



Published in final edited form as:

J Pain Symptom Manage. 2018 July ; 56(1): 44–52. doi:10.1016/j.jpainsymman.2018.03.001.

Psychiatric Comorbidity, Health-Related Quality of Life, and Mental Health Service Utilization Among Patients Awaiting Liver Transplant

Rebecca M. Saracino, PhD,

Department of Psychiatry, Yale School of Medicine, New Haven, Connecticut

Devika R. Jutagir, PhD,

Department of Psychiatry, Yale School of Medicine, New Haven, Connecticut

Amy Cunningham, PsyD,

Department of Psychiatry, Yale School of Medicine, New Haven, Connecticut

Kelly A. Foran-Tuller, PsyD,

Department of Psychiatry, Yale School of Medicine, New Haven, Connecticut

Mary A. Driscoll, PhD,

Department of Psychiatry, Yale School of Medicine, New Haven, Connecticut

William H. Sledge, MD,

Department of Psychiatry, Yale School of Medicine, New Haven, Connecticut

Sukru H. Emre, MD, and

Department of Surgery, Yale School of Medicine, New Haven, Connecticut, Yale-New Haven Transplantation Center, New Haven, Connecticut, USA

Dwain C. Fehon, PsyD

Department of Psychiatry, Yale School of Medicine, New Haven, Connecticut, Yale-New Haven Transplantation Center, New Haven, Connecticut, USA

Abstract

Context.—The prevalence of psychiatric disorders and mental health service utilization among patients with end-stage liver disease awaiting transplant remains understudied.

Objectives.—This study assessed the prevalence of psychological disorders and symptoms with the use of a structured diagnostic interview and self-report measures, and examined patient-reported mental health service utilization and barriers to care.

Methods.—Waitlisted liver transplant candidates ($N = 120$) completed assessments during routine clinic appointments at a single time point.

Address correspondence to: Dwain C. Fehon, PsyD, Department of Psychiatry, Yale School of Medicine, 20 York Street, Fitkin 601, New Haven, CT 06510, USA. dwain.fehon@yale.edu.

Disclosures

The authors of this manuscript have no conflicts of interest to disclose.

Results.—Participants endorsed moderate-to-severe levels of depression (19.2%), anxiety (26.7%), and Post Traumatic Stress Disorder (PTSD) (23.3%). Forty-three percent had received some form of mental health treatment in the recent past, and a range of barriers to accessing mental health services were endorsed. In a subset of 39 participants who received a structure diagnostic assessment, there was a high prevalence of current (51.3%) and past (82.1%) psychiatric disorders. Elevated scores on depression, anxiety, and PTSD measures were associated with significant decrements in health-related quality of life, but were not differentially associated with mental health service utilization.

Conclusion.—There are a significant number of end-stage liver disease patients who could benefit from intervention who are not currently connected to treatment. Many patients do not see the need for accessing services, perhaps because of a lack of insight or knowledge about the benefits of mental health treatment. Future research should determine optimal treatment and service delivery methods for this vulnerable population.

Keywords

Depression; anxiety; liver transplant; health-related quality of life; mental health services; barriers

Introduction

Patients with end-stage liver disease (ESLD) awaiting transplant often face long wait times during which they experience not only deterioration in health,¹ but also ongoing psychosocial stressors associated with chronic illness management.^{2,3} Currently, in the U.S., over 14,000 people are awaiting liver transplantation; every year, 6000 are transplanted and upward of 2000 of these individuals die or become too ill for transplant.⁴ Patients with liver disease often have a history of psychiatric illness such as substance use disorder and depression.⁵ These individuals are inherently at risk for increasing psychological distress as they cope with the stresses of chronic illness and awaiting transplant. Thus, the importance of accurately identifying and intervening with these high-risk patients is vital to optimize quality of life and transplant outcomes over time.

Psychopathology before liver transplant is often associated with poorer transplant outcomes and health-related quality of life (HRQOL⁵). Poor HRQOL among patients with ESLD is associated with increased mortality, regardless of disease severity and complications.^{6–8} Not surprisingly, several studies have established elevated rates of depressive disorders in patients with ESLD, with estimates as high as 64%.^{5,9,10} A meta-analysis of 20 studies found that depression increased the relative risk of post-transplant mortality by 65% (relative risk, 1.65; 95% CI=1.34–2.05).¹⁰ Few studies, however, have focused on assessing additional types of psychological distress during this uncertain waiting period. For example, despite reports of elevated depression prevalence, studies examining anxiety and trauma symptoms among patients with ESLD are rarer.^{11–13} Patients with ESLD with more advanced physical symptoms such as dyspnea may experience elevations in anxiety because of uncomfortable breathlessness, which, in extreme cases, can even lead to panic attacks.^{14,15} Similarly, as in other illnesses, the fatigue associated with advanced disease can prevent individuals from engaging in regular activities, contributing to a lack of positive reinforcement in one's environment and leading to social withdrawal and disengagement.¹⁶

The impact of anxiety and trauma symptoms on physical health has been demonstrated in other seriously medically ill populations such as patients with cancer,¹⁷ heart failure,^{18,19} and end-stage renal disease (ESRD²⁰); these symptoms may first predispose, and second, worsen, health outcomes over time (e.g., adherence, inflammation, mortality). Moreover, a review of the literature does not reveal any formal assessment of patient-reported mental health service utilization or perceived barriers regarding access to psychological services. These gaps in the literature are salient among other transplant populations such as those with ESRD as well, but the present study focuses on those with ESLD as a starting point for future research.

