Perceptions and attitudes on hepatitis C in Ürümqi, China

Degree project in Medicine

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Abbreviations

HCV	Hepatitis C virus
CHC	Chronic hepatitis C
IDU	Intravenous drug user
FAH XMU	First Affiliated Hospital Xinjiang Medical University
ID	Infectious Department
DAA	Direct acting antivirals
WHO	World Health Organisation
HCC	Hepatocellular Carcinoma
HIV	Human immunodeficiency virus
HBV	Hepatitis B virus
SPSS	Statistical package for the social sciences

Abstract

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Perception and attitudes on hepatitis C in China

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Background

Hepatitis C (HCV) is the fourth most common infectious disease and a major public health issue, estimated to affect 13-25 million people in China. To improve the situation, it has been suggested that overall knowledge and awareness about HCV needs to increase, although little is known about perception and attitudes on HCV in China.

Aim

This study intended to evaluate perception and attitudes on hepatitis C, to deepen the understanding of factors that influence HCV management in Ürümqi, China.

Method

A total of 120 questionnaires and 8 interviews were conducted at the Department of Infectious Diseases at First Affiliated Hospital, Xinjiang Medical University, Ürümqi, China between 20160301- 20160415. Questionnaires were distributed to patients and interviews were conducted with HCV-patients, nurses and physicians at the study location.

Results

70.3% of the respondents indicated knowledge on that HCV is a blood borne disease, 88.3% that it affects the liver, 45.4% that HCV infection can be asymptomatic and 64.4% that the infection can lead to cancer. 33,9% felt that people with HCV diagnosis are discriminated. Interviews exampled ways HCV infected experience discrimination and misconceptions about HCV.

Conclusion

Despite many of the respondents were knowledgeable about the true nature of HCV, this study found that there are misperceptions regarding transmission routes and course of infection. These misperceptions affect a sound awareness about HCV and attitudes towards people living with HCV. Apart from maintaining discrimination, impairing quality of life for those living with the infection, it may also affect care seeking behaviour keeping people from getting tested and discover the disease at an early stage- issues that needs to be addressed in order to achieve a successful management of HCV in China.

Keywords

Hepatitis C, Perception, Attitudes, Discrimination

Background

Hepatitis C (HCV) is a blood borne pathogen, transmitting after exposure of infected blood. The most common transmission routes are syringe sharing among intravenous drug users (IDU) and medical procedures- where re-use or use of not sufficiently sterilized medical equipment transmits the disease (1). Other sources of transmission, however less common, are unsafe sex, vertical transmission, tattooing or needle stick injury among health care workers (1, 2). In resource high countries, where blood is screened for HCV and medical practice are safer, there is a low risk of iatrogenic spread of disease and IDU is the driving force behind HCV transmission. However, in resource limited countries it is more common with iatrogenic transmission in addition to transmission within the IDU community (1). Meaning that recipients of blood, blood products and patients in need of haemodialysis are at high risk of acquiring the disease (1, 2).

Once infected, the natural history of HCV infection is complex. It is estimated that about 15% of infected experience a symptomatic infection, showing signs of liver disease with fatigue, fever, nausea, pain and sometimes, but not always, showing typical signs of liver failure as jaundice or clay like stool (3). Many infected individuals remain however asymptomatic, showing no signs of disease. This occurs among as many as 85%, meaning that they remain unaware about their infection (3, 4). Estimations, and the numbers published by WHO, are that 15-45% of the HCV infected spontaneously clear the infection and 55-80% remain viremic after 6 months, the limit for chronic hepatitis C (CHC) (3-6). This is important, not only might the infected remain unaware about their disease, at risk of infecting others, but also that CHC leads to a slow but steady disease progress with 41% developing cirrhosis after 30 years (7).

This can lead to end stage liver failure and in some cases development of hepatocellular carcinoma (HCC) (6, 7). The progress of disease and level of liver damage is dependent on several factors, which some are able to modify and others not. Male sex, HCV genotype, duration and age when infected are examples of non-modifiable risk factors that are associated with higher level of disease progression. Other risk factors such as excessive drinking, smoking and co-infection with Hepatitis B or HIV are also contributors to disease progression, however able to act upon either with lifestyle choices or by health care measures (8).

There is no vaccine against HCV, but CHC is treatable and the landscape of treatment is currently changing. The old golden standard treatment consists of Pegylated-Interferon and Ribavirin. A treatment regime with long treatment time, 6-12 months, and complex due to both oral and injected administration. With this old regime cure-rates vary between 50-80% depending on HCV-genotype (9). In addition, this treatment has severe side-effects and keeps the individual undergoing treatment in an influenza-like state (10, 11). This regime is being phased out in many countries, replaced by the new generation of drugs called direct acting antiviral (DAA). These drugs treat CHC with higher efficacy, having less side-effects, easier administration and shorter time of treatment (11). However, they are much more expensive and not available in all countries, even though efforts have been made to increase access to these new treatment regimes (12).

Current estimates claim that 184 million people across the globe are anti-HCV positive, a world prevalence rate of 2.8% (13). This meaning, they either have a present infection or have had the infection in the past, now cleared. In comparison, the estimated corresponding numbers in 1990 were 122 million and 2.3%, respectively, indicating an emerging infectious disease of importance (13). The disease burden of HCV is highest in low- or middle-income countries and two of the regions with the highest prevalence rates are Central- and East-Asia (13). It is estimated that HCV contributes to 27% of all cirrhosis and 25% of all HCC worldwide, being the cause of 211.000 cirrhosis associated- and 155.000 HCC associated-deaths annually (14). In 2014 the World Health organization (WHO) published guidelines for policy-makers, government officials and health care workers to be a support on decision making in low- and middle-income countries on how to manage treatment and prevention of HCV. In these guidelines WHO states that, among other actions, access to screening, reliable testing, assessment for risk behaviour and access to treatment are the most important factors for successful HCV-management (5). Resource limited countries struggle however to cope with HCV. WHO acknowledges this and conclude that treatment associated side-effects, the need of advanced testing and costs remain barriers to manage the issue of HCV in these countries (5, 15). Experts claim that the overall knowledge and awareness about HCV is low throughout the world, ultimately leading to continued transmission of HCV and patients remaining unaware of being infected (15-17).

Hepatitis C in China

HCV is the fourth most common infectious disease and a major public health issue in China (18). It is estimated that the current prevalence is 1-1.9%, but these numbers are uncertain and there are substantial regional differences in prevalence (19, 20). To put this uncertainty in context, the overall prevalence was estimated to 3.2% in 1992 and in 0.4% in 2006, numbers however disputed because of the sampling strategies used in these studies (18, 21). But, it is believed that China has experienced a true decline in prevalence, a decline attributed to safer medical practice, screening of blood products, banishing of paid blood donors and better access to testing and treatment for HCV infected (21, 22). Even though this trend is positive-it should be remembered that due to Chinas large population, a prevalence of 1-1.9% means that 13-25 million people are anti-HCV positive (22). It should also be noted, regarding transmission routes and prevalence, that China is currently facing a situation where medical practice has become more safe and IDU has become the driving force behind HCV transmission (23). The use of drugs has increased since 1990, and in 2005 there were 1,16 million registered drug users, a number that in reality could be higher (23). In the group of IDUs, it has been reported that the HCV-prevalence could be as high as 61%, and Xinjiang, a node for drug trafficking, is considered to be a high-prevalence region (23, 24).

