RESEARCH



Mental health and quality of life in patients with chronic liver disease: a single-center structural equation model

Sara Rizvi Jafree¹, Ammara Naveed², Humna Ahsan³, Syeda Khadija Burhan⁴, Masha Asad Khan⁵, Amna Khawar⁶ and Florian Fischer^{7*}

Abstract

Background Chronic liver disease (CLD) is one of the leading disease burdens in Pakistan. Until now, there has only been limited focus in the country on providing health services through tertiary services in urban cities, whereas there is almost no research in Pakistan on the mental health and quality of life of CLD patients. This study aimed to understand which predictors influence the mental health and quality of life of CLD patients in order to advise better policy protection.

Methods Data was collected from CLD patients at the Pakistan Kidney and Liver Institute and Research Centre, Lahore, Pakistan. A total of 850 respondents were part of the final sample. The age of respondents ranged from 18 to 79 years and included the following diagnosis: (i) Chronic Viral Hepatitis (n=271), (ii) Cirrhosis (n=259), (iii) Hepatocellular Carcinoma (n=193), and (iv) Non-viral Liver Disease (n=127).

Results Mean results reveal that females as well as illiterate patients need more support for mental health and communication with their physician; whereas men need more support to develop coping strategies. Structural equation modelling results reveal that the severity of symptoms ($\beta = 0.24$, p < 0.001), coping strategies ($\beta = -0.51$, p < 0.001), and doctor communication ($\beta = -0.35$, p < 0.001) predict mental health. Quality of life is associated with the severity of symptoms ($\beta = -0.36$, p < 0.001), coping strategies ($\beta = 0.26$, p < 0.05), and doctor communication ($\beta = 0.09$, p < 0.05).

Conclusions A 'bio-psycho-social-spiritual' model is recommended for Pakistan's CLD patients which includes the integration of social officers to provide support in four key areas to secure mental health and quality of life of patients. **Keywords** Chronic liver disease, Pakistan, Mental health, Quality of life, Coping

*Correspondence:

Florian Fischer

florian.fischer1@charite.de

¹Department of Sociology, Forman Christian College University, Lahore, Pakistan

²Pakistan Kidney Liver Institute and Research Centre, Lahore, Pakistan
³Department of Economics, Forman Christian College University, Lahore, Pakistan

⁴Department of Education, Forman Christian College University, Lahore, Pakistan

 $^{\rm 5}\mbox{Academic Dean of Humanities and Social Sciences, Kinnaird College for Women, Lahore, Pakistan$

⁶Department of Psychology, Lahore College of Women University, Lahore, Pakistan

⁷Institute of Public Health, Charité – Universitätsmedizin Berlin, Berlin, Germany

© The Author(s) 2024. **Open Access** This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by/4.0/. The Creative Commons Public Domain Dedication waiver (http://creativecommons.org/publicdomain/zero/1.0/) applies to the data made available in this article, unless otherwise stated in a credit line to the data.

Background

Chronic liver disease (CLD) has become one of the most significant concerns of public health worldwide and is known to be one of the leading causes of death in the developing world [1]. Exact statistics for mortality and disability-adjusted life years are not available for regions like Asia and Africa due to lack of coordinated efforts for data collection [2]. Most of the studies conducted in Pakistan are hospital-based studies with small sample sizes and there is lack of community-based data or confirmed national data about the actual prevalence of CLD [3]. Despite the confirmation about prevalence, CLD has been classified as the fifth most common cause of morbidity and mortality in Pakistan and the country has been labelled by some as a "cirrhotic state" [4]. Yet, there is very little policy attention and investment for prevention or disease management of CLD to date in Pakistan [5].

Globally, there is great concern about the lack of support for mental health in patients suffering from CLD [6], and their quality of life [7]. In Pakistan specifically, there is even greater concern as mental health is not a priority area for the health sector [8], and the 'bio-psycho-socialspiritual model' [9] which is important to secure the quality of life in patients is less understood or integrated in the health system [10]. The bio-psycho-social-spiritual model was proposed by Engel (1977) as an inclusive model of healthcare which supports patients of chronic disease for not just biomedical care, but with care for the social, psychological, and behavioral dimensions of illness [11-13]. With gaps in statistics and limited efforts in Pakistan focused on delivering services to diagnosed patients of CLD in urban zones [14], there is even less empirical evidence about the mental health and quality of life of CLD patients. The aim of this study is to identify which predictors influence the mental health and quality of life of CLD patients in order to advise better policy protection for patients as they receive health services and support from family and providers. Data collected in this study has been analysed using structural equation modelling, which is less used in health research [15], even though it has benefits over the multivariate statistical techniques [16].

Literature review

Quality of life in patients of CLD is affected primarily by the severity of symptoms, long period of treatment, and overall burden of care management [17, 18]. Common physical symptoms of patients with CLD include fatigue, inability to function at work, loss of appetite, and abdominal pain and swelling [19]. Personality changes have also been evidenced in CLD patients, such as loss of self-esteem, preference to remain isolated, and unwillingness to continue seeking health services [20, 21]. Patients of CLD are also known to suffer from common mental health challenges including anxiety, depression, constant worry, and even suicide ideation [22]. As severity of symptoms progresses in patients of CLD, their mental health and quality of life are known to decline [23]. Conversely, the occurrence of depressive indicators has an adverse impact on the progression of illness, reduced compliance with treatment, and quality of life [24, 25]. Local research also confirms that high levels of anxiety and depression are experienced by patients suffering from various liver diseases in Pakistan [26].

Effective doctor communication plays a salient role in CLD patients and their mental health and quality of life [27]. Comfort with doctor relations and good communication with physicians is known to facilitate increased awareness and understanding about the disease, timely check-up and testing, and compliance for health recovery [28]. Patients who do not have good communication with their physicians are known to suffer from additional stress and anxiety [29]. Local studies confirm that compliance of patients is strongly linked to empathetic communication and information sharing of doctors [30]. Previous research stresses that physicians need support for training in communication skills to improve quality services for patients and that their training needs are compromised due to low investment and prioritization by the health administration [31].

