Nationwide Survey of Palliative Care for Patients With Heart Failure in Japan

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Background: Palliative care for heart failure (HF) patients is recommended in Western guidelines, so this study aimed to clarify the current status of palliative care for HF patients in Japan.

Methods and Results: A survey was sent to all Japanese Circulation Society-authorized cardiology training hospitals (n=1,004) in August 2016. A total of 544 institutions (54%) returned the questionnaire. Of them, 527 (98%) answered that palliative care is necessary for patients with HF. A total of 227 (42%) institutions held a palliative care conference for patients with HF, and 79% of the institutions had <10 cases per year. Drug therapy as palliative care was administered at 403 (76%) institutions; morphine (87%) was most frequently used. Among sedatives, dexmedetomidine (33%) was administered more often than midazolam (29%) or propofol (20%). Regarding the timing of end-of-life care, most institutions (84%) reported having considered palliative care when a patient reached the terminal stage of HF. Most frequently, the reason for the decision at the terminal stage was “difficulty in discontinuing cardiotonics.” A major impediment to the delivery of palliative care was “difficulty predicting an accurate prognosis.”

Conclusions: This large-scale survey showed the characteristics of palliative care for HF in Japan. The present findings may aid in the development of effective end-of-life care systems.

Key Words: Heart failure; Morphine; Nationwide survey; Palliative care

Chronic heart failure (HF) is one of the most common cardiovascular diseases. Because of the aging of populations and the high survival rate after myocardial infarction, an increase in its prevalence in the coming years and decades has been predicted.1 Despite the introduction of new and more effective pharmacological and nonpharmacological therapies, the mortality rate of HF remains high.2,4,5 HF is characterized by unpredictable decompensation and stabilization, with a gradual decline over time.5 Thus, we need to discuss individualized management strategies with the patient, family, and hospital caregivers in each case. Initially, the main treatment goals are to improve clinical outcomes, reduce mortality, and minimize hospitalizations. However, the primary goal may change from improving prognosis to improving quality of life (QOL).6 Palliative care is recommended in the American College of Cardiology (ACC)/American Heart Association (AHA) HF guidelines to improve QOL (level of evidence: B).7 The guidelines state that aggressive procedures, including intubation and the implantation of an implantable cardioverter defibrillator (ICD), performed in the last several months of life do not contribute to recovery or improve QOL. However, these guidelines do not clearly state specific methods of palliative care.

Palliative care has historically been associated with
support for individuals with advanced incurable cancer; thus, cardiologists and cardiac nurses may be unfamiliar with its practice. To improve the quality of palliative care for patients with HF within resource limits, it is necessary to determine the status of care and the factors that positively effect it. To date, these issues have not been clarified in Japan, so we developed a nationwide survey of palliative care for HF.

Methods

The design of the present survey has been published in detail. In addition, its implementation is disclosed on the home page of the Heart Failure Palliative Care Study Group (http://shinfuzen-kanwa.jp/activity/index.html).

In the current study, a self-reported questionnaire was sent to all cardiology training hospitals authorized by the Japanese Circulation Society (n=1,004) in August 2016. The response deadline was December 2016. Return of questionnaires was considered as consent to participate. Regarding palliative care for HF, it is important to provide general palliative care that is applicable to all care settings. Therefore, we based the questions on the symptoms or psychosocial distress that should be screened and assessed in general palliative care. In this study, palliative care was defined using the World Health Organization (WHO) definition of “an approach that improves the QOL of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

The survey contained questions on the following topics for each institution: basic information about the institution and multidisciplinary team, patient symptoms requiring palliative care, drug therapy as palliative care for patients with HF, advance care planning with patients and their families, positive outcomes after performing palliative care, and impediments to providing palliative care to patients with HF. The survey comprised 7 questions, most of which permitted more than 1 response. When calculating the percentage in each question, we used the denominator that subtracted insufficient responses. Descriptive statistics were calculated.

