



Approaches to Assessing Burden in Caregivers of Patients with Cirrhosis

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Abstract

Background and Aims: Being a caregiver for a patient with chronic liver disease (CLD) can be burdensome mentally, emotionally financially, and physically. The aim of this study was to systemically review the available tools and propose tools that can comprehensively evaluate caregiver burden for individuals caring for patients with CLD. **Methods:** We searched the PubMed database for all studies on the impact of patients with CLD on caregiver burden without timeframe restriction. Eligible studies included cohort studies, review studies, or cross-sectional studies. The number of patients and caregivers was isolated from each paper. Studies in the same categories were isolated and statistically compared. **Results:** A total of 13 studies meeting our inclusion criteria as stated in the methods sections were included. In total, 2528 caregivers were taking care of 2003 patients with CLD. Women made up the majority of caregivers at 78.2%, 95.7% of whom identified as the patient's spouse. Caregiver strain index is one of the most comprehensive tools; however, the questions are very general and do not fully elucidate financial strain. Beck depression and anxiety were correlated ($p=0.0001$), and both depression and anxiety were correlated with perceived caregiver burden (PCB) and Zarit Burden Interview (ZBI) ($p=0.002$). Depression scale correlated with Interpersonal Support Evaluation – Short Form, and Model for End-Stage Liver Disease score correlated with ZBI and PCB (total and in most domains; $p=0.001$). Patient's poorer cognitive performance correlated with higher ZBI and PCB (employed patients had higher cognitive performance and lower ZBI and PCB). **Conclusions:** Caregiver burden remains poorly understood due to the lack of uniformity in the assessment tools used to evaluate caregiver burden. None of the tools used to evaluate caregiver burden are comprehensive;

however, most tools correlate statistically in the ability to identify caregiver burden. A comprehensive tool is lacking for identifying caregiver burden in patients with CLD.

Citation of this article: Yanny B, Pham NV, Saleh H, Saab S. Approaches to assessing burden in caregivers of patients with cirrhosis. *J Clin Transl Hepatol* 2020;8(2):127–134. doi: 10.14218/JCTH.2019.00054.

Introduction

Liver disease causes approximately 2 million deaths per year worldwide.^{1,2} In the USA, liver disease is the twelfth most common cause of mortality.^{1,2} Approximately 34,000 deaths are reported annually from liver cirrhosis.³ Liver transplant (LT) has dramatically improved survival and quality of life (QOL) for patients with complicated liver disease.^{1,2} Transplant is a life-altering change for the patient and their families. The process of LT evaluation is long and stressful. Patients' families provide care and support for their loved ones mentally, emotionally, medically, and financially. Research shows that family support is essential for a good LT outcome.⁴

The LT waitlist contains approximately 16,000–17,000 patients awaiting transplantation.⁵ All patients on this waitlist undergo a social evaluation and should have family members who are willing to be fulltime caregivers during the transplant process and after LT, as required by most transplant centers in the USA. Caregivers play an important role in a transplant patient's health care during the whole process and particularly recovery. Having a responsible caregiver can strengthen the information relayed to the patients and effectively help them with treatment, ultimately improving LT outcomes and compliance.

Accordingly, caregivers for LT recipients play a critical role in the pre- and post-LT stages. Previous studies have shown that a poor caregiver QOL predicts that a LT recipient will receive low quality care by their caregiver.^{1,2,6} Furthermore, caregivers with a heavy financial burden have a poorer QOL, which leads to less optimal care delivery for the LT recipient.^{1,2} The focus during the LT evaluation process is often shifted to the individual receiving the transplant. The caregiver assessment often stops after ensuring that a dedicated caregiver and possibly a secondary caregiver will be present to help the LT recipient. Most transplant centers do not assess caregivers' QOL or other burdens such as mental, physical, psychological and financial despite their proven role in providing a good post-LT outcome to their loved ones who have received a LT.¹ Therefore, this study focuses on caregiver

Keywords: Caregiver burden in liver disease; Liver cirrhosis; Liver transplant.

