BARRIERS AND FACILITATORS TO ENGAGEMENT IN HEPATITIS C CARE IN THE GREATER NEW ORLEANS AREA

A DISSERTATION

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Abstract

An estimated 2.4 million people are living with chronic Hepatitis C (HCV) in the United States. HCV has become a major topic of discussion due to recent increases in new infections attributed to injection drug users’ transition from prescription opioid use to heroin use and increased treatment costs among older people living with HCV. New direct-acting antiviral (DAA) therapy has improved HCV cure rates, even among the hardest to treat. Nonetheless, Americans living with chronic HCV are not adequately engaged in care. Furthermore, there is a critical knowledge gap about factors influencing engagement in HCV care, especially related to DAA treatment. This explorative study aimed to understand these factors better to develop more effective care models and interventions that facilitate engagement in care. Increasing engagement in care and HCV treatment will help mitigate HCV incidence, morbidity, and mortality in the United States. This study was conducted in three parts: 1) a systematic review of best practices for facilitating linkage and retention in HCV care in the United States 2) a qualitative analysis of factors that influence engagement in HCV care as perceived by patients in the Greater New Orleans area (GNO), and 3) a qualitative analysis of factors that influence engagement in HCV care as perceived by providers in the GNO area. A systematic review of best practices for facilitating linkage and retention in HCV care yielded 15 articles. The identified best practices were classified using the social-ecological model as a framework. The most common practices included patient-level (i.e., patient outreach, financial incentives), provider level (i.e., ECHO, task-shifting), health care system level (i.e., care integration, pharmacist-led teams). Data analysis of semi-structured interviews with HCV-positive individuals and HCV care providers revealed significant barriers to HCV care stemming from the patient, provider, health care system, and structural-related factors. The barriers commonly discussed by patients included
current drug use, lack of provider education, stigmatizing attitudes, and lack of widespread HCV awareness. In addition, providers mentioned that mental illness, drug use, and discrimination made it challenging for patients to engage in HCV care. Facilitators of engagement in care mentioned by both providers and patients included providing supportive services, patient education, and coverage for treatment costs. This study revealed that significant barriers to engagement in HCV care persist during the DAA treatment era. Interventions to improve engagement in HCV care must address barriers at multiple levels. Additionally, the study highlighted gaps in intervention research on linkage and retention in HCV care during the DAA treatment era. Additional research is needed to identify and implement optimal strategies for engaging and retaining HCV-positive individuals in treatment in the United States.
Dedication

I dedicate this dissertation to my parents. My parents worked hard to ensure my sisters and I had everything we needed while instilling important values and building our confidence. To my mom, who is the ultimate role model, who would do anything for anyone, prayed every single day, and who is truly the angel in my life. My dad, who always has our back, bought us cabbage patch dolls for every report card, treats my sisters and me like princesses, and has been my cheerleader throughout this whole process. Because of their prayers, I have been able to persevere and overcome the challenges of this program to become Dr. Lane. Thank you, mommy and daddy.
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Next, I would like to thank Pastor Mel and Pontilly Coffee for being a place of refuge during one of the most challenging seasons of my life. Thank you for showing God’s love to me.

Lastly, I would like to thank my sisters (Candace and Dominique) and friends (Joycelyn, Ty, Olivia, Shanta, LaShelle, Dee, and Brianna) who made sure that I did not lose myself while going through this process. Thank you for talking me through the tears. Thank you for consistently making sure that I was prioritizing self-care. Thank you for believing in me and helping me to see the finish line.
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Chapter 1: Introduction

Hepatitis C virus (HCV), discovered in 1989, is a small enveloped, positive-sense single stranded RNA virus (Vieyres et al., 2010). It is the original member of the Hepacivirus genus within the Flaviviridae family; but unlike the other viruses in the Flaviviridae family (e.g. Yellow Fever, Dengue, West Nile virus) there is no invertebrate vector for HCV. Ongoing transmission of HCV is limited to humans primarily by parenteral exposure to contaminated blood (Smith et al., 2016). HCV infection predominantly affects the hepatocytes or liver cells and is the leading cause of cirrhosis, liver cancer, end stage liver disease, and liver transplantation in the United States (Alter, 2007; Kim, 2002).

The estimated 380,000 new infections annually in the 1980s has decreased drastically due to the initiation of better blood screening technologies and sterilization techniques in the 1990s, and the development of curative treatments (Armstrong, 2000; Kim 2002; Ward & Mermin, 2015). Despite progress, HCV persists as a significant health problem in the United States. The number of new HCV infections is on the rise and HCV-related mortality remains high (CDC, 202; Ryerson, Schillie, Barker, Kupronis, & Wester, 2020) HCV has become a major topic of discussion among public health professionals attributed to injection drug users’ transition from prescription opioid misuse to heroin use (Jones, 2013; Klevens, Hu, Jiles, & Holmberg, 2012). Furthermore, chronic HCV infection poses a significant economic burden on work productivity, use of healthcare resources, and health-related quality of life (Davis, Mitra, Medjedovic, Beam, & Rustgi, 2011; El Khoury, Vietri, & Prajapati, 2012).

The US Food and Drug Administration (FDA) recently approved direct-acting antivirals (DAA), which are significantly more efficacious than the old treatment regimens in treating chronic HCV infection (Ward & Mermin, 2015). HCV treatment is curative, with cure rates for
the new DAA therapy reaching nearly 100% in most patient populations (Feld et al., 2015).
Despite availability of highly effective therapy, Americans living with chronic HCV are not adequately engaged in care and very few are cured of the disease. The following sections of the prospectus will first present information on the epidemiology and biology of HCV, then a literature review of the barriers and facilitators to linkage and retention in HCV care. Following the literature review, the methods to address identified gaps in the literature will be discussed.

**Epidemiology of Hepatitis C in the United States**

There are 2.4 million people living with chronic HCV in the United States, making it the most common blood borne disease in the country (Hofmeister et al., 2019) Although the incidence of HCV has decreased drastically since the 1990s, the number of new infections remains high and is increasing (CDC, 2017; Kim, 2002). **From 2010 to 2019, the number of estimated new HCV infections increased by 387% (CDC, 2021)** Persons with HCV have a mortality rate that is 12 times higher than the general population (Mahajan et al., 2014). In 2018, more than 15,000 people died from chronic HCV-related causes. However, this is an underestimation, as a significant proportion of individuals who died from HCV-related causes were not attributed to HCV infection as the cause of death on their death certificates (Mahajan et al., 2014). A multisite cohort study of patients with known HCV infection who received care at four large health care organizations in the United States found that more than 70% of the study sample had evidence of HCV-related liver disease, yet only HCV infection as the cause of death was listed for only 19% of people who had died (CDC, 2018a). People with chronic HCV in the United States are more likely to be non-Hispanic black and born from 1945-1965 (Denniston et al., 2015). They are also more likely to report a history of injection drug use, less education, and low socioeconomic status (Denniston et al., 2015; Ditah et al., 2014).
HCV Among Baby Boomers and Young People

A recent study, which tested 24,966 persons born between 1945-1965, estimated the HCV prevalence among baby boomers at 11.6%, which is significantly higher than the national HCV prevalence of 1.6% (Patel, Vellozzi, & Smith, 2016). HCV-related mortality is also significantly higher among the baby boomer population, with baby boomers accounting for 73% of all HCV-related mortality (CDC, 2017b; Smith et al., 2012). The high prevalence of chronic HCV infection among this population has been primarily attributed to injection drug use and blood transfusions prior to 1992, before HCV screening processes were available (Spach, 2014). However, the reasons for the high rates of infections among this group are not completely understood because a significant proportion of persons in this cohort do not report any known risk factors (Denniston et al., 2015; Drainoni et al., 2012; Smith et al., 2014).

In more recent years, the number of people living with Hepatitis C has as steadily declined, mainly attributed to effective curative treatment and all-cause mortality among the baby boomer population (Hofmeister et al., 2019). However, the number of new cases of chronic HCV are rising exponentially, primarily among young people (CDC, 2020). In 2019, the highest rates of new HCV infections occurred in persons 20-39 years, primarily attributed to the prescription opioid epidemic and the increase in injection drug use (CDC, 2020; Zibbell et al., 2018).

HCV Transmission

Injection drug use is the predominant mode of transmission, accounting for nearly 70% of all new HCV infections in 2019 (CDC, 2021). Prevalence of HCV among injection drug users is estimated at 53% (CDC, 2018a). Increased transmission via injection drug use is a result of the frequent practice of sharing needles (and other drug paraphernalia) and the direct passage of
infected blood to the bloodstream (Spach, 2014). The recent surge in the incidence of new HCV infections has been attributed to the transition to injecting heroin from prescription opioid use (Ryerson et al., 2020) Yet, the burden of HCV among people who inject drugs is not fully understood. Injection drug use behavior is highly stigmatized in society, such that many people who inject drugs are not willing to report the behavior and physicians are not likely to ask about it when screening for HCV (Bruggmann & Grebely, 2015; Denniston et al., 2015). The term people who inject drugs (PWID), includes people who are actively using drugs and those who have previously injected drugs.

Transmission occurs less frequently by blood transfusion, mother to child transmission, occupational exposure, and sexual transmission. Before the implementation of blood screening practices in 1992, HCV transmission via blood transfusion was common, estimated at 20% per unit of blood transfused (Hendersen, 2003). Since then, transmission by transfusion has been reduced to less than 1% per unit of blood transfused (Hendersen, 2003). The risk of mother to child transmission is 4-7% per pregnancy and is greater in mothers with a high HCV viral load and/or HIV coinfection. Breastfeeding has not been found to increase vertical transmission of HCV (CDC, 2018b). Occupational transmission is uncommon and is mostly caused by a percutaneous exposure by needle stick or invasive medical procedures from patient to health care worker. Risk of HCV transmission due to occupational exposure accounts for approximately 1.8% of HCV cases. A high HCV viral load also increases the risk of occupational transmission (Strasser et al., 2013).

The topic of sexually transmitted HCV is controversial, with studies reporting mixed results. Sexual contact is an inefficient mode of HCV transmission (Nijmeijer, Koopsen, Schinkel, Prins, & Geijtenbeek, 2019). However, prior research does suggest a risk of sexual
transmission via sexual contact (Nijmeijer et al., 2019). A systematic review of studies in
developed countries, which investigated sexual transmission of HCV among gay and bisexual
men, found that the prevalence of sexually transmitted HCV among gay and bisexual men
without HIV infection was 1.5% compared to a pooled prevalence of 8.3% among gay and
bisexual men with HIV coinfection (Jin, Matthews, & Grulich, 2017). Among heterosexual
couples, risk of sexual transmission is extremely rare. A large study of 500 monogamous
heterosexual couples reported that the incidence of sexual transmission was .7% per year
(Terrault et al, 2013).

**Biology of Hepatitis C**

*Evolution of HCV*

HCV is a highly variable disease due to its high replication rate and the existence of the
error-prone enzyme, RNA-dependent RNA polymerase. RNA-dependent RNA polymerase is
unable to correct mutations as they arise; as a result, many variants of HCV are produced
(Moradpour et al., 2004). These variants are classified as genotypes and subtypes. There are
seven (1-7) known HCV genotypes and 67 subtypes (Smith et al., 2014). Genotype 1 is the most
common in the United States, followed by genotype 2 and 3. Among people living with HCV in
the United States, more than 70% of those with HCV have genotype 1 infection, approximately
13% have genotype 2, and 12% have genotype 3 infection (Germer, Mandrekar, Bendell,
Mitchell, & Yao, 2011). Genotypes have not been found to be associated with liver disease
progression; rather, genotypes significantly influence the HCV treatment response (Zeuzem,
2004).

*Acute and Chronic Infection*

HCV infection results in acute and chronic infection. Acute HCV infection is defined as
the 6-month time period following acquisition of the disease. Acute HCV is usually asymptomatic, but those who develop symptoms (e.g., jaundice, low grade fever, nausea, and muscle pain) typically do so within 4 to 12 weeks of infection. These symptoms include jaundice, low-grade fever, and nausea. During the acute infection period, the viral load peaks at its highest and then drops significantly as people move into the chronic phase (Chen & Morgan, 2006). For approximately 25% of those infected, spontaneous clearance of the disease will occur within the acute infection period. For the majority (75-85%), however, the viral load will rebound or remain consistent, resulting in chronic infection (infection lasting more than six months) (Chen & Morgan, 2006).

**Disease Progression**

Disease progression for HCV is slow; progression to cirrhosis is 20 to 30 years. The longer an individual is infected with chronic Hepatitis C infection, the higher chance of progression to liver disease. Approximately 10-20% of people infected with HCV will develop cirrhosis, among which 1-5% and 2-6% will go on to develop liver cancer and/or decompensated liver disease, respectively (CDC, 2018a). Studies using modeling assimilations predict that HCV disease progression, primarily among older people, is expected to rise over the next 10-13 years (Davis, Alter, El-Serag, Poynard, & Jennings, 2010; Rein et al., 2011). A multi-cohort natural history model predicted that the proportion of persons with chronic HCV infection with cirrhosis is expected to reach 45% in 2030 (Davis et al., 2010). Another study predicts that without efforts to identify and treat those with chronic HCV the incidence of end-stage liver disease will likely quadruple within the next 20 years and will cause the deaths of an estimated 13% and 36% of people with HCV chronic infection by 2030 and 2060, respectively (Rein et al., 2011).
rapid disease progression has been found to be associated with older age, daily alcohol consumption, male gender, obesity, HIV coinfection, and diabetes (Massard et al., 2006).

**HIV/HCV Coinfection**

HCV coinfection among persons living with HIV is common. Approximately 25% of persons infected with HIV in the United States are co-infected with HCV (CDC, 2014). The rate of coinfection is significantly higher among PWID, with estimated rates up to 80% (CDC, 2014). Compared to persons living with HCV monoinfection, a person living with HIV/HCV co-infection has an increased risk of developing liver disease (Sohrab et al., 2018). The process of HCV disease progression to cirrhosis occurs much earlier in individuals with HIV/HCV coinfection (Lee, Yang, Yuan, L'Italien, & Chen, 2014). HCV infection reduces the CD4+ T cell response to antiretroviral therapy, resulting in a decrease in CD4+ T-cell counts (Sohrab et al., 2018). Also, HCV-related liver disease behaves like an opportunistic infection in persons living with HIV, accelerating the progression from HIV to AIDS (Lesens, Deschenes, Steben, Belanger, & Tsoukas, 1999).

**Hepatitis C in Louisiana**

There are 50,000 people living with HCV in Louisiana (Ryerson et al., 2020). There are approximately 9000 new cases of HCV cases each year (Louisiana Department of Health 2019). Between 2014-2018 the number of new chronic HCV cases increased by 222% (Louisiana Department of Health, 2019). According to the most recent data available on mortality, between 250 and 500 new HCV infections and 150 HCV-related deaths occur each year in Louisiana (Louisiana Department of Health and Hospitals Office of Public Health Infectious Disease, 2015). The highest prevalence of HCV is found in urban areas, including the Greater New Orleans area (GNO), Baton Rouge, and Lafayette. The GNO is the highest populated area in
Louisiana, with most of the population living in Orleans Parish/New Orleans. The area includes Orleans Parish/New Orleans, St. Bernard, Jefferson Parishes and the suburban areas north of Lake Pontchartrain. Overall, Orleans Parish has the highest HCV prevalence (Louisiana Department of Health and Hospitals Office of Public Health Infectious Disease, 2015). Approximately 6% of people with chronic HCV infection in Louisiana are coinfected with HIV (Louisiana Department of Health and Hospitals Office of Public Health Infectious Disease, 2015).

Similar to the rest of the nation, the primary risk factor for HCV in Louisiana is injection drug use. Approximately 80% of the new HCV cases were acquired through injection drug use (Louisiana Department of Health, 2019). Historically, baby boomers are the hardest hit group, accounting for the majority of the HCV cases in the state. However, there has been an increasing trend in new HCV infections among young people, primarily due to injection drug use (Louisiana Department of Health, 2019). In 2019, 39 years and younger accounted for an estimated 36% of chronic HCV diagnoses in Louisiana (Louisiana Department of Health, 2020). People of low-income status, Medicaid enrollees, and incarcerated are disproportionately affected (Louisiana Department of Health, 2020).

**Hepatitis C Care and Treatment**

The American Association for the Study of Liver Disease (AASLD) recommends treatment for all with chronic HCV infection except persons with a short life expectancy that would not be remediated by HCV treatment, liver transplantation, or another directed therapy (American Association for the Study of Liver Disease (AASLD), 2017). HCV treatment is considered curative when there is sustained virologic response (SVR), defined as absence of detectable HCV 12-weeks post-treatment completion (AASLD, 2017). The current standard of
HCV care is direct acting antiviral therapy (DAA). DAA specifically targets the encoded proteins that are critical to the replication of the virus (Poordad & Dieterich, 2012). Compared to the old treatment regimen, these direct-acting antivirals have significantly improved cure rates, particularly for those with genotype 1 infection, individuals who previously failed treatment, and those with moderate to severe liver disease progression (Ward & Mermin, 2015).

Prior treatment regimen for HCV consisted of a combination of pegylated interferons, administered as an injection, and ribavirin. The regimen required long treatment durations, up to 48 weeks for some patients, and had many severe adverse side effects, including depression, muscle aches, and cognitive deficits (Dusheiko, 1997; Manns, Wedemeyer, & Cornberg, 2006). During this treatment period, HCV genotype was the strongest predictor of treatment response (Fried et al., 2002; Manns et al., 2001). Genotype 1 infection was considered the hardest to treat, requiring the longest duration of treatment with the least likelihood of success (Pearlman, 2008). Less than 50% of treatment naïve patients infected with genotype 1 achieved SVR with the old standard of care therapy (Fried et al., 2002; Manns et al., 2001). Advancements in HCV treatment have significantly improved SVR outcomes, especially for individuals with genotype 1 infection (Feld et al., 2015; G. R. Foster et al., 2015; Ward & Mermin, 2015).

