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# Exploring Perception of Chronic Hepatitis C: An Idiographic Case Study

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The disease Hepatitis C has devastating impact on the individual and their family members. This study demonstrates the case of a 45 year old woman suffering from chronic Hepatitis C. The methods of data collection employed were Mental Status Examination and semi-structured interview. Furthermore, the participant's caregiver (sister) was also interviewed. For this purpose, two separate interview schedules were prepared. Data was interpreted by using Interpretative Phenomenological Approach. The most dominant themes extracted within this study were overshadowing physical health; psychological and emotional distress; coping with disease; and social support from family members. In addition, the study showed that the perception of social support and coping have an influence on chronic Hepatitis C individuals. The present study's findings would be fruitful for Pakistani people in enhancing their understanding about chronic Hepatitis C.

*Keywords:* Chronic Hepatitis C, semi-structured interview, Interpretative Phenomenological Approach

Approximately, 3% of the world's population is afflicted with Hepatitis C virus (HCV), with the highest prevalence rates prominent in Africa and Asia (Alter, 2007). In the United States and Europe, numerous liver transplants were carried out for persistent HCV patients (Rockstroh et al., 2012). However, Khattak, Salamat, Bhatti, and Qureshi (2002) have found that Pakistan was on the second highest incidence of HCV varying from 4.5% to 8%. Furthermore, another study has indicated that the occurrence of positive HCV was high in rural regions as compared to urban districts of Pakistan (Aziz, Khanani, Noorulain, & Rajper, 2010).

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Chronic HCV disease does not depend on a single factor. It affects various aspects of life, for example, lack of ability to carry out everyday activities, problems to manage expenses, marital distress, family issues, difficulties in social relations, as well as the trauma of dealing with the diseased status and symptoms. The incidence of symptoms most reported in HCV patients are sleep disturbances in less than 50% patients, fatigue, irritability, cognitive disturbances with impairment of concentration and memory (Dieperink & Willenbring, 2000; Schaefer, Wittchen, Seufert, & Kraus, 2007), 30-45% with anxiety, 30-60% with mild depression, decreasing self-esteem, loss of interest, anhedonia, spontaneous crying, 20-30% with moderate to severe depressive episodes, 0-0.02% suicidal thoughts, and 3-10% suicidal attempts (Bonaccorso et al., 2002). Other symptoms observed in these participants of the study were red palms, muscle and joint aches, itchy skin (usually no rash), and right side pain. These symptoms can occur in the early stages of infection or develop gradually (Dieperink & Willenbring, 2000).

Furthermore, hypertension, diabetes, liver diseases, gastrointestinal disorders, connective tissue diseases, and non traumatic joint disorders were also more common in HCV population (Ali et al., 2015; Qureshi, 2002). A number of researchers (Gohier et al., 2003; Hilsabeck & Malek, 2004) have found that anxiety and depression levels not merely elevate when taking interferon therapy, but also prolong later. In addition, the progression of HCV may also differ depending on several factors such as age and gender (Svirtlih et al., 2007), ethnic background (Sterling et al., 2004), environmental factors (Lim & Kim, 2008), HCV-specific cellular immune response (Hraber, Kuiken, & Yusim, 2007), and viral co-infections (Gebo et al., 2002).

One of the most fundamental predictor of mental control and psychological adjustment is social support (Norbeck & Tilden, 1988). It may have an effect on health in varied ways that is, physiological, emotional, and behavioral. A significant social aspect in prolonging the quality of life and reducing psychological side effects of Hepatitis C treatment schedules is support from loved ones, especially, life partners. A study was conducted to explore the reasons to initiate the treatment of HCV based on patient’s choices (McNally, Temple-Smith, & Pitts, 2004). These researchers also noticed that such patients were commonly expressing depression and mood swings when they went through the stress of demanding support from family members and were required to remain calm and silent at the given time.

Furthermore, the relationship between being healthy and social support was mediated by people's preferences in using different coping techniques (Holland & Holahan, 2003). For example, perceived social support might encourage a person to rely on many types of coping and manipulate one's preference or make use of particular coping strategies that might improve or worsen the social support effects on health. Therefore, social support contributes to play a vital role to increase the coping ability of a person (Tam, 2008).

