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Stigma Faced by Patients with Hepatitis in Türkiye: A Cross-sectional Study

Türkiye’de Hepatit Hastalarının Maruz Kaldığı Damgalama: Kesitsel Bir Çalışma

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Abstract

Introduction: Structural stigma (SS) is one of the main types of stigma and refers to stigmatizing processes that occur above the individual level. SS among patients with hepatitis in Türkiye and worldwide has rarely been studied. We aimed to determine the experiences of SS among patients with chronic hepatitis B (CHB) or chronic hepatitis C (CHC) and identify factors that may be associated with SS.

Materials and Methods: A cross-sectional survey was conducted among patients with CHB or CHC infection. The survey included questions about experiences of SS in five different domains: the workplace, marriage procedures, healthcare settings, military service, and procedures for traveling abroad. Experiencing stigma in at least one domain or being required to undergo hepatitis testing and obtain physician approval in any domain was defined as overall SS experience.

Results: The study included 221 patients with CHB and 15 with CHC. When all SS domains were evaluated, 113 (47.9%) patients were found to have experienced SS in at least one domain. Univariate analysis showed that the experience of SS was significantly more common among younger patients ($p < 0.001$). Overall SS was most common among unemployed patients. A significant association was observed between educational level and stigma ($p = 0.010$). In the multivariable analysis, several factors were significantly associated with overall stigma. These included younger age [adjusted odds ratio (aOR): 0.95, 95% confidence interval (CI): 0.92-0.98, $p = 0.001$], a diagnosis of hepatitis C (aOR: 3.6, 95% CI: 1.0-12.3, $p = 0.045$), and belonging to the laborer group (aOR: 6.1, 95% CI: 1.6-24.0, $p = 0.010$).

Conclusion: Patients with hepatitis experience SS in multiple domains. Addressing SS should be a key focus of multilevel interventions.

Keywords: Hepatitis, structural stigma, institutional stigma, discrimination

Öz

Giriş: Yapısal damgalanma (YD), damgalanmanın temel türlerinden biri olup, birey düzeyinin üzerinde gerçekleşen damgalama süreçlerini ifade eder. Ülkemizde ve dünyada hepatit hastalarında YD nadiren incelenmiştir. Bu çalışmada, viral hepatit hastalarının YD deneyimlerinin ve bununla ilişkili olabilecek durumların belirlenmesi amaçlanmıştır.

Gereç ve Yöntem: Kronik hepatit B (HBV) ve Kronik hepatit C (HCV) hastaları arasında kesitsel bir anket çalışması yürütülmüştür. Ankette, iş yeri, evlilik işlemleri, sağlık hizmetleri, askerlik hizmeti ve yurt dışına çıkış işlemleri olmak üzere beş farklı alanda YD deneyimlerini sorgulayan sorular yer almıştır. En az bir alanda damgalanma yaşanması veya herhangi bir alanda hepatit testi yaptırılması ve hekim onayı istenmesi, genel YD olarak tanımlanmıştır.

Bulgular: Çalışmaya 221 HBV ve 15 HCV hastası dahil edilmiştir. Tüm YD alanları birlikte değerlendirildiğinde, 113 (%47,9) hastanın en az bir alanda YD’a maruz kaldığı saptanmıştır. Tek değişkenli analizde, YD deneyiminin genç yaşlarda istatistiksel olarak daha yüksek olduğu görülmüştür ($p < 0,001$). Genel YD deneyiminin en sık işsiz grupta görüldüğü belirlenmiştir. Eğitim düzeyi ile damgalanma arasında anlamlı bir ilişki gözlenmiştir.



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$p = 0,010$). Çok değişkenli analizde, genel damgalanma deneyimi üzerinde anlamlı etkisi olan bazı faktörler belirlenmiştir. Bunlar; genç yaş [düzeltilmiş olasılık oranı (aOR): 0,95, %95 güven aralığı (GA): 0,92-0,98, $p = 0,001$], hepatit C tanısı alma (aOR: 3,6; %95 GA: 1,0-12,3; $p = 0,045$) ve işçi grubuna dahil olma (aOR: 6,1; %95 GA: 1,6-24,0; $p = 0,010$) olarak bulunmuştur.

