

# How Do Patients With Cirrhosis and Their Caregivers Learn About and Manage Their Health? A Review and Qualitative Study

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The complexity of cirrhosis requires patients and their caregivers to be well educated to improve outcomes. Data are lacking regarding how to best educate patients and their caregivers in the setting of cirrhosis. Our aim is to understand (both through existing literature and by asking patients and their caregivers) how patients learn about their disease, barriers in their education and disease management, and self-management strategies. We performed a structured search of published articles in PubMed (1973 to 2020) using keywords “cirrhosis” plus “barriers”, “education”, “self-management”, or “self-care”. Additionally, we conducted a focus group of a representative sample of patients and their caregivers to understand how knowledge about cirrhosis is found and incorporated into self-management. Of 504 returned manuscripts, 11 pertained to barriers in cirrhosis, interventions, or educational management. Barriers are well documented and include disease complexity, medication challenges, comorbid conditions, and lack of effective education. However, data regarding addressing these barriers, especially effective educational interventions, are scarce. Current strategies include booklets and videos, patient empowerment, and in-person lectures. Without widespread use of these interventions, patients are left with suboptimal knowledge about their disease, a sentiment unanimously echoed by our focus group. Despite linkage to subspecialty care and consistent follow-up, patients remain uncertain about their disease origin, prognosis, and therapies to manage symptoms. It is clear that more data are needed to assess effective strategies to address unmet educational needs. Existing strategies need to be blended and improved, their effectiveness evaluated, and the results distributed widely. (*Hepatology Communications* 2021;5:168-176).

Cirrhosis is increasingly common and morbid. Deaths due to cirrhosis have risen by at least 65% since 2009, and hospitalization rates for cirrhosis now exceed those for congestive heart failure.<sup>(1,2)</sup> Complicating the increasing burden of cirrhosis is the complexity of the condition and its medical management.<sup>(3)</sup> Ascites requires close monitoring, dietary modification, and adjunctive diuretic therapy that requires frequent dose

adjustment; hepatic encephalopathy is often unpredictable, reduces one’s ability to effectively self-care, yet depends on insight regarding one’s symptoms to guide frequent lactulose dose adjustment; pain is frequently comorbid, and concerns over medication safety increase anxiety while limiting the efficacy of pain-control strategies. This complexity demands substantial support and rapid “on-the-job” training in cirrhosis management for patients and caregivers.

Received June 28, 2020; accepted September 20, 2020.

Additional Supporting Information may be found at [onlinelibrary.wiley.com/doi/10.1002/hep4.1621/suppinfo](https://onlinelibrary.wiley.com/doi/10.1002/hep4.1621/suppinfo).