Similarly, coping of the patient with a persistent disease can be considered as a central and vital element in the recovery process. It is an altering and dynamic method sustained by the approach in which patients with chronic HCV manage new stressors of the illness and prior coping behaviors (Hobfoll, 1989). In addition, it is effective as a psychological and emotional way for dealing with strain and pain. Gordon et al. (2002) revealed that religious coping techniques were viewed as essential in adjustment to chronic ailments. Research conducted by Kausar and Yusuf (2011) showed that the HCV patients have varied anxiety levels and the coping strategies they use. HCV patients who were not going through interferon therapy were using active and religious coping techniques more and had high anxiety levels than those who had completed this therapy. In contrast, HCV patients who had completed interferon therapy were using avoidance coping techniques extensively.

It is concluded that chronic HCV can influence nearly every sphere of a person's life. Daily routines are disturbed and domestic responsibilities are hard to accomplish like, washing clothes, cleaning dishes, cooking, and climbing stairs. The entire body system of a HCV patient is affected having feeling of illness, low energy, and sleep disturbances. Physical functioning as well as social and psychological performances of such patients may also be afflicted. Coping techniques and social support are significant psychosocial factors that have immense impact on the HCV patients' lives. Therefore, it is important to know more about this disease as the incidence of chronic Hepatitis C is growing very rapidly in Pakistan and globally. The main aims of this study were to determine psychosocial difficulties that chronic HCV patient is experiencing and investigate how chronic HCV patient cope up with the disease.

## Research Questions

a) What psychological difficulties do chronic HCV patient face?
b) What type of coping strategies do chronic HCV patient use?
c) What kind of social support does the HCV patient receive?

## Method

### Research Design

A case study research design was well suited for this research because there is a connection of circumstances in naturally occurring real-life circumstances and the researcher tries to make a complete portrait of experiences and stories of the individual (Blanche, Durrheim, & Painter, 2006). In addition, the epistemology of present research was laid on the views of “social constructivism”. It is a way to understand the world of the patient in which he/she lives, developing multiple meanings, and the addressing complexity in viewpoints (Becvar & Becvar, 2006).

### Participants

HCV patient (SY) and her sister were selected on the basis of purposive-convenience sampling in the current study. The age of SY was 45 years and she was married belonging to upper middle class, having completed her secondary education, and was the resident of Lahore city, Pakistan. She was suffering from chronic HCV since 5 years and having Interferon injections since last six months. Her sister was 26 years, unmarried, and had completed her Masters.

### Data Collection Tool

Semi-structured interviews were carried out with HCV patient and her sister individually. Mental Status Examination (MSE) of SY was also done.

### Procedure

To conduct semi-structured interviews, two interview schedules were prepared to collect inclusive information from HCV patient and her caregiver (sister), separately. The schedules were structured and planned according to the factors shown in the previous researches. Interview with HCV patient (SY) was conducted in two sessions at her home. Each session lasted for 35 to 45 minutes and was audio-taped. Written consent was obtained from both the participants and the researcher assured them that all information obtained would be kept confidential. Moreover, MSE was also applied on SY through careful observation. After that, the interview began with the demographic information and general questions on health, locus of control, coping, and social aspects were asked. The patient was offered some fruits as a token of thanks for her time and cooperation. In addition, some suggestions were also given to her by researcher verbally to deal with her problems and formal good-bye was exchanged.

Since family members have direct and mutual influences through network of communication to persuade each other (Huitt, 2003). Therefore, her sister was also chosen for interview. This helped to validate and crosscheck the findings obtained from SY. The interview with her sister lasted for 20 to 25 minutes. Her sister was interviewed as SY mentioned that her sister was closest to her and she shared everything with her.

### Analysis

After conducting interviews, the audio-recorded data were transcribed. Data were analyzed through Interpretative Phenomenological Approach (IPA). This method helps to explore the subjective experiences of the participants in detail (Smith & Osborn, 2003). In the first step, transcripts of interview were examined individually and were coded. Usually the use of one independent coder is supported in research (Creswell, 2009). After this, the second author reviewed all the findings vigilantly. Then, the themes were extracted and finally clustered into subthemes. The transcript was evaluated through inter-rater reliability (Hallgren, 2012; Marques & McCall, 2005). Five experts were requested to review the findings on two point rating scale (0 = *disagree* and 1 = *agree*). An initial discriminant capability was the measurement level of intercoder reliability (Campbell, Quincy, Osserman, & Pedersen, 2013), which was found to be 71% in this study. All experts agreed on four themes and one theme was discarded as four experts showed disagreement.

