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Pain and Self-Care Behaviors in Adult Patients with ESLD: A Longitudinal Description

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Abstract

This prospective descriptive study investigated pain characteristics in 20 outpatients with endstage liver disease (ESLD) approaching end of life, described variability in pain between and within patients, and described pharmacological and non-pharmacological pain management strategies used. The instruments utilized were: the Wisconsin Brief Pain Inventory (BPI) and the Self-Care Behavior Log for Pain (SCB). Data were collected once a month over a 6-month period. BPI severity of and interference from pain mean scores ranged from 5.52 to 6.03 and 5.36 to 6.64, respectively. The top three behaviors for relieving pain patients reported were "taking pain medication," "taking a nap," and "asking for help." Pain medication intake differed between patients who were pursuing a liver transplant and those who were not eligible for transplantation. To effectively improve care for ESLD, it is essential to understand the ways in which these patients experience pain and the pain management strategies they employ.

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Introduction

In the United States (U.S.) an estimated 400,000 Americans have end-stage liver disease (ESLD), and more than 33,000 people die each year from liver disease (1). Despite the morbidity and mortality associated with ESLD, surprisingly little is known about the characteristics of pain outpatients with ESLD experience approaching the end of life. In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) conducted two decades ago (2, 3), 60 percent of seriously ill hospitalized patients with liver failure experienced pain (4, 5), and 45 percent reported severe pain 3 days before death (6). The high burden of pain experienced in this population was comparable to that of patients dying from lung and colon cancer (3-5). Pain continues to be a significant problem among patients with ESLD (7). Madan and colleagues found that 77 percent of patients with ESLD who were liver transplant candidates experienced moderately levels of body pain within 24 hours of their pain evaluation using the Brief Pain Inventory-Short form (7). In other studies, pain has been assessed by a single item within the context of quality of life measurements limiting a detailed description of the pain experienced by these patients (8, 9). Using the SF-36, Perez-San-Gregorio and colleagues found that patients with liver cirrhosis who had not received liver transplants had worse bodily pain than two groups of patients who were transplant recipients (10).

Patients with ESLD who have pain may experience ineffective pain management for several reasons. Health care providers may under treat pain in these patients due to concerns about poor medication metabolism and hepatic encephalopathy (3, 11, 12). Patients may be stigmatized due to an increased prevalence of alcohol and drug abuse, leading to under treatment of pain (3). Referral to palliative care or hospice is uncommon and occurs very late in disease progression in this population (13, 14) potentially leaving patients as they are facing death without the pain management expertise of palliative care and hospice professionals. Additionally, patients with ESLD report limited perceived analgesic effect, despite being prescribed pain medications (7).

Research on pain in patients with ESLD has primarily been cross sectional and has included pharmacological pain management (7, 10). Less emphasis has been given to pain in these patients as they are approaching the end of life and on the non-pharmacological pain management strategies they use. To effectively care for patients with ESLD and to facilitate appropriate and timely referral to palliative care and/or hospice requires an understanding of how these patients experience and manage pain. The purpose of this study was to provide a longitudinal description of pain characteristics in outpatients with ESLD approaching the end of life, describe variability in pain between and within patients over time, and to describe both pharmacological and non-pharmacological pain management strategies used.

Methods

For this pilot study we employed a prospective, longitudinal descriptive design. Approval for the study was obtained from the Oregon Health & Science University (OHSU) and Portland Veterans Affairs Medical Center (PVAMC) Institutional Review Boards.

Sample

A total of 20 Hepatology Clinic outpatients with ESLD were included in the sample. Patients were eligible if they had reported and documented a pain level of 3 or greater on a 0 to 10 numeric rating scale, had medical record documentation of liver cirrhosis, and a Model for ESLD (MELD) score of 18 or greater. Because a MELD score of 18 or greater indicates increased short term (3-month) mortality (15, 16), it was used as a cut-off. Patients who were non-English speaking and those who were younger than 21 years of age were excluded. The exclusion of patients, who were younger than 21 years of age, was based on the National Institutes of Health, U. S. Department of Health and Human Services' definition of children (17). According to this definition, children are individuals under the age of 21. Patients were also excluded if they had a diagnosis of liver cancer or had received a previous liver transplant because these patients' disease progression and therefore their pain experience may be different from the disease progression of patients with ESLD.

We used a purposive sampling strategy to obtain the sample. A nurse, nurse practitioner or physician from the Hepatology Clinics at OHSU or PVAMC identified eligible patients for potential participation in the study during the patient's scheduled appointment. The health care professional briefly explained the study and provided patients with a study pamphlet. If a patient was interested in talking with the principal investigator (PI) about the study, the health care professional gave the patient's name and contact information to the PI. After explaining the study during patients' clinic visits or later at home by telephone, the PI invited them to participate. All patients who agreed to participate provided informed written consent before data were collected. Patients' level of orientation and decisional capacity were assessed by the PI using clinical judgment prior to receiving patients' informed consent for enrollment in the study and also before each data collection (18). Orientation was assessed by asking patients questions related to person, place, and time. Decisional capacity was assessed using the Guidance on Human Subjects Research with Decisionally Impaired Adults (19). This assessment and the data collection procedures have been described in more detail elsewhere (20).

