End-of-Life Communication in End-Stage Liver Disease: Three Empirical Studies

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Abstract

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There is very little literature on palliative approaches to end-of life care discussions in those with chronic life limiting liver disease. Studies in other life limiting chronic illnesses have shown that patients rarely discuss end- of- life care preferences with their health care providers in spite of the desire to do so, suggesting poor quality of communication.

There are effective and dynamic systems of palliative care that ensure that the final illness of a patient will be of the highest quality possible. Establishing these systems of palliative care has in part been based on studies that have measured quality of communication after a specific intervention or treatment. But in order to evaluate the quality of communication after an intervention or treatment, a baseline understanding of patient needs and expectations is needed.

The three empirical papers that are the core of this dissertation address the needs and expectations of patients by describing the transition to end-of-life and timing of care in end-stage liver disease, along with an exploring end-of- life communication preferences, and the barriers to

and facilitators to patient- provider communication about end-of-life issues. These studies suggest practical guidance to health care providers about timing and approach to end-of life discussions, identify patient barriers and facilitators to discussions of end-of life care issues, and identify future targets for interventions aimed at improving the quality of communication.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Figure Number Page

CHAPTER ONE

INTRODUCTION

My interest in end-of-life care issues grew out of my own professional experiences as a nurse practitioner caring for patients with end-stage liver disease. In recent years, I have spent a growing amount of time managing both symptoms of advanced liver disease and the complications such as portal hypertension, hepatic encephalopathy, and hepatocellular carcinoma. The response in the hepatology community to these increased clinical challenges and demands has been to refine hepatic transplantation and improve interventional radiology strategies. Both hepatic transplantation and radiologic hepatocellular carcinoma therapies have transformed the prognosis in many patients with end-stage liver disease; however, in spite of these advances there still remain numerous cohorts of patients that will not be able to pursue or benefit from these therapies.

I often reflect back on cases that I have encountered in my career, in which I could have done things better. One case that stands out in my mind is a patient that was clearly within weeks of the end of his life and required hospitalization. He would not give up his hope for transplantation and life saving measures in spite of not even being listed for transplant at that point, after years of trying. This particular situation was further complicated by the involvement of family surrogate decision makers from which I later discovered the patient himself had been quite detached from for many years. Their wishes were different from what the patient was expressing, however due to severe hepatic encephalopathy he was not felt by the medical team to be reliable enough to make his own decisions. I can see now that my own ineptness with my understanding of my patient's needs, his uncertainty, and perhaps fear was in part responsible for his undesirable course and poor quality care. I never discussed end-of –life issues with this patient because I fell into an old paradigm. I never felt that I could tell him for "certain" when he

might die, and because I worried that if I brought up the topic of death he would lose all hope since he was devoted to that transplant. I never discussed it at all.

The literature tells us that people are different in their needs and hopes for prognostic information and that the fear of being uncertain often causes confusion about timing and nature of interventions (Lasker, Sogolow, Olenik, Sass, & Weinrieb, 2010). There is no clear way to deliver poor prognostic information; therefore, health providers need to depend on their intuition and the dynamics of their patient provider relationship to help determine the best method for which to deliver prognostic information and maintain hope (Curtis, Engelberg, Young, Vig, Reinke, & Wenrich, 2008). I realize now that being "certain" about the exact timing of one's death is far less important than being willing to provide the level of information that patients desire, and pay greater attention to individual psychological and physical qualities that contribute most to one's uncertainty (Lasker, et al., 2010).

A recurrent theme throughout these dissertation studies is the high symptom burden experienced by those with end-stage liver disease contributing to greater dependence on others, and also often creating a greater need for surrogate decision makers. This poses another level of complexity to discussing end-of-life issues in that individuals often have difficulty predicting what they want in future circumstances, especially in the context of health status changes. Surrogate decision makers have similar difficulties, but also have the influences of their own hopes, desires, and needs, that they use to inform their decisions which can cause conflicts if not discussed or agreed upon in advance. Our goal as health providers should be to help the patient and caregivers face the crisis together in order to achieve acceptance to the final reality simultaneously, however, this cannot be achieved unless healthcare providers and their patients and surrogates are willing to have open discussions about end-of- life care issues.

Within the three chapters that follow, there are two findings that diverge. There is ambivalence in those with end-stage liver disease to initiate discussions about end-of-life care preferences; however, they do not mind having the discussions if their health provider initiates it. Currently, these discussions are rarely occurring. Chapter two of this dissertation discusses the transition to end-of-life in end-stage liver disease. In particular this paper describes the symptom burden of patients with end-stage liver disease, how these symptoms affect the transition to end-of life care, and compares and contrasts the transition in end-stage liver disease to other end organ life limiting illnesses. It goes on to review current palliative care strategies for end-stage liver disease, and make specific recommendations for timing and strategies in those with end-stage liver disease.

Chapter three reports the results of individual patient interviews, whose aim was to identify the barriers to and facilitators of communication about en-of-life care and to adapt a questionnaire designed to identify barriers to and facilitators of communication about end-of-life care among patients with other chronic life-limiting diseases for use among patients with end-stage liver disease (Curtis & Patrick, 1997; Curtis, Patrick, Caldwell, & Collier, 2000; Knauft, Nielsen, Engelberg, Patrick, & Curtis, 2005). In this study, the barriers and facilitators described in patients with end-stage liver disease were similar to those described by those with other life limiting illnesses. Moreover, patients with end-stage liver disease are unsure of what kind of care they would want, are reluctant to raise the topic of dying, and prefer, in many cases, to focus on hope for continued life rather than on planning for death.

Finally, chapter four reports the results of a cross sectional study in end-stage liver disease patients aimed at identifying patients desire to discuss EOL issues, the most common barriers of and facilitators to end-of-life communication, and explore the frequency and types of barriers

and facilitators endorsed by those with a history of substance abuse and depression which are common co-morbidities in those with liver disease. This study found evidence suggesting that only a small proportion of patients with end-stage liver disease are discussing their care preferences, and endorse a large number of different barriers, again suggesting that health providers need to acknowledge this difficult topic on and individual basis in those with end-stage liver disease and become skilled in discussing this subject with patients that would rather not discuss it.

To my knowledge this is the first study to describe barriers to and facilitators of end-of-life communication in patients with end-stage liver disease. It has shown us that communication about end-of-life issues is clearly lacking in this subset of patients with life limiting chronic illness, and has identified possible targets for future interventions aimed at improving discussion in end-of-life care in this population.

CHAPTER 2

THE TRANSITION TO END-OF-LIFE CARE IN END-STAGE LIVER DISEASE

Introduction

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 (OPTN/SRTR Annual Report, 2009). 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 paper 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, 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 end-of-life 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 account for approximately 600,000 deaths annually with an additional 610,000 deaths annually from hepatobiliary cancer (World Health Organization, 2010). In the United States chronic liver disease is the 12th leading cause of death and the seventh leading cause of death in people between the ages of 25 and 64 (Kung, Hoyert, Xu, & Murphy, 2008; Hoyert, Kung, & Smith, 2005). 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 6-24 months (Sanchez & Talwalkar, 2006).

