

Patients' Expectations and Success Criteria for Liver Transplantation

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Patient-reported outcomes are important to consider when the relative success of liver transplantation (LT) is being evaluated. Our primary objective was to examine the expectations for LT and the criteria for its success across 4 domains of functioning (pain, fatigue, emotional distress, and interference with daily activities) from the perspective of patients who were wait-listed for LT. One hundred four adult patients with a mean wait-list time of 16.5 ± 13 months completed a semi-structured interview with a modified version of the Patient-Centered Outcomes Questionnaire (PCOQ). The patients reported moderate usual levels of pain, fatigue, emotional distress, and interference with daily activities (mean rating range = 3.8-6.2), and they attached great importance to improvements in these domains after LT (mean rating range = 7.3-8.0). Patients considered a mean reduction in pain of 33% to be a successful LT outcome. A reduction in fatigue of 56%, a reduction in emotional distress of 44%, and a reduction in interference with daily activities of 54% represented successful LT across these domains. Patients with more severe illness had higher expectations for fatigue ($r = -0.30$, $P = 0.002$) and interference with daily activities ($r = -0.24$, $P = 0.015$). Cluster and correlational analyses provided support for the validity of the PCOQ with LT patients. Our findings underscore the importance and value of using patient-centered assessments to better understand the ways in which patients prioritize LT outcomes and define transplantation success. Patient-centered assessments have the potential to facilitate provider-patient communication by helping patients to prioritize their goals for LT and make informed choices on the basis of those priorities. *Liver Transpl* 17:1309-1317, 2011. © 2011 AASLD.

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Liver transplantation (LT) offers patients with end-stage liver disease the opportunity for longer survival and improved quality of life.^{1,2} In the United States, the unadjusted patient and graft survival rates are 88% and 84% at 1 year, respectively, and 74% and 68% at 5 years, respectively.¹ The success of LT and programs offering LT have largely been evaluated on the basis of these patient and graft survival outcomes. Moreover, for decisions about the approval or re-approval of LT programs, the Centers for Medicare and Medicaid Services considers a transplant program's expected 1-year patient and graft survival rates (risk-adjusted) and its observed patient and graft survival rates.³

Certainly, patients pursuing LT want to live a longer life. However, it is likely that patients evaluate the success of transplantation on the basis of not only their long-term survival but also the reduction of their symptoms and the improvement of their quality of life. Indeed, patient-reported outcomes should be considered when the success of any medical intervention is being evaluated. The World Health Organization, for instance, has stressed the importance of a patient's subjective perception of life in the context of his or her value systems, goals, expectations, and standards when the benefits of medical interventions are being evaluated.⁴ There are numerous studies on the

Abbreviations: CTP, Child-Turcotte-Pugh; LT, liver transplantation; MELD, Model for End-Stage Liver Disease; PCOQ, Patient-Centered Outcomes Questionnaire; SF-36, Short Form 36.

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quality of life before and after LT,⁵⁻⁸ but they have not shed light on what constitutes successful transplantation or clinically important improvements in functioning from the patient's perspective.

Only 1 published study has examined patients' expectations for LT. Holzner et al.⁹ interviewed 55 LT recipients from a transplant program in Germany, and they found that two-thirds of the patients who had expected their lives to normalize after LT did not feel that this expectation had been met. Although this study offers important insights into patient expectations, it is limited: patients were asked a single general question about whether they felt that life would be normal after LT, the study asked recipients to retrospectively report expectations that they had several years earlier, and it did not assess what criteria patients used to assess the success of LT. Therefore, the primary aims of our study were to examine the expectations for LT, to define successful LT from the perspective of patients wait-listed for LT, and to determine the relationships between these parameters and certain sociodemographic and medical variables.

