Relationship Between Quality of Life and an Educational Strategy Based on the Information Needs of Patients With Liver Cirrhosis

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Abstract

Introduction: Implementation of educational strategies in patients with liver cirrhosis has been shown to improve quality of life. However, these results may not be generalizable to all populations, as information needs vary according to sociodemographic characteristics, cultural factors, and specific determinants of health-related quality of life (HRQoL). The aim of this study was to evaluate the relationship between an educational strategy—designed based on previously identified local needs—and quality of life in a population of patients with cirrhosis. **Methods:** A prospective, longitudinal, analytical study was conducted at a second-level outpatient center specializing in chronic liver diseases in Cartagena (Gastropack S. A. S.). All adult patients diagnosed with liver cirrhosis who attended in May 2024 were included. The intervention consisted of providing written informational materials about cirrhosis and its complications, supplemented by synchronous virtual sessions conducted by a hepatology specialist, followed by a final Q&A session. After signing informed consent, patients completed the Chronic Liver Disease Questionnaire (CLDQ), and caregivers completed the Zarit Burden Interview before and after the intervention, administered by a trained interviewer. **Results:** Forty patients were included, with one excluded due to death during follow-up. 64% (n = 25) were female. At the conclusion of the intervention, the CLDQ score increased by an average of 29 points (95% CI: 24–34; $p < 0.001$), representing a 21.8% improvement from baseline, and caregiver burden decreased by 46%. **Conclusion:** An educational strategy incorporating written materials and virtual sessions significantly improved patient quality of life and reduced caregiver burden in individuals with chronic liver disease.

Keywords

Quality of life, liver cirrhosis, health education, caregiver burden.

INTRODUCTION

Liver cirrhosis is the consequence of a chronic necroinflammatory response triggered by various etiological agents, and represents one of the main causes of liver-related mortality, with approximately 2 million deaths annually worldwide[1]. *Quality of life* is a broad concept encompassing the positive and negative aspects of a person's life[2,3]. A systematic review of 109 studies identified multiple factors affecting quality of life in patients with cirrhosis, including hepatic encephalopathy, psychiatric comorbidities (anxiety or depression), frailty, falls, malnutrition, physical symptoms (such as muscle cramps or sleep disorders), and anemia[4]. A Colombian study additionally identified that viral etiology, female sex, and low albumin levels were related to worse quality of life in this population[2].

Caregiver burden is defined as the sustained impact of caregiving on the caregiver's emotional, physical, social, and financial health over time[5]. This situation has been linked to symptoms of depression, anxiety, and burnout

syndrome, and can even impact the clinical outcomes of the patient under their care, although it is often an overlooked aspect in medical practice.

Information need, in turn, is defined as "the recognition that available knowledge is insufficient to achieve a goal within a specific context or situation, at a given moment"[6]. A 2015 qualitative study, which included 10 cirrhotic patients, showed that the lack of information and emotional support at the time of diagnosis generated greater anxiety about the disease; additionally, family-centered educational interventions and effective communication with the healthcare team were identified as some of the main priorities for patients in their care process[7].

A local study also indicated that the main information needs of cirrhotic patients included knowledge about complications and disease prognosis, pharmacological treatment, cancer risk, liver transplantation, and nutrition[8]. Dissatisfaction with the information received has been associated with a negative perception of the disease and poor understanding of the prognosis and treatment[9].

Finally, an experimental study conducted in 44 cirrhotic patients in Iran, with a control group (n = 23) and an intervention group (n = 21), observed that an educational strategy significantly increased quality of life in the intervention group (from 139 to 171.6; $p = 0.001$) and decreased in the control group (from 137 to 112.2; $p = 0.001$)[10]. However, these results cannot necessarily be extrapolated to other populations, as information needs and determinants of quality of life may vary according to the sociocultural factors of each region.

MATERIALS AND METHODS

A prospective, longitudinal, and analytical study was conducted. All patients and their relatives who attended the hepatology outpatient clinic at the Gastropack medical center in the city of Cartagena during May 2024 were considered eligible to enter the study, after signing the informed consent.

