they rarely engaged in social activities:

"[...] before the sickness, I have so many activities outside, but since I get this disease now it is rare to join the activities [...]" (P3).

Spiritual

One of the participants said that chronic heart failure has become a limitation in participating in religious services:

"[...] I did not do the religious activities because my limitations in doing because I am tired [...]" (P2).

However, four of them said that the disease did not affect the religious aspect of their lives.

Patients' needs in palliative care

Palliative care consists of several elements, as follows.

Management of signs and symptoms

Patients who were coming to the hospital with some complains such as dyspnea, fatigue, edema and others in this study said that health care professionals performed well in taking care patients' signs and symptoms:

"[...] yesterday I felt dyspnea, when I arrive I get medicine and some treatments and it make me feel relief [...]" (P2).

Psychological aspect

Some patients expressed that they need health care for psychological aspects:

"[...] to help me with my problem, if I have a chance, I want to have discussion with professional to discuss my problem [...]" (P2).

Support and motivation

Support and motivation are identified as patient needs in living with chronic heart disease.

"[...] I want to get spirit in living with chronic heart failure disease; I don't want to be like this [...]" (P3).

End-of-life care

End-of-life care that is care given in the last part of patients' life has not been explored yet for patients with chronic heart failure who participated in this study:

"[...] the doctor said all disease is curable, so it just let it go, about the disease and end-of-life care, I haven't got information about it yet [...]" (P2).

Hope

Participants felt that hope is associated with an improvement in the future:

"[...] I want to do daily activities, such as cooking, walking [...]" (P3).

Discussion

Need of palliative care

This study found that palliative care needs of patients with chronic heart failure was based on and low quality of life, repeated symptoms and decreased body function. The reason for the need to palliative care in patients with chronic heart failure is in line with World Health Organization (2008) statement that explained declining in the quality of life associated with life-threatening illness is an indication to palliative care needs. A condition that occurs in patients also similar with previous studies that reported low quality of life, poor prognosis, and high incidence of hospital admission associated with recurrent disease of chronic heart failure (Juenger et al, 2002; Masoudi et al, 2004).

The decreased body function and repeated symptoms of chronic heart failure patients are the reasons for the high incidence of hospital readmission. According to Ross et al (2010) and Krumholz et al (2009), more than 50% of patients with chronic heart failure are readmitted to the hospital within six months after their first hospitalization. The research shows that the repeated symptoms of patients with chronic heart failure are one indicator of the importance of palliative care. The evidence shows that palliative care programs can reduce the incidence of recurrent hospital admissions (Jencks et al, 2009); indeed, Smith (2014) in his study stated that palliative care has reduced the incidence from 24% to 15%.

The quality of life of patients with chronic heart failure has physical, psychological, social, and spiritual aspects. Improving patients' condition in all these aspects is the reason palliative care is needed for chronic heart failure patients. The results show that the main physical complaints are dyspnea, fatigue, insomnia, coughing, leg edema, and nausea. Johnson (2007) and Albert et al (2010) reported that dyspnea and fatigue are the common complaints. A qualitative study that explored the experience of patients with chronic heart failure also reported severe fatigue as a major complaint (Ryan and Farrelly, 2009). Other studies report edema, nausea, sleep disturbances, and cough as the most common complaints of chronic heart failure patients (Albert et al, 2010; Davidson et al, 2010).

The study results show that stress and fear are often felt by patients. This is consistent with previous qualitative research that states that patients with chronic heart failure live with fear (Ryan and Farrelly, 2009; Jeon et al, 2010). Some studies report that the fear felt by patients is a result of the limitations put on their physical and social activities (Costello and Boblin, 2004), anxiety (Martensson et al, 1998), emotional distress (Regel and Carlson, 2002), and impending death (Ryan and Farrelly, 2009).

The physical and psychological symptoms of patients with chronic heart failure limit their social and physical activities outside home. The current study noted that decreased body functions as a result of fatigue and shortness of breath are the reasons patients are more often at home. A similar study also found that the limitations in social activities are due to the physical limitations experienced by patients, particularly dyspnea and fatigue (Jeon et al, 2010; Leeming et al, 2014).

The spiritual aspect is one of the most important aspects that affects the quality of life of patients with chronic heart failure. One of the participants stated that the physical complaints were a limitation in terms of performing prayers. This is in line with other studies that show patients with chronic heart failure have a lower spiritual value compared to cancer patients (Bekelman et al, 2009). However, the four other participants explained that their situation makes them feel closer to the Almighty. Naghi et al (2012) state that chronic heart failure patients' spiritual beliefs affect their preparedness and serve as a coping mechanism.

