



FINAL REPORT
January 2006

**PREVENTING HEP C IN THE PUNJABI COMMUNITY” –
A Community Development Project**

**Research on Hep C Related Issues in the
Punjabi Community In the Region of Peel**

**Baldev Mutta
Amandeep Kaur**

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2006

COMMUNITY DEVELOPMENT PROJECT – Preventing Hep C In the Punjabi Community

Hep C Related Issues

Project funded by:
Public Health Agency of Canada

Prepared by:
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PREFACE AND ACKNOWLEDGEMENTS

The vision and work for building Social Capital in the Punjabi Community in the Region of Peel, has been greatly complemented by the relentless perseverance and persistent commitment of The Punjabi Community Health Centre (PCHC), established in the summer of 1990. The work on Hep C in the Punjabi Community in the GTA has been groundbreaking in many ways: It is the first of its kind in the history of an ethnic community in peel which becomes even more commendable in the light of the fact that it is publicly raising a complex and forbidden issue which was seldom whispered about in the South Asian community. To have Hep C was to be stigmatized and to be ostracized from the community for life. If a Punjabi suffered this disease it was seen as a result of past sins from a previous life, something to be swept under the carpet, to be hushed behind closed doors. To have drawn attention to not only the consequences of this deadly disease facing the Punjabi Community, but also to the multiple ingrained challenges affecting the appropriate redress of this problem, consequence of denial, neglect, lack of education and hence treatment options, is a phenomenal break though for this project.

The unparallel hard work of the treasured volunteers of the PCHC, dedicated efforts of various service providers and the imperative inputs from community members have made this project see light of the day.

The project was completed with the support of the following persons:

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The Project Supervisor –

Baldev Mutta

Project Staff –

Amandeep Kaur

Data Entry and Analysis –

Jatinder Saggu

Volunteers –

Kim Natasha Mutta, Rakhi Mutta

Lastly we hail Public Health Agency of Canada for funding the “Preventing Hep C in the Punjabi Community Project” and thereby recognizing the urgency of addressing the criticalness of the situation of Hep C within the Punjabi Community.

THE REPORT ORGANIZATION

A goal of the research team has been to present the findings and recommendations of its research on Hep C in the Punjabi community to a variety of readers in an easily accessible manner. Therefore, the material in this report is organized in a well compiled format. The material may slightly over lap occasionally in different sections of the report.

The chapters in the report are organized in a way to present information in most precise and comprehensive form.

The chapters present the following information:

Chapter	1	EXECUTIVE SUMMARY
Chapter	2	PREVENTING Hep C in the PUNJABI COMMUNITY PROJECT
Chapter	3	PCHC & RESEARCH REPORT
Chapter	4	SUMMARY OF FINDINGS
Chapter	5	SUMMARY OF RECOMMENDATIONS
Chapter	6	LITERATURE REVIEW
Chapter	7	FOCUS GROUP FINDINGS

CHAPTER 1

EXECUTIVE SUMMARY

HCV was discovered in 1989 by investigators at Chiron, Inc. Portions of the HCV genome were isolated by screening cDNA expression libraries made from RNA and DNA from chimpanzees infected with serum from a patient with post-transfusion non-A, non-B hepatitis¹.

It was not a concern for Canadians as an important health concern until the early 1990s when it became apparent that up to 160,000 Canadians had contracted HCV through contaminated blood products². At present the Public Health Agency of Canada is spearheading a public awareness campaign to highlight the awareness and education about Hep C virus.

Approximately 170,000,000 people worldwide and 4,000,000 in the United States are infected with HCV³. The virus is transmitted primarily by blood and blood products. The majority of infected individuals have either received blood transfusions prior to 1990 (when screening of the blood supply for HCV was implemented) or have used intravenous drugs. Sexual transmission between monogamous couples is rare but HCV infection is more common in sexually promiscuous individuals. Perinatal transmission from mother to fetus or infant is also relatively low but possible (less than 10%). Many individuals infected with HCV have no obvious risk factors. Most of these persons have probably been inadvertently exposed to contaminated blood or blood products.

According to experts, it is estimated that 250,000⁴ Canadians are infected with HCV, for which there is no vaccine. It is also estimated that up to 80,000 are destined for liver

¹ By Howard J. Worman, M. D., *The Hep C Source Book*,

² Health Canada, *Hepatitis C Prevention, Support and Research Program: Get the Facts: Mid-term Evaluation Report* (Health Canada, 2003), 3.

Available at www.phac-aspc.gc.ca/hepc/hepatitis_c/pdf/hepcMidterm/

³ **By Howard J. Worman, M. D., *The Hep C Source Book*,**

⁴ Public Health Agency of Canada, *About Hepatitis C: Virus Information*. Available at www.phac-aspc.gc.ca/hepc/hepatitis_c/aboutvirus.html

scarring, cancer, and liver failure. One-third of those with HCV⁵ still do not know they have it, and may be unwittingly passing the virus to others. More than 5,000 new infections occur in Canada per year⁶, most frequently among those least equipped to access prevention education, effective intervention and treatment supports.

During the literature review, we were unable to find a single document that would give us the current status of how Hep C issues and complexities are viewed in the Punjabi or South Asian community. The authors were able to view some research articles from Pakistan which talked about Hep C prevalence and other issues.

There has been groundbreaking work undertaken in area of HIV/AIDS. Alliance for South Asian Aids Prevention⁷ (ASAP) has completed a number of research studies. There is also evidence that there might be people infected with both Hep C and HIV viruses. Again, we were unable to find any study which would give us more insight into the complexities surrounding Punjabis or South Asians.

Methodology

The research team:

- Worked in a cooperative and collaborative manner from beginning discussions to the analysis of the data and the compiling of the report.

- Decided that the research would be based on the principles of Participatory Action Research.

- Initially formed a research committee of four professionals and one community member who helped to give the research project guidance.

⁵ Remis, R.S. *A Study to Characterize The Epidemiology Of Hepatitis C Infection In Canada, 2002. Final Report.* (Ottawa: Health Canada)

⁶ Public Health Agency of Canada, *Hepatitis C: Frequently Asked Questions.* Available at www.phacaspc.gc.ca/hepc/hepatitis_c/drhepc.html

⁷ ASAP can be reached at: 20 Carlton Street, Suite 126, Floor M (College subway station), Toronto, ON. M5B 2H5, Canada

- Reviewed existing literature on Hep C in relation to other communities. There was a grave scarcity of information relevant to South Asian communities and Hep C. Given both the limited time and available resources a significant effort was made to unearth and develop a quality literature review.
- Developed a question set that would be administered to five community groups. Focus group questions were qualitative in nature. The five selected focus groups, represented five sub-groups within the Punjabi community; Youth (male and female), adults (male and female), Seniors (male and female), women, and religious leaders and community leaders (all males).

Major Findings

The research study has highlighted some very important findings related to Hep C. There is little understanding of how Hep C is contracted and the myths and misconceptions are very pervasive in the community. In addition, there seems to be a wall of secrecy and denial around talking, acknowledging and dealing with Hep C issues. The general consensus seems to be that within Punjabi culture “illnesses of grave nature” is just not talked about. The study also highlighted a need for “sensitivity training” to be imparted to mainstream agencies and to the South Asian health care providers.

The research had to find answer to this question, “Is there a need for culturally appropriate service delivery to the Punjabi community for Hep C and if so what services would be the best to meet that need?”

The immediate research question was answered and that answer is YES. There is most definitely a significant need to provide culturally appropriate service to the Punjabi community around Hep C.

The findings are compiled in detail in a separate section called summary of findings.

Major Recommendations

The research team successfully conducted a Participatory Action Research of Hep C within the Punjabi community and was also able to ascertain what the community wanted to see done regarding the issue of Hep C. The Following areas were identified:

1. Raise awareness about Hep C as an issue within the Punjabi community using a variety of mechanisms
 - TV, radio and print media. Specifically ethnic TV, radio and print media in the appropriate languages
 - Workshops for community members and for mainstream organizations working with the South Asian community
 - Develop an outreach campaign that specifically targets the Punjabi community and their needs around Hep C

2. Develop inter-generational programming that allows for the lines of communication to be opened, for all age groups to share their thoughts and allows for Hep C to be an issue that can be discussed

3. Address needs of the Punjabi community around Hep C
 - Support to the infected and affected
 - Support to those dealing with Hep C related issues; drug or substance abuse, new immigrants, blood transfusions, MSM, homosexuality and trans-gendered
 - Access and awareness of services
 - Cultural factors (myths and stereotypes held)

4. Develop resources
 - Videos, DVDs and print literature

Detailed recommendations are compiled in the report.

Summary

This study has presented strong evidence that Hep C is an important issue in the Punjabi community that must be addressed. The Punjabi Community Health Centre has shown interest in developing future projects related to these recommendations.

The Board of the Punjabi Community Health Centre has approved the research report and would provide assistance in implementing the findings of the report.

Chapter 2

HIV/AIDS RESEARCH PROJECT

INTRODUCTION

Global Problem

According to the World Health Report published by the World Health Organization in October 1996:

"Hepatitis B has infected 2,000 million people alive today, of whom 350 million are chronically infected and therefore at risk of death from liver disease.

About 100 million are chronically and incurably infected with Hepatitis C and are similarly at risk."

In a Fact Sheet published in June 1997 WHO estimates that *"a proportion in the order of 3% of the world population has been infected with HCV and that there are more than 170 million chronic carriers who are at risk of developing liver cirrhosis and/or liver cancer"*.

Unfortunately, unlike Hepatitis B, which has a rate of chronicization of about 17.5% of the number of people infected, Hepatitis C turns into a chronic disease in over 70% of the people infected.

However, the 170 million figure is probably an under-estimate, for several reasons: either the people do not go to see a doctor (because they are asymptomatic) and therefore they are not registered as being ill, or due to the action or inaction of the authorities, as was the case in Britain, where the English authorities (unlike their Scottish counterparts) decided for a while not to inform the people who received transfusions with blood infected with Hepatitis C.

If we consider together the figures for Hepatitis B and Hepatitis C, we reach the astronomical figure of almost 2.2 billion people infected with a serious infectious disease, of whom 450 million already developed chronic hepatitis.

Conclusion

By any standards, to have 450 million people suffering from chronic Hepatitis B or C (9% of the world population) means we are facing a very serious problem. And if we consider the total number of people infected with Hepatitis B and C (almost 2.2 billion - nearly half the world population) then what the World Health Organization is saying in the World Health Report 1996: "***Hepatitis is emerging as a global health issue***" is by all means an understatement.

Underfunding of research seems to be the biggest hurdle in finding a cure for Hepatitis: although in terms of numbers in the whole world there are 9 times more people with chronic Hepatitis than people infected with HIV (50 million), the research funds are disproportionately smaller for Hepatitis C.

Far from us the idea of advocating a reduction in the funds allocated for HIV... We only used the comparison in order to show that Hepatitis is almost ignored by the authorities, despite the huge spread of this illness. Our ultimate goal is to see a substantial increase in the funds allocated for the research and treatment of Hepatitis.

Unfortunately, according to the World Health Organization Report: "*Despite the emergence of some 29 new diseases in the last 20 years, there is still a lack of national and international political will and resources to develop and support the systems necessary to detect them and drop their spread.*"

<http://www.hepatitis.org.uk/s-crina/statistics-f3-main.htm>

World Health Organization

http://w3.who.sea.org/EN/Section10/Section17/Section58/Section220_217.htm

Overview of HEPATITIS C Problem in Countries of the South-East Asia Region

Regional Overview

Dr Sudarshan Kumari, Regional Adviser, WHO/SEARO, presented the current knowledge about hepatitis C virus and the status of hepatitis C carriage in the Member Countries of SEAR based on published reports as well as estimates made by WHO. HCV was an RNA virus with six major genotypes and more than 130 subtypes. After its discovery in 1989, it had been found to be an important cause of chronic liver diseases. Transfusion of unsafe blood, use of non-sterile syringes and equipment, injectable drug use, repeated haemodialysis and high-risk sexual activity were major known modes of transmission of HCV.

A global pool of an estimated 170 million carriers of HCV acted as a reservoir of this infection in the world. Whereas the USA and Western Europe had 4 and 5 million carriers respectively, nine countries of the SEA Region accounted for 25 million carriers - 12 million of whom lived in India. According to WHO estimates, the following was the status of HCV carriers in the countries of this region.

Country	Carrier Rate %	Carrier number in millions
Bangladesh	2.4	3.08
Bhutan	1.3	0.03
India	1.2	12.8
Indonesia	2.5	5.31
Maldives	1.8	0.005
Mynmar	3.9	1.92
Nepal	1.1	0.26
DPR Korea	1.6	0.38
Sri Lanka	1.4	0.26
Thailand	2.9	1.75
Total		25.075

Dr Sudarshan Kumari suggested that a strategy that ensured safe blood for transfusion and strict adherence to universal precautions in health settings might considerably reduce the burden of HCV in the future. To achieve this, mandatory screening of HCV in

blood banks needed to be undertaken with extensive education for all categories of health care professionals.

Country Reports

Nepal

Various community based studies have shown the prevalence of anti-HCV antibody in 0.4% of soldiers as well as healthy people of four districts in Nepal; 1.1% in hospital staff and 1.5% in relatives of patients with chronic liver disease. None of the HCW (student nurses) or pregnant women was found to be a carrier of HCV. Among the blood donors 0.4% were reactive for anti-HCV antibody in 1994 and 1.8% in 1996. All blood banks in Nepal are under the control of the Red Cross and the testing of blood for anti-HCV is mandatory.

Almost three-fourths of the injectable drug addicts tested in Nepal are carriers of HCV. An estimated 40,000 youth in the age group of 18-25 are considered to be injectable drug users and most of them are anti-HCV positive.

Social customs such as using the same razor for shaving the head among various subpopulations are widely prevalent and conducive for the spread of HCV.

Myanmar

During 1997-98, out of 1018 blood donors, 103(10.1%) were found to be reactive for anti-HCV antibody. However, a study conducted among the normal population (n=161) and patients with chronic liver diseases (n=210) during 1998-99 revealed the presence of HCV-RNA in 1.9% and 24.3% individuals respectively.

India

Review of various published data from India suggests a carrier rate for HCV in the general population represented by voluntary blood donors and pregnant women ranging between 0.09 and 2.5%. In studies where strict donor selection criteria were adopted, the carrier rates were extremely low.

Initial results obtained from studies being performed in communities also indicate a much less carrier rate than the estimated one. The mandatory testing of blood from

voluntary blood donors for HCV is planned to start from June 2000 in all 1455 licensed blood banks of the country.

