



Sookyung Kim, PhD, RN
Kyunghwa Lee, PhD, RN
Changhwan Kim, MSN, RN
Jahyun Choi, MSN, RN
Sanghee Kim, PhD, RN

OPEN

How Do We Start Palliative Care for Patients With End-Stage Liver Disease?

ABSTRACT

Patients with end-stage liver disease undergo repetitive patterns of recovery and deterioration and are burdened with uncertainty. Although quality of life is low in patients with end-stage liver disease and their family members, few studies have been conducted to identify what palliative care should be provided for them. This integrative review aimed to explore palliative care for patients with end-stage liver disease, focusing on the components and outcome measurements for further research. After searching for studies on palliative care for end-stage liver disease published between 1995 and 2017, 12 studies that met the inclusion criteria were analyzed. The common components of palliative care for patients with liver disease were: (a) an interdisciplinary approach, (b) early palliative care, (c) discussion goals of care with patient and family members, (d) symptom management, and (e) psychosocial support. It was reported that patients who were provided palliative care had improved itching, well-being, appetite, anxiety, fatigue, and depression, increased the number of do-not-resuscitate orders, palliative care consultations, and decreased length of stay. These findings could guide the development of palliative care for end-stage liver disease patients.

Approximately 2.14 million people died from liver disease in 2017 globally, of which 38.3% deaths were attributed to liver cancer and 61.7% were due to liver cirrhosis (Paik, Golabi, Younossi,

Mishra, & Younossi, 2020). Chronic liver disease was the fifth leading cause of death for people between the ages of 45 and 64 years, consistently from 1980 to 2017, in the United States (Centers for Disease Control and Prevention, 2018). According to the Global Burden of Disease Study 2017, the burden of chronic liver disease has increased in many countries since 1990 (Sepanlou et al., 2020). There were 106 million prevalent cases of decompensated chronic liver disease globally in 2017 (Sepanlou et al., 2020). In particular, because the morbidity of chronic nonmalignant liver disease is rapidly increasing (Udompap, Kim, & Kim, 2015), care needs for its patients had been rising in recent years.

End-stage liver disease (ESLD), also called chronic liver disease, means that the liver has been failing gradually, with irreversible status without a transplant. Decompensation includes variceal bleed, ascites, hepatorenal syndrome, and encephalopathy (Hospice and Palliative Nurses Association, 2005). Although ESLD (such as decompensated cirrhosis) has an impact on quality of life and life expectancy, efforts to improve the quality of life for these patients have been lacking (Patel & Ufere, 2020).

Background

Patients with ESLD experience lots of physical and psychosocial distress with gastrointestinal problems, fatigue, nausea, anxiety, and depression (Hansen et al.,

Received March 2, 2021; accepted April 30, 2021.

About the authors: Sookyung Kim, PhD, RN, is Postdoctoral Researcher, College of Nursing & Mo-Im Kim Nursing Research Institute, Yonsei University, Seoul, Republic of Korea.

Kyunghwa Lee, PhD, RN, is Assistant Professor, College of Nursing, Konyang University, Daejeon, Republic of Korea.

Changhwan Kim, MSN, RN, is Staff Nurse, Department of Critical Care Nursing, Samsung Medical Center, Seoul, Republic of Korea.

Jahyun Choi, MSN, RN, is Doctoral Student, Department of Nursing, Yonsei University Graduate School, Seoul, Republic of Korea.

Sanghee Kim, PhD, RN, is Associate Professor, College of Nursing & Mo-Im Kim Nursing Research Institute, Yonsei University, Seoul, Republic of Korea.

This research was supported by the National Research Foundation of Korea (2016R1D1A1B03934948).

The authors declare no conflicts of interest.

This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

Correspondence to: Sanghee Kim, PhD, RN, College of Nursing & Mo-Im Kim Nursing Research Institute, Yonsei University, 50-1 Yonsei-ro, Seodaemun-gu, Seoul 03722, Republic of Korea (SANGHEEKIM@yuhs.ac).

DOI: 10.1097/SGA.0000000000000611

2015; Kimbell & Murray, 2015). As the symptoms of patients with ESLD accelerate, their quality of life decreases and gives rise to emotional and psychological pain (Hansen et al., 2017). Moreover, the caregivers of patients with ESLD also experience depression (Malik et al., 2014) and have a lower psychological quality of life (Rodrigue et al., 2011). Therefore, care for patients with ESLD and their caregivers is needed to decrease the burden of disease and improve their quality of life.

The World Health Organization (2020) defined palliative care as “an approach that improves the quality of life of patients and their families who are facing problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification, correct assessment and treatment of problems of physical, psychosocial and spiritual.” Palliative care has been proposed to be continuously provided to patients and families from the time of diagnosis to the end of life (Lynn, 2005). Although it has been confirmed that palliative care improves the quality of life of patients, alleviates symptoms, and has positive effects on caregivers (Kavalieratos et al., 2016), it has mainly focused on cancer patients (Bostwick et al., 2017), and has evolved based on their demand.

Demand for palliative care targeting noncancer patients has recently been on the rise (Bostwick et al., 2017). Liver disease has a different development pattern from that of cancer, which grows over time. Patients with ESLD undergo repetitive patterns of recovery and deterioration and are burdened with uncertainty (Kirsty, Barbara, Scott, & John, 2012). Patients with ESLD toward the end of life need to manage the pain before hepatic encephalopathy progresses, and promote comfort according to their priorities (Hansen et al., 2015).