### Table 1. Characteristics of Participating Institutions

<table>
<thead>
<tr>
<th>Category</th>
<th>n</th>
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<tbody>
<tr>
<td><strong>No. of hospital beds</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤200</td>
<td>73</td>
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<tr>
<td>201–400</td>
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<td></td>
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<tr>
<td>401–600</td>
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<td></td>
</tr>
<tr>
<td>≥601</td>
<td>114</td>
<td></td>
</tr>
<tr>
<td><strong>No. of cardiovascular departments</strong></td>
<td></td>
<td></td>
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<tr>
<td>≤20</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>21–40</td>
<td>304</td>
<td></td>
</tr>
<tr>
<td>41–60</td>
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<td></td>
</tr>
<tr>
<td>61–80</td>
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<td></td>
</tr>
<tr>
<td>≥81</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td><strong>No. of patients admitted to the cardiovascular department per year</strong></td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>≤500</td>
<td>65</td>
<td></td>
</tr>
<tr>
<td>501–1,000</td>
<td>192</td>
<td></td>
</tr>
<tr>
<td>1,001–1,500</td>
<td>142</td>
<td></td>
</tr>
<tr>
<td>1,501–2,000</td>
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<td></td>
</tr>
<tr>
<td>≥2,001</td>
<td>45</td>
<td></td>
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<tr>
<td><strong>Certified chronic HF care nurse</strong></td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>146</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>391</td>
<td></td>
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<tr>
<td><strong>Certified palliative care nurse</strong></td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>366</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>161</td>
<td></td>
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</tbody>
</table>

HF, heart failure; NA, not available.
that palliative care is necessary for patients with HF. Questions assessed the symptoms requiring palliative care for patients with HF and the results are shown in Figure 1. Dyspnea (91%) was the most common symptom, followed by anxiety (71%), depression (61%), and malaise (57%), whereas pain (34%) and leg edema (29%) were relatively rare.

Conference Regarding Palliative Care Provided to HF Patients
A total of 227 (42%) institutions had held a palliative care conference for patients with HF, but only 20 (9%) held them regularly and 138 (61%) rarely held them. Furthermore, 178 (79%) institutions discussed <10 palliative care cases in the conference per year. Regarding conference members, HF palliative care teams had a cardiologist (92%), nurse (97%), pharmacist (58%), nutritionist (47%), physical therapist (57%), medical social worker (40%), and psychology professional (13%). Furthermore, physicians other than cardiologists (27%) also participated in the conference (Figure 2). Of the 514 institutions, less than half (46%) held postmortem multidisciplinary conferences (death

Results

Basic Institution Information
Of the 1,004 institutions contacted, 544 (54%) returned the questionnaire. The characteristics of the participating institutions are summarized in Table 1. A total of 146 (27%) institutions had certified chronic HF care nurses, 366 (69%) institutions had certified palliative care nurses, and 115 (21%) institutions had both types of certified care nurses. We indicate the relationship between institution scale and certified nurses in Table S1. The number of institutions with both types of certified care nurses increased with the increase in the total number of hospital beds. We show the multidisciplinary team structure of each institution (Figure S1). A total of 129 (25%) institutions had a multidisciplinary HF team consisting of a nurse (99%), pharmacist (86%), nutritionist (82%), physical therapist (88%), medical social worker (52%), psychology professional (21%), and physicians other than cardiologists (25%).

Need to Provide Palliative Care for HF Patients
Of the 544 responding institutions, 527 (98%) answered
managing patients and family members during palliative care

of the 489 responding institutions, 40 (8%) had a HF palliative care team at each hospital, whereas 377 (77%) institutions had a conventional palliative care team focusing on cancer, and only 25 (5%) institutions had both. Of the 296 responding institutions, only 9 (3%) regularly held conferences between the HF palliative care team and the general palliative care team (conventional palliative care focusing on cancer), and 218 (74%) institutions had not at all. The most common reason was “The staff’s schedules do not match,” followed by “The method of palliative care differs between cancer and non-cancer diseases.”

