

# Knowledge and attitudes about hepatitis C virus (HCV) infection and its treatment in HCV mono-infected and HCV/HIV co-infected adults

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**SUMMARY.** Hepatitis C virus (HCV) treatment is rapidly changing but little is known about patients' attitudes and knowledge about HCV. This study used a cross-sectional survey to examine the relationship between HCV knowledge and attitudes towards HCV in patients with HCV mono-infection and HIV/HCV co-infection. Subsequently, an education intervention was developed with an abridged version of the cross-sectional survey administered before and after the education session to assess changes in knowledge and attitudes. 292 people participated in the cross-sectional survey, and 87 people participated in the education intervention. In the cross-sectional survey, the mean knowledge score regarding HCV was low (<50% of the total possible score). Mono-infected and co-infected individuals shared similar knowledge deficits and attitudes towards HCV despite having distinct demographic differ-

ences. Attitudes endorsed by patients included the following: 57% feared the consequences of HCV on their life, 37% felt HCV was not fatal, 27% did not believe they needed HCV medication, 21% felt ashamed of having HCV and 16% felt HCV treatment was not important. Attitudes that reflected indifference and shame towards HCV were associated with lower knowledge scores (HCV knowledge score of 15.1 vs. 17.5,  $P < 0.01$  for indifference and 15.3 vs. 17.2 for shame,  $P = 0.02$ ). The education intervention improved knowledge scores but did not modify the assessed attitudes. Intervention studies are needed to effectively change attitudes towards HCV infection and treatment.

**Keywords:** attitude, health beliefs, hepatitis C virus, human immunodeficiency virus, intervention research, knowledge.

## INTRODUCTION

Hepatitis C virus (HCV) and human immunodeficiency virus (HIV) infections are preventable and treatable. In the United States, an estimated 3.2 million people live with chronic hepatitis C currently and 20 000 new cases are reported each year [1]. Nearly 8000 Americans die each year from HCV-related complications such as hepatocellular carcinoma, decompensated cirrhosis and liver failure [2]. With the advent of direct-acting antiviral agents such

as boceprevir and telaprevir, 59–73% of patients may be cured of hepatitis C infection after treatment, as measured by the sustained virological response (SVR) [3–6]. Achieving SVR is associated with reduced incidence of hepatocellular carcinoma and liver-related morbidity and mortality [7–10]. Similar SVR outcomes are observed in patients co-infected with HCV and HIV [11], in whom chronic liver disease is becoming increasingly important as AIDS-related deaths have decreased with the use of highly active antiretroviral therapy [12].

Nevertheless, many of those who are 'mono-infected' with HCV and those 'co-infected' with both HCV and HIV have low rates of obtaining treatment for HCV. Health outcome analysis projects that current treatment patterns will prevent only 14.5% of liver-related deaths attributed to hepatitis C between 2002 and 2030 [13], suggesting that efforts to increase treatment rates are needed to decrease liver-related mortality. Understanding barriers to HCV treatment is important not only for this long-term goal of

Abbreviations: HCV, hepatitis C virus; HIV, human immunodeficiency virus; IMB, information motivation behavioral; SVR, sustained virological response.

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decreasing mortality but also for patients' ongoing quality of life [14]. Studies have identified both knowledge (information) and attitudes (motivation) as major factors that influence behaviour related to HIV therapy adherence and are best described by the Information Motivation Behavioral skills (IMB) model [15]. For instance, being afraid and feeling asymptomatic were prominent reasons for inadequate follow-up care for people with HIV [16]. More importantly, improving knowledge and motivational states has been shown to help patients with HIV form action plans for maintaining care [17]. The IMB model can be used as a theoretical framework for the understanding of treatment barriers found in those with HCV infection.

Barriers to HCV treatment exist in both HCV mono-infected and HIV/HCV co-infected patients. The aim of this study was to first evaluate knowledge and attitude differences between these two groups, second to examine the association between knowledge and attitudes and lastly to design and implement an education intervention that would modify knowledge deficits or attitudes related to HCV infection or treatment.

## METHODS

### *Study design overview*

A cross-sectional survey was developed from published literature and themes elicited from patient focus groups conducted by this team. After approval was obtained from the Institutional Review Board, the survey was administered to prospectively enrolled participants who had provided written informed consent. Subsequently, a one-hour teaching and question-answer session in groups of approximately 10 people each was developed to address the knowledge deficits and attitudes elicited by the cross-sectional survey. An abridged version of the cross-sectional survey was given before and after the education intervention to assess the intervention's efficacy. The education intervention also tested the hypothesis that improvement in HCV knowledge score would be associated with a change in attitudes related to HCV treatment and infection.