Health Related Quality of Life (HRQOL) is a key outcome in the evaluation of many therapeutic interventions in chronic illnesses. HRQOL is more important than length of life for many patients with chronic life-limiting illness (McNeil, Weichselbaum, & Pauker,1981). 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 (Marchesini et. al., 2001).

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 (Janssen, Spruit, Wouters, & Schols, 2008). When compared to ESLD, the amount and burden of physical symptoms are similar, but those with ESLD report higher levels of mental health

functional impairment (Younossi, Boparai, Price, Kiwi, McCormick, & Guyatt, 2001). 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 co-morbid conditions such as substance abuse, depression and anxiety (Roth, Lynn, Zhong, Borum, & Dawson, 2000; Janssen, Spruit, Wouters, & Schols, 2008). Therefore, it is very important that the nurse's assessment encompass both physical, mental health, and social support quality of life components.

End of Life 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 (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; Fox, Landrum-McNiff, Zhong, Dawson, Wu, & Lynn, 1999) Healthcare 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 (Curtis, 2008) which further contributes to poor quality care. ESLD patients often pursue curative efforts until the end-of-life (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 (Rossaro, Troppmann, McVicar, Sturges, Fisher, & Meyers, 2004).

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 two

most common indices are the Child-Turcotte- Pugh (CTP) classification and the Model for End Stage Liver Disease (MELD). CTP 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 (Child & Turcotte, 1964). It is comprised of 5 clinical variables; ascites, encephalopathy, serum bilirubin, serum albumin and prothrombin time and classifies patients as A equating a 90% chance of 5 year survival, B equating a 80% chance of 5 year survival and C equating a median survival of about 1year. There are problems with this classification system as some of these indices are subjective assessments; 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. In spite of 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 (Kanwal, Hays, Kilbourne, Dulai, & Gralnek, 2004).

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 (Kamath, Wiesner, Malinchoc, Kremers, Therneau, Kosberg, 2001). It is comprised of 4 variables: serum bilirubin, creatinine, International Normalized Ratio (INR) for the prothrombin time, and presence or absence of kidney dialysis. MELD has improved the 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 to those without portal hypertension and similar MELD scores. In addition, the longitudinal ability of MELD to predict survival accurately beyond 3

months is uncertain (Sanchez & Talwalkar, 2006) 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 (Kamath, Wiesner, Malinchoc, Kremers, Therneau, Kosberg, 2001).

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 end-of-life (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

EOL is often considered the final stage of life, although 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 the patient and their family and 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 end-stage liver disease.

The Study to Understand Prognosis and Preferences for Outcome and Risk of Treatment (SUPPORT) enrolled seriously ill, hospitalized patients, with one of nine 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 (Fox, Landrum-McNiff, Zhong, Dawson, Wu, & Lynn, 1999). Challenges in prognostication and uncertainty are not distinct to ESLD; efforts to identify disease specific prognostic models in similar trajectory diseases like COPD and CHF have also presented challenges in predicting short-term survival (Adler, Goldfinger, Kalman, Park, & Meier, 2009). Uncertainty plays a prominent role for both healthcare providers and patients when discussing prognosis and EOL care. In addition to causing confusion about 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 four variables were associated with uncertainty: depression, fatigue, fear/anxiety, and satisfaction with information (Lasker, Sogolow, Olenik, Sass, & Weinrieb, 2010).

It is not surprising that with so much uncertainty, 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 in order to facilitate high quality care and easier transition for patients and their families (Rossaro, Troppmann, McVicar, Sturges, Fisher, & Meyers, 2004). This communication should include open-ended questions, neutral topic introductions, specific phrasing, focused listening, soliciting patient goals and values, and clarifying 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 appear to contribute most to uncertainty (Pfeifer, Mitchell, & Chamberlain, 2003). Nurses can play a particularly important role 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 (Reinke, Engelberg, Shannon, Wenrich, Vig, Back & Curtis, 2008). 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 End-Stage Liver Disease

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 want 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 (Sudore & Fried, 2012). Surrogate decision-makers 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 (Braun, Beyth, Ford, & McCullough, 2008).

A systematic review of accuracy of surrogate decision making concluded that surrogates incorrectly predict patient's treatment preferences in one-third of cases (Shalowitz, Garrett-Mayer, & Wendler, 2006). Pre-specifying 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 pre-specified wishes (Sudore & Fried, 2012). 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 pre-specified 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 three 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 healthcare decisions are based on a comprehensive set of considerations, such as clinical context, shifting and evolving goals, and patients and surrogates needs (Braun, Beyth, Ford, & McCullough, 2008).

The healthcare 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 states that palliative care is interdisciplinary, with a focus in 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 CKD, 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 (Mast, Salam, Silverman, & Arnold, 2004).

In both COPD and CHF profiles have been identified that suggest types of patients that are at high risk of mortality or morbidity in the next 6 months in whom discussions about EOL issues would be especially important (Curtis, 2008; Adler, et al., 2009). 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 (Wright, Pape, Ross, Campbell, & Bowman, 2007) and that a referral for hospice should be made when MELD scores reach 17 (Rossaro, et al.,

2004). However, based on HRQOL data and clinical experience, we know that patients with ESLD suffer 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 that 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; MELD score of 6 or greater; a complication from liver disease such as ascites, varices, or hepatic encephalopathy; one 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 one 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 a 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 (Curtis, Wenrich, Carline, Shannon, Ambrozy, & Ramsey, 2002; Knauft, Nielsen, Engelberg, Patrick, & Curtis, 2005). Discussion of patient preferences for EOL in ESLD should be ongoing with patients and their family/caregiver, provide current updates and information, 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 like. The health care providers should also validate a person's wishes

for through written orders and advance directives that are accessible to healthcare providers in all settings (Table 2.1).

Table 2.1 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 multi-morbidities such as varices, encephalopathy, hepatocellular carcinoma, ascites, and kidney dysfunction	Education and communication regarding advance care planning: • formulating goals of care • identifying healthcare proxies or surrogates • implementing advance directives
Disease progression	Continuity of care: ●Communication between in-patient and out-patient 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, patient and their proxies or surrogates.
Increasing symptom burden	ESLD specific approaches to symptom management: • Mild pain – limited to no more than acetaminophen 1gm 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 management. • Ascites-oral diuretic therapy w/wo therapeutic paracentesis with consideration of TIPS 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 Caucasian man with ESLD secondary to hepatitis C most likely acquired from a blood transfusion in the 1970's. He has a remote history of alcohol abuse but none in the last 15 years. He presented with an episode of upper GI bleeding from esophageal varices requiring banding and ICU 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 prior that he had cirrhosis, but never had any medical follow up for this. He has no other co-morbidities. His MELD score is 14 and he has Child's B cirrhosis on this presentation. Mr. B works doing various mechanic jobs, lives alone in a RV on a friend's property, he has a sister that he is close with and is supportive. She has a teenage son and works full time lives about 40 minutes away. His varices are managed with serial banding and beta 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 suffers another episode of upper GI bleeding requiring hospitalization, and a severe tibia fracture requiring surgery x 2, with several months of external fixation. After these events he has a worsening of his underlying liver disease and is now a Child's C cirrhotic with a MELD of 17 suggesting a median survival of 1 year and 3 month mortality of about 6%. He has developed

significant ascites that over time becomes refractory to diuretics, and leaks ascitic fluid from a large umbilical hernia. He is now requiring weekly to bi-weekly paracentesis for comfort management. A transjugular intrahepatic portosystemic shunt (TIPS) 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 end of life 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 to patients with cancer (Au, Udris, Fihn, McDonell, & Curtis, 2006). For healthcare 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 (Rossaro, et al., 2004). 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 in order to improve quality of care. 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 development of interventions that are geared towards identifying profiles that would most benefit from palliative care and from EOL discussions, improving quality of surrogate decision making, uncertainty management, and aiding in early and ongoing advance care planning. The number of patients with ESLD that 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.

