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Patients' Perspective regarding Counselling about Hepatitis C Transmission: A Mixed Method Study in Rawalpindi, Pakistan

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ABSTRACT

Objective: To identify patient's perceptions regarding counselling by health care workers about modes of transmission of Hepatitis C and to explore barriers to counselling.
Study Design: Mixed method study.
Place and Duration of Study: Outpatient and Inpatient of Medical, Surgical, Gynaecology, and Pre-Anaesthesia Departments of Tertiary Care Hospital, Rawalpindi Pakistan, from Aug 2019 to Feb 2020.
Methodology: After rigorous inclusion and exclusion criteria, 400 patients were selected for the study through consecutive sampling. After taking IRB an interviewer-administered structured questionnaire was used to determine the level of counselling, and two focus group discussions were conducted to explore the patient's perspective regarding barriers to counselling.
Results: The results show that 56.5% (n=226) patients perceived the level of counselling to be poor, 34.3% (n=137) found it to be satisfactory, and a mere 9.3% (n=37) perceived it to be good. Barriers to counselling were attitude, time, attention given by health care providers, the environment, monetary issues, and a lack of communication skills and professionalism.
Conclusion: The majority of the respondents reported that the level of counselling regarding the modes of transmission of HCV was poor. Moreover, the lack of attention, time, and attitude of the health care professionals were considered significant barriers to counselling.

Keywords: Counselling, Hepatitis C, Health Education, Modes of Transmission.

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INTRODUCTION

WHO has declared hepatitis a "viral time bomb." 170-180 million, 3% of the global population, suffer from Hepatitis C infection.[1] WHO gave an estimate that approximately 71 million people have already progressed to chronic HCV, and around 0.4 million people die every year from HCV mostly progressing to Cirrhosis and liver cancer.[2]

Prevalence in the different regions of the world ranges from 1.5% and 1.7 % in Europe and America, respectively, and around 2.3% in the East Mediterranean region to the highest of about 5.3% in Africa. Pakistan ranks second in the global burden of Hepatitis C where, as in Egypt, the prevalence peaks at 10%- 20%.[3] Amongst our neighbouring countries, the projected prevalence of Hepatitis C is 0.5%–1.5% in the Indian population only.[4] Hepatitis C in Bangladesh is around 1% in the general population. However, the data on this is still minimal.[5] Pakistan, with 5% of its infected population, leads globally with the second highest burden, i.e. 8 million people.[6] Pakistan is facing an HCV epidemic of significant magnitude where 1 in every 20 Pakistani is infected. There are about 0.24 million new cases diagnosed in Pakistan every year.[7] Pakistan is having one of the peak new annual incidence rates of hepatitis C infection.[8]

In Pakistan, most people are not aware of their hepatitis status, and those infected are unaware of the cause or source of it.[9] There are certain misapprehensions and lack of information about hepatitis C, which can be subdued by proper health education and the introduction of awareness programs via media campaigns and multisectoral collaborations amongst the governments, healthcare setups and non-governmental organizations, which will help in disseminating valuable information to improve the public awareness regarding HCV transmission.[7] Counseling, health awareness, and

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testing of those at risk are the recommended strategies by WHO for controlling HCV transmission.

The main objectives of the study are to identify patients' perceptions regarding counselling practices of health care workers regarding modes of transmission of HCV infection and also to explore the patients' perspective regarding barriers to counselling about hepatitis C transmission. Health education, particularly one-to-one counselling of the patients, is one of the most impactful ways to halt the disease. However, in Pakistan, health education and counselling are still neglected fields. Proper counselling of HCV patients is important in controlling their spread as they are the potential source of infection transmission. This study will help to determine the level of counselling imparted by healthcare workers to patients with Hepatitis C. The study's results will help provide evidence-based recommendations for improving counselling practices to control disease transmission.

METHODOLOGY

It was a mixed-method study comprising both the qualitative and quantitative components. The study was conducted at different Outpatient and Inpatient Departments Medical, Surgical, Gynaecology, and Pre-Anaesthesia Departments of a Tertiary Care Hospital at Rawalpindi, Pakistan from August 2019 to February 2020. IRB approval (197-AAA-ERC-AFPGMI,10 Dec 2019) was taken from the Armed Forces Post Graduate Medical Institute for the research. Institutional consent was also obtained before collecting data.

Inclusion Criteria: Adult HCV PCR-positive patients who gave consent for participation in the research were included.

Exclusion Criteria: Children and adolescents below the age of 18 years and HCV patients who were critical or terminally ill were excluded.

The study population included hepatitis C-positive patients who were undergoing treatment or those who had already undergone treatment and were presenting for follow-up to the outpatient departments.