Figure 3 illustrates the positive outcomes obtained through palliative care. Physical and mental symptomatic relief was most frequently reported. Although rare, there was an opinion that life expectancy was improved.

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Drug Therapy as Palliative Care for Patients With HF

Of the 531 responding institutions, 403 (76%) prescribed analgesics and/or sedatives for patients with HF, whereas 128 (24%) did not. Of the 403 institutions using drugs, the most frequently used medication was morphine (87%) (Table 2). Intravenous injection was the most common administration route (91%) for morphine, and the subcutaneous and oral routes were used similarly (19% each). Among sedatives, dexmedetomidine (33%) was administered most often, followed by midazolam (29%) and propofol (20%). The non-opioid analgesics included acetaminophen (25%) and nonsteroidal anti-inflammatory drugs (22%). A total of 364 (91%) institutions prescribed analgesics and/or sedatives during hospitalization only, and 34 (9%) institutions prescribed them for both at home and during hospitalization.

The following question was asked: “Do you collect patients’ written approvals (informed consent sheets) when using drugs as a part of palliative care?” Of the 400 responding institutions, 133 (33%) collected written approvals when using drugs, but 267 (67%) institutions did not at all. Of the 133 institutions, morphine was most frequently collected by 116 (87%). Despite being classified as the same opioid, fentanyl and codeine phosphate were collected by 26% and 5% institutions, respectively. When administering sedatives, most institutions did not collect written approvals for midazolam (14%), propofol (14%) or dexmedetomidine (15%).

Managing Patients and Family Members During Palliative Care

A total of 440 (83%) institutions answered that palliative care was discussed with patients and/or their family members. Of these, 62 (14%) institutions discussed with only the family, 184 (42%) institutions with both the patient and family, and 176 (40%) institutions changed the target of the discussion on a case-by-case basis. Figure 4 shows the content of the discussion “Understanding of the disease and prognosis” and “Approval pertaining to life-support treatment,” which were accounted for by many, and “The availability of advance directives (living will),” which was also discussed in approximately half of the institutions. Furthermore, we examined the timing of the discussion about palliative care. Most institutions (84%) reported having considered palliative care when a patient reached the terminal stage of HF, whereas 7% discussed the option at the time of diagnosis (Figure S2). Our results demonstrated how the institutions determined whether a patient

<table>
<thead>
<tr>
<th>Table 2. Drug Therapy as Palliative Care for HF</th>
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<tbody>
<tr>
<td>Type of drug</td>
</tr>
<tr>
<td><strong>Opioid</strong></td>
</tr>
<tr>
<td>Morphine</td>
</tr>
<tr>
<td>Fentanyl</td>
</tr>
<tr>
<td>Codeine phosphate</td>
</tr>
<tr>
<td><strong>Non-opioid analgesics</strong></td>
</tr>
<tr>
<td>Acetaminophen</td>
</tr>
<tr>
<td>NSAIDs</td>
</tr>
<tr>
<td><strong>Sedatives</strong></td>
</tr>
<tr>
<td>Midazolam</td>
</tr>
<tr>
<td>Propofol</td>
</tr>
<tr>
<td>Dexmedetomidine</td>
</tr>
<tr>
<td>Others</td>
</tr>
<tr>
<td>Valid responses n=403. HF, heart failure; NSAIDs, nonsteroidal anti-inflammatory drugs.</td>
</tr>
</tbody>
</table>
had reached the terminal stage. The most common reason was difficulty in discontinuing cardiotonics (62%), followed by difficulty taking meals (46%) and a reduced level of consciousness (43%).

Figure 5 shows the treatment limit and interruption in patients with terminal HF. Regarding the limitations, such as not starting new or additional treatments, setting an upper limit, a ventilator (85%) was the most common, followed by assisted circulation, such as percutaneous cardiopulmonary support (PCPS) and intra-aortic balloon pumping (IABP) (83%), and dialysis (78%). Regarding the discontinuation of current treatment, dialysis (39%) was most frequently discontinued, followed by assisted circulation such as PCPS and IABP (28%), tube feeding (25%) and the defibrillation function of an ICD (24%).