In light of these limitations, the current investigation sought first, to identify the prevalence of symptoms of psychological distress with the use of both a gold standard clinical assessment tool and self-report measures of depression, anxiety, and trauma and second, to conduct a needs assessment regarding patient-reported experiences with mental health service utilization and barriers to access. Relationships between the presence of a psychiatric disorder, clinically significant mood symptoms, HRQOL, and mental health treatment history were also explored to clarify the mental health service needs of this patient population. We hypothesized that there would be a high prevalence of psychiatric disorders and psychological symptoms and that these symptoms would be associated with worse HRQOL. We also hypothesized that many participants would not be engaged in mental health treatment despite significant psychiatric symptoms.

Method

Participants and Procedure

Participants were recruited from the outpatient clinic at the Yale-New Haven Transplantation Center between 2008 and 2011. To be eligible for participation, patients had to be 18 years or older, fluent in English, have ESLD, and currently be on the United Network for Organ Sharing wait-list for liver transplantation. Research personnel approached eligible patients waiting for routine clinic appointments and/or contacted them by telephone and offered them participation in the study. Eligible patients were informed of study procedures, risks, and benefits, and offered participation. In total, 125 of 223 eligible patients agreed and provided written informed consent to participate in the study. This study was approved by the Yale University School of Medicine's Human Investigation's Committee (HIC#0807004087).

All participants completed assessments in a fixed order during a single time point. Medical information was accessed and recorded through the medical records system. All study data were collected by trained research assistants.

Measures

Sociodemographic and Medical Information.—Participants self-reported key demographic variables. Medical information including liver disease etiology, performance status (i.e., Karnofsky Performance Rating Scale²¹), and Model for End-Stage Liver Disease²² score were obtained from patients' medical records.

Mental Health Care Service Utilization.—Participants were asked to indicate whether or not they had received mental health services in the past and in what format (e.g., individual, group, medication), and to rate their satisfaction with those services (i.e., “do you think the therapy was effective?” on a Likert scale from 1 [very unhelpful] to 5 [very helpful]). Participants also indicated perceived barriers to accessing mental health treatment (i.e., selected from a checklist of potential barriers, included items such as “Insufficient money to pay for therapy or counseling” and “Didn’t know how to find treatment”).

Health-Related Quality of Life.—The Medical Outcome Study Short-Form 36 Health Survey²³ measured over-all HRQOL. This widely used measure includes eight subscales that capture both physical and mental health. Higher scores indicate higher HRQOL.

Mood and Psychosocial Functioning.—Research assistants conducted the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) Axis I Disorders (SCID), Clinician Version,²⁴ to determine the presence of psychiatric diagnoses. Depression and anxiety were also assessed for all participants with the *Beck Depression Inventory* (BDI²⁵; Cronbach $\alpha=0.91$) and the *Beck Anxiety Inventory* (BAI²⁶; Cronbach $\alpha=0.94$); higher scores indicate higher levels of symptom severity. The Post Traumatic Stress Disorder (PTSD) Checklist, Civilian Version (PCL-C²⁷; Cronbach $\alpha=0.92$) was also administered; items are summed to a total score, with 36 as the cut-off for indicating the presence of possible PTSD in specialized medical clinics.²⁸

Statistical Analyses

Data missingness was analyzed through both visual inspection of the data set and Little’s test. Five cases were not included because of missing key demographic information; the final sample included in analyses was 120 participants. Missing data were characterized as missing completely at random (see Fernandez et al.²⁹). Descriptive statistics reporting symptom prevalences are provided first; frequency data are provided regarding the barriers to service utilization noted by participants. Chi-squared tests of association were used to determine potential differences in demographic and clinical characteristics among those with and without elevated scores on the BDI, BAI, and PCL-C, and mental health treatment history. Independent samples *t*-tests were used to examine differences on other key variables among participants with a current SCID diagnosis and between those with and without clinically significant BDI, BAI, and PCL-C scores. Cohen’s *d*,³⁰ an indicator of effect size, is reported where relevant. The level of significance was set at an alpha of 0.05 with a two-tailed test. Data were analyzed with Statistical Package for the Social Sciences, Version 25 (IBM Corp., Armonk, NY).

