

Formal Patient Education Improves Patient Knowledge of Hepatitis C in Vulnerable Populations

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Received: 2 June 2010 / Accepted: 5 October 2010 / Published online: 24 October 2010
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Abstract

Background Hepatitis C (HCV) knowledge is limited in injection drug users (IDU). Vulnerable populations including IDUs are disproportionately affected by HCV. Effective HCV education can potentially reduce disparity in HCV prevalence and its outcome in this population.

Aim This study aimed to assess the impact of formal HCV education and factors associated with improved HCV knowledge in the vulnerable population.

Methods Over 18 months, 201 HCV-infected patients underwent a 2-h standardized education and completed demographic and pre- and post-education questionnaires.

Results Patient characteristics were: 69% male, mean age 49 ± 10 , 49% White (26% AA, 10% Latino), 75% unemployed, 83% high school education and above, 64% were IDU, and 7% were HIV co-infected. On multivariate analysis, baseline knowledge scores were higher in patients with at least a high school education (coef 7.1, $p = 0.045$). Baseline knowledge scores were lower in African Americans (coef -12.3 , $p = 0.004$) and older patients (coef -0.7 , $p = 0.03$). Following HCV education, the overall test scores improved significantly by 14% ($p = 0.0001$) specifically in the areas of HCV transmission ($p = 0.003$), general knowledge ($p = 0.02$), and health care maintenance ($p = 0.004$).

There was a high compliance with liver specialty clinic attendance following education.

Conclusions Formal HCV education is effective in improving HCV knowledge. Although White race, younger age, and higher education were predictors of having more HCV knowledge prior to education, all patients independent of racial background had a significant improvement in their knowledge after education. Therefore, promoting effective HCV education among vulnerable populations may be an important factor in reducing the disparities in HCV disease.

Keywords Hepatitis C · Hepatitis C education · Vulnerable populations · Hepatitis C knowledge · Disparity of care

Abbreviations

HCV Hepatitis C virus
IDU Injection drug user

Introduction

Hepatitis C virus (HCV) affects 4.1 million Americans and is the leading cause of chronic liver disease and death from liver disease in the country [1]. The diagnosis of hepatitis C can also affect a person's quality of life, finances, productivity, and psychological status [2, 3]. Prior studies have shown that HCV-infected individuals have limited knowledge of HCV disease and improvement in HCV knowledge can influence a patient's decision to explore and initiate HCV therapy [4, 5].

The majority of studies evaluating the impact of HCV education on patients' health have focused on injection

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drug users (IDUs) and often within the context of drug treatment programs [6, 7]. IDUs are considered hard to reach populations with a high prevalence of HCV infection [8]. Drug treatment programs therefore represent an opportunity for providing health care to these individuals. In addition, many IDUs are actively using drugs at the time of HCV diagnosis, thereby education about modes of transmission of HCV is important to prevention of transmission of HCV in this population. Studies to date have shown that IDUs have many misconceptions about HCV transmission, symptoms, clinical markers, and treatment, including a perceived fear of HCV treatment [4, 9]. These individuals are generally interested in educational services and improved knowledge of HCV disease is associated with increasing interest in receipt of HCV treatment [7, 10].

Although IDUs are considered a vulnerable population and represent the majority of HCV-infected individuals within the safety net system, these findings may not necessarily be applicable to other non-IDU vulnerable populations with HCV infection who are uninsured or underinsured with limited access to care. In addition, while HCV education can vary among different health systems and studies have shown that patients attending liver specialty clinics have higher HCV knowledge compared to those in the primary care setting, there are reports of sub-optimal (60%) rates of formal education among patients attending specialty clinics [11]. The purpose of this study was to prospectively evaluate the impact of formal HCV education given by liver specialty providers on patient's knowledge of hepatitis C disease and interest in pursuing liver specialty care for evaluation of HCV therapy among a large cohort of vulnerable and ethnically diverse safety net population.