### *Sample population*

A nonsystematic sample of individuals with HCV infection was recruited for the cross-sectional survey from the outpatient clinics in the Parkland Health and Hospital System, an urban safety-net hospital system in Dallas, as well as from local substance recovery programmes between November 2009 and March 2011 through flyers and direct recruitment from clinics. Patients were included if they were at least 18 years old and had medical documentation of a diagnosis of chronic hepatitis C as well as HIV for those who were co-infected. Patients were excluded if they had prior HCV treatment, had substantial cognitive

impairment or were not proficient in English or Spanish. Participants were similarly recruited nonsystematically for the education intervention through the Parkland outpatient clinics between July 2011 and November 2011. Additionally, participants in the cross-sectional survey who provided contact information were also eligible to attend the education intervention and were invited to participate. Monolingual Spanish speakers were excluded from the education intervention because it was available only in English.

### *Data collection*

The cross-sectional survey was designed to assess knowledge and attitudes about HIV and HCV and to collect data on participants' demographics (age, gender, race, sexual orientation, education and employment), medical history, risk factors and social history. Multiple-choice and true/false questions testing HCV knowledge were grouped into three sections: transmission, disease and treatment. Questions related to HIV knowledge were selected from the HIV Knowledge Questionnaire-45 [18]. Survey items related to attitudes towards HCV infection and treatment covered indifference, fears, shame and stigma, pertaining to themes synthesized from transcripts of nine focus groups conducted with samples of a similar population in the year prior to this study. The attitude items were assessed with a three-point importance scale (Very important, Important or Not Important) or with a five-point agreement scale (Strongly Agree, Agree, Neutral, Disagree or Strongly Disagree). Ten attitude items related to HCV treatment or infection in this study are paraphrased in Table 1. The first seven items are related to indifference, and the last three are related to shame, stigma or fear, respectively. Key items from the HCV knowledge, HCV attitude and demographic sections of the cross-sectional survey were selected for the pre- and posteducation survey based on observed HCV knowledge deficits and attitudes found in the cross-sectional survey. Participants were offered a \$15 gift card for completing the cross-sectional survey or pre- and post-education intervention surveys. Participants were also given the option of completing surveys with the assistance of study staff to enhance comprehension of all questions.

### *Data analysis*

Data pertaining to demographics, knowledge scores and attitudes questions were first computed descriptively as counts, proportions and means. Knowledge questions in related groups were then organized into scales, with zeros assigned to blank and incorrect answers and scores calculated from correct answers. Names for the attitude items were paraphrased to represent undesired response values (e.g. indifference, shame, stigma and fear), and data for these items were realigned to reflect this directionality by

**Table 1** Original attitude questions from the cross-sectional survey and their corresponding paraphrase to the undesired response

	Original cross-sectional survey question	Paraphrased to the undesired response value	Type of scale	Use in pre- and post- education intervention
1	'How important is it for you to get treatment for hepatitis C?'	HCV treatment is unimportant	Importance scale	√
2	'I do not think that I need to take medication for my hepatitis C'.	HCV medications are not needed	Likert scale	√
3	'I don't believe that I will die from hepatitis C'.	HCV is not fatal	Likert scale	–
4	'Treating my other illnesses is more important than treating my hepatitis C'.	Treating other illness is more important	Likert scale	√
5	'Treating hepatitis C will make my life better'.	Treating HCV will not improve life	Likert scale	–
6	'Hepatitis C does not cause any problems in my body'.	HCV causes no health problems	Likert scale	–
7	'I do not think I need treatment for hepatitis C because I can't tell that I have it'.	No need for HCV treatment because no symptoms	Likert scale	√
8	'Feeling ashamed of having hepatitis C makes me uncomfortable seeking hepatitis C treatment or care'.	Feeling ashamed prevents seeking HCV treatment	Likert scale	√
9	'People may treat me differently if they know that I have hepatitis C'.	HCV is stigmatizing	Likert scale	–
10	'I am scared about what might happen to me because I have hepatitis C'.	HCV is scary	Likert scale	–

