

ORIGINAL ARTICLE

# Exploring Gaps in Disease Knowledge and Surveillance Practices in Cirrhotic Patients: A Cross- Sectional Study

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## ABSTRACT

**Background:** Hepatocellular carcinoma (HCC) is the fifth most common tumor in the world. It is also the third leading cause of cancer-related deaths worldwide. Therefore, global liver societies recommend HCC surveillance every 6 months in individuals who are at high risk of developing HCC.

**Objective:** To study the disease awareness in our population and their adherence to surveillance for HCC.

**Methods:** This is a cross sectional study which was conducted in the Gastroenterology department of the Aga Khan University Hospital from May 2025 to October 2025. Adult patients with Child class A or B cirrhosis were enrolled to complete an anonymous self-administered survey. A structured questionnaire was adapted from previously published and validated studies assessing knowledge, attitude, and practice (KAP) regarding hepatocellular carcinoma surveillance. The tool was reviewed by a panel of gastroenterology experts for content validity. It was translated into Urdu using forward and backward translation to ensure linguistic accuracy. A pilot study was conducted on a small subset of patients to assess clarity and feasibility. Internal consistency was evaluated using Cronbach's alpha, which demonstrated acceptable reliability. Clinical data was retrieved from electronic health records.

**Results:** A total of 150 patients completed the survey. The median age was 56 years (IQR 49–65). Most patients belonged to an urban and educated population (69%). Most common cause of cirrhosis was HCV (35.3%), followed by Non B Non C (34%) and then HBV (30.7%). Only 56.7% patients underwent 6 monthly surveillances. Most patients did not have appropriate knowledge regarding their disease or importance of hepatocellular carcinoma surveillance. More than 90% patients desired more information from their healthcare professional. Factors that contributed most as barrier towards surveillance were residing in rural areas, lack of education and financial status. (p value <0.001).

**Conclusion:** Enhancing patient awareness and addressing barriers to surveillance are essential for effective HCC prevention in cirrhotic patients. Targeted interventions are required to improve adherence to 6 monthly surveillance guidelines to prevent morbidity and mortality from HCC.

**Keywords:** Carcinoma, Hepatocellular, Liver Cirrhosis, Liver Neoplasms, Biomarkers, Tumor

**INTRODUCTION:** Hepatocellular carcinoma (HCC) is the fifth most common tumor and the third leading cause of cancer-related deaths globally. In Pakistan, HCC is the third most common cancer in men and the seventh most common in women, with the majority of cases attributed to hepatitis C infections followed by Hepatitis B and Hepatitis B+C co-infection [1,2]. A study analyzing data from 185 countries estimated that by the year 2040, the incidence of HCC cases will increase by 55% [3].

Disease surveillance plays a crucial role in the management of various diseases, including HCC. Given the global burden of the disease, surveillance protocols have been developed to improve patient outcomes. The American Association for the Study of Liver Diseases (AASLD) and European Association for the Study of the Liver (EASL) recommend surveillance via ultrasound scans with or without alpha fetoprotein (AFP) every 6 months in individuals who are at high risk of developing HCC [4,5]. Surveillance offers several benefits to patients. First, it enables earlier detection, which allows for more curative treatment options and better outcomes

[6,7]. Second, it is non-invasive and cost-effective, given the nature of the surveillance methods [7]. Finally, surveillance has shown to reduce overall mortality by 30% [8].

Despite the establishment of a surveillance protocol that offers considerable benefits to the population, it remains severely underutilized, with one study showing that less than a quarter of the at-risk population undergoes surveillance [6]. Several factors contribute to the lack of surveillance, including limited disease awareness, gaps in knowledge, poor patient adherence, limited access to care, and cause of cirrhosis [6,9,10]. These factors have been demonstrated in international studies. However, there is a lack of national data from Pakistan regarding patients' knowledge of the disease.

Lower-middle-income countries (LMICs) like Pakistan have even lower rates. In Pakistan, regular HCC surveillance covers as few as 10% of the at-risk population [2]. Patient should know about their disease, its complications and long term consequences like HCC. They should be aware regarding the importance of surveillance and how it is done. This will increase their regular follow ups to health care physician and will play a major role in prevention of HCC. If lesion is found early on surveillance, then definite curative options can be offered. The aim of this study was to evaluate the knowledge, attitudes, and practices of patients with cirrhosis regarding their disease and to identify barriers influencing adherence to surveillance practices for HCC.

