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Original Article

Reproductive Health Needs of Women with Hepatitis B: A Qualitative Study

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Abstract

Background: Hepatitis B is one of the most important diseases in the world that imposes substantial financial burdens upon patients and health systems. Women with hepatitis B, like any other woman, have the right to access reproductive and sexual health services tailored to their needs as well as those of their sexual partners and children. However, the reproductive health needs of this group of patients have been subject to negligence.

Methods: This qualitative study was conducted using in-depth semi-structured interviews in randomly selected hospitals and health centers of Tehran, Iran in 2015. A total of 40 women with hepatitis B and 30 reproductive health care providers were individually interviewed. Interviews were conducted based on topic guides, including a series of broad questions used to explore and probe the experiences of the interviewees. All interviews were recorded and each interview lasted from 60 to 90 minutes. The collected data were analyzed using the content analysis method.

Results: Data analysis yielded 88 codes and 186 items. Two main themes were extracted from the analyzed data including *the need for information* and *the need for health care*. The first theme involved two categories (*the patient's need for information* and *the health provider's need for information*) and four subcategories. The second theme included three categories (*supportive care*, *disease and reproductive health care*, and *capacity building*) and thirteen subcategories.

Conclusion: From the viewpoint of women with hepatitis B interviewed in this study, a successful program that meets the special reproductive health needs of these patients is required to respond to the need for information and the need for health care. Meeting treatment needs should include responding to the informational needs of both patients and service providers. Besides, satisfying the need for health services should focus on support services, disease care, reproductive health care, and capacity building.

Keywords: Hepatitis B, Needs assessment, Reproductive health, Content analysis

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Introduction

Hepatitis B is one of the most important diseases in the world that imposes substantial financial burdens upon patients and health systems. (1) Most patients with hepatitis B have been reported to have a low quality of life and high levels of stress and anxiety (2-5). Moreover, the disease is often accompanied by high levels of social stigma that can cause stress and negatively impact the patient's social relations and activities as well as their use of healthcare services (6,7). Due to the possibility of vertical transmission and transmission through sexual intercourse, screening of the disease during pregnancy and the subsequent disclosure of the disease for the first time during pregnancy become vitally important, making hepatitis B closely related to the field of reproductive health (8-10). Furthermore, women with hepatitis B, like their healthy counterparts, have the right to have safe and desirable sexual relations and access sexual and reproductive health care services tailored to their needs as well as to those of their children and sexual partners (3,11). However, the overall costs of health care are rising and the resources available for health care are limited (12). Moreover, the needs of this group of patients regarding reproductive health care are not fully elucidated. Therefore, this study aimed to determine the reproductive health needs of women with hepatitis B.

Methods

This qualitative study was conducted based on a specific and well-defined protocol, and data were analyzed using the conventional content analysis method. The study was carried out using in-depth semi-structured interviews in randomly selected hospitals and health centers of Tehran, Iran, in 2015. A total of 40 women with hepatitis B and 30 reproductive health care providers were individually interviewed. The women were eligible to participate in the study if they were married and at reproductive age (15-45 years old), asymptomatic carriers of hepatitis B (positive result for hepatitis B surface antigen), negative for hepatitis B e-antigen, and receiving any reproductive health care. The conventional content analysis method was used for data analysis. The lead researcher who conducted the interviews had notable experience in qualitative research in general and needs assessment strategies in particular. The participants were selected with maximum diversity to include patients with a variety of demographic and reproductive characteristics. The participants were selected from hospitals, health clinics, and gastroenterology and liver research centers of Tehran University of Medical Sciences, Iran University of Medical Sciences, Shahid Beheshti University of Medical Sciences, and Baqiyatallah University of Medical Sciences. The questions asked to guide the interviews included: “What do you need when you visit reproductive health centers?”, “What is your perception about reproductive health service delivery at the time of childbirth, prenatal visits, genital infection treatments, etc?”, and “What do you think are the main needs of women with hepatitis B at the time of receiving reproductive health services?”

All interviews were recorded and transcribed verbatim after receiving permission from the participants. The transcripts were then coded through the conventional content analysis method. Based on the comparison of the interview transcripts, the main themes of the study were extracted. Data collection and analysis continued until data saturation. Credibility and confirmability were enhanced through member checking (the transcripts and codes were returned to several interviewees to verify their authenticity), and the validity of emerging codes was checked by two supervisors. The collected data were analyzed using the content analysis method.