Results

Sample Demographics

Mean age of the sample was 56 (± 8.71) years and 60.8% ($n=73$) of participants were male. Approximately, two-thirds of the sample were white (75.8%, $n=91$) and half were married (50.8%, $n=61$). Half of the sample reported having completed some college, vocational training, or graduate school (49.1%; $n=59$) and 38.3% ($n=46$) completed high school only.

Most participants reported being unemployed and/or collecting disability at the time of assessment (77.5%, $n = 93$; Table 1).

Participants were heterogeneous in primary liver disease etiology: 52% ($n=62$) had hepatitis C virus, followed by 15% ($n=18$) with alcoholic liver disease; and 9.2% ($n=11$) with nonalcoholic steatohepatitis (see Table 1). Model for End-Stage Liver Disease scores ranged from 6 to 26. Karnofsky Performance Rating Scale scores ranged from 40 to 100, with most participants in the 80–90 range (83.3%, $n=100$), indicating that they were generally able to carry out daily activities with minimal illness impact.

Psychosocial Functioning

Approximately, one-third of participants completed SCID interviews ($n = 39$): 51.3% ($n = 20$) met criteria for an existing psychiatric diagnosis (Table 1) and two participants had two concurrent diagnoses. Of participants with complete SCID data, 82.1% ($n = 32$) also met criteria for a past psychiatric diagnosis and nine participants had two past diagnoses.

Participants endorsed a range of current depressive, anxiety, and trauma symptoms (Table 2). Moderate-to-severe levels of anxiety were reported by one-fourth of the sample (26.7%, $n = 32$) and 19.2% ($n = 23$) endorsed moderate-to-severe depressive symptoms. For symptoms of PTSD, 23.3% ($n = 28$) of participants scored at or above the cut-off indicating the presence of significant trauma symptoms. These measures were significantly correlated with one another (i.e., Pearson r ranged from 0.49 to 0.60).

Compared with population means,²³ the sample reported lower HRQOL across several domains: Physical Functioning, Role Limitations—Physical, Social Functioning, Pain, and General Health Short-Form 36 Health Survey subscales (Table 3).

Mental Health Service Utilization

In total, 43% ($n = 52$) of the sample endorsed having received mental health treatment in the past and/ or at the time of study participation. Of these, one-third (33.3%; $n = 40$) had received individual treatment and gave it a mean rating of 3.78 (i.e., on a scale of 1–5; $SD=1.24$; Table 4) for perceived effectiveness, followed in frequency by “self-help programs” (e.g., Alcoholics Anonymous, Overeaters Anonymous) endorsed by 11.7% ($n = 14$) of the sample and given a mean effectiveness rating of 4.1 ($SD=1.20$). In addition, 22.5% ($n = 27$) of participants reported that they were currently taking psychotropic medications and 12.5% ($n = 15$) reported the use of psychotropic medications before being listed on the transplant waiting list. Patients reported a range of barriers to accessing mental health treatment (see Table 4).

Relationships Between Psychosocial Variables

Chi-squared tests of association revealed no significant differences in demographic or clinical characteristics between those with and without clinically significant anxiety and depressive symptoms. Participants who reported elevated trauma symptoms, however, tended to have fewer years of education than their less symptomatic counterparts ($\chi^2 [10, N = 113] = 20.77, P < 0.02$).

Among those completing the SCID, independent samples *t*-tests indicated that self-reported anxiety ($t[37] = -0.88, P = 0.38$), depressive ($t[37] = -0.72, P = 0.48$), and trauma symptoms ($t[37] = -0.48, P = 0.63$) were not significantly different between those participants with and without a current SCID diagnosis. However, those with a current SCID diagnosis reported significantly worse emotional mental health HRQOL ($t[37] = 2.39, P = 0.02$; Table 3) compared with those without a diagnosis.

Regardless of SCID diagnosis, participants with significant levels (i.e., at or above “moderate” cut-off score) of self-reported depression, anxiety, and trauma had worse scores across most HRQOL domains ($P < 0.001$; see Table 3 for effect sizes). There were two domains of HRQOL that were not consistently significantly different between clinical groups. Pain was not significantly different between anxious/not anxious ($t[115] = 0.72, P = 0.38$), depressed/not depressed ($t[116] = 1.68, P = 0.10$), and trauma symptom severity participants ($t[115] = 0.92, P = 0.36$). Similarly, social functioning was not significantly different between depressed and non-depressed ($t[115] = 1.31, P = 0.19$) nor between trauma symptom severity groups ($t[114] = 0.79, P = 0.43$).

Mental health treatment history was not associated with the presence of a current SCID diagnosis ($\chi^2 [1, N = 39] = 0.03, P = 1.00$), nor was current clinically significant depressive symptoms ($\chi^2 [2, N = 119] = 2.55, P = 0.28$), anxiety symptoms ($\chi^2 [2, N = 118] = 3.55, P = 0.17$), or trauma symptoms ($\chi^2 [2, N = 118] = 2.91, P = 0.23$).