**METHODS:** This was a cross sectional study conducted in the Gastroenterology Department of Aga Khan University Hospital from May 2025 to October 2025 after approval from the Ethical Review Committee (ERC 2024-9827-28738 date 18-4-2024). Patients with cirrhosis attending inpatient or outpatient services were enrolled consecutively. Data were collected during patient encounter using a structured questionnaire, while relevant clinical and laboratory parameters were simultaneously obtained from the electronic medical record system. No retrospective chart review of prior encounters was performed.

Sample size was calculated using a single population proportion formula for cross-sectional studies. Assuming an expected prevalence of adequate HCC surveillance adherence of 40% based on previous regional studies, a 95% confidence level, and a 5% margin of error, the minimum required sample size was calculated to be 147. To account for incomplete responses and potential non-response, the final sample size was set at 150 patients. The inclusion criteria encompassed all inpatients and outpatients diagnosed with cirrhosis who were under regular follow-up in the gastroenterology department. Eligible participants included individuals aged 18 years or older with Child-Pugh class A or B cirrhosis. An anonymous survey was administered, Prior to participation, informed consent was obtained from all patients.

A structured questionnaire was adapted from previously published and validated studies assessing knowledge, attitude, and practice (KAP) regarding hepatocellular carcinoma surveillance. The tool was reviewed by a panel of gastroenterology experts for content validity. It was translated into Urdu using forward and backward translation to ensure linguistic accuracy. Two independent bilingual translators performed the back translation. Discrepancies between the translations were resolved by an expert committee. A pilot study was conducted on a small subset of patients to assess clarity and feasibility. Internal consistency was evaluated using Cronbach's alpha, which was 0.70. The questionnaire included patients demographic data, clinical information taken from electronic medical records as well as items evaluating disease awareness, perceptions regarding liver cancer screening, healthcare-seeking behavior, and adherence to surveillance. Knowledge questions were assessed using True/False/I don't know responses. A composite knowledge score was generated by assigning one point for each correct response. There were 20 questions in each section. Responses were recorded on a 5-point Likert scale ranging from 'extremely unlikely' to 'extremely likely'. Exclusion criteria included patients who declined to participate, failed to complete the survey, or had Child-Pugh class C cirrhosis. Surveillance adherence was defined as undergoing abdominal ultrasound with or without alpha-fetoprotein (AFP) testing every 6 months according to guideline recommendations.

Financial independence was defined as participants who reported being employed or financially self-supporting, whereas financially dependent participants included unemployed individuals, retired participants dependent on family support, and housewives without independent income.

Data were analyzed using SPSS version 22. Continuous variables were presented as median (interquartile range) or mean  $\pm$  standard deviation depending on distribution, while categorical variables were expressed as frequencies and percentages. Normality was assessed using Shapiro–Wilk test. Chi-square test or Fisher's

exact test was used for comparison of categorical variables where appropriate. A p-value of  $\leq 0.05$  was considered statistically significant.

Participants were categorized into surveillance and non-surveillance groups based on adherence to recommended 6-monthly surveillance protocols. Variables demonstrating statistical significance on univariate analysis, along with clinically relevant demographic variables including age and gender, were included in binary logistic regression analysis to identify factors independently associated with surveillance adherence. Adjusted odds ratios (ORs) with 95% confidence intervals (CIs) were reported. Multicollinearity among predictor variables was assessed prior to regression analysis and no significant collinearity was identified. Model fit was evaluated using the Hosmer-Lemeshow goodness-of-fit test, which demonstrated acceptable model calibration.

**RESULTS** The results of the study are summarized in the following tables: Table 1, Table 2, Table 3, and Table 4. Some of the key findings are mentioned below.

