

Pragmatic barriers for delay in access to HCV testing services: Perspective of People With Injecting Drugs and living with HIV

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Abstract

Background: Hepatitis C (HCV) is emerging as a major public health problem and its co-infection with HIV is on the rise especially in People With Injecting Drugs (PWID). Barriers for delay in accessing services for HCV care may lead to disease progression and impact the society in the form of loss of productive workforce.

Aim: This qualitative research was undertaken to explore the barriers for delay in testing for HCV amongst PWIDs.

Methods and Material: The study was conducted in two districts of India i.e. Imphal (Manipur state) and Amritsar (Punjab state). A total of 32 PWIDs participated through In-Depth Interviews (IDI) and Focus Group Discussions (FGD).

Results: Mostly, the barriers reported for delay in HCV testing were related to socio economic context in which the PWIDs live; inhibitions to get tested due to fear of a positive result, unavailability of HCV services particularly in rural and remote areas, financial costs and long waiting period. Drug use amongst females influenced care seeking behavior.

Conclusion: PWIDs face significant health risks of HCV. The socio economic and health systems related barriers create gap for continuum of care for PWIDs. Supportive role of the health care providers, awareness on viral hepatitis, care and support from family is thus fundamental to PWIDs living a healthy life.

Introduction:

HCV infection is a major public health problem. World Health Organization data (2016) suggests that globally there are 37 million people infected with HIV, and around 115 million people with chronic HCV infection. Also, an estimated 2.3 million people living with HIV are co-infected with HCV. It is observed that in the regions of Asia and Eastern

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Europe, HCV cases in high endemic areas of HIV is becoming a major public health problem because it disproportionately affects vulnerable populations and there could be risk of developing HCV and HIV co-infection (Swan D, *et al* 2010 and Barocas, *et al* 2014). Co-infection rates of HCV are higher among HIV-positive especially in PWIDs, i.e. about 75-99 per cent (Harris and Rhodes, *et al* 2013 and Grebely and Raffa, *et al* 2008). The risk of developing cirrhosis is twice while risk of end-stage liver disease is six times higher in co-infected individuals (Grebely and Raffa, *et al* 2008 and Perz JF, *et al* 2006).

There are many barriers to treatment access and uptake of health care services for PWIDs and these are broadly conceptualized at the level of the individual, health care providers and health systems (Grebely, *et al* 2008). Literature on HIV/AIDS has documented that the commonly cited barriers are concerns related to treatment side effects, efficacy, duration, confidentiality and stigma (Shaodong Ye, *et al* 2014). These barriers could lead to 'de-prioritizing' of testing and treatment services among PWIDs (Jones and Atkinson *et al*, 2008).

Despite of scaling up the HIV programme and creating awareness on the disease transmission, most of the people living with HIV and hepatitis remain unaware of their chronic carrier status hence; continue to infect others for decades and eventually the impact of which is seen on the society in the form of loss of productive workforce and the burden on health care systems to treat those affected. Therefore, it is crucial to study and understand these barriers so that appropriate intervention can be undertaken.

This qualitative research study was undertaken with the aim of exploring the barriers for delay in testing for HCV amongst the PWID.

Subjects and Methods

The study was conducted in two geographically and culturally different districts in India,

Imphal and Amritsar. These districts were selected based on the high prevalence of HCV infection among the Injecting Drug Users and state willingness to support the study. The facility from where the PWIDs were enrolled for the study was a Needle and Syringe Exchange Programme run by the Targeted Intervention- Non Governmental Organisation (TI- NGO) under the National AIDS Control Organisation (NACO).

Sample size and coverage

As the study was qualitative in nature, the sample size was determined through theoretical saturation. Theoretical saturation is reached when ongoing data collection no longer yields new information or insights (Ezzy D, 2003). In this context, Morse suggests a range of sample size from 30-50 as a good number to achieve the desired qualitative results (Morse 2002). When the sample size of 32 respondents was achieved and the data did not produce new insights it was decided to close the process of recruitment. A total of 15 In-Depth Interviews (IDIs) and 4 Focus Group Discussion (FGDs) were conducted. PWIDs that were above 18 years of age were selected for the interview.

