Published in final edited form as:

Clin Gastroenterol Hepatol. 2014 April ; 12(4): 699–700. doi:10.1016/j.cgh.2013.11.010.

Palliative Care and End Stage Liver Disease

Anne M. Walling, MD, PhD^{1,3,4} and Neil S. Wenger, MD, MPH^{1,2,4}

¹ Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine at University of California, Los Angeles, CA

² UCLA Health System Ethics Center, Santa Monica, CA.

³ Greater Los Angeles Veterans Affairs Healthcare System, Santa Monica, CA.

⁴ RAND Health, Santa Monica, CA.

The concurrent care model of palliative care is a widely accepted model for how palliative care should be delivered (1). A palliative care approach is focused on improving the quality of life for a patient and often involves symptom management and communication about the disease process and overall goals of care. Patients with life-limiting illness receiving concurrent palliative care receive high quality communication and symptom support simultaneous with receipt of other disease directed care. An oft-cited example of concurrent palliative care randomized patients with non-small cell lung cancer to receive an early palliative care consult or usual care. Patients who received palliative care in addition to their cancer care had better quality of life and even longer survival (2). Concurrent palliative care may benefit patients with many advanced medical conditions, such as end stage liver disease (ESLD).

It is well recognized that patients with ESLD have a profound level of discomfort and often substantial suffering. More than a decade ago, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) demonstrated that patients with ESLD had rates of moderate to severe pain toward the end of life for patients similar to patients with lung and colorectal cancer (3). The study by Poonja et al in this issue confirms the substantial rates of pain and other symptoms among a cohort of patients with ESLD after they were denied liver transplants. They proceed to demonstrate that a minority (29%) of these patients had orders to limit resuscitation and that a substantial proportion of these patients continued to receive intensive and life-sustaining care (48% had subsequent ICU admissions) despite a median survival of less than two months.

© 2013 The American Gastroenterological Association. Published by Elsevier Inc. All rights reserved.

¹Corresponding author and author to receive reprint requests: Anne M. Walling, MD, PhD, UCLA Division of General Internal Medicine, 911 Broxton Plaza, Los Angeles, CA 90024. (310) 794-0741; Fax (310) 794-0732; awalling@mednet.ucla.edu.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

There are no conflicts of interest to disclose.

This small, single site study is limited by its retrospective study design, focus only on patients who were considered for liver transplant and limited ability to follow up patients who returned to their local hospitals. The authors also did not capture medical record documentation about goals of care discussions that did not result in resuscitation decisions or other types of advance care planning. Furthermore, because symptoms were abstracted from the medical record, the prevalence and severity of discomfort is likely under-reported. Nevertheless, the lack of a palliative care focus is startling given that for this cohort of patients symptom control and comfort-oriented care were likely what medicine most had to offer.

Pain management is often more complicated in the patient with ESLD. NSAIDs should be avoided because of increased risk of renal toxicity and even low dose opioids can cause profound side effects such as altered mental status (due to alterations in liver metabolism), often complicating other already present and distressing symptoms such as hepatic encephalopathy. Other common symptoms such as fatigue, decreased appetite, and pruritis are challenging to treat. Liver disease is also often associated with substance abuse and lack of social supports that complicate communication and care planning. Caregivers of patients with end stage liver disease carry a substantial burden, which is even greater when patients evidence hepatic encephalopathy (4,5).

In addition, the disease course of organ failure is less predictable than with advanced cancer (6). While prospectively following a patient with organ failure there are often periods of exacerbation followed by stabilization or even improvement making prognostication and care-planning more challenging, especially among patients who remain hopeful for transplantation.

The transition from aiming for a potentially lifesaving transplant to palliative care is particularly difficult. In a study of patients dying at a quaternary care hospital, we found that consideration of transplant was associated with 7% lower quality end of life care, and this was predominately concerning care discussions and planning (7). This is presumably because patients striving for a transplant (and their families) aim to receive the most aggressive of care and because transplant is a “game changer” when patients on the brink of death are rescued. Even in the study by Poonja et al, four of the patients delisted by the studied center ended up receiving transplants at other centers and one patient recovered from the acute liver injury.

Thus, patients with ESLD are prime candidates for a concurrent care palliative care model that focuses less on a patient's transplant status and more on the patient's palliative care needs (8). This model allows for palliative care support for patients even while patients await liver transplant or undergo active evaluation. For example, a pilot study at UC Davis concurrently provided hospice care for potential transplant patients; among 157 patients, six were offered a liver graft during the combined program (9). Barriers to integration of palliative care into the treatment plan for these patients warrants further study and innovative programs of concurrent palliative care alongside active treatment for end-stage organ disease are needed.

There are many aspects of palliative care and symptom control in patients with ESLD that need research. Further work should clarify how hepatologists, transplant teams, and primary care physicians can collaboratively provide the components of palliative care and what threshold of disease or set of needs should trigger palliative care specialist involvement. Many of the symptoms of ESLD may be best handled by hepatologists. For example, management of ascites often limits abdominal pain and anorexia in this population. While life is being sustained and symptoms are being managed, ongoing discussions can clarify patients' willingness to tolerate adverse health states. It should be noted that among patients with ESLD in SUPPORT, 43% would rather die than receive care in a nursing home and most reported wanting to die rather than live in a coma or with a ventilator or feeding tube (3).

It is clear that the expectation of appropriate elicitation of goals and management of symptoms should be part of treatment of the cirrhotic patient toward the end of life. Expanding the role of concurrent palliative care is one mechanism to achieve this goal.

Acknowledgments

Dr. Walling is supported by NIH/NCATS UCLA CTSI Grant Number KL2TR000122. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

References

1. Emanuel, LL.; von Gunten, CF.; Farris, F. The Education of Physicians on End of Life Care (EPEC) Curriculum. Chicago IL: 1999.
2. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care in patients with metastatic non-small cell lung cancer. *NEJM*. 2010; 363:733–42. [PubMed: 20818875]
3. Roth K, Lynn J, Zhong Z, et al. Dying with End Stage Liver Disease with Cirrhosis: Insights from SUPPORT. *Journal of the American Geriatrics Society*. 2000; 48:S122–130. [PubMed: 10809465]
4. Bajaj JS, et al. The multi-dimensional burden of cirrhosis and hepatic encephalopathy on patients and caregivers. *Am J Gastroenterol*. 2011; 106:1646–1653. [PubMed: 21556040]
5. Miyazaki, et al. Patients on the waiting list for liver transplantation: caregiver burden and stress. *Liver Transpl*. 2010; 16:1164–1168.
6. Freedman VA, Hodgson N, Lynn J, et al. Promoting Declines in the Prevalence of Late-life disability: Comparisons of Three Potentially High-Impact Interventions. *Milbank Q*. 2006; 84:493–520. [PubMed: 16953808]
7. Walling AM, Asch SM, Lorenz KA, Wenger NS. Impact of consideration of transplantation on end-of-life care for patients during a terminal hospitalization. *Transplantation*. 2013; 27:641–6. [PubMed: 23197177]
8. Larson AM, Curtis RJ. Integrating Palliative Care for Liver Transplant Candidates: “Too Well for Transplant, Too Sick for Life.”. *JAMA*. 2006; 18:2168–2176. [PubMed: 16684988]
9. Medici V, Rossaro J, Wegelin A, et al. The utility of the model for end-stage liver disease score: a reliable guide for liver transplant candidacy and, for select patients, simultaneous hospice referral. *Liver Transpl*. 2008:1100–6. [PubMed: 18668666]