

# UCLA

## UCLA Previously Published Works

### Title

Palliative Care Quality Indicators for Patients with End-Stage Liver Disease Due to Cirrhosis

### Permalink

<https://escholarship.org/uc/item/97p6r9t2>

### Journal

Digestive Diseases and Sciences, 62(1)

### ISSN

0163-2116

### Authors

Walling, AM  
Ahluwalia, SC  
Wenger, NS  
[et al.](#)

### Publication Date

2017

### DOI

10.1007/s10620-016-4339-3

Peer reviewed



Published in final edited form as:

*Dig Dis Sci.* 2017 January ; 62(1): 84–92. doi:10.1007/s10620-016-4339-3.

## Palliative Care Quality Indicators for Patients with End-Stage Liver Disease Due to Cirrhosis

A. M. Walling<sup>1,2,3</sup>, S. C. Ahluwalia<sup>3,9</sup>, N. S. Wenger<sup>2,3</sup>, M. Booth<sup>3</sup>, C. P. Roth<sup>3</sup>, K. Lorenz<sup>7,8</sup>, F. Kanwal<sup>4,5</sup>, S. Dy<sup>6</sup>, and S. M. Asch<sup>7,8</sup> the Palliative Care Cirrhosis Quality Expert Panel

<sup>1</sup>Greater Los Angeles Veterans Affairs Healthcare System, Los Angeles, CA, USA

<sup>2</sup>Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine at University of California, Los Angeles, CA, USA

<sup>3</sup>RAND Health, Santa Monica, CA, USA

<sup>4</sup>Michael E. DeBakey Veterans Affairs Medical Center, Houston, TX, USA

<sup>5</sup>Division of Gastroenterology, Baylor College of Medicine, Houston, TX, USA

<sup>6</sup>Johns Hopkins Kimmel Cancer Center, Baltimore, MD, USA

<sup>7</sup>Palo Alto VA Health System, Palo Alto, CA, USA

<sup>8</sup>Division of General Medical Disciplines, Stanford, CA, USA

<sup>9</sup>UCLA Fielding School of Public Health, Los Angeles, CA, USA

### Abstract

**Background and Aims**—There are guidelines for the medical management of cirrhosis and associated quality indicators (QIs), but QIs focusing on standards for palliative aspects of care are needed.

**Methods**—We convened a 9-member, multidisciplinary expert panel and used RAND/UCLA modified Delphi methods to develop palliative care quality indicators for patients with cirrhosis. Experts were provided with a report based on a systematic review of the literature that contained evidence concerning the proposed candidate QIs. Panelists rated QIs prior to a planned meeting using a standard 9-point RAND appropriateness scale. These ratings guided discussion during a day-long phone conference meeting, and final ratings were then provided by panel members. Final QI scores were computed and QIs with a final median score of greater than or equal to 7, and no disagreement was included in the final set.

---

Correspondence to: A. M. Walling.

Preliminary data was presented as a poster at the April 2015 Society of General Internal Medicine Annual Conference.

**Author contributions** All authors were involved in the study concept and design and also in the data collection, analysis, and interpretation. AW, NW, and SA drafted the manuscript. All authors were involved in the critical revision of manuscript. AW, KL, and SA were involved in the study supervision. All authors were involved in the administrative, technical or material support. AW, MB, and SA were involved in the statistical analysis. AW, KL, and SA obtained the funding.

**Conflict of interest** For Drs Walling, Ahluwalia, Wenger, Booth, Dy and Asch there are no conflicts to disclose. Carol Roth has Johnson and Johnson stock. Dr. Lorenz is serving as a consultant to Otsuka Pharmaceuticals for data monitoring and safety in the evaluation of a Phase II trial of Sativex, a novel cannabinoid analgesic.

**Results**—Among 28 candidate QIs, the panel rated 19 as valid measures of quality care. These 19 quality indicators cover care related to information and care planning (13) and supportive care (6).

**Conclusions**—These QIs are evidence-based process measures of care that may be useful to improve the quality of palliative care. Research is needed to better understand the quality of palliative care provided to patients with cirrhosis.

### Keywords

Palliative care; End-stage liver disease; Quality

---

## Introduction

Several studies have shown evidence of the poor quality of end-of-life care in the USA [1, 2]. Understanding and meeting palliative care needs of patients with serious illness has become increasingly recognized as an important part of high-value care [3]. A recent study by Wachterman et al. showed that end-of-life care for patients with cancer as rated by families in after-death surveys was higher than for patients who died of non-cancer organ failure. Patients with cancer were more likely to have a palliative care consult or a decision about code status compared to patients with other serious illnesses [4].

Similarly, while there are several quality measures developed for palliative or supportive care in cancer [5], there is a dearth of commonly used guidelines or process of care quality measures specifically designed for measuring the quality of palliative care for patients with cirrhosis. Despite this lack of guidelines, patients with cirrhosis have significant communication challenges and symptom burden suggesting similar palliative care needs as in the cancer population.