Data Collection

The PI collected data from patients once a month over a 6-month period at a scheduled time and location convenient for the patients. Patients rated their pain and self-care behaviors (SCBs) using the Wisconsin Brief Pain Inventory (BPI) (Modified) and Self-Care Behavior Log for Pain. Patients' medical records were reviewed to obtain information about prescribed pharmacological pain management strategies. Patients were invited to complete the BPI and Self-Care Behavior Log for Pain at the time of enrollment. If it was not convenient, a future time to complete the instruments was scheduled.

Instruments

The BPI is a multidimensional pain instrument. Items on the instrument address pain history, etiology, location, quality, intensity, and interference with activities. The BPI has been used to measure pain in cancer and other diseases (21-23). The BPI is easily understood and can be self-administered or administered by a trained investigator (21). The mean of the four severity items and the mean of the seven interference with activities items were used as

measures of pain severity and pain interference, respectively. Scores for both scales can range from 0 to 10. Higher scores indicate greater pain or more interference as a result of pain. The BPI has sufficient reliability and validity for clinical (24) and research purposes (21). In our study, Cronbach's alphas were 0.88 and 0.92 for the pain severity and interference scales, respectively.

The Self-Care Behavior Log for Pain, a 24-item questionnaire, is a list of activities individuals can use to help relieve pain. Patients were asked to answer "yes" or "no" to each SCB as to whether they used the activity during the past week to manage pain. If they performed an activity, they were asked to rate the effectiveness of each activity in managing pain using a 0 to 10 numeric rating scale, with higher scores indicating greater effectiveness. The number of SCBs was derived from summing the "yes" responses. The overall effectiveness of all of the patients' SCBs was determined by the sum of the relief scores of those SCBs performed divided by the total number of behaviors. Permission was obtained to use this log (C. Miaskowski, written communication, 2009).

Statistical Analysis

We provide a descriptive interpretation based on mean scores across time using all available data. We examined the relationships between baseline pain and SCBs and etiology, liver transplant candidacy, and MELD scores using one-way ANOVAs, independent-samples t-tests, and Pearson correlation coefficients, respectively. We used Stata 11 to analyze the data (College Station, TX) (StataCorp 2009).

Results

To collect at least 3 months of data from a sample of 20 patients, 26 patients were enrolled in the study. During data collection eight patients died, four patients died before and four patients died after 3 months of data were collected, two received a transplant, two developed confusion, two had medical emergencies, one moved away from the area, and one was lost to follow up contact. Due to life events, two patients declined to participate in the study. None of the enrolled patients withdrew from the study, none received a palliative care consultation, and two were enrolled in hospice.

Of the 20 patients participating in the study 15 (75 percent) were male, 15 were European American, three (15 percent) were Hispanic, and two (10 percent) of them were African Americans. Average age was 59 years (median=59, SD=5.29, range 51–76 years). Fourteen patients (70 percent) reported their employment status as disabled, three (15 percent) were unemployed, two (10 percent) were employed outside the home, and one (5 percent) was employed at home. Eighteen (90 percent) patients had a high school diploma or higher. Nine of the patients had ESLD due to Hepatitis C cirrhosis, five due to alcoholic cirrhosis, two due to Hepatitis B cirrhosis, and one due to non-alcoholic steatohepatitis. MELD scores ranged from 18-19 with the exception of one patient who had a MELD score of 21 (mean=18.45, SD=.95). Of the total patient sample, 11 were not liver transplant candidates, four were placed on the liver transplant waiting list during the study period, three were on the waiting

list at study entry, two were being evaluated for potential wait-listing, and two were denied listing during the study.

Pain Characteristics

Based on the pain history items included in the BPI, 12 patients reported having experienced pain for 1 year or longer, four for 6 to 12 months, and four for 6 months or less. Nineteen of the 20 patients believed that their primary experience of pain was related to ESLD, one believed that it was due to a previous accident. Patients reported experiencing pain in their liver, right upper quadrant of the abdomen, and generalized abdominal pain and back pain from ascites. Abdominal cramping was also a source of pain. To describe the quality of the pain, 17 of the patients chose the word "exhausting," 12 chose "tiring," and 11 selected "aching," "intense," "stabbing," and "sharp." Other words chosen frequently by patients included "annoying," "penetrating," "cramping," and "nauseating."