Although the referral to palliative care for patients with ESLD and their family members is specifying a new role for nurses (Wundke, McCormick, Narayana, Sorensen, & Wigg, 2020), few studies have been conducted to determine what kind of palliative care should be provided to this population and how to evaluate its effectiveness. Therefore, this evidence is crucial to explore the components and outcome measurements for developing a palliative care model for patients with ESLD.

Aims

The purpose of this integrative review is to explore the literature related to palliative care for patients with ESLD to suggest a palliative care model for this population.

Methods

The integrative review method suggested by Whittimore and Knafl (2005) was used to search and evaluate the evidence related to palliative care for patients with ESLD. This method consists of five steps.

Problem Identification

Three questions were raised for the integrative review regarding palliative care in patients with ESLD: (a) What were the characteristics of the studies (study purpose, design, setting, and country in which research was conducted) related to the palliative care of patients with ESLD? (b) What components of palliative care have been used or recommended for this population? (c) What outcome measurements of palliative care in patients with ESLD have been used and recommended? And, what are the results of palliative care in this population?

Literature Search

An electronic search for articles was conducted using six databases (PubMed, CINAHL, Cochrane Library, Embase, KMBase, and RISS). The search terms included “end-stage liver disease,” “liver cirrhosis,” “palliative care,” “hospice and palliative care nursing,” “palliative medicine,” “hospice care,” “terminal care,” “end of life care,” and “end of life care nursing” combined through “AND.” Studies were limited to those published between the years 1995 and 2017, including online publications.

The criteria used to select studies for analysis included: (1) peer-reviewed articles; (2) published in English or Korean languages; (3) experimental, cross-sectional, prospective, retrospective, qualitative, case studies, or review; and (4) articles about the components and/or outcome measurements of palliative care for patients with ESLD. The exclusion criterion was research conducted just for patients with hepatocellular carcinoma, in order to focus on noncancer diseases.

The search yielded 804 titles for review. Titles and abstracts were screened according to their relevance on the topic based on their components or outcome measures of palliative care for this population. After excluding articles that were not relevant to the topic, 12 articles remained for analysis. Articles were excluded if the research population was patients with liver cancer or liver cirrhosis, not mentioned as ESLD, or family caregivers or medical staff. The flowchart is shown in Figure 1.

Data Evaluation

Accordingly, the quality assessment criteria used in the studies of Boyles, Bailey, and Mossey (2008) were modified to evaluate the quality of sources through the clear statement of research aims, the methodological quality, and the sources’ information value. Two researchers evaluated the studies independently, and after they reached a consensus on their assessments, 12 articles were determined to be of sufficient quality for this review.

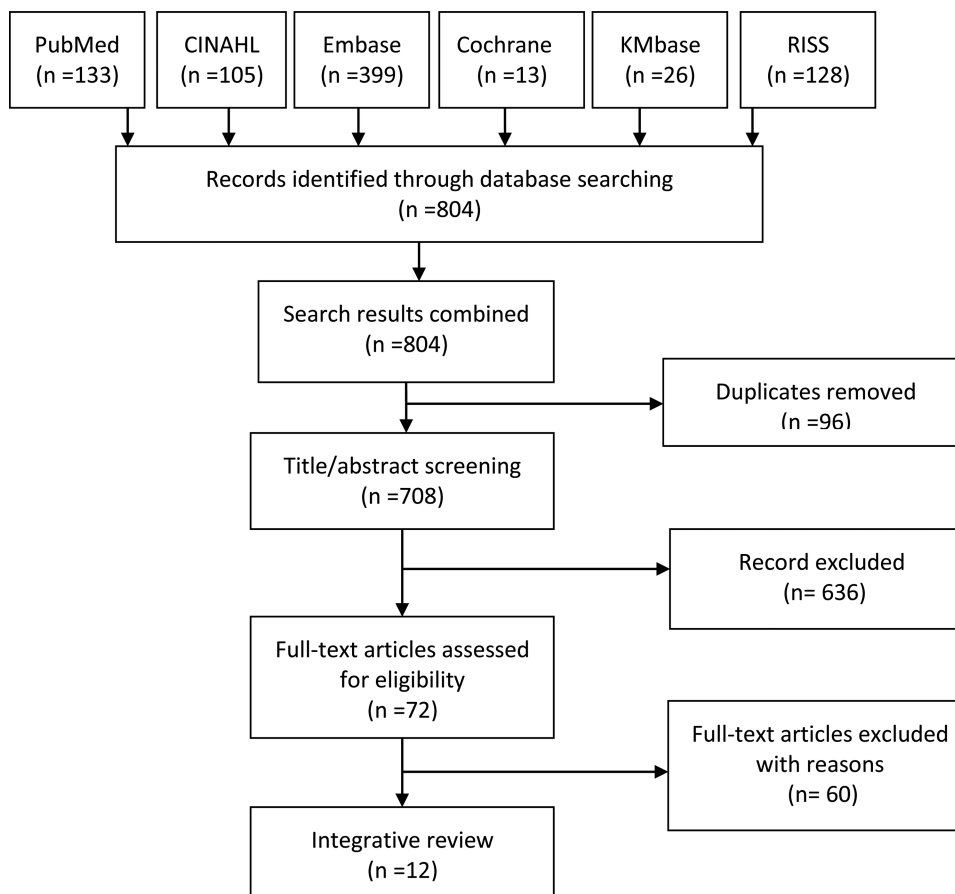


FIGURE 1. Flow diagram for literature search process.

