

Patient perceptions of Hepatitis C among those failing to pursue treatment: A qualitative study of barriers and facilitators to care

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Abstract

Background Most people diagnosed with Hepatitis C virus (HCV) have not linked to care. The patient perspective on decision-making regarding linkage to care (LTC) in the direct acting antivirals treatment era is limited. We assess perceptions that impacted the choice not to pursue care among non-urban patients in the South who failed to attend an HCV clinic appointment.

Methods We conducted a demographic survey and semi-structured interview with participants referred to our HCV clinic between 2014 and 2018 who did not attend an appointment. Data collection and analyses were guided by the Health Belief Model.

Results Twelve participants enrolled, including 7 men and 5 women. Barriers to care were common including being uninsured (33%), having unreliable transportation (42%), unstable housing (33%), and a history of substance use disorder requiring treatment (58%). Participants demonstrated good knowledge of HCV disease, complications, and treatment. Emerging themes regarding failure of LTC included: (1) ambivalence due to uncertainty regarding the impact of HCV on one's own health, (2) logistical barriers such as financial concerns, lack of insurance, transportation, scheduling conflicts, (3) prior negative experiences with HCV care resulting in hesitance to seek care, (4) stigma, and (5) patient-provider relationships as a barrier when the relationship is poor and a facilitator when good.

Conclusions A strong HCV knowledge base was not sufficient for participants to seek care. Strategies to increase treatment uptake by changing patient perceptions include addressing the uncertainty of how HCV impacts one's health, acknowledging challenges with HCV treatment in the past, eliminating stigma in health care settings, and promoting education regarding treatment ease and availability. Expanding access to Medicaid may overcome perceived financial barriers. Providing HCV care in settings with an established patient-provider relationship may increase treatment uptake.

Introduction

For the 2.4 million Americans currently infected with Hepatitis C virus (HCV) (1), the development of direct acting antivirals (DAAs) has dramatically improved the tolerability and ease of HCV treatment. Earlier interferon-based treatment regimens were associated with long treatment courses, significant toxicities, and low cure rates. With DAA treatment, HCV is curable in more than 95% of infected patients. Curing HCV improves patient related outcomes, reduces HCV complications related to cirrhosis and liver cancer, and prevents ongoing transmission of this blood borne virus (2,3). Unfortunately, national studies estimate that only 17% of people living with HCV have been linked to specialty care (4).

The presence of effective treatment alone is not sufficient to increase engagement with HCV care, particularly among marginalized populations (5,6). To connect diagnosed patients to HCV specialty care, linkage to care (LTC) programs including nurse-driven care, intensive case management, and peer support have been implemented (7). In our HCV referral clinic, implementation of a nurse navigator model has led to a 76% LTC rate (8). Yet even in this model of patient education and intensive care coordination, nearly

a quarter of patients failed to link to care. The most common reasons provided for failure to link to care included multiple no-shows to scheduled appointments, inability to contact patients to schedule an initial visit, and incarceration. The reasons for missed appointments for HCV care are often complicated and varied (9), incorporating patient-related, provider-related, and health system related barriers (10).

Patient perceptions regarding HCV care may be changing with the availability of DAAs. Most of the literature exploring the patient perspective on living with HCV and decision-making regarding pursuit of HCV care was performed in the earlier interferon-based treatment era. Understanding patient decision-making regarding HCV care is essential to continuing to move towards the national goal of HCV elimination by 2030 (11). This is particularly relevant as concern is raised that LTC rates may be plateauing, or even declining, following treatment of an initial group of highly motivated patients who sought care once DAAs were available (4,12).

The purpose of this study was to explore and understand how people experience living with HCV as well as how they make decisions regarding HCV care utilizing a qualitative approach to identify perceptions or barriers that have prevented patients from pursuing HCV care.

Methods

Study Design and Study Population

This study took place at the University of Virginia (UVA) Infectious Diseases HCV clinic which employs a nurse-navigator model of HCV care, previously described in detail (8). The study population was defined to be all patients ages 18 years and older referred to the HCV clinic between November 2014 and March 2018 who failed to link to care. Linkage to care was defined as attending an initial HCV specialty visit. This study was approved by the UVA Health Sciences Research Institutional Review Board and participants provided verbal consent.

