ORIGINAL PAPER



Health Beliefs and Co-morbidities Associated with Appointment-Keeping Behavior Among HCV and HIV/HCV Patients

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Abstract Appointment-keeping behavior is an important requisite for HCV linkage and treatment initiation. In this study we examine what impact hepatitis C (HCV) knowledge and attitudes has on appointment-keeping behavior among a cohort of HCV and HCV/HIV patients. Knowledge scores and attitude scales, obtained from a cross-sectional survey, were correlated with proportion of appointments kept 1 year prior to taking the survey. Independent risk factors for missing appointments were examined by multiple regression analysis. 292 HCV patients completed the survey, and 149 (51 %) were co-infected with HIV. HCV patients kept 67.5 \pm 17.4 % of their total appointments and a similar proportion (67 \pm 38.2) of Liver Clinic appointments, but they attended a higher proportion (73 ± 24.4) of Primary Care Clinic appointments. However, certain health beliefs, psychiatric illness, and HIV co-infection were independently associated with lower levels of appointment-keeping behavior. HCV knowledge was not associated with appointment-keeping behavior. Health beliefs, psychiatric illness, and HIV co-infection are associated with missing appointments, but no link between knowledge and appointment keeping behavior is apparent. In order to increase engagement into HCV care, HCV care coordination

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programs need to focus on addressing health beliefs and providing resources to those at highest risk for missing appointments.

Keywords HCV \cdot Appointment-keeping behavior \cdot HIV \cdot Health beliefs

Introduction

HCV treatment, especially with new oral therapies, can cure a high proportion of infections [2, 3, 9, 21, 22, 26] and halt disease progression [23]. Yet studies have shown that the proportion of patients actually placed on treatment is less than 10 % [7]. Barriers to treatment include treatment side effects, medical co-morbidities, and lack of patient interest [17]. Studies examining referrals to HCV treatment and engagement have found high rates of drop-out especially among injection drug users in the early stages of service delivery [14]. Prior studies conducted in HCV-infected patients have demonstrated the following patientrelated factors deterring HCV care: lack of adequate financial resources, lack of knowledge of HCV, feeling stigmatized, and having to travel long distances or devoting extra time for a liver/HCV clinic visit [6, 25]. Other studies have also shown that psychiatric co-morbidities affect patients' health-seeking behavior for HCV [6, 15]. Yet no studies have examined the relationship of health beliefs and appointment-keeping behavior.

Adherence to appointments is often used as a criterion to determine a patient's interest in and motivation for HCV treatment. In other disciplines such as HIV, failure to keep appointments has been linked to higher rates of mortality due to medication non-compliance [11]. Thus missed appointments suggest an inability to adhere to medications

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which can reduce the likelihood of treatment initiation for HCV. A study among US veterans found a 41 % discontinuation rate due to reasons other than lack of response with pegylated interferon and ribavirin regimen [12]. Although the new generation of all oral HCV therapies have fewer side-effects and shorter duration, poor adherence will likely lead to a failure in achieving a sustained viral response (a clinical cure). In addition, poor adherence increases the risk of resistance developing to one or more classes (i.e., NS3/4a protease, NS5A or NS5B polymerase inhibitors) of the oral treatment regimen thus limiting future treatment options. Appointment-keeping behavior has been shown to be a proxy for likelihood of an individual to adhere to medications [8, 24]. This study examines appointment-keeping behavior in HCV-infected patients and analyzes clinical characteristics, demographics, knowledge, and health beliefs, to give insight into why some patients with HCV may not engage in care. More importantly, understanding which patients are at risk for not keeping-appointments and potentially being medication non-adherent can help prioritize those who may need additional HCV care coordination in order to succeed in HCV treatment.

Materials and Methods

Population

Patients over 18 years of age with HCV or HCV/HIV coinfection were recruited between November 2009 and February 2011 from the Parkland Health and Hospital System, the safety-net hospital for Dallas County. Patients were recruited from the Parkland HIV, Liver, and Primary Care Clinics, as well as from local substance-abuse treatment centers and recovery housing centers as long as HCV infection could be verified. Patients were excluded if they had substantial cognitive impairment or were not proficient in English or Spanish.

Study Design and Data Collection

A cross-sectional survey assessment was developed from validated questions in the published literature with themes elicited from prior focus groups and given to prospectivelyenrolled patients who provided written informed consent. The survey had 121 questions and took 45–60 min to complete. Patients had the option of taking a computerized or written survey, each one available in both English and Spanish. The study was approved by the UT Southwestern Institutional Review Board. Data were collected regarding demographics, medical history, knowledge of both HCV and HIV, and attitudes/health beliefs towards HCV infection. Participants were asked several questions about having a diagnosis of depression or other psychiatric illness.