Methods

Subject Eligibility

The Hepatology service at San Francisco General Hospital and Trauma Center, a safety net institution affiliated with University of California San Francisco (UCSF), instituted a formal HCV education session accessible to all HCV-infected individuals within San Francisco's safety net healthcare system. The initial diagnosis of HCV infection was made by the primary providers. Primary providers refer their adult patients for HCV education prior to being permitted to have their patients scheduled for the liver specialty clinics. Patients who attend the education session may or may not be candidates for HCV therapy but referral to liver specialty clinics are primarily made for consideration for initiation of HCV therapy.

The study population consisted of subjects attending this educational session. All study participants provided informed consent prior to enrollment. This study was approved by the UCSF Committee on Human Research and SFGH Data Governance Committee.

Education Session

The HCV education session consisted of a 2-h standardized in-person didactic PowerPoint presentation facilitated by a specialized hepatology nurse practitioner. Up to 25 subjects attended each session. The session was offered in English and with the aid of certified interpreters in Spanish, Cantonese, and Vietnamese. Subjects were encouraged to ask questions during the session and each session was followed by an interactive discussion. The educational materials consisted of information on HCV diagnosis, symptoms, transmission, natural history, assessment of severity of liver disease and candidacy for treatment, virologic response rates with PEGylated interferon and ribavirin combination therapy, adverse effects of treatment, and resources for obtaining further HCV healthcare and specialty access.

Data Collection Procedures

Participants completed a demographic questionnaire at baseline followed by a questionnaire assessing HCV knowledge as well as interest in obtaining HCV care and treatment both before (pre-education) and immediately after (post-education) completion of the session (Table 1). The questionnaire was developed by study investigators, reviewed by three hepatology providers and pilot tested in 20 patients and revised. Subjects who then attended the liver specialty clinic were asked to complete another post-education questionnaire at the time of their clinic visit in order to assess the retention of knowledge overtime. The pre-education and post-education questionnaires consisted of 31 multiple-choice and true/false questions. The total number of correct answers was then scored for overall knowledge and also in the following knowledge categories (assigned by the investigators): HCV general knowledge, HCV diagnosis, HCV transmission, HCV treatment, and health care maintenance.

Statistical Analysis

Baseline characteristics of subjects were summarized using mean \pm SD, median (range), and frequencies. Paired *t* test was used to assess the change in knowledge score after education overall and within each knowledge categories. Univariate analysis using *t* test and analysis of variance was performed evaluating factors associated with

Table 1 Summary of components of HCV knowledge questionnaire

Multiple-choice questions	Correct at baseline (%)
Hepatitis C is caused by?	83
What is hepatitis C?	51
How does a person know that he/she has hepatitis C?	65
What is the treatment for hepatitis C?	65
What are the side-effects of treatment for hepatitis C?	51
<i>True or false questions</i>	
Hepatitis C is a common chronic disease	51
Hepatitis C has different genotypes	44
Genotype 1 is the most common in the United States	27
Hepatitis C usually has no symptoms	37
Hepatitis means inflammation of the liver	89
Alcohol makes hepatitis C disease worse	95
Most people with hepatitis C develop liver cancer	54
Most people with hepatitis C do not develop cirrhosis	29
Most people with hepatitis C eventually need a liver transplant	69
People with HIV can also receive hepatitis C treatment	79
Liver biopsy is helpful in assessing damage to the liver from hepatitis C	78
There are vaccines available for	
Hepatitis A	74
Hepatitis B	76
Hepatitis C	38
How does a person get or spread hepatitis C?	
Sharing needles	88
Blood transfusion	83
Through childbirth	35
Hugging	58
Toilet	61
Sexual intercourse	63
Tattoos/piercings	78
Sharing food/utensils	57
Sharing razor	74

pre-education knowledge scores and change in knowledge score following education. Multivariate regression modeling was used to evaluate factors independently associated with pre-education score and change in knowledge score following education. A p value < 0.05 was considered statistically significant. All analysis was performed using STATA version 8.0 (STATA Corp., College Station, TX).

