



How to deliver palliative care for patients with management in decompensated cirrhosis

Beom Kyung Kim^{1,2,3}

¹Department of Internal medicine, Yonsei University College of Medicine, Seoul, Republic of Korea; ²Institute of Gastroenterology, Yonsei University College of Medicine, Seoul, Republic of Korea; ³Yonsei Liver Center, Severance Hospital, Seoul, Republic of Korea

Correspondence to: Beom Kyung Kim, MD, PhD. Department of Internal Medicine, Yonsei University College of Medicine, 50-1 Yonsei-ro, Seodaemun-gu, Seoul 03722, Republic of Korea; Institute of Gastroenterology, Yonsei University College of medicine, Seoul, Republic of Korea; Yonsei Liver Center, Severance Hospital, Seoul, Republic of Korea. Email: beomkkim@yuhs.ac.

Comment on: Rogal SS, Hansen L, Patel A, *et al.* AASLD Practice Guidance: Palliative care and symptom-based management in decompensated cirrhosis. *Hepatology* 2022;76:819-53.

Keywords: Palliative; care; decompensation; cirrhosis

Submitted Apr 29, 2023. Accepted for publication Jun 22, 2022. Published online Jun 29, 2023.

doi: 10.21037/hbsn-23-222

View this article at: <https://dx.doi.org/10.21037/hbsn-23-222>

Palliative care is defined as multidisciplinary, specialized medical care that meets the needs of patients with serious illnesses and their caregivers from the standpoints of the physical, spiritual, and emotional levels (1). Nowadays, it is also considered to be one of the fundamental care programs for patients with decompensated cirrhosis, as has also been demonstrated in the field of other cancers (2). Recently, the guidance regarding “palliative care and symptom-based management in decompensated cirrhosis” had been published in 2022 by the American Association for the Study of Liver Diseases (AASLD) (3). Literally, the “guidance” differs slightly from practice guidelines that are typically based on systematic reviews of the literature, formal ratings of evidence quality and strength of recommendations, and, if appropriate, meta-analyses of outcomes. The lack of randomized controlled trials was a major factor in the development of guidance, rather than guideline, by AASLD, which was decided upon by a panel of experts (3).

Hospice, which primarily treats patients with a short life expectancy and focuses solely on comfort rather than disease-directed curative treatment (4), is not the same as palliative care. Palliative care is therefore available at all stages of decompensated cirrhosis: (I) the early phase, which is supported by disease-directed and curative treatments (including liver transplants), (II) the end of life, which

is supported by hospice care, and (III) even after death for the patients’ caretakers (2). In contrast, patients with decompensated cirrhosis and those who care for them frequently have important unmet needs in terms of their psychological, physical, social, economic, and spiritual well-being (5), because cirrhosis is closely linked to poor health-related quality of life brought on by numerous difficult-to-manage physical, cognitive, psychological, and social stressors (6). In particular, the final disease trajectory of decompensated cirrhosis is progressive, even though a 5-year mortality varies between 20% and 80% across studies (7), with worsening health, an increase in symptom burden, and numerous hospitalizations at the end of life (8-10). Therefore, to positively affect the symptoms of all patients and their caregivers, evaluation for unmet palliative care needs and specialty palliative care consulting should be taken into consideration.

While outpatient palliative care may be associated with improved symptoms, improved care coordination, and better anticipatory planning, inpatient specialty palliative care consultations with post-discharge follow-up may be associated with establishment of greater consensus between patients and clinicians in which the goals of care, reduced life-sustaining treatment use, earlier provision of comfort-focused care, and reduced readmission can be mediated (11). Although it is preferable for specialists to provide palliative

care, due to their shortages, hepatologists should take a key role in modifying primary palliative care services (12).

