

ORIGINAL ARTICLE

The emotional burden of caregiving for patients with cirrhosis

Zachary M. Saleh¹  | Najat E. Salim² | Samantha Nikirk² | Marina Serper³  | Elliot B. Tapper^{2,4} 

¹Department of Internal Medicine, University of Michigan Health System, Ann Arbor, Michigan, USA

²Division of Gastroenterology and Hepatology, University of Michigan, Ann Arbor, Michigan, USA

³Division of Gastroenterology and Hepatology, University of Pennsylvania Perelman School of Medicine, Philadelphia, Pennsylvania, USA

⁴Gastroenterology Section, VA Ann Arbor Healthcare System, Ann Arbor, Michigan, USA

Correspondence

Elliot Tapper, Division of Gastroenterology and Hepatology, University of Michigan, 3912 Taubman, SPC 5362, 1500 E. Medical Center Dr., Ann Arbor, MI 48109, USA.

Email: etapper@umich.edu

Funding information

National Institute of Diabetes and Digestive and Kidney Diseases, Grant/Award Number: 1K23DK117055-01A1

Abstract

Caregivers for patients with cirrhosis face immense physical and psychological strain that negatively impact quality of life and ability to care for oneself. The aim is to explore the caregiver experience for patients with cirrhosis, identify prominent stressors, and understand the multidimensional contributors to caregiver burden, to help tailor effective interventions. The caregivers of 25 patients with decompensated cirrhosis underwent semistructured in-person interviews and completed written exercises targeting emotional disclosure or resilience training that were analyzed for dominant emotions and themes. Burden was quantified using the Zarit Burden Interview-12 (ZBI, range 0–48), Distress Thermometer (0–10), and Caregiver Captivity Index (0–4). Quality of life was assessed with a visual analog scale (0–100). Median ZBI was moderate (14 [10–19]), as was distress (5 [2–7]), and captivity (2 [1–4]). Quality of life was fair (80 [70–85]). Dominant emotions included anxiety, guilt, fear, frustration, captivity, and resentment. Prominent themes included lack of time for self-care, hierarchy of caregiver role, support from versus frustration with medical professionals, social support, spirituality and religion, and disease-related restrictions. Hepatic encephalopathy, and need to follow strict nutrition and diet recommendations, are frequent sources of disease-related caregiver burden. The health care system confers some degree of burden, especially when doubts arise regarding physician competence. *Conclusion:* Caregiver burden is significant. The impact of interventions to alleviate caregiver burden should be explored, so that their appreciated efforts do not have such detrimental effects on their quality of life.

INTRODUCTION

Cirrhosis and its complications result in disability, frequent hospitalization, and death.^[1–4] Patients rely on

informal caregivers (often family members) to assist them with many of their needs. Caregivers play a major role in the management of cirrhosis.^[5] Caregivers perform the equivalent of \$522 billion in uncompensated

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Hepatology Communications* published by Wiley Periodicals LLC on behalf of American Association for the Study of Liver Diseases.

services in the United States annually.^[6] The prevalence, morbidity, and mortality of cirrhosis are rising,^[7–10] increasing the present and future burden placed on caregivers of patients with cirrhosis. It is known that caregivers of patients with cirrhosis experience a substantial burden.^[5,11] Data are limited, however, regarding the emotional dimensions of the caregiver experience as well as the specific drivers of their burden.

Caregiver responsibilities create physical and psychological strain, which affect both the health of the caregiver and, reciprocally, the patient.^[12,13] Caregiver-assisted management of cirrhosis complications causes caregiver suffering, deterioration in quality of life, loss of employment, and inability to care for one's own medical problems.^[5,14] The broad downstream impacts of these detriments on both caregiver and patient outcomes are likely severe, and yet not well-documented.

Herein we present a qualitative study nested within a randomized trial of coping strategies for cirrhosis caregivers (CAREGIVER NCT04205396). Our aim is to summarize the nature and sources of caregiver burden and develop targets for interventions that can provide caregiver relief.

METHODS

Subject recruitment

This was a prospective qualitative study that recruited informal caregivers of persons with decompensated cirrhosis between December 2019 and May 2021 to analyze the magnitude of and factors associated with caregiver burden. Caregivers were identified by the patients. It was nested as a part of a larger trial, whose aim was to evaluate the effectiveness of (1) emotional disclosure and (2) resilience training on caregiver burden and burnout. The interviews and written prompts completed therein were used to complete this analysis. Decompensated cirrhosis was defined as an adult ≥ 18 years of age with any of the following criteria: (1) cirrhosis with an all-cause hospitalization within the previous 30 days; (2) one of the following within the prior 6 months from the date of consent: ascites (requiring paracentesis or diuretics), overt hepatic encephalopathy (requiring lactulose or rifaximin, metronidazole, or neomycin), spontaneous bacterial peritonitis, hepatic hydrothorax (requiring diuretics or thoracentesis), or variceal bleed; or (3) hepatocellular carcinoma with Barcelona Clinic Liver Cancer Stage C or D. Caregivers were identified by screening outpatient and inpatient patient schedules, by clinician referral, and directly emailing patients. Caregivers were defined by the patient as the primary relative, spouse, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance for a

person with decompensated cirrhosis, including consistent involvement in their medical care. Exclusion criteria were non-English speaking, unable/unwilling to provide consent, severe cognitive impairment, concurrent participation in another interventional study, or use of a personal diary in the last 12 months (due to similarity to the written response intervention). Caregivers allowed their interviews and written responses to be published anonymously. This study was approved by the University of Michigan Medical School Institutional Review Board (identifier HUM00167479).