Results

From October 2007 to June 2009, 201 HCV-infected subjects who attended the HCV education session participated in the study and 197 subjects completed both pre-education and post-education questionnaires. Subjects were mostly middle-aged males who were unemployed with incomes of

less than \$15,000 per year (Table 2). Approximately half of the subjects were minorities and had high school or higher education. About two-thirds had a history of IDU and heavy alcohol use. Although patients were referred by their primary providers to the sessions, 13% indicated that they had never heard of HCV. Among those who had heard of HCV, 64% learned about HCV from their primary care providers and the rest of the subjects had most commonly heard of HCV from friends/family members, magazines/books/newspapers, and media. The majority of subjects were interested in receiving HCV therapy (97%).

At baseline, the overall mean percent knowledge score was 61. The percent baseline HCV knowledge scores were significantly higher in individuals with age less than 45 years (68 vs. 58, $p = 0.01$), White race (70 vs. 53, $p = 0.007$), high school and above education (66 vs. 56, $p = 0.006$), income less than \$15,000 per year (65 vs. 51,

Table 2 Patient characteristics ($n = 201$)

Age mean \pm SD (years)	49 \pm 10
Males (%)	136 (69)
Race/ethnicity (%)	
Caucasian	96 (49)
African American	51 (26)
Latino	20 (10)
Asian/Pacific Islander	13 (7.0)
Other	15 (8)
Born in United States (%)	161 (83)
Married/living together (%)	29 (15)
Temporary housing or homeless (%)	36 (18)
Employed (%)	48 (25)
Income: \$15,000 or less (%)	135 (74)
High school and above education (%)	159 (83)
HIV co-infection (%)	14 (7)
Methadone maintenance/drug rehabilitation program (%)	31 (16)
Current alcohol use (%)	21 (13)
History of heavy alcohol use > 50 g/day (%)	100 (59)
HCV risk factors (%)	
IDU	125 (64)
Blood transfusion	49 (26)
Sexual	17 (9)
Other	10 (5)
Never heard of hepatitis C (%)	25 (13)
Prior treatment of hepatitis C (%)	23 (12)

$p = 0.0001$), exposure to hepatitis B (72 vs. 60, $p = 0.003$), and current or prior history of IDU (65 vs. 53, $p = 0.001$). On multivariate analysis, education of high school and above was independently associated with higher baseline knowledge scores and African American (compared to White) race and older age were associated with lower baseline knowledge scores (Table 3).

Following HCV education, the mean percent knowledge score improved by 14 points (61–75, $p < 0.0001$). Patients specifically gained the most knowledge in three categories (Table 4): HCV transmission (mean change in percent score = 10, $p = 0.0003$), HCV general knowledge (mean change in percent score = 16, $p = 0.02$), and health care maintenance (mean change in percent score = 17, $p = 0.004$). Although there was an improvement in knowledge in the categories of HCV diagnosis, HCV natural history, and HCV therapy, these changes did not reach statistical significance.

There was a greater increase in HCV knowledge in those who were employed (mean change in percent score 19 vs. 13, $p = 0.01$). Other potential predictors such as gender, age, racial background, US birth, education level, marital status, mode of acquisition of HCV, alcohol use or IDU use, methadone maintenance therapy, and presence of HIV

Table 3 Multivariate analysis of predictors of knowledge scores prior to HCV education

Variable	Coefficient	95% CI*	p value**
Age	-0.7	-1.3 to -0.8	0.03**
Female gender	-1.8	-10 to 6.5	0.7
Race (compared to White)			
African American	-12.3	-20.8 to -3.9	0.004**
Latino	-10.0	-23.9 to 3.83	0.2
Asian	1.8	-23.2 to 26.8	0.9
Other	-5.0	-19.9 to 9.9	0.51
Education: high school and above	7.1	0.2 to 14.0	0.045**
IDU	-5.1	-13.3 to 3.2	0.2
Methadone maintenance	6.2	-3.6 to 15.9	0.2
Current alcohol use	-0.06	-0.6 to 0.5	0.8
High interest in obtaining medical care	7.2	-0.4 to 14.8	0.06