Only patients over 18 years of age with a new or previous diagnosis of liver cirrhosis, established through clinical, imaging, histological, or elastographic criteria, were included. Pregnant patients, those with concomitant chronic pathologies that could significantly affect their quality of life, and individuals with severe cognitive impairment or hepatic encephalopathy were excluded.

Educational Strategy

An educational intervention was designed based on the information needs previously identified in patients with liver cirrhosis, according to a local study, which determined the following topics as priorities: decompensations and complications, progression and prognosis, pharmacological treatment, risk of hepatocellular carcinoma, liver transplantation, and nutrition.

The strategy consists of weekly 30-minute virtual educational sessions over a period of three months with a question-and-answer session at the end, supplemented by the delivery of written material aimed at both the patient and the caregiver. At the beginning of the intervention, an educational kit is delivered, including printed material with information in simple language about the mentioned topics, as well as a practical guide for accessing the virtual sessions and learning about their thematic content.

Data Collection and Follow-up

Clinical and sociodemographic information was extracted from the medical record and the initial interview. Laboratory and other imaging test results were only considered valid if they did not exceed a period of 30 days from their performance until the patient's inclusion in the study.

A trained interviewer assessed the patients' quality of life and the caregiver burden using the Chronic Liver Disease Questionnaire (CLDQ) and the Zarit questionnaire, respectively. All questionnaires were administered before and after completing the educational intervention.

Quality of Life Assessment (Chronic Liver Disease Questionnaire)

The impact of the educational intervention on quality of life is assessed using the CLDQ questionnaire, a validated tool for patients with chronic liver disease. It consists of 29 items distributed across six domains: abdominal symptoms, fatigue, systemic symptoms, activity, emotional function, and worry. Each item is scored using a Likert scale from 1 to 7, where 1 represents the highest frequency of symptoms (all the time) and 7 the lowest (never). It can be self-administered or applied by a trained interviewer, in person or by telephone[11]. The overall score for the questionnaire is obtained by summing the scores for each dimension. The lower the score, the worse the quality of life.

Caregiver Burden Assessment (Zarit)

The Zarit Burden Interview (ZBI) is composed of 22 items exploring areas such as support network, quality of life, self-care capacity, and skills for coping with the patient's behavioral and clinical challenges. It is a validated tool for clinical and research use and can be self-administered or applied by a trained interviewer, in person or by telephone. With a scoring scale from 0 to 4, where 0 is the minimum

frequency (never) and 4 the maximum frequency (almost always), it classifies caregiver burden as no burden with a score less than 46 points, mild burden between 47 and 55 points, and intense burden greater than or equal to 56 points[12].

Statistical Analysis

Numerical and categorical variables were described as means (standard deviation [SD]) and percentages, respectively. To determine the relationship between the educational strategy and quality of life, a comparison of means test for related samples was performed. A *p*-value of 0.05 was considered statistically significant.

RESULTS

A total of 40 patients diagnosed with liver cirrhosis were initially included, one of whom was excluded during follow-up due to death before the start of the educational intervention. Sixty-four percent (n = 25) of the participants were women. The most frequent socioeconomic status was status 2, at 41% (n = 16). Regarding etiology, the most common was metabolic dysfunction-associated steatotic liver disease (MASLD), at 33% (n = 13), followed by autoimmune cirrhosis at 23% (n = 9), and cryptogenic at 15% (n = 6). The majority of patients (86%, n = 34) were in the compensated phase of the disease (Child-Pugh A). The average body mass index (BMI) was 30.4 kg/m² (SD: 5.8). The complete baseline characteristics of the sample are presented in **Table 1**.

Thirty-three caregivers were also included, with a mean age of 50.1 years (SD: 13.7); 78.1% (n = 25) were women and 21.8% (n = 7) were men. Regarding educational level, 53.1% (n = 17) were technologists, 34.3% (n = 11) had completed high school, and 12.5% (n = 4) had university education. Adherence to the strategy varied between patients and relatives. The attendance percentage for the virtual sessions was 64% and 72% for patients and family members, respectively.

