

Original Article

Repercussions of chronic hepatitis C treatment

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Abstract

Introduction: Individuals living with hepatitis C experience a series of changes in their lives, caused by either the disease itself or its treatment or both. In this sense, living with a chronic disease such as hepatitis C implies that patients must change their lifestyles, which requires that they rethink their habits in light of the new reality. To comprehend chronic hepatitis C patients' perceptions, meanings, and quality-of-life effects. **Methodology:** Qualitative research; interviews with 12 patients at a specialized outpatient clinic from February to July 2012. The cohort size was determined by theoretical saturation and the interviews were analyzed by means of content analysis. **Results:** Data were organized into four categories: on medication, referenced fears, impact on sexuality, and coping with the new reality. The categorized data were discussed around the following themes: "Becoming sick" due to treatment and perceived aspects and Undergoing treatment and how to cope with it. **Conclusion:** Patients' everyday lives and quality of life in general are affected especially by adverse side effects of hepatitis C medication and an assortment of feelings and uncertainties about the disease prognosis. Notwithstanding, most patients manage to find ways to cope with the treatment and complete it expecting a satisfactory outcome.

Key words: Adherence to medication; nursing; chronic hepatitis C; perceptions.

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Introduction

Hepatitis C, formerly classified as non-A and non-B hepatitis, has been considered one of the chief causes of chronic liver disease worldwide since its discovery in 1989 [1].

Globally, it is estimated that approximately 1% to 3% of people are infected with hepatitis C virus — amounting to 130-150 million people (either with nonspecific symptoms or asymptomatic) — and over 500 thousand deaths every year [2]. In Brazil, it is believed that 1,400,000 to 1,700,000 people live with this virus, with 10,000 new notifications every year and 86% of all cases in the south and southeast regions [3].

Hepatitis C is predominantly transmitted via the parenteral route, which makes IV drug users and people exposed to biohazards highly susceptible [4]. Treatment for hepatitis C is free and conducted at outpatient clinics in Brazil. It encompasses many therapeutic schemas to meet the needs of different patients in order to promote their adherence to treatment. Notwithstanding, hepatitis C treatment often causes many adverse side effects such as hematological disorders, thyroid dysfunctions,

headache, fatigue, fever, and myalgia. It has been also associated to psychiatric disorders such as depression, mood swings, violent temper, and suicidal behavior, which have a significant impact on patients' quality of life [3,5].

Individuals living with hepatitis C experience a series of changes in their lives, caused by either the disease itself or its treatment or both. In this sense, living with a chronic disease such as hepatitis C implies that patients must change their lifestyles, which requires that they rethink their habits in light of the new reality [6].

Therefore, this study aims to comprehend the perceptions, meanings, feelings, and quality-of-life effects of individuals that are undergoing or have just undergone hepatitis C treatment.

Methodology

This research is of a clinical-qualitative nature, i.e., it focuses on conscious and unconscious meanings conferred to phenomena by those who experience them [7]. The study was carried out in a medium-size city

upstate São Paulo, Brazil (220,000 inhabitants). Data collection took place at an outpatient clinic specialized in infectious diseases from February to July 2012.

The research participants were patients at the said clinic. Inclusion criteria consisted of: undergoing treatment or having completed it no longer than one month before the interview date; having no comorbidities; being older than 18 years; and being in good intellectual, emotional, and physical state so as to be able to undergo interview. Participants were thus selected as per convenience and their number (n = 12) was defined by theoretical saturation of data [8].

After the participants had signed an informed consent form, interviews were conducted at the said clinic. Interviews were individual, semi-structured, and taped to be later transcribed.

The participants' accounts were analyzed by means of content analysis (enunciation analysis), which gave rise to four categories: *on medication*, *referenced fears*, *impact on sexuality*, and *coping with the new reality*. To ensure the participants' anonymity, excerpts of their interviews were coded with the letter E, followed by numbers in ascending order of interview occurrence (E1, E2, ... E12).

This study was approved by the Research Ethics Committee at Federal University of São Carlos (Opinion No. 418/2011) and meets the ethical requirements of Resolution 196/96 of the National Health Council.