Data Collection

The open ended IDIs and FGD guide consisted of guiding questions and structured probes. The questions were on people's knowledge, experience of accessing HCV services and management of HCV infection, and family support. The interview format enabled us to pursue new themes, encourage respondents to elaborate answers, and explore the context of responses. The interviews were conducted in local language (Punjabi and Manipuri) that enabled the researcher to connect with the participants and internalize their world in terms of patterns of beliefs, fears, expectations, dominant

ideas, values and behaviors of the clients who inject drugs. Interviews were conducted at the NGO-Targeted Intervention site by the research team and typically lasted 40–60 minutes.

Data Coding and Analysis

Initially line-by-line coding was done manually. The qualitative research team independently reviewed each document and coded emergent themes and all the discrepancies were resolved through discussion. Coding and emerging definitions were recorded electronically. The results of the study have been categorized into various themes related to pragmatic barriers in access to health services for HCV. They were: (a) lack of knowledge about HCV (b) fear from getting detected as HCV positive, (c) financial constraints, (d) perceived stigma and discrimination, (e) Unavailability of HCV services, (f) barriers related to lack of outreach services, (g) lack of support from family and community.

Ethical Statement

Prior to the interviews, participants were informed about the purpose of the study and were told they could choose to withdraw at any time. Informed consent was obtained before each interview began. To protect confidentiality, potential personal identifiers were deleted from the database. The Technical Review Committee and Ethical Committee of MAMTA Health Institute for Mother and Child approved the study, and the local government and the head of the community organization facilities of the State AIDS Control Program supported to conduct the study.

Results

A. Profile of the study participants:

Of the 32 interviewed participants in the study, 28 were male and four were female. The age of the participants ranged between 20 to 53 years, with a median age 28 years. The mean

age of PWIDs who initiated drugs was 11 years. Out of the total sample, 22 respondents studied till secondary level, seven completed higher level education and three completed their primary education. On an average the monthly income of the PWID family was INR 6,000.

B. Emerging barrier related themes:

Table 1 shows number of respondents that reported barriers with regards to fear of a positive result, outreach services, diagnostics and treatment, lack of family support and perceived stigma and discrimination in receiving HCV care. The most significant reported barriers were related to downplaying their health status, fear of a positive result, lack of knowledge and finance.

Theme-1: “Lack of knowledge’: None of the PWIDs had complete knowledge on HC

...Virus can be flushed out by washing the syringes and needles. HCV gets killed in sunshine.

FGD_PWID_HIV positive_23 years_Imphal

All the PWIDs mentioned that peer educators and Out Reach Workers (ORWs) talk about HIV and safe injecting practices but never talk about HIV. Five respondents from Imphal region mentioned that they received incomplete

Table 1: Number of respondent reported barriers in receiving HCV care

Barrier	Number
Lack of Knowledge	28
Downplaying their health	32
Fear of a positive result	29
Finance related	32
Perceived stigma and discrimination	13
Unavailability of HCV services	20
Lack of Outreach Services	9
Lack of support from family	17

information on HCV from the peer educators and the ORWs. About 23 PWIDs had heard the name HCV for the first time. Following this it was mentioned that HCV is addressed as “*Kalapiliya*” (a local colloquial for HCV) in Amritsar. Even though the PWIDs are familiar with the term, this did not necessarily mount to awareness on the disease and it is clear from their narration below:

...HCV can be transmitted through sweats and eating food with each other.
IDI_PWID_28 years_Imphal

In Imphal, three out of twelve participants were ever tested for HCV. Those who tested negative had common misunderstanding that they do not need to get tested again and their blood report will be negative for HCV. In an FGD in Amritsar, some mentioned that sitting together, eating together could transmit the virus.

...Even if anyone has HCV, he has yellow eyes. So if you stare his eyes for a minute you can be infected or if you are wearing yellow dress at that time the risk of transmission get increased.
FGD_PWIDs_Amritsar

In Amritsar, most of the participants were aware that sharing of needles is risky and yet ten PWIDs mentioned they shared syringes while injecting drugs. The two main reasons reported for sharing needle are i) reluctance in using a new syringe when they have urge to inject drugs, ii) waste of time in getting new syringes and iii) Financial inability to pay for the new syringes was a concern for the PWIDs. Some of them mentioned that good connection with pharmaceuticals from the medical stores is an important if one wishes to receive new syringes as and when required.

