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Physical and Mental Quality of Life in Patients With End-Stage Liver Disease and Their Informal Caregivers

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Abstract

Background & Aims: Management of end-stage liver disease (ESLD) has implications for not only patients' quality of life (QOL), but also their caregivers'. We aimed to identify characteristics of patients with ESLD and their caregivers that are associated with QOL.

Methods: We obtained cross-sectional baseline data from patients and their caregivers (132 dyads; 62% were married or partners), recruited from outpatient hepatology clinics within 2 healthcare centers. Patients were included if their model for end-stage liver disease score was 15 or more; caregivers were identified by the patient as the primary informal caregiver. QOL was measured by the SF-36 and relationship quality using the mutuality scale. We measured uncertainty using the uncertainty in illness scales for patients and caregivers. Multilevel modeling was used to analyze the data.

Results: Refractory ascites was associated with worse physical QOL for patients (unstandardized beta [B], −9.19; standard error [SE], 2.28) and caregivers (B, −5.41; SE, 2.33); history of hepatic encephalopathy was associated with worse patient physical QOL (B, −3.86; SE, 1.65). High levels of uncertainty were associated with worse physical and mental QOL for both members of the dyads; relationship quality was significantly associated with patient mental QOL (B, 2.73; SE, 1.19).

Conclusions: Clinicians and researchers should consider the effects of ESLD on caregivers as well as their patients to optimize the QOL for both.

Keywords

cirrhosis; family members; children; psychologic factor

In the United States approximately 4.5 million individuals who have chronic liver disease (CLD) and 633,000 who have cirrhosis may receive help from family members functioning as informal caregivers.[1] As patients develop end-stage liver disease (ESLD), their quality of life (QOL) becomes worse and their need for assistance to help manage their illness increases.[2] Despite caregivers playing a significant role in helping patients manage their illness,[3] little research has focused on caregivers' QOL.[4] The small body of research that exists has shown that these caregivers experience depression,[5] uncertainty,[6] and high levels of strain from providing care.[7] Caregiver strain is significantly higher for caregivers of patients with previous hepatic encephalopathy compared to caregivers of patients without or with previous encephalopathy controlled on treatment.[8] The burden of hepatic encephalopathy affects both patients' and caregivers' QOL.[9] Thus, management of the ESLD has implications for the health of the patient and their caregiver.

Across illness contexts, patients and caregivers influence each other's health outcomes,[10] making it relevant to focus on the patient and caregiver simultaneously, as a unit or dyad, to optimize the QOL of both.[11] A dyadic approach to illness represents a more realistic context of how patients and their caregivers (e.g., partners, adult-children) experience and manage the illness and emphasizes the importance of the interpersonal context of illness. Positive relationship quality between patient and caregiver has a protective factor against negative aspects of illness; patients and caregivers who perceive the relationship more positively tend to have better outcomes.[12, 13] Better relationship quality between patients with heart failure and their informal family caregivers has been related to reduced patient mortality risk.[14] Additionally, given the unpredictable of CLD,[15] uncertainty can be high for both patients and caregivers.[16, 17] Uncertainty has been associated with symptoms and QOL for patients.[6, 18] Yet, little is known about the roles of relationship quality and uncertainty on the QOL of ESLD dyads. The purpose of the study was to examine both the physical and mental QOL of patients with ESLD and their informal caregivers and identify the patient and caregiver characteristics associated with QOL in the ESLD dyad.

Methods

Design

We used cross-sectional baseline data from a larger longitudinal descriptive study (NINR: 1R01NR016017–01). The study protocol and study measures were published elsewhere.[19]