Results

Characterization of Participants

Participants were mostly female (75.0%), aged from 40 to 50 years (49 years old in average), from the city of São Carlos, São Paulo State, Brazil (66.7%), elementary or secondary school graduates (83%), and married (75.0%). At the time of the interviews, most of them were working (75%), received more than three times the minimum wage (58.3%), mentioned some religious affiliation (66.7%), and reported not having a private health plan (58.3%).

Qualitative Analysis of Participants' Answers

Category 1 – On Medication

This category presents descriptions of difficulties encountered by the participants when undergoing treatment due to several adverse side effects of hepatitis C medications as well as their administering: *It was hard because I had all of the side effects. I had to take time off work (E2); My taste has changed; I have a bitter taste in my mouth now (E10); My hair is falling*

out. I'm all swollen. [...] Many side effects on top of all the psychomotor troubles (E7).

These effects were identified as altering the patients' lives in significant ways, causing physiological disorders such as diarrhea, vomiting, headache, altered taste, weight loss, alopecia, fever, myalgia, altered reflex, and dizziness. The participants also mentioned mood disorders and depression: *A lot of diarrhea, a lot of vomiting, a lot of headache (E2); I have no heart for anything; I don't even feel like getting out of bed. Headache, very strong headache. It doesn't happen every day, but when it does, it's very painful [...], but I think it's due to fatigue, right? (E10); It makes me despondent. A lot of pain all over the body, too! I get a little depressed. Also, I have no energy to do stuff I used to do. Almost every day (E6); I have many mood swings. [...] Today I'm euphoric; tomorrow I'm dying; the next day I'm happy [...]. My mood changes a lot and I know it's because of the treatment. I'm trying to control myself, but it doesn't always work [...]; sometimes I end up quarreling for no reason at all [...]. A really short fuse... (E7).*

The participants pointed to the discomfort due to the administration of the medication, such as skin alterations, aversion to procedures, among others. All these changes directly affected the patients' everyday lives, from absence from work to hospitalization to mitigate these side effects: *Having to take the shot... my skin hurts! (E7); I hate needles, so I've been forced to see them differently! (E4); I often put the medicine in my mouth and then rush to the bathroom to throw up (E8); I felt terrible. I was hospitalized several times during treatment, because as I lost a lot of weight [...], I am still underweight, [...] a lot of weakness, dizziness (E3).*

In addition, the participants spoke about everyday situations in which they felt harassed and discriminated against ("marked") because of their having a hepatitis C diagnosis as well as noticeable physical changes due to the adverse side effects of treatment: *I'll be very thin; I'll look very sick! (E5); Some people say 'Wow! You've lost so much weight! Why are you so skinny?' 'You're so yellow!' [...] I've talked about it with very few people; people are very prejudiced (E8); I say to those who don't know and I don't want them to know, 'loads of work, loads of work! I've lost weight because I've been working a lot!' (E6).*

Category 2 – Referenced Fears

This category depicts different types of fear generated by uncertainties as to the effectiveness and benefits of medication, disease progression, and

fantasies about the future and death: *I was really scared about the treatment because it is serious stuff... If I take this medication, will I get better? Won't it affect something else? (E1); I see older people in perfect health and think to myself, 'Oh my God, I'm not sure I'll get there!' It's hard; it's really hard! (E4).*

The data also revealed the participants' need to deny their medical condition for fear of being discriminated against, resulting in their hiding the disease from others: *I dare not tell anyone! Nobody in my family knows. I say that it's something else. Fear of discrimination! (E10). I say nothing because of prejudice. Because my sons-in-law (and family in general), they might stop me from having contact with my grandchildren. That's why I haven't told them! (E4).*

Lack of knowledge about how the disease is transmitted was identified as conducive to social isolation due to fear of transmission: *I isolated myself; I thought I was going to transmit the disease to my son! I didn't want to pass it on to anyone! I know it cannot be transmitted by mere kissing [on the face], but I stand back (E10); It's prejudice; I think they don't understand it. It's prejudice or, better, fear of catching it! Because they lack information (E3); There's a lot of prejudice; people don't know what hepatitis C is! (E8).*

Anxiety was present in the participants' feeling of incapacity and dependence on others: *It changed my ability to work and I hate to be idle! I'm a little depressed, crying for no good reason. This is very distressful! (E2); I'm a very independent person and I haven't been able to drive... I'm very dependent now and that bothers me a lot! It's a real pain for me! (E7).*

