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Predictors of health-seeking behavior in patients with chronic liver disease and a comparison of health-seeking based on patient-type

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Abstract

Background Pakistan has one of the highest rates of chronic liver disease (CLD) burden in the world. Poor and underserved patients of CLD in the country may suffer from limited health-seeking behaviors, but there is not much research in this area. The aim of this study is to better plan support for CLD patients by identifying: (i) Health-seeking behaviors (HSB) according to patient-type; and (ii) the relationship of HSB with patient socio-demographic variables and independent study domains.

Methods We conducted a cross-sectional study. Data was collected over a four-month period from May 2022 to August 2022. A total of 850 patients visiting the Pakistan Kidney and Liver Institute and Research Centre were part of the study. We used correlation tests and multivariate logistic regression to investigate the relationship between the health-seeking behavior and the independent study domains (economic stability, health literacy, social support, experiencing grief, mental health, healthcare service quality, and coping strategies).

Results Main results suggest that patients with hepatocellular carcinoma, non-viral liver disease, and cirrhosis have less HSB, compared to patient with chronic viral hepatitis. Multivariate logistic regression results reveal that the following groups have lower odds for health-seeking behavior: (i) illiterate people; (ii) those living in rented homes; (iii) those belonging to nuclear families; and (iv) those with low monthly household income. The following study domains also show lower odds for HSB: (i) health illiteracy; (ii) low health service quality; (iii) low ability to use coping strategies; (iv) grief; (v) lack of social support; (vi) mental health challenges; and (vii) economic instability.

Conclusions Our study highlights that the majority of CLD patients are poor, illiterate, or semi-literate and in urgent need of holistic care with respect to health literacy, mental health counseling, financial help, and improved support from provider and families. This is only possible through the integration of social policy officers and social workers in the tertiary health sector of the country.

Keywords Chronic liver disease, Pakistan, Health-seeking, Social determinants, Holistic care

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Background

Chronic disease burden has been increasing over the years globally, in particular diseases of the liver which are considered a major public health problem [1]. It is estimated that almost 1.5 billion people suffer from chronic liver disease (CLD) worldwide, with high prevalence in developing countries, though estimates are uncertain due to an absence of comprehensive nation-wide databases [2]. CLD contributes significantly to mortality and morbidity rates, but also negatively impacts the quality of life and wellbeing of patients, their care providers, and family members [3, 4]. In developing countries, where patients face greater challenges due to inadequate health structures and social support, there is great concern about low health-seeking behaviors (HSB) [5].

HSB of CLD patients is closely linked to their social determinants, life circumstances, environment, and the quality of health services [6]. The World Health Organization (WHO) advises that HSB may be influenced by patients' type of chronic disease, disease severity, mental health, and other chronic disease burdens [1]. Additionally, HSB also vary according to region and cultural context, necessitating investigation in individual countries. For example, some countries have more shame and stigmatization associated with certain types of liver disease which can contribute to low HSB. Post the COVID-19 pandemic, loss of livelihood and physical distancing policies have exacerbated disparities and led to even less HSB in patients with CLD [7]. This study aims to identify predictors for HSB in CLD patients, an area which has almost no research in the country [8], in order to help bridge gaps in health equity and advise better health and social interventions for patients.

Literature review

CLD is associated with considerable financial burden for patients and their families [9]. Direct financial burden includes expenditure on healthcare, but CLD patients with deteriorating health conditions also suffer from indirect financial burdens due to inability to continue with paid employment. Previous studies report that advancement in health treatment of CLD patients comes at high costs and that in another twenty years patients will suffer from an estimated 83% increase in forecasted health costs [10]. COVID-19 inflationary pressures have doubled health expenditures, and patients from developing regions with underfunded public health sectors are expected to suffer the most with regard to financial burden for disease management [11]. CLD patients are also known to bear the most out-of-pocket medical expenses post diagnosis as the treatment period is long and disease progression can take considerable time [12, 13].

Mental health issues are a common problem facing CLD patients, and a cause for isolation and withdrawal in health-seeking [14]. The financial burden for CLD patients is known to be associated with anxiety and depression [15], as well as worry and fatigue [16]. Patients of CLD have been found to display negative emotions and unwillingness to continue treatment when they are faced with high medical costs [17]. Severity of disease and length of years since diagnosis are also associated with higher levels of depression and mental distress in patients of CLD [18]. Mental health issues in CLD patients are associated with other behaviors that can contribute to low HSB, such as low self-esteem, inability to communicate with healthcare provider, low compliance with physicians' guidance, and cognitive impairment [19].

Some scholars argue that in order to deal with the chronic nature and comorbidity associated with liver disease, the development of coping strategies is integral for patients and their care givers which can help in willingness to seek healthcare [20, 21]. CLD patients who develop adaptive and problem-solving coping strategies are able to manage their disease better as they have more positive health-seeking attitudes [18]. Conversely, patients of CLD who suffer from grief are less willing to adopt coping strategies or HSB as they have more intense feelings of hopelessness and disorientation [22]. Scholarship suggests that grief is common in patients of CLD, as they perceive their disease to be progressive, without hope for recovery [23].

Furthermore, HSB in patients of CLD is associated with support from family, friends, and healthcare providers [24]. The absence of family members and care providers are known to prevent patients from continuing with healthcare and resolving for more advanced treatment requiring physical support, such as surgery. In addition, the support from loved ones and family builds commitment to health management and recovery in patients. Social support networks are also essential to help manage fatigue and other symptoms which prevent CLD patients from managing disease at home and improving treatment outcomes [25].