Today, there are still many HCV-infected in China that remain undiagnosed and fail to complete treatment, even though efforts have been made (18, 22, 25). This situation is although not unique for China. From a world perspective it has been reported that as many as 50-75% of HCV-infected remain unaware about their infection and when diagnosed they fear treatment related side-effects, economical and social hardships as a result of HCV infection (26, 27). These are examples of barriers to care, issues that can be improved with education and higher knowledge when health care keeps patients and public informed (28, 29). As a result of the infection, HCV infected may also encounter discrimination, stigmatisation and social vulnerability, both in health care and society (30, 31). This may not only affect treatment and care seeking behaviour, but also how HCV infected is viewed upon, affecting them on a personal level (28).

The view among Australian women living with HCV is that this situation of discrimination and stigmatisation is due to low knowledge about the true nature of HCV among non-infected (32). It should be remembered that knowledge is one of the factors that influences attitudes and perceptions of a disease (28, 31). Sadly, it has been reported that maybe as low as 1% of the Chinese population have some kind of knowledge about HCV, especially in rural areas (21, 22, 33). Further, it has also been reported that Chinese non-hepatitis specialist have little knowledge about HCV, a threat for early detection, care and treatment of HCV-patients (34).

The issue of public and health care knowledge about HCV was addressed by Duan et al in a review article from 2014. Duan et al states that China should, to lower its HCV disease burden, strive to meet earlier diagnosis with screening risk populations, exchange current treatment regimes to DAA and raise public and health care awareness about hepatitis C virus infection (22). To understand the circumstances and the Chinese prerequisites under which these changes are to be made, it should be remembered that the Chinese health care struggles with health inequities, trust issues and a failing medical insurance system (35). And, even though China reported to WHO in 2013 that development of guidelines and actions to act on the issue of HCV was undertaken, it has been indicated that there are differences between guidelines and the real-life clinical care of HCV-infected (25, 36).

The field of research regarding perception and attitudes towards hepatitis C in a Chinese general population is scarce. Since these factors influence the management of HCV, the objective of this study was to investigate and hopefully display a wide extent of perceptions and attitudes associated with hepatitis C.

Ürümqi, Xinjiang and study setting

Ürümqi is situated in the absolute North West of China and is the regional capital of Xinjiang Uyghur Autonomous Region. By 2010 it was estimated to have approximately 3 million inhabitants (37). Ürümqi is home to Uyghurs, one of Chinas acknowledged minority groups, but the majority of the city’s population is Han-Chinese. It is an important economical and industrial node of Western China inland. This study was conducted at The First Affiliated Hospital of Xinjiang Medical University, which serves a great number of patients being the largest hospital in the region. The department of infectious disease had 64635 patient visits during 2015 and has 1399 patients registered with HCV-diagnosis.

Purpose and Aim

To evaluate perceptions and attitudes regarding hepatitis C among both hepatitis C infected and non-infected patients in Ürümqi, China.

Scientific issues

- To evaluate perceptions of HCV disease, -transmission and -prevention.
- To investigate perceptions on accessibility to testing and treatment of HCV.
- To investigate attitudes towards HCV infected, regarding discrimination by either health care or society.

Method

This explorative study, including a questionnaire based survey and complementary interviews, was conducted at Department of Infectious Diseases (ID), First Affiliated Hospital (FAH), Xinjiang Medical University (XMU) in Ürümqi, China between 20160301 to 20160415.

Method considerations

Before the study was conducted, it was assessed that a mixed methodology was the best way of answering the scientific purpose given the prerequisites with short time period for data collection and none of the researchers speaking Chinese. Using questionnaires and interviews was assessed to generate both quantitative and nuanced data, possibly generating hypotheses in this field of research.

After searching the existing literature, looking for similar studies with published or validated questionnaires, no questionnaire was found that suited this study. Therefore, a questionnaire was developed and designed, aiming to in greatest possible extent answer the scientific purpose. The final questionnaire was intended to be kept short, to maximise participation. A questionnaire design with a majority of closed end, one answer alternative questions were chosen. This design generates comparable data, enables questionnaire interpretation without re-translation and makes the questionnaire easy to complete.

The interview must be constructed in a manner that allows the participant to speak freely about the subject, still keeping the subject in mind. Therefore, a semi-structured model of interviewing was chosen.

Participants and study population

All patients over 18 years of age, reading or speaking Chinese, seeking care or being admitted to ID XMU FAH were regarded eligible for the questionnaire part of the study. This group consists of both individuals with and without HCV, with their perception and attitudes on HCV respectively. From this cohort a convenience sample was taken. Participants were chosen as randomly as possible but without formal randomization. Declination was planned to be recorded by the persons distributing the questionnaire. The aim was to include 90 HCV-infected or a total of 120 respondents- consisting of both HCV-infected and non-infected. These numbers were estimated, based on previous similar explorative studies to yield interesting results and generate stringent hypothesis that could be explored in future studies. The calculations were made in collaboration with my supervisor and a statistician.

The interviews were conducted on 2-3 patients, physicians and nurses, to represent a broad spectrum of views on HCV. Patients were recruited from the same cohort that was eligible for questionnaires, adding the inclusion criteria of participant having HCV and currently being admitted to the in-patient ID. All of the physicians and nurses currently working at the ID were regarded as eligible for interviews, this being the inclusion criteria. All participants were recruited through a physician working in ID and regarded as convenience samples. Declination was recorded by the physician recruiting individuals for the interview.

Questionnaire

The purpose of this questionnaire was to be an instrument to assess the respondents' perceptions on HCV as a disease, their attitudes on HCV-management and if they believe HCV-infected experience discrimination by any means. The questionnaire was developed by reviewing previously published questionnaires and British Medical Journals guidelines for developing questionnaires and existing literature (38). The final questionnaire consisted of 12 questions regarding HCV and 5 demographical questions. On questions regarding HCV, the optional answer of "don't know" or "other" was added to minimize bias of participants guessing. To let the respondent answer more freely about the subject, a partial open end answer on question number 5 was kept. The demographical questions number 14 and 17 were also open ended, since this suits the nature of these questions. The complete questionnaire can be reviewed in appendix 1.