CHAPTER THREE

END-OF-LIFE COMMUNICATION IN END-STAGE LIVER DISEASE: EXPLORATION OF BARRIERS AND FACILITATORS TO COMMUNICATION

Abstract

Patients with end-stage liver disease and their health providers do not adequately discuss patient preferences for medical care at end-of-life. The objective of this study was to perform a qualitative study using individual patient interviews to identify barriers and facilitators to communication about end-of life care in patients with end-stage liver disease. The sample consisted of 20 adults with end-stage liver disease recruited from and academic and community based setting. Topics addressed during interviews included a review of a currently established barriers and facilitators of communication questionnaire, and identification of any new barriers or facilitators that may be present in those with end-stage liver disease. Results found that health providers of those with end-stage liver disease do not readily initiate end-of-life conversations, and even though patients are willing to discuss end-of life care preferences, they will not initiate these conversations with their providers. This study suggests that there may be some deficits in patient-provider communication, and in patient self- efficacy skills in discussing end-of life preferences. Further investigation is needed to delineate these barriers and facilitators for possible use as targets for future interventions.

Introduction

End-stage liver disease (ESLD) is the final phase of the disease trajectory for people who suffer from cirrhosis of the liver. Life-threatening complications such as variceal hemorrhage or hepatoma combined with debilitating symptoms such as ascites, encephalopathy, muscle wasting and cachexia, pruritis, fatigue, muscle cramps, insomnia, pain, depression, anxiety, fear, and greater dependence on others have significant impact on the quality of life of people who suffer from ESLD (Marchesini et al., 2001). Moreover, there is a tremendous socioeconomic, financial, and personal burden placed on the caregivers and families of people who suffer from ESLD (Bajaj et al., 2011). Although ESLD is the 12th leading cause of death in the United States (Kung, Hoyert, Xu, & Murphy, 2008), and the seventh leading cause of death in those between the ages of 25 and 64 (Hoyert, Kung, & Smith, 2005), there is a dearth of literature addressing end-of-life (EOL) care preferences for people with ESLD. In practice, health care providers have been reluctant to discuss or refer patients with liver disease to palliative care or hospice until the hope of recovery is very diminished, often in the last weeks of life (Rossaro et al., 2004). Many ESLD patients are cared for by liver specialists whose primary focus is on therapeutic management, which may limit their consideration of psychosocial needs. This situation may result in patients receiving more aggressive care in spite of constantly declining poor health, particularly when liver transplantation is being considered (Roth, Lynn, Zhong, Borum, & Dawson, 2000). It may be that inadequate communication and poor understanding of EOL care issues in ESLD between health care providers, patients and their families contribute to poor-quality EOL care. Understanding how ESLD patients, their caregivers, and their health care providers perceive communication around EOL issues would be important in order to improve quality of care (Curtis, 2008).

In studies of patients with other life-limiting illnesses such as heart failure (HF) and chronic obstructive pulmonary disease (COPD), several patient barriers to EOL care communication have been identified. These include (a) lack of continuity of care providers, (b) fear or anxiety of making others uncomfortable, (c) inability to initiate EOL conversations in spite of desire to do so, (d) uncertainty related to the future, and (e) personal readiness for information (Barnes et al., 2012). It is unknown whether patients with ESLD share these same barriers to communication. Looking at barriers to and facilitators of this type of communication for patients with ESLD is the first step in helping provide some insight into perspectives, feelings, and values that can help guide EOL conversations, while still maintaining hope for curative treatments such as liver transplantation (Braithwaite et al., 2011).

Theoretical Model

Social cognitive theory (SCT) posits that human functioning is influenced by behavioral, cognitive, and personal factors, which in turn are influenced by the environment. According to SCT, human health-related behavior is determined by a dynamic reciprocal interaction between persons and their environments. Within the construct of SCT, behavior is influenced by psychosocial factors (e.g., social support, hospital or community setting), cognitive factors (e.g., information needs or knowledge), and personal factors (e.g., self-regulatory capacity, past experience, social/family history, reflexivity) (Bandura, 1986). With EOL issues, self-efficacy or the beliefs that patients and families have about their capabilities, sense of control, and ability to cope with advanced illness and dying are critical determinants of the goals they pursue (Larson & Tobin, 2000), and enhancing self-efficacy is an area of ongoing research. Studies using the SCT framework in EOL care have looked at changing or augmenting behaviors around surrogate decision making (Purvis, 2006), provider communication (Treece, et al., 2006), and completion

of advance care directives (Fried, Bullock, Iannone, & O'Leary, 2009) with varying degrees of success. The varied findings from using SCT to study EOL care may be attributed to difficulty in understanding what the meaningful outcomes are, ability to overcome communication barriers, and readiness within the complex relationship network for quality EOL care. Because ESLD patients experience uncertainty, high symptom burden, and increased dependence on family members and friends, these patients have a greater dependence on their relationship network to guide responses and behaviors. This factor supports the usefulness and relevancy of SCT as a framework; however, understanding communication barriers, readiness factors, and translation to meaningful outcomes in this population needs to be further characterized in order to guide future interventions (Figure 1).

The purpose of this study was twofold: (a) to identify the barriers to and facilitators of communication about EOL care in patients with ESLD, and (b) to adapt a questionnaire designed to identify barriers to and facilitators of communication about EOL care among patients with other chronic, life-limiting diseases (Curtis & Patrick, 1997; Curtis, Patrick, Caldwell, & Collier, 2000; Knauft, Nielsen, Engelberg, Patrick, & Curtis, 2005) for use among patients with ESLD.

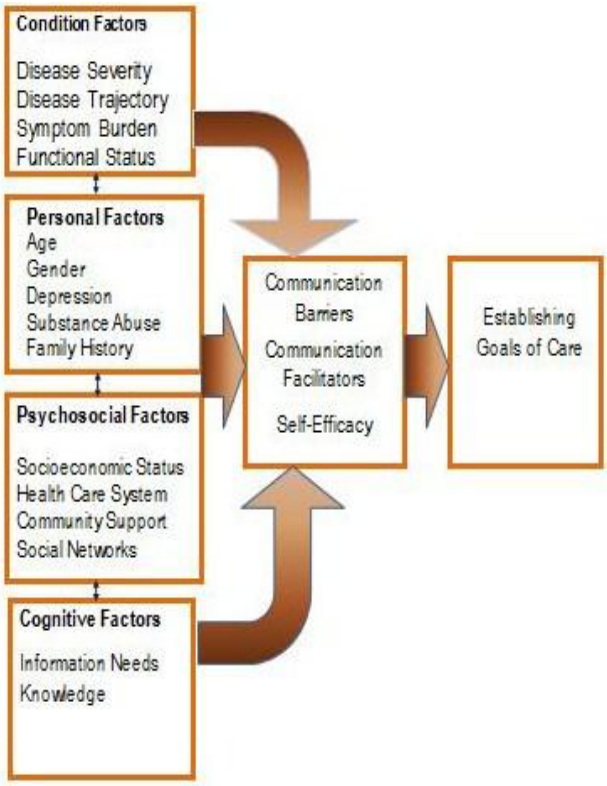

Figure 3.1. Social cognitive theoretical model for end-of-life communication readiness in end-stage liver disease.