PATIENTS AND METHODS

Study Design, Setting, and Participants

This study was performed over a 10-month period at Beth Israel Deaconess Medical Center (Boston, MA). Patients who were scheduled for a routine appointment at the outpatient clinic for transplant hepatology were evaluated for study eligibility. Eligible patients were on the waiting list for LT, were at least 18 years old, and spoke English. Patients were excluded if they were listed for retransplantation or combined liver-kidney transplantation or if they were acutely ill and were unable to provide informed consent or take part in the study procedures. All study procedures were approved by the Beth Israel Deaconess Medical Center institutional review board.

Assessment

Patients who provided written, informed consent participated in a semistructured interview with a modified version of the Patient-Centered Outcomes Questionnaire (PCOQ), which has been validated for use with other medical conditions.^{10,11} The PCOQ interview guided patients through a series of questions about 4 domains of functioning: pain, fatigue, emotional distress, and interference with daily activities. The interviewer stated the following:

Many patients with liver disease experience pain/discomfort, fatigue, emotional distress (worries, sadness, etc.), and interference with daily activities (not being able to work, do chores, or enjoy hobbies). We would like to understand how you have been impacted in each of these areas. We would also like to know more about what you want your transplant to do for you.

First, patients were asked to use a numerical rating scale [0 (none) to 10 (worst imaginable)] to indicate their usual levels of pain, fatigue, emotional distress, and interference with daily activities during the past week. Second, patients used the same numerical rating scale to indicate their desired level of functioning in these domains if they had an ideal transplant outcome. Third, patients rated the level of functioning that they would need to achieve in each domain for them to consider LT successful (the success level). Fourth, patients were asked to indicate the levels of pain, fatigue, emotional distress, and interference with daily activities that they expected after LT (the expected level). Finally, patients used a different numerical rating scale [0 (not at all important) to 10 (extremely important)] to rate how important it was for them to see improvements after LT in each of the 4 domains (the importance level).

The Short Form 36 (SF-36) health survey (version 2),¹² which assesses health-related quality of life, also was administered to the patients. This measure has 8 subscales: Physical Functioning (the extent to which health limits physical activities such as self-care, walking, climbing stairs, bending, lifting, and other moderate to vigorous activities), Role-Physical [the extent to which physical health interferes with work or other daily activities (eg, less than desired is accomplished, or the types of activities are limited)], Role-Emotional [the extent to which emotional problems interfere with work or other daily activities (eg, the productivity or quality of time spent on activities is reduced)], Bodily Pain (the intensity of pain and the effect of pain on activities), General Health (a personal evaluation of a patient's health, health outlook, and perceived resiliency to illness), Vitality (the extent of feelings of energy versus feelings of fatigue), Social Functioning (the extent to which physical health or emotional problems interfere with normal social activities), and Mental Health (general mental health, including depression, anxiety, behavioral-emotional control, and positive affect). These subscales are included in 2 composite scores: the Physical Component Summary and the Mental Component Summary. The subscale and composite scores are standardized to the general population with a mean score of 50 and a standard deviation of 10; higher scores reflect better quality of life. The administration of the SF-36 health survey (version 2) allowed us to examine the relationship between the patients' quality of life and their expectations and success criteria for LT and to evaluate the concurrent validity of the PCOQ in the transplant setting.

The following information was also retrieved from each patient's medical records: age, sex, race, marital status, education, employment status, primary liver disease etiology, and current disease severity [as measured by the most recently calculated laboratory Model for End-Stage Liver Disease (MELD) score¹³ and the Child-Turcotte-Pugh (CTP) score^{14,15}]. The MELD score was calculated as follows:

$$\begin{aligned} \text{MELD score} = & [0.957 \times \log_e \text{Creatinine (mg/dL)} \\ & + 0.378 \times \log_e \text{Bilirubin (mg/dL)} + 1.12 \\ & \times \log_e \text{International normalized ratio} \\ & + 0.64] \times 10 \end{aligned}$$

The CTP score was determined by the presence and grade of encephalopathy, the presence and severity (mild/moderate or severe) of ascites, the bilirubin level, the albumin level, and the prothrombin time or international normalized ratio.