Data Analysis

The 12 selected studies were analyzed in alignment with the purpose of this study. After analyzing its characteristics, two researchers prepared a draft of the study analysis results in accordance with the palliative care services for patients with ESLD and focusing on the components and outcome measurements. Two researchers then cross-checked the consistency of their analyses. When articles showed inconsistency, the team discussed its validity for the final analysis. Data were categorized according to the research questions (Table 1).

Data Presentation

Whittemore and Knafl (2005) stated that primary data should be summarized into unified and integrated conclusions about the research problem. Therefore, results were integrated using research questions. The characteristics of the studies are presented in Table 1. The components of palliative care are presented in Table 2. Outcome measurements of palliative care and their main findings are shown in Table 3.

Results

Characteristics of the Studies on Palliative Care for Patients With ESLD

Of the 12 studies selected, six articles were literature reviews and the other six articles were empirical. More than half of the empirical studies were conducted at liver transplant centers ($n = 4$). Medical records were used in five studies to evaluate the effects of palliative care. Ten articles were from Western countries, whereas two were from Asia (Table 1).

Components of Palliative Care for Patients With ESLD

A total of 11 major components for palliative care of patients with ESLD were identified from the 10 articles (Table 2). The most frequently conducted or recommended components were the following: (1) interdisciplinary approach, (2) early palliative care, (3) discussion goals of care with patients and family, (4) symptom management, and (5) psychological support for patients identified in seven articles. Six articles included family support (e.g., psychosocial and/or bereavement support),

TABLE 1. A Summary of Studies of Palliative Care for Patients With ESLD

Authors (Year) Country	Purpose	Study Design	Setting	Sample	Answer of Research Question
Baumann et al., 2015 USA	To determine EPCI to reduce the symptom burden and depressive symptoms associated with ESLD	Retrospective study of medical records, survey using a questionnaire on symptoms and depression	Liver transplant center	n = 50 Only preparticipants = 20 Both pre- and postparticipants = 30	A, B, C
Boyd, Kimbell, Murray, & Iredale, 2015 UK	An overview of the good death with irreversible liver disease	Literature review	Not applicable	Not applicable	A, B
Cox-North et al., 2013 USA	To summarize the transitions often experienced by patients with ESLD, as they approach end-of-life, compare illnesses, and review current palliative care strategies recommended for ESLD	Literature review	Not applicable	Not applicable	A, B
Fahlberg et al., 2016 USA	To describe nurses' approach for patients in palliative or hospice care planning	Literature review	Not applicable	56-year-old woman with readmission due to hepatic encephalopathy	A, B
Kathpalia et al., 2016 USA	To evaluate utilization of palliative care services and understand patient characteristics associated with palliative care consultation	Retrospective study of medical records	Liver transplant center	n = 790	A, B, C
Kim & Choi, 2017 South Korea	To discuss eligibility for hospice/palliative care (HPC) and special considerations for ESLD at the point of HPC	Literature review	Not applicable	Not applicable	A, B
Lamba et al., 2012 USA	To determine whether early communication with physicians and families would improve end-of-life care	Retrospective study of medical records, observation of physician rounds, survey using a questionnaire	Liver transplant center	n = 183	A, B, C

(continues)

TABLE 1. A Summary of Studies of Palliative Care for Patients With ESLD (Continued)

Authors (Year) Country	Purpose	Study Design	Setting	Sample	Answer of Research Question
Larson & Curtis, 2006 USA	To address the challenges of integrating palliative care into the pretransplant setting and talking about the issues surrounding the potential need for end-of-life care with these patients and their families	Literature review	Not applicable	Not applicable	A, B
Lee et al., 2014 Taiwan	To explore the best time and methods of palliative care	Case study	Hospital	56-year-old woman with alcoholic LC, admitted due to hypovolemic shock and esophageal varices, repeat surgery, died postoperatively in the SICU due to bleeding tendency and hypovolemic shock	A, B
Poonja et al., 2014 Canada	To evaluate how frequently patients received appropriate palliative care	Retrospective study of medical records	Liver transplant center	n = 102	A, C
Rakoski & Volk, 2015 USA	An overview of barriers, indications of palliative care for patients with ESLD	Literature review	Not applicable	Not applicable	A, B
Roth et al., 2000 USA	To evaluate patterns of care and end-of-life preferences for patients dying with ESLD and cirrhosis	Retrospective study of medical records, interviews with patients and/or patients' surrogate decision-makers	Hospital	n = 332	A, C

Note. A = research question: What were the characteristics of studies (study purpose, study design, setting, country where research conducted) related to palliative care of patients with ESLD?; B = research question: What contents of palliative care have been used or recommended in this population?; C = research question: What outcome measurements of palliative care in patients with ESLD have been used and recommended?; ESLD = end-stage liver disease; LC = liver cirrhosis; SICU = surgical intensive care units.