Sonuç: Hepatit hastaları birçok alanda YD'a maruz kalmaktadır. YD ile mücadele, çok düzeyli müdahalelerin temel odak noktalarından biri olabilir.

Anahtar Kelimeler: Hepatit, yapısal damgalanma, kurumsal damgalanma, ayrımcılık

Introduction

Globally, an estimated 254 million people live with hepatitis B virus (HBV) and 50 million with hepatitis C virus (HCV)^[1]. There have been many important developments in the fight against viral hepatitis, including the development of vaccines and antiviral drugs. Despite these achievements, stigma remains a significant challenge that needs to be addressed.

The classification of stigma varies across diseases and among authors. Some classify stigma into three major subtypes, whereas others distinguish up to five subtypes^[2,3]. Structural stigma (SS) is one of the most significant forms of stigma. It encompasses processes that operate beyond the individual and interpersonal levels and is best defined as “societal-level conditions, cultural norms, and institutional policies that impinge upon the opportunities, resources, and well-being of stigmatized individuals”^[4].

Stigma can have negative consequences that may hinder global hepatitis strategies by reducing the uptake of diagnostic screening and clinical care and lowering medication adherence^[5,6]. The World Health Organization 2022-2030 viral hepatitis strategy includes addressing stigma and discrimination, as well as social and structural barriers^[7]. Beyond the treatment process and disease elimination, stigma also affects quality of life^[8,9]. People with hepatitis face inequalities in education, employment, and career development^[5]. Many employers and institutions refuse to accept individuals with a positive HBV test result^[10,11]. Indeed, once SS becomes established, institutional policies and practices can become normalized, and stigma can have negative consequences beyond the context of interpersonal interactions^[12].

Although they vary between countries and institutions, practices and laws are in place to protect the rights of patients with hepatitis^[13]. However, these laws and policies may not be sufficient to overcome SS because healthcare practitioners and even patients are often unaware of SS and may normalize stigmatizing practices.

In some diseases, such as HIV infection, stigma has been more extensively addressed and studied in relation to its causes, effects, and potential solutions^[5]. There are few quantitative or qualitative studies addressing SS among patients with hepatitis.

Most stigma studies have been conducted in urban areas. However, understanding experiences and practices in rural areas, where community dynamics, perceptions, and attitudes may differ, is important for future improvements.

In this study, we aimed to determine the SS experiences of patients with chronic hepatitis B or C in a rural area and identify situations that may be associated with SS.

Materials and Methods

Study Design and Participants

A cross-sectional survey was conducted to explore experiences and perceptions of SS among patients with HBV and HCV infection. The study was conducted among adults (≥ 18 years of age) with HBV or HCV infection who presented for care at the outpatient infectious diseases clinic of Fatsa State Hospital between November 20, 2022, and May 20, 2023. All patients with HBV or HCV infection who presented to the outpatient clinic during the study period were assessed for eligibility. Consecutive sampling was used, and all eligible patients presenting during the study period were invited to participate.

Inclusion criteria:

Hepatitis B surface antigen (HBsAg) or HBV DNA positivity, with or without treatment

Anti-HCV or HCV RNA positivity, with or without treatment

Exclusion criteria:

Individuals with communication difficulties that prevented them from sharing their experiences of stigma, such as those with intellectual disabilities

Patients with false-positive HBsAg or anti-HCV results

Patients first diagnosed with hepatitis during the outpatient visit

Patients with HIV coinfection

Instruments

A custom-built questionnaire was administered to patients by two infectious diseases specialists. The questionnaire was developed based on previously published studies on stigma and was reviewed by two infectious diseases specialists for content validity. The survey included demographic information

and questions regarding experiences of SS in five different domains (Supplementary Table 1). Verbal informed consent was obtained from all participants before the interview.

The primary outcome was overall SS experience, defined as reporting at least one episode of perceived discrimination or being subjected to hepatitis-specific institutional requirements, such as additional medical testing or physician approval, in any of the five predefined domains. Although some of these requirements may reflect legal or administrative procedures, they were included because they may function as structural barriers and contribute to stigmatizing experiences from the patient's perspective. All questions were answered using a yes/no response format. In cases of discrimination, additional details regarding the discriminatory experience were collected.