Statistical Analysis

All data were coded and entered into the PASW Statistics database (version 17.0, SPSS, Inc., Chicago, IL) for analysis. The data are expressed as means and standard deviations, as medians, or as percentages of the participants with specific responses. Pearson correlations, independent *t* tests, and 1-way analyses of variance were used to assess the relationships between the PCOQ ratings and sociodemographic characteristics, medical variables, and subscale scores of the SF-36 health survey (version 2). We performed paired *t* tests to look across PCOQ domains for differences in the amount of change necessary for LT to be considered successful. Paired *t* tests were also used to assess whether patients' success criteria differed from their expected post-LT outcomes across the 4 PCOQ domains. A hierarchical exploratory cluster analysis was performed to identify subgroups or clusters of patients according to their importance ratings for each of the PCOQ domains. We then conducted 1-way analyses of variance to look for cluster differences in relevant sociodemographic and medical variables. Statistical significance was set at *P* < 0.05.

RESULTS

Patient Characteristics

The patients were recruited as part of a larger study assessing patients' quality of life, willingness to accept expanded criteria donor LT, and perceptions of success criteria for LT. We previously reported data on the willingness to accept expanded criteria donor LT.¹⁶ One hundred four of the 132 patients who were eligible for the study completed all study requirements and were included in the final analysis. Twenty-four patients refused to participate in the study, and 4 patients discontinued their participation after they had consented; the overall participation rate was 79%.

The mean age was 54.4 years, 71% were male, 53% were married, 30% were employed, and 30% had a college degree; 79% were white, 9% were black, 7% were Hispanic, 3% were Asian, and 2% were other. The mean time on the LT waiting list was 16.5 ± 13 months, most patients had viral hepatitis (54%) or alcohol abuse (25%) as their primary liver disease etiology (8% had an autoimmune or cholestatic etiology,

TABLE 1. Scores for Each PCOQ Domain

PCOQ Domain	Mean ± Standard Deviation	Range
Usual level*		
Pain	3.8 ± 2.9	0-10
Fatigue	6.2 ± 2.8	0-10
Emotional distress	4.9 ± 3.0	0-10
Interference with daily activities	6.0 ± 2.6	0-10
Desired level*		
Pain	0.6 ± 1.2	0-5
Fatigue	0.7 ± 1.1	0-4
Emotional distress	0.8 ± 1.2	0-5
Interference with daily activities	0.7 ± 1.2	0-5
Success level*		
Pain	2.0 ± 1.8	0-9
Fatigue	2.4 ± 1.8	0-8
Emotional distress	1.9 ± 1.8	0-7
Interference with daily activities	2.5 ± 1.5	0-7
Expected level*		
Pain	2.6 ± 1.9	0-7
Fatigue	1.7 ± 1.6	0-8
Emotional distress	1.9 ± 1.9	0-7
Interference with daily activities	2.2 ± 1.7	0-7
Importance level†		
Pain	7.3 ± 3.0	0-10
Fatigue	8.0 ± 2.3	1-10
Emotional distress	7.6 ± 2.5	0-10
Interference with daily activities	7.9 ± 2.4	0-10

NOTE: There were 104 patients.
 *A numerical rating scale was used: 0 (none) to 10 (worst imaginable).
 †A numerical rating scale was used: 0 (not at all important) to 10 (extremely important).

and 7% had nonalcoholic steatohepatitis or a cryptogenic etiology), and 34% had hepatocellular carcinoma. The mean MELD score (without exception points) was 15.1 ± 7, and the mean CTP score was 8.4 ± 3.