Regarding validity, the questionnaire was reviewed by two independent statisticians and two pilot studies were conducted, on both a Swedish and Chinese population. This resulted in small corrections regarding syntax and order of questions. To suit the study setting, the questionnaire was also reviewed by Professor Zheng, associated to the ID XMU FAH. This review resulted in exclusion of a five grade likert scale on attitude questions and adding of question 5 regarding symptoms of HCV-disease and 17 regarding occupation of the participant. One question regarding if the respondent have HBV was also added, although disappeared in translation. The final questionnaire was translated to Chinese, the official language of the hospital, by the Chinese supervisor associated to this study, and re-translated to English by a non-professional translator. After distribution it was realised that the Chinese characters for hepatitis C are translated to "the third virus liver inflammation". Even though this affects interpretation of the data, the original form was kept, since this issue did not appear until a substantial amount of questionnaires had been distributed.

Data Collection

A cover letter was developed to introduce, retrieve informed consent and information on how to complete the questionnaire. This letter of introduction was however not used since, in China, this information is traditionally given orally by the person handing out the questionnaire. All questionnaires were given an individual number and were handed out by a physician or a nurse to patients they judged fulfil our inclusion criteria, which took between 1 and 21 days. The respondents' answers were not planned to be validated in any way. Patients were approached, given a short introduction and then filled out the questionnaires with no assistance. If the participant had trouble reading, the questionnaire was completed orally, assisted by the person distributing the questionnaire. After the questionnaire was completed, the participant handed in the questionnaire to the health care staff who had distributed it. The questionnaires were then retrieved, either later that same day or several days later. Distribution can be reviewed in table 1.

Table 1: Displaying distribution of questionnaires, which department, date distributed, how many that responded and how many questionnaires that were lost.

Department	Date distributed	Distributed	Respondents	Lost
Inpatient dpt*	160310-160311	24	17	1
Inpatient dpt*	160314-160318	32	18	11
Outpatient dpt*	160322-160412	50	24	1
Inpatient dpt*	160406-160406	51	34	17
Inpatient dpt*	160413-160414	27	27	0
			Total: 120	Total: 30

* Dpt = department

Questionnaire data input

A questionnaire input sheet was constructed in Software Package of Social Sciences (SPSS) and participants' answers were filled in this sheet. On all questions the absence of an answer or unable to understand the respondents answer was marked in SPSS as missing. Regarding questions 1-9, aiming to measure the respondents' perception of HCV, each correct answer was given one point and failing to do so, or leaving the question unanswered, gave zero points. If an answer consisted of conflicting data, for instance given 2 or more answers, it was regarded as don't know. On questions 1-9 the total score of correct answers was calculated manually and then added to SPSS, maximum score being 15. Since this study did not aim to evaluate if the respondents has sufficient knowledge about HCV or not, a total score that correlates to this was not decided. On question 5 and 17, were participants stated symptoms and occupation in Chinese, translation to English was conducted at with the assistance of a non-professional English speaking colleague associated to the hospital.

Interviews

The purpose of the interviews was to nuance and deepen the understanding of the perceptions and attitudes about HCV. After primary analysis of the questionnaire generated data, three main topics for the interview were decided and both open and focused questions were generated. Two interview sheets were developed, addressing health care professionals and patients respectively. The questions were kept simple and understandable since none of the participants were native English speakers. The questions can be viewed in appendix 2.

The interviews were conducted in a closed room or aside in the ID, using a voice memo for recording. Fredrik Askeroth and Jonas Eriksson conducted the interviews. The interviews were conducted in English and if the participant needed translation, the interview was interpreted by a non-professional English-speaking colleague associated with the hospital. Some of the patients asked to have their relative also attending the interview, this was accepted, although the relative was encouraged to not influence the participant. The time for interview was between 20-45 minutes. The interviews were transcribed to written English. Minor language errors were corrected as to make the transcript readable.

Data analysis

Questionnaire-based data were analysed and presented using descriptive statistics. Mann-Whitney U-test was used to analyse means between the groups and Chi-squared test to analyse possible differences in frequencies between the groups. To compare groups, a composite knowledge score was manually calculated and added to SPSS. This way of comparing groups has been used in prior studies (28). Data was analysed using the software SPSS, statistical package for the social sciences.

The transcript generated from interviews was interpreted by analysing the answers, trying to keep it to as few words as possible, without losing the participants view on the matter. Interview generated data were then processed by reading the transcript and important aspects were condensed into codes and then analysed.

Ethical considerations

No formal official ethical approval was judged to be needed by the Chinese supervisor since the research did not involve any data or methods requiring such. Although it was no formal ethical approval, the study was approved by the Xinjiang Medical University.

Questionnaires and interviews were anonymous and participation was voluntary. Participants were able to not complete the questionnaire or interview, leaving at any point without stating why. This information was given before the questionnaire or interview were conducted and was regarded as informed consent. No informed consent form was signed. All data was handled confidential and is anonymous.

The research in this study did not involve any of the methods or data that require an ethical approval according to Swedish legislation, although a Swedish ethics committee does not assess the need of an ethical approval when research is carried out in foreign countries.

Results

Questionnaire study population

In total, 120 patients agreed to participate in the questionnaire part of the study. The study sample was equally distributed regarding gender, but there was an overweight of participants between 18-29 (31.9%), college educated (57.1%) and not having HCV (80.5%). Among HCV infected, there were 13 males and 8 females, mean age was 40 and 56.5% had college education. Demographics are shown in table 2.

Table 2: Demographic presentation of questionnaire participants, displaying each group by quantity, age and percental distribution within the group (N=120)

		Age					
		Total N	Mean age	SD*	Median age	Missing	Total N%**
Gender	Male	64	41	15	40	4	54.7%
	Female	53	39	13	39	1	45.3%
Level of education	None	0	.	.	.	0	0.0%
	Elementary school	11	54	16	60	1	9.2%
	High school	40	44	14	46	3	33.6%
	College	68	36	12	32	2	57.1%
HCV Diagnosis	Yes	23	40	15	41	3	19.5%
	No	95	40	14	40	2	80.5%
	Don't know	0	.	.	.	0	0.0%

* SD = standard deviation, ** Percentages within group

Results introduction

The results are presented by each scientific issue with the most important findings displayed using charts. In total, frequency of correct answer differed between 88.3% and 45.4%. Mean percentage of correct answers regarding disease was 70.7% (median 70.1%), transmission routes 66.4% (median 70.3%) and prevention 66.7% (median 66.7%) (a summary of correct answers is presented in table 3). Number of participants who choose to not answer the question (missing) differed between 0 and 23 and questions regarding transmission routes (missing mean 11.2, median 13) and symptoms of HCV disease (missing mean 20.s 3, median 23) were associated with most missing values. All questionnaire related data is presented in its whole, with missing values per question, in appendix 3.