CLD management and recovery has a significant relationship with the patient's overall quality of life [17, 32]. Along with the physical deterioration, and mental health impact, patients can suffer from socio-economic problems such as financial issues, lack of support from family and friends, and inability to continue with work [33, 34]. Some studies also highlight that low quality of life is associated with the stage of disease or number of symptoms, the level of liver function, and the extent of social support in patients [35]. During and in the aftermath of the COVID-19 pandemic, CLD patients have known to suffer a greater decline in quality of life due to a lack of clarity about how to manage their disease during and after the lockdown and how to deal with infection and vaccination protocols in a world with Coronavirus and its many variants [36]. The theoretical model for this study which is based on the previously described literature is summarized in Fig. 1.

Aim and research questions

Much has been written about the causes of CLD, early screening, and preventive measures [37]. However, there is less research about the management and support of patients with CLD [38]. CLD is a progressive illness with high incidence of comorbidity, leading to decline in mental health and quality of life, necessitating holistic patient support. This study aims to bridge this gap and collect perception-based data from patients of CLD to identify





Fig. 1 Conceptual model for the study

which factors determine mental health and quality of life. Based on this study's finding we would be able to advise more holistic care for patients of CLD in Pakistan.

The research questions for this study are:

(1) Which sociodemographic characteristics of patients with CLD (including age, gender, and literacy), are associated with severity of symptoms, coping strategies, doctor communication, mental health, and quality of life?

(2) What is the relationship between independent study constructs (severity of symptoms, coping strategies, doctor communication) with the dependent variables of mental health and quality of life?

Study hypotheses

The following research hypotheses are tested in this study:

H1 Mental health has a positive relationship with severity of symptoms (i.e., the higher the disease symptoms, the greater the mental health challenges faced by patients of liver disease) and a negative relationship with coping strategies and doctor communication (i.e., the higher the coping strategies and the better the doctor communication, the lesser the mental health challenges faced by patients).

H2 Quality of life has a negative relationship with severity of symptoms (i.e., the greater the disease symptoms, the lesser the quality of life for patients of liver disease) and a positive relationship with coping strategies and doctor communication (i.e., the higher the coping strategies and the better the doctor communication, the better the quality of life of patients).

Methods

Research design

The study collected quantitative data, based on patients' perceptions, through a closed-ended survey from the Pakistan Kidney and Liver Institute and Research Centre (PKLI&RC), Lahore, Pakistan. PKLI&RC is a single public centre dedicated for patients with liver diseases. Since its inception in December 2017, it has served 3.5 million

patients, and almost 80% of them have received free or subsidized treatment [39].

Sample

The selection criterion for this study was patients of CLD presenting to the outpatient Gastrointestinal Department of PKLI&RC for health services. 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. Sampled patients fell under the following disease classifications: (i) Chronic Viral Hepatitis (n=271), (ii) Cirrhosis (n=259), (iii) Hepatocellular Carcinoma (n=193), and (iv) Non-viral Liver Disease (n=127). Data was not collected further on disease severity for cirrhotic patients, and parameters like CHILD, MELD and decompensation were not available to the research team.

Data collection

Data was collected between May 2022 and August 2022 by experienced field researchers who were trained over a period of two weeks by the authors of this study. The survey was translated to Urdu, the local language through the forward and backward method by authors who are bilingual in English and Urdu [40]. All data was collected in a private space provided by PKLI&RC with data collectors assisting illiterate and semi-literate respondents for survey completion. The data has been analysed using SPSS and AMOS, considering a *p*-value less than 0.05 as significant.

Instruments

Severity of symptoms

For this study, severity of symptoms is measured based on scores for three areas according to the Chronic Liver Disease Questionnaire [41]: Fatigue, abdominal symptoms, and systemic symptoms. A seven-point Likert scale was used to measure responses ranging from 'All the time' to 'None of the time'.

Fatigue has been measured for this study using the following three items: 'How much of the time have you been tired or fatigued during the last two weeks?, 'How much of the time in the last two weeks have you been bothered by having decreased strength?, and 'How often during the last two weeks have you felt a decreased level of energy?'

Abdominal symptoms have been measured using the following three items: 'How much of the time during the last two weeks have you been troubled by a feeling of abdominal bloating?', 'How much of the time during the last two weeks have you experienced abdominal pain?' and 'How much of the time during the last two weeks have you been troubled by a feeling of abdominal discomfort?'

Systemic symptoms have been measured using the following three items: 'How much of the time during the last two weeks has shortness of breath been a problem for you in your daily activities?', 'How much of the time during the last two weeks have you been unable to fall asleep at night?', and 'How much of the time have you been troubled by itching during the last two weeks?'

Coping strategies

We used the COPE Inventory to measure coping [42]. Four items were used to measure religious coping: 'I seek God's help', 'I put my trust in God', 'I try to find comfort in my religion, and 'I pray more than usual'. Three items were used to measure active coping, with language modified to suit the study: 'I take action to try to get the help I need, 'I concentrate my efforts on doing something about my disease, and 'I take measures to gain health/recovery'. Three items were used to measure planning strategies and language was modified to suit the study: 'I try to come up with a strategy about what to do next to gain recovery/ health stability, 'I have a plan of action to manage my illness, and 'I think about how I might best handle my health problems'. A four-point Likert scale was used to measure responses ranging from 'I usually do this a lot' to 'I usually don't do this at all'.

Doctor communication

We used the QUOTE-liver scale to measure doctor communication quality [43]. The following three areas were measured: Knowledge, interaction and care. Knowledge was measured using the following three items: 'Doctor is knowledgeable', 'Answers all questions', and 'Gives enough information about your disease/treatment'. Interaction

 Table 1
 Psychometric properties of study variables

Variable	α	Number of items
Severity of symptoms		
Fatigue	0.840	3
Abdominal symptoms	0.795	3
Systemic symptoms	0.813	3
Coping strategies		
Religious	0.915	4
Active	0.909	3
Planning	0.800	3
Doctor communication		
Knowledge	0.924	3
Interaction	0.707	3
Care	0.802	3
Mental health		
Illness worry	0.926	4
Anxiety	0.839	3
General fear and hopelessness	0.814	3
Depression	0.885	3
Quality of life		
General quality of life	0.711	3
Level of independence	0.830	3

Page 4 of 11

was measured using the following three items: 'Takes you seriously', 'Makes you feel safe', and 'Takes enough time for you'. Care was measured using the following three items: 'Takes time to discuss emotional issues', 'Refers you well when you present with complaints that are not liver disease related', and 'Listens to you'. A four-point Likert scale was used to measure responses ranging from 'Yes', 'Not really', 'Mostly Yes' to 'No'.