Abbreviations: AUDIT, alcohol use disorders identification test; BDI-II, Beck depression inventory-II; CLD, chronic liver disease; HADS-A, hospital anxiety and depression scale-anxiety; HADS-D, hospital anxiety and depression scale-depression; HCC, hepatocellular carcinoma; HRQOL, health-related quality of life; ISEL-SF, interpersonal support evaluation – short form; LT, liver transplant; MCS, mental component summary; MCSDS, Marlowe Crowne social desirability scale; MELD, model for end-stage liver disease; NAFL, non-alcoholic fatty liver disease; PBC, primary biliary cirrhosis; PCB, perceived caregiver burden; PCRS, Picot caregiver reward scale; PCS, physical component summary; QOL, quality of life; SD, standard deviation; STAI, state trait anxiety information; ZBI, Zarit burden interview; ZBI-SF, Zarit burden interview – short form.

Received: 9 November 2019; Revised: 12 February 2020; Accepted: 15 March 2020

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burden, and tools available to the clinician and transplant center to evaluate the burden.

In this systemic review, we evaluated caregiver burden assessment tools available to the clinician by reviewing the available literature specifically for individuals with chronic liver disease (CLD), and compared the tools utilized. We identified the most appropriate tools in each category including mental, emotional, financial, and physical, and proposed a combination of tools that can comprehensively evaluate caregiver burden for individuals caring for patients with CLD.

Methods

Search strategy and identification of studies

We searched the MEDLINE database for all studies on the impact of patients with CLD on caregiver burden without timeframe restriction. We used a combination of keywords 'caregiver,' 'care giving,' 'informal care,' 'caretaker,' 'family,' 'spouse,' 'parents,' 'friends,' 'mother,' 'father,' 'liver cirrhosis,' 'liver,' 'liver disease,' 'cirrhosis,' 'chronic liver disease,' and 'PBC.' Bibliographies of all identified studies were searched for relevant articles for additional studies. We also searched additional electronic databases such as ProQuest.

Inclusion and exclusion criteria

We included all studies published in scientific journals that investigated burden experienced by individuals who are caregivers for patients with CLD or cirrhosis, or who are on the LT waitlist. As our study attempted to assess all available information on caregiver's burden as a result of caring for adult patient with liver disease, studies whose source populations were above 18 years of age and resided in or outside the USA, and studies published in English were included. We included studies that used a quantitative method of analysis to describe the burden of caregiving, mental health outcomes of caregivers, and their QOL. Studies that only used qualitative interview-based instruments were excluded from our review. The inclusion criteria were: all studies published in scientific journals that investigated burden experienced by caregivers of patients with CLD, cirrhosis, or who are on the LT waitlist; peer-reviewed articles in English and a full-text version of the study available; source populations residing in or outside the USA; source populations only including adult patients and caregivers (18 years old or above); patients diagnosed with CLD, cirrhosis of any etiologies, or who are on the LT waitlist; and studies that used a quantitative method of analysis to describe burden of caregiving or mental health (stress, distress, depression, anxiety) of caregivers or QOL or a combination of these outcomes. We excluded the following: experimental trial study design, systemic review, dissertations/theses, published abstracts, studies published in language other than English leading to unavailable full-text articles, patient population or caregiver population <18 years of age, patient population with primary diagnosis other than CLD, cirrhosis, or not on the LT waitlist such as hepatocellular carcinoma, non-alcoholic fatty liver disease, post-LT studies, studies that investigated caregivers impacted by their own liver disease, and studies that only utilized a qualitative interview-based instrument to assess caregiver's burden (qualitative methodology).

