

## LIVING WITH HEPATITIS: THE EFFECT OF INFECTED SUBJECTS ON EVERYDAY LIFE

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### Abstract

To identify changes in the everyday life of hepatitis subjects, we conducted a descriptive, exploratory, and qualitative analysis. Data from 12 hepatitis B and/or C patients were collected in October 2011 through a semi-structured interview and subjected to thematic content review. Most subjects have been diagnosed with hepatitis B. The diagnosis period ranged from less than 6 months to 12 years, and the diagnosis was made predominantly through the donation of blood. Interferon was used in only two patients. The findings were divided into two groups that define the interviewees' feelings and responses, as well as some lifestyle changes. It was concluded that the magnitude of phenomena about the disease process and life with hepatitis must be understood to health professionals.

**Keywords:** Hepatitis; Nursing; Communicable diseases; Diagnosis; Life change events; Nursing care.

### Introduction

Brazil is in a complete epidemiological transformation, but the major cause of death is non-communicable chronic diseases, and infectious disease prevention remains a public health issue. Among these diseases, due to its high prevalence, potential complications of its acute or chronic manifestations and the need for long-term monitoring, hepatitis is a significant concern for health services. The World Health Organization reports that there are about 325 million people with hepatitis B and 170 million with hepatitis C worldwide, with estimates ranging from 2 to 3 million in Brazil. Moreover, at least 15% of the population is currently susceptible to the hepatitis B virus (HBV) and 1% to the chronic form of the disease. There were 130,354 cases of hepatitis A, 104,454 cases of hepatitis B, and 69,952 cases of hepatitis C in the 1999-2010 period, with major differences between the different states of Brazil [1]. It should be emphasized that most individuals are unaware of their serological status, which further aggravates the chain of transmission of infections. An significant cause of morbidity and mortality worldwide and one of the key causes of hepatic decompensation, cirrhosis and

hepatocellular carcinoma is chronic hepatitis B or C infection. Chronic infection may trigger greater stress and have a detrimental effect on the quality of life of patients, their social relationships and the output of daily activities, irrespective of the hepatic clinical symptoms associated with extrahepatic manifestations and cognitive changes. Hepatitis is therefore an important health care concern, not only because of its high prevalence, but also because of the potential for complications of its acute manifestations, long-term chronification, and the impact it has on infected subjects. Several studies report that chronic diseases influence the lives of patients, triggering changes in psychology and actions that involve analysis of everyday behaviors and strategies to face this new reality [2]. In certain cases, the discovery or onset of treatment of the disease will lead to major changes in patients' lives. For example, subjects with hepatitis C are more constrained when conducting everyday activities (work, school, home) and have less faith in the efficacy of the treatment, indicating a quality of life trend lower than subjects who do not have the disease. Given the complexity of the phenomena related to the disease process and life with

hepatitis, interventions that allow patients to transcend the biological dimension are placed on care practices. For this, health practitioners need to have attitudes towards recognizing the different aspects of the biological, cultural, social and subjective phase of living and being healthy. According to values, attitudes, behaviors, images, interpretations, and personal and collective experiences, the effect of disease on everyday life varies from individual to person. Therefore in order to allow their integration and engagement in this culturally diverse environment it is important that nursing practitioners recognize, from the perspective of patients, the effect of the diagnosis on their daily lives. In addition, a new approach to nursing care is required to ensure individualized service that values the individual as a holistic person as opposed to reductionist and technocratic views [3].

The aim of this research, given the above exposure, was to recognize improvements in the everyday life of subjects diagnosed with hepatitis [4].