Baseline data

Baseline data collected about the patients with cirrhosis for whom the caregivers provide care included cirrhosis etiology, complications, medications, recent procedures, transplant status, and daily needs. Baseline data collected about the caregivers included age, sex, race, education level, marital status, employment, duration and duties as a caregiver, and recent hospitalizations. Structured baseline questionnaires obtained were Zarit Burden Interview-12 (ZBI) Score,^[15,16] Distress Thermometer Score (score 0–10, highest possible distress),^[17] Visual Analogue Scale Score (VAS) for global health-related quality of life (scored 0–100, best possible health), and Caregiver Captivity Index (CCI).^[18] The ZBI score is based on a set of 12 questions that pertain to the frequency of burdensome aspects of caregiving. Each question is scored from 0 (rarely) to 4 (nearly always). Cumulative scores < 10 indicate no-to-mild burden, 10 to 20 indicate mild-to-moderate burden, while scores > 20 indicate high burden. The CCI is based on three questions that pertain to feelings of captivity, each scored from 1 (not at all) to 4 (very much), with an average score.

Qualitative interview analysis

In addition to these baseline survey data, there are two other sources of data from the study: (1) caregiver interviews and (2) caregiver written exercises. After the study intervention concluded, caregivers were invited to partake in a semistructured interview. The guidebook was developed by three members of the investigative team (ET, SN, and NS) based on prior experience with caregiver-focused interventions and preliminary assessment of the caregiver written exercises. The interview guide was refined with input from patients and tailored to the arm of the trial to which the caregiver was allocated. The interviewees were asked open-ended questions by a single interviewer. The results were professionally transcribed verbatim, de-identified, and redacted in accordance with established qualitative methodologies.^[19–22] The interviews

were completed by two investigators with qualitative research experience. The codebook was developed by conducting a thorough review of transcripts to identify recurrent concepts and generate preliminary codes. The codebook was refined and expanded in an iterative process to reflect emerging themes throughout the data collection and analysis phases. The coding team developed open codes using four interviews separately, meeting frequently to establish the consistency of the codebook via grounded theory.^[20] We reached thematic saturation wherein no novel codes were generated after 20 transcripts and confirmed with five additional analyses. Recurrent themes and impactful quotes were analyzed and compiled into tables. These were examined for how they relate to patient, caregiver, or health system factors.

Written report analysis

Caregivers were drawn from a randomized trial of coping strategies: no intervention, emotional disclosure, or resilience training prompts. The emotional disclosure group asked caregivers to recollect their experiences as a caregiver via written stories. In the resilience group, caregivers were asked to identify and detail “three good things” each day and any emotions that surrounded them. These transcripts were reviewed and coded as previously.

RESULTS

Quantitative data

Of the 25 caregivers enrolled in this study, the median age was 62, 20% were male, half were college graduates, and one quarter were working full time (Table 1). Most caregivers were a spouse or partner of the patient, and the median number of years of caregiving was 3.2. Caregivers, on average, had mild-to-moderate burden according to the ZBI and Distress Thermometer but reported good health-related quality of life on a VAS (80 of 100). The patients predominantly had alcohol-related cirrhosis (52%), complicated by hepatic encephalopathy (HE) and ascites. Many (44%) needed help with more than one activity of daily living. Half of the patients required emergency room evaluation and hospitalization within the 90 days before study enrollment.

Semistructured interviews

“It’s so easy for caregivers to not take care of themselves. Then there’s physical health, there’s mental health, emotional health and all that stuff gets set aside.”

TABLE 1 Caregiver and patient characteristics

N	25
<i>Caregiver characteristics</i>	
Age (median, IQR)	62 years (57–65)
Male	20%
College graduate	48.0%
Married	88.0%
Employment full-time, part-time	24.0%, 8.0%
Years as caregiver (median, IQR)	3.2 years (1.0–5.0)
<i>Relationship to patient</i>	
Spouse	56.0%
Ex-spouse	4.0%
Partner	12.0%
Parent	8.0%
Child	20.0%
Zarit Burden Interview-12 Score (median, IQR)	14 (10–19)
Distress Thermometer Score (median, IQR)	5 (2–7)
Visual Analogue Scale Score of health-related quality of life (median, IQR)	80 (70–85)
Caregiver Captivity Index Score (median, IQR)	2 (1–4)
<i>Patient characteristics</i>	
<i>Etiology of cirrhosis</i>	
Alcohol	52.0%
NAFLD	28.0%
Primary biliary cholangitis	12.0%
Hepatitis C	8.0%
Hepatic encephalopathy	68.0%
Ascites	72.0%
Paracentesis in prior 90 days	36.0%
History of hepatocellular carcinoma	4.0%
Listed for transplant	20.0%
Unable to operate a vehicle ^a	48.0%
Requiring help with ≥ 1 ADL	44.0%
Hospitalized, prior 90 days ^{b,c}	52.0%
Visit to ER, prior 90 days ^{b,c}	48.0%

Abbreviations: ER, emergency room; IQR, interquartile range (listed as quartile 1–quartile 3); NAFLD, nonalcoholic fatty liver disease.