The current HCV standard of care therapy (interferon-free, direct-acting antivirals) is more effective, has significantly less severe side effects, and shorter treatment durations (8-24 weeks) (Ward & Mermin, 2015). Results of four randomized clinical trials of the direct-acting antiviral combination- sofosbuvir and velpatasvir-, showed nearly 100% efficacy in treatment naïve patients and those who previously failed treatment, including patients with genotype 1 and cirrhosis (Feld et al., 2015; G. R. Foster et al., 2015; Ward & Mermin, 2015). In addition, the FDA recently approved the first all oral DAA regimen for treatment of genotype 1 (Das &
Pandya, 2017). Despite improvements in HCV therapy, HCV treatment uptake remains low in the United States and less than 20% of HCV infected individuals achieve SVR (Brady et al., 2018).

People living with chronic HCV infection must achieve specific care milestones to achieve a sustained virologic response. Engagement in HCV care occurs along a continuum, and the process is bi-directional as it is not uncommon for persons living with chronic HCV to drop out of care before initiation (or completion) of treatment. The HCV treatment cascade outlines the stages of engagement in care for persons living with chronic HCV (Figure 1).

**Figure 1:** Treatment Cascade for People Living with HCV Infection as Developed by Brady, 2018

---

**Figure 1.** Care Cascade Among HCV Antibody–Positive Patients Born From 1945-1965 at 3 Academic Medical Centers, December 2012-October 2015.

<table>
<thead>
<tr>
<th>Cascade Steps</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCV seropositive</td>
<td>130 (100%)</td>
</tr>
<tr>
<td>RNA tested</td>
<td>118 (91%)</td>
</tr>
<tr>
<td>RNA positive</td>
<td>75 (59%)</td>
</tr>
<tr>
<td>Received an evaluation from an HCV specialist</td>
<td>73 (54%)</td>
</tr>
<tr>
<td>Initiated treatment</td>
<td>22 (17%)</td>
</tr>
<tr>
<td>Completed treatment</td>
<td>21 (14%)</td>
</tr>
<tr>
<td>Viral load indicating virologic response at end of treatment</td>
<td>16 (11%)</td>
</tr>
</tbody>
</table>

HCV indicates hepatitis C virus.

*The proportions of patients in each step of the HCV care cascade from the patients who were HCV antibody–positive are shown in parentheses above each bar. The proportions of patients in each step of the HCV care cascade from the patients in the preceding step are shown in the arrows between each bar.

*Only 14 patients completing treatment had viral load data available and all 14 patients showed a virologic response at the end of treatment.

**HCV Treatment Cascade**
The stages of the HCV treatment cascade are: 1) HCV diagnosis, 2) HCV appointment attendance, 3) treatment initiation, and 4) treatment completion 5) achieved SVR (US Department of Health and Human Services, 2015; (Brady et al., 2018). A retrospective analysis, which investigated the gaps along the HCV treatment cascade, found that among those living with chronic HCV in the United States, only 58% were diagnosed chronic HCV positive, 56% attended an HCV evaluation appointment, 17% initiated treatment, and 11% were cured (Brady et al., 2018). A study conducted by Chhatwal et al. (2019) reports that among all persons living with chronic HCV in the United States, less than 40% have been linked to HCV care.

**Summary**

The vast majority of people living with chronic HCV do not progress through the HCV treatment cascade, and as a result, they do not benefit from HCV treatment. A study, which uses a mathematical model to predict the impact of testing and treatment on the burden of HCV at the country level, demonstrates a significant decrease in HCV prevalence and incidence as more people with HCV are successfully treated (Weydemeyer, 2014). Reducing the burden of HCV has become a national priority, as evidenced by the development of The U.S. National Viral Hepatitis Action Plan: 2020-2025, which aims to: 1) prevent new viral hepatitis infections, 2) reduce deaths and improve the health of people living with viral hepatitis, and 3) reduce viral hepatitis disparities by 2030 (CDC, 2020).

There is a critical knowledge gap about factors influencing linkage and retention in HCV care, especially related to DAA treatment. Gaining a better understanding of these factors can result in the development of care models and interventions that facilitate engagement in HCV care; and help mitigate HCV incidence, morbidity, and mortality in the United States.
Chapter 2: Literature Review

Theoretical Framework

The social-ecological model (SEM) will be used to guide the study of barriers and facilitators to HCV care. The social-ecological model (SEM) is a theory-based framework that is used to understand the complex interplay between the individual and environmental factors on health behavior. The SEM posits that individual behavior affects and is affected by multiple levels of influence and that the relationship between the individual and his/her environment is reciprocal. That is, the individual shapes and is shaped by the environment (McLeroy, Bibeau, Steckler, & Glanz, 1988).

A number of researchers have contributed to the development of the social-ecological model. In 1977, Bronfenbrenner first introduced the social-ecological perspective through his ecological systems theory, which focused on the relationship between the individual and the environment (Bronfenbrenner, 1979). A decade later, McLeroy, Bibeau, Steckler, and Glantz (1988) argued that health behavior is influenced by factors at five levels: intrapersonal (e.g. biological and personal history factors), interpersonal (e.g. relationships with peers, partners, providers), organizational (e.g. institutional rules, policies, and structures), community (e.g. community norms), and policy level environments (e.g. local, state, and federal policies).

The use of the SEM is an appropriate framework for exploring the barriers and facilitators to HCV care. Within this framework, neither individual nor environmental factors are mutually exclusive in their influence on engagement in HCV care, but rather their interaction. Prior studies have applied the SEM framework to study barriers and facilitators to cervical cancer screening, prenatal care for low-income women, and adherence to HIV treatment among
Puerto Rican HIV patients (Castro, Santiago, Jimenez, Davila-Vargas, & Rosal, 2015; Daley, Alio, Anstey, Chandler, Dyer & Helm, 2011; Sword 1999). One researcher also demonstrated the applicability of the SEM model in exploring barriers and facilitators to prenatal care from the provider perspective (Sword, 1999). In this study, I will explore multiple levels of the SEM, which may influence engagement in care.

Figure 2 depicts an adaption of Kauffman’s (2014) SEM as it relates to engagement in HCV care (Kaufman, Cornish, Zimmerman, & Johnson, 2014). Within this adapted social-ecological framework, the factors that influence linkage and retention in HCV care occur at the patient, provider, health care system, and structural levels. The patient level comprises HCV specific barriers (e.g. disease status, HCV perceptions) and general barriers (e.g. stability factors, competing health social priorities). The provider level includes patient-provider relationships and provider knowledge. At the health care system level, factors include testing experience, access to health care, and fragmented health care services. Factors at the structural level include treatment costs, insurance reimbursements, and criminalization.

**Figure 2:** Factors influencing linkage and retention in HCV care at each level of the socio-ecological model adapted from Kaufman et al., 2014
**Barriers and Facilitators to Linkage and Retention in HCV Care**

Patients living with chronic HCV infection often face challenges, which make linkage and retention in HCV care difficult. Researchers have identified multilevel challenges to linkage and retention in HCV care, occurring at the patient, provider, health care system, and structural levels (See Table 1). Further, there is no standardized definition for linkage or retention in HCV care, which varies across studies. For the purpose of this review, linkage to HCV care definitions include having obtained access to HCV care, referral to a specialist or someone who can treat HCV or attending an appointment for HCV care. Retention or care engagement in care definitions include being followed by a physician for HCV related care, HCV care appointment adherence, and treatment initiation (Butt, McGuinness, Buller-Taylor, & Mitchell, 2013; Janjua et al., 2016; Ramirez et al., 2016; Reynolds, Fisher, Jaffe, & Edwards, 2006; Tohme, Xing, Liao, & Homberg, 2013; Trooskin, Reynolds, & Kostman, 2015).
Table 1: Barriers to HCV Care at Each Level of the Social-Ecological Model

<table>
<thead>
<tr>
<th>Patient</th>
<th>Provider</th>
<th>Health Care System</th>
<th>Structural</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HCV-Specific Barriers</strong></td>
<td><strong>Provider-patient relationship</strong></td>
<td><strong>Testing experience</strong></td>
<td><strong>Cost of treatment</strong></td>
</tr>
<tr>
<td>• Disease status (e.g. genotype, fibrosis stage)</td>
<td>• Knowledge</td>
<td>• Fragmented health care services</td>
<td>• Insurance reimbursements</td>
</tr>
<tr>
<td>• Lack of symptoms</td>
<td>• Training and skills</td>
<td>• Availability and access to health care (appt availability, restrictive appointment policies, long wait times, geographic location)</td>
<td>• Criminalization</td>
</tr>
<tr>
<td>• Treatment side effects and duration</td>
<td>• Cultural sensitivity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Negative beliefs surrounding HCV and HCV treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• HCV stigma</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>General Barriers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Competing health and social responsibilities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Access to healthcare</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Stability factors (e.g. income, housing, transportation)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Patient**

**HCV-Specific Barriers.**

*Disease status.* Treatment is recommended for all persons living with HCV, regardless of genotype and liver disease severity, unless life expectancy is low and could not be remedied by treatment (AASLD, 2017). However, previous research indicates HCV genotype and severity of liver disease may impact linkage and retention in HCV care, especially as it relates to the consideration for treatment and treatment initiation (Grebely, Oser, Taylor, & Dore, 2013; Spradling et al., 2017). (Bass et al., 2018; Spradling et al., 2018) A study, which followed a cohort of HCV patients from Johns Hopkins HIV clinic found that non-HCV genotype 1 was a predictor of HCV treatment initiation among HIV/HCV coinfected indiviudals (Wansom et al., 2017). A similar finding was reported by Spradling et al. (2017), with patients with HCV genotype 2 infection more than two times more likely to initiate DAAs compared to patients with HCV genotype 1 infection.
The severity of liver disease may deter or encourage linkage and retention in HCV care. Spradling et al. (2017) found that higher fibrosis scores were significantly associated with DAA initiation compared to individuals with lower Fibrosis scores. Another study found that retention in HCV care was more likely among those with cirrhosis compared to those without (Janjua et al., 2016).

**HCV Treatment Perceptions.** Among infected patients, misconceptions about HCV and treatment, due to poor knowledge, are a significant barrier to linkage and retention in HCV care (Jordan et al., 2013; Pundhir et al., 2016). One study which conducted focus groups with PWID found that beliefs revolving around HCV being an untreatable disease was a barrier to treatment (Jordan et al., 2013). A cross-sectional study, which examined factors associated with appointment keeping behavior found that fears that treatment would worsen other diseases and the belief that HCV infection is not an important health risk were significantly associated with lower HCV-related care appointments adherence (Pundhir et al., 2016). Persons living with HCV have also reported doubts about the efficacy of HCV treatment and have therefore decided not to seek or initiate treatment for the infection (Rebeiro et al., 2013; Rogal et al., 2017; Treloar, Rance, & Backmund, 2013).

**Treatment Related Factors.** Factors such as treatment duration, side effects, and regimen have been reported as barriers to linkage and retention in HCV care (Harris & Rhodes, 2013; Khokhar & Lewis, 2007); (Adams, Balderson, & Packett, 2018) Researchers have demonstrated that being treatment naive, or not ever receiving treatment for HCV, is a barrier to retention in HCV care, specifically treatment initiation (Cope, Glowa, Faulds, McMahon, & Prasad, 2016; Fusfeld et al., 2013). A retrospective cohort study found that HCV treatment naïve individuals were significantly less likely to be considered for treatment and initiate therapy
(Cope et al., 2016). During the interferon era, the need to inject HCV medication was found to be a barrier to treatment uptake due to the fear of needles, discomfort with self-injections, and potential reminders of illicit drug use (Fusfeld et al., 2013). Though DAAs are now the standard of care, inadequate knowledge about HCV treatment may cause these perceptions to persist among persons living with chronic HCV infection.

**HCV-Related Stigma and Discrimination.** A consistently reported barrier to linkage and retention in HCV care throughout the literature is stigma and discrimination (Grebely & Tyndall, 2011; North et al., 2013; Searson, Engelson, Carriero, & Kotler, 2014). Individuals whose disease status is due to engaging in a stigmatized behavior (e.g. PWID), fear being judged negatively by providers. As “self-protection” from stigma and discrimination, some infected individuals choose not to seek care and treatment for HCV (Butt et al., 2013). Conversely, stigma has been found to positively impact engagement in HCV care (Sublette, Smith, George, McCaffery, & Douglas, 2015). Sublette et al. (2015) conducted interviews with twenty patients at a liver clinic in Australia and found that fear of stigma and discrimination due to positive HCV status was a motivator for initiating and completing HCV treatment.

**General Barriers.**

**Competing Health and Social Priorities.** Mental health problems has been a commonly reported issue among persons living with HCV, irrespective of HCV antiviral therapy (Rifai, Gleason, & Sabouni, 2010). A number of studies have mentioned psychiatric disorders as a significant barrier to retention in HCV care, specifically treatment eligibility and treatment initiation (North et al., 2013; Rogal et al., 2017). Rogal et al. (2017) conducted interviews with primary care and liver care specialists and found that presence of mental health disorders was a frequently reported barrier to treatment eligibility and initiation.
Several studies describe substance use (including alcohol) as a barrier to accessing and remaining engaged in HCV care (Astell-Burt, Flowerdew, Boyle, & Dillon, 2012; North et al., 2013; Poll, Allmark, & Tod, 2017). Grebely et al., (2008) found individuals who reported current heroin use were significantly less likely to initiate HCV treatment. A multisite prospective cohort study found a significant association between alcohol assumption and reduced HCV treatment candidacy and early discontinuation of HCV therapy (Seal et al, 2007).

The literature further shows that the presence of comorbidities facilitates linkage to HCV care (M. A. Foster et al., 2016; Franco et al., 2016). Foster et al. (2015) found that patients that had more than two comorbidities at the time of diagnosis were more likely to have had an HCV specialty care visit compared to those without any comorbidities. In this study, comorbidity status was measured by the Charlson Comorbidity index, which assesses the presence of a number of comorbidities, including Chronic Pulmonary Disease, liver disease, HIV/AIDS.

While the presence of comorbidities facilitates linkage to HCV care, researchers have found the opposite to be true as it relates to retention in HCV care. A number of researchers have reported the presence of comorbidities (e.g. diabetes, renal disease, hypertension, mental disorders) as a barrier to retention in HCV care (King & Bornschlegel, 2016; Poll et al., 2017). In contrast, persons living with HIV/AIDS coinfection have better retention in HCV care compared to individuals with HCV monoinfection (Janjua et al., 2016; Spradling et al., 2017). In the Chronic Hepatitis C Cohort Study, researchers found that persons with HIV/HCV coinfection had nearly two times higher odds of DAA initiation (Spradling et al., 2017).

Competing social responsibilities, such as work, family, and caregiver duties have also been reported as a barrier to attending HCV care appointments and HCV treatment initiation (Butt et al., 2013; Grebely et al., 2013; (Butt et al., 2013; Grebely et al., 2013; Treloar, Newland,
Rance, & Hopwood, 2010). In a qualitative study of HCV patients and providers conducted by Butt et al. (2013), one woman described how concern for her HCV infection was replaced by the needs of her sick husband. In another qualitative study, several women described how parental duties were a barrier to initiating HCV therapy (Treloar et al., 2010). For instance, one woman discussed how she did not go on HCV treatment, specifically interferon therapy, because she just had a baby and was responsible for taking care of four children, including the baby. The woman went on to discuss how she did not want to develop depression, a common side effect of treatment, because she would not be able to take care of her children (Treloar et al., 2010).

**Access to Health Care.** Insurance status is a major factor that could hinder or facilitate engagement in care. Persons who lack insurance or have public health insurance (vs. private insurance) have difficulty accessing HCV care (Falade-Nwulia, 2019; Higashi et al., 2020). A retrospective cohort study of baby boomers newly diagnosed with HCV found that uninsured individuals had significantly higher odds of failure to link to HCV care compared to persons with any insurance (Franco et al., 2016). Another retrospective cohort study found that individuals with commercial insurance coverage were 6.5 times more likely to initiate HCV therapy compared to individuals with Medicaid coverage (Younossi et al., 2016).

**Stability Factors.** Financial instability, lack of transportation, housing instability, and food insecurity make linkage and retention in HCV care difficult (Colasanti, Stahl, Farber, Del Rio, & Armstrong, 2017; Noska, Belperio, Loomis, O'Toole, & Backus, 2017). Prior research shows a higher income status is significantly associated with better linkage and retention in HCV care (Spradling et al., 2017; Tohme et al., 2013). Interviews with patients who had poor attendance at an HCV outpatient clinic described financial constraints, due to low income and
other financial priorities (e.g. high cost of travel, drug addiction) as barriers to attending their HCV care appointments (Poll et al. 2015).

Similarly, a number of researchers have consistently reported a lack of transportation as a major barrier to appointment adherence and initiation of HCV treatment (Butt et al., 2013; Clark & Garcia-Tsao, 2012; Rogal et al., 2017). Unstable housing, especially homelessness, has also been identified as a barrier to HCV treatment eligibility and initiation (Rogal et al., 2017).

**Social Networks and Support.** Social networks can impede or enable linkage and retention in HCV care. Peer support groups have been found to encourage engagement in care due to having had a positive and successful care and treatment experience. Respondents of one study indicated that their peer support network, comprised of patients who had completed treatment and achieved a sustained virologic response, served as encouragement for their own care and treatment process (Rich et al., 2016).

**Provider**

**Patient-Provider Relationships.** One of the most important factors affecting engagement in HCV care is the quality of the relationship a patient has with his/her provider. One study, which conducted focus groups with PWID, found that mistrust in provider’s motivations for diagnosing and recommending treatment was a barrier to HCV treatment (Jordan et al., 2013). Rude, patronizing, and judgmental attitudes coupled with poor communication and lack of encouragement by providers and other clinic staff negatively impact linkage and retention in HCV care (Butt et al., 2013; Harris & Rhodes, 2013; North et al., 2013; Poll et al., 2017).