Methods

Setting and Participants

Patients were eligible for study participation if they met the following inclusion criteria: (a) diagnosis of cirrhosis from chronic liver disease with a Model for End Stage Liver Disease (MELD) (Kamath et al., 2001) score between 6 and 40, (b) English fluency, and (c) outpatient status at time of interview. Patients with significant hepatic encephalopathy as determined by their health care provider were not entered in the study. All patients were identified from one of two hepatic disease clinics affiliated with the University of Washington including a university referral clinic and a county hospital clinic between May 2012 and August 2012. The researchers used purposive sampling to identify patients who had well-established ESLD, variable MELD scores, and to establish equal representation of patients who were listed and not listed for liver transplantation.

Procedures

Potential participants were introduced to the study by a member of their health care team at a routine clinic visit. Interested patients gave permission to be contacted by the principal investigator to receive additional information about the study, provide informed consent, and set up an interview appointment. Written, informed consent was obtained prior to any study procedures. This study was approved by the Institutional Review Board of the University of Washington.

The barriers and facilitators questionnaire was originally developed from focus groups and validated in patients with Acquired Immune Deficiency Syndrome (AIDS) (Curtis & Patrick, 1997; Curtis, Patrick, Caldwell, & Collier, 2000) and COPD (Knauft et al., 2005). To validate

and adapt this questionnaire for patients with ESLD, the researchers conducted single in-person interviews with 20 participants with ESLD. Interviews were conducted and digitally recorded by the principal investigator or a trained research assistant in a private room at one of the two participating clinics, based on participant convenience. Interviews took 40–60 minutes. Participants read or were read the 26 previously identified barriers to and facilitators of communication and were asked to state whether the statements applied or did not apply to them. If a barrier to communication was positively identified as applicable, then the participant was asked if this barrier made it harder or not harder for them to discuss their care preferences with their providers. Conversely, if a facilitator of communication was positively identified as applying, the participant was asked if this facilitator helped or did not help them to discuss their care preferences with their providers. During the interviews, participants were asked probing questions to (a) encourage elaboration, (b) obtain descriptions of how a barrier or facilitator might or might not have relevance to them, and (c) add clarity to an item.

The sample size in this study was determined by redundancy and saturation of data (Polit & Beck, 2008). Data collection stopped when all existing barriers and facilitators in the questionnaire were well developed and no new relevant data emerged from the interviews. Investigators reviewed the data by listening to digital recordings and reviewing the field notes and memos that were written following each interview.

Data Analysis

This study used a directed content analysis approach (Hsieh & Shannon, 2005). Given prior research using the barriers and facilitators questionnaire, the interview coding for barriers and facilitators began immediately. Each interview was listened to by the principal investigator

upon completion and comments were grouped by the individual barriers and facilitators. If any participant commented about the relevancy of an item (barrier or facilitator), then the item was retained. If all participants endorsed the lack of relevance of an item, then the item was deleted from the questionnaire. If a participant identified a new barrier or facilitator not already identified in the existing questionnaire, then all subsequent participants were queried about this barrier or facilitator. If any subsequent participant endorsed this barrier or facilitator, then it was added to the questionnaire.

Rigor was demonstrated by (a) maintaining an audit trail of digital recordings, field notes, and memos; (b) gathering data from a diverse group of participants from two different clinics (including a university referral clinic and a county hospital clinic); (c) using data from the current study and comparing it to previous studies to identify barriers and facilitators for possible modification. The barriers and facilitators were analyzed using descriptive statistics.

Results

Descriptive statistics for barrier items are reported in Table 3.1. The three most common barriers reported were (a) I would rather concentrate on staying alive than talk about death, (b) I don't know what kind of care I want if I get very sick, and (c) I don't like to talk about getting very sick. Several of the participants who endorsed the first statement further elaborated that although they preferred not to talk about death, they also understood the need to be prepared and felt that they would want to be prepared.

Descriptive statistics for facilitator items are reported in Table 3.2. The two facilitators to communication that were least reported were (a) My doctor often asks me about end-of-life care, and (b) My doctor is very good at talking about end-of-life care. One participant, when asked

about the statement My doctor is very good at talking about end-of-life care, responded, “We have never discussed it, and I do not think he is ready to go there either.” Two participants, when asked about the statement “My doctor often asks me about end-of-life care”, responded that they had only been asked about end-of-life care by an unknown person when they were in the hospital.

Table 3.1 Patient-Endorsed Barriers to Communication

Barriers	Applies	Does Not Apply	Do Not Know	No Answer
I would rather concentrate on staying alive than talk about death.	18	2	0	0
I don't know what kind of care I want if I get very sick	11	9	0	0
I don't like to talk about getting very sick.	10	10	0	0
I feel that talking about death can bring death closer.	8	12	0	0
I have a living will, and that means I don't need to talk with my doctor about the care I want if I'm too sick to speak for myself.	8	12	0	0
My ideas about the kind of medical care I want change at different times.	8	8	0	4
I'm not sure which doctor will be taking care of me if I get very sick.	8	11	0	1
I have not been very sick.	6	13	0	1
My doctor doesn't like to talk about me getting very sick.	5	15	0	0
Doctors look down on people who developed liver disease because of drugs and/or alcohol.	4	14	0	2
I'm not ready to talk about the care I want if I get very sick.	3	17	0	0
I worry that talking about getting sick is too depressing for my doctor.	3	16	0	1
My doctor never seems to have the time to talk about issues like end-of-life care.	2	18	0	0
I don't want to make plans for the future.	2	17	0	1
I have concerns about bringing up assisted suicide.	2	17	0	1

Note. N = 20. *Curtis, JR, Patrick, DL, Caldwell, E. & Collier, AC, (2000) Used with permission*

Table 3.2 Patient-Identified Facilitators to Communication

Facilitators	Applies	Does Not Apply	Do Not Know	No Answer
My doctor often asks me about end-of-life care.	4	15	0	1
My doctor is very good at talking about end-of-life care.	4	15	0	1
Someone other than my doctor has talked with me about the care I would want if I got too sick to speak for myself (like a nurse home health worker, chaplain or clergy, social worker).	10	9	0	1
I worry about the quality of my life in the future.	14	5	0	1
I worry that I could be a burden on my friends and family if I got very sick.	14	5	0	1
I have been very sick.	15	4	0	1
I trust my doctor.	17	2	0	1
I feel sure that my doctor will be there for me if I get very sick.	17	2	0	1
I have had family or friends who have died.	18	1	0	1
My doctor is very good at taking care of liver disease.	17	0	0	3
My doctor cares about me as a person.	19	0	0	1

Note. N = 20. *Curtis, JR, Patrick, DL, Caldwell, E. & Collier, AC, (2000) Used with permission*

During the interviews, the researchers asked participants to elaborate on all the barriers and facilitators that had been identified. Two participants who endorsed the statement I'm not ready to talk about the care I want if I get very sick also added that they would not mind talking about the care they wanted if their provider initiated the conversation, but they would not bring it up themselves. One participant commented on fear of hospitalization: "I have known for years that I have bad liver disease, but it was not until just recently that I ended up in the hospital and began to worry that I might die." Several participants also stated that they did not feel like they knew what symptoms to expect as a consequence of their liver disease. One patient, when asked if he thought talking about getting sick was too depressing for his doctors, was surprised by this question and reported, "How my doctor felt never crossed my mind."