The means of the four BPI severity items aggregated across time for patients ranged from 3.49 to 8.52 (SD=2.47–3.04). Pain at its worst was rated as severe and excruciating (mean=8.52, SD=2.32) and pain at its least as mild and moderate (mean=3.49, SD=2.47). The means of the seven interference items ranged from 4.80 to 6.92 (SD=2.98–3.69). Pain most interfered with general activity (mean=6.92, SD=2.98) and least interfered with relations with other people (mean=4.80, SD=3.69).

Pharmacological and Non-pharmacological Pain Management Strategies

Means and standard deviations for each measure of pain and the Self-Care Behavior Log for Pain at each time point for patients are presented in Figures 1 - 4. For severity and interference of pain over the six-month period, the pain reported by patients appeared to be relatively stable across time (means ranged from 5.52 to 6.03 (SD=1.89–2.32) and from 5.36 to 6.64 (SD=2.58–3.11), respectively) (Figures 1 and 2). The average number of SCBs reported by patients ranged from 6.40 to 7.35 (SD=1.53–2.99), and that number was relatively stable across time (Figure 3). The effectiveness of these SCBs was also relatively stable across time with a small increase at Time 5 (mean ranged from 3.82 to 4.86 (SD=1.86–3.13)) (Figure 4).

Aggregating across time, frequency distributions were examined for the percentage of patients for each of the 24 SCBs, and the results are presented in Table 1. The most commonly used SCBs reported by patients were taking a nap (79.8 percent), watching TV (78.7 percent), taking pain medicine (69.1 percent), reducing activity levels (69.1 percent), and asking for help (53.2 percent). In addition to the 69.1 percent of patients taking pain medication, 23.4 percent took tranquilizers and 8.5 percent drank alcohol.

We also aggregated across time to examine mean ratings of effectiveness for each of the 24 SCBs. The 10 most effective SCBs that patients engaged in are presented in Table 2. Patients reported that taking pain medication (mean=5.77, SD=2.97), asking for help (mean=5.66, SD=3.56), and taking tranquilizers (mean=5.60, SD=2.52) were the most effective (mean greater than 5, at least 5 percent frequency) SCBs.

Pain medications taken by patients during the study period are presented in Table 3. We categorized medications according to the World Health Organization's three-step ladder for analgesic potency: 1) a non-opioid for mild pain (e.g. acetaminophen); 2) a weak opioid for moderate pain (e.g. codeine); and 3) a strong opioid for severe pain (e.g. morphine).

At baseline, 30 percent of the patients were not taking any pain medication. This percentage increased to 42 percent of patients not taking any pain medication at 5 months. During the study period, the percent of patients who took a strong opioid increased from 40 percent to 58 percent. The percentages of patients who took a non-opioid and a weak opioid decreased from 30 to 17 percent and from 20 to 8 percent, respectively. The mean patient level of relief from pain medication was 46 percent (SD=35 percent). The mean level of satisfaction with overall pain treatment was 4.98 (SD=3.39) on a 0 to 10 numeric rating scale, with higher scores indicating higher satisfaction.

A general observation of the sample revealed that of the 11 patients who were *not* liver transplant candidates, nine were on opioids (91 percent), with eight taking a strong opioid and one taking a weak opioid. In contrast, of the remaining nine participants who were pursuing a liver transplant, only four out of nine reported taking opioids (44 percent); two used a strong opioid and two used weak opioids.

Variability in Pain Between and Within Patients over Time

Average daily pain scores between patients ranged across time from 2.00 to 8.17 (M=5.47; SD=1.92). Within patients variability across time measured by standard deviations ranged from 0.41 to 4.20 (M of SD= 1.41). The worst pain scores between patients ranged across time from 3.00 to 10.00 (M=8.25; SD=2.32); the standard deviations within patients across time ranged from 0.00 to 4.36 (M of SD = 1.02). Pain at its least scores between patients ranged across time from 0.00 to 6.33 (M=3.29; SD=2.23); the standard deviations within patients across time ranged from 0.00 to 6.33 (M=3.29; SD=2.23); the standard deviations within patients deviations within patients across time ranged from 0.00 to 3.06 (M of SD=1.06). There were no significant differences in pain between male (n=15) and female (n=5) patients.

Associations between Baseline Pain and Liver Disease Etiology, Liver Transplant Candidacy, and MELD Scores

None of the one-way ANOVAs comparing the different liver disease etiologies on pain and SCBs were significant. Descriptively, those with a mixed/other etiology tended to have lower pain at baseline and more effective SCBs for pain at baseline (Table 4). Those with hepatitis C cirrhosis had slightly higher pain severity and used more SCBs for pain than those with alcoholic cirrhosis. Patients with hepatitis C cirrhosis rated their SCBs as less effective. In comparing those who were liver transplant candidates to those who were not, there were no significant differences. In this sample, non-transplant candidates reported using more SCBs and were more likely to rate them as effective. There were no significant associations between MELD scores and pain and SCBs. The magnitudes of the correlations were not strong; the largest was with the effectiveness of SCBs (*r*=.19).