All patients who met the inclusion criteria (n = 200) were eligible for study recruitment. Consecutive sampling was used with attempts to contact all eligible patients. Potential participants were contacted, and if agreeable, interviewed over telephone. Use of telephone calls was chosen to minimize barriers to participation. Interviews took place during June to August 2018 and were performed by two study personnel, one male, and one female. The participants did not have a prior relationship with the interviewers. Research goals and the role of the interviewers in the study were explained to the participants. Participants were asked if they were in a comfortable setting where they could talk freely on the phone. Participation in the study required approximately 30–60 minutes and participants received compensation for their time. Interviewers maintained field notes following each interview. Transcripts were not returned to participants for comment and participants did not provide input on findings of the study.

Data Collection

Our study included a survey and semi-structured interview administered verbally. The survey included questions regarding demographic characteristics, experiences with the medical system, unstable housing (13,14), unreliable transportation, history of substance and alcohol use (15,16), self-evaluation of overall health (17), trust in the medical system (18) and HCV knowledge questions. Survey questions were based on validated measurements when available, including questions regarding housing stability, self-evaluation of health, and substance and alcohol use. Knowledge questions were adapted from the literature and public health resources (19–21).

The Health Belief Model (HBM) provided a theoretical framework for the development of a semi-structured interview guide. The HBM was initially developed to explain engagement in health-promoting behavior and explores patient behaviors through six central constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (22–24). The HBM has been used to explore patient perceptions regarding preventive medical care or asymptomatic conditions where patient beliefs may be most important in making medical decisions (25). Given the chronic and often asymptomatic nature of HCV, this model was appropriate for our objective.

The semi-structured interview guide included central questions related to the HBM constructs outlined above with additional probe questions available to the interviewer if needed. Interviewers proceeded through the constructs in the same order for each participant and were instructed to ask clarifying questions or pursue new ideas raised by participants as indicated. Interviews were audio-recorded and transcribed verbatim.

Data Analysis

Interviews were imported into Dedoose for analysis (Dedoose Version 8.0.35, web application for managing, analyzing, and presenting qualitative and mixed method research data (2018). Los Angeles, CA: SocioCultural Research Consultants, LLC www.dedoose.com). An initial codebook was developed deductively utilizing the HBM theoretical framework constructs as key themes. The codebook was modified as additional themes emerged inductively from the interviews. Each interview was coded by at least two members of the research team. Discrepancies in coding were resolved by consensus. Codes and descriptions applied inconsistently by study team members were revised. The codebook was refined until excellent inter-rater reliability was achieved with a kappa statistic of 0.76. Data saturation occurred after analysis of 8 interviews. The final codebook was applied to all interviews so that frequencies of codes could be determined. [Supplementary Table 1]

Results

Participant Characteristics and Survey Responses

Of the 200 patients meeting inclusion criteria, 184 had contact information available and contact via telephone was attempted. Of these 184, 99 could not be reached by telephone despite up to three attempts, 64 declined participation, 8 initially expressed interest in participation but could not find a

potential time to talk with interviewers, and 13 people provided consent to participate. One participant completed less than half of the survey questions and none of the interview. This person was not included in the analysis. A second participant completed the full survey but none of the interview, and this person is included in the survey analysis.

Of the 12 participants who completed the survey, the mean age was 46.3 (Standard Deviation 14.5) years with a range of 24 to 64 years, 7 (58%) were men, and 10 (83%) were white. [Table 1] Nearly all had seen a physician in the past year, but only 7 (58%) had an established primary care provider. One-third were uninsured. Unstable housing and transportation were common, present for 4 (33%) and 5 (42%) of participants respectively. All participants were aware of their diagnosis of HCV and that they had been referred for specialty care. Trust in medical systems was highly variable among participants. Seven participants (58%) reported a prior history of treatment for substance use or alcohol use disorder.

Table 1

Participant Characteristics, Healthcare Experiences, Barriers to Care, and Self-Reported Substance Use History (N = 12).