Usual Levels of Pain, Fatigue, Emotional Distress, and Interference

Table 1 presents descriptive statistics for the PCOQ. On average, patients reported moderate usual levels (3.8-6.2) of pain, fatigue, emotional distress, and interference with daily activities. The distribution of the usual levels across these domains (Fig. 1) suggests that fatigue and interference ratings are clustered predominantly in the moderate to extreme ranges, whereas pain and emotional distress are more evenly distributed. High current levels (PCOQ rating ≥ 7) were reported by 24% of the patients for pain, by 48% for fatigue, by 30% for emotional distress, and by 46% for interference with daily activities. The MELD and CTP scores were positively correlated with the usual level of fatigue (MELD, *r* = 0.38, *P* < 0.001; CTP, *r* = 0.31, *P* < 0.001) and the usual level of interference with daily activities (MELD, *r* = 0.23, *P* =

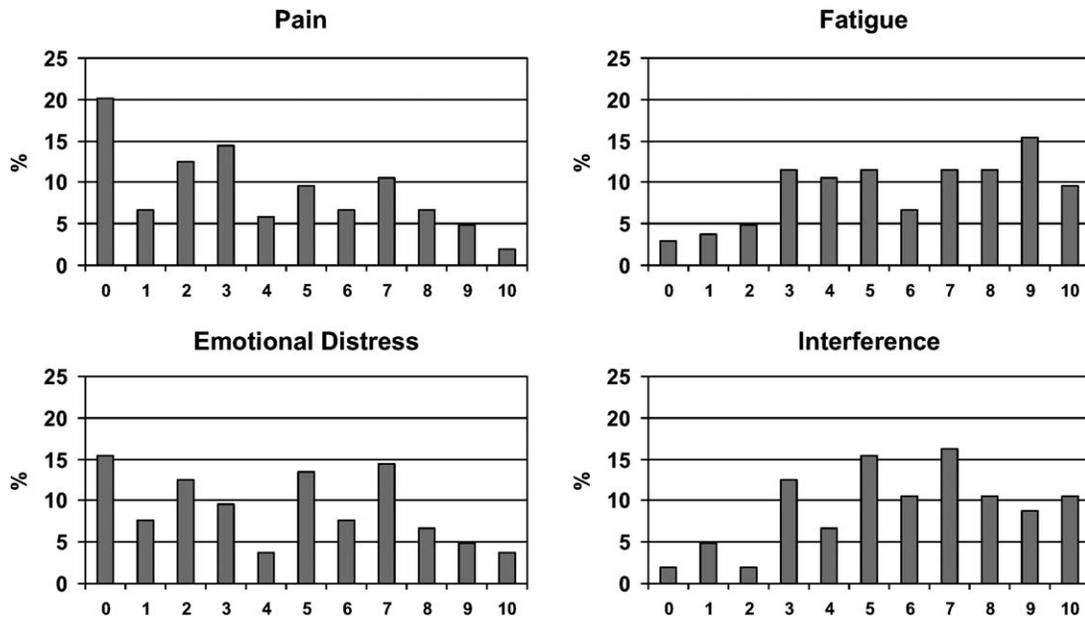


Figure 1. Proportional distributions of the PCOQ ratings for pain, fatigue, emotional distress, and interference with daily activities

0.02; CTP, $r = 0.21$, $P = 0.03$). Patients who were not working had higher usual levels of fatigue in comparison with employed patients ($t = 2.1$, $P = 0.04$). Age, sex, race, marital status, education, time on the LT waiting list, and hepatocellular carcinoma were not associated with the usual levels of pain, fatigue, emotional distress, and interference with daily activities ($P > 0.05$). The disease type was also not significantly associated with the usual levels of these domains. However, when we categorized patients according to their history of alcohol abuse or dependence, regardless of the primary disease etiology, we found that those with a history of alcohol abuse ($n = 49$) had significantly higher usual levels of pain ($t = 2.2$, $P = 0.02$), fatigue ($t = 2.6$, $P = 0.01$), and interference with daily activities ($t = 2.5$, $P = 0.02$) in comparison with those without a history of alcohol abuse ($n = 55$).