^aNewly unable to operate a motor vehicle within the 6 months before enrollment.

^bIn the specified number of days before enrollment.

^cMedian number of hospitalizations and emergency room visits among those who were hospitalized or visited the emergency room, respectively.

Table 2 highlights the responses from the caregiver interviews. Participants experience various emotional strains that affect their ability to care for themselves and their loved ones—commonly anxiety, fear, guilt, sadness, and frustration. Caregivers tend to feel “alone” and “guilty for making time for [themselves].” They are unable to “get out and clear [their] thoughts.” They feel overwhelmed,

TABLE 2 Dominant themes identified in semistructured interviews

Emotions	Notable quotations
Anxiety	"I try not to worry about it too much when I'm gone. I can't help it. I still do."
Captivity/isolation	"I feel alone in this." "I don't have that ability to just get out and clear my thoughts and clear my mind, and get a cup of coffee and just let her have some space too."
Guilt	"You can feel almost guilty for making time for yourself, or thinking of something that you would like to do because ... if you're a good person, you'll think of someone else all the time."
Fear	"She went into mild rejection. We were all freaked out and just scared to death, all them feelings started coming back again."
Fulfillment	"You love them, you care for them, and maybe they don't always know how to say thank you, but you see the results. You see the improvement. It's a remarkable thing." "It's a beautiful thing. I'm glad every morning I wake up. I've learned that this process has made me appreciate life a whole lot more."
Frustration	"I get frustrated 'cause she can do more for herself than what she does sometimes." "I just could no longer help her ... it was affecting my health. I had issues. I went to the doctor. Bit one of the nurse's heads off because anger—that was the only emotion I had left."
Sadness	"We used to go out dancing, and stuff like that. Now, we don't do anything like that anymore 'cause we can't. That makes me sad, frustrated, and that's it." "Maybe it is just—it's super depressing when you think about it, when you think about the timeline and the shortened time you have left with them."
Resentment	"It's hard to emotionally, physically, mentally, keep up on just your everyday daily things because you have that extra weight of emotional stress from your person ... because they're suffering or because they're suffering then now you have to suffer because you've got this added weight on your shoulders ... it's hard to be a caregiver."
Unpredictability/ Variability	"I just didn't understand 'cause I thought it was me doing something wrong. In actuality, it was just part of this disease, or symptoms of the liver."
Dynamics	Notable quotations
Perceived caregiver role	"I have to know what's on the horizon, have everything prepared so nobody even has to ask for anything." "Pretty much everything. Making sure she's up ... gets her meds ... doesn't fall ... eats ... doesn't hurt herself... tries to be active ... It's overwhelming."
Power/hierarchy of caregiver	"You have to stand back and go, okay, am I babying too much? Am I tending too much? ... Is this something that she could do for herself?" "I [feel like] a dad teaching a 14-year-old adolescent the facts of life"
Support from medical professionals	"Gosh, they're actually helping. He's talking to us. He has answers. That was priceless."
Frustration with medical professionals	"I know she's been to multiple doctors, and some doctors are a lot more—I don't want to say bedside manner, but it's like, it was a machine ... they're giving you all this horrible information, and then they send you a survey question." "They'll say, well, if this happens, get to the hospital, go to the ER, so then something will happen. We'll go to the ER, and they'll—they look at you like, oh, well, why are you here? I can't see anything wrong, go home." "I felt I was being shunned, looked down upon. You are just a caregiver. Do what we say."
Lack of time for self-care	"There's enjoyment in helping to care for somebody, but there has to be a time whenever your life is not—you aren't losing your life in order to help someone else save theirs." "It's so easy for a caregiver to not take care of themselves. Then there's physical health, there's mental health, emotional health, and all that stuff gets set aside."
Social support	"Even if you do nothing with that information, that human contact of somebody reaching out and saying, 'Hey, what do you think, and how is this affecting you,' getting them involved ... it pulls them into a community and gives them a sense of, I'm not alone."
Religion/spirituality	"I pray a lot for patience and understanding."
Clinical resources	"What if somebody called once a week and said, 'Hey, what's going on this week?' ... maybe having somebody that would basically check up on you, I think would help?"
Material resources	"It's hard to find practical solutions for the things that are happening to him, for instance, because of liver cirrhosis, he's unable to take certain pain drugs, they all affect the liver in a bad way, so now he has double hernia, which involves a lot of pain at times."
Patient restrictions due to disease	"I've noticed in the last couple years she has slowed down quite a bit ... We were going out to different places before. Now, we're ... stuck at home. She's not even able to go do any estate sales, really like we used to go. Antique hunting, or anything like that." "I guess the ammonia that was building up in her system ... Reasoning was out the door."