Based on these interviews, no new barriers or facilitators were added to the original questionnaire, and no existing barrier or facilitator items were deleted from the original questionnaire. Comments and discussions by participants during the interviews, although rich and informative, were primarily expansions on existing themes rather than additional new themes.

Discussion

Patients with ESLD suffer from a high burden of symptoms (Marchesini et al., 2001) compared to many end-stage illnesses. Although ESLD is the 12th leading cause of death in the United States (Hoyert, 2012), patients with ESLD liver disease have not been a focus for EOL care conversations in the way those with cancer diagnoses have. This study's interviews suggest that similar to people with other end-stage diseases, people with ESLD were unsure of what kind

of care they would want if they got too sick to speak for themselves, were reluctant to raise the topic of dying, and preferred, in many cases, to focus on hope for continued life rather than on planning for death. In contrast to prior published findings with COPD and CHF patients (Barnes et al., 2012), patients with ESLD did not report that their health care providers initiated EOL conversations. These findings suggest a potential deficit in patient-provider communication and self-efficacy for patients with ESLD that should be further explored.

Comparing data from this study to data from studies about patients with other chronic illnesses that have similar trajectories, such as COPD and CHF, all the identified barrier and facilitator themes were similar. Therefore, the tool seems likely to be relevant for use in ESLD care.

A recent randomized trial among patients with COPD used these patient-specific barriers and facilitators to feedback information to patients and their health care providers to enhance communication about end-of-life care (Au et al., 2012). The study found that this approach increased the occurrence of communication about EOL care from 11% in the control group to 30% in the intervention group, and also resulted in a significant, albeit moderate, increase in the patient participants' ratings of the quality of communication about EOL care. A similar approach may be worthy of investigation among patients with ESLD, since the current study found this population to endorse these same barriers and facilitators.

Limitations

The results of this study are based on a small sample size from one geographic region drawn for the purpose of providing content validation of a questionnaire; results may not be reflective of the ESLD population at large. The exploratory design and purposive sampling may limit generalizability. However, the study results may provide insights to guide further research.

An additional limitation was the potential for reporter bias because the lead researcher of the study also provided clinical care in one of the two study settings. To limit the potential for bias, participants who were under the clinical care of the lead researcher were interviewed by a trained research assistant who was unknown to them.

Conclusion

There is currently very limited understanding of patients with ESLD perspectives as they relate to EOL care preferences and participation in advance cares planning. This study provides validation of a questionnaire that assesses barriers to and facilitators of communication about EOL care for patients with ESLD. It also provides a snapshot of communication barriers and facilitators for those suffering from ESLD. Further investigation is needed with a larger and more generalizable sample to further delineate the barriers and facilitators to communication about EOL preferences for patients with ESLD. Improving the quality of communication between patients with ESLD and their care providers is critical to achieving patient-centered outcomes, including quality end-of-life care.

CHAPTER FOUR

BARRIERS AND FACILITATORS TO END-OF-LIFE COMMUNICATION IN END-STAGE LIVER DISEASE

Abstract

Objectives: Little is known about appropriate palliative care strategies in patients with end-stage liver disease. We sought to identify the proportion of patients with end-stage liver disease who have discussed end-of-life care with their clinicians and identify the barriers and facilitators to end-of-life communication as well as examine the influence of depression and substance abuse on preferences for discussing end- of-life care.

Design: We conducted a cross-sectional study of 77 participants with end- stage liver disease to identify common barriers and facilitators and examine the association of these barriers and facilitators with communication about end-of-life care.

Measurements and Results: Data was collected by a trained researcher. Only 25% of participants reported having discussions about end-of-life care with their health providers and, of those who had not discussed end-of-life care, 50% reported they would like to have such a discussion. Although some participants endorsed all 15 barriers, only 1 barrier was endorsed by greater than 50% of participants. The most commonly endorsed barrier was "I would rather concentrate on staying alive than talk about death". All 11 facilitators of communication about end-of-life care were endorsed by some patients and 9 of 11 were endorsed by more than 50%. There was no difference in overall occurrence or desire for end- of life communication in those with depression or substance abuse nor were there any specific barriers inherent to these subgroups.

Conclusion: Although participants endorsed many barriers and facilitators, few were identified by most of the participants. Improving communication about end-of-life issues may require

development of interventions that can overcome the identified barriers to communication in order to improve discussions of end-of-life care in those with end-stage liver disease.

Introduction

Cirrhosis is the 12th leading cause of death in the United States (Kung, Hoyert, Xu, & Murphy, 2008), and the 7th leading cause of death in those between the ages of 25 and 64 (Hoyert, Kung, & Smith, 2005). Life-threatening complications such as variceal hemorrhage, infection, or hepatoma combined with debilitating symptoms such as ascites, encephalopathy, muscle wasting and cachexia, fatigue, emotional and financial burdens, have significant impact on quality of life in these patients and their caregivers (Marchesini et al., 2001;Bajaj et al., 2011). Communication about palliative and end-of-life care has been shown to improve patients' symptoms, quality of life, and increase the concordance between the care patients' desire and the care they receive (Curtis, 2008; Lasker, Sogolow, Olenik, Sass, & Weinrieb, 2010). Yet, in practice health care providers have been reluctant to discuss end-of life care preferences (Roth, Lynn, Zhong, Borum, & Dawson, 2000), and only refer patients with end-stage liver disease (ESLD) to palliative care or hospice when the hope of recovery is very diminished and often in the last weeks of life (Rossaro, Troppmann, McVicar, Sturges, Fisher, & Meyers, 2004). Understanding how ESLD patients perceive communication around end-of-life (EOL) issues would be an important first step in improving the quality of care (Curtis, 2008).

In studies of patients with other life-limiting illnesses such as heart failure (HF) and chronic obstructive pulmonary disease (COPD), several patient barriers to EOL care communication have been identified. These include (a) lack of continuity of care providers, (b) fear or anxiety of making others uncomfortable, (c) inability to initiate EOL conversations in spite of desire to do so, (d) uncertainty related to the future, and (e) personal readiness for information (Barnes et al.,

2012). Understanding patient-specific barriers and facilitators may enhance communication about EOL issues, while still encouraging appropriate hope for curative treatments such as liver transplantation (Braithwaite et al., 2011). In addition, five patient specific factors; gender, race, ethnicity, substance abuse, and depression have been identified as affecting EOL communication (Knauft, Nielsen, Engelberg, Patrick, & Curtis, 2005; Roth, Lynn, Zhong, Borum, & Dawson, 2000; Curtis, Patrick,Caldwell, & Collier, 2000; Haas, et al.,1993). Several of these identified factors, substance abuse and depression have particular relevance in ESLD. Hepatitis C and alcohol induced liver disease are the two leading causes of cirrhosis and ESLD in the United States. Injection drug use is now the primary cause of hepatitis C infection in the United States, with prevalence between 27 to 93% depending on length of injection drug use (Chak, Talal, Sherman, Schiff & Saab, 2011). Moreover, the prevalence of mental health disorders including depression is estimated to be as high as 85% (Chainuvati, et al., 2006) in those with liver disease.