Low health literacy in patients of CLD is associated with depression and lack of willingness to continue with treatment [26]. However, most patients report a lack of knowledge about the disease as one of the key factors in poor perception and negative attitude towards the disease [17]. The complexity of the disease and uncertainty of how to manage the disease or prevent advancement means that CLD patients require continuous support for health literacy [27]. In developing countries, where many patients and their families come from backgrounds of less schooling years or illiteracy, specific support for health awareness and health literacy during disease management is even more essential. In fact, CLD patients who receive support for health literacy have shown improved utilization of health resources [28].

Patients' willingness to return for health services is strongly dependent on the quality of healthcare services, and the cooperation between the patient and the healthcare provider [29]. Healthcare providers who support patients with more information, clarification, and counseling support, are able to encourage trust and compliance in patients of CLD [30]. Many patients in the developing world may resort to seeking healthcare from faith healers if they do not gain quality care from trained providers. The hospital setting, expert facilities, coordination between consultants, and the overall health support provided by practitioners are essential in positive HSB of patients [31].

Situation in Pakistan

Some estimates report that CLD is the fifth most common cause of death in Pakistan [32]. This is mainly due to the overwhelming burden of chronic hepatitis C and hepatitis C related liver decompensations and death [33]. Pakistan has a mixed health care system, with services being provided by both the public and private sectors. The public sector is poorly funded, but the only option for the majority of poor people in the country [34]. Recent implementation of universal health coverage offers a ray of hope; however, close to half of the population still remains uninsured or partially covered for hospitalization without all the required medication support [35].

The medical costs of liver disease, depends on the type of disease and the severity, but it can be as much as PKR 5 million (USD 18,108.56), which only 2% of CLD patients can afford [36]. Even when patients are seemingly being provided 'free' services from public sector hospitals, they require almost PKR 250,000 (USD 905.43) for each admission and more for miscellaneous costs such as medicines and tests not covered by the government and transport. It must be noted that the average monthly earning of the lower and middle classes of Pakistan is estimated at PKR 30,000 (USD 108.65).

From the limited number of dedicated hospitals caring for patients with CLD, Pakistan Kidney and Liver Institute and Research Centre (PKLI&RC), Lahore, Pakistan, stands out. It is a public private partnership and the largest and leading provider, which has treated an estimated 3.5 million patients, with nearly 80% receiving free or subsidized treatment [37]. PKLI&RC is visited not just by inhabitants of Lahore, which has a population of near 12 million people, but also surrounding districts and areas of the city. Treatment services at PKLI&RC include inpatient and outpatient treatment for patients with liver disease. It provides interventional radiology services for the treatment of hepatocellular carcinoma (HCC) and liver transplantation at subsidized cost for those with decompensated liver disease and HCC. A recent study based on proxy means test score confirms that more than half of PKLI&RC patients are from the low and middle socioeconomic groups [38].

Theoretical framework

A literature review was conducted and identified three theoretical models as relevant and complementary to discuss HSB which will be discussed in this section. Other research supports the inclusion of multiple theories in a single study analysis [39, 40]. The Health Belief Model suggests that financial costs and economic stability plays a role in HSB of patients [41]. This is especially true for patients from lower-income countries, who bear the burden of out-of-pocket expenses for better quality health services from the private sector [42]. Though public sector healthcare services are labelled as free, there are other financial burdens associated with seeking care such as expense for transport, medication, and in-patient care [43]. The Health Belief Model also elaborates on how the ability to cope with illness [44] and mental health [45] influences HSB of patients. Given that Pakistan is a country dominated by religious and spiritual beliefs, religious coping is an important factor in determining choice to continue with health-seeking [46]. Similarly, the state of mental health, including feelings of stress, depression, and anxiety play a significant role in the ability to seek healthcare and pursue recovery in patients.

The Burden of Treatment Theory argues that three important areas influence HSB in patients. First, grief is an important factor in determining willingness to seek healthcare and stay motivated for recovery [47]. Second, having a strong social network including family and friends who provide support and assistance propel patients to seek healthcare [48]. Third, the ease of seeking quality services from healthcare practitioners is an integral factor in the willingness to return for health services [49]. The quality of communication and respectful behavior of the provider also influences patient understanding and willingness to comply with health instructions.

The Theory of Planned Behavior proposes that health literacy influences the willingness to seek health services in patients with chronic liver disease [50]. Patients who have less health awareness and literacy are less motivated and prepared to seek healthcare or purse recovery [51]. Furthermore, people who may have less social and financial support, would be less willing and committed to comprehensive or complete HSB, for example they may plan not to complete the expensive tests to avoid the financial burden on their family.

Based on these three theories, we have used standardized tools to measure seven hypotheses to be tested in this study, summarized in Table 1. The following research aims are addressed within this study:

- Identify which groups of chronic liver disease patients have less health-seeking practices in comparison to each other.
- Identify which socio-demographic groups (gender, age, marital status, literacy, family and household characteristics, employment status, and provincial

and religious belonging) are associated with lower odds for HSB in patients.

- Identify which of the seven study domains (economic stability, health literacy, social support, experiencing grief, mental health, healthcare service quality, and coping strategies) are associated with lower odds for HSB in patients.

