



Understanding, Acceptance, and Disclosure of Status Among Patients with Hepatitis C Virus Infection: A Qualitative Analysis

Siti Maisarah Md Ali*; Mohd Azri Mohd Suan; Mohamad Faiz Mustafa; Muhammad Radzi Abu Hassan

Clinical Research Centre, Hospital Sultanah Bahiyah, Ministry of Health Malaysia, KM 6 Jln Langgar, 05460 Alor Setar Kedah, Malaysia

***Corresponding Author(s): Siti Maisarah Md Ali**

Clinical Research Centre, Hospital Sultanah Bahiyah, Ministry of Health Malaysia, KM 6 Jln Langgar, 05460 Alor Setar Kedah, Malaysia
Email: sara_ally85@yahoo.com

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Abstract

Objective: Although the number of individuals contracted with hepatitis C virus infection is increasing, there is limited research locally on acceptance and disclosure of diagnosis among hepatitis C patient. This study aimed to explore views and experiences of patient following the diagnosis of hepatitis C infection at a tertiary centre in Kedah state, Malaysia.

Method: Twenty participants with hepatitis C infection participated in semi-structured, face to face interviews on their views and experience of a recent hepatitis C diagnosis. The interviews were audio-recorded, transcribed verbatim, and translated before data analysis. Content analysis was performed on the translated interview, followed by a systematic classification of data by major themes.

Results: Four main themes emerged (1) Understanding about hepatitis C infection, (2) First reaction to the diagnosis, (3) Accepting their diagnosis, and (4) Disclosing their disease status to others. Most participants had limited understanding of the disease due to the lack of information received. While some of them well accepted their diagnosis, many had expressed their unhappiness, distressed and regret following the diagnosis. Due to fear of negative response or stigma that follows with the diagnosis of hepatitis C, many participants were keeping the diagnosis to themselves. For those who had disclosed their hepatitis status to others, they experienced discrimination and rejection from family members and co-workers.

Conclusion: Study findings indicate that those with hepatitis C infection often had a misunderstanding about the disease, hiding the diagnosis from others and facing stigma in their family relationships and work environments.



Introduction

Globally, hepatitis C virus infection has become a major health concern. World Health Organization estimated the prevalence of hepatitis C infection at 2% which equate to 123 million people [1]. The burden of this infection has been shifted from acute infection to chronic infection [2]. Despite much advancement in screening and treatment modalities for past decades, individuals living with hepatitis C remain reluctant to disclose their diagnosis because of perceived negative feedback or stigma experienced when doing so.

Many studies have described the stigma associated with hepatitis C. Stigma often arise as an association of hepatitis with injection drug use or risky activities and misconception about virus transmission [3]. Previous studies also showed that hepatitis C have negatively impacted patient's feeling [4], their relationship with others [5], quality of life [5] and employment [6]. Due to fear of negative connotation that follows with the diagnosis of hepatitis C, patients were afraid to disclose their hepatitis status to others [7]. Poor self-acceptance on diagnosis [8], coupled with the presence of stigma towards them, can disrupt effort of individuals with hepatitis C to assess and seek treatment [6,7] which in turn can thwart the plan to eliminate this viral infection.

In Malaysia, the number of hepatitis C infected person is growing over years [9,10]. Nevertheless, there is limited research on views and experienced faced by hepatitis C patient, particularly on acceptance and disclosure of infection status. Whether the stigma exists towards people living with hepatitis C in the local population also needs to be confirmed. Thus, this study aims to explore views and experiences of patient following diagnosis of hepatitis C infection at a tertiary centre in Kedah state, Malaysia.

Methods

Study design and setting

Qualitative research using semi-structured interviews was used to explore the views and experiences of hepatitis C infected patients after diagnosed with this chronic virus infection. This study was conducted at Hospital Sultanah Bahiyah (HSB), Alor Setar, Kedah. This centre is a tertiary, government hospital, and served as a referral centre for hepatitis C treatment for the northern region of Malaysia. All patients with hepatitis C infection were seen by a team of physician at the Gastroenterology Clinic, HSB during scheduled follow-up.