Mental health

We used the Instrument for Common Mental Disorders to measure mental health [44]. Four sub-domains were included: (i) Illness worry, (ii) anxiety, (iii) general fear and hopelessness, and (iv) depression. Illness worry was measured using the following three items: 'Worry that there is something seriously wrong with your body, 'Worry about health all the time,' and 'Thoughts that the doctor may be wrong in telling you not to worry'. Anxiety was measured using the following three items: 'Feeling suddenly scared for no reason,' 'Nervousness or shakiness inside, and 'Spells of terror and panic'. General fear and hopelessness was measured using the following three items: 'Feeling fearful', 'Feeling hopeless about the future,' and 'Feeling everything is an effort'. Depression was measured using the following three items: 'Feelings of worthlessness, 'Thoughts of ending life' and 'feelings of being trapped or caught'. A five-point Likert scale was used to measure responses ranging from 'Not at all' to 'Extremely'.

Quality of life

We used the brief WHOQOL survey to measure quality of life in CLD patients [45]. General quality of life was measured using three items: 'How satisfied are you with the quality of your life?', 'In general, how satisfied are you with your life?', and 'How satisfied are you with your health?'. Level of independence was measured using the following three items: 'How satisfied are you with your ability to perform your daily living activities?', 'How satisfied are you with your capacity for work?', and 'How satisfied are you with your ability to move around?'. A five-point Likert scale was used to measure responses ranging from 'Very dissatisfied' to 'Very satisfied'.

Reliability analysis

The Cronbach's alpha (α) results for study variables have been reported in Table 1. All study variables have satisfactory Cronbach's alpha values above 0.700 [46].

Ethics

This study received ethics clearance from the Ethics Review Committees of Forman Christian College University, and The Pakistan Kidney and Liver Institute and Research Centre (PKLI&RC), Lahore, Pakistan. Informed consent was taken from all respondents who participated in this study willingly.

Results

Sociodemographic characteristics

Table 2 summarizes the sociodemographic characteristics of participants. The majority of the 850 respondents of this study are above the age of 40 years (73.2%) and married (83.4%). The sample is split almost evenly between men and women and the majority have a monthly household income of USD 22.20–221.00 (66.7%), suggesting that most of the sample is from the lower middle class of Pakistan. Very few of the respondents have a graduate or postgraduate degree (14.7%) and few are currently employed (33.6%).

Prevalence of common mental health disorders

Respondents reported experiences in facing common mental health disorders (Fig. 2). The majority of CLD patients suffered from high incidence of worry about health overall (94.9%). Almost all patients felt that everything they do is an effort (90.9%), and felt blue or sad (89.4%). The majority also experienced loneliness (81.5%), fear (74.9%), and worthlessness (70.0%). More than half of respondents were hopeless about the future (66.1%) and felt trapped (63.3%). Of most concern is that almost half of CLD patients had thoughts of ending their life (36.5%).

Variable	n (%)
Age	
18–39	228 (26.8%)
40–79	622 (73.2%)
Gender	
Female	422 (49.6%)
Male	428 (50.4%)
Marital status	
Currently married	709 (83.4%)
Unmarried	141 (16.6%)
Literacy	
Illiterate	315 (37.1%)
Primary/secondary schooling	410 (48.2%)
Graduate/post-graduate	125 (14.7%)
Employment status	
Employed	445 (33.6%)
Unemployed	394 (46.4%)
Monthly income	
PKR 5,000-49,999 (USD 22.20-221.00)	567 (66.7%)
PKR 50,000 and above (USD 222.00 and above)	228 (33.4%)

Mean comparisons

Mean results for age and study variables are presented in Table 3a. None of the results are significant.

Mean results for gender and study variables are presented in Table 3b. Significant results show that women have higher coping strategies (4.24 vs. 3.91, p < 0.001), less



Fig. 2 CLD patients' experience of common mental health disorders

Table 3	Independ	lent samp	le t-tests	between ((a) age,	(b)
gender, a	nd (c) lite	racy and s	tudy vari	ables		

a) Age				
Variable	Age (in years)	Mean (SD)	t	p-value
Severity of symptoms	18–39	7.96 (3.60)	0.852	0.395
	40 and above	7.71 (3.81)		
Coping strategies	18–39	4.17 (1.46)	1.168	0.243
	40 and above	4.04 (1.36)		
Doctor communication	18–39	12.85 (2.62)	-1.728	0.084
	40 and above	13.21 (2.62)		
Mental health	18–39	9.63 (4.05)	0.305	0.760
	40 and above	9.53 (4.32)		
Quality of life	18–39	5.87 (1.69)	1.626	0.104
	40 and above	5.76 (1.95)		
b) Gender				
Variable	Gender	Mean (SD)	t	p-value
Severity of symptoms	Men	7.91 (3.81)	0.997	0.319
	Women	7.65 (3.69)		
Coping strategies	Men	3.91 (1.31)	3.531	< 0.001
	Women	4.24 (1.45)		
Doctor communication	Men	13.36 (2.37)	2.836	0.005
	Women	12.86 (2.83)		
Mental health	Men	9.14 (4.42)	-2.878	0.004
	Women	9.98 (4.03)		
Quality of life	Men	5.75 (1.97)	-1.418	0.157
	Women	5.83 (1.78)		
c) Literacy				
Variable	Literacy	Mean (SD)	t	p-value
Severity of symptoms	Illiterate	7.72 (3.84)	0.636	0.525
	Literate	7.44 (3.56)		
Coping strategies	Illiterate	4.00 (1.37)	-0.955	0.340
	Literate	4.15 (1.40)		
Doctor communication	Illiterate	12.57 (2.87)	-4.795	< 0.001
	Literate	14.03 (2.01)		
Mental health	Illiterate	10.71 (4.29)	3.998	< 0.001
	Literate	8.64 (4.84)		
Quality of life	Illiterate	5.74 (1.97)	0.168	0.866
	Literate	5.72 (1.07)		

Table 4 Correlation analysis between study variables

	Mental health	Quality of life
Mental health	1	-0.297*
Severity of symptoms	0.288*	-0.220*
Coping strategies	-0.243*	0.051
Doctor communication	-0.258*	0.016
Quality of life	-0.297*	1
* p<0.05		

communication with doctor (12.86 vs. 13.36, p<0.001), and suffer from greater problems related to mental health (9.98 vs. 9.14, p<0.005) compared to men.