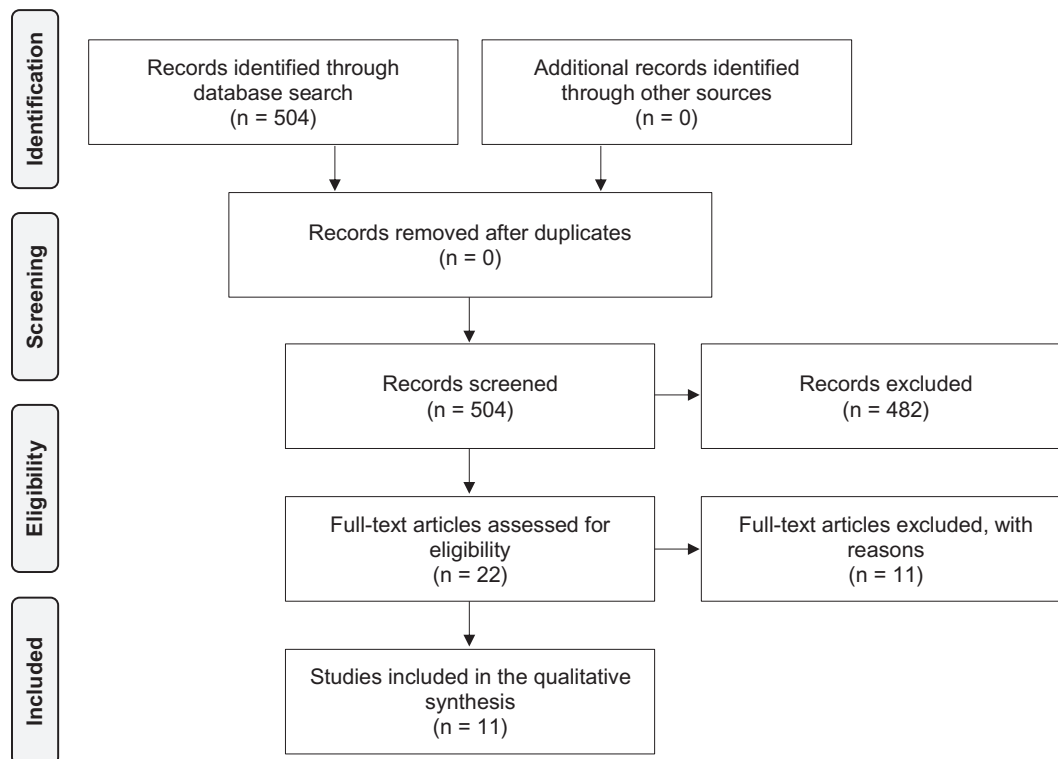
Supported by the National Institutes of Health (DK117055 to E.T.).

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DOI 10.1002/hep4.1621

Potential conflict of interest Dr. Bloom consults for Synlogic. Dr. Tapper consults for Mallinckrodt, Axcella, Allergan, and Kaleido; he advises Novo Nordisk, Rebiotix, and Takeda and has received grants from Valeant and Gilead. The other authors have nothing to report.



PRISMA Diagram, Source: Moher et al.<sup>(24)</sup>

Implementation of provider-recommended screening, diet, and medication management is imperfect, likely in part due to failures in patient and caregiver education. We therefore sought to describe the barriers to optimal patient education for persons with cirrhosis and strategies for improvement. To this end, we reviewed the literature on patient education and also conducted a focus group with patients to identify their unmet needs and desired solutions. Our goal was to compile and synthesize these data from existing literature and to understand efforts being made to deconstruct these barriers to improve care for our patients.

## Materials and Methods

### LITERATURE REVIEW

We first conducted a structured literature review. We searched PubMed by combining “cirrhosis” with keywords, including “barriers”, “education” (Medical Subject Headings term), “self-management”, and “self-care”, which returned 504 results from December 1973 to January 2020. All results were analyzed for mentions of 1) barriers to care, 2) interventions that have been investigated in improving care, and 3) models to educate patients with cirrhosis. Of those, 482 manuscripts

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matched but did not pertain to the barriers, interventions, or educational models in cirrhosis. Of the remaining manuscripts, four discussed barriers, four discussed interventions, and three discussed education in the context of cirrhosis. Additionally, each of the full-text articles was scanned for references that matched the themes of this paper.

## FOCUS GROUP

We next conducted a focus group. We contacted a random purposive selection of 38 patients with cirrhosis who had recent outpatient visits to the Hepatology (nontransplant) clinic at the University of Michigan to participate in a 2-hour focus group for patients and caregivers in June 2019. A total of 11 patients and caregivers attended. Patients and their caregivers were offered dinner as thanks for participating. A semistructured interview guidebook was developed before the meeting that had input from hepatologists, nurses, social workers, and pharmacists (see Supporting Materials). Facilitation questions addressed patients' experiences with cirrhosis education, current knowledge of cirrhosis management, and desired aspects of a future patient education model. Our current patient education practice is at the discretion of each clinician with verbal education and/or handouts. The proceedings were recorded by four independent reviewers who routinely conduct focus groups with patients as part of patient education program development and quality improvement. Their notes were combined and examined for consistent themes. Multiple coders (Z.S., E.T.) evaluated the notes to distill themes with differences reconciled by a third reviewer (K.G.). The review of this study for quality improvement was institutional review board exempt.

