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The Transition to End-of-Life Care in End-stage Liver Disease

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Abstract and Introduction

Abstract

In the United States, end-stage liver disease (ESLD) is the 12th leading cause of death and the 7th leading cause of death in people between the ages of 25 and 64 years. Complications of ESLD such as ascites, variceal hemorrhage, hepatic encephalopathy, and renal impairment primarily account for these deaths. Patients with ESLD require increasingly complex medical support and manifest a spectrum of complications and symptoms that have significant impact on both survival and quality of life.

Introduction

Because of the possibility of liver transplantation, patients with ESLD are more likely to receive aggressive care despite constant declining poor health. In current practice, discussions and referrals to palliative or hospice care are not done until the hope of recovery is diminished, which is often in the last weeks of life. There is little literature on the appropriate palliative care approach for those with ESLD. The purpose of this article is to summarize the transitions often experienced by patients with ESLD as they approach end-of-life, compare and contrast these transitions to other life limiting illnesses, and review current palliative care strategies recommended for ESLD.

Cirrhosis is a final common endpoint in patients with chronic progressive liver disease from a variety of etiologies. Patients who have abnormalities of liver synthetic and excretory function and who develop ascites, variceal hemorrhage, hepatic encephalopathy, or renal impairment are considered to have end-stage liver disease (ESLD). Liver transplantation is a valid treatment option for ESLD; however, with increased waiting times for organ transplantation, approximately 17% of listed patients die annually while waiting for transplantation, and many other patients with ESLD are not candidates for liver transplantation.[1] Patients with ESLD are generally managed in the community and face a variety of symptoms and disease-related complications, which affect survival and health-related quality of life.

The purpose of this article is to discuss the symptom burden of patients with ESLD, describe how symptoms affect the transitions patients experience as they near the end-of-life (EOL), compare and contrast these transitions to other life limiting illnesses, and review current palliative care strategies recommended for ESLD. Palliative care for patients with ESLD is often poor, in part because of inadequate communication between patients and their providers, lack of criteria to help clinicians determine which patients would benefit from EOL conversations, and the lack of clear understanding of the contribution of common psychosocial issues and their effects on successful implementation of palliative care strategies. Further research is needed in these areas to improve EOL care for these patients.

Symptom Burden

Globally, chronic liver disease accounts for approximately 600 000 deaths annually, with an additional 610 000 deaths annually from hepatobiliary cancer.[2] In the United States, chronic liver disease is the 12th leading cause of death and the 7th leading cause of death in people between the ages of 25 and 64 years.[3,4] Complications of ESLD, such as ascites, variceal hemorrhage, hepatic encephalopathy, hepatocellular carcinoma, and renal impairment, primarily account for these deaths, with an estimated survival from onset of complications of 6 to 24 months.[5]

Health-related quality of life (HRQOL) is a key outcome in the evaluation of many therapeutic interventions in chronic illnesses. For many patients with chronic life-limiting illness, HRQOL is more important than length of life.[6] Each of the complications of ESLD has been shown to reduce HRQOL to the point of being disabling, by increasing malaise and illness awareness. Numerous non–life-threatening physical and psychosocial symptoms such as muscle wasting and cachexia, pruritis, fatigue, muscle cramps, insomnia, pain, depression, anxiety, fear, and greater dependence on others have also been reported to have significant impact on HRQOL in this population.[7]

The daily symptom burden in other end-stage chronic organ failure diseases such as advanced congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD) are high, with the most frequently reported symptoms being fatigue, dyspnea, insomnia, and pain.[8] When compared with ESLD, the amount and burden of physical symptoms are similar, but those with ESLD report higher levels of mental health functional impairment.[9] It is unclear why patients with ESLD report higher

levels of mental health functional impairment. It may be that patients with ESLD have more cognitive impairment from hepatic encephalopathy; more social and family distress associated with the illness; or more comorbid conditions such as substance abuse, depression, and anxiety.[8,10] Therefore, it is very important that the nurse's assessment encompass both physical, mental health, and social support quality of life components.