## Findings

### Observation Through MSE

When researcher first met the HCV patient, she was wearing neat and clean clothes. She looked physically tired and exhausted. Her facial expressions revealed that she was a bit low in mood, but was interested for interview. She maintained a good eye contact. Her speech tone was low, but speech rate and volume were moderate. No impulsive actions or involuntary movement were evident. Her level of consciousness was fluctuating a little. No phobia, hallucinations, and delusions were found. She had an average level of general knowledge. Her memory was intact and she had insight of her disease and problems.

## Interview of SY's Sister

When her sister first came to know about her disease she said that "We all were very disturbed that how treatment will be done as she was taking homeopathic medicines and we have to convert it into allopathic, so it was very problematic for all of us".

She reported that her sister had more psychological issues due to the treatment than Hepatitis C. She was in depression due to which her disease reached its peak and had developed a negative thinking. However, she had a friendly and reasonable behavior with everyone at home. At present, SY was happy as she had started living with her parental family and had shifted from village to Lahore. Her attention was diverted towards her family members. Before that she was mentally disturbed as her husband was also living in Lahore and visited village after one or two months only on weekends. Now, they had developed more frankness and had a strong bonding. She had good relationship with her children and was more attached to her elder son and considered him trustworthy to share her feelings.

SY shared every problem with her sister even those related to argument with her husband or study issues related to her children. On asking question about what behavioral changes has she observed in SY after onset of her disease? She reported that:

> "To tell you honestly, I have noticed two changes in her. First, she repeats herself a lot. For example, she tells you something in phone and after some time, she calls again and tells you the same thing again. I think it may be because she forgets. Second, she now has a suspicious nature. Even if her daughters are talking with one another or talking in another room she thinks that they are talking about her"

Her parental family supported her morally and financially in her treatment. Emotional support was also provided. Sister said that "More than her husband, I feel that I should give more time to her and try to make her understand that she should be positive and suppress her negativity".

## Findings Based on SY's Interview

All the themes were generated based on SY's interview. Major themes and subthemes along number of frequency of appearing these in interview that emerged through IPA analysis are presented in Table 1.

Table 1

*Major Themes and Subthemes Extracted From HCV Patient*

| Major Themes | Sub themes | *f* |
|---|---|---|
| Overshadowing Physical Health | Fatigue | 5 |
| | Weakness | 6 |
| | Burning sensation in liver, eyes, hands and feet | 3 |
| | Laziness | 3 |
| | Sleep disturbance | 5 |
| | Fever | 2 |
| | Headache | 3 |
| | Pain in joints | 3 |
| HCV Related Psychological and Emotional Distress | Irritability | 3 |
| | Hopelessness | 4 |
| | Sadness | 5 |
| | Depression | 4 |
| | Weeping | 4 |
| | Tension | 6 |
| | Suspiciousness | 4 |
| | Forgetfulness | 3 |
| | Denial | 3 |
| | Locus of control | 2 |
| Coping with HCV | Self-distraction, | 3 |
| | Positive reframing | 4 |
| | Religious coping | 4 |
| Social Support from family members | Brother | 3 |
| | Sister | 4 |
| | Son | 3 |
| | Husband | 3 |
| | Emotional | 4 |
| | Instrumental | 4 |
| | Appraisal | 3 |

## Discussion

After analysis, four major themes emerged from HCV patient's interview. These themes are presented in Figure 1.