Table 3: displaying questions, correct answer option, number and percentages of respondents marking the correct answer. The table is coded with colour according to which scientific issue the question it belongs (legend in bottom of table)

Question		Correct option	Count	% of correct responses
Hepatitis C is a	🟥	Virus	94	78.3%
Hepatitis C transmits via	🟩	Blood	83	70.3%
Hepatitis C primarily affects	🟥	Liver	106	88.3%
A person with hepatitis C can share a towel	🟩	Yes	51	47.7%
A person with hepatitis C can share a razor	🟩	No	80	71.4%
A person with hepatitis C can share a syringe	🟩	No	80	70.2%
A person with hepatitis C can share a shower	🟩	Yes	74	71.2%
A person with hepatitis C can share a meal	🟩	Yes	72	67.3%
A person infected with hepatitis C can get yellow skin and eyes	🟥	Yes	68	70.1%
A person infected with hepatitis C does not always have symptoms	🟥	Yes	44	45.4%
A person infected with hepatitis C can experience fatigue	🟥	Yes	83	79.0%
Hepatitis C is diagnosed with a specific blood test	🟦	Yes	92	76.7%
Hepatitis C can cause cancer	🟥	Yes	76	64.4%
A person can die of hepatitis C	🟥	Yes	83	69.7%
Hepatitis C is treatable	🟦	Yes	68	56.7%

Association with scientific issue is marked by following color:
Questions regarding perception of HCV as a disease 🟥
Questions regarding perception of HCV transmission routes 🟩
Questions regarding perception of HCV prevention 🟦

Comparison of total correct answers

An overall mean score (MS) of correct answers was calculated and used to compare groups. From a maximum of 15, overall MS was 9.6 (SD 3.3). Females (MS 10.3) were significantly better compared to males (MS 9.1, $p<0.05$) although there was no difference between respondents having HCV (MS 9.7) and not having HCV (MS 9.6 $p>0.05$). Persons aged 18-29 (MS 11.4) scored significantly better compared to those aged 40-49 (MS 8.6, $p<0.001$), 50-59 (MS 8.8, $p<0.05$) and older than 60 (MS 7.2, $p<0.001$) but no significant difference was seen compared to those aged 30-39 (MS 10.7, $p>0.05$). College educated (MS 10.5) were significantly better than those with elementary school education (MS 6.2, $p<0.001$) and high school educated (MS 8.9, $p<0.05$).

Perceptions of HCV as a disease

Among all the participants, a knowledge that hepatitis C is a virus and that it affects the liver was indicated by 78.3% and 88.3% of respondents, respectively. That jaundice and fatigue are symptoms of HCV disease was recognised by 70.1% and 79.0% respectively. Regarding that HCV infection can be asymptomatic was correctly indicated by 45.4% of the respondents, being the lowest correct percentage of the questionnaire and associated with many of the respondents being uncertain of the answer as 21.6% answered don't know and 33.0% answered no (presented in figure 1). Concerning disease outcomes, 64.4% correctly marked that HCV-infection can lead to cancer and 69.7% of the respondents indicated knowledge that HCV-infection can be fatal. When comparing groups, females knew that infection can be asymptomatic to a significantly ($p<0.05$) greater extent then males and respondents with HCV knew that the infection can lead to cancer in significantly ($p<0.05$) greater extent than those not having HCV. No other significant difference was found ($p>0.05$) between males and females or between respondents having HCV compared to those not having HCV.

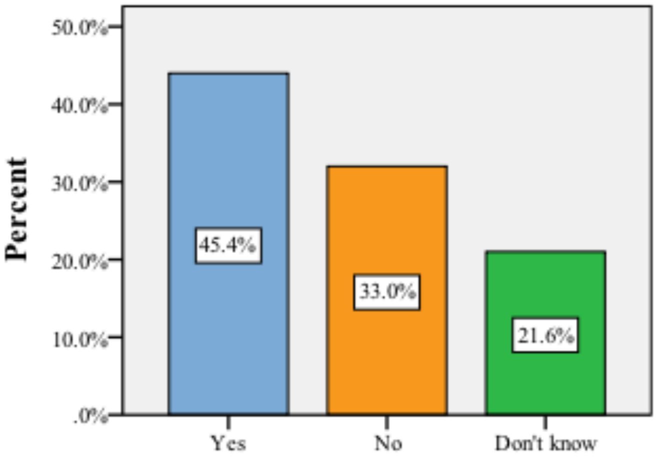

Figure 1: Percentages of how many of all respondents that considered infection with hepatitis C can be asymptomatic with the optional answers "yes" (Blue), "no" (orange) and "don't know" (green). Total amount of respondents: 97, missing 23.

Perceptions of HCV transmission routes

Among all of the respondents, 70.3% indicated correct knowledge about that HCV transmits via blood. A majority, 71.4%, indicated that HCV infected should not share a razor and 70.2% that HCV-infected should not share a syringe. 71.2% indicated that HCV infected can share a shower, 67.3% that they can share a meal and 47.7% stated correctly that HCV infected can share a towel. No significant difference was found (p>0.05) between males and females or between respondents having HCV compared to those not having HCV. Among respondents having HCV 42.9% indicated that people with HCV should not share towel, 14.3% that people with HCV should not share shower and 28.6% that people with HCV should not share meal (presented in figure 2).

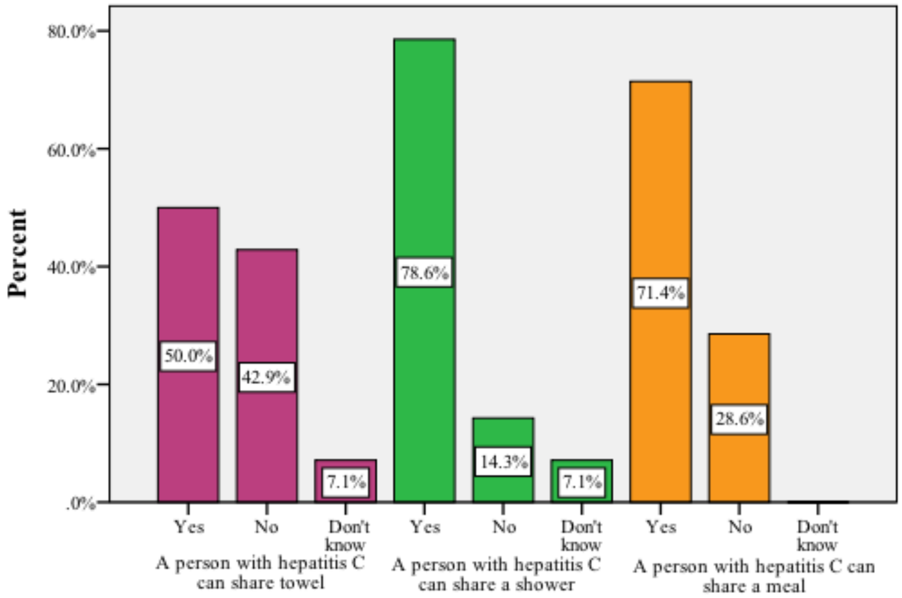

Figure 2: Distribution of answers among respondents with hepatitis C, regarding if a person with hepatitis C can share towel (purple), shower (green) or meal (orange). Total amount of respondents: 14, missing 9 (on all questions)

Perceptions of HCV prevention

Among the respondents, 76.7% indicated knowledge about that HCV is diagnosed with a specific blood test and 56.7% stated correctly that HCV infection is treatable. No significant difference was found ($p>0.05$) between males and females or between respondents having HCV compared to those not having HCV.

