

## HIV and HCV health beliefs in an inner-city community

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**SUMMARY.** Chronic infection with the hepatitis C virus (HCV) is more prevalent than human immunodeficiency virus (HIV) infection, but more public health resources are allocated to HIV than to HCV. Given shared risk factors and epidemiology, we compared accuracy of health beliefs about HIV and HCV in an at-risk community. Between 2002 and 2003, we surveyed a random patient sample at a primary care clinic in New York. The survey was organized as domains of Common Sense Model of Self-Regulation: causes ('sharing needles'), timeline/consequences ('remains in body for life', 'causes cancer') and controllability ('I can avoid this illness', 'medications may cure this illness'). We compared differences in accuracy of beliefs about HIV and HCV and used multivariable linear regression to identify factors associated with relative accuracy of beliefs. One hundred and twenty-two subjects completed the survey (response rate 42%). Mean overall health belief accuracy was 12/15 questions (80%) for HIV vs 9/15 (60%) for HCV ( $P < 0.001$ ).

Belief accuracy was significantly different across all domains. Within the causes domain, 60% accurately believed sharing needles a risk factor for HCV compared to 92% for HIV ( $P < 0.001$ ). Within the timeline/consequences domain, 42% accurately believed HCV results in lifelong infection compared to 89% for HIV ( $P < 0.001$ ). Within the controllability domain, 25% accurately believed that there is a potential cure for HCV. Multivariable linear regression revealed female gender as significantly associated with greater health belief accuracy for HIV. Thus, study participants had significantly less accurate health beliefs about HCV than about HIV. Targeting inaccuracies might improve public health interventions to foster healthier behaviours and better hepatitis C outcomes.

**Keywords:** attitudes and practice, health beliefs, health knowledge, hepatitis C virus, human immunodeficiency virus.

Human immunodeficiency virus (HIV) and hepatitis C virus (HCV) cause two of the most common chronic blood-borne infections in the United States. Over one million people in the United States are living with HIV, and an even greater number, approximately 2.7–3.9 million, are chronically infected with HCV [1–3]. While HIV is transmitted through contact with bodily fluids (semen, vaginal fluid and breast milk), both diseases are transmitted by direct contact with infected blood. As a result, HIV and HCV share risk factors – most notably injection drug use. Consequently, these diseases are also linked through common epidemiological features.

Abbreviations: HCV, hepatitis C virus; HIV, human immunodeficiency virus.

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However, while the age-adjusted HIV death rate has been decreasing or stabilizing in the United States since the mid-1990s, the number of deaths caused by HCV is projected to increase two to fourfold over the next two decades [4,5]. Fewer public health resources have been directed at HCV when compared to HIV, and prior studies suggest that at-risk communities lack awareness about HCV [3]. In combination with improved biological and behavioural treatments aimed at these viruses and at behaviours such as addiction that increase their risk of being acquired, educational programmes are needed to increase awareness and promote better health behaviours related to both viruses, especially HCV. Understanding current health beliefs held by at-risk populations might be the first step in designing programmes to increase awareness and knowledge regarding both diseases.

A growing body of literature demonstrates that patients' beliefs about diseases influence their health behaviours [6–8]. Stigma associated with injection drug use, limited access to health services for injection drug users, and limited

federal and public health funding for HCV-related services in general may all contribute to inaccurate beliefs about HCV. In comparison, the stigma around HIV testing and treatment has diminished significantly over time, and government resources for medical and public health support around HIV are well-established. Thus, in spite of important similarities between HCV and HIV, it is likely that at-risk populations have less accurate beliefs about HCV when compared to HIV. Understanding and comparing health beliefs about HIV and HCV may be useful in identifying erroneous beliefs most in need of modification, to improve health outcomes in these populations. The Leventhal Common Sense Self-Regulation Model has been used to understand health beliefs about common chronic conditions like asthma, hypertension, heart failure and diabetes [7,9–11]. Less has been done regarding use of the Self-Regulation model as a means of assessing health beliefs about chronic infectious diseases such as HCV and HIV. According to the Common Sense Model, individuals develop health beliefs through personal illness episodes and socio-cultural associations that can be organized into five interconnected domains: (i) identity (the label ascribed to a condition and its associated symptoms), (ii) cause (based on both biomedical and nonscientific sources), (iii) temporal features or time-line (disease rate of onset, symptom duration as acute or chronic), (iv) consequences (impacts of a disease, including physical, psychological and social) and (v) controllability or curability (the degree to which a disease may be treated or controlled) [12,13].