Patient-Reported Criteria for Successful LT and Outcome Expectations

Patients reported LT success criteria that represented significant reductions in all clinical domains (all P values < 0.05). The success criteria for pain ($r = 0.22$, $P = 0.02$) and fatigue ($r = 0.26$, $P = 0.01$) were positively correlated with the body mass index, and this suggests that patients with lower body mass indices have lower target values or more stringent criteria for successful LT in these 2 domains. Also, patients with a history of alcohol abuse or dependency had significantly lower target values for pain, fatigue, emotional distress, and interference with daily activities in comparison with those without a history of alcohol abuse (all P values < 0.05). No other sociodemographic or medical variables were significantly correlated with success criteria.

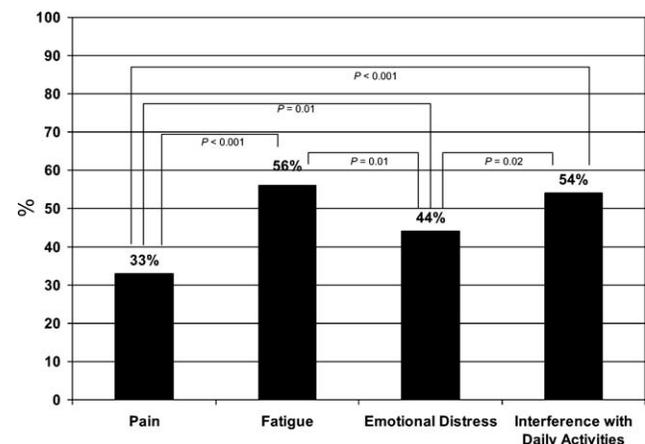


Figure 2. Mean percentage reductions in pain, fatigue, emotional distress, and interference with daily activities that patients would need to experience to consider LT successful.

To determine the amount of change necessary for patients to judge LT successful, we subtracted the success levels for pain, fatigue, emotional distress, and interference with daily activities from the usual levels of these 4 domains for each patient. Figure 2 highlights the mean percentage reductions in each domain that patients would need to experience to consider LT successful. Patients considered a mean reduction in pain of 33% to be a successful LT outcome. A reduction in fatigue of 56%, a reduction in emotional distress of 44%, and a reduction in interference with daily activities of 54% represented successful LT across these domains. Individual comparisons showed that the reductions in fatigue and interference necessary for LT to be considered successful by patients were significantly greater than the required reductions in pain and emotional distress (Fig. 2).

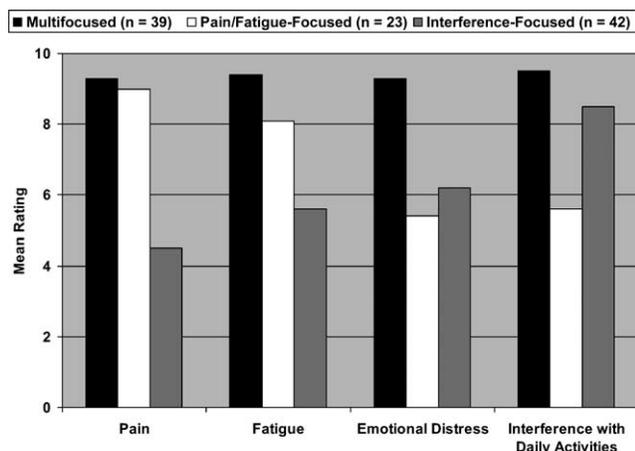


Figure 3. Mean importance ratings for the PCOQ domains by clusters.

The expected levels of pain, fatigue, and interference with daily activities after LT differed significantly from the LT success criteria. Patients expected their level of pain after LT (2.6 ± 1.9) to be higher than their success criterion for pain (2.0 ± 1.8 , $t = 4.4$, $P < 0.001$). However, their expected level of fatigue (1.7 ± 1.6) after LT was significantly lower than their success criterion for fatigue (2.4 ± 1.8 , $t = 4.6$, $P < 0.001$). Correlational analyses showed a negative relationship between the CTP score and the expected levels of fatigue and interference with daily activities and indicated that patients with more severe illness had higher expectations with respect to fatigue ($r = -0.30$, $P = 0.002$) and interference with daily activities ($r = -0.24$, $P = 0.015$). Age, sex, race, employment status, marital status, education, time on the LT waiting list, primary disease etiologies, hepatocellular carcinoma, and MELD scores were not associated with expected levels of pain, fatigue, emotional distress, or interference with daily activities after LT ($P > 0.05$).