## Results

### LITERATURE REVIEW

Many of the barriers to self-management faced by patients with cirrhosis are detailed in Table 1. Patients with cirrhosis have a high average number of medications (from seven to 10),<sup>(4,5)</sup> many of which require monitoring and titration,<sup>(3)</sup> which likely contributes to the low rates of medication adherence described in the literature.<sup>(6)</sup> Long medication lists combined with frequent discrepancies between the patients' listed

prescriptions and their actual regimen<sup>(4)</sup> lead to a cluster of barriers to self-management. The incidence of medicine-related problems can approach 40% in patients with cirrhosis.<sup>(7)</sup>

To make medication adherence even more challenging, many patients with cirrhosis have cognitive impairment secondary to hepatic encephalopathy, ongoing alcohol use, or comorbid depression, all of which translates to reduced ability to manage their cirrhosis.<sup>(8-11)</sup> It is also apparent that these patients lack the knowledge or resources to address some of these cognitive and mental health barriers, as evidenced by the misconceptions and perceived lack of benefit surrounding alcohol use-disorder treatment<sup>(12)</sup> and the small percentage of patients (19%-56%) familiar with lactulose titration.<sup>(13,14)</sup> Additionally, lower socioeconomic status is a barrier that negatively correlates with outcomes in cirrhosis.<sup>(15)</sup>

These barriers are compounded by our lack of effective disease education<sup>(16)</sup> and disease management programs<sup>(17)</sup> to help patients overcome these barriers. In an interview study of 50 patients admitted for a complication of cirrhosis, 79% were interested in using a digital health management tool that could provide information about cirrhosis and 75% were interested in more education on a low-salt diet.<sup>(18)</sup>

Few cirrhosis education programs were described in our literature review (Table 2), and the ones that exist demonstrated improvement on a small scale. Volk et al.<sup>(13)</sup> administered a knowledge assessment questionnaire to 115 patients before and after an educational intervention (concise educational booklet), with scores increasing from 53% to 67% before and after intervention, respectively. Goldworthy et al.<sup>(19)</sup> demonstrated the utility of a video-based educational intervention, improving knowledge assessment questionnaires from 25.0% to 66.7% before and after intervention, respectively. Zhang et al.<sup>(20)</sup> showed that modifying patient education with a focus on patient empowerment yields statistically significant improvement in patient disease management knowledge and improvement in activities of daily living scores in a study of 60 patients. Zandi et al.<sup>(21)</sup> found that educational sessions on the nature of cirrhosis, coping strategies for symptoms/comorbidities, and therapies for treatment side effects resulted in increased patient quality of life and decreased fatigue, anxiety, and abdominal symptoms.