Lack of knowledge about HCV, its transmission and risk factors played as contributive factor for delay in testing. The evidence identified from this study suggested that PWIDs have different concepts of illness and disease from the biomedical understandings of Hepatitis C, thus indicating that there is low level of awareness regarding HCV.

Theme-2: “Using strategies to trivialize their HCV health status”: Downplaying their health condition causes delay in testing and increases the risk

Health problems in PWIDs are well documented. PWIDs face significant health risks, many of which are increasingly preventable and treatable. Some of the problems as mentioned by PWIDs are pain in the liver area mild discomfort, pain in lower abdomen, chronic fatigue, loss of appetite, weakness, unbearable body ache, memory loss, stress, lack of presence of mind and getting violent.

When no symptoms were experienced, the participants felt they are healthy and not at risk for any infection. As one of the PWIDs from Amritsar has put it, ‘*it is normal to feel pain, fatigue, stress and weakness. There is nothing to worry about it.*’ However, when the pain gets severe and becomes unbearable, they were uncertain of the cause and therefore, provided other possible explanations for their illness. “*It would go in a day or two. I work too hard that is why I have this pain*” was the common reason cited for not using institutional health care services. Home remedies were the preferred choice of treatment during this stage. All the PWIDs were worried about their health, expensive services and had anxiety about their future and family life.

Theme-3: “Fear from getting detected as HCV positive”: Most of the PWIDs had re-

frained from getting tested due to embarrassment of having done something wrong

There was feeling of sadness amongst the PWIDs once they learn about the positive status. One of the respondents in Imphal who was tested positive before the study stated that,

....after the status was known I wanted to commit suicide but the thought of my children stopped me as I have to take care of them. There was a time when I wanted to kill them too. But I got in touch with NGOs who educated on avoiding risky behaviours and improving quality of life. This helped me to live for myself and my children.

PWID_HIV/HCV co-infected_30 years_Imphal

Results indicate that barring three PWIDs (who were HCV positive at the time of the interview) none of the PWIDs in Imphal and Amritsar themselves felt the need to get tested as to prevent the disease from advancing. The key reasons reported for not testing are lack of awareness on HCV, feeling scared and hesitant to take test results because of the fear of getting a positive result.

In this study it was observed that the social pressure to be exposed as PWID and possible side effects of HCV would refrain them to get tested. There were feelings of guilt and fright of being detected as positive for HCV. In Amritsar, there were cases of police beating the PWIDs if they were seen at the chemist shop to buy syringes. Force, control and violence were seen as common ways to prevent the PWIDs from injecting drugs. PWIDs in Imphal and Amritsar were looked upon as thefts in the eyes of community. Unnecessary interrogation and interference in the lives of PWIDs becomes a double burden on their lives.

Harris and Rhodes pointed out the impact of criminalization of PWID on HIV treatment and adherence. They posit that the

...drug policies emphasizing criminalization can adversely affect treatment access through the confiscation of medications by police, reluctance among PWID to seek help, and the interruption of treatment following arrest, detention or incarceration (Harris and Rhodes 2013:11).

Theme-4: “Financial Constraints to access services”: Most of the participants were helpless for not being able to afford the services and mentioned that suffering due to illness was the only option

Financial issues were a matter of concern for all the clients. Access to treatment was perceived to increase daily living costs, for example public transport and cost of treatment.

....I hardly earn INR 2000 per month and have a family of four people to take care of. I had shared needle once with my friend. In Integrated Counselling and Testing Center, I was detected HIV positive but don't know about HCV. HCV testing is not free of cost yet. The government charges are 150 INR for screening and about 6000 INR for confirmatory test. It is very expensive and the travel cost to the hospital and back home is a costly affair. It will cost me around INR 200-300 per visit to the doctor. Should I take care of my family or keep visiting doctors!!

IDI_HIV_39 years_Amritsar

...We don't know if complete package of HCV services are available in the public sector. They are available in private settings and it is very expensive. Therefore, we cannot afford 100,000 – 150,000 INR for the treatment. It would be a dream to be healthy now. Government should reduce the cost or give it for free.