reversing response codes for questions originally phrased towards the desired responses. The realigned three-point importance scale responses were dichotomized into Very Important/Important versus Not Important. The realigned Likert scale responses were dichotomized into Strongly Agree/Agree versus Neutral/Disagree/Strongly Disagree. Missing data and uncertain answer choices in the attitude items were excluded from further analysis. Differences between mono-infected and co-infected individuals were compared using chi-square tests for categorical variables (dichotomized attitude items and most demographic data) and Student's t-tests for continuous variables (knowledge scores, age and education). Internal consistency of the HCV and HIV knowledge scales was assessed by Cronbach  $\alpha$  coefficient. Mean knowledge scores were compared with dichotomized attitude variables using Student's t-tests. Mean knowledge scores from the pre- and posteducation surveys were compared using paired t-tests and assessed individually by Cronbach  $\alpha$  coefficient. Pre- and posteducation dichotomized attitude variables were compared using McNemar's tests. Both pretest mean knowledge scores and the change in knowledge scores (pretest score subtracted from post-test score) were compared with the dichotomized pretest attitude items using Student's t-tests. All analyses

were performed using SAS Version 9.2 (SAS Institute, Inc., Cary, NC, USA).

## RESULTS

Two hundred ninety-two patients with HCV agreed to participate in the cross-sectional survey, and 87 patients participated in the education intervention; 25 completed both. Demographics of the cross-sectional survey and education intervention samples are shown in Table 2. Both samples consisted of about equal numbers of mono-infected and co-infected participants; mean age was just over 50 years, about two-thirds were male, and the majority were African American. At least 20% of the participants self-identified as homosexual or bisexual orientation. In the cross-sectional survey, compared with the mono-infected participants, the co-infected participants were significantly younger (48.1, SD = 8.0 vs. 53.2, SD = 8.1,  $P < 0.01$ ) and had a significantly higher proportion of males (70.1% vs. 57.5%,  $P = 0.03$ ) and African Americans (69.9% vs. 46.5%,  $P < 0.01$ ). The co-infected participants also had a greater proportion that identified as homosexual or bisexual (44.5% vs. 3.0%,  $P < 0.01$ ) or reported disability status (51.4% vs. 36.4%,  $P = 0.01$ ) or a diagnosis of a psychiatric

**Table 2** Demographics of HCV individuals from the cross-sectional survey and the education intervention

	Cross-sectional survey participants	No of 292	Education intervention participants	No of 87
HIV co-infection, <i>n</i> (%)	149 (51.5)	292	46 (52.9)	87
Years of age, mean (SD)*	50.6 (8.4)	287	50.2 (7.3)	86
Male, <i>n</i> (%)	184 (63.9)	288	63 (72.4)	87
Black or African American, <i>n</i> (%)	168 (58.3)	288	57 (69.5)	82
Heterosexual, <i>n</i> (%)	209 (75.2)	278	47 (56.0)	84
Years of education, mean (SD)*	11.7 (2.0)	288	–	–
Employment, <i>n</i> (%)	55 (18.9)	291	–	–
Disability, <i>n</i> (%)	128 (44.0)	291	–	–
Depression diagnosis, <i>n</i> (%)	162 (56.3)	288	–	–
Any psychiatric diagnosis, <i>n</i> (%)	177 (61.2)	289	–	–
Liver biopsy, <i>n</i> (%)	89 (31.8)	280	–	–
HCV diagnosis >1 year, <i>n</i> (%)	244 (85.7)	285	–	–

\*SD = standard deviation.

**Table 3** Mean knowledge scores and corresponding intra-item reliabilities from the cross-sectional survey

	Total possible score	Mean score (SD)* (N = 292)	Intra-item reliability (cronbach alpha coefficient)
HIV knowledge score	11	6.7 (2.3)	0.77
HCV composite knowledge score	40	16.4 (5.7)	0.79
HCV disease subscale	19	9.3 (3.4)	0.68
HCV transmission subscale	15	5.3 (2.7)	0.73
HCV treatment subscale	6	1.9 (1.5)	0.52

\*SD = standard deviation.

disorder (68.2% vs. 53.9%,  $P = 0.01$ ) compared with the mono-infected participants.

### Cross-sectional survey findings

The HCV composite knowledge scale had a total of 40 items and was subdivided into 3 knowledge subcategories: disease (19 items), transmission (15 items) and treatment (six items). As seen in Table 3, intra-item reliabilities for the HCV composite knowledge scale and the HIV knowledge scale, which had 11 items, were high. Overall, HCV knowledge was limited, with less than 50% of the questions answered correctly. Table 4 shows responses to the items reflecting attitudes in the cross-sectional study. Only a minority of the sample endorsed the undesired responses on attitudes regarding indifference, shame and stigma. In contrast, more than half strongly agreed or agreed with

**Table 4** Proportions of HCV individuals from the cross-sectional survey who endorsed undesired responses on 10 attitude items relating to indifference, shame, stigma and fear

	Endorsement of undesired response to the attitude items	Strongly endorsed or endorsed (%)	No of 292
1	HCV treatment is unimportant	42 (16.3)	258
2	HCV medications are not needed	67 (26.6)	252
3	HCV is not fatal	84 (37.0)	227
4	Treating other illness is more important	55 (21.2)	259
5	Treating HCV will not improve life	30 (11.9)	253
6	HCV causes no health problems	46 (18.0)	255
7	No need for treatment because no symptoms	39 (15.2)	257
8	Feeling ashamed prevents seeking treatment	56 (20.7)	271
9	HCV is stigmatizing	58 (31.7)	183
10	HCV is scary	151 (56.8)	271

the item 'I am scared about what might happen to me because I have hepatitis C'.