HCV is also responsible for considerable morbidity and mortality in chronic liver diseases in India. In sporadic acute viral hepatitis cases, HCV positivity has ranged between 0.2 and 17.6% while the rates in fulminant hepatic failure and subacute hepatic failure range from 6.2 to 45%. HCV has been incriminated as the cause of liver cirrhosis in 3.3% to 31.5% cases and that of hepatocellular carcinoma in 15.1 to 42% cases.

Bangladesh

While reports on hepatitis A and B are available from Bangladesh, those on hepatitis C are extremely limited. In a limited study 2.4% HCV positivity in professional blood donors and 0% of voluntary blood donors has been demonstrated; 45.3% of the primary hepatocellular carcinoma cases were also found to be positive for HCV antibodies.

Bhutan

Studies on hepatitis C are limited in Bhutan as well, except for the report by WHO in its Weekly Epidemiological record (1997) and a WHO SEARO publication, SEA/HS/209 (Health Situation in the South-East Asia Region, 1994-1997). The HCV prevalence in the general population of Bhutan according to these reports is 1.30%.

Indonesia

An estimated 45,000 cases of liver cirrhosis and 18,000 cases of hepatocellular carcinoma are detected every year in Indonesia. Reports based on surveys in the general population and voluntary blood donors in the provinces project HCV carrier status ranging from 2.1 to 3.9%. The range of HCV positivity in blood donors is between 0.5 and 3.4%; 0.8% of medical students carry HCV. Among the cases with hepatocellular carcinoma, 47.3% were reactive for anti-HCV antibody and so were 8% of patients on maintenance haemodialysis. Household contacts, sharing private items (such as tooth brushes) and extramarital sexual activity have been identified as probable risk factors in the development of HCV infection.

Maldives

HCV studies from Maldives are once again scanty and the available data through a WHO SEARO report (1999) project HCV positivity in the general population of Maldives as 1.8%. No report is available on HCV-related liver diseases or about its involvement in the high-risk groups.

Democratic People's Republic of Korea

HCV prevalence in the general population of DPRK has been reported to be 1.6%; 53.1% in chronic hepatitis, 30.5% in patients with cirrhosis of liver, and around 30% in hepatocellular carcinoma cases.

Sri Lanka

From the limited literature available, HCV in the general population of Sri Lanka is reported to be 1.4% (WHO, SEARO), while no report is available on its role in acute and chronic liver diseases besides the high-risk groups.

Thailand

The general population has HCV infection ranging between 0.5 and 5.6% (mean + SD : 2.94 + 2.15) with commercial sex workers having a higher risk of acquiring HCV infection (9.5%). In the liver diseases group, 23.0% of CLD patients and 8.4-17.0% of HCC cases were (mean +SD 12.23 + 4.37) due to HCV. The problem of HCV is implicated in 20% of haemodialysis cases, 23.8% of thalassaemics and 95.3% of injectable drug users.

Pakistan

<http://www.pitt.edu/~super1/lecture/lec17631/>

According to Rashid A Chotani, Assistant Professor and Director, The John Hopkins Bloomberg school of Public Health has presented the following findings from Pakistan:

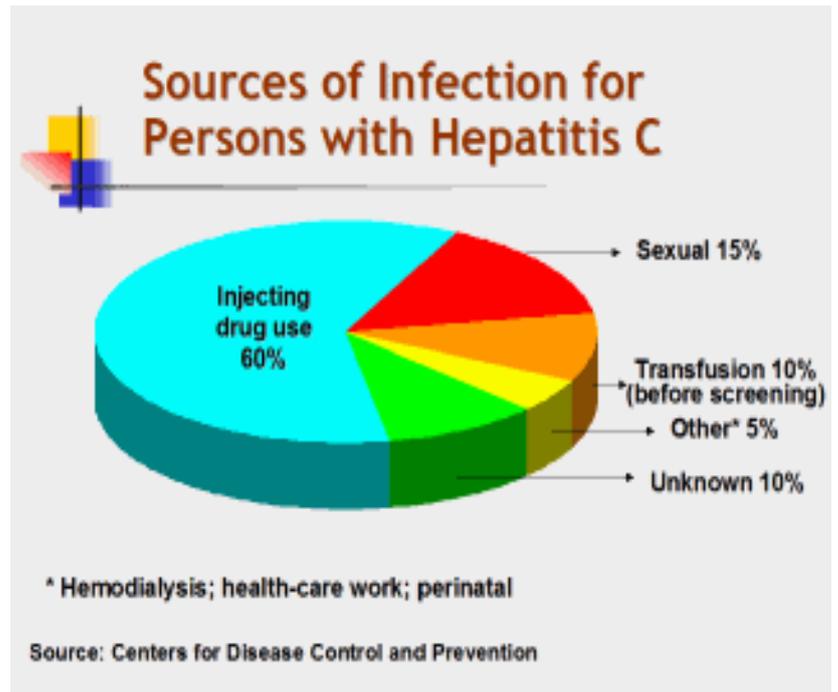
Burden of diseases in Pakistan – Studies in Pakistan have found HCV:

- 60% among liver cancer patients
- 51% among beta thalassemia major patients
- 46% among chronic liver disease patients
- 18% among cirrhotic patients
- 20% among commercial blood donors

Risk factors

Persons	Risk of Infection	Testing Recommended
Injecting Drug Users	High	Yes
Recipients of clotting factors made before 1987	High	Yes
Hemodialysis patients	Intermediate	Yes
Recipients of blood and/or solid organs before 1992	Intermediate	Yes
People with undiagnosed liver problems	Intermediate	Yes
Infants born to infected mothers	Intermediate	After 12-18 months old
Healthcare/public safety workers	Low	Only after known exposure
People having sex with multiple partners	Low	No
People having sex with a steady partner	Low	No

**Sources of Infection for
Persons with Hepatitis C**



Risk Factors

- 6.5% antibodies positive for HCV in Hafizabad, Pakistan. Shows an increased prevalence in Pakistan compared to world.
- Follow up case control study to identify risk factors. Positive individuals were 8.2 times more likely to receive >5 injection per year.
- Investigated relationship between hepatitis B and C and injections in periurban Karachi. 44% hepatitis C positive. Those who received more injections were more likely to be hepatitis C infected. 94% of the needles/syringes were reused.

Risk Factor – Tattooing

- CDC found that in Pakistan, 7% of those with tattoos were positive for HCV.

Risk Factor – Body Piercing

- In Pakistan, 7% of those with body piercing tested positive for HCV.

Hep C in Canada

According to experts, it is estimated that 250,000 Canadians are infected with HCV, for which there is no vaccine. It is also estimated that up to 80,000 are destined for liver scarring, cancer, and liver failure. One-third of those with HCV still do not know they have it, and may be unwittingly passing the virus to others. More than 5,000 new infections occur in Canada per year, most frequently among those least equipped to access prevention education, effective intervention and treatment supports.

According to Alan Franciscus at the Hep C BC "Living Well with Hepatitis C" Workshop in Victoria, February, 2001., there are 40,000 people infected with Hep C virus and out of these 85 to 95% are Intravenous drug users (IDUs). It is also estimated that in prisons there are about 41% of the inmates infected with Hep C virus.

See site: <http://www.hepcbc.ca/Presentations.htm>

South Asian Culture and Hep C in the Indian sub-continent

In the Indian sub-continent, Hep C is not well known and if it is known then it is associated with people who are poor, sex trade workers, migrants, truck drivers, intravenous drug users (IDUs), hizras (genital organs not fully developed), zanas (men who dress in women's clothing), and homosexuals. These strata face discrimination, ostracization, and stigmatization and are shunned by the general society. Individuals who are infected with Hep C receive poor health care due to societal indifference.

It is generally believed that the nature of illness is such that it can lie dormant for many years and people may not even know that they have contracted Hep C virus. Due to little understanding of how Hep C is contracted, the myths and misconceptions continue to prevail, which leads to treating individuals infected with Hep C with disdain and disrespect. This results in the delivery of poor health care services to those that need help the most.

Understanding Hep C

What is Hep C?

Hepatitis C is a blood-borne virus that infects and can seriously damage the liver. A test for hepatitis C was first discovered in 1989 and introduced in Canada in June 1990. Before that, this and other hepatitis viruses were referred to as non-A, non-B and surrogate tests were available to test for this prior to the discovery of a hepatitis C test. Those most at risk include people who received blood transfusions prior to the onset of screening for the virus in 1990, people exposed to contaminated needles (through tattooing, acupuncture, IV drug use or inoculations in developing countries), and health care workers. But the source of infection is simply unknown for 15-40% of sufferers. It is estimated that up to 2% of the Canadian population carry the hepatitis C virus.

(Hepatitis Society of Canada: <http://www.hepatitiscsociety.com/english/HepCBasics.htm>)

How sick will one get?

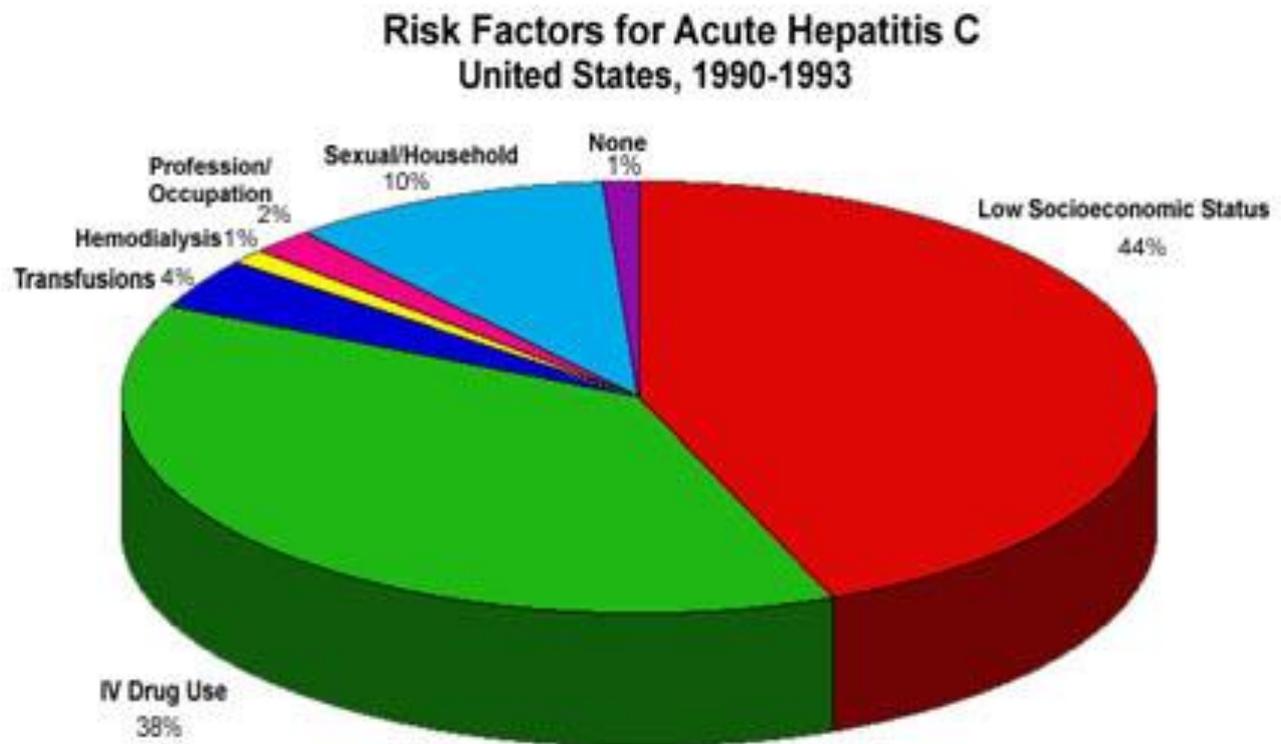
Hepatitis C is still a mystery virus. Many of those infected do not get sick, or feel ill only for a brief time, but 80% will develop chronic hepatitis C. Chronic hepatitis C can lead to liver disease, including cirrhosis (scarring of the liver) and liver cancer. An estimated 20% of people with chronic hepatitis will develop cirrhosis. Hepatitis C

accounts for about one third of cases of cirrhosis, the seventh-leading cause of death in Canada. Symptoms of chronic hepatitis C accounts for about one third of cases of cirrhosis, the seventh-leading cause of death in Canada.

Symptoms of chronic hepatitis C, which may not appear for a long time after the initial infection, include fatigue, jaundice (yellowing of the skin or eyes), nausea and hair loss. In more serious cases, loss of liver function leads to buildup may include unresponsiveness, forgetfulness, trouble concentrating or sleeping. Weight loss and water retention may occur.

(Hepatitis Society of Canada: <http://www.hepatitiscsociety.com/english/HepCBasics.htm>)

Risk Factors



Source: CDC Sentinel Counties Study of Acute Viral Hepatitis C

Blood Transfusions

Many of the high risk groups for hepatitis C are easily identified, due to practices resulting in frequent exposures to blood or risk factors for transmission.

Blood transfusions currently seem to account for only approximately 5-10% of all cases of hepatitis C. Prior to 1990, there were no tests for hepatitis C against the

blood supply, and the rate of post-transfusion hepatitis was between 8% and 10%. Anyone who received a blood transfusion prior to that time is at risk for having been infected. Incidence among hemophiliacs, who receive frequent transfusions of blood and blood products, is particularly high, ranging between 25-40%. Women who have had Cesarean sections prior to 1990 represent another significant risk group, as these operations were frequently accompanied by blood transfusion.

Blood tests have greatly reduced the rate of post-transfusion hepatitis C - CDC estimates the risk factor for transfusion-contracted HCV during the 1990-1993 period at 5%, and risk of infection was brought down to less than 1% after 1993. Today, the risk of post-transfusion infection is negligible, at approximately 1 per 100,000 units of blood. Blood banks also now also notify donors if they detect the virus.

Intravenous Drug Users

IV drug users represent the largest single risk group. Hepatitis C infection among intravenous drug users occurs at an alarming rate. As with HIV, the sharing of contaminated needles and syringes increases the chance of infection dramatically: incidence of HCV antibody rates among I.V. drug users has surpassed 50 percent in many studies and almost reached 100 percent in others. Within only six months to a year after beginning intravenous drug use, 50-80 percent of drug users test positive for the hepatitis C antibody. I.V. drug users account for about 30-40% of all identified cases, and about 50 percent of all new cases of the disease.