Educational attainment was classified according to International Standard Classification of Education 1997

(ISCED-97)^[14]. Levels 4-6 of ISCED-97 were grouped under a single category, tertiary education, because of the small number of patients in these levels. Occupations were categorized according to an article-specific occupational classification based on the field in which participants worked. Data were collected between November 20, 2022, and May 20, 2023.

This study was conducted in accordance with the principles of the Declaration of Helsinki (2000). Ethical approval was obtained from the Ordu University Ethics Committee (approval number: 2022-234) on October 27, 2022.

Data Analysis

SPSS Statistics for Windows, version 25 (IBM Corp.), was used for the statistical analyses. Descriptive statistics, including medians and percentages, were used to summarize patient characteristics. The normality of continuous variables was assessed using both visual methods (histograms and probability plots) and analytical methods (Kolmogorov-Smirnov and Shapiro-Wilk tests). All continuous variables were non-normally distributed and were therefore analyzed using non-parametric methods. The Pearson chi-square test and Fisher exact test were used to evaluate categorical variables. The Mann-Whitney U test was used to compare the distributions of continuous variables between two independent groups. Results were evaluated using a 95% confidence interval, and statistical significance was defined as $p < 0.05$. A multivariable logistic regression model was used to assess independent predictors of SS. This analysis was limited to the factors evaluated in the questionnaire. Variables associated with SS at $p < 0.20$ in univariate analysis, as well as variables identified as predictors in similar studies in the literature, were included in the multivariable models. Final models were calculated using the enter method. Model fit was evaluated using the Hosmer–Lemeshow goodness-of-fit test. Model discrimination was assessed using Nagelkerke's pseudo- R^2 . Odds ratios (ORs) were used to report statistical associations.

Results

The study included a total of 236 patients, including 221 with CHB, and 15 with CHC. The median age was 47 years; 51.3% of the patients were female and 48.7% were male. The demographic characteristics of the patients and their experiences of SS across different domains are shown in Table 1.

When all SS domains were evaluated together, 113 (47.9%) patients were found to have experienced SS in at least one domain. The ways in which patients experienced SS are summarized in the Figure 1.

Table 1. Characteristics of the participants.

Demographic characteristics	n (236)	(%)
Age		
Median (IQR)	47 (38-56)	
Sex		
Female	121	51.3
Male	115	48.7
Diagnosis		
CHB	221	93.6
CHC	15	6.4
Treatment		
Yes	150	63.6
No	86	36.4
Marital Status		
Married	209	88.6
Single	22	9.3
Divorced	5	2.1
Occupation		
Unemployed	98	41.5
Laborer	67	28.4
Office worker	30	12.7
Farmer	20	8.5
Other ^a	21	8.9
Education		
Illiterate/primary education	109	46.2
Lower secondary education	81	34.3
Upper secondary education	24	10.2
Tertiary education	22	9.3

a, furniture craftsman, civil engineer, tradesman, masseur, and marketer. IQR, interquartile range; CHB, chronic hepatitis B; CHC, chronic hepatitis C.

