

Living with hepatitis: impact on the daily life of infected subjects

CONVIVENDO COM HEPATITE: REPERCUSSÕES NO COTIDIANO DO INDIVÍDUO INFECTADO

CONVIVIENDO CON HEPATITIS: REPERCUSIONES EN EL COTIDIANO DEL INDIVIDUO INFECTADO

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ABSTRACT

We performed a descriptive, exploratory, and qualitative study, to identify changes in the daily life of subjects with hepatitis. The data were collected in October 2011 from 12 patients with hepatitis B and/or C, through semi-structured interview, and subjected to thematic content analysis. The majority of the subjects were diagnosed with hepatitis B. The time of diagnosis ranged from less than 6 months to 12 years, and the diagnosis was made mainly through blood donation. Only two patients were taking interferon. The results were divided into two categories that describe feelings and reactions experienced by the interviewees, as well as some lifestyle changes. It was concluded that health professionals need to be aware of the complexity of phenomena concerning the illness process and life with hepatitis.

DESCRIPTORS

Hepatitis
Nursing. Communicable diseases
Diagnosis
Life change events
Nursing care

RESUMO

Estudo descritivo, exploratório, de abordagem qualitativa, desenvolvido com o objetivo de identificar as alterações no cotidiano do indivíduo com hepatite. Os dados foram coletados em outubro de 2011, junto a 12 pacientes com hepatite B e/ou C, por meio de entrevista semiestruturada e submetidos à análise de conteúdo do tipo temática. A maioria dos indivíduos tinha o diagnóstico de hepatite B. O tempo de diagnóstico variou de menos de 6 meses até 12 anos e o diagnóstico foi feito principalmente por meio da doação de sangue. Somente dois pacientes faziam uso de Interferon. Os relatos deram origem a duas categorias, as quais evidenciam sentimentos e reações experimentados pelos entrevistados, bem como alterações em alguns hábitos de vida. Concluiu-se ser necessário aos profissionais de saúde atentar para a complexidade que envolve os fenômenos concernentes ao processo de adoecimento e vivência com a hepatite.

DESCRIPTORIOS

Hepatite
Doenças transmissíveis
Diagnóstico
Acontecimentos que mudam a vida
Cuidados de enfermagem

RESUMEN

Estudio descriptivo, exploratorio, de abordaje cualitativo, desarrollado con el objetivo de identificar las alteraciones en el cotidiano del individuo con hepatitis. Los datos fueron recolectados en octubre de 2011 en 12 pacientes con Hepatitis B y/o C, por medio de entrevistas semiestructuradas y luego, sometidos al análisis del contenido de tipo temático. La mayoría de los individuos tenía el diagnóstico de hepatitis B. El tiempo de diagnóstico varió de menos de 6 meses hasta 12 años, y la principal forma de diagnóstico fue a través de la donación de sangre. Solamente dos de los individuos estaban usando Interferón. Los relatos dieron origen a dos categorías relacionadas con los sentimientos y reacciones vividas por los entrevistados así como alteraciones en algunos hábitos de vida. Se concluye que es necesario que los profesionales de la salud contemplen con mayor cuidado la complejidad que involucra los fenómenos concernientes al proceso de la enfermedad y la convivencia con la hepatitis.

DESCRIPTORIOS

Hepatitis
Enfermedades transmisibles
Diagnóstico
Acontecimientos que cambian la vida
Atención de enfermería

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INTRODUCTION

Brazil is in full epidemiological transition, but noncommunicable chronic diseases are the major causes of death, and the control of infectious disease remains a challenge to public health⁽¹⁾. Among these diseases, hepatitis is a serious problem for health services due to its high incidence, possible complications of its acute or chronic forms, and the need for long-term monitoring⁽²⁾.

The World Health Organization estimates that there are about 325 million individuals across the world with hepatitis B and 170 million with hepatitis C; in Brazil, estimates range from 2 to 3 million. In addition, at least 15% of the population has already been in contact with the hepatitis B virus (HBV), and 1% has the chronic form of the disease. In the 1999-2010 period, there were 130,354 cases of hepatitis A, 104,454 cases of hepatitis B, and 69,952 cases of hepatitis C, with important variations among different Brazilian states⁽³⁾. It is important to highlight that most people are unaware of their serological status, which further aggravates the chain of infection transmission⁽⁴⁾.