Mean results for literacy and study variables are presented in Table 3c. Significant results show that illiterate patients have less communication with doctor (12.57 vs. 14.03, p < 0.001), and suffer from greater problems related to mental health (10.71 vs. 8.64, p < 0.001) compared to literate ones.

Correlation analysis

Pearson correlation results (Table 4) show that mental health is positively correlated with severity of symptoms (r=0.288) and negatively correlated with coping strategies (r=-0.243), doctor communication (r=-0.258), and quality of life (r=-0.297).

Quality of life is negatively correlated with severity of symptoms (r=-0.220). Though quality of life is positively correlated with coping strategies and doctor communication, the results are not significant.

Structural equation model

The Chi square test (χ 2=2.26, p<0.05) and goodness of fit index (GFI=0.965) demonstrated a good model fit. The alternate fit indices confirmed the acceptable fit of the sample (CFI=0.983, AGFI=0.950, RMSEA=0.070).

All the coefficients between mental health and quality of life, and the three observed variables were found to be significant (Fig. 3). The results show that the three observed variables of severity of symptoms (β =0.242, p<0.001), coping strategies (β =-0.505, p<0.001), and doctor communication (β =-0.352, p<0.001), significantly explain mental health in patients of CLD. Similarly, the three observed variables of severity of symptoms (β =-0.363, p<0.001), coping strategies (β =0.258, p<0.05), and doctor communication (β =0.094, p<0.05), significantly explain quality of life in patients of CLD.

Discussion

With Pakistan's high incidence of CLD burden, the public sector liver institute sampled in this study is playing a critical role in providing free and subsidized services to majority poor patients in the country who do not have out-of- pocket expenses [47]. Our findings show that women patients suffering from CLD have less communication with doctors and suffer from greater mental health challenges. It may be that women from more disadvantaged, semi-literate or illiterate backgrounds, and those belonging to conservative families have less ability to communicate and interact with physicians [48]. It may also be that doctors communicate less with female patients due to issues of 'cultural conflict', and perceptions that women complain more or misrepresent symptoms [49]. Other studies have also found that female CLD patients suffer from greater mental health disorders compared to male patients [50, 51]. This may be because women have less social support and face more stigma in Pakistani society when they suffer from a chronic disease [52]. Furthermore, women may also have more fears and anxiety when facing chronic disease burden due to their inability to continue care and nurturing for family, children, and other dependents [53].

Similarly, our results also show that illiterate patients suffering from CLD have less communication with

Fig. 3 Structural equation model of severity of symptoms, coping strategies, doctor communication, mental health, and quality of life

physicians and suffer from greater mental health challenges. Other studies confirm that illiterate patients face problems in understanding medical vocabulary, reading prescriptions and physician's instructions, and understanding patient education pamphlets and instructions for revisits and further tests [54]. A study conducted in Pakistan confirms that illiterate patients of CLD gain less information from doctor consultations and have low knowledge about how to manage disease and diet, consequently leading to adverse health results [55]. Another local study reports that illiterate patients suffering from CLD experience higher incidence of depression [56]. Anxiety and stress in illiterate populations of CLD has been found to be high due to lack of awareness and clarity, misconceptions and myths, and language barriers about disease [57].

Our results also show that men have fewer coping strategies pertaining to religion, active behaviour, and planning for disease management. Another study confirms that women are better at adopting coping strategies during illness, as they are more comfortable in showing emotions, turning to religion, and dealing with challenges by using social support [58]. Comparatively, men are less inclined to turn to religion or exhibit the emotions needed for adaptive coping during illness [59]. Patients of CLD are not always hospitalized or in doctor consultations, and thus development of self-care and coping strategies are integral to maintain their quality of life and mental health [60].

With regard to our first hypothesis, the study findings confirm that mental health of patients with CLD has a significant and positive relationship with severity of symptoms and a negative relationship with coping strategies and doctor communication. The second hypothesis of the study is also proven correct, and quality of life of patients with CLD has a significant and negative relationship with severity of symptoms and a positive relationship with coping strategies and doctor communication. Our findings confirm research from the developed world and that the management of patients with CLD is incomplete without interventions to improve and maintain mental health [22] and quality of life [61]. Based on the findings of this study, five areas need to be urgently addressed to improve the mental health and quality of life of CLD patients.

First, the management of severity of symptoms needs to be improved effectively through improved surveillance of high-risk groups at early stage and in primary settings [62]. Early treatment and effective lifestyle changes are needed for CLD patients of Pakistan [63], which is a partnership between the health sector, the patient, and their family. The support of the family and awareness and willingness of the patient to seek early treatment and commit to weight management, improved physical activity, and better nutrition can play an integral role in preventing advancement of symptoms [64]. Scholarship asserts that managing symptoms of CLD patients and preventing or delaying progression requires intensive surveillance and individually tailored therapeutic approaches, which is only possible through joint efforts by the provider, patient and support network including family and friends [65, 66]. In addition, a systematic literature review confirms the integral role of social workers or social policy officers in being integrated in the hospital team and managing the psychosocial aspects of CLD patients and progression of symptoms [67].