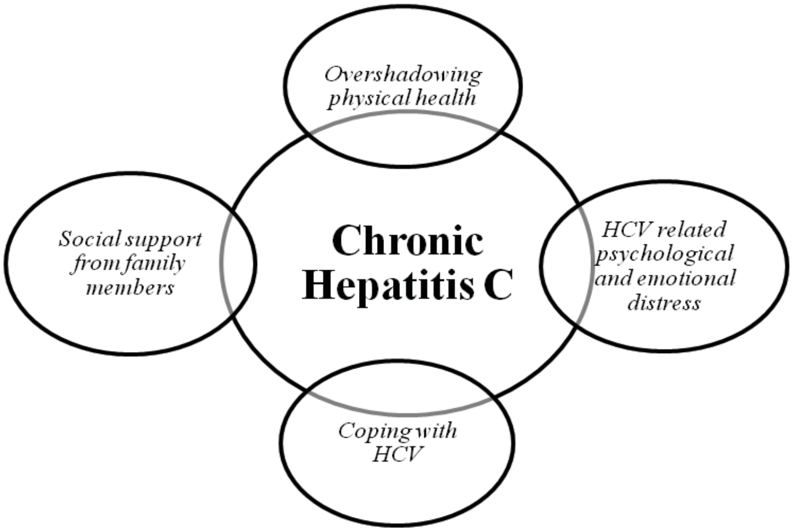

*Figure 1.* Themes related to Chronic Hepatitis C.

## Overshadowing Physical Health

First theme emerging in HCV patient was *"Overshadowing Physical Health"*. This theme reflects those indicators that are a result of the patient's disease. The findings revealed that SY was facing different kinds of physical problems as a result of Hepatitis C including fatigue; weakness; burning sensation in liver, eyes, hands and feet; laziness; sleep disturbance; fever; and headache. Being fatigued was the problem which was most commonly experienced by her.

> "Every part of my body is weak, even brain; little talk gives me tension; pain in joints; I feel much exhausted and tiredness, after 3 o'clock, I have fever. I cannot do any task because if I work for half an hour, I get tired and then, I cannot do my daily chores. For one hour, I take rest then I am able to do it again".

And again she reported that

> "Now, when I do any domestic chores, I cannot do them. I feel lethargic and fatigued. Then I get upset about what to do. I have children, my daughters are studying, my son studies, oh Allah! what can I do. Before this, I was fond of doing daily chores. Now, I have a maid, I can't do all chores alone".

Previous researches support this finding, which showed that fatigue had a negative impact on physical health and quality of life of HCV sufferers (Gill, Atiq, Sattar, & Khokhar, 2005; Glacken, Kernohan, & Coates, 2001).

Furthermore, Wessely, Hotopf, and Sharpe (1998) found that HCV patients have sleep disturbances, pain, and depression. SY's sleep was disturbed since when she knew that her reports were not normal.

> "Sometimes I don't sleep for two, two, three, three days. I have tension in those days. In this disease, you have more tension. Small thing happens, but you feel that it is big and what can a person do? In this way, I feel that my brain is weak; my mind is not working properly. I remain awake and cannot fall asleep for many days".

## HCV Related Psychological and Emotional Distress

This theme reflects the impact on quality of life of such patients and side effects of treatment (Cho & Park, 2017). SY experienced different psychological and negative emotional responses consisting of sadness, irritability, tension, hopelessness, weeping, depression, suspiciousness, forgetfulness, and denial. She took tension about her husband not giving her attention and mentioned that in her whole life, she had fulfilled her responsibilities adequately, but now, when time had come to see happiness of her children, she had fallen sick.

> "Not now, I was mentally stressed before (pauses) because I kept on thinking that whether my husband is happy with me or not. At the moment any task which I cannot perform for him….produces doubts in my mind that I am not beautiful and this has developed after this disease".

As her husband was living in Lahore and visited the village only on weekends (reported by sister) she had doubts about her relationship which produced stress. This can also be explained in the context of body image. Satisfaction with body image is a contributing factor in the level of marital satisfaction. The more positive this mental image of the body is, the more positive is the relationship between spouse and ultimately lead to greater marital satisfaction (Givi & Setayesh, 2018). However, after developing the disease she had developed doubts about her body image.

When she first came to know about her disease she reported that:

> "I take a lot of tension. I was in tension for almost 1 year. I thought that I will die. My children will suffer. My daughters…this and that….this was going on in my mind. Now I don't take tension so much, but when I am not feeling well then I take tension".