Providers can facilitate retention in HCV care by supporting, encouraging, and keeping patients informed about the success of HCV treatment (Fusfeld et al., 2013; Lebovics, Torres, &
Porter, 2017; Rogal et al., 2017). Through the fostering of a positive relationship with a patient, providers may also serve as a form of social support for persons living with chronic HCV infection (Rich et al., 2016).

**Provider Knowledge.** Other provider-related factors that impact linkage and retention in HCV care include lack of HCV knowledge, training, or skills to diagnose and treat HCV, lack of confidence, and poor communication (Chastain et al., 2015; Grebely et al., 2013; North et al., 2013). Patients whose provider have more confidence about their ability to provide HCV care and treatment were more likely to accept the recommendation to start treatment (Osilla et al., 2011). However, a survey analysis of infectious disease physicians in North America found that a substantial proportion (61%) of providers did not feel they had not received adequate training to evaluate, treat, and manage HCV in clinical practice (Chastain et al., 2015).

Provider perceptions about who should receive treatment and who would be successful on treatment are consistently reported as barriers to retention in care (Grebely et al., 2013; North et al., 2013). A common misconception among providers is that persons who are actively using drugs would not successfully complete treatment. Due to this misconception, providers fail to refer persons with active drug use to HCV treatment, which often leads to delays or failure to entry into HCV care (Grebely et al., 2013).

**Cultural Sensitivity.** Persons living with chronic HCV infection have reported provider insensitivity related to drug using behavior as a barrier to accessing care. It is important that providers understand drug-using identity to facilitate linkage and retention in care among this high-risk population (Rich et al., 2016).

*Health Care System*
Testing Experience. Factors at the health care system level make it challenging for persons living with HCV to access and remain in care. Prior research has found the testing experience and type of test administered to impact engagement in HCV care. For instance, Morano et al. (2014) found that individuals who selected point of care, rapid testing were significantly more likely to link to HCV specialty care compared to those who selected the traditional blood test for HCV.

Additionally, the testing experience as a whole, can impact engagement in care for persons diagnosed with HCV. In a qualitative study examining the factors contributing to nonattendance for HCV care, many respondents said they felt judged and discriminated against during their initial visit, which prevented them from seeking further care (Butt et al., 2013).

Fragmented Health Care Services. A number of studies have reported that segregated services, such as the exclusion of supportive services (e.g. substance abuse treatment, mental health services, case management services), as a crucial barrier to engagement in HCV care (Butt et al., 2013; North et al., 2013; Rich et al., 2016). Provision of supportive services has been found to improve HCV care and treatment outcomes (Falade-Nwulia et al., 2016; Norton et al., 2017). Butt et al. (2013) reported that patients were more likely to attend HCV care appointments if services were fully integrated and co-located (Butt et al., 2013).

Access to Health Care Services. Researchers have consistently reported factors related to access to services as barriers to linkage and retention in HCV care (Butt et al., 2013; Harris & Rhodes, 2013; Poll et al., 2017). Limited appointment availability coupled with restrictive appointment policies can create challenges for persons to adhere to HCV care appointments (Butt et al., 2013; Harris & Rhodes, 2013; Poll et al., 2017). Long wait times, especially for
patients with competing responsibilities (e.g., work, caregiving responsibilities), make it difficult for patients to engage in care.

Lack of access due to geographic location has been reported as a barrier to accessing HCV care and initiating treatment (Clark & Garcia-Tsao, 2012; Crowley et al., 2017; Poll et al., 2017). Results from a community-based HCV screening, linkage to care, and patient navigation program, demonstrated that long travel times increased the likelihood of non-referral to HCV specialty care (Astell-Burt et al., 2012).

**Structural**

**Treatment Costs.** The high cost of treatment serves as a major barrier to accessing and remaining in HCV care (Iyengar et al., 2016; Lynch & Wu, 2016; Trooskin et al., 2015). The cost of HCV treatment for a 12-week regimen ranges from $84,000 (Solvadi) to $95,000 (Harvoni) (Trooskin et al., 2015). The cost increases if the treatment duration is greater than 12 weeks. Because of the exorbitant costs of treatment, Medicaid is rationing the medication, and other insurers have implemented restrictions preventing many from even being eligible to receive coverage for the treatment costs (Trooskin et al., 2015). Lobbying efforts and threats of legal proceedings for generic drug options to lower HCV treatment costs have become major topics of discussion. These efforts are expected to decrease HCV treatment costs and help to improve access to treatment for all persons living chronic HCV infection.

**Insurance Reimbursements.** Due to the high treatment costs, insurance companies have made efforts to ration treatment by imposing restrictions for treatment reimbursement. These strict restrictions for insurance reimbursements, especially under the Medicaid program, hinder linkage and retention in HCV care (Barua et al., 2015; Butt et al., 2013). A systematic evaluation of state Medicaid policies was conducted to examine the nationwide restrictions for
Medicaid reimbursements (Barua et al., 2015). Results from the policy analysis indicated that approximately 25% of policies required that persons with HIV/HCV coinfection be receiving antiretroviral therapy or be virally suppressed. Nearly 90% of policies had restrictions due to alcohol and drug use, with 50% requiring abstinence for 30 days or more. More than 60% of the policies required urine drug screening tests. Though prevalent, these restrictions do not fall in line with the current medical recommendations and guidelines for treatment of HCV (Barua et al., 2015).

**Criminalization.** Patients have reported criminalization of drug using behavior as a barrier to linkage and retention in HCV care. Patients who inject drugs fear being arrested or charged with a crime if they disclose injection drug using behavior, making it less likely they will link to or remain in care (Ford & Bressan, 2014)

**Summary**

HCV incidence and mortality are on the rise. Though highly curative DAA therapy for HCV is available, less than 10% of people living with HCV are cured of the disease. The reason the vast majority of persons with HCV are not cured is because multi-level barriers make it challenging for them to access and remain in care. The economic considerations of HCV treatment appear to be widely known. However, there is a critical knowledge gap about other important factors influencing linkage and retention in HCV care, especially related to DAA treatment. Gaining a better understanding of all of the factors influencing linkage and retention can result in the development of care models and interventions that improve HCV care engagement, and help to mitigate HCV incidence, morbidity, and mortality in the United States. Most prior research has focused on barriers and facilitators to care during the interferon and ribavirin treatment period. Among the studies, which have explored barriers and facilitators to
care in this new treatment period, few have been conducted in the United States. Even fewer studies have been conducted which investigated the barriers and facilitators to HCV care for persons living with HCV mono-infection. The following sections will discuss the study research questions and the methods to address this gap in the literature.

**Research Questions**

1) What are the strategies that are being used to facilitate linkage to and retention in HCV care in the United States?
   a) What is the state/quality of studies which examined strategies to facilitate linkage to and retention in HCV care in the United States?
   b) What are the effects of these strategies on linkage to and retention in HCV care as defined by HCV appointment attendance, treatment initiation, treatment completion, and achievement of SVR-12?
   c) What are the gaps in evidence in the existing literature on strategies to facilitate linkage to and retention in HCV care?

2) What are the barriers and facilitators to HCV care among persons (ages 18 years and older) living with HCV in the Greater New Orleans area?
   a) What are the patient level barriers and facilitators to care?
   b) What are the provider level barriers and facilitators to care?
   c) What are the health care system barriers and facilitators to care (e.g., fragmented health care services, facility policies and procedures)?
   d) What are the structural barriers and facilitators to care (e.g., cost of treatment, national standard of care policies, criminalization)?
Specific Aims

1) To identify and evaluate strategies that have been used to link and retain individuals in HCV care in the United States.

2) To explore the multilevel barriers and facilitators to linkage and retention in HCV care in New Orleans.

3) To develop recommendations for an evidence-based comprehensive standard of care model to facilitate linkage and retention in HCV care.
Chapter 3: A SYSTEMATIC REVIEW OF BEST PRACTICES TO FACILITATE LINKAGE TO AND RETENTION IN HEPATITIS C CARE

Introduction

Globally, Hepatitis C continues to be a significant public health problem. An estimated 71 million people are living with chronic Hepatitis C worldwide, and approximately 2.4 million people are living with chronic Hepatitis C in the United States (Hofmeister, 2019; World Health Organization, 2020). In the United States, chronic Hepatitis C is a major cause of liver damage, cirrhosis, hepatocellular carcinoma, and the primary reason for liver transplantation (CDC, 2020). In 2018, nearly 16,000 people died of Hepatitis C-related causes (CDC, 2020). This number is believed to be underestimated as many Hepatitis C-related deaths go undocumented on death certificates (Mahajan et al., 2014).

The number of people living with chronic Hepatitis C has declined, which has been chiefly attributed to the highly effective therapy and high all-cause mortality among the HCV infected population (Hofmeister et al., 2019). Though we are experiencing progress in reducing the number of people living with chronic Hepatitis C, the number of new chronic Hepatitis C diagnoses continues to rise (Ryerson et al., 2020). Historically, the number of people living with chronic Hepatitis C has been the highest among baby boomers (persons born between 1945 and 1965) (Hofmeister et al., 2019). However, in recent years the number of younger people living with chronic Hepatitis C has steadily increased (Ryerson et al., 2020). In 2018 millennials (persons born during 1981-1996) accounted for an estimated 37% of newly reported chronic Hepatitis C cases, followed by baby boomers and Generation X (persons born during 1966-1980), which accounted for 36% and 23% of newly reported chronic Hepatitis C infections, respectively (Ryerson et al., 2020). The increase in chronic Hepatitis C infections among young
adults is attributed to the opioid epidemic, specifically the transition from prescription drug use to heroin use via injection (Zibbell et al., 2018).

There is no vaccine to prevent Hepatitis C infection; however, Hepatitis C can be treated and cured (Panel, 2018). The treatment for chronic Hepatitis C has evolved within the last ten years. The former treatment for chronic Hepatitis C was a combination of interferon, administered via injection, and ribavirin, which had severe side effects, long treatment durations, and low cure rates (Dusheiko, 1997; Manns, Wedemeyer, & Cornberg, 2006). In 2014, the FDA approved the first all-oral DAA regimen to treat chronic Hepatitis C, which subsequently became the standard of care for persons with chronic Hepatitis C infection (Das & Pandya, 2018). Compared to the old treatment, the new DAA therapy has fewer side effects, shorter treatment durations, and nearly 100% cure rates (Feld et al., 2015; G. R. Foster et al., 2015; Ward & Mermin, 2015).

The World Health Organization has made the Hepatitis C epidemic a public health priority. In 2016, WHO set goals for eliminating Hepatitis C, calling for a 90% reduction in new HCV infections, a 65% reduction in HCV mortality, and treatment of 80% of all eligible patients by 2030 (World Health Organization, 2020). In order to meet the WHO achievement goals, persons living with Hepatitis C must successfully progress through the HCV treatment cascade. The Hepatitis C treatment cascade serves as a framework for monitoring the progress of the stages of engagement in care for persons living with chronic HCV (Yehia et al., 2014). The stages of the HCV treatment cascade are 1) HCV diagnosis, 2) linkage to care, 3) treatment initiation, and 4) achieved sustained virologic response (SVR) (Yehia, Schransz, Umscheid, & Lo Re, 2014). Despite the availability of the highly effective and more tolerable DAA therapy to
treat Hepatitis C, a large proportion of persons are not successfully engaged in care and cured of their infection.

Being engaged in Hepatitis C care (i.e., linkage to and retained in) is vital to achieving a cure for persons with chronic Hepatitis C infection. Chhatwal et al. (2019) found that among all persons with chronic Hepatitis C infection in the United States, only an estimated 37% received treatment, and 37% were cured in 2018. Haley et al. (2021) paints a grimmer picture. Among women with chronic Hepatitis C living in the United States, 17% initiated treatment, 10% completed treatment, and 9% were cured. Similar rates were found among men living in the United States, with 12% having initiated treatment, 12% having completed treatment, and 11% being cured (Haley et al., 2021).

Although Hepatitis C is a curable disease, these low estimates are evidence that engagement in care remains a challenge. Identifying best practices in HCV care will provide researchers, health care practitioners, and policy makers with useful information to develop evidence-based care models that facilitate engagement in care. “Best practices” are defined as those practices that on rigorous evaluation have shown evidence of effectiveness in a particular setting and are likely to be replicable in other situations (Ng & de Colombani, 2015).

Though Hepatitis C is a curable disease, it continues to have significant medical and social implications. This systematic review aims to identify best practices that may help to increase the percentage of people with chronic Hepatitis C infection who are linked to and retained in Hepatitis C care during the DAA therapy era. Improving engagement in Hepatitis C care outcomes is vital to reaching the WHO Hepatitis C by 2030 achievement goals.

Methods
This systematic review was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement guidelines (Page et al., 2021). The PRISMA checklist is provided in Appendix A. At the start of conducting this review, there were very few published studies which assessed engagement in Hepatitis C care practices, particularly during the DAA era. Due to the dearth of literature on the topic, databases were searched periodically, beginning in 2019, to capture as many relevant articles as possible for the systematic review. All database searches ceased March 2021. Ethics approval was not required as this was a systematic review of already published studies. Covidence (Melbourne, Australia), a web-based software platform that streamlines the production of systematic reviews, was used to screen, select, and extract data from the included studies (Babineau, 2014).

Search Strategy

The following four electronic databases were searched for peer-reviewed and grey literature publications: CINAHL, PUBMED, EMBASE, PROQUEST. The search terms were developed by reviewing the literature, reviewing medical subject heading (MESH) terms, and consulting with a librarian from Tulane Rudolph Matas Library of Health Sciences. The search of the electronic databases was geared towards identifying studies that aimed to address engagement in Hepatitis C care in the United States, specifically linkage and retention in care. The following search terms were used for each electronic database: Hepatitis C AND United States AND Care OR (Patient Care). The search of the electronic databases was limited to publications written in the English language and published between 2011 to 2021. The year 2011 was chosen as the starting point because it is the year that the FDA approved the first DAAs for the treatment of Hepatitis C; thus, changing the standard of care for Hepatitis C to include the new DAAs. Before 2011, the combination of Ribavirin and Interferon was used as the standard
of care treatment for Hepatitis C infection (Dusheiko, 1997; Manns, Wedemeyer, & Cornberg, 2006). Moreover, because the goal of this systematic review was to identify “best practices,” only those studies which aimed to establish cause and effect were included in the review.

The results from each database search were imported into Covidence. Once imported into Covidence, duplicate publications were automatically removed. The abstracts were screened and any studies that did not meet the inclusion criteria were removed. Next, the full texts of publications were reviewed and that did not meet the inclusion criteria were removed. Data were extracted from the remaining publications.

**Inclusion and Exclusion Criteria**

The studies in the systematic review were selected based on the criteria outlined in Table 1. PICOS (Population, Intervention, Comparison, Outcomes, and Study) design was used as the framework to outline inclusion criteria (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014).

<table>
<thead>
<tr>
<th>PICOS Strategy</th>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
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<tbody>
<tr>
<td>P (Population)</td>
<td>Persons diagnosed with Hepatitis C, 18 years or older, living in the United States</td>
<td>Pregnant women, infants, children, and individuals with HIV/HCV coinfection</td>
</tr>
<tr>
<td>I (Intervention)</td>
<td>Engagement in Hepatitis C Care interventions, specifically those targeting linkage and retention in care</td>
<td></td>
</tr>
<tr>
<td>C (Comparison)</td>
<td>Control or comparison group is required</td>
<td></td>
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<tr>
<td>O (Outcome)</td>
<td>Health records and self-reported measures on</td>
<td></td>
</tr>
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</table>
linkage and retention in Hepatitis C care | Quantitative or qualitative study designs
---|---
S (Study Design) |  

Studies were excluded if they specifically targeted pregnant women, infants, children, and individuals with HIV/HCV coinfection. These groups are considered unique and special populations, such that the general care and treatment guidelines may not apply (American Association for the Study of Liver Disease, 2020). No specific study designs were excluded from the review.

**Engagement in Hepatitis C Care Definitions**

To date, there are no standardized definitions for engagement in Hepatitis C care (Chhatwal et al., 2019; Haley et al., 2021; Yehia et al., 2014). For the purpose of this systematic review, linkage to care was defined as Hepatitis C care appointment attendance and treatment initiation. Retention in care was defined as completion of Hepatitis C treatment or achieved SVR.

**Data Abstraction**

Joanna Briggs Institute (JBI) guidelines for data extraction were used to create a template to standardize the data extraction process for each eligible study (Munn, Tufanaru, & Aromataris, 2014). The Joanna Briggs Institute is an international research and development organization within the Faculty of Health Sciences at the University of Adelaide, which specializes in promoting and supporting evidence-based healthcare. Appendix B provides a copy of the JBI informed standardized data extraction template. Relevant information from each study was extracted including the study aim, study design, the setting where the study was conducted,
sample size, participant characteristics, the indicators used to measure linkage and retention in HCV care, key findings, and study strengths and limitations.

**Quality Assessment**

The quality of all studies was assessed using the JBI Critical Appraisal tool. This standardized tool was chosen because it can be used to assess diverse study designs. **Appendices F-G** provides a copy of the JBI Critical Appraisal Checklist used for the relative study design.

**Data Synthesis**

A qualitative synthesis was conducted (Creswell, 2007). Data summary tables were created to present the findings (**Appendices H & I**)

**Results**

**Search Results**

For this systematic review, 2167 studies were identified in the electronic search. After 300 duplicates were removed, 1867 abstracts were screened, and 111 full-text manuscripts were evaluated. Fifteen manuscripts were included in the review. The PRISMA Diagram is found in **Appendix D**.

**Study Characteristics**

The majority of studies were conducted in a healthcare setting, four of which were conducted in a Veterans Affairs health care system. Eleven of the studies took place in a community clinic or teaching health care center. One study took place in a drug rehabilitation program and one at a harm reduction organization. One study utilized the state department of health database to recruit participants into the study. Five of the studies utilized a randomized controlled trial (RCT) study design. Five studies used a quasi-experimental study design. Three
studies utilized a cohort study design. Among the fifteen included studies, only one used a case-control study design.