TABLE 2. Components of Palliative Care for Patients With End-Stage Liver Disease

Authors (Year)	Interdisciplinary Approach	Palliative Care Overall Assessment	Early Palliative Care	Discussion Goals of Care With Patients and Family	Specialist Consultation	Advance Care Planning	Advance Directives	Hospice Referral	Symptom Management	Psychosocial Support	Family Support
Baumann et al., 2015	X	X	X	X	X		X		X	X	
Boyd et al., 2015			X	X		X		X	X	X	X
Cox-North et al., 2013	X	X	X	X	X	X	X		X	X	X
Fahlberg et al., 2016	X	X	X		X			X	X	X	X
Kathpalia et al., 2016	X		X					X	X		
Kim & Choi, 2017	X		X	X							
Lamba et al., 2012	X	X		X					X	X	X
Larson et al., 2006	X		X	X	X				X	X	X
Lee et al., 2014				X							
Rakoski et al., 2015										X	X
Total frequency	7	4	7	7	4	3	2	3	7	7	6
Ranking	1	7	1	1	7	9	11	9	1	1	6

TABLE 3. Measurements and Main Findings of Palliative Care for Patients With ESLD

Authors (Year)	Measurements	Main Findings
Baumann et al., 2015	1. liver-specific ESAS 2. CES-D	1. 50% of moderate-to-severe symptoms improved. 2. Patients with more symptoms showed a greater improvement in CES-D. 3. 17% documented advance directives after EPCI.
Lamba et al., 2012	1. DNR orders 2. Withdrawal of life support 3. Length of stay 4. Goal of care discussions on physician rounds 5. QODD questionnaire	1. DNR orders increased (52%→81%). 2. Withdrawal of life support increased (35%→68%). 3. Mean length of stay decreased (by 3 days). 4. Goals of care discussions on physician rounds increased from 2% to 38%. 5. Family perceptions: more time with family, more time to say goodbye.
Roth et al., 2000	1. POMS 2. ADL score 3. Perceived QoL 4. Preferences DNR 5. DNR and ventilator decision	1. Depressed mood increased gradually before death for inpatients. 2. ADL had mild limitations for inpatients and outpatients. 3. Most of their QoL rated poor. 4. Most hospitalized patients (66.8%) preferred CPR, but DNR orders and orders against ventilator use increased near death.
Poonja et al., 2014	1. Days from denial of LT to death 2. Days in hospital after removed LT waiting list 3. ESAS 4. DNR order 5. Utilization of palliative care consultation	1. Median days from denial of LT to death was 52 days (10–332 days). 2. Median days in the hospital after removed from LT waiting list was 14 days (6–33 days). 3. ESAS: 65% of patients had pain, 58% had nausea, 10% had depression, 36% had anxiety, 48% had dyspnea, and 49% had anorexia. 4. 28% of patients had documentation of DNR. 5. 11% were referred for palliative care. More older patients were assessed by palliative care.
Kathpalia et al., 2016	1. Utilization of palliative care consultation 2. Days from palliative care consultation to death	1. 17% received a palliative care consult in the 2-year period of which 89% occurred in inpatient setting. 2. Mean 4 days from PC consultation to death. 3. Patient characteristics associated with PC consultation: younger age, White race, higher MELD at listing

Notes. ADL = activities of daily living; CES-D = Center for Epidemiological Studies Depression Scale; DNR = do not resuscitate; CPR = cardiopulmonary resuscitation; EPCI = Early Palliative Care Intervention; ESAS = Edmonton Symptom Assessment System; LT = liver transplantation; MELD = Model for End-Stage Liver Disease; PC = palliative care; POMS = Profile of Mood States; QODD = Quality of Dying and Death; QoL = quality of life.

four included overall palliative care assessment, four included specialist consultation (psychiatry, chaplaincy, etc.), three articles included hospice referral, three included advance care planning, and only two articles addressed advance directives (Table 2).

To explain the top five components, first, an interdisciplinary approach was emphasized as the core value that was taken from the initiation of palliative care. Team members who would provide palliative care for patients included doctors, palliative care nurses, transplant coordinators, social workers, pastors, and psychotherapists. Lamba, Murphy, McVicker, Smith, and Mosenthal (2012) reported that treatment goals should be discussed with interdisciplinary teams, patients, and family together, either at the time of or within 2 days of hospitalization.

Second, seven studies stated that palliative care should be provided early. Studies reported that it is important to understand patients' preferences regarding the end of their lives at an early date because symptoms such as progressive encephalopathy can interfere

with decision-making in the later stages of treatment (Baumann et al., 2015; Cox-North, Doorenbos, Shannon, Scott, & Curtis, 2013; Kathpalia, Smith, & Lai, 2016; Lee, Lo, Ko, Huang, & Lee, 2014).

Third, the aim of discussing treatment goals with patients and families was to ensure that medical staff communicated smoothly with patients and their families. The studies reported that patients should not be immediately corrected or judged for their problems, but should be respected and listened to. Additionally, it is necessary to encourage patients and their families to discuss difficult topics with the medical staff, such as the end-of-life treatment preferences; confirm what patients valued most; and refer to future treatment directions.

Fourth, symptom management for patients with ESLD was divided into two types: general symptoms and symptoms related to complications of liver disease. Symptoms related to complications of liver disease, which received medical intervention, included pain, nausea, loss of appetite, abdominal distractions, and

discomfort caused by ascites, encephalopathy, esophageal varix, and deterioration of kidney functions caused by complications from liver disease.

