Pak J Med Res
Vol. 56, No. 1, 2017

Original Article

Assessment of Attitude, an Insight from Hepatitis Patients and their Relatives/ Attendants of Islamabad, Pakistan

Ibrar Rafique,[1] Muhammad Arif Nadeem Saqib,[1] Shajee Siddiqui,[2] Muhammad Arif Munir,[1] Iftikhar Ahmed Malik,[3] Najma Javed,[1] Sumera Naz,[1] Huma Qureshi[1]
Pakistan Health Research Council,[1] Pakistan Institute of Medical Sciences,[2] Federal Government Services Hospital,[3] Islamabad.

Abstract

Background: Pakistan is the 2nd highest hepatitis C prevalent country while hepatitis B endemnicity is intermediate. Population has poor knowledge and understanding of these diseases therefore they face different types of stigmas. Stigmatization leads to barriers in the access of prevention and care of this disease. This study was conducted to evaluate the feelings and experiences of patients and their attendants (relatives) about hepatitis B and C and identify the gaps to ease access to treatment and care.
Study design, settings and duration: Qualitative study conducted in Pakistan Institute of Medical Sciences and Federal Government Services Hospital, Islamabad for 08 months.
Patients and Methods: Patients suffering from hepatitis B and C and their relatives who came to the OPDs of PIMS and Polyclinic were selected from the study. After taking consent from these 2 hospitals and consent from participants, the patients and relatives were grouped into 4 groups each comprising of 5-8 participants. Four focus group discussions (FGD's) were conducted for these patients and their attendants separately. Structured FGD guide was developed and special probes were used to stimulate discussion.
Results: There were 06 participants in each of patient group and 07 subjects in relative groups. Among patients, majority had negative perceptions about disease and related the disease with fear. They had misconceptions about disease spread. Most of them experienced change in the attitude of family members, relatives and friends especially in sharing clothes, shoes, and utensils. Break up of relationships and discrimination in getting a job due to the disease was also reported resulting in social and financial problems. The attendants also had negative perception about the disease and its mode of transmission. Although they were cautious about the sharing of utensils and during patient care but they had positive feeling for their patient.
Conclusion: Due to misconception about disease spread, the attendants/relatives were not sharing items of daily use items like cloths, crockery and bed linen with the patients thus giving them a feeling of dejection. Proper information about disease spread and its prevention along with the counseling of the patients and their attendants/relatives may build a positive relationship between them and thus ease help and care which is required for these patients.
Policy message: There is need of public awareness about mode of transmission of hepatitis B and C and its preventive measures.
Key words: Hepatitis, perception, behavior, attitude.

Corresponding Author:
Ibrar Rafique
Pakistan Health Research Council
Islamabad.
Email: ibrarpmrc@gmail.com

Received: 10 October 2016, **Accepted:** 16 February 2017,
Published: 20 March 2017

Authors Contribution

IR wrote the project, organized, interpreted the data and wrote the manuscript, MANS conceived the idea, support in designing study and writing final report and manuscript. SS, NJ, SN and IAM conducted FGDs. MAM and HQ support in designing of the study, writing of final report and manuscript. All authors read and approved the final manuscript.

Introduction

Hepatitis B and C virus are major causes of liver cirrhosis and hepatocellular carcinoma.[1,2] It is estimated that almost 170 million people live with chronic HCV worldwide.[3] The prevalence of hepatitis B (HBV) in Pakistani population is 2.5% and hepatitis C (HCV) is 4.9%.[1]

Patients suffering from hepatitis experience physical, social, psychosocial and financial problems.[4] They also feel fatigued and complain of joint pains, weight loss and other physiological problems.[5] A change in the life style, relationships, financial issues and isolation from the society is also reported in these patients along with reduced self esteem, diminished

mental health (including depression, anxiety and increased pessimism), less access to medical care and a persistent fear of being disclosed as a positive case.[2-7]

A study reported that 50% of the patients suffered discrimination which included alienation from co-workers, family members and even health care providers.[2] In addition shame, worry and hesitation in discussing disease status also created a barrier in seeking health care and preventing disease spread. In developed countries, stigma of hepatitis is associated with intravenous drug injection users and lay people associate Hepatitis C with AIDS.[8] Stigma of hepatitis is reported in both genders but in females it mostly affects their marital relationships.[9] A KAP study on viral hepatitis B and C done earlier by us showed that both patients and general population had inadequate knowledge about the disease, its mode of transmission, prevention and overall impact on the health resulting in different types of stigmas.[10-12] As a continuation of the same study, the experiences of stigma among these patients,[13] we conducted focus discussions with patients and their attendants (family, relative and friends) to assess their feeling and experiences to identify the gaps resulting in the stigma.