The purpose of this study is examine the perspectives of patients with end-stage liver disease to identify; (a) the proportion of patients who have discussed end-of-life care with their clinicians (b) patients' desire to discuss end-of-life care, (c) the most common and median number of barriers of and facilitators to communication about end-of-life care, and (d) whether there are specific barriers and facilitators that are more likely to be endorsed by those with substance abuse or depression.

Methods

Setting and Participants:

Patients with ESLD were recruited from two ambulatory liver clinics affiliated with the University of Washington in Seattle WA., including a university referral clinic and a county hospital clinic between August 2012 and April 2013. Patients were eligible for enrollment if they

had (a) diagnosis of cirrhosis from chronic liver disease with a Model for End Stage Liver Disease (MELD) (Kamath et al., 2001) score between 6 and 40, (b) English fluency, (c) age 18 or older, and (d) outpatient status at time of participation. MELD (Kamath et. al, 2001) scores which were used to determine eligibility were calculated using lab values and provider reported visit symptoms. Patients with significant hepatic encephalopathy as determined by their health care provider were not enrolled in the study. This sample consisted of patients both listed and not listed for liver transplantation.

Potential participants were introduced to the study by a member of their health care team at a routine clinic visit. Interested patients gave permission to be contacted by the principal investigator to receive additional information about the study, and provide informed consent. Written informed consent was obtained prior to any study procedures. This study was approved by the Institutional Review Board of the University of Washington.

Data Collection

Participant data collection was conducted by a single in-person interview by the principal investigator. Demographic information was gathered including age, gender, race, income, number of hospitalization in the last 6 months, diagnosis of underlying liver disease, and whether actively listed for transplantation. In addition, participants were asked to complete a Trail Making Test to quantify hepatic encephalopathy (Reitan, 1955 ; Zeegan, Drinkwater & Dawson, 1970), and were asked about substance abuse using the NIDA quick screen which is a tool adapted by the National Institute of Drug Abuse for use by clinicians in screening adults for substance use (Smith, Schmidt, Allensworth-Davies, & Saitz, 2010). The NIDA quick screen has a sensitivity of 92.9%, specificity of 94.1% for detection of current drug use, and 100% sensitivity, 73.9% specificity for drug use disorders.

Participants were also asked to complete the PHQ-8 depression scale (Kroenke, Strine, Spitzer, Williams, Berry, & Mokdad, 2008), which is a widely used scale with established reliability and validity. A PHQ-8 score of ≥ 10 has 88% sensitivity and 88% specificity for major depression. The PHQ-8 was chosen because of its generalizability in the outpatient setting, its good agreement with the gold standard, a psychiatrist interview, and its previous use in patients with liver disease (Scott, Wang, Coppel, Lau, Veitengruber, & Roy-Byrne, 2011).

The health care communication questionnaire, which is comprised of questions to determine if discussions of end-of-life care have taken place or are desired between participants and their providers (Curtis & Patrick, 1997; Curtis, Patrick, Caldwell, & Collier, 2000 ; Knauft et al., 2005).

Lastly, participants completed the barriers and facilitators of EOL communication questionnaire, (Curtis & Patrick, 1997; Curtis, Patrick, Caldwell, & Collier, 2000 ; Knauft et al., 2005) which was originally developed through patient focus groups and was validated for use in ESLD prior to use in this study (Cox-North, Doorenbos, Shannon, Scott, & Curtis, 2013).

Data Analysis

Demographic information, end-of-life discussions, barriers and facilitators were all analyzed using descriptive statistics. To determine whether each barrier or facilitator was associated with patient demographic information, substance abuse, and depression scores chi-square analysis for dichotomous variables and Mann-Whitney U-test for continuous variables were performed. For frequency measurements we did proportions with 95% confidence intervals. Mann-Whitney U- tests were done to examine the differences between median number of barriers and facilitators endorsed by patients who had end-of-life conversations with their

healthcare providers and those that did not. A two-tailed p value of ≤ .05 was considered statistically significant.

Results

Of the 122 eligible participants contacted, 77 were enrolled in the study for 63% participation. Of the eligible participants 20 did not want to participate 25 agreed to participate but were unable to complete the interview due to various reasons: unable to contact to schedule (n=16), obtaining liver transplantation (n=3), hospitalization for complications (n=2), hepatic encephalopathy (n=3), and death (n =1).

Demographic characteristics of the participants are shown in Table 4.1. Participants were primarily male and white. The mean age was 55, with a mean MELD score of 15, ranges (6-31), and mean Child-Turcotte-Pugh score of 9. In all, 88% had grade 0 or grade 1 hepatic encephalopathy based on the West Haven criteria. Hepatitis C and hepatitis C with alcohol were the two leading causes of underlying liver disease.

Table 4.1. Participant Characteristics

Characteristics	**Participants (n=77)**
	Mean and SD
Age, yr	55 ±.71
MELD	15 ±5.6
CTP	9 ±2.25
Number hospitalizations in last 6 months	1 ±.25
	N (%)
Male Gender	52 (68)
Race White African American Pacific Islander American Indian/Alaskan Native Hispanic or Latino More than one race	 61 (79) 8 (10) 1 (1) 2 (3) 4 (5) 1 (1)
Income ≤ $20,000 > $20,000- ≤ $40,000 > $40,000-≤ $60,000 > $60,000	 51 (66) 14 (18) 4 (5) 8 (10)
Number listed for liver transplant	23 (30)
History of substance abuse	54 (70)
Alcohol	52 (67)
Other substance not alcohol	36 (47)
Diagnosis for underlying liver disease Cryptogenic Alcohol Hepatitis C Hepatitis C/Alcohol Hepatitis B NASH PSC Polycystic disease	 3 (4) 14 (18) 31 (40) 21 (27) 1 (1) 4 (5) 2 (2) 1 (1)

*Data represented as mean ±SD or No (%) unless otherwise indicated

Occurrence of Communication about End-of-Life Care

Participants were asked several questions about communication with their healthcare providers. Descriptive statistics for some of these items are reported in Table 4.2. Only 25% of the participants reported having a discussion with their provider about the care they might want if they got too sick to speak for themselves. Nonetheless, over half of the participants thought their doctor probably or definitely knew the kinds of treatment they would want if they got too sick to speak for themselves. Of participants that reported not having discussions with their health care provider half reported that they would like to have this discussion with their health care provider, Other variables such as MELD score, age, race, income, and being listed for liver transplantation comparisons were done to explore if there were any differences between those that had end-of-life conversations and those that had not had end-of-life conversations. Only MELD score was found to be associated with having conversations about end-of-life care issues ($p=.01$). In those that had conversations the median MELD score was 18 (95% confidence level, 13-19), compared to those that had not had conversations where the median MELD score was 13 (95% confidence level, 11-15).