TABLE 1. PATIENT BARRIERS TO SELF-MANAGEMENT OF THEIR CIRRHOSIS

Barriers to Self-Management		
Barrier	Description	Intervention
Disease complexity	Cirrhosis and its management are complex even for hepatologists.	Education improvement
High number of medications	Average number of medications can approach seven to 10 in patients with cirrhosis. <sup>(4,5)</sup>	Reduce PIMs; primary care collaboration
High medication complexity	Many medications in this patient population have variable dosing frequencies and the need to be frequently titrated (diuretics, lactulose, beta blockers). <sup>(3)</sup>	Education improvement; primary care collaboration
Low medication adherence	Over half of patients with cirrhosis report missing one or more doses of their medications each month. <sup>(6)</sup>	Education improvement
Faulty medication reconciliation	Patients often have multiple prescribing providers with discrepancies between the prescribed regimen and what the patient is actually taking in more than 50% of patients. <sup>(3)</sup>	Primary care collaboration
Managing comorbid conditions	Therapies for common comorbid conditions put patients with cirrhosis at higher risk for adverse effects (analgesics for pain, PPIs for PUD, statins for cardiovascular disease). <sup>(3)</sup>	Education improvement; primary care collaboration
Lack of education	Over 50% of patients cannot provide a meaningful definition of cirrhosis, its long-term complications, or warning signs of worsening disease. <sup>(8)</sup>	Education improvement
Misconceptions	Patients commonly believe HCC screening is not indicated with a healthy diet (47%) or with a normal exam/without symptoms (34%). Misperceptions lead to lower screening adherence. <sup>(16)</sup> Many misconceptions exist, but their impact on outcomes is to be determined. <sup>(7)</sup>	Education improvement
Cognitive impairment	Concomitant hepatic encephalopathy is associated with a lower health-related quality of life <sup>(9)</sup> and affects patients' and their caregivers' abilities to manage their disease.	Optimized therapy
Ongoing alcohol use	Patients with cirrhosis and ongoing alcohol use are less likely to use available resources to learn about their disease and its management. <sup>(8)</sup>	Education improvement; Addiction counseling; AUDIT-C screening
Comorbid depression	56%-64% of patients with cirrhosis have comorbid depression, <sup>(10,11)</sup> which has been linked to impaired self-management and reduced adherence to treatment in other chronic diseases. <sup>(11,12)</sup>	Psychiatry collaboration; optimized therapy; PHQ-9 screening
Lack of chronic disease management programs	Standardized programs improve quality of care, adherence to screening and prevention guidelines, and clinic attendance rates. <sup>(17)</sup>	Program creation
Socioeconomic status	Lower socioeconomic status has a clear negative impact on survival in patients with cirrhosis. <sup>(14)</sup>	Social work collaboration

Abbreviations: AUDIT-C, Alcohol Use Disorders Identification Test-Concise; HCC, hepatocellular carcinoma; PHQ-9, Patient Health Questionnaire-9; PIMs, potentially inappropriate medications; PPI, proton pump inhibitor; PUD, peptic ulcer disease.

## FOCUS GROUP

Common patient knowledge gaps observed in our focus group, their experiences with cirrhosis education, and potential solutions for areas of concern are outlined in Table 3. Participants were uniformly distressed about not understanding which factors led to their development of cirrhosis and its complications. Patients felt unsure of their prognosis. Multiple patients reported being told they were “on a cliff,”

but some had heard this phrase years before. Many wondered why they could not be told the percentage of their liver function and why they were not offered biopsies to stage their cirrhosis; 1 participant reported finding indocyanine green clearance testing online and requesting it from the hepatologist. Most participants voiced concern that they did not know how to safely treat musculoskeletal and neuropathic pain, reporting frustrations with conflicting opinions from multiple providers. Similarly, participants were frustrated by a

TABLE 2. SUMMARY OF EDUCATIONAL INTERVENTIONS AND THEIR OUTCOMES IN THE LITERATURE FOR PATIENTS WITH CIRRHOSIS

Author	Aim	Population	Educational Intervention	Methods	Outcome
Beg et al. <sup>(8)</sup>	To assess baseline knowledge in patients, and the impact of an informational leaflet on their cirrhosis knowledge base	n = 39 Compensated and decompensated	Informational leaflet	Before and after intervention knowledge questionnaire	Baseline knowledge was poor (mean score 3.4 out of 9 points), improved to 7.5 after intervention ( $P = 0.0006$ )
Goldworthy et al. <sup>(19)</sup>	To assess baseline knowledge in patients, and the impact of an informational video on their cirrhosis knowledge base	n = 52 Compensated and decompensated	Informational video	Before and after intervention knowledge questionnaire	Baseline knowledge was poor (median score 25.0%), improved to 66.7% after intervention ( $P < 0.001$ )
Hayward et al. <sup>(22)</sup>	To assess receptiveness and retention to an informational booklet	n = 50 Compensated and decompensated	Informational booklet	After intervention cued-recall questionnaire	Most patients found the booklet helpful (85%) and reported using it (78%), but retention was poor (mean score 8.1 out of 13)
Volk et al. <sup>(13)</sup>	To understand and improve patient knowledge about cirrhosis self-management	n = 150 Compensated and decompensated	Informational booklet	Before and after intervention knowledge questionnaire	Baseline knowledge was poor (median score 53%), improved to 67% after intervention ( $P < 0.001$ ). All questions were answered correctly more frequently after intervention.
Zandi et al. <sup>(21)</sup>	To determine the effects of a self-care educational program on QoL	n = 44 Compensated and decompensated	In-person educational sessions on the nature of disease, coping strategies, relaxation techniques, diet and nutrition, and of complexities of medical therapies.	Before and after intervention QoL (as measured by the CLDQ)	QoL significantly improved after intervention in multiple domains (abdominal symptoms, fatigue, systemic symptoms, and emotional symptoms; all $P = 0.001$ )
Zhang et al. <sup>(20)</sup>	To evaluate the effect of education using health empowerment theory on ADL and patient knowledge in hospitalized patients	n = 30 Compensated and decompensated	Incorporating health empowerment theory into patient education	Study group with intervention versus control group without; effect on ADL (Barthel index score) and disease knowledge questionnaire	Understanding of major clinical symptoms, etiology, diet and nutrition, use of medication, treatment, and disease awareness were higher in the study group on discharge ( $P < 0.05$ ) as were ADL scores at 2-month follow-up (81.5 vs. 68.5; $P = 0.006$ )