Table 1 Study theories, operationalization, and hypotheses

Theory	Operationalization (scale/items)	Study constructs (hypotheses)
Health belief model		
Potential costs and financial stability influences health-seeking behavior	Comprehensive Score for Financial Toxicity (COST) Patient-Reported Outcome in Cancer (PROM) [87] • My out-of-pocket medical expenses are more than I thought they would be • I worry about the financial problems I will have in the future as a result of my illness or treatment • I feel I have no choice about the amount of money I spend on care • I am frustrated that I cannot work or contribute as much as I usually do • I feel financially stressed	Independent variable: Economic stability (H1: The higher the economic instability, the less the health-seeking behavior in patients with liver disease)
Coping strategies influence health-seeking behavior	Brief Coping Scale [88] • I pray for God's help to recover from this disease • I often ask Allah to forgive your sins • I derive strengths from religious beliefs • I share my problems with Allah • I cope with loneliness through spirituality • I feel Allah's presence in your daily life • I participate in the normal daily activities • I can resist to this disease • I am hopeful to be healthy • I like to talk to people (such as family and friends) around you • I feel motivated to take medicine • I take a good sleep • My attitude with people around me is normal • I want to leave bed for some time daily	Independent variable: Coping strategies (H2: The higher the coping strategies adopted, the more the health-seeking behavior in patients with liver disease)
Mental health challenges (including stress, depression, anxiety) influence health-seeking behavior	The Instrument for Common Mental disorders (CMDQ) [89] In the last 4 weeks did you experience: • Worries that there is something seriously wrong with your body • Thoughts, that the doctor may be wrong if telling you not to worry • Feeling suddenly scared for no reason • Worries about your health • Spells of terror and panic • Nervousness or shakiness inside • Feeling hopeless about the future • Feeling everything is an effort • Feeling fearful • Feeling blue • Feeling of worthlessness • Thoughts of ending your life • Feelings of being trapped and or caught	Independent variable: Mental health (H3: The higher the mental health challenges, the less the health-seeking behavior in patients with liver disease)
Burden of treatment theory		
Grief influences willingness to seek health services	Grief Scale [90] • Having trouble accepting eventual death/death as a reality • Grief (sadness and longing) is interfering with life • Having images or thoughts of death or related images that really bother me • There are things I used to do before the diagnosis that I don't feel comfortable doing anymore or avoid (e.g. going somewhere, eating certain things, meeting people) • Feeling cut off or distant from other people since diagnosis, even people you used to be close to like family or friends	Independent variable: Experiencing grief (H4: The higher the grief, the less the health-seeking behavior in patients with liver disease)

Table 1 (continued)

Theory	Operationalization (scale/items)	Study constructs (hypotheses)
Lack of social network influences health-seeking behavior	Social Support Pakistani Hepatitis Patients [91] • I prefer to ask family/friends for their advice in critical times • Presence of family/friends make me feel good • I participate in social activities with my friends • My relationship with my family is good • Whenever I am sad, family/friends cheer me up • I spend maximum time with my family members • I have some family/friends upon whom I can always rely • Family/friends provided me disease/health related information	Independent variable: Social support (H5: The higher the social support, the higher the health-seeking behavior in patients with liver disease)
Difficulty with healthcare service quality influences health-seeking behavior	QUOTE-Liver [92] Do the following describe your doctor: • They are knowledgeable • Takes time to discuss emotional issues • Takes you seriously • Makes you feel safe • Believes what you say • Takes enough time for you • Is friendly • Is open • Listens to you • Answers all of your questions • Gives you enough information about your disease/treatment • Gives you a say in your treatment • Answers your questions clearly • Gives you medical/technical information about your disease when you ask for it • Gives enough explanation about your medication and possible side effects • Refers you well when you present with complaints that are not liver disease related • Takes action quickly	Independent variable: Healthcare service quality (H6: The higher the health service quality, the higher the health-seeking behavior in patients with liver disease)
Theory of planned behavior		
Health literacy influences willingness to seek health services	BRIEF Health Literacy Screening Tool [93] • I do not have anyone to help read hospital materials • I have problems learning about my medical condition because of difficulty understanding written information • I often have a problem understanding what is told to me about your medical condition • I am not confident filling out medical forms by myself	Independent variable: Health literacy (H7: The higher the health illiteracy, the less the health-seeking behavior in patients with liver disease)
Willingness and commitment to recovery influences health-seeking behavior	Health-seeking behavior (self-constructed) • Committed to spending time seeking advice and help for recovery from people with similar illnesses, relatives, friends and media, alternative providers • Committed to returning for scheduled physician visits, getting needed and regular physician-recommended tests and scans, recommended surgery/next step of recommended care plan by physician team • Committed to consulting other care providers recommended by your primary consultant (e.g. physiotherapist, nutritionist, hematologist, interventional radiologist, surgeon)	Dependent variable: Health-seeking behavior

Methods

We conducted a cross-sectional study. The selection criteria for this study were (i) patients with CLD presenting to the outpatient Gastrointestinal and Hepatology Department Department of PKLI&RC for health services, (ii) out-patients seeking health services from PKLI&RC, and (iii) those who were willing to participate without any compensation. Initial screening was done by the PKLI&RC doctors to exclude from the sample patients who were mentally infirm, delirious, or diagnosed with hepatic encephalopathy.

Data collection

The survey was translated in Urdu through the forward backward method. A total of 28 student data collectors, experienced in field research, collected the data

(Appendix 1). They were trained over a two-week period in person and also provided video tutorials which they could refer to if needed. The training included information about consideration for the hospital setting and sensitivity of the patients undergoing treatment for chronic disease [52]. The Google Survey form was used to collect data on tablets or smartphones of data collectors. Data was collected over a four-month period from May 2022 to August 2022. The data collectors visited PKLI&RC thrice a week between 10am to 3pm and collected data from participants while they waited for their appointment or tests. Willing participants were accompanied to a private enclosure for survey completion. Each survey took between 35 and 40 min to complete.