The fifteen studies were conducted between 2008 and 2019 and published between 2013 and 2020. A total of 312,363 individuals participated in the 15 included studies. The study subjects included in this review were adult patients with Hepatitis C infection. Among these studies, one studied Veterans, two studied individuals with a history of psychiatric illness (i.e., depression, post-traumatic stress disorder), and two studied individuals with a history of illicit drug use. The majority of participants in the 15 included studies were male and of older age (45 years and older). The length of follow-up time ranged from ten months to four years. Only two studies reported outcomes which included interferon-based regimens.

**Linkage to and Retention in Care Measures**

Seven studies examined the effects of an intervention on linkage to care. Among these seven studies, five defined linkage to care as HCV appointment attendance. Six of the studies defined linkage to care as treatment initiation. Linkage to care was defined as the time to treatment initiation in two studies. Researchers examined the effects of an intervention on retention in care in nine of the studies. Retention in care was defined as treatment completion in four studies. Nine studies defined retention in care as achieving a sustained virologic response 12 weeks post-treatment completion (SVR-12).

**Quality Assessment Review**

None of the RCTs fulfilled the checklist criteria of the JBI Critical Appraisal Checklist for Randomized Controlled Trials (Ho et al., 2015; Kanwal et al., 2018; Masson et al., 2013; Webster, Moore, Bocour, Johnson, & Winters, 2020; Wohl et al., 2017). Missing or unclear information was found in all five of the RCTs. Specifically, the articles were missing or provided
unclear information regarding true randomization (n=3), concealment of treatment group allocation (n=4), blinding of treatment (n=5), reliability of measures (n=4), and the appropriateness of the statistical analysis (n=1). Out of thirteen criteria, the highest-scoring article fulfilled 12 out of 13 criteria. The lowest scoring article fulfilled four.

None of the six included quasi-experimental studies completely fulfilled the checklist criteria on the JBI Critical Appraisal Checklist for Quasi-Experimental Studies (Beste et al., 2017; Boodram et al., 2020; Hodges, Reyes, Campbell, Klein, & Wurcel, 2019; Kattakuzhy et al., 2017; Lee et al., 2020; Norton et al., 2019). The fifth question on the checklist was not applicable to the studies for this review. Out of eight criteria, the highest-scoring article received seven. Missing or unclear information was found in all of the quasi-experimental articles. This information included the similarity of comparison groups (n=3), an adequate description of follow-up (n=3), reliability of outcome measures (n=6), and the appropriateness of statistical analysis (n=3).

None of the cohort studies received a complete score on the JBI Critical Appraisal Checklist for Cohort Studies, with the highest scoring 10 out of the 11 criteria (Adamson, Miceli, Shiferaw, Villanueva, & Canterino, 2020; Naidjate et al., 2019; L. Tran, Feldman, Riley, & Jung, 2021). The lowest scoring article scored six. There was unclear or missing information as found in all three articles, including information regarding the similarity of the intervention groups (n=2), validity and reliability of outcome measurements (n=2), and a complete description of follow-up (n=1).

The systematic review included only one case-control study, which did not receive a complete scoring on the JBI Critical Appraisal Checklist for Case-Control Study (Houck et al., 2019). The article received a seven out of the ten criteria. Missing or unclear information was
found in the article regarding confounding factors, and reliability and validity of outcome measurements.

**Interventions**

The included studies were broadly classified into types of interventions, and then were further categorized into smaller groups using the social-ecological model as a framework. Four studies, composed of three types of interventions (i.e., outreach, financial incentives, case management and care coordination) were included in the patient category. Three studies, comprised of two interventions (i.e., task shifting and ECHO), fell into the provider category. Six studies, using four different interventions (i.e., colocation, care integration, group treatment, and pharmacist led teams), were included in the health care system category.

**Patient**

**Patient Support.** Four studies examined patient support interventions, including case management and care coordination, outreach, and financial incentive strategies (Boodram et al., 2020; Lee et al., 2020; Masson et al., 2013; Norton et al., 2019; Webster et al., 2020; Wohl et al., 2017). Masson et al. (2013) conducted a randomized controlled trial, which examined the effects of a care coordination intervention, including case management. The study demonstrated that care coordination, with the inclusion of case management, was efficacious in increasing retention in care (Masson et al., 2013). Specifically, the study found that compared with the control group, the intervention group participants were more likely to receive an HCV evaluation within 6 months (OR=4.10; 95% CI=2.35, 7.17).

One study evaluated case management as a strategy for facilitating progress along the HCV treatment cascade. This study evaluated a treatment case management strategy which
provided direct supportive case management services to HCV positive individuals (Boodram et al., 2020). Boodram et al. (2020) found that among those who received the treatment case management intervention, 79.8% linked to care and 75% achieved SVR. Additionally, this study found that the number of individuals who initiated treatment increased steadily from year 1 to year 2 after implementation of the intervention (Boodram et al., 2020).

**Financial Incentives.** Three studies described interventions which provided financial support to patients to increase linkage and retention in care (Lee et al., 2020; Norton et al., 2019; Wohl et al., 2019). Lee et al (2020), examined a strategy which provided patients with a $15 Target or CVS gift card for progressing along the HCV care continuum. Of patient visits in the intervention group, 72.7% attended relative to 61.2% in a historical comparison group from the previous year (Lee et al., 2020). Moreover, this cohort study found that patient appointments in the intervention group were more likely to be attended ([aOR] 1.94 95% [CI] 1.16-3.24 p=0.01) (Lee et al., 2020). One non-randomized controlled trial provided $25 cash for attending each of nine HCV treatment visits and $10 for each weekly medication pack that was returned empty? (Norton et al., 2019). This study found that financial incentives led to higher rates of linkage to care. Specifically, among patients in the contingency management (CM) arm, 74% were linked to HCV care compared to 30% in the enhanced standard of care arm which consisted of an expedited appointment at the health center (within one week of study enrollment), a round-trip transit fare card, and reminder call (p= 0.01) (Norton et al., 2019). Wohl et al. (2019) conducted a randomized controlled trail which evaluated the effect of financial incentives on retention in care. Both study arms received financial incentives, with one receiving a fixed incentive and the other arm receiving a lottery incentive (Wohl et al., 2019). Patients in the fixed financial incentive arm received $40 for each HCV visit, $20 for each completed HCV pill pack, and a
bonus of $50 for achieving SVR 12 weeks post treatment completion. In the lottery incentive arm, participants were asked to draw a card from a bag to determine the amount they would receive for each milestone (i.e., $10, $30, or $100). The study found that all participants in the lottery arm and 86% in the fixed arm completed 12 weeks of therapy. By intent-to-treat analysis, researchers found that 93% in the lottery arm and 92% in the fixed arm achieved SVR. The study found that both incentive strategies were acceptable to patients.

**Outreach.** Evidence which supports utilizing outreach methods to linkage to HCV care were found (Webster et al., 2020). A randomized controlled trial with 4 study arms, examined the effects of various patient outreach methods- including phone call, letter, and text messages- on linkage to HCV care (Webster et al., 2020). This study found that people in all three outreach groups had higher odds of linkage to HCV care than individuals in the no outreach control group (letter only: adjusted odds ratio [aOR] = 1.81 [95% CI, 1.18-2.91]; letter and telephone: aOR = 3.11 [95% CI, 1.67-5.79]; letter, text, and telephone: aOR = 3.17 [95% CI, 1.48-6.51] ) (Webster et al., 2020). People in the letter and telephone group had higher odds of linkage to HCV care than people in the letter group only ([aOR]= 1.72; 95% CI, 1.04-2.74).

**Provider**

**Telehealth mentorship.** Two studies evaluated ECHO, a telehealth mentorship program for facilitating engagement in HCV care (Beste et al., 2016; Tran et al, 2021). Beste et al. (2016) conducted a non-randomized controlled trial which found that after adjustment, patients who had received care from an ECHO exposed provider received significantly higher rates of treatment compared with patients with unexposed providers? (adjusted hazard ratio, 1.20 95% confidence interval 1.10-1.32; p< .01.). There were no differences in adjusted rates of sustained virologic
response of patients with exposed primary care providers versus specialists (Beste et al., 2016). Additionally, a cohort study, with a comparison group, found higher odds of DAA initiation among patients who received care from exposed HCV patients, compared to those who received care from specialists (Tran et al., 2021). The study also found that for every 100 clinicians attending a Project ECHO training, the odds of treatment initiation among patients with HCV infection increased by 9% (adjusted odds ratio [OR], 1.09; 95% CI, 1.07-1.11; \( P < .001 \)) in nonrural areas with few specialists (Tran et al., 2021).

**Task Shifting.** One study evaluated task-shifting as an intervention to expand Hepatitis C care (Kattakuzhy et al., 2017). A nonrandomized controlled trial which evaluated a task shifting program found that SVR rates among patients treated by all three provider types - primary care providers, nurse practitioners, and specialists (89.3%, 86.9%, and 83.8%, respectively) found that after adjustments for demographic variables and disease status (i.e., cirrhosis) the overall SVR rate was 87.1% (Kattakuhzy, et al., 2017). The study found that treatment by non-specialist providers were was just as effective as treatment with specialist, with SVR rates slightly higher in the non-specialist provider groups (Kattakuzhy et al., 2017).

**Health Care System**

**Care Integration.** Two studies, both of which had had a comparison or control group, evaluated care integration as a strategy to facilitate engagement in HCV care (Adamson et al., 2020; Ho et al., 2015;). A cohort study conducted by Adamson et al. (2020) examined the effects of integrating infectious disease care within a primary care clinic. This study found that patients in the integrated care clinic had significantly higher odds of being linked to care compared with patients in the non-integrated clinic (adjusted odds ratio [OR] 2.5, 95% confidence interval [CI]=1.3-4.8) (Adamson et al., 2020). One study examined the integration of HCV care and
mental health care services (Ho et al., 2015). They conducted a randomized controlled trial to evaluate a care integration model, which combined care coordination and patient case management services with mental health interventions. This study found that over a mean follow-up period of 28 months, a greater proportion of patients in the integrated care group-initiated therapy (31.9% vs 18.8% for controls; \( P=.005 \)) and achieved a SVR (15.9% vs 7.7% of controls).

**Colocation.** One study evaluated a colocation intervention (Kanwal et al., 2017). A randomized controlled trial found that participants who accessed collocated mental health services with HCV care services were more likely to initiate therapy for HCV (9.7 percent vs. 5.5 percent) (Kanwal et al., 2017). However, the results of this study were not statistically significant.

**Pharmacist Led Teams.** Two cohort studies, both with comparison groups, focused on interventions which used pharmacist led multidisciplinary care teams to facilitate engagement in HCV care. Houck et al. (2018) found that the pharmacist driven multidisciplinary pretreatment workup process is an effective way to facilitate HCV care and decrease time to treatment initiation. The cohort study reports that patients who completed the pharmacist driven multidisciplinary process initiated HCV treatment on an average of 42.2 days compared to 184.1 days for patients who completed the usual care process (\( P=0.0001 \)) (Houck et al., 2018). Another cohort study evaluated pharmacist-managed and pharmacist-assisted HCV care clinics and found that both were effective in facilitating retention in care. Specifically, Niadjate et al. (2019) found high rates of treatment completions in both the pharmacy-managed and pharmacy-assisted clinics, 97% and 95%, respectively. Additionally, the study found high rates of SVR achievement 12 weeks post treatment completion in both groups, 80% SVR-12 in the pharmacy-
managed clinic and 84% SVR-12 in the pharmacist-assisted clinic (Naidjaite, et al., 2019). There were no differences between the clinic groups in treatment completion status (OR, 1.1; 95% CI, 0.1–13.8; p = 0.93) or SVR-12 achievement (OR, 1.0; 95% CI, 0.2–4.5; p = 0.62) (Naidjaite et al., 2019).

**Group Treatment.** One study reported on a shared appointment model intervention. This nonrandomized controlled trial found that 99% of patients who opted for shared appointment model of care completed the full treatment course, and 91% of those patients achieved SVR. Moreover, this study found that people who opted for the shared medical appointment model trended towards more likely completion of treatment [OR 10, (95% CI 0.99-101)] and more likely to achieve SVR [OR 6.33 (95% CI 2.09-19.2)] but possible selection bias, to note.

**Discussion**
Fifteen studies, which examined best practices for linkage to and retention in HCV care, were included in this review. The identified interventions addressed engagement in HCV care at different levels, including patient, provider, and health care system levels. No interventions addressed engagement in HCV care at the broader structural level. The outcome measurements of the selected studies did not vary widely. There were concerns about the quality of all the studies identified, primarily due to unclear reporting of essential methodological characteristics. Based on this review, several interventions effectively facilitate engagement in HCV care in the United States.

This systematic review has found similar results as other studies reviewing interventions that facilitate engagement in HCV care (Bajis et al., 2017; Brew, Butt, & Wright, 2013; Socias et al., 2019). Socias et al. (2019) reviewed HCV care models for PWID and found that colocation and care integration were effective ways to engage PWID into HCV care. Similarly, Brew et al. (2013) reviewed ways to provide HCV care in a primary care setting effectively and found that
teleconferencing training methods, such as ECHO, effectively engaged patients in HCV care. A systematic review that reviewed interventions that enhance engagement in HCV care found that integrated care and case management services facilitate linkage and retention in care (Bajis et al., 2017).

This systematic review stands out among others for several reasons. First, this review aimed to provide information on evidence-based practices to facilitate engagement in HCV care. Therefore, this review was limited to only those studies which could show cause and effect (i.e., randomized controlled trials, quasi-experimental, case-control, and cohort studies with comparison groups. Second, to increase the applicability of the findings to the United States context, the review was limited to studies conducted in the United States. Third, this review highlights best practices that address both linkage and retention in care. Additionally, this review categorizes and analyzes interventions across multiple levels at which they would be implemented (i.e., patient, provider, and health care system). Lastly, to my knowledge, this is the only review that has identified best practices during the new direct-acting antiviral therapy era.

This review has several limitations. The study might have report bias due to non-published studies not being included in the review. Although there was a search through the grey literature, no studies were identified which fit the inclusion criteria. Additionally, it is more likely that published studies will report positive findings, adding to the possibility of report bias in this review. Since all of the studies were conducted in the United States, the applicability of the best practices to other cultural contexts may be limited. Lastly, this study did not include any observational studies, specifically those with no comparison groups, even though they reported significant results. Because of this, interventions that show promise in facilitating linkage and retention in HCV care were not considered.
Overall, there is limited evidence on the best practices which facilitate linkage and retention in HCV care, specifically in the context of the HCV epidemic during the direct-acting antiviral era in the United States. This review highlighted the lack of quality studies on this topic. Future research is needed to improve the quality of the studies which demonstrate effectiveness for facilitating engagement in HCV care. Though this review included studies with relatively homogenous outcome measurements, linkage to and retention in HCV care outcome measurements are varied across the literature. Future research should focus on standardizing these measurements to allow for study comparisons.

Additionally, this review identified studies with mostly older-aged (45 years and older) male participants. Future intervention research needs to target younger populations because of the trend in increasing HCV cases among younger people due to injection drug use. Moreover, this review failed to identify interventions that equally represented women among study participants. Though HCV risk is highest among males, CDC has reported a three-fold increase in HCV infections among females within the last ten years (CDC, 2021). Future research needs to focus on targeting recruitment of women for study participation. Lastly, this systematic review provided evidence of successful strategies to improve linkage to and retention in HCV care. Future studies should explore the ease of application and cost effectiveness of the interventions identified. Additionally, the information from this review should be used to develop standard of care recommendations to enhance HCV care engagement.
References


## Appendix A

**PRISMA 2020 Checklist**

<table>
<thead>
<tr>
<th>Section and Topic</th>
<th>Item #</th>
<th>Checklist item</th>
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<td>Rationale</td>
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<td>Describe the rationale for the review in the context of existing knowledge.</td>
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<tr>
<td>Objectives</td>
<td>4</td>
<td>Provide an explicit statement of the objective(s) or question(s) the review addresses.</td>
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<tr>
<td><strong>METHODS</strong></td>
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<td>Eligibility criteria</td>
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<td>Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.</td>
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<tr>
<td>Information sources</td>
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<td>Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.</td>
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<tr>
<td>Search strategy</td>
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<td>Present the full search strategies for all databases, registers and websites, including any filters and limits used.</td>
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<tr>
<td>Selection process</td>
<td>8</td>
<td>Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.</td>
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<tr>
<td>Data collection process</td>
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<td>Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.</td>
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<tr>
<td>Data items</td>
<td>10a</td>
<td>List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.</td>
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<td>10b</td>
<td>List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.</td>
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<td>Section and Topic</td>
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<td>Study risk of bias assessment</td>
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<td>Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.</td>
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<td>Synthesis methods</td>
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<td>Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).</td>
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<td>Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.</td>
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<td></td>
<td>13c</td>
<td>Describe any methods used to tabulate or visually display results of individual studies and syntheses.</td>
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<td>13d</td>
<td>Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.</td>
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<td>Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).</td>
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<td>Describe any sensitivity analyses conducted to assess robustness of the synthesized results.</td>
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<td>Reporting bias assessment</td>
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<td>Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).</td>
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<td>Certainty assessment</td>
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<td>Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.</td>
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**RESULTS**

<p>| Study selection         | 16a    | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram. |                                 |
|                         | 16b    | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.                                                                                     |                                 |
| Study characteristics   | 17     | Cite each included study and present its characteristics.                                                                                                                                                |                                 |</p>
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<td>Present assessments of risk of bias for each included study.</td>
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<td>Results of individual studies</td>
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<td>For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.</td>
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<td>Results of syntheses</td>
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<td>For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.</td>
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<td>Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.</td>
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<td>Present results of all investigations of possible causes of heterogeneity among study results.</td>
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<td>Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.</td>
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<td>Provide a general interpretation of the results in the context of other evidence.</td>
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<td>Discuss any limitations of the evidence included in the review.</td>
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<td>23c</td>
<td>Discuss any limitations of the review processes used.</td>
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<td>23d</td>
<td>Discuss implications of the results for practice, policy, and future research.</td>
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# Appendix B