### Material and Methods

We conducted an exploratory, descriptive, cross-sectional and qualitative analysis of patients with hepatitis B or C who were followed by the Hepatology and Infectious Diseases clinic at the University Hospital of Maringá. The service applies to the 30 municipalities forming the 15th Regional Health Service of Paraná in relation to the care of patients with suspected or confirmed viral hepatitis diagnosis. The service is carried out twice a week and five appointments are scheduled every day on average. 87 suspected cases of hepatitis were identified in 2011, all of which were investigated and when confirmed, monitored by the infection clinic. Of the 87 cases suspected, 33 had a confirmed diagnosis of hepatitis B, 30 had a confirmed diagnosis of hepatitis C, 18 were still under investigation and 6 had a confirmed diagnosis of not being infected. The data was collected in October 2011 through semi-structured interviews in the private rooms of the Maringa University Hospital. While waiting for consultation with an infectologist, the subjects were approached, told about the study's goals, and invited to participate. The interviews were performed in a private room, recorded with the consent of the interviewees and directed by an instrument consisting of two parts: the first concerned patient characterization issues, and the second was introduced as

follows: Speak about the changes in your everyday life after hepatitis diagnosis. We interviewed a total of 12 patients. The interviews ended when the data needed to achieve the study's target began to be replicated. The subject being 18 years of age or older and getting a diagnosis of hepatitis were the conditions followed for inclusion in the report. Gender, age, marital status, education, occupation, time of diagnosis, type of hepatitis, and interferon use were characterized according to the following variables. The interviews were transcribed for data analysis and then subjected to thematic content analysis, followed by pre-analysis, information discovery, processing, and outcome interpretation phases. The speeches were read during the pre-analysis to identify the points important to the study's target. The material was codified during the discovery phase, a mechanism in which raw data is converted and aggregated systematically into units. In the last step, a categorization was drawn up by classifying the elements according to their similarities and differences and subsequently regrouping them in relation to common characteristics. The study was established in compliance with the recommendations of Resolution No. 196/96 of the National Health Council and approved by the Committee on the Control and Supervision of Academic Activities and Volunteer Services of Maringá University Hospital and the Ethics and Research Committee on Human Research of Maringá State University (Protocol No. 724-2011). All subjects have signed, in duplicate, an informed consent form. The following codes were used to distinguish between subjects and protect their identity: letter I (interviewee), followed by a number indicating the order of the interview, and letters M and F for the identification of males and females, with another number indicating the informant's age and a third letter indicating the type of hepatitis.

### Results

Chart 1 shows the features of certain subjects. Most of them were male, married and undereducated. The age of the subject varied from 21 to 57 years, averaging 43 years. The time of diagnosis was very variable and the interviewees were diagnosed with hepatitis after blood donation, except for I6 and I12, and the most frequent form was hepatitis B. The I2 and I7 interviewees had the disease in its chronic phase and also took interferon [5].

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

<b>Id</b>	<b>Gender</b>	<b>Age</b>	<b>Marital Status</b>	<b>Education</b>	<b>Occupation</b>	<b>Type of hepatitis</b>	<b>Time of diagnosis</b>
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

### Opinion towards the disease

Some of the feelings and reactions encountered by the interviewees after the diagnosis of hepatitis B or C were illustrated in many studies, such as the concern and fear of transferring the virus to their partners, the feeling of helplessness because of the lack of information about the disease, and the distress of wanting to know how they contracted hepatitis [6].

The doctor said that I had hepatitis (...) I was terrified because I had no idea what it was. I haven't thought anything () (I1, F54, B).

I was very sad, I was shocked, I thought it was the end, a very serious illness... I was terrified because I didn't know anything about this illness, but then the doctor told me that I didn't have to worry about it that she would still do all the tests to see if it shows up (I6, F35, B).

It was found that the diagnosis was accompanied by negative and troubling feelings for most of the interviewees (8), primarily due to the lack of signs and lack of information about the disease. The fear/distress in learning how they contracted the disease was another feeling found.

I became very alarmed and suspicious. I wanted to know how I came up with it. My husband said that I had no reason to think about it (...).

I don't know how I got it, because I just have my husband, and he doesn't have sex with anyone, only me () (I1, F54, B) [7].

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).

They said that you get it through sex and a blood transfusion. In 1979, I had a blood transfusion, but my husband was a truck driver and a lot of women were on the road. He learned he had hepatitis after we split, so maybe that's why I got it... I wonder if I just had that disease (I5, F56, B).

I just expected it wasn't anything I should pass on to anyone because I didn't want anything to pass on to my family (I11, M57, B and C).