Abbreviations: ADL, activities of daily living; CLDQ, chronic liver disease questionnaire; QoL, quality of life.

**TABLE 3. PATIENT AND CAREGIVER CONCERNS ABOUT THEIR HEALTH AND THEIR EXPERIENCES WITH EDUCATION ABOUT THEIR DISEASE DURING A STRUCTURED FOCUS GROUP**

	Themes	Consensus Needs	Contrasting Opinions	Solutions
Concerns about their health	Difficulty understanding disease origin	Clear explanation of cirrhosis etiology. <i>"Why me? Why does cirrhosis develop?"</i>	None	Standard illustrations covering "Basics of Cirrhosis." New "Expand your Knowledge" re-sources: available videos with patient testimonials or links to additional reading in patient portal.
		Tools to explain cirrhosis to family and friends. Risk of disease in family members (transmission and genetic basis).		
	Uncertainty regarding prognosis	Uncertainty about prognosis. <i>"How long until I become sicker?"</i> <i>"Do I have months or years to live?"</i> How cirrhosis affects other medical problems. Why decompensation happens. When patients need a liver transplant.	None	Illustrated document covering spectrum of chronic liver disease to decompensated cirrhosis, including often unpredictable course of disease. "Expand your Knowledge" resources.
		Uncertainty regarding diagnostics and therapeutics	Pain control in cirrhosis. <i>"What can I use for pain control?"</i> Health and diet in cirrhosis. <i>"Is exercise safe? Is there a liver diet?"</i> Understanding cirrhosis health maintenance testing.	None
Experiences with education in the health care system	Written education	High-quality color diagrams including stages of cirrhosis, physiology, and prognosis.	Some reported simply throwing away written resources.	Clear language in clinic notes available to patients online.
		Centralized, searchable resources with hyperlinks for greater detail. Insight into medical decision-making process.		Standard illustrations covering "Basics of Cirrhosis." Create videos with patients sharing hopeful stories.
	Patient "Quick Guides"	Simple list of "things to avoid" with cirrhosis. Mnemonics preferred.	Some patients would like explanations in addition to quick list.	Pocket cards covering safe pain control, diet, and exercise recommendations, and recurring tests (e.g., ultrasound, upper endoscopy).
	Verbal education	Highlights given verbally, and detailed information available in writing.	All pertinent information to be provided during visit discussion.	Query education preference: mostly verbal vs. written. Diagrams clinicians annotate during the clinic visit. "Expand your Knowledge" resources.
Psychosocial support	Psychosocial support	Help locating patient support groups	Preference for online ("Facebook") vs. in-person support groups.	Create hospital support group including patient facilitators with stable disease.
		Connecting with patients who have "made it to the other side."		Create videos with patients sharing how they managed their condition successfully.