To date, a handful of studies evaluate or compare lay understanding (knowledge, beliefs or attitudes) of HIV and HCV in the general population or in at-risk communities (injection drug users, for example). These studies suggest that the public has variable understanding of these infections and that beliefs tend to be more concordant with the biomedical model for HIV than for HCV [14–21]. At present, we are not aware of studies that formally compare health beliefs about HIV and HCV in the United States using a theory-based model of health beliefs.

To characterize and contrast health beliefs about HIV and HCV, we surveyed patients using questions structured according to the Common Sense Model. We targeted patients from an at-risk, inner-city community where rates of HCV and HIV are disproportionately high. We hypothesized that despite the greater prevalence of HCV over HIV, health beliefs about HCV would be less accurate than beliefs about HIV [22,23].

## METHODS

Our study population was comprised of patients attending an adult internal medicine clinic affiliated with a large academic medical centre in the East Harlem neighbourhood of New York City. East Harlem has the second highest AIDS case rate in the United States (36.6 per 100 000 population) and the highest HCV infection rate in New York City (451.1/

100 000 population) [1,2,24,25]. All patients seen in the clinic between April 2002 and November 2003 for a scheduled visit with a provider or for an unscheduled visit for an urgent problem were eligible for this study. Potential subjects were randomly selected from this population as they presented to clinic and offered participation by bilingual research assistants. Exclusion criteria included age younger than 18 years and primary language other than English or Spanish. The study protocol was approved by the Mount Sinai School of Medicine Institutional Review Board, and all patients signed informed consent prior to study participation.

Participants were surveyed about their health beliefs regarding HIV and HCV through face-to-face interviews conducted by trained, bilingual research assistants. The survey consisted of 15 'yes' or 'no' items (Table 1). Survey items were organized into the three domains relevant to the Common Sense Model: (i) causes, (ii) timeline/consequences and (iii) curability/controllability. Examples of survey items included: 'this illness may be caused by sharing needles' (causes domain), 'this illness may remain in the body for life' (timeline/consequences domain) and 'medications may cure this illness' (curability/controllability domain).

**Table 1** Health beliefs survey with answers scored as accurate

Belief domain	Accurate statement	
	HIV	HCV
<b>Causes</b>		
This illness may be caused by		
Eating contaminated food	No	No
Shaking hands	No	No
Being coughed on	No	No
Sharing needles	Yes	Yes
A virus	Yes	Yes
Stress	No	No
<b>Timeline/consequences</b>		
This illness		
Usually causes problems that last only a short time	No	No
May cause problems that last many years	Yes	Yes
May remain in the body for life	Yes	Yes
May never cause problems	No	Yes
May cause problems only after many years	Yes	Yes
May cause cancer	Yes	Yes
<b>Curability/controllability</b>		
Regarding this condition		
There are things I can do to avoid developing this illness	Yes	Yes
Medications may cure this illness	No	Yes
Vaccines can prevent this illness	No	No

HIV, human immunodeficiency virus; HCV, hepatitis C virus.

Information regarding participants' sociodemographic status, exposure to HIV and HCV, and risk factors for both illnesses was also obtained through patient interview.