Caregiver's burden definition

The definition of caregiver's burden has been a topic of ongoing discussion. Caregiver's burden is defined as the impact of caregiving on caregiver's perceived emotion, physical health, social life, and finance over time.^{7,8} There have been attempts to distinguish caregiver's burden into subjective and objective burdens.^{9,10} Subjective burden refers to caregivers' reflection on their caregiving experience through their attitude, emotion, awareness, perception, and affective orientation.⁹ Objective burden reflects the disruptions of caregivers' physical health, household, financial status, and other aspects of life that are the results of caregiving.

Caregiver assessment tools

Zarit burden interview – Short form (ZBI-SF): This 12-item self-reported instrument assesses caregiver's burden with a total score of 48. It is a shortened version of the 22-item Zarit Burden Scale. Higher score indicates higher caregiver burden. This tool focuses on time schedule, physical health, mental and psychosocial burden.^{1,11,12}

Zarit burden scale: This 22-item self-reported instrument assesses caregiver's burden with each item on a 9-point rating scale. A rating of 9 for each item indicates a higher level of burden. The scale measures physical, emotional, and financial toll of providing care. This also focuses on time schedule, physical health, mental and psychosocial burden.¹³

Health-related QOL: This 136-item questionnaire used to assess patient's physical, psychosocial, and general health outcomes. It has two overall domains: physical and psychosocial; 12 subcategories: sleep and rest, eating, work, home management, recreation and pastimes, ambulation, mobility, body care and movement, social interaction, alertness behavior, emotional behavior, communication. Higher score indicates a poorer level of health.^{11,14}

Perceived caregiver burden scale (PCB): This 31 item self-reported questionnaire assesses perceived caregiver's burden with five domains: impact on finances, impact on schedule, sense of abandonment, impact on health, sense of entrapment. A higher score indicates a higher level of perceived burden. Although brief, this tool asks questions regarding physical health, mental health, social situation, finance, and sleep.¹⁵

Caregiver strain index: This 13-item questionnaire to assess caregiver burden. Higher scores mean more strain. If caregiver answers "yes" to seven or more items, clinically significant caregiver strain is indicated. This briefly asks about time schedule, physical health, mental health, finance, and sleep. We suggest this tool be used as a pathway to determine the reason for the patient's caregiver's most serious concern, and based on the concern, another in depth tool may be utilized to further evaluate the burden.^{16,17}

Caregiver benefit index: This index examines benefits perceived by transplant caregivers in 12 areas. Higher scores mean more benefits. Questions focus on benefit gained from helping patient, spending time with patients, personal growth, and interpersonal benefits.^{16,18}

Results

A total of 13 studies meeting our inclusion criteria as stated in the Methods section were included (Fig. 1).^{7-10,12-13,16,19-24}

A total of 2528 caregivers were taking care of 2003 patients with CLD. Women made up the majority of caregivers at 78.2%, of whom 95.7% identified as the patient's spouse. Overall caregiver burden fell on 73.5% of spouses, parents made up 12.7% of the caregiver cohort, 3.2% were children, and 10.5% fell into the 'other' relationship category. The cumulative mean (\pm standard deviation [SD]) age of the caregiver was 52.7 (\pm 7.2) years. Unemployed caregivers made up 65.2% of the caregiver cohort. Viral hepatitis contributed to 54.3% of patients being cared for by a caregiver, alcoholic liver disease made up 23%, non-alcoholic steatohepatitis was 12.7% and 10% contributed to other liver diseases.

Patients on the LT list made up 20.1% of the entire cohort included in this systemic review.^{7-10,12-13,16,19-24} None of the tools were incorporated during the LT evaluation to aid in determining outcomes. Caregiver burden was highest in those taking care of patients on the LT list with a mean (\pm SD) Zarit burden assessment score of 14.8 (\pm 1.01). PCB and ZBI were correlated ($p=0.0001$).^{7-10,12-13,16,19-24}

Beck depression and anxiety were correlated ($p=0.0001$), depression and anxiety both correlated with PCB and ZBI ($p=0.004$), the depression scale correlated with the Interpersonal Support Evaluation – Short Form, and Model for End-Stage Liver Disease (MELD) score correlated with ZBI and PCB (total and in most domains; $p=0.002$). Patient's poorer cognitive performance correlated with higher ZBI and PCB (employed patients had a higher cognitive performance and lower ZBI and PCB).