Characteristic	N (%)
Demographic Characteristics	
Age group	
20–39 years	4 (33)
40–59 years	5 (42)
≥ 60 years	3 (25)
Sex	
Male	7 (58)
Female	5 (42)
Race	
White	10 (83)
Black	1 (8)
Indian American	1 (8)
Healthcare Experiences and Barriers in LTC	
Healthcare Exposure	
Has an Established primary care provider	7 (58)
Visited emergency room in past year	6 (50)
Has seen any doctor in past year	11 (92)

^aHousing instability defined as moving 2 or more times in the past 6 months or concerned about housing stability in the upcoming 6 months. (Rollins 2012, Cox 2016)

^bTrust in medical system is quantified based on response to five questions and potential scores can range from 5 to 25, with higher scores indicating more trust (Dugan 2005)

^cDrug Screen Single Question, “How many times in the past month have you used an illegal drug or used a prescription medication for non-medical reasons?”, Any response ≥ 1 time is positive for drug use (Smith 2010)

^dAlcohol Single Question Screen How many times in the past month have you had X or more drinks in a day?, (X = 5 for men, X = 4 for women) (Smith 2009)

Abbreviations: LTC = linkage to care.

Characteristic	N (%)
Health Insurance Status	
Uninsured	4 (33)
Insured	8 (67)
Private Insurance	3 (25)
Medicaid	4 (33)
Medicare	1 (8)
Unreliable Transportation	
Yes	5 (42)
No	7 (58)
Unstable Housing ^a	
Yes	4 (33)
No	8 (67)
Rating of own Health	
Excellent	0 (0)
Very Good	3 (25)
Good	4 (33)
Fair	2 (17)
Poor	3 (25)
Knowledge of Hepatitis C status	12 (100)

^aHousing instability defined as moving 2 or more times in the past 6 months or concerned about housing stability in the upcoming 6 months. (Rollins 2012, Cox 2016)

^bTrust in medical system is quantified based on response to five questions and potential scores can range from 5 to 25, with higher scores indicating more trust (Dugan 2005)

^cDrug Screen Single Question, "How many times in the past month have you used an illegal drug or used a prescription medication for non-medical reasons?", Any response ≥ 1 time is positive for drug use (Smith 2010)

^dAlcohol Single Question Screen How many times in the past month have you had X or more drinks in a day?, (X = 5 for men, X = 4 for women) (Smith 2009)

Abbreviations: LTC = linkage to care.

Characteristic	N (%)
Knowledge of Hepatitis C Specialty Referral	12 (100)
Trust in Medical System ^b , possible scores 5 to 25	
Median Score, [Interquartile Range]	18, [12-19.25]
Minimum Score	9
Maximum Score	25
Substance Use History	
Substance Use ^c	
In the Past Month	3 (25)
In Past Year	5 (42)
Alcohol Use ^d	
In the Past Month	2 (17)
In Past Year	4 (33)
Treatment for Substance Use Disorder	
Any prior treatment	7 (58)
Alcohol	2 (17)
Drug Use	4 (33)
Both	1 (8)
No prior treatment	5 (42)
^a Housing instability defined as moving 2 or more times in the past 6 months or concerned about housing stability in the upcoming 6 months. (Rollins 2012, Cox 2016)	
^b Trust in medical system is quantified based on response to five questions and potential scores can range from 5 to 25, with higher scores indicating more trust (Dugan 2005)	
^c Drug Screen Single Question, "How many times in the past month have you used an illegal drug or used a prescription medication for non-medical reasons?", Any response > = 1 time is positive for drug use (Smith 2010)	
^d Alcohol Single Question Screen How many times in the past month have you had X or more drinks in a day?, (X = 5 for men, X = 4 for women) (Smith 2009)	
Abbreviations: LTC = linkage to care.	

For each of six HCV knowledge questions, at least 75% of participants answered correctly. [Table 2] Each participant correctly answered over half of the questions, with 5 (42%) correctly answering four questions, 3 (25%) correctly answering five questions, and 4 (25%) correctly answering all six questions.