Chronic infection by hepatitis B or C is an important cause of morbidity and mortality worldwide and one of the main causes of hepatic decompensation, cirrhosis, and hepatocellular carcinoma. Chronic infection can cause higher stress and negatively impact patient quality of life, their social relations, and performance of daily tasks, regardless of hepatic clinical symptoms, which themselves are related to extrahepatic manifestations and cognitive changes⁽⁵⁾. Thus, hepatitis is an important problem for health services, not only because of its high incidence, but also because of the possibility of complications of its acute forms, long-term chronification, and the consequences it brings to infected subjects⁽³⁾.

Several studies report that chronic diseases affect patients' lifestyles, causing psychological and behavioral changes that require review of daily habits and strategies to face this new reality⁽⁵⁾. In some situations, the discovery of the disease or the beginning of the treatment can lead to significant changes in the lives of patients. Subjects with hepatitis C, for instance, are more limited when performing daily activities (work, school, home) and have less confidence in the success of the treatment, which suggests a pattern of quality of life inferior to subjects who do not have the disease⁽⁶⁾.

Given the complexity involved in the phenomena concerning the illness process and life with hepatitis, practices of care are imposed with approaches that allow patients to overcome the biological dimension. For that, health professionals need to have attitudes towards the comprehension of the various dimensions that constitute the process of living and being healthy, that is biological, cultural, social, and subjective⁽⁷⁾.

The influence of disease on daily life varies from person to person according to values, beliefs, practices, representations, meanings, and personal and collective experiences. Therefore, it is essential that nursing professionals know, from the patients' perspective, the impact of the diagnosis on their everyday lives, in order to enable their integration and interaction in this culturally diverse context. Furthermore, a new approach is needed regarding nursing care to ensure individualized service that values the human as a holistic being, as opposed to reductionist and technocratic views⁽⁷⁾.

Given the above exposition, the objective of this study was to identify changes in the daily life of subjects diagnosed with hepatitis.

METHOD

We performed an exploratory, descriptive, cross-sectional, and qualitative study that was developed at the University Hospital of Maringá of patients with hepatitis B or C who were monitored by the Hepatology and Infectious Diseases clinic. The service is a reference to the 30 municipalities comprising the 15th Regional Health of Paraná regarding the monitoring of patients with a suspected or confirmed diagnosis of viral hepatitis. The service is conducted twice a week, and an average of five appointments are scheduled per day. In 2011, 87 suspected cases of hepatitis were notified; all of them were investigated and, when confirmed, they were monitored by the infectology clinic. Out of the 87 suspected cases, 33 had a confirmed diagnosis of hepatitis B, 30 of hepatitis C, 18 were still under investigation, and 6 were confirmed not to be infected.

The data were collected in October 2011 through semi-structured interviews in private rooms of the University Hospital of Maringá. The subjects were approached while waiting for consultation with an infectologist, informed about the objectives of the study, and invited to participate.

The interviews were conducted in a private room, recorded with the consent of the interviewees and guided by an instrument consisting of two parts: the first involved questions relating to patient characterization, and the second one was introduced with the following prompt: *Talk about the changes in your daily life after the hepatitis diagnosis.*

A total of 12 patients were interviewed. The interviews ended when the information needed to meet the objective of the study started to be repeated. The criteria adopted for inclusion in the study were the subject being 18 years old or over and having a diagnosis of hepatitis. They were characterized according to the following variables: gender,

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age, marital status, education, occupation, time of diagnosis, type of hepatitis, and interferon use.

For the data analysis, the interviews were transcribed and then subjected to thematic content analysis⁽⁸⁾, followed by phases of *pre-analysis, material exploration, processing, and interpretation of the results*. During the pre-analysis, the speeches were read to identify the points relevant to the objective of the study. During the exploration phase, the material was codified, a process through which raw data are systematically transformed and aggregated into units. In the last phase, a categorization was elaborated by classifying the elements according to their similarities and differences, with subsequent regrouping in relation to common characteristics⁽⁸⁾.

The study was developed in accordance with the recommendations by the Resolution No. 196/96 of the National Council of Health, and the project was approved by the committee that regulates and monitors the academic activities and volunteer services of the University Hospital of Maringá

and by the Ethics and Research Committee on Research Involving Humans of the State University of Maringá (Protocol No. 724-2011). All subjects signed an informed consent form in duplicate. For the differentiation of subjects and to preserve their identity, the following codes were used: letter I (interviewee), followed by a number indicating the order of the interview, and the letters M and F to identify males and females, with another number indicating the age of the informant and a third letter indicating the type of hepatitis.