No differences were found between the mono-infected and co-infected groups regarding HCV knowledge score or the subscales representing HCV disease and transmission. Co-infected participants, however, had a higher mean HCV treatment knowledge score compared with mono-infected participants (2.1, SD = 1.5 vs. 1.6, SD = 1.4,  $P < 0.01$ ). They also had higher mean HIV knowledge score compared

**Table 5** Pretest and post-test. (a) mean HCV knowledge scores; (b) response to the attitude items from the education intervention

(a)					
HCV Knowledge Score (34 points total)	Pretest	N	Post-test	N	P value
Mean (SD)	17.2 (6.4)	87	23.3 (5.5)	87	<0.01
Cronbach $\alpha$ coefficient	0.86	–	0.83	–	–
(b)					
HCV attitudes (5 items)	Pretest		Post-test		
Undesired response value	No. (%) endorsed	N	No. (%) endorsed	N	P value
HCV treatment is unimportant	0 (0)	68	0 (0)	68	–
HCV medications are not needed	14 (22.6)	62	14 (22.6)	62	–
Treating other illness is more important	10 (14.9)	67	10 (14.9)	67	–
No need for HCV treatment because no symptoms	9 (12.9)	70	10 (14.3)	70	0.71
Feeling ashamed prevents seeking HCV treatment	12 (17.4)	69	7 (10.1)	69	0.10

with mono-infected participants (7.8, SD = 1.9 vs. 5.5, SD = 2.1,  $P < 0.01$ ). The only attitude item that differed between mono-infected and co-infected participants was pertaining to HCV stigma, endorsed by 39% of the mono-infected group and 25% of the co-infected group ( $P = 0.04$ ).

In the cross-sectional survey, HCV composite knowledge scores were compared with items reflecting attitudes. One attitude related to indifference towards treatment and one related to shame were both associated with lower HCV knowledge scores. The mean knowledge score was lower among participants who endorsed 'HCV medications are not needed' than among those who did not endorse this item (15.1, SD = 5.9 vs. 17.5, SD = 5.4,  $P < 0.01$ ). Participants who endorsed 'feeling ashamed prevents HCV treatment' had a lower mean knowledge score compared with those who did not (15.3, SD = 5.6 vs. 17.2, SD = 5.4,  $P = 0.02$ ). No significant associations were found between the mean HCV knowledge score and the other eight attitude items.

#### Pre-/postsurvey findings

The abridged pre-/postsurvey used in the education intervention had 34 HCV knowledge items and 5 attitude statements. The shortened HCV knowledge scale used in the education intervention had an even higher internal reliability value (Cronbach  $\alpha = 0.83$ ) than that obtained for the cross-sectional survey (Cronbach  $\alpha = 0.79$ ). As shown in Table 5, participants in the education intervention demonstrated significant increase in mean knowledge score from pretest to post-test, but no significant changes were found in their attitudes.

As in the cross-sectional survey, education intervention participants who endorsed the attitude items, 'HCV medications are not needed' and 'feeling ashamed prevents HCV treatment', also had significantly lower pretest knowledge

scores than those who did not (indifference: 16.0, SD = 4.7 vs. 19.7, SD = 4.9,  $P = 0.02$ ; shame: 15.0, SD = 4.7 vs. 19.9, SD = 4.3,  $P < 0.01$ ). In a subanalysis of those who endorsed the undesired responses on attitude items, their mean knowledge scores improved significantly after the education intervention (HCV medications are not needed: 16.0, SD = 4.7 vs. 22.6, SD = 3.9,  $P < 0.01$ ; treating other illness is more important: 17.2, SD = 6.5 vs. 22.6, SD = 5.6,  $P < 0.01$ ; no need for HCV treatment because no symptoms: 15.9, SD = 4.9 vs. 22.2, SD = 4.6,  $P < 0.01$ ; feeling ashamed prevents seeking HCV treatment: 15.0, SD = 4.7 vs. 21.3, SD = 3.8,  $P < 0.01$ ). Similar changes were seen in those who endorsed the desired response on attitude items. However, despite significant changes in knowledge scores, there was no significant change in attitudes between the pre- and post-test.