Setting and Participants

Patients with ESLD and their informal caregivers were recruited from outpatient liver clinics at an academic center and a VA medical center. They are the only liver transplant referral centers in the state, providing advanced care for patients throughout the state. All liver providers (n=14) at the centers participated in the study. The joint Institutional Review Board (IRB) for the two centers approved the study and all participants provided written consent. Patients' inclusion criteria were: (1) age ≥21 years, (2) Model for End-Stage Liver Disease including sodium (MELD-Na) score ≥ 15, and (3) an identified primary informal caregiver. Patients' exclusion criteria were: (1) liver cancer, (2) prior liver transplant, and (3) active hepatitis C treatment. Exclusion criteria for both patients and caregivers were: major uncorrected hearing impairment and uncontrolled major psychiatric illness (disorganized thinking or erratic behavior not considered hepatic encephalopathy precluding data collection). Caregivers' inclusion criteria were: ≥18 years and identified by the patient as the primary informal caregiver or other support person. Patients with active encephalopathy at the time of recruitment were followed up at a later visit. Prior to each data collection point, if patients were found to be encephalopathic, data were not collected for that time point, and surveys were mailed later. At the time of enrollment patients and their informal caregivers were given a survey to complete separately at home and return in a stamped, addressed envelope. If requested, surveys were administered in person or via telephone.

Of the 202 dyads who enrolled in the study (see supplemental material), 135 dyads had complete data on the independent variables in the models. Three dyads had partial missing data on QOL and were included consistent with multilevel approaches, which stipulates that for dyadic data at least one member of the dyad must have data. HLM uses full information maximum likelihood estimation for missing data on dependent variables (QOL), but does not address missing data on independent variables. Three dyads had patients with untreated hepatic encephalopathy and were removed, leaving a sample of 132 dyads for the analysis.

Measures

Patient and caregiver physical and mental QOL were the outcome variables measured using the reliable and valid Short Form (SF)-36.[20] From the SF-36 physical and mental health summary scores can be derived.[20, 21] Higher scores indicate better QOL with a score of 50 as the norm.

Uncertainty was measured using the 33-item Uncertainty in Illness Scales for Adults (MUIS-A) for patients and the 31-item Uncertainty in Illness Scale for Family Members (MUIS-FM) for caregivers.[22] Both scales are highly reliable and valid; for both scales each item is scored from 1 (Strongly Disagree) to 5 (Strongly Agree).[22] Higher scores indicate more uncertainty.

Relationship Quality of the patient-caregiver dyad was measured using the 15-item Mutuality Scale, a reliability and validity measure.[23, 24] Each item is scored on a 5-point scale (0 = not at all; 4 = a great deal). Higher scores indicate better relationship quality.

Sociodemographic characteristics were collected from patients and caregivers (age, comorbidities) as well as liver specific disease variables from patients' medical records (e.g., MELD-Na scores).

Analysis Plan

Multilevel modeling was used to analyze data at the level of the caregiving dyad to control for interdependencies.[25] Two cross-sectional dyadic models (one for physical QOL and one for mental QOL) were tested using HLM 7.[26] Dyadic approaches have several important advantages over traditional methods. First, the dyad is the unit of analysis rather than the individual patient or caregiver. Second, within-dyad interdependence in outcomes is controlled. Third, both actor (e.g., patient characteristics predicting patient QOL) and cross-partner effects (e.g. patient characteristics predicting caregiver QOL) can be examined simultaneously.

Two within-dyad models were run first to estimate the QOL (both physical and mental) within dyads and to determine the variability in QOL scores across dyads. These initial models represented physical and mental QOL for both patients and caregivers as the sum of a latent score plus a residual term that captures measurement error and was specified as:

$$\mathrm{Y}_{ij} = \beta_{1j}(\mathrm{PATIENT}) + \beta_{2j}\left(\mathrm{CAREGIVER}_{ij}\right) + \mathrm{r}_{ij}$$

where Y_{ij} represents the QOL score i in dyad j ($i = 1, \ldots$k responses per dyad). PATIENT and CAREGIVER are indicator variables taking on a value of 1 if the response was obtained from a patient or caregiver, respectively, and 0 otherwise. Thus, β_{1j} and β_{2j} represent the patient's and caregiver's latent QOL scores respectively (these are also known as fixed effects in the model) and become dependent variables in between-dyad models. The r_{ij} represents within-dyad residuals (also known as level 1 random effects). These unadjusted within-dyad models provide estimates of the population averages of physical and mental

QOL within dyads, the interdependence of QOL within-dyads (represented by a tau correlation), and the variability in QOL across dyads (tested with a chi-square).

Next, two conditional (i.e. adjusted for covariates) between-dyad models were run, each of which consisted of simultaneous regression equations for patients and caregivers. Both of these between-dyad models (one for physical QOL and one for mental QOL) allowed for the examination of patient and caregiver characteristics on QOL and actor and cross-partner effects.