* 95% confidence intervals; ** $p < 0.05$ is considered significant

Table 4 Change in knowledge score after HCV education

Knowledge categories	Mean change in % knowledge score	95% CI*	p value**
HCV transmission	10	6 to 14	0.0003**
HCV diagnosis	9	-56 to 74	0.3
HCV knowledge	16	3 to 29	0.02**
Natural history of HCV	13	-4 to 30	0.1
HCV treatment	10	-7 to 29	0.2
Health care maintenance	17	12 to 22	0.004**

* 95% confidence intervals; ** $p < 0.05$ is considered significant

coinfection were not different. On multivariate analysis, the only independent predictor of change in HCV knowledge after education was interest in obtaining medical care for medical conditions. Patients who were interested in obtaining medical care had a 6.7% (95% CI -11.3 to -2.1, $p = 0.005$) lower change in knowledge scores after education compared to those who were not interested in obtaining medical care.

Interest in HCV Treatment and Specialty Referral After Education

After education, once again the majority of subjects (94%) indicated that they were interested in HCV treatment and referral to a liver specialist. Since 2005, interested HCV patients have been scheduled in the liver specialty clinics within the San Francisco safety net system following approval by a hepatologist who reviews the electronic referral submitted by the primary provider and who

determines potential candidacy of the patient for HCV treatment work-up. Before initiation of the HCV education class (historical control) and during the same length of time as the study period (19 months), 322 patients were referred to the liver specialty clinics and 180 (56%) were scheduled in the liver specialty clinics. A similar number of patients were referred ($n = 358$) and scheduled ($n = 206$, 58%) in the liver specialty clinics during the study period ($p = 0.4$). However, there were significantly higher show rates in the liver specialty clinics among those who were scheduled after initiation of mandatory education class than the historical controls who did not receive disease-specific formal education (64 vs. 39%, $p < 0.0001$). The characteristics of patients who were scheduled in the liver clinic and attended their visit during the study period was similar to the historical control with respect to mean age (52 ± 11 vs. 53 ± 10 years, $p = 0.4$), gender (proportion male 59 vs. 65%, $p = 0.4$), and race (White 38 vs. 35%, African American 22 vs. 34%, Latino 17 vs. 10%, $p = 0.3$).

Long-Term Retention of HCV Knowledge After Education

Nineteen study subjects who attended the liver specialty clinic after HCV education agreed to complete the same post-education questionnaire at the time of their clinic visit to evaluate retention of HCV knowledge. The primary reason for low response rates was related to the time constraints on patients (and providers) to complete the questionnaire during the busy clinic setting. In these patients, their HCV knowledge immediately after education had substantially improved compared to before education (mean percent score 45–64, $p = 0.005$). The median time elapsed between attending the HCV education class and liver clinic visit was 4 months (range 1–13 months). The mean percent knowledge scores at the time of liver clinic attendance were similar to that immediately following education session (61 vs. 65, $p = 0.7$) suggesting that HCV knowledge following education can be retained long-term.

Discussion

In this study, we have shown that HCV education substantially improves patient knowledge of HCV disease in the vulnerable, ethnically diverse, safety net population. Although we identified gaps in almost all areas of HCV knowledge, patients gained the most knowledge in the categories of general HCV disease knowledge, HCV transmission, and health care maintenance. We also showed that HCV knowledge may possibly be retained long-term. Moreover, there were substantially higher liver

clinic show rates compared to those who were not offered disease-specific education.

Our education session was specially designed to encompass all aspects of HCV disease management from diagnosis, transmission, natural history, candidacy for treatment, and benefits and adverse effects of therapy, to resources for access to specialty care and general health care maintenance. In a study of 115 patients with newly diagnosed HCV, the most common volunteered patient concerns included disease progression, premature death, infecting family members and side-effects of treatment [3]. This highlights the necessity for a comprehensive HCV educational program such as that implemented in our study in order to adequately address patient's concerns.

