

Palliative Needs of Patients with Decompensated Cirrhosis Being Considered for Liver Transplantation

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Background

- Palliative care (PC) is interdisciplinary care that *anticipates, prevents, and manages* physical, psychological, social, and spiritual issues in patients with serious illness and their families¹
- PC improves quality of life in patients with serious illness²
- Interviews with patients with decompensated cirrhosis (DC) show they have limited knowledge of PC despite facing various quality of life challenges²
- Patients with DC face fatigue, abdominal pain, confusion and depression from hepatic encephalopathy, mobility issues due to ascites³

Objective

- To identify the unmet palliative needs of DC patients at liver transplant (LT) centers

Methods

- **Study design:** qualitative; data collection method: in-person, semi-structured interviews, July 2017 – May 2018
- **Setting:** three high-volume LT centers in Los Angeles
- **Participants:** *Patients (N=30):* 1) adults, 2) history of DC (cirrhosis of the liver, complication of portal hypertension, history of a Model of End-Stage Liver Disease-Sodium [MELD-Na] score ≥ 15); 3) English-speaking, 4) no overt encephalopathy (West Haven < 3), 5) no history of hepatocellular carcinoma (HCC)
- **Liver Transplant Status:** too early to be considered for transplant (N=10), evaluated for liver transplant (N=9), listed for transplant (N=11)
- **Analysis:** a combination of coding, analytic memos, and iterative discussions with team members to discuss themes

Major Themes and Representative Quotes

1. Poor Quality of Life Most Impacted by Physical Symptoms and Caregiver Burden

“My whole life has been changed. Whatever I could do before, I can't do. **I need a care giver.** I just can't do the things I want to do. I can't eat what I want to eat. **It's hard for me to even get dressed.** I have to have a care giver with me all the time.” (*Evaluated for LT*)

2. Physical Symptoms Largely Prioritized During Healthcare Encounters

“No, **I really don't talk about the quality of life.** [The doctor] just says, ‘What's ailing you?’ I give her the lowdown, and then she goes, ‘Oh, let's try this. Go see this guy. I'll make an appointment for you to see this guy.’” (*Too early for LT*)

3. Active Mental Health and Spiritual Needs Addressed Outside of Hepatology Visits

“I talk to **my sister.** She brought **my Priest from my church** over in the hospital. So, there we prayed, and he gave me a communion. And anyway, I felt better after he left.” (*Listed for LT*)

“**My family, my brother,** they don't really understand what autoimmune hepatitis is. But they're there to provide **emotional support.** My close friends who I work with and see on a regular basis, they also know about my condition. And they're very supportive...” (*Listed for LT*)

4. Patients Without Active Palliative Needs Would Be Comfortable Addressing Issues with Hepatologists

“I'd be comfortable going to [my primary care provider] and I'd be comfortable going to [my hepatologist]. I feel that we come a ways now that I do have a relationship with him and that he is very knowledgeable. It's like **I just want to go to the right person** for that recommendation versus having it be a guessing game.” (*Too early for LT*)

5. Limited Time and Priority as Major Barriers

“I feel like for healthcare providers **there is certain amount of time** that is allotted for patient care. So we really try to get to the core of things of like, what are your physical elements?... There is like sense of boundaries... and then **how personal you want to become** with a patient in that essence and all that. Also, **that requires time.** I feel like I always goes back to the idea of time.” (*Too early for LT*)

Conclusions

- DC patients face many palliative needs that are variably addressed by hepatology teams, with physical symptoms being the biggest priority in physician visits
- Patients without active needs are comfortable talking about these issues with their physicians but have limited time to address these needs
- Hepatology teams should focus on comprehensive assessments of palliative needs and develop systems to deliver palliative care
- Future plans include analyzing provider interviews to identify what they see as palliative care needs in their patients

Citations

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