Discussion

Over a six-month period, 20 outpatients with ESLD without liver cancer described consistent levels of moderate pain. The experience of pain by patients in this study is similar to findings from the SUPPORT study by Roth and colleagues who examined the pattern of care and end of life preferences for patients dying of ESLD (3). One third of the patients in the SUPPORT study reported moderately severe pain in all time windows (3). To describe symptom progression up to the time of death, Roth and colleagues retrospectively constructed observational windows starting from the date of the patient's death and going back to the date of study entry. Responses to pain experiences were gathered by interviews with patients or their surrogate decision makers. Of 575 patients with ESLD in the SUPPORT study, 334 died either during the index hospitalization (n=166), or in the following year (n=168). In contrast to the SUPPORT study which included seriously ill hospitalized patients, our study focused on outpatients with ESLD. Of a total of 92 collected pain scores, only 3 were collected in a hospital.

An interesting finding in this study was that 30-40 percent of patients in this cohort, despite reporting moderate pain, reported no pain medication use, and the ones who used pain medication received less than 50 percent relief and were moderately satisfied with their overall pain treatment. The mean effectiveness rating for SCBs showed that taking pain medication proved the most effective for patients. Although patients in this study rated taking pain medication as most effective, Madan and colleagues found that patients with ESLD experienced limited analgesic effect despite being prescribed often more than one pain medication and that they received only 33 percent pain relief on average (7).

In this study, it is unclear why the percent of patients who took pain medication was not higher. At the same time, for those who used pain medication, the percent of patients who took a strong opioid increased from 40 percent to 58 percent over the study period. Eight of the 11 patients who were not liver transplant candidates took a strong opioid compared to two of the nine patients who were working toward a liver transplant. The difference in use of pain medications between those working towards transplant and those who were not eligible may be related to criteria for liver transplant candidacy that require at least 6 months abstinence from alcohol and substance abuse (25) and different approaches to pain management by either the patient, physician, or both. Because of transplant candidacy criteria, the pain experienced by patients with ESLD who are working toward a liver transplant may be challenging for health care professionals to effectively manage due to the dichotomy of patients pursuing life while approaching the end of it. Approximately 15 percent of patients listed on the liver transplant waiting list die while waiting (26). Furthermore, treating pain in patients with ESLD at the end of life may be challenged because of professionals' fear of complicating the disease (12, p. 2172) and a lack of reliable information and evidence regarding the use of medications in this population compared to patients with other types of organ failure (27, 28, p. 677). In a study by Wang and colleagues, 56 percent of patients with pathologically-diagnosed metastatic cancer took strong opioids for severe pain, which is similar to the percent of patients in our study (29). In the cancer literature, patients report reluctance to take pain medication due to (1) fear of addiction (30), (2) being labeled as a complainer (31), and (3) concerns of becoming tolerant

to pain medication (31). The level of pain experienced by patients with ESLD in this study, their level of pain relief, and satisfaction with their overall pain treatment speaks to the importance of assessing and treating pain in this population.

Patients with ESLD may have or had prior substance abuse, knowing the history of this abuse may be important for health care professionals to address the pain patients' experience. Research shows that patients with AIDS-related pain and a history of substance abuse may require higher doses of strong opioids than patients without a history of abuse (32). Schieffer and colleagues found that patients with chronic pain diagnoses and a history of substance abuse reported greater belief in opioid effectiveness and a need for more control over their medications than patients without a history (33).

In contrast to patients with a dual diagnosis of both drug and alcohol abuse, patients with a history only of alcohol abuse have been found not to misuse medications more than those without a history of substance abuse (33). The percent of patients drinking alcohol in this study needs attention, as the combination of alcohol and opioids in addition to other centrally acting medications can lead to serious health concerns affecting motor skills and cognitive impairment. Cognitive impairment or hepatic encephalopathy may progress rapidly to coma, a stage of unresponsiveness that can lead to death. In addition to the effects of opioids on cognition, side effects such as constipation may also contribute to hepatic encephalopathy. A history of or current substance abuse, the focus of pain control in palliative care, and the labile inter-individual and intra-individual variability scores on the BPI over time in patients with ESLD approaching the end of life support the importance of individualized tailored assessment and treatment for each patient despite a somewhat average trajectory of the group as a whole.

In this study, the sample size was small, but those with hepatitis C cirrhosis had slightly higher pain severity than those with alcoholic cirrhosis. This tentative finding is supported by findings from the study by Madan and colleagues (7). They found that patients with alcoholic cirrhosis experienced significantly less pain than did patients with hepatitis C cirrhosis.