Their reported perceptions pointed to stigma and prejudice arising from others' commiseration, which may have affected some of the participants' self-esteem: *I know that people feel sorry for me, have pity on me! It's horrible to know that! (E12).*

Accepting the new situation, i.e., the fact that they have a chronic disease and need to undergo a treatment that implies a number of lifestyle changes, also generates anxiety. Patients are compelled to reflect on their self-concepts and beliefs, which inevitably leads them to perceive and face their own fragility, inherent in their values and certainties: *I never thought I'd get this sick! God knows how full of life I was! But today I'm really down low, feeling awful (E12).*

The participants also reported uncertainty about the future regarding employment, which caused emotional instability and distress: *I had to stop cleaning houses. So I'm afraid that when I go back to work after taking two months off, my job won't be there anymore! (E12);*

I ask myself, 'Will I ever get out of this? This treatment, this strong medication, and all?' (E5).

Category 3 – Impact on Sexuality

This category comprises several behaviors and difficulties in dealing with sexuality in the context of a contagious disease and changes generated by its treatment, as evidenced by the participants' fear of transmission and embarrassment and shame in their intimate relationships: *About the relationship with my husband, it's sort of lacking intimacy; there's a lot to be desired. We haven't been able to work it out. First, because I'm afraid, 'Oh my God, the virus might be in full bloom today and if we have sex, I may pass it on to him!' (E6); I'm a little ashamed to talk about it, because people may say, 'Ah, she got it from another man'. That really bothers me. I'm ashamed to talk about it [...]. Even when I found out I had this problem, I thought my husband had it, too, because in spite of the fact that we had been together for six years by then, we had also been estranged for some time every year. I thought he had caught something out there and passed it on to me (E12).*

The data also indicated the participants' tacit behavior concerning the need to explain their medical condition to their partners as well as to find explanations that rule out infection through sexual contact: *I was ashamed when I told my husband because I did not know where I had caught it. [...] So I was like... I said, 'Oh my God, we'll have to figure out how I caught it because if it's only through sex...' [...] 'Needles, needles...As I've never done [IV] drugs, it can only have taken place in a relationship, right? [...]. But it may have happened through ha syringe that my father used on us when I was little or a pint of blood I had to take when my last child was born 25 years ago. There was no control at that time. Then, I've relaxed a bit (E6).*

In addition, there is the difficulty in talking to one's partner about the risk of transmission and use of condoms: *He's madly in love with me, you know; so [...] he says that if he must die, both of us will die [crying and laughing]. For this reason, he doesn't take precautions. He says that we'll both die then. If one dies, both will die. It's hard to convince him! (E10).*

Category 4 – Coping with the New Reality

In this category, it is possible to observe several strategies devised by the participants to cope with and complete their treatment. Feelings of acceptance and hope, change of values as well as the support of family and friends were extensively present in most patients'

accounts. However, it should be noted that there was ambiguity in their feelings. In addition, to moments of unrealistic hope, there was lack of knowledge about the seriousness of the disease: *My focus is on getting better, OK? I believe I've reached my goal because, to me, this treatment has already cured me! (E8). I don't let myself think that I have this disease! In my mind, I don't have it! In my mind... Good for me, isn't it? (E12).*

The participants' disposition to reflect on their own lives and to change their life styles to counter the adverse effects of hepatitis C diagnosis and treatment appears to have been an important coping strategy: *I see things in a different light now. [...] It seems that it will never happen to you, right? One is Superman! It's your neighbor who gets sick; you never do! So, you arrogantly assume [...] that it will never happen to you; it only happens to others and, sometimes, people are suffering [...]. We judge them! [...] You end up becoming more conscious [...]. I think that I've grown a lot as a man. I value my life more now and that of others, too (E3).*

The support offered by the Internet and other media outlets was also mentioned. However, it should be noted that this type of resource can generate not only useful information, but also distorted concepts, which can jeopardize the achievement of a satisfactory outcome to the treatment: *You can read a lot about it. I've already searched the internet. Today, I know it's going to be tough (E4).*