Patients and Methods

Patients were recruited from OPD of Pakistan Institute of Medical Sciences (PIMS) and Federal Government Services Hospital (Poly Clinic), Islamabad which are tertiary care health facilities at the Federal Capital of Pakistan. The eligibility for patients were: (a) age more than 18 years (b) diagnosed to have hepatitis B or C at least one year back (c) not hospitalized at the time of interview and (d) ability to speak in Urdu or local language (Punjabi); while for attendants, the eligibility was: persons accompanying the patients in the hospital and were living with them.

From June to November 2012, four focused group discussions (FGDs) were conducted with these patients and their attendants. FGDs were conducted by the investigator along with two moderators and a note taker using FGD questionnaire guide. Each FGD had an average of five participants and took 60-90 minutes to complete the discussion. To maintain standard, same investigator moderated all sessions. Probes (planned and unplanned) were used for accurate understanding. Discussion was conducted in Urdu or local language (Punjabi) where necessary to facilitate interaction and was audio taped. All sessions were separate for males and females and participants were grouped as group 1 and group 3 of male and female patients while group 2 and 4 were male and female attendants respectively (Table-1&2).

The study was approved by the Ethics Review Committee of PIMS and Federal Government Services Hospital (Poly Clinic), Islamabad. Written informed consent was taken from all patients and their attendants before the start of focus group discussions. Counseling was provided when patients or attendants become emotionally overwhelmed.

Table 1: Focus group discussion guide for patient.

S.#	*Questions*	*Probe*
1	Have you informed others about disease	When, how, why, why not
2	Change in relationships after disease	Family members, friends, colleagues at work place, routine life
3	Behavior of surrounding people when they know about hepatitis	Avoid, Interest, Sympathy, helping attitude,
4	Have you been invited to family ceremonies like before	How you have been treated
5	Behavior of health care providers after the disease	Friendly, avoid, see later, refer to some other doctor
6	What is your responsibility as a patient to avoid the spread of disease?	-
7	Describe an incident which have changed your life	-
8	Recommendations How to aware people? How to alleviate misconceptions about disease?	By imam masjid, television, newspaper, school and college, radio

Table 2: Focus group discussion guide for relatives of patient.

S.#	*Questions:*	*Probe*
1	What comes to your mind when you listen about hepatitis?	
2	How this disease spread?	
3	What should be the behavior with patient of hepatitis?	Eating and sitting with them Sharing of towels
4	What should be precautions during caring of patient	Cleansing of wound Change of clothes
5	Which word is commonly used for hepatitis	
6	Recommendations How to aware people? How to alleviate misconceptions about disease?	By Imam Masjid, Television, newspaper, school and college, Radio

FGDs that were audio taped were transcribed verbatim to written form. Their accuracy was checked by reading the transcript and listening to the recordings. Two analyst independently developed list of themes which are revised and refined.

Results

All the participants discussed at length about their experiences, perception of hepatitis and its impact on their daily lives. Several themes emerged from the FGDs which are narrated in Table-3.

Table 3: Theme and quotes of patients with hepatitis.

S.#	*Theme*	*Representative Statement*
1	Perception	Worry and fear are alternate names of the disease. There is no complete treatment of the disease. It is extremely difficult to return to normal life after suffering from this disease
2	Misconception	"Hepatitis spreads by eating together and also by blood, faeces, urine, sewerage water, injury, wound and used syringes."
3	Self stigma (emotional disturbances and fear of transmission)	"I get irritated very quickly and on little things and loose temper as compared to before the disease diagnosis, sometimes I talk nonsense and start beating myself or others."
4	Stigma from family members	"I used to live with my brother and his family, when they came to know that I have hepatitis C, they have separated everything. They don't want to eat with me and this hurts me a lot, and I wonder why I am given such punishment. What wrong I have done (Participants of Group 3)".
5	Stigma from relatives	"Relatives avoided inviting us in parties/gatherings. They thought that they might also get infected from our presence. We are also human being; why we are hated so much"
6	Attitude of health care providers	"Attitude of doctors is not good. Specialist doctors don't give time and don't check properly. They do not listen to the problem and avoid the patient".
7	Financial hardships	The patients "I have lost my job due to this disease. I am the only breadwinner of my family. I am worried about my children that how will they survive."