RESULTS

Chart 1 displays some subjects' characteristics. Most were male, married, and with low education. Subject age ranged from 21 to 57 years, with an average of 43 years. The time of diagnosis was quite variable and, except for I6 and I12, the interviewees were diagnosed with hepatitis after blood donation, and hepatitis B was the most frequent type. The interviewees I2 and I7 had the disease in its chronic phase and, therefore, were taking interferon.

Chart 1 – Sociodemographic and clinical characteristics of the subjects with hepatitis - Maringá, 2011

Id	Gender	Age	Marital Status	Education	Occupation	Type of hepatitis	Time of diagnosis
I1	F	54	Married	IEE	Janitor	B	3-4 years
I2	M	44	Married	CEE	Builder	B and C	4-5 years
I3	M	42	Married	IEE	Driver	B	1-2 years
I4	M	56	Married	IEE	Driver	B	>5 years
I5	F	56	Divorced	IEE	Housewife	B	<6 months
I6	F	35	Married	IEE	Sugarcane cutter	B	<6 months
I7	M	21	Single	CHS	Mechanic	B	>5 years
I8	M	27	Single	HIS	Art finisher	C	<1 year
I9	M	48	Married	IEE	Plumber	C	3-4 years
I10	F	42	Married	IEE	Babysitter	B	>5 years
I11	M	57	Married	HIS	Salesman	B and C	12 years
I12	M	39	Married	IEE	Builder	B	<1 year

* IEE/CEE, Incomplete/Complete Elementary Education; IHS/CHS, Incomplete/Complete High School

The analysis of the data allowed the identification of two thematic categories: *Feelings towards the disease* and *Attitudes and behaviors after the infection*, which are described below.

Feelings towards the disease

Several reports have highlighted some of the feelings and reactions the interviewees experienced after the diagnosis of hepatitis B or C, such as the worry and fear of having transmitted the virus to their partners, the feeling of helplessness due to the lack of knowledge about the disease, and the distress in wanting to know how they contracted hepatitis.

The doctor said I had hepatitis (...) I got scared because I didn't know what was it. I wasn't feeling anything (...) (I1, F54, B).

I was very sad, I was caught by surprise, I thought it was the end, a very serious disease... I was scared because I didn't know much about this disease, but then the doctor told me I didn't need to get worried, that she would always do all the exams to see if it manifests (I6, F35, B).

It was observed that, for the majority of the interviewees⁽⁸⁾, the diagnosis was followed by negative and disturbing feelings, mainly caused by the surprise due to the lack of symptoms and lack of knowledge about the disease. Another feeling identified was the worry/distress in knowing how they contracted the disease.

I got very worried and suspicious. I wanted to know how I had gotten it. My husband said I didn't have to worry about this (...). (I10, F42, B).

I have no idea how I got this, because I only have my husband, and he doesn't have sexual intercourse with anybody, only with me (...) (I1, F54, B).

They told it's through sex and blood transfusion you get it. I had a blood transfusion in 1979, but my husband was a truck driver and there were lots of women on the road. After we divorced he found out he had hepatitis, so maybe that's why I got it... I wonder if I got only that disease (I5, F56, B).

I just expected it wasn't anything I could transmit to somebody because I didn't want to pass anything on to my relatives (I11, M57, B and C).

In the reports of the studied women, it was observed that they usually associate the infection with extramarital affairs of their husbands because sex is one of the main forms of transmitting the disease, somehow interfering with the relationship and trust between partners.

With regard to the form of infection, some interviewees, after being informed in the service about the different modes of transmission of the disease, they pointed out situations they believed to be responsible for the infection.

Once I was fishing in a small river, then the drinking water ran out, and since I was very thirsty, I was forced to drink the water from the river. It happened around 15 years ago. The water was brown, but I was dying of thirst. Sometimes I think I got it from this water, you know. (I2, M44 and B).

When I think about it, I guess I got it when I was a child, because I used to go to the dentist very often (...) My nails, I've never been used to do them (I10, F42, B).

One of the issues consistently raised at the moment of hepatitis diagnosis refers to the fear of transmitting the virus to partners and family.