> Her sister also reported that: "She (SY) takes tension a lot even if it is a minor family problem. She thinks that as if it is a very huge problem and cannot be solved".

Due to her repeated visits to the hospital for her scheduled treatment and as HCV treatment is expensive, SY developed tension, Furthermore, she worried a lot about not being able to do household chores and about the future of her children. All these reasons were adding to further enhance her stress level. SY also had a suspicious nature. She said, "I think my treatment is not going well… I am in doubt… I should have been well by now. May be the injections are not working'.

The natural course of Hepatitis C disease differs from person to person. Since it is a prolonged therapy and the symptoms keep reoccurring, therefore, the patients of HCV usually develop a suspicious nature. Cognitive dysfunction characterized by forgetfulness and attention and concentration difficulties has been recognized in 13-50% of persons with chronic HCV infection (Irwin, & Terrault, 2008). SY also experienced forgetfulness as she said, "I forgot where I have put my clothes ….in the cupboard or in the machine? Then I forgot if I had added salt in the gravy?"

Taylor (2006) has observed that immediate action repeatedly showed better adjustment to a distressing event as compared to coping efforts intended to explain the difficulty of denial or avoidance. Denial is described as rejecting the reality. SY was in denial period when she first came to know about her disease. "I have been saying to myself that this is not true. It is wrong. This cannot happen to me."

Kübler-Ross' model (stages of grief) presented in 1969 can best describe SY's interview as she went through the four stages: a) Denial phase; b) started display of anger on herself and others; c) became depressed; and d) finally, accepted her disease. At the time of interview, the patient was at 'acceptance stage' as she had accepted her disease.

SY reported that in past, she also used to suppress everything inside her. She said, "I did not tell my private worries to anyone, nor to my mother, not to my sisters, nor brothers; I kept everything inside me; I did not share with anyone; neither have I shared with my husband."

Stigma associated with diagnosis and feelings of anger are common among HCV patients. Earlier researches revealed that HCV patients undergoing interferon therapy have expressed increased anger and hostility (Kraus, Schafer, Faller, Csef, & Scheurlen, 2003;

Yovtcheva, Rifai, Moles, & Van der Linden, 2001). According to SY, now she gets depressed and angry quickly and wants to be alone. She also reported that she displays anger towards her family and later on she regrets it.

> "I have started becoming angry since 2-3 years before because of my high blood pressure. Now, I like isolation. I like to be alone. I feel low and depressed, now I want to sit alone, this depression, this is inside me a lot, and doubt, all this came after this disease."

She also reported, "When I get angry, I beat and yell at my children. After that I feel guilty about it." A study also showed that HCV patients often direct anger feelings towards other people around them (Janke, McGraw, Garcia-Tsao, & Fraenkel, 2008). In addition, SY seems to have an internal locus of control as she agreed that she is responsible for her disease. However, she has strong faith in Allah. "My disease is due to my carelessness, I did not pay attention. I did not take it seriously", she said. On the other hand, she claimed, "Allah is controlling my disease. He does everything. I have strong belief in Allah." Her strong devotion to Allah is also showing religious coping.

## Coping With HCV

From analysis, it is apparent that SY was frequently using self-distraction, positive reframing, and religious coping strategies. SY is not using avoidant coping because she is engaging in positive and healthy lifestyle strategies. Active engagement in these strategies serve as protective factor, as she has developed an awareness regarding coping with her disease. Self-distraction is thinking less about the problem and concentrating on other activities. She has been diverting her attention to other household responsibilities, so that she should not think about her disease. She reported, "I try to keep myself busy in children, preparing food before children come from school and colleges."

On the other hand, positive reframing means seeing things in a more positive light. It is mainly essential in lessening negative effect of pains. However, it may be considered a significant element of spiritual health in HCV patients. SY said, "Yes! I say that I will take care of myself and will be alright. Allah will give me long life. I say that Ya Allah (Oh, God)! I want to see my children get married then after that whatever happens."