The largest study evaluated seven caregiver assessment tools,¹¹ and the smallest two tools.¹⁹ The number of unique tools identified and used in the different studies was 27. Select studies that validated and utilized the instruments are shown Table.²⁵⁻⁴⁸ The mean (\pm SD) number of assessment tools used was 3.42 (\pm 1.7). The most commonly used caregiver burden assessment tool used in the studies was the Zarit Burden score assessment, which was used in 77% of the studies looking into caregiver burden.^{1,2,4,12,13} BDI-II: 21-item validated questionnaire assessing depression was used

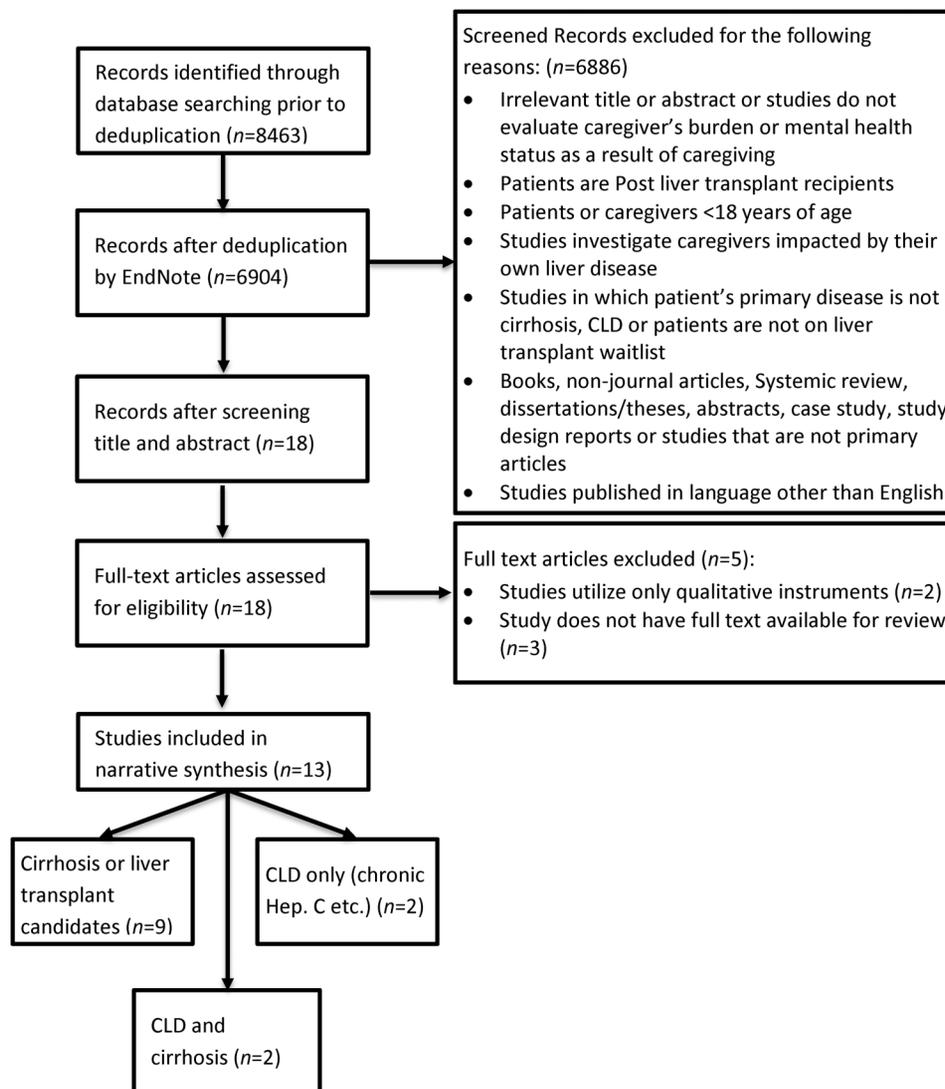


Fig. 1. Methods utilized to isolate the included articles.