Sexual Activity

Sexual contact has been clearly identified as a means of transmitting hepatitis C. Several studies of risk factors in sexual activity found rates of infection between 1 and 18% for homosexually active individuals, 1 to 10% among heterosexually active individuals, and 1 to 12% among female prostitutes, with the primary risk factors for infection being greater numbers of partners, unprotected sex, simultaneous infection with other STD's, and traumatic sexual activity. Seroprevalence for long term partners of hepatitis C patients was found to be around 5%.

Household contact with another household member that has hepatitis C has also been strongly implicated, and this, in combination with heterosexual exposure, is believed to be responsible for approximately 13% of all infections. The incidence of

household-member transmission cases has more than doubled since 1990. Maternal-infant transmission has also been documented as a mode of spread, occurring in no more than six percent of children of hepatitis C positive mothers.

Healthcare Workers

Around 2% of all cases of hepatitis C are thought to be contracted through the occupational risk (needle-stick injuries, blood spills, etc) involved with the health care profession.

Prisoners

Prisoners have enormous incidence of infection - rates reported in some California prisons exceed 80%, with certain institutions reporting nearly 100% of their prisoners infected.

Body Piercing and Tattoos

Some skin piercing practices, notably tattooing, body piercing, and acupuncture, have contributed significantly to the spread of HCV, particularly in less industrialized nations. Tattooing in particular poses a serious risk. Even in the presence of good sterilization, studies have suggested that the ink used in tattooing can become contaminated and transmit the virus.

Blood in Body Secretions

Several studies have shown that adequate blood can be present in other body secretions to transmit infection. Cocaine users have an abnormally high risk of infection due to the fact that they frequently share snorting straws, which may have small amounts of blood-carrying mucous on them. Such indirect sources of blood may explain many cases of inter-household transmission.

Less obvious, specialized risk factors have been identified resulting from indirect exposures to blood - including manicures, shared toothbrushes and razors, and straight razors in barber shops.

Racial, Ethnic, and Income groups

Particular racial, ethnic, and income groups are at higher risk of infection. An ethnic analysis in one earlier, somewhat underestimated study (1994) determined that

Caucasian Americans statistically accounted for the most number of infected persons, while the highest incidence rates were among African and Hispanic Americans. The highest prevalence of the disease was found in middle-aged people (30 to 49 years old) who accounted for 3% -4% of the cases. Prevalence among black men in this age group approached 9% to 10%. Gender, however, did not emerge as a significant risk factor in the population as a whole. In the United States, blacks have the highest incidence rates, followed by Native Americans, Hispanics, and whites.

Similarly, low income groups seem to have the highest risk of infection. In one study at the inner city VA Hospital in Washington, D.C., one in five people admitted tested positive for HCV. Similar results (18%) were obtained at the John Hopkins University Hospital, located in Baltimore's inner city.

The higher incidence among certain racial, ethnic, and income groups is probably the result of higher rates of other cofactors, but may also be the result of unidentified modes of transmission. Many groups showing high incidence of infection do not have obvious correlations with known modes of transmission, pointing towards the existence of unknown routes of transmission. For example, there is a serious question as to why many alcoholics are infected with HCV. In many surveys, about a third of people who are alcoholics are also infected with the HCV virus. Whether alcoholics are in fact more prone to infection has not been firmly established.

<http://www.epidemic.org/theFacts/theEpidemic/USRiskGroups.html>

Interesting Facts

Did you know.....

- Hepatitis C can be treated. It is important to find out if you have the virus and get treatment as soon as possible.
- 251,000 Canadians are infected with hepatitis C and, because there are no symptoms, 95,000 of them don't know it.
- Most people newly infected with hepatitis C have no symptoms and are unaware of their infection, but they are still infectious.
- Avoid the risk of hepatitis C: don't share needles or injection drug equipment.
- Hepatitis C is NOT spread by hugging, kissing or shaking hands. It is NOT spread by means of food or water.
- More than 5,000 Canadians - many of whom are young people - are infected with the hepatitis C virus each year.
- There is no vaccine for hepatitis C.

Public Health Agency of Canada

http://www.phac-aspc.gc.ca/hepc/hepatitis_c/aboutfacts.html

CHAPTER 3

PCHC AND THE RESEARCH PROJECT

History of the Punjabi Community Health Centre

The Punjabi Community Health Centre (PCHC) is a non-profit community based agency in the Region of Peel. It was incorporated as a community based agency and a resource centre in 1995.

Developed in the spring of 1990, the Punjabi Community Health Project in Peel was an innovative Health Promotion Project based on the principles of Community Development.

Vision

The Punjabi Community Health Centre strives to create a healthy and vibrant community, which values the cultural mosaic of the Region of Peel.

Mission

The PCHC will serve the Peel community through community development, culturally appropriate service delivery, partnership with other organizations, research and asset inventories, developing resources and recruiting volunteers from within the community, and consulting and promoting diversity through community outreach.

Introduction to the Project

The Research on Hep C in the Punjabi Community is a community based research and development project. The Punjabi Community Health Centre started the work towards the end of November 2005.

Information gathered for this project was collected using two deliverable methods; in depth literature review and qualitative focus groups. The aim of the literature review was to unearth a depth of information regarding Hep C and the Punjabi community. While the search for qualified information proved difficult, the end result was a comprehensive literature review that highlighted Hep C and South Asian communities in India, Pakistan, and Vancouver Canada. Three qualitative focus groups were held with different segments of the South Asian community; Youth, Seniors and Religious Members.

Background

The South Asian community is the largest ethnic community in the Region of Peel. According to the 2001 Canada census, just one of the South Asian, the Punjabi language was identified as the 2nd most spoken mother tongue after English in the Region of Peel⁸.

Large pockets of the South Asian population can be found in Malton, Mississauga and Brampton. The community is quite closely knit with its own media, small to medium size businesses, its own schools, religious institutions and inroads in the hospitality, travel and tourism industry. Nonetheless, as a whole it is not an isolated community but members within it can remain isolated not having to associate with the mainstream community.

Hep C has remained at the forefront of disease notoriety. Despite its world renowned epidemic, it is a topic that easily gets pushed into background. In mainstream communities strong efforts have been made and continue to be made, in order to keep Hep C at the forefront. This is not to say ethnic communities are left unspoken of regarding Hep C. South Asian communities are oft spoken of regarding Hep C. However specific research regarding the Punjabi or South Asian community and Hep C is limited as are resources to the Punjabi or South Asian community regarding Hep C and related issues.

⁸ 582350 persons identified English as their mother tongue. 58105 persons identified Punjabi as their mother tongue. Only 12350 persons identified French as their mother tongue.

Scope of the Study

The Punjabi Community Health Centre commissioned this study and the purpose of the study was:

- to determine the level of understanding of Hep C within the Punjabi community
- to determine whether the Punjabi community accepts that Hep C is an issue to be dealt with within their community
- to identify steps in order to raise community's consciousness in order to address the complexities surrounding Hep C in the Punjabi community
- to identify the complexities surrounding Hep in the Punjabi community

Objectives of the Study

The specific objectives of the study were to obtain an understanding related to Hep C within the South Asian community

- the nature of stigma within the Punjabi community
- what cultural factors contribute to myths and stigma held
- degree of services available to the Punjabi community around Hep C related issues
- ascertain gaps in services available to the Punjabi community around Hep C related issues
- best ways to de-stigmatize Hep C within the Punjabi community
- determine modalities for intervention within the Punjabi community

Approach

The research completed was done using Participatory Action Research⁹ methodology to undertake research within the South Asian community. It was strongly desired that the research conducted be used to build communities not just collect information from them. Therefore the role of participants will be to be more

⁹ Please see appendix for a detailed overview of Participatory Action Research methodology.

than just sources of data but rather involved community members throughout the project.

As a requirement of the projects objectives to appreciate the communities understanding for Hep C, five focus groups were held. Each of the groups represented different segments of the Punjabi community allowing for capturing of a collaborative of qualitative information.

The research team was well aware that the topic of Hep C often generates feelings of discomfort within individuals which might compromise the results of this study to some extent. However, once the data was collected and analyzed findings of some significance had emerged.

Methodology

The work plan consisted of the following: 1) Forming a research team, 2) Developing a research committee, 3) Undertaking review of literature, 4) Developing, focus testing, revising and finalizing a questionnaire to collect qualitative data using focus groups, 5) Analysis of qualitative and quantitative information collected and 6) writing and compilation of the final report

1. The research team:

The research team comprised of three individuals who had long experience working in the field of social work with project staff taking the research lead.

2. The research committee:

The research committee consisted of social service professionals and community members who had extensive experience in the field of social services and some research background.

3. Review of literature:

The research team read several articles, research papers, and examined several internet sites in order to review the current research on Hep C and Punjabi populations. The team discovered that research on Hep C and South Asian and Punjabi populations proved difficult to unearth, in particular to western South

Asian and Punjabi populations. Research particular to Canadian South Asian and Punjabi populations was non-existent however some resources are available in Punjabi from British Columbia Hep C organizations and from the Public Health Agency Canada websites. However, some studies were relevant to this project. The literature section of this report contains the review of those studies.

4. *Qualitative data gathering process:*

- 4.1 Focus group questions were developed and the supervisory staff critiqued it. A revised draft was presented for their approval. The approved draft was then tested. The final set of questions was again revised. The final questions are attached in the appendices.
- 4.2 Five focus groups were organized.
- 4.3 The discussion was noted by a scribe and then entered into the computer.

Analysis

Each data set was analyzed separately for findings and recommendations.

Focus groups were analyzed from written notes for themes. As participants were not comfortable, tape recordings were not used. The themes formed the basis for findings and recommendations.

Findings

Thus each data gathering process contains a section on the findings. There is a section under findings – focus group.

Recommendations

Similarly, each data gathering process contains a section on recommendations. There is one section under recommendations – focus groups.

CHAPTER 4

SUMMARY OF FINDINGS

The findings presented in this section represent the views and the opinions of the community members residing in the Regional Municipality of Peel. All participants belonged to the Punjabi community. The opinions expressed by the participants were very frank, candid and respectful. While participants had their different views and opinions on the issue of Hep C, nonetheless, they all agreed that the research project is very important and worth while. The research team through this study has come across experiences which will highlight the “gaps” in service delivery, the need for community development projects, the need for developing culturally appropriate service delivery, and the need to develop a variety of training workshops for health care providers.

The research elicited the following findings which have been compiled under the themes. We must note that some findings could easily fit into many themes but in order to preserve the context of the participant’s discourse, the findings have been inserted into a given theme.

The themes and findings are as follows:

Prevention

The literature review highlighted that there is evidence of significant Hep C infection in Indian sub-continent. Within Canada and within Punjabi community, there could be people infected and affected with Hep C virus and significant efforts need to be made in order to develop awareness by undertaking education.

Awareness

The general understanding of participants of perceived risk for contracting Hep C is low as they have little factual knowledge of the illness. The research study also found that there seems to be a lack of Hep C awareness among Punjabi and South Asian professionals. The general consensus from the participants seemed to be that the Punjabi community seems to be in “denial” about the Hep C illness.

Misconceptions

The participants outlined some strong myths, misconceptions about Hep C which are as follows:

- Health care workers reusing old needles
- Prostitutes
- “gay men”
- Taxi Drivers and “Truckers” (Truck drivers)
- Poor morality
- Discussion on this topic or any topic related to “sex” is taboo

Health Promotion

The participants felt that Hep C is an issue which cannot be easily addressed in the community. They felt that the new immigrants have a different priority while establishing themselves in Canada and they are least concerned with “sexual health education”. A five step model was suggested by the participants in order to diffuse health promotion strategies.

High Risk Groups

The literature review highlighted that the following were categorized as high risk for Hep C infections: Blood Transfusions, Intravenous Drug Users, Sexual Activity, Healthcare Workers, Prisoners, Body Piercing and Tattoos, Blood in Body Secretions, Racial, Ethnic, and Income groups

Barriers

The research also outlined that Punjabis are “unlikely to seek medical assistance”.

The barriers identified in the survey were:

- Lack of language and culturally appropriate resources
- Lack of funding
- Lack of knowledge of community needs
- Lack of outreach to the community
- Lack of networking with mainstream organizations
- Length of time, skill required for clinical intervention

Service Provision

There seems to be a reluctance by community members to access medical practitioners for the fear of “confidentiality” and lack of understanding and compassion.

Training Needs

The participants outlined the need for cultural sensitive training of mainstream professionals. They felt that often the cultural nuances are not understood or taken into account when mainstream services are accessed by Punjabis.

The participants also felt a need to train South Asian health care professionals who are working in the health care setting. Specific references were made regarding “violations of confidentiality”.

The participants also felt a need to educate the community about the complexities surrounding Hep C issues.

Punjabi and South Asian Context

Many myths and misconceptions exist in the community about Hep C, homosexuality and HIV/AIDS which need to be addressed. The focus group highlighted the following issues which would be faced by the infected individual:

- Shame, and Stigma
- Isolation, and Loneliness
- Abandonment
- Disownment
- No support from family, friends or the community

SUMMARY OF FINDINGS – LITERATURE REVIEW

These are the collective findings which are relevant to the project:

Hep C

1. There is evidence of significant Hep C infection in Indian sub-continent. The need is expressed by professionals to raise education and awareness about Hep C issues and its complexities.
2. High rates of hepatitis B and C infection in many South Asian countries are attributed to:
 - a. unsafe blood supply,
 - b. reuse of contaminated syringes,
 - c. lack of maternal screening to prevent perinatal transmission, and
 - d. delay in the introduction of hepatitis B vaccine.
 - e. India, Pakistan, and Bangladesh have the highest rates of infection, with prevalence ranging from 2% to 8% in different population groups
3. In Hafizabad, Pakistan, the greatest risk for HCV infection to household members of infected people is **injections given by health-care workers** rather than household contact with infected persons.
4. Risk factors for acute Hep C are: 1) Transfusions 2) Intravenous Drug Users 3) Sexual Activity 4) Household contact 5) Healthcare Workers 6) Prisoners 7) Body Piercing and Tattoos 8) Blood in Body Secretions 9) Racial, Ethnic, and Income groups

HIV/AIDS

1. Low condom use and reuse of condoms (with wives as well).
2. Very little knowledge about HIV/AIDS and its complexities in the South Asian community.
3. HIV/AIDS issues and concerns also remain low for human care professionals in the South Asian community.
4. HIV is closely associated with taboo issues of sex and sexuality and therefore cannot be easily addressed within the community.
5. Health promotion is mainstream and service providers are too unfamiliar with cultural and faith backgrounds to offer the necessary support.

