

## Position Paper



# Palliative Care and Hospice for Heart Failure Patients: Position Statement From the Korean Society of Heart Failure

Seung-Mok Lee , MD<sup>1</sup>, Hae-Young Lee , MD, PhD<sup>1</sup>, Shin Hye Yoo , MD, PhD<sup>2</sup>, Hyun-Jai Cho , MD, PhD<sup>1</sup>, Jong-Chan Youn , MD, PhD<sup>3</sup>, Seong-Mi Park , MD, PhD<sup>4</sup>, Jin-Ok Jeong , MD, PhD<sup>5</sup>, Min-Seok Kim , MD, PhD<sup>6</sup>, Chi Young Shim , MD, PhD<sup>7</sup>, Jin Joo Park , MD, PhD<sup>8</sup>, Kye Hun Kim , MD, PhD<sup>9</sup>, Eung Ju Kim , MD, PhD<sup>10</sup>, Jeong Hoon Yang , MD, PhD<sup>11</sup>, Jae Yeong Cho , MD, PhD<sup>9</sup>, Sang-Ho Jo , MD, PhD<sup>12</sup>, Kyung-Kuk Hwang , MD, PhD<sup>13</sup>, Ju-Hee Lee , MD, PhD<sup>13</sup>, In-Cheol Kim , MD, PhD<sup>14</sup>, Gi Beom Kim , MD, PhD<sup>15</sup>, Jung Hyun Choi , MD, PhD<sup>16</sup>, Sung-Hee Shin , MD, PhD<sup>17</sup>, Wook-Jin Chung , MD, PhD<sup>18</sup>, Seok-Min Kang , MD, PhD<sup>7</sup>, Myeong Chan Cho , MD, PhD<sup>13</sup>, Dae-Gyun Park , MD, PhD<sup>19</sup>, and Byung-Su Yoo , MD, PhD<sup>20</sup>

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### Correspondence to

**Hae-Young Lee, MD, PhD**

Department of Internal Medicine, Seoul National University Hospital, Seoul National University College of Medicine, 101 Daehak-ro, Jongno-gu, Seoul 03080, Korea.  
Email: hylee612@snu.ac.kr

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<sup>1</sup>Department of Internal Medicine, Seoul National University Hospital, Seoul National University College of Medicine, Seoul, Korea

<sup>2</sup>Center for Palliative Care and Clinical Ethics, Seoul National University Hospital, Seoul, Korea

<sup>3</sup>Division of Cardiology, Department of Internal Medicine, Seoul St. Mary's Hospital, Catholic Research Institute for Intractable Cardiovascular Disease, College of Medicine, The Catholic University of Korea, Seoul, Korea

<sup>4</sup>Division of Cardiology, Department of Internal Medicine, Korea University Anam Hospital, Korea University College of Medicine, Seoul, Korea

<sup>5</sup>Department of Internal Medicine, Chungnam National University Hospital, Chungnam National University College of Medicine, Daejeon, Korea

<sup>6</sup>Division of Cardiology, Department of Medicine, Asan Medical Center, University of Ulsan College of Medicine, Seoul, Korea

<sup>7</sup>Division of Cardiology, Severance Cardiovascular Hospital, Yonsei University College of Medicine, Seoul, Korea

<sup>8</sup>Department of Internal Medicine, Seoul National University Bundang Hospital, Seoul National University College of Medicine, Seongnam, Korea

<sup>9</sup>Department of Cardiovascular Medicine, Chonnam National University Hospital, Chonnam National University Medical School, Gwangju, Korea

<sup>10</sup>Division of Cardiology, Korea University Guro Hospital, Seoul, Korea

<sup>11</sup>Division of Cardiology, Department of Internal Medicine, Heart Vascular Stroke Institute, Samsung Medical Center, Sungkyunkwan University School of Medicine, Seoul, Korea

<sup>12</sup>Division of Cardiology, Department of Internal Medicine, Hallym University Sacred Heart Hospital, Anyang, Korea

<sup>13</sup>Division of Cardiology, Department of Internal Medicine, Chungbuk National University College of Medicine, Cheongju, Korea

<sup>14</sup>Division of Cardiology, Department of Internal Medicine, Keimyung University Dongsan Hospital, Keimyung University School of Medicine, Daegu, Korea

<sup>15</sup>Department of Pediatrics, Seoul National University Children's Hospital, Seoul National University College of Medicine, Seoul, Korea

<sup>16</sup>Division of Cardiology, Department of Internal Medicine, Pusan University Hospital, Busan, Korea

<sup>17</sup>Division of Cardiology, Department of Internal Medicine, Inha University Hospital, Incheon, Korea

<sup>18</sup>Division of Cardiology, Department of Internal Medicine, Gachon University Gil Medical Center, Incheon, Korea

<sup>19</sup>Division of Cardiology, Department of Internal Medicine, Kangdong Sacred Heart Hospital, Seoul, Korea

<sup>20</sup>Division of Cardiology, Yonsei University Wonju Severance Christian Hospital, Wonju, Korea

## ABSTRACT

Heart failure (HF) is a major cause of mortality and morbidity in South Korea, imposing substantial physical, emotional, and financial burdens on patients and society. Despite the high

burden of symptom and complex care needs of HF patients, palliative care and hospice services remain underutilized in South Korea due to cultural, institutional, and knowledge-related barriers. This position statement from the Korean Society of Heart Failure emphasizes the need for integrating palliative and hospice care into HF management to improve quality of life and support holistic care for patients and their families. By clarifying the role of palliative care in HF and proposing practical referral criteria, this position statement aims to bridge the gap between HF and palliative care services in South Korea, ultimately improving patient-centered outcomes and aligning treatment with the goals and values of HF patients.

**Keywords:** Heart failure; Palliative care; Hospices

## BACKGROUND

Heart failure (HF) is one of the leading causes of death in South Korea, and its prevalence keeps increasing. Mortality of HF is also increasing both in men and women, resulting in greater burden to society in the aspect of healthcare cost.<sup>1)</sup> Regardless of its etiology, HF is usually life-long disease requiring continuous medical therapy with appropriate care for acute exacerbation.