The pain experienced by patients with liver disease has typically been described as dull or vague, or else sharp (34). In this study, most of the patients labeled their pain as "exhausting" and "tiring." Research is needed to explore the relationship between descriptors of pain, and the pain frequency and intensity (e.g., does improvement in pain itself change or improve the exhaustion or tiredness these patients experience?). The most commonly used SCB by patients was "taking a nap," yet it was only the ninth most effective SCB at addressing the pain itself.

An examination of the trends over time shows that the number of SCBs and the effectiveness of SCBs appeared stable, suggesting that the effects of the interventions were durable and did not lose efficacy over time. SCBs and complementary and alternative therapies not included in the Self-Care Behavior Log for Pain such as therapeutic touch may be useful adjuvants to pharmacological pain management in patients with ESLD approaching the end of life and should be further studied. Acupuncture was not a SCB used

by any patients in this study but may be a reasonable option for patients with ESLD who experience pain. There is evidence in the chronic pain (35) and oncology (36) literature that acupuncture helps in control of pain.

As in other studies (13, 14), findings from this study show few referrals by health care professionals to hospice and no referrals to palliative care. In addition to pain, patients with ESLD often experience complex physiological symptoms (37, 38) and psychological distress (39, 40), and these patients may benefit from hospice and palliative care. The integration and benefits of palliative care for patients with ESLD who are pursuing a liver transplant or are on the liver transplant waiting list are not clear (12). It is possible that such integration will further enhance the care of these patients, as it may for those patients who are not pursuing a liver transplant or are deemed ineligible for one (37). Hospice and palliative care have shown to improve pain control and quality of life in patients with terminal illness (41-43). In 2011 in the U.S., 2.1 percent of patients admitted to hospice had liver disease compared to 11.4 percent with heart disease and 8.5 percent with lung disease (44). Given the relatively small percentage of patients with liver disease admitted to hospice care in the U.S. and the increasing number of persons dying with ESLD, there is likely a need for additional education and training of health care professionals caring for these patients, especially in addressing their pain management needs.

Limitations

This study emphasizes the moderate level of pain experienced by outpatients with ESLD. However, there are potential limitations. The sample size was small, and the sample was not compared to another group of patients with an end-stage medical condition (e.g., patients with lower MELD sores or heart or lung diseases). Also future studies should include a larger ethnically diverse sample, and, based on our results, an examination of differences between liver transplant candidates and non-transplant candidates in the relation to pain and symptom management. This examination should include complementary and alternative therapies, and integration of palliative care.

Conclusion

Based on findings from our study and other studies, and in particular the inter-individual and intra-individual variability on the BPI over time, a detailed assessment by health care professionals of individual patient pain characteristics, intake of pain medication, and use of complementary and alternative therapies should be completed at each clinic appointment. Information from these assessments is essential for professionals to effectively prescribe and recommend pharmacological and non-pharmacological pain management strategies and refer patients to hospice and palliative care.

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References

- 1. Hoyert, DL.; Xu, JQ. National vital statistics reports. Vol. 61. Hyattsville, MD: National Center for Health Statistics; 2012. Deaths: preliminary data for 2011.
- 2. SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatment (SUPPORT). JAMA. 1995; 274(20):1591–1598. [PubMed: 7474243]
- 3. Roth K, Lynn J, Zhong Z, et al. Dying with end stage liver disease with cirrhosis: insight from SUPPORT. J Am Geriatr Soc. 2000; 48(5):S122–S130. [PubMed: 10809465]
- Desbiens NA, Wu AW, Broste SK, et al. Pain and satisfaction with pain control in seriously ill hospitalized adults: findings from the SUPPORT research investigators. Crit Care Med. 1996; 24(12):1953–1961. [PubMed: 8968261]
- Desbiens NA, Wu A. Pain and suffering in seriously ill hospitalized patients. J Am Geriatr Soc. 2000; 48(5):S183–S186. [PubMed: 10809473]
- Lynn J, Teno JM, Phillips RS, et al. Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Ann Intern Med. 1997; 126(2):97–106. [PubMed: 9005760]
- 7. Madan A, Barth KS, Balliet E, et al. Chronic pain among liver transplant candidates. Progr Transplant. 2012; 22(4):379–384.
- Ratcliffe J, Longworth L, Young T, et al. Assessing health-related quality of life pre- and post-liver transplantation: a prospective multicenter study. Liver Transpl. 2002; 8(3):263–270. [PubMed: 11910572]
- Younossi Z, Boparai N, Price LL, et al. Helath-related quality of life in chronic liver disease: the impact of type and severity of disease. Am J Gastroenterol. 2001; 96(7):2199–2205. [PubMed: 11467653]
- Perez-San-Gregorio M, Martin-Rodriquez A, Dominguez-Cabello E, et al. Quality of life and mental health comparison among liver transplant recepients and cirrhotic patients with different self-perceptions of health. J Clin Psychol Med Setting. 2013; 20(1):97–106.
- Chandok N, Watt KDS. Pain management in the cirrhotic patient: the clinical challenge. Mayo Clin Proc. 2010; 85(5):451–458. [PubMed: 20357277]
- Larson AM, Curtis JR. Integrating palliative care for liver transplant candidates. JAMA. 2006; 295(18):2168–2176. [PubMed: 16684988]
- Medici V, Rossaro L, Wegelin JA, et al. The utility of the model for end-stage liver disease score: a reliable guide for liver transplant candidacy and, for select patients, simultaneous hospice referral. Liver Transpl. 2008; 14(8):1100–1106. [PubMed: 18668666]
- Antaki F, Lukowski A. The model for end-stage liver disease (MELD) predicts survival of liver cirrhosis patients after discharge to hospice. J Clin Gastroenterol. 2007; 41(4):412–415. [PubMed: 17413612]
- Kamath PS, Wiesner RH, Malinchoc M, et al. A model to predict survival in patients with endstage liver disease. Hepatology. 2001; 33(2):464–470. [PubMed: 11172350]
- 16. Kamath PS, Kim WR. Is a change in MELD score a better indicator of mortality than baseline MELD score? Liver Transpl. 2003; 9(1):19–21. [PubMed: 12514768]
- 17. National Institutes of Health; U. S. Department of Health & Human Services. [Assessed October 21, 2013] Guidelines for human subjects protection and inclusion of women, minorities, and children. http://grants.nih.gov/grants/peer/guidelines_general/ Human_Subjects_Protection_and_Inclusion.pdf
- Casarett DJ. Assessing decision-making capacity in the setting of palliative care research. J Pain Symptom Manag. 2003; 25(4):S6–S13.