Fifth, studies noted that emotional and spiritual support was provided to patients who exhibited psychological symptoms such as depression and anxiety. Research by Baumann et al. (2015) included support that addresses fears and concerns about treatment plans to patients with ESLD.

The evidence also indicated the medical team should intentionally make efforts to actively listen to the financial difficulties, emotional pain, patient treatment goals, and conflicts among family members or primary caregivers of these patients. Emotional support for family members to overcome grief after death was also included. For the overall palliative care assessment, it was confirmed that medical staff should identify the level of family support to the patient as well as the patients' physical, emotional symptoms, and prognosis. It was also confirmed that the presence of advance directives and decision-making agents should be reviewed.

When the interdisciplinary team found it difficult to resolve complex situations and make decisions, a consultation with a palliative care specialist was recommended. Studies reported that hospice referrals should be conducted if the patient's treatment goal includes or aligns with hospice, or if the interdisciplinary team determines hospice as necessary. Although the majority of studies emphasized that it is important to respect the opinions of patients and families rather than the opinions of the medical team, Kim and Choi (2017) noted that because liver transplantation and treatments are advancing, the first priority for medical staff should be to fully explain the treatment potential to the patient and family, and that hospice should be considered.

It was confirmed that advance care planning should be written and modified as all patients' disease progresses when providing palliative care for patients with ESLD. The studies reported that the medical team should encourage patients and families to establish advance care planning early, for it can clarify a patient's values and goals of treatment. Particularly when difficult issues arise, advance care planning should be discussed repeatedly between patients and medical staff over the course of diagnosis until death. Because the incidence of complications with liver diseases is high, it was emphasized that education and communication about advance care planning is necessary for patients with ESLD. Of note advance directives were mentioned in two studies.

Outcome Measurements and Results of Palliative Care for Patients With ESLD

Five studies found that the palliative care provided to patients with ESLD was effective (Table 3). Outcome

measure approaches included surveys with patients and their families, a review of the information in medical records, and an observation of the discussion on treatment objectives. Two studies (Baumann et al., 2015; Poonja et al., 2014) utilized the Edmonton Symptom Assessment System (ESAS) Scale to measure patient symptoms, one of which modified the scale to assess the characteristic symptoms of liver disease (Baumann et al., 2015). The existing ESAS has six categories: pain, nausea, depression, anxiety, shortness of breath, and poor appetite. When the original tool was compared with the modified ESAS, four items (pain, anxiety, appetite, and shortness of breath) were similar, whereas the modified version included six additional items (fatigue, muscle cramps, sexual dysfunction, sleep disorders, feeling of well-being, and itching). Patients with ESLD who received early palliative care significantly improved in five areas: itching, well-being, appetite, anxiety, and fatigue.

Psychological measurements were used in two studies using the Center for Epidemiological Studies Depression Scale (Baumann et al., 2015) and the Profile of Mood States (Roth, Lynn, Zhong, Borum, & Dawson, 2000). It was confirmed that the depression symptoms of patients who were provided with palliative care decreased (Baumann et al., 2015; Roth et al., 2000). Family members expressed that the time spent with the patient and the time to say goodbye increased through palliative care, despite insufficient data on the Quality of Dying and Death survey (Lamba et al., 2012).

In the medical records, the measures that confirmed the effects of the palliative care applied to patients with ESLD were three studies with do-not-resuscitate (DNR) orders, two studies with referrals of palliative care, and three studies related to timing, such as length of stay. The DNR order (Lamba et al., 2012; Poonja et al., 2014; Roth et al., 2000) and the consultation on palliative care (Kathpalia et al., 2016; Roth et al., 2000) increased in the medical records of patients receiving palliative care. Studies noted that older patients had higher needs for palliative care (Poonja et al., 2014), and the younger the age and higher their Model for End-Stage Liver Disease score, the more their referrals to palliative care (Kathpalia et al., 2016). Measurements of the effectiveness of day-related palliative care used the date of hospitalization and the days from palliative care consultation to death. In terms of outcomes of palliative care, the days of hospitalization of patients with palliative care have decreased (Lamba et al., 2012). The level of discussion of treatment goals during rounding was increased in case patients received palliative care, but it was identified that discussions on treatment goals were rare in medical records of patients with ESLD who died (Lamba et al., 2012).

Discussion

This integrative review aimed to synthesize literature related to components and outcome measurements of palliative care for patients with ESLD, and guide the development of future palliative care programs. Significant findings pointed to integrated evidence of the 11 core components of palliative care that were provided to patients with ESLD in previous studies, or suggested based on evidence (see Table 2). It was confirmed that very few experimental studies were conducted to examine the effectiveness of palliative care on ESLD patients. The review showed that patients who were provided palliative care improved itching, well-being, appetite, anxiety, fatigue, and depression, increased the number of DNR orders and palliative care consultations, and decreased their length of stay.

Although a majority of the articles were studies from Western countries, only two were from Asia. In Taiwan, many doctors felt uncomfortable discussing palliative care with patients, as they considered it similar to euthanasia (Liu et al., 2005). In Korea, when medical staff suggests palliative care to patients, they might reject it because they believe that the staff is giving up on the treatment itself (Shin et al., 2017). This may explain the passive attitude of medical staff toward palliative care, along with the fact that palliative care was just initiated in Asia.