Although the wish to stop treatment was reported, the will to cope with it, overcome its difficulties, and complete it was stronger: *I've thought about quitting because it affects me physically, but my mother says that I'm very stubborn. I haven't quit out of stubbornness (E3); It makes you want to give up! You really feel like quitting. Yes, I've wanted to give up. But you have to set some goals, right? [...] I want to be cured! I want to be cured! (E2); I've wanted to quit many times! Oh, because this medication is just horrible! (E8); Because I'm very spiritual, I harbor no dark feelings [...]. This treatment will come and go and I'll stick to it; that's it! No big deal; I'm not angry or anything [...]. I'll do the treatment if I must, and that's the end of the story! (E7); My goal was to be cured, right? And I've achieved my goal! To me, this treatment, it has cured me, right? I've been cured! [...] I'm a winner! I'm so happy that today is my last day [crying]. Really happy! [crying] God knows it hasn't been easy [crying] (E8).*

The above and following excerpts also convey some of the participants' sense of religiosity and hope, which appears to have determined their adherence to

treatment: *From the very beginning, I've placed everything in God's hands and God is doing his job. So to me, everything's just fine! Everything! (E12); I have to do meditation; I try to stay calm. I do get out of balance at times, but it's possible to rise above these tough times! (E4).*

Discussion

The results have pertinent observations about the treatment, which can influence hepatitis C patients' feelings and emotions, quality of life, interpersonal relationships, and outlook on life. In this sense, it was possible to identify two issues relevant to the discussion: "becoming sick" because of the treatment and undergoing treatment.

"Becoming Sick" Because of the Treatment: Perceived Aspects

The hepatitis C diagnosis proper promotes several changes in a person's life. It constitutes an unexpected and stressful event, which may engender feelings of fear, denial, grief, anger, sadness, and stigma. Since hepatitis C is a frequently-asymptomatic and slowly-evolving chronic disease, it is the diagnosis itself that causes patients to realize they are sick, which is further corroborated when the first adverse side effects of treatment set in [6,9].

Because it is a chronic disease, the literature acknowledges the fact that hepatitis C gives rise to psychological stress and is responsible for other important stressors such as undesired changes in lifestyle and looks, low vitality, and the treatment proper [5].

Hepatitis C medication may bring about adverse side effects, which have also been identified as important daily life stressors and changers. As these side effects interfere with patients' quality of life, they can affect the treatment outcome [6,9].

Occurrence of interpersonal conflicts, hostility, irritability, and mood swings has been reported during the medication phase [5]. Patients' quality of life decreases due to the negative impact of hepatitis C medication on their vitality, which concurs to changes in their physical and mental states (e.g., depressive moods), especially in the first months of treatment [10].

The different forms of viral hepatitis (including hepatitis C) are still largely unknown to the public as well as many healthcare professionals. This results in lack of awareness about bio safety measures, which can in turn lead to unfounded fears of transmission [11]. In view of this fact, hepatitis C patients experience feelings of fear, anger, shame, and isolation in response

to stigma, thus opting to remain anonymous for fear of being discriminated against [10].

Given the difficulties and distress reported above, it is important to consider the perception and interpretation of the coping strategies devised by the study participants to facilitate adherence to treatment and promote its successful completion. It is up to health professionals directly involved with patients undergoing treatment of life-threatening diseases to reflect on and work through the importance of coping. Health professionals should not reinforce patients' fantasies and unrealistic hopes about their disease, which in themselves can be even more distressing and scary. On the contrary, hepatitis C patients should be supported and assisted so as to gain accurate knowledge of their medical condition, thereby promoting a satisfactory outcome to their treatment.

Undergoing Treatment: Coping Strategies

Given the abovementioned facts, it is vital to devise strategies for hepatitis C patients to cope with undesired changes and to undergo and complete their treatment expecting a satisfactory outcome. The participants' accounts indicate that despite their moods swinging between realistic and unrealistic hopes, it is possible to find self-acceptance amidst a new reality. This shows the importance of supporting hepatitis C patients, often fraught with disease-related uncertainties and challenges.

In their relationship with the supernatural, human beings set up exchange rituals by means of which previous achievements may be repeated and failures justified. These rituals operate in between hope and hopelessness [12]. This indicates that although the participants in this study may have struggled with the meaning of punishment and guilt involving their whole lives and were ultimately unable to detach themselves from the reality of their disease, they believed they would be somehow rewarded for their good conduct.