The first thing I asked my doctor was if the hepatitis I have could infect someone, then he said no, so I didn't get worried. (...) because I don't want to pass it on to anybody (I5, F56, B).

At that time, I talked to my girlfriend too, I asked her to do the exam (...). I got worried and distressed, wondering if I had passed on somebody; even the beard device my sister used was mine; I got worried and paid a private doctor for her to do the exam (I8, M27, C).

We also identified feeling of anxiety due to uncertainty regarding disease evolution.

I get worried, afraid of having something later, because nothing has shown so far (...) (I1, F54, B).

When I come here I get a little bit anxious, to know what they will say in there, how the disease is. (...) (I6, F35, B).

I'm worried about the disease having reached my liver, then I don't know what's going to happen (...) (I2, M44 and B).

It is interesting to observe that the interviewees expressed insecurity regarding the disease and feel apprehensive at every clinical monitoring because they are afraid of the

possibility of disease progression to the chronic form. While waiting for the consultation, I6 was sweating and performing repetitive movements with her hands, and I2 moved his legs as he was interviewed; that is, both showed physical signs of distress and anxiety.

Two of the twelve interviewees were being treated with interferon, and both reported fear of possible reactions associated with the use of this medicine:

When I started taking the injections it gave me some strange reactions, insomnia, I fell into depression, it appeared I was going to die, and everything because of the medicine. It interfered with my job, it also affected me while driving. One day I was driving my car and stopped when the traffic light was green and then accelerated when it was red. There were moments when I was kind of weird, kind of strange, some strange reactions. My mind went blank, I got scared (I2, M44 B and C).

On the first day I took the medicine I felt sick, my body and throat were bad, I had a fever, I started to throw up. I got a little bit afraid, then I took a medicine, slept and the other day I woke up a little bit better. (...) There are days when I wake up kind of bad, discouraged, wanting to do nothing and very sleepy. I think it's because of the hepatitis and the medicines. I asked my doctor and he said it's a normal feeling (I7, M21, B)

Attitudes and behaviors after the infection

The diagnosis of hepatitis, as well as any other disease, cause changes in some life habits, which will occur differently in each subject. Changes in dietary habits and alcohol consumption was observed in the patients' reports:

Last time I came here, the doctor explained to me I should avoid greasy food. Drinks, I've never been used to drink very much and nowadays I don't drink anything at all (...) Greasy meat, I don't eat it. I eat lots of whole grains, cereals, whole grain bread. I tried to improve my diet (I2, M44, B and C)

(...) It's been a year I started to take a medicine, then I decided not to drink any beer, I thought it was better to stop, you know. The doctor had told me that if I could quit it'd be good, so I quit. (I4, M56, B)

One thing I had to change but I didn't like much, the doctor said I should not drink anymore the beer I liked. Then I quit. Food too, I try not to eat greasy things, you know, I avoid them (I5, F56, B)

I have been avoiding going to parties, I'm doing so because I can't drink, so I end up feeling bad. Instead of going to parties I prefer to stay on the computer playing games. Sometimes I spend all day long on the computer (I8, M27, C)

The speeches also revealed changes at work and in their relationships.

I used to work at night, but after getting sick, I started to take the medicine, I changed the shift, I started to work in the morning. I was afraid of feeling bad at night, you know, and

also because of the reactions of the medicine (I7, M21, B)

My relationship ended because my girlfriend didn't want to do the exam. Then she decided to do it later, and it came out negative, but then she told me she wanted to break up because I didn't trust her (I8, M27, C)

In relation to work, it is noteworthy that the lack of accurate information about the forms of disease transmission abruptly changed the lives of some subjects.

At that time, when the doctor said I had to be monitored because I was suspected of having hepatitis I quit the job, because I worked in a kitchen, with food...I was afraid of cutting myself, getting hurt and ending up passing it on someone. So I decided to quit the job. I wasn't sure if I had it or not, but I was too afraid of passing it on to someone (I5, F56, B)

I worked at a cold-storage room, I was a cutting machine operator, the first thing I did was to quit the job, because I worked with food. Then I thought: if I cut myself the problem wasn't me, the problem was the person who was going to eat the food later. Nobody asked me to quit the job, but I wanted to do so, because I felt bad, and I also thought about the others, you know. (I8, M27, C).