Eleven essential components of palliative care to be provided to patients with ESLD were identified. Each of the items is intertwined, and not mutually exclusive of each other. Discussion goals of care should be made with the family using an interdisciplinary approach. Symptom management and psychosocial support should be provided early in terms of palliative care. The components of palliative care for patients with ESLD were not significantly different from those for patients with cancer or other diseases (Kavalieratos et al., 2017; Shin et al., 2017). For example, there were three major aspects of palliative care for heart failure patients: general symptom and emotional, heart failure-related, and family palliative care (Cagle et al., 2017). Similarly, patients with ESLD may also be provided general symptom management and emotional support, as well as palliative care related to liver diseases such as hepatic encephalopathy and ascites.

The ESLD symptoms may repeatedly cause patients to deteriorate and recover, which poses economic and psychological difficulties on the patients' families for a relatively long period (Shin et al., 2017). Therefore, interventions for the family should be considered when developing palliative care for ESLD patients. The families of patients admitted to the intensive care unit with ESLD likened the decision-making process "to a train" and noted that they would like more information to

orient themselves to the complexity of the patient's disease (Hansen et al., 2012). Because providing information at an early stage could improve the decision-making process for the patient's treatment (Hansen et al., 2012), and education on the patient's symptoms and pain management for the family could provide high-quality palliative care for the patient (MacKenzie, Meghani, Buck, & Riegel, 2015), it is necessary to prepare a practical plan to provide palliative care information to families.

"Cultural aspects of care" and "care of nearing the end of life" recommended by the National Consensus Project (NCP) guidelines (National Consensus Project for Quality Palliative Care, 2018) were not found as an essential aspect in this review. According to the NCP guidelines, the cultural-specific needs of patients and their families should be assessed and provided in accordance with the cultural needs such as locus of decision-making, preferences regarding disclosure of information, family communication, and perspectives on death. For an example of palliative care considering cultural aspects, in Korea, the opinion of the family plays a crucial role in the decision rather than the opinion of the patient (Kim & Choi, 2017); therefore, palliative care should be developed considering this context in Korea. When a patient is about to die, palliative care in Korea is about communicating with the patient, their family, and medical staff, and educating the family with relevant information at the right time. In the future, palliative care regarding to cultural aspects and to patient nearing the end of life will have to be reinforced in research and practice.

Generally, an essential part of palliative care is to suggest the timely provision of advance care planning (Patel & Ufere, 2020). So, palliative care for ESLD should also include advance care planning although only two studies addressed it. Particularly, nurses can play a role in facilitating advance care planning with trained volunteers and connecting them to services in the community (National Consensus Project for Quality Palliative Care, 2018).

The effectiveness of palliative care in patients with ESLD was conducted via surveys, medical records, and the discussions of care goals. Based on the general (Poonja et al., 2014) and liver-specific (Baumann et al., 2015) versions of the ESAS Scale, itching, well-being, and fatigue were positively impacted by palliative care, suggesting that the tool is reliable and feasible with this population. Although the liver-specific ESAS Scale includes anxiety among the characteristics of liver disease, symptoms of depression have been excluded, which is important for consideration when using the scale in each country. Symptom assessments should not be conducted only once at discharge or within 3 days of hospitalization; rather, they should be checked

regularly to systematically manage the patient's symptoms. However, because medical staff are already carefully managing symptoms through communication with patients, it is necessary to sufficiently discuss the evaluation cycle so that it does not become irrelevant.

In previous studies, it was insufficient to identify the effects of palliative care on family members. Notably, there are limitations to using the Quality of Dying and Death scale (Lamba et al., 2012) with families who provide palliative care before a patient's death. Support for family members and caregivers as part of palliative care is essential; therefore, it is necessary to develop a suitable tool for measuring the psychological, emotional, and economic difficulties of the ESLD patient's family in further studies.

In the case of ESLD, the healthcare team should carefully determine palliative care for patients, and discuss it sufficiently with patients and caregivers, as it is possible to recover from ESLD with a liver transplant. However, in the case of septic shock by ascites, patients may die suddenly (Shin et al., 2017). If the patient suffers from chronic hepatic encephalopathy, the patient's consciousness and judgment are compromised, which limits direct communication with the patient regarding palliative care (Smith, 2018). Decision-making may also be impeded by alcoholic dementia (Smith, 2018). An ideal provision of palliative care for patients with ESLD is more likely if discussions begin early on when patients are still able to communicate and make decisions.

Limitations

The small number of empirical studies was the major limitation of this integrative review. If more empirical studies were available, the objective evidence reflecting the clinical situation could be better integrated; but due to the lack of prior studies, the literature was integrated based on a wide range of selection criteria to obtain current insights into developing palliative care for patients with ESLD. In addition, the lack of empirical studies means that palliative care for such patients is still at the beginning stage, and more empirical research should be performed in the near future. Another limitation of this review is that two of the 12 articles were published more than 10 years ago. Therefore, we tried to pay attention to their interpretation in the current context.

Implications for Practice

Because the levels of palliative care needs are different and the details vary, all 11 derived components are not necessarily applicable to each ESLD patient but have to be provided according to the patient's and family members' preferences and values. Regular communication with the medical staff will be essential to

understand and reflect these values, and advance care planning through discussions with an interdisciplinary team will be helpful so that all involved parties are well prepared. Because the healthcare team are likely the ones who would suggest the option of palliative care to patients who are hospitalized, it is imperative to develop and provide practical training programs for the healthcare team, including nurses, to communicate with patients smoothly.