The palliative care needs of patients with chronic heart failure have been identified by examining their experiences during hospitalization. Decreased body function, repeated symptoms, and decreased quality of life that is visible as a result of the physical, psychological, social, and spiritual aspects of the disease are all important aspects that health care professional must pay more attention to in terms of the needs of chronic heart failure patients. All these aspects must be carefully considered in developing and implementing palliative care services to manage patients' symptoms. A multidisciplinary approach to these services is critical to improve patients' quality of life.

Palliative care needs

Management of signs and symptoms

This study showed that patient complaints related signs and symptoms can be handled properly by health care providers.

According to the National Consensus Project for Quality Palliative Care (2013), managing the signs and symptoms is one of the most important ways to improve patients' quality of life. This can be done pharmacologically or with behavioral management strategies (Morrison and Meier, 2004). Further research related to managing chronic heart failure patients' symptoms need to be conducted to determine the effectiveness of hospital care in this regard.

Psychological aspects

The results showed that patients with chronic heart failure experience psychological problems particularly fear and stress that affect their quality of life and that can be addressed in palliative care. According to the studies conducted by Barnes et al (2006) and Wotton, et al (2005), health care workers tend to focus on physical signs and symptoms. The holistic management of patients is an important concern for health professionals, and they need to pay more attention to the psychological conditions of patients. In implementing palliative care, a multi-disciplinary approach should be taken to provide optimal service to patients (Spruyt, 2011).

Support and motivation

Support and motivation provided by health care workers and family for patient. Uncertain disease conditions and patients' feelings of fear and stress are the reasons patients need support and motivation to live. World Health Organization (2008) states that support and motivation are part of palliative care that can ultimately improve patient quality of life during treatment. The role of health personnel (both doctors and nurses) needs to be improved to identify the problems that occur in patients, as does the support and motivation necessary to maximize patients' health status.

End-of-life care

End-of-life care is identified as one of the patient requirements. Braithwaite et al (2011) reported that one unmet need of palliative care is related to end-of-life care. Yet the implementation of good end-of-life care for patients with chronic heart failure is associated with certain difficulties. Glogowska et al (2015) state that giving information about end-of-life care is a challenge for health workers providing palliative care for chronic heart failure patients who are facing uncertainty as they approach death. According to Boyd et al (2004), health workers have difficulty in finding the appropriate words to describe patients' condition. Interestingly, Goodlin (2005) states that not all patients want to know the details of the disease prognosis. The existence of a variety of factors that affect the implementation of end-of-life care for patients with chronic heart failure is an important point of interest for further study.

Hope

The expectations of patients with chronic heart failure about future conditions have changed their mindset about the meaning of health. In line with a qualitative study of Horne and Payne (2004) which reported that patients hope were they can walk and do outside activities independently.

A change in healthy meaning of patients with chronic heart failure is a condition that patients try to be realistic with their hope for the diseases healing process.

Clinical implication

The study results showed that patients' perceptions about palliative care are various. There are several reasons why patients with chronic heart failure requiring palliative care. The specific needs of palliative care identified in this study that needs to be focused on include psychological aspect, spiritual, support and motivation as well as end of life care.

In clinical practice, health care professionals may concern more in psychological aspect which related to patients' fear and stress, because if it is treated unwell, it may affect patients' physical status. Furthermore, in spiritual aspect, for some patients, their condition may influence their ability to worship. In this condition, nurses may pay attention to assist, encourage and facilitate patients to pray. Support and motivation from health care providers which is beside from family also important in improving patients' condition to keep moving from their sadness related to their current status. Hence, end of life care also need to be socialize earlier to patients by health care professionals in order to prepare patients' about the worse condition that may happen to them. All above, this study results are expected to be important information for health care professionals in developing a better palliative care for patients with chronic heart failure in Indonesia.

Conclusions

The study explored the experiences of patients with chronic heart failure during treatment at a hospital and their needs in relation to palliative care. The results showed there are several reasons patients with chronic heart failure require palliative care. Decreased body function, repeated complaints, and decreased quality of life are the basic reasons patients need palliative care. The specific needs in terms of palliative care identified in this study are psychological support and motivation and end-of-life care, which can be met once the physical symptoms of patients are properly managed. The results of this study provide important information for health care professionals in developing palliative care for patients with chronic heart failure in Indonesia.

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