IDI_HIV/HCV positive_27 years_Imphal

According to the declaration by the Ministry of Health and Family Welfare in Punjab, Hepatitis C treatment upto Rs, 150,000 (2192 USD\$) would be provided free of cost under the “Mukh Mantri Punjab Hepatitis C Relief Fund. However, the PWID is required to pay approximately Rs. 6000 (87USD\$) for the viral load and genotype testing before they are considered eligible for the treatment. In Manipur, Hepatitis C treatment upto Rs 150,000 (2192 USD\$) is reimbursed to the PWID under the “Manipur State Illness Fund”. However, financing for health by the state comes along with stringent inclusion criteria’s and challenges like delay in reimbursement. The PWIDs cannot afford to bear these expenses and therefore access to health care still remains a major challenge in India.

Theme-5: “Perceived Stigma and discrimination”: Many participants felt if privacy and confidentiality is maintained it would minimize stigma

...There is stigma and discrimination in the society for HCV and PWIDs. The society does not accept them as normal people. Some clients live on roads in open. This leads to sense of hopelessness.

IDI_PWID_HIV_23 years_Amritsar

PWIDs may not disclose a positive status of HIV or HCV status due to fear of a negative reaction, isolation and social exclusion because they did something that is considered ‘morally wrong’.

The factors that discouraged some of the PWIDs to access any services from government facilities were due to their past experience of HIV/AIDS treatment. Four participants mentioned that impolite interactions of health care providers, no counselling, and lack of support are excruciating than the pain of actual infec-

tion. Nine PWIDs mentioned there was discrimination in terms of touch, long waiting time, concern about lethargy on treatment, and lack of interest. However, due to high cost of services in the private sector they put their concerns aside and visit the public sector services for needles, screening and other care. Five PWIDs mentioned that they go to private medical practitioners. According to them, the private medical practitioners have better understanding of the disease and treatment. As quoted by one of the PWIDs-

...at first I use to go to government hospital for psychological support but I stopped going there because of the long waiting hours for treatment and when we say something they cut the conversation and do not listen properly. Private clinic doctors listen carefully and they give time. Private hospitals are costly but they are better.

FGD_HIV positive_25 years_Imphal

Anxiety about being judged as ‘morally wrong’ made some of the study participants difficult to voice their opinion on care and support needed during the traumatic period of their life.

...I feel that healthcare services at govt. level are very poor. Most of the service providers treat us with negligence, sometimes we feel discriminated at their derogatory remarks, even when we go for routine health check-ups at OPD we often face harassment like making us wait unnecessarily for our turn while they let others who come after us get in before us to consult the doctor. Even the nurses at Govt. Hospitals throw unnecessary tantrums when they see us.

IDI_HIV positive_24 years_Imphal

Total twelve PWIDs identified stigma as a barrier and used words such as “shame,” “embarrassment,” and “taboo” to describe their experiences.

Women, Drug Use and Stigma

...They verbally abuse and refuse to give treatment. It is a curse on us....we have done bad things so we are getting these results because of our bad behavior.

IDI_Female drug user_48 years_Amritsar

...It's shocking for the society to learn that women also inject drugs. They consider us as bad woman and therefore, speak ill of us. Due to this notion, it is scary and embarrassing to visit the health care facilities. They teach us morality than giving treatment. Even at home, we cannot tell them why we are going to hospital for checkup. We have to ask money also from family which is big problem.

IDI_Female drug user_HIV positive_45 years_Amritsar

There were four females in the study who were injecting drugs. It was observed that gender inequality in one of the major issue that influences care seeking behavior amongst female drug users. As mentioned by them many recovering female clients often come to the Anti Retroviral Treatment counselor with the complaints that they have very less social acceptance and that could be a major stumbling block to effective rehabilitation. The treatment involves many tests and costly therapy as well. They could not complete the full treatment due to socio cultural reasons of dependence on husband and family for treatment services. Female clients felt stigmatized out of the fear of exposure of their health status, which impacted negatively on help-seeking.