EOL Transitions

The trajectories of functional decline in those diseases that commonly cause end organ failure such as COPD, CHF, and ESLD are similar in that they tend to be longer and more erratic with a constant state of poor and declining health that is interspersed with intermittent exacerbations requiring hospitalization. Death is often relatively sudden and unpredictable, generally arising from complications of the underlying disease.[11,12] Health care delivery is often reactive rather than proactive and is often initiated in response to acute exacerbations rather than based on a proactive plan of care,[13] which further contributes to poor quality care. Patients with ESLD often pursue curative efforts until the EOL, and palliative care and or hospice is frequently not provided or even suggested until the hope of recovery or transplantation is extinguished, which is often in the last weeks of life.[14]

In an attempt to guide treatment decisions and more accurately predict long-term outcomes in ESLD, many classification schemes have been developed for clinical use. The 2 most common indices are the Child-Turcotte-Pugh (CTP) classification and the Model for End Stage Liver Disease (MELD). The CTP classification has been used widely for many years and was originally developed as a prognostic tool for determining operative risk for patients undergoing portosystemic shunt surgery.[15] It is composed of 5 clinical variables: ascites, encephalopathy, serum bilirubin, serum albumin, and prothrombin time, and classifies patients as A, equating to a 90% chance of 5-year survival; B, equating to an 80% chance of 5-year survival; and C, equating to a median survival of about 1 year. There are problems with this classification system because some of these indices are subjective assessments and some are influenced by arbitrary cutoffs. In addition, CTP does not account for renal dysfunction, which has been shown to have prognostic importance in patients with ESLD. Despite these problems, it is useful clinically in that it can provide rapid risk assessment, easily calculated at the bedside, and has been found to correlate with HRQOL.[16]

The MELD classification was developed in 2001 and was also designed to predict 90-day mortality in those undergoing portosystemic shunts. It has since been adopted by the United Network for Organ Sharing to determine priorities for allocating donor livers and has been used to determine prognosis of groups of patients with chronic liver disease.[17] It is composed of 4 variables: serum bilirubin, creatinine, International Normalized Ratio for prothrombin time, and presence or absence of kidney dialysis. The MELD classification has improved ability to predict 90-day mortality risk but is not without limitations. Clinical markers such as ascites or varices that represent portal hypertension are excluded from the model. Patients with portal hypertension are often at higher risk of short-term death compared with those without portal hypertension and similar MELD scores. In addition, the longitudinal ability of MELD to predict survival accurately beyond 3 months is uncertain,[5] and MELD has not been found to correlate well with HRQOL. A study in ambulatory adult patients with ESLD, looking at correlations between MELD and HRQOL, found that even despite low mean MELD scores of 12 (mortality rate of 6% at 3 months), 70% reported their liver disease symptoms moderate to severe and disabling.[17]

Accurate estimates of risk of mortality are important in determining timing of care interventions. Current classifications do not clearly align with patients' reported functional status and sense of well-being and, alone, are not useful in determining individual risk or timing for initiation of palliative or EOL care. However, functional status and ability to manage daily activities are especially important measures in assessing and discussing desired patient-centered outcomes that extend beyond physiological measures and, along with MELD and CTP, should be incorporated into nursing clinical practice.

Communicating Prognosis

End of life is often considered the final stage of life, although the precise time of transition to EOL is not clear. Palliative care, however, should be initiated in all patients with a serious or life-threatening illness even if patients are still pursuing curative care such as liver transplantation. Palliative care is focused on improving quality of life, reducing symptoms, and relieving distress and incorporates both patients and their family; this is discussed in more detail below. Because of variability in functional decline and pursuit of curative therapies, palliative care should be incorporated into the care of all patients with ESLD.

