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# Burden of Cirrhosis on Patients and Caregivers

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## Burden of Cirrhosis on Society

Cirrhosis is the final common pathway for most chronic liver diseases, affecting approximately 0.27% of the adult population and accounting for over 60,000 deaths in the United States each year.(1,2) Although the general public perceives liver disease to be rare, cirrhosis-attributable mortality surpasses that from diabetes or kidney disease.(2,3) Cirrhosis is a very resource-intensive condition. In the United States, more than half a million cirrhosis hospitalizations occur each year, at a rate that is rising much faster than other chronic illnesses.(4) Nearly 70% of patients with cirrhosis survive their hospitalization experience readmission, at a cost of over $20,000 each time.(5) In 2015, the total cost of medical care for patients with cirrhosis in the employer-sponsored insurance population was more than $9.5 billion.(6) Because employer-based insurance covers approximately half of the US population, the medical costs for all patients with cirrhosis in the United States likely approximates the $21 billion spent on congestive heart failure.(7) Finally, the national and global prevalence appears to be increasing, driven by an aging population as well as a rise in alcoholic and nonalcoholic fatty liver disease.(8)

At the population level, the prevalence of cirrhosis is highest among blacks and those with lower levels of education and income.(1) These disparities indicate that cirrhosis burden is experienced disproportionately by already disadvantaged groups.

## Burden of Cirrhosis on Individual Patients

The major complications of cirrhosis include ascites, hepatic encephalopathy, and variceal bleeding, and these are the focus of most medical management. However, there are several additional unique "minor" complications such as pruritis, muscle cramps and insomnia, which deserve medical attention. Malnutrition is present in more than two-thirds of patients due to various mechanisms, with a disproportionately high rate of muscle loss (sarcopenia).(9) Finally, a surprising number of cirrhosis patients experience symptoms typically associated with end-stage cancer, such as pain, nausea and fatigue, as shown in Fig. 1.(10) As a result, patients with compensated cirrhosis have lower health-related

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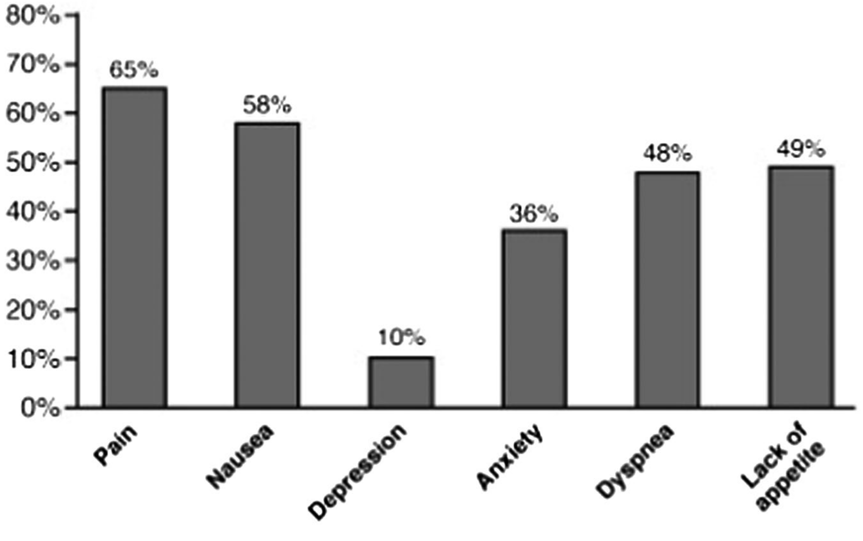

**FIG. 1.** Proportion of patients with cirrhosis who experience symptoms in the Edmonton Symptom Assessment System.(10)

quality of life (HRQOL) than the general population, and those with decompensated cirrhosis have among the lowest HRQOL scores of any medical condition short of death.(11)

More than one-third of patients with cirrhosis suffer from diagnosed mental health disorders, and many others suffer from situational emotional distress.(12) In one study, more than half of patients screened positive for depression using the Beck inventory.(13) Comorbid psychiatric disease (dual diagnosis) may be even more common among patients with alcoholic liver disease.(14) Not only do comorbid mental health disorders affect quality of life for patients with cirrhosis, but they also complicate clinical management.

# Burden of Cirrhosis on Caregivers

Patients with cirrhosis have high caregiving needs; many cannot drive to their frequent medical appointments due to hepatic encephalopathy, and up to one-third experience impairment in their activities of daily living due to frailty and cognitive impairment.(15,16) As a result, a typical patient with cirrhosis requires 9 hours per week of informal caregiving by friends and family.(15) This poses a significant burden on these caregivers, leading to worse quality-of-life scores than the general population.(17) This responsibility also interferes with caregivers' work schedules, thus compounding the negative financial impact caused by the patient's inability to work and accumulating medical expenses, as shown in Fig. 2.(18) Most caregivers experience high levels of stress and depression; in the case of patients on the transplant list, this is exacerbated even further by the incredible pressure to be a "model caregiver," to maintain the patient's candidacy.(19)

The burden of caregiving is particularly difficult for family members of patients with a substance abuse disorder. By the time cirrhosis develops in the patient, many caregivers have already suffered years