Discussion

Patients with ESLD who are awaiting a transplant are susceptible to a number of psychosocial stressors related to illness management and often, pre-existing psychiatric symptoms.⁵ This study first characterized the nature of psychological distress across domains (e.g., depression, anxiety, and trauma-related symptoms) and second, assessed patient-reported experiences with mental health service utilization and barriers to access.

As in a handful of previous studies,^{5,9–13} participants reported high levels of depression and anxiety such that one-third of participants endorsed at least mild levels of these symptoms. Of those participants interviewed with the SCID, over half met criteria for a current psychiatric diagnosis, and the majority also met criteria for a past diagnosis. In addition, nearly one-quarter of the sample reported clinically significant levels of trauma symptoms. This is one of the first studies to document the high prevalence of trauma symptoms among patients with ESLD, and provides an indication that the longitudinal course and impact of trauma symptoms on both the etiology and progression of disease, as well as post-transplant outcomes should be further studied. For example, patients who experienced their disease as traumatic may avoid attending follow-up appointments or be susceptible to substance use relapse both during and after transplant. Connection to mental health services during this time could be the difference between life and death for many of these patients.

Interesting relationships between indicators of psychological stress emerged. First, there were no significant differences on self-report of depression, anxiety, and trauma-related symptoms between those with and without a current psychiatric diagnosis, which supports

the notion that psychological support services should be routinely offered to waitlisted patients. Emotional role functioning and mental health HRQOL were significantly worse among those participants with psychiatric diagnoses. This suggests that sole reliance on the presence or absence of psychiatric illness is inadequate when identifying those patients with ESLD who are experiencing elevations in mood symptoms. Instead, repeat screening for these symptoms should be integrated into routine clinical practice for all patients presenting to transplant clinics.

Those participants with elevated depression, anxiety, and trauma scores had significantly worse HRQOL on most domains. However, pain and social functioning were not consistently different between those with and without clinically significant scores. Thus, even patients without clinically significant mood symptoms may benefit from intervention tailored to these specific presenting problems. HRQOL scores in the current sample were comparable, but consistently lower across all domains relative to those identified in previous studies of patients with other advanced illness, where deficits were restricted to only select domains (e.g., ESRD,³¹ cancer,³² congestive heart failure³³). The presence of poorer pain-related HRQOL in this sample is also consistent with past studies that have found moderate levels of pain in upward of 77% of waitlisted patients with ESLD.^{34,35} These findings suggest the potential benefit of focusing interventions on cognitive behavioral interventions for pain to help ESLD patients cope with ongoing symptoms. Social functioning has received less research attention in this patient population, but the benefits of improving patients' social connectedness have been documented in other chronically ill patient populations.^{36–38} The recent pilot work of Bailey et al.^{39,40} to develop an uncertainty management intervention focused on coping skills and symptom management for patients with ESLD also has great promise for this patient population.

Forty-three percent of participants reported receiving mental health treatment at some point in their lifetime, and those who had engaged in treatment reported high levels of satisfaction with the efficacy of these treatments. However, those meeting criteria for a current psychiatric diagnosis and those with clinically significant elevations on self-report measures were no more likely to have received treatment than their less distressed peers. In addition, only a very small percentage of participants cited barriers to accessing mental health services. In fact, although all participants were asked to indicate barriers, only a very small percentage of the sample indicated any barriers to treatment (Table 4). These results were surprising given the obvious elevation in psychological symptoms for many participants. Although it is possible that this section of the questionnaire was subject to an order effect (i.e., it was the last page of the self-reported demographic questionnaire), the findings are so striking that other processes are also likely to be involved. For example, 5.0% of participants did not feel they “had any problems” that warranted treatment. It is possible that those participants who did not indicate any barriers on this checklist self-selected out of this part of the questionnaire, indicating that they did not feel it was relevant to them, but this is only speculative, at best. Although “not having any problems” may be true for some patients, our results do indicate a high prevalence of psychiatric symptoms and impaired HRQOL, including many with past substance use disorders. Borrowing from the substance use literature provides putative explanations. Substance use disorders have some of the lowest treatment rates. One large epidemiological study found that 55.3% of patients with alcohol

use disorder reported the largest barrier to seeking treatment was “lack of problem awareness”.⁴¹ Although the waitlisted participants in the present study did not have active substance use disorders, 76.8% (Table 1) of them did in the past. Thus, perhaps underlying personality and coping characteristics of these patients persist even during recovery.