According to World Health Organization, palliative care is defined as 'an approach that improves the quality of life (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, whether physical, psychosocial and spiritual.'<sup>2)</sup> Palliative care has been implemented in several diseases in South Korea, such as cancer, chronic obstructive respiratory disease (COPD), acquired immunodeficiency syndrome and chronic liver cirrhosis.<sup>3)</sup>

However, there is still a gap between palliative care-applicable diseases in South Korea and other countries, as palliative care is not provided for HF patients in South Korea. In USA, 8% of overall hospice-using patients are HF patients, and patients diagnosed with 'unspecified HF' according to International Classification of Diseases-10 code is 5th among the patients enrolled in hospice.<sup>4)</sup> Also, the Centers for Medicare & Medicaid Services suggests criteria for eligibility to use hospice in chronic heart disease patients.<sup>5)</sup> In their own guideline for HF, American Heart Association (AHA) and European Society of Cardiology (ESC) give statement about palliative care and hospice in HF patients.<sup>6,7)</sup> Like this, palliative care is actively offered to HF patients in western countries, but not in South Korea. According to the fact sheet by Korean Society of Heart Failure (KSHF), nearly 40,000 of overall HF patients got hospitalized annually mainly due to HF, and they seem to be the potential beneficiary group from palliative care and hospice

although proper palliative care services have not been provided to them yet.<sup>8)</sup>

The role of palliative care starts early in HF, and it gradually grows up following disease progression, resulting in bereavement care after passing away. Like terminal stage cancer patients, advanced or end-stage HF patients have similar symptom like dyspnea, fatigue, pain, depression and anxiety, and their burden increases and becomes refractory to traditional treatment as disease progresses.<sup>9,10)</sup> Thus, like the case in cancer patients, integration of palliative care and hospice into care of HF can fulfill unmet needs for palliative, supportive care in HF.

But there are some barriers blocking it. Usually, HF patients and their caregivers do not think HF as life-threatening disease, like cancer, and they overestimate patients' life expectancy.<sup>11)</sup> They also think that palliative care or hospice can potentially hastening death. In addition, decision of prognosis in HF patients is hard to make due to its natural course, and clinicians engaging in HF treatment are reluctant to make discussion about patients' prognosis, life expectancy, dying and end of life (EOL) care, resulting in failure of timely discussing palliative care in HF patients.<sup>12)</sup>

This position statement by the KSHF aims to develop recommendations that reflect the real-world situation of South Korea by conducting a 2-round Delphi survey involving palliative care providers, general physicians, and HF specialists. We presented the full results of the Delphi survey in a companion paper.

## DEFINITION OF TERMS RELATED TO PALLIATIVE CARE

Diverse terms are used around palliative care, and they are applied with different interpretation depending on context and articles. This ambiguity and misperception among the patients, their

caregiver, and even clinicians not involved in palliative care, blocks active usage of palliative care in various diseases. To overcome this obstacle and convey the correct meaning of each term, the meaning of palliative care-related terms used in this article are defined in the following sections.

‘Palliative care’ means an approach to improve QoL of patients and their caregivers, who experience stressful situations due to life-long incurable disease. The primary goals of palliative care are to alleviate symptoms, improve QoL, support emotional and spiritual well-being, aid in decision making, and provide comprehensive care for both patients and their caregivers facing severe illness. In South Korea, the term is often misinterpreted as synonymous with ‘hospice’ in legal contexts, limiting its use in the early stages of incurable diseases. However, in this document, we aim to clarify and emphasize the original meaning of palliative care as comprehensive, holistic support aimed at improving the QoL for patients and their families by addressing their physical, psychological, social, and spiritual needs.

‘Hospice’ is one of the subtypes of palliative care prepared for those who are in the ‘EOL’ stage or who love her/him. EOL is the period of human being followed by natural death. Patients in this period show continuous aggravation of underlying disease which are not postponed by medical treatment. The length of EOL can be variable, from a few days to several months, depending on patient’s underlying disease and previous performance status. EOL is different from ‘active dying,’ which means a short period preceding imminent death limited to the last hours or days of life.<sup>13)</sup> Basic concept of focusing on QoL does not change in hospice care, but it puts more emphasis on respecting each patient’s personal goal, value, and preference for selecting therapeutic interventions as the underlying disease progresses to the natural death.

‘Shared decision-making’ is traditionally defined as a collaborative approach between patients, their caregivers and clinicians to share patient’s goal, value and preference about medical options and think about potential harm and benefits following certain medical decisions. From this deliberative process, the best medical option to respect patients and their caregivers can be derived.<sup>14)</sup> ‘Advance care planning’ is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. It aims to ensure respecting people’s value, goals and preferences during providing medical services to them.<sup>15)</sup> ‘Advance directives’ are legal documents that outline an individual’s preference regarding major medical decisions.<sup>16)</sup> It contains personal preferences or rejects about current and future treatment options. Further discussion

about advance care planning and advance directives will be presented below.

## **PRECEDING RESEARCH DATA ABOUT USING PALLIATIVE INTERVENTION IN HF PATIENTS**

Many studies revealed potential beneficial effects of palliative care in HF patients. In a prospective, 2-arm, single-center randomized controlled clinical trial aimed at patients with advanced HF and expected high 6-month mortality risk, outpatient palliative care intervention provided by multidisciplinary team consists of certified palliative care nurse practitioner, palliative medicine board-certified physician and cardiologist, showed greater improvement in KCCQ (Kansas City Cardiomyopathy Questionnaire) and FACIT-Pal (Functional Assessment of Chronic Illness Therapy-Palliative care) compared with usual care alone.<sup>17)</sup> Randomized controlled trial to compare inpatient palliative care consultation and usual care in patients hospitalized with acute HF, palliative care consultation revealed better improvement in QoL, symptom burden, and documentation rate of advance care planning.<sup>18)</sup> Palliative care intervention as weekly home visit and telephone call to end-stage HF patients recently discharged home from hospitals also showed statistically significant benefit in depression, dyspnea and QoL improvement in randomized controlled trial.<sup>19)</sup> Several other studies exist that demonstrate effectiveness of palliative care to HF patients in setting of outpatient, inpatient, or home-based approaches.<sup>20-23)</sup> Meta-analysis of previous high-quality studies (Jadad scale  $\geq 3$ ) about palliative care in HF patients suggests same positive impact on patient-reported outcomes like QoL.<sup>24)</sup>

In contrast, other several studies revealed mixed or not significant outcomes in palliative care intervention group. A single-blind randomized clinical trial in patients with New York Heart Association (NYHA) class III or IV or American College of Cardiology stage C or D HF, telehealth-based palliative care intervention did not show improved QoL or mood compared with usual care.<sup>25)</sup> Some studies also demonstrate no significant improvement in depression and anxiety,<sup>26)</sup> or dyspnea.<sup>27)</sup> The authors of these studies find the cause of failing to reproduce positive impact of previous studies in inappropriate target patients, low intensity of palliative care intervention, small sample size, high baseline QoL and low baseline symptom burden. Therefore, to maximize the effect of palliative care intervention in HF patients, selecting appropriate target patients and secure enough intervention intensity seems important.