- Office of Integrity Oregon Health & Science University. [Accessed October 19, 2012] Guidance on human subjects research with decisionally impaired adults. 2007. http://www.ohsu.edu/xd/ about/services/integrity/policies/policy-detail.cfm?policyid=265745&WT_rank=1
- 20. Hansen L, Leo M, Chang M, et al. Symptom distress in patients with end-stage liver disease toward the end of life. Gastroenterol Nurs. (in press).
- Daut RL, Cleeland CS, Flanery RC. Development of the Wisconsin Brief Pain Questionnaire to assess pain in cancer and other diseases. Pain. 1983; 17:197–210. [PubMed: 6646795]
- 22. Cowan DT, Wilson-Barnett DJ, Griffiths P, et al. A randomized, double-blind, placebo-controlled, cross-over pilot study to assess the effects of long-term opiod drug consumption and subsequent abstinence in chronic noncancer pain patients receiving controlled-release morphine. Pain Med. 2005; 6(2):113–121. [PubMed: 15773875]
- 23. Chang VT, Hwang SS, Kasimis B. Longitudinal documentation of cancer pain management outcomes: a pilot study at a VA medical center. J Pain Symptom Manag. 2002; 24(5):494–505.
- Tan G, Jensen MP, Thornby JI, Shanti BF. Validation of the Brief Pain Inventory for chronic nonmalignant pain. J Pain. 2004; 5(2):133–137. [PubMed: 15042521]
- 25. Oregon Health & Science University & Portland Veterans Affairs Medical Center Combined Liver Transplant Program. [Accessed January 13, 2013] A guide to liver transplantation. http:// www.ohsu.edu/transplant/liver-pretx_ptmanual-040210.pdf
- 26. U.S. Department of Health and Human Services.Health Resources and Services Administration. [Accessed January 10, 2013] OPTN/SRTR 2011 Annual Data Report: Liver. 2011. http:// srtr.transplant.hrsa.gov/annual_reports/2011/flash/03_liver/index.html#/6/
- 27. Boyd K, Kimbell B, Murray S, et al. Living and dying well with end-stage liver disease: time for palliative care? Hepatology. 2012; 55(6):1650–1651. [PubMed: 22290640]
- Rhee C, Broadbent AM. Palliation and liver failure: palliative medication dosage guidelines [review]. J Palliat Med. 2007; 10(3):677–685. [PubMed: 17592979]
- 29. Wang XS, Cleeland CS, Mendoza TR, et al. The effects of pain severity on health-related quality of life: a study of Chinese cancer patients. Cancer. 1999; 86(9):1848–1855. [PubMed: 10547560]
- Simone CB, Vapiwala N, Hampshire MK, et al. Palliative care in the management of lung cancer: analgesic utilization and barriers to optimal pain management. J Opioid Manag. 2012; 8(1):9–16. [PubMed: 22479880]
- Ersek M, Kraybill BM, Pen AD. Factors hindering patients' use of medications for cancer pain. Cancer Pract. 1999; 7(5):226–232. [PubMed: 10687591]
- 32. Kaplan R, Slywka J, Slagle S, et al. A titrated morphine analgesic regimen comparing substance users and non-users with AIDS-related pain. J Pain Symptom Manag. 2000; (19):265–273.
- Schieffer BM, Pham Q, Labus J, et al. Pain medication beliefs and medication misuse in chronic pain. J Pain. 2005; 6(9):620–629. [PubMed: 16139781]
- Riley IIITR, Koch K. Characteristics of upper abdominal pain in those with chronic liver disease. Dig Dis Sci. 2003; 48(10):1914–1918. [PubMed: 14627332]
- Vickers AJ, Cronin AM, Maschino AC, et al. Acupuncture for chronic pain: individual patient data meta-analysis [review]. Arch Intern Med. 2012; 172(19):1444–1453. [PubMed: 22965186]
- 36. Lu W, Rosenthal DS. Acupuncture for cancer pain and related symptoms [review]. Curr Pain Headache Rep. 2013; 17(3):321–328. [PubMed: 23338773]
- Hope AA, Morrison RS. Integrating palliative care with chronic liver disease. J Palliat Care. 2011; 27(1):20–27. [PubMed: 21510128]
- Hansen L, Sasaki A, Zucker B. End-stage liver disease: challenges and practice implications. Nurs Clin North Am. 2010; 45(3):411–426. [PubMed: 20804886]
- Davis H, De-Nour AK, Shouval D, et al. Psychological distress in patients with chronic, nonalcoholic, uncomplicated liver disease. J Psychosom Res. 1998; 44(5):547–554. [PubMed: 9623875]
- 40. De Bona MP, Ermani P, Lemmolo M, et al. The impact of liver disease and medical complications on quality of life and psychological distress before and after liver transplantation. J Hepatol. 2000; 33(4):609–615. [PubMed: 11059865]