Second, CLD patients need to be supported for religious and spiritual coping, as well as in the development of active and planning coping behaviours. Numerous interventions which include emotional support, selfdistraction, positive reframing, and acceptance [68] have been used to develop coping skills in patients with CLD, with the role of religious coping shown to be the most effective in Pakistan [69]. Developing coping strategies suited to the individual depends on early screening of personality behaviour and life circumstances and requires the support of a counsellor [70]. Recommended steps for developing coping behaviours in chronically ill people includes assisting patients in expressing grief, providing opportunities to seek personal meaning, and training to gain mastery in managing emotions and challenges, which are best achieved through a combination of support from the counsellor, social worker, provider, and family members [71]. Other research confirms that religious leaders and community notables can play an integral role in addressing challenges of the chronically ill and supporting patients with spiritual coping [72].

Third, training for doctor communication skills needs to be improved and maintained as a continued learning model. Studies show that doctors have less interest in continued learning for communication skills due to excessive workload and preference for expanding or updating medical knowledge [73]. It is thus important for health administration to ensure mandatory and continued training, and to ensure providers gain the relevant communication skills needed for different patients, as hepatocellular carcinoma patients may require different communication methods compared to patients with cirrhosis [74]. The unfavourable doctor to patient ratio, estimated at 1:1,300, also needs to be improved to support doctor communication and efficiency [75]. Supervision of doctor communication with patients by independent bodies in the hospital setting can be an important means of providing support to both the patient for better quality care and the doctor who can share needs and concerns about role burden or lack of administrative support [76]. Health sector regulatory bodies who have used patient satisfaction questionnaires to assess communication skills of providers, have been able to develop an effective action plan for improved healthcare services [77]. Social workers and social policy officers working in the hospital setting have been found to be useful partners in supporting doctors for improved communication and decision-making for patients [78].

Fourth, mental healthcare services and counselling of CLD patients must be introduced in the tertiary institutes of Pakistan [79]. Our study found that the prevalence of mental health disorders in CLD patients is very high, including feelings of worry, sadness, loneliness, and fear for the future. Other local scholarship confirms that mental health in CLD patients is a considerable challenge [80], but this study has determined statistical frequencies for different mental health disorders which highlight the need for early screening and management. Of great concern is that suicide ideation has been indicated by a significant number of CLD patients in our sample. Given that Pakistani society is known to underreport suicide due to religious and cultural reasons [81], it may be that suicide ideation prevalence is even greater than what is indicated in this study. Not only is integration of mental health services by counsellors essential at tertiary level for CLD patients [82], but there is need for mental health services to be designed according to the cultural and religious beliefs for improved uptake [83]. Social workers and social policy officers have been found to be effective in providing mental healthcare support to patients as they are trained to manage cultural differences and provide religiously sensitive services [84].

Finally, health literacy for CLD patients is integral as the disease is complex and even educated patients need awareness and support for disease management. As mentioned earlier, Pakistani CLD patients suffer from backgrounds of low literacy and there is no support for health literacy in the hospital setting. Studies have found that the integration of social case workers in the hospital team can improve health literacy in patients leading to better health outcomes [85]. Table 5 summarizes what has been discussed above and recommends a 'bio-psycho-socialspiritual model' to improve mental health and quality of life among CLD patients in Pakistan. This model can be managed by social workers or social protection officers in the tertiary setting, who are known to be successful patient case managers on interdisciplinary disease management teams [86].

Conclusions

This study is limited to a single centre sample and is not representative of the entire nation. We recommend future studies to sample other provinces and to attempt longitudinal intervention-based research to assess the impact of improved care plans for patients with CLD. However, this study is an important contribution to the limited research about CLD patients who need support for mental health and quality of life, and it recommends the adoption of a holistic bio-psycho-social-spiritual model of care for CLD patients of Pakistan. Given that Pakistan

Intervention	Elements	Responsibility
Health literacy	Literacy for CLD management Specific and additional support for illiterate and semi-literate patients	Social officers
Prevent and manage severity of symptoms	Early detection Effective lifestyle changes	Provider / Patient / Support network and family
Coping strategies	 Active and planning coping Religious and spiritual coping Emotional coping 	Counsellor / Support network and family / Religious notables
Doctor communication	 Continued training of providers Linking professional advancement to patient surveys Gender sensitization training 	Health administra- tion / Independent surveyors
Integrating mental health services	Routine counselling for CLD patients	Counsellor / Health administration

Table 5 A 'bio-psycho-social-spiritual model' to improve mental health and quality of life among chronic liver disease patients in Pakistan

is a developing nation with low allocation of health budget, inefficient governance and planning, and a large rural and impoverished population, it is imperative to design prudent interventions for CLD patients using culturespecific and self-care initiatives. Early treatment and effective lifestyle changes are essential to manage severity of symptoms. Mental health service models which are culturally appropriate and regionally accepted need to be considered. The study also highlights that female patients of CLD need support through female HCPs and female coordinators at health centres for better communication and compliance. Self-care programs and education for adopting coping strategies related to religion and spirituality, active behaviour, and planning for disease management and recovery are also needed. Education of medical students and continued training of physicians is needed for improved patient-doctor communication overall, and specific doctor training for gender sensitization and support for illiterate patients. Finally, the overburdened and understaffed healthcare provider teams at hospital settings and tertiary sector of Pakistan must be reinforced and made more efficient through the integration of social policy officers or social workers.

Abbreviations

AGFI	Adjusted goodness of fit index
CLD	Chronic liver disease
CFI	Comparative fit index
COVID-19	Coronavirus Disease 19
GFI	Goodness of fit index
PKLI&RC	Pakistan Kidney and Liver Institute and Research Centre
RMSEA	Root mean square error of approximation
SD	Standard deviation
USD	US -Dollar

Acknowledgements

We are extremely grateful to the PKLI&RC administration and coordinators for their support during data collection. This research would not have been possible without the time and commitment of our students, who spent long hours travelling to PKLI&RC and collecting data from each respondent, with each survey taking 35 to 40 min. At times the students had to wait all day or many hours waiting for patients to have some free time in between visits with their doctor. They collected data and supported respondents with empathy and compassion, and they worked without funding and compensation. We are deeply indebted to each and every one of them including the following: (i) Nine students from LCWU: Farwa Ashfaq; Sana Shahid; Ayesha Ishfaq; Uswa Ziyad; Nimra Riaz; Komal Riaz; Fatima-tul-Zahra; Dua Fatima; and Mariam Zulfqar; (ii) Six students from Kinnaird College: Tania Waseem; Fajar Rizwan; Emen Ali; Iffa Irshad; Shagufta Ashraf; and Adeena Sohail; and (iii) Thirteen students from UCP: Siddiqa Allah Yar; Farwa Malik; Zoha Aziz; Muzhdah Hasan; Rehab Ali; Muhammad Natiq; Kinza Kaleem; Sawera Khadim; Aiza Humayun; Safa Jamil; Javeria Iftikhar; Rija Shahzad; and Rabia Saeed.