Data pertaining to appointment-keeping behavior was collected from medical records from those who received care through the Parkland system. The frequency of keeping appointments was examined by reviewing the number of clinic appointments kept compared to the number of scheduled appointments during the 1 year prior to the date of taking the survey. Appointment-keeping behavior was divided into and examined in three categories. First, the proportion of total appointments kept, including specialty care, primary care, nutrition, radiology, etc., was examined to evaluate the general pattern of keeping appointments. Second, the proportion of primary care appointments was examined to determine the behavior and interest in primary versus liver specialty care. The primary care provider was determined by listing in the medical record; for the HIV patients this was an HIV provider and for the HCV mono-infected patients, an internal or family medicine provider. Finally, Liver Clinic appointments were examined because treatment for HCV was offered only in these clinics. Liver specialty appointments were classified as those at the Parkland Liver Clinic or the HIV Hepatitis Clinic. Only patients with a record of "no show" were considered missed visits. Other changes in the schedule were not counted as missed visits. Patients for whom no appointments were found in the year prior to taking the survey were not included in the analysis.

Data Analysis

Data pertaining to demographics, proportion of appointments kept, knowledge scores, and attitudes regarding HCV treatment were first computed descriptively as counts, proportions, and means. Knowledge questions were organized into scales, with those unanswered or incorrect assigned a zero and the correct ones summed to obtain a knowledge score. Attitude questions appear in quotations as they appeared on the survey, but data for some of these items were realigned to reflect undesired response values (e.g., indifference, shame, stigma, and fear) by reversing response codes for questions originally phrased toward 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. The relationships between proportion of appointments kept with knowledge scores, attitudes, and HIV disease status were examined by Spearman's correlation. Non-parametric tests were used to examine the relationships of appointments kept with clinical and demographic variables. Attitudes correlating negatively with proportion of kept appointments were examined by multiple regression model adjusting for clinical and demographic risk factors. All analyses were performed using SAS Version 9.2 (SAS Institute, Inc., Cary, NC, 2008).

Results

Demographics and Patient Characteristics

A total of 292 patients with HCV agreed to participate in the cross-sectional survey. Demographic information was missing for 5 patients. The survey group was predominantly African-American men with a mean age of 51 years (see Table 1). 51 % of the participants were co-infected with HIV. The mean years of school completed was 11.7 ± 2.0 and 31.6 % of the participants reported being unemployed. "Employed" included those who reported being full time employed, part time employed, full time students, retired individuals or those on disability; all others were "unemployed." 61 % of the participants reported a diagnosis of one or more psychiatric disorders 53 % reported past or current injection drug use.

Table 1	Demographic	and	clinical	characteristics	of	the	survey
group							

Characteristic	N = 292 N (%)
Race/ethnicity*	
White	77 (26.7)
Black	168 (58.3)
Hispanic	16 (5.2)
Other	43 (14.9)
Male*	184 (63.9)
HIV-infected	149 (51)
Age [mean (years) \pm SD]	50.6 ± 8.4
Employment*	199 (68.4)
Disability*	128 (44)
Education completed [mean (years) \pm SD]*	11.7 ± 2.0
Drinks of alcohol per week (mean \pm SD)*	2.1 ± 6.0
History of injection drug use*	152 (53.3)
History of psychiatric illness**	177 (61.3)

* Missing data

** Psychiatric disorders included: major depression, psychoses, and bipolar disorder

Appointment-Keeping Behavior

Appointment-keeping behavior was examined in three ways (see Table 2). Overall, HCV patients kept about twothirds of the total scheduled appointments in the previous 1 year. Almost three-fourths of primary care provider appointments and two-thirds of liver specialist appointments were kept. In the survey, participants were asked, "What has made it difficult for you to get the hepatitis C care you need?" Among the 182 who answered this question, the two most common barriers identified were, "I don't like to think about HCV" (28 %) and "I don't know where to get treatment [for HCV]" (28 %). Other less common reasons included inability to pay for clinic visits (17 %), inability to pay for prescriptions (15 %), and lack of transportation (13 %).

Association of Appointment-Keeping Behavior with Patient Characteristics

Factors significantly associated with fewer kept appointments for all clinics and procedures (see Table 2) included African-American race, HIV infection, and psychiatric comorbidities. For primary-care appointments, those with psychiatric co-morbidities and HIV-co-infection were found to have a lower proportion of appointments kept. For Liver Clinic appointments, HIV-infected patients kept a significantly lower proportion of Liver Clinic appointments compared to patients with HCV alone. Age, sex, disability, and history of injection drug use (IDU) were not associated with appointment-keeping behavior.