Participants

We used purposive sampling from a list of hepatitis C infected patients attending follow up at the Gastroenterology Clinic, HSB. Patients with the following criteria were identified; (i) diagnosed with hepatitis C infection (positive serology test results for hepatitis C antibody and detectable hepatitis C RNA) for at least 1-year duration, (ii) age above 17 years and (iii) able to understand and converse in Bahasa Malaysia (national language). All potential participants were approached outside the clinic consultation room after seen by the attending physician. They were informed regarding the objective and methods of the study by the researchers. Any queries regarding the study were answered before the participant signed the informed consent form. A face to face in-depth interview session was arranged in the private room at the Gastroenterology Clinic for all agreeable participants. During the recruitment period, none of the partici-

pant refused to participate, withdrew consent or dropped out.

Data collection

A semi-structured interview guideline was created to guide during the interview process. The guideline was developed based on the input from the consultant gastroenterologist, trained nurses in the Gastroenterology Clinic and findings from the literature review. A pilot interview was conducted with several pre-identified hepatitis C infected patient to refine the questions before the first interview session. In brief, participant was asked regarding their experience with acceptance and reaction from people surrounding them when knew about their hepatitis C status.

The first author, a female medical doctor with experience in conducting a qualitative study, led all the interview sessions. The third author, a male staff-nurse, helped with notes taking during each interview session. Only the first author knew the participants while the third author only knew the participants before the interview session. Each interview lasted approximately 30 to 45 minutes. The interview session continued until the researchers felt that the session had reached a saturation point and was no longer hearing anything new from participants. All interviews were audiotaped, transcribed verbatim and translated before data analysis. No repeated interviews were carried out.

Data analysis

Data analysis was conducted using the thematic analysis method [11]. The translated interviews texts were read by the authors to familiarize with the participants' responses. Similar points in the text data were combined to form codes. All codes then collated to form themes. The authors continuously reviewed the themes to make sure it constant with the initial data. The finalized themes that fit the outcome of interest were presented in the report. The study methods and findings were reported according to the consolidated criteria for reporting qualitative research (COREQ) [12].

Ethical statement

This study was approved by the Medical Research and Ethics Committee, Ministry of Health Malaysia (NMRR-19-858-46391).

Results

Total of 20 participants was interviewed in this study. All participants completed the interview sessions, none withdrew consent or dropped out. Almost all the participants were male and majority of them were of Malay ethnic, had secondary education and former injection drug user. Other characteristics of participants interviewed were summarised in Table 1. Four main themes emerged from data analysis: (1) Understanding about hepatitis C infection, (2) First reaction to the diagnosis, (3) Accepting their diagnosis, and (4) Disclosing their disease status to others.

Understanding about hepatitis C infection:

All participants in this study had been diagnosed with hepatitis C for more than a year (Table 1). However, most of participants have minimal to none information on hepatitis C infection. The common reason given for having limited understanding on the disease was no further explanation given by the health care provider after diagnosis was made.

"I do not know much about this disease. I only knew that the virus infected the liver." – Participants #05

"I knew nothing about it (hepatitis C). Nobody had ever informed me about this disease." – Participant #08

"Hepatitis C is more about disease of the liver. It can cause low body immunity, just like HIV. But I'm not sure how the virus spread to others" – Participant #14

Surprisingly, three respondents mentioned that there is no treatment available for hepatitis C. Some of their quotes were as follow:

"It caused by virus infection and no treatment yet for hepatitis C." – Participants #09

For participants who knew about hepatitis C, they gained the information by attending course or had joined Non-Government Organization (NGO) health education-related activities in the past.

"Previously, I have joined health activity in the local community by NGO. I met with few NGO personnel, they shared information on hepatitis C, its mode of transmission and available treatment." – Participant #07

"I'm sure that I got hepatitis C by sharing needles from injection drug use. I knew this (hepatitis C and risk factors) from a course on hepatitis that I have attended previously." – Participant #10

First reaction to the diagnosis

Participants expressed mixed feelings when asked about their first response after been diagnosed with hepatitis C infection. Seven participants informed that they accepted the fate being infected with hepatitis C virus as they were actively involved in drug injection. Knowing the risk of sharing needles, they seem not surprised when informed about their infection status.

"I'm fine when the doctor told me (that) I had hepatitis C (injection). Live must goes on." – Participant #01

"The news (on diagnosis of hepatitis C infection) is expected as I was previously injection drug user. I know the risk when sharing needles." – Participant #18

While some participant accepted their diagnosis well, more than half of the participants (n=13, 65%) expressed their unhappiness, distress, and regret after been diagnosed with hepatitis C. These negative feelings are shown in the following quotations.