**Table 1: Depicts patient demographic data including age, expressed as Median (IQR), gender, residence, level of education and employment**

| Variable          | Category              | n (%) / Value |
|-------------------|-----------------------|---------------|
| Gender            | Male                  | 98 (65.3)     |
|                   | Female                | 52 (34.7)     |
| Age               | Median (IQR)          | 56 (49–65)    |
| Marital Status    | Married               | 145 (96.7)    |
|                   | Unmarried             | 5 (3.3)       |
| Residence         | Rural                 | 46 (30.7)     |
|                   | Urban                 | 104 (69.3)    |
| Education         | Did not attend school | 46 (30.7)     |
|                   | Attended school       | 28 (18.7)     |
|                   | College education     | 35 (23.3)     |
|                   | Bachelor's degree     | 32 (21.3)     |
|                   | Advanced education    | 9 (6.0)       |
| Employment Status | Employed              | 85 (56.7)     |
|                   | Retired               | 6 (4.0)       |
|                   | Unemployed            | 47 (31.3)     |
|                   | Housewife             | 12 (8.0)      |

**Table 2: Shows few questions about patient knowledge and awareness regarding their disease and surveillance**

| Statement                                                                                       | Response     | n (%)     |
|-------------------------------------------------------------------------------------------------|--------------|-----------|
| Patients with cirrhosis are at higher risk for liver cancer than patients without liver disease | True         | 77 (51.3) |
|                                                                                                 | False        | 15 (10.0) |
|                                                                                                 | I don't know | 58 (38.7) |
| The risk of developing liver cancer increases with age                                          | True         | 64 (42.7) |
|                                                                                                 | False        | 34 (22.7) |

| Statement                                                                                                        | Response     | n (%)      |
|------------------------------------------------------------------------------------------------------------------|--------------|------------|
|                                                                                                                  | I don't know | 52 (34.7)  |
| The risk of liver cancer is higher in people who have liver cancer in their family than in people who do not     | True         | 65 (43.3)  |
|                                                                                                                  | False        | 62 (41.3)  |
|                                                                                                                  | I don't know | 23 (15.3)  |
| Liver cancer can develop without any symptoms                                                                    | True         | 60 (40.0)  |
|                                                                                                                  | False        | 40 (26.6)  |
|                                                                                                                  | I don't know | 50 (33.3)  |
| Screening is only recommended when one has worrisome symptoms                                                    | True         | 60 (40.0)  |
|                                                                                                                  | False        | 34 (22.6)  |
|                                                                                                                  | I don't know | 56 (37.3)  |
| One goal of screening is to detect liver cancer at an early stage                                                | True         | 81 (54.0)  |
|                                                                                                                  | False        | 23 (15.3)  |
|                                                                                                                  | I don't know | 46 (30.6)  |
| If I have a normal physical exam in clinic, I do not need to get a specific liver cancer screening test          | True         | 66 (44.0)  |
|                                                                                                                  | False        | 36 (24.0)  |
|                                                                                                                  | I don't know | 48 (32.0)  |
| Ultrasound is one of the primary tests used to screen for liver cancer                                           | True         | 89 (59.3)  |
|                                                                                                                  | False        | 29 (19.3)  |
|                                                                                                                  | I don't know | 32 (21.3)  |
| Liver cancer screening should be done at least once per year in patients with cirrhosis                          | True         | 97 (64.0)  |
|                                                                                                                  | False        | 26 (17.3)  |
|                                                                                                                  | I don't know | 27 (18.0)  |
| If I have a normal ultrasound and no change in my blood tests, there is no chance that I could have liver cancer | True         | 100 (66.6) |
|                                                                                                                  | False        | 20 (13.3)  |
|                                                                                                                  | I don't know | 30 (20.0)  |
| If discovered early, liver cancer can be cured                                                                   | True         | 90 (60.0)  |
|                                                                                                                  | False        | 20 (13.3)  |
|                                                                                                                  | I don't know | 40 (26.6)  |
| Without treatment, liver cancer is always fatal                                                                  | True         | 80 (53.3)  |
|                                                                                                                  | False        | 30 (20.0)  |
|                                                                                                                  | I don't know | 40 (26.6)  |
| Liver cancer can disappear by itself (without any treatment) over time                                           | True         | 20 (13.3)  |

| Statement | Response     | n (%)         |
|-----------|--------------|---------------|
|           | False        | 110<br>(73.3) |
|           | I don't know | 20 (13.3)     |