expressing that they “just could no longer help [the patient]” because it “was affecting [their own] health.” They often feel that when the patient is suffering, they also suffer. These emotions intensify and have numerous downstream effects. Caregivers often sacrifice the time allotted for themselves to tend to their patients. They develop hypervigilance, always having “to know what’s on the horizon [and] have everything prepared.” They question whether they are enabling certain behaviors and “babying too much,” or even causing more harm than good (“I thought it was me doing something wrong”). There is a significant element of frustration and sadness due to disease-related restrictions, whether it is being “stuck at home,” “confusion ... and not [being] able to reason,” or inability to partake in historically enjoyable activities such as “dancing” and “estate sales.” Surprisingly, there is not much mention of struggles with ongoing alcohol use, but there is a significant amount of shame in disclosing liver disease to friends and family due to the perceived stigma—even if the etiology is not alcohol.

There is also a variety of emotions derived—both positive and negative—pertaining to health care experiences. Caregivers frequently recount frustration with clinician competence, contrasting their experiences from institution to institution. One caregiver reflects on their experience at one hospital, where they felt the medical team had labeled their loved one as “comfort care” and initiated palliative opioids, only to be surprised when another institution subsequently provided aggressive care that kept the patient alive and home for years to come. One patient suffered for years with HE until switching health systems and being prescribed lactulose and rifaximin. On the other hand, positive experiences with health care providers instill a strong sense of confidence and hope into caregivers. One caregiver recounts the easily digestible explanations about cirrhosis and treatment options from a “rock star” physician. One reports “immediately, this calm came over [them]” when they felt heard and understood by a physician. Caregivers also grasp for social support, affirming it “pulls them into a community and gives them a sense of ‘I’m not alone.’” Although caregiving comes with considerable stress, there is prevailing sense of fulfillment: “You love them, you care for them, and maybe they don’t always know how to say thank you, but you see the results. You see the improvement. It’s a remarkable thing.”

Written responses

“I get angry when I think about him being sick. It is not fair. It took me 30 years to find someone to love me and it’s not fair.”

In [Table 3](#), samples of the written responses from the trial are presented. Central themes elicited were similar to the in-person interview responses. Even

though caregivers were asked to detail things they were grateful for, the strain of their role was apparent. Instead, they frequently discussed the downsides to caregiving. Resentment was a dominant theme. For instance, “his illness derailed all of our plans. There are times that he makes requests for his food that I have to get up many times. Meanwhile, my food gets cold and sits there.” The toll caregiving takes is clear, as participants recollect: “I’m not a happy person any longer” and “I’m tired of having to care 24/7 and wish he’d just go away and let me live my own life.” Even positive experiences were couched in the experience of loss: “Today, we made burgers! We haven’t really been able to enjoy them because of all the sodium and fat and grease.”

On the other hand, a few responses demonstrated the positive effects that gratitude has on their sense of self. One caregiver stated, “I helped my mom for 3 months straight last summer after she was hospitalized. I am also helping my mom now since she broke her foot. Everyone is recognizing my kindness and caring towards the ones I love. I’ll continue to help whenever and whoever I can, when I can.” Lastly, religion often minimized burden, allowing “comfort,” “peace,” “love,” and “guidance.” Religion was felt to provide a coping framework. As one caregiver explained: “Suffering is a normal part of life, and suffering can be learned from.”

DISCUSSION

In this study, we describe the multidimensional caregiver burden and specific drivers that contribute to it ([Figure 1](#)), as organized into recurring themes throughout our qualitative data. The patient factors that drive burden are HE—above all else—along with frailty, falls, malnutrition, and dietary restrictions. The emotional dimensions of caregiver burden are diverse, but resentment, frustration, and sadness are dominant themes. Financial burden is also prominent—both associated with the increased cost of caring for someone with cirrhosis and the opportunity cost of the patient not being able to earn income. Some caregivers use seemingly successful coping strategies, namely spiritual, religious, and psychological reframing.

Disease factors associated with caregiver burden

Cirrhosis confers inherent challenges for the patient and the caregiver. HE and nutrition are two factors frequently described a source of burden by these caregivers. HE causes significant frustration and sadness, not only in its severest form, but also due to its unpredictable nature. In 2011, Bajaj et al. found that