Our first study outcome was accuracy of health beliefs. We determined the accuracy of participants' health beliefs about HIV and HCV according to whether survey responses were concordant with the accepted biomedical models for each disease. For example, an answer of 'yes' to the survey item: 'this illness may be caused by sharing needles' would have been considered an accurate health belief for both HIV and HCV. We next summed the number of accurate survey items and generated accuracy percentages for each survey item, each domain and each disease overall. Our second outcome was the difference in these health belief accuracy percentages between HIV and HCV. We used the paired *t* test to compare HIV and HCV health beliefs by assessing for significant differences in the accuracy across individual health beliefs and for differences in health belief accuracy across individual Common Sense Model domains and overall. Differences were considered significant at a *P* value <0.05. Participants who reported a history of a positive blood test for HIV or HCV were excluded from our analyses (zero for HIV and five (4.1%) for HCV) as these participants were expected to have distinct health beliefs based on their differing personal histories with the conditions.

We performed an exploratory analysis to determine factors significantly associated with overall health belief accuracy for HIV and for HCV. Univariate analyses were performed using the paired *t* test, Pearson's correlation and ANOVA depending on the characteristics of the variables. Linear regression was then used to assess the multivariable association between overall health belief accuracy and independent variables, as well as those variables with a *P* value <0.05 for their association with overall health belief accuracy on univariate analysis. Independent variables included in our linear regression models were baseline sociodemographics (age, race, primary spoken language, insurance status and education level); personal risk factors for HIV and HCV (history of sexually transmitted infection, history of illicit drug use, history of sex without a condom with a person at risk for HCV); and knowledge of someone with HIV and/or HCV. These predictor variables were selected a priori and were chosen to identify potential targets for interventions to improve belief accuracy regarding HCV and HIV. All analyses were conducted using SPSS version 16 (IBM Company, Chicago, IL, USA).

## RESULTS

We approached 288 clinic patients and 122 agreed to participate for a response rate of 42%. Characteristics of the survey participants are provided in Table 2. The mean age was 46 years, 78% were women and 88% self-identified as nonwhite (Latino or Hispanic, African American and/or

**Table 2** Demographic characteristics of respondents

Characteristics	<i>n</i> = 122
Age, mean (SD), years	45.8 (14.0)
Race, %	
White	12.3
Nonwhite	87.7
Gender, %	
Female	78.0
Language, %	
English	79.5
Insurance coverage, %	
Medicaid	54.1
Other	45.9
Level of education, %	
Grades 0–9	20.8
Grades 10–12	42.5
>12th grade	36.7
HCV infected ever, %	4.1
HIV infected, %	0.0
Know someone with HCV infection, %	19.7
Know someone with HIV infection, %	42.6
IDU ever, %	5.7
Cocaine use ever, %	14.8
>50 lifetime sexual partners, %	7.4
Unprotected sex ever with partner with known behavioural risk factors, %	14.8

HCV, hepatitis C virus; HIV, human immunodeficiency virus; IDU, injection drug use.

Black). Slightly more than half were Medicaid recipients. Eighty per cent had at least some high school-level education. Six per cent of participants reported a history of injection drug use and 15% reported having either injected or inhaled cocaine. Overall, 43% of participants knew someone with HIV and 20% knew someone with HCV.

### Health belief accuracy

#### Causes/risk factors

Almost all participants (92%) accurately believed sharing needles is a risk factor for HIV, compared to only 60% who accurately believed sharing needles is a risk for HCV (*P* < 0.001) (Table 3).

#### Timeline/consequences

Most participants accurately believed that HIV infection could cause long-term problems (84%) or remain in the body for life (89%). In contrast, significantly fewer participants accurately believed the same for HCV (58% and 42%, respectively, *P* < 0.05). Fewer than 25% of participants accurately believed that HIV or HCV could result in cancer as a long-term consequence of either infection (23% and 21% respectively, *P* = 0.73).

**Table 3** Health belief accuracy, mean per cent, HIV vs HCV

Belief domain	Health belief	% Participants with accurate belief		
		Regarding HIV	Regarding HCV	P value
Causes	This illness may be caused by			
	Eating contaminated food	92.3	76.1	<0.001
	Shaking hands	98.3	93.2	0.01
	Being coughed on	90.6	85.5	0.13
	Sharing needles	91.5	59.8	<0.001
	A virus	53.9	28.2	<0.001
	Stress	97.4	97.4	1.000
Timeline/consequences	This illness			
	Usually causes problems that last only a short time	100.0	91.0	0.001
	May cause problems that last many years	83.8	58.1	<0.001
	May remain in the body for life	88.9	41.9	<0.001
	May never cause problems	94.9	6.0	<0.001
	May cause problems only after many years	40.2	40.2	1.000
	May cause cancer	23.0	21.4	0.73
Curability/controllability	Regarding this condition			
	There are things I can do to avoid this illness	85.5	68.4	<0.001
	Medications may cure this illness	92.3	24.8	<0.001
	Vaccines can prevent this illness	93.2	78.6	0.001

HIV, human immunodeficiency virus; HCV, hepatitis C virus.