TABLE 3. *Continued*

Themes	Consensus Needs	Contrasting Opinions	Solutions
Communication outside of clinic	Contact by phone important for urgent issues.  Patient portal also beneficial for less urgent issues.  Patients appreciate being called after hospital discharge to check-in.	None	Ensure patients can contact clinic by phone or portal and that they understand when to use each.  Standardized phone call after hospital discharge.

lack of clarity regarding which foods and exercises were safe. Caregivers expressed the need to know anything the patient needed to know and reiterated the need for clear discussions regarding prognosis. Caregivers also specifically felt that they needed education about symptoms to watch for and how to administer medications.

The group agreed that current written educational materials are inadequate. Some participants said written material should be brief and direct, while others felt it should be more detailed. Most participants reported conducting their own research. By consensus, the Mayo Clinic website was felt to be the best source, followed by social media support groups, and open access journal articles searched for using keywords specific to their condition. Some voiced concern that it was their physician's responsibility to educate them on their condition while in clinic. The group ultimately reached consensus that educational material should be succinct with optional links to more information. Many were interested in online videos of patients telling their story of diagnosis and survival or how they learned to manage their hepatic encephalopathy. All participants requested pocket reference cards for topics such as dietary instruction and pain control. Regarding verbal education, participants requested high-level illustrated explanations given in person, using visual aids that were preprepared or even sketched on the exam table paper. Patients wanted multiple avenues of contact with the clinic (e.g., patient portal, phone) and appreciated posthospital discharge phone calls. They were interested in assistance locating support groups for patients with cirrhosis.

## Discussion

Our study combines a literature review and focus group to define and outline solutions for the present

needs for educational efforts in contemporary cirrhosis clinics. We have summarized our findings in a conceptual model for modernized educational efforts in cirrhosis care (Fig. 1).

## FOCUS GROUP

Education is a core clinical competency for delivering effective care. Patients with cirrhosis face large barriers to managing their disease, and our current patient education practice is not optimally helping patients overcome these barriers. Our qualitative study shows that contemporary patients and their caregivers are unsatisfied with available educational materials. Our participants shared multiple generalizable lessons. First, their key unmet needs were an understanding of the mechanisms of disease and prognosis as well as how to manage their pain and optimize their diet. Second, even where educational materials are lacking, patients are resourceful and turn to the Mayo Clinic website for information but also often read open-access journal articles that may not apply to their cases. Third, our participants highlighted multiple ways in which they wish to receive information. Above all, patients appreciate expert clinicians who can explain their disease, particularly using charts and figures. In addition, patients prefer printed synopses with hyperlinks to more extensive online information and videos as well as clear-cut upfront recommendations regarding pain control and diet. Fourth, patients and caregivers also want to connect with peers who can share their experiences and offer advice. They view online support groups as desirably as in-person groups.

These findings must be interpreted in the context of the study design. Our data are derived from a small single-center sample at risk for selection bias toward healthier patients able to attend. This was also a well-informed group with self-reported high confidence in