Regardless of the explanation for low indication of barriers to treatment, these patterns suggest that there is room for improvement in connecting patients who are in need of treatment through outreach and psychoeducation about the benefits of treatment. There is not only a clear need for addressing patients’ psychological needs in this setting, but first to educate patients and providers about the potential benefits of mental health treatment during this time. Given that those patients who were successfully connected to mental health treatment generally found it to be efficacious, a primary issue appears to be connecting patients to these services in the first place, or reconnecting them to services once they become patients in the transplant clinic. Although the results of the present and other studies among patients with liver disease document mental health concerns,^{5,9–13} there are no clear guidelines for ongoing mental health screening and intervention in liver transplant clinics. Recommendations for psychosocial evaluation of transplant candidates exist,⁴² but the literature is scant with regard to management of these patients during routine follow-up, or after they have been declined for transplant.

Despite its contributions, there are several limitations of the current investigation. First, these data were collected within a single transplantation clinic. Thus, the generalizability of the data is limited and geographic and clinic-specific differences would likely account for additional variability in patient-reported psychosocial stress experiences. There were no data available regarding the psychiatric comorbidity among those patients who presented for liver transplant evaluation but were not waitlisted, nor among those who declined to participate in the study. In addition, because of changes in study resources, the SCID was discontinued and therefore we did not assess the entire sample with regard to formal psychiatric diagnoses. Taken together, these limitations mean that the current findings likely underestimate the prevalence and severity of psychopathology in this population. Similarly, the sample was predominately non-Hispanic white and the application of these findings to other racial and ethnic minority groups is limited. In addition, the data were collected at a single time point and relied heavily on patient self-report. For unknown reasons, many participants did not endorse barriers to mental health services. Whether this reflects a genuine lack of perceived barriers or an artifact of measurement (e.g., ordering effect is possible given that these questions were at the end of the demographic questionnaire) cannot be determined. Because of limitations in sample size, relationships between psychosocial variables and liver disease etiology could not be determined and we did not have information related to time on waitlist, which may have important relationships with the variables explored here. Future research should focus on differentiating the psychiatric sequelae associated with different disease etiologies, as subgroups are likely to have differing psychopathology and health risk behaviors (e.g., substance use history, obesity, etc.). Although these data were collected beginning in 2008, the findings still represent an important contribution to the literature given that there have been no published needs assessments or reports on ESLD patients’ mental health service utilization.

Future research endeavors should examine psychological functioning and its relationship to liver disease longitudinally with the aim of identifying those patients who are most at risk for poor outcomes or “falling through the cracks” during follow-up. These studies should include multiple transplant centers with racially and ethnically diverse patient populations to address potential subgroup differences. In addition, the elevated prevalence of depressive, anxiety, and trauma symptoms in the current sample, coupled with the reported lack of connection to ongoing psychiatric care services underscores the need for the development of interventions that are tailored to the unique needs of this population. For example, managing pre-transplant stress and learning techniques to engage social supports could bolster patients’ ability to navigate the transplant experience, facilitating better psychosocial adaptation and medical outcomes over time.

In sum, this study demonstrated a high prevalence of psychiatric diagnoses, depressive, anxiety, and trauma symptoms among ESLD patients awaiting transplant. This was one of the only studies to use a gold standard psychiatric interview in combination with self-report measures; we demonstrated their relationships with poor HRQOL across domains. The disconnection revealed between those experiencing clinically significant psychological symptoms and those connected to mental health services suggests that clinical and research attention should be focused on the development and implementation of mental health interventions aimed at ameliorating distress and undue suffering among patients with ESLD.

Acknowledgments

This research was supported by funding from the George D. & Esther S. Gross Endowment and the National Cancer Institute (2T32CA009461-31). The funding sources had no role in study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the article for publication.

References

1. Lai JC. Defining the threshold for too sick for transplant. *Curr Opin Organ Transplant* 2016;21:127–132. [PubMed: 26825359]
2. Sinclair M, Poltavskiy E, Dodge JL, Lai JC. Frailty is independently associated with increased hospitalisation days in patients on the liver transplant waitlist. *World J Gastroenterol* 2017;23:899. [PubMed: 28223735]
3. Stewart KE, Hart RP, Gibson DP, Fisher RA. Illness apprehension, depression, anxiety, and quality of life in liver transplant candidates: implications for psychosocial interventions. *Psychosomatics* 2014;55:650–658. [PubMed: 24360533]
4. Kim WR, Lake JR, Smith JM, et al. OPTN/SRTR 2015 annual data report: liver. *Am J Transplant* 2017;17:174–251. [PubMed: 28052604]
5. Grover S, Sarkar S. Liver transplantdpsychiatric and psychosocial aspects. *J Clin Exp Hepatol* 2012;2:382–392. [PubMed: 25755459]
6. Kanwal F, Hays RD, Kilbourne AM, Dulai GS, Gralnek IM. Are physician-derived disease severity indices associated with health-related quality of life in patients with end-stage liver disease? *Am J Gastroenterol* 2004;99: 1726–1732. [PubMed: 15330910]
7. Kanwal F, Gralnek IM, Hays RD, et al. Health-related quality of life predicts mortality in patients with advanced chronic liver disease. *Clin Gastroenterol Hepatol* 2009;7: 793–799. [PubMed: 19306949]
8. Orr JG, Homer T, Ternent L, et al. Health related quality of life in people with advanced chronic liver disease. *J Hepatol* 2014;61:1158–1165. [PubMed: 25010259]