The presence of religious support is important to promote patients' hope for a cure as well as make them more prone to accept disease-related situations [13]. In this study, this acceptance was corroborated by the participants' disposition to acknowledge, understand, and respond positively to the commitment and distress generated by the disease and its treatment without losing focus on their hopes and expectations, balancing out the troubles and changes imposed by the disease on their lives. It can also be said that in addition to accepting, the participants in this study had resigned themselves to the treatment even before the manifestation of its first adverse side effects.

However, regardless of the different religions reported by the participants in this study, whether or not they practiced them, and the presence or absence of faith and guilt, acceptance of the treatment and hope to be able to cope with it and complete it successfully can be found, albeit implicitly, in their words and wishes. The participants' will to continue treatment, which counterbalanced their desire to quit, was present in spite of their life stories and its resulting negative impacts on their everyday lives.

In fact, hope encourages patients to undergo treatment, despite its adverse side effects on their quality of life. Hope is imbued with perseverance, which makes it an important coping mechanism. Hope influences the individual as a whole; it boosts patients' self-confidence and leads them to devise mechanisms to achieve their desired goals [14,15,16]. In this study, hope encouraged participants to complete treatment expecting good outcomes.

Notwithstanding, some participants' statements depicted unrealistic hopes, which lead to questions such as: What do these patients really know about the disease progression and treatment effectiveness? Is hope in this case just a way of avoiding thinking about or denying the impact hepatitis C has on their lives? Or else, is it a psychological strategy to overcome the negative feelings and changes engendered by the disease and treatment?

Hope is known to vary according to each individual's expectations and possibilities, which in turn may lead to different ways of construing the same situation [16]. Even if this hope is false in light of Western culture standards, it can assist the patient in coping with the disease situation. On the other hand, it should be noted that unrealistic hope should unfavorably affect treatment and follow-up continuity, since patients might consider themselves already cured. Patients may deny their medical condition and interrupt follow-up.

Hence, it is important to emphasize and encourage effective and informative communication to patients before, during, and after treatment [17]. In this context, nurses' role in therapeutic communication is of great importance, as it may be of significant help to hepatitis C patients, especially during the first three months of treatment, improving their adherence and virologic response [18,19].

A study indicates that the administration of medication by professionals knowledgeable of the treatment implications is highly beneficial to patients [20]. In this light and given the widespread lack of knowledge about hepatitis C, judicious support to

patients should be considered from the very beginning, as many doubts arise when the disease is first diagnosed.

Participants in this study did not argue whether or not support was needed; nor did they mention the need for changes to improve treatment and follow-up. However, they did point to support provided by family and friends as important determinants of treatment adherence and completion. Hence, family support can effectively contribute to patients' ability to cope with a chronic disease, thereby strengthening their affective relationships [5].

In this study, the Internet was also cited as an important source of hepatitis C representations. It may be inferred that this medium contributes easy access to information that can mitigate patients' uncertainties and cater to their interest in the disease and treatment. Some researchers suggest that the patient's attitude of participating and bringing information about the disease found on the Internet and other media outlets to the doctor's office can have a positive effect on the therapeutic process [21].

Conclusion

This study indicates that the treatment of chronic hepatitis C has a negative impact on patients' everyday lives and quality of life. In addition, it expounds the strategies patients employ to cope with difficulties deriving from their perception of being chronically sick and the adverse side effects of medication.

The administration of hepatitis C medication at the outpatient clinic provides an excellent opportunity for sharing information and experiences. Nurses and other healthcare professionals can make use of this occasion to resolve patients' doubts and encourage them to adhere to and complete treatment. Moreover, spaces should be made available to patients in which they may find support and reassurance in difficult times and become conscious required habit changes so as to improve their quality of life and response to therapy.

Finally, it must be pointed out that the commitment seeks to assist patients in overcoming the adversities inherent to hepatitis C diagnosis and treatment as well as in searching for new meanings. That is, healthcare professionals should help hepatitis C patients not only to live through their new reality, but also to turn this undesired reality into an opportunity for major changes in their lives. of healthcare professionals to this phenomenon is vital. In this sense, they should.

At the end of this study, it was possible to identify a limitation regarding the production of empirical data. The fact that the chief investigator was also the nurse

responsible for administering most medications to the participating patients may have influenced their accounts, especially regarding the quality of the health services provided.

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