End-stage liver disease (ESLD), the twelfth leading cause of death in the USA [6], is known to be a life-limiting illness whose only cure is transplant. Transplant, when possible, can have 1-year survival of greater than 80 %, but patients who do not undergo transplant will die from their disease and little is known about the outcomes of those patients with difficult post-transplant courses [7], highlighting the need for nuanced advance care planning specific to the population [8]. In fact, we learned from the SUPPORT study that discrepancies between reported desired care and care received among patients with cirrhosis at end of life were likely, in part, due to communication challenges related to the possibility of transplant [9].

Prior to death, patients with liver disease often suffer from poor health-related quality of life [10] and their burden of pain is similar as that for patients with lung and colon cancer [9]. Further supporting the need for cirrhosis-specific palliative care measures, there are treatment challenges unique to this disease since liver dysfunction often leads to variation in metabolism of commonly used supportive medications [8].

There are guidelines for the medical management of cirrhosis and an accompanying comprehensive set of quality indicators (QIs) [11]; however, this set does not include

advance care planning and some aspects of symptom management. We aimed to supplement that set of quality indicators with QIs that focus on palliative care for this population.

## Methods

We used the RAND/University of California, Los Angeles (UCLA) appropriateness method to supplement a previously developed set of cirrhosis QIs with QIs specifically designed to measure the quality of palliative care among patients with ESLD [11]. This method for developing QIs includes three distinct steps ([1] development of candidate indicators [2] systematic review of the literature and [3] expert panel review) and has been shown to be a reliable and valid method for development of process of care quality measures that are linked to important patient outcomes [12–16].

### Development of Quality Indicators

In prior work, quality of care measured using process of care measures has been linked with improved survival and quality of life consistent with the Donabedian Quality of Care Framework [14, 15, 17]. Conceptually, palliative care QIs focused on symptom management and communication link to improved outcomes of quality of death, health-related quality of life, and patient and family experience of care (Fig. 1).

We developed candidate QIs after reviewing palliative care guidelines, review articles related to palliative care and cirrhosis [8, 18–26], palliative care QIs that have been developed for other populations [27, 28], and conducting a systematic literature review. While palliative care can cover many domains, we restricted indicators to those that were primarily about clinical decision making and these were categorized into *Information and Care Planning* and *Supportive Care* domains. We excluded indicators specifically related to palliative treatments for hepatocellular cancer (HCC) such as the use of sorafenib, transcatheter arterial chemoembolization (TACE), and radiofrequency ablation (RFA) since it was beyond the scope of this effort.

Each QI contains an “IF” statement that defines the eligible population to which the indicator applies, a “THEN” statement indicating the recommended care process to be measured, and a “BECAUSE” statement that summarizes the primary indication for the care process.

### Review of Literature

We searched the literature to capture all relevant data for interventions aimed at addressing common symptoms and problems at the end of life for patients with ESLD. Articles were identified through MEDLINE, the Cochrane Database of Systematic Reviews, Cochrane Database of Abstracts of Reviews of Effects and the Cochrane Register of Clinical Trials (1990 through 12/14/2012, details in appendix). Two reviewers (AW and SA) conducted dual review using review criteria of 1888 titles in groups of 100 and resolved conflicts. For the third set of 100 titles, we achieved 96 % agreement (Kappa 0.78) suggesting excellent agreement and thus conducted single review for the remainder of the titles. The same dual-review process for abstract review yielded 82 articles that were reviewed for evidence related to relevant quality indicators.

To enrich the review, we later performed supplemental searches and included high-impact articles addressing palliative care that included patients other than those with ESLD since there are few studies in this area. The importance of the expert panel for determination of these measures is highlighted by the fact that many of the QIs proposed here are supported by expert clinical approach and foundational ethical principles rather than empiric evidence.

We also evaluated guidelines published after 1997 using the National Guidelines Clearinghouse and all data available related to liver disease from CareSearch, a palliative care knowledge network.

For each QI, we rated the evidence as Level I (randomized control trials), Level II (non-randomized controlled trials, cohort or case analysis, or multiple time series), or Level III (textbooks, opinions, and descriptive studies). All of the proposed QIs had level III evidence using these standards. All indicators were conservatively rated Level III given limited data specific to advanced end-stage liver disease. However, the expert panel did review evidence from the cancer literature that provided Level I for palliative care indicators (QI #1,2,5) and Level II evidence for advance care planning indicators (QI #6,7,8,9,10,13,14A,15) within the information and care planning domain [29–32].

### Expert Panel

The multidisciplinary expert panel included various clinical specialties (one hospitalist, one palliative care physician, one primary care physician, and 5 gastroenterologists) and experts from varied geographic locations (Missouri, Maryland, Virginia, Texas, California, Connecticut, and Washington, DC). The hospitalist, palliative care physician, and primary care physician all had extensive health services research experience and had been involved in the past with the development of QIs using this same methodology. The gastroenterologists represented varied interests and skills including transplant hepatology, health services research, and public health.