On average, 450 out-patients visit PKLI&RC in one day just for the Gastrointestinal and Hepatology Department. In total, data collectors were able to request 1,500 patients, of which 625 refused to participate. Reasons for refusal included: (i) lack of time, (ii) general unwillingness to participate in a survey, and (iii) not feeling too well to participate or give complete attention. Data collectors were able to start surveys with 875 willing respondents but were able to complete a final 850 surveys. The drop-out of 25 respondents was due to patients being called in by the physician and not being willing to continue the survey upon exit from the meeting.

Data analysis

The data was analyzed using SPSS 25.0. Descriptive statistics were used to present sociodemographic characteristics of respondents and their willingness to seek healthcare. ANOVA tests were used to compare which groups of patients have less health-seeking practices. Pearson correlation results have been derived to show the relationship between the dependent variable (HSB) and the independent study domains (economic stability, health literacy, social support, experiencing grief, mental health, healthcare service quality, and coping strategies).

Most literature refers to either commitment to continuum of care, continued health-seeking, or HSB. As we want this research to be disseminated in Pakistan and for the health sector and social welfare departments to develop policy support accordingly, we chose to use the term 'health-seeking behavior (HSB)' which is more commonly used in Pakistan and well understood by the masses. We measured HSB using a self-constructed scale comprising of 11 items (Table 2). The development process and validation results are summarized in Appendix 2. These items were developed based on three steps: First, a literature review; second, during consultation meetings with gastroenterologists, hepatologists, and psychologists, working at PKLI&RC who had been treating CLD patients for at least 4 years or more; and third, having the questions reviewed by patients of CLD [53]. It was important to develop a scale to measure HSB for the following two reasons: (i) To measure the cultural and socio-demographic realities of patients visiting PKLI&RC [54], for example their preference to visit traditional healers; and (ii) to include reference to the treatment options offered by PKLI&RC, for example the necessity of multidisciplinary referral and patient compliance with this.

Questions such as the following were asked: 'Do you spend time seeking advice and help for recovery from people with similar illnesses', 'Are you committed to returning for your scheduled physician visits', and 'Are you committed to getting your regular and physician-recommended tests and scans'? Items were measured on a 5-point Likert scale ranging from "Not at all (1)" to "To a large extent (5)", with maximum score of 55 and minimum of 11 (Table 2). Higher scores indicated more commitment to HSB in patients and lower scores indicated low HSB. For bivariate analysis cut-off values were assigned and dummy variables were created as advised by experts [55], with scores of 11–33 indicating "low HSB" and coded = 0, and scores of 34–55 indicating "medium to high HSB" and coded = 1. Multivariate logistic regression has been used to show which socio-demographic characteristics and study domains show lower odds for HSB in patients. For adjusted odds ratio (OR), age, gender, and monthly household income were used as control variables. We considered these three to be adequate control variables for our study context. They were additionally guided by experts, who also consider these to be the most commonly used control variables [56, 57]. Confidence intervals have been reported for regression results and p-values of less than 0.05 have been considered significant for the study. The reliability results of the study domains are presented in Appendix 2, Table 3. All scales show satisfactory Cronbach's alpha results above 0.7 [58].

Ethics

This study has received ethics clearance from both the Institutional Review Boards of Forman Christian College University and Pakistan Kidney and Liver Institute and Research Centre. The study is based on a perception-based survey and does not involve any clinical interventions. No names were recorded during data collection. Respondents provided informed consent and data collectors assisted in recording data to facilitate illiterate or semi-literate participants. Data was entered in private and quiet spaces at PKLI&RC.

Results

Descriptive results

The descriptive results for respondents are presented in Appendix 2, Table 4. The majority of patients with liver disease are aged between 40 and 49 years (28.4%) and 50 to 59 years (25.2%). The sample is almost evenly

Table 2 Study scales and information about items, response measurement, and scoring

Scale	Items	Likert scale	Sample question	Scoring	Max score, Min score	Dummy score	Reverse coding
Economic stability	11	1 = Not at all 2 = To a small extent 3 = To some extent 4 = To a moderate extent 5 = To a large extent	I know that I have enough money in savings to cover the costs of my treatment	The higher the score, the more the economic stability, and vice versa	55, 11	0 = Low economic stability 1 = Medium to high economic stability	2,3,4,5,8,9,11
Health literacy	15	1 = Yes 0 = No	Please repeat these words: flu, anemia, fatigue…	The higher the score, the more the health literacy, and vice versa	15, 0	0 = Low health literacy 1 = Medium to high health literacy	15
Social support	8	5 = Always 4 = Often 3 = Sometimes 2 = Occasionally 1 = Never	In critical situations I prefer to ask family and friends for their advice	The higher the score, the more the social support, and vice versa	40, 8	0 = Low social support 1 = Medium to high social support	All reverse coded
Experiencing grief	5	1 = Not at all 2 = Somewhat 3 = A lot	How much are you having trouble accepting eventual death as a reality	The higher the score, the more the grief, and vice versa	15, 5	0 = Medium to high grief grief 1 = Low grief	-
Mental health	31	1 = Not at all 2 = A little 3 = Moderately 4 = Quite a bit 5 = Extremely	Do you feel hopeless about the future	The higher the score, the more the mental health challenges, and vice versa	155, 31	0 = Medium to high mental health challenges 1 = Low mental health challenges	All reverse coded
Healthcare service quality	20	5 = Always 4 = Often 3 = Sometimes 2 = Occasionally 1 = Never	Does your healthcare provider take time to discuss your emotional issues	The higher the score, the better the health service quality, and vice versa	100, 20	0 = Low mental health service quality 1 = Medium to high health service quality	-
Coping strategies	14	1 = To a great extent 2 = To some extent 3 = Not at all	You cope with your health issues through spirituality	The higher the score, the lower the coping strategies, and vice versa	70, 14	0 = Low coping strategies service quality 1 = Medium to high coping strategies	All reverse coded
Health-seeking behavior	11	1 = Not at all 2 = To small extent 3 = To some extent 4 = To moderate extent 5 = To large extent	Are you committed to getting your regular physician-recommended tests and scans	The higher the score, the more the health-seeking behavior, and vice versa	55, 11	0 = Low health-seeking behavior 1 = Medium to high health-seeking behavior	-

