Patient concerns regarding chronic hepatitis B and C infection

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ما يثير قلق المرضى حول العدوى بالتهاب الكبد «بي» و «سي»

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الخلاصة: تنحصر التوعية لمرضى التهاب الكبد في غالب الأحيان بمناقشات حول كيفية سراية الفيروس. وتهدف هذه الدراسة لتوثيق المخاوف الرئيسية للمرضى الذين يعانون من عدوى التهاب الكبد «بي» و «سي»، وقد كانت أكثر ما يثير القلق شيوعاً لدى المتطوعين، هو نقل العدوى لأفراد الأسرة (80.6٪)، ونقل العدوى للآخرين (66.7٪)، والتأثيرات الجانبية للمعالجة (50.0٪)، وتطور المرض إلى التشمُّع الكبدي (44.4٪)، وعدم التوظّف (41.7٪)، وزرع الكبد (36.1٪)، والوصمة الاجتماعية (36.1٪)، وتغير أنماط الحياة (33.3٪)، ونشوء سرطان الكبد (25٪) والتكاليف والأموال (22.2٪)، والخوف من المرض (5.6٪) والمرض النفسي (5.6٪). ومن غير المحتمل أن يتصدَّى القائمون على إيتاء الرعاية الصحية ممن يقتصرون جهودهم على تقديم التوعية حول سراية الفيروس، إلى التطرُّق إلى عدد من المواضيع الأخرى التي تشغل بال المرضي يثير قلق المرضى من المواضيع الأخرى.

ABSTRACT Counselling of patients with viral hepatitis is often limited to discussions about how the virus is transmitted. The aim of the present study was to document the principal concerns of patients suffering from chronic hepatitis B and C infection. The most common volunteered concerns were infecting family members (80.6%), infecting others (66.7%), side-effects of treatment (50.0%), disease progression to cirrhosis (44.4%), loss of employment (41.7%), liver transplantation (36.1%), social stigma (36.1%), change in lifestyle (33.3%), development of liver cancer (25%), costs and money (22.2%), fear of disease (5.6%) and psychological disease (5.6%). Health care providers who focus counselling efforts exclusively on viral transmission are unlikely to address other important concerns.

Préoccupations des patients concernant les hépatites chroniques B et C

RÉSUMÉ Le conseil aux patients atteints d'hépatite virale se limite souvent à des discussions sur le mode de transmission du virus. L'objectif de la présente étude était de recueillir des informations sur les principales préoccupations des patients atteints d'hépatite chronique B ou C. Les préoccupations les plus souvent citées spontanément étaient la crainte d'infecter les membres de la famille (80,6 %), la crainte d'infecter les autres (66,7 %), les effets secondaires du traitement (50,0 %), l'évolution de la maladie vers la cirrhose (44,4 %), la perte d'emploi (41,7 %), une greffe du foie (36,1 %), les préjugés (36,1 %), le changement de mode de vie (33,3 %), le développement d'un cancer du foie (25 %), les coûts et les questions d'argent (22,2 %), la peur de la maladie (5,6 %) et les maladies psychologiques (5,6 %). Les prestataires de soins de santé qui ne s'intéressent qu'à la transmission du virus dans le cadre de leurs activités de conseil risquent de ne pas répondre aux autres préoccupations importantes des patients.

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Introduction

The estimated global prevalence of viral hepatitis is around 3%–5%, which means that approximately 400 million people are infected with hepatitis B virus (HBV) [*1*] and around 170 million with hepatitis C virus (HCV) [*1–4*]. Given the variability that exists with respect to the features and outcome of chronic HBV and HCV infection, appropriate counselling to address patient concerns is an integral component of patient management. Yet the precise content of that counselling remains to be defined.

In those few reports that specifically address counselling in HCV-infected individuals, the focus has largely been on routes of viral transmission and what can be done to decrease the risk of transmission to others [*5–8*]. To date, only one study has prospectively documented the principal concerns of infected individuals [*2*] and what should be incorporated into patient counselling.

The present study aimed to document the principal concerns about HBV and HCV infection of patients attending a viral hepatitis clinic in Tehran, Islamic Republic of Iran, to provide information for future counselling strategies.

Methods

This descriptive study was conducted during April to September 2005 on consecutive patients with hepatitis B or C who were admitted to a viral hepatitis clinic in Tehran, Islamic Republic of Iran. The referral clinic is staffed by gastroenterologists and serves patients with hepatitis. The diagnosis of hepatitis was based on history of HBV surface antigen (HBsAg) or HCV antibody (HCVAb) positivity in 2 separate laboratory examinations. Patients with other documented transmittable diseases such as HIV, mentally retarded patients and those less than 14 years old were excluded.

