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Original article

Design of a nationwide survey on palliative care for end-stage heart failure in Japan

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ABSTRACT

Background: The term *palliative care* has historically been associated with support for individuals with advanced incurable cancer, so cardiologists and cardiac nurses may be unfamiliar with its principles and practice. However, palliative care is now a part of end-stage heart failure management. We conducted the first nationwide survey to investigate the status of palliative care for heart failure in Japan.
Methods and results: A self-reported questionnaire was mailed to all Japanese Circulation Society – authorized cardiology training hospitals (n = 1004) in August 2016. The response deadline was December 2016. The survey focused on the following topics: basic information about the facility and multidisciplinary team, patient symptoms for palliative care, positive outcomes after providing palliative care, drug therapy as palliative care for patients with heart failure, advance care planning with patients and their families, and impediments to providing palliative care to patients with heart failure. The results of the survey will be reported in detail elsewhere.
Conclusions: Current guidelines on palliative care do not specifically address what team members should be involved, what drugs should be used, or when palliative care should be started. This survey collected information to improve the quality of palliative care and provide more specialized palliative care within the limits of resources.
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Introduction

Heart failure is the end stage of cardiac disease. Despite the introduction of new and more effective pharmacological and nonpharmacological therapies, the mortality rate from heart failure is still high. Patients are often admitted repeatedly (a predictor of mortality) and sustain additional organ damage [1,2]. However, each hospitalization provides an opportunity for clinicians to discuss individualized management strategies with the patient, family, and hospital caregivers. Initially, the main treatment goals are to improve clinical outcomes, reduce mortality, and minimize hospitalizations. However, the primary goal may change at the end stage of heart failure, with quality of life (QOL) becoming particularly important.

Guideline-recommended therapy must be terminated occasionally because of side effects, such as hypotension and renal failure. In the end stage of heart failure, managing dyspnea, pain, agitation, and delirium also becomes increasingly important. Some patients may need palliative care, including morphine use; however, these choices should be carefully considered for each case by the multidisciplinary team [3–5].

The term *palliative care* has historically been associated with support for individuals with advanced incurable cancer, so cardiologists and cardiac nurses may be unfamiliar with its principles and practice. To improve the quality of palliative care and provide more specialized palliative care for heart failure within the limits of resources, it is necessary to determine the status of care and the factors that have a positive impact on care. To date, these issues have not been clarified in Japan. Therefore, we developed a nationwide survey on palliative care for end-stage heart failure.

Methods

A self-reported questionnaire was mailed to all Japanese Circulation Society–authorized cardiology training hospitals ($n = 1004$) in August 2016 (Table 1). The survey focused on the following topics: basic information about the facility and multidisciplinary team, patient symptoms for palliative care, positive outcomes after performing palliative care, drug therapy as palliative care for patients with heart failure, advance care planning with patients and their families, impediments to providing palliative care to patients with heart failure. Because, in regards to palliative care for heart failure, it is important to provide general palliative care that is applicable to all care settings, we included questions based on symptoms or psychosocial distress which should be screened and assessed in general palliative care [3,5,6]. In addition, the implementation of this survey was disclosed on the home page of Heart Failure Palliative Care Study Group (http://shinfuzen-kanwa.jp/activity/index.html). The results of the survey will be reported in detail elsewhere.

Discussion

Palliative care for end-stage heart failure

Although guideline-recommended medications (including angiotensin-converting enzyme inhibitors and beta-blockers) have marked benefits on systolic heart failure, morbidity and mortality rates have not decreased for patients who have progressed to advanced heart failure. Palliative care is a multidisciplinary team approach to optimizing QOL and symptom management. It does not necessarily exclude any form of medical therapy and takes into account physical, psychological, and spiritual needs as well as patient and family preferences [3–5].

Palliative care is recommended in the American College of Cardiology Foundation/American Heart Association heart failure guidelines to improve QOL (level of evidence: B) [7]. The guidelines state that aggressive procedures, including intubation and implantation of a cardiac defibrillator, performed in the last several months of life do not contribute to recovery or improve QOL and therefore are not appropriate. However, the current guidelines do not specifically address what team members should be involved in palliative care, what drugs should be used, or when palliative care should be started [7,8]. To the best of our knowledge, our questionnaire is the first nationwide survey to investigate the current status of palliative care for heart failure.

Basic information about the facility and multidisciplinary team

Multidisciplinary management has been studied and used for decades in Western societies. In contrast, its use is just beginning in Japan [9]. In 2012, the Japanese Nursing Association created a certification in nursing for patients with chronic heart failure. However, only 296 nurses were certified from 2012 to 2016. Moreover, there may be two types of treatment teams in Japan: a palliative care team (conventional palliative care focusing on cancer) and a heart failure care team. Although the role of multidisciplinary teams in the treatment of patients with heart failure has been described, the individual team members have been less clearly characterized and the members of these multidisciplinary teams vary by institutions [10,11]. Therefore, we collected basic information on hospital beds, certified heart failure care nurses, certified palliative care nurses, multidisciplinary teams, and collaboration with cancer palliative teams. The team members may be different in each institution, which may influence the effects of palliative care.

Patient symptoms for palliative care and drug therapy

Patients with end-stage heart failure may experience intolerable dyspnea, pain, and delirium. Managing these symptoms is particularly important, and improving these conditions is one of the main goals of palliative care for heart failure [3–5]. Some studies have demonstrated the efficacy and safety of opioids for dyspnea. For patients with heart failure, doses are typically lower than those required for patients with cancer. Oral morphine at a dose of 2.5–5 mg/day was reported to be safe and to relieve dyspnea in patients with chronic heart failure [12]. Continuous morphine infusions should also be considered for patients with intractable dyspnea. However, Setoguchi et al. reported that patients dying of heart failure are relatively unlikely to benefit from hospice and opiates [13]. The reason might be that patients and families are unwilling to hear about limited life expectancies. Furthermore, medical efforts may occasionally improve the patient's condition, even for severe end-stage heart failure. The implementation of early appropriate advance care planning may improve palliative care efforts.

Pain is common and undertreated in end-stage heart failure. Nonsteroidal anti-inflammatory drugs should not be administered because of the risks for gastrointestinal bleeding, renal failure, and fluid retention. Opioids should be used for moderate to severe pain; fentanyl might also be considered. Moreover, patients with heart failure may experience recurrent or persistent delirium, which is occasionally associated with agitation. Midazolam or propofol may be used for sedation, at low doses that do not affect vital signs. The correlation between symptoms, drugs, and positive endpoints will be discussed.

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