Method of Conveying Bad News
Regarding communication skills, 389 (73%) institutions reported lacking an opportunity to learn a method of conveying bad news.

Impediments to Providing Palliative Care of Patients With HF
We examined the barriers to palliative care faced by patients with HF. Figure 6 shows the impediments to the delivery of palliative care: “Inability to predict life expectancy” was the most common, followed by “Lack of criteria in the guidelines” and “Difficulty for patient to make his/her own decisions at the terminal stage.”

Discussion
Basic Institutional and Multidisciplinary Team Information
To the best of our knowledge, this is the first large nationwide survey to investigate the current state of palliative care for HF in Japan. Palliative care is known to reduce
patients’ symptom burden and improve the QOL of HF patients as well as those with cancer. Nevertheless, chronic HF patients are less likely to receive palliative care than cancer patients, as described in other studies. In our study findings, most institutions agreed that patients with HF need palliative care, but less than half had a palliative care team for HF patients. In contrast, almost all (99%) of the regional cancer centers had both a palliative care team and widespread multidisciplinary team management. Palliative care multidisciplinary team management for HF is not as well known as that for advanced cancer. In fact, there is no hard evidence that multidisciplinary team treatment is effective for palliative care for HF. The role of multidisciplinary teams in the treatment of patients with HF should be discussed in the near future.

Patients’ Symptoms Indicating Need for Palliative Care and Drug Therapy

The course of HF is characterized by worsening symptoms such as dyspnea, pain, and fatigue, which lead to a reduction in daily activities and poor QOL. Symptom management is particularly important in HF patients. However, analgesia/sedation management via drug therapy has not been adequately debated in Japan. The ACC/AHA HF guidelines reserve morphine for palliative care. Indeed, opioids, although traditionally used for pain relief, significantly improve dyspnea. Some studies have demonstrated the efficacy and safety of opioids for dyspnea in doses typically smaller than those used to manage cancer. Nonetheless, these drugs continue to be underused in patients with terminal HF.

Palliative Sedation

Palliative sedation is defined by the European Association for Palliative Care as “the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and healthcare providers.” Palliative sedation is a therapeutic option when symptom relief is difficult to achieve. The J-Proval study reported that continuous deep sedation does not affect life prognosis in patients with advanced cancer. The guidelines of the Japanese Society for Palliative Medicine recommend the initiation of intermittent and shallow sedation rather than deep and continuous sedation. In patients with HF, symptoms typically include uncontrollable dyspnea, general malaise or delirium. However, there are no guidelines on palliative sedation in patients with HF.

Sedative drugs such as midazolam and propofol frequently cause deep sedation and respiratory depression, and titration can be difficult to achieve. In contrast, dexmedetomidine, a new α-2 agonist with analgesic and sedative properties, does not cause respiratory depression. Furthermore, it causes shallow sedation, allowing the patient to communicate with his/her family. Indeed, the use of dexmedetomidine was most commonly reported in this study. Therefore, dexmedetomidine may be considered as the drug of choice over midazolam and propofol. Past studies have reported that dexmedetomidine is useful in pediatric palliative care, but evidence in elderly HF patients is lacking.

Following the statement on treatment of elderly HF patients published in 2016, it is recommended that written approvals for sedation be prepared by a multidisciplinary team. In this study, most institutions reported not having collected written approvals when using drugs as part of a palliative care plan. This finding suggested that consensus is lacking between patients or their families and healthcare providers regarding palliative sedation, and there are no guidelines on how to proceed with appropriate protocols at the institutional level. Further discussion and evidence are required about the role of palliative sedation for terminal-stage HF patients.