A physician or nurse interviewed each patient in private. No patient refused to be interviewed. Patients were initially asked in an open-ended manner about their principal concern regarding their HBV or HCV infection (volunteered concern). In most patients more than 1 principal concern was volunteered. Patients were then provided with a list of 8 potential concerns and asked to prioritize them. The list had been developed by the attending physicians and the priority scores ranged from 1 (most important) to 8 (least important). The following items were included in the list of concerns: social stigma of having liver disease; loss of employment; development of liver cancer; development of cirrhosis; infecting family members; infecting others; requiring a liver transplant; and side-effects of treatment.

The categorization process was performed in a semi-blinded fashion such that physicians were unaware of the nature of the patient (HBV or HCV infected) or their demographic status. We also documented whether these concerns varied with respect to the demographic characteristics of the patient population, including age, sex, ethnicity, level of education, marital status, employment (yes or no), mode of acquisition of the virus, residence (urban/rural) and type of hepatitis (HBV or HCV).

All data were analysed with *SPSS*, version 13. Continuous variables were summarized as mean and standard deviation (SD), and frequencies were shown by percentages.

Results

The demographic characteristics of the 36 patients interviewed during the 6-month study period (19 with chronic HBV infection and 12 with chronic HCV) are shown in Table 1. The mean (SD) age of patients was 32.1 (11.2) years. The mean follow-up

Table 1 **Demographic characteristic of the study patients with chronic hepatitis B virus (HBV) or C virus (HCV) infection**

Characteristic	**Overall (n = 36)**		**Hepatitis C cases (n = 12)**		**Hepatitis B cases (n = 19)**		***P*-value**[a]
	No.	**%**	**No.**	**%**	**No.**	**%**	
Age							
Mean (SD) (years)	32.1 (11.2)		32.9 (10.0)		32.8 (13.2)		0.97
Sex							0.108
Male	28	77.8	11	91.7	12	63.2	
Female	8	22.2	1	8.3	7	36.8	
Ethnicity							0.026
Turk	6	16.7	0	0.0	4	21.1	
Kurd	9	25.0	1	8.3	7	36.8	
Fars	20	55.6	11	91.7	7	36.8	
Lurs	1	2.8	0	0.0	1	5.3	
Education							0.783
Below grade 12	15	41.7	5	41.7	7	36.8	
High-school diploma	11	30.6	4	33.3	5	26.3	
University	10	27.8	3	25.0	7	36.8	
Marital status							0.710
Single	14	38.9	6	50.0	7	36.8	
Married	22	61.1	6	50.0	12	63.2	
Employment							1.000
No	18	51.4	5	45.5	9	47.4	
Yes	17	48.6	6	54.5	10	52.6	
Mode of acquisition of virus							0.014
Unknown	15	41.7	3	25.0	8	42.1	
Injection	4	11.1	4	33.3	0	0.0	
Sexual contact	2	5.6	0	0.0	2	10.5	
Transfusion	4	11.1	2	16.7	2	10.5	
Congenital	3	8.3	0	0.0	3	15.8	
Dentistry	4	11.1	0	0.0	4	21.1	
Needlestick	2	5.6	1	8.3	0	0.0	
Tattoo	2	5.6	2	16.7	0	0.0	
Residence							1.000
Urban	27	77.1	9	75.0	14	77.8	
Rural	8	22.9	3	25.0	4	22.2	
Follow-up							
Mean duration (SD) (months)	21.9 (25.2)		7.6 (7.5)		33.1 (29.3)		0.005

[a] *P-values are based on 2-tailed Fisher exact, Yates' corrected χ^2 test or independent samples t-test, as appropriate, between patients with HBV and HCV infection (P < 0.05 is significant).*
SD = standard deviation.

period was 21.9 (25.4) months; 77.8% of cases were followed up for ≤ 24 months (range 0–108 months).

The majority were male (28 cases; 77.8%) and living in the city (27 cases; 77.1%). There was a relatively even distribution of education level attained, marital status, employment, ethnicity and (volunteered) mode of acquisition of the virus.

The principal concerns that were volunteered spontaneously by patients are shown in Table 2. The most common concern was infecting family members (80.6%), followed by infecting others (66.7%) and side-effects of treatment (50.0%).

When the results were analysed by mean score, the rankings for volunteered concerns were slightly different; the highest priority [mean score (SD)] was for infecting family members [1.76 (SD 1.18], followed by fear of disease [2.50 (SD 2.12)], disease progression to cirrhosis [2.69 (SD 1.53)] and infecting others [2.83 (SD 1.34)] (Table 2).

From the list of potential concerns presented to patients the highest priority [mean score (SD)] was given to infecting family members [2.59 (SD 1.98)], followed by disease progression to cirrhosis [2.87 (SD 1.58)], infecting others [3.71 (SD 1.88)] and developing liver cancer [4.03 (SD 2.11)] (Table 2).