The Study to Understand Prognosis and Preferences for Outcome and Risk of Treatment enrolled seriously ill, hospitalized patients with 1 of 9 life-limiting illnesses, including ESLD. In those with ESLD, more aggressive therapy choices were made by both patients and providers, largely because of the potential availability of liver transplantation.[11] Challenges in prognostication and uncertainty are not distinct to ESLD; efforts to identify disease-specific prognostic models in similar trajectory diseases such as COPD and CHF have also presented challenges in predicting short-term survival.[18] Uncertainty plays a prominent role for both health care providers and patients when discussing prognosis and EOL care. In addition to causing confusion about the timing and nature of interventions, uncertainty has been shown to be associated with decreased quality of life and poorer coping with symptoms in patients. A recent study looking at uncertainty in women with primary biliary cirrhosis waiting for liver transplant found that 4 variables were associated with uncertainty: depression, fatigue, fear/anxiety, and satisfaction with information.[19]

It is not surprising that with so much uncertainty, the timing of discussions about EOL issues continues to be confusing. There has been growing evidence that communication about EOL care should occur early in the course of many chronic life-limiting illnesses to facilitate high-quality care and easier transition for patients and their families.[14] This communication should include open-ended questions, neutral topic introductions, specific phrasing, focused listening, solicitation of patient goals and values, and clarification of strategies. In addition, nurses need to be willing to provide their patients with the level of information they desire and pay greater attention to the individual psychological and physical qualities that seem to contribute most to uncertainty.[20] Nurses can play a particularly important role not only both in terms of answering questions from patients and families and encouraging patients and families to discuss these issues but also in encouraging and supporting communication between patients and their physicians or nurse practitioners.[21] It is the responsibility of nurses to ensure that their patients are informed about EOL issues and that patients and their families receive the type of care they desire.

Decisional Capacity in ESLD

In addition to the challenges that uncertainty poses on treatment decisions and EOL transitions discussed above, patients with ESLD often have hepatic encephalopathy, which causes cognitive impairment and can require a surrogate to assume or assist with decision-making responsibilities. Surrogates often report a great deal of stress associated with decision-making responsibilities. Individuals often have difficulty predicting what they or their loved one wants in future circumstances because these predictions may not reflect their future medical, emotional, or social context. In addition, preferences and values can change when health status changes.[22] Surrogate decision makers not only express similar difficulties with future prediction but also report that uncertainty about patient's values, beliefs, or preferences in the context of decisions that must be made under time pressure contribute to higher levels of stress and increased burden.[23]

A systematic review of accuracy of surrogate decision making concluded that surrogates incorrectly predict patient's treatment preferences in one-third of cases.[24] Prespecifying preferences or treatments is the current strategy used to articulate care preference in life-limiting illnesses; however, these may be too broad to extrapolate precisely to specific clinical situations, and this can be particularly true in ESLD, where the clinical course is often unpredictable. If surrogates are making decisions based on patient preferences, they may be influenced by their own hopes, desires, needs, and current context to inform their decisions, which may contradict patient's prespecified wishes.[22] Patients vary as to how much leeway they would want to give their surrogates for using their own values or concerns, and this should be discussed in advance. Given these problems with prespecified preferences, an alternative approach that has been suggested as an objective in advance care planning is focusing on preparing patients and surrogates to participate with the clinical team in making the best possible in-the-moment decision. This process involves 3 key steps: choosing an appropriate surrogate decision maker, clarifying and articulating patients' values over time, and establishing the acceptable leeway in surrogate decision making. This preparation of patients and surrogates ensures that complex health care decisions are based on a comprehensive set of considerations, such as clinical context, shifting and evolving goals, and patient and surrogate needs.[23]

The health care team cannot make high-quality in-the-moment recommendations or offer guidance without incorporating patients' and surrogates' needs and values, which can only be provided by them. There is limited research specifically looking at decision making and EOL issues in ESLD. Given the uncertainty, erratic trajectory of functional decline, and potential mortality and morbidity of complications associated with ESLD, this approach seems promising in aiding early and ongoing advance care planning in ESLD and improving patient-centered outcomes and, thus, quality of care. Nurses can play an important role in raising questions about patients' values and goals of care and facilitating advance care planning with other clinicians.

Palliative Care Strategies and Hospice

Hospice eligibility requires that patients have a prognosis for survival of less than 6 months and historically has not been thought of as being compatible with pursuing curative treatment. More recently, palliative care has presented itself as a viable option in bridging this gap. The National Consensus Project for Quality Palliative Care[25] states that palliative care is interdisciplinary, with a focus on care of providing optimal functioning, relief of suffering, and support of optimal quality of life for patients and their families regardless of the stage of disease or need for other therapies. This is operationalized by effectively managing distressing symptoms, supporting the patient and family with psychosocial, spiritual, belief, cultural, or value concerns and preferences, including those with life-threatening or debilitating illness.