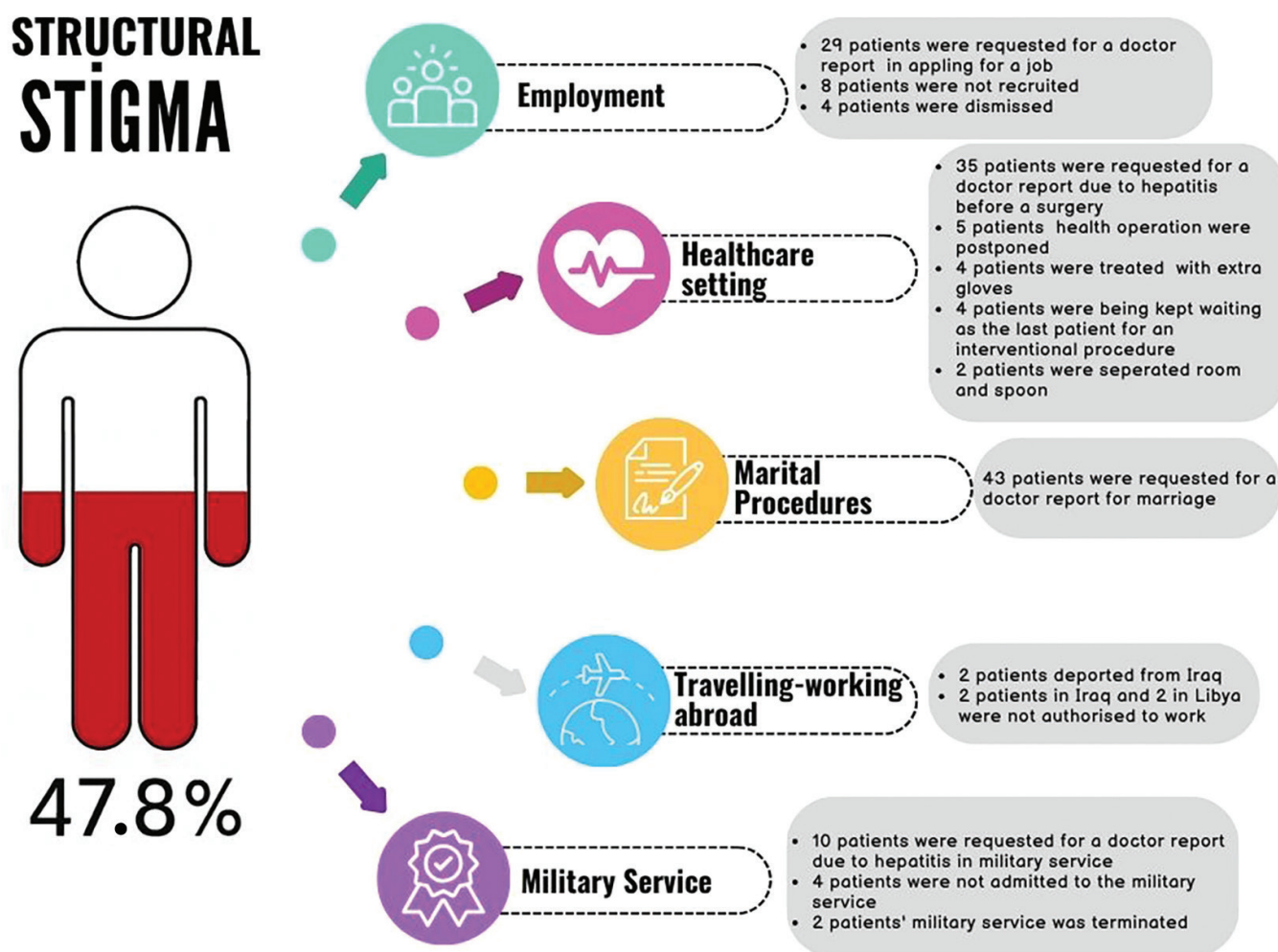


Figure 1. Details of SS experiences evaluated across five domains. SS, structural stigma.

Overall, 39.0% of participants reported being asked to provide a physician's report because of their hepatitis status. The distribution of variables according to SS is shown in Table 2.

Univariate analysis showed that SS was significantly more common among younger patients ($p < 0.001$). Overall SS experience was most common among unemployed patients. A significant association was observed between educational level and stigma ($p = 0.010$). Factors associated with overall SS experience are shown in Table 3.

Table 4 presents the results of the multivariable regression analyses of overall SS, employment-related stigma, and healthcare-setting stigma. Several factors were identified as significantly associated with overall SS experience. These included younger age [adjusted OR (aOR): 0.95, 95% confidence interval (CI): 0.92-0.98, $p = 0.001$], a diagnosis of hepatitis C (aOR: 3.6, 95% CI: 1.0-12.3, $p = 0.045^{**}$), and belonging to the laborer group (aOR: 6.1, 95% CI: 1.6-24.0, $p = 0.010$). The goodness-of-fit of the multivariable logistic regression model

was acceptable, as demonstrated by the Hosmer-Lemeshow goodness-of-fit test ($\chi^2: 6.771$, $df: 8$, $p = 0.562$). The model explained approximately 20.3% of the variance in overall SS according to Nagelkerke R^2 (Cox and Snell $R^2: 0.152$).