When asked about their perception of hepatitis or what comes to their mind when they hear the word "hepatitis". The participants associated this word with fear and worry and many of them considered hepatitis as a dangerous disease. Few representative statements are:

"It is a dangerous disease and causes weakness. My in-laws did not believe that I am suffering from hepatitis (Patients of Group 1 & 3)"

"It is a fearful and dangerous disease (Participants of Group 2 & 4)".

"Worry and fear are alternate names of the disease. There is no complete treatment of the disease. It is extremely difficult to return to normal life after suffering from this disease (Participant of Group 4)".

Most of the patients were not aware about the modes of transmission of hepatitis. Many thought that hepatitis might have occurred after using high potency tablets or following tension and worries, while others thought it spreads from sharing towel and linen. Following are some of the representative statements from the respondents:

"Disease spreads by taking high potency tablets, tension, worry, wound, injury, surgery or using comb of the patient."

"I ensure that my clothes are separately washed as disease may spread from clothes."

Many patients disclosed fear of disease transmission during FGDs.

"I don't want someone else to eat with me as I fear that they might get the disease. If some water or milk is left in the cup, I discard it away so that nobody takes it and get infected (Patients of Group 1)".

"Family members and relatives don't want to eat or drink with me. They are afraid of getting disease (Patients of Group 1)".

Majority of attendants also had misconception about the mode of transmission while others have mixed risk factors with others

"It is spread by eating with the patient, towel sharing and dirtiness."

Although few of them mentioned correct risk factors a but they also have mixed others things as a pot

"Hepatitis spreads by eating together and also by faeces, urine, sewage water, injury and wound.

Most patients were of the opinion that treatment of hepatitis is expensive and not affordable.

"Lot of financial constraints, treatment is expensive and not affordable (patient of Group 1)".

The attendants were also worried about the financial issues associated with hepatitis especially the expensive treatment and narrated this;

"Its treatment is expensive, not affordable, and troublesome for the patient and family" (Participants of Group 2).

The patients were quite vocal about the change in the attitude of their family members, relatives and friends towards them. Many felt hated but concealed their feelings from others. They also pointed out that their family members and relatives have separated their daily use items like clothes, shoes, utensils etc. from others and this practice hurts them a lot. Following statements express their feelings:

"Children and relatives have distanced themselves from me. Some became sympathetic but most people have misconceptions about this disease. My sister in law told her husband not to drink in my glass. I was very hurt when I heard this (patient of Group 1)".

"People talk to us in a bad tone as if we are spreading this disease intentionally. My life style has completely changed after the disease (patient of Group 1)".

"I used to live with my brother and his family. When they came to know that I have hepatitis C, they separated everything. They don't want to eat with me and this hurts me a lot, and I wonder why I am given such punishment. What wrong I have done (Participant of Group 3)".

"Relatives said that everything belonging to the patient should be separated. Family members wash my clothes separately; even the remaining soap/detergent water is disposed off with precaution so that no one gets this disease; this really hurts me (Patient of Group 3)".

One patient said "I have lost my job due to this disease. I am the only breadwinner of my family. I am worried about my children that how will they survive." (patient of Group 1). In some cases, patients themselves have distanced and separated their clothes and utensils.

"I have separated my eating utensils, cups and glasses and even my cloths (patient of Group 1)".

Females reported many difficulties with their in laws, who treated them badly which in some cases resulted in separation or divorce.

"When my in-laws came to know that I am suffering from hepatitis C, they warned me to stay away from my husband and children. They even asked me not to kiss my own children. They treated me so badly that I had no other option but to leave my home (Patient of Group 3)".

Some patients said that their relatives avoid inviting them to parties and social gatherings like marriage, engagement and other ceremonies because of their disease.

"Relatives avoided inviting us in parties/gatherings. They thought that they might also get infected from our presence. We are also human being; why we are hated so much (Patient of Group 3)".

When the attendants were asked about their attitude and care towards the patients, majority of them showed positive feelings and sympathies for the patients and many said that:

"The disease is from ALLAH. It is not fair that we leave the patient untouched and don't care those (Participant of Group 2)".

"Precautions should be taken during handling of patients but they should not be hated, as they are already suffering from dangerous disease. Our bad attitude will further deteriorate their feelings (Participant of Group 4)".