**Data Abstraction Template**

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<td>Limitations</td>
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Appendix C
PRISMA Diagram

2170 studies imported for screening

300 duplicates removed

1870 studies screened

1759 studies irrelevant

96 studies excluded
Reasons:
Wrong outcomes
Not original research
No intervention
No control/comparison group
Wrong population
Wrong setting

15 studies included
## Appendix D

### Critical Appraisal Checklist for Randomized-Controlled Trials

Reviewer______________________________________________________
Date________________________________________________________

Author________________________________________________________ Year__________ Record__________

Number__________

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### Appendix E

**JBI Critical Appraisal Checklist for Quasi-Experimental Studies**

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**Date** ________________________________________________________________

**Author** ______________________________________________________________
**Year** ________ **Record Number** ________

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<td></td>
<td>Was there a control group?</td>
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<td>5</td>
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<td></td>
<td>Were there multiple measurements of the outcome both pre and post the intervention/exposure?</td>
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<td>6</td>
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<tr>
<td></td>
<td>Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?</td>
<td>☐</td>
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<td>7</td>
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<td></td>
<td>Were the outcomes of participants included in any comparisons measured in the same way?</td>
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<td>8</td>
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<tr>
<td></td>
<td>Were outcomes measured in a reliable way?</td>
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<tr>
<td></td>
<td>Was appropriate statistical analysis used?</td>
<td>☐</td>
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</table>
Appendix F
JBI Critical Appraisal Checklist for Cohort Studies

Reviewer ________________________________
Date _________________________________
Author ________________________________ Year __________ Record Number __________

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Were the two groups similar and recruited from the same population?</td>
<td></td>
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<tr>
<td>2. Were the exposures measured similarly to assign people</td>
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<tr>
<td>3. to both exposed and unexposed groups?</td>
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<tr>
<td>4. Was the exposure measured in a valid and reliable way?</td>
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<tr>
<td>5. Were confounding factors identified?</td>
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<tr>
<td>6. Were strategies to deal with confounding factors stated?</td>
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<tr>
<td>7. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?</td>
<td></td>
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<tr>
<td>8. Were the outcomes measured in a valid and reliable way?</td>
<td></td>
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<tr>
<td>9. Was the follow up time reported and sufficient to be long enough for outcomes to occur?</td>
<td></td>
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<tr>
<td>10. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?</td>
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<tr>
<td>11. Were strategies to address incomplete follow up utilized?</td>
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<td></td>
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<tr>
<td>12. Was appropriate statistical analysis used?</td>
<td></td>
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</table>
# Appendix G

**JBI Critical Appraisal Checklist for Case Control Studies**

Reviewer: ________________________________

Date: ________________________________

Author: ________________________________ Year: __________

<table>
<thead>
<tr>
<th>Record Number</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
<th>Not applicable</th>
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</thead>
<tbody>
<tr>
<td>1. Were the groups comparable other than the presence of disease in cases or the absence of disease in controls?</td>
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<td>☐</td>
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<tr>
<td>2. Were cases and controls matched appropriately?</td>
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<td>3. Were the same criteria used for identification of cases and controls?</td>
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<td>☐</td>
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<tr>
<td>4. Was exposure measured in a standard, valid and reliable way?</td>
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<td>☐</td>
<td>☐</td>
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</tr>
<tr>
<td>5. Was exposure measured in the same way for cases and controls?</td>
<td>☐</td>
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</tr>
<tr>
<td>6. Were confounding factors identified?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. Were strategies to deal with confounding factors stated?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. Were outcomes assessed in a standard, valid and reliable way for cases and controls?</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>9. Was the exposure period of interest long enough to be meaningful?</td>
<td>☐</td>
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<tr>
<td>10. Was appropriate statistical analysis used?</td>
<td>☐</td>
<td>☐</td>
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## Appendix H
### Study Characteristics

<table>
<thead>
<tr>
<th>Author(s), year</th>
<th>Study design</th>
<th>Intervention</th>
<th>Intervention Description</th>
<th>Study Population</th>
<th>Controlled or Comparison Group</th>
<th>Linkage to Care Outcome</th>
<th>Retention in Care Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adams et al., 2020</td>
<td>Retrospective cohort with comparison group</td>
<td>Care integration</td>
<td>Integrated clinic practice, led by an infectious disease physician and a general internist with expertise in treating Hepatitis C. The clinic is physically located in the same space where patients receive primary care.</td>
<td>HCV patients</td>
<td>Non-integrated clinic</td>
<td>HCV appointment attendance</td>
<td>Treatment initiation</td>
</tr>
<tr>
<td>Bœe et al., 2016</td>
<td>Non-randomized controlled trial</td>
<td>VA-ECBD</td>
<td>Videodriven videoconference-based HCV specialist support</td>
<td>Veterans HCV patients</td>
<td>Usual care</td>
<td>Treatment initiation</td>
<td>Time to treatment initiation</td>
</tr>
<tr>
<td>Broedrum et al., 2020</td>
<td>Non-randomized controlled trial</td>
<td>Case management</td>
<td>Case managers identified barriers to HCV care and then created a plan to prioritize and address those barriers. Case managers also provided intensive follow-up to address barriers to care.</td>
<td>HCV patients</td>
<td>Previous year of intervention</td>
<td>Treatment initiation</td>
<td>Treatment initiation</td>
</tr>
<tr>
<td>He et al., 2015</td>
<td>Randomized controlled trial</td>
<td>Care integration</td>
<td>Integrated practice, which provided psychological interventions with comprehensive intervention counseling for HCV care.</td>
<td>Veterans with HCV with a history of substance use and psychiatric illness</td>
<td>Usual care</td>
<td>Treatment initiation</td>
<td>Treatment completion: SVR-12</td>
</tr>
<tr>
<td>Hodges et al., 2019</td>
<td>Non-randomized controlled cohort</td>
<td>Group treatment</td>
<td>Patients were seen in a group setting by a multidisciplinary team for counseling and education (topics included harm reduction, nutrition, re-infection). One-on-one care was provided by a clinician during the sessions.</td>
<td>HCV patients with risk of homelessness</td>
<td>Individual treatment</td>
<td>N/A</td>
<td>Treatment completion: SVR-12</td>
</tr>
<tr>
<td>Houch et al., 2018</td>
<td>Retrospective case control</td>
<td>Pharmacy-led team</td>
<td>A pharmacist-driven multidisciplinary pre-treatment assessment process, which includes same-day pharmacy consultation, provider visit, social work assessment, PEPFAR, and laboratory assessments, in approximately 2.5 hours.</td>
<td>Veterans with HCV</td>
<td>Usual care</td>
<td>Time to treatment initiation</td>
<td>N/A</td>
</tr>
<tr>
<td>Kamal et al., 2017</td>
<td>Randomized controlled trial</td>
<td>Care integration</td>
<td>Integrated clinic practice which integrated comprehensive HCV care in an off-site depression care team.</td>
<td>HCV patients with depression</td>
<td>Usual care</td>
<td>Treatment initiation</td>
<td>SVR-12</td>
</tr>
<tr>
<td>Kannmack et al., 2017</td>
<td>Non-randomized clinical trial</td>
<td>Task shifting</td>
<td>Patients received treatment from nurse practitioners and primary care providers that completed an HCV care training course.</td>
<td>HCV patients</td>
<td>Treatment provided by specialist</td>
<td>N/A</td>
<td>SVR-12</td>
</tr>
<tr>
<td>Lee et al., 2020</td>
<td>Prospective cohort with comparison group</td>
<td>Financial incentives</td>
<td>Patients were given a $15 pill card to Target or Walmart for HCV appointment attendance. The patients received two $15 cards.</td>
<td>HCV patients</td>
<td>Historical comparison group/ no incentive</td>
<td>HCV appointment attendance</td>
<td>N/A</td>
</tr>
<tr>
<td>Mousen et al., 2013</td>
<td>Randomized controlled trial</td>
<td>Care coordinator with case management</td>
<td>Case managers coordinated with primary care and endocrinology clinics on scheduling initial and follow-up HCV evaluation appointments, accompanied patients to the appointments, and negotiated new appointments, if needed. Case managers also assisted patients in accessing psychiatric and substance use services and other social services.</td>
<td>Patients of risk for HCV with no prior treatment history</td>
<td>Usual care</td>
<td>HCV appointment attendance</td>
<td>N/A</td>
</tr>
<tr>
<td>Naidjale, 2019</td>
<td>Retrospective cohort with companion group</td>
<td>Pharmacist-led care team</td>
<td>Clinic managed primarily by pharmacist</td>
<td>HCV patients</td>
<td>Pharmacare-assisted care</td>
<td>Treatment initiation</td>
<td>SVR-12</td>
</tr>
<tr>
<td>Neves et al., 2019</td>
<td>Nonrandomized-controlled trial</td>
<td>Financial incentives</td>
<td>Patients received a $25 gift card for HCV care visits, $10 for treatment completion, and $30 for an undetectable HCV viral load</td>
<td>HCV patients with a history of drug use in the last 8 months</td>
<td>Uninsured patient</td>
<td>HCV appointment attendance</td>
<td>Treatment initiation</td>
</tr>
<tr>
<td>Tran et al., 2021</td>
<td>Prospective cohort with comparison group</td>
<td>Project ECHO</td>
<td>Videodriven videoconference-based HCV specialist support</td>
<td>HCV patients who receive Medicare</td>
<td>Care with specialists</td>
<td>Treatment initiation</td>
<td>N/A</td>
</tr>
<tr>
<td>Webber et al., 2020</td>
<td>Randomized controlled trial</td>
<td>Outreach</td>
<td>Receipt of 1-2 letters, 2-3 letters, text messages, and telephone call</td>
<td>HCV patients</td>
<td>No outreach</td>
<td>Extended HCV appointment as indicated HCV RNA laboratory result</td>
<td>N/A</td>
</tr>
<tr>
<td>Wold et al., 2019</td>
<td>Randomized clinical trial</td>
<td>Financial incentives</td>
<td>Patients received a fixed income in the amount of $49 for each scheduled HCV care visit (or for each scheduled within five business days after the original appointment) and $25 for treatment completion (greater than 90%)</td>
<td>HCV patients</td>
<td>Lottery incentive</td>
<td>N/A</td>
<td>Treatment completion: SVR-12</td>
</tr>
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## Appendix I

### Study Findings

<table>
<thead>
<tr>
<th>Author(s), year</th>
<th>Intervention</th>
<th>Sample Size</th>
<th>Sample Description</th>
<th>Key Findings</th>
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<tr>
<td><strong>Patient Level</strong></td>
<td></td>
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</tr>
<tr>
<td>Bowden et al., 2019</td>
<td>Case management</td>
<td>18 participants</td>
<td>Morbid male; from the baby boomer cohort, and African-American</td>
<td>Linkages to care among patients receiving care management was approximately 90%. The number of individuals initiating treatment increased steadily from year 1 (n = 1) to year 2 (n = 26) and then leveled off in year 3.</td>
</tr>
<tr>
<td>Lee et al., 2020</td>
<td>Financial incentives</td>
<td>127 participants</td>
<td>Morbid, female, non-Hispanic white, between the ages of 41-66</td>
<td>Appearances in the intervention group were more likely to be admitted (adjusted odds ratio 1.94, 95% confidence interval 1.16-3.24)</td>
</tr>
<tr>
<td>Maassen et al., 2013</td>
<td>Case coordination</td>
<td>48 participants</td>
<td>Morbid male</td>
<td>Intervention group participants were significantly more likely to receive an HCV evaluation within 6 months (OR: 4.19, 95% CI: 2.30, 7.17)</td>
</tr>
<tr>
<td>Naclerio, 2019</td>
<td>Pharmacists-led teams</td>
<td>127 participants (36y)</td>
<td>Morbid white; male, with a mean age was 55 years</td>
<td>High rates of linkage and retention in care among the intervention group. However, there was no difference in treatment completion (odds ratio [OR] 0.3, 95% confidence interval [CI] 0.13 – 0.88), achievement of sustained virologic response at 12 months (SVR12) (OR: 0.8, 95% CI: 0.2-4.5). p = 0.62</td>
</tr>
<tr>
<td>Norton et al., 2019</td>
<td>Financial incentives</td>
<td>59 participants (28y)</td>
<td>Majority male, Hispanic, with median age of 47</td>
<td>In the intervention, 74% were linked to HCV care, compared to 39% in the comparison group (p &lt; 0.01). In the intervention arm, 79% (92) of treatment eligible patients initiated treatment, compared to 108% (49) in the comparison group (p = 0.53). All patients (99%) achieved care in the CM arm, as compared to 75% (34) of patients in the comparison group. There were no significant differences between the two groups.</td>
</tr>
<tr>
<td>Wolf et al., 2019</td>
<td>Financial incentives</td>
<td>59 patients</td>
<td>Majority male, half non-white, with median age of 58 years</td>
<td>High rates of linkage and retention in care in both groups. All 33 (100%) in the nontreatment arm and 23 of 26 (88%) in the final arm completed 12 weeks of therapy. By intent-to-treat, 93% in the nontreatment arm and 92% in the final arm achieved SVR (estimated difference: 0.5%, 95% confidence interval, -17.6 to 18.8). Overall, 92% of scheduled visits were attended without significant differences between arms. There were no significant differences between the two groups.</td>
</tr>
<tr>
<td><strong>Provider Level</strong></td>
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<tr>
<td>Beires et al., 2016</td>
<td>VITA-ECHO</td>
<td>3873 participants (33y)</td>
<td>Morbid male, white, with mean age of 58 years</td>
<td>EECHO exposed patients received significantly higher rates of antiviral treatment compared with unexposed patients (adjusted hazard ratio, 1.20; 95% confidence interval, 1.01–1.42) (p = 0.04). The rate of primary care provider-initiated treatment was 24.8% among treatment patients and varied on VITA-ECHO networks compared to 2.8% among unexposed patients (p &lt; 0.01). No difference in adjusted rates of SVR was observed for patients with exposed primary care providers (p = 0.32), with similar crude rates for primary care providers versus specialists.</td>
</tr>
<tr>
<td>Austad et al., 2017</td>
<td>Task-shifting</td>
<td>606 participants</td>
<td>Majority male, black, with mean age of 59 years</td>
<td>SVR rates were high among all provider type were as follows: NPs, 88.7%; PACs, 84.9%; and specialists, 83.8%.</td>
</tr>
<tr>
<td>Tran et al., 2021</td>
<td>Project ECHO</td>
<td>287, 938 participants (24y)</td>
<td>Morbid male, mostly white, with mean age of 62 years</td>
<td>For every 10% discussion attending a Project ECHO training, the odds of DAA treatment initiation among patients with HCV infection increased by 9% (adjusted odds ratio [OR] 1.09; 95% CI, 1.05–1.15; p = 0.001)</td>
</tr>
<tr>
<td>Weisner et al., 2020</td>
<td>Outreach</td>
<td>2023 participants (30y)</td>
<td>Morbid male and of baby boomer age</td>
<td>People in all outreach groups had higher odds of a subsequent test than people in the control group (unadjusted odds ratio [OR] = 1.31 [95% CI 1.16-1.49]; odds ratio [OR] = 1.31 [95% CI 1.17-1.50]; and odds ratio [OR] = 1.31 [95% CI 1.17-1.49]). People in the letter and tele-phoneline group had higher odds of a subsequent test than people in the letter-only group (OR = 1.72; 95% CI, 1.68-1.74).</td>
</tr>
<tr>
<td><strong>Health-Care Systems-Level</strong></td>
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<tr>
<td>Adimom et al., 2020</td>
<td>Care integration</td>
<td>362 participants</td>
<td>Morbid male; largest proportion white, with a mean age of 54 years</td>
<td>In a multivariable analysis, patients in the integrated clinic practice had significantly higher odds of being linked to care than patients in the nonintegrated clinic practice (adjusted odds ratio [OR] 2.5, 95% confidence interval [CI] = 1.3-4.5).</td>
</tr>
<tr>
<td>Ho et al., 2015</td>
<td>Care integration</td>
<td>573 participants (28y)</td>
<td>Morbid male; large proportion were African-American, with a mean age of 55</td>
<td>Over a mean follow-up period of 28 months, a greater proportion of patients in the IC group began receiving antiviral therapy (31.9% vs 18.8% for controls; p: 0.05) and achieved a SVR (13.9% vs 7.7% of controls; odds ratio 2.24, 95% confidence interval, 1.20-4.44; p: 0.018)</td>
</tr>
<tr>
<td>Hodges et al., 2019</td>
<td>Group treatment</td>
<td>182 participants (27y)</td>
<td>Morbid, male, non-Hispanic white, with a mean age of 45 years</td>
<td>99% of patients opting for the SMA (77 of 78) completed the full treatment course, and 97% of SMA patients (71 of 71) achieved SVR12</td>
</tr>
<tr>
<td>Rezaei et al., 2018</td>
<td>Pharmacists-led teams</td>
<td>201 participants</td>
<td>Mean age of 68 years</td>
<td>From time of HCV enrollment to date of treatment start, patients were initiated on HCV treatment in an average of 42.2 ± 7.5 days and 164.1 ± 27.6 days (p = 0.0000) within the intervention and treatment-waiting groups, respectively.</td>
</tr>
<tr>
<td>Kamol et al., 2017</td>
<td>Care integration</td>
<td>242 participants</td>
<td>Largest proportion were African-American, with a mean age of 49 years</td>
<td>Intervention participants were more likely to receive antiviral treatment, however, the difference was not statistically significant.</td>
</tr>
</tbody>
</table>
Chapter 4: BARRIERS AND FACILITATORS TO ENGAGEMENT IN HEPATITIS C CARE FROM THE PATIENT PERSPECTIVE

Introduction

An estimated 2.4 million people are living with chronic Hepatitis C (HCV) in the United States. HCV is the primary cause of cirrhosis and liver cancer and is the most common reason for liver transplantation in the United States. Between 5-25% of people with chronic HCV will develop cirrhosis, and an estimated 1- 4% will ultimately develop liver cancer (Seeff, 2002). In recent years the number of people living with chronic HCV has steadily declined, mainly attributed to all-cause mortality among the baby boomer population. However, the number of new infections is on the rise, particularly among young people (Hofmeister et al., 2019). The rise in new chronic HCV infections among the younger population has been attributed to the opioid epidemic. Specifically, the transition from prescription opioids to heroin, resulting in increased injection drug use (Zibbell et al., 2018).