In aspect of cost for providing palliative care services and cost-effectiveness of palliative interventions, some studies revealed the cost-effectiveness of palliative care services in HF patients. In the Palliative Care in Heart Failure study providing outpatient palliative care for patients with advanced HF, at an estimated program reimbursement of 73 USD per month, the palliative intervention resulted in an incremental payments of 964 USD per patient for an incremental cost-effectiveness ratio of 29,041 USD per quality-adjusted life years (QALY) after 36 months.<sup>28)</sup> Wong et al.<sup>19)</sup> demonstrated that structured home-based palliative care programs saved 7,935 HK\$ (approximately 1,023 USD) in 28 days and 26,084 HK\$ per patient in 84 days compared to control group who only got scheduled palliative care clinic follow-up and episodic unstructured nurse home visits, although overall 80,500 HK\$ (1,872 HK\$ per patient) was required to train 4 nurse practitioners and 14 volunteers and to pay the salary of them. Sahlen et al.<sup>20)</sup> suggested subtle improvement in QALY by using palliative intervention, and the costs for human resources were offset by decreased hospital utilization. However, palliative interventions used in these studies were mainly home-based, so it does not fit perfectly to the domestic palliative care settings in South Korea.

## WHICH PATIENTS SHOULD BE REFERRED TO SPECIALTY PALLIATIVE CARE OR HOSPICE?

Palliative care and hospice services are critical components of the comprehensive management of patients with advanced HF. These services focus on improving QoL, managing symptoms, and providing psychosocial support. The decision to refer a patient to specialty palliative care or hospice should be guided by the patient's clinical status, prognosis, and goals of care. In addition, clinicians should provide enough information about the patient's future disease course and prognosis before making the decision to respect patient's autonomy.

As described in previous paragraphs, palliative care and hospice are different from each other, which is important to understand comprehensive patient care. However, in the current policy-making process in South Korea, the 2 terms are used together to represent limited meaning, restricted mainly to EOL care. Considering easiness to utilize during policy-making process and the policies currently in effect for cancer and other non-cancer patients, the authors decided that appropriate referral criteria for domestic HF patients should be summarized in terms of EOL care. Since palliative care and hospice services in South Korea are provided based on consultations to related experts, we summarized referral criteria to

specialty palliative care or hospice including criteria suggested in overseas literatures in the next section. In addition, detailed criteria tailored to the specific domestic situations will also be presented based on Delphi study aimed at HF specialists, hospice nurse practitioners and residents of internal medicine.

### General criteria for referral to specialty palliative care or hospice

#### *Advanced HF with refractory HF symptoms*

Patients who have advanced HF, typically categorized as NYHA class III or IV should be considered for specialty palliative care referral, particularly when symptoms such as dyspnea, fatigue, or pain are not adequately controlled despite optimal therapy. These patients often experience a significant decline in functional status and recurrent hospitalizations, which are indicative of poor prognosis and substantial symptom burden. ESC propose the symptom-based referral criteria, including progressive functional decline, dependence in most activities of daily living, severe HF symptoms with poor QoL despite optimal pharmacological and non-pharmacological therapies, frequent admissions to hospital or other serious episodes of decompensation despite optimal treatment, exclusion of heart transplantation and mechanical circulatory support, and cardiac cachexia.<sup>6)</sup>

#### *End-stage HF with a life expectancy of 6 months or less*

AHA suggests that hospice care is appropriate for patients with end-stage HF when the patient's life expectancy is estimated to be 6 months or less, assuming the disease follows its natural course.<sup>7)</sup> Criteria indicating this stage include recurrent hospitalizations despite maximal medical therapy, dependence on intravenous inotropes, and progressive functional decline with a poor response to diuretics. Although AHA does not provide specific criteria to determine patient's life expectancy, the 'surprise question' may be helpful to identify patients with limited life expectancy.<sup>29)</sup>

#### *Psychological and spiritual distress*

Patients experiencing significant emotional, psychological, or spiritual distress related to their illness or its implications for the future should be referred to specialty palliative care. This is particularly relevant for patients and families grappling with existential questions, loss of autonomy, or the burdens associated with long-term illness management.

#### *Severe functional impairment*

Patients with severe functional impairment, such as being predominantly bedbound or unable to perform activities of daily living without assistance, are likely to benefit from specialty palliative care or hospice services. The focus shifts to maintaining comfort, dignity, and QoL in the patient's remaining time.



*Uncertainty regarding prognosis and complex decision-making needs*

Specialty palliative care can enhance the assessment of a patient's health status and support the decision-making process. Patients who face uncertainty about their prognosis or who need to make complex decisions regarding their care, such as the choice between pursuing aggressive treatment options versus focusing on comfort, can benefit from the expertise of a palliative care team. It can assist in aligning treatment goals with the patient's values and preferences, ensuring that care decisions are made in a patient-centered manner.

*Decision to forego disease-modifying therapies*

Patients who elect to discontinue disease-modifying treatments, such as certain cardiac medications, implantable defibrillators, or left ventricular assist devices (LVADs), should be considered for hospice. This decision often follows a comprehensive discussion about the expected benefits and burdens of continued aggressive treatment versus focusing on comfort and QoL. This criteria is also clarified in Centers for Medicare & Medicaid Services coverage indication for using hospice due to heart disease; 'Optimally treated for heart disease, or either not candidates for surgical procedures or decline these procedures' and 'NYHA class IV or documented ejection fraction 20% or less.'<sup>5)</sup>

*Multidisciplinary support needs*

Hospice care is also indicated for patients who require extensive multidisciplinary support, including pain and symptom management, spiritual care, and bereavement services for the family. This integrated approach ensures that both the patient and their loved ones receive comprehensive care during the final stages of illness.