Table 2
Hepatitis C Knowledge Questions and Response Rates

Hepatitis C Knowledge Questions	Correct Responses N (%)
Most people with hepatitis C don't have symptoms. <i>True, False</i>	10 (83)
Most people with hepatitis C know they are infected. <i>True, False</i>	9 (75)
A person who injected drugs one time should be tested for hepatitis C. <i>True, False</i>	11 (92)
A person born between 1945 and 1965 should be tested for hepatitis C. <i>True, False</i>	10 (83)
Hepatitis C can cause: <i>Cirrhosis, Liver failure, Liver cancer, All of the above</i>	10 (83)
With treatment, what percent of people with hepatitis C can be cured? <i><25%, 50%, 75%, > 90%</i>	9 (75)
Answer choices are in italics following question stem. Correct answer choice is in bold. Questions are adapted from the Centers for Disease Control Hepatitis C fact sheet, the World Health Organization Hepatitis C webpage, and Zeremski 2014.	

Transcribed and coded semi-structured interviews were then analyzed using the constructs of the HBM as the theoretical framework. Emerging themes within each construct are presented.

Diagnosis Experience

The complete codebook with code descriptions, example quotes, and frequencies is present in the Supplementary Table. Diagnosis of HCV occurred during routine bloodwork (N = 5), when donating blood (N = 2), while incarcerated (N = 2), and during screening at a methadone program (N = 1). Initial reactions to the diagnosis included confusion (“where did it come from?” [1020]), surprise (“I wasn’t sick. At least I didn’t think I was” [1089]), and fear (“I thought I was going to die” [1912]). Reactions were influenced by knowledge of friends and family members’ experiences with HCV. Some found reassurance in the stories of asymptomatic family members who had been cured, while others who knew of family and friends’ experience with severe illness and complications related to HCV reported fear and concern on diagnosis. Most participants received counseling at the time of diagnosis which could mitigate negative initial feelings and confusion. One participant reflected that “the lady that did [the test] told me that I could get treatment. It eased my mind” [1148].

Perceived Susceptibility

Participants identified drug use as the primary risk factor for HCV. Perceptions regarding one's history of injecting behaviors modified risk perception and influenced response to initial diagnosis of HCV. One participant surprised by the diagnosis explained, "I thought I was being careful. I never used a dirty needle" [1634], whereas for another participant, the diagnosis was almost expected: "I was about 80 percent sure that I had it...I used a lot of needles after not just one person – probably 50 people. It wasn't good" [1506]. Sexual transmission was a less commonly cited perceived risk factor.

Perceived Severity

Most participants perceived HCV to be a severe infection associated with complications such as liver failure, cirrhosis, and cancer. HCV was perceived to cause symptoms including fatigue, changes in mood, sleep disturbances, and jaundice. For some participants, concurrent substance use made it difficult to elucidate the cause of these non-specific symptoms.

A sense of ambivalence emerged, whereby participants perceived HCV to be a severe disease for others, but felt that HCV has not impacted their own health. When asked if HCV is a serious medical condition, one participant replied "In general yes, I think so. In my case, I don't know" [1089] and another responded "all diseases are serious. I think it's something you can live with" [1020]. The perception of HCV as a disease that can be lived with was shared by others, including one who explained "I'm looking at my hepatitis C like prostate cancer. Men die with prostate cancer. They don't die of it. I'm probably going to die with my hepatitis C not of it" [1017]. For some, this perception was based on knowing other people who were infected with HCV but remained asymptomatic. For some, limited knowledge regarding HCV led to difficulty drawing conclusions about the implications of HCV on their health.