Some subjects reported that, despite the diagnosis, they continued to adopt risky behaviors for virus transmission:

The doctor also asked me to use condoms to avoid passing it on to my wife, but we don't use it. Even my wife says she doesn't want to use it because if she had to get it she'd already got it (I4, M56, B) 8

We are not using condoms yet, we are waiting for the result of the exam (I6, F35, B)

DISCUSSION

The fact that most subjects are aware of the diagnosis of hepatitis as a result of blood donation is understandable because hepatitis is a disease that can present symptoms long after the initial infection. For this reason, it is common that the diagnosis occurs due to routine laboratory tests that reveal hepatic changes. A study pointed out that the main sources of diagnosis are blood centers and banks, hemodialysis clinics, and laboratories⁽⁹⁾.

Hepatitis has proven itself to be persistent given the difficulty diagnosing patients in the acute stage; thus, it is necessary to strengthen prevention strategies aimed to interrupt the chain of transmission. The addition of counseling, viral hepatitis testing in primary care, and the performance of health education campaigns are important measures recommended by the Ministry of Health with the aim of informing subjects about the risks of infection and whether they should submit to diagnostic tests⁽²⁾. This, however, requires prior knowledge of specific content related to the disease, including the identification of aspects indicative of greater vulnerability and the singular needs of the users. The knowledge

of vulnerability to communicable diseases assists in identifying individuals' health needs, which are marked by stigma, social exclusion, and fear⁽¹⁰⁾. There are groups historically excluded from health services because of their lifestyle, consumption habits, or sexual orientation, such as drug users, transvestites, prostitutes, and homeless people, but these are the same conditions that make these groups more vulnerable to hepatitis; therefore, it is important to increase their access to services while respecting their specificities⁽²⁾.

The feelings and changes in the daily life resulting from hepatitis diagnosis that were reported by the study subjects confirm what has been described in the literature: the diagnosis of an infectious and communicable disease brings worries and uncertainties to patients, especially when it comes to silent and slow diseases, with variable prognosis⁽¹¹⁾. Both feelings and changes appear to be associated with when and how they are informed of the diagnosis and with the lack of knowledge the general population has about the disease, more precisely about the form of transmission, evolution, prognosis, and treatment side effects, among other aspects, all of which make subjects feel vulnerable and powerless to cope with the disease.

It is noteworthy that the lack of knowledge about specific hepatitis symptoms and the possibility of its chronicity in the testimony of 11 are not only related to patients. A study conducted with nursing, pharmacy, and biology students at Vale do Araguaia found that they had little knowledge about these same aspects⁽¹²⁾. Another study conducted with health professionals of a military hospital in Rio de Janeiro found that only 20.5% of them knew the modes of disease transmission⁽¹³⁾.

These results suggest that health professionals should be properly sensitized about this disease and prepared to offer appropriate orientation, answer patients' questions, and even anticipate them in their approach, favoring knowledge about the disease, which is essential to prevent complications and promote self-care⁽¹⁴⁾. Moreover, professionals must be able to identify disease manifestations, provide support to help patients face it, and encourage them to commit to disease treatment and monitoring because as patients process information about the infection, they build a representation and use it to regulate their behavior⁽¹⁵⁾.

Also in relation to the knowledge of the disease, one of the aspects that incited some of the subjects, especially females, was to discover how they had contracted the disease. This is understandable because it is an infectious disease that can be transmitted through sex. In these cases, it is common for one of the members of the couple to associate contamination by a sexually transmitted disease (STD) to an extramarital relationship of his/her partner, excluding other possibilities, such as the latency period and other possible forms of infection⁽¹⁶⁾. It must be also

considered that women are in a situation of great vulnerability to STDs and, due to unequal gender relations, they usually accept unprotected sexual behavior because they trust their partners⁽¹⁴⁾.

These issues need to be addressed during health care. Thus, it is important that professionals offer emotional support; precise orientation about transmission modes, prevention, and latency period of the virus; and that they are available for listening and dialoguing to clarify patients' doubts and assist them in emotional conflicts, which is possible with a multi-professional, humanized, and holistic approach⁽¹⁶⁾.

Psychological problems after the start of interferon treatment, described by I2 and I7, including impact on their daily lives, are similar to the side effects described in the literature. Interferon is the only therapeutic modality approved by the Food and Drug Administration and can be used as a monotherapy or in combination with ribavirin⁽¹⁴⁾. About 20-40% of patients taking this medication may experience depression, anxiety, difficulty of concentration, apathy, sleep disorders, irritability, and even suicidal tendencies, symptoms that can have a negative impact on the course of the disease because of treatment interruption and change in quality of life⁽¹⁷⁾.