"Gloves should be used to clean the wounds of the patient. Contaminated clothes, bed linen should be cleaned using soap (Participant of Group 2)".

Discussion

This study indicated that both patients and attendants considered hepatitis as a dangerous disease and had misconception about its mode of transmission. Further they also had fear of disease transmission due to sharing of daily use items like eating utensils, towels, clothes and bed linen etc. The patients also reported change in the attitude of family members and community resulting in psychosocial problems which were further aggravated due to financial problems related to the treatment and difficulty in maintaining or getting a job.

The presence of wrong perception about hepatitis among patients and their attendants creates a fear of disease in their mind. It was reported that negative perception about the diseases reduces the will and commitment to combat the disease.[14] Similarly most of the participants had misconceptions about the mode of transmission of disease indicating lack of knowledge. Another study reported that deficient knowledge about the risk factors for disease spread was the major barrier between the patients and their family which resulted in stoppage or avoidance of sharing of routine daily use items.[15]

The economics has critical role in the well being of any individual or a family.[16] In the present study, financial hardships were reported by the patients as well as the attendants especially because of high treatment expenses. In Pakistan, 40% of the population in the country is living below the poverty line[17] and the head of the household (often a male) is the sole source of earning; if he becomes sick, the whole family suffers from the financial hardships.[18] Similar findings were also seen in the current study. Besides this, most of the patients reported that they were stigmatized to the extent that they were either not given jobs or lost their job when found hepatitis positive. This discrimination was an added factor towards the financial hardships. Many workers have reported that discrimination leads to the negative change in the patient's behavior.[19-21]

The attitude and behavior of family members, relatives and friends is critical to keep the patient's integrity, moral and willingness intact to combat the disease. This also emotionally affects the patients as they feel low or rejected if the family behavior or attitude becomes hostile towards them.[22] In the present study, discussion with patients showed that in many cases, the family members, relatives and friends avoided eating and drinking with them due to fear of contracting the disease which is consistent with the previous reports.[18,19] The change in the attitude and behavior affected patient's life style as they felt that they are the source of disease spread. Some patients voluntarily isolated themselves from the family and friends by not participating in the social events, while others separated their utensils and towels. These findings are in agreement with a study that concluded that "patients felt fear about transmission of infection to others.[23] Similarly, the present study showed that due to hepatitis, patients faced difficulties in their marital life and many a times it went to an extent that resulted in breakup of their relationship with spouse or in laws.[22]

Discussion with the attendants showed that though they were aware of the impact of their attitude and behavior with patient and they believed that their bad attitude might hurt the patient's feeling. However, they

were careful in the handling the patients and took precautionary measures especially while handling the wounds and body secretions. Majority of the attendants had positive feeling for the patients and wanted to take care of them.

Due to poor knowledge, both patients and their attendants were being over cautious in sharing daily use items like utensils, clothes and there were financial issues too both due to out of pocket expenses on the treatment and joblessness due to being discriminated as a result of suffering from hepatitis. There is a need to inform the patients and their family members regarding mode of transmission of hepatitis and its risk factors to reduce the stigma among these patients.

Acknowledgement

The study was funded by Pakistan Health Research Council. We acknowledge the efforts of Dr. Iftikhar Naru, Federal Government Services Hospital, Islamabad, Mr. Rizwanullah for data analysis, Saeed Ahmed Shahid, Saqib Mehmood and Junaid Raza for assistance.

Conflict of interest: None declared.