We used the RAND/UCLA process to rate the appropriateness of each QI that was proposed by the research team. The process included two rounds of rating the validity of the indicators, one prior to the interactive telephone conference and one at the conclusion of this conference. The rating system involved a 1–9 scale where 1 represented the least valid indicator and 9 represented the most valid. Panel members were provided written instruction regarding the process for the first round of rating and both written and verbal instructions for the final rating that included the standard definitions for appropriate and inappropriate from RAND/UCLA methodology [16].

Prior to the first round of rating, panel members reviewed a report based on the systematic literature review. This report included data relevant to the proposed QIs as well as a set of definitions for terms used in the QIs. For purposes of the initial round of rating, ESLD was defined as a patient with CTP Class C or MELD score greater than or equal to 20. Initial ratings of the panel were de-identified and distributed to all panel members to guide discussion during the interactive conference.

The expert panel conference took place via a conference phone and interactive-web meeting over a period of seven hours during which panelists discussed each proposed definition and quality indicator in detail in preparation for final ratings. QIs with a final median score of greater than or equal to 7 were included in the final set. We decided a priori that if there was disagreement, meaning at least 3 panelists rated in lowest tertile [1, 2] despite having a median score in the highest tertial (7–8–9), the indicator would not be included in the final set [16]. None of the indicators, however, were excluded based on disagreement. All nine panel members participated in both rounds of ratings.

## Results

During the panel conference, the first point of discussion was the definition of ESLD. After substantial discussion, panel members decided to make a slight alteration to the definition of ESLD and limited the denominator for these QIs to patients with advanced ESLD who have either a MELD score of greater than or equal to 20 or a CTP score of 12 (rather than that of 10 used for pre-panel ratings). All other definitions were left unchanged after discussion (Table 1).

During panel discussion, slight modifications were made to candidate QIs resulting in 3 additional QIs (details of modifications are in footnote of Table 2). There were 28 initial candidate QIs and 31 total QIs were reviewed during the second and final rounds. The panel rated 19 as valid measures of quality care (Table 2) and 12 were rejected from inclusion in the final set (Table 3). The 19 included quality indicators cover the domains of information and care planning (13 indicators) and supportive care (6 indicators).

## Discussion

High-quality care should promote quality of life as well as longevity, and yet, patients and families often are placed in the position of having to make trade-offs between these goals. It is crucial that clinicians help patients with advanced illness navigate these choices. While there are general guidelines for offering palliative care for “persons with debilitating and life-threatening illness” [18], how to apply such general guidelines to patients with cirrhosis is challenging at best. In order to fill this gap and supplement an already developed comprehensive set of QIs for cirrhosis, we developed 19 QIs focused on the provision of high-quality palliative care for patients with advanced cirrhosis.

These QIs were developed based on previously fielded palliative care QIs for vulnerable elders and patients with cancer [27, 28] and evidence-based approaches to care for patients with serious illness [29–34]. Notably, good communication about end-of-life care and early elicitation of preferences have been associated with better quality-of-life outcomes for patients and caregivers. Most of the identified care processes do not require specialty palliative care teams; primary care and specialist clinicians can integrate these practices into care of seriously ill patients.

There are several limitations to this quality indicator set. It is important to note that palliative care can be provided throughout the trajectory of illness, and these indicators simply serve as a marker of what a minimally acceptable bar of care should be. They provide a tool to

measure the quality of palliative care provided to patients with advanced end-stage liver disease using a comprehensive set of measures. However, any quality indicator set is necessarily limited in scope for several reasons and this is also the case for these quality indicators. We do not cover topics that have limited evidence for explicit indicators among patients with serious illness (for example, spiritual care or dealing with comorbid substance abuse), and in other instances, proposed indicators on specific topics (such as caregiver support) were not included after review by expert panel. Furthermore, the expert panel did not have non-MD clinician representation, such as social work and nursing, and this should be considered for future work in this area.

High-quality end-of-life care from the perspective of the patient requires open, patient-centered communication, effective pain and symptom management, and the facilitation of the patient's ability to prepare for death [35]. These indicators provide a practical first step to measuring how well these goals for patients with cirrhosis are being met. The comprehensive nature of the UCLA/RAND methodology used here supports the content validity of these measures. Future research should investigate the feasibility and reliability of these measures and their link to important outcomes such as patient and caregiver satisfaction with care.

## Acknowledgments

We acknowledge the significant contributions of the Palliative Care Cirrhosis Expert Panel including Bruce Bacon, MD, Sydney Dy, MD, MSc, Douglas Heuman, MD, Fasiha Kanwal, MD, MSHS, Timothy Morgan, MD, Teryl Nuckols, MD, MSHS, David Ross, MD, PhD, Tamar Taddei, MD, and Neil Wenger, MD, MPH. We appreciate the administrative support of Patricia Smith.

**Funding** This project was supported by the HIV/Hepatitis QUERI, Veterans Administration and VA HSR&D (PPO 14-372). Dr. Walling was also supported by NIH/National Center for Advancing Translational Science (NCATS) UCLA CTSI Grant Number (UL1TR000124) and the NIH loan repayment program.