Author 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 drafted the manuscript. AN, HA, SKB, MAK, AK and FF revised the manuscript for important intellectual content. All authors read and approved the final version of the manuscript.

Funding

This study has not received funding.

Data availability

Data is available from corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

This study received ethics clearance from the Ethics Review Committees of Forman Christian College University, and Pakistan Kidney and Liver Institute and Research Centre (PKLI&RC), Lahore, Pakistan. The study was conducted in accordance with the Declaration of Helsinki. Informed consent was taken from all respondents who were willing to participate in the study; for illiterate persons, we relied on verbal consent after explaining the aims and procedures of the study and leaving space for questions. This procedure has been approved by the ethics committees.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Received: 11 June 2023 / Accepted: 15 May 2024 Published online: 05 June 2024

References

- Williams R. Global challenges in liver disease. Hepatology. 2006;44(3):521–6.
 Asrani SK. Devarbhavi H. Eaton J. Kamath PS. Burden of liver diseases in the
- Asrani SK, Devarbhavi H, Eaton J, Kamath PS. Burden of liver diseases in the world. J Hepatol. 2019;70(1):151–71.

- Butt AS. Epidemiology of viral hepatitis and liver diseases in Pakistan. Euroasian J Hepato-Gastroenterology. 2015;5(1):43.
- Parkash O, Hamid S. Next big threat for Pakistan hepatocellular carcinoma (HCC). J Pakistan Med Association. 2016;66(6):735.
- Ullah K, Dogar AW, Ochani S, Ahmad HB. Hepatitis E infection in chronic liver disease patients causing acute on chronic liver failure: vaccination is need of the hour. BMJ Open Gastroenterol. 2022;9(1):e001051.
- Häuser W, Holtmann G, Grandt D. Determinants of health-related quality of life in patients with chronic liver diseases. Clin Gastroenterol Hepatol. 2004;2(2):157–63.
- Gutteling J, De Man R, Van Der Plas S, Schalm S, Busschbach J, Darlington AS. Determinants of quality of life in chronic liver patients. Aliment Pharmacol Ther. 2006;23(11):1629–35.
- Khan AN, Abbassi MA, Gandapur A, Alam A, Haroon MZ, Hussain J. Frequency of depression among patients with chronic liver disease. J Ayub Med Coll Abbottabad. 2020;32(4):535–9.
- Megari K. Quality of life in chronic disease patients. Health Psychol Res. 2013;1(3):e27.
- Nadir M, Hamza M, Mehmood N. Assessing the extent of utilization of biopsychosocial model in doctor-patient interaction in public sector hospitals of a developing country. Indian J Psychiatry. 2018;60(1):103.
- 11. Engel GL. The need for a new medical model: a challenge for biomedicine. Science. 1977;196:129–36.
- 12. Braganza M, Oliveira J. Using the bio-psycho-social-spiritual framework in holistic health and well-being: a case example of a community-and faith-based sports program. Christ J Global Health. 2022;9(1):94–104.
- Kazlauskaite V, Angelkova E. Medical family therapists working with culturally diverse patients using the Bio-psychosocial-spiritual Model with chronically and terminally ill patients and their families. In The Routledge International Handbook of Couple and family therapy (pp. 247–66). Routledge.
- Khokhar N, Niazi SA. Chronic liver disease related mortality pattern in Northern Pakistan. J Coll Physician Surg Pak. 2003;13(9):495–7.
- 15. Hays RD, Revicki D, Coyne KS. Application of structural equation modeling to health outcomes research. Eval Health Prof. 2005;28(3):295–309.
- 16. Kaplan D. Structural equation modeling: foundations and extensions. Volume 10. SAGE; 2008.
- Younossi ZM, Boparai N, Price LL, Kiwi ML, McCormick M, Guyatt G. Healthrelated quality of life in chronic liver disease: the impact of type and severity of disease. Am J Gastroenterol. 2001;96(7):2199–205.
- Nguyen DL, Chao D, Ma G, Morgan T. Quality of life and factors predictive of burden among primary caregivers of chronic liver disease patients. Annals Gastroenterology: Q Publication Hellenic Soc Gastroenterol. 2015;28(1):124.
- Gralnek IM, Hays RD, Kilbourne A, Rosen HR, Keeffe EB, Artinian L, Kim S, Lazarovici D, Jensen DM, Busuttil RW. Development and evaluation of the liver disease quality of life instrument in persons with advanced, chronic liver disease—the LDQOL 1.0. Am J Gastroenterol. 2000;95(12):3552–65.
- Samoylova ML, Covinsky KE, Haftek M, Kuo S, Roberts JP, Lai JC. Disability in patients with end-stage liver disease: results from the functional assessment in liver transplantation study. Liver Transpl. 2017;23(3):292–8.
- 21. Ghany MG, Strader DB, Thomas DL, Seeff LB. Diagnosis, management, and treatment of hepatitis C: an update. Hepatology. 2009;49(4):1335.
- 22. Whitsett MP, Banerjee AG, Serper M. Assessment of mental health in patients with chronic liver disease. Clin Liver Disease. 2022;20(2):52.
- 23. Sharma A, Nagalli S. Chronic liver disease. StatPearls Publishing LLC; 2024.
- Dwight MM, Kowdley KV, Russo JE, Ciechanowski PS, Larson AM, Katon WJ. Depression, fatigue, and functional disability in patients with chronic hepatitis C. J Psychosom Res. 2000;49(5):311–7.
- AbdAllah M, Sharafeddin AA, Depression M. Anxiety and stress in Egyptian patients with Chronic Liver diseases. Egypt Family Med J. 2020;4(1):42–57.
- Dogar I, Siddiqui N, Bajwa A, Bhatti A, Haider N, Hashmi ZY. Relationship between liver diseases and levels of anxiety and depression. J Pak Psych Soc. 2009;6(2):61–4.
- Gutteling JJ, Darlington A-SE, Janssen HL, Duivenvoorden HJ, Busschbach JJ, De Man RA. Effectiveness of health-related quality-of-life measurement in clinical practice: a prospective, randomized controlled trial in patients with chronic liver disease and their physicians. Qual Life Res. 2008;17:195–205.
- Li DJ, Park Y, Vachharajani N, Aung WY, Garonzik-Wang J, Chapman WC. Physician-patient communication is associated with hepatocellular carcinoma screening in chronic liver disease patients. J Clin Gastroenterol. 2017;51(5):454–60.
- 29. Firth-Cozens J. Interventions to improve physicians' well-being and patient care. Soc Sci Med. 2001;52(2):215–22.