HCV is a significant public health problem in Louisiana, with approximately 50,000 people living with chronic Hepatitis C in the state (Rosenberg et al., 2018). In Louisiana, the number of new chronic HCV cases has increased 222% between 2014 and 2018, with more than 9,000 chronic HCV cases reported in 2018 (Louisiana Department of Health, 2019). The majority of new chronic HCV cases are found among baby boomers (Louisiana Department of Health, 2019). The primary risk factor for HCV in Louisiana is injection drug use. In Louisiana, an estimated 80% of new HCV cases are acquired through injection drug use (Louisiana Department of Health, 2019). Recently, there has been a significant increase in new chronic HCV infections among young people, primarily due to injection drug use (Louisiana Department of Health, 2019). In 2019, people 39 years and younger accounted for an estimated 36% of chronic Hepatitis C diagnoses in Louisiana (Louisiana Department of Health, 2019). People that
are of low-income status, Medicaid enrollees, and incarcerated are disproportionately affected with chronic HCV (Louisiana Department of Health, 2020).

The new direct-acting antiviral (DAA) therapy became the standard of care to treat HCV since the Food and Drug Administration approved an all-oral regimen in 2014 (Ward & Mermin, 2015). Before that, the old therapy was a combination of pegylated interferon and ribavirin, administered via injection. Compared to the old therapy, DAAs are more effective, more tolerable, and require shorter treatment durations. Researchers found DAAs to be nearly 100% effective in curing chronic HCV infection in clinical trials. Despite the availability of curative treatment in the United States, a significant proportion of people are not engaged in care for their HCV infection. Among all people living with chronic HCV in the United States, only an estimated 37% received treatment, and 37% were cured in 2018 (Chhatwal et al., 2019). If left untreated, HCV care can lead to cirrhosis, liver cancer, or even death. In 2018, more than 15,000 people died of HCV-related causes in the United States (CDC, 2020).

Supportive of the social-ecological model (SEM), researchers suggest that multilevel factors influence engagement in HCV care. Specifically patient, provider, health care system, and structural-level factors. The SEM is a theory-based framework used to understand the complex interplay between the individual and environmental factors on health behavior (McLeroy, Bibeau, Steckler, & Glanz, 1988). The SEM posits that individual behavior affects and is affected by multiple levels of influence and that the relationship between the individual and his/her environment is reciprocal (McLeroy et al., 1988).

Patient-level factors such as negative beliefs, disease status or severity, and access to healthcare have all been reported to influence engagement in HCV care (Bass et al., 2018; Jordan et al., 2013; Pundhir et al., 2016; Spradling et al., 2017). Among infected patients,
misconceptions about HCV and treatment, due to poor knowledge, are a significant barrier to linkage and retention in HCV care (Adams, 2018; Jordan et al., 2013; Pundhir et al., 2016). The severity of the liver disease may deter or encourage linkage and retention in HCV care. Spradling et al. (2017) found that higher fibrosis scores were significantly associated with DAA initiation compared to individuals with lower Fibrosis scores. Insurance status is a significant factor that could hinder or facilitate engagement in care. Persons who lack insurance or have public health insurance (vs. private insurance) have difficulty accessing HCV care (Falade-Nwulia, 2019; Higashi et al., 2020).

Additionally, provider-level factors, including patient-provider relationship and knowledge, can influence engagement in HCV care. One of the most important factors affecting engagement in HCV care is the quality of the relationship a patient has with his/her provider. Rude, patronizing, and judgmental attitudes coupled with poor communication and a lack of encouragement by providers and other clinic staff negatively impact linkage and retention in HCV care (Falade-Nwulia, 2019; Poll et al., 2017; Trooskin, Door & Kostman, 2020). Mistrust of healthcare providers also negatively impacts engagement in Hepatitis C care (Masson et al., 2020).

Researchers also have found that influential factors at the health care system level include testing experience, availability, and access to healthcare. The testing experience as a whole can impact engagement in care for persons diagnosed with HCV. In a qualitative study examining the factors contributing to nonattendance for HCV care, many respondents said they felt judged and discriminated against during their initial visit, which prevented them from seeking further care (Butt et al., 2013). Limited appointment availability coupled with restrictive appointment
policies can create challenges for persons to adhere to HCV care appointments (Amoako et al., 2021; Harris & Rhodes, 2013; Poll et al., 2017).

Moreover, structural factors, including the cost of treatment and insurance reimbursement restrictions, have been reported to influence engagement in HCV care outcomes. Many people living with HCV are aware of the high cost of care. Until recently, the high cost of the new DAAs treatment served as a significant barrier to accessing and remaining in HCV care (Iyengar et al., 2016; Lynch & Wu, 2016; Trooskin et al., 2015). The cost of one pill of Solvaldi is about $1,000 (Henry, 2018). The cost of HCV treatment for a 12-week regimen is $84,000 (Solvadi) (Henry, 2018). Some states still require drug screenings and months of abstinence from drugs and alcohol before covering the cost of Hepatitis C treatment (Trooskin et al., 2019). Strict restrictions for insurance reimbursements, especially under the Medicaid program, hinder linkage and retention in HCV care (Haley et al., 2020; Trooskin, 2020).

Although prior research has shed light on the barriers and facilitators to engagement in HCV care, little research has explored the experiences of patients seeking care for HCV infection during the direct-acting antivirals therapy era. Examining these patient experiences, specifically the most vulnerable, is crucial to gaining firsthand knowledge of the real-world challenges of accessing HCV care during this new therapy era.

This chapter will review the findings the qualitative study which explored the multilevel barriers and facilitators to linkage and retention in HCV care among patients attending a federally funded health care facility. This information will be useful to inform the development of recommendations for interventions to improve linkage and retention in HCV care. Ultimately, reducing chronic HCV morbidity and mortality.

Methods
A qualitative study was conducted to explore patients’ perspectives regarding the barriers and facilitators to engagement in HCV care in the Greater New Orleans area. A qualitative research design was the appropriate choice for this study because it allows for exploring a topic that has not been widely studied. It also supports the collection of detailed, rich information to answer the research questions adequately and provide information necessary to guide future descriptive or explanatory studies. The study received support from DePaul Community Health Center and ethical approval from the Tulane University Institutional Review Board.

**Setting**

Participants were recruited from DePaul Community Health Center, a community-based health care center located in the Greater New Orleans area. DePaul Community Health Center is a Federally Qualified Health Center (FQHC), which receives funds from the Health Resources and Services Administration (HRSA) to provide primary care services in underserved areas. DePaul Community Health Center has ten locations throughout the Greater New Orleans area. In addition to primary care services, DePaul Community Health Center provides pediatrics, dental, optometry, chronic disease management, prenatal care, behavioral health, and onsite laboratories and pharmacies. The healthcare center serves a majority Medicaid patient population. Study participants were recruited during designated HCV clinic hours.

**Participants**

A convenience sampling method was used to recruit 40 patients into the study. Participants were recruited from May 2020 to February 2021. To be eligible for the study, patients had to have confirmed chronic HCV infection, be 18 years or older, able to speak and understand English, live in the Greater New Orleans area, and have the ability to provide informed consent. Patients who were pregnant or who were HIV/HCV co-infected were
excluded from the study. Persons with HIV/HCV coinfection make up a unique population related to HCV treatment and are considered a priority for treatment initiation (Panel, 2018). Different funding sources for HCV treatment are also available for persons living with HIV/HCV coinfection due to their positive HIV status. Currently, DAA therapy is not recommended for pregnant women due to limited data on the safety of the treatment (Panel, 2018).

The first author enlisted the help of the infectious disease care coordinator and infectious disease physician to recruit patients into the study. Before study recruitment began, the principal the ID care coordinator and ID physician were provided with a brief description of the study and eligibility criteria for participants. Any questions or concerns they might have had were addressed. Fliers were posted in the waiting room during the HCV clinic hours. The flier included necessary information about the study and instructed interested patients to notify the ID care coordinator or ID physician if they were interested in participating in the study. The ID physician confirmed participant eligibility, including chronic HCV diagnosis, by reviewing the patient’s medical file. Eligible participants were directed to the principal investigator for participation in the study.

**Procedures**

Patient interviews were conducted onsite at DePaul Community Health Center in a private room during the HCV clinic hours. At the beginning of each interview, the principal consent information was reviewed, questions addressed, and verbal informed consent was obtained. Also, before the interview, the screening questionnaire used to collect demographic information and further confirm participant eligibility was completed. The screening questionnaire collected information such as age, race, education level, residence (**Appendix A**).
Before the interview, any questions participants may have had were addressed. The principal investigator conducted the interviews. An interview guide was developed to direct the semi-structured interviews with the patients. A comprehensive review of the literature on barriers and facilitators to HCV care informed the interview topic guide (Appendix B). The interview guide consisted of open-ended questions designed to elicit in-depth responses. The patient interviews explored the: 1) feelings about positive HCV diagnosis, 2) knowledge, thoughts, and beliefs about HCV infection, care, and treatment, 3) relationship with their provider and their provider’s ability to treat HCV infection. 4) factors that affect linkage and retention in care, 5) HCV-related stigma and discrimination, and 6) suggestions on improving linkage and retention in HCV care. The interview guide was pilot tested with three patients and questions were modified, if necessary. The interviews lasted approximately 30-45 minutes and were audio-recorded using the study laptop. Participants were provided a $20 Walmart gift card for their participation in the study.

Data Analysis

A social-ecological framework guided the design and analysis. The principal investigator and a research assistant transcribed the interviews verbatim. The transcripts were entered into ATLAS.ti version 8 (Berlin, 1989) for coding and analysis. The analytic process began with a thorough reading of the interview transcripts as they were transcribed. As interviews accumulated partial summaries of each interview guide question were developed. A base set of theoretical concerns from SEM were present, but the interviews were read to explore respondent characteristics, treatment status and the range of responses and any social and behavioral factors that emerged. As the interviews were read, a coding scheme was developed to identify underlying issues, themes, and events relevant to the analysis. The coding scheme adopted the
integrated approach proposed by Hsieh and Shannon (Hsieh & Shannon, 2005). The first author applied this scheme to the transcripts. Transcripts were reviewed by the first author only, as the research assistant was not adequately trained in qualitative analysis methods. The development of the coding structure was an iterative process. This deductive approach to code development consisted of developing preliminary codes before the transcripts were reviewed and assigning codes. The preliminary codebook incorporated well-known concepts from the social-ecological framework. Though a preliminary codebook was developed, data were not forced into the predetermined categories. The initial codebook only served as a guide and evolved as data collection continued, and new codes, or modifications of existing codes were identified. Thus, an inductive approach to the development and application of codes was also used.

The inductive approach drew from Grounded Theory to cross-check the applicability and meaning of initial codes, attempting to avoid wrongly assigning codes to the data to fit predetermined concepts or a theoretical framework (Creswell, 2007). The process continued throughout data collection as the emerging codes were developed and improved to fit the data.

**Results**

**Participants**

Forty patients were recruited into the study. Among those recruited, one patient was excluded due to positive HIV status. As a result, the sample consisted of 39 patients. Of the 39 participants enrolled into the study, 72% were men (n=28), 26% women (n=10), and 3% transgender (n=1). The sample included participants of varying care statuses, including those recently linked to care and who had not initiated treatment, those who had initiated treatment, and those who had completed or were nearing the end of treatment. The majority of the sample (72%, n=28) identified as black, while 28% (n=11) identified as white. Only 3% (n=1) identified as Hispanic. The remaining participants identified as non-Hispanic.
Forty-five percent of the sample (n=17) were older than 55 years, 26% (n=10) were between the ages of 46-55, 21% (n=8) were between the ages of 36-45, 8% (3) were 25-35, and 3% (1) was between the ages of 18-24. Seventy-Four percent (n=29) of the sample reported living in Orleans Parish, 23% (n=9) in Jefferson Parish, and 3% (n=1) in St. Bernard Parish. Among the sample, 33% (n=13) did not graduate high school, 23% (n=9) graduated from high school or received a GED equivalent, 31% (n=12) completed some college, 8% (n=3) graduated college, and 2% reported other. When asked to specify why they responded with other, one participant reported having completed special education classes, and the other reported having attended technical school. The participants of the study were similar to the clinic population. Table 1 Describes the participant characteristics.

**Key Findings**

The overarching themes were organized using the social-ecological model as the guiding framework, which resulted in themes organized around the following factors: patient-level, provider-level, health care system-level, and structural-level. In addition, each theme contained several subthemes. The identified subthemes were categorized as either a barrier or facilitator to engagement in Hepatitis C care (i.e., linkage to or retention in care) (*Appendix D.*)

**Patient-Level**

**Access to Health Care**

**Insurance coverage.** According to participants, proper insurance coverage was crucial in their ability to engage in care and receive treatment for Hepatitis C. A lack of adequate insurance coverage was a significant hurdle for participants when trying to access care for Hepatitis C infection. Many participants described having tried to get care for their infection in the past and not being successful because they did not have the proper insurance coverage at the time. One
participant said, “I felt like maybe I had to go and not use Medicaid and pay with the company that you make payments and maybe I'll get a better result.” (Age 25-35, black, man) Another said “When I went to get treated, my insurance wouldn't pay for it, so I couldn’t get it…then until I came here. They tried everything that they could for me to get the medication.” (Age 55+, black, woman)

Conversely, several participants reported that inadequate coverage was no longer an issue, since they now have coverage. Participants reported having coverage, including Medicaid, and receiving treatment for their Hepatitis C infection with no issues. As was said by participant 11, “There's nothing I could do cause I couldn't pay for the medication, so I was really upset about it when I first found out about it. Now since I knew when I first came here, and I said, when they told me my insurance could pay for it, I was ready to get on it right there.” Another participant added “I got Medicare, its ok right away. Some girls just had Medicare she got it too. There has to be something for poor people that don't have insurance.” (Age 55+, white, woman)

Several participants expressed their excitement and gratitude for receiving treatment for their infection after having been denied in the past. One participant said, “I got approved for Medicaid. I was just thanking God because he covered me for that treatment. With all those other problems I was dealing with, I want the treatment.” (Age 25-35, white, man) Another stated, “When I tell you we were so excited, there was no stopping we would have come at midnight, but we were so excited. We came in as soon as he said he had an opening cause we wanted to come in right away.” (Age 46-55, white, woman)

However, though many participants seemed to be excited about the opportunity to receive treatment, one participant was very skeptical about the receipt of free treatment and was fearful that the government would want something in return for the treatment. This participant
stated, “I think that governments don't do things for people for free. They always have some type of motive for doing it. Maybe it's making somebody that owns a pharmaceutical company rich or something. Start getting federal money for it, it is something, nobody is just doing this from the kindness of their heart.” (Age 36-45, white, man)

**Primary Care Physician.** Having a regular primary care provider was an important factor for several participants. Participants expressed that during their visit with a primary care provider, they confirmed their Hepatitis C diagnosis and learned about treatment for their infection. One participant stated, “I came to the doctor for other reasons, and he told me that it looked like something was wrong with my liver and he mentioned to me Hepatitis C and I got tested and things like that. He called back like a week later and told me it was Hep C.” (Age 36-45, black, man) Said another participant “I went in and gave them my provider information and ask them if they could do blood tests on everything for me, from cancer and all that. They took about ten vials of blood. Once they did, Dr. NAME, he brought it up to me. He said look if you want to start a Hep C treatment, we can do this.” (Age 46-55, white, man)

A couple of participants expressed that not having a primary care provider made it difficult for them to get the care they needed for their infection. One participant expressed constant changes in their primary doctor made accessing care frustrating. Another participant expressed “…Well when I first found out, it's been about thirty years ago, it seemed that long, I know it's been at least twenty years, but then later on, I lost my doctor…lost sight of him so I said I didn't have any so, until recently.” (Age 55+, black, man) Another stated, “I go see a doctor, I go back, the doctor gone. I got to get a new doctor. Every time I go, a new doctor. I need a steady primary care doctor; you know what I am saying…because I wasn’t getting nowhere.” (Age 55+, black, man)
**Comorbidities.** The presence of an ailment or illness(es) was a catalyst for engaging in care. Participants mentioned during their visit with the primary care provider, they learned of their positive HCV status and were subsequently referred to care. Additionally, participants who were aware of their status, informed the doctor of their positive Hepatitis C status when seeking care for another ailment. This was expressed by the statement “I had gone to a doctor about problems I been having with…with the bleeding ulcers they had done some blood work and came back telling me I was positive for Hep C. Which I was that was probably 20 years ago... I was told I had it.” (Age 46-55, white, man) As said by another participant, “Due to the whole back pain, shoulder injury, nerve damage up there, that's what brought me in and of course they did the blood test, and so forth and so forth, and here we are today.” (Age 46-55, white, man)

One patient even stated that while seeking care for another ailment, the doctor mentioned that they would not address the primary issue of concern unless he sought treatment for the Hepatitis C infection: “So, I want to my primary doctor, then he referred me to Dr. NAME. He was supposed to give me some shots in my knees, and he said he didn't want to give me the shots because it may give me an infection while dealing with the Hep so he said he wanted to get that straight first. He said they can get it straight. He told me. So that's what brought me here right now.” (Age 55+, black, man)