Attitudes on HCV management

A majority of all the respondents, 79.8%, considered that people who wants to test for HCV can do so and 76.5% believed that HCV-infected receives the correct treatment. Among respondents with HCV, the majority (82.6%) felt that people who wants to test for HCV can do so but, there was a significant amount ($p<0.05$) that stated no (17.4%) compared to the group of persons not having HCV where 78,9% stated yes, 4.2% no and 16.8% don't know (presented in figure 3). There was no significant ($p>0.05$) difference between the males and females.

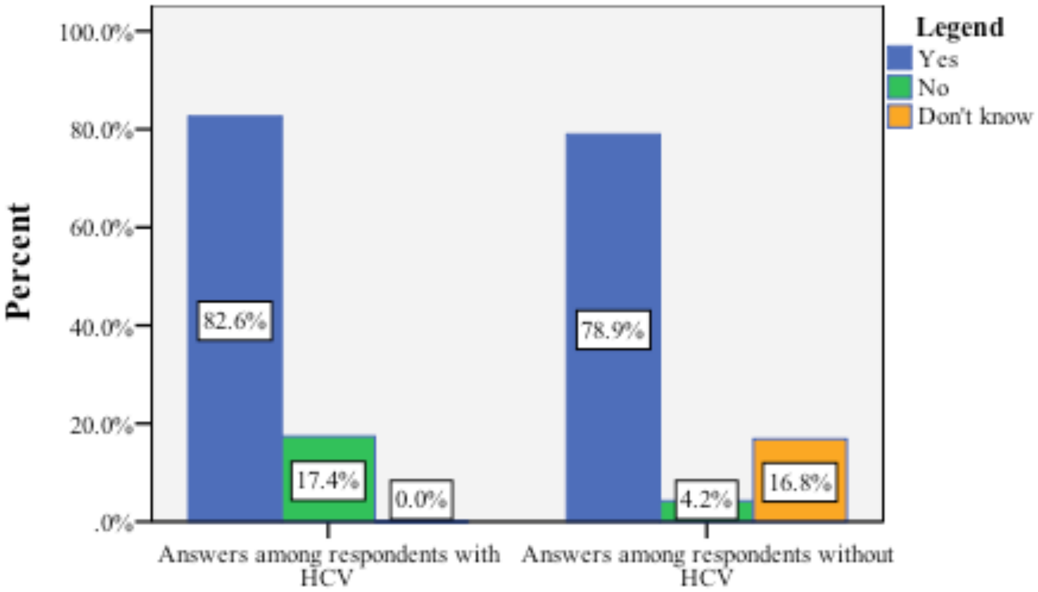

Figure: 1 Distribution of answers regarding if a person who wants to test for hepatitis C can do so, comparing answers between respondents with and without hepatitis C. Total amount of respondents with HCV: 23, missing 0. Total amount of respondents not having HCV 96, missing 1.

Attitudes on discrimination of HCV-infected

HCV-infected were believed to experience discrimination from health care by 10,1% of the respondents and the corresponding number for societal discrimination was 33.9% (displayed in figure 4). There was a significantly higher proportion of those with HCV ($p<0.05$) that considered that HCV-infected are discriminated by health care, but no significant difference was found either between males and females or between people with or without HCV diagnosis regarding societal discrimination.

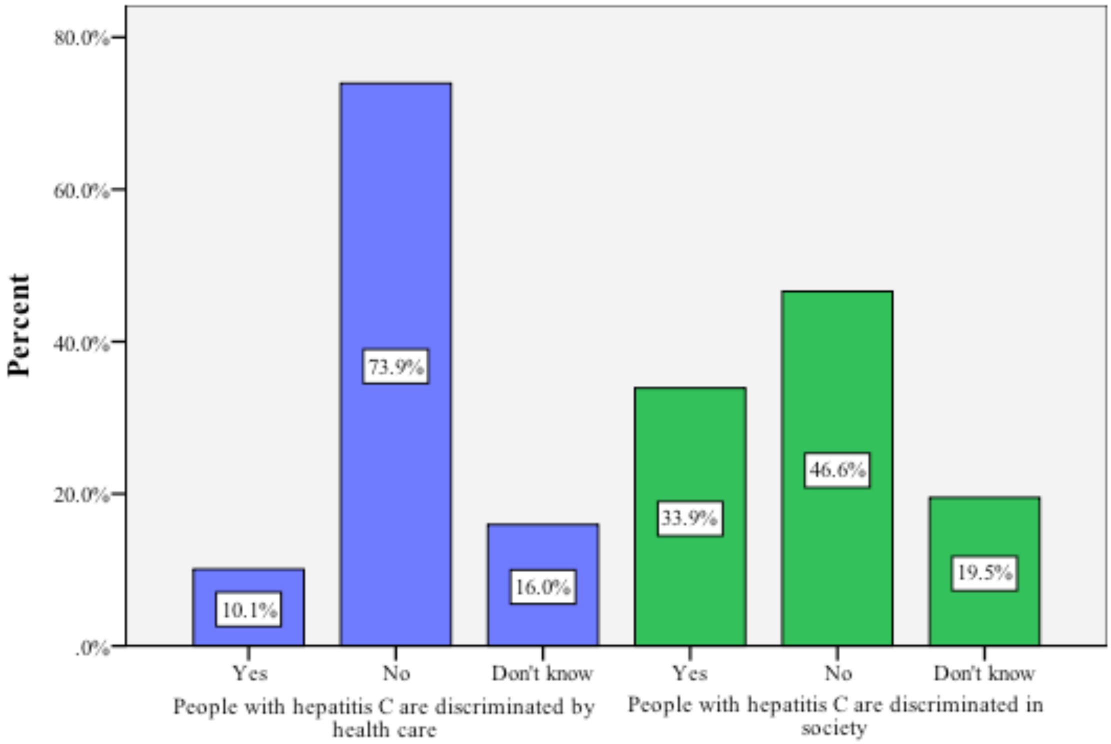

Figure: 2 Distribution of answers regarding if respondents considered that people with hepatitis C experience discrimination in either health care (blue) or society (green). Total amount of respondents: 119, missing 1 (both questions).