6. Sexual Health is of low priority for new immigrant (in Canada less than five years)
7. South Asians do not acknowledge gay or bisexual South Asian identities, and view HIV/AIDS as a gay white man's disease. Accordingly, the (mis)perception is that HIV/AIDS *does not happen* to South Asians.
8. The community's silence and denial about HIV/AIDS results in stigma being experienced by South Asians who are HIV-positive. They fear being mistreated, abandoned, or isolated if they tell other South Asians about their status.
9. South Asian women face a particularly difficult burden in dealing with HIV/AIDS, since codes of sexual conduct or behaviour are more rigidly applied to them. Women risk being labeled promiscuous and as falling below the high standard expected of caregivers/nurturers in the South Asian family unit.
10. Faith is a central part of many South Asians' lives, yet faith communities are often the guardians of the prevailing myths that contribute to the silence about HIV/AIDS in the first place.
11. South Asians with HIV/AIDS experience discrimination in the areas of health care, welfare, employment, housing, immigration, travel, business, and the law.

SUMMARY OF FINDINGS - FOCUS GROUPS

Finding number one

While youth had some general information regarding Hep C the other four focus groups had limited knowledge of Hep C. The seniors, women and religious members did not have a clear understanding about the contraction of the disease, who it affects.

Finding number two

Many participants had not heard the word hepatitis. Out of 60 participants, 42 (70%) were not able to identify with the word hepatitis and Hep C. The least awareness and or information related to Hep C was elicited from women's, seniors and religious leaders focus group.

Finding number three

Excessive alcohol use by men in the Punjabi community may lead to liver related diseases (perhaps Hep C).

Finding number four

The majority of participants did not hear about Hep C back home.

Finding number five

The majority 44 participants (73%) did not know if Hep C is a problem in Canada within the Punjabi community.

Finding number six

The majority 58 (97%) of participants had heard about HIV/AIDS. *An interesting observation: the majority had heard about AIDS and not about HIV. They did not know the difference between these two terms.* All youth participants had heard about HIV virus.

Finding number seven

The participants felt that Hep C is a problem back home. The reasons are: reused needles, and prostitutes. Middle aged men, truck drivers and sales agents might be at risk of getting this disease from prostitutes.

Finding number eight

Everyone and everybody is at risk of getting Hep C – men, women, children and drug users, prostitutes, gays, families with people affected by Hep C, Poor people, truck drivers, taxi drivers, blood donors and recipients.

Finding number nine

People get infected with Hep C from: blood transfusions, sleeping with prostitutes, being born with Hep C virus, via sexual transmission and or sharing needles, “gay sex” or unprotected sex, tattooing and Body Piercing.

Finding number ten

People can protect themselves by: using a condom, not sharing needles, more education and awareness, regular medical check ups, practicing spirituality, keeping your own blood at a safe place.

Finding number eleven

Medical practitioners were seen as “insensitive” by the participants and felt that they would not have the sensitivity to address the needs surrounding people infected with Hep C virus.

Finding number twelve

The person infected with Hep C would face enormous problems such as: isolation, loneliness, confused, scared, depressed, suffer pain from the illness and then probably get suicidal ideation, bringing their shame to their family, also face the brunt of stigma from the community, disowned and abandoned, face ridicule and embarrassment, and community will discard and boycott them.

Finding number thirteen

Treatment to include the following: support groups, more research into finding a cure, community awareness, medication should be provided by the government, hospital or clinics should be built for people infected with Hep C.

Finding number fourteen

Stigma, myths, social taboos surrounding Hep C in the Punjabi community is as follows:

1. The culture tends to be shame oriented.
2. The fear of shame leads into denial and minimization about the problem.
3. The shame of fear leads one into secrecy.
4. Due to fear, the person will be ostracized, shunned, and isolated.
5. The Punjabi community tends to function on “clan” based norms and traditions.
6. The women often bear the brunt of “conservative” norms and traditions.
7. The Punjabi community already faces discrimination and by disclosing the illness they are further exposing themselves.

Finding number fifteen

The participants could not identify any other South Asian agency or professional other than Punjabi Community Health Centre in the Region of Peel which brings issues like this forward. They were not aware of any Punjabi doctor who would specialize in Hep C treatment.

Finding number sixteen

The majority 55 (92%) participants wanted to seek culturally appropriate services for seeking services related to Hep C.

Finding number seventeen

The participants had the following suggestions regarding outreach to the community: Develop culturally relevant resources, organize educational forums and workshops, organize culturally competent training for mainstream professionals, use of electronic media, and disseminate information.

Finding number eighteen

Awareness would help with de-stigmatization of the issue. The community’s consciousness could be developed in order to deconstruct the myths, rigid norms and traditions which impede the compassionate understanding of the complexities surrounding Hep C.

Finding number nineteen

Step by step education needs to be imparted so that stigma is replaced by compassion and kindness.

Steps

- Step One. General education about Hep C with statistics (nurse or medical doctor)
- Step Two. General education about Hep C with statistics (community/religious leader)
- Step three. Specific education regarding Hep C as to how it is effecting Punjabis (possibly a client)
- Step Four. Specific education related to Risk Groups (professional/health care worker)

Finding number twenty

Punjabi Community Health Centre should undertake the following:

1. More research into the topic
2. Organize more discussion groups.
3. Develop more resources - target education to high risk groups and women.
4. Use of media campaigns using ethnic television stations or OMNI 1 or 2 and Sur Sagar Television and ethnic radio stations
5. Use of print, and electronic media to raise awareness

CHAPTER 5

SUMMARY OF RECOMMENDATIONS

The Research study brought into light the fact that Hep C is prevalent in the Punjabi community but the community is not aware of it. Although, the infected and affected individuals face extreme isolation, ostracization, the problem does exist in the community. The research also highlighted that individuals may have difficulty accessing services for a variety of reasons. The following recommendations are suggested which would address the needs of the Punjabi community in the areas of Hep C.

Recommendation One

Develop research projects to explore the specific needs of Hep C in the Punjabi community.

Recommendation Two

Develop culturally appropriate resources for the community.

Recommendation Three

In order to deal with the aftermath of Hep C, PCHC should develop culturally appropriate:

- Support groups for the infected and the affected
- A therapeutic group program for the infected

Recommendation Four

Develop culturally appropriate comprehensive programs aiming at prevention, curative and rehabilitative aspects of Hep C.

Recommendation Five

In order to educate the Punjabi community, the preventative programs should be comprised of:

- Awareness campaigns
- Educational workshops
- Use of electronic mass media (internet, radio, television)
- Plays and dramas (the arts community)
- Resources (videos, handbooks, brochures)

Recommendation Six

Develop culturally sensitive workshops for the mainstream and multicultural healthcare providers.

Recommendation Seven

Develop specific community development project related to addressing discrimination and stigmatization against “Women and Hep C” for being responsible for more contraction for the disease

SUMMARY OF RECOMMENDATIONS – LITERATURE REVIEW

1. More in-depth study on complexities surrounding Hep C in the Punjabi community.
2. Normalize Hep C and HIV/AIDS as a part of health promotion.
3. Generate support from community and faith leaders.
4. Promote the discussion of seeking help within the community.
5. Gear specific information to high risk groups and then to general public.
6. Addressing Hep C and HIV/AIDS in the South Asian community would require a culturally appropriate and holistic approach.
7. Work with mainstream organizations to develop build their cultural competencies

SUMMARY OF RECOMMENDATIONS – FOCUS GROUPS

1. Undertake another in-depth research study exploring the complexities surrounding Hep C.
2. Organize community development project which would raise the awareness about the issues pertaining to Hep C in the Punjabi community in a culturally appropriate manner.
3. Organize community development project which would educate the community about the issues pertaining to Hep C in the Punjabi community in the following areas:
 - Address myths and stereotypes about how disease is contracted
 - How can we protect ourselves
 - What is involved in testing
 - Where can one go for testing
 - What is confidentiality and the responsibilities of the health care providers
 - Compassion and kindness towards the “ill”
 - Address some of the cultural norms and traditions related to stigma, isolation, abandonment, un-acceptance, disownment, and ostracization
 - a. For the infected
 - b. For the family
4. Specific community development project related to addressing discrimination and stigmatization against “Women and Hep C” for being responsible for more contraction for the disease.
5. Develop culturally appropriate services. In particular, support groups for the infected and the affected.
6. Develop culturally appropriate resources (print, video and audio) for the community.
7. Develop culturally sensitive workshops for the mainstream and multicultural service providers.

CHAPTER 6

REVIEW OF LITERATURE

Preventing Hep C in the Punjabi Community

Literature Review

Introduction

Nine relevant articles were reviewed and analyzed. This section contains relevant findings which are meaningful for the research study.

Review

Hepatitis C in India

Hepatitis C virus infection in the general population: A community-based study in West Bengal, India

Limited information is available about the prevalence and genotype distribution of hepatitis C virus (HCV) in the general population of India. A community-based epidemiologic study was carried out in a district in West Bengal, India. By a 1:3 sampling method, 3,579 individuals were pre-selected from 10,737 inhabitants of 9 villages of the district, of whom 2,973 (83.1%) agreed to participate. Twenty-six subjects (0.87%) were HCV antibody positive. The prevalence increased from 0.31% in subjects <10 years of age to 1.85% in those 60 years. No difference in prevalence between men and women was observed. Serum alanine aminotransferase (ALT) levels were elevated in 30.8% (8 of 26) of anti-HCV-positive subjects compared with 3.2% (94 of 2,947) anti-HCV-negative subjects ($P < .001$). HCV RNA was detectable in 80.8% (95% CI, 65.6%-95.91%) of the anti-HCV-positive subjects by reverse transcription-primed polymerase chain reaction (RT-PCR). The participants were HCV types 1b in 2 (9.5%), 3a in 8 (38.1%), 3b in 6 (28.6%), and unclassified in 5 (23.8%). Nucleotide sequencing and phylogenetic analysis assigned the unclassified type to genotype 3e. In conclusion, this study provides general population-based estimates of HCV prevalence, including genotypes, from a South Asian country. Although the prevalence of HCV infection in this population was lower than that reported from industrialized countries of the west, the total reservoir of infection is significant and calls for public health measures, including health education to limit the magnitude of the problem. (HEPATOLOGY 2003;37:802-809.)

Relevant Findings:

Although the prevalence of HCV infection in this population was lower than that reported from industrialized countries of the west, the total reservoir of infection is significant and calls for public health measures, including health education to limit the magnitude of the problem.

http://www.natap.org/2003/may/050503_3.htm

Hep C Awareness Day in India

Friday, October 01, 2004 10:00 IST

With the objective of educating people about hepatitis C, October 1 will be observed as the world Hepatitis-C awareness day by the WHO.

In India alone, it is estimated that 1.09 crore people have chronic hepatitis C. National trends indicate a sizeable concentration of hepatitis C cases in North Eastern India. Among the metros, 4 lakh Delhiites are suffering from Hepatitis C and Mumbai accounts for 3 lakh cases. Gujarat also carries a patient load of 3.37 lakh.

The objective of the World Hepatitis-C awareness day is to draw the attention of people towards a virus that has emerged as a major global healthcare problem, infecting approximately three per cent of the world's population.

Every year the number of people infected with the Hepatitis C virus (HCV) increases by 30-40 lakh worldwide, adding to the 17 crore people already infected. The spurt in number is primarily attributed to low awareness about the disease.

"Today, new therapies have been shown to successfully treat between to 50 to 80 per cent of people infected with Hep C. Currently Roche offers Pegylated Interferon Alpha 2A (40KD)," said Dr. G. L. Telang, Managing Director, Roche Scientific Company India Pvt. Ltd.

Relevant Findings:

In India alone, it is estimated that 1.09 crore (19 million) people have chronic hepatitis C. National trends indicate a sizeable concentration of hepatitis C cases in North Eastern India.

Among the metros, 4 lakh (400,000) Delhiites are suffering from Hepatitis C and Mumbai accounts for 3 lakh (300,000) cases. Gujarat also carries a patient load of 3.37 lakh (337,000).

http://hepatitis-central.com/mt/archives/2004/10/hepatitis_c_awa.html

TITLE: Household members of hepatitis C virus-infected people in Hafizabad, Pakistan: infection by injections from health care providers

AUTHOR: Pasha O; Luby SP; Khan AJ; Shah SA; McCormick JB; Fisher-Hoch SP

AFFILIATION:

SOURCE: EPIDEMIOLOGY AND INFECTION 1999, Vol 123, Iss 3, pp 515-518

ABSTRACT: Household members of people with hepatitis C are at increased risk of HCV infection. The prevalence and routes of transmission of HCV to household members in Hafizabad, Pakistan were investigated. Household members of 24 index cases were given a risk factor questionnaire, tested for HCV infection, and the risk factors between the infected and uninfected were compared. Twelve of 74 household members (16.2 %) were seropositive for HCV antibody. This was 21/2 times the rate of infection in the general population (OR = 2.8; P = 0.01). None of the routes of transmission studied within the household was associated with an increased risk. Household members who received more than 4 injections per year were 11.9 times more likely to be infected than those who had not (P = 0.016). In Hafizabad, the greatest risk for HCV infection to household members of infected people is injections given by health-care workers rather than household contact with infected persons.

Relevant Findings:

In Hafizabad, the greatest risk for HCV infection to household members of infected people is **injections given by health-care workers** rather than household contact with infected persons.

http://www.sawnet.org/health/misc_abstracts.html#pasha99

The hepatitis B and C epidemics

High rates of hepatitis B infection in many South Asian countries are attributed to unsafe blood supply, reuse of contaminated syringes, lack of maternal screening to prevent perinatal transmission, and delay in the introduction of hepatitis B vaccine. India, Pakistan, and Bangladesh have the highest rates of infection, with prevalence ranging from 2% to 8% in different population groups.²⁰ Prevalence rates in Sri Lanka are under 1%.²¹ Hepatitis C infections in South Asia are also rising, and chronic liver diseases increasingly burden the region's health systems.^{21 22} Prevalence rates were estimated to be 1-2.4% in 1999.²² Infections seem to be acquired at an early age, and reuse of contaminated syringes is strongly implicated in transmission of **hepatitis B and hepatitis C infection**.^{23 24}

Relevant Findings:

High rates of hepatitis B and C infection in many South Asian countries are attributed to:

1. unsafe blood supply,
2. reuse of contaminated syringes,
3. lack of maternal screening to prevent perinatal transmission, and
4. delay in the introduction of hepatitis B vaccine.