National clinical guidelines for CHF and COPD include language regarding ongoing discussions about prognosis, advance directives, palliative care, and hospice but do not specifically address when to refer patients for hospice or palliative care.[19] National clinical guidelines for ESLD do not discuss either of these issues. In a review of clinical guidelines for EOL content in chronic kidney disease, ESLD, COPD, and CHF, guidelines for ESLD were the only ones that failed to identify clinical or psychosocial criteria that should lead providers to think about, evaluate, or discuss palliative care or hospice.[26]

In both COPD and CHF, profiles have been identified that suggest types of patients who are at high risk of mortality or morbidity in the next 6 months in whom discussions about EOL issues would be especially important.[14,19] It has been suggested in the transplant literature that the optimal time to discuss EOL care and advance care planning is when patients are listed for transplantation[27] and that a referral for hospice should be made when MELD scores reach 17.[15] However, on the basis of

HRQOL data and clinical experience, we know that patients with ESLD experience a significant amount of physical and psychological functional impairment and adverse effects of complications long before that time. For many patients, waiting until the MELD score reaches 17 would be too late for meaningful discussions about EOL issues and palliative care. In addition, this approach fails to address those patients who do not desire or are ineligible for transplantation. Profiling patients with ESLD with whom discussions about treatment preferences or end-of life care is important would be clinically useful and an area for further research. This profile could include anyone with a CTP score of B or greater; a MELD score of 6 or greater; a complication from liver disease such as ascites, varices, or hepatic encephalopathy; 1 or more hospitalization in the last 6 months for a liver-related complication; severe muscle wasting and cachexia; decreased functional status; or increased dependence on others. Presence of any 1 of these prognostic indicators should be cause for discussions about EOL issues and assessment of unmet palliative care needs. Multiple criteria would increase the relevance and urgency for these discussions. Based on what we know from data in COPD, these discussions are less stressful when patients are feeling relatively well, and having these discussions early in the trajectory of disease will make it easier to return to these discussions at a later time if needed.[28,29] Discussion of patient preferences for EOL in ESLD should be ongoing with patients and their family/caregiver, provide current updates and information, and include wishes for CPR, intubation with mechanical ventilation, invasive medical procedures such as endoscopy, and whether hospitalization for unstable illness is desired. It should also include discussions of how long the patient might live, what the trajectory might be like, and what dying might be like. The health care providers should also validate a person's wishes for through written orders and advance directives[5] that are accessible to health care providers in all settings ().

Table. Palliative Care Strategies for End-Stage Liver Disease (ESLD)

Key Points in ESLD	Palliative Care Strategies
At diagnosis of cirrhosis	Timely and effective patient and family education
▪	Pattern of symptom progression
▪	Strategies for improving functional capacity
▪	Liver health-promotion strategies
▪	Initial discussion of benefits, risks, and feasibility of liver transplantation
Development of multimorbidities such as varices, encephalopathy, hepatocellular carcinoma, ascites, and kidney dysfunction	Education and communication regarding advance care planning
▪	Formulating goals of care
▪	Identifying health care proxies or surrogates
▪	Implementing advance directives
Disease progression	Continuity of care
▪	Communication between inpatient and outpatient providers
▪	Continuity around patient's goals of care
▪	Thoughtful planning regarding interventions
▪	Plans for managing progressive deterioration and episodes of acute decompensation
▪	Documentation of advance care planning and advance directives, making this information accessible to all providers, patients, and their proxies or surrogates
Increasing symptom burden	ESLD-specific approaches to symptom management
▪	Mild pain—limited to no more than acetaminophen 1 g daily
▪	Mild to severe pain—low-dose opioids; hydromorphone, oxycodone, or fentanyl
▪	Itching—rule out biliary obstruction and treat if bothersome: cholestyramine, colestipol, naloxone for medical anagement
▪	Ascites—oral diuretic therapy with/without therapeutic paracentesis with consideration of transjugular intrahepatic portosystemic shunt or indwelling catheters.
▪	Hepatic encephalopathy—lactulose and rifaximin to control

	symptoms
▫	Functional limitations—Involve occupational and physical therapy to maximize functional ability. Caregiver support services and groups

Primary palliative care should be provided by all clinicians who care for patients with ESLD and represents incorporating the principles of palliative care into routine care. Referral to a palliative care specialist or palliative care team should be considered when primary palliative care is not able to control symptoms and adequately address quality of life and distress for patients or their families.

