

# Importance of Palliative Care in the Disease Burden of End Stage Liver Disease: A Rising Global Issue



Renee Pozza<sup>1,2</sup>, PhD, NP, FAASLD; Bonita Huiskes<sup>1</sup>, PhD, NP; Anna Marie Hefner<sup>1,2</sup>, PhD, NP  
<sup>1</sup>Azusa Pacific University; Azusa, California; United States  
<sup>2</sup>Southern California Liver and GI Centers, Coronado, United States



## Background and Significance

Incidence of end-stage liver disease (ESLD) increasing globally despite dramatic advances in treatment options for hepatitis C. Liver transplant a limited option due to scarce organ supply and/or patient ineligibility. ESLD patients have multiple symptoms: ascites, pain, fatigue, confusion and GI bleeds which require intensive medical management and negatively impact their health-related quality of life (HRQOL). ESLD mortality rate is 50% at 5 years, with frequent clinic visits and hospitalizations.

Guidelines for heart failure, another major chronic illness, at end of life may have utility in further development of ESLD guidelines. Heart failure guidelines were first published in 1994. In the following decades, North American and European guidelines saw a steady increase in end of life and palliative care content concurrent with medical advances in heart failure. Current North American and European heart failure guidelines include significant palliative and end of life content.

Growing awareness of the need for palliative care for life-limiting chronic illness is evident in the European Association of Palliative Care Taskforce production of a primary palliative care toolkit (2015) and the recent American Nurses' Association (ANA) and Hospice and Palliative Nurses Association (HPNA) *Call for Action: Nurses Lead and Transform Palliative Care* (2017).

## Purpose

The purpose of the study was to trace the development of palliative care content in heart failure guidelines during a period of remarkable progress in treatment with a focus on development of palliative care content in end stage liver disease guidelines.

## Methods

Sixteen major North American and European heart failure guidelines published between 1994 and 2016 were examined for palliative content and compared to end stage liver disease guidelines as published by the American Association for the Study of Liver Diseases (AASLD) and the European Association of Liver Diseases (EASL). Keywords of end of life and palliative care as they apply to end stage liver disease content domains were determined from the guidelines. Characteristics of end stage heart failure and end stage liver disease were also compared.

**Table 1.** Common End-Stage Symptoms in Heart Failure and Liver Disease.

| End-Stage Heart Failure*  | End-Stage Liver Disease            |
|---------------------------|------------------------------------|
| Pain                      | Portal Hypertension                |
| Breathlessness            | Ascites                            |
| Persistent cough          | Edema                              |
| Fatigue                   | Hepatic encephalopathy             |
| Limited physical activity | Esophageal varices w/ or w/o bleed |
| Anxiety                   | Renal dysfunction                  |
| Depression                | Jaundice                           |
| Sleep problems            | Itching                            |
| Nausea                    | Bleeding disorders                 |
| Constipation              |                                    |

\*Jaarsma et al. (2009). *European Journal of Heart Failure*, 11, 433-443.

## Results

**Table 2.** End of Life Domains in Major North American and European HF Guidelines/Guideline Update and Applicability to ESLD

| Domain                                | Description   | Applicability to ESLD   |
|---------------------------------------|---|---|
| Prognosis                             | Estimation of survival and likely course of HF disease trajectory                                     | Similar disease trajectory as HF challenges prognosis                                   |
| Provider-Patient-Family Communication | Discussions among provider/patient/ family re: advanced and end-stage HF                              | Essential for patients and caregivers dealing with high level need and uncertain course |
| Advance Directives                    | Recommendations re: documentation of patient treatment decisions                                      | Early discussion re: patient treatment options key to approach to advanced disease      |
| Identification of End-Stage HF        | Information re: pt characteristics & Rx consideration in end-stage HF                                 | Prognostic indicators in ESLD require additional research validation                    |
| Symptom Palliation                    | Identification of end-stage HF symptoms & options for Rx  | Significant symptom burden in ESLD early integration of palliative care                 |
| Inotropes/ Vasodilators               | Recommendations re: use in advanced & end-stage HF  | Palliative treatment for HCC described.   |
| Device Deactivation                   | Consideration of disabling implanted technology (i.e., ICDs) at end of life                           | Not relevant in ESLD  |
| Family/ Caregiver Support             | Specific recommendations for support (other than information) for families/ caregivers of HF patients | Families/caregivers of ESLD patients need supportive care                               |
| Hospice/Palliative Care               | Provision for goals of care directed toward comfort in end-stage HF                                   | As in HF, hospice and palliative care less familiar with non-cancer dx                  |
| Advanced Therapies                    | Specialized, more invasive treatment focus in advanced HF   | Consider addition of care for patients ineligible for liver tx                          |

## Discussion

Liver disease management is focused on early identification and therapy intervention to reduce the impact on the functioning of the organ; however, late stage end organ damage remains common, especially in the setting of hepatitis C and non-alcoholic fatty liver disease (NAFLD/NASH) with prevalence rates skyrocketing globally. Once cirrhosis develops the individual is at increasing risk for development of hepatocellular carcinoma. While many individuals with ESLD are candidates for liver transplantation some are outside eligibility criteria. Palliative therapies often refers to the medications or procedures used as adjuvant treatment that supports but does not provide cure. With the diagnosis of end organ failure and cancer, guidelines are necessary to inform the practice of palliative care. Two of the eight reviewed practice guidelines contained content about end of life care and palliative care, but neither of these were guidelines developed for cirrhosis or transplantation. Especially lacking is the guidance for someone who is not a candidate for liver transplantation. The nursing professional is a key provider of care to these patients and families and is in a vital position to make a difference in the quality of life.

## Conclusion

Heart failure guidelines and the content domains for the end stage patient can inform the development of palliative care content in the liver disease patient. Clinical practice guidelines for the care of the liver disease patient, especially in the setting of cirrhosis and hepatocellular carcinoma should include palliative care content. Collaborative efforts, led by nurses is necessary for development of this vital content area. Further palliative guideline development in the ESLD patient will require research to build an evidence base, to foster translation into practice, and to help ensure this need in the setting of ESLD is met.

## Contact

Renee Pozza, PhD, RN, FNP-BC, FAASLD  
[rpozza@apu.edu](mailto:rpozza@apu.edu)  
 Bonita Huiskes, PhD, RN, FNP-BC  
[bhuiskes@apu.edu](mailto:bhuiskes@apu.edu)  
 Anna Marie Hefner, PhD, RN, PNP  
[ahefner@apu.edu](mailto:ahefner@apu.edu)  
 Azusa Pacific University School of Nursing  
 Website: [www.apu.edu](http://www.apu.edu)