## Appendix

End-stage liver disease—search methodology

Database searched and time period covered:

PubMed—1990-3/22/2012

Language:

English

Search strategy;

End-stage liver disease OR (cirrhosis AND (child AND c))

AND

“dying loved one” OR “dying patient” OR “dying patients” OR “dying people” OR “dying person” OR “last year of life” OR “end of life” OR “end-of-life” OR “terminal illness” OR “terminal illnesses” OR terminal care OR “limited life expectancies” OR “limited life

expectancy” OR “limited life span” OR “limited lifespan” OR “limited life spans” OR terminally ill OR critical illness OR frail elderly OR palliative OR hospice OR “advance care” OR advance directive\* OR surrogate decision maker\* OR surrogate decision-maker\* OR caregiver\* OR care giver\* OR “care giving” OR diet\* OR nutrition\* OR supportive medication\* OR hepatorenal syndrome AND dialysis) OR “mechanical ventilation” OR pain OR esophageal varices OR constipat\* OR ascites OR bone OR bones OR fatigue OR pruritis OR gonadal dysfunction OR dyspnea OR tylenol OR nsaid OR sorafenib

Number of results: 1776

Database searched and time period covered:

PubMed—1/1/2012–12/14/2012

Language:

English

Search strategy:

End-stage liver disease OR (cirrhosis AND (child AND c))

AND

“dying loved one” OR “dying patient” OR “dying patients” OR “dying people” OR “dying person” OR “last year of life” OR “end of life” OR “end-of-life” OR “terminal illness” OR “terminal illnesses” OR terminal care OR “limited life expectancies” OR “limited life expectancy” OR “limited life span” OR “limited lifespan” OR “limited life spans” OR terminally ill OR critical illness OR frail elderly OR palliative OR palliat\* OR hospice OR “advance care” OR advance directive\* OR surrogate decision maker\* OR surrogate decision-maker\* OR caregiver\* OR care giver\* OR “care giving” OR diet OR dietary OR nutrition\* OR supportive medication\* OR (hepatorenal syndrome AND dialysis) OR “mechanical ventilation” OR pain OR esophageal varices OR constipat\* OR ascites OR bone OR bones OR fatigue OR pruritis OR gonadal dysfunction OR dyspnea OR tylenol OR nsaid OR sorafenib

Number of results: 213

Database searched and time period covered:

Cochrane databases—1/1/2012–12/14/2012

Language:

English

Search strategy:

‘End-Stage Liver Disease OR (cirrhosis AND (child AND c)) in title abstract keywords



AND

dying loved one” OR dying patient OR dying patients” OR “dying people OR dying person OR last year of life OR end of life OR end-of-life OR terminal illness OR terminal illnesses OR terminal care OR limited life expectancies OR limited life expectancy OR limited life span OR limited lifespan OR limited life spans OR terminally ill OR critical illness OR frail elderly OR palliative OR palliat\* OR hospice OR advance care OR advance directive\* OR surrogate decision maker\* OR surrogate decision-maker\* OR caregiver\* OR care giver\* OR care giving OR diet OR dietary OR nutrition\* OR supportive medication\* OR (hepatorenal syndrome AND dialysis) OR mechanical ventilation OR pain OR esophageal varices OR constipat\* OR ascites OR bone OR bones OR fatigue OR pruritis OR gonadal dysfunction OR dyspnea OR tylenol OR nsaid\* OR sorafenib

Number of results: 2

Cochrane reviews (2)

Other reviews (0)

Trials (2)

Methods studies (0)

Technology assessments (0)

Economic evaluations (0)

Cochrane groups (0)

After removing duplicates:

1888 is the final after removing all duplicates

144 after title search

82 after abstract search

Database searched and time period covered:

National guidelines clearinghouse—1/1/1997–12/14/2012

Language:

English

Search strategy #1:

Keyword: liver

IOM care need: end-of-life care

Number of results: 41

Search strategy #2:

Keyword: cirrhosis

Age of target population: exclude infant (1–23 months), child (2–12 years), adolescent (13–18 years)

Number of results: 38

No Palliative care guidelines for cirrhosis, General Palliative care guidelines for pain management (1) and for all life-limiting illnesses (2)

Database searched and time period covered:

CareSearch—all years

Search strategy:

Liver

Number of results: 25

One report for homeless, one report for pain management in liver disease, and fast fact #189 for prognosis in cirrhosis

## Abbreviations

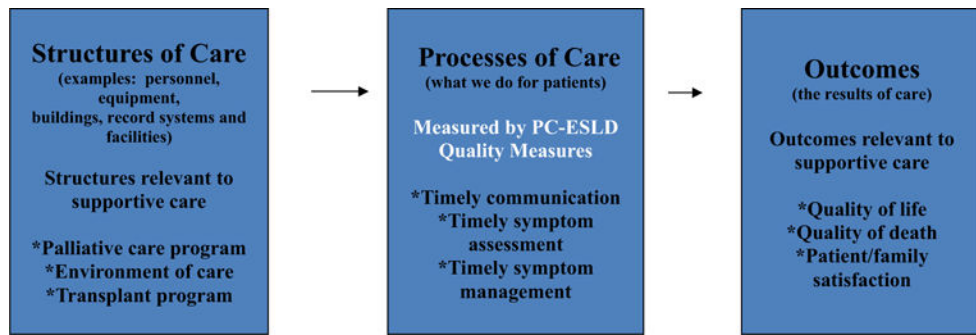
<b>ESLD</b>	End-stage liver disease
<b>QI</b>	Quality indicator
<b>VA</b>	Veterans affairs