We have shown that African American race, older age, and lower level of education are independently associated with lower HCV knowledge. This is consistent with disparities of access to care that have been previously described in the vulnerable populations [7, 12]. Similarly, in a cohort of 110 patients attending a methadone detoxification and methadone maintenance program in San Francisco, Walley et al. [7] showed that White race and Latinos had significantly higher knowledge of HCV treatment than African Americans. However, we have also shown that the gain in knowledge after education was similar across all ages, genders, and racial background, suggesting that HCV education can play an important role in reducing health care disparity in this population. The fact that patients who were interested in obtaining medical care had a lesser change in knowledge scores after education was likely because these patients were well informed about HCV disease at baseline with higher knowledge scores compared to those who were not interested in obtaining medical care (66 vs. 58%, $p = 0.05$).

Prior studies have shown a large gap in HCV knowledge about HCV therapy in IDUs [7, 13]. We found that IDUs had 12% higher baseline knowledge scores compared to other HCV-infected individuals. This may reflect heightened awareness of HCV in this population due to the high prevalence of HCV among peers, exposure to substance abuse counselors and mental health professionals, and potentially integrated substance abuse and HCV management in this population [14]. This result also suggests that there is likely a great need in educating individuals with modes of acquisition of HCV other than IDU.

Despite being engaged with the health care system and being referred by their primary providers, 13% of our study subjects had never heard of HCV prior to the session and 36% had become aware of HCV from sources other than primary providers. A survey of 388 family physicians in New Jersey showed that family physicians had insufficient knowledge about screening and counseling for chronic hepatitis and 83% of respondents were interested in

receiving education about chronic hepatitis [15]. In addition, a survey of 629 chronically infected veterans showed that only 60% of patients who attended liver specialty care underwent formal HCV education [11]. While our study was not designed to address health system or institutional barriers to access to HCV care, the initiation of an educational session provided by liver specialists along with a patient-centered approach to HCV management has substantially improved access to HCV care in our population. A significantly higher proportion of patients attended their liver specialty clinic visit after initiation of the educational sessions, and about 30% had received HCV therapy during the study period. In addition, the wait times for liver specialty clinic appointments have been reduced from 6 to 2 months in our safety net system.

Since the HCV education class was instituted as a mandatory component of referral of patients with HCV to the liver specialty clinics in this safety net system, the study was limited by a lack of randomization of patients to education versus no education class in determining the rates of liver specialty clinic attendance. However, we were able to utilize a historical control of HCV patients prior to initiation of education class to compare liver specialty clinic show rates in those with scheduled appointments. Both the study patient cohort and the historical controls likely represent individuals who are motivated to receive HCV therapy and management. Therefore, selection bias is unlikely to play a role in our finding that HCV education significantly improves liver specialty clinic attendance rates when these cohorts are compared. The low response rate to the questionnaire in the busy clinic setting was primarily related to the time constraints on patients and selection and/or reporting biases are less likely to have played a significant role in the reported retention of HCV knowledge long-term in nearly one-quarter of patients. Nevertheless, this result requires confirmation with a larger number of patients.

In summary, education plays an important role in improvement of HCV knowledge in HCV-infected subjects. Although African Americans and older individuals had lower baseline HCV knowledge, the improvement of HCV knowledge was observed across all ages, racial backgrounds, IDUs, education levels, and socioeconomic status. As vulnerable populations are disproportionately affected by HCV and adverse disease outcomes, this suggests that promoting effective HCV educational programs among vulnerable populations may be an important factor in reducing the disparities in HCV disease. Prior studies have shown that HCV patients consider HCV education as an important HCV health care need that results in a marked increase in willingness to accept HCV treatment [16, 17]. A patient-centered approach to health care in HCV-infected vulnerable population is likely to result in higher

compliance with pursuing HCV health care and potentially create efficiencies in the health system to better access specialty care for these individuals.

Acknowledgments National Institute of Health Grant numbers R01 DK074673 (M.K.), P30 DK 026743 (UCSF Liver Center), ADA Grant number 1-08-CR-30 (M.K.). H.F.Y. was supported in part by the William and Mary Ann Rice Memorial Distinguished Professorship.

Conflict of interest No conflicts of interest exist.

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