Table 1. Tools studied in the evaluation of caregiver burden in patients with chronic liver disease

Instrument (validation studies)	Description (selected studies utilized the instrument)
Perceived caregiver burden scale ¹⁵	31-item self-reported questionnaire assesses perceived caregiver's burden with 5 domains: impact on finances, impact on schedule, sense of abandonment, impact on health, sense of entrapment. A higher score indicates a higher level of perceived burden. ^{1,11}
Zarit burden interview – short form ¹²	12-item self-reported instrument assesses caregiver's burden with total score of 48. It is a shortened version of the 22-item Zarit Burden Scale. Higher score indicates higher burden. ^{1,11}
Zarit Burden Scale ¹³	22-item self-reported instrument assesses caregiver's burden with each item on a 9-point rating scale. A rating of 9 for each item indicates higher level of burden. The scale measures physical, emotional, and financial toll of providing care. ^{4,12}
Beck depression inventory (BDI-II) ²³	21-item validated instrument assesses depression (including attitude, depressive symptoms, and suicidal ideation). Each item is rated on a scale of 0 to 3. The cutoff scores are: <11, minimal depression; 12 to 19, mild to moderate depression; 20 to 35, moderate depression; and 36 to 63, severe depression. ^{1,11,14,16}
Beck Anxiety Inventory ²⁴	21-item validated instrument assesses anxiety. Score 0 to 21 indicates mild to very low anxiety; score 22 to 35 indicates moderate anxiety; score above 36 indicates severe anxiety. ^{1,11}
Interpersonal support evaluation list – short form inventory ²⁸	16-question validated questionnaire assesses level of social support perceived by caregiver. Each question has 2 answer options, "probably false" or "probably true." Higher score is worse. ¹
Pittsburgh sleep quality index ²⁹	24-item questionnaire assesses quality of sleep and sleep disturbances over 1 month. 19 questions are self-reported and 5 are rated by bed partner or roommate. There are 7 component scores: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, daytime dysfunction and a global score. Higher score indicates worse quality of sleep or higher sleep disturbance. ¹¹
Epworth sleepiness scale ³⁰	8-item questionnaires on a 4-point scale with score ranging from 0 to 24 assessing daytime sleepiness. The higher the score means the higher the person's daytime sleepiness. ¹¹
HRQOL: sickness impact profile ¹⁴	136-item questionnaire used to assess patient's physical, psychosocial, and general health outcomes. It has 2 overall domains: physical and psychosocial; 12 subcategories: sleep and rest, eating, work, home management, recreation and pastimes, ambulation, mobility, body care and movement, social interaction, alertness behavior, emotional behavior, communication. Higher score indicates a poorer level of health. ¹¹
Medical outcomes Study SF-36 ³¹	36 questions assessing 8 domains of health including physical functioning, bodily pain, role limitations due to physical condition, role limitations due to emotional health, social functioning, energy/fatigue, emotional well-being, and general health perceptions. Mean score is compared to national norms. ⁴
Center for epidemiological studies depression scale ³²	20-item scale used to measure extents of depressive symptoms experienced by caregivers. Score of 0 to 15 indicates no depressive symptoms; 16 to 20 indicates mild distress; 21 to 30 indicates moderate distress; 31 and higher indicates severe distress. ^{12,15}
Hamilton anxiety rating scale ³³	Self-report instrument with 14 items, each on a 5-point scale from 0 to 4, assess level of anxiety. A score of 18 indicates mild anxiety, a score of 25 indicates moderate anxiety, and a score of 30 is severe anxiety. ¹²
Alcohol use disorders identification test ³⁴	10-item screening tool assesses alcohol intake, use frequency, dependency, and problems caused by drinking. The AUDIT distinguishes between at-risk users and alcohol-dependent users. ¹²
Picot caregiver reward scale ³⁵	25-item self-report scale assesses caregiver's perceived rewards. The PCRS measures pleasures, satisfactions, good feelings, and positive consequences connected to caregiving responsibilities. Scores range from 0 to 64, with higher scores indicating greater perceived reward. ¹²