"At first (after being informed that infected with hepatitis C), I'm scared and very stressful. Since then (after diagnosed), I become unhappy, not as usual." – Participant #13

"When I knew that I had hepatitis C, I regret taking injection drugs. If I knew the risk, I definitely would not take it (injection drugs)." – Participants #11

A female participant who felt that she did not involve in any high-risk activities felt perturbed by her diagnosis.

"(crying) I can't believe that I had this infection. How can I get this infection? I did not involve in any high-risk activities that may exposed myself to this virus. I am worried and unhappy". – Participant #02

Accepting their diagnosis

Participants described various changes while trying to accept the fact that they had been contracted with hepatitis C. Those who have accepted, are coping well with their diagnosis.

"... I still had the same daily activities. Probably, I do extra prayers nowadays." – Participants#20

"... nothing changes (in day to day life). I knew there is a treatment for this hepatitis C. My wife also encouraged me to seek for treatment." – Participants #06

Yet, some of them are still in bereavement and adjusting their day to day life following the diagnosis. Fear of rejection, worried of others response and prevailing stigma around hepatitis C are the main reason for many participants keeping their infection status to themselves.

"I keep it (the diagnosis) to myself until now. Even my wife doesn't know about my diagnosis. I don't want to tell her. I'm sure she will be afraid of me ... if she got infected too, she definitely will put all the blame on me." – Participant #7.

"My friends didn't know that I'm infected (with hepatitis C), because if they do, I'm sure they will avoid and keep distance from me." – Participants #20.

"... still awaiting suitable time to tell my family members (about my diagnosis). My brother recently passed away due to liver disease. I don't want my mom and sister worried about me if they know I had hepatitis C." – Participant #17.

"My officemate did not know about my condition. Probably they will assume that hepatitis C is like HIV, and (will) get infected if working in the same office with me." – Participant #11

Disclosing the diagnosis to others

Breaking the news of having hepatitis C to the family members triggered various responses. Although few participants received good feedback from the family members, many participants reported some kind of discrimination and rejection when their status was disclosed.

"Although my family seems to accept my condition, they put my body wash, tooth brush and hair comb in a special container, so that my toiletries did not mix with theirs." Participant #16

"I think there is a gap in relation between me and other family members after I informed them (about my hepatitis C diagnosis). My uncle started to segregate glasses that I used at his house. My mom also seems not to like me. I was warned not to kiss her, and I'm not allowed to sleep in her house." Participant #12

Of three participants that revealed their hepatitis C status to their neighbors and co-workers, all of them received negative response from people surrounding them.

"When my workmate knew about it (hepatitis C infection), they started to talk bad about me. They did many nasty things to me, to make me quit from my job." -Participant #16

"I noticed that my neighbors try to avoid from seeing and talking with me after someone had told them about my diagnosis." – Participant #03

Table 1: Summary of socio-demographic characteristics of interviewed participants.

Patient ID	Age (years)	Sex	Ethnicity	Level of education	Duration of been diagnosed with HCV (years)	Main risk factor
#1	25	male	Malay	Secondary	3	Injection drug use
#2	55	female	Malay	Secondary	3	Unknown
#3	44	male	Malay	Secondary	3	Injection drug use
#4	47	male	Indian	Primary	5	Tattooing
#5	43	male	Malay	Secondary	9	Injection drug use
#6	58	male	Malay	Secondary	10	Injection drug use
#7	47	male	Malay	Secondary	12	Injection drug use
#8	67	male	Indian	Secondary	3	Tattooing
#9	42	male	Malay	Secondary	10	Injection drug use
#10	50	male	Malay	Secondary	5	Injection drug use
#11	59	male	Chinese	Secondary	5	Tattooing
#12	44	male	Indian	Secondary	19	Injection drug use
#13	39	male	Malay	Tertiary	5	Injection drug use
#14	53	male	Malay	Secondary	11	Injection drug use
#15	44	male	Chinese	Secondary	3	Tattooing
#16	42	male	Malay	Secondary	3	Injection drug use
#17	35	male	Malay	Secondary	17	Injection drug use
#18	36	male	Malay	Secondary	14	Injection drug use
#19	53	male	Malay	Secondary	4	Injection drug use
#20	26	male	Malay	Secondary	5	Tattooing

Discussion

Majority of the participants recruited in this study were infected with hepatitis C virus through injection drug use. This finding is parallel with result from other local studies [13,15] that indicate injection drug use is the main risk factor for hepatitis C infection in Malaysia. Despite being diagnosed for several years, participants understanding of hepatitis C is lacking due to minimal information on the disease. Not familiar with the disease risk factor, unavailability of hepatitis treatment, and regards hepatitis as the same as HIV are among the misunderstandings reported by participants. Beside misunderstanding about the disease, patient who lacking information on hepatitis C is prone to continue their high-risk behavior which could hinder the prevention and treatment program to eliminate hepatitis C [16]. Increase stigma and poor self-acceptance were also reported among hepatitis C patient with poor information on the infection.