**Hepatitis C Knowledge and Beliefs.** Most of the participants believed they had limited knowledge of Hepatitis C-related issues. Many of the participants reported not knowing anything about Hepatitis C. As a result, they felt worried and afraid of their diagnosis. For example, one participant stated “I mean, it bothered me. It was on the back of my mind all the time. That's what made me come to get treated. Yeah, it stays in the back of your mind. you can't blot it out. You know, it stays in the back of your head. You know it worried me.” (Age 55+, black, man)
Another said “I just want someone to explain it to me more, understand that the effects are. If I
don't understand the effects of what they do, I don't know how to call somebody or go to
somebody. I just sleep it off, and you might not wake up your next sleep off, because you don't
know no better. I don't know nothing about it, all I know is that I got Hepatitis C, what is
Hepatitis C?” (Age 55+, black, woman)

Some participants mentioned they were not aware there was treatment available at the
time of their Hepatitis C treatment. “Well at the time well I mean they didn’t tell me whether
there was treatment or nothing. I didn’t know nothing about it anything about.” (Age 55+, black,
man) One participant stated “It's not a good feeling, cause I didn’t know a thing about Hepatitis
C, if it was curable or not. After that I found out that I was able to get treated for it.” (Age 46-55,
black, man) Another said “I was not aware of any medication; it was something totally new to
me. I just wasn't aware of anything about it, like I said 20 years ago just heard nothing about it.”
(Age 25-35, white, man)

Others expressed having knowledge of the current treatment and that it was effective. As
indicated by one participant, “They just told me, come back and they were going to put me on
this medicine. That I had to take for three months and that it would clear it up. There is a 90%
chance that it was going to clear up.” (Age 18-24, black, man) Another participant mentioned, “I
was pretty surprised, because I don't use needles, or I'm not the typical candidate I don't drink. So
I was pretty surprised and upset but I knew there was a cure. So I immediately got in touch with
DePaul to kind of take care of it.” (Age 55+, black, woman)

The Hepatitis C-related knowledge that participants possessed was centered around
transmission and how they contracted the disease. One participant expressed “I didn't really
know till it was explained to me where I could have gotten it from. And it’s kind like had me
hesitant like I didn't know until me and my partner discussed it. Like when we were young, we had taken some vaccine shots back in the 70s they used to shoot you and they never changed the needles as we were going down the line they was just giving us these shots.” (Age 55+, black, woman) Another person said “I knew a couple of different ways I could have gotten it, which all point back to my ex-boyfriend. He and I were sharing needles, and he knew he had it and didn't tell me.” (Age 36-45, white, woman)

Participants' beliefs about the effects of Hepatitis C were an essential factor in their decision to seek care. Participants expressed fear that Hepatitis C could cause severe liver damage, cancer, and even death if left untreated. “I had a want to get this pill, or I was gonna die. My liver had stage three and four cirrhosis of the liver, either I get the Hep C, or I was gonna die. That's how far along I am. I don't have a choice.” (Age 46-55, white, woman) One participant stated “It was a shock. What happened that I had gotten this virus that was deadly if left untreated. At the time they were talking about there is no treatment for it, and I was very worried.” (Age 46-55, white, man)

Several participants communicated their understanding of Hepatitis C care processes, including monitoring requirements and assessments as reflected in the following statement: “When I found out that they had the treatment, I had mentioned it to the nurse practitioner, I think. And they told me they were in the process of setting it up, but I had to go through certain things. I had to get an ultrasound, had to do different things over the course of a couple of months, then I would be able to get the medication.” (Age 46-55, white, man)

In contrast, some participants believed that the care process was an easy one. As said by one participant, “I understand completely, they gonna send you or they gonna get the medication, then we go to the phone interview and of course he wants the ultrasound which they gonna do?
tomorrow at New Orleans East. That's pretty much straight across the board. It's not a math class.” (Age 46-55, white, man). Another said “I don't have to ask for anything, the appointments are set, everything is in order, they got it down packed? They help me with everything I need. It is easy, they make it easy.” (Age 46-55, white, woman)

Perceived Discrimination. Participants expressed fear of disclosure as a reason for not seeking care earlier. Participants believed they would be discriminated against because of their positive Hepatitis C status. One participant said “I just like I don't want nobody to know, people have ways and just, you know what I mean, just too obvious. You know what I mean, not everybody is like that, it’s a cruel world.” (Age 55+, white, woman) Another expressed, “The way people look at you, they hear you got Hepatitis and it's like you are the scum of the earth and nobody wants to be around you. And your whole life gets messed up cause people don't understand it. They think Hepatitis is like Oh my God I can't even be around him or I might get it. That's what scared me. I was like man; I'm not going to be able to get a job because of it. That's what scared me about it. It's going to ruin my life.” (Age 46-55, white, man) While another participant stated “I was worried, that’s the reason I was scared about it cause the way they presented it to me and the way they talked to me, and I was marked and tagged as someone who was like stay away from us. They made it sound very scary even though like I said, I felt normal.” (Age 46-55, white, man)

Transportation. Participants discussed transportation being an essential part of their ability to engage in care. Several participants discussed their experiences taking public transportation to attend routine appointments. As said by one participant, “You can call for a ride, but this location be like right around the house, I can really walk or get on the bus to get here, so transportation really ain't a problem.” (Age 46-55, black, man) Other participants relied
on transportation provided by Medicaid to attend appointments. One participant mentioned “I had rides, but my rides like have other places to go so I went on and got my little card and I asked the nurses can you do transportation. And I just hooked up my appointment and stuff today and that's where I'm at today with the transportation.” (Age 55+, black, transgendered woman)

Among those participants that utilized Medicaid provided transportation, several expressed that this mode of transportation was dangerous and sometimes caused them to be late or miss their appointments. Participant 25 stated “Medicaid comes to get me. They don't have very good drivers but at least they get here…I mean they are late, and then I miss my appointment and then I have to sit and wait for the next appointment.” (Age 46-55, white, woman) Another participant mentioned “I couldn't depend on them cause they get me to my appointments late. Then I was afraid. They drive terrible on the highway, and I been in two accidents. And I'm scared. I would rather catch the bus then to drive with transportation…through Medicaid.” (Age 55+, black, man)

Some participants also discussed that it was a challenge for them to attend appointments because transportation was an issue. One participant stated, “I was running late today because I had to take the bus. I was standing out there in the rain. I was kind of frustrated, but I still had to come in…I had just wrecked my car, somebody ran in to me, and I don't have no car right now.” (Age 46-55, black, man)

Participants without their own means of transportation communicated that family members were an essential resource for transportation to their appointments. As said by one participant, “I could have done the same thing with busses and so forth, but I did have a family member that would let me use their vehicle to go in the first month or two of the treatment if it
were on Carrollton or the other, you know. So, I was fortunate on that end. Not many people are as fortunate.” (Age 46-55, white, man)

**Desire to Get Well.** Participants expressed a strong desire to achieve a cure for their infection because they wanted to improve their health and live longer. One participant expressed “All I wanna do is hopefully get me a better cure to Hepatitis C… live a little longer.” (9) Another stated “I didn't want to have it in my body period. I wanted to get rid of it and get healthier, so I went into treatment.” (Age 46-55, white, man)

The primary motivation expressed for getting healthy and living longer was due to the responsibility they had to their family. “My motivation is my kids and my grandchildren, that's my motivation, I want to be here for them. I want to show that I'm better, that's it.” (Age 46-55, black, woman) As one participant said, “I don't wanna have chronic liver failure in the next twenty thirty years. I just had a three-year-old son so I'm tyin to get myself together so I can see him when he's growing old you know? Life is not about me anymore.” (Age 35-45, white, man)

Participants expressed their fear of the "deadly" disease. Several participants mentioned wanting to be cured of their Hepatitis C infection because they did not want to damage their liver or develop cancer or transmit the virus to someone else. As expressed by the one participant “I think they could have explained it more in depth, you know what I mean. Cause it's like it's a disease you know, and you don't wanna spread that disease to anyone else. And it's like it needs to be explained more in depth.” (Age 46-55, black, man)

**Achieving Care Milestones.** Several participants expressed excitement about achieving care milestones, making them more willing to remain in care and complete treatment. One participant stated “It eases my mind a little bit…. he made me feel comfortable. He let me know that the medicine was working and things and that it will be over I think a three-month time
period.” (Age 18-24, black, man) Another expressed “I went every two weeks to see them. To see how the medicine was working. Then I just became relived to know that it was working.” (Age 36-45, black, man)

**Signs and Symptoms of Hepatitis C**

**Disease Severity.** Participants reported not seeking care or initiating treatment because their Hepatitis C disease was not severe. Participants believed they had a significant amount of time before becoming sick and did not think it was a priority. Participants said providers told them that treatment was not necessary at the time or could be delayed due to the lack of severe signs of liver damage. As said by one participant, “I took that for granted because when I found out I had it, and I know it's something that works on the liver. And when they tested me, my liver was fine so I'm like I have a little time or whatever.” (Age 46-55, black, woman) Another stated, “I been known I had Hepatitis C since 2010 like I said. They told me at that time that it wasn't bad or something.” (Age 55+, black, man)

Because of this, participants described treatment alternatives, such as changing their diets and limiting alcohol consumption, to manage their Hepatitis C infection. “I didn't have to worry about needing it real soon but to eat healthier watch my health and everything will be all right.” (Age 55+, black, man) Participant 7 mentioned “It was just like it basically made me feel like oh, it's not that bad, you are ok, just stick with a diet.” (Age 25-35, black, man)

**Symptoms of Hepatitis C.** Perceived HCV symptoms or lack thereof influenced the decision to engage in care for many participants. Participants perceived symptoms- such as fatigue, jaundice, and abdomen pains- to be indicators of their worsening Hepatitis C infection. One participant expressed “I talked to the doctor about a couple of problems that I been having. I came originally for a cold I can't get rid of. I been taking cough medicine. I can't get rid of it. I had
told her about me going to the hospital two days after Christmas. I was having sharp pains on both
sides. I was scared that my Hep had gotten worse.” Another participant stated “Right now, it's
kind of taking its toll cause I can feel my liver working hard, I know it. I can still work like a young
man, but I get tired way easier, like when I eat a big meal, I can feel it struggling. Then I am like
damn, I need to do something about this.” (Age 36-45, white, man)

In contrast, several participants reported the lack of any signs or symptoms as a reason
for not engaging in care for their infection sooner. One participant said “I didn't really care to be
honest with you. It was like oh, ok. I didn't really feel any different, you know, basically.” (Age
36-45, white, man) Another participant expressed “I felt I really didn't have any reason to go. I
don't think anybody really likes going to the doctor… I felt I had no reason. I didn't see or have
any ailments or sicknesses often, things that would make me thing I need to have this checked
out. (Age 46-55, white, man)

Peer and Family Hepatitis C Experiences

Participants discussed how the Hepatitis C experiences of their family members and peers
played a role in deciding to engage in care. Several participants described how their family
members suffered from Hepatitis C and how these grave experiences influenced their decisions
to get care. Some participants even reported having lost loved ones to the disease. “I've lost a
cousin, two cousins… From Hepatitis, and I see how it pulled them down. Basically, they were
deteriorating from the inside, and I didn't want that for myself.” (Age 46-55, black, woman)
Another participant expressed “My uncle passed away but he had cirrhosis of the liver and
Hepatitis C… You didn't really hear about people dying from that unless they got cirrhosis of the
liver and it wind up affecting their liver.” (Age 25-35, black, man)
Several participants mentioned that they learned about Hepatitis C treatment from their peers and family members. Participants expressed how their peers had positive experiences accessing care for Hepatitis C and how their experiences influenced them to seek care for themselves. As said by the following participant, “I always knew I had it. This time I am in NAME Treatment Center, rehab. I have heard other clients tell me you can schedule an appointment, and they will give you some medicine. We did it and we feel like ten years younger. I’m like dude, I gotta do that, man, I really, it inspired me to like to do that.” (Age 36-45, white, man) Another participant stated “I talked to a guy that had that he had got treated for it. The treatment was a success I wanted to see success rate so naturally I would be interested in that.” (Age 46-55, black, man)

One participant even mentioned having received a recommendation for a specific doctor that would help take care of his Hepatitis C infection. “Strike up a conversation with somebody talk about, you got Hepatitis and you want to get cured of it, somebody in that crowd has heard of X, they like you gotta go see X look I'm gonna give you the information and everything. They say he has helped me out. He's got me on the medicine quickly efficiently. He didn't mess around.” (Age 36-45, white, man)

Conversely, a few participants described how their peers' negative experiences influenced their decision about engaging in Hepatitis C care. The negative experiences participants discussed mainly were regarding the old treatment for chronic Hepatitis C. As expressed by one participant, “I was kind like, just like, I had a friend that went thru the first like trial drug that just came out for it so like I seen him and he was like literally sick for like weeks or months. So it kind of had me like I really don't want to deal with that.” (Age 46-55, white, woman)

*Competing Priorities*
**Current Drug Use.** For many participants, current drug use and the battle with addiction were the primary reason for failing to care for Hepatitis C infection. Several patients mentioned that using drugs was their main priority and that they were not ready to stop. For many participants, they needed to get "clean" to be successful during their care process. One participant stated, “I stopped going to the doctor, cause at the present time they did tests work on me, and I think my liver was fine so, you know. I just brushed it off cause I wanted to continue using.” (Age 46-55, black, woman) Another expressed “I was on drugs. So when I first time I found out about it, I think I was in a rehab place and they told me about it. That's how I got to know about. But I never got treated for it because I had to get off the drugs to get treated for it. So, you know the drugs was calling me so that wasn't even a major issue for me” (Age 55+, black, transgendered woman)

Participants described their process of achieving sobriety by participating in drug rehabilitation programs and discussed that now that they are sober, they were ready to access care. “I'm in recovery actually. I have a history of drug use in the past. I finally cleaned up. I been going thru programs NA based type stuff and I was like maybe should go get checked up on everything and I went to DePaul Center.” (Age 46-55, white, man) Another participant mentioned not wanting to be reinfected, so making sure he discontinued his drug use was vital to him before caring for his Hepatitis C infection “I want it done. I just think that willingness and I don't wanna come back and say hey, I know I was fixed on such and such, and I backtracked, and now I have it again.” (Age 25-35, black, man)

**Other Priorities.** Participants expressed that they had other responsibilities, which were considered a top priority, over caring for their Hepatitis C infection. For example, the responsibility of caring for children, work, and school sometimes made it challenging for them to
keep appointments. One participant said, “I am a single mother with disability. I don't have transportation. I don't have childcare. Just a lot of factors that have prevented me from being able to do anything.”

One patient described their responsibilities at a drug rehabilitation facility and expressed how even these responsibilities were a prime priority as illustrated by the following statement: “We all have jobs in all three portions. It is a working rehabilitation. We work six days a week. I work in the kitchen. That's why I couldn't get my blood work done last week for the appointment. I did it Monday because I got done a quarter to twelve with my appointment. I have to cook supper. I had to hurry up and get home and cook for everybody.” (Age 36-45, white, woman)

**Instability**

**Incarceration.** Many participants reported having been incarcerated, making caring for their Hepatitis C infection difficult. In addition, participants mentioned not being offered care or treatment for their Hepatitis C infection while incarcerated. One participant expressed, “I was real transient at the time. I’ve also been back and forth quite often in the justice system.” (Age 55+, black, man)

**Homelessness.** Participants expressed that being homeless made it challenging to care for their Hepatitis C infection. As said by one participant, “When you are out there homeless, you just don't follow up on a lot of things, cause you out here struggling trying to feed yourself every day.” (Age 55+, black, man) Participants mentioned that their provider encouraged them to delay treatment until their housing status changed. One participant said, “She told me if I was approved for the medication, I was homeless at that time, she said I would need to be in my own place, cause she said the medication was gonna make me very tired and that I need to be in my place
before I get treated” (Age 55+, black, woman) Another expressed, “I thank God that he got me a place with a roof over my head. I was with the Salvation Army when I was going thru this back and forth with the Hepatitis C doctor. But she kept telling me you wanna wait till you are in your own place before you start doing the medication.” (Age 55+, black, man)

**Social Support**

Support proved to be an essential factor for many participants deciding to seek care for their Hepatitis C infection. Support from family members and employers positively impacted engagement in Hepatitis C care as seen in the following statement: “My parents. They helped me a lot. They were in the same boat as me, my mom especially. When she gets her mind on something, she's like a bloodhound, she gets it done. She helped a lot with it. It was my parents that helped me a lot.” Another participant said, “Me and my husband, we both supported each other and our son, him especially, and told each other lets go get it.” (Age 55+, black, woman)

Participants discussed how family members supported them by encouraging them to seek care and sometimes providing transportation to appointments when needed. Said one participant “Between my mother and a couple of good friends, during the whole thing. The encouragement to do positive things. They have been supportive of it. Help me use their car for these things when I didn't have it. That was totally vital to that.” (Age 46-55, white, woman) Another participant stated “I call my family if I really need a ride or something. My friend, they come around every once in a while.” (Age 55+, black, man)

Participants with a history of drug use mentioned that support from their drug rehabilitation support group helped hold them accountable and provided the support they needed to stop using drugs. One participant mentioned “I'm in recovery so like I am being sober. So I go to meetings and they help people and stuff like that so like that part of my life is complete. Like I
don't have no problems with that so.” (Age 35-45, white, man) Another one said “It's like therapy treatment group or whatever. It's like a part of it kind of like a reentry program type thing, but you just go in a group process it. I just use it for extra accountability cause they drug screening me, you know. And I always do good in things like that. I ain't never had no problem with that. But you know just so that I have more foundation, in a way, until I can pretty much get on my feet.” (Age 25-35, white, man)