India, Pakistan, and Bangladesh have the highest rates of infection, with prevalence ranging from 2% to 8% in different population groups

20. World Health Organization. Hepatitis B. www.who.int/emc-documents/hepatitis/docs/whocdscsrlyo20022/index.html (accessed 28 Feb 2004).
21. Khan M, Ahmad N. Epidemiology of hepatitis B in SAARC countries. In: Sarin SK, Okuda K, eds. *Hepatitis B and C: carrier to cancer*. New Delhi: Harcourt 2002; 19-23.
22. World Health Organization. Hepatitis C—global prevalence (update). www.who.int/docstore/wer/pdf/2000/wer7503.pdf (accessed 28 Feb 2004).
23. Usman HR, Akhtar S, Rahbar MH, Hamid S, Moattar T, Luby SP. Injections in health care settings: a risk factor for acute hepatitis B virus infection in Karachi, Pakistan. *Epidemiol Infect* 2003;130: 293-300. [\[CrossRef\]](#) [\[ISI\]](#) [\[Medline\]](#)
24. Khan AJ, Luby SP, Fikree F, Karim A, Obaid S, Dellawala S, et al. Unsafe injections and the transmission of hepatitis B and C in a periurban community in Pakistan. *Bull WHO* 2000;78: 956-63. [\[ISI\]](#) [\[Medline\]](#)

Articles on HIV/AIDS in the South Asian Community

We have taken the liberty to include five research articles which are **indirectly** related to the research project. It has been observed that there is a correlation between people who are affected with Hep C to be also affected by HIV/AIDS virus. There are additional similarities of stigma and myths surrounding both diseases.

1. Bryon, Angela D. Fisher, Jeffrey. “Determinants of HIV Risk among Indian Truck Drivers.” Social Science & Medicine 2001: V53. Pp1413-1426

Details, concern over the HIV epidemic in India reaching similar status as Africa. The study addresses the fact that not much research has been done concerning high risk sexual behavior. Article states that the primary barrier to in depth research is cultural barriers that taboo discussing sexual matters. The study was focused on truck drivers because while unprotected heterosexual intercourse is the number one means of transmission, second is the truck drivers and commercial sex workers. High risk sexual behaviours lead to spread of HIV from primary partners to secondary partners placing the general population at risk.

Relevant Findings:

- Low condom use
- Reuse of condoms
- High commercial sex trade
- Low to non-existent condom use with wives
- Use of pull out method as prevention
- Perceived risk of HIV is low
- Little factual knowledge of HIV

2. Indian HIV & Aids Statistics. www.avert.org

HIV infection is reported in all states and union territories for India. The concentration of the HIV epidemic is primarily in the South of India having 96% of all reported cases. Infection is deemed mostly as a result of heterosexual contact amongst injecting drug users and their partners. It is strongly speculated that the epidemic is under estimated as a result of patients dying prior to being diagnosed.

Relevant Findings:

- Of the 42947 cases as of December 2002, 74% were male
- 84% of all infections were transmitted sexually
- Some areas of India report HIV prevalence as 0% but these same areas report HIV infection at STD clinics and amongst injecting drug users.

3. **Upadhyay, Akhilesh. HEALTH- U.S: Denial Marks South Asians' HIV/AIDS Experience. Inter Press Service – May 9th, 2003**

The article discusses the prevalence of HIV in the South Asian community in New York. Service providers and community advocates detail their perceptions to barriers within that community.

Relevant Findings:

- AIDS happens to “other” people – white gay men and taxi drivers
- HIV/AIDS is associated with poor morality
- South Asians do not discuss sexual matters with friends, family or anyone else
- South Asians are unlikely to seek professional assistance
- A study of South Asian adolescents indicates they know of HIV but have little knowledge regarding transmission.
- Even for second generation South Asians AIDS is still a taboo topic
- Those getting assistance from service providers are generally couples age 30-40yrs. HIV was transmitted from husband to wife, who first was infected by a prostitute or through gay sex.
- Need to promote more dialogue about sexual and reproductive health
- 64% of South Asians in Queens, New York have no health coverage
- Since 1998 Chlamydia has risen 34%, the highest in all ethno-cultural groups
- AIDS awareness remains low even among South Asian professionals
- High rates of MSM who lead a heterosexual family man life as a result of social expectations and parental pressure to marry

4. HIV/AIDS in the Context of Culture: Report for the South Asian Communities. Ethnocultural Communities Facing AIDS: A National Study. 1993. National AIDS Clearing House.

The report was done to gain a better understanding of social, cultural and personal factors related to HIV transmission in the South Asian community, specifically the South Asian community in Vancouver. The report is from the perspective of community leaders, health care professionals, educators, people working in the AIDS field and other members of the community. South Asian Community identifies itself by religion, linguistic background and geographic region where they or their family came from. In the case of Vancouver 70% of the South Asian population was identified as Punjabi.

Relevant Findings:

- Western values taught to youth in Canada are in conflict with the good of the family.
- South Asian women are defined by the community and their role as wives, mother, and daughters.
- Female virginity is of high priority prior to marriage, “family honour”
- Many myths and misconceptions exist in the community regarding homosexuality and bisexuality.
- Gay, bisexual or MSM keep hidden and go through with marriage to avoid conflict within the family – this is even greater amongst new immigrants. Concept of “private shame” and a public heterosexual lifestyle.
- Non-acceptance of gay lifestyle or HIV positive health status by family and community.
- Many taboos within the South Asian community: sex before marriage (especially for women), sex during menstruation, masturbation is seen as “dirty and impure” and a waste of semen.
- Sexual discussion is also taboo. This results in knowledge coming from peers.
- Women are not to have sexual knowledge they are expected to learn from their husbands.

- If caught dating a South Asian girl the male may be forced into marriage to preserve her purity. This results in many South Asian males looking outside of the community for casual sex
- Prescribed sex roles for men and women after marriage
- Women are not to be sexually aggressive or aware this may be perceived as having slept around or with someone else.
- MSM must be the aggressor this to them means they are not gay.
- Married men “tend to roam around”, covertly have unprotected sex with other men or women but these behaviours are not discussed.
- Predominantly men bringing infection into the community and infecting women
- Prior to and during marriage many men go to prostitutes, “always present, always hidden” or deemed “private business”
- Many young men are encouraged to lose their virginity to prostitutes – this behaviour is greater with new immigrants
- Young women concerned with protecting their virginity may have anal sex but are unaware of the risk of HIV infection.
- In traditional household little to no permission is allowed to wives to question the behaviours of her husband.
- Decisions regarding condom use is made by the male
- Perception that they can't get HIV because they don't do drugs and are not gay.
- Very limited knowledge of HIV/AIDS, and prevention/safer sex
- Perception that HIV is a gay or “white” disease
- Strong lack of AIDS prevention/education programs within South Asian communities
- Lack of culturally appropriate resources
- Community has a history of “shunning” or ostracizing others – those infected keep their status hidden
- Community denies the existence of risk behaviours this contributes to the denial of HIV/AIDS in the community.

Recommendations

- Information resources in plain non-jargon language
- Obtain recent statistics on the relevance of HIV/AIDS in the community.
- Identify and ease the fear of AIDS and its denial in the South Asian community – link fear to the risk of HIV infection
- Avoid HIV/AIDS education in religious institutions because of religious barriers and taboos
- Generate support from community leaders
- Provide testimonials from respected professionals
- Approach individuals in the community directly for their input
- Provide information to youth in schools
- Resources should be in the language of the community
- Pictures should be used to make the material easier to identify
- Distribute pamphlets with information on community groups and counseling
- Use community television, print and radio

5. HIV/AIDS and Discrimination in South Asian Communities: An Ethnocultural Perspective

South Asians with HIV/AIDS experience stigma within a silent community that denies HIV/AIDS is a reality for South Asians. This is the main finding of a project sponsored by the Alliance for South Asian AIDS Prevention (ASAP), one of the first of its kind in Canada to examine HIV/AIDS in a specific cultural community.

Background

In 1998 the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society's Joint Project on Legal and Ethical Issues issued two reports, *HIV/AIDS and Discrimination: A Discussion Paper*⁽¹⁾ and *Gay and Lesbian Issues and HIV/AIDS: Final Report*⁽²⁾ both of which recognized that people with HIV/AIDS who identify with a specific ethnic or cultural community face unique challenges. This project builds on the work already completed and makes an important contribution to the understanding of the barriers and challenges faced by members of the South Asian communities.

Sponsored by ASAP and funded by Health Canada, the project was carried out by an independent consultant team under the guidance of a Project Advisory Committee comprised of South Asian community members, half of whom were HIV-positive. The consultant team conducted in-depth, confidential interviews with 21 South Asians living with or affected by HIV/AIDS, as well as 31 key informants, most of whom were from AIDS service and South Asian organizations in the Toronto area.

Key Findings

South Asian women face a particularly difficult burden in dealing with HIV/AIDS, since codes of sexual conduct or behaviour are more rigidly applied to them.

The key findings of the project are as follows:

- South Asians have a very strong collective culture that is protective of traditional ideas about male/female roles and sexuality. South Asians perceive themselves as being monogamous, sexually inactive (outside of marriage), and family-oriented.

South Asians do not acknowledge gay or bisexual South Asian identities, and view HIV/AIDS as a gay white man's disease. Accordingly, the (mis)perception is that HIV/AIDS *does not happen* to South Asians.

- The community's silence and denial about HIV/AIDS results in stigma being experienced by South Asians who are HIV-positive. They fear being mistreated, abandoned, or isolated if they tell other South Asians about their status.
- South Asian women face a particularly difficult burden in dealing with HIV/AIDS, since codes of sexual conduct or behaviour are more rigidly applied to them. Women risk being labeled promiscuous and as falling below the high standard expected of caregivers/nurturers in the South Asian family unit.
- Faith is a central part of many South Asians' lives, yet faith communities are often the guardians of the prevailing myths that contribute to the silence about HIV/AIDS in the first place. Religion and spirituality are nevertheless important means by which South Asian people with HIV/AIDS become reconciled with their lives.
- There is limited experience within the organized South Asian communities, including South Asian physicians, in dealing with HIV/AIDS issues. This means that South Asians are typically turning to mainstream support services that are not reflective of their linguistic, social, and cultural reality.
- South Asians with HIV/AIDS experience discrimination in the areas of health care, welfare, employment, housing, immigration, travel, business, and the law.

Given the silence about HIV/AIDS within the South Asian communities and the everyday racism encountered by South Asians as members of a marginalized part of Canadian society, it is difficult to know the degree to which individuals experience discrimination related specifically to HIV/AIDS. The larger implication of the findings is that South Asians, already vulnerable to racism and marginalization in Canada, are also at risk for the spread of HIV/AIDS. Denial, ignorance, stigma, and silence are all conditions that can lead people to engage in high-risk behaviour, and education strategies to be rendered ineffective.

Key Recommendations

The project's central recommendation is that a broad, multi-pronged social marketing strategy be developed in South Asian communities to change prevailing ideas and break

the silence about HIV/AIDS. The strategy should be publicly funded and guided by a consortium of key South Asian business people, physicians, media, faith leaders, and South Asians with HIV/AIDS. Once piloted in Toronto, the strategy should be implemented nationally in major centres across Canada, taking local realities into account.

The project also recommended that:

- funders require mainstream AIDS service organizations in Toronto to become representative of and responsive to Toronto's diverse ethnic communities;
- ASAP improve its own reflectiveness and representation of people with HIV/AIDS at the governance and staff levels of the organization;
- ethno-specific AIDS service organizations such as ASAP advocate to ensure that people of colour and women are included in HIV/AIDS clinical research initiatives underway in Canada;
- ethno-specific AIDS service organizations such as ASAP advocate for changes to Canada's immigration policies and to health and social services policies that have detrimental effects on people with HIV/AIDS.

Many of the project participants commented that ASAP, as the only South Asian HIV/AIDS agency in Canada, must play a leading role in responding to the recommendations. Yet participants also acknowledged that in light of ASAP's modest size and budget, and marginalized status within the broader South Asian community, it could not do this alone. The problems and potential solutions lie in the broader South Asian and mainstream communities and should therefore be addressed by a coalition or consortium.

Conclusion

Many of the project's findings should not come as a surprise to those who work on HIV/AIDS issues in ethno-specific communities. However, perhaps for the first time a clear link has been drawn between the community's silence and denial and the detrimental impact these have on South Asian lives - both within and outside the communities they call home.

In documenting the voices and lived experiences of South Asian people with HIV/AIDS, the project report makes an important contribution to the fight against the denial of HIV/AIDS in

South Asian communities. Implementing the recommendations, particularly an aggressive advocacy agenda to implement systemic change, should result in an improved quality of life for South Asians with HIV/AIDS and decreased spread of HIV/AIDS through South Asian communities.

- submitted by Meena Radhakrishnan

Meena was a member of the Project Advisory Committee for this project. She is a trained lawyer and social worker currently practicing in the area of children's mental health in Toronto.

Copies of the full June 1999 Project Report are available through ASAP, which has also undertaken to translate the report, or significant parts thereof, into various South Asian languages. Please direct inquiries to: ASAP, 126-20 Carlton Street, Toronto ON M5B 2H5, Canada. Tel: 416 599-2727; fax: 416 599-6011.

ASAP is a charitable, non-profit AIDS service organization based in Toronto and working with Canadians of South Asian origin. ASAP was formed in 1989 in response to the deaths of a Tamil-speaking man and woman who had difficulty accessing health-related services from mainstream AIDS organizations. The agency works to promote HIV/AIDS prevention and education in Canadian South Asian communities, supports people with HIV/AIDS, and helps partners, family members, and friends cope with a loved one living with HIV/AIDS.

1. T de Bruyn. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

2. J Fisher et al. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

General Terms

AIDS: Acquired Immunodeficiency Syndrome

HIV: Human Immunodeficiency Virus

Incidence: The number of new occurrences of a disease in a specified time period

Prevalence: The number of people with the disease who are living during a specified time period

Exposure Categories

MSM: Men who have sex with men; this includes men who report either homosexual or bisexual contact

MSM/IDU: Men who have had sex with men and have injected drugs.