Written informed consent was obtained from all participants prior to the commencement of the study. Since getting infected with hepatitis B is a socially sensitive issue, the patients were privately interviewed, and their privacy was strictly protected. They were also assured that all their information would remain confidential and the recorded content would be eliminated after the research was completed.

Results

The present study included two groups of participants (reproductive-aged women affected with hepatitis B and reproductive health care providers). The demographic characteristics of the participants are listed in Tables 1 and 2. Data analysis yielded 88 codes and 186 items. Two themes emerged from the data including *the need for information* and *the need for health care*. The need for information involved two categories (*the patient’s need for information* and *the health provider’s need for information*) and four subcategories. In addition, *the need for health care* had three categories (*supportive care*, *disease and reproductive health care*, and *capacity building*) and 13 subcategories (Table 3).

Table 1. Demographic characteristics of reproductive-aged women with hepatitis B

Characteristics	No. (%)
Age (y)	
15-25	7 (17.5)
26-40	25 (62.5)
≥41	8 (20)
Education	
Illiterate	5 (12.5)
Primary and secondary school	7 (17.5)
High School	16 (40)
University	12 (30)
Occupation	
Housewife	24 (60)
University student	2 (5)
Clerk	6 (15)
Other	8 (20)
Parity	
Nulliparous	16 (40)
Multiparous	24 (60)

Table 2. Demographic characteristics of reproductive health care providers

Characteristics	No. (%)
Age (y)	
20-30	5 (15.63)
31-40	18 (56.25)
≥41	9 (28.12)
Work experience (y)	
≤10	7 (21.88)
11-20	19 (59.37)
≥21	6 (18.75)
Occupation	
Gynecologist	6 (18.75)
General physician	3 (9.38)
Midwife (Bachelor’s degree)	14 (43.75)
Midwife (Master’s degree)	5 (15.62)
Family health expert	4 (12.5)

Theme 1: The need for information

According to the participants interviewed in this study, the need for information is one of the most important health needs of women with hepatitis B. More particularly, the participants had limited awareness of the

Table 3. Reproductive health needs of women with hepatitis B (themes, categories, subcategories, and codes)

Themes	Categories	Subcategories	Codes
The need for information	Patient's need for information	Hepatitis B-related education	Information about the disease before doing hepatitis B screening test
			Information about the disease after a positive diagnosis
			Correcting myths about hepatitis B
			Self-care
			Fetal care and care for family members
		Information quality	Timely information
			Accurate source of information
			Appropriate information transfer method
	Health care provider's need for information	Disease-related education	Disease-related information
			Disease management during pregnancy and childbirth
			Self-care against hepatitis B
		Healthcare information related to hepatitis B	Accurate information about the hepatitis B health centers available
			Awareness of the health services provided at hepatitis B health centers
The need for healthcare	Supportive care	Stigmatization	Stigmatization from health care providers' behavior
			Receiving required services without any stigma
		Adaptation	Consultation after a positive diagnosis
			Meeting people with similar experience
		Disclosure	Support for how to disclose the disease
			Support for solving the post-disclosure conflicts
		Privacy	Confidentiality
			Patient satisfaction
	Disease and reproductive health care	Visiting health centers	Visiting a reliable laboratory for accurate diagnostic tests
			Visiting free or low-cost special health centers for the follow-up of the disease
			Visiting specialist health centers, which have easy–admission policies, for receiving reproductive health services
			Visiting specialist health centers, which have easy–admission policies, for receiving dental health services
		Follow-up	Follow-up of reproductive health care
			Follow-up of disease-related care
			Follow-up of family members' care
		Consultation	Pre-pregnancy consultation
			Consultation for sexual disorders
			Consultation for family planning and contraception
		Neonatal care	Follow-up of neonatal care
			Vaccination and immunoglobulin injection
			Rooming-in
			Breastfeeding
	Capacity building	Planning	Mandatory global hepatitis B screening program during pregnancy
			Global program for disease registration and follow-up
			Disease control in the immigrant population
		Supervision	Supervising health care provision
			Supervising health care costs
		Promotion of facilities	Increasing the number and capacity of hepatitis B research centers
			Increasing the capacity of public health centers
			Increasing the number of outreach laboratories for hepatitis B diagnosis
		Modification of programs	Isolation policies
			Providing hepatitis B immunoglobulin
			Integration of the services of hepatitis B with those of reproductive health
		Supply of resources	The costs of laboratory tests
			The costs of medication

hepatitis B disease, its transmission routes, prevention, and treatment, the importance of screening tests during pregnancy and their probable results, the importance of treatment during pregnancy, the effects of the disease on neonatal health, the ways of preventing feto-maternal transmission, self-care, and care for family members against the disease. One of the participants put it as follows: "*Before I got the test result, I knew nothing about hepatitis B. When they said, 'you have hepatitis B', I was shocked. I thought that I was getting AIDS. It was so annoying*" (Patient 7).