In such cases, the existence of a protocol for the psychological assessment of patients treated with interferon would allow the monitoring of psychological symptoms and the need for intervention, as well as identifying the main problems experienced by patients during treatment, thus providing subsidies for the development of programs consistent with the identified needs⁽¹⁷⁾.

Along with psychologists, nurses must become vigilant in order to identify depressive symptoms early. Patients who have chronic diseases, such as hepatitis and depression, need a higher number of consultations, which increases treatment costs. They are unable to perform daily activities and experience consequent deterioration in quality of life, a higher number of somatic complaints, difficulties adapting to aversive symptoms associated with the disease, and may be less compliant to prescribed treatment and have an increased risk of mortality⁽¹⁸⁾.

Moreover, it is important to highlight that identifying the difficulties experienced by patients with chronic diseases, as well as the strategies used by those who adapt to these adverse conditions, can assist professionals in designing more effective intervention programs for those who have adaptation difficulties⁽¹⁹⁾.

In this study, it is interesting the subjects reported that they were not sure if the symptoms they had resulted from the medicine they were taking, indicating, to some extent, a failure of communication with the health professionals, because prior knowledge about adverse medication effects helps patients to face the treatment more positively⁽¹⁷⁾.

Thus, considering that it is not always possible to prevent the occurrence of adverse effects, it is necessary that patients and professionals are attentive to their manifestation in order to detect them early, which facilitates their control and promotes treatment compliance⁽¹⁹⁾. Thus, health professionals must be prepared to identify difficulties experienced by patients who use the medication and provide clear and precise information concerning side effects to equip patients and families so that they can quickly identify disease manifestations of the disease and inform them about the importance of the treatment and the need to adhere to it, despite the existence of side effects that may negatively influence their daily lives.

The diagnosis of a chronic disease can affect a patient's entire life. This new condition requires changes in their lifestyle, relationships, and behaviors and in how they deal with themselves and their health, as they need to adapt to the new demands and overcome new difficulties and obstacles. In the case of hepatitis, patients fear the evolution to the disease's chronic form, as this will require more radical changes in different aspects of their daily life. The everyday reality of a person with a disease with the possibility of chronicity is marked by limitations in daily activities due to necessary lifestyle changes.

Changing eating habits is a measure that can reduce disease progression by slowing the damaging effects of the virus in the body and the appearance of symptoms⁽⁶⁾. Nevertheless, it can be seen in the subjects' comments that this change is hardly accepted by the patients due to the difficulty in following the recommendations, especially early in the process.

Changes in habits are usually experienced with difficulty; therefore, professionals must be able to orient subjects and point out the risks of alcohol consumption as the liver is the main organ affected by alcohol ingestion. The patient's commitment and accountability for their own health condition is a *sine qua non* condition for successful treatment.

Given this, it is necessary to provide, in an individual and specific way for each case, orientation that can guide subjects toward food choices that are best suited to their health condition. This also enables the use of an assessment in subsequent consultations regarding the adaptation of the subjects to what was proposed to them. It is necessary to adapt these orientations to the socio-economic and cultural conditions of the subjects and describe the importance of the treatment to encourage its adoption⁽⁶⁾.

In addition to dietary changes, the studied subjects reported relatively frequently the reduction or even cessation of alcohol consumption. A study about the effect of addictive substances in the progression of hepatitis C pointed out that the association of hepatitis virus infection and high consumption of alcoholic drinks may result in the synergistic acceleration of hepatic fibrosis⁽²⁰⁾.

It is also interesting that some subjects abandoned their jobs due to a lack of accurate knowledge about the modes of disease transmission and their fear of infecting other people. Given that, it should be emphasized once more that professionals have to describe the disease immediately after giving the diagnosis and offer patients general information that clarify the modes of transmission. This information must be reinforced during all contacts with the patients.