- 41. McMillan SC, Small BJ, Haley WE. Improving hospice outcomes through systematic assessment: a clinical trial. Cancer Nurs. 2011; 34(2):89–97. [PubMed: 20885302]
- 42. Higginson IJ, Evans CJ. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? Cancer J. 2010; 16(5):423–435. [PubMed: 20890138]
- El-Jawahri A, Greer JA, Temel JS. Does palliative care improve outcomes for patients with incurable illness? A review of the evidence. J Support Oncol. 2011; (9):87–94. [PubMed: 21702398]
- 44. National Hospice and Palliative Care Organization. NHPCO facts and figures: hospice care in America. Alexandria, VA: Hospice Statistics & Research; 2012. http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf [Accessed July 12, 2013]

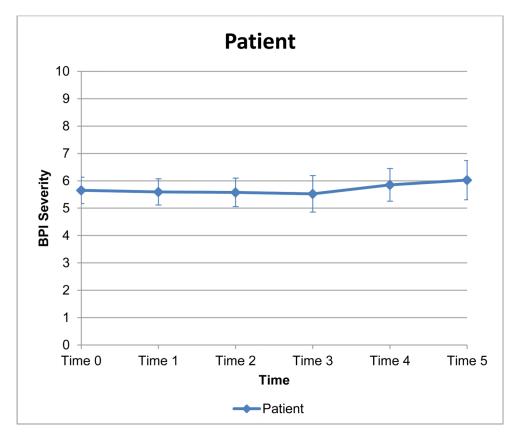


Figure 1. Mean BPI Severity Scores and Associated $\pm\,1$ Standard Errors across the Six Data Collection Times

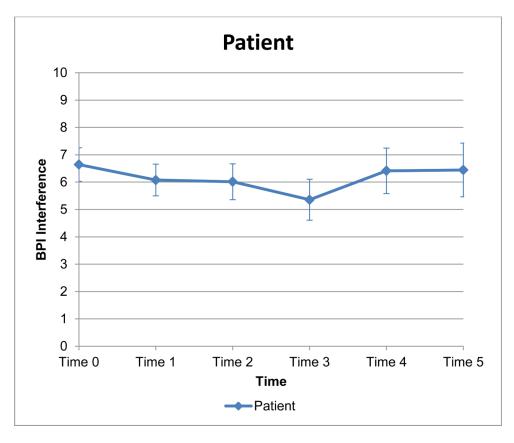


Figure 2. Mean BPI Interference Scores and Associated \pm 1 Standard Errors across the Six Data Collection Times

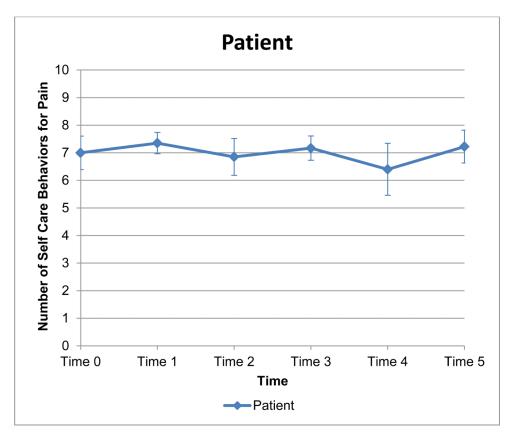


Figure 3. Mean Number of Self-Care Behaviours and Associated \pm 1 Standard Errors across the Six Data Collection Times