It was found in the reports of the women studied that they typically associate the infection with their husbands' extramarital affairs because sex is one of the primary ways of transmitting the disease, interfering somehow with the relationship and trust between partners [8].

With regard to the type of infection, some of the interviewees, having been told by the department of the various modes of transmission of the disease, pointed out circumstances which they considered to be responsible for the infection.

When I was fishing in a tiny river, the drinking water ran out, and I was forced to drink water from the river because I was very thirsty. About 15 years ago, it happened. It was brown in the water, so I was dying of thirst. I think I've got it from this water sometimes, you know [9].

When I think about it, I suppose I got it when I was a kid, because very much I used to go to the dentist. (...) My nails, I never got used to doing them (I10, F42, B).

The fear of transmitting the virus to partners and family relates to one of the concerns regularly posed at the time of hepatitis diagnosis.

The first thing I asked my doctor was whether anyone was sick with the hepatitis I had and then he said no, so I didn't worry. (...) Because I wouldn't want to pass it on to someone (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 have also reported feelings of fear due to confusion about the evolution of diseases.

It is important to note that at any clinical monitoring, the interviewees expressed insecurity about the disease and felt apprehensive because they are afraid of the possibility of disease progression to chronic type. I6 was sweating and doing repetitive motions with her hands while waiting for the appointment, and I2 moved her legs while he was interviewed; that is, both showed physical signs of discomfort and anxiety [10].

### Post-infection attitudes and practices

As with any other illness, the diagnosis of hepatitis induces changes in some life behaviors, which will happen differently in each subject. Changes in food and alcohol intake habits have been observed.

### The speeches also showed alterations at work and in their interactions.

I used to work at night, but I started taking medication after I got sick, I changed my shift, and I started working in the morning. I was scared of feeling bad at night, you know, and of the medicine's reactions, too (I7, M21, B) [11-13].

### Discussion

It is understandable that most subjects are aware of the diagnosis of hepatitis as a result of blood donation, since hepatitis is a disease that can have effects long after the initial infection. For this reason, due to routine laboratory tests that show hepatic changes, it is normal that the diagnosis takes place. The key sources of diagnosis are blood centers and banks, hemodialysis clinics and laboratories, a study pointed out. Given the challenge of diagnosing patients in the acute stage, hepatitis has proven to be persistent; hence, preventive measures aimed at interrupting the chain of transmission need to be improved [14]. Important interventions suggested by the Ministry of Health are the addition of counselling, viral hepatitis testing in primary care, and the execution of health education programs in order to warn subjects about the dangers of infection and whether they can submit to diagnose test. However this involves prior awareness of relevant disease-related content, including the identification of aspects that are indicative of greater vulnerability and of the users'

particular needs. Awareness of susceptibility to communicable diseases helps to recognise the health needs of individuals characterized by stigma, social isolation, and anxiety [10-14]. Owing to their diet, consumption patterns, or sexual preference, there are individuals traditionally excluded from health care. Since these are the same factors that make these groups more vulnerable to hepatitis, such as drug users, transvestites, prostitutes and homeless people, it is important to improve their access to care while respecting their unique characteristics [15].

The emotions and changes in daily life arising from the diagnosis of hepatitis identified by the subjects of the study confirm what has been stated in the literature: the diagnosis of an infectious and communicable disease brings patients with variable prognosis concerns and uncertainties, particularly when it comes to silent and slow diseases. When and how they are told of the diagnosis and with the lack of knowledge of the general public about the disease, more specifically about the mode of transmission, evolution, prognosis, and side effects of treatment, among other things, all of which make subjects feel helpless and unable to cope with the disease, both feelings and changes seem to be associated with [16].

It is interesting that the lack of awareness of particular symptoms of hepatitis and the likelihood of its chronification in the II testimony are not only patient-related. A research conducted at Vale do Araguaia with nursing, pharmacy, and biology students found that they had little knowledge of the same aspects. Another survey conducted with health professionals at a Rio de Janeiro military hospital found that only 20.5% of them understood the modes of transmission of diseases [12-16].