#### Curability/controllability

Significantly, more participants accurately believed that they could take measures to avoid contracting HIV when compared to HCV (86% and 68%, respectively,  $P < 0.001$ ). The majority of participants (92%) accurately believed that medications would not cure HIV. In contrast, only one quarter of participants accurately believed that medications could cure HCV (curative treatments were available for this infection at the time this study was conducted).

#### Overall health beliefs

By each health belief domain and for the survey overall, beliefs were significantly more accurate for HIV than for HCV (Table 4). Specifically, health belief accuracy for HIV

was greatest in the curability/controllability domain (90%) and for HCV in the causes domain (73%). Health beliefs for both diseases were the least accurate in the timeline/consequences domain.

#### Factors associated with overall health belief accuracy

Linear regressions were performed for both HIV and HCV to determine any factors that might be associated with greater health belief accuracy for either disease. Only female gender was significantly associated with greater health belief accuracy and only in our adjusted model for HIV ( $P = 0.02$ ).

## DISCUSSION

In this study of inner-city adults from a community at high risk for HIV and HCV, participants were more likely to have inaccurate health beliefs about risks factors for causes, sequelae and control of HCV than of HIV. Overall, our results demonstrate that study participants have accurate health beliefs for HCV only 58% of the time. Furthermore, as hypothesized, our study population demonstrated significantly less accurate health beliefs about HCV than about HIV, despite the fact that participants were recruited from a community with higher prevalence of HCV than of HIV. This discrepancy in health beliefs for the two infections was present for several key domains within the Common Sense Model.

Results of our study also highlight specific health belief inaccuracies that might be important targets for public health interventions. When compared to HIV, fewer

**Table 4** Health belief accuracy by belief domain, HIV vs HCV

Belief domain	% participants with accurate beliefs, HIV	% participants with accurate beliefs, HCV	P value
	Mean	Mean	
Causes	87.3	73.4	<0.001
Timeline	71.8	43.0	<0.001
Consequences			
Controllability	90.3	57.3	<0.001
Overall	81.7	58.0	<0.001

HIV, human immunodeficiency virus; HCV, hepatitis C virus.

participants accurately believed that HCV could be prevented, fewer believed that HCV could be transmitted by sharing needles, and less than half accurately believed that it is a potentially life-long infection. The fact that beliefs were more accurate for HIV than for HCV in our study suggests that lessons might be learned from successful HIV interventions to improve similar health beliefs about the risk for and long-term consequences of HCV.

In contrast with HIV that cannot yet be cured, HCV treatments are curative (defined as sustained viral response 6 months after completing treatment). While treatment with pegylated interferon and ribavirin is involved and often arduous, a sustained viral response can be obtained in 40–80% of treated cases of chronic HCV, depending on viral genotype and certain patient characteristics. Furthermore, the advent of new therapies suggests that cure rates may rise in the near future. Yet, only 25% of our study participants believed there to be a potential cure for HCV infection. In general, low uptake of HCV treatment poses a persistent challenge – despite the possibility of SVR, 20–30% of patients with HCV initiate and complete therapy [26,27]. The decision to initiate treatment for HCV is complex and health beliefs may pose an important component. The commonly held belief among patients in our study that HCV is not curable may stem in part from limited knowledge about treatment options. It is also possible that treatment side effects or treatment failures have been disproportionately represented in our survey community, thus contributing to the belief that HCV is not curable.