Relationship Between the Educational Strategy, Quality of Life, and Caregiver Burden

An average increase of 29 points was observed in the CLDQ questionnaire score (95% confidence interval [CI]: 24-34; *p* <0.001) compared to the initial measurement, representing a 21.8% improvement from the baseline assessment (**Table 2**). This improvement was consistent across all subscales of the questionnaire and reached statistical significance in all CLDQ domains except for abdominal symptoms. The largest increases were observed in the emotio-

Table 1. Sociodemographic and Clinical Characteristics of Cirrhotic Patients Undergoing an Educational Strategy*

Variable	n = 39
Male Sex	35.9 (14)
Age	67.4 (11.8)
Strata	
- 1	17.9 (7)
- 2	41.0 (16)
- 3	35.9 (14)
- 4	2.6 (1)
- 6	2.6 (1)
Etiology	
- Cryptogenic	15.4 (6)
- MASLD	33.3 (13)
- Autoimmune	23.1 (9)
- Alcoholic	10.3 (4)
- Hepatitis B	5.1 (2)
- Hepatitis C	12.8 (5)
Child-Pugh-Turcotte	
- A	87.2 (34)
- B	12.8 (5)
BMI	30.4 (5.8)
Total Bilirubin	0.9 (0.6)
Indirect Bilirubin	0.5 (0.3)
INR	1.1 (0.3)
PT	12.1 (1.8)
PTT	31.1 (1.5)
ALT	31.3 (13.2)
AST	39.9 (18.8)
Platelets	152.5 (92.7)
Creatinine	0.9 (0.3)
BUN	15.0 (6.9)
Albumin	3.8 (0.5)

*Quantitative variables are expressed as mean (standard deviation) and numerical variables as percentages (absolute number). BUN: blood urea nitrogen; AST: aspartate aminotransferase; ALT: alanine aminotransferase; BMI: body mass index; INR: international normalized ratio; PT: prothrombin time; PTT: partial thromboplastin time. Table prepared by the authors.

nal function and worry domains, while the smallest were reported in the abdominal symptoms, fatigue, and systemic symptoms domains (**Table 3**).

Regarding caregiver burden, the average score on the Zarit scale decreased from 21.2 to 11.5 points, with a mean reduction of 9.7 points, equivalent to a 46% percentage improvement. The reduction in burden was more pronounced among caregivers over 50 years old (10.5 points) compared to those under that age (7.8 points), although the difference did not reach statistical significance.

Table 2. Impact of the Educational Strategy on Quality of Life and Caregiver Burden*

Impact of the Educational Strategy	Before	After	95% CI	p
Global CLDQ Scale Score	133	162	24-34	<0.001
Global Zarit Scale Score	21.2	11.5	12-7.5	<0.001

*Analysis of means comparison for related samples. CLDQ: Chronic Liver Disease Questionnaire; CI: confidence interval. Table prepared by the authors.

Table 3. Differences in the Various CLDQ Domains Before and After the Educational Strategy

Type of Score	Before	After	95% CI	p
Abdominal Domain	4.8	5.3	0.09 a -1.09	0.1
Fatigue Domain	4.1	4.7	-0.26 a -1.08	0.002
Systemic Domain	4.4	5	-0.19 a -1.04	0.005
Activity Domain	4.8	5.5	-0.3 a -1.12	0.001
Emotional Domain	4.5	5.8	-0.9 a -1.6	<0.001
Worry Domain	4.8	6.5	-1.2 a - 2.2	<0.001

CLDQ: Chronic Liver Disease Questionnaire; CI: confidence interval. Table prepared by the authors.

DISCUSSION

An educational strategy based on the specific information needs of patients with liver cirrhosis demonstrated a significant improvement in quality of life and a substantial reduction in caregiver burden.

Our findings are consistent with a study conducted in cirrhotic patients in Iran[10], where an educational intervention based on a questionnaire about information needs (fatigue, pruritus, xerostomia, cramps, flatulence, nutrition, and pharmacological treatment) showed a significant increase in quality of life in the intervention group (increase of 32 points, $p = 0.001$) and a decrease in the control group (reduction of 25 points, $p = 0.001$).