TABLE 3 Dominant themes from caregiver writings

Emotions	Notable quotations
Anxiety	"I'm also worried/afraid of when he becomes sicker. Will I be able to care for him?"
Captivity/isolation	"I used to love the freedom of Sundays, but since I have turned into a caregiver Sundays are more difficult and I find myself comparing what I used to have." "I'm not a happy person any longer. His illness came the year I retired so I'm stuck in the house." "I struggle with wanting to go out with friends ... I feel guilty for experiencing a moment of pleasure."
Guilt	"The biggest reason for guilt is I am healthy and have quality of life and his is so limited. The guilt is draining and helpless feeling. You try to help to maintain their quality of life by preserving and making their old life as close as possible."
Fear	"I am also afraid of what it will be like for [him] as this disease gets worse." "Strangely, my biggest fear isn't her dying. It's being needed for a decision and being unable to make it."
Fulfillment	"I helped my mom for 3 months straight last summer after she was hospitalized. I am also helping my mom now since she broke her foot. Everyone is recognizing my kindness and caring towards the ones I love. I'll continue to help whenever and whoever I can, when I can."
Frustration	"The hepatic encephalopathy makes me angry, because he's in a brain fog, confused and acidic and he doesn't even know when it's happening." "I hate that I get upset over the little things and then feel guilty I got upset! It is unfair that this man who I chose to be my man is sometimes not the man I married."
Despair	"My best is not going to cure him."
Resentment	"His illness derailed all of our plans. There are times that he makes requests for his food that I have to get up many times. Meanwhile, my food gets cold and sits there." "I get angry when I think about him being sick. It is not fair. It took me 30 years to find someone to love me and it's not fair." "I'm tired of having to care 24/7 and wish he'd just go away and let me live my own life."
Unpredictability/variability	"As [our hepatologist] once told us, we can do everything right and things will still go wrong. The fear of the unknown can be worse than knowing what to expect."
Dynamics	Notable quotations
Perceived caregiver role	"I'm there for support no matter what happens." "I am his memory!"
Hierarchy	"I talk to him like he is my child, not my husband at times."
Frustration with medical professionals	"When you have to wait 72 hours for a response to a portal message or a callback it's very stressful."
Lack of time for self-care	"My son's illness takes time away from my personal time. This exercise become a dread at the end of day. It was another 'chore' I had to complete." "My life revolves around doctors' appointments and taking care of [him]."
Sexual dysfunction	"It has robbed us of our sexual intimacy as a couple."
Social support	"My neighbor heard about our son and invited me for coffee. I had some apprehensions. Once we started sharing it felt wonderful ... I opened up to her and I was given a gift."
Religion/spirituality	"When we were told that he would not be a candidate for a transplant, I was angry at God for not giving us many more years." "I had to learn the Catholic concept of "redemptive suffering." It means suffering is not an end in itself. Suffering is a normal part of life, and suffering can be learned from." "I'm so thankful for God's loving arms to bring comfort back to me and the peace that no matter what the future holds, He understands and loves me and will continue to guide me."
Finances	"Since my spouse's illness has taken him out of work, finances have been super tight and everything is past due. It's been paycheck to paycheck and even that hasn't been enough."
Clinical resources	"I hate having to use the emergency room as a means to deal with problems, but was advised it's better to error on the side of caution."
Material resources	"As a caregiver, there are times I get angry about there not being more education provided to me so I would feel better equipped to help him."
Patient restrictions due to disease	"We've been in the house for 3½ years. He can't go far. The lactulose keeps him in the bathroom." "Her balance is off. She has ... muscle cramping and she's very weak. All this caused her to fall." "Was happy as day before she did not have bowel movement and was showing in her ability to make sense of what was going on ... Forgetful ... Stops in mid-sentence." "Today, we made burgers! We haven't really been able to enjoy them because of all the sodium and fat and grease." "With this disease and the fatigue, exhaustion and pain, it is so miserable." "He's slow and has a hard time getting around. We used to be so active and do things together; I still can and he can't. I have to keep reminding myself how blessed I am."

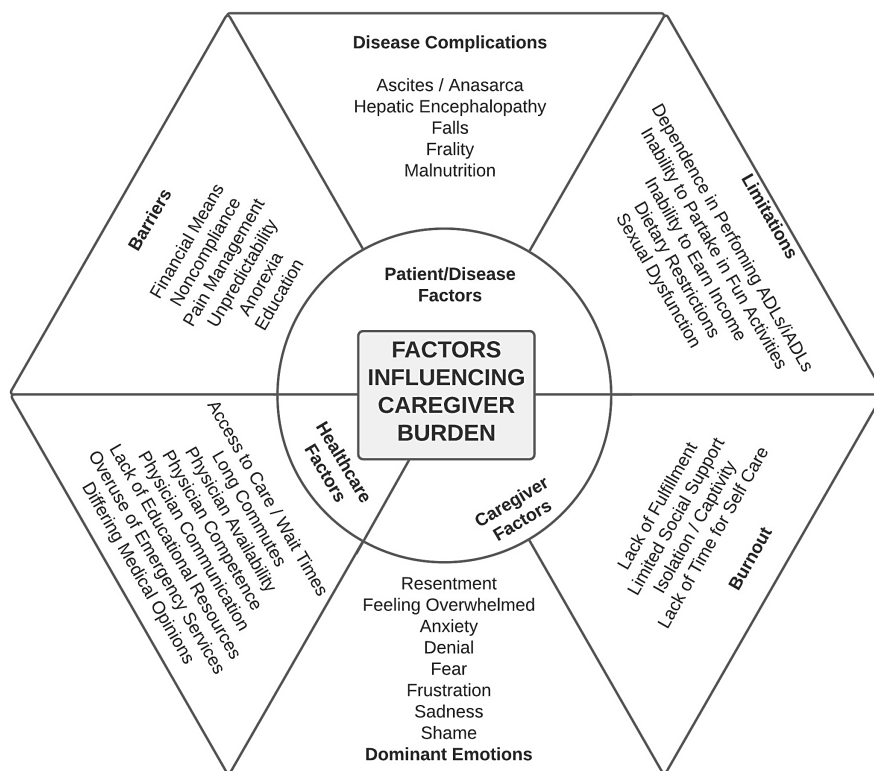


FIGURE 1 Multidimensional factors affecting caregiver burden and burnout. ADLs, activities of daily living; iADLs, instrumental ADLs.