#### DISCUSSION

Both mono-infected and co-infected individuals had limited knowledge of hepatitis C, scoring less than 50% of the items correctly. Approximately one-fourth to one-third of patients endorsed attitudes reflecting shame, stigma or indifference towards HCV treatment and infection and over 50% indicated fears about having HCV. Prior studies have shown that the major reasons for not seeking HCV treatment are fears about HCV or its treatment, limited HCV knowledge, stigma related to HCV infection and lack of symptoms [19–22]. In our sample, many more expressed fear about the impact that HCV may have on them than other attitudes even though this item was not associated with limited knowledge about HCV. Instead, correlations between lack of knowledge and specific attitudes such as indifference and shame were found in both the cross-sectional survey and the education intervention. According to the IMB model used in patients with HIV, knowledge about

HIV is positively associated with motivation to adhere to HIV treatment [23]. Similarly, this study demonstrated that lower knowledge scores about HCV were associated with endorsing undesired responses to attitudes such as indifference and shame. Both of these attitudes could interfere with motivation to obtain HCV treatment.

The co-infected and mono-infected participants in this study differed in several important respects. Although they had similar knowledge scores and attitudes in this study, co-infected participants had more HCV treatment knowledge, more HIV knowledge and fewer perceived stigma from HCV. Their knowledge about HCV treatment and HIV may be attributed to their ongoing HIV care, as co-infected populations have been found to receive more hepatitis-related follow-up care [24]. Co-infected individuals may report less HCV-associated stigma than mono-infected individuals because they may perceive having HIV as more stigmatizing to the extent that their HCV seems relatively less important to them [25]. Other differences (i.e. age, race, sexual orientation and psychiatric diagnosis) between mono-infected and co-infected patients found in this study could relate to barriers to HCV treatment, especially in the co-infected populations. Studies have found that co-infected populations encounter additional treatment barriers related to their higher prevalence of medical and psychiatric contraindications to HCV medications and ongoing substance use [26,27]. Knowledge about HCV, nevertheless, was equivalent in mono-infected and co-infected patients in this study. Thus, although this study found that mono-infected and co-infected patients shared many similar HCV knowledge deficits and attitudes towards HCV treatment and disease, the co-infected patients may have additional psychosocial factors that serve as treatment barriers.

Hepatitis C virus knowledge improved significantly after the education intervention even in those who had attitudes reflecting indifference or shame towards HCV disease and treatment. Improving knowledge through education has been shown to increase willingness of patients with HCV to obtain treatment [28]. However, re-education and ongoing support may be necessary to maintain patients' knowledge level about HCV [29]. There also remains a need to develop interventions that could specifically modify attitudes towards HCV treatment.

There were several study limitations. First, the sample population came from an indigent care setting and may not accurately reflect the level of HCV knowledge and attitudes among the general population. They were also selected nonsystematically, which could have introduced bias. Second, the cross-sectional survey could not determine the direction of causality in the association between knowledge and specific attitudes. Third, the differences in demographic factors between mono-infected and co-infected participants could introduce bias with regard to knowledge and attitudes, but the sample size was insufficient to adjust for these variables. Information regarding

participants' suitability for HCV treatment such as medical co-morbidities and psychiatric stability also was not obtained to evaluate the attitude differences between those who are reasonable treatment candidates and those who have relative contraindications. Fourth, differences in knowledge scores in subpopulations such as injection drug use versus those who acquired HCV from transfusions could not be explored due to the sample size. Further, the survey assessment relied on self-reported data, which depended on participants' effort and honesty. An important study limitation was that the cross-sectional survey did not examine the association of both knowledge and attitudes on HCV treatment-seeking behaviour nor was the change in knowledge scores through education intervention compared with change in health-seeking behaviour. Because both knowledge and attitudes may directly affect health behaviour, as described by the IMB model, further studies are needed to examine these correlations.

This study demonstrated that knowledge about HCV infection and treatment was limited among HCV-infected and HIV/HCV-infected individuals in an urban indigent care setting. Even so, knowledge improved after a brief education session. For the most part, participants did believe their hepatitis C was important; however, they were fearful about having HCV. Neither of these attitudes was associated with limited knowledge; in contrast, attitudes related to shame and indifference were associated with lower HCV knowledge scores. Future studies are needed to effectively change attitudes and determine whether those changes will affect health behaviour among mono-infected and co-infected populations.

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