As Jones, Atkinson *et al* have pointed out that,

*... Women could have less control over their injecting practices and are therefore restricted in the extent to which they can perform safe injecting practices and access services (Jones, Atkinson *et al*, 2008:43)*

Theme-6: “Unavailability of HCV services”: Provider – Client Interaction can affect the utilization of HCV services

.....whenever we go to hospital the services related to HCV are not there. Sometimes the doctors say there are no kits and sometimes they say there is no need to get tested because you won't be able to afford treatment anyway. Therefore, we find no use going to the facilities.

FGD_PWID_HIV positive_32_Amritsar

A number of clients reported HCV care being unavailable at an affordable cost, the doctors being judgemental and unresponsive to their needs, treated without respect, there was long waiting period, the lack of trust between patients and providers and unfamiliar hospital settings that add to their negative experience. On the other hand doctors opined that PWIDs are not in a state to adhere to medicines and keep their appointments. There is no mechanism in the health systems or communities to track the PWID for regular health check up. Overall this could lead to neglect of health care and worsen the condition.

Theme-7: “Lack of outreach services for HCV”

...In my opinion, Medical Officers at hospitals should give orientation about Hepatitis C and HIV/AIDS to his staff nurses and other clinical staffs. I would also like to request the NGOs who are working upon these issues to give awareness about HCV & HIV/AIDS to general public and families of infected people as well. If we get moral support from general public towards the people living with HCV then, things could have been much better. Further, if NGOs or Government could support us with medications for improving functioning of liver then it can be very helpful.

PWID_IDI_HIV/HCV positive_40 years_Imphal

This study showed that barriers related to outreach services include lack of infrastructure to treat the disease, lack of constant engagement

of medical care staff, unavailability of treatment facilities in the public sector, expensive services in the private sector and irregular tracking of their overall health condition.

Theme-8: “Lack of support from the family”: If families are unaware of HCV infection it could lead to lack of care of those infected.

....My family members do not care of my health so I consult to those who understand my problems. I want family to support me.
PWID_FGD_HIV positive_45 years_Imphal

...Not even my parents know that I am tested positive for HIV. If I say they will not accept me. I can't even think of anyone in the society knowing about my HIV status. They will discriminate and abandon me after knowing my status. No one will talk with my family. I want to be with family.

IDI_HIV/HCV positive_38 years_Amritsar

There is lack of support from most of the family members of PWIDs owing to the limited information on HCV infection, its spread, treatment and precautions. This often instigates inferiority complex and may lead to relapse in health condition. It has been reported that many recovering clients come to the ART counselor with the concern of having very less social acceptance which is a major stumbling block to effective rehabilitation.

The PWIDs interact mostly with friends who understand and support them, who are primarily people with infections of HIV or HCV. It was also observed that participants resort to groups/civil society organizations that work for HIV positive people and help them to cope with the HIV status and life in general.

....Recovery Self Help Groups are there in some communities. Awareness on HIV, HCV is given. The feeling of ‘I am not alone’ is there. It becomes very easy to accept the status when there are friends to support. Health seeking behaviour is also realised.

In some cases spouses are supportive- in cooking and taking care.

PWID_HIV positive_FGD_Amritsar

Theme-9: Problems of the young PWIDs: A challenge for the future

One of the PWIDs from Imphal mentioned he started taking drugs when he was 11 years old and two PWIDs started taking drugs when they were less than 14 years. They had lied, cheated, robbed money and also worked as a labourer to get money for drugs. One of the respondents mentioned he had sold his clothes, shoes, kitchen items to buy drugs. He also utilized his school fees to buy drugs. This shows that the problem of drug use has reached the younger adolescents.

Peer pressure was the most common reasons given by PWIDs. One of the respondents who was 22 years old had tried heroin out of curiosity. He mentioned,

.....One of my friends insisted me to taste the drug. I found the use of drug more enjoyable and

different than alcohol to which he was addicted earlier.

IDU_HIV/HCV co-infected_Imphal_Manipur

Even if the drug causes health problems like discomfort and vomiting, they would resort to the drug again with insistence of friends to enjoy the “kick.” To put in their words, “later, it becomes difficult to withdraw due to craving”. The PWIDs mentioned that they feared the symptoms of withdrawal so giving up on drugs made the process very difficult.