representing males (50.4%) and females (49.6%). The majority of the sample is married (83.4%), from Punjab province (91.9%), and Muslim (98.1%). The sample represents both the urban (53.4%) and rural population (46.6%). A significant percentage of the sample is either illiterate (37.1%) or have attained secondary education grade 10 or less (48.2%). Almost half of respondents are unemployed (46.4%) and from those who are working the majority are unskilled workers (5.8%) or laborers (42.9%). The monthly household income is between US-Dollars (USD)[1] 22.20–110.00 (26.7%) or USD 111.00–221.00 (40.0%), suggesting that the sample mainly belongs to the lower middle class wealth background of Pakistan. With regards to household data, the majority of respondents lives in a house which has 5 to 7 members (65.9%), and in nuclear families (51.6%). Most live in homes owned by their families (66.7%) and most have elder male relatives or spouses as the heads of household. The majority have between 1 and 4 children (73.9%) and 1 to 2 aging dependents (52.2%).

Table 3 presents the descriptive results for the individual items used to measure HSB and willingness to seek care from provider. The majority of patients indicate that they never, to some extent, or only moderately engage in the following practices: (i) Seeing advice for recovery from people with similar illnesses (65.7%); (ii) Seeking advice and help for recovery from relatives, friends, and

Table 3 Frequencies of HSB and willingness to seek care

Variables	*n* (%)
Do you believe following the physician's advice is the best option for you?	
Not at all/To some extent/Moderately	263 (30.9%)
To a large extent	587 (69.1%)
Seeking advice for recovery from people with similar illnesses	
Not at all/To some extent/Moderately	558 (65.7%)
To a large extent	292 (34.4%)
Seeking advice and help for recovery from relatives	
Not at all/To some extent/Moderately	591 (69.5%)
To a large extent	259 (30.5%)
Seeking advice for recovery from alternative providers or healers	
Not at all/To some extent/Moderately	591 (69.5%)
To a large extent	221 (26.0%)
Committed to returning for your scheduled physician visits	
Not at all/To some extent/Moderately	295 (34.7%)
To a large extent	555 (65.3%)
Getting your regular physician recommended tests and scans	
Not at all/To some extent/Moderately	303 (35.6%)
To a large extent	547 (64.4%)
Committed to getting the recommended surgery or next step of care plan	
Not at all/To some extent/Moderately	321 (37.8%)
To a large extent	529 (62.2%)
Committed to consult the other care providers recommended by consultant	
Not at all/To some extent/Moderately	336 (39.6%)
To a large extent	514 (60.5%)
Seeking advice and help for recovery from friends	
Not at all/To some extent/Moderately	314 (36.9%)
To a large extent	536 (63.1%)
Seeking advice and help for recovery from media	
Not at all/To some extent/Moderately	311 (36.7%)
To a large extent	539 (63.4%)
Committed to getting the next step of care plan	
Not at all/To some extent/Moderately	318 (37.5%)
To a large extent	532 (62.6%)

Table 4 Mean results for HSB by liver disease

	n	Mean (SD)	95% CI
Chronic viral hepatitis	271	11.01 (3.55)	10.59–11.44
Cirrhosis	259	10.52 (3.28)	10.11–10.92
Hepatocellular carcinoma	193	10.21 (3.49)	9.71–10.71
Non-viral liver disease	127	10.32 (2.91)	9.81–10.83

p-value = *0.022*

media (69.5%); and (iii) Seeking advice for recovery from alternative providers or healers (69.5%).

Mean comparison of liver disease type and health-seeking practice

Figure 1 shows that from the sample the majority of respondents are chronic viral hepatitis patients (31.9%), followed by patients with cirrhosis (30.5%), hepatocellular carcinoma (HCC) (22.7%), or non-viral liver disease patients (14.9%). The ANOVA results, presented in Table 4, show significant results, and reveal that the following three groups have less health-seeking practices (Fig. 2): (i) hepatocellular carcinoma patients (M = 10.21, SD = 3.49); (ii) non-viral liver disease patients (M = 10.32, SD = 2.91); and (iii) cirrhosis patients (M = 10.52, SD = 3.28).

Regression results

Pearson correlation results, presented in Appendix 2, show that all study domains have significant associations with the dependent variable of HSB, with values above 0.200 [59]. Multivariate regression results reveal that patients with the following socio-demographic characteristics have lower odds for HSB (Table 5): (i) Illiterate people (AOR = 3.62, 95% CI: 1.32–6.14); (ii) those living in rented homes (AOR = 3.32, 95% CI: 1.11–6.93); (iii) those belonging to nuclear families (AOR = 2.77, 95% CI: 0.88–5.73); and (iv) those with monthly household income below PKR 75,000 (AOR = 2.47, 95% CI: 0.79–5.80).