On further question, few participants reported no detail information given by the health care provider after diagnosis was made. Physicians may unintentionally present health information on hepatitis at a literacy level higher than their patients can grasp. On patient perspective, complex information received makes them unable to process and understand the health information leading to the assumption that no details were explained to them. Efforts to bridge this communication gaps between health care provider and patient should be strengthened in local practice. Providing information leaflet

[17], using friendly-patient language [18] and allowing patient to bring family members or friends during the consultation [19] are among the alternatives suggested to reduces the barriers in health care provider - patients communication. Participants are also encouraged to gain more information on hepatitis C from other sources as suggested by their peers such as from NGO's and health-related activities conducted in their community.

After receiving a positive hepatitis C diagnosis, participants report a range of emotions, including sad, depressed and guilt. One participant who denied engaging in any high-risk behaviors felt perturbed with her diagnosis. However, participants who used injection drugs expressed an expectation of infection and well accept their diagnosis. They viewed hepatitis C as an inevitable consequence of sharing needles and injection drug use. A previous study also shared a similar finding, which suggests that hepatitis C has become "normalized" among injection drug user because of its high prevalence within this high-risk group [20]. In another study [21], injection drug users viewed hepatitis C as being a less serious issue in relation to HIV, which was not seen in this study. Expressing the view that hepatitis C is an expected consequence or just a minor health concern may reflect an underlying sense of unimportance to seek for treatment among the injection drug users [22]. It is important to examine further the association between perceived having hepatitis C as normal and treatment-seeking behavior among this at-risk population.

Various challenges were faced by study participants when trying to accept their diagnosis. While some continue their normal daily activities and received support from their beloved one, many participants often afraid to disclose their hepatitis status because they know the negative implication or stigma that comes with having this viral infection. Fear of rejection and uncertainty about other's response are among the prevailing stigma reported by participants in the current study. For participants who had disclosed their status to the family members and co-workers, they experienced discrimination and rejection. They described how those around them afraid of touching them and afraid of sharing toiletries and plates used by them. The co-workers even had tried to expel them from work. This is an important finding on how stigma had negatively impacted local people living with hepatitis C.

As mentioned in the earlier part of the discussion, lack of information could be the underlying factor of this stigma. It is likely that health education for family and friends of individuals diagnosed with hepatitis C, and public education may reduce the stigma associated with this infection [3] [23]. Information on the risk factors for hepatitis C, as well as the treatment availability, may reduce the feelings of stigmatization felt by those diagnosed and facilitate the disclosure and acceptance of hepatitis C in the broader community.

Several limitations of this study were identified. First, data analysis for the current study consisted of a small convenience sampling of hepatitis C-infected respondents from a single centre, which limits the findings' generalization. Additionally, as majority hepatitis C patient receiving treatment at this centre was male and of Malay ethnicity, samples to represent female participant and other ethnic was not possible. Future studies need to involve more female patient with different ethnic compositions to obtain more views related to understanding, acceptance and disclosure of status among patients with hepatitis C infection. Second, majority of the participants were former injection drug user. Only a few participants contracted the virus thru tattooing. Individuals with other risk factors (e.g. vertical transmission, high-risk sexual behavior, prisoners) may have different views on understanding, acceptance and disease disclosure that should be explored in the future study. Third, views on understanding, acceptance and disease disclosure were drawn solely from hepatitis C patients. Future studies may need to include health care providers that managing the hepatitis patient, family members, neighbors and workmate of individuals living with hepatitis C to develop a more comprehensive picture of the problem, particularly the prevailing stigma surrounding this infectious disease. Despite these limitations, the findings obtained from this study provide useful information on the level of understanding about hepatitis C and issues surrounding patient self-acceptance and stigma from others, which may help the healthcare providers and stakeholders to improve management and treatment for hepatitis C patient.

Conclusions

In conclusion, this study on understanding, acceptance and disease disclosure indicates that those with hepatitis C infection often had a misunderstanding about the disease, hiding the diagnosis from others and facing stigma in their family relationships and work environments. The views expressed point to several areas where better communication skills and greater health education could improve the experience of people living with hepatitis C.

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