Discussion

This study demonstrated that SS, which has not been widely studied in patients with chronic hepatitis, is relatively common and warrants greater attention. Nearly half (48%) of our patients with chronic hepatitis had experienced SS at least once in their lifetime.

The prevalence of stigma among patients with chronic hepatitis has varied across studies because stigma encompasses multiple subtypes and its measurement has not been standardized worldwide. Although comprehensive stigma scales are available, the lack of validation and reliability studies across all countries, substantial differences in the perception of stigma among societies, and the presence of antistigma legislation

Table 2. Distribution of patients with hepatitis according to different SS domains and overall SS experience.

Structural stigma domain	n (236)	%
Employment-related stigma ^a	33	14.0
Stigma in healthcare settings	60	25.4
Stigma in military service ^b	12	25.5
Stigma related to traveling abroad ^c	6	11.3
Request for a physician's report before applying for a job ^a	29	16.3
Request for a physician's report before a surgery ^d	35	24.5
Request for a physician's report in military service ^b	10	21.7
Request for a physician's report in marital procedures ^e	43	33.1
Request for a physician's report from any institution	92	39.0
Overall SS experience	113	47.9

a, Persons who had applied for a job at least once and had been diagnosed with chronic hepatitis at the time of application were evaluated. b, Persons who had applied for military service and had been diagnosed with chronic hepatitis at the time of application were evaluated. c, Persons who had traveled abroad at least once and had been diagnosed with chronic hepatitis during this period were evaluated. d, Persons who had at least one planned surgery and had been diagnosed with chronic hepatitis during this period were evaluated. e, Persons who had applied for marriage at least once and had been diagnosed with chronic hepatitis at that time were evaluated. SS, structural stigma.

Table 3. Factors associated with overall SS experience.

	Experienced stigma n (%)	Did not experience SS n (%)	p	OR (95% CI)
Median age (min-max)	42 (20–67)	50 (20–69)	<0.001*	
Sex				
Female	56 (49.6)	65 (52.8)	0.614	1
Male	57 (50.4)	58 (47.2)		1.1 (0.7–1.9)
Diagnosis				
CHB	104 (92.0)	117 (95.1)	0.332	1
CHC	9 (8.0)	6 (4.9)		1.7 (0.6–4.9)
Treatment				
No	46 (40.7)	40 (32.5)	0.192	1
Yes	67 (59.3)	83 (67.5)		0.7 (0.4–1.2)
Occupation				
Farmer	3 (2.7)	17 (13.8)	0.020**	1
Unemployed	46 (40.7)	52 (42.3)		5 (1.4–18)
Other	10 (8.8)	11 (8.9)		5.2 (1.2–23)
Office worker	15 (13.3)	15 (12.2)		5.7 (1.4–24)
Laborer	39 (34.5)	28 (22.8)		7.9 (2.1–29)
Education				
Tertiary education	13 (11.5)	9 (7.3)	0.010***	1
Upper secondary education	18 (15.9)	6 (4.9)		2.1 (0.6–7.3)
Lower secondary education	39 (34.5)	42 (34.1)		0.6 (0.3–1.7)
Illiterate/primary education	43 (38.1)	66 (53.7)		0.5 (0.2–1.2)
Total	113	123		

*Mann-Whitney U test was applied. **The groups that accounted for the difference were the farmer and laborer groups, respectively. ***The illiterate/primary education group was combined and analyzed. The groups that accounted for the difference were the upper secondary education and illiterate/primary education groups, respectively. OR, odds ratio; CI, confidence interval; min-max, minimum-maximum; CHB, chronic hepatitis B; CHC, chronic hepatitis C.

Table 4. Evaluation of factors associated with employment-related, healthcare-setting, and overall stigma using multivariable logistic regression models.