Advance Care Planning With Patients and Their Families

HF is comparable to cancer in terms of its 5-year mortality rate. Thus, the provision of appropriate information to patients is important to achieving optimal palliative care. According to the WHO, palliative care should be applied at an early stage of the disease. Our study revealed that most institutions considered administering palliative care only when a patient reached the terminal stage of HF, and only 6% had discussed the option at the time of diagnosis. The main reason for not discussing palliative care at an early stage was reportedly the difficulty physicians faced in accurately assessing the prognosis of these patients, which is consistent with the findings of another study. We agree that it is difficult to determine the appropriate time to start palliative care. A common approach to identifying patients who need palliative care is asking a “surprise” question: “Would I be surprised if this patient was to die in the next 6–12 months?” This question is highly accurate for predicting the survival prognosis of cancer patients, although some authors have concerns about its use in chronic HF patients.

Furthermore, our results showed there is little opportunity for physicians to learn how to convey bad news. Most cardiologists are not trained on how to communicate and discuss palliative care issues. Thus, when speaking with patients, cardiologists tend to focus on the pathophysiology and treatment options, and few discuss palliative care issues. In fact, patients dying of HF were shown to have a poorer understanding of their condition and be less involved in the decision-making process regarding their care. In cancer care, the Palliative care Emphasis program on symptom management and Assessment for Continuous Medical Education (PEACE) was established to provide primary palliative care education for all physicians engaged in cancer care. The PEACE education program reportedly improved palliative care outcomes. Therefore, in HF care, all cardiologists should receive palliative care education so HF patients can more likely benefit from it at an early stage.

Palliative Care for HF

A meta-analysis demonstrated that a palliative care intervention for HF is associated with improved QOL. In patients with metastatic lung cancer, appropriate palliative care reportedly has a life-prolonging effect. The recent Palliative Care in Heart Failure trial demonstrated that multidimensional palliative care intervention improved patient QOL and spiritual well-being but not mortality or hospitalization rates. In our study, physical and mental symptomatic relief was the most common outcome obtained through palliative care, but a minority expressed improvement in life expectancy. Although there is no evidence, palliative care might relieve dyspnea, attenuate the activation of the sympathetic nervous system and limit the risk of life-threatening arrhythmias, and thus, prolong survival.

Further studies should examine whether palliative care
improves the prognosis of patients with HF in Japan.

**Study Limitations**

First, the survey was conducted only in cardiology training hospitals authorized by the Japanese Circulation Society. Therefore, other institutions wherein super-elderly patients are hospitalized were not included. This could have led to a potential selection bias. Moreover, the survey response rate was only 54%, suggesting that a majority of answers may have been provided by medical practitioners interested in palliative care. If this was the case, the status of palliative care may have been overestimated. Second, the respondents were medical practitioners and not patients; furthermore, the responses were based on these practitioners' subjective opinions. Because it is difficult to decide what constitutes the terminal stage of HF, the definition of end-stage HF might have differed among responders. Therefore, we did not define “end-stage HF”. Furthermore, we were unable to check whether the responses from other team members would have been consistent. However, it is unlikely that this would lead to significant errors because the questions were simple, objective, and semi-quantitative.

**Conclusions**

Many HF patients require palliative care to alleviate various symptoms, improve communication, and facilitate the decision-making process. Guidelines suggest that HF patients benefit from receiving palliative care in Western countries. However, this approach has just started in Japan and some caution should be exercised when applying clinical management practices from other countries to Japanese patients. Our results might help optimize the use of palliative care in Japan. Finally, the number of patients with HF is increasing, and we believe that the information derived from this survey will be useful for updating our clinical knowledge of palliative care for patients with HF.

**Acknowledgments**

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**Disclosures**

The authors declare no conflicts of interest.

**Name of Grants**

None.

**References**


**Supplementary Files**

**Supplementary File 1**

- **Figure S1.** Do you have a multidisciplinary team?
- **Figure S2.** When is the time to start a discussion?
- **Table S1.** Relationship between institution scale and certified nurses