(continued)

Table 1. (continued)

Instrument (validation studies)	Description (selected studies utilized the instrument)
Hospital anxiety and depression scale ³⁶	14-item measure assesses anxiety and depression. A 4-point severity scale is used for each item. The HADS has two subscales, anxiety (HADS-A) and depression (HADS-D). Scores higher than or equal to 11 on either scale indicate a definitive anxiety and/or depression. ^{13,17,18}
Caregiver burden scale (Brazilian version) ³⁷	22 questions used to assess caregiver's burden with 5 subscales: general strain, isolation, disappointment, emotional entanglement, environment. Higher scores indicate higher burden.
Inventario de sintomas de stress para adultos de Lipp ³⁸	Instrument used to assess stress based on a 4-phase model and the effects of stress in the somatic and cognitive domains. First phase is the alert phase; second phase is the resistance phase; third phase is almost-exhaustion phase and fourth phase is exhaustion phase.
Spielberger state trait anxiety inventory-state form ³⁹	20-item self-report measure assesses state-related anxiety. Participants rate descriptive statements on their emotion with a 4-point scale (not at all to very much). Scores range from 20-80. Higher score indicates elevated anxiety. Normative data are used to categorize clinically elevated anxiety (STAI >48).
Medical coping modes questionnaires ⁴⁰	20-item self-report questionnaire assesses coping mechanism of caregivers among 4 categories: resignation, avoidance, social support seeking, information seeking. A 5-point scale is used to rate each item. Higher scores indicate higher use of each coping mechanism.
Scale for caregiver burden ⁴⁴	20-item self-report questionnaire measures objective and subjective burden. 10 items measure objective burden which reflects the amount of practical caregiving based on severity of patient's condition and functional needs. 10 items measure subjective burden which reflects caregiver's perceived distress due to caregiving tasks and quantity of caregiving activities. Scores range from 0 to 40 for each subscale with higher scores indicating more burden.
Marlowe Crowne social desirability scale-short form ⁴⁵	13 scored items separated into 2 sets measure an individual's level of socially acceptable and/or unrealistic responses. The scale assesses the degree to which participants providing responses that are favored by others such as over reporting positive attributes or underreporting negative attributes. Score range from 0 to 13 with higher scores indicating higher level of socially desirable responding. Normative data is used to classify individuals who respond in often unrealistic, socially desirable way (MCSDS>7).
SD-36v2 health survey ^{46,47}	Measures Quality of Life (QOL) by assessing perceptions of health in eight domains: physical functioning, role functioning-physical, role functioning-emotional, vitality, pain, general health, social functioning, and mental health. Scores range from 0-100. Higher scores reflect higher QOL. SD-36 has 2 component scores – physical component summary (PCS) and mental component summary (MCS). ¹⁹
Quality of life inventory ⁴⁸	32 statements on 16 life domains which reflect life satisfaction. 16 Life domains include health, self-esteem, goals-and-values, money, work, play, learning, creativity, helping, love relationship, friendships, relationship with children, with relatives, home, neighborhood, community. Higher scores indicate higher life satisfaction. ¹⁹
Profile of mood states-short form ⁴⁹	Assesses mood disturbance. Caregivers read descriptive adjective and rate how they feel about them on a 5-point scale. Form provides total score and factor scores: tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, confusion-bewilderment. Higher score means more mood disturbance. ¹⁹
Caregiver strain index ⁵⁰	13-item questionnaire to assess caregiver burden. Higher scores mean more strain. If caregiver answers "yes" to 7 or more items, clinically significant caregiver strain is indicated. ¹⁹
Caregiver benefit index ^{30,51}	Examines benefits perceived by transplant caregivers in 12 areas. Higher scores mean more benefits. Questions focus on benefit gained from helping patient, spending time with patients, personal growth, interpersonal benefits ¹⁹
Miller social intimacy scale ⁵²	Assesses caregiver's perceived closeness to their spouse. It provides two intimacy subscales: Frequency and Intensity and culminated in a total intimacy score. Higher score indicates greater intimacy. ¹⁹