HE and cognitive complications of cirrhosis are associated with worse financial standing and increased caregiver burden^[5]—themes that remain evident a decade later in our study, along with a number of other factors. Medication optimization to minimize cognitive fluctuations is critical. Lapses in medication access and refills are common.^[23] Ensuring continuous access to and use of evidence-based therapies through proactive monitoring and outreach is recommended. Caregivers would benefit from extended outpatient support to guide them when HE is worsening. Nutrition is another factor associated with caregiver burden—balancing addressing frailty while adhering to dietary restrictions. Education, especially in this domain, is desired by caregivers,^[24] and its ongoing improvement would be beneficial. Although increasingly common, cirrhosis is rare enough and beset by stigma such that sustainable support groups (online and in person) are lacking. Efforts to connect caregiver electronically are needed. Further studies are needed to evaluate the impact of dietary restrictions and recommendations, including the potential to lift or relax certain restrictions, particularly regarding sodium intake.^[25] Finally, given the variability in age of onset of cirrhosis, caregivers were from a variety of ages and stages in their lives. Twenty percent of the caregivers included in this study were the patient's child, which is likely accompanied by personal sacrifices at an earlier age (such as careers and relationships) as a result of these unexpected responsibilities.

Health care provider/system factors associated with caregiver burden

Interactions with health care providers were a significant source of frustration among caregivers, frequently pertaining to doubts regarding the providers' competence, time limits for patient interactions, poor access to care, and variable medical opinions from provider to provider. Clinician communication was a prominent source of dissatisfaction, which is potentially modifiable with improved training. Positive impressions frequently stemmed from confidence in a physician's expertise, sound explanations of medical concepts, and the sense that the physician cared about the patient and caregiver on a personal level. Interactions can be improved with a focus on anticipatory guidance, nutrition, pain management, and communication. Ufere et al. described notable gaps in care after an index hospitalization for decompensated cirrhosis, with a major contributor being delay in timely receipt of supportive care services.^[11] Even after a longstanding diagnosis of cirrhosis, our study suggests that this remains a barrier. The health care system itself can alleviate caregiver burden by expanding homecare, broadening outpatient support with an emphasis on avoiding emergency room care when possible, and offering support programs directed at caregiver mental wellbeing. From a policy perspective, interventions to provide caregiver training and paid benefits for informal caregiving could be enacted to lessen their burden.

Psychological interventions to improve caregiver burden

Unless caregivers are very proactive in seeking out clinical or social support for themselves (which is difficult to do with the full-time responsibilities of being a caregiver), they can often go years without support. It is crucial to address these deficits to promote the health and well-being of both parties. It is possible that palliative care consultation may be helpful, but the impact on burden is unknown, and it is essential to develop interventions targeted to the caregiver's needs. In other disease conditions, caregivers have been shown to have unmet social and religious needs^[26]; and spirituality and religiosity have been shown to correlate with improved caregiver burden,^[27,28] coping ability,^[29] and even situational adjustment.^[30]

Interventions geared toward the well-being of caregivers for persons with advanced cirrhosis are limited. Bajaj et al. showed that mindful meditation improved caregiver burden and depression.^[31] Elsewhere, it has been shown that translating personal experiences into a written or spoken story is associated with both physical and mental benefits^[32] and a reduction in health care use.^[33] Furthermore, writing has been associated with lower reported pain levels, medication use, and depression levels.^[34] Caregivers may also benefit from reframing via positive psychology and resilience training. Seligman et al. demonstrated a simple intervention: Writing things that went well (and an explanation why) daily for 1 week can yield a 5-fold reduction in depressive symptoms.^[35] Randomized controlled trials should be performed to assess the impact of resilience training, psychological support, and education materials on the health and well-being of caregivers for patients with cirrhosis. If these interventions were to prove beneficial, their impact on patient outcomes could be analyzed to support their broader integration. While we await the results of our ongoing CAREGIVER trial, our qualitative data highlight the specific emotional responses triggered by caregiving. Being a caregiver undoubtedly elicits multiple stressors, but psychological interventions may increase the likelihood of success by addressing the ways in which caregivers respond to them.

Additional sources of caregiver support deserve consideration. Peer support groups have been effective, less so for caregiver burden, but for the management of depression.^[36] Providers can be taught communication skills to avoid exacerbating caregiver burden. Finally, policy can be implemented to allow for paid informal caregiving.