With regard to the importance of awareness of hepatitis B screening tests, one of the patients recounted: "*My doctor didn't ask me about the hepatitis B diagnostic test. I went to the laboratory with my sister-in-law. She learned about my infection and told the whole family, and all my social interactions with others were negatively affected*" (Patient 3). The majority of participants in the study agreed that the quality of the information provided to them (in terms of timeliness, the methods of providing information, and reliable sources) was not suitable. They believed: "*If we received our needed information on time, we wouldn't be so confused*", or as another woman said: "*Since I've been diagnosed with hepatitis, I haven't yet found a reliable source of information*" (Patients 3, 6, 9, 11).

Theme 2: The need for health care

Based on the statements of the patients and health care providers, the need for health care was another important need pointed out in the interviews. Most of the interviewees in this study highlighted the need for supportive care focusing on destigmatization, adaptation, disclosure, and privacy. As one of the participants pointed out: "*The behaviors of health providers must be changed. My doctor was so cautious that I decided to visit another. I felt that she was not willing to touch my stomach or even talk to me. I only expected her to have normal behavior*" (Patient 4). One of the health care providers said, "*These patients are not provided equal health services. The services they receive are often delayed or are of low quality compared with healthy women. For example, they say that because of their illness, they come for women's examination at the end of office hours*" (Health provider 9). Another health provider reflected: "*When these patients are known to be infected, they are really shocked especially because of the disease stigma and pregnancy-related hormonal instability, so they need to be supported and must not be left alone*" (Health provider 4). According to another health provider, "*These individuals need to receive counseling services with regard to disease disclosure to decide who should know about their disease (health provider and their husband and children) and who should not*" (Health provider 8). One of the patients said, "*We need to be equipped with correct information. During my hospital stay, I was asked questions about the condition of my disease and other annoying questions*" (Patient 4).

The findings also revealed the need to have access to health services related to hepatitis B and reproductive health. In this regard, the participants acknowledged certain needs such as the need for referral, follow-up, and counseling. One of the patients explained: "*One of my concerns during the whole period of pregnancy was disapproval. I was afraid I would never be admitted to the hospital at the time of delivery. I needed guidance about health centers which were not strict on admission for my delivery*" (Patient 7). Another patient said, "*We need to be followed up. For example, when I found out that I had hepatitis, I was never referred to receive specialized services related to pregnancy and hepatitis, and none of the health care providers contacted me*" (Patient 8).

Data analysis indicated a higher level of needs referred to as capacity building needs. These needs broadly involved planning, supervision, promotion of facilities, modification of programs, and supply of resources. As one of the health providers suggested, "*One of the main requirements for treating hepatitis during pregnancy is planning for the mandatory screening of the disease in pregnancy. This can unveil the hidden nature of the disease in pregnant mothers and prevent the baby from getting hepatitis by taking appropriate actions*" (Health provider 6). Another health provider commented, "*This group of patients need a hospital supervisory committee to protect them from injustice and being charged for additional fees*" (Health provider 14). In this respect, one of the patients said, "*We need to increase the number of free-of-charge or low-cost specialist health centers. I live in the south of Tehran, and my husband is simply a worker. I have to spend a lot of time and money to come to this center. That's why I didn't go for follow-up*" (Patient 19). Another patient said "*I wish the hospital would provide the immunoglobulin for newborns instead of patients. My husband could not get hold of it. We were very tired*" (Patient 16). One of the health providers made the following suggestion, "*The policymakers must make serious decisions to cover the expenses for the patient's lab tests. Some of their lab tests such as the viral load tests are very expensive. However, many people with the disease can't afford the medications or simple tests, let alone expensive tests like the one I told you*" (Patient 11).

Discussion

According to the results of previous studies, the general health status of individuals affected with hepatitis B is not desirable. In fact, their low quality of life, emotional and health problems, and interfamilial conflicts basically affect their use of health services, visiting voluntary testing centers, and pursuing follow-up care (13-16). The present study investigated the health needs of women directly related to reproductive health services.