9. Baumann AJ, Wheeler DS, James M, Turner R, Siegel A, Navarro VJ. Benefit of early palliative care intervention in end-stage liver disease patients awaiting liver transplantation. *J Pain Symptom Manage* 2015;50:882–886. [PubMed: 26303186]
10. Dew MA, Rosenberger EM, Myaskovsky L, et al. Depression and anxiety as risk factors for morbidity and mortality after organ transplantation: a systematic review and meta-analysis. *Transplantation* 2015;100:988. [PubMed: 26492128]
11. Potosek J, Curry M, Buss M, Chittenden E. Integration of palliative care in end-stage liver disease and liver transplantation. *J Palliat Med* 2014;17:1271–1277. [PubMed: 25390468]
12. Santos GR, Boin IF, Pereira MI, et al. Anxiety levels observed in candidates for liver transplantation. *Transplant Proc* 2010;42:513–516. [PubMed: 20304181]
13. Peng JK, Hepgul N, Higginson IJ, Gao W. Symptom prevalence of patients with end-stage liver disease: a systematic review. *BMJ Support Palliat Care* 2016;6:401–402.
14. Kaltsakas G, Antoniou E, Palamidis AF, et al. Dyspnea and respiratory muscle strength in end-stage liver disease. *World J Hepatol* 2013;5:56. [PubMed: 23646230]
15. Smoller JW, Pollack MH, Otto MW, Rosenbaum JF, Kradin RL. Panic anxiety, dyspnea, and respiratory disease. Theoretical and clinical considerations. *Am J Respir Crit Care Med* 1996;154:6–17. [PubMed: 8680700]
16. Eisenberger NI, Inagaki TK, Mashal NM, Irwin MR. Inflammation and social experience: an inflammatory challenge induces feelings of social disconnection in addition to depressed mood. *Brain Behav Immun* 2010;24:558–563. [PubMed: 20043983]
17. Palmer SC, Kagee A, Coyne JC, DeMichele A. Experience of trauma, distress, and posttraumatic stress disorder among breast cancer patients. *Psychosom Med* 2004;66: 258–264. [PubMed: 15039512]
18. Garfield LD, Scherrer JF, Hauptman PJ, et al. Association of anxiety disorders and depression with incident heart failure. *Psychosom Med* 2014;76:128. [PubMed: 24434950]
19. Watkins LL, Koch GG, Sherwood A, et al. Association of anxiety and depression with all-cause mortality in individuals with coronary heart disease. *J Am Heart Assoc* 2013;2: e000068. [PubMed: 23537805]
20. Corruble E, Durrbach A, Charpentier B, et al. Progressive increase of anxiety and depression in patients waiting for a kidney transplantation. *Behav Med* 2010;36:32–36. [PubMed: 20185399]
21. Karnofsky DA, Burchenal JH. The clinical evaluation of chemotherapeutic agents in cancer. In: MacLeod CM, ed. *Evaluation of Chemotherapeutic Agents* New York: Columbia University Press, 1949.
22. Kamath PS, Kim WR. The model for end-stage liver disease (MELD). *Hepatology* 2007;45:797–805. [PubMed: 17326206]
23. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Med Care* 1992;30:473–483. [PubMed: 1593914]
24. First MB, Spitzer RL, Gibbon M, Williams J. *Structured Clinical Interview for DSM-IV Axis I Disorders, Clinician Version (SCID-CV)* Washington, DC: American Psychiatric Press, Inc, 1996.
25. Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Arch Gen Psychiatry* 1961;4:561–571. [PubMed: 13688369]
26. Beck AT, Epstein N, Brown G, Steer RA. An inventory for measuring clinical anxiety: the Beck Anxiety Inventory. *J Consult Clin Psychol* 1988;56:893–897. [PubMed: 3204199]
27. Weathers FW, Litz BT, Herman D, Huska J, Keane T. *The PTSD Checklist-Civilian Version (PCL-C)* Boston, MA: National Center for PTSD, 1994.
28. National Center for PTSD. *Using the PTSD Checklist (PCL)* Washington, DC: U.S. Department of Veteran Affairs, 2012.
29. Fernandez AC, Fehon DC, Treloar H, Ng R, Sledge WH. Resilience in organ transplantation: an application of the Connor-Davidson Resilience Scale (CDerISC) with liver transplant candidates. *J Pers Assess* 2015;97:487–493. [PubMed: 25915726]
30. Cohen J *Statistical power analysis for the behavioral sciences*, 2nd ed. Hillsdale, NJ: Erlbaum, 1988.