Contextual factors

This study was conducted at a large, single-center academic institution, which may limit its applicability to broader populations. Additionally, caregivers who volunteered for these interventions may have been the

most distressed or in need of help, biasing the results of the interviews and written prompts. Only a small portion of patients included in the study had a history of hepatocellular carcinoma and/or were listed for transplant, both of which would contribute to different caregiver experiences. Finally, the ongoing COVID-19 pandemic may have affected the ways in which patients, caregivers, and clinicians interact.

CONCLUSIONS

We identified many negative factors and several positive caregiving factors in decompensated advanced liver disease. Key modifiable themes emerged. Disease-specific factors can be targeted by educational interventions, medication optimization, and dietary improvements. The most intervenable clinician factor is communication. Health care factors can chiefly be improved by offering additional support in between clinic visits and improving access to care. Health care policies to provide training and financial support will minimize caregiver burden. Finally, addressing psychological well-being and coping strategies for caregivers has marked potential to improve their quality of life and minimize their burden.

AUTHOR CONTRIBUTORS

Study concept: Elliot B. Tapper. *Data acquisition:* Elliot B. Tapper, Najat E. Salim, and Samantha Nikirk. *Analysis:* Zachary M. Saleh, Elliot B. Tapper, Najat E. Salim, Samantha Nikirk, and Marina Serper. *Manuscript draft:* Zachary M. Saleh. *Manuscript revisions:* Elliot B. Tapper, Najat E. Salim, Samantha Nikirk, and Marina Serper.

FUNDING INFORMATION

The Gloria Wendling Research Fund and the National Institutes of Health through the National Institute of Diabetes and Digestive and Kidney Diseases (1K23DK117055-01A1).

CONFLICT OF INTEREST

Dr. Serper consults for Gilead. Dr. Tapper has research funds provided to the institution from Valeant, Madrigal, Novo Nordisk, Lipocine, and Ambys.

DISCLOSURES

Elliot Tapper is the guarantor of this article.