Another study, conducted in 20 patient-caregiver dyads, evaluated the effect of a brief mindfulness program combined with group support therapy over 4 weeks aimed at patients with cirrhosis and mild depression (Beck Depression Inventory [BDI] >14) using the Beck Depression Inventory to assess depression severity with 21 items and a Likert scale from 0 to 3; the scores for each item are summed to classify depression severity: 0-13: minimal or no depression, 14-19: mild depression, 20-28: moderate depression, 29-63: severe depression, and their caregivers[17]. A significant improvement in health-related quality of life was observed, a reduction in depression in 55% of patients (who went from BDI >14 to BDI <14), and improved sleep. Furthermore, a significant decrease in caregiver burden, measured by the Zarit scale, was evidenced, from 13.0 ± 9.0 to 9.8 ± 6.9 ($p = 0.04$). Although the focus of that intervention differs from ours, both share the goal of reducing anxiety and stress, in our case by decreasing uncertainty about the prognosis through education, and in the case of mindfulness, by regulating the physiological stress response[13].

In Australia, a study conducted in an outpatient center with 116 patients with decompensated cirrhosis implemented an educational intervention focused on treatment adherence, perceptions about the disease, medication, and lifestyle[14]. The intervention group showed significant improvements in illness perception (Brief Illness Perception Questionnaire [B-IPQ]), including greater understanding ($p = 0.004$), perception of symptoms ($p = 0.003$), and their impact on daily life ($p = 0.005$). The CLDQ score also improved, even in patients ineligible for liver transplantation.

Improvement in disease knowledge does not seem to depend on the intervention format. A study using educational videos showed an increase in global knowledge from 65% to 83% ($p < 0.001$) and was associated with greater adherence to medical check-ups, imaging studies, endoscopies, and treatments[14]. This type of intervention has also been linked to a reduction in hospitalizations and better clinical outcomes[15].

A prospective multicenter study with 402 cirrhotic patients evaluated the predictive value of health-related quality of life on unplanned hospital admissions and mortality[16]. Over 50% of the cohort had low quality of life (CLDQ and EuroQol visual analog scale [EQ-VAS]). Each additional point in CLDQ and each 10 points in EQ-VAS were associated with a 30% and 13% reduction, respectively, in the risk of hospitalization and mortality. Although our study did not evaluate long-term clinical outcomes, it is reasonable to hypothesize that the improvement in quality of life could translate into better clinical progression.

In chronic diseases such as asthma, heart failure, and ischemic heart disease, improving patient knowledge has been shown to be associated with a reduction in hospital readmissions (relative risk [RR] = 0.64; 95% CI: 0.50-0.82), unscheduled appointments (RR = 0.68), emergency room visits (RR = 0.82), and work absenteeism (RR = 0.79)[17-19].

Knowledge questionnaires about cirrhosis, differentiated for compensated and decompensated patients, have recently been designed and validated, addressing topics such as diet, medication, warning signs, screening for liver cancer, and Baveno VII consensus recommendations[20]. These tools can be useful for designing health literacy strategies tailored to the disease stage.

Our results align with this evidence: the educational strategy produced a significant improvement in quality of life, especially in the emotional and worry domains, without requiring high resource consumption. The virtual format allowed for wide coverage at low cost, requiring only access to a computer or a smartphone, technology common even in low socioeconomic contexts. Virtual delivery also helped overcome mobility and logistical barriers, facilitating the participation of patients and caregivers and achieving an attendance rate above 50%, reflecting good acceptance and adherence.

The caregiver plays an essential role in the management of patients with cirrhosis, from compliance with medical indications to the early identification of signs of decompensation[21]. However, caregiver burden and burnout can negatively impact the course of the disease. In pathologies such as dementia and amyotrophic lateral sclerosis, higher mortality has been documented when caregivers experience high levels of stress[22].

In a study including 100 patients with cirrhosis and their caregivers, factors associated with higher caregiver burden were identified as low educational level of the patient or the caregiver themselves, alcoholic etiology, the presence or history of hepatic encephalopathy, repeated hospitalizations, ascites, and low income or socioeconomic status of the patient[23]. Our educational strategy precisely addressed complications associated with these conditions, which likely facilitated a more effective approach to care and reduced the perceived burden on caregivers.

CONCLUSIONS

The education and training of patients and caregivers, focused on improving the understanding of the disease, was associated with a 46% reduction in caregiver burden and a 22% improvement in the quality of life of patients with chronic liver disease. These findings highlight the value of education as an effective non-pharmacological strategy in the comprehensive management of liver cirrhosis.

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