Table 4.2. Health Care Communication

	No	Yes	Unsure	Only if I got sicker
Do you think your doctor knows the kinds of treatments you want if you get too sick to speak for yourself?	27 (35)	46 (60)		
Have you ever discussed with your doctor in a face to face discussion the kind of treatments you want if you get too sick to speak for yourself?	54 (70)	19 (25)		
Would you like to discuss with your doctor the kinds of treatments you want if you get too sick to speak for yourself?	7 (13)	27 (50)	9 (17)	13 (24)

*Data is presented as No (%)

Barriers and Facilitators of Communication about End-of Life Care

No participant endorsed all barriers. The median number of barriers reported was 4 (95% confidence level, 3-5), with four participants reporting no barriers and one participant reporting 12 barriers. Only 1 barrier was endorsed by more than 50% of participants: " I would rather concentrate on staying alive than talk about death" (68%) (Table 3.).

The median number of facilitators endorsed was 7 (95% confidence level, 7-8) with no one endorsing no facilitators and 2% (2) endorsing all 11 facilitators. The minimum number of facilitators endorsed was 3. The three most commonly endorsed facilitators were; (1) "I trust my doctor" (90%); "My doctor cares about me as a person" (90%); "I have had family or friends who have died" (84%). Of all 11 facilitators, nine were endorsed by greater than 50% of participants. The remaining two facilitators, "My doctor often asks me about end-of life care" and "My doctor is very good at talking about end-of-life care were endorsed by 18% and 38% of participants respectively Table 4 shows descriptive statistics for these individual facilitators.

Table 4.3 Barriers to Communication

Barriers	**Applies**	**Does Not Apply**	**Do Not Know**	**Not Answered**
I don't know what kind of care I want if I get very sick.	32(42)	44(57)		1(1)
I'm not ready to talk about the care I want if I get very sick.	18(23)	59(75)		
I don't like to talk about getting very sick.	34(44)	42(55)		1(1)
My doctor doesn't like to talk about me getting very sick.	13(17)	64(83)		
My doctor never seems to have the time to talk about issues like end-of-life care.	13(17)	63(83)		1(1)
I would rather concentrate on staying alive than talk about death.	52(68)	24(31)		1(1)
I feel that talking about death can bring death closer	14(18)	63(82)		
I have a living will, and that means I don't need to talk with my doctor about the care I want if I'm too sick to speak for myself.	22(29)	55(71)		
My ideas about the kind of medical care I want change at different times.	24(31)	52(68)		1(1)
I worry that talking about getting sick is too depressing for my doctor.	3(3)	73(95)	1(1)	
I don't want to make plans for the future.	18(23)	59(77)		
I have not been very sick.	29(38)	48(62)		
I have concerns about bringing up assisted suicide.	12(16)	65(84)		
I'm not sure which doctor will be taking care of me if I get very sick.	38(49)	39(51)		
Doctors look down on people who developed liver disease because of drugs and/or alcohol	25(32)	52(68)		

*Data presented as No. (%) (n=77) *Curtis, JR, Patrick, DL, Caldwell, E. & Collier, AC, (2000) Used with permission*

Table 4.4 Facilitators of Communication

Facilitators	**Applies**	**Does Not Apply**	**Do Not Know**	**Not Answered**
I have been very sick	47(61)	20(26)		1(1)
I have had family or friends who have died	65(84)	11(14)		1(1)
I worry about the quality of my life in the future	62(81)	14(18)		1(1)
I trust my doctor	69(90)	7(9)		1(1)
My doctor cares about me as a person	69(90)	7(9)		1(1)
My doctor is very good at taking care of liver disease	62(81)	13(17)		2(2)
I worry that I could be a burden on my friends and family if I got very sick.	52(68)	24(31)		1(1)
My doctor often asks me about end of life care.	14(18)	62(81)		1(1)
My doctor is very good at talking about end-of-life care	29(38)	46(60)		2(2)
I feel sure that my doctor will be there for me if I get very sick	59(77)	16(21)		2(2)
Someone other than my doctor has talked with me about the care I would want if I got too sick to speak for myself (like a nurse home health worker, chaplain or clergy, social worker)	39(51)	36(47)		2(2)

Data presented as No.(%); (n=77) *Curtis, JR, Patrick, DL, Caldwell, E. & Collier, AC, (2000) Used with permission*

Barriers and Facilitators That Predict Having Discussions about End-of Life Care

We examined number of barriers and whether each barrier or facilitator was more common among those that did not have end-of life discussions. There was no difference in the median number of barriers and facilitators endorsed between those that had end-of-life discussions and those that had not had end-of life discussions. The median number of barriers was 4 (95% confidence level 2-6) and the median number of facilitators was 8 (95% confidence level, 7-9) in both those that had end-of life conversations and those that had not had end-of-life conversations.

The two most reported barriers by participants who had not had end-of-life care discussions were "I would rather concentrate on staying alive than talk about death" (51%) and "I am not sure which doctor will be taking care of me if I get very sick" (38%) There were two facilitators that were reported most often by participants reporting having discussions about end-of-life care "My doctor care about me as a person" (67%) and "I feel sure that my doctor will be there for me if I get very sick" (55%).

Barriers and Facilitators to End-of –Life Communication and Depression and Substance Abuse

We examined whether depression had an effect on whether participants discussed end-of-life care and what barriers were most prominent among participants with depression. Depression did not have an effect on whether or not participants had discussions with their health care providers about the care they wanted if they got too sick to speak for themselves. The median number of barriers in those that were depressed was 5 (95% confidence level, 4-6), the median number of barriers in those not depressed was 3 (95% confidence level, 3-5), therefore those that were depressed had more barriers than those that were not depressed ($p=.01$). Although

depression did not affect whether or not a participant had a discussion about end-of-life care, the desire to have a conversation about end-of-life care tended to be endorsed more frequently in those without depression (p=.05) There were no barriers that were endorsed by half of the participants.

The median number of facilitators in those with depression was 8 (95% confidence level, 7-8), the median number of facilitators in those without depression was 7 (95% confidence level, 6-8) with no difference in median number of facilitators between those that had depression and those that were not depressed.

We also examined whether substance abuse had an effect on whether participants discussed end-of-life care and what barriers were prominent among participants with substance abuse. Substance abuse had no effect on whether participants desired to discuss or actually discussed end-of-life care issues with their providers. The median number of barriers was 5 (95% confidence level, 3-5) in those with substance abuse and 4 (95% confidence level, 2-5) in those without substance abuse with no difference in number of barriers between those that were substance abusers and those that were not substance abusers. There were no barriers that were endorsed by half of the participants

The median number of facilitators in those with substance abuse was 8 (95% confidence interval 7-8), the median number of facilitators in those without substance abuse was 7 (95% confidence level 6-8) showing no difference in the median number of facilitators between those that were substance abusers and those that were not substance abusers.