## References

1. Walling AM, Asch SM, Lorenz KA, et al. The quality of care provided to hospitalized patients at the end of life. *Arch Intern Med.* 2010; 170:1057–1063. [PubMed: 20585072]
2. Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000 2005, and 2009. *JAMA.* 2013; 309:470–477. [PubMed: 23385273]
3. Meier DE. Increased access to palliative care and hospice services: opportunities to improve value in health care. *Milbank Q.* 2011; 89:343–380. [PubMed: 21933272]
4. Wachterman MW, Pilver C, Smith D, et al. Quality of end-of-life care provided to patients with different serious illnesses. *JAMA Intern Med.* 2016; 176:1095–1102. [PubMed: 27367547]
5. Kamal AH, Gradison M, Maguire JM, et al. Quality measures for palliative care in patients with cancer: a systematic review. *J Oncol Pract.* 2014; 10:281–287. [PubMed: 24917264]
6. Action Plan for Liver Disease Research: National Institute of Diabetes and Digestive Diseases and Kidney Disease. [http://www2.niddk.nih.gov/AboutNIDDK/ResearchAndPlanning/Liver\\_Disease/ActionPlanforLiverDiseaseResearchSlidesMinutes.htm](http://www2.niddk.nih.gov/AboutNIDDK/ResearchAndPlanning/Liver_Disease/ActionPlanforLiverDiseaseResearchSlidesMinutes.htm). Last Accessed August 12, 2013.

7. UNOS Donate Life America Statistics. <http://donatelife.net/understanding-donation/statistics/>. Last Accessed December 30, 2014.
8. Larson AM, Curtis JR. Integrating palliative care for liver transplant candidates: “too well for transplant, too sick for life”. *JAMA*. 2006; 295:2168–2175. [PubMed: 16684988]
9. Roth K, Lynn J, Zhong Z, et al. Dying with end stage liver disease with cirrhosis: Insights from SUPPORT. *J Am Geriatr Soc*. 2000; 48:S122–S130. [PubMed: 10809465]
10. Younossi ZM, Bopari N, Price L, et al. Health-related quality of life in chronic liver disease: the impact of type and severity of disease. *Am J Gastroenterol*. 2001; 96:2199–2205. [PubMed: 11467653]
11. Kanwal F, Kramer J, Asch S, et al. An explicit quality indicator set for measurement of quality of care in patients with cirrhosis. *Clin Gastroenterol Hepatol*. 2010; 8:709–717. [PubMed: 20385251]
12. The RAND/UCLA appropriateness method user’s manual. Santa Monica, CA: RAND Corporation; 2001.
13. Shekelle PG, Chassin MR, Park RE. Assessing the predictive validity of the RAND/UCLA appropriateness method criteria for performing carotid endarterectomy. *Int J Technol Assess Health Care*. 1998; 14:707–727. [PubMed: 9885461]
14. Zigmond DS, Ettner SL, Wilber KH, Wenger NS. Association of claims-based quality of care measures with outcomes among community-dwelling vulnerable elders. *Med Care*. 2011; 49:553–559. [PubMed: 21499140]
15. Higashi T, Shekelle PG, Adams JL, et al. Quality of Care is associated with survival in vulnerable older patients. *Ann Intern Med*. 2005; 143:274–281. [PubMed: 16103471]
16. Shekelle P. The appropriateness method. *Medical Decision Making*. 2004; 24:228–231. [PubMed: 15090107]
17. Kahn KL, Tisnado DM, Adams JL, et al. Does Ambulatory process of care predict health related quality of life outcomes for patients with chronic disease. *Health Serv Res*. 2007; 42:63–83. [PubMed: 17355582]
18. National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. Executive summary. *J Palliat Med*. 2004; 7:611–627. [PubMed: 15588352]
19. National Quality Forum. NQF endorses palliative and end-of-life care measures. [http://www.qualityforum.org/News\\_And\\_Resources/Press\\_Releases/2012/NQF\\_Endorses\\_Palliative\\_and\\_End-of-Life\\_Care\\_Measures.aspx](http://www.qualityforum.org/News_And_Resources/Press_Releases/2012/NQF_Endorses_Palliative_and_End-of-Life_Care_Measures.aspx). Accessed August 15, 2013
20. Spengler U. Management of end-stage liver disease in HIV/ hepatitis C virus co-infection. *Curr Opin HIV AIDS*. 2011; 6:527–533. [PubMed: 21918437]
21. Perumalswami PV, Schiano TD. The management of hospitalized patients with cirrhosis: the Mount Sinai experience and a guide for hospitalists. *Dig Dis Sci*. 2011; 56:1266–1281. [PubMed: 21416246]
22. Hansen L, Sasaki A, Zucker B. End stage liver disease: challenges and practical implications. *Nurs Clin North Am*. 2010; 45:411–426. [PubMed: 20804886]
23. Garcia-Tsao G, Lim JK. Management and treatment of patients with cirrhosis and portal hypertension: recommendations from the Department of Veterans Affairs Hepatitis C Resource Center Program and the National Hepatitis C Program. *Am J Gastroenterol*. 2009; 104:1802–1829. [PubMed: 19455106]
24. Heidelbaugh JJ, Sherbondy M. Cirrhosis and chronic liver failure: part II. Complications and treatment. *Am Fam Physician*. 2006; 74:767–776. [PubMed: 16970020]
25. Soncini M, Leo P, Triossi O, et al. Management and outcomes of hepatic cirrhosis: Findings from the RING study. *Hepatol Rs*. 2006; 36:176–181.
26. Sanchez W, Talwalkar JA. Palliative care for patients with end-stage liver disease ineligible for liver transplantation. *Gastroenterol Clin North Am*. 2006; 55:201–219.
27. Lorenz KA, Rosenfeld K, Wenger NS. Quality indicators for palliative and end-of-live care in vulnerable elders. *JAGS*. 2007; 55:S318–S326.
28. Lorenz KA, Dy SM, Naeim A, et al. Quality measures for supportive cancer care: The Cancer Quality-ASSIST Project. *J Pain Symptom Manage*. 2009; 37:943–964. [PubMed: 19359135]

29. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care in patients with metastatic non-small cell lung cancer. *NEJM*. 2010; 363:733–742. [PubMed: 20818875]
30. Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manag*. 2003; 25:150–168.
31. Bakitas M, Lyons Hegel MT, et al. Effects of palliative care intervention on clinical outcomes in patients with advanced cancer: the project ENABLE II randomized controlled trial. *JAMA*. 2009; 302:741–749. [PubMed: 19690306]
32. Walling AM, et al. Evidence-based recommendations for information and care planning in cancer care. *J Clin Oncol*. 2008; 23:3896–3902.
33. Wright AA, Zhang AA, Huskamp H, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008; 300:1665–1673. [PubMed: 18840840]
34. Zimmermann C, Swami N, Krzyzanowskam M, et al. Early palliative care for patients with advanced cancer: a cluster-randomized controlled trial. *Lancet*. 2014; 383:1721–1730. [PubMed: 24559581]
35. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004; 291:89–93.
36. 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; 95:641–646. [PubMed: 23197177]



**Fig. 1.** Donabedian model adapted for development of palliative care quality indicators for patients with end-stage liver disease due to cirrhosis

**Table 1**

## Definitions for palliative care cirrhosis quality indicators

Medical term	Definition
Advanced end-stage liver disease	A patient with documented cirrhosis and after all reversible causes of ongoing liver injury have been identified and addressed (i.e., alcoholic hepatitis, autoimmune hepatitis), the patient has either a Model for End-Stage Liver Disease (MELD) score of greater or equal to 20 OR a Childs–Turcotte–Pugh (CTP) score of 12 or greater
Not a candidate for transplant	Not listed or not in the process of being listed for transplant. Cannot be assumed if patient was never considered for transplant
Considered for transplant	Documentation in the medical record that a patient was listed as a transplant candidate or under active consideration or evaluation for transplantation. This variable was abstracted successfully from the medical record in a prior study with a reabstraction kappa of 0.89 and 96 % agreement [36]
Advance care planning	Documentation of a surrogate and/or patient preferences in the medical record or in an advance directive, and/or in a Physician Orders for Life-Sustaining Treatment (POLST) form
Expected death	Any physician documentation at least 3 days before death that the patient was dying, terminal, had a grave prognosis, or had imminently life-threatening disease in the context of a poor prognosis. This variable was abstracted successfully from the medical record in a prior study with a reabstraction kappa of 0.67 and 91 % agreement [36]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 2**