**Experts consensus in South Korea**

In addition to the criteria listed above, substantial effort to make consensus about referral criteria is going on, using Delphi method. In one study, authors represented 25 criteria using Delphi method.<sup>30)</sup> Experts in cardiology or palliative care agreed that it is enough to refer to specialty palliative care or hospice to fulfill one of these 25 criteria. These criteria contain cardiac cachexia, 2 hospitalizations within 3 months, clinician estimated life expectancy of 6 months or less, and refractory symptoms requiring palliative sedation. Likewise, we conducted Delphi study to cardiologists, palliative care nurse practitioners, and residents of internal medicine in South Korea, to make expert consensus about specialty palliative care or hospice referral criteria in HF patients. The result is represented in **Table 1**. According to the study, over 90% of overall responders agreed the need for specialty palliative care or hospice service in HF. Although it does not have high-level evidence, it seems to be able to present rough criteria about when

**Table 1.** Consensus about referral criteria for specialty palliative care or hospice in South Korea

Referral criteria
Complication & comorbidity
- Oxygen dependency
- Recurrent ICD shocks
- Multi-organ failure (3 or more)
- Presence of one or more life-threatening disease (ex. cancer, advanced COPD)
Cardiac therapies
- Intolerable/resistant to GDMT
- Ineligible for or not interested in advanced cardiac therapies (ex. LVAD, HT)
Hospital use
- Two or more hospitalization due to heart failure within last 3 months
Severity of HF
- NYHA class IV
- ACC/AHA stage D
Life expectancy (based on 'surprise question')
- Physician would not be surprised if patient dies in 6 months
Symptom burden
- Severe physical symptoms (NRS $\geq 7$ )
- Severe emotional symptoms (NRS $\geq 7$ )
- Palliative sedation-requiring severe symptoms according to physician's decision
Functional impairment
- Dependent in 3 or more ADLs
Psychosocial needs
- Patients or their caregiver's request for specialty palliative care or hospice
- Assistance with difficult decision making or discussion for hospice referral

ICD = implantable cardioverter-defibrillator; COPD = chronic obstructive pulmonary disease; GDMT = guideline-directed medical therapy; LVAD = left ventricular assist device; HT = heart transplantation; HF = heart failure; NYHA = New York Heart Association; ACC/AHA = American College of Cardiology/American Heart Association; NRS = numeric rating scale; ADL = activity of daily living.

to consider specialty palliative care or hospice in HF patients in South Korea.

## ADVANCE CARE PLANNING AND ITS ESSENTIAL TOPICS IN HF PATIENTS

Palliative care for HF patients is a multifaceted approach aimed at improving QoL by addressing the physical, emotional, social, and spiritual needs of patients and their families. Advance care planning can facilitate appropriate palliative care, and it can obtain legal validity by documenting advance directives. Advance care planning is not just a one-time procedure and should be repeated regularly as patients' clinical status changes.

Additionally, several critical topics must be addressed during thoughtful conversation during advance care planning, particularly for those getting close to the EOL. These topics include identifying the preferred place of death, managing cardiovascular implantable electronic devices (CIEDs), and preparing well-designed substitute decision making. Shared decision-making has an important role during discussing these topics to facilitate communication between patients, their caregivers and health care providers. It also ensures patient's right to make decision based on fully provided medical information, leading to aligning treatment strategies to patient's will and preferences well.

### Documenting advance directives

Advance directives are vital for ensuring that patient's care preferences are respected, particularly in the advanced stages of HF when the patient's ability to communicate may be compromised. Ideally, advance directives should include a living will for treatment preferences in a variety of specific situations and a designation of surrogate decision-maker.<sup>15)</sup> However in South Korea, advance directives only contain patient's preferences regarding life-sustaining treatment, and the withholding or withdrawal of life-sustaining treatment is permitted legally only in the EOL stage. Although contents of advance directives in South Korea are too poor to represent patient's detailed will, documenting advance directives is important in that it allows the patients to think about life-sustaining treatment and provides legal basis for stopping life-sustaining treatment in the future. Before documenting advance directives, clinicians should provide information about patient's present and future disease status and disease prognosis to help patient decide his choice about future treatment options. Regular updates to these documents are necessary as the disease progresses or significant health events occur, changing goals of care. This documentation is foundational for aligning care with the patient's goals and avoiding unnecessary or unwanted interventions.

### Identifying the preferred place of death

A critical aspect of palliative care discussions is understanding where the patient wishes to spend their final days. Studies indicate that many patients prefer to die at home, surrounded by loved ones, yet there is often a significant mismatch between these preferences and reality.<sup>31)</sup> In South Korea, for example, the limited availability of home-based care exacerbates this discrepancy, often resulting in patients dying in hospitals or other institutions against their wishes. Despite these challenges, it is crucial to identify and document the patient's preferred place of death early in the care process. Doing so facilitates the development of a patient-centered care plan that honors the patient's values and goals, potentially enhancing the quality of the EOL experience.

### Managing CIEDs

CIEDs, including implantable cardioverter-defibrillators (ICDs), cardiac resynchronization therapy-defibrillators (CRT-Ds), and VADs, play a significant role in the management of HF. However, their management at the EOL presents complex ethical dilemmas and requires careful consideration. Some ethicists argue deactivation of CIED is killing, not allowing-to-die, because the CIED treatment is completed, not on-going.<sup>32)</sup> But recent guideline or statement advocates deactivation of CIED, at least to some extent.<sup>13,33)</sup>

#### ICD deactivation

ICDs are designed to prevent sudden cardiac death by delivering shocks in response to life-threatening arrhythmias. However, for patients with a limited life expectancy and poor QoL, these shocks can be distressing, prolonging the dying process unnecessarily.<sup>34)</sup> Thus generally, it is recommended to discuss ICD deactivation with the patient when they enter the end-stage of HF, ensuring that the decision aligns with the patient's autonomy and goals of care.

#### CRT-D and pacemaker management

Unlike ICDs, CRT-Ds and pacemakers primarily serve to improve symptoms and QoL by optimizing cardiac function. Therefore, deactivation of these devices is more controversial. Pacemakers, for instance, do not typically prolong the dying process,<sup>35-37)</sup> as they prevent symptomatic bradycardia rather than life-threatening arrhythmias. Similarly, CRT-D devices improve HF symptoms by synchronizing ventricular contractions.<sup>38)</sup> Therefore, considering their symptom-relieving effect, their deactivation is usually not recommended unless it aligns with the patient's wishes and has been thoroughly discussed with a multidisciplinary team.