IDU: Injecting drug users

Blood/blood Products

SUMMARY OF FINDINGS – LITERATURE REVIEW

These are the collective findings which are relevant to the project:

Hep C

3. There is evidence of significant Hep C infection in Indian sub-continent. The need is expressed by professionals to raise education and awareness about Hep C issues and its complexities.
4. High rates of hepatitis B and C infection in many South Asian countries are attributed to:
 - a. unsafe blood supply,
 - b. reuse of contaminated syringes,
 - c. lack of maternal screening to prevent perinatal transmission, and
 - d. delay in the introduction of hepatitis B vaccine.
 - e. India, Pakistan, and Bangladesh have the highest rates of infection, with prevalence ranging from 2% to 8% in different population groups
5. In Hafizabad, Pakistan, the greatest risk for HCV infection to household members of infected people is **injections given by health-care workers** rather than household contact with infected persons.
6. Risk factors for acute Hep C are: 1) Transfusions 2) Intravenous Drug Users 3) Sexual Activity 4) Household contact 5) Healthcare Workers 6) Prisoners 7) Body Piercing and Tattoos 8) Blood in Body Secretions 9) Racial, Ethnic, and Income groups

HIV/AIDS

12. Low condom use and reuse of condoms (with wives as well).
13. Very little knowledge about HIV/AIDS and its complexities in the South Asian community.
14. HIV/AIDS issues and concerns also remain low for human care professionals in the South Asian community.
15. HIV is closely associated with taboo issues of sex and sexuality and therefore cannot be easily addressed within the community.
16. Health promotion is mainstream and service providers are too unfamiliar with cultural and faith backgrounds to offer the necessary support.

17. Sexual Health is of low priority for new immigrant (in Canada less than five years)
18. South Asians do not acknowledge gay or bisexual South Asian identities, and view HIV/AIDS as a gay white man's disease. Accordingly, the (mis)perception is that HIV/AIDS *does not happen* to South Asians.
19. The community's silence and denial about HIV/AIDS results in stigma being experienced by South Asians who are HIV-positive. They fear being mistreated, abandoned, or isolated if they tell other South Asians about their status.
20. South Asian women face a particularly difficult burden in dealing with HIV/AIDS, since codes of sexual conduct or behaviour are more rigidly applied to them. Women risk being labeled promiscuous and as falling below the high standard expected of caregivers/nurturers in the South Asian family unit.
21. Faith is a central part of many South Asians' lives, yet faith communities are often the guardians of the prevailing myths that contribute to the silence about HIV/AIDS in the first place.
22. South Asians with HIV/AIDS experience discrimination in the areas of health care, welfare, employment, housing, immigration, travel, business, and the law.

SUMMARY OF RECOMMENDATIONS – LITERATURE REVIEW

1. More in-depth study on complexities surrounding Hep C in the Punjabi community
2. Normalize Hep C and HIV/AIDS as a part of health promotion
3. Generate support from community and faith leaders
4. Promote the discussion of seeking help within the community
5. Gear specific information to high risk groups and then to general public
6. Addressing Hep C and HIV/AIDS in the South Asian community would require a culturally appropriate and holistic approach.
7. Work with mainstream organizations to develop build their cultural competencies

CHAPTER 7

FOCUS GROUP - FINDINGS

The findings presented in this section represent the views and opinions of youth, seniors and religious and community members from the Punjabi community. The youth, seniors and religious members all participated with great enthusiasm in this study.

In total *five focus groups* were organized. The attendance (60 participants) varied with the

- youth having ten members,
- Adults having fifteen members,
- seniors with eleven,
- women with sixteen members, and
- religious and community leaders with eight attending the focus groups.

The discussion was transcribed by two note takers and no tape recorder was used.

Almost all the participants informed us of their gratefulness in being able to share their thoughts and opinions, and have expressed the strong desire to participate in future like projects. The research team has tried to capture the experiences, thoughts, sentiments and opinions share by the community members.

The findings from all three focus groups are “collapsed” together. The words in inverted commas are direct quotes from the participants. All other information has been synthesized by the research team and collapsed into themes, findings and recommendations.

Findings - Focus Groups

1. When you hear Hep C or hepatitis C, what comes to your mind?

- Many participants had not heard the word hepatitis. Out of 60 participants, 42 (70%) were not able to identify with the word hepatitis and Hep C. The least awareness and or information related to Hep C was elicited from women's, seniors and religious leaders focus group.
- Liver problem and liver disease
- Too much drinking. Participants discussed that alcohol use may cause Hep C.
- Homosexuals, MSMs (men having sex with men). The participants felt that any other type of sexual behaviour other than heterosexual behaviour is a cause for serious health risks. Although, we are stressing that people should use precautions, why can't we stress the importance of not engaging in "unheterosexual behaviours".
- HIV/AIDS related problem. The participants felt that AIDS is a "gay" disease and perhaps Hep C is also a "gay" disease. They questioned whether human behaviour needs to be regulated. Because we are "unregulating" human behaviour now, is it the reason that we have more and more complex form of illnesses. On the one hand we have freedom of choice and on the other we have "death" associated with that freedom. Perhaps, the society should reconsider "homosexual" behaviour.
- Prolonged suffering. The participants felt that this disease would prolong suffering of the patients. The medications keep one alive a lot longer but the quality of life deteriorates.
- Thoughts of death and sickness and pity for the infected. Many participants expressed a concern for the infected. They expressed that it would be very hard to survive in Punjabi community. Virtually no body would talk to you. They even expressed the concern whether the "infected person's" loved ones would even shun them. They shared stories from India where people with AIDS are not admitted to hospitals and are not allowed into villages and are left to die. There have been cases where human care workers have refused to "treat" patients identified as having AIDS.

- Sharing needles with others. Basically this is a disease of “sick” people. Sickness was defined as “people with no or low moral conscience”. Examples were cited as “druggies”, homosexuals, hookers, prisoners.

2. Have you heard about this word or illness in India, Pakistan or back home?

- The majority of people did not hear about this illness. Some did remark, however, that now back home the doctors are using disposable “injections” meaning “needles”. They did not the reasons why disposable needles are being used.

3. Is this a problem within the Punjabi Community in Canada?

- The majority (44) did not know that this is a problem in Canada within the Punjabi community.
- It is not a problem here in Canada but it is a problem back home. The participants felt that it would be difficult to know who has Hep C in Canada, especially with the Punjabi community. Some participants were of the opinion that Hep C doesn’t exist in the Punjabi community. Others argued that we have serious drinking problem and many of the participants knew people who had liver problems. They were wondering whether these “people” had liver cirrhosis or Hep C. Some shared their experiences of Punjabi gay men who frequent the “gay scene” in Toronto. Others shared about Punjabis living in “homeless shelters”. For some this was clearly a big surprise to know that Punjabis could be living a life of drugs and homelessness.
- The problem is hidden cannot be identified. Perhaps we can find out from doctors or from hospitals or from health departments. Why are the departments of health not keeping statistics of which community is mostly effected by Hep C. The participants felt that it is not about “giving the community a bad name” rather it would help us to determine where to channel our efforts.

4. Just to check the perception or awareness of the participants a questions was asked “Have you heard about HIV/AIDS?”

- The majority (58) of participants had heard about HIV/AIDS. An interesting observation: the majority had heard about AIDS and not about HIV. They did not

know the difference between these two terms. All youth participants had heard about HIV virus.

5. Is this a problem for community back home?

- Yes, back home, some doctors are not using clean needles. Sometimes they just “boil” the needles in hot water and keep reusing the same needle over and over again.
- Another participant added that prostitutes might be at risk of spreading this disease.
- The discussion also centered on “who frequents these prostitutes” and the consensus was that middle aged men, truck drivers and sales agents might be at risk of getting this disease from prostitutes.
- It is a problem in all areas of India special mention was made of Kerala, Mumbai and Kolkatta.
- Those who get infected in India are people who stay away from home.
- The problem is not that serious and only concerns a small group of the population

6. Who gets infected by Hep C?

- Everyone and everybody is at risk of getting Hep C – men, women, children and drug users, prostitutes, blood donors and recipients. Kids also get from their parents (mostly from mothers). Wives get this disease from their husbands.
- People who live in Africa and Indian sub-continent. They identified the countries as: India, Pakistan, Afghanistan, Nepal, Bhutan, Bangladesh, Sri Lanka, and Maldives.

7. How do people get infected with Hep C?

- From blood transfusions, sleeping with prostitutes, being born with Hep C virus, via sexual transmission and or sharing needles
- “Gay sex or by just being Gay”

- From cuts in the mouth and from seeing a dentist. (The facilitator had to clarify that that the dentists “sterilize the tools”).
- Not wearing a condom or having unprotected sex.
- Being exposed to infected blood. Discussion centered around blood donation. People expressed their reluctance about donating blood. They are still not clear about how blood is collected and managed.
- Tattooing and Body Piercing. The participants expressed a concern that a lot of young people are having their body parts pierced. The concern was that perhaps not everyone maybe taking precautions.
- Get it from sharing needles – the homeless and the people with drug problems get it from sharing needles. Or rather the not wealthy get it from sharing needles
- The homosexual population. Perhaps heterosexual population who frequently have more than one partner.
- Prostitutes/hooks and those involved with prostitutes.
- “Women whose husbands see hookers”.
- “Gays are affected and kids born with Hep C”.
- Families of people with Hep C are affected.
- Poor people and truck drivers – perhaps also taxi drivers.
-

8. How do people protect themselves from getting Hep C?

- Use a condom. The concern was that this might be the single most cause for spreading Hep C. The women felt that Punjabi men seem to be taking more sexual risks and entering into extra-marital affairs than Punjabi women. Many Punjabi men are having relations outside the Punjabi community. The women also felt that Punjabi tend to drink “excessively”. To what extent has the link been established by the scientific community about alcohol use and having Hep C? The women also felt that it would be hard for them to ask their husbands to wear “condoms” – as this would raise “alarm bells” in the minds of husbands. The women also expressed that boys are given freedom to explore their sexuality but women are required to be “virgin” till their marriage.

- Don't share needles – Use the needle exchange programs (added answer by youth)
- Birth control – “this does not protect you” (the answer came out in the youth focus group)
- All participants wanted the community to have more education regarding Hep C and HIV/AIDS. These two disease can “kill you” and have not cure.
- “Don't be stupid, if anything is questionable don't do it. You can't look at a person and know if they have Hep C, ask them” (youth focus group)
- Having no sexual contact with gays or people with Hep C or people with HIV/AIDS. (Religious leaders)
- Go to the Gurdwara (Church) daily (Religious leaders)
- Regular check up with one's doctor. Have the doctor check you for Hep C virus if you have had surgery back home or if you had needles back home.
- Get disposable needles
- Don't kiss a person infected with Hep C
- Donate your own blood and keep that blood in case you need it. The discussion followed that some participants did not trust the Canadian Blood Services that are responsible for collecting blood.

11. Do you feel that you are able to talk to a health care provider (doctor, social workers etc.) about Hep C?

- The first preference was to talk to some one they knew. They felt that they should find on their own as much information as possible.
- The second preference was to talk to professionals whom they trust.
- “Doctors are good for giving medications but are not good for emotional support”. The participants felt that most doctors do not have any “bed side manners”. They are either very busy dispensing medications or they are not trained in compassionate counselling.
- Maybe if they had questions they would talk to a doctor but if they had Hep C they would not talk to a doctor rather go to someone who doesn't know the family.
- Find another doctor because their family doctor would tell their parents (youth focus group).

- They would not see a South Asian doctor because they would definitely tell others (the majority of participants).
- They would get tested at a clinic in the area they lived in. They felt that this method is the safest way to get tested.
- They would talk to health care provider but not without a relative present (seniors & religious members focus groups).
- Only if the health care provider spoke their language (seniors & religious members focus groups)
- No, because there is no literature available for them to read (seniors & religious members focus groups)
- “No because no one listens to me” (seniors focus group)
- “If you don’t have it why bother talking to a doctor” (seniors)

12. What problems would a person face if he/she suffered from Hep C?

- Others around you would act differently
- It’s an illness that never goes away and can only get much worse
- It will lead to isolation and loneliness
- The infected person would be confused, scared, depressed, suffer pain from the illness and then probably get suicidal ideation
- They would be seen as bringing their shame to their family
- The family would also face the brunt of stigma from the community
- People would not marry into the family because they have the “disease”
- People in the community will talk about them
- They will be disowned and abandoned
- The person would suffer death, disease and health problems
- Face ridicule and embarrassment from family and the community
- Face prejudice at work and by society
- Community will discard and boycott them

13. What can be done to assist/provide treatment to that person?

- “Prevention is better than a cure”
- Treatment should be provided

- Visits to the doctor and seeing a specialist
- “One should be their own doctor”
- The government should cover the cost of treatment and medication
- Create support groups
- Create community awareness through education
- Offer financial assistance for buying drugs and for treatment
- “Tolerance” – “Can you teach tolerance?” – “You can try” (youth focus group)
- Overall support is necessary from family, friends and strangers too
- Research is needed to find a cure
- Hospitals and clinics should be built strictly for Hep C patients
- “Nothing should be done, because people with Hep C deserve it” (religious members focus group). “It is their own deeds that are coming back to haunt them” said a senior.

14. What contributes to stigma, myths, social taboos surrounding Hep C in the Punjabi community?

- The topics that are related to “illness which leads to death” or “mental health issues” are not discussed in the community. The discussion would lead to shame and isolation of the individual and the family. The individual or family may either minimize or deny about the illness or seek treatment away from the family of origin.
- The fear of ostracization, isolation is very real. It leads to people not marrying into the family. At special occasions people shy away from inviting relatives or friends who are “ill”.
- The faith is controlled by “older” adults in each of the three religions (Sikh, Hindu and Islam). The “management committee” is more interested to look good in the eyes of the congregation than to address the complexities of modern diseases.
- The youth (often young girls) and women bear the brunt of rigid social norms in the Punjabi community. They are expected to “bow their head and serve their men folk”.
- Punjabi community tends to function on “clan” basis. Each clan member is expected to interfere in the other clan member’s affair. Every clan member knows everyone’s business. The clan boundaries are stronger than

professional (human care professional) boundaries. Therefore, the participant's believed that "confidentiality may not and cannot be kept by Punjabi professionals.

- The Muslim community and the Sikh community is facing the brunt of discrimination in Canada. While the community may not trust their own human care professionals but when given a choice between "mainstream" professionals and "their own professionals" – the choice was very clear; they would go and see their own professional.

15. Are you aware of any human care professionals or organizations within the Punjabi community in the Region of Peel who is providing services to the people infected and affected by Hep C?

- No one identified any agency or professional other than Punjabi Community Health Centre which brings issues like this forward. They were not aware of any Punjabi doctor who would specialize in Hep C treatment. The participants cited many Punjabi doctors who are heart specialists, kidney specialist, orthopedic specialist, ENT specialists but could not cite a single doctor who is specializing in Hep C or HIV/AIDS.