Perceived Benefits

Nearly all participants perceived treatment to be beneficial due to the high cure rate with treatment. This perception was based on excellent knowledge of the treatment process, described by one patient as "my understanding is it's completely curable...The medication is expensive. But with some programs and everything, it's fairly reasonably priced. And if you have the correct insurance that's free and it's an eight-to twelve-week program – and it usually comes in pill form." [1943]

Perceived Barriers

Perceived barriers were common and included financial barriers, limited knowledge of the treatment or referral process, and logistical barriers such as scheduling conflicts and lack of transportation. Two participants identified current pregnancy as a barrier to care. Participants frequently identified multiple barriers to care, including one gentleman who described his hesitation to pursue treatment due to barriers that may limit his ability to follow-through: "I got money issues, transportation issues. And quite frankly, I'm a little scared to make a commitment because I don't know whether I can honor the commitment because of my near homelessness and financial capabilities and transportation capabilities. I hate to say I'll be here at some certain time and then I can't find a ride, ya know. I would definitely love to pursue [HCV treatment]" [1634].

Perceived financial barriers pose a major challenge. These beliefs are based on prior experience with insurance company denials for HCV treatment, awareness of the high cost of HCV medication, or belief that insurance will not cover expensive medications. Patients perceived the cost of medication to be exorbitant, including one who expected the cost to be “thousands of dollars...It’s not like a house payment. It’s more like a whole house” [1912].

Participants held mixed beliefs regarding potential barriers of stigma and substance use. Stigma was perceived to be a barrier by four participants, who felt that “I go into the doctor’s office with that stigma like, here comes that dude with that hep C - everybody glove up” [1017], whereas others “don’t expect to be treated any differently, just as a normal patient that has a disease that needs to be cured” [1943]. Substance use was not perceived to be a barrier, and one patient identified substance use as beneficial to his relationship with the healthcare system because “now I can have a little access to medical services; I believe I wouldn’t have access to if I wasn’t a substance abuser” [1634].

Clinic level factors constituted barriers to care including difficulty contacting clinic staff, limited appointment availability, and gaps in time between referral and date of initial visit. Trust in the medical system and concerns regarding confidentiality were perceived barriers for three participants. One participant, describing an event where the clinic called her work number, reaching a colleague, and the caller identification displayed “Infectious Disease clinic”, explained feeling “like I had just been labeled...I felt violated” [1020]. Participants also expressed frustration with prior experiences seeing an HCV specialist that did not ultimately result in treatment due to insurance restrictions on treatment and resulting loss of care connection.

Participants who had personal knowledge of earlier treatment for HCV, primarily interferon based treatment, perceived treatment to be potentially harmful, with one patient who had previously trialed interferon stating “[The interferon] made me feel like I was going to die, man...And that is the reason why I will not be treated - because the medication is so dangerous.” [1017]. Another participant described his friend’s experience with interferon: “I had a buddy of mine that was given the interferon, and it made him so weak, I had to help him from his couch to the bathroom. He used to give himself three injections a week in the stomach. I said man, I just couldn’t go through that” [1506].

Self-Efficacy and Cues to Action

Seeing an HCV specialist was perceived to be important to participants’ health. All participants were confident in their self-efficacy to pursue HCV treatment if they decided to do so, drawing on experiences taking medications and attending appointments for other medical problems as a source of confidence. Four participants described their ability to overcome financial barriers by obtaining new insurance coverage through a change in jobs or by working with clinic staff to access financial assistance programs.

Sources of motivation included children, trusted medical providers, and a desire to improve one’s health. In the setting of becoming pregnant shortly after being diagnosed with HCV, a participant noted “I was

really trying to just figure something out so it wouldn't hurt my child in the long run" [1148]. Another acknowledged the encouragement of his family physician, who has been "very adamant about trying to get me cured" [1017]. Social support was the primary cue to action.

Participants proposed modifications to the care process that would allow them to pursue treatment, including changes regarding transportation (N = 2), insurance/cost (4), social support (3), more flexible scheduling (1), ability to easily contact doctors (1), medication side effects (1), more knowledge of the process (1), and addressing addiction (1). One participant suggested the process would be more accessible to patients if streamlined and "you could do it all at one time instead of three different appointments...It was hard enough for me to go to one" [1332].

Discussion

In this population of patients who have been diagnosed with HCV and referred to specialty care but who have not successfully linked to care, we identified themes that influenced patient decision making using the HBM as a framework. Our patients were aware of their diagnosis and had high levels of HCV knowledge, yet they noted multiple, complicated, and varied factors leading to the behavior of not seeking care. Dominant themes included ambivalence regarding the impact of HCV on self, presence of logistical barriers, impact of substance use and stigma, the influence of patient-provider relationships, and the prior lived experiences of self and others with HCV. [Table 3]

Table 3

Barriers and facilitators of linkage to Hepatitis C care with suggested interventions to improve care based on qualitative patient interviews.