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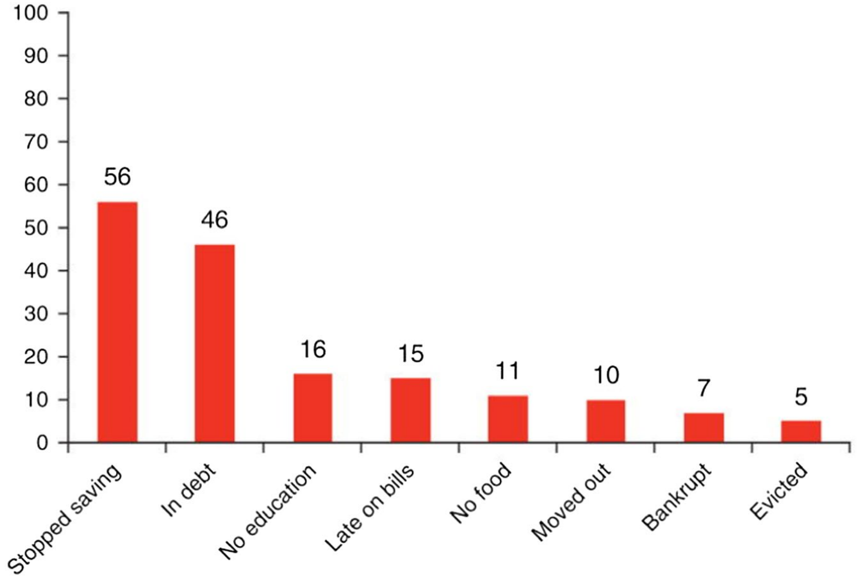

**FIG. 2.** Proportion of families experiencing negative financial impact related to cirrhosis.

of psychological, financial, and even physical harm caused by their loved one's addiction. Spouses in particular experience high rates of mental and physical health problems, and tend to have less well developed social networks due to substance abuse induced isolation.(20) Unfortunately, caregivers often neglect their self-care in order to focus on the needs of the patient.

## Interventions to Ease Burden on Society

Although most clinicians may feel this is out of their control, there are simple steps that can decrease the burden of hospitalizations, which is the major driver of health care costs. These include educating patients and caregivers on titration of lactulose, making sure they get labs soon after changes in diuretics, and seeing them in clinic within 1 week of hospital discharge. It is also important to provide alternatives to hospitalization, such as ready access to outpatient paracentesis.(21) Other interventions include the use of technology to track hepatic encephalopathy, such as the "Patient Buddy" app, which has been shown to reduce hospital admissions.(22)

## Interventions to Ease Burden on Patients

The simplest intervention is to provide more patient education, which is often inadequate even among patients followed in specialized liver clinics.(23) By empowering patients to take control of their disease, this may improve their feelings of self-efficacy and help them treat their symptoms. However, most clinical encounters are focused on managing major complications, discussing transplant listing, and other urgent matters. As a result, the "minor complications" (which bother patients the most!) are often overlooked.

A new paradigm for improving symptoms is being adopted from palliative care. The traditional approach is to refer patients with cirrhosis to palliative care specialists for symptom management, while the hepatologist manages the cirrhosis complications. However, only a small minority of patients are referred.(10) Another approach would be to train hepatologists in palliative care methods, and bring patients in for separate clinic visits to focus on symptom management. These two different strategies are currently being compared in a multicenter randomized trial (PAL-LIVER) funded by the Patient-Centered Outcomes Research Institute.(24)

Another approach would be to focus on psychological wellness, such as meditation or other stress relief. For example, mindfulness-based stress reduction therapy has been shown to reduce both patient distress and caregiver burden in a pre-post study design.(25) Although this type of therapy is typically not covered by insurance, there are free internet-based programs or smartphone apps available.

Most important is to address comorbid psychiatric disease such as depression, anxiety, and any underlying substance abuse disorder. This may entail referral to psychiatry, or novel models of care such as co-located multidisciplinary clinics with both a hepatologist and psychiatrist managing patients together.(26)

# Interventions to Ease Burden on Caregivers

The first step is to recognize the importance of caregivers and involve them in the care of patients. This sometimes requires flexible scheduling and signing of release of information documents. The next step is to take time to specifically inquire about how caregivers are holding up. It is often helpful to emphasize self-care, and reinforce the message that if the caregiver gets sick, both the caregiver and patient suffer. This is why a “backup caregiver” is so important, to give the primary caregiver the occasional respite. Some centers even have dedicated caregiver advocates, who can tend to their mental and physical health needs. Stress reduction techniques as mentioned previously can also help the caregiver, but most caregivers of patients with alcoholic liver disease in particular require dedicated management by a primary care physician and/or mental health professional. Finally, it is important to realize that caregiving skills are not always intuitive, and can be learned. Resources such as www.cirrhosis-caregivers.com should be provided, and caregivers should be encouraged to use them.

# Conclusion

Cirrhosis poses among the greatest burden of any chronic illness, to society as well as patients and caregivers. By implementing simple evidence-based interventions, clinicians can help mitigate this burden.

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