Final set of quality indicators for palliative care in cirrhosis by domains

Quality indicator number	Domains/quality indicator (evidence)	Median score by expert panel
<i>Information and Care Planning Quality Indicators</i>		
1	<b>IF</b> a patient has advanced end-stage liver disease and hepatocellular carcinoma (HCC) with a BCLC Stage D and is not a candidate for transplant, <b>THEN</b> the patient should be offered palliative and/or hospice services or a reason why not should be documented <b>BECAUSE</b> survival is likely less than 6 months and hospice provides additional support for patients and caregivers/family	7
2	<b>IF</b> a patient has advanced end-stage liver disease and is diagnosed with hepatorenal syndrome and is not a liver transplant candidate, <b>THEN</b> the patient should be offered palliative and/or hospice services <b>BECAUSE</b> these patients have a poor prognosis and would benefit from the additional supportive services	8
5	<b>IF</b> a patient with advanced end-stage liver disease dies an expected death, <b>THEN</b> there should be evidence that he or she has been offered palliative care or hospice within 6 months before death <b>BECAUSE</b> palliative care teams can improve a range of patient and caregiver outcomes	7
6	<b>IF</b> a patient has advanced end-stage liver disease and is being considered for transplant, <b>THEN</b> the patient should be offered advance care planning within 3 months of consideration of transplant or a reason why such a discussion did not occur <b>BECAUSE</b> effective communication about goals of care is important to ensure that patient preferences are followed during the course of their illness	7
7	<b>IF</b> a patient is newly diagnosed with advanced end-stage liver disease and is not considered for transplant, <b>THEN</b> the patient should be offered advance care planning within 3 months or a reason why such a discussion did not occur <b>BECAUSE</b> effective communication about goals of care is important to ensure that patient preferences are followed during the course of their illness	7
8	<b>IF</b> a patient with advanced end-stage liver disease dies an expected death, <b>THEN</b> there should be documentation of advance care planning in the medical record within 6 months before death <b>BECAUSE</b> a patient's goals and values should guide treatment and life-sustaining care decisions	7
9	<b>IF</b> a patient with advanced end-stage liver disease is admitted to a hospital or nursing home, <b>THEN</b> within 48 h of admission the medical record should contain the name of the patient's surrogate decision maker, or documentation of a discussion to identify/search for a surrogate decision maker <b>BECAUSE</b> patient's values and preferences should guide life-sustaining care and patients with end-stage liver disease often cannot make decisions for themselves	9
10	<b>IF</b> a patient with advanced end-stage liver disease is newly diagnosed with hepatic encephalopathy and does not have advance care planning previously documented, <b>THEN</b> the medical record should document advance care planning or lack of ability to do so within 1 month <b>BECAUSE</b> patients with a history of hepatic encephalopathy are at higher risk of lacking capacity to make decisions for themselves and care should be guided by their goals and preferences	7
11	<b>IF</b> a patient with advanced end-stage liver disease is admitted to the ICU and survives 48 h, <b>THEN</b> within 48 h, the medical record should document that the patient's preferences for care have been considered or an attempt was made to identify them <b>BECAUSE</b> patients with end-stage liver disease are at a high risk of requiring life-sustaining treatment decisions	7
12	<b>IF</b> a patient with advanced end-stage liver disease requires mechanical ventilation for greater than 48 h, <b>THEN</b> within 48 h of the initiation of mechanical ventilation, the medical record should document the goals of care and the patient's preference for mechanical ventilation or why this information is not available <b>BECAUSE</b> patients' values and preferences should guide life-sustaining care	7
13	<b>IF</b> a patient with advanced end-stage liver disease has orders in the hospital or nursing home to withhold or withdraw a life-sustaining treatment (e.g., DNR, no tube feeding, no hospital transfer), <b>THEN</b> these treatment preferences should be followed <b>BECAUSE</b> patients' values and preferences should guide end-of-life care	8
14A*	<b>IF</b> a patient with advanced end-stage liver disease who is not a candidate for transplant has the following: new hemodialysis or placement of a pacemaker or ICD, <b>THEN</b> within one month prior to the procedure, the medical record should document the goals of care and the patient's preference for the intervention, <b>BECAUSE</b> a patient's treatment should reflect his or her goals of care	7
15	<b>IF</b> an inpatient with advanced end-stage liver disease has an advance directive or DNR at the time of discharge and the patient receives care in a second venue, <b>THEN</b> the advance directive and/or DNR should be present in the medical record of the second venue or documentation should acknowledge its existence, its contents, and the reason it is not in the medical record, <b>BECAUSE</b> an advance directive can guide care only if its existence is recognized and its contents are known	8

Quality indicator number	Domains/quality indicator (evidence)	Median score by expert panel
<i>Supportive Care Quality Indicators</i>		
20	<b>IF</b> a patient with advanced end-stage liver disease is receiving acetaminophen, <b>THEN</b> the total daily dose should not exceed 3 grams or a reason why the patient is receiving more should be documented <b>BECAUSE</b> acetaminophen-induced hepatotoxicity may have serious consequences in cirrhosis	7
21	<b>IF</b> a patient has advanced end-stage liver disease, <b>THEN</b> the patient should not be prescribed NSAIDs <b>BECAUSE</b> of the increased risk of renal toxicity and bleeding	8
26A*	<b>IF</b> a patient with advanced end-stage liver disease who is not enrolled in hospice presents with ascites with moderate to severe symptoms (pain, shortness of breath, or non-reducible hernia), <b>THEN</b> the patient should be offered a paracentesis within 48 h or a reason why not should be documented <b>BECAUSE</b> treatment can improve patients' symptoms	7
27A	<b>IF</b> a patient with advanced end-stage liver disease is not expected to survive and a mechanical ventilator is withdrawn or withheld, <b>THEN</b> the medical chart should document whether the patient has dyspnea <b>BECAUSE</b> dyspnea can be controlled in the setting of comfort care when mechanical ventilation is withdrawn or withheld	8
27B	<b>IF</b> a patient with advanced end-stage liver disease is not expected to survive and a mechanical ventilator is withdrawn or withheld, <b>THEN</b> the medical chart should document whether the patient should receive (or have orders available for) dyspnea management <b>BECAUSE</b> dyspnea can be controlled in the setting of comfort care when mechanical ventilation is withdrawn or withheld	8
28	<b>IF</b> a patient with advanced end-stage liver disease who had dyspnea in the last 3 days of life died an expected death, <b>THEN</b> the chart should document dyspnea care and follow-up <b>BECAUSE</b> dyspnea can be effectively treated with pharmacological agents	7