31. Blake C, Codd MB, Cassidy A, O'Meara YM. Physical function, employment and quality of life in end-stage renal disease. *J Nephrol* 2000;13:142–149. [PubMed: 10858978]
32. Shadbolt B, Barresi J, Craft P. Self-rated health as a predictor of survival among patients with advanced cancer. *J Clin Oncol* 2002 5 15;20:2514–2519. [PubMed: 12011130]
33. Juenger J, Schellberg D, Kraemer S, et al. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. *Heart* 2002;87:235–241. [PubMed: 11847161]
34. Hansen L, Leo MC, Chang MF, Zucker BL, Sasaki A. Pain and self-care behaviours in adult patients with end-stage liver disease: a longitudinal description. *J Palliat Care* 2014;30:32–40. [PubMed: 24826441]
35. Madan A, Barth KS, Balliet WE, et al. Chronic pain among liver transplant candidates. *Prog Transplant* 2012; 22:379–384. [PubMed: 23187056]
36. Efficace F, Innominato PF, Bjarnason G, et al. Validation of patient's self-reported social functioning as an independent prognostic factor for survival in metastatic colorectal cancer patients: results of an international study by the Chronotherapy Group of the European Organisation for Research and Treatment of Cancer. *J Clin Oncol* 2008;26: 2020–2026. [PubMed: 18421055]
37. Jason L, Brown M, Evans M, et al. Measuring substantial reductions in functioning in patients with chronic fatigue syndrome. *Disabil Rehabil* 2011;33:589–598. [PubMed: 20617920]
38. Barth J, Schneider S, von Känel R. Lack of social support in the etiology and the prognosis of coronary heart disease: a systematic review and meta-analysis. *Psychosom Med* 2010; 72:229–238. [PubMed: 20223926]
39. Bailey DE, Jr, Steinhauser K, Hendrix C, Tulskey JA. Pairing self-management with palliative care: intervening in life-limiting illness. *J Nurs Healthc Chronic Illn* 2011;3:1–3. [PubMed: 21643547]
40. Bailey DE, Hendrix CC, Steinhauser KE, et al. Randomized trial of an uncertainty self-management telephone intervention for patients awaiting liver transplant. *Patient Educ Couns* 2017;100:509–517. [PubMed: 28277289]
41. Probst C, Manthey J, Martinez A, Rehm J. Alcohol use disorder severity and reported reasons not to seek treatment: a cross-sectional study in European primary care practices. *Subst Abuse Treat Prev Policy* 2015;10:1. [PubMed: 25575428]
42. Morana JG. Psychological evaluation and follow-up in liver transplantation. *World J Gastroenterol* 2009;15:694. [PubMed: 19222092]

Table 1Demographic and Medical Characteristics of the Sample (*N* = 120)

Participant Characteristic	<i>n</i> (%)	
Age, yrs (mean [SD]; range)	56.0 (8.7)	27.0–76.0
Gender		
Male	73 (60.8)	–
Female	47 (39.2)	–
Race/Ethnicity		
White	91 (75.8)	–
Black	12 (10.0)	–
Hispanic	11 (9.2)	–
American Indian/Alaskan Native	1 (0.8)	–
Other	3 (2.5)	–
Marital status		
Married or cohabiting	61 (50.8)	–
Separated	4 (3.3)	–
Divorced	29 (24.2)	–
Widowed	5 (4.2)	–
Single	19 (15.8)	–
Occupational status		
Full-time	20 (16.7)	–
Part-time	5 (4.2)	–
Unemployed	34 (28.3)	–
Disability	59 (49.2)	–
Income ^a		
<5000	6 (5.0)	
5000–19,999	26 (21.7)	
20,000–34,999	19 (15.8)	
35,000–49,999	12 (10.0)	
50,000–64,999	8 (6.7)	
65,000–89,999	10 (8.3)	
90,000–119,999	13 (10.8)	
120,000 or more	5 (4.2)	
Liver disease etiology ^b		
HCV	62 (51.7)	–
ALD	18 (15.0)	–
HCC alone	2 (1.7)	–
NASH	11 (9.2)	–
Other ^c	26 (21.7)	–
HCC status		
Yes	30 (25.0)	–

Participant Characteristic	n (%)	
No	89 (74.2)	
Disease severity		
MELD	12.50 (4.5)	6.0–26.0
Karnofsky	85.0 (9.0)	40.0–100.0
Current psychiatric diagnosis (<i>n</i> = 39) ^d		
Anxiety disorder	5 (12.8)	–
Depressive disorder	10 (25.6)	–
Adjustment disorder	6 (15.4)	–
Binge eating disorder	1 (2.6)	–
No diagnosis	19 (48.7)	–
Not assessed/incomplete	81	–
Past psychiatric diagnosis		
Alcohol use disorder	20 (51.3)	–
Cocaine dependence	2 (5.1)	–
Depressive disorder	7 (17.9)	–
Heroin dependence	2 (5.1)	–
Marijuana abuse	2 (5.1)	–
Opioid dependence	2 (5.1)	–
Panic disorder	1 (2.6)	–
Polysubstance dependence	5 (5.1)	–
No diagnosis	7 (17.9)	–
Not assessed/incomplete	81	–

HCV = hepatitis C virus; ALD = alcoholic liver disease; HCC = hepatocellular carcinoma; NASH = nonalcoholic steatohepatitis; MELD = Model for End-Stage Liver Disease; SCID = Structured Clinical Interview for DSM-IV Axis I Disorders.