#### LVAD deactivation

The decision to deactivate a LVAD is particularly challenging. LVADs are used in end-stage HF to support cardiac function and

alleviate symptoms. However, when non-congestive symptoms or psychosocial issues cause extreme distress, deactivation may be considered. The decision to deactivate an LVAD, especially when used as destination therapy, must involve a careful, multidisciplinary evaluation of the potential benefits and harms,<sup>39,40)</sup> as deactivation typically leads to death within hours.<sup>41)</sup>

### Preparing well-designed substitute decision making

HF patients are at a high risk of cognitive impairment and may experience acute exacerbations that compromise their decision-making capacity.<sup>42)</sup> Traditionally, decision-making process in South Korea is usually family-centered, so patient's spouse or children mainly have a role to decide on behalf of the patient. As mentioned above, advance directives in South Korea does not fully contain detailed information of patient's preference in specific situations. Therefore, patients and their families should prepare well-designed substitute decision making aligned with patient's detailed will and preferences during advance care planning. By discussing sophisticated strategies for each specific situation when patients are alert and oriented, their families will be able to represent them appropriately in the future.

Essential topics of advance care planning in HF are summarized in **Table 2**.

## MULTIDISCIPLINARY TEAM APPROACH

Palliative care for HF patients aims to optimize the QoL by managing symptoms, adjusting medical treatments, and addressing psychosocial issues. Given the complex and progressive nature of HF, various occupations should be involved in palliative care to respond to patient's diverse needs.

### Multidisciplinary palliative care team

Palliative care has an inherent role in providing care aligned to patient's diverse needs. To deal with these multiple care settings, palliative care team consists of various occupations. Multidisciplinary palliative care team can include primary physician (in case of HF, cardiologist), palliative care specialist, nurse or nurse practitioner, counselor or psychologist, spiritual care practitioner, social worker and volunteer. The roles of members in multidisciplinary palliative care team are diverse and may overlap with each other. For instance, cardiologists should keep following patients about HF, and deal with patient's mild to moderate symptoms primarily. Palliative physicians can support cardiologists to manage more severe and complex symptoms, while facilitating communications between patients, caregivers, and healthcare professionals. Example of multidisciplinary palliative care team members and their role is represented in **Table 3**.<sup>43,44)</sup>

## PHYSICAL SYMPTOM MANAGEMENT

HF patients typically present more diverse and severe physical symptoms as underlying HF progresses, and they cause substantial distress to the patient's life. Thus, managing and alleviating physical symptoms is one of the essential aspects of palliative care in HF, especially in those with advanced HF. While adjusting previous HF-related medical therapies, symptom-based approaches can also be helpful to reduce symptom burdens.

### Adjustment of previous HF medications

Even in palliative care, continuation of guideline-directed medical therapy (GDMT) is often necessary due to its dual role in disease modification and symptom relief. However, as HF progresses and patient goals shift, clinicians must reassess the need for certain medications in terms of respecting patient's own goal and preferences about treatment options.

**Table 2.** Essential topics of palliative care in HF

Topics	Description
Documenting AD	<ul style="list-style-type: none"><li>- Provide information about disease course and prognosis</li><li>- Clarify patient's value, goal and preference on treatment</li><li>- Update regularly as disease progresses and patient's status changes</li></ul>
Checking preferred place of death	<ul style="list-style-type: none"><li>- Identify patient's hope about place of death</li><li>- Make effort to reflect their preference as much as possible</li></ul>
Managing CIED	<ul style="list-style-type: none"><li>- Discuss the specific situation when to consider deactivating CIED</li><li>- If CIED doesn't alleviate patient's symptom, timely deactivation can be considered</li><li>- If CIED helps reduce patient's symptom, deactivation should be decided after thorough discussion within patient, caregivers and professionals</li></ul>
Preparing well-designed substitute decision making	<ul style="list-style-type: none"><li>- Important due to fluctuating natural course of HF</li><li>- Should be completed when patient is alert and oriented</li><li>- Discussing detailed strategies for each specific situation is helpful for representing patient's will in the future</li></ul>

HF = heart failure; AD = advance directives; CIED = cardiac (cardiovascular) implantable electronic device.

**Table 3.** Example of multidisciplinary palliative care team members and their role<sup>43,44)</sup>

Team members	Role
Cardiologists	<ul style="list-style-type: none"> <li>- Continue or adjust ongoing HF treatment</li> <li>- Manage patient's symptom primarily</li> <li>- Collaborate with other team member to coordinate holistic care</li> <li>- Organize hospital admission or hospice referral if patient's status changes</li> </ul>
Palliative care physicians	<ul style="list-style-type: none"> <li>- Deal with more complex symptoms, giving consultations to cardiologists</li> <li>- Facilitate discussion about difficult decision-making between team member, patients, and their caregiver</li> <li>- Refer to other team members like counsellors if needed</li> </ul>
Nurse practitioners	<ul style="list-style-type: none"> <li>- Help patients manage their symptoms with prescribed medicines and practical strategies</li> <li>- Visit patient or provide telephone-based checkup in outpatient setting</li> <li>- Make informal interaction about patient's status with cardiologist or palliative physicians</li> </ul>
Psychologists (counsellors)	<ul style="list-style-type: none"> <li>- Help patients talk about any fears, worries or mixed emotions</li> <li>- Allow caregivers to show their fear of loss or grief</li> <li>- Coordinate communication between patients and their caregivers</li> <li>- Suggest coping strategy to alleviate distress, anxiety, and depression</li> </ul>
Religious workers	<ul style="list-style-type: none"> <li>- Support patients and their caregivers to talk about spiritual topics</li> <li>- Help patients reflect their life and find their meaning of life</li> <li>- Connect with other members of patient's faith if needed</li> </ul>
Social workers	<ul style="list-style-type: none"> <li>- Provide emotional, social, financial and legal support to patients and their caregivers</li> <li>- Connect to welfare services if needed</li> </ul>

HF = heart failure.

### Statin

Given their long-term benefits, statins may be discontinued as they are less likely to provide immediate symptomatic relief.