Sample Size was calculated using the WHO calculator and the following equation:

$$SS = \frac{z2 \times (p)(1-p)}{e2}$$

Keeping the Confidence Interval (CI) to be =95% or Z=1.96 and Precision rate (e)=0.05%. Awareness about modes of transmission of hepatitis C was found to be around 49% of the population in a study in Pakistan.[8] The sample size was calculated to be 384. Taking the response rate of 95%, a sample of 400 patients was collected and included in the study. The sample was collected through non-probability consecutive sampling till the sample size was achieved. Two Focus Group Studies, each comprising 10 patients, were conducted till the saturation of response. Patients from the original sample who gave consent for participation in FGDs were selected. 02 facilitators/ Moderators were also present. Questions were self-administered by the principal investigator. Reflective notes were taken during FGDs, and the data gathered was transcribed as soon as the conversation was completed. Data was manually written due to the prohibition on using recorders and media devices near the hospital.

The data collection tool comprises an Interviewer-administered structured questionnaire. The questionnaire has two sections; 1st section describes the socio-demographic characteristics of the participants. The 2nd section comprises 10 questions that help to determine the perceived counselling level and patient's perception of the source of acquisition of infection. Cronbach alpha was used to check the internal validity of the questionnaire using SPSS software, and it was found to be 0.78. For FGDs, the questionnaire was adapted from the Communication Assessment Test (CAT), a pre-validated and pretested questionnaire to assess responsiveness.

Quantitative data was analyzed using SPSS software version 21. Numerical variables are expressed as means and standard deviation, whereas categorical variables are expressed as frequencies and percentages. For analyzing the perceived level of counselling, scoring criteria were set for questions in section 2. Each "Yes" was marked as '2' and each "No" was marked as '1' making a minimum score of 10 and a maximum score of 20. A score between 10 to 13 was considered poor counselling, 14 to 17 as satisfactory counselling and a score of 18 to 20 was reported as good counselling. Qualitative data obtained during FGDs was analyzed using thematic analysis. Manual identification of themes and subthemes was done following FGDs.

RESULTS

Out of the sample of n=400 patients, there were 250(62.5%) males and 150(37.5%) female respondents. The socio-demographic statistics show that 211(52.8%)

respondents were rural, whereas 189(47.3%) had urban roots. Most patients, i.e. 253(64.6%), had acquired some level of education from primary to postgraduate level. About 93(23.3%) of the HCV patients had a positive family history of HCV infection incl, including the spouse or one of the parents who tested positive for HCV infection (Table-I).

Table-I: Socio-Demographic Statistics of Study Population (n=400)

Categories	n(%)
Gender	
Males	250(62.5%)
Females	150(37.5%)
Residence	
Rural	211(52.8%)
Urban	189(47.3%)
Education	
Never went to school	142(35.5%)
Primary to Matric	165(41.3%)
FA to Masters	93(23.3%)
Occupation	
Employed	210(52.5%)
Retired	62(15.5%)
Others e.g. Students & Housewives.	128(32.0%)
Marital Status	
Married	309(77.3%)
Unmarried	26(6.5%)
Widow	65(16.3%)
Duration of HCV Infection	
Up to 2 years	229(57.3%)
3 to 5 years	103(25.8%)
More than 5 years.	68(17.0%)
Family History of HCV Infection	
Positive	93(23.3%)
Negative	307(76.8%)

In the 2nd part of the questionnaire, where the respondents were asked whether they were counselled about the different modes of transmission of HCV, only a little more than half of the participants reported having been informed about the reuse of infected syringes 225(56.3%) as a source of spread of HCV. Similarly, only 186(46.5%) and (207)51.8%, reported being counselled about the transmission through infected blood transfusion and the use of unsterilized razors and trimmers at barber shops, respectively. However, most of the people claimed that they had never been told that HCV infection also spreads through vertical transmission during pregnancy, through unsafe sexual activity, needle prick injury from infected source and also during dialysis, as demonstrated in Table-II.

The aggregate score of the reported response regarding modes of transmission of HCV shows that more than half of the patients, i.e. 226(56.5%), perceived the level of counselling to be poor. 137(34.3%) respondents found the level of counselling satisfactory, and a mere 37(9.3%) perceived the level of counselling to be good. The majority of the patients 175(43.8%) did not know the source from where they acquired the HCV infection, whereas about 56(14%) respondents reported having acquired the infection from reused syringes due to malpractice in healthcare setups. Approximately 12% of the respondents also perceived that they acquired HCV infection from sources like mosquitoes, medicines, food, and water, which are not the actual means of spreading HCV infection, depicting the gap in counselling.