	Employment-related stigma		Healthcare setting stigma		Overall stigma	
	p	OR _{adj} (95% CI)	p	OR _{adj} (95% CI)	p	OR _{adj} (95% CI)
Age	0.022	0.95 (0.91–0.99)	0.961	1 (0.97–1.04)	0.001	0.95 (0.92–0.98)
Diagnosis						
Hepatitis B	0.443	1		1	0.045	1
Hepatitis C		2 (0.3–12)	0.154	2.4 (0.7–7.7)		3.6 (1.0–12.3)
Treatment						
No				1		1
Yes	0.880	1.1 (0.5–2.5)	0.309	1.5 (0.7–2.8)	0.718	0.9 (0.5–1.6)
Occupation						
Farmer		1 ^a		1		1
Unemployed		-	0.044	4.8 (1.04–22.6)	0.065	3.5 (0.9–13.4)
Other		-	0.527	1.8 (0.3–12)	0.166	3 (0.6–14.9)
Office worker		-	0.714	1.4 (0.2–9.4)	0.370	2.1 (0.4–10.1)
Laborer		-	0.293	2.4 (0.5–12)	0.010	6.1 (1.6–24)
Education						
Tertiary education		1		1		1
Upper secondary education	0.645	1.5 (0.3–7.9)	0.666	1.4 (0.3–5.7)	0.931	1.1 (0.3–4.2)
Lower secondary education	0.460	0.6 (0.1–2.7)	0.503	0.6 (0.2–2.4)	0.072	0.3 (0.1–1.1)
Illiterate/primary education	0.682	0.7 (0.1–3.7)	0.570	0.7 (0.2–2.5)	0.091	0.4 (0.1–12.2)

a, Adjusted odds ratio (OR_{adj}) and confidence intervals (CIs) could not be calculated since the number of people experiencing employment-related stigma in the farmer group was 0.

in various countries pose significant challenges to assessing stigma using a universal scale.

Since, most studies have evaluated knowledge and attitudes among different populations and the number of studies specifically addressing SS is limited, it is not possible to determine the prevalence of SS among patients with hepatitis from the existing scientific literature. However, some studies have shown that patients with hepatitis experience stigma in various institutional settings, consistent with our findings^[11,15–17]. A study comparing patients with hepatitis B and non-hepatitis B controls found that the majority of controls believed that HBV carriers should not be employed in the restaurant industry. Similarly, 44.0% of controls stated that HBV carriers should not work with children^[18]. The same study reported that 40.0% of patients with HBV had been required to undergo preemployment HBV testing, and 29.0% of these individuals believed that they had lost job opportunities because of their disease status^[18]. In another study on barriers faced by people with hepatitis B, Na et al.^[19] reported that institutional discrimination was the most frequently identified environmental barrier. In a study conducted among patients with hepatitis B in Sierra Leone, 73.6% of respondents reported at least one instance of enacted stigma^[20].

In our study, a high proportion of patients diagnosed with hepatitis reported being asked to provide a medical report because of their hepatitis status. There may be several reasons why an institution might request a medical report from a physician stating that “there are no medical reasons why the individual is unable to work.” Fear and misconceptions regarding the transmission of hepatitis B and C viruses through bodily fluids may be leading causes of SS^[11].

Many unnecessary precautions, such as the inappropriate use of gloves and isolation of patients in separate rooms, are implemented when caring for patients diagnosed with hepatitis in healthcare settings^[21,22]. In our study, patients reported frequent discrimination in healthcare settings, including practices such as refusing to perform dental procedures, keeping patients waiting until they were the last to undergo interventional procedures, requesting unnecessary preoperative infectious disease consultations, and wearing additional gloves. In our opinion, stigma reproduced through healthcare practices and settings may reinforce social stigma because healthcare professionals are expected to possess evidence-based knowledge and avoid misconceptions about viral hepatitis. Similarly, the perceptions of institutional managers, legislators, and other leaders can influence public

attitudes and behaviors and contribute to both formal and informal discrimination.

In a review evaluating factors associated with stigma, the factors varied across studies^[5]. Among studies of stigma in patients with hepatitis, the associations between educational level, age, and stigma have varied, as most studies were cross-sectional and conducted in different regions^[23]. Because these studies investigated not only SS but also other types of stigma, their findings may differ from those of our study, in which younger age was associated with greater SS experience. Our study was conducted in a rural area, where older people may tend to live more isolated lives. However, increased hepatitis testing and greater awareness of hepatitis in society and institutions compared with the past may have contributed to lower levels of stigma toward older people.