Interviews

The interview part of the study was conducted on 8 persons consisting of 3 physicians, 2 nurses and 3 patients. The physicians were 35, 40 and 58 years of age and had been working as physician for 10, 16 and 35 years respectively. The nurses were 33 and 43, working as nurse for 13 and 19 years respectively. One of the patients was 45 and the other two were 66, diagnosed with HCV for 2, 13 and 14 years respectively.

Perceptions on hepatitis C

Seven of the eight interviewed (87.5%) expressed in some way that there are issues regarding perceptions of HCV, associated either with low knowledge, among health care professionals or in the general population, or the perception that HCV infection is not a severe disease.

> *"Most people think it is like having a cold, my friend told me that it is a minor disease and that I should not care about it."*
>
> Patient, 45

> *"People do not know about HCV, even physicians not working with infectious diseases do not pay attention to HCV … Some people believe it transmits by speaking and body contact."*
>
> Physician , 58

HCV management

All of the interviewed nurses and physicians stated in some way that there are issues regarding HCV management. They considered that knowledge and awareness needs to be improved in both health care, among those not working with hepatitis C, and the general population.

> *"There are a lot of patients who don't know that they have HCV"*
>
> Physician, 58

> *"Physicians working in other departments know too little about HCV, there is a need to improve the management of HCV on all levels"*
>
> Physician, 40

Discrimination of HCV-infected

Seven of eight interviewed (87.5%) expressed that people with HCV diagnosis experience discrimination in various extent. The exception being one interviewed patient who expressed that having HCV does not affect the daily life and had no experience of discrimination. One interviewed physician estimated that 30% of the HCV infected experience discrimination. The interviewed mentioned issues regarding that it is hard for people with HCV-diagnosis to be open about it and that other people are afraid to touch or meet them.

> *"People think that HCV infected should be kept away, only a few think it is ok. People who have HIV, can maybe tell, but not as many with HCV. People with HCV only tell persons close to them, so they can have a normal life."*
>
> - Nurse, 43

> *"Me, working as a physician, experience discrimination, people are afraid of me, working at the infectious department. It is really hard to change."*
>
> - Physician, 35

> *"In China, because 20 years ago, China was a developing country and a poor country. So especially in Xinjiang there were often outbreaks of infectious diseases. Now China is richer than 20 years ago but the feeling is that, the mentality has not changed regarding infectious diseases. I think this is some of the discrimination. But now it is changing, but I think it is changing very slowly. Since the recent development of treatment, I hope that people stop fearing HCV."*
>
> - Physician, 58

“*I don’t think anyone with HCV tell other people about it … My old friends do not meet me as often anymore, they do not want to eat with me, they’re afraid of the HCV that I have.”*

- Patient, 66

“A lot of people hate people with HCV. I am depressed and feel so much pain, both physical and mental. People say “you have HCV, I do not want to be near you”, although I think that it is a minority who thinks like this. People who have no knowledge discriminate people with HCV.”

- Patient, 66

Discussion

The findings in this study suggest that the majority, about two thirds, of the respondents had a correct perception of the core characteristics about HCV, knowing it is a viral, blood borne disease that affects the liver and that can be detected by a specific blood test. The overall findings of 50-90% correct answer rate are in line with previous studies (27, 28, 33). Level of education, being female and between 18-29 years of age were associated with a higher indicated composite knowledge, differing from a previous partly Chinese study were only length of education were associated with a higher test score (33). This study found no difference in composite knowledge between responders having HCV compared to those who have not. Regardless was this stand for, it could be argued that a person having a disease should be more educated compared to those who have not, especially since patient education have been shown to improve treatment rates and patient attitude towards treatment (29). It is hard to determine whether or not this is representative for a bigger population, but underlines the need for further research to decrease transmission of disease.

Despite that many of the respondents displayed knowledge on transmission routes, 20-25% of the respondents indicated that there is no harm in sharing razor or needle with a person who has HCV infection, putting them at risk for acquiring the infection. In addition, several of the HCV-infected did not indicate knowledge of the true transmission routes of infection, putting them in situations where they might experience internal shame or insecurity, which have been shown in prior studies (30). A limited knowledge on transmission routes among the infected and in the general population could contribute to discrimination of HCV infected (32). This discrimination is further exampled by the views expressed during interviews were physicians and patients stated that people believing it can be transmitted by skin contact or by sharing meal and thus leading to avoidance of normal social contact (30, 32).

The questionnaire data in this study indicate that, one third of the respondents (33.9%) felt that HCV infected experience discrimination. The impact of discrimination on quality on daily life for people living with HCV was further stressed by the interview participants, confirming findings in prior studies (30, 31). The discrimination of HCV infected has in previous studies been shown to range from social situations, work relations and even health care, hence affecting the infected on a several levels (30-32, 39).

Discrimination of HCV infected could also negatively affect care seeking behaviour, both among people with HCV and those suspecting that they have HCV, hence avoiding being tested (31, 39). Although the majority of the responders (79.8%) in this study indicated that access to testing is sufficient, there was a significant amount of persons having HCV (17.4%) indicating that not everyone can test for HCV, wishing to do so. What this stands for is hard to discuss, but studies have reported that HCV infected experience stigmatisation when seeking care (31, 32).

Hepatitis C infection is commonly asymptomatic with only half of the infected being aware of having HCV (27). The data in this study suggests that 45.4% of the responders had knowledge on that HCV-infection can be asymptomatic, being the lowest percentage of correct answers in this study. Since the asymptomatic nature of HCV keeps many unaware about their infection, an issue that have been called the greatest barrier for treatment of hepatitis C (by McGowan et al in 2012), it could be argued that this question should have the highest percentage of correct answers (26). This being a bold statement, but a successful management of hepatitis C is founded on access to testing and treatment (5, 15, 40).

Ideas for future studies

The findings in this study suggest that future studies are needed, to both deepen and broaden the understanding of the subject. A broad, more controlled survey matching participants both having and not having HCV could possibly demonstrate correlations with knowledge and attitudes towards people having HCV, displaying the findings in this study but more nuanced. A study with this design could possibly test the hypothesis that knowledge of, for example, transmission routes is a factor influencing discrimination. To fully succeed with such study, a complementary qualitative study trying to address the when, why and how persons with HCV experience discrimination in a Chinese society, would be of benefit as it would generate more precise questions from a Chinese perspective.

Limitations

We experienced translational and language barriers throughout the whole study. Since we are not speaking Chinese, we did not have the possibility to always communicate instructions regarding sample, distribution and completion of questionnaires and interviews, why some issues regarding reliability occur. We did also realise that Hepatitis C translates to "the third liver inflammation" in Chinese characters, which gives away the answer on question 1 and 3, possibly affecting the rate of correct responses. Possible participants, who are illiterate, do not read Chinese and because of study location do not visit the hospital, were further excluded from participation, which might have affected the results. Although the aim was higher, not many participants having HCV were included, and the sample size needs to be regarded when interpreting the results. By constructing our own questionnaire, the possibility to extrapolate and interpret our result, putting it in a broader context, is limited. Also, the scientific issue regarding attitudes to access to treatment were not evaluated as the question "*people with HCV gets correct treatment*" was considered not answering the question hence no conclusions was drawn. In conclusion, the findings must be regarded as uncertain and interpreted with care. But, the overall findings about HCV perception are in line with previous studies and questionnaire data were validated by interviews, possibly strengthening the questionnaire data.