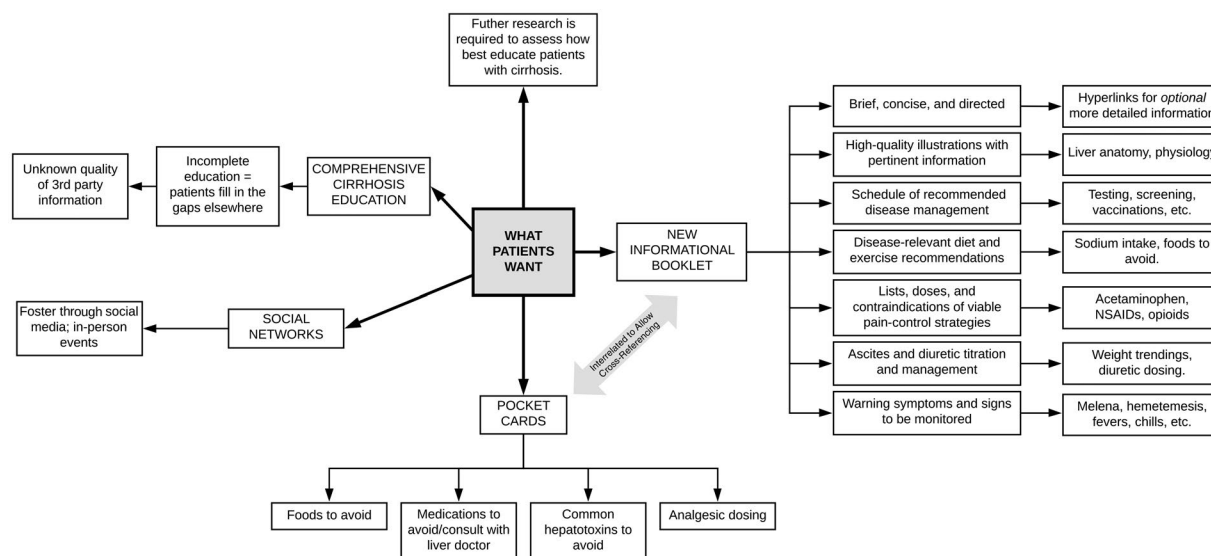


FIG. 1. What patients want. Abbreviation: NSAID, nonsteroidal anti-inflammatory drug.

managing their health problems. Notwithstanding this, clear knowledge gaps were identified.

## LITERATURE REVIEW

Despite these gaps in our patient education practice, based on our literature review, few scientific data are available regarding existing educational interventions and their effectiveness. Most interventions documented in the literature are performed within small cohorts, and follow-up studies assessing their impact on quality of life, clinical outcomes, and patient satisfaction are lacking. It is also unclear whether the studied interventions were implemented on a grander scale to benefit a larger number of patients. Hepatologists must address how patients and their caregivers want to learn and be supported outside of the traditional clinic model and formally evaluate clinical and patient satisfaction outcomes regarding these interventions to address our current system's shortcomings.

On the other hand, the barriers to effective self-care in cirrhosis are well documented. At present, data regarding addressing these barriers through education (or other interventions) are limited.

## FUTURE DIRECTIONS

Our focus group suggests that patients and their caregivers crave more robust education regarding

cirrhosis. This notion is echoed by Hayward et al.,<sup>(22)</sup> where 64% of a 50-patient cohort felt they needed to turn to external resources for their education. Half of these patients reported that they still were unable to locate the information they desired. What changes do we make to our current education practice to ensure patients are able to receive the knowledge they desire while simultaneously limiting the amount of externally sought (and unfiltered) information?

Our educational system must be revamped to address 1) knowledge gaps, 2) barriers to care, 3) varying patient preferences, 4) poor knowledge assessment tools, and 5) a desire for peer support and education. To address knowledge gaps, we must develop an easily understood curriculum that explains cirrhosis development, disease and comorbidity management, trajectory, and prognosis. To accommodate varying patient preferences, this curriculum should have concise information that can be quickly read but also accompanying expansive information to satisfy patient curiosity for more information. It must address the barriers to care detailed in Table 1 by providing descriptions and methods for overcoming them (whether by self-interventions or collaborating with other physicians). To further accommodate varying patient preferences, the written information must be accompanied by optional in-person or electronic educational sessions, as described by Goldsworthy et al.<sup>(19)</sup> and Zandi et al.<sup>(21)</sup> Caregivers should also receive copies of



the educational materials. There must be a focus on patient empowerment rather than externally imposed interventions, given its demonstrated improvement both within cirrhosis and other chronic diseases.<sup>(20)</sup>

Additionally, to expand implementation, we must be able to assess improvement in patient knowledge after interventions, which could involve the use of a validated knowledge-assessment questionnaire.<sup>(23)</sup> Furthermore, the educational intervention must be studied both in terms of knowledge improvement as an outcome, in addition to effect on clinical outcomes, quality of life, and patient satisfaction. Lastly, the questionnaire, educational materials, and data on outcomes must be disseminated to address the widespread patient education deficit in cirrhosis.

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