Advance care planning (ACP) is a proactive, ongoing, collaborative process of decision making about health care preferences, goals, and values in the context of a life-limiting illness (13). For patients with decompensated cirrhosis, it is an iterative procedure that should begin with diagnosing cirrhosis and ideally take place prior to hepatic decompensation and the loss of patients' decision-making capacity (3,13). Patients with decompensated cirrhosis experience a wide range of co-occurring symptoms (9,14), hence treating these symptoms is an essential part of providing high-quality cirrhosis care. Such symptoms may include pain, nausea & vomiting, abdominal distension caused by refractory ascites, dyspnea, hepatic encephalopathy, muscle cramps, sleep disturbances, fatigue, pruritis, sexual dysfunction, and depression & anxiety (3,15-17). In order to properly manage different types of symptoms, it is first necessary to assess their intensity and focus on the symptoms that matter most to patients. Many times, the nonpharmacological approach such as behavioral intervention, physical therapy, or other modalities that address various symptoms may be the primary method of symptom management. It is important to concurrently identify and treat any underlying causes of symptoms. When possible, interdisciplinary teams from other fields, such as nursing, social work, and chaplaincy, should evaluate and manage symptoms. Patients and caregivers also require so-called end-of-life care when the liver disease eventually worsens. Patients with decompensated cirrhosis have a similar number of symptoms and anguish during this time as those with advanced colorectal and lung cancer. In order to address palliative needs at the end of life, end-of-life treatment preferences should be elicited under agreement among physicians, patients, and caregivers, care plans should be also modified accordingly. Furthermore, patients and caregivers must be informed about scenarios like infection, bleeding, and hepatic encephalopathy.

Contrary to patients dying of advanced cancer, patients dying of decompensated cirrhosis underutilize hospice, that is, a patient- and caregiver-centered alternative for end-of-life care. In this instance, balancing both aggressive and nonaggressive goals may frequently be necessary in the establishment of care plans in the real-world practice. Even while the majority of patients with decompensated cirrhosis pass away in a hospital, this can be a particular problem for physicians as well as patients and caregivers who choose to seek end-of-life care at home or in the community (18).

Hepatology teams may practically think about using the Model of End-stage Liver Disease (MELD) >21 and Child-Pugh >12 to identify whether patients are prognostically suitable for hospice care (i.e., have an anticipated life of less than six months) (19). The optimal criteria, however, have not yet been identified. Informing caregivers of the patient's impending death may promote choices that are in line with patients' prognosis.

There are still many barriers to be overcome in order to successfully integrate the ideas of palliative care into the treatment of hepatology (3). First, developing programs and training the personnel to support palliative care is a crucial first step. There is growing agreement that clinicians across all medical and surgical specialties should learn core competencies in delivery of palliative care and engage with experts as necessary. However, given the crisis of shortage in palliative care workforce—primarily as a result of the aging population's increasing demand for palliative care—this is even more important (20). Future studies should examine how to effectively educate palliative care providers from the viewpoint of socioeconomic burden. Second, it is important to talk about creating policies and infrastructure to support the use of palliative care in the field of hepatology. For instance, laws that support payment for speciality palliative services should be taken into account. The introduction of palliative care in the routine practice for patients with decompensated cirrhosis may also be facilitated by formal contact and collaboration between the hepatology and palliative care societies. Furthermore, it is important to promote the spread of knowledge about the supports and advantages that are available (3). Actually, a lot of patients with decompensated cirrhosis are not aware that they can get hospice care while they are waiting on the transplant list to find a donor organ. Additionally, by including measurements for hospice and palliative care in cirrhosis quality indicators, clinicians and payors may see how important these subjects are. Third, as was already mentioned, there are large discrepancies between findings from the study and real-world experience (3). Therefore, more research is needed to establish the evidence around which interventions work at what times for patients with decompensated cirrhosis. It will result in the identification of the most effective techniques for gauging and summarizing patient-reported outcomes for patients with decompensated cirrhosis. Palliative care for patients with decompensated cirrhosis must therefore be completely implemented, which calls for a multifaceted strategy to address ongoing training, practice, policy, and research

shortages.

In conclusion, palliative care for patients with decompensated cirrhosis is a multidisciplinary strategy to enhance the emotional, spiritual, and physical health of patients themselves and their caregivers. However, in the real-world practice, it is still not being used to its full potential. Palliative care should be complemented by proper hepatology care, communication, thorough symptom management, and coordinated interdisciplinary care that is in line with patients' values and wishes. Therefore, additional study is needed to determine the optimal strategies for medical staff education and training, symptom management, the use of specialized palliative care, and more economical models.

Acknowledgments

Funding: None.

Footnote

Provenance and Peer Review: This article was commissioned by the editorial office, *Hepatobiliary Surgery and Nutrition*. The article did not undergo external peer review.