Table 6 presents the bivariate and multivariate regression results for lower odds for HSB with respect to the

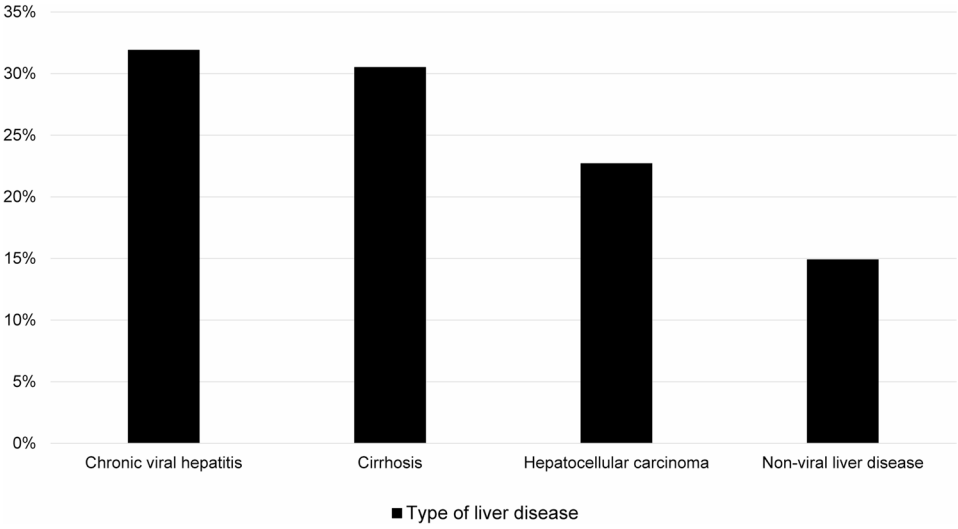

Fig. 1 Type of physician-diagnosed liver disease

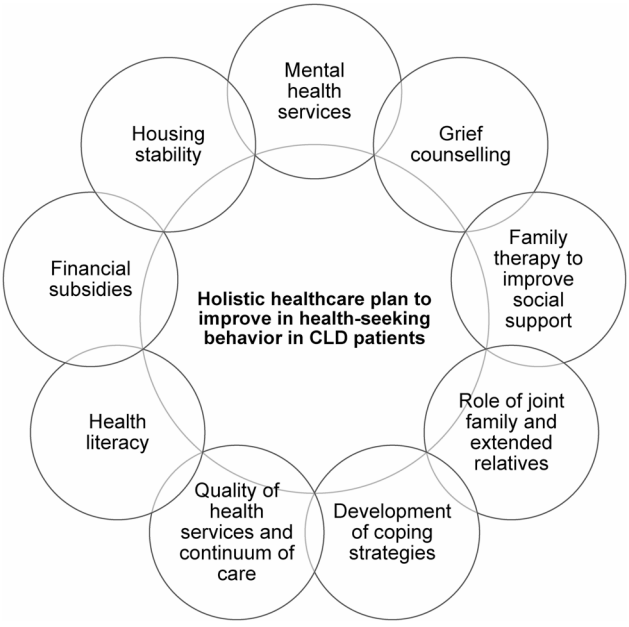

Fig. 2 A tertiary care plan of action suited for Pakistani patients of CLD

study domains. The results show that patients have low probability for HSB when they suffer from: (i) health illiteracy (AOR = 4.25, 95% CI: 0.95–6.92); (ii) low health service quality (AOR = 2.97, 95% CI: 0.81–5.90); (iii) low ability to use coping strategies (AOR = 2.70, 95% CI: 0.60–5.02); (iv) grief (AOR = 2.45, 95% CI: 0.31–4.89); (v) lack of social support (AOR = 1.70, 95% CI: 0.60–3.75); (vi) mental health challenges (AOR = 1.44, 95% CI: 0.49–4.24); and (vii) economic instability (AOR = 1.09, 95% CI: 0.27–2.16).

Discussion

Contrary to previous research [60], our study indicates that CLD patients in Pakistan are not merely from the older population group: More than 50% of our sample lies between the ages of 40 to 59 years, and nearly 30% between 18 and 39 years, suggesting that Pakistan's CLD burden impacts the young and middle-age population. Younger populations may have a high burden of CLD in the country due to several factors including biliary atresia, genetic-metabolic diseases, autoimmune hepatitis, Wilson's disease, alpha-1-antitrypsin deficiency and primary sclerosing cholangitis, non-alcoholic fatty liver disease, being overweight/obese, and hepatitis C [61]. More research is needed in the country about different Pakistani ethnicities and the comparative risk of getting CLD in younger age groups and how to integrate early care and preventive strategies in the local health model.

The majority of our sample belongs to the lower middle class of Pakistani society, with an average income of less than USD 221 per month; which matches both previous patient demographic results of PKLI&RC [38] and the Pakistan Bureau of Statistics Survey results for Punjab wealth demographics [62]. Poorer patients of CLD suffer from dual problems of (i) not having enough money for preventive practices such as healthy eating habits [63] and having low health literacy [28], and (ii) less finances and resources to get tested and treated which can contribute to the progression of disease [9]. Studies from the developed world stress that CLD patients with lower income and lower occupations skills are strongly associated with more severe disease at diagnosis and poorer survival [64], implying that financially vulnerable patients need more support for health promotion and disease management.