Results

Sample Characteristics

Characteristics of the sample are shown in Table 1. Patients with ESLD, diagnosed with a mix of etiologies, were, on average, 56.05 (11.35) years old, predominantly men (63%). Sixty-eight percent had a history of ascites and 64% of hepatic encephalopathy. Informal caregivers were, on average, 57.22 (12.53) years old, predominantly women (71%) and married/partnered with the patient (62%). Patients had significantly higher rates of poorer physical and mental health and uncertainty than their caregivers. Caregivers perceived the quality of the relationship significantly worse than patients.

Quality of Life in ESLD Dyads

Fixed effects results of unconditional multilevel models found average patient physical QOL was 33.53 (0.88) and caregiver physical QOL was 48.69 (0.85). The SF-36 has a population mean of 50 and standard deviation of 10; patient physical QOL was 1.5 standard deviations lower than the population norm. A multi-parameter hypothesis test confirmed that patients, on average, reported significantly worse physical QOL than caregivers ($p < .001$). Variance components indicated significant heterogeneity in physical QOL across dyads ($p < .001$) and a tau correlation of .18 between patient and caregiver physical QOL, demonstrating a low level of interdependence in physical health.

Fixed effects results of unconditional multilevel models found average patient mental QOL was 42.89 (1.00), over a half standard deviation lower than population norm and caregiver mental QOL was 45.83 (0.99), almost a half standard deviation lower than the population norm. A multi-parameter hypothesis test confirmed that patients, on average, reported significantly worse mental QOL than caregivers ($p < .05$). Variance components indicated significant heterogeneity in mental QOL across dyads ($p < .001$) and a tau correlation of .32 between patient and caregiver mental QOL, demonstrating a moderate level of interdependence in mental health.

Predictors/Determinants of Physical Quality of Life in ESLD Dyads

Patient and caregiver characteristics that were significantly associated with physical QOL are shown in Model 1 (Table 2). Patient physical QOL was significantly worse when they had refractory ascites (vs no clinically significant ascites), had managed hepatic encephalopathy (vs. no history), and reported higher levels of uncertainty and better relationship quality with their caregiver. No caregiver characteristics were found to significantly predict patient physical QOL, controlling for patient covariates. Caregiver physical QOL was significantly worse when they provided care to an older patient, provided care to a patient with refractory ascites, and when they reported high levels of uncertainty.

Predictors/Determinants of Mental Quality of Life in ESLD Dyads

Patient and caregiver characteristics that were significantly associated with mental QOL are shown in Model 2 (Table 2). Patient mental QOL was significantly worse when they were younger, reported higher levels of uncertainty, and their caregiver perceived worse relationship quality with them. Caregiver mental QOL was significantly worse when the patients reported high levels of uncertainty and when caregivers were spouses/partners of the patients.

Discussion

This study examines the physical and mental QOL of ESLD patient-caregiver dyads and identify patient and caregiver characteristics associated with dyadic QOL. It has several important findings. First, similar to other illness and caregiving contexts, both patients and caregivers experienced lower mental QOL than population norms, demonstrating the need for intervention with both members of the ESLD dyad, particularly given the association between mental QOL and quality of care provided by informal caregivers and in some contexts patient survivability.[27] Second, QOL within ESLD dyads was found to be interdependent (i.e., covaried); low interdependence for physical QOL and moderate interdependence for mental QOL. Third, having refractory ascites was associated with worse physical QOL for both patients and their caregivers; having hepatic encephalopathy was associated with worse physical QOL for patients. Fourth, high levels of uncertainty were associated with worse physical and mental QOL for both members of the dyad; relationship quality was associated with patient QOL only. Finally, younger patients and spouse caregivers experienced worse mental health. These results underscore the importance of the interpersonal context of ESLD and both the interdependent (correlation of their QOL) and transactional (influence each other’s QOL) nature of the illness, particularly for mental QOL.