Conflicts of Interest: The author has completed the ICMJE uniform disclosure form (available at <https://hbsn.amegroups.com/article/view/10.21037/hbsn-23-222/coif>). The author has no conflicts of interest to declare.

Ethical Statement: The author is accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Open Access Statement: This is an Open Access article distributed in accordance with the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the non-commercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>.

References

1. Radbruch L, De Lima L, Knaut F, et al. Redefining Palliative Care-A New Consensus-Based Definition. *J Pain Symptom Manage* 2020;60:754-64.
2. Verma M, Tapper EB, Singal AG, et al. Nonhospice Palliative Care Within the Treatment of End-Stage Liver Disease. *Hepatology* 2020;71:2149-59.
3. Rogal SS, Hansen L, Patel A, et al. AASLD Practice Guidance: Palliative care and symptom-based management in decompensated cirrhosis. *Hepatology* 2022;76:819-53.
4. Ferrell BR, Twaddle ML, Melnick A, et al. National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *J Palliat Med* 2018;21:1684-9.
5. Langberg KM, Kapo JM, Taddei TH. Palliative care in decompensated cirrhosis: A review. *Liver Int* 2018;38:768-75.
6. Loria A, Escheik C, Gerber NL, et al. Quality of life in cirrhosis. *Curr Gastroenterol Rep* 2013;15:301.
7. D'Amico G, Garcia-Tsao G, Pagliaro L. Natural history and prognostic indicators of survival in cirrhosis: a systematic review of 118 studies. *J Hepatol* 2006;44:217-31.
8. Volk ML, Tocco RS, Bazick J, et al. Hospital readmissions among patients with decompensated cirrhosis. *Am J Gastroenterol* 2012;107:247-52.
9. Lee HL, Lee SW. The role of transjugular intrahepatic portosystemic shunt in patients with portal hypertension: Advantages and pitfalls. *Clin Mol Hepatol* 2022;28:121-34.
10. Kim TH, Jung YK, Yim HJ, et al. Impacts of muscle mass dynamics on prognosis of outpatients with cirrhosis. *Clin Mol Hepatol* 2022;28:876-89.
11. Kimbell B, Murray SA, Byrne H, et al. Palliative care for people with advanced liver disease: A feasibility trial of a supportive care liver nurse specialist. *Palliat Med* 2018;32:919-29.
12. Ufere NN, Donlan J, Waldman L, et al. Barriers to Use of Palliative Care and Advance Care Planning Discussions for Patients With End-Stage Liver Disease. *Clin Gastroenterol Hepatol* 2019;17:2592-9.
13. Myers J, Cosby R, Gzik D, et al. Provider Tools for Advance Care Planning and Goals of Care Discussions: A Systematic Review. *Am J Hosp Palliat Care* 2018;35:1123-32.
14. Han JW, Kim DI, Nam HC, et al. Association between serum tumor necrosis factor- α and sarcopenia in liver cirrhosis. *Clin Mol Hepatol* 2022;28:219-31.
15. Peng JK, Hepgul N, Higginson IJ, et al. Symptom prevalence and quality of life of patients with end-stage liver disease: A systematic review and meta-analysis. *Palliat Med* 2019;33:24-36.

16. Sarkar M, Brady CW, Fleckenstein J, et al. Reproductive Health and Liver Disease: Practice Guidance by the American Association for the Study of Liver Diseases. *Hepatology* 2021;73:318-65.
17. Lin H, Wong GL, Zhang X, et al. U-shaped relationship between urea level and hepatic decompensation in chronic liver diseases. *Clin Mol Hepatol* 2022;28:77-90.
18. Altaïi H, Al-Kindi SG, Yaqoob Z, et al. Place of Death and Hospice Utilization Among Patients Who Die From Cirrhosis in the United States. *Clin Gastroenterol Hepatol* 2018;16:142-3.
19. Salpeter SR, Luo EJ, Malter DS, et al. Systematic review of noncancer presentations with a median survival of 6 months or less. *Am J Med* 2012;125:512.e1-6.
20. Lupu D, Quigley L, Mehfood N, et al. The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up? *J Pain Symptom Manage* 2018;55:1216-23.

Cite this article as: Kim BK. How to deliver palliative care for patients with management in decompensated cirrhosis. *HepatoBiliary Surg Nutr* 2023;12(4):576-579. doi: 10.21037/hbsn-23-222