One of the major needs of patients was related to information. The literature review revealed that hepatitis

B patients are particularly at a disadvantage in this respect (17-21). According to Wallace et al, there is inadequate information about the disease and related care among hepatitis B patients. Both the service providers and patients in their study believed that patients need counseling before and after the diagnostic test, and their lack of information in this respect causes confusion after the patients are given the diagnostic test results, making them anxious and fearful of their future (15). In line with these results, Ng et al. also came up with information needs as a theme in their study. Most of the participants in their study stated that they did not have enough information about this disease when they went to get the results of the hepatitis B diagnostic test and that they felt anxious and fearful thereafter (16). The need for information has also been reported to be related to issues such as disease transmission and prevention, diagnostic tests, access to medication and special care, and prognosis (18). In line with the present study, a previous study on the health needs of hepatitis B and C patients in Sweden showed that service providers felt the need to increase their knowledge and skills in relation to screening, management, follow-up, and referral procedures. Unlike the present study, in this study, the information needs were not expressed by the patients. This, the authors believed, was due to the implementation of a comprehensive educational program in the studied city which had satisfied the information needs of the patients, and thus this need was not expressed by the patients (19). In a needs assessment study aimed at designing a 5-Year program for Hepatitis B in Minnesota, the participants, who were all service providers, highlighted the role of information in improving service quality. Details of their results showed that they have serious deficiencies in terms of counseling, referrals, prevention, care, and management of hepatitis B, which is consistent with the results of the present study (20). In addition, Tan et al reported information needs as a key concept in their study of people with hepatitis B. Participants of their study believed that the service providers who provided the first levels of service had serious information and skill deficiencies, and for this reason, many patients preferred to go to specialists, but the high cost of visits made them avoid pursuing their care (19).

One of the findings of the present study was the need for health services as a theme. The results of previous studies showed that the stigma of the disease is one of the main barriers to receiving health services. According to these studies, providing a supportive environment with possible support services can improve the quality of services. Wallace et al, for example, maintained that the need for support services includes the need for support to disclose the disease and the need for support to adapt to the disease. The participants of their study believed that the need for support by health care providers is neglected (15). The same need has also been highlighted in two other major studies on this topic that were discussed earlier (18,20-23). In Swindon's study, hepatitis B and unwanted drug effects were found to affect patients' mental health and quality of life (17).

Unfortunately, studies dealing with both reproductive health and disease services are limited, and to the best of our knowledge, this study was the first to evaluate the specific needs of women with hepatitis B as far as reproductive health is concerned. To compare our results with those of other studies, we used data from studies related to HIV/AIDS and reproductive health, which was the closest to hepatitis B. In their study on the reproductive health needs of HIV-infected women, Behboodi-Moghadam et al reported important concepts such as concerns about the disease, life instability, adaptation to the disease, and needs related to disclosure and support. Many of these concepts, such as coping with the illness, disclosure needs, and support needs, were exactly the same as the ones expressed by the participants in the present study, while some others appeared in our study under different terms and categories (24,25).

Furthermore, the need for referral and follow-up among women with hepatitis B was noted in Swindon's study (17). In another study which evaluated the general needs of hepatitis B patients, and not specifically those related to reproductive health, the needs for referral, follow-up, counseling services, and childcare services were mentioned by the participants (26).

The final category of the need for health care extracted in this study was capacity building. Consistent with the results of the present study, Wallace et al highlighted the need for planning at a macro level, which involved the need for more access to health care and evidence-based guidelines for treatment and consultation (15).

One of the major limitations of this study was related to the hepatitis B disease and the stigma around it, that led to the patients not easily explaining their real beliefs. Moreover, there was no special room for conducting the interviews. Besides, the experiences of infertile women or couples with hepatitis, cancer-affected women, or other affected women with special reproductive health needs were not investigated.

Conclusion

From the viewpoint of women with hepatitis B interviewed in this study, a successful program that meets their special reproductive health needs must respond to the need for information and the need for health care. Meeting treatment needs should include responding to the informational needs of both patients and service providers. Moreover, satisfying the need for health services should focus on support services, disease care, reproductive health care, and capacity building.

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Competing Interests

The author declared no conflict of interest.

Ethical Approval

This study was approved by the ethical committee of Shahroud University of Medical Sciences with the code IR.SHMU.REC.1394.75.

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