Conclusion

There is a need of improving knowledge and awareness about HCV in China (22). The findings in this study suggest that about two-thirds of the respondents have a correct perception HCV disease and transmission routes. But, unfortunately the study found a relatively low indicated knowledge about that HCV-infection can be asymptomatic and many respondents considered HCV infected as discriminated. These are issues of importance for China to manage and further research is needed to in a more controlled manner assess perceptions of HCV and fully understand the how, when and why people with HCV are discriminated in the Chinese society. This could present a broader base for intervention, possibly improving knowledge through patient and public education, hence improving the living conditions for people with hepatitis C and attitudes towards testing and treatment, having a sound awareness of hepatitis C.

Populärvetenskaplig sammanfattning på svenska

Uppskattningsvis är 184 miljoner människor i världen (2.8%) smittade med hepatit C virus och i Kina är motsvarande uppskattning 13-25 miljoner (1-1.9%). Hepatit C är ett virus som infekterar och bidrar till inflammation i levern. Viruset är blodburet, vilket betyder att den överförs efter exponering av infekterat blod. Överföring sker oftast efter att människor som injicerar droger delar sprutor eller på grund av osäkra metoder inom sjukvården, vilket är associerat till sjukvård i resurssvaga länder där tillgången till säkra metoder kan vara begränsad.

Inflammationen leder till ärrbildning, nedsatt funktion av och kan också leda till cancer i levern. Hepatit C uppskattas ligga bakom en fjärdedel av världens dödsfall på grund av cirros (skrumplever) och levercellscancer. Utvecklingen av skadorna på levern tar ofta lång tid och få upplever symtom, vilket leder till att många infekterade inte söker vård.

Kunskap och medvetenheten om hepatit C är en central fråga för smittades tillgång till behandling och för minskad smittspridning. För att kunna förbättra kunskapen om hepatit C och påverka inställningen till smittade är de viktigt att utforska vilka uppfattningar och attityder som finns om hepatit C. Vår studie syftade till att utröna detta genom att använda enkäter patienter samt genomföra intervjuer med både patienter, sjuksköterskor och läkare, samtliga på en infektions avdelning i Ürümqi, Kina. Totalt delades 120 enkäter ut och 8 intervjuer genomfördes.

Drygt två tredjedelar av studiedeltagarna uppgav att de visste att hepatit C är en blodburen smitta som drabbar levern och kan leda till cancer. Knappt hälften svarade att de visste om att smittade kan vara fria från symtom. Ungefär en tredjedel ansåg att de med hepatit C blir diskriminerade i samhället, något som också uttrycktes under intervjuerna, där de intervjuade patienterna bland annat gav exempel på att före detta vänner tagit avstånd på grund av att de har sjukdomen. Under intervjuerna berättade även en läkare att det finns de som tror att hepatit C kan överföras genom kroppskontakt, vilket är fel.

Fynden i studien talar för att flertalet studiedeltagare hade kunskap om hur hepatit C viruset smittar, vilka risker för komplikationer som finns och att det finns behandling. Dock förekom det missuppfattningar om att infektion kan smitta via mat och genom att dela dusch med smittad samt att smittade kan vara fria från symtom. Detta kan påverka människors risktagande, hur de uppfattar sjukdomen samt hur de söker vård. Det kan också bidra till den diskriminering som studien fann. Diskrimineringen påverkar inte bara livskvalitén för de som har infektionen utan kan även påverka i vilken utsträckning de med hepatit C eller odiagnostiserade söker vård och är därmed ett hinder för Kina att förbättra sin hantering av hepatit C. Fynden i studien talar för att det finns ett behov att dels förbättra informationen som ges angående hepatit C, men också att det finns ett behov av att genomföra fler studier om den diskriminering som de med hepatit C utsätts för- då detta är en central faktor i hur människor förhåller sig till sjukdomen.

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Appendices

Appendix 1 – Questionnaire

Hepatitis C survey at First Affiliated Hospital, Ürümqi, Xinjiang, China
Part of master thesis project by student of Programme in Medicine, University of Gothenburg, Sahlgrenska Academy

On each question, mark one answer closest to your opinion

No

1. Hepatitis C is a?

Bacteria ☐
Virus ☐
Other ☐
Don't know ☐

2. Hepatitis C transmits via?

Skin ☐
Mucus ☐
Blood ☐
Air ☐
Other ☐
Don't know ☐

3. Hepatitis C primarily affects?

The kidneys ☐
The Liver ☐
The Lung ☐
The Heart ☐
Other ☐
Don't Know ☐

4. Can a person with hepatitis C share one or more of following items with another person?

Please mark Yes/No or Don't know on each item
"**Yes**" means that a person with hepatitis C can share this item
"**No**" means that a person with hepatitis C should not share this item

Towel	Yes ☐	No ☐	Don't know ☐
Razor	Yes ☐	No ☐	Don't know ☐
Syringe	Yes ☐	No ☐	Don't know ☐
Shower	Yes ☐	No ☐	Don't know ☐
Eating together (share meal)	Yes ☐	No ☐	Don't know ☐

5. A person infected with hepatitis C can get different symptoms, which of following symptoms can occur

Please mark Yes/No or Don't know on each item
"**Yes**" means that this symptom can occur because of hepatitis C
"**No**" means that this symptom can not occur

Yellow skin and yellow eyes	Yes ☐	No ☐	Don't know ☐
Often there are no symptoms	Yes ☐	No ☐	Don't know ☐
Fatigue	Yes ☐	No ☐	Don't know ☐

Other symtoms, please write: ____________________

The questionnaire continues on page 2

6. **Hepatitis C is diagnosed with a specific blood test?**
Yes ☐ No ☐ Don't know ☐

7. **Hepatitis C can cause cancer?**
Yes ☐ No ☐ Don't know ☐

8. **A person can die because of Hepatitis C?**
Yes ☐ No ☐ Don't know ☐

9. **Hepatitis C is curable?**
Yes ☐ No ☐ Don't know ☐

In following statements please mark the answer that is closest to your opinion

10. **If a person wants to test for hepatitis C, they can do so**
Yes ☐ No ☐ Don't know ☐

11. **A person diagnosed with hepatitis C gets the correct treatment**
Yes ☐ No ☐ Don't know ☐

12. **People with hepatitis C is discriminated by health care**
Yes ☐ No ☐ Don't Know ☐

13. **People with hepatitis C is discriminated in society**
Yes ☐ No ☐ Don't Know ☐

13. **Do you have hepatitis C diagnosed by a doctor?**
Yes ☐ No ☐ Don't know ☐

15. **Age?** ____________

16. **Gender?**
Male ☐
Female ☐

17. **What is your level of education?**
None ☐
Elementary school ☐
High school ☐
College ☐

18. **What is your occupation?** ______________________________

The questionnaire is now finished, please hand it in.