As Pakistan is a Muslim country, people practice and get involved in religious activities. They pray in their routine lives. In addition, religious coping is trying to have comfort in one's religion. It promotes physical and mental health benefits which may prolong life. It may offer solace to individuals and make them look for reasons and meanings in the traumatic situations. Typically, women, in response to problem-focused coping often utilize religious ways, distraction techniques, and look for social support (Rao, 2009). Therefore, SY has been trying to find comfort in her religion or spiritual beliefs. When she was anxious or worried, she mentioned, "I recite *Darood Sharif*, any *Zikar* of Allah, in this way, I feel I am relaxed or I come downstairs, sits with my sisters or my son takes me outside for outing. I recite *Darood Sharif* a lot." She further reported, "I pray regularly and pray for my health and long life."

Religious coping is extensively used by patients of HCV (Sohail & Yasin, 2017). Religious beliefs have been found as source of diverting attention from pain for such patients. Another Pakistani study has shown that HCV patients use prayer as a coping strategy (Sohail, 2018).

## Social Support From Family Members

This theme covers different kinds of support that SY mobilized around herself. A study has revealed that when caregivers know about their patient's disease, they tend to be more caring and nurturing (Lackey & Gates, 2001). Another research by Maureen (2005) supported the premise that social support facilitates the HCV patients' well-being and contributes to health promotion, especially, through family members. In particular, the support that SY receives from her family members was emotional, instrumental, and appraisal social support.

Taylor (2006) found that assistance and informational support were provided by specialists whereas emotional support was primarily received from family members. Emotional support is searching for sympathy or chatting to others about one's thoughts and feelings. SY has sought emotional support from her sister. According to SY, "This is my sister (pointing her finger towards her sister), I share everything with her. I have started sharing with her now when I have no control. Now, I tell her all my worries (private talks), then my mind is calm".

Her sister also confirmed that she provides emotional support to her sister and was concerned about her. She used to accompany SY during her visits to hospital. Furthermore, instrumental support is assistance received from others that is tangible. This kind of support was provided by her brother in the form of payment for the treatment; her brother also provides her emotional support. She said,

"One of my brothers went abroad. He has main role in changing me. He used to call me and said sister nothing will happen to you, don't take so much tension, this disease remains with people in their whole life, people take medicines and feel alright. Everyone can get sick." She also mentioned, "My brother sends me money for my treatment as this treatment is very expensive… He supports me financially."

Appraisal support is perceived availability of somebody to discuss about individual's troubles and this kind of support was provided by her son and husband. There was her son whose advice she really trusted. She also reported, "If a family crisis arises, my husband can also give me good advice about how to handle it. Then my son is there."

Furthermore, she did not experience disappointing views from her extended families and friends on having HCV disease. She reported that she did not hide her disease from anyone. However, she does not visit her friends and relatives home much. It may be a result of fatigue due to illness that she often did not go to family and other gatherings at present.

## Conclusion

Chronic Hepatitis C is a progressive illness that may slowly deprive an individual from living a healthy life. HCV has a significant impact on the patient's lifestyle. The findings of this study indicated that social support and coping have an effect on the personal satisfaction and future outcomes of chronic Hepatitis C. The data of this study also provided an indication that family support has positive influences on HCV patients. The other important outcome of the research was that physical functioning of HCV patient was hindered. Furthermore, the study draws consideration to approach particular coping technique such as religious coping when examining the significance of Hepatitis C on mental and physical well-being. However, in present study, physical problems in HCV patient did not perturb religious activities.

## Limitations of the Study

This study merely looked into how a female HCV patient gave meaning to her experience of chronic Hepatitis C. The findings would be different to some extent if male HCV patient was included.

Furthermore, HCV patient’s husband’s and son’s views about her disease and how they reacted to her are missing. Both of them did not agree for an interview. Other family members (mother and brother) were unapproachable for interview as her mother was in village and her brother was out of country.

## Suggestions for Future Research

Mixed methods, quantitative as well as qualitative can be used to see more causes and problems in HCV patients. The role of extended family members' of HCV can also be investigated through interviews to probe more causes and reasons in HCV patients. In future, gender differences can also be included in the study to explore different kinds of social support and coping strategies used by both HCV male and female patients.

## Implications

The current study has highlighted the need for an in-depth examination of perception of chronic Hepatitis C. It will encourage other researchers to investigate chronic Hepatitis C in more detail and from various angles that focus specifically on indigenous level as well as other aspects of HCV patients.

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