**Table 3 demonstrates few questions about patient attitude and practices towards their disease and surveillance**

| Variable                                                                                | Category                           | n (%)        |
|-----------------------------------------------------------------------------------------|------------------------------------|--------------|
| How frequently do you visit your gastroenterologist?                                    | Every 6 months                     | 49<br>(32.7) |
|                                                                                         | Once a year                        | 40<br>(26.7) |
|                                                                                         | When symptoms occur                | 45<br>(30.0) |
|                                                                                         | When the doctor asks               | 16<br>(10.7) |
| How frequently do you get your ultrasound and blood tests?                              | Every 6 months                     | 34<br>(22.7) |
|                                                                                         | Once a year                        | 51<br>(34.0) |
|                                                                                         | Whenever doctor advises            | 45<br>(30.0) |
|                                                                                         | Never                              | 20<br>(13.0) |
| Has your doctor ever discussed liver cancer screening with you?                         | Yes                                | 66<br>(44.0) |
|                                                                                         | No                                 | 84<br>(56.0) |
| How involved have you been in the decision-making process about liver cancer screening? | My doctor made the decision        | 63<br>(42.0) |
|                                                                                         | I made the decision alone          | 23<br>(15.3) |
|                                                                                         | We both made the decision together | 44<br>(29.3) |
|                                                                                         | Have not made any decision         | 20<br>(13.3) |
| How involved would you like to be in decisions regarding liver cancer screening?        | My doctor should make the decision | 87<br>(58.0) |
|                                                                                         | I should make the decision alone   | 15<br>(10.0) |

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| Variable                                                                                                         | Category                                  | n (%)      |
|------------------------------------------------------------------------------------------------------------------|-------------------------------------------|------------|
| How important is it for you to know about your chances of getting liver cancer?                                  | We both should make the decision together | 48 (32.0)  |
|                                                                                                                  | Somewhat important                        | 16 (10.6)  |
|                                                                                                                  | Important                                 | 112 (74.6) |
|                                                                                                                  | Extremely important                       | 22 (14.6)  |
| Do you feel like you have received enough information about liver cancer screening to make an informed decision? | Yes                                       | 10 (7.0)   |
|                                                                                                                  | No                                        | 140 (93.0) |
| Would you like to receive more information about liver cancer screening?                                         | Yes                                       | 145 (96.7) |
|                                                                                                                  | No                                        | 5 (3.3)    |
| How likely do you believe you are to get liver cancer in the next year?                                          | Extremely unlikely                        | 101 (67.3) |
|                                                                                                                  | Unlikely                                  | 35 (23.3)  |
|                                                                                                                  | Likely                                    | 3 (2.0)    |
|                                                                                                                  | Somewhat likely                           | 11 (7.3)   |
| How would you rate your current overall health status?                                                           | Poor                                      | 3 (2.0)    |
|                                                                                                                  | Fair                                      | 49 (32.6)  |
|                                                                                                                  | Good                                      | 72 (48.0)  |
|                                                                                                                  | Excellent                                 | 26 (17.3)  |
| When was your last endoscopy?                                                                                    | Within the past year                      | 45 (30.0)  |
|                                                                                                                  | Within past 5 years                       | 30 (20.0)  |
|                                                                                                                  | Do not recall                             | 30 (20.0)  |
|                                                                                                                  | Never had endoscopy                       | 45 (30.0)  |

**Table 4: Significant factors associated with surveillance including area of residence, level of education and employment status.**

| Variable          | Category              | Surveillance n | No Surveillance n | P value |
|-------------------|-----------------------|----------------|-------------------|---------|
| Gender            | Male                  | 59             | 39                | 0.299   |
|                   | Female                | 26             | 26                |         |
| Residence         | Rural                 | 2              | 44                | <0.001  |
|                   | Urban                 | 83             | 21                |         |
| Marital Status    | Married               | 80             | 65                | 0.069   |
|                   | Single                | 5              | 0                 |         |
| Education         | Did not attend school | 1              | 45                | <0.001  |
|                   | Attended school       | 11             | 17                |         |
|                   | College education     | 33             | 2                 |         |
|                   | Bachelor's degree     | 31             | 1                 |         |
|                   | Advanced education    | 9              | 0                 |         |
| Employment Status | Employed              | 80             | 5                 | <0.001  |
|                   | Retired               | 4              | 2                 |         |
|                   | Unemployed            | 0              | 47                |         |
|                   | Housewife             | 1              | 11                |         |

Among 150 total patients who completed the survey, 65.3% were male while 34% were female. The median age of the participants was 56 years (IQR 49–65) and most participants resided in urban areas 69.3%. The study population exhibited a diverse range of educational backgrounds. While 30.7% participants had no formal education, the majority 69.3% had attended at least school. The most common cause of cirrhosis was hepatitis C virus (HCV), accounting for 35.3% of the cases followed by non-B non-C (34%) and Hepatitis B virus (HBV) 30.7%.