Importance of Improvements in Pain, Fatigue, Emotional Distress, and Interference With Daily Activities

Overall, patients attached high importance to improvements in pain (7.3 ± 3.0), fatigue (8.0 ± 2.3), emotional distress (7.6 ± 2.5), and interference with daily activities (7.9 ± 2.4) after LT. However, a cluster analysis of importance ratings showed 3 prominent clusters (Fig. 3). The first cluster, which is labeled *multifocused*, included 39 patients who had very high ratings of importance across all 4 domains. The second cluster, which is labeled *pain/fatigue-focused*, comprised 23 patients who placed greater importance on post-LT reductions in pain and fatigue. The third cluster, which is labeled *interference-focused*, included 42 patients whose importance ratings suggest greater interest in reducing interference with daily activities after LT. The clusters differed significantly in their

MELD scores ($F = 3.1$, $P = 0.02$) and CTP scores ($F = 4.6$, $P < 0.001$). The interference-focused cluster had a significantly higher mean MELD score than the pain/fatigue-focused cluster ($P = 0.02$), whereas the multifocused cluster had a significantly higher mean CTP score than the pain/fatigue-focused cluster ($P = 0.04$). The clusters did not differ significantly with respect to age, sex, race, employment status, marital status, education, time on the LT waiting list, primary disease etiologies, hepatocellular carcinoma, or SF-36 health survey (version 2) scores ($P > 0.05$).

PCOQ: Concurrent Validity

Correlations between the usual levels of the PCOQ domains and the SF-36 health survey (version 2) were generally strong and in the expected direction, with lower quality of life associated with higher usual levels of pain, fatigue, emotional distress, and interference with daily activities (Table 2). As expected, usual pain correlated most highly with the Bodily Pain subscale of the SF-36 health survey (version 2), usual fatigue was most strongly associated with the Role-Physical and Vitality subscales, usual emotional distress correlated most highly with the Mental Health subscale and Mental Component Summary, and usual interference with daily activities correlated strongly with the Role-Physical and Role-Emotional subscales ($P < 0.05$).

DISCUSSION

This is the first study to evaluate patients' LT expectations and success criteria across several domains that are highly relevant to them. Our findings underscore the importance and value of using patient-centered assessments to better understand the ways in which patients prioritize LT outcomes and define transplantation success. Patient-centered assessments have the potential to facilitate provider-patient communication by helping patients to prioritize their goals for LT and make informed choices on the basis of these priorities (eg, the pursuit of living donor LT, wait listing in more than 1 geographic region, and the acceptance of an expanded criteria donor liver). In addition to promoting better health care communication, patient-centered assessments of current symptoms and expectations for improvement may guide transplant providers' clinical decision making both before and after transplantation. The study findings further indicate that the ways in which patients define LT success are quite heterogeneous, and individual discussions with patients should focus primarily on those clinical domains in which improvements after transplantation are most important to them. This will ensure that patients' expectations do not exceed likely LT outcomes and may prevent post-LT feelings of disappointment, dissatisfaction, and regret.

Patients reported moderately high levels of pain, fatigue, emotional distress, and interference with daily activities in the past week. It is not surprising,

TABLE 2. Correlations Between the Usual Levels of Each PCOQ Domain and the Subscales of the SF-36 Health Survey (Version 2)