These findings indicate that health professionals should be adequately sensitized to the disease and prepared to provide sufficient advice, answer questions from patients, and even predict them in their approach, cultivating awareness of the disease that is necessary for avoiding complications and promoting self-care. In addition, clinicians must be able to recognise disease symptoms, offer resources to help patients face it and enable them to participate in disease care and monitoring so they create a representation and use it to control their actions as patients' process information about the infection [17].

One of the aspects that prompted some of the subjects, particularly women, to discover how they had contracted the disease was also linked to the understanding of the disease. This is understandable because it can be transmitted by sex as an infectious disease. In these cases, it is normal to link sexually transmitted disease (STD) contamination with the extramarital relationship of one of the members of the pair, excluding other explanations, such as the latency duration and other potential modes of infection. It must also be considered that women are in a situation of great vulnerability to STDs and typically tolerate unprotected sexual activity because they trust their partners because of unequal gender ties [18].

Such questions must be resolved during the process of health care. It is therefore vital that practitioners have

emotional support; correct orientation on the modes of transmission, prevention, and latency of the virus; and that they are available for listening and dialoguing to explain the doubts of patients and assist them in emotional disputes, which is possible with a multi-professional, humanized, and holistic approach.

The psychological symptoms identified by I2 and I7 after the start of interferon therapy, including the impact on their everyday lives, are similar to the side effects described in the literature. Interferon is the only Food and Drug Administration-approved therapeutic modality that can be used as monotherapy or in conjunction with ribavirin. Approximately 20-40% of patients taking this drug can experience depression, anxiety, trouble concentrating, apathy, sleep disorders, irritability, and even suicidal impulses, symptoms that may have a detrimental effect on the course of the disease due to disruption of care and improvements in the quality of life [19].

In such cases, the presence of a psychological evaluation procedure for patients treated with interferon will allow for the tracking of psychological symptoms and the need for intervention, as well as the recognition of the key issues faced by patients during care, thus providing incentives to establish interventions compatible with the needs found.

In order to detect depressive symptoms early, nurses must become attentive, along with psychologists. For patients with chronic diseases such as hepatitis and depression, a higher number of consultations is expected, which raises the cost of care. They are unable to carry out everyday activities and experience a consequent decline in the quality of life, a greater number of somatic complaints, difficulties responding to disease-related aversive symptoms, and may be less compliant with prescription medication and have an increased risk of mortality.

In addition, it is important to emphasize that the recognition of the challenges faced by patients with chronic diseases, as well as the methods used by those who adapt to these adverse conditions, may help clinicians develop more successful intervention systems for those with adaptation issues.

In this study the participants indicated that they were not sure if the symptoms they had originated from the drugs they were taking, suggesting, to some degree, a failure to interact with health providers, since previous awareness of adverse drug effects enables patients to face the treatment more favorably.

Therefore, given that it is not always possible to avoid the development of adverse effects, in order to detect them early, patients and clinicians must be attentive to their manifestation, which encourages their monitoring and promotes compliance with care. Health practitioners must also be prepared to recognise problems faced by patients who use the drug to provide consistent and reliable information on side effects to equip patients and families to easily identify disease manifestations and advise them of the effectiveness of the treatment and the need to stick to it, considering the presence of side effects.

A chronic disease diagnosis can affect the whole life of a patient. This new condition involves changes in their lifestyle, relationships, and attitudes as they need to adapt to the new demands and overcome new challenges and obstacles, and in how they cope with themselves and their wellbeing. Patients fear the progression of the disease to its chronic phase in the case of hepatitis, as this would entail more drastic changes in various aspects of their everyday lives.

Non-adherence to safe sex practices is a daunting situation that can have significant repercussions for the pair. This reveals a pre-existing problem in sustaining relationship dialogue, a condition that is compounded when the couple encounters a contradictory situation, such as the diagnosis of an STDD [17-19].

### Conclusion

The study findings indicate that living with the diagnosis of hepatitis B or C affects a number of emotions and induces suffering and behavioral changes that interfere with the quality of life of patients. The thoughts and experiences of infected subjects are pervaded by uncertainties about the diagnosis, lack of professional awareness of the disease, the likelihood of chronic infection, the mode of transmission, and anxiety and distress triggered by drug reactions.

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