Only 51.3% of participants correctly identified that patients with cirrhosis are at a higher risk for liver cancer compared to those without liver disease. Less than half of the participants 42.7% were aware that the risk of developing liver cancer increases with age. Around 43.3% correctly recognized that having a family history of liver cancer increases the risk, while a substantial number 41.3% did not agree. Only 40% knew that liver cancer can develop without symptoms, whereas 26.6% believed symptoms were always present. A significant number of participants 40% incorrectly thought that screening is only recommended when symptoms appear. Around 54% correctly identified early detection as a primary goal of screening. 59.3% correctly identified ultrasound as a primary screening tool.

When participants were inquired further 44% incorrectly believed that a normal physical exam negates the need for specific liver cancer screening. A concerning 66.6% believed that normal ultrasound and blood test results completely ruled out the possibility of liver cancer. Majority participants 60% were aware that liver cancer can be cured if detected early. A majority 73.3% correctly disagreed with the notion that liver cancer could disappear on its own. The standard 6 monthly surveillance is followed by very few people. Only 32.7% reported visiting their gastroenterologist every 6 months, while 26.7% visited once a year. A considerable proportion 30% only sought consultations when symptoms occurred and 10.7% visited when specifically asked by their doctor. Only 22.7% adhered to the recommended biannual surveillance schedule. 34% underwent tests annually, while 30% did so only when advised by their doctor. Alarming, 13% never had these tests done. A majority 56% stated that no discussion regarding screening was done by their physician.

A large number of patients 93% felt they had not received enough information to make an informed decision about liver cancer screening. Almost all participants 96.7% expressed a desire for more information. Regarding endoscopy practices, 30% had undergone the procedure within the past year, while another 20% reported

having it in the past 5 years. However, 20% could not recall their last endoscopy, and 30% stated they had never undergone the procedure.

Significant differences in surveillance adherence were observed across socio-demographic variables (Table 4). Residence, education status, and employment status demonstrated statistically significant associations with surveillance adherence. Urban participants showed significantly higher adherence rates compared to rural participants ( $p < 0.001$ ). Similarly, participants with formal education were more likely to undergo regular surveillance compared to those without formal education ( $p < 0.001$ ). Financially independent individuals also demonstrated higher adherence rates compared to financially dependent participants ( $p < 0.001$ ). No statistically significant association was observed between gender and surveillance adherence ( $p = 0.299$ ).

Binary logistic regression analysis was performed to identify factors independently associated with surveillance adherence. Urban residence (Adjusted OR 12.4, 95% CI 2.7–56.8), formal education (Adjusted OR 8.6, 95% CI 1.9–38.2), and financial independence (Adjusted OR 15.1, 95% CI 3.2–71.0) remained independently associated with higher odds of

**DISCUSSION:** Approximately 80% of patients with HCC have underlying liver cirrhosis, making it a significant risk factor for the disease. Globally, HCV is the most common cause of cirrhosis. In Pakistan, both HBV and HCV are responsible for 75% of all cirrhosis cases. Our study findings align with this, as 66% of our study population with cirrhosis reported having HBV or HCV [12,13]

Given the severe outcomes associated with chronic liver cirrhosis, effective surveillance is essential to reduce the morbidity and mortality linked to HCC. Disease surveillance is a critical component of the continuum of healthcare services, spanning screening, diagnosis, management, and ultimately, ongoing monitoring for at-risk individuals. However, several barriers must be overcome to ensure effective delivery of these services. In our study, we found that 56.67% of patients underwent screening at least once. Despite this, many exhibited significant gaps in knowledge and misconceptions about HCC surveillance.