Although hepatitis C infection emerged as an independent predictor of overall SS in the multivariable analysis, this finding should be interpreted with caution. Only 15 participants in our cohort had hepatitis C infection, resulting in wide confidence intervals and limiting the precision and stability of the estimated effect. Therefore, the observed association may have been influenced by sparse-data bias and should be considered hypothesis-generating rather than conclusive. Nevertheless, the finding is biologically and socially plausible. In Türkiye, hepatitis B is moderately endemic and is predominantly acquired through perinatal or early childhood transmission, making it a more familiar condition to the general population than hepatitis C. Consequently, misconceptions and limited public awareness regarding hepatitis C may contribute to higher levels of SS. Furthermore, hepatitis C has historically been associated with injection drug use, a behavior that is itself highly stigmatized, which may further reinforce the SS experienced by affected individuals. Further studies involving larger numbers of patients with hepatitis C are needed to confirm this association.

When stigma was analyzed according to occupation, a heterogeneous distribution was observed. The lower prevalence of stigma among farmers may be explained by their less frequent interaction with institutions. The higher levels of stigmatization observed among laborers and unemployed individuals suggest that these groups may have fewer opportunities or resources to protect their rights than other occupational groups.

SS should also be interpreted within the context of national legal and institutional regulations. In Türkiye, certain administrative procedures, such as requests for physician reports or hepatitis-related medical evaluations, may be implemented for legal, occupational, or public health

purposes rather than with discriminatory intent. Nevertheless, when such requirements are applied exclusively to individuals with viral hepatitis without clear evidence-based justification, or when they exceed existing recommendations, they may function as structural barriers and contribute to patients' experiences of stigma. From the patient's perspective, repeated hepatitis-specific administrative requirements may reinforce perceptions of exclusion or unequal treatment, regardless of the original intent of the policy.

Study Limitations

The present study has several limitations. First, it was conducted at a single center and was not designed to provide national-level estimates; therefore, the findings may not be generalizable to the broader population. Another limitation is the use of a custom-developed questionnaire. Although the questionnaire was developed based on previously published stigma studies and its content validity was reviewed by two infectious diseases specialists, formal psychometric evaluation, including reliability testing (e.g., Cronbach's alpha), construct validity assessment, and pilot testing, was not performed. Therefore, some degree of measurement error cannot be excluded. Nevertheless, because no validated instrument specifically assessing SS related to hepatitis in the Turkish context was available at the time of the study, a purpose-built questionnaire was considered the most appropriate approach for capturing context-specific experiences. Future studies should focus on developing and validating standardized instruments for measuring SS among people living with viral hepatitis. Despite these limitations, this study is among the few to evaluate SS among patients with hepatitis B and C in Türkiye and globally.

Conclusion

In conclusion, SS is highly prevalent among patients with hepatitis, with nearly half of the participants reporting stigma in at least one institutional domain. Younger age, hepatitis C diagnosis, and being a laborer were independently associated with greater experiences of stigma. These findings suggest that SS is not only a social concern but may also constitute a barrier to equitable access to care, patient well-being, and engagement with health services. Targeted multilevel interventions, including institutional policy review, healthcare worker education and awareness, and patient rights-based approaches, are needed to reduce stigma and improve clinical and public health outcomes.

Supplementary Table 1: <https://d2v96fxpocvxx.cloudfront.net/bda9171a-fae8-4995-8276-2138323f1e16/content-images/ed801de8-acd3-431b-a231-2f77ae0ecfa6.pdf>

Ethics

Ethics Committee Approval: Ethical approval was obtained from the Ordu University Ethics Committee (approval number: 2022-234) on October 27, 2022.

Informed Consent: Verbal informed consent was obtained from all participants before the interview.

Footnotes

Authorship Contributions

Concept: T.K., A.D., Design: T.K., Data Collection or Processing: T.K., A.D., Analysis or Interpretation: T.K., A.D., Literature Search: T.K., Writing: T.K., A.D.

Conflict of Interest: No conflict of interest was declared by the authors.

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