PCOQ Domain	SF-36									
	Physical Functioning	Role-Physical	Bodily Pain	General Health	Vitality	Social Functioning	Role-Emotional	Mental Health	Physical Composite Score	Mental Composite Score
Usual pain	-0.27*	-0.18	-0.45*	-0.24 [†]	-0.28*	-0.23 [†]	-0.33*	-0.33*	-0.23 [†]	-0.33*
Usual fatigue	-0.38*	-0.52*	-0.32*	-0.42*	-0.49*	-0.37*	-0.41*	-0.31*	-0.46*	-0.37*
Usual emotional distress	-0.27*	-0.35*	-0.22 [†]	-0.28*	-0.43*	-0.41*	-0.33*	-0.45*	-0.22 [†]	-0.46*
Usual interference with daily activities	-0.33*	-0.41*	-0.32*	-0.30*	-0.36*	-0.35*	-0.39 [†]	-0.28*	-0.35*	-0.29*

NOTE: There were 104 patients.
 * $P < 0.01$.
[†] $P < 0.05$.

therefore, that they attached high importance to improvements in all of these domains after LT. Upper abdominal pain is a commonly reported symptom of chronic liver disease.¹⁷⁻¹⁹ Fatigue is the most frequent and distressing symptom for patients before LT²⁰ and is a major contributor to poor quality of life, especially for those whose disease severity is greater and who are unemployed.²¹⁻²⁵ Depression and anxiety also are common and may play important roles in patients' expectations and appraisal of LT.^{26,27} Also, disease-related symptoms and their management, comorbid conditions, medication side effects, and frequent health care appointments can interfere with work, household chores, relationships, and leisure activities and thus disrupt daily routines and impair the overall quality of life.^{19,20,25,28,29}

The findings of our study emphasize the necessity of assessing the expectations for post-LT improvements in those clinical domains that are important to patients. For instance, a reduction in pain intensity is a desired outcome of LT for most patients, but most do not expect LT to satisfy their pain reduction criteria for transplant success. Gross et al.²⁰ found that half of LT recipients reported either no improvement in pain symptoms or worse pain 1 year after LT in comparison with the period before LT, and those whose pain symptoms improved did not report complete relief. Moreover, osteoarticular and rheumatic complications associated with immunosuppression medications as well as abdominal pain secondary to disease recurrence are common after LT.³⁰ Thus, it is important for transplant physicians, nurses, and other clinicians to help patients to develop a more realistic appraisal of LT success for pain symptoms. Such discussions are especially relevant for those patients who are focused on pain reduction as an important outcome of transplantation (eg, the pain/

fatigue-focused cluster) because the risk of LT not meeting their pain criteria for transplant success may be higher. Interestingly, although most patients in our study also desired a substantial reduction in fatigue intensity after LT, they were still likely to view transplantation as successful even if their expected levels of fatigue were not met. Recent findings about persistently high fatigue after LT underscore the need to assess whether patients (particularly those in the pain/fatigue-focused cluster) have realistic expectations about fatigue reduction after LT.^{25,31,32}

The majority of published studies, including this one, have shown that patients awaiting LT have clear quality of life deficits.^{19,20,30} A return to normalcy in their daily activities is very important to most patients, and they expect LT to yield substantial improvements in this aspect of their lives. On the surface, the success criteria that patients reported for improvements in daily activities appear to be reasonable and realistic on the whole. Indeed, most studies have reported substantial improvements in the functional status and the overall quality of life in the post-transplant period versus the pretransplant period. However, there are very few longitudinal quality of life studies for LT,^{8,19,33,34} and findings suggest that many LT recipients continue to have significant deficiencies in most quality of life domains in comparison with the general population. Also, some evidence suggests that the quality of life benefits associated with LT have been overstated in the literature.¹⁹ The symptom burden remains high for a large cohort of patients after LT,^{35,36} so it is essential to inform them about persistent or new symptom experiences that have the potential to affect their activities of daily living and quality of life in the months or years after transplantation. Patients' appraisals of anticipated symptoms and side effects associated with immunosuppression

therapy, for instance, may influence their expectations and success criteria for LT.