Table 5 Bivariate and multivariate logistic regression results for socio-demographic predictors for lower HSB in patients with liver disease

	OR for low HSB (95% CI)	*p*-value	AOR for low HSB (95% CI)	*p*-value
Age		0.132		
40 years or more	2.16 (0.79–5.86)			
Less than or equal to 39 years	1			
Gender		0.133		
Female	2.26 (0.78–6.57)			
Male	1			
Marital status		0.659		0.362
Unmarried	1.40 (0.32–6.22)		2.04 (0.44–6.46)	
Married	1		1	
Literacy		0.013		0.026
Illiterate	3.83 (1.32–6.14)		3.62 (1.16–6.26)	
Literate	1		1	
Family structure		0.017		0.028
Nuclear	2.85 (0.92–5.93)		2.77 (0.88–5.73)	
Joint	1		1	
Head of family		0.772		0.767
Other	1.15 (0.42–3.14)		1.49 (0.77–3.01)	
Self	1		1	
Employment status		0.229		0.235
Unemployed	1.92 (0.66–5.58)		2.84 (0.93–6.72)	
Employed	1		1	
Monthly household income		0.041		0.017
Less than PKR 75,000	2.57 (0.82–5.04)		2.47 (0.79–5.80)	
PKR 75,000 and above	1		1	
Household family members		0.225		0.206
5 and above	1.46 (0.41–3.20)		1.57 (0.43–4.63)	
4 or less	1		1	
House ownership		0.005		0.032
Rented/Living with others	5.45 (1.56–8.21)		3.32 (1.11–6.93)	
Owned	1		1	
Total aging dependents		0.711		0.730
One or more	1.24 (0.39–3.88)		1.20 (0.38–3.82)	
None	1		1	
Total number of children		0.155		0.172
Three or more	2.49 (0.71–8.83)		3.02 (0.82–9.01)	
Two or less	1		1	
Provincial belonging		0.997		0.996
Other	1.24 (0.21–3.22)		1.33 (0.49–3.64)	
Punjab	1		1	
Religious belonging		0.437		0.446
Other	3.64 (0.45–5.36)		2.86 (0.34–4.67)	
Muslim	1		1	

Notes: Age, gender, and monthly household income are held constant

p-value is considered significant less than 0.05

Our results show that the following three groups have less health-seeking practices: patients with HCC, non-viral liver disease, and cirrhosis (compared to patient with chronic viral hepatitis). This is possibly because patients of cancer have less perceptions, social support, finances, and healthcare support from providers and public sector, as is true for Pakistan and other developing nations [65]. Similarly, patients of cirrhosis, fatty liver disease, and non-viral liver disease have greater risk of developing tumors or cancer and have less curative treatment options [66]. The findings imply that specific CLD patient groups (HCC, non-viral liver disease, and cirrhosis patients) require more support from provider, family, and other support networks to encourage HSB.

Table 6 Bivariate and multivariate logistic regression results for study domains for lower HSB in patients with liver disease

	OR for low HSB (95% CI)	*p*-value	AOR for low HSB (95% CI)	*p*-value
Economic stability		0.003		0.005
Low economic stability	2.46 (0.31–5.46)		1.09 (0.27–2.16)	
Moderate to high economic stability	1		1	
Health literacy		0.004		0.002
Low health literacy	4.07 (0.92–7.06)		4.25 (0.95–6.92)	
Moderate to high health literacy	1		1	
Social support		< 0.001		< 0.001
Low social support	1.69 (0.61–3.71)		1.70 (0.60–3.75)	
Moderate to high social support	1		1	
Experiencing grief		< 0.001		< 0.001
Moderate to high feelings of grief	2.04 (0.26–4.63)		2.45 (0.31–4.89)	
Low feelings of grief feeling	1		1	
Mental health		< 0.001		< 0.001
Moderate to high challenges with mental health	1.86 (0.64–5.42)		1.44 (0.49–4.24)	
Low challenges with mental health	1		1	
Healthcare service quality		0.050		0.003
Low health service quality	3.47 (0.96–6.56)		2.97 (0.81–5.90)	
Moderate to high health service quality	1		1	
Coping strategies		< 0.001		< 0.001
Low coping	2.71 (0.61–5.03)		2.70 (0.60–5.02)	
Moderate to high coping	1		1	

Notes: Age, gender, and monthly household income are held constant for multivariate regression results

p-value is considered significant less than 0.05

A recent study has classified the most common causes of prevalent liver disease as Non-alcoholic fatty liver disease (59%), followed by hepatitis B virus (HBV) (29%), hepatitis C virus (HCV) (9%), and alcoholic liver disease (2%) [67]. For a country like Pakistan with low health literacy there is very little awareness about contracting chronic viral hepatitis, with few patients actually seeking treatment for HBV [67]. Pakistan is one of the six countries that has the highest HCV burden [67], mainly due to reuse of unsterilized medical equipment, an absence of blood screening programs, and the absence of effective vaccines.

Needle-sharing and intravenous drug use is a common and rising problem in Pakistan, especially amongst the middle class or poor, the youth, and male populations [68]. Non-viral disease, including fatty liver disease, is caused primarily by Pakistan's rising burden of obesity [69] and high prevalence of diabetes [70]. Physicians in the country have indicated that alcohol consumption is on the rise, and due to cultural reasons may be underreported [71]. Pakistan also has a high incidence of intoxicant consumption [72], and there is less research about the possible relationship between consumption of tobacco, cigarettes, betel quid, chewing smokeless tobacco (which are consumed commonly in Pakistan) and liver disease [73]. It is thus that Pakistan is in critical need for integrated preventive strategies, through a continuum of care approach, by the health sector, to reduce the CLD burden which includes universal childhood vaccination to reduce HBV burden, sterilization of medical equipment, and improved blood product screening.

Major health and social interventions are also needed in the country to reduce risk factors for obesity and diabetes as partner programs if CLD is to be reduced. This may include early screening, primary level prevention strategies better dietary and nutrition interventions, and community programs to improve physical activity. Furthermore, there is an important role of social policy, educational policy, and the legal sector in improving public awareness about needle reuse and exchange, strict monitoring of intravenous drug use, legal restrictions on alcohol and intoxicant use, and awareness about sexual transmission of disease. Part of WHOs strategy to treat HCV is through direct-acting antiviral therapies [74] which needs to become a political and health sector priority in the country.