Discussion

To our knowledge this is the first study to describe barriers to and facilitators of end-of-life communication in patients with ESLD. This study suggests that only one quarter (25%) of

patients with end-stage liver disease discuss with their health care provider the type of care they might want if they get too sick to speak for themselves. Participants endorsed a large number of different barriers. However, only one barrier was endorsed by more than half of the participants "I would rather concentrate on staying alive than talk about death" which could be a target for future interventions. We have previously found that patients with ESLD are not comfortable initiating discussions of care preferences with their providers; but are willing to have this type of discussion if their provider initiates the conversation. (Cox-North, Doorenbos, Shannon, Scott, & Curtis, 2013.) This suggests that health providers need to acknowledge this difficult topic in those with ESLD and become skilled in discussing this subject with patients that would rather not discuss it.

One method that may help health care providers initiate a discussion of end-of life care issues would be to use a clinical checklist to assist providers judge patients willingness or readiness to have a discussion about end-of-life issues in addition to feedback the patient-specific barriers and facilitators to patients and health care providers with suggestions for how to overcome barriers and utilize facilitators. A recent randomized trial among patients with COPD who had similar barriers to our group, used these patient-specific barriers and facilitators to feedback information to patients and their health care providers to enhance communication about end-of-life care (Au et al., 2012). The study found that this approach increased the occurrence of communication about EOL care from 11% in the control group to 30% in the intervention group, and also resulted in a significant, albeit moderate, increase in the patient participants' ratings of the quality of communication about EOL care. A similar approach may be worthy of investigation in patients with ESLD.

The second most commonly endorsed barrier reported by almost half of the participants, was uncertainty about which doctor would be taking care of them if they got too sick to speak for themselves. Many patients with ESLD are cared for by liver specialists whose primary focus is on therapeutic management, which may limit their consideration of psychosocial needs. It may be that inadequate communication and poor understanding of end-of-life care issues in ESLD between health care providers, patients and their families contribute to confusion and communication breakdown.

Finally, we did not find that depression or substance abuse had any effect on whether or not participants discussed end-of-life care issues with their providers. Depressed participants were less likely to want to discuss end-of- life care, and had a large number of different barriers. Therefore, those with depression may benefit from more education aimed at helping them understand the kinds of care and preferences available to them.

Limitations and Conclusion

There were several limitations to our study. First, our study sample was from one geographic area and may limit the generalizability of our results to other regions and settings. Second, we did allow participants with hepatic encephalopathy to participate in this study and therefore their responses may be different than they might have been without encephalopathy. The majority of participants had mild encephalopathy grade 0 or 1 by West Haven criteria. Third, our sample size did not allow us to control for etiology of liver disease and co-morbidities which might play a role in participant's responses, in particular to those questions dealing with depression and functional impairment. Lastly, we did not control for the number of multiple comparisons done in the study, as the goal of this study was to generate hypothesis about the

barriers and facilitators that could be used in a future intervention studies. Therefore, some of the associations may have occurred by chance alone

There is little information to guide providers on the communication about advance care planning and end-of-life care with patients with ESLD. There is a need for us to define what problems and issues they face in confronting end-of –life preferences and advance care planning. The majority of patients with ESLD reported that they wanted to discuss their preferences for end-of-life care but in fact only a quarter had actually had those discussions. With this study we have identified specific barriers and facilitators to this communication that may be useful targets for future interventions aimed at improving communication about end-of life issues in those with ESLD.

CHAPTER FIVE

CONCLUSION

This journey began out of a need to improve my own clinical practice, and prevent future patients from experiencing an undesirable path to the end of their life. I hoped that my data might provide evidence of some very clear patient barriers and facilitators to end-of life communication that might be easily targeted for interventions. And although the study did identify a barrier that would be a suitable target for an intervention, I discovered that it is much more complex than a simple intervention.

Death is seen by many to be associated with a bad act, a frightening happening, or a punishment (Kubler-Ross, 1969). As shown in Chapter four, participants in these studies overwhelmingly endorsed not having had discussions with their health providers about end-of-life care issues, with over half expressing that they would rather spend time concentrating on staying alive rather than talk about death in spite of significant functional limitations and decreased quality of life (Marchesinsi, et al., 2001). In addition, chapter three demonstrated that study participants were not opposed to discussing end-of-life care issues if someone else brought it up, but were unwilling to initiate the conversation themselves. Therefore an intervention targeted at increasing end-of-life conversations would need to be aimed not only initiating end-of-life care discussions in a group of patients that would rather not discuss it, but would need to be done so in a manner that did not create more fear and feelings of punishment.

Chapter four examined two common co-morbidities in those with liver disease, substance abuse, and depression and their impact on end-of-life discussions. Interestingly, there was no impact on whether or not discussions occurred or were desired with these co-morbidities; however, there were barriers that were specific to these groups. Since these groups comprised a large percentage

of our study population, 70% and 50% respectively consideration of the highest reported barriers in these participants must also be addressed in an intervention. These two groups reported barriers that were associated with uncertainty such as confusion about which doctor will be taking care of them and confusion about the kind of care they might want if they get too sick to speak for themselves. Therefore, the intervention in addition to stimulating these conversations would need to be educative and communicative to decrease uncertainty and confusion.

I was quite surprised how willing participants were to talk to me about this topic. However, I found that if I used the wording "end-of- life care" participants were less likely to want to talk to me, so in any further studies, I would phrase things differently with language more centered around "care preferences" or "planning" rather than end-of-life care. Another difficulty I encountered was with the barriers and facilitators questionnaire. Participants had difficulty interpreting some of the questions and commented on the oddity of a question or the purpose of a question which may have led to misunderstanding of the question and misreporting. In future use, I would consider rephrasing, and removing first person implications from some of the barrier and facilitator questions for more clarity.

The participation rate in this study was higher than had been previously reported in other studies. I attribute this to a couple of factors. All eligible participants for the studies were initially approached for participation by their regular provider. After approach and discussion they were then referred for study participation. I believe that this improved participation in two ways. One because participants felt more reassured that they were not being referred to the study because death was more imminent, and two since their doctor referred them they felt that this information was more valid or would be useful to their overall healthcare. I would recommend that this approach or similar approach with validation from regular provider be used in future studies.

In looking back at the case I presented in the introduction, I believe another reason that I did not discuss end-of-life care issues with this patient was because I assumed that he already understood what the possible scenarios were for his future since we were discussing transplantation. And although, maybe he did know at some level he was dying, based on what these studies have suggested I am fairly certain that he did not fully understand what that might look like. Initiating a discussion with him would have relieved a great deal of stress both for him and his family, and freed him to use his time left pursuing what was important to him rather than dying alone in the hospital.

My next step(s) in relationship to the foundation that has been set forth in this dissertation is to continue my investigation into barriers to and facilitators of discussions of end-of-life care in this population. These studies demonstrated that there is a need to start discussing care preferences in this population in addition to giving us leads to a few barriers that may be amendable to change and improving communication. With the identification complete, next steps should be centered on creating an intervention that can provide the backbone, tool, or process that "breaks the ice" to initiating these discussion, educates, and is easily translatable to clinical practice.

In conclusion, the studies that formed the basis for this dissertation have been the first to identify in patients with end-stage liver disease the desire to discuss end-of-life care issues, in addition to the associated barriers and facilitators to these types of discussions. It is clear that there is a lot of suffering in these patients and their families, and with the emergence of this new data, patients have thrown the gauntlet and challenged health care providers to start initiating these types of discussions. It is now time as healthcare providers that we rise to that challenge and begin discussing care preferences in those with end-stage liver disease.

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