- 30. Parkash O, Hamid S. Are we ready for a new epidemic of under recognized liver disease in South Asia especially in Pakistan? Non alcoholic fatty liver disease. J Pakistan Med Association. 2013;63(1):95.
- Avan BI, Raza SA, Afridi H. Residents' perceptions of communication skills in postgraduate medical training programs of Pakistan. J Postgrad Med. 2005;51(2):85.
- Ufere NN, Satapathy N, Philpotts L, Lai JC, Serper M. Financial burden in adults with chronic liver disease: a scoping review. Liver Transpl. 2022;28(12):1920–35.
- Salem AA, Ismail MA, Salem MF. Health related quality of life of patients with chronic liver disease attending Family Practice Clinic, Suez Canal University Hospital, Ismailia, Egypt. J Fam Med. 2013;99(404):1–10.
- Li L, Mo F, Hui EP, Chan SL, Koh J, Tang NL, Yu SC, Yeo W. The association of liver function and quality of life of patients with liver cancer. BMC Gastroenterol. 2019;19:66.
- Kondo Y, Yoshida H, Tateishi R, Shiina S, Mine N, Yamashiki N, Sato S, Kato N, Kanai F, Yanase M. Health-related quality of life of chronic liver disease patients with and without hepatocellular carcinoma. J Gastroenterol Hepatol. 2007;22(2):197–203.
- 36. Zannella A, Fanella S, Marignani M, Begini P. COVID-19 emergency: changes in quality of life perception in patients with chronic liver disease - An Italian single-centre study. World J Hepatol. 2022;14(1):274.
- Wiegand J, Berg T. The etiology, diagnosis and prevention of liver cirrhosis: part 1 of a series on liver cirrhosis. Deutsches Ärzteblatt International. 2013;110(6):85.
- Burnham B, Wallington S, Jillson IA, Trandafili H, Shetty K, Wang J, Loffredo CA. Knowledge, attitudes, and beliefs of patients with chronic liver disease. Am J Health Behav. 2014;38(5):737–44.
- 39. Pakistan Kidney and Liver Institute and Research Centre. Available online: https://pkli.org.pk/
- Ozolins U, Hale S, Cheng X, Hyatt A, Schofield P. Translation and back-translation methodology in health research – a critique. Expert Rev Pharmacoeconom Outcome Res. 2020;20(1):69–77.
- 41. Younossi ZM, Guyatt G, Kiwi M, Boparai N, King D. Development of a disease specific questionnaire to measure health related quality of life in patients with chronic liver disease. Gut. 1999;45(2):295–300.
- Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. J Personal Soc Psychol. 1989;56(2):267.
- 43. Gutteling JJ, De Man RA, Busschbach JJ, Darlington A-SE. Quality of health care and patient satisfaction in liver disease: the development and preliminary results of the QUOTE-Liver questionnaire. BMC Gastroenterol. 2008;8:25.
- 44. Christensen KS, Fink P, Toft T, Frostholm L, Ørnbøl E, Olesen F. A brief casefinding questionnaire for common mental disorders: the CMDQ. Fam Pract. 2005;22(4):448–57.
- The WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. Psychol Med. 1998;28(3):551–8.
- 46. Tavakol M, Dennick R. Making sense of Cronbach's alpha. Int J Med Educ. 2011;2:53.
- 47. Khalid M, Sattar A. Households study on out-of-pocket health expenditures in Pakistan. Forman J Economic Stud. 2016;12(1).
- Sobhonslidsuk A, Silpakit C, Kongsakon R, Satitpornkul P, Sripetch C, Khanthavit A. Factors influencing health-related quality of life in chronic liver disease. World J Gastroenterol. 2006;12(48):7786.
- 49. Todd AD. Intimate adversaries: Cultural conflict between doctors and women patients. University of Pennsylvania; 2016.
- Afendy A, Kallman J, Stepanova M, Younoszai Z, Aquino R, Bianchi G, Marchesini G, Younossi Z. Predictors of health-related quality of life in patients with chronic liver disease. Aliment Pharmacol Ther. 2009;30(5):469–76.
- Popović DD, Ćulafić DM, Tepavčević DBK, Kovačević NV, Špuran MM, Djuranović SP, Pekmezović TD. Assessment of depression and anxiety in patients with chronic liver disease. Vojnosanit Pregl. 2015;72(5).
- 52. Jafree SR. The sociology of south Asian women. 's Health: Springer; 2020.
- Jafree SR. Determinants of depression in women with chronic disease: evidence from a sample of poor loan takers from Pakistan. J Community Psychol. 2020;48(7):2238–51.
- Williams MV, Davis T, Parker RM, Weiss BD. The role of health literacy in patient-physician communication. Family Medicine-Kansas City. 2002;34(5):383–9.
- Khan R, Ahmed A, Ismail FW, Abid S, Awan S, Shah H, Hamid S, Jafri W. Perception and knowledge about dietary intake in patients with liver cirrhosis and its relationship with the level of education. J Coll Physicians Surg Pakistan. 2012;22(7):435.