Table 2. Instruments used to assess rewards and benefits perceived by caregivers of patients with chronic liver disease or cirrhosis.

Instrument (validation study)	Number of items	Subscale/Domain	Score report	Number of pre-transplant caregiver administered from selected studies
Caregiver benefit index ³⁰	12	4 benefit categories: helping the patient, time with patient, self/personal growth, relationship with others Assess: benefits from caring, spending time with patient, personal growth, interpersonal benefits	Composite score is reported 0 to 1 scale (yes or no response) used for each item	49 pre-transplant patients' caregivers
Picot caregiver reward scale ³⁸	25	2 subscales: external and Internal Reward Assess: perceived pleasures, satisfactions, good feelings, positive consequences	Composite score is reported 5- point scale ("Not at all" to "A Great Deal") used for each item	73 caregivers of patients with cirrhosis

in 23% of the studies; Beck Anxiety Inventory: 21-item validated questionnaire assessing anxiety was used in 23% of the studies; Pittsburgh Sleep Quality Index: self-rated questionnaire assessing sleep quality and disturbances over a 1-month interval was used in 15.3% of the studies; and Epworth Sleepiness Scale: 8-item questionnaire on a 4-point scale ranging from 0 to 24 assessing daytime sleepiness was used in 15.3% of the studies.^{2,19-21,23,24,26,29,30} A higher score indicating a poorer level of health was used in 77% of the studies.^{20,21,25} Perceived Caregiver Burden: 31-item questionnaire was used in 77% of the studies.^{15,16,22,25,27}

Overall, only 7.6% of the studies included a comprehensive assessment that included mental, emotional, physical, financial, and psychological.^{1,2,4,16,18-22,25,27,49-52} The study included a 20-patient caregiver dyad and used a total of seven assessment tools in order to be inclusive. Financial burden was considered in 38% of the studies and psychological in 77% of the studies, which included anxiety, depression, sleep health, and feeling of entrapment.^{2,16,19-22,25-27,49} QOL was assessed in 53.8% of the studies. Caregiver burden assessed with the Zarit Burden tool with a score of 15 (\pm 0.8) posed the poorest outcomes for patients with CLD.^{1,2,4,11,19,20,21,26}

A number of other instruments were used in assessing caregiver burden in patients with CLD (Table 1), which measured different aspects of burden in caregivers. All studies are listed in Tables 1 and 2 with references. The studies evaluated caregiver burden both in the inpatient and outpatient settings. Inpatient questionnaires were answered in 38% of the studies, and 62% evaluated the caregivers in the outpatient setting. The assessment tools were administered to

patient's primary and secondary caregivers who care for patients with CLD.