Table-II: Patients' Response to the Questions regarding Counseling about Modes of Transmission of HCV (n=400)

Variables	Yes (Counseled)	No (Not Counseled)
Re-use of infected syringes	225(56.3%)	175(43.8%)
Non- Sterile Dental Equipment	160(40%)	240(60%)
Infected blood products transfusion	186(46.5%)	214(53.5%)
Vertical transmission during birth	85(21.3%)	315(78.8%)
Unsafe sexual activity	117(29.3%)	283(70.8%)
Sharing of infected toothbrush	38(9.5%)	362(90.5%)
Needle prick injury from infected source	122(30.5%)	278(69.5%)
During Dialysis	78(19.5%)	322(80.5%)
Unsterilized Razors and trimmers	207(51.8%)	193(48.3%)
Unsterilized equipment for tattooing and piercing.	141(35.3%)	259(64.8%)

The themes and subthemes identified are shown in the flow chart in Figure. Most of the patients in the focus group discussions thought the doctor's attitude made all the difference. They suggested that if the doctor is friendly and welcoming, it becomes easier for them to inquire about the subsequent health issues. However, if they are snubbed, the whole process becomes way harder. As expressed by one of the patients, "It is the way the doctor greets the patient that sets the whole thing in motion and makes all the difference." According to the participants, the lack of compassion and empathy on the part of healthcare workers is one of the significant barriers to counselling. Patients also consider that the time given and required by every patient becomes a hurdle in counselling. Participants also recognized that the doctors in our setup are overburdened and cannot give each patient the full time required, leading to knowledge transfer gaps. One of the participants said: "We come to the doctor so that our concerns are addressed and we are given proper attention. Another patient also stated, "The time given by doctors and the

words of consolation coming from the doctors is a sigh of relief for the patient in distress."

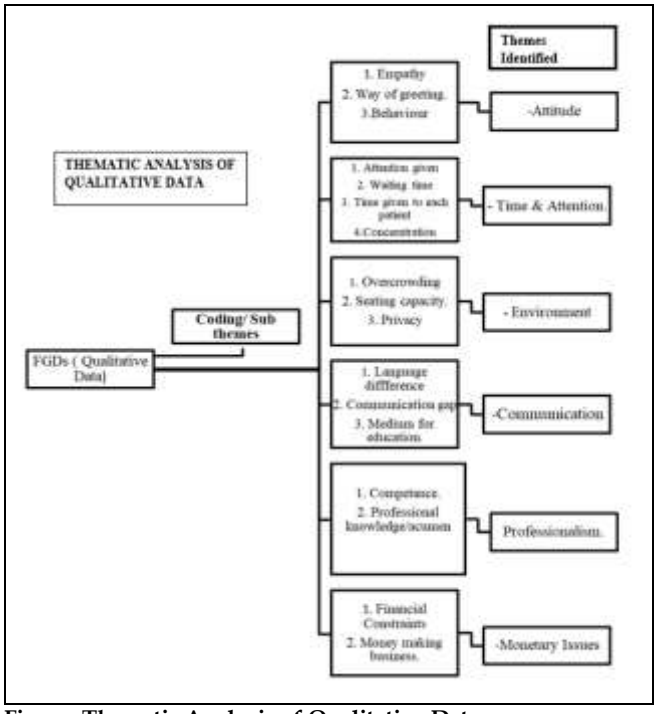

Figure: Thematic Analysis of Qualitative Data

The counselling process requires a peaceful environment and uninterrupted attention for one-on-one complete interaction between patients and doctors. However, most of the time, the clinics' doctors are overcrowded with patients and staff, leading to many disturbances and an uncomfortable environment for the doctor-patient interaction. Thus, the lack of privacy is also perceived as a counselling barrier. Patients also considered that one of the reasons for the failure of effective communication is the difference in language. In our country, the official language for transcripts is English, but most of the population fails to read or understand it, and subsequently, the patients fail to comply with the instructions. Some patients also perceived that they were not counselled because it was incompetence on the doctor's part. They presumed the doctor was not knowledgeable enough and lacked updated information on the subject matter. Participants also recommended that continued medical education be mandatory and that all doctors be assessed upon current practices and knowledge before renewal of their medical licenses to improve healthcare provision services. Many patients also perceived that doctors counsel well only when they get financial benefits and when the patients pay for checkups privately, not in government or social welfare hospitals. Patients also claimed that financial constraints on the patient's side are why they cannot receive good and complete health care. As one of the participants expressed: "The medical profession is sadly just a money-making business now, and no one cares for the diseased."