The most common concerns were analysed by demographic characteristic. Infecting family members was the most common volunteered concern of HBV patients among males (66.7%), Fars ethnicity (71.4%), below grade 12 education (57.1%), high-school diploma education (80%), single (57.1%), married (66.7%), unemployed (55.6%), employed (70.0%) and living in a village (100%). However, side-effects of treatment was the most common vol-

Table 2 **Distribution and ranking of principal concerns (both volunteered and those presented as a list) of patients with chronic hepatitis B or C infection (*n* = 36)**

Concern	**Volunteered by patients**		**List presented to patients**
	%[a]	**Mean (SD) score**[b]	**Mean (SD) score**[b]
Fear of disease	5.6	2.50 (2.12)	
Costs and money	22.2	3.63 (2.72)	
Lifestyle change	33.3	4.83 (2.82)	
Psychological disease	5.6	7.00 (2.82)	
Infecting family	80.6	1.76 (1.18)	2.58 (SD 1.98)
Disease progression (cirrhosis)	44.4	2.69 (1.53)	2.87 (SD 1.58)
Infecting others	66.7	2.83 (1.34)	3.70 (SD 1.88)
Developing liver cancer	25.0	4.00 (2.06)	4.03 (SD 2.11)
Side-effects of treatment	50.0	3.83 (1.75)	4.93 (SD 1.84)
Need for liver transplant	36.1	4.69 (1.60)	5.20 (SD 1.49)
Social stigma	36.1	4.15 (2.60)	5.35 (SD 2.54)
Loss of employment	41.7	4.60 (2.72)	6.00 (SD 2.35)

[a]% of patients mentioning this concern.
[b]Lower score = higher ranking.
SD = standard deviation.

unteered concern of patients with HBV infection among females (71.4%), university education (71.4%), congenital mode of acquisition (100%) and urban residence (64.3%). Infecting others was the most common concern among Turks (100%) and loss of employment among Kurds (57.1%).

On the other hand, the commonest volunteered concern in all subgroups of patients with HCV infection was infecting family members.

Discussion

The results of this study indicate the most common concern in patients with chronic HBV and HCV infection relate to viral transmission. The other concerns were disease progression, side-effects of treatment and loss of employment. Similar results were obtained in both subgroups of HBV- and HCV-infected patients. With a few exceptions, these concerns were consistent regardless of sex, ethnicity, level of education, marital status, employment, mode of viral acquisition and residence of patients. Differences between rank order of the volunteered concerns in HBV- and HCV-infected patients may be influenced by follow-up duration, mode of acquisition or ethnicity, but the 3 first concerns in both groups of patients were the same.

As discussed earlier, the principal focus of patient counselling for HCV-infected individuals described in previous reports is what can be done to decrease the risk of viral transmission to others [*5–7,9*]. According to the results of this study, the risk of viral transmission to family members and others, when combined, represented the volunteered concern of 66.7% to 80.6% of patients. Thus, if counselling were limited to discussions about HBV and HCV transmission, the main concerns of approximately 60%–80% of infected individuals would be addressed. Of course, we should consider that the high concern about transmitting the infection to others may have resulted from the participants' desire to please the interviewer and give a response that seemed most appropriate and least selfish.

Disease progression is a general term that describes patients' concern that "the disease would get worse" or "I will become too tired in the future to do what I can do now". It was considered a distinct concern if patients failed to offer a specific outcome such as cirrhosis or liver cancer from that progression. If considered as one principal concern, based on the results of both volunteered and prioritized rankings, cirrhosis was the most feared outcome of disease progression, followed by liver cancer and liver transplantation.

In practical terms, the relative consistency of findings across the various demographic profiles of patients facilitates counselling efforts in HBV- or HCV-infected individuals [*7*]. For example, regardless of whether patients are employed or unemployed, male or female, HBV-infected or HCV-infected, etc., if physicians address the issues of disease progression, side-effects of treatment and infection of family members or others, the principal concerns of these patients will have been addressed.

The limitations of this study include the following: first, investigators could not control the extent of counselling provided to newly diagnosed patients by their referring physicians in the community. However, based on the differences between volunteered and prioritized concerns, it would appear that such counselling was limited. Secondly, although the centre to which the patients were referred tends to see the majority of HBV- and HCV-diagnosed cases in the region, we cannot rule out referral bias. Thirdly, because of the cross-sectional design of the study, patients were not followed to determine whether their concerns changed with time. Finally, similar data do not exist in the medical literature. Hence, we cannot determine whether these findings are site-specific.

In summary, counselling of HBV- and HCV-infected patients that is limited to discussions about viral transmission would satisfy the principal concerns of approximately 60%–80% of patients. But disease progression and side-effects of treatment and loss of employment are also common concerns of patients with chronic HBV and HCV.

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