16. There are two types of community based agencies which provide two types of services. One, is called culturally sensitive services and the other is called culturally appropriate services. (The difference¹⁰ between these two types of service delivery was explained to them). Which one would you prefer?

- The majority 55 (92%) participants wanted to seek culturally appropriate services. They said that "they would feel comfortable speaking to them in their own language." In addition they said "they would understand our culture and provide us with culturally appropriate care and services".

¹⁰ Baldev Mutta, 2003, outlined the difference between these two types of service delivery as follows:

- Within culturally appropriate work, clients have a world view and professionals need to adjust their philosophy, way of work and service delivery to suit their clients' needs.
- Within culturally sensitive work, clients adjust their worldview and help seeking behaviours to suit the service delivery arrangements and intervention modalities of the professionals.

17. This could be a deadly disease, in your opinion, what would be effective ways to do outreach?

- Flyers, brochures and videos would be useful tools
- Speeches at Gurdwaras and Mandirs. I don't know if Mosques allow awareness raising seminars inside the Mosque. Other people in the group said that some Mosques do allow awareness raising seminars.
- Doctors should be informing patients
- Information about Hep C should be shared with family and relatives, they should be educated
- Workshops would be a good tool
- Use of print materials
- Sex education should be given to the community in a sensitive manner
- Hep C testing should be made mandatory, part of ones yearly check up. This would make it more normal
- Outreach should be done to health service providers so that they are not insensitive and not so uncomfortable
- Websites and newsletters should be developed
- Community groups and schools should be used to do outreach, not religious institutions because they would never allow anything that could be seen as promoting sex (youth focus group)
- Groups should remain separate, one for youth, parents etc. There is no point in doing a group for seniors because they're not going to talk about Hep C and they're not going to change (youth focus group)

18. What is the best way to de-stigmatize Hep C within the Punjabi community?

- Awareness would help with de-stigmatization of the issue. The community's consciousness needs to be developed in order to deconstruct the myths, rigid norms and traditions which impede the compassionate understanding of the complexities surrounding Hep C.
- Step by step education needs to be imparted so that stigma is replaced by compassion and kindness.

Steps

1. General education about Hep C with statistics (nurse or medical doctor)

2. General education about Hep C with statistics (community/religious leader)
3. Specific education regarding Hep C as to how it is effecting Punjabis (possibly a client)
4. Specific education related to Risk Groups (professional/health care worker)

19. What would you like to see PCHC do to address this issue?

- More research into the topic
- More discussions, similar to the focus group that they participated in
- More translation of available material. Target education to high risk groups and women.
- Use of media campaigns using ethnic television stations or OMNI 1 or 2 and Sur Sagar Television and ethnic radio stations
- Call in radio shows aimed at specific target audiences (youth, parents etc.) - “pointless to do shows aimed at seniors because they’re not going to listen to stuff on Hep C” (comment added by youth focus group)
- Flyers, videos, and brochures in their own language
- Speeches at Gurdwara and Mandirs
- Newspapers should put the information in the paper
- Local ethnic media to attend a half day workshop on Hep C

20. Would you like to share any other suggestion related to the Hep C topic?

- “This is our fate we must accept it” (religious members focus group)
- “Prevention is better than a cure”
- The cost of health care should be covered
- Inform youth not to be promiscuous (seniors group)
- We (women) need more education about this topic

SUMMARY OF FINDINGS - FOCUS GROUPS

Finding number one

While youth had some general information regarding Hep C the other four focus groups had limited knowledge of Hep C. The seniors, women and religious members did not have a clear understanding about the contraction of the disease, who it affects.

Finding number two

Many participants had not heard the word hepatitis. Out of 60 participants, 42 (70%) were not able to identify with the word hepatitis and Hep C. The least awareness and or information related to Hep C was elicited from women's, seniors and religious leaders focus group.

Finding number three

Excessive alcohol use by men in the Punjabi community may lead to liver related diseases (perhaps Hep C).

Finding number four

The majority of participants did not hear about Hep C back home.

Finding number five

The majority 44 participants (73%) did not know if Hep C is a problem in Canada within the Punjabi community.

Finding number six

The majority 58 (97%) of participants had heard about HIV/AIDS. *An interesting observation: the majority had heard about AIDS and not about HIV. They did not know the difference between these two terms.* All youth participants had heard about HIV virus.

Finding number seven

The participants felt that Hep C is a problem back home. The reasons are: reused needles, and prostitutes. Middle aged men, truck drivers and sales agents might be at risk of getting this disease from prostitutes.

Finding number eight

Everyone and everybody is at risk of getting Hep C – men, women, children and drug users, prostitutes, gays, families with people affected by Hep C, Poor people, truck drivers, taxi drivers, blood donors and recipients.

Finding number nine

People get infected with Hep C from: blood transfusions, sleeping with prostitutes, being born with Hep C virus, via sexual transmission and or sharing needles, “gay sex” or unprotected sex, tattooing and Body Piercing.

Finding number ten

People can protect themselves by: using a condom, not sharing needles, more education and awareness, regular medical check ups, practicing spirituality, keeping your own blood at a safe place.

Finding number eleven

Medical practitioners were seen as “insensitive” by the participants and felt that they would not have the sensitivity to address the needs surrounding people infected with Hep C virus.

Finding number twelve

The person infected with Hep C would face enormous problems such as: isolation, loneliness, confused, scared, depressed, suffer pain from the illness and then probably get suicidal ideation, bringing their shame to their family, also face the brunt of stigma from the community, disowned and abandoned, face ridicule and embarrassment, and community will discard and boycott them.

Finding number thirteen

Treatment to include the following: support groups, more research into finding a cure, community awareness, medication should be provided by the government, hospital or clinics should be built for people infected with Hep C.

Finding number fourteen

Stigma, myths, social taboos surrounding Hep C in the Punjabi community is as follows:

1. The culture tends to be shame oriented.
2. The fear of shame leads into denial and minimization about the problem.
3. The shame of fear leads one into secrecy.
4. Due to fear, the person will be ostracized, shunned, and isolated.
5. The Punjabi community tends to function on “clan” based norms and traditions.
6. The women often bear the brunt of “conservative” norms and traditions.
7. The Punjabi community already faces discrimination and by disclosing the illness they are further exposing themselves.

Finding number fifteen

The participants could not identify any other South Asian agency or professional other than Punjabi Community Health Centre in the Region of Peel which brings issues like this forward. They were not aware of any Punjabi doctor who would specialize in Hep C treatment.

Finding number sixteen

The majority 55 (92%) participants wanted to seek culturally appropriate services for seeking services related to Hep C.

Finding number seventeen

The participants had the following suggestions regarding outreach to the community: Develop culturally relevant resources, organize educational forums and workshops, organize culturally competent training for mainstream professionals, use of electronic media, and disseminate information.

Finding number eighteen

Awareness would help with de-stigmatization of the issue. The community’s consciousness could be developed in order to deconstruct the myths, rigid norms and traditions which impede the compassionate understanding of the complexities surrounding Hep C.

Finding number nineteen

Step by step education needs to be imparted so that stigma is replaced by compassion and kindness.

Steps

- Step One. General education about Hep C with statistics (nurse or medical doctor)
- Step Two. General education about Hep C with statistics (community/religious leader)
- Step three. Specific education regarding Hep C as to how it is effecting Punjabis (possibly a client)
- Step Four. Specific education related to Risk Groups (professional/health care worker)

Finding number twenty

Punjabi Community Health Centre should undertake the following:

6. More research into the topic
7. Organize more discussion groups.
8. Develop more resources - target education to high risk groups and women.
9. Use of media campaigns using ethnic television stations or OMNI 1 or 2 and Sur Sagar Television and ethnic radio stations
10. Use of print, and electronic media to raise awareness

SUMMARY OF RECOMMENDATIONS – FOCUS GROUPS

1. Undertake another in-depth research study exploring the complexities surrounding Hep C.
2. Organize community development project which would raise the awareness about the issues pertaining to Hep C in the Punjabi community in a culturally appropriate manner.
3. Organize community development project which would educate the community about the issues pertaining to Hep C in the Punjabi community in the following areas:
 - Address myths and stereotypes about how disease is contracted
 - How can we protect ourselves
 - What is involved in testing
 - Where can one go for testing
 - What is confidentiality and the responsibilities of the health care providers
 - Compassion and kindness towards the “ill”
 - Address some of the cultural norms and traditions related to stigma, isolation, abandonment, un-acceptance, disownment, and ostracization
 - a. For the infected
 - b. For the family
4. Specific community development project related to addressing discrimination and stigmatization against “Women and Hep C” for being responsible for more contraction for the disease.
5. Develop culturally appropriate services. In particular, support groups for the infected and the affected.
6. Develop culturally appropriate resources (print, video and audio) for the community.
7. Develop culturally sensitive workshops for the mainstream and multicultural service providers.

APPENDICES

The hepatitis C quiz

The hepatitis C quiz consists of nine specially selected questions which the public should know the answers to. Please take your time to read through the questions.

1. Hepatitis C is a disease that affects the:

- a) Heart
- b) Liver
- c) Kidneys
- d) Intestines

2. Acute hepatitis is defined as an infection that

- a) lasts longer than one year
- b) cannot be cured
- c) lasts no longer than six months
- d) immediately precedes the development of hepatocellular carcinoma (liver cancer)

3. Hepatitis C cannot be transmitted through:

- a) contaminated food or water
- b) injection drug use by sharing needles
- c) blood transfusions
- d) direct exposure to blood (cuts, injuries)

4. Who is at risk for becoming infected with hepatitis C?

- a) People who have used a needle to inject drugs such as heroin or cocaine, even if it was only once, many years ago
- b) People who had a blood transfusion prior to 1992
- c) Health care workers who have come in direct contact with blood
- d) All of the above

5. The risk of getting hepatitis C infection through a blood transfusion today is extremely low.

- a) True
- b) False

6. Presently, the major mode of transmission of the hepatitis C virus is by:

- a) sexual intercourse
- b) mother-to-child transmission
- c) injection drug use
- d) blood transfusion

7. Many people who have been infected with hepatitis C do not know they have the disease because they feel healthy and show no symptoms.

- a) True
- b) False

8. Which of the following is NOT considered a risk behaviour for contracting hepatitis C?

- a) Snorting
- b) Tattooing
- c) Body piercing
- d) Giving blood

9. It is possible to contract the hepatitis C virus by _____ an infected person.

- a) sharing a toothbrush with
- b) kissing
- c) shaking hands with
- d) hugging

Thank you for taking the time to take this quiz.

1. Hepatitis C is a disease that affects the:

The correct answer is 'b'

Hepatitis C infection is characterized by inflammation of the liver. Many infected people may have no symptoms and are unaware of their condition, and unknowingly act as sources of infection and run the risk of developing chronic liver disease, cirrhosis and liver cancer.

2. Acute Hepatitis C is defined as an infection that

The correct answer is 'c'

Acute Hepatitis C lasts no longer than six months. Most people with acute Hepatitis C infection show no symptoms. Patients who do not completely resolve the infection after six months develop chronic Hepatitis C infection.

3. Hepatitis C cannot be transmitted through:

The correct answer is 'a'

Unlike Hepatitis A, Hepatitis C cannot be spread through contaminated food or water. The Hepatitis C virus is a pathogen that is transmitted through the transfer of infected blood. Therefore, needle-sharing among injection drug users is a risk behaviour. People who received blood transfusions prior to 1992 faced the risk of becoming infected with HCV. However, sophisticated blood screening techniques have now virtually eliminated that risk. Direct contact with blood from an infected individual also carries a risk of infection.

4. Who is at risk for becoming infected with hepatitis C?

The correct answer is 'd'

All of the above. Hepatitis C is a virus that is spread through direct blood-to-blood contact with an infected individual. Injection drug users (even one-time users) who have ever shared needles are at risk of HCV infection. People who received blood products before 1992 and health care workers exposed to needlestick injuries are also at risk.

5. The risk of getting hepatitis C infection through a blood transfusion today is extremely low?

The correct answer is 'a'

The risk of getting hepatitis C infection through a blood transfusion is now extremely low given the precautions that are taken in screening blood donors.

All blood donors in Canada have been routinely tested for hepatitis C since 1990. However, as with many diagnostic tests, these are not 100% accurate in detecting the virus, especially if the donor has very recently become infected. The probability of detecting hepatitis C is 1 in 103,000 units of blood. However, with the implementation of a new HCV screening technique called Nucleic Acid Amplification Technique, the risk is expected to decrease to 1 in 500,000. Inquire about the possibility of donating your own blood before surgery.

6. Presently, the major mode of transmission of the hepatitis C virus is by:

The correct answer is 'c'

These are all possible modes of transmission. However, the major mode is through injection drug use. It is estimated that 60% of all new HCV infections are due to injection drug users sharing contaminated needles and related equipment. It need not be regular or heavy drug use, nor do users have to share needles to be at risk of contracting hepatitis C. Transmission through blood transfusions was a higher risk with insufficient blood screening techniques prior to 1992. Current research tells us that the risks of transmitting hepatitis C through sexual intercourse is very low. Mother-to-child transmission ranges from 5 - 10% and slightly higher if the mother is co-infected with HIV.

7. Many people who have been infected with hepatitis C do not know they have the disease because they feel healthy and show no symptoms?

The correct answer is 'a'

Many people who have been infected with hepatitis C do not know they have the disease because they show no symptoms. Hepatitis C is a disease that progresses slowly. Some people infected with HCV may show no symptoms until 20 or 30 years after the initial infection. Symptoms can include fatigue, loss of appetite, abdominal pain or discomfort, or jaundice (a condition where the eyes and skin have a yellow appearance).

8. Which of the following is NOT considered a risk behaviour for contracting hepatitis C?

The correct answer is 'd'

Blood donors are not at risk of contracting hepatitis C. Sterile equipment is used and needles are never shared between donors, nor is there any contact with other blood products. Intra nasal (snorting) cocaine use is considered a risk behaviour for contracting hepatitis C. Needles that have become contaminated with infected blood during tattooing and piercing practices are also a risk for HCV infection. Therefore, hygiene and infection control are an important part of ensuring that HCV is not transmitted by these means.

9. It is possible to contract the hepatitis C virus by _____ an infected person.

The correct answer is 'a'

Hepatitis C is not spread through casual physical contact. A person cannot contract hepatitis C by shaking hands, hugging or kissing an infected individual. However, it is possible to become infected by sharing a toothbrush or razor with an infected person. This is because the toothbrush or razor may contain traces of blood that carry the virus.