DISCUSSION

It can be deduced from the study results that most patients reported that they were never counselled about most of the modes of transmission of HCV. Awareness about modes of transmission of hepatitis C was found in around 49% of the population in a study in Pakistan.[10] Despite medical treatment, most respondents were not given information about disease transmission. They had never been counselled enough to know that they were the potential source of infection for others. Patients reported that they were not informed about most of the modes of spread of infection like vertical transmission, needle prick injury with infected syringes or the sharing of infected toothbrush; however, only half of the respondents reported being informed that HCV spreads through infected blood transfusions and reuse of infected syringes which is in consistence with a study carried out in Karachi, Pakistan showing an average of 80% of the sample being aware of transmission of disease through these two modes of spread only.[11] According to the study's results, most people did not know the source from where they acquired the infection, which also depicts that proper medical history was not taken to identify the source of the infection. Subsequently, they were not counselled about a possible source of acquiring the infection. A few patients also reported having acquired the infection from contaminated food and mosquitoes, which are not the actual ways of spreading HCV infection. This further signifies the gap in the transfer of knowledge. This finding is also consistent with the study carried out in Rawalpindi Medical University, where 70% of patients reported that Hepatitis C can spread through contaminated food and water.[12] The study by Mustafa et al. found that a small percentage (30%) of people had awareness about vertical transmission of disease, which resonates with the study results where only 21% of the people have reported being counselled about the vertical transmission of disease.

In a study carried out in Lahore, Pakistan. 79% of the children who tested positive for HCV had a family

history of HCV, but they were unaware of the potential risk that it posed.[13] In this study, approximately 23% reported having a positive family history of HCV. In contrast, only 29% of the people reported having been counselled about the transmission of diseases through sexual activity and being aware that having an HCV-positive in the family increases the chances of contracting the infection. In another study carried out at the University of Virginia, USA, to determine the perceptions of patients of HCV, it was identified that most people did not perceive sexual transmission as a risk factor, showing similarity with the results of the study where only 7.5% of people perceived to have acquired the disease from sexual partners.[14]

As found in the results of the thematic analysis, the attitude and behaviour of the doctor are perceived to be one of the significant barriers in counselling. It was reported that the attitude of the doctors directly resonates with patients' satisfaction. Unmet expectations can lead to dissatisfaction, derailing the patient's confidence in health care providers and, at large, from the health system.[15] Another coherent study states that treating patients with dignity and maintaining a good and empathic attitude towards patients is also one of the important domains of health system responsiveness, which further constitutes a primary goal of the WHO health system framework.[16]

In another study carried out to assess patient satisfaction and identify the barriers in a tertiary care hospital in Rawalpindi, it was found that the attitude of the healthcare workers plays a significant role in patient satisfaction, patient-reported lack of attention, lack of information from providers, long waiting times and rude behaviour amongst the problems faced during the hospital visits which are similar to the barriers identified during the focus group discussions.[17] Another factor attributed to patients as a barrier to counselling was the environment. As reported by the patients, the uncomfortable environment and multiple disturbances during the interaction interrupt the flow of knowledge. The study supports the idea that a conducive environment enhances health and increases health-seeking behaviour in addition to the improved assimilation of health information.[18] Another study carried out in Iran also shows the impact of the environment on patient health and treatment; it stated that patients who are treated with concern and cared for in a pleasant environment respond better to the counselling advice by health care providers along the course of treatment.[19]

Patients also perceived that the healthcare workers are not well versed in updated and modern counselling practices and cannot address their patients' queries. In a study carried out in Abha Saudia Arab, only 61% of the healthcare workers were aware that needle stick injury could lead to HCV infection, which proves the claim of the patients. In a study conducted in Riyadh, Saudia Arab, it was found that the quality of provided services relied upon the doctor's communication, politeness and kindness.[20]

LIMITATION OF SUDY

Despite being thoroughly done, the survey data was entirely patient-reported and depicted patients' perceptions. Therefore, it is subject to recall bias.

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CONCLUSION

Most patients perceived the level of counselling to be poor. Despite the provision of medical care, most of the patients reported being never counselled about transmission through needle prick injury with infected syringes, sharing of an infected toothbrush, during dialysis or through vertical transmission during pregnancy. Furthermore, as identified in focus group discussions, poor attitude and communication on the part of health care workers, uncomfortable environment and lack of proper time and attention act as hindrances in the counselling process.

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Authors' Contribution

Following authors have made substantial contributions to the manuscript as under:

NI & AK: Study design, data interpretation, drafting the manuscript, critical review, approval of the final version to be published.

HM & SR: Conception, data analysis, drafting the manuscript, approval of the final version to be published.

SMA & ZUDB: Data acquisition, critical review, approval of the final version to be published.

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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