^aIncome in U.S. dollars.

^bThese data were collected between 2008 and 2011; subsequently there has been a national decline in the number of waitlisted patients with HCV because of the introduction of antiviral agents in late 2014.⁴

^cOther diagnoses include genetic, metabolic, autoimmune, and unknown etiologies of liver disease.

^dThe SCID was removed from the study protocol because of time and resource limitations. Two patients met criteria for two current DSM-IV diagnoses.

Table 2

Depression, Anxiety, and Trauma-Related Symptom Scores

Scoring Guidelines	Measure
	BDI
0–13 (minimal)	64.2% (<i>n</i> = 77)
14–19 (mild)	15.8% (<i>n</i> = 19)
20–28 (moderate)	14.2% (<i>n</i> = 17)
Severe (29–63)	5.0% (<i>n</i> = 6)
	BAI
0–7 (minimal)	55.0% (<i>n</i> = 66)
8–15 (mild)	16.7% (<i>n</i> = 20)
16–25 (moderate)	16.7% (<i>n</i> = 20)
26–63 (severe)	10.0% (<i>n</i> = 12)
	PCL-C
0–35 (minimal)	75.0% (<i>n</i> = 90)
36 (clinically significant)	23.3% (<i>n</i> = 28)

BDI=Beck Depression Inventory; BAI=Beck Anxiety Inventory; PCL-C=PTSD Checklist, Civilian Version.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 3

Effect Sizes (Cohen's *d*) of Differences in SF-36 HRQOL Domains Between Those Participants With and Without Clinically Significant Elevations on Psychological Symptom Measures

SF-36 Domain	M (SD)	SCID, <i>d</i>	BAI, <i>d</i>	BDI, <i>d</i>	PCL-C, <i>d</i>
Physical functioning	56.72 (30.9)	0.15	0.99 ^a	1.15 ^a	0.61 ^a
Role physical	35.29 (41.61)	0.41	0.94 ^a	0.99 ^a	0.68 ^a
Role emotional	65.00 (43.83)	0.54	1.19 ^a	1.17 ^a	0.73 ^a
Vitality	48.69 (22.59)	0.27	0.91 ^a	1.20 ^a	0.65 ^a
Mental health	70.05 (19.22)	0.77 ^a	1.11 ^a	1.22 ^a	1.10 ^a
Social functioning	48.73 (11.01)	0.25	0.46 ^a	0.25	0.17
Pain	53.66 (10.22)	0.10	0.17	0.35	0.21
General health	45.56 (14.37)	0.13	1.03 ^a	0.96 ^a	0.76 ^a

SF-36 = Short-Form 36 Health Survey; HRQOL = health-related quality of life; SCID = Structured Clinical Interview for DSM-IV Axis I Disorders; BAI = Beck Anxiety Inventory; BDI = Beck Depression Inventory; PCL-C = PTSD Checklist, Civilian Version.

^aIndicates between group differences using independent samples *t*-test at the $P < 0.01$ significance level; Cohen's *d* 0.2 = small effect, *d* 0.5 = medium effect, and *d* 0.8 = large effect.³⁰

Table 4
Mental Health Service Utilization and Access Barriers Reported by All Study Participants

Treatment Type	Frequency, n (%)	Perceived Effectiveness, Mean (SD)
No treatment	62 (51.7)	–
Any treatment	52 (43.3)	–
Individual	40 (33.3)	3.78 (1.24)
Group	11 (9.2)	4.0 (.94)
Family/couples	5 (4.2)	3.75 (1.26)
Medication only	11 (9.2)	3.86 (.90)
Self-help	14 (11.7)	4.10 (1.20)
Other	8 (5.7)	3.33 (1.60)
Barriers to treatment access		
	Frequency n (%)	
Insufficient money to pay for therapy or counseling	6 (5.0)	
Therapy or counseling has not been effective	1 (0.8)	
Does not believe he/she has any problems	5 (4.2)	
Does not believe in going to therapy for these problems	1 (0.8)	
Did not know how to find treatment	1 (0.8)	
Insufficient time to attend treatment	2 (1.7)	
Stigma of treatment (e.g., worried someone would find out, embarrassed)	0 (0.0)	
Believed treatment received was adequate and problems are solved	2 (1.7)	
Other reason	6 (5.0)	
Not (psychologically) ready to address problems	2 (1.7)	