We hope you have learned more about hepatitis C. Do you think you could be infected with the hepatitis C virus? Only a blood test can accurately determine if you are infected or not. If you think you might be at risk after doing this quiz, make sure you discuss it with your family physician at your next visit.

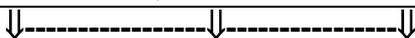
Taken from: Public Health Agency of Canada website

1. SUMMARY OF APPROACH TO Hep C RESEARCH PROJECT

<p>1. Social Policy Context of Project</p> <ul style="list-style-type: none"> • Healthy Communities • Building Community Capacity • Building Social Capital • Valuing Diversity (Equity, access, etc.) 	<p>↔</p>	<p>2. Purpose of Project</p> <ul style="list-style-type: none"> • To develop individual, family and community's capacity to understand, acknowledge and address the challenges associated with Hep C Issues in the Punjabi community.
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<p>3. Project objectives</p> <ul style="list-style-type: none"> • To identify the challenges associated with Hep C in the Punjabi community. <ul style="list-style-type: none"> • To build linkages with internal and external stakeholders to identify, acknowledge and address the issues of Hep C. • To identify how the complex problems of Hep C can be dealt within the Punjabi community at the individual, familial and community level.



<p>4. Approaches to developing asset inventory</p> <ul style="list-style-type: none"> • Link the collection of data on Hep C issues and Aspirations identified by the respondents. (This gives the Research personal and social meaning for the community). • Do an analysis of the implications of the research for program planning, activities etc. <ul style="list-style-type: none"> • Identify how community can participate in the program planning and delivery of services. 	<p>5. Research questions</p> <ol style="list-style-type: none"> a. How is Hep C defined in the Punjabi community? b. What are the challenges and complexities of Hep C in the community? c. How do respondents think these concerns should be addressed? d. How would respondents like to contribute to addressing these concerns? e. Which health promotion strategies will be effective in the Punjabi community? 	<p>6. Research Methodology</p> <p>A. Data Collection*</p> <ol style="list-style-type: none"> (i) Qualitative research <ul style="list-style-type: none"> • 5 Focus groups (iii) Literature review <ul style="list-style-type: none"> • From previous survey/reports / internet <p>B. Data Analysis</p> <p>C. Report Writing (Formal)</p> <ul style="list-style-type: none"> • Report for the Punjabi Community Health Centre • Presentation package on findings & recommendations • Summary of findings & recommendations for distribution to the community • Community forum to release findings • Publish findings in academic journals
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* Data collection methods will be discussed in detail at the meeting.

Participatory Action Research (PAR)

Participatory Action Research¹¹ engages practitioners, researchers and citizens in a collaborative process to meet the specific needs of the community (Israel *et al.*, 1994). Participatory research¹² originated from community development and determines the process whereby people are engaged in creating knowledge for themselves and they in turn take actions on the findings (The Royal Society of Canada, 1995).

In the less developed countries, PAR was used as a method to engage the masses in community development work (Brown and tendon, 1983). The following characteristics form the basis of PAR (adapted from Israel *et al.*, 1994 & The Royal Society of Canada, 1995):

- The issues are identified by the citizens and not by the health care professionals.
- The collaborative process forces cooperation and collaboration between practitioners (community developers), researchers and citizens.
- Citizens have wisdom¹³ (A Community Development Strategy for the Health Department, Region of Peel, 1989) to understand and assess their needs which can be incorporated by researchers in order to obtain valid and reliable results.
- This process ensures that citizens have control over the final outcome of the study. The decisions regarding research are made collectively by the research team which has representation from the citizens. Through this process the citizens do get empowered and develop leadership in order to take actions on identified needs.

The process used in this research report has already generated interest amongst seniors to address the identified needs. They have organized themselves into a seniors group. They have named their group as SAHARA¹⁴ Seniors Group. They are meeting on a weekly basis and are working on a wall hanging¹⁵ that would depict various forms of senior abuse.

¹¹ Israel, B.A., Checkoway, B., Schulz, A. & Zimmerman, M. (1994). Health education and community empowerment: Conceptualizing and measuring perceptions of individual, organizational, and community control. *Health Education Quarterly*, 21(2), 149-170.

¹² The Royal Society of Canada (1995). *Study of Participatory research in Health Promotion*, University of British Columbia, Institute of Health Promotion Research.

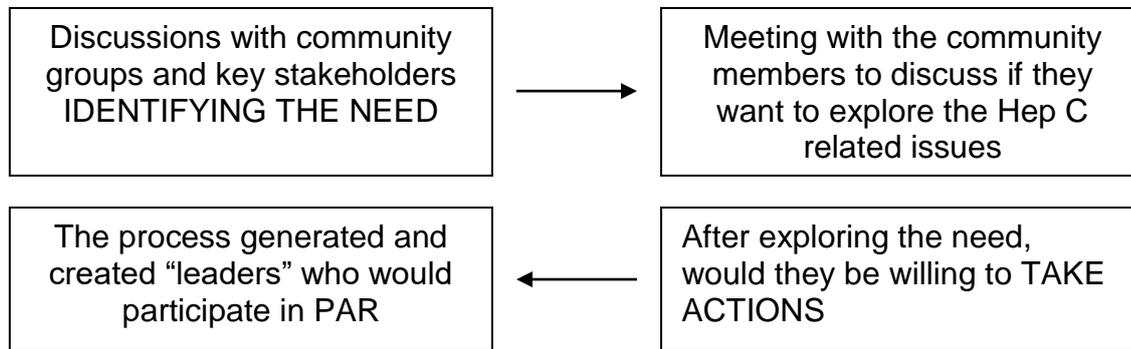
¹³ Commissioner and Medical Officer of Health, *A Community Development Strategy for the Health Department, Region of Peel*, January 1989

¹⁴ SAHARA in Punjabi language means “ to support”.

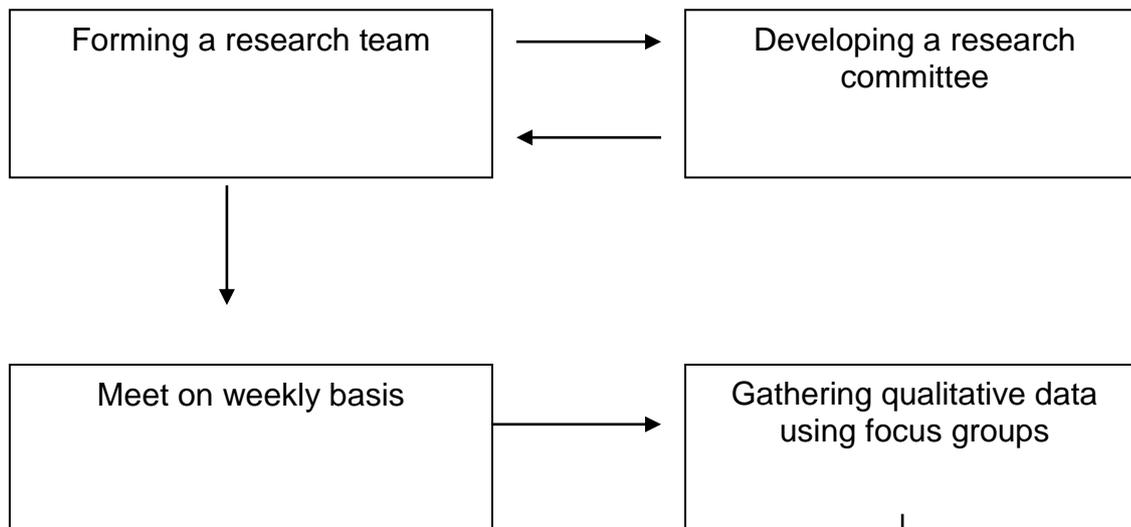
¹⁵ Wall Hanging is an arts and crafts activity that the SAHARA Senior’s Group is undertaking which will be displayed at the PCHC’s office to raise awareness of senior abuse within the community.

The process could be summarized as follows:

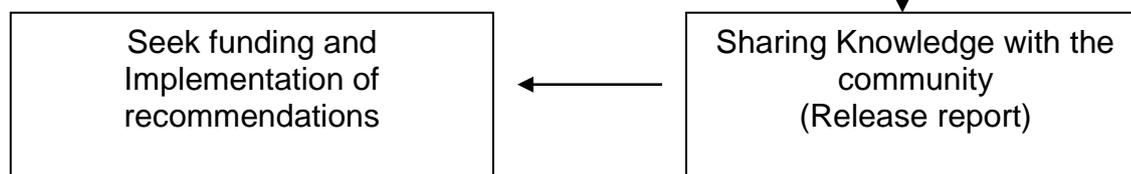
Pre-Research Work:



Research Work:



Post Research Work:



Focus Group Questions

- 1. When you hear Hep C or hepatitis C, what comes to your mind?**
- 2. Have you heard about this word or illness in India, Pakistan or back home?**
- 3. Is this a problem within the Punjabi Community in Canada?**
- 4. Just to check the perception or awareness of the participants a questions was asked “Have you heard about HIV/AIDS?”**
- 5. Is this a problem for community back home?**
- 6. Who gets infected by Hep C?**
- 7. How do people get infected with Hep C?**
- 8. How do people protect themselves from getting Hep C?**
- 9. Do you feel that you are able to talk to a health care provider (doctor, social workers etc.) about Hep C?**
- 10. What problems would a person face if he/she suffered from Hep C?**
- 11. What can be done to assist/provide treatment to that person?**
- 12. What contributes to stigma, myths, social taboos surrounding Hep C in the Punjabi community?**
- 13. Are you aware of any human care professionals or organizations within the Punjabi community in the Region of Peel who is providing services to the people infected and affected by Hep C?**
- 14. There are two types of community based agencies which provide two types of services. One, is called culturally sensitive services and the other is called culturally appropriate services. (The difference¹⁶ between these two types of service delivery was explained to them). Which one would you prefer?**
- 15. This could be a deadly disease, in your opinion, what would be effective ways to do outreach?**
- 16. What is the best way to de-stigmatize Hep C within the Punjabi community?**
- 17. What would you like to see PCHC do to address this issue?**
- 18. Would you like to share any other suggestion related to the Hep C topic?**

¹⁶ The difference between these two types of service delivery is as follows:

- Within culturally appropriate work, clients have a world view and professionals need to adjust their philosophy, way of work and service delivery to suit their clients' needs.
- Within culturally sensitive work, clients adjust their worldview and help seeking behaviours to suit the service delivery arrangements and intervention modalities of the professionals.

**Building Social Capital in the Punjabi Community
HIV/AIDS Research Project**

CONSENT FORM

Greetings and Welcome!

The Punjabi community Health Centre is a non-profit community based social service organization whose main mission is to deliver culturally appropriate social work intervention in the Punjabi community. PCHC strongly believes in partnerships with other mainstream and ethno-specific organizations. PCHC has partnerships with Victim Services of Peel, Coalition of Agencies Serving South Asians, COSTI, Women Abuse Council of Metro Toronto, William Osler Hospital, Can-Sikh Cultural Centre, and Sikh Heritage Centre.

Punjabi Community Health Centre also runs the following Core Programs:

- SAHARA Men's group is operated from two locations (Brampton and Mississauga). This is a culturally appropriate group program designed to meet the needs of Punjabi men in the areas of addiction and anger management.
- SAHARA Women's group is operated from Brampton. This is a culturally appropriate group program designed to meet the needs of Punjabi women. The group program deals with the after care needs of abused women and children.
- SAHARA Senior's group addresses the needs of the seniors and currently operates on one day per week basis.
- Parenting sessions are organized in collaboration with the Mississauga Gurdwara, Peel District School Board and other religious institutions.
- PCHC provides individual, family, couples, and group counselling programs.
- PCHC provides foodbank which addresses the needs of the abused women. Our volunteers drop off the food to the abused women.

Punjabi Community Health Centre has received four years funding from the Ontario Trillium Foundation to Build Social Capital in the Punjabi Community. One of the objectives of this four-year project is to undertake research in the Punjabi community to explore the challenges associated with Sexual Abuse of Punjabi women. After the conclusion of the research phase, the project will continue to work with the community to address the identified challenges.

The research team is seeking your cooperation to participate in the focus groups and to complete individual questionnaires. Your knowledge, expertise, and beliefs will help us in identifying the challenges associated with HIV/AIDS related issues within the Punjabi community. Your participation in the focus groups will require a commitment of two hours. However, the individual questionnaires could be filled within one hour. If you need more information on any of the questions, please do not hesitate to ask me.

YOUR NAME WILL NOT APPEAR IN THE FINAL REPORT. INFORMATION PROVIDED BY YOU WILL BE KEPT CONFIDENTIAL. YOU DO NOT HAVE TO PROVIDE ANSWER TO ANY QUESTION YOU ARE UNCOMFORTABLE ANSWERING.

Thank you for completing this questionnaire. The Punjabi Community Health Centre will release its findings to the community by organizing a public forum. All participants are welcome to attend the community forum. Thank you!

Building Social Capital in the Punjabi Community

HIV/AIDS Research Project

CONTACT INFORMATION

Please contact any of the following persons if you have any questions about the project, the survey questionnaire, the interviews conducted, etc.

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WWW.pchealthcentre.com

PREVENTING HEP C IN THE PUNJABI COMMUNITY

HEP C RESEARCH PROJECT

STATEMENT TO TREAT INFORMATION COLLECTED FROM PARTICIPANTS

AS CONFIDENTIAL INFORMATION

Name of Interviewer: _____

The interviewer understands and promises to abide by the following terms and conditions:

1. The interviewer will not personally use or disclose the information collected from the persons interviewed to anyone.
2. The interviewer will keep the questionnaires completed in a physically secure location and give them to the Coordinator of the Punjabi Community Health Centre as directed during the training session for interviewers.
2. The interviewer will return all completed and non-completed survey questionnaires to the Coordinator of the Punjabi Community Health Centre at the end of the interviewing period.
3. The interviewer will not contact any individual to whom the personal information collected, relates, directly or indirectly, without the prior written consent of the person who provided the information and the Coordinator of the Punjabi Community Health Centre.
4. The Coordinator of the Punjabi Community Health Centre will ensure that no personal information provided by the persons interviewed will be used or disclosed in a form in which the individual to whom it relates can be identified, without the prior written consent of the said individual and the Coordinator of the Punjabi Community Health Centre.

Signature of Interviewer: _____

Date:

Signature of the Coordinator : _____

Date:

Punjabi Community Health Centre