Correlation of HCV Knowledge and Attitudes with Appointment-Keeping Behavior

There was no correlation between HCV knowledge and appointment-keeping behavior. Patients were asked about their health beliefs regarding HCV in an Agree/Do Not Agree format. The attitudes or health beliefs assessed in the survey were correlated with appointment-keeping behavior in the prior year, and those with a significant association are presented in Table 3.

All questions on HCV-associated health beliefs were focused on perceptions of or barriers toward HCV treatment. Most of the health beliefs that were negatively correlated with appointment-keeping behavior reflected themes such as fear, isolation, and indifference. Patients who agreed with "I will not be able to work if I get treatment for my hepatitis C" were also those who kept fewer appointments for any clinic. Those who agreed with the statement, "Waiting too long to get an appointment to see a doctor about my hepatitis C makes me feel that hepatitis C must not be that important to treat" kept a lower

 Table 2
 Association of appointment-keeping behavior with demographic and clinical variables

ype of appointment Patient characteristic		Percent of appointments kept (Mean \pm SD)	p value	
Primary Care Clinic*		73 ± 24.4		
Liver Clinic**		67 ± 38.2		
Total appointments***		67.5 ± 17.4		
Race				
Primary Care Clinic	African American	73 ± 22	0.18	
	Non-African American	75 ± 28		
Liver Clinic	African American	61 ± 41	0.15	
	Non-African American	73 ± 34		
Total appointments	African American	65 ± 17	0.008	
	Non-African American	70 ± 18		
Employment status				
Primary Care Clinic	Unemployed	75 ± 25	0.27	
	Employed	76 ± 23		
Liver Clinic	Unemployed	63 ± 41	0.16	
	Employed	77 ± 28		
Total appointments	Unemployed	66 ± 18	0.09	
	Employed	70 ± 17		
HIV co-infection				
Primary Care Clinic	Co-infected	71 ± 23	0.014	
	Mono-infected	76 ± 26		
Liver Clinic	Co-infected	52 ± 44	0.003	
	Mono-infected	78 ± 29		
Total appointments	Co-infected	63 ± 7	<0.0001	
	Mono-infected	72 ± 17		
Psychiatric co-morbidities				
Primary Care Clinic	Present	71 ± 24	0.004	
	Absent	78 ± 4		
Liver Clinic	Present	66 ± 39	0.98	
	Absent	67 ± 38		
Total appointments	Present	65 ± 17	0.004	
	Absent	71 ± 18		

Bold values indicate statistical significance (p < 0.05)

* Includes appointment with HIV, family medicine, or internal medicine provider

** Includes appointment with hepatology or HIV hepatitis specialist

*** Includes all appointment types including specialty care, primary care, radiology, nutrition, etc.

proportion of appointments for any clinic and also a lower proportion of Primary Care Clinic appointments. Those who agreed with the statement, "My regular doctor not talking to me about my hepatitis C makes me feel that my hepatitis C must not be that important to treat" had kept fewer Primary Care Clinic appointments. Patients who agreed with "I do not want to be treated for hepatitis C because it will make my other diseases worse" had kept fewer Primary Care Clinic appointments. Those who agreed with "Having no one to talk to about my hepatitis C makes me feel alone" had kept fewer Primary Care Clinic and Liver Clinic appointments. Those who agreed with "Too much information about hepatitis C will scare me from wanting to be treated" also had kept fewer Liver Clinic appointments. The only statement positively correlated with appointment-keeping behavior for any clinic was "Treating hepatitis C will make my life better."

Multiple regression analysis with each attitude was adjusted for age, sex, race, employment, education, HIV co-infection, and psychiatric co-morbidities. As seen in Table 4, participants who indicated dissatisfaction with waiting too long to see a liver specialist had infrequent overall appointments kept for any clinic. In addition, HIV co-infection was found to be an independent factor associated with lower appointment-keeping behavior for all appointments. Those who felt they would be unable to