Regression results reveal that the following sociodemographic characteristics of CLD patients are associated with lower HSB: illiterate people; those facing housing insecurity and rental burden; those belonging to nuclear families and having less joint family support; and those with monthly household income below USD 332. Other studies corroborate that literacy [75], financial stability [76], and extended family support [77] are critical for positive HSB in patients of CLD. International literature confirms that CLD patients with low housing

stability, including having to pay high rents, those living with relatives or friends, or living in houses with inadequate amenities have less ability to continue with health-seeking [78]. CLD patients need consistent and dedicated support from family members, which can be a problem for smaller families with fewer adults who have limited time due to work pressures. Though Pakistan is known for its joint family culture, local scholarship suggests that nuclear families are on the rise and there is less support for chronic disease management for the elderly in smaller families [79]. There is a need for families with CLD patients to be encouraged to return to the joint family system and to integrate extended family members for specific roles and care duties [80].

All seven hypotheses of the study are proven correct. Low HSB in CLD patients is associated with economic instability, lower coping strategies, higher mental health challenges, higher grief, lower social support, lower health service quality, and lower health illiteracy. Even scholarship from the developed world confirms that CLD patients face immense cost burdens, especially those who suffer from the disease from a younger age, who suffer complications during treatment, who have other co-morbidities, and who have to travel far for treatment or pay some or all costs out-of-pocket [81]. The majority of Pakistan's population is poor and dependent on the public sector for health services, however not all the costs for recovery and treatment are efficiently covered by the underfinanced and understaffed public sector, with chronic disease patients receiving the least care and attention [82].

A local study confirms that CLD patients in the country have low social support and provider trust, thus causing them to seek help from multiple providers and faith healers [83]. Pakistan is also known for its low health literacy, which contributes to low medical adherence, inability to independently manage disease, and low return for testing and treatment in patients [84]. Health literacy for CLD patients and constant support for bridging knowledge gaps, dispelling misconceptions, and disease management protocols, especially for illiterate and semi-literate populations is critically needed. International scholarship has stressed that mental health problems are common among CLD patients and if left untreated can contribute to a worsening of liver disease outcomes [85]. Pakistan does not have an integrated care model at tertiary level for mental health services for chronic disease patients, which contributes to worsening of disease and also economic burdens [86]. There is a critical need to integrate counselling services for CLD patients to support psychiatric disorders, counselling for grief, and family therapy to improve social support.

Limitations

The study results need to be interpreted with caution, because it is cross-sectional data which does not necessarily allow for causal conclusions. Furthermore, it is not a population representative study, because it only focusses on patients visiting one of the largest public sector hospitals dedicated to liver and kidney care for poor populations in the Punjab province. In addition, we did not conduct secondary tests to explore other cut-off points for the analysis. There was also high refusal in patients to participate due to lack of time, general unwillingness to participate in research, and not feeling well enough to participate.

Conclusions

Our study confirms that the majority poor and illiterate or semi-literate CLD patients have low HSB and that they need to be carefully screened by the health sector and streamed for holistic healthcare support in hospital settings of Pakistan. Ultimately, reducing the CLD burden requires region-specific and cultural interventions which addresses the local realities. Preventive and early primary healthcare support are needed, along with partner social and education-based interventions for parallel issues such as low vaccination, obesity, early health-seeking, and drug abuse. Specific to our study results, we are able to recommend a tertiary care plan of action suited for Pakistani patients of CLD (Fig. 2). Integration of a social policy officer or social worker at the hospital is recommended who will manage the following support and also coordinate the multi-disciplinary needs of the patient, including (i) mental health screening; (ii) grief counselling; (iii) financial planning and subsidy transfer coordination; (iv) housing policy and adequacy support; (v) planning and monitoring and evaluation for improved quality of care by health team and continuum of care; (vi) family therapy for improved social support; (vii) awareness of benefits of joint family for chronic disease management and integration of extended family for specific care roles; (viii) workshops for developing coping strategies (spirituality and active coping); and (ix) health literacy and disease management sessions.

Abbreviations

CI	Confidence interval
CLD	Chronic liver disease
HBV	Hepatitis B virus
HCC	Hepatocellular carcinoma
HCV	Hepatitis C virus
HSB	Health-seeking behavior
SPSS	Statistical Package for Social Sciences
OR	Odds ratio
PKLI	Pakistan Kidney and Liver Institute and Research Centre
USD	US-Dollars
WHO	World Health Organization

Supplementary Information

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Supplementary material 1.

Supplementary material 2.

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Authors' contributions

SRJ, AN, and HA conceptualized this project and developed the tool for data collection. SKB, AK, and MAK supervised the data collection. SRJ conducted the data analysis and wrote the manuscript; AN, HA; SKB, AK, MAK and FF revised it critically for important intellectual content. All authors read and approved the final manuscript.

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Data availability

Data is available from corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

This study has received ethics clearance from both the Institutional Review Boards of Forman Christian College University (Reference Number: FCCU-IRB-367/05-2022; Dated: 05/18/2022). and Pakistan Kidney and Liver Institute and Research Centre (Reference Number: PKLI-IRB/AP/68; Dated: 13/04/2022). Respondents provided informed consent and data collectors assisted in recording data to facilitate illiterate or semi-literate participants.
The research has been performed in accordance with the Declaration of Helsinki.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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