### Angiotensin converting enzyme inhibitors (ACEIs), angiotensin receptor blockers (ARBs), and angiotensin receptor neprilysin inhibitors

These medications can reduce pulmonary congestion but may also cause hypotension and renal dysfunction. Dose titration is necessary, particularly in patients with symptomatic hypotension or declining renal function.<sup>45)</sup>

### Diuretics

Essential for managing pulmonary congestion, diuretics should be continued unless there is a specific contraindication.<sup>46)</sup>

### Beta-blockers

Beta-blockers are beneficial in reducing increased sympathetic tone and can help suppress rapid ventricular response in patients with atrial fibrillation. However, in cases of symptomatic hypotension or low cardiac output, dose reduction or discontinuation may be necessary. Alternative medication like digoxin may replace beta-blockers depending on the patient's arrhythmic burden.

## Dyspnea management

Dyspnea is a prevalent and distressing symptom in advanced HF. More than half of patients with severe HF experience dyspnea at rest or with minimal exertion, significantly limiting daily activities.<sup>13,47)</sup>

### Optimizing HF medications

The first step in managing dyspnea is optimizing HF medications, particularly diuretics, to reduce pulmonary congestion.<sup>48)</sup>

### Palliative pharmacologic interventions

For refractory dyspnea, opioids such as morphine may be used despite mixed evidence in HF. It has proved its safety in HF patients, but its impact on dyspnea is still conflicting.<sup>13,49,50)</sup> Initial dosing typically starts at 10 mg per day, with careful titration up to 30 mg per day based on response.<sup>13,51)</sup> Side effects of morphine like nausea, constipation can occur, but they were usually mild in previous studies.<sup>49)</sup>

### Benzodiazepines

Although studied in COPD, evidence for their use in HF is limited. Because there is a lack of evidence whether benzodiazepine is useful to treat chronic dyspnea in HF patients, and due to its risk of all-cause mortality and other side effects like fall-down in COPD patients, benzodiazepine should be used with caution and as a second- or third-line choice.<sup>13,52)</sup>

### Supplemental oxygen

Oxygen therapy is appropriate for hypoxemic patients but does not benefit those with normoxemia or mild hypoxemia.<sup>53)</sup>

## Pain management

Pain is a common but often underrecognized symptom in HF, especially in advanced stages, where over 80% of NYHA class IV patients report significant pain.<sup>54)</sup> Chronic, poorly-controlled pain makes great physical burden to patients and lowers QoL,<sup>55)</sup> so pain



**Table 4.** Palliative interventions to reduce dyspnea and pain in HF patients

Variables	Palliative interventions
Dyspnea	<ol style="list-style-type: none"> <li>1. Optimizing GDMT and diuretics to tolerable dose</li> <li>2. If dyspnea still exists, opioid can be a reasonable first treatment option</li> <li>3. Benzodiazepine should be considered as second- or third-line option due to side effects</li> <li>4. Supplemental oxygen can be helpful when patients are hypoxemic</li> </ol>
Pain	<ol style="list-style-type: none"> <li>1. Try to identify mechanism of pain first</li> <li>2. Select generally used painkiller (paracetamol, opioid) or etiology-specific drug (anti-anginal medication, antidepressant, anticonvulsant)</li> <li>3. NSAIDs are generally contraindicated due to fluid retention and potential DDI</li> </ol>

GDMT = guideline-directed medical therapy; NSAID = non-steroidal anti-inflammatory drug; DDI = drug-drug interaction.

of HF patients should not be neglected. Integration of palliative care in HF can reduce pain burden.<sup>56)</sup>

#### *Etiology-based approach*

The management of pain should be tailored to its underlying cause.<sup>57)</sup> Ischemic pain requires anti-anginal medications. Also, HF patients may have neuropathic, nociceptive or inflammatory pain. If such pain exists chronically, non-pharmacologic and non-opioid pharmacologic treatment is preferred.<sup>58)</sup> Anticonvulsants or antidepressants is reasonable option when treating neuropathic pain.<sup>41)</sup>

#### *Non-steroidal anti-inflammatory drugs (NSAIDs)*

Generally, NSAIDs are contraindicated in HF due to the risk of fluid retention and potential interactions with other HF medications like ACEIs or ARBs. Even previously stable HF patients can experience disease worsening after starting NSAIDs.<sup>59)</sup>

#### *Paracetamol and opioids*

Paracetamol seems to be safe in HF. Opioid can be one of the last resorts if chronic pain is not controlled by non-opioid medications, although data of using opioid in chronic non-cancer pain is limited.<sup>13,40)</sup> Because of its renal-excreted neurotoxic metabolite, cautious discussion about benefit and risk of opioid is needed before using opioid in patients with reduced renal function.

Palliative interventions to reduce dyspnea and pain in HF patients are summarized in **Table 4**.

### **Palliative inotropes**

Inotropic agents may be used to improve cardiac contractility and alleviate symptoms in advanced HF, particularly in the context of palliative care.

#### *Intravenous inotropes*

Agents like dobutamine or milrinone can be administered to reduce symptom burden and improve QoL,<sup>13,60)</sup> although they are generally reserved for inpatient settings due to the need for close monitoring. However, they are still hard to use in outpatient

setting in South Korea due to lack of medical facilities outside the hospital.

#### *Oral inotropes*

These may be considered in outpatient settings, though evidence is limited, and further research is needed.<sup>61)</sup>

#### *Risks and considerations*

While inotropes can provide symptomatic relief, they carry risks such as provoking arrhythmias and potential ICD shocks.<sup>62)</sup> Additionally, maintaining intravenous access can increase the risk of infection.<sup>62,63)</sup> Therefore, case-by-case approach is appropriate to determine whether to use inotropes in HF patients as palliative intervention. Inotropes are not recommended when patient is actively dying, because it has no symptomatic benefit in such circumstances.<sup>64)</sup>

### **Palliative sedation**

Palliative sedation is considered a last-resort intervention for patients with intractable symptoms that cannot be managed by other palliative measures.<sup>65)</sup> Only limited data exists about using sedative medications in HF as palliative care interventions. One study based on single-center experience demonstrated sedating efficacy of continuous midazolam and dexmedetomidine in terms of Richmond Agitation-Sedation Scale. In the same study, palliative sedation did not induce significant hemodynamic or respiratory instability.<sup>66)</sup> The decision to initiate palliative sedation should involve careful deliberation among the care team, the patient, and their family, with a thorough discussion of the potential benefits and risks.