...Research on social networks has suggested that peer context is a robust predictor of adolescent substance uses (Mayes and Suchman, 2006; Valente et al., 2005 as cited in Mennis and Mason 2010: 153).

Discussion

This study aimed at exploring the barriers for delay in testing and attempted to retain the

voices of the PWIDs from Amritsar and Imphal. Despite National AIDS Control Organisation's (NACO) programme on Harm Reduction Practices and Syringe Exchange Programme, there were PWIDs who continued to share needles. Overall the findings revealed that PWIDs lack correct information about HCV and its transmission. The social contexts in which the experiences of PWID are shaped are complex. "Human behaviour and experiences are complex interplay between larger social, cultural, biological and historical forces which determines the outcome of interactions, feelings and thoughts" (Habitus as cited in Burke and Joseph *et al.* 2009:43).

The study observed that 29 PWIDs were infected with HIV at the time of interview. Within five years of initiation of injection practices, 50-80 per cent of PWIDs are infected with HCV. It is estimated that 50-90 per cent of PWIDs with HIV also have HCV infection. Since there is no vaccine for HCV in the market, prevention strategies is the only hope and it is relied on limiting the exposure to virus. The goal of National Viral Hepatitis Programme should be to decrease hepatitis related morbidity, mortality, and transmission. Such efforts require global, regional, and national stakeholders to develop high-level political commitment, mobilize resources, and propose targets. For those who are infected with HIV and HCV the new treatment regimens should be affordable and easily available (Suthar and Harries 2015).

The current study concurs with a study by Cullen and Stanley which also observed that PWIDs had difficulties to access services as they had limited knowledge of testing locations, not being referred for treatment due to lack of financial support, PWIDs ineligibility for treatment because of overdose of drug or alcohol abuse, and the inconvenience of travelling (Cullen, Stanley *et al.*, 2007). Harris and Rhodes emphasize that

..health system's information on sharing and confidentiality policies have shown to perpetuate perceptions of stigma and negative treatment experiences (Harris and Rhodes 2013:6).

There were three PWIDs in this study whose HIV and HCV status was known to family members, and they were supportive towards them as they lived with the expectation that someday their loved ones would stop injecting drugs. Care and support for people living with HCV is an issue of great importance for improving the quality of life, treatment success and HCV prevention. Evidence from literature has suggested that access to care and support is associated with psychological well-being, reduced risk behaviour and, use of health services. Family support has a positive effect on medical and treatment decisions and the person's attitude towards life in general.

Some of other important issues that came up during discussion were counseling of youths for leading a positive lifestyle, counseling of families of people from High Risk Group (HRG) to ensure family support, ongoing awareness programmes, affordable screening and testing facilities. There is a dearth of research, however, with PWIDs of both genders. It is challenging to comment on what in reality enables a person to try the drugs.

There are few limitations in the study. The sample size for the qualitative study was limited to only 32 PWIDs and this cannot be generalised to overall population. There were challenges in approaching PWIDs especially the female drug users since they are a hidden population. Therefore the voices of female PWIDs are not fully expressed in the study.

Conclusions

It can be concluded that the overall barriers to testing included an absence of clear symptoms of infection, lack of knowledge on hepatitis, practical obstacles such as inconvenience

and time constraints, loss of daily wages, were documented that discouraged some PWIDs from seeking care and testing for hepatitis. The education on prevention and management of HCV should be provided across spectrum of health care providers and the PWIDs. It is clear that HCV screening should be done as soon as an HIV-positive test is confirmed. This permits prevention of disease progress, appropriate treatment of co-infection and provision for quality care.

Due to limited resources for population screening, epidemiological data should guide who should be prioritized for testing. Through educational campaigns and World Hepatitis Day people should be encouraged to discover their HCV status and reduce transmission. Advocacy can be done on harm reduction practices for HIV and HCV. Counselling may focus on how to reduce the risk of acquiring or transmitting HCV and the need for repeat testing. To improve accessibility and linkage to care, HCV treatment should be integrated into existing HIV/AIDS related health services. Needle and syringe exchanges, opioid substitution therapy and condom use are all advisable for persons who use drugs

Supportive role of the health care providers, government health policies and care and support from family is fundamental that helps PWIDs to live a healthy life.

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