Major Themes	Interventions to Improve Care
Logistical Barriers: Financial, Scheduling, Transportation, Health-system level	Expand Medicaid; Utilize pharmaceutical company drug assistance programs; Educate patients on available resources and supportive care; Aim for clinic responsiveness, ease of scheduling, and confidentiality
Patient-Provider Relationship	Encourage expansion of HCV treatment to where patients are already receiving care and have established relationships
Ambivalence	Acknowledge and address the uncertainty related to having HCV; Focus patient education campaigns on ambivalence and the potential for treatment to relieve patients of the burden of uncertainty
Substance Use and Stigma	Provide education on harm reduction strategies; Co-locate treatment for substance use disorder and HCV; Educate clinic staff on creating a welcoming atmosphere
Prior Lived Experience of HCV	Explore patients' or others' prior experiences with HCV treatment; Address favorable changes in treatment since earlier therapies
Inability to Contact Referred Patients	Consider alternative methods to reach patients and increase access to HCV specialty care, including providing phones for the course of HCV treatment to ensure stable contact
Abbreviations: HCV = Hepatitis C virus	

Ambivalence emerged as the most notable theme related to perceived severity. Ambivalence takes the form of people knowing that HCV is a serious illness, while also feeling that their own health has not been impacted by HCV. People living with HCV experience a sense of “sustained uncertainty” (26). This uncertainty can relate to the potential development of complications at an unknown future date, misinformation, or lack of knowledge regarding HCV (26,27). While DAAs have drastically improved the effectiveness and ease of treatment, this new era of treatment may not be influencing established patient narratives of HCV illness, limiting the uptake of new treatments (28). To reach these patients, it may be helpful to highlight improvements in patient related outcomes with HCV cure (2). The most significant impact of HCV cure may be an improved sense of psychological wellbeing related to relief about no longer living with the burden of an uncertain future or the fear of transmitting the infection to others (29). Addressing the uncertainty of living with HCV and the potential to alleviate this uncertainty through treatment may be a strategy to address ambivalence.

The majority of participants reported a history of substance use and perceived substance use to be the primary risk factor for HCV. Participants incorporated their personal history of risk behaviors into their perceived risk for HCV. Our study did not identify substance use as a perceived barrier to HCV care, in contrast to prior studies (30). This is encouraging, as our state does not have sobriety restrictions related to treatment access, though restrictions remain in other states (31). People who use drugs can face

stigma during HCV treatment resulting in feeling a lack of support during treatment (32). While experienced stigma was uncommon among our participants, when present, stigma lowered motivation to pursue care. Among people who use drugs, HCV treatment can be a motivating factor to reduce substance use and/or to participate in harm reduction activities (29,33). Therefore, ensuring access to HCV care for people who use drugs in an environment free from stigma is critical.

Prior experiences with HCV care, either personal experiences or those of family and friends, are common and influenced all HBM constructs. Some patients have experienced discontinuous HCV care (34), in which patients diagnosed prior to DAA therapy have been lost to HCV care. Experience with interferon-based treatment regimens can motivate some patients to seek the more patient-friendly DAA treatment (35), though in our study, the severe side effects associated with interferon persist in patients' memories and discourages them from reconnecting to care. Providers of HCV treatment must address the patients' and others' prior experiences with HCV treatment to provide appropriate counseling.

Established patient-provider relationships influence perceived barriers and self-efficacy. The quality of these patient-provider relationships determines if they serve as barriers or facilitators to care. Positive patient-provider relationships are beneficial in HCV treatment (35,36). Multiple patients cited their trusted provider as a key source of motivation for pursuing treatment and someone they could turn to for assistance. To build on established relationships, HCV treatment can be expanded to sites where patients are already receiving care such as primary care practices, health departments, or substance use disorder treatment programs. Expansion into other sites of care may also serve to decrease logistical barriers and decrease stigma. Yet, primary care providers remain hesitant to treat HCV, and HCV providers hesitate to treat those with substance use, resulting in limited uptake of these models of care (37–39).