## **PSYCHOSOCIAL SUPPORT**

Chronic, incurable diseases lead patients to continuous deconditioning, and it is the same in case of HF. As physical status and performance of HF patients decline, they encounter various psychosocial issues including depression and anxiety. Patients' caregivers can also experience psychological crisis, and one of the

important crises is bereavement of their loved one. Therefore, psychosocial support is a key aspect of palliative care in HF, and it is not confined to the patients but extends to their caregivers.

### Depression and anxiety management

Depression and anxiety are common comorbidities in HF, particularly in advanced stages, and significantly impact QoL and treatment outcomes.<sup>67)</sup>

#### Screening and treatment

Screening depression for HF patients is reasonable, especially when there is a clinical sign of depression,<sup>67)</sup> as it is a risk factor for hospitalization, symptom exacerbation, and poor adherence to treatment.<sup>10,68)</sup> In contrast, anxiety is often related to depression, and does not carry the same risk as depression.<sup>69)</sup> Although no single treatment has proven superiority, a combination of pharmacologic and non-pharmacologic interventions is recommended.

#### Pharmacologic option

Selective serotonin reuptake inhibitors such as sertraline and escitalopram have a tolerable safety profile but have not shown significant benefits over placebo in HF patients.<sup>70,71)</sup> Tricyclic antidepressants should be avoided due to their arrhythmogenic potential.

#### Psychotherapy

Cognitive-behavioral therapy and other forms of psychotherapy may be beneficial as part of a comprehensive treatment plan.<sup>13)</sup>

Palliative interventions about inotropes, sedation, depression and anxiety are summarized in **Table 5**.

### Bereavement care: essential support in hospice

Bereavement care is a crucial aspect of palliative care, designed to support individuals who have lost a loved one. It addresses the emotional, psychological, and social challenges following a death, helping individuals navigate their grief.

#### Understanding bereavement and grief

Bereavement is used to refer to the fact of loss or the period of mourning after a loss, and grief encompasses the physical,

emotional, and behavioral response to that loss. Grief varies widely in intensity and duration, influenced by factors such as the relationship with the deceased and the circumstances of the death.<sup>72)</sup>

#### Components of bereavement care

##### 1) Pre-loss care

Pre-loss care, or anticipatory grief support, helps families prepare for the impending death of a loved one. It includes education and communication. Providing clear information about the patient's condition and prognosis helps families prepare emotionally and practically. Also, counseling and support groups help family members process anticipatory grief. Through pre-loss care, caregivers become able to cope with upcoming bereavement and can evacuate from prolonged grief.<sup>73)</sup>

##### 2) Immediate post-loss care

Following the death, immediate support to the bereaved caregivers is essential. Healthcare providers offer empathy, listening, and reassurance during this vulnerable time. Helping with tasks like funeral arrangements and legal matters can ease the burden on grieving families. In addition, assessing bereaved caregiver's physical and emotional symptoms is important, to refer patients to counsellors if needed.<sup>74)</sup>

##### 3) Long-term support

Grief can be a prolonged process, requiring ongoing care. Regular follow-up can identify individuals struggling with prolonged grief, allowing for timely intervention. Individual or group therapy provides a structured environment to explore emotions and develop coping strategies.<sup>74)</sup>

#### Special considerations in bereavement care

Bereavement care must be tailored to individual needs and cultural contexts. Respecting cultural and religious practices ensures that support is appropriate and aligned with the family's values. Young people need age-appropriate interventions, such as art therapy or play therapy, to process their grief.

#### The role of healthcare providers

Healthcare providers play a key role in bereavement care. Early

**Table 5.** Palliative interventions about inotropes, sedation, depression and anxiety

Variables	Palliative interventions
Inotropes	<ul style="list-style-type: none"> <li>- Intravenous inotropes can be considered to reduce congestive symptoms</li> <li>- Due to its arrhythmogenic risk, evaluation of risk and benefit of inotropes is necessary before using it</li> </ul>
Sedation	<ul style="list-style-type: none"> <li>- Despite of limited evidence, midazolam and dexmedetomidine can be last palliative care intervention to alleviate symptom burden</li> </ul>
Depression and anxiety	<ul style="list-style-type: none"> <li>- Screening for depression is reasonable to improve management in HF patients</li> <li>- Considering known side effects, SSRIs are safer than TCAs in HF patients</li> <li>- Non-pharmacologic therapy like cognitive behavioral therapy is also helpful</li> </ul>

HF = heart failure; SSRI = selective serotonin reuptake inhibitor; TCA = tricyclic antidepressant.

identification of those at risk for complicated grief allows for targeted support. Also, maintaining a supportive presence after the patient's death ensures that the bereaved feel supported.

## **NARRATIVE REVIEW FROM HF SPECIALISTS AND PALLIATIVE CARE SPECIALISTS: PERSPECTIVES ON PALLIATIVE AND HOSPICE CARE INTEGRATION IN SOUTH KOREA**

In the final part, we aimed to present expert perspectives on the current state and future directions of HF palliative care in South Korea, based on focus interviews with past and current presidents, chairperson, and the chair of the ethics committee of the KSHF.

### **General perspective**

The integration of palliative and hospice care in the treatment of HF patients is emerging as a critical need, especially as South Korea faces a growing prevalence of HF, an aging population, and increasing healthcare demands. Unlike cancer patients, HF patients often require ongoing, intensive medical management, which complicates the integration of palliative care. Interviews with HF experts reveal several key themes related to the unique challenges and considerations in implementing effective palliative and hospice care for HF patients in South Korea.

### **Care setting and implementation models**

Experts highlighted the potential for inpatient or consultation-based hospice services as a starting point for HF palliative care. Currently, many patients express a preference for inpatient care over home-based care due to cultural perceptions that hospital care equates to better management, particularly given the limited availability of home-based resources such as visiting physicians, nurses, and necessary equipment. Consultation-based hospice services seem to be more prompt way to deliver hospice services to HF patients, because it is also applicable to patients hospitalized in general wards. Inpatient-based hospice services are not available for patients with non-cancer diseases and need designation of government as a hospice-specialized ward, requiring some time-consuming process to provide hospice services. Ultimately, policy to enable inpatient-based hospice services to non-cancer patients and expansion of hospice-specialized wards and hospitals are required to enrich beneficiaries of hospice services for non-cancer patients including HF.