Table 3	Correlation b	etween attitudes	and health	beliefs t	towards HCV	treatment	and a	appointment-	-keeping	behavior	by	clinic	type
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Attitude/health beliefs	Correlation	p value	
Primary Care Clinic appointments kept			
Agree with "Waiting too long to get an appointment to see a doctor about my hepatitis C makes me feel that hepatitis C must not be that important to treat"	-0.20	< 0.01	
Agree with "My regular doctor not talking to me about my hepatitis C makes me feel that my hepatitis C must not be that important to treat"	-0.18	0.01	
Agree with "I do not want to be treated for hepatitis C because it will make my other diseases worse"	-0.22	< 0.01	
Agree with "Having no one to talk to about my hepatitis C makes me feel alone"	-0.15	0.02	
Liver Clinic appointments kept			
Agree with "Having no one to talk to about my hepatitis C makes me feel alone"	-0.24	0.01	
Agree with "Too much information about hepatitis C will scare me from wanting to be treated"	-0.19	0.04	
Total appointments kept			
Agree with "Treating hepatitis C will make my life better"	0.13	0.04	
Agree with "I will not be able to work if I get treatment for my hepatitis C"	-0.14	0.04	
Agree with "Waiting too long to get an appointment to see a doctor about my hepatitis C makes me feel that hepatitis C must not be that important to treat"	-0.14	0.03	

Table 4 Multiple regressionanalysis models of appointment-keeping behavior with attitudesand clinic-demographicvariables

Type of appointment	Adjusted <i>p</i> value
Primary Care Appointment	
Agree with waiting too long means HCV not important	0.0004
Presence of psychiatric co-morbidities	0.0175
Agree with my doctor not talking about HCV means HCV not important	0.0066
Presence of psychiatric co-morbidities	0.0447
Agree with treatment will make my other diseases worse	0.0046
Presence of psychiatric co-morbidities	0.0085
Agree with having no one to talk to about my hepatitis C makes me feel alone	0.0989
Liver Clinic Appointments	
Agree with having no one to talk to about my hepatitis C makes me feel alone	0.0014
Age	0.0340
HIV Co-infection	<0.0001
HIV Co-infection	0.0005
Total Appointments	
Agree with I will not be able to work if I get HCV treatment	0.0510
HIV Co-infection	0.0229
Agree with waiting too long means HCV not important	0.0273
HIV Co-infection	0.0010

Bold values indicate statistical significance (p < 0.05)

Adjusted for age, gender, race, employment status, education level, HIV-infection

Health belief variables were shortened for this table

work due to HCV treatment also had a trend for keeping fewer overall appointments. Attitudes or health beliefs that HCV was less important because of long wait times to see a specialist, lack of physician engagement, and fear of other diseases worsening were independently associated with having kept fewer primary are Clinic appointments. In addition, psychiatric co-morbidities were independently associated with fewer Primary Care Clinic appointments kept. There was also a trend toward fewer primary care appointments kept among those who felt alone with regards to HCV. Those who held health beliefs reflecting isolation had kept fewer Liver Clinic appointments. In addition, older age and HIV-infection were independently associated with fewer Liver Clinic appointments kept.

Discussion

In our multiple regression model, we found three variables significantly associated with appointment-keeping behavior, namely HIV infection, psychiatric co-morbidities, and patient perceptions. The perceptions revolved around fear about inability to work or worsening of other diseases during HCV treatment, feeling HCV is not important due to long wait or no discussion with PCP, and feeling isolated. In contrast, HCV knowledge was not associated with appointment-keeping behavior. Although some studies have reported poor HCV knowledge as a barrier for HCV care [6], others have not. This study is consistent with other studies that have found that knowledge of HCV did not lead to seeking medical care [19].

Barriers to appointment-keeping behavior were not related to knowledge but instead health perceptions about HCV care and patient co-morbidities. In this study, almost one-third of the total appointments were missed by HCV patients. Those who displayed infrequent appointment keeping-behavior held more negative perceptions such as long waits for appointments and fear of health care interfering with work responsibilities, which may reflect the underlying reasons why perceptions such as "waiting too long for an appointment to get HCV care" or "I will not be able to work if I get HCV treatment" were associated with fewer appointments kept. Positive attitudes towards health care ("HCV treatment will make my life better") were more often held by those who had kept a higher proportion of appointments for any clinic. Thus, this study demonstrates that attitudes towards health care have a positive or negative association with health-seeking behavior.