- 57. Dahl TF, Cowie BC, Biggs B-A, Leder K, MacLachlan JH, Marshall C. Health literacy in patients with chronic hepatitis B attending a tertiary hospital in Melbourne: a questionnaire based survey. BMC Infect Dis. 2014;14:537.
- Bianco T, Cillo U, Amodio P, Zanus G, Salari A, Neri D, Bombonato G, Schiff S, Baggio G, Ronco C. Gender differences in the quality of life of patients with liver cirrhosis related to hepatitis C after liver transplantation. Blood Purif. 2013;36(3–4):231–6.
- Soderstrom M, Dolbier C, Leiferman J, Steinhardt M. The relationship of hardiness, coping strategies, and perceived stress to symptoms of illness. J Behav Med. 2000;23(3):311.
- Fagerström C, Frisman GH. Living with liver cirrhosis: a vulnerable life. Gastroenterol Nurs. 2017;40(1):38–46.
- Gutteling J, De Man R, Busschbach J, Darlington A. Overview of research on health-related quality of life in patients with chronic liver disease. Neth Med. 2007;65(7):227–34.
- Tognarelli J, Ladep NG, Crossey MM, Okeke E, Duguru M, Banwat E, Taylor-Robinson SD. Reasons why West Africa continues to be a hotbed for hepatocellular carcinoma. Nigerian Med J. 2015;56(4):231.
- Jalan R, Gines P, Olson JC, Mookerjee RP, Moreau R, Garcia-Tsao G, Arroyo V, Kamath PS. Acute-on chronic liver failure. J Hepatol. 2012;57(6):1336–48.
- 64. Nobili V, Carter-Kent C, Feldstein AE. The role of lifestyle changes in the management of chronic liver disease. BMC Med. 2011;9:70.
- Zhang C, Shi L, Wang F-S. Liver injury in COVID-19: management and challenges. Lancet Gastroenterol Hepatol. 2020;5(5):428–30.
- Conrad S, Garrett L, Cooksley W, Dunne M, MacDonald G. Living with chronic hepatitis C means 'you just haven't got a normal life any more'. Chronic Illn. 2006;2(2):121–31.
- Ufere NN, Hinson J, Finnigan S, Powell EE, Donlan J, Martin C, Clark P, Valery PC. The impact of social workers in cirrhosis care: a systematic review. Curr Treat Options Gastroenterol. 2022;20(2):160–76.
- Funuyet-Salas J, Pérez-San-Gregorio MÁ, Martín-Rodríguez A, Romero-Gómez M. Quality of life and coping in nonalcoholic fatty liver disease: influence of diabetes and obesity. Int J Environ Res Public Health. 2021;18(7):3503.
- 69. Sohail MM. Belief in God's help during hepatitis C: a qualitative study on muslim patients in Pakistan. J Relig Health. 2020;59:928–45.
- Livneh H, Antonak RF. Psychosocial adaptation to chronic illness and disability: a primer for counselors. J Couns Dev. 2005;83(1):12–20.
- Comer EW. Integrating the health and mental health needs of the chronically ill: a group for individuals with depression and sickle cell disease. Soc Work Health Care. 2004;38(4):57–76.
- 72. Iannello NM, Inguglia C, Silletti F, Albiero P, Cassibba R, Lo Coco A, Musso P. How do religiosity and spirituality associate with Health-related outcomes of

adolescents with chronic illnesses? A scoping review. Int J Environ Res Public Health. 2022;19(20):13172.

- Rotthoff T, Baehring T, David DM, Bartnick C, Linde F, Willers R, Schäfer RD, Scherbaum WA. The value of training in communication skills for continuing medical education. Patient Educ Couns. 2011;84(2):170–5.
- Fontana RJ, Kronfol Z. The patient's perspective in hepatitis C. Hepatology. 2004;39(4):903–5.
- 75. Khan S. Situation analysis of health care system of Pakistan: post 18 amendments. Health Care Curr Reviews. 2019;7(3):244.
- Bianchi EF, Bhattacharyya MR, Meakin R. Exploring senior doctors' beliefs and attitudes regarding mental illness within the medical profession: a qualitative study. BMJ Open. 2016;6(9):e012598.
- 77. Al-Abri R, Al-Balushi A. Patient satisfaction survey as a tool towards quality improvement. Oman Med J. 2014;29(1):3.
- Abramson JS, Mizrahi T. Understanding collaboration between social workers and physicians: application of a typology. Soc Work Health Care. 2003;37(2):71–100.
- 79. Siddiqui F. Barriers and challenges to mental health care in Pakistan. Pakistan J Neurol Sci. 2021;16(3):1–2.
- 80. Bukhari MH, Tariq A, Khalid MS, Sufyan A. The frequency of anxiety and depression in patients with Hepatitis C at a Public Sector Liver Centre in Pakistan. J Rawalpindi Med Coll. 2019;23:94.
- Salman M, Shehzadi N, Mustafa ZU, Mallhi TH, Khan YH, Khan TM, Hussain K. Self-harm and suicidal ideation in Pakistani youth amid COVID-19 pandemic: findings of a large, cross-sectional study. Psychol Health Med. 2022;28(8):2225–33.
- Knott A, Dieperink E, Willenbring ML, Heit S, Durfee JM, Wingert M, Johnson JR, Thuras P, Ho SB. Integrated psychiatric/medical care in a chronic hepatitis C clinic: effect on antiviral treatment evaluation and outcomes. Official J Am Coll Gastroenterol. 2006;101(10):2254–62.
- Tanhan A, Young JS. Muslims and mental health services: a concept map and a theoretical framework. J Relig Health. 2022;61:23–63.
- Graham JR, Bradshaw C, Trew JL. Cultural considerations for social service agencies working with muslim clients. Soc Work. 2010;55(4):337–46.
- Bittermann T, Dwinnells K, Chadha S, Wolf MS, Olthoff KM, Serper M. Low health literacy is associated with frailty and reduced likelihood of liver transplant listing: a prospective cohort study. Liver Transpl. 2020;26(11):1409–21.
- Claiborne N, Vandenburgh H. Social workers' role in disease management. Health Soc Work. 2001;26(4):217–25.

Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.