In addition, some specialists envision a future where home-based hospice care can be effectively expanded, as seen in Japan, where

regional HF-specialized hospitals provide home visits and essential monitoring services. To reduce the need of HF patients for hospital visits and easing the burden of caregivers to take them to hospital, it seems like an ideal way to deliver hospice service to HF patients. This approach would also help reduce medical expenses incurred during hospital visits, thereby benefiting the financial sustainability of insurance systems. Yet, until comprehensive home-care systems and support structures are in place, initiating HF hospice services in hospitals or designated facilities may better suit Korea's healthcare infrastructure.

### **Barriers to deactivation of implanted devices**

The deactivation of CIEDs, such as ICDs, remains a controversial topic in the palliative management of HF in Korea. Although ICD deactivation may be appropriate for end-stage HF patients experiencing painful shocks, cultural and ethical considerations have limited its acceptance among patients, caregivers, and healthcare providers. Specialists expressed that ICD deactivation should be reserved for carefully selected patients, as widespread consensus on this issue remains elusive. Importantly, some experts noted the need for societal education to reduce resistance to discussing deactivation of life-sustaining interventions in palliative contexts.

### **Ongoing medical management in palliative care**

One of the unique aspects of palliative care for HF patients, compared to other terminal illnesses, is the need for continued management of HF. Specialists recommend individualized lab monitoring and adjustment of GDMTs based on the patient's physical resilience, socio-economic status, and care support. Where possible, simplified and less frequent laboratory tests can help balance symptom management with the minimalistic approach encouraged in palliative settings. This flexibility supports better outcomes without overly burdening patients and caregivers or contravening the principles of palliative care.

### **Education and support for hospice transitions**

Educating patients and caregivers about the progression of HF, realistic prognoses, and the benefits of palliative care was identified as a critical but challenging aspect of care. Some specialists observed that many families in South Korea have difficulty discussing and accepting non-curative care due to concern about diminishing patient's will to live, leading to a preference for aggressive interventions during acute episodes. Experts stressed the importance of thorough discussions with families during hospital stays to eliminate this cultural barrier and ensure they understand the role and limitations of palliative care for HF patients, as this can reduce unnecessary emergency room visits and better align expectations for the disease's trajectory.

Likewise, some specialists pointed out the importance of educating physicians to improve awareness of palliative care. Education can serve a crucial role to inform physicians about the fact that HF patients are also potential beneficiaries of palliative care, and to diminish their guiltiness about discussing palliative care with patients and their families which acts as a barrier to implement effective palliative care in HF patients.

### Development of specialist training programs

To effectively meet the needs of HF patients in hospice and palliative settings, HF experts advocate for structured training programs for healthcare providers. Given the complex and varied symptomatology of HF, especially as patients approach end-stage, there is a need for specialized training in symptom management, including managing refractory dyspnea, frailty, and arrhythmias. Such programs would enhance the capability of healthcare providers across different care settings, from tertiary hospitals to nursing homes, to deliver compassionate, HF-tailored palliative care.

### Legal and policy foundation

Appropriate legal and policy foundation is also essential to facilitate implementation of palliative care in HF patients. Above all, revision of the law about palliative care and hospice should be prioritized to define HF as a palliative care-applicable disease. Unbarring the hospitalization-based hospice services to non-cancer patients can be an example of appropriate policy foundation. The establishment of an appropriate reimbursement system for hospice services, the development of appropriate HF-specific evaluation tool to identify palliative care needs of HF patients are also good policy foundations to facilitate palliative care for HF patients.

## CONCLUSION

The integration of palliative care in HF management is critical for enhancing patient-centered care, especially as the disease progresses to its advanced stages. By focusing on symptom management, medication adjustments, and psychological support, palliative care can significantly improve the QoL for HF patients. Additionally, bereavement care offers essential support to families, helping them navigate the complex emotions associated with loss. Overall, a multidisciplinary approach involving timely palliative interventions and sensitive bereavement care ensures that both patients and their families receive comprehensive, compassionate care during one of life's most challenging transitions.

### ORCID iDs

Seung-Mok Lee   
<https://orcid.org/0009-0002-2030-1954>  
Hae-Young Lee   
<https://orcid.org/0000-0002-9521-4102>  
Shin Hye Yoo   
<https://orcid.org/0000-0001-7473-1082>  
Hyun-Jai Cho   
<https://orcid.org/0000-0002-2779-4037>  
Jong-Chan Youn   
<https://orcid.org/0000-0003-0998-503X>  
Seong-Mi Park   
<https://orcid.org/0000-0002-6710-685X>  
Jin-Ok Jeong   
<https://orcid.org/0000-0003-0763-4754>  
Min-Seok Kim   
<https://orcid.org/0000-0003-0860-3650>  
Chi Young Shim   
<https://orcid.org/0000-0002-6136-0136>  
Jin Joo Park   
<https://orcid.org/0000-0001-9611-1490>  
Kye Hun Kim   
<https://orcid.org/0000-0002-6885-1501>  
Eung Ju Kim   
<https://orcid.org/0000-0003-2322-6267>  
Jeong Hoon Yang   
<https://orcid.org/0000-0001-8138-1367>  
Jae Yeong Cho   
<https://orcid.org/0000-0002-9393-2821>  
Sang-Ho Jo   
<https://orcid.org/0000-0002-2063-1542>  
Kyung-Kuk Hwang   
<https://orcid.org/0000-0003-3464-3023>  
Ju-Hee Lee   
<https://orcid.org/0000-0002-0858-0973>  
In-Cheol Kim   
<https://orcid.org/0000-0002-5751-2328>  
Gi Beom Kim   
<https://orcid.org/0000-0002-7880-280X>  
Jung Hyun Choi   
<https://orcid.org/0000-0001-7171-8843>  
Sung-Hee Shin   
<https://orcid.org/0000-0002-8306-9622>  
Wook-Jin Chung   
<https://orcid.org/0000-0002-9767-7098>  
Seok-Min Kang   
<https://orcid.org/0000-0001-9856-9227>  
Myeong Chan Cho   
<https://orcid.org/0000-0002-0047-0227>  
Dae-Gyun Park   
<https://orcid.org/0000-0001-5150-9729>  
Byung-Su Yoo   
<https://orcid.org/0000-0002-3395-4279>

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### Author Contributions

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