Patient Clinical Characteristics

Controlling for all other variables in the model, only two patient clinical characteristics were significant predictors of QOL - refractory ascites and hepatic encephalopathy. When compared to patients with no ascites, refractory ascites had a significant negative impact on both patient and caregiver physical QOL. No significant association was found for the presence of managed versus no ascites. This finding emphasizes the critical impact of disease management for the provider. Likewise, awareness by the provider that worsening hepatic encephalopathy and ascites can lead to non-compliance and the effect this can have on both the patient and caregiver QOL highlights the importance of aggressive management of decompensation. Multidisciplinary support of the patient beyond pharmacologic intervention could include physical therapy to improve overall physical functioning and influence QOL. Poor caregiver physical health has been associated with the poor physical health of the patient and the related strain of providing care, particularly for older caregivers with their own health challenges.[28] Thus, illness management has the potential to optimize physical QOL of both members of the ESLD dyad.

Patient and Caregiver Uncertainty

Across chronic illnesses, a higher level of uncertainty has been associated with higher levels of patient pain, depression, anxiety, and worse QOL.[18, 29] Less is known about the association of uncertainty on caregiver health and QOL or the transactional role of uncertainty within dyads. Our findings show that when patients and caregivers had high levels of uncertainty, they were more likely to experience worse physical QOL. However, only patient levels of uncertainty were associated with mental QOL for both patients and caregivers. One's own sense of uncertainty was directly associated with physical QOL, but the dyad's mental QOL was only associated with how uncertain the patient felt, controlling for caregiver uncertainty. Patient uncertainty is associated with both their own health and that of their caregiver. Dyadic approaches to intervention and practice are needed to fully acknowledge and target this transactional influence between two members of an informal caregiving relationship to maximize the health of both members.[13] Targeting only one member of the caregiving dyad increases the potential for differential effects on health within dyads and ignores the process of collaborative illness management promoting positive outcomes for both members.[30]

Relationship Quality

Consistent with other chronic illness research, relationship quality played a significant protective role for the mental QOL of patients.[31, 32] Controlling for the patient's perception of the relationship, caregiver's perception of a positive relationship played an important protective role, further highlighting the importance of the interpersonal context, facilitating positive interactions within the dyad in a life-threatening context and salient role of caregivers for ESLD outcomes. The illness and care can often disturb the homeostasis of existing familial relationships and lead to deterioration in meaningful interactions and reciprocity. Interventions that support the interpersonal context and facilitate positive interactions may benefit both patients' and caregivers' ability to manage illness.[32, 33]

The current study uncovered the complexity of the interpersonal context in ESLD. Patient perception of the relationship was negatively associated with patient physical QOL. When patients rated their relationship with the caregiver more positively, they were more likely to report worse physical health. Similar results have been found for patients in the contexts of heart failure and lung cancer.[32, 34] One potential explanation is that patients who are sicker are more in need of care and more reliant on their caregiver to manage their illness and as their primary social support, placing greater appreciation and more positive perceptions of the relationship than perhaps their caregiver.[35]

Strengths and Limitations

The current study has several notable strengths. The findings reinforce the need for a dyadic approach to ESLD to optimize the outcomes of both patients and their informal caregivers. Mental QOL was moderately interdependent within dyads highlighting the negative impact of the illness on patients and caregivers. Interventions that target the dyad as a unit of care by supporting positive interactions, communication, and collaboration within dyads may hold promise for the health of the dyad.[33] Dyadic interventions that involve counseling, cognitive behavior therapy, and mindfulness training[36] to decrease levels of uncertainty, increase levels of confidence within the dyad to manage the illness, and facilitate positive dyadic interactions are important lines of inquiry for improving outcomes. Multicomponent dyadic interventions that integrate patient, caregiver, and dyadic issues may be particular beneficial given the current findings.

The study has several limitations. It used a cross-sectional design which does not allow for an investigation into changes over time as the disease progresses, nor the ability to untangle direction of effects. Most dyads were White (88%).

Conclusions

The study findings emphasize the need for a dyadic focus in research including diverse samples as well as a nuanced approach to clinical practice settings to optimize the outcomes of both patients with ESLD and their informal caregivers.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

CLD	Chronic liver disease
ESLD	End-stage liver disease
QOL	Quality of Life
MELD-Na	Model for End-Stage Liver Disease including sodium

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Need to Know

Background:

As patients develop end-stage liver disease, their quality of life becomes worse and their need for assistance by informal caregivers to help manage their illness increases.