In some cases, we identified changes in social relations, especially in young patients for whom fun means being in fashionable places, with friends, and enjoy activities related to music and dance. The problem is that such activities have an intrinsic connection with alcohol and drug use, which are considered risk factors⁽²¹⁾. A study conducted in nine Portuguese cities with young people attending nighttime recreational environments showed that 59.44% of them valued the accessibility of alcoholic beverages as a major factor when they chose a place to have fun⁽²⁰⁾, which supports an objective relationship between these places and the consumption of psychoactive substances for recreational purposes⁽²²⁾. However, these substances potentiate the adoption of risky behaviors, for example, in the area of sexuality.

It is noteworthy that the choice not to attend certain events as a way to avoid the consumption of alcohol can further impair the quality of life of subjects due to various losses, for example, in social relationships, leisure activities, and pleasure.

Regarding sexual behavior, we note that although subjects were warned about the need to use condoms, some deliberately chose not to. Some studies have highlighted gender relations as responsible for the fact that women – even those with a reasonable knowledge of the epidemiological point of view on ways of contamination of STDs – are unable to or have difficulty implementing the use of condoms and seek ways to change this situation. Furthermore, the adoption of preventive behavior tends to decrease when the partner is known⁽¹⁴⁾. Some factors influence this decision, such as: a) the mate's power to decide on the adoption of preventive measures; b) cultural issues; c) gender differences that become evident when women face difficulties using condoms, leaving the decision to the man; d) lack of empowerment of women, who do not adhere to safer sex, becoming susceptible to illness, or an unplanned and even unwanted pregnancy; and e) confidence in their mates⁽¹⁴⁾.

Non-adhesion to safe sex practices is a difficult situation and can bring serious consequences for the couple.

REFERENCES

1. Cruz CRB, Shirassu MM, Martinsb WP. Comparação do perfil epidemiológico das hepatites B e C em um Serviço Público de São Paulo. *Arq Gastroenterol*. 2009;46(3):225-9.
2. Brasil. Ministério da Saúde; Secretaria de Vigilância em Saúde, Departamento de Vigilância Epidemiológica. Manual de aconselhamento em hepatites virais. Brasília; 2005.

This demonstrates a pre-existing difficulty in maintaining dialogue in the relationship, a situation that is aggravated when the couple is faced with a conflicting situation, such as the diagnosis of an STD⁽⁸⁾.

CONCLUSION

Given the complexity involved in the process of receiving a diagnosis of hepatitis, knowing the patient experience is essential to ensure quality, total care that values patients as individual human beings. The results of the study suggest that living with the diagnosis of hepatitis B or C impacts a variety of feelings, and causes suffering and behavioral changes that interfere with patients' quality of life. Concern with the diagnosis, lack of clinical knowledge of the disease, the possibility of chronic infection, the mode of transmission, and the fear and discomfort caused by medication reactions permeate the feelings and experiences of infected subjects.

Changes in habits and behavior, especially in relation to food and alcohol consumption, the impact on social relations (primarily pointed out by young people), and maintenance of risky sexual behavior are important indications that people with hepatitis need to be understood in the contexts of illness and living with a communicable and chronic disease. Achieving this requires support from health care professionals.

Although these results are limited to the subjects of the study and cannot be generalized in view of human subjectivity, they inform an approach to the different disease-related experiences in the subjects' lives and contribute to the expansion of knowledge in this area. Nevertheless, further studies with this approach are fundamental to the enrichment and better understanding of the changes that occur in subjects' lives after being diagnosed with hepatitis.

Finally, it is important to emphasize that in order to define strategies for the control of viral hepatitis, it is necessary to recognize the magnitude of the problem. Epidemiological surveillance of hepatitis is possible from the mandatory and qualified reporting of suspected cases.

Nurses, besides being prepared to assist and orient patients, also need to be attentive to signs of clinical complication, the occurrence of adverse reactions to treatment, and the quality of the notification. All of these aspects are important in the assessment and monitoring of disease progression, as well as early intervention, which is always the best option. This combination of measures will ensure greater quality of life and facilitate health care workers understanding of the epidemiological characteristics of sick patients.