Conclusion

For palliative care for patients with ESLD, the essential components and measurements were explored by this integrative review. This review identified 11 basic components of palliative care for patients with ESLD. Palliative care must take an interdisciplinary approach, and needs should be assessed with patients and their families, followed by further discussion on treatment goals. Palliative care should then be provided based on the assessment results and discussed treatment goals. If needed, consultation with palliative care specialists and hospice referrals should be available. Importantly, advance care planning should be prepared and revised at any time.

Based on our review of evidence, the effectiveness of palliative care has been validated using the ESAS Scale and psychosocial measurements that were modified specifically for patients with ESLD. The effects were identified based on medical records, such as DNR orders, consultation of palliative care, days of hospitalization, and days from palliative care consultation to death. It is expected that this integrative review will contribute to the development and implementation of practical palliative care programs for patients with ESLD and that such programs will align with the healthcare system and culture of each country, thereby ultimately improving the lives of liver disease patients and their families. 🌟

REFERENCES

- Baumann, A. J., Wheeler, D. S., James, M., Turner, R., Siegel, A., & Navarro, V. J. (2015). Benefit of early palliative care intervention in end-stage liver disease patients awaiting liver transplantation. *Journal of Pain and Symptom Management, 50*(6), 882–886.
- Bostwick, D., Wolf, S., Samsa, G., Bull, J., Taylor, D. H., Jr., Johnson, K. S., & Kamal, A. H. (2017). Comparing the palliative care needs of those with cancer to those with common non-cancer serious illness. *Journal of Pain and Symptom Management, 53*(6), 1079–1084.e1.
- Boyd, K., Kimbell, B., Murray, S., & Iredale, J. (2015). A “good death” with irreversible liver disease: Talking with patients and families about deteriorating health and dying. *Clinical Liver Disease, 6*(1), 15–18.
- Boyles, C. M., Bailey, P. H., & Mossey, S. (2008). Representations of disability in nursing and healthcare literature: An integrative review. *Journal of Advanced Nursing, 62*(4), 428–437.
- Cagle, J. G., Bunting, M., Kelemen, A., Lee, J., Terry, D., & Harris, R. (2017). Psychosocial needs and interventions for heart failure