A number of additional associations deserve comment. First, only one quarter of our survey participants accurately believed that both HIV and HCV can cause cancer. These are concerning results as HCV continues to represent the leading cause of liver transplantation in the United States, contributing significantly to growing rates of cirrhosis and hepatocellular carcinoma [28]. Similarly, since the advent of HAART, rates of cancer – in particular non-AIDS malignancies – continue to rise in the HIV-infected population [29,30]. It may be difficult for individuals to modify perceptions of HIV and HCV as infectious diseases that are capable of resulting in long-term, even chronic, health consequences. Interventions to improve health beliefs about HIV and HCV might highlight the growing overlap of infectious disease elements with long-term, chronic disease characteristics within these illnesses. Helping patients understand that engaging in healthier behaviours related to HIV and HCV may prevent not just the infection, but also the development of chronic disease and cancer, may prove to be a compelling public health strategy. Sylvestre *et al.* [31], for example, have demonstrated that peer-based educational interventions have successfully engaged members of an urban community of drug users in care, with subsequent increases in HCV testing and treatment uptake. Broader application of these techniques might serve to improve health beliefs and HCV health outcomes in additional at-risk communities.

Second, the association between female gender and accurate health beliefs about HIV deserves some exploration. Perhaps this association reflects the fact that women, more often than men, participate in the health care system and in accessing community-based health information – either in caring for themselves or as caregivers for others [32–34]. As a result, women may come into contact more often with accurate health information, may be more motivated themselves to seek screening and treatment in general, and may be more likely to encounter others seeking screening and treatment for HIV. These factors may subsequently contribute to more accurate HIV health beliefs.

To our knowledge, at present there are no studies formally comparing health beliefs about HIV and HCV in an at-risk community in the United States, using the Self-Regulation model. Several limitations of our study are worth noting. The overall sample size and response rate were modest. Yet the sociodemographics of participants in our study were representative of the clinic population in general, and the high rate of Medicaid insurance was reflective of the study community at large. In addition, our study was conducted in a single, hospital-based, academic internal medicine practice, and findings should therefore be interpreted carefully in the context of other settings. Interviews for this study were conducted in-person, which may have resulted in some response bias because of the highly personal and sensitive nature of some of the survey questions. Less-public approaches to asking them, such as audio computer assisted self-interviews, might have been more effective at eliciting some participants' health beliefs. In addition, 'history of sex without a condom with a person at risk for HCV' was included as an independent variable in our regression model. Use of this variable as a predictor is ambiguous, as evidence in the time period since this study was conducted demonstrates that HCV is not a sexually transmitted infection in the traditional sense, given that its mode of transmission is blood borne. Finally, our study suggests that further research might explore health beliefs compared to health knowledge in a similar population.

Prominent public health messages about HIV appear to have largely been received and remembered by this at-risk population. This does not appear to have been the case with HCV in this same population, despite shared risk factors. This deficit, therefore, is likely not due to underlying low health literacy of this population. Instead, it may reflect that our study population has not been effectively exposed to detailed HCV public health messages or that these messages simply do not exist. As Klein *et al.* describe, despite the creation of the National Hepatitis C Prevention Strategy in 2001, federal funding for HCV in the United States through the Centers for Disease Control and Prevention Division of Viral Hepatitis has been limited to supporting HCV coordinators on a State level. Thus, federal funding has not been sufficient for the development of sustainable HCV public health prevention programmes or services implementation [35].

Furthermore, if HCV public health messages have been created on a local level, they may not have effectively connected with our study population. As the burden of HCV infection continues to mount in the United States and promising new therapies become available to combat it, screening and treatment must increase beyond their current, disappointingly low rates. The Institute of Medicine recently acknowledged this need when it issued its Report on Hepatitis Prevention and Control, which recommends the development of national public health strategies to improve awareness of HCV in at-risk communities and in the general population [3]. Disseminating accurate information about HCV may be a key element to modifying patient behaviour and may subsequently result in better health outcomes for patients. Educational efforts should extend beyond providing correct health information to improve knowledge and should also address specific socio-cultural experiences that influence the development of health beliefs to perhaps foster healthier behaviours.

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