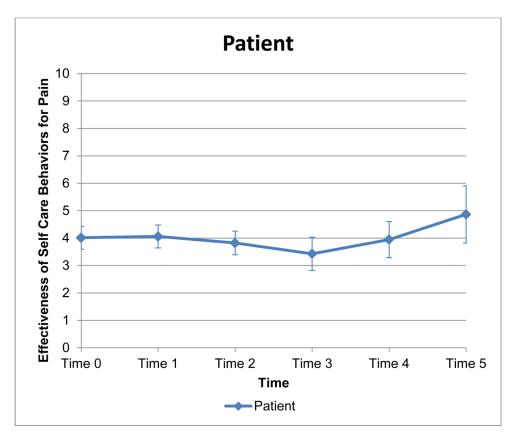


Figure 4. Mean Effectiveness of Self-Care Behaviours and Associated $\pm\,1$ Standard Errors across the Six Data Collection Times

Table 1

Average Percentage of Self-Care Behaviors Performed Across Time as Reported by Patients with End-Stage Liver Disease^{*a*}

Self-care behavior	%
Took a nap	79.8
Watched TV	78.7
Took pain medicine	69.1
Reduced my level of activity	69.1
Asked for help	53.2
Listened to radio, music	41.5
Took a hot bath	36.2
Read a book, newspaper, or magazine	36.2
Went for a walk	35.1
Reduced my work hours	35.1
Did relaxation exercises, meditated	27.7
Used a heating pad or hot water bottle	27.7
Took tranquilizers	23.4
Did exercises (jogging, swimming, etc.)	19.1
Had a massage	10.6
Used an ice pack	10.6
Drank beer, wine, or other alcohol	8.5
Went to a chiropractor	6.4
Went for counseling	6.4
Had a trigger point injection	3.2
Used a transcutaneous electrical stimulator (TENS)	2.1
Did hypnosis	.0
Went for acupuncture treatment	.0
Used magnets	.0

 $^{a}\mathrm{Data}$ are presented in descending relative frequency as indicated by the patient.

Table 2 Average Effectiveness of Self-Care Behaviors Performed Across Time as Reported by Patients with End-Stage Liver Disease^a

Self-care behavior	Mean	SD
Took pain medicine	5.77	2.97
Asked for help	5.66	3.56
Took tranquilizers	5.60	2.52
Took a hot bath	4.71	2.22
Reduced my work hours	4.63	3.69
Did relaxation exercises, meditated	4.20	2.58
Went for counseling	4.17	3.31
Used a transcutaneous electrical stimulator (TENS)	4.00	1.41
Took a nap	3.99	2.82
Reduced my level of activity	3.82	2.93

 $^{a}\mathrm{Data}$ are presented in descending average effectiveness scores by the participant.

Percentage of Patients with End-Stage Liver Disease Taking Pain Medications^a

Dain madication 0 1				
	7	3	4	Ŋ
None, n (%) 6 (30) 6 (30) 6	6 (30)	5 (42)	4 (36)	5 (42)
Non-opioid, n (%) 6 (30) 6 (30)	6 (30)	2 (17)	3 (27)	2 (17)
Weak, n (%) 4 (20) 4 (20)	4 (20)	1 (8)	2 (18)	1 (8)
Strong, n (%) 8 (40) 8 (40) 8 (40)	8 (40)	6 (50)	$6(50)$ $6^{b}(55)$ $7^{b}(58)$	7 ^b (58)
Total N 20 20	20	12	11	12

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		BPI Se	verity	BPI Inter	ference	BPI Severity BPI Interference Number of Self-Care Behaviors for Pain Effectiveness of Self-Care Behaviors for Pain	Behaviors for Pain	Effectiveness of Self-Ca	tre Behaviors for Pain
	Z	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Etiology									
Hepatitis C	6	6.14	1.53	6.89	2.61	8.00	1.80	3.48	1.79
Mixed/Other	9	4.79	2.82	5.50	2.04	6.67	2.73	4.94	1.68
Alcohol	5	5.80	2.46	7.57	3.73	5.60	3.78	3.86	2.17
Liver Transplant Candidacy	~								
Not Candidate	11	5.43	2.62	6.61	3.21	7.55	2.25	4.22	2.09
Candidate	6	5.92	1.55	6.68	2.24	6.33	3.20	3.76	1.65
MELD Score	20								
Pearson r		-0.16		-0.11		-0.06		0.19	

Note. There were no significant associations (*p>.*,05).