Adherence to HCV treatment, even with one pill once a day, is critical to achieving a cure. Considering patients for treatment is often based on their motivation and reliability, measured by how well appointments are kept. In this study, we found a higher frequency of appointment-keeping behavior in the primary care setting. Opportunities for engagement and treatment for HCV can occur in the primary care setting and may be more successful than in HCV specialty care settings. Without the side effects of interferon and with the improvement in efficacy and ease of administration, primary care physicians can vastly increase the number of patients engaged and treated for HCV. However, in this study, we found that those who kept fewer primary care appointments held attitudes including feeling that HCV was not important because their primary care provider did not discuss it with them. Other themes included fear of worsening of other diseases if HCV treatment occurred, which may lead to avoidance in health seeking behavior. In addition, psychiatric co-morbidity also was independently associated with poorer PCP appointment-keeping behavior. These findings represent an opportunity to educate primary care physicians to engage HCV patients, especially those with psychiatric co-morbidities, to address some of these perceptions. Thus, developing resources for HCV care coordination targeted to those at risk of missing appointments could lead to improved HCV treatment outcomes. These findings support the AASLD/IDSA recommendations for engagement of case management and/or patient navigation and co-location of services such as primary care in order to reduce barriers and loss to follow-up [1].

Reported reasons in other studies for missing HCVspecific appointments included psychosocial difficulties, lack of knowledge, active substance abuse problems, and less importance placed on chronic hepatitis C relative to other priorities. HCV patients have been reported to not disclose and seek support from those within their informal networks because they did not want to burden family and friends with knowledge of their diagnosis and some also felt that others will not understand their experience [20]. In this study, health perceptions reflecting isolation and patient characteristics such as HIV co-infection and age were factors found to be independent predictors of missing more Liver Clinic appointments. Perhaps isolation, a form of stigma [10], may be a barrier to engaging in health seeking behavior including HCV treatment. Fear of too much information initially correlated with fewer Liver Clinic appointments but was likely confounded, as this was not seen in the multiple regression models. This may be because HIV co-infection correlated with this perception.

HIV co-infection was an important risk factor for lower levels of total appointment-keeping behavior and Liver Clinic appointments. This study had an equal proportion of mono-infected and HIV co-infected patients. In other studies, HIV uninfected HCV patients have been likely to report denial and infectious disease-based stigma than those with HIV co-infection [5]. Though HIV-infected patients were found to miss more appointments overall than patients with HCV alone, they did keep primary care appointments. One reason could be perceiving HCV infection to not be as significant as HIV infection. Findings from previous studies reveal that co-infected patients admit to being more worried about HIV than HCV, thereby being more reluctant to consult a liver specialist [4, 16]. Missing Liver Clinic appointments in co-infected individuals has been linked specifically to denial of having HCV, fear of liver biopsy, and knowledge of complications of end-stage liver disease and exposure to information about debilitating side effects of therapy from fellow patients [13]. HIV coinfected patients appeared to be less engaged in HCV care than HCV mono-infected patients.

Other studies have shown that many HCV co-infected patients have one or more psychiatric disorders, as did most patients in this study (61 %) [6, 18, 20]. Multiple regres-References sion analysis showed psychiatric co-morbidity to be an independent predictor of missing primary care appointments but not total appointments. Those with psychiatric co-morbidities kept appointments for Liver Clinic with

rates similar to those without these co-morbidities. The lower number of scheduled Liver Clinic appointments may have limited the ability to detect a difference. More attention is needed at the primary-care level on how to engage and keep these patients in care.

Limitations of this study include an oversampling of HIV co-infected patients yielding equal proportions of co-infected and HCV mono-infected patients, which may have biased the results. Additionally the fewer scheduled Liver Clinic appointments (n = 362) for all patients compared to total primary care provider appointments (n = 1423) may have limited the ability to detect a statistically significant correlation of patient characteristics with Liver Clinic appointment-keeping behavior. Another limitation is the use of Agree/Disagree question formats that did not focus specifically on barriers to appointment-keeping behavior but instead on barriers to HCV treatment. Also, only those appointments kept within the Parkland system were recorded. Outside appointments could not be obtained, which may not give an accurate reflection of total appointments kept. The number of study participants recruited from outside of Parkland Hospital was limited and is unlikely to have affected the analysis. The study was a sub-analysis of a primary study designed to examine knowledge and attitudes towards HCV infection and treatment in HCV patients.

HCV-infected patients missed about 1/3 of all appointments in this study. However, they were less likely to miss their PCP appointments. In addition, this study demonstrated that current perceptions about HCV, not knowledge, correlated with prior appointment-keeping behavior. Apart from attitudes, psychiatric co-morbidities and HIV-infection were found to be negatively and significantly associated with appointment-keeping behavior. Attitudes towards HCV can be substantial facilitators or barriers to clinic appointment adherence. Increasing engagement into HCV treatment may require additional resources for those who are at risk for missing appointments. Interventions to change perceptions could have a positive impact on healthseeking behaviors and improve clinical outcomes in patients with HCV.

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