Findings:

Patients with end-stage liver disease had worse physical and mental quality of life than caregivers; both had scores below normed population averages. Physical and mental quality of life were interdependent within patient-caregiver dyads.

Implications for patient care:

Awareness about the relationship between patient and caregiver health supports changes in clinical practice, to focus on patients as well as caregiver as a unit and improve the quality of life for both.

Table 1.

Patients and Caregiver Characteristics (N= 132 dyads)

Characteristic	Patients	Caregivers
Age (years), mean (SD)	56.05 (11.35)	57.22 (12.53)
Women (%)	37%	71%
Married/partnered (%)	62%	-
Years of Cirrhosis, mean (SD)	4.7 (6.10)	-
Liver Etiology (%)		
Viral Hepatitis	23%	
NASH/Cryptogenic	29%	
ETOH	32%	
Other	16%	
MELD-Na, mean (SD)	17.07 (4.30)	-
Charlson Comorbidity Index, mean (SD)	3.61 (1.94)	-
Hepatic encephalopathy (%)		
No history	36%	-
Managed	64%	-
Ascites (%)		
None	32%	-
Managed	48%	-
Refractory	20%	-
Uncertainty, mean (SD)	88.38 (16.74)	82.56 (16.26) ***
Relationship quality, mean (SD)	3.32 (0.70)	3.09 (0.80)**
Physical quality of life, mean (SD)	33.72 (9.91)	48.68 (9.78) ***
Mental quality of life, mean (± SD)	42.74 (11.46)	45.72 (11.34)*

Note. Paired t-tests were used to compare patient and caregiver characteristics.

*** $p < .001$.

MELD-Na = Model for End-Stage Liver Disease including sodium; NASH, nonalcoholic steatohepatitis; SD, standard deviation.

Table 2.

Multilevel Models Predicting Physical and Mental QOL in ESLD Dyads (N=132)

	Physical QOL (Model 1)		**Mental QOL (Model 2)**	
	Patient	**Caregiver**	**Patient**	**Caregiver**
	B (*SE*)	**B (*SE*)**	**B (*SE*)**	**B (*SE*)**
Patient Characteristics				
Gender (women)	1.76 (1.95)	2.82 (1.96)	−1.73 (2.07)	0.32 (2.31)
Age	0.13 (0.08)	−0.20 (0.08)*	0.26 (0.08)**	0.14 (0.09)
Years Cirrhosis	−0.16 (0.13)	−0.19 (0.13)	−0.16 (0.14)	−0.01 (0.15)
MELD-Na	−0.25 (0.19)	−0.13 (0.19)	0.03 (0.21)	0.04 (0.23)
Charlson	0.18 (0.42)	−0.50 (0.43)	0.25 (0.44)	0.16 (0.50)
Hepatic Encephalopathy ([a]managed vs no history)	−3.86 (1.65)*	0.88 (1.67)	−2.02 (1.76)	−0.81 (1.97)
Ascites (managed vs none)	−3.47 (1.83)	−1.94 (1.85)	−3.15 (1.94)	−1.98 (2.18)
Ascites (refractory vs none)	−9.19 (2.28)***	−5.41 (2.33)*	−3.46 (2.42)	−1.86(2.75)
Uncertainty	−0.14 (0.05)**	0.06 (0.05)	−0.31 (0.06)***	−0.15 (0.06)*
Relationship quality	−3.26 (1.33)*	1.91 (1.37)	1.69 (1.41)	1.94 (1.61)
Caregiver Characteristics				
Gender (women)	3.09 (2.20)	0.96 (1.37)	−3.05 (2.34)	−0.56 (2.61)
Spouse Caregiver	2.34 (1.82)	1.48 (1.86)	−2.46 (1.94)	−5.04 (2.19)*
Uncertainty	−0.10 (0.06)	−0.16 (0.06)**	0.06 (0.06)	−0.02 (0.07)
Relationship quality	0.66 (1.12)	−0.19 (1.13)	2.73 (1.19)*	2.51 (1.33)

Note. Higher scores indicate greater uncertainty and better relationship quality.

[*] *p* < .05.

[**] *p* < .01.

[***] *p* < .001.

[a] Results did not differ when liver etiology included.

MELD-Na = Model for End-Stage Liver Disease including sodium.