Logistical barriers were prevalent including financial concerns related to lack of insurance, inadequate insurance, or the general cost of treatment. At the time this study was performed, our nurse coordinator was able to obtain medication for all patients who were seen in clinic who completed required paperwork, laboratory testing, and imaging studies through either insurance coverage or pharmaceutical company patient assistance programs. Therefore, from a clinic perspective, lack of insurance or underinsurance has not been a barrier to HCV care. However, the perception remains that treatment can be unaffordable. Multiple participants described the ability to overcome financial barriers by obtaining insurance that covers HCV treatment, and the recent Medicaid expansion in our state provides an opportunity for additional coverage. Medicaid expansion may also provide additional resources to address transportation needs. Pregnancy arose as a barrier for multiple patients. HCV treatment guidelines do not recommend treatment during pregnancy (40), and therefore clinics need to maintain a relationship with these patients in order to provide access to treatment when it is appropriate in the future. Patients also raised concerns about clinic level factors including scheduling availability, responsiveness to calls, and concerns regarding confidentiality, including the possibility of inadvertent disclosure that a patient receives care at an infectious disease clinic.

Notable limitations of our study include an inability to contact a majority of those who did not link to care in our clinic. Patients who could not be contacted may have different experiences living with HCV, including unstable phone numbers, which likely impacts their experience seeking care. Our clinic employs a nurse-navigator model. This model likely contributed to the excellent HCV knowledge among these patients, as the nurse provides education over the phone while discussing the logistics of referral. However, this may limit the generalizability of our findings. Basic knowledge about HCV was important, but not sufficient, for patients to pursue care as barriers prevent patients from acting on this knowledge.

Future education and public health campaigns for HCV should address the changes in HCV treatment and challenge the ambivalence felt by many, as these changes have led to a more streamlined, patient-friendly treatment regimen. People living with HCV have varied reasons for not pursuing care, and providers should explore patient perceptions, including knowledge of others' experiences with HCV treatment, and an individual's own prior experiences, in order to provide appropriate patient-centered counseling. Referral clinics can promote available resources to overcome perceived logistical barriers including lack of transportation, high cost of medications, and lack of insurance. Clinics should consider their limited timeframes for available appointments and how this can impact patients' ability to attend appointments. Simplifications to the care model have been proposed, including rapid testing, minimal on-treatment monitoring, and limited patient visits, which may serve to reduce barriers, make treatment more accessible, and facilitate treatment expansion (41). Finally, we had difficulty contacting the majority of patients who failed to link to care. Alternative methods for contacting, linking, and retaining patients in care should be explored.

Conclusions

Knowledge of the potential complications of Hepatitis C was not sufficient for participants to seek care. To increase treatment uptake, public health campaigns should focus on the ease of treatment, address the uncertainty that arises regarding how Hepatitis C will affect one's own health, and emphasize potential improvements in patient related outcomes with treatment. Expanding access to Medicaid may overcome perceived financial barriers. Providing HCV care in settings with an established patient-provider relationship may increase treatment uptake.

Abbreviations

HCV
Hepatitis C Virus
DAAs
Direct Acting Antivirals
LTC
Linkage to Care
UVA
University of Virginia

Declarations

Ethics Approval and Consent to Participate: This study was approved by the University of Virginia Institutional Review Board for Health Sciences Research. All participants provided verbal, informed consent prior to participation in the study.

Consent for Publication: Not applicable

Availability of Data and Materials: The datasets generated and/or analysed during the current study are not publicly available due to the sensitive and personal nature of qualitative interviews but are available from the corresponding author on reasonable request.

Competing Interests: KAM reports stock ownership in Gilead Sciences, Inc. RD provides consulting services for Warm Health Technologies, and mHealth company. RD and KAM are recipients of an investigator-initiated grant from Gilead Sciences, Inc. All other authors declare no competing interests.

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