3. Brasil. Ministério da Saúde; Secretária de Vigilância em Saúde. Doenças infecciosas e parasitárias: guia de bolso [Internet]. Brasília; 2005 [citado 2011 mar. 5]. Disponível em: http://bvsmms.saude.gov.br/bvs/publicacoes/guia_bolso_5ed2.pdf
4. Brasil. Ministério da Saúde; Secretaria de Vigilância em Saúde. Plano Nacional de Prevenção e Controle das Hepatites Virais [Internet]. Brasília; 2006 [citado 2011 mar. 5]. Disponível em: http://hepato.com/pnhv/Plano%20_PNHV.pdf
5. Sousa VV, Cruvinel KPS. Ser portador de hepatite C: sentimentos e expectativas. *Texto Contexto Enferm.* 2008;17(4):689-95.
6. Blatt CR, Roda JA, Sander G, Farias MR. Tratamento da hepatite C e qualidade de vida. *Rev Bras Farm.* 2009;90(1):19-26.
7. Melo LP, Silva NP, Silva KCL, Ponte MPTR, Gualda DMR. Representações práticas do cuidado com a ferida crônica de membro inferior: uma perspectiva antropológica. *Cogitare Enferm.* 2011;16(2):303-10.
8. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 11ª ed. São Paulo: Hucitec; 2008. p. 219-60.
9. Araújo MAL, Silveira CB. Vivências de mulheres com diagnóstico de doença sexualmente transmissível - DST. *Esc Anna Nery Rev Enferm.* 2007;11(3):479-86.
10. Nichiata LYI, Bertolozzi MR, Gryscek ALPL, Araújo NVDÁL, Padoveze MC, Ciosak SI, et al. The potential of the concept of vulnerability in understanding transmissible diseases. *Rev Esc Enferm USP [Internet].* 2011 [cited 2012 Jan 12]; 45(n. spe2):1769-73. Available from: http://www.scielo.br/pdf/reeusp/v45nspe2/en_23.pdf
11. CampolinaAG, Dini PS, Ciconelli RM. Impacto da doença crônica na qualidade de vida de idosos da comunidade em São Paulo (SP, Brasil). *Ciênc Saúde Coletiva.* 2011;16(6):19-25.
12. Ferrari CKB, Savazzi K, Honório-França AC, Ferrari GSL, França EL. Conhecimentos sobre hepatites virais numa amostra de estudantes brasileiros do Vale do Araguaia, Amazônia Legal. *Acta Gastroenterol Latinoam.* 2012;42(1):120-6.
13. Pinheiro J, Zeitoune RCG. Hepatite B: conhecimento e medidas de biossegurança e a saúde do trabalhador de enfermagem. *Esc Anna Nery Rev Enferm.* 2008;12(2):258-64.
14. Ávila MP, Freitas AM, Isaac DLC, Bastos ALM, Pena RV. Retinopatia em paciente portador de hepatite C tratado com interferon peguilado e ribavirina: relato de caso. *Arq Bras Oftalmol.* 2006;69(2):255-9.
15. Carlo FS, Lima JF, Sene MC, Rosa NM, Cardoso VH, Aguiar JE. Perfil do portador de hepatite B do Município de Maringá. *Saúde Pesq.* 2008;1(3):241-6.
16. Barroso MGT, Souza LB. DST no âmbito da relação estável: análise cultural com base na perspectiva da mulher. *Esc Anna Nery Rev Enferm.* 2009;13(1):123-30.
17. Miyazack MCOS, Domingos NAM, Valério NI, Souza EF, Silva RCMA. Tratamento da hepatite C: sintomas psicológicos e estratégias de enfrentamento. *Rev Bras Ter Cogn.* 2005;1(1):119-28.
18. Kraus MR, Schaefer A, Csef H, Scheurlen M, Faller H. Emotional state, coping styles, and somatic variables in patients with chronic hepatitis C. *Psychosomatics.* 2000;41(5):377-84.
19. Carvalho MF, Zanini AC, Camacho JLP, Barone AA. Monitoramento de reações adversas da interferona alfa no tratamento ambulatorial da hepatite C crônica. *RBCF Rev Bras Ciênc Farm.* 2001;37(1):27-38.
20. Ferreira AIG. Substâncias aditivas como fatores de progressão na Hepatite C crônica [dissertação]. Porto (PT): Instituto de Ciências Biomédicas Abel Salazar, Universidade do Porto; 2007.
21. World Health Organization (WHO). Working Group on Youth Violence, Alcohol and Nightlife. Global Campaign for Violence Prevention [Internet]. 2012 [cited 2012 Mar 5]. Available from: <http://www.who.int/violenceprevention/en/>
22. Stamm M, Bressan L. Consumo de álcool entre estudantes do Curso de Enfermagem de um Município do Oeste Catarinense. *Ciênc Cuidado Saúde.* 2007;6(3):319-24.