Appendix 2 – Interview sheet

Interview sheet for doctor and nurses

1. What do you think is the general populations view on Hepatitis C?
    a. If you have experienced, please describe any kind of misperceptions about hepatitis C that you have met during your clinical work?
    b. Do you believe this affects HCV management? Why?
    c. Do you agree to following statement: general populations perceptions (view) of hepatitis C affects HCV management?

2. From your perspective, please describe the HCV-infecteds’ situation in the society?
    a. Can HCV-infected tell other person they have HCV
    b. How do you believe this affects the HCV situation? How?
    c. Do you agree with following statement: HCV-infected experience discrimination?

3. If you could change anything regarding HCV in china, what would you change? Why?
    a. Do you agree with the following statement: there is a need to act on HCV in China?

4. Regarding this, are there anything else that you would like to add?

Time
Age
Title
Duration working

Follow ups:
Please give examples
What is the biggest challenge with?
What are your thoughts on?
Do you see any other explanations?
Have I understood you correct?

Interview sheet for patients

1. What is your view on hepatitis C?
    a. What do you believe is the general populations view on hepatitis C?
    b. Do you agree with the following statement: most people have an in-correct view on hepatitis C?

2. How would you describe living with hepatitis C?
    a. How does having HCV affect your daily life? Examples?
    b. How would you describe your relationship to healthcare?
    c. If a person has HCV, do you think they can tell other people about it?
    a. Do you agree with the following statement: HCV-infected experience discrimination?
    b. Have you experienced discrimination

3. What are your thoughts regarding your future, since you have hepatitis C?
    a. If you could change anything regarding HCV in china, what would you change? Why?
    b. Do you agree with the following statement: there is a need to act on HCV in China?

4. Regarding this, are there anything else that you would like to add?

Time
Age
Title
Duration with HCV

Follow ups:
Please give examples
What is the biggest challenge with?
What are your thoughts on?
Do you see any other explanations?
Have I understood you correct?

Appendix 3 – Tables

Demographic distribution

		Count	Column Valid N %	Missing
Gender	Male	64	54.7%	
	Female	53	45.3%	
	Total	117		3
Age by category	18 - 29	36	31.9%	
	30 - 39	20	17.7%	
	40 - 49	26	23.0%	
	50 - 59	17	15.0%	
	60 or older	14	12.4%	
	Total	113		7
Hepatitis C diagnosis	Yes	23	19.5%	
	No	95	80.5%	
	Don't know	0	0.0%	
	Total	118		2
Level of education	None	0	0.0%	
	Elementary school	11	9.2%	
	High school	40	33.6%	
	College	68	57.1%	
	Total	119		1
Department	In-patient department	96	80.0%	
	Out-patient department	24	20.0%	
	Total	120		0

Age

N	Mean	Median	Std. Deviation	Minimum	Maximum
113	39.90	40.00	13.969	18	76

Perceptions about HCV as a disease

		Count	Column Valid N %	Missing
Hepatitis C is a	Bacteria	7	5.8%	
	Virus	94	78.3%	
	Other	4	3.3%	
	Don't know	15	12.5%	
	Total	120		0
Hepatitis C primarily affects	Kidneys	0	0.0%	
	Liver	106	88.3%	
	Lung	0	0.0%	
	Heart	0	0.0%	
	Other	0	0.0%	
	Don't know	14	11.7%	
	Total	120		0
A person infected with hepatitis C can get yellow skin and eyes	Yes	68	70.1%	
	No	11	11.3%	
	Don't know	18	18.6%	
	Total	97		23
A person infected with hepatitis C does not always have symptoms	Yes	44	45.4%	
	No	32	33.0%	
	Don't know	21	21.6%	
	Total	97		23
A person infected with hepatitis C can experience fatigue	Yes	83	79.0%	
	No	7	6.7%	
	Don't know	15	14.3%	
	Total	105		15
Hepatitis C can cause cancer	Yes	76	64.4%	
	No	18	15.3%	
	Don't know	24	20.3%	
	Total	118		2
A person can die of hepatitis C	Yes	83	69.7%	
	No	16	13.4%	
	Don't know	20	16.8%	
	Total	119		1

Perceptions about HCV transmission routes

		Count	Column N %	Missing
Hepatitis C transmits via	Skin	0	0.0%	
	Mucus	2	1.7%	
	Blood	83	70.3%	
	Air	2	1.7%	
	Other	0	0.0%	
	Don't know	31	26.3%	
	Total	118		2
A person with hepatitis C can share a towel	Yes	51	47.7%	
	No	48	44.9%	
	Don't know	8	7.5%	
	Total	107		13
A person with hepatitis C can share a razor	Yes	23	20.5%	
	No	80	71.4%	
	Don't know	9	8.0%	
	Total	112		8
A person with hepatitis C can share a syringe	Yes	27	23.7%	
	No	80	70.2%	
	Don't know	7	6.1%	
	Total	114		6
A person with hepatitis C can share a shower	Yes	74	71.2%	
	No	18	17.3%	
	Don't know	12	11.5%	
	Total	104		16
A person with hepatitis C can share a meal	Yes	72	67.3%	
	No	27	25.2%	
	Don't know	8	7.5%	
	Total	107		13

Perception about HCV prevention

		Count	Column Valid N %	Missing
Hepatitis C is diagnosed with a specific blood test	Yes	92	76.7%	
	No	5	4.2%	
	Don't know	23	19.2%	
	Total	120		0
Hepatitis C is treatable	Yes	68	56.7%	
	No	30	25.0%	
	Don't know	22	18.3%	
	Total	120		0

Attitudes on HCV management

		Count	Column Valid N %	Missing
If a person wants to test for hepatitis C, they can do so	Yes	95	79.8%	
	No	8	6.7%	
	Don't know	16	13.4%	
	Total	119		1
A person diagnosed with hepatitis C gets the correct treatment	Yes	91	76.5%	
	No	8	6.7%	
	Don't know	20	16.8%	
	Total	119		1

Attitudes on discrimination of HCV infected

		Count	Column Valid N %	Missing
People with hepatitis C are discriminated by health care	Yes	12	10.1%	
	No	88	73.9%	
	Don't know	19	16.0%	
	Total	119		1
People with hepatitis C are discriminated in society	Yes	40	33.9%	
	No	55	46.6%	
	Don't know	23	19.5%	
	Total	118		2