- patients and families receiving palliative care support: A systematic review. *Heart Failure Reviews*, 22(5), 565–580.
- Centers for Disease Control and Prevention. (2018). *National Center for Health Statistics*. Retrieved from https://www.cdc.gov/nchs/hsu/contents2018.htm?search=Chronic_liver_disease_and_cirrhosis
- Cox-North, P., Doorenbos, A., Shannon, S. E., Scott, J., & Curtis, J. R. (2013). The transition to end-of-life care in e-stage liver disease. *Journal of Hospice and Palliative Nursing*, 15(4), 209–215.
- Fahlberg, B. (2016). My patient needs palliative care: Now what? *Nursing*, 46(11), 14–16.
- Hansen, L., Leo, M. C., Chang, M. F., Zaman, A., Naugler, W., & Schwartz, J. (2015). Symptom distress in patients with end-stage liver disease toward the end of life. *Gastroenterology Nursing*, 38(3), 201–210.
- Hansen, L., Lyons, K. S., Dieckmann, N. F., Chang, M. F., Hiatt, S., Solanki, E., & Lee, C. S. (2017). Background and design of the symptom burden in end-stage liver disease patient-caregiver dyad study. *Research in Nursing & Health*, 40(5), 398–413.
- Hansen, L., Press, N., Rosenkranz, S. J., Baggs, J. G., Kendall, J., Kerber, A., ... Chesnutt, M. S. (2012). Life-sustaining treatment decisions in the ICU for patients with ESLD: A prospective investigation. *Research in Nursing & Health*, 35(5), 518–532.
- Hospice and Palliative Nurses Association. (2005). *Compendium of treatment of end stage non-cancer diagnoses: hepatic*. Dubuque, IA: Kendall/Hunt Pub.
- Kathpalia, P., Smith, A., & Lai, J. C. (2016). Underutilization of palliative care services in the liver transplant population. *World Journal of Transplantation*, 6(3), 594–598.
- Kavalieratos, D., Corbelli, J., Zhang, D., Dionne-Odom, J. N., Ernecoff, N. C., Hanmer, J., ... Schenker, Y. (2016). Association between palliative care and patient and caregiver outcomes: A systematic review and meta-analysis. *JAMA*, 316(20), 2104–2114.
- Kavalieratos, D., Gelfman, L. P., Tycon, L. E., Riegel, B., Bekelman, D. B., Ikejiani, D. Z., ... Arnold, R. M. (2017). Palliative care in heart failure: Rationale, evidence, and future priorities. *Journal of the American College of Cardiology*, 70(15), 1919–1930.
- Kim, D. J., & Choi, M. S. (2017). Life-sustaining treatment and palliative care in patients with liver cirrhosis—legal, ethical, and practical issues. *Clinical and Molecular Hepatology*, 23(2), 115–122.
- Kimbell, B., & Murray, S. A. (2015). What is the patient experience in advanced liver disease? A scoping review of the literature. *BMJ Supportive & Palliative Care*, 5(5), 471–480.
- Kirsty, B., Barbara, K., Scott, M., & John, I. (2012). Living and dying well with end-stage liver disease: Time for palliative care? *Hepatology*, 55(6), 1650–1651.
- Lamba, S., Murphy, P., McVicker, S., Smith, J. H., & Mosenthal, A. C. (2012). Changing end-of-life care practice for liver transplant service patients: Structured palliative care intervention in the surgical intensive care unit. *Journal of Pain and Symptom Management*, 44(4), 508–519.
- Larson, A. M., & Curtis, J. R. (2006). Integrating palliative care for liver transplant candidates: “too well for transplant, too sick for life”. *JAMA*, 295(18), 2168–2176.
- Lee, P.-C., Lo, C., Ko, W.-J., Huang, S.-J., & Lee, P.-H. (2014). When and how should physicians determine the need for palliative and hospice care for patients with end-stage liver disease? An experience in Taiwan. *American Journal of Hospice and Palliative Care*, 31(4), 454–458.
- Liu, W.-J., Hu, W.-Y., Chiu, Y.-F., Chiu, T.-Y., Lue, B.-H., Chen, C.-Y., & Wakai, S. (2005). Factors that influence physicians in providing palliative care in rural communities in Taiwan. *Supportive Care in Cancer*, 13(10), 781–789.
- Lynn, J. (2005). Living long in fragile health: the new demographics shape end of life care. *Hastings Center Report*, 35(7), S14–S18. doi:10.1353/hcr.2005.0096
- MacKenzie, M. A., Meghani, S. H., Buck, H. G., & Riegel, B. (2015). Does diagnosis make a difference? Comparing hospice care satisfaction in matched cohorts of heart failure and cancer caregivers. *Journal of Palliative Medicine*, 18(12), 1008–1014.
- Malik, P., Kohl, C., Holzner, B., Kemmler, G., Graziadei, I., Vogel, W., & Sperner-Unterweger, B. (2014). Distress in primary caregivers and patients listed for liver transplantation. *Psychiatry Research*, 215(1), 159–162.
- National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for quality palliative care* (4th ed.). Richmond, VA: National Coalition for Hospice and Palliative Care.
- Paik, J. M., Golabi, P., Younossi, Y., Mishra, A., & Younossi, Z. M. (2020). Changes in the global burden of chronic liver diseases from 2012 to 2017: The growing impact of NAFLD. *Hepatology*, 72(5), 1605–1616.
- Patel, A., & Ufere, N. N. (2020). Integrating palliative care in the management of patients with advanced liver disease. *Clinical Liver Disease*, 15(4), 136–140.
- Poonja, Z., Brisebois, A., van Zanten, S. V., Tandon, P., Meeberg, G., & Karvellas, C. J. (2014). Patients with cirrhosis and denied liver transplants rarely receive adequate palliative care or appropriate management. *Clinical Gastroenterology and Hepatology*, 12(4), 692–698.
- Rakoski, M. O., & Volk, M. L. (2015). Palliative care for patients with end-stage liver disease: An overview. *Clinical Liver Disease*, 6(1), 19–21.
- Rodrigue, J. R., Dimitri, N., Reed, A., Antonellis, T., Hanto, D. W., & Curry, M. (2011). Quality of life and psychosocial functioning of spouse/partner caregivers before and after liver transplantation. *Clinical Transplantation*, 25(2), 239–247.
- Roth, K., Lynn, J., Zhong, Z., Borum, M., & Dawson, N. V. (2000). Dying with end stage liver disease with cirrhosis: Insights from SUPPORT. Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment. *Journal of the American Geriatrics Society*, 48(Suppl. 1), S122–S130.
- Sepanlou, S. G., Safiri, S., Bisignano, C., Ikuta, K. S., Merat, S., Saberifrooz, M., ... Malekzadeh, R. (2020). The global, regional, and national burden of cirrhosis by cause in 195 countries and territories, 1990-2017: A systematic analysis for the Global Burden of Disease Study 2017. *The Lancet Gastroenterology & Hepatology*, 5(3), 245–266.
- Shin, J., Yoon, S.-J., Kim, S.-H., Lee, E. S., Koh, S.-J., & Park, J. (2017). A qualitative study of physicians’ perspectives on non-cancer hospice-palliative care in Korea: Focus on AIDS, COPD and liver cirrhosis. *Korean Journal of Hospice and Palliative Care*, 20(3), 177–187.
- Smith, L. (2018). *Palliative and end of life care for people with alcohol related brain damage*. Retrieved from <https://www.iriss.org.uk/sites/default/files/2018-04/iriss-esss-outline-palliative-eol-care-arbd-2018-2-2.pdf>
- Udompap, P., Kim, D., & Kim, W. R. (2015). Current and future burden of chronic nonmalignant liver disease. *Clinical Gastroenterology and Hepatology*, 13(12), 2031–2041.

Whittemore, R., & Knaf, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52(5), 546–553.

World Health Organization. (2020). *Definition of palliative care*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/palliative-care>

Wundke, R., McCormick, R., Narayana, S. K., Sorensen, L., & Wigg, A. (2020). The chronic liver disease nurse role in Australia: Describing 10 years of a new role in cirrhosis management. *Gastroenterology Nursing*, 43(1), E9–E15.