\* For quality indicator number 14, the expert panel decided to include an option which limited the denominator to patients who were not a candidate for transplant (ultimately included in final QI set) and option b which did not limit to patients who were not a candidate for transplant (not included in final indicator set). For quality indicator number 26, the expert panel included a dominator that included and excluded hospice patients. Ultimately the QI that excluded hospice patients was included in the final quality indicator set since it was felt that paracentesis was not always indicated in these patients when considering burdens and benefits of procedure. Lastly quality indicator number 27 was separated into two separate indicators so that dyspnea assessment and dyspnea management would be measured separately



**Table 3**

Rejected quality indicators for palliative care in cirrhosis by domains that did not meet validity requirements

Quality indicator number	Domains/quality indicator (evidence)	Median
3	<b>IF</b> a patient is being considered for transplant and has advanced end-stage liver disease, <b>THEN</b> the patient should be offered a palliative care consult within 1 month of consideration of transplant <b>BECAUSE</b> patients with end-stage liver disease have a significant risk of mortality and palliative care can be delivered concurrent with curative care	4
4	<b>IF</b> a patient is newly diagnosed with advanced end-stage liver disease and is not considered for a liver transplant, <b>THEN</b> the patient should be offered a palliative care consult within one month or a reason why not should be documented <b>BECAUSE</b> patients with end-stage liver disease have a significant risk of mortality and would benefit from palliative care	6
14B	<b>IF</b> a patient with advanced end-stage liver disease has the following: new HD, pacemaker or ICD placement, <b>THEN</b> within one month prior to the procedure, the medical record should document goals of care and the patient's preference for the intervention, <b>BECAUSE</b> a patient's treatment should reflect his or her goals of care	6
16	<b>IF</b> a patient with advanced end-stage liver disease patient has an outpatient visit, <b>THEN</b> the patient should be screened for pain using a standardized scale (or they should be screened for the presence and absence and intensity of pain) <b>BECAUSE</b> pain is common and often undertreated and pain identification is required to initiate treatment	5
17	<b>IF</b> an inpatient with advanced end-stage liver disease has a new complaint of severe pain, <b>THEN</b> the medical record should indicate that an intervention and follow-up assessment of the pain occurred within 24 h or a reason why not should be documented <b>BECAUSE</b> pain is common and often undertreated and pain identification is required to initiate treatment	5
18	<b>IF</b> a inpatient with advanced end-stage liver disease was conscious during the last 7 days of life and died an expected death, <b>THEN</b> the medical record should contain documentation about the presence or absence of pain in the last 7 days of life <b>BECAUSE</b> pain is common at the end of life and can be effectively treated	5
19	<b>IF</b> a patient with advanced end-stage liver disease has stage IV or V chronic kidney disease and an opioid is needed for pain control, <b>THEN</b> the patient should not receive morphine or there should be documentation regarding justification for why another opioid was not used <b>BECAUSE</b> Morphine-6-glucuronide (M6G) is a major metabolite of morphine and can accumulate to toxic levels in kidney failure	6
22	<b>IF</b> a patient is newly diagnosed with advanced end-stage liver disease, <b>THEN</b> the chart should document caregiver burdens and needs for practical assistance within 3 months, <b>BECAUSE</b> these concerns are known to be important to patients and their caregivers with advanced illness as part of their end-of-life care	5
23	<b>IF</b> a patient with advanced end-stage liver disease is newly diagnosed with hepatic encephalopathy, <b>THEN</b> the chart should document caregiver burdens and needs for practical assistance within 3 months, <b>BECAUSE</b> these concerns are known to be important to patients and their caregivers with advanced illness as part of their end-of-life care	5
24	<b>IF</b> a patient with advanced end-stage liver disease has a known history of bleeding esophageal varices and is enrolled in hospice, <b>THEN</b> there should be documentation that the patient and family were counseled regarding preparation for bleeding as a potential end-of-life event <b>BECAUSE</b> bleeding at the end of life can be a stressful event for caregivers	5
25	<b>IF</b> a patient with advanced end-stage liver disease presents with new or worsening pruritus, <b>THEN</b> the patient should be offered treatment within 1 week or a reason why not should be documented <b>BECAUSE</b> pruritus is an uncomfortable symptom	5
26B	<b>IF</b> a patient with advanced end-stage liver disease who is not enrolled in hospice presents with ascites with moderate to severe symptoms (pain, shortness of breath, or non-reducible hernia), <b>THEN</b> the patient should be offered a paracentesis within 48 h or a reason why not should be documented <b>BECAUSE</b> treatment can improve patients' symptoms	5