Case Presentation

Mr B is a 47-year-old white man with ESLD secondary to hepatitis C most likely acquired from a blood transfusion in the 1970s. He has a remote history of alcohol abuse but none in the last 15 years. He presented with an episode of upper gastrointestinal (GI) bleeding from esophageal varices requiring banding and intensive care unit admission. During his admission, he developed ascites and was started on diuretics. This was his first complication from his liver disease. He had been told several years before that he had cirrhosis but never had any medical follow-up for this. He has no other comorbidities. His MELD score is 14, and he has Child B cirrhosis on this presentation. Mr B works doing various mechanic jobs, lives alone in an recreation vehicle on a friend's property, and has a sister that he is close with and is supportive. She has a teenage son, works full-time, and lives about 40 minutes away. His varices are managed with serial banding and β-blockade. After discussion of curative options as well as disease progression and trajectory, the patient wants to pursue transplant evaluation. Over the next few months Mr B, with the help of his sister, actively pursues the requirements for liver transplant listing. During this time, however, Mr. B experiences another episode of upper GI bleeding requiring hospitalization and a severe tibia fracture requiring surgery twice, with several months of external fixation. After these events, he has a worsening of his underlying liver disease and is now has Child C cirrhosis with a MELD score of 17, suggesting a median survival of 1 year and 3-month mortality of about 6%. He has developed significant ascites, which, over time, became refractory to diuretics, and leaks ascitic fluid from a large umbilical hernia. He is now requiring weekly to biweekly paracentesis for comfort management. A transjugular intrahepatic portosystemic shunt to reduce portal hypertension is being considered for long-term management of GI bleeding and refractory ascites, but with risk of further decompensation of liver function and possible death with this procedure, his decision to either pursue or forego transplantation becomes imperative. Mr B states he wants to finish evaluation, but as the urgency for transplant listing becomes greater, the increasing functional decline, depression, and health demands experienced by Mr B make managing multiple appointments very difficult and he begins to miss or cancel appointments more frequently, further delaying the process and care decisions. At this time, he is referred for palliative care evaluation, which is able to focus on maximizing his quality of life and avoiding burdensome treatments that he does not desire.

Conclusion

In summary, palliative care is an important piece in the treatment of patients with ESLD. There is a dearth of research regarding palliative and EOL care issues in patients with ESLD; however, there is strong evidence in other chronic life-limiting illnesses that these patients receive poor quality palliative care compared with patients with cancer.[30] For health care providers caring for ESLD patients, there has been a reluctance to discuss or refer patients to palliative care or hospice until the hope of recovery is diminished, which is often in the last weeks of life.[15] This suggests that inadequate communication and poor understanding of palliative care and EOL care issues in ESLD are contributing to poor quality care. Understanding how clinicians, patients, and their caregivers perceive communication about palliative care and EOL issues in this population is important to improve quality of care.[14] Furthermore, understanding the impact of psychosocial issues such as family/caregiver burden, depression, fear, anxiety, and substance abuse on symptom burden, transition, decision making, and interdisciplinary communication would be important in addressing palliative care and EOL issues in ESLD. Studies are needed to guide the development of interventions that are geared toward identifying profiles that would most benefit from palliative care and from EOL discussions, improving the quality of surrogate decision making, uncertainty management, and aiding in early and ongoing advance care planning. The number of patients with ESLD who need to be managed without liver transplantation will continue to increase in the future, largely as a result of the increasing age of the population and the shortage of available organs. Patients with ESLD are subject to many physical and psychosocial symptoms that negatively affect HRQOL. Pursuing curative treatments and discussions about EOL and use of palliative care are not mutually exclusive. Discussions about palliative care and EOL issues should be initiated early, preferably in the outpatient setting before an acute deterioration, and palliative care and hospice services should be explored and supported by all members of the health care team.

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