Discussion

Caregivers have a critical role in the outcome and disease progression of patients with CLD. Multiple studies have shown a better outcome in patients with a responsible caregiver.^{1,2} The results of our systemic review revealed that there is no comprehensive way to evaluate caregiver burden via one tool. A comprehensive evaluation of caregiver burden is possible by combining multiple tools; however, this can be cumbersome as many tools have similar questions that can be redundant for the patient and family (Table 3). Although difficult, it is doable. Higher MELD score correlated with ZBI and PCB (total and in most domains). Patient's poorer cognitive performance correlated with higher ZBI and PCB (employed patients had higher cognitive performance and lower ZBI and PCB), and not a single tool was able to evaluate mental, physical, social, and financial burden all together.² Our study also noted that caregivers of those who are on the transplant list have the highest caregiver burden based on ZBI and PCB score, and higher caregiver burden correlates with poor patient outcomes. Patients with a caregiver who had a ZBI score of 15.7 or higher had the poorest outcomes with increased number of hospitalizations and higher number of missed appointments, which ultimately leads to increased morbidity and mortality. Financial burden seems to have the most impact on outcomes.

LT centers do not use a caregiver burden tool and there are no cutoff values to move forward with transplant evaluation.

Table 3. Components of caregiver burden assessed by different burden instrument utilized

	PCB	ZBI-22	ZBI-SF	Scale for caregiver burden	Caregiver strain index
Time/schedule	X	X	X		X
Physical health	X	X	X	X	X
Mental/psychosocial health	X	X	X	X	X
Finance	X	X		X	X
Sleep					X

Components of caregiver burden are selected based on established domains for each burden instrument or based on the items or questions asked. Abbreviations: PCB, perceived caregiver burden; ZBI-22, 22-item Zarit burden interview; ZBI-SF, Zarit burden interview-short form.

The social evaluation prior to LT is a subjective evaluation in most cases. An objective measure is needed to evaluate the caregiver situation prior to moving forward with transplantation. Perhaps transplant centers should utilize caregiver burden tools more often as a standard practice in LT evaluation. However, those would be limited, as based on previous studies, in order to have a comprehensive assessment, one must use a total of seven assessment tools. This would most likely be cumbersome for the patient and family. Our study showed that the most commonly used tool for evaluating caregiver burden in patients with CLD is the Zarit caregiver burden tool.

Another suggestion is to use a general tool to evaluate what the patients' caregivers preserve as the highest burden then follow-up with a more in detail tool that correlates to the caregivers concern. A tool that is general and brief is the Caregiver Strain Index, which is a brief 13-question survey that evaluates time schedule, physical health, metal, social, finance, and sleep. Based on the answers, Table 1 may be used to hone in on a more specific tool that matches the caregivers' needs for evaluation. Table 3 includes components of caregiver burden assessed by the different burden instrument utilized.

This study is the only systemic review available with the greatest number of patients. It is limited as it is review, and there was no uniformity in the tools used by the research papers. This does not undermine the strength of the study due to number of patients included. In the future, work should be focused on developing a comprehensive tool to assess social, financial, physical, psychological burden with one tool, and incorporating the caregiver burden assessment tool into the LT evaluation process as an objective measure. The limitations of the study included the absence of an index assessment to use for comparison, which caused heterogeneity in the statistical analysis; this was balanced by the number of patients included. The abovementioned limitation does not undermine the strength of the study, which included the large number of studies and patients studied. Future research should focus on a more comprehensive tool to assess caregiver burden.

Conclusions

Caregiver burden remains poorly understood due to the lack of uniformity in the assessment tools used to evaluate caregiver burden. None of the tools used to evaluate caregiver burden are comprehensive; however, most tools correlate statistically with the ability to identify caregiver burden. A comprehensive tool is lacking for identifying caregiver burden in patients with CLD. Due to the correlation between caregiver burden and outcomes in patients with CLD, one should highly consider using a standard caregiver assessment tool in the LT evaluation process.

Funding

None to declare.

Conflict of interest

The authors have no conflict of interests related to this publication.

Author contributions

Study concept and design (SS, BY), acquisition of data (NP, HS), analysis and interpretation of data (SS, BY, NP), drafting

of the manuscript (BY), critical revision of the manuscript for important intellectual content (SS, BY), statistical analysis (BY, PN), obtained funding (N/A), administrative, technical, or material support, study supervision (SS).

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