References

1. Ali SA, Donahue RM, Qureshi H, Vermund SH. Hepatitis B and hepatitis C in Pakistan: prevalence and risk factors. Int J Infect Dis 2009;13(1):9-19.
2. Silberbogen AK, Ulloa EW, Janke EA, Mori DL. Psychosocial issues and mental health treatment recommendations for patients with hepatitis C. Psychosomatics 2009;50(2):114-22.
3. WHO. Hepatitis C facts and figures. 2011. (Accessed on 10th March 2017) Available from URL: http://www.euro.who.int/en/what-we-do/health-topics/diseases-and conditions/hepatitis/factsand-figures/hepatitis-c.
4. Blacklaws H, Veysey H, Skinner V, Reid RS, Hawken G, Veysey M. Interferon treatment for chronic hepatitis C: a family impact study. Gastroenterol Nurs2009;32(6):377-83.
5. Bailey DE Jr., Landerman L, Barroso J, Bixby P, Mishel MH, Muir AJ, et al. Uncertainty, symptoms, and quality of life in persons with chronic hepatitis C. Psychosomatics 2009; 50(2):138-46.
6. Attitudes about Hepatitis C education campaign for people newly diagnosed with Hepatitis C Market Street Research Northampton, Massachusetts And Policy Studies, Cambridge, May 2001. (Accessed on 10th March 2017) Available from URL: http://marketstreetresearch.com/ news_and_press/HepC-FULL_REPORT.pdf
7. SLZ. Psychosocial Issues and HCV. Mental Health and Hepatitis C Caring. 4th ed: Ambassadors Program; 2008.
8. Grundy G, Beeching N. Understanding social stigma in women with hepatitis C. Nurs Stand 2004; 19(4):35-9.
9. Jokhio AH, Bhatti TA, Memon S. Knowledge, attitudes and practices of barbers about hepatitis B and C transmission in Hyderabad, Pakistan. East Mediterr Health J 2010; 16(10):1079-84.
10. Haq N, Hassali MA, Shafie AA, Saleem F, Farooqui M, Aljadhey H. A cross sectional assessment of knowledge, attitude and practice towards Hepatitis B among healthy population of Quetta, Pakistan. BMC Public Health 2012;12:692.
11. Shah HB, Dar MK, Jamil AA, Atif I, Ali RJ, Sindhu AS, et al. Knowledge, Attitudes and Practices of Hepatitis B and C among Barbers of Urban and Rural Areas of Rawalpindi and Islamabad. J Ayub Med Coll Abbottabad 2015;27(4):832-6.
12. Rafique I, Saqib MA, Siddiqui S, Munir MA, Qureshi H, Javed N, et al. Experiences of stigma among hepatitis B and C patients in Rawalpindi and Islamabad, Pakistan. East Mediterr Health J 2015;20(12):796-803.
13. Conversano C, Rotondo A, Lensi E, Della Vista O, Arpone F, Reda MA. Optimism and its impact on mental and physical well-being. Clin Pract Epidemiol Ment Health 2010;6:25-9.
14. Jiwani NS, Gul RB, Sultan R. Experience of caregivers with the survivors of hepatitis C. J Pak Med Assoc 2012; 62(10):1057-61.
15. Case A. Health, Income and Economic Development. 345 Wallace Hall, Princeton University, Princeton NJ 08544 USA: Princeton University, 2000 1-2 May. (Accessed on 10th March 2017) Available from URL:https://pdfs.semanticscholar.org/5d8c/6031ca9c9a701ba0234166654d17f624471f.pdf
16. Poverty in Pakistan – 40 % people living below poverty line. (Accessed on 23rd January 2016) Available from URL:http://www.geotauaisay.com/poverty-in-pakistan-40-people-living-below-poverty-line.html
17. Poverty and Social Safety Nets. Chapter 15. (Accessed on 10th March 2017) Available from URL:http://finance. gov.pk/survey/chapters_14/15_Poverty_Social_Safety_Nets. pdf
18. Zacks S, Beavers K, Theodore D, Dougherty K, Batey B, Shumaker J, et al. Social stigmatization and hepatitis C virus infection. JClin Gastroenterol 2006;40(3):220-4.
19. Zickmund S, Hillis SL, Barnett MJ, Ippolito L, LaBrecque DR. Hepatitis C virus-infected patients report communication problems with physicians. Hepatol 2004; 39(4):999-1007.
20. Gail Butt BLP, Liza K. McGuinness. Living With the Stigmaof Hepatitis C. West J Nurs Res 2008;30(2):204-21.
21. Blasiole JA, Shinkunas L, Labrecque DR, Arnold RM, Zickmund SL. Mental and physical symptoms associated with lower social support for patients with hepatitis C. World J Gastroenterol 2006;12(29):4665-72.
22. Zickmund SL, Bryce CL, Blasiole JA, Shinkunas L, LaBrecque DR, Arnold RM. Majority of patients with hepatitis C express physical, mental, and social difficulties with antiviral treatment. Eur J Gastroenterol Hepatol 2006;18(4):381-8.
23. Conrad S, Garrett LE, Cooksley WG, Dunne MP, MacDonald GA. Living with chronic hepatitis C means 'you just haven't got a normal life any more'. Chronic Illn 2006;2(2):121-31.