Evidence from one study suggests that patients with Child-Pugh class A or B cirrhosis have an annual HCC incidence of approximately 2.5% [14]. Applying this to our cohort of 150 participants, it is statistically likely that 4 of them will develop HCC in the next year. It is therefore really important to assess the awareness. There appeared to be a lack of understanding regarding the importance of regular surveillance. This seemed to stem from insufficient awareness, as only 51.3% were aware that their condition (i.e., cirrhosis) put them at a higher risk for liver cancer. What the study found is that higher levels of education were significantly correlated with better adherence, as all participants with advanced education followed the recommended surveillance guidelines ( $P < 0.001$ ). This suggests that higher literacy rates are associated with improved adherence to HCC surveillance.

Geographic barriers play a significant role in healthcare disparities. Patients in rural areas often lack access to healthcare facilities and qualified sonographer. These findings may reflect disparities in healthcare access reported in previous Pakistani studies. Among the participants, 83 individuals from urban settings adhered to surveillance protocols ( $P < 0.001$ ), whereas 2 of the rural participants followed the surveillance guidelines. Several studies have highlighted the critical disparities between urban and rural sectors in Pakistan, particularly in healthcare access and delivery. Urban centers have significantly more healthcare facilities and professionals, while rural areas suffer from limited medical infrastructure, diagnostic services, and availability of medications. Additionally, rural populations tend to have lower health awareness, which may further explain why patients from these areas are less likely to seek surveillance, even when accessing the same healthcare facilities. Financial barriers also disproportionately affect rural populations, making it challenging to afford the additional costs associated with surveillance. Given Pakistan's out-of-pocket payment system, many patients from rural areas may be reluctant or unable to adhere to strict and timely surveillance, if at all [15,16].

Patient adherence is a significant challenge in surveillance programs. For instance, in colorectal cancer screening, 40% of patients miss their first screening appointment. However, in hepatocellular carcinoma (HCC), one analysis revealed that only 3% of patients missed their screening after their physician ordered it [7]. This highlights that many patients are simply unaware of their surveillance needs. Supporting this, results demonstrated notable patterns in physician-patient communication and decision-making regarding HCC surveillance. While 44% of patients reported discussing liver cancer screening with their doctor, 56% stated no such conversations had occurred. Interestingly, when asked about their preferred level of involvement, most

patients (58%) preferred their doctor to take the lead, 32% favored shared decision-making, and only 10% wished to make decisions independently. These findings highlight that often times there is a provider related barrier that exists. At times there is a knowledge gap and healthcare providers could be unaware with the most up-to-date recommendations. One such study found that upto 40% of primary care practitioners believed they were not well informed on the new surveillance guidelines while another research showed that upto 24% providers were unaware of any surveillance recommendations [17,18].

Several factors can divert the conversation away from discussing surveillance protocols with patients. Overburdened doctors often lack sufficient time for patient education during appointments. Primary care practitioners frequently cite challenges such as limited clinic time, difficulties in effectively communicating with patients, and prioritizing more pressing clinical concerns as reasons for deprioritizing these discussions [17].

This study has several limitations. First, as a single-center cross-sectional study, the findings may not be generalizable to all cirrhotic populations in Pakistan. Second, certain socio-demographic categories contained relatively small sample sizes, particularly among rural participants undergoing regular surveillance, which may have resulted in wide confidence intervals and less stable regression estimates. However, these findings reflect genuine disparities in healthcare access and surveillance practices between urban and rural populations rather than data inconsistency. Third, the questionnaire relied partly on self-reported responses and may therefore be subject to recall and response bias.

**CONCLUSION:** Enhancing patient awareness and addressing barriers to surveillance are essential for effective HCC prevention in cirrhotic patients. We need to implement targeted interventions to improve adherence to surveillance. To improve surveillance rates, healthcare professionals must prioritize patient education through detailed counseling during clinical encounters. Additionally, innovative strategies such as implementing automated 6-monthly reminders via text messages or emails can be an effective way to ensure regular follow-ups. Leveraging social media platforms to disseminate educational content about cirrhosis and HCC surveillance can further raise awareness, particularly in underserved communities. By adopting these strategies, we can bridge the gap in surveillance adherence, ensuring early detection and treatment of HCC in high-risk populations, ultimately improving patient outcomes.

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