With a few exceptions, the sociodemographic and medical characteristics were not consistently associated with the current or expected levels of pain, fatigue, emotional distress, or interference with daily activities. In agreement with previous research, patients with greater disease severity had higher current levels of fatigue intensity and more limitations in their daily activities.²⁵ Patients with higher MELD or CTP scores were more likely to experience physical, emotional, and mental fatigue, and this may have contributed to greater impairments in activities of daily living as well as psychological functioning. They also had higher expectations for LT with respect to the resolution of these symptoms. Interestingly, we found that patients with a history of alcohol abuse or dependency had higher usual ratings of pain, fatigue, and interference with daily activities and expected more improvement in these domains in comparison with those without a history of alcohol abuse. Eshelman et al.³⁷ found that in comparison with patients without a history of alcohol abuse, patients with alcohol-related cirrhosis experienced less improvement in their physical quality of life, had more pain symptoms, and reported greater physical limitations after LT. Adults with a history of alcohol abuse or dependency may have poorly developed coping strategies for effectively managing pain and emotional distress, and this could alter their perceptions about their functional status and symptomatology after transplantation.

Patients expected LT to meet or exceed their criteria for success in the fatigue and interference domains, but they did not expect LT to meet their criteria for success in the pain and emotional distress domains. This suggests that patients' expectations and success criteria for LT may differ for certain clinical domains. It is important for providers to assess which domains are most important to patients and what their expectations are for improvements in these domains so that they can help patients to appropriately calibrate their criteria for successful transplantation. Our cluster analysis suggests that wait-listed patients are not a homogeneous group, with some patients prioritizing improvements in some domains over others and some patients focused on symptom reduction in multiple areas. Patient-provider communication can be tailored to target those domains that are most relevant to the patient, and this is likely to lead to higher rates of post-LT satisfaction and more favorable patient-oriented outcomes.

The study findings should be considered in the context of some methodological limitations. We assessed patients at only 1 point in time. Patients likely adjust their expectations and success criteria with more exposure to transplant providers, other patients, and LT recipients. We are currently developing a prospective assessment protocol that includes an evaluation of whether patients' pre-LT expectations and success

criteria are realized after transplantation. Also, our assessments were general and included only 1 question per clinical domain. It is possible that the frequency or duration of pain and fatigue, for instance, could affect patients' criteria for successful transplantation, but this was not assessed in the current study. The PCOQ appears to be a useful and valid tool for assessing patients' usual and expected levels of clinical domains that are important to patients. Although we chose to focus on 4 clinical domains (pain, fatigue, emotional distress, and interference with daily activities), we did not assess others that may be equally important to patients, including sleep disturbance^{25,38} and cognitive functioning.^{39,40} Also, it would be interesting to examine whether providers' expectations and criteria for success differ significantly from those of their patients.

These limitations notwithstanding, providers should consider using the PCOQ to better tailor their discussions with patients about what improvements in functioning they can anticipate after LT. As previously noted, the PCOQ can be modified to include additional clinical domains that are relevant to the LT patients of interest, including those with decompensated cirrhosis or hepatocellular carcinoma. Clinically, patients could be administered the PCOQ during their initial transplant evaluation. Eliciting their goals and success criteria for LT will help providers to identify any unrealistic expectations that patients may be harboring about symptom reduction after transplantation. For instance, in our clinical experience, not all patients attach the same level of importance to improvements in specific symptoms after LT. For some, improvements in emotional disturbance may be most essential, whereas for others, improvements in sleep quality may be most important. Moreover, some patients with preexisting health problems (eg, chronic pain) expect LT to reduce their pain burden, and this is an unlikely clinical outcome after transplantation. The PCOQ can be used by the provider to guide discussions about the likely LT outcomes that are most relevant to the patient and thereby enhance patient-provider communication and potentially prevent future patient dissatisfaction. Communication facilitated by the PCOQ also may help patients to make more informed choices about LT. For example, many patients have to make the challenging decision of accepting or not accepting an extended criteria donor liver for transplantation. The decision to accept or reject the graft undoubtedly is influenced by many factors. However, the provider's review of the risks and benefits of the liver offer should also include some discussion of the patient's individual treatment goals and criteria for success as measured by the PCOQ.

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