ORCID

Zachary M. Saleh  <https://orcid.org/0000-0001-9273-2417>

Marina Serper  <https://orcid.org/0000-0003-4899-2160>

Elliot B. Tapper  <https://orcid.org/0000-0002-0839-1515>

REFERENCES

1. Tapper EB, Sullivan A, Tess A. Teaching quality improvement (QI) on the wards: how we do it. *MedEdPORTAL*. 2015;11:10211.
2. Tapper EB, Su GL. Does Karnofsky performance status of patients with cirrhosis on the transplant waitlist meet the eyeball test? *Clin Gastroenterol Hepatol*. 2016;14:1196–8.
3. Vilstrup H, Amodio P, Bajaj J, Cordoba J, Ferenci P, Mullen KD, et al. Hepatic encephalopathy in chronic liver disease: 2014 Practice Guideline by the American Association for the Study Of Liver Diseases and the European Association for the Study of the Liver. *Hepatology*. 2014;60:715–35.
4. Rakoski MO, McCammon RJ, Piette JD, Iwashyna TJ, Marrero JA, Lok AS, et al. Burden of cirrhosis on older Americans and their families: analysis of the health and retirement study. *Hepatology*. 2012;55:184–91.
5. Bajaj JS, Wade JB, Gibson DP, Heuman DM, Thacker LR, Sterling RK, et al. The multi-dimensional burden of cirrhosis and hepatic encephalopathy on patients and caregivers. *Am J Gastroenterol*. 2011;106:1646–53.
6. Arno PS, Levine C, Memmott MM. The economic value of informal caregiving: President Clinton's proposal to provide relief to family caregivers opens a long-overdue discussion of this "invisible" health care sector. *Health Aff*. 1999;18:182–8.
7. Beste LA, Leipertz SL, Green PK, Dominitz JA, Ross D, Ioannou GN. Trends in burden of cirrhosis and hepatocellular carcinoma by underlying liver disease in US veterans, 2001–2013. *Gastroenterology*. 2015;149:1471–82.e5.
8. Fleming KM, Aithal GP, Card TR, West J. All-cause mortality in people with cirrhosis compared with the general population: a population-based cohort study. *Liver Int*. 2012;32:79–84.
9. Asrani SK, Devarbhavi H, Eaton J, Kamath PS. Burden of liver diseases in the world. *J Hepatol*. 2019;70:151–71.
10. Tapper EB, Parikh ND. Mortality due to cirrhosis and liver cancer in the United States, 1999–2016: observational study. *BMJ*. 2018;362:k2817.
11. Ufere NN, Donlan J, Indriolo T, Richter J, Thompson R, Jackson V, et al. Burdensome transitions of care for patients with end-stage liver disease and their caregivers. *Dig Dis Sci*. 2021;66:2942–55.
12. Hareendran A, Devadas K, Sreesh S, Tom Oommen T, Varghese J, Lubina S, et al. Quality of life, caregiver burden and mental health disorders in primary caregivers of patients with Cirrhosis. *Liver Int*. 2020;40:2939–49.
13. Hopps M, Iadecola L, McDonald M, Makinson GT. The burden of family caregiving in the United States: work productivity, health care resource utilization, and mental health among employed adults. *JMDH*. 2017;10:437–44.
14. Fabrellas N, Moreira R, Carol M, Cervera M, de Prada G, Perez M, et al. Psychological burden of hepatic encephalopathy on patients and caregivers. *Clin Transl Gastroenterol*. 2020;11:e00159.
15. Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: a new short version and screening version. *Gerontologist*. 2001;41:652–7.
16. Higginson IJ, Gao W, Jackson D, Murray J, Harding R. Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. *J Clin Epidemiol*. 2010;63:535–42.
17. Zwahlen D, Hagenbuch N, Carley MI, Recklitis CJ, Buchi S. Screening cancer patients' families with the distress thermometer (DT): a validation study. *Psychooncology*. 2008;17:959–66.
18. Pearlman LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist*. 1990;30:583–94.
19. Carlozzi NE, Tulsy DS. Identification of health-related quality of life (HRQOL) issues relevant to individuals with Huntington disease. *J Health Psychol*. 2013;18:212–25.
20. Carlozzi NE, Fyffe D, Morin KG, Byrne R, Tulsy DS, Victorson D, et al. Impact of blood pressure dysregulation on health-related quality of life in persons with spinal cord injury: development of a conceptual model. *Arch Phys Med Rehabil*. 2013;94:1721–30.
21. Carlozzi NE, Tulsy DS, Kisala PA. Traumatic brain injury patient-reported outcome measure: identification of health-related quality-of-life issues relevant to individuals with traumatic brain injury. *Arch Phys Med Rehabil*. 2011;92(10 Suppl):S52–60.
22. Kisala PA, Tulsy DS. Opportunities for CAT applications in medical rehabilitation: development of targeted item banks. *J Appl Meas*. 2010;11:315–30.
23. Thomson MJ, Lok AS, Tapper EB. Optimizing medication management for patients with cirrhosis: evidence-based strategies and their outcomes. *Liver Int*. 2018;38:1882–90.
24. Saleh ZM, Bloom PP, Grzyb K, Tapper EB. How do patients with cirrhosis and their caregivers learn about and manage their health? A review and qualitative study. *Hepatol Commun*. 2021;5:9.
25. Lai JC, Tandon P, Bernal W, Tapper EB, Ekong U, Dasarathy S, et al. Malnutrition, frailty, and sarcopenia in patients with cirrhosis: 2021 practice guidance by the American Association for the Study of Liver Diseases. *Hepatology*. 2021;74:1611–44.
26. Kim SY, Yim HJ, Park SM, Kim JH, Jung SW, Kim JH, et al. Validation of a Mayo post-operative mortality risk prediction model in Korean cirrhotic patients: post-operative mortality in cirrhotics. *Liver Int*. 2011;31:222–8.
27. Torabi Chafjiri R, Navabi N, Shamsalinia A, Ghaffari F. The relationship between the spiritual attitude of the family caregivers of older patients with stroke and their burden. *Clin Interv Aging*. 2017;12:453–8.
28. Kes D, Yildirim TA. The relationship of religious coping strategies and family harmony with caregiver burden for family members of patients with stroke. *Brain Inj*. 2020;34:1461–6.
29. Farinha FT, Bom GC, Manso MMFG, Prado PC, Matiole CR, Trettene ADS. Religious/spiritual coping in informal caregivers of children with cleft lip and/or dysphagic palate. *Rev Bras Enferm*. 2021;75(Suppl 2):e20201300.
30. Chardon ML, Brammer C, Madan-Swain A, Kazak AE, Pai ALH. Caregiver religious coping and posttraumatic responses in pediatric hematopoietic stem cell transplant. *J Pediatr Psychol*. 2021;46:465–73.
31. Bajaj JS, Ellwood M, Ainger T, Burroughs T, Fagan A, Gavis EA, et al. Mindfulness-based stress reduction therapy improves patient and caregiver-reported outcomes in cirrhosis. *Clin Transl Gastroenterol*. 2017;8:e108.
32. Pennebaker JW. The effects of traumatic disclosure on physical and mental health: the values of writing and talking about upsetting events. *Int J Emerg Ment Health*. 1999;1:9–18.
33. Pennebaker JW, Seagal JD. Forming a story: the health benefits of narrative. *J Clin Psychol*. 1999;55:1243–54.
34. Greenberg MA, Wortman CB, Stone AA. Emotional expression and physical health: revising traumatic memories or fostering self-regulation? *J Pers Soc Psychol*. 1996;71:588–602.
35. Seligman MEP, Steen TA, Park N, Peterson C. Positive psychology progress: empirical validation of interventions. *Am Psychol*. 2005;60:410–21.
36. Pfeiffer PN, Heisler M, Piette JD, Rogers MAM, Valenstein M. Efficacy of peer support interventions for depression: a meta-analysis. *Gen Hosp Psychiatry*. 2011;33:29–36.

How to cite this article: Saleh ZM, Salim NE, Nikirk S, Serper M, Tapper EB. The emotional burden of caregiving for patients with cirrhosis. *Hepatol Commun*. 2022;6:2827–2835. <https://doi.org/10.1002/hep4.2030>