**Provider-Level**

**Patient Education**

According to participants, providers can promote or hinder engagement in Hepatitis care by providing education about Hepatitis C and treatment. Many participants believed they did not receive adequate information about Hepatitis C and treatment and did not know anything about it. One participant stated “Well at the time well I mean they didn’t tell me whether there was treatment or nothing. I didn’t know nothing about it anything about.” (Age 55+, black, man) Another expressed, “I think it really needs to be explained. Not just tell me go look it up and get it explained to me…so that was my biggest thing about it, what it was, how you contracted it those are the things. They just told was that it was contracted or how it could be contracted and everything else was like they said look it up figure it out.” (Age 46-55, black, man) Even after engaging in care, participants expressed that they still did not feel they had enough information about Hepatitis C. One person said “ I think just tell somebody you have Hepatitis C and you know, It's treatable, but you don't hand no pamphlet out that explains what that disease is. I just think it should be, I not saying a book, but a decent pamphlet to explain it, you know in detail, you know, what you’re dealing with I mean how to get the help to get treated for it.” (Age 46-55, black, man)
Conversely, some participants expressed having received adequate information from their provider about Hepatitis C, which put them at ease. Participant 34 mentioned that “My primary provider, and I mean I had her for like six years, she was just straight forward with me. She sat me down and explained everything to me from point A to point B. And, like I said, she was good at what she did as far as the Hepatitis C.” (Age 55+, black, man) Another participant said, “It kind of scared me at the beginning. But once she explained everything to me, I kind of relaxed cause they said it is curable. That’s the good thing about it.” (Age 55+, black, woman)

**Provider Attitudes about HCV Infection**

Participants expressed that providers' attitudes about their positive Hepatitis C diagnosis influenced their decision to engage in HCV care. Many participants mentioned that their provider did not seem concerned about their Hepatitis C diagnosis. One participant expressed, “They just said I had Hepatitis C. They didn't make it look like no emergency or nothing.” (Age 46-55, black, man) This led participants to believe that caring for their Hepatitis C infection was not urgent causing them to delay care and treatment. As said by one participant “Well, they didn’t go into no detail with it. Just like get checked on cause it can cause cancer and all that. As they were doing my bloodwork, they were like everything was good so…There was no big issue.” (Age 46-55, black, man) Another mentioned “I think some places that I went was like pretty much nonchalant about it. Because it was like, you didn’t really explain it to me you know what I mean. It’s like this is what you have so you can get treatment for this. You didn’t really tell me what the treatments was.” (Age 46-55, black, man)

**Patient-Provider Relationship**

Having trust in the provider had an impact on the decision to engage in care. Positive relationships and those relationships built on trust facilitated engagement in care. Participants
often mentioned experiences with providers that were caring and compassionate towards them. As said by one participant “This is the way I would like it to be. This is the way it is, the way it is. You know they caring about the patient and do they job. What they supposed to do for the patient. And everything else. It's all good because he about to take care of me. So, that's all that matters.” (Age 55+, black, transgendered woman) Another stated “He's very concerned, I mean he calls me if I call him and tell him I'm feeling bad. And he tell me to come in now or something like that. Or he'll tell me what to take, so he's very concerned. He's a good doctor as far as I'm concerned because they got so many that some doctors don't even much call you and tell you anything. As far as me being with him, I know that he's very concerned about his patients.” (Age 55+, black, woman)

Providers that were personable, compassionate, and non-judgmental made participants feel comfortable coming in for Hepatitis C care. Several participants mentioned they appreciated providers that they were relatable, encouraged them, and answered questions they had about their infection. One participant said, “Everybody been good. They ain't talking ‘bout aww, get away from me, you got Hepatitis C or none of that. They treat me like I'm human.” (Age 46-55, black, man) While another expressed “The whole staff here is very polite, very understanding, and quick to answer a question if you ask. That means a lot in any kind of treatment as far as I’m concerned. They are willing to answer my questions when I'm concerned about something.” (Age 46-55, white, man)

Conversely, participants noted that prior experiences with providers with poor attitudes were a barrier to engagement in Hepatitis C care. Many participants believed providers did not care about them. In addition, participants mentioned having encounters with providers who exhibited stigmatizing attitudes towards them because of their drug-using history. As stated by
participant 15, “It seemed like they didn't care. I don't really know if saying they don't care is the correct phrase to use, but it just seemed like they weren’t willing to help me. For instance, I am an addict. And it felt like because I am or was an addict, that they didn’t say it, but it's like it was your fault, you know, that's how it felt.” (Age 36-45, white, woman) Another participant said “He was uncaring, very uncaring. He didn't give a crap, didn't concern him…I figured that every doctor would feel that way. They would look at us like you’re just a drug addict. It's your fault, don't feel sorry for you one bit.” (Age 46-55, white, woman).

Participants also mentioned being discriminated against because of their health insurance status. Moreover, participants believed providers they have encountered cared only about money and did not want to help them. Only there to do a job. One participant mentioned “That's what discourage me from going to the hospital cause, they don't do you right. Especially when they find out you ain't got the insurance or the money to pay for it right off the top. They don't even examine you right.” (Age 55+, black, man) Another expressed “It was more their methods, you know. Didn't really show that they were really concerned. It was like it's their job, they just come in, you know.” (Age 46-55, black, woman)

Health Care System-Level

Collocated services

Participants communicated that having complete scans and blood work at one spot would improve their Hepatitis C care experiences. As expressed in the following statement, “It would be nice if they did it all at one spot…The ultrasound and everything else at the same spot.” (Age 25-35, white, man) Another participant mentioned “Some facilities maybe able to handle everything in one area. You see the scan I'm going to tomorrow is at Touro, you see that is
outside of the link. It's part of it but its outside of it. I guess their facility doesn’t have those type of things to do that.” (Age 46-55, white, man)

**Supportive Services**

The provision of supportive services- such as transportation, medication delivery, and care coordination- positively affected patients' ability to engage in care.

Several patients reported having received help to navigate the healthcare system. One participant said “She never gave me the number, she did the blood work on me, which I had already told her. And after she did the blood work on me, I received a phone call from him, and he told me about my primary care doctor…He said that Ms. X had gave him my number to contact me, and that was…that meant something to me. Wow someone does care, you feel what I'm saying, cause most people will just tell you what's wrong with you and you're on your own. You got to go find a way to you know... and that played a big part of my change.” (Age 46-55, black, woman)

Another patient mentioned that they would like to receive help setting up appointments for follow up scans and bloodwork. “It would be nice if they set up the appointments…yeah, from what I'm hearing with my aunt and their doctors, they usually set it up with the other place.” (P38)

Participants expressed that having their medication delivered helped make the care process easier. As expressed by participant 7, “He said something about someone coming to drop the medication off or pick the medication. Now I have a vehicle, but I know that that would be a barrier now probably being able to get (inaudible), get your medication, probably miss a day or two. That alone being able to drop medication off at the house would make things easier.”

Another participant stated “They actually sent it straight to my front door. It was great. I couldn't ask for anything more. The actually sent it by. I had to call a certain number and when I was
about a week before empty, when I didn't have anymore. So I called them a week there, and by the time it would be like three days later, I would have the dude knock on my door. And I would have my medicine.” (Age 25-35, white, man) The provision of transportation also was mentioned as a factor which helped to ensure that patients could come to attend Hepatitis C care appointments. As said by one participant “I have even had them pay for me a taxi at one time to get here and back. That meant lot. They do a lot here. I appreciate him a lot.” (Age 25-35, white, man)

**Out-of-State Care Experiences**

Participants described the less than pleasant experiences of accessing health care out of state, including South Carolina, Mississippi, and Alabama. Participants expressed that trying to access care Hepatitis C care out of state was difficult. One participant stated “At this present time no, I don't because I haven't been dealing with any of this for a long time. I gotten frustrated with the process in Mississippi to the point where I quit trying.” (Age 36-45, white, woman)

Participant 17 expressed “I can't remember who it was it was so long ago. I just do remember it was over here, because really, this was the only area that had good doctors that we could get to. The ones in Mississippi, we have horrible medical centers, they are just not very good.” In addition, several patients mentioned that providers out of state did not care and discriminated against them, primarily because of their drug-using history. One participant stated “I found out everything about what I have here in New Orleans. South Carolina like I said, South Carolina much different then here. They don't care nothing about you if you ain't got no insurance or no money they look at you like I said. They do a dog better than they'll do you.” (Age 55+, black, man)
One participant communicated that since moving to Louisiana, it has been easy getting Medicaid and accessing care for their Hepatitis C infection as expressed in the following statement: “It's easy to get Medicaid down here and people care. That’s why... people care. It's so much easier down here to get treatment. If you are in Mississippi or Alabama, you are like I said, screwed.” (Age 25-35, white, man)

**Geographic Location**

Participants discussed how the location of the healthcare facility impacted engagement in Hepatitis C care. Several participants discussed the ease of accessing the facility due to the location. They stated that they could make their appointments because the facility was close and within walking distance. One participant stated “I don't stay too far from here, right on Tulane and Carrolton. If it wouldn't have been raining, I would have started walking till the bus caught up with me. That's a good thing cause it ain't too far.” (Age 46-55, black, man) Another said “It was pretty easy. He said he wanted to see me come in...I live just right up there, so I walked here.” (Age 18-24, black, man)

However, other participants mentioned that the healthcare facility's location made it challenging for them to engage in care for Hepatitis C infection as expressed by the following statement: “What happened was they moved my Hepatitis C doctor to Causeway and Jefferson Parish. It was difficult for me to get there from where I lived to there, and that's what made me stop going.” (Age 55+, black, woman) Another participant stated, “I was supposed to see NAME in Gentilly, and he wound up going somewhere else. So, I never pursued it.” (Age 55+, black, man)

**Facility Procedures and Regulations**
Participants discussed several facility procedures and regulations which impacted engagement in care. For example, many participants described the ease of scheduling and rescheduling appointments and how accommodations, such as walk-in appointments and virtual appointments, made it easier for them to remain engaged in care. One participant said “Well, I didn't have any difficulties into appointments because it wasn’t really appointments, it was just me walking in. It's like they gave me a list, you know, and I just walked in the made an appointment for me and that was fine. But most of the time they see you and tell you to have a seat. See if they got a time that they could get me in.” (Age 46-55, black, man) Another participant expressed “It was hard to make an appointment at first because of COVID. When they got to June and started seeing people it was easy. They always offered the virtual or the phone call, things like that.” (Age 18-24, black, man)

Additionally, participants expressed that the appointment reminders they received helped them keep track of their appointments. As stated by one participant “I have never had an experience like this…this place is amazing. They will call you to remind you of your appointment.” (Age 46-55, white, woman) Participant 26 expressed “You get constant reminders. They might text you and remind you. They call and remind you. Sometimes it will be twice a day they text to remind you. They are great.” (Age 55+, black, woman)

However, a few participants expressed that the clinic regulations, such as appointment scheduling and clinic hours, made it difficult to engage in Hepatitis C care. For instance, once participant mentioned that he had difficulty scheduling an appointment, which made him disengage from care. Another participant said “The scheduling be messed up over there too. I have to see the nurse. I have to see the doctor. I be trying to see both of them at the same time, but they didn’t... I done missed the appointment. I was supposed to go over there to see the nurse
in two weeks but because that lady done what she done, some kind of way, my appointment got messed up. So, I ain't been back to her.” (Age 55+, black, man) Another participant expressed “I would need it to be after hours after work hours cause it be hard for me to keep a job, knowing I gotta come here or there on a weekly basis. So if need be, if it would possible I would like it to be after hours something like that cause it's hard for me to keep a job.” (Age 25-35, black, man)

Referral Process

Participants mentioned that they had been referred to a specialist following their Hepatitis C diagnosis, which helped to facilitate linkage to care. Participants described how providers helped to schedule appointments and reach out to them to ensure they were engaged in care for their infection. As stated by one participant “She's the one I told about the Hep C and drug thing. And she recommended Dr. NAME, and I got a phone call from him about three days later, and it's been on ever since.” (Age 46-55, black, woman) Another participant stated, “I told the doctor about what I was dealing with and what I was with, and he told me if I ever got treated or for it and he gave me the proper route to talk to talk to Dr. NAME and set me up with an appointment. And we've been going on from there and this has been six months ago.” (Age 35-45, white, man)

In contrast, some participants discussed that their primary care doctors failed to adequately assist with linking them to care. For instance, one participant who was diagnosed in the hospital described having to “demand” assistance in order to be referred. Another participant mentioned “They gave me the information for DePaul because I had a fit when they are trying to release me. Like I didn't know what to do, what are you putting me out now and I am not ready to go?... And by the way I don't know what to do. So, once I had a total breakdown, then they came in with all the information I needed and some referrals for me. I had to have a fit to get that done.” (Age 46-55, white, woman)
Another participant described being given a list of specialists, with no help scheduling appointments. The participant felt defeated as he believed he could not afford the specialists that were recommended to him. “They just told me I could follow up with a doctor that deals with the liver and all and tell me the nurse can give me a list of doctors I can make an appointment with, which at the time I didn’t have insurance that could cover it. Any of those specialists. They were high dollar. Like I said, I did not have any way of seeing none of these physicians. Just kind of tagged with it and had to deal with it and let it go.” (Age 46-55, white, man)

**Structural-Level**

**Corrections System**

Many participants discussed their experiences of having Hepatitis C while incarcerated. The majority of participants noted that, while in prison, they were not offered or receive treatment, nor did they receive adequate information about Hepatitis C and treatment. As said by one participant, “I was incarcerated…They don't give you know medication when you are incarcerated for this type…Those people don't care about you. I just told them I'm going as soon as I get out and get this taken care of…I said why you don't give me medicine for it? ‘We don't have medicine for Hepatitis C.’” (Age 46-55, black, man) Another expressed “I was told that I was gonna go to this facility to talk to this person and do this and do that. Well within the 6 years, I was incarcerated for six years, and I seen one lady at Angola penitentiary, and she basically came and said that my levels are not high. They only have to treat it if it's chronic, or something like that. And she made me feel like if it wasn't that bad, so, but I still have it.” (Age 25-35, black, man)

In jails and prisons, mistrust in medical and short stays negatively impacted participants' decision to seek care for Hepatitis C infection. Participants expressed that they did not trust
medical to care for them properly while incarcerated. Participant 25 stated “She was asking me if I willing to seek treatment. I said yeah. See once you're in prison, they tell you all these different things, but they don't go the proper way of doing things. They give you all these generic brand stuff you know what I'm saying. I didn't have no life sentence so I rather take care of it when I get home cause I figure it will be better for me.” (Age 46-55, white, woman)

Several patients mentioned that they did not receive treatment because they were only incarcerated for a short period or were going through a transfer. As expressed by one participant “I ain't been following up with it. They told me about medication, but I was going thru a transfer, wasn’t following up on nothing up. didn't have a mailing address or nothing so I missed out on medication.” (Age 55+, black, man) Another participant said “That camp is all about money. So, they not just going to just you know, they don't do the small things, so the big issue, they not going to do it. And I feel like, they probably thought that. They knew I was short enough to go home…I don't think that that's right because I feel like y'all...and it's free. I feel like y'all should have the medication for to take care of us too. So y'all start us off since y'all know about it and can help us. Then we can move on to the next person and let them take care of us afterwards but...jail is different.” (Age 55+, black, transgendered woman)

Accessibility of Treatment

Participants mentioned that there was no treatment for Hepatitis C at the time of their diagnosis, so they did not seek care for their infection. Participants noted that they were even told this by providers. One participant mentioned “I never followed up with it. I knew I had it and I did check into it from the doctor, I would ask questions. Pretty much they didn't have treatment and that I know of but it was never offered to me.” (Age 46-55, white, man) Those who knew of the treatment expressed that the cost of treatment was a significant barrier at the time. Participant
11 stated “I didn't have the financial assistance and I knew I couldn't pay for it. And that was the delay for me.” (Age 55+, black, woman)

A couple of participants acknowledged that laws were passed and that treatment for Hepatitis C became accessible to them. One participant said, “I mean the best thing that I can say about that from what I understand they passed a period of legislation so there’s no red tape for the medication. So, like that should encourage a lot of people to try and seek it as soon as possible…I have friends that are in prison right now that are getting it with no problem.” (Age 35-45, white, man) Another participant mentioned “She was like there's new laws passing whatever. They can't turn you down so you can go back up and see.” (Age 46-55, white, woman)

Now that the medication cost is covered, people are able to care for their Hepatitis C infection. One participant expressed “It’s been hard, very hard, and it's so expensive. For the common man or woman if they don't have a lot of money and they don't have Medicaid, it's just impossible, impossible. It's hard trying to find the places that will do it that help. It's hard.” (Age 25-35, white, man) Another expressed “I heard was they were gonna start giving the medication out to anybody who has Hepatitis for free. You don't have to wait to see if they are gonna approve it or not. So, one I heard that they were gonna give it to everyone that has it, that is when I said it's time for me to make an appointment.” (Age 55+, black, woman)

Insurance reimbursement restrictions were noted as major barriers to engaging in HCV care, with the majority of participants mentioned having been denied treatment coverage in the past. The most commonly reported reasons mentioned were disease severity and drug use. This was expressed in the following statement “They went through another insurance company to see if I could get the medication, but nothing that they did…I had to be in some stage, I think there's different stages you have to be in…you must be almost terminal sick to get it.” (Age 55+, black,
woman) Another participant expressed “They just kept denying that they were gonna pay for the medication for me…She wasn't telling me why, but I was thinking maybe because I was smoking marijuana, that they kept denying me. I did hear that people would say that if you are on drugs, that they gonna deny you.” (Age 55+, black, woman)

One participant mentioned delaying care, until they were ready, because insurance restrictions limited them to one free treatment course. “I wasn't ready for that, I wasn't ready for nothing…Because like I heard like people talking about like when you do that, it only covered one time or whatever like that…When you get your Hepatitis C taking care of, the state only covers it one time.” (Age 25-35, white, man)

Participants acknowledged the fact that the restrictions have since been changed, making treatment more accessible to them. One participant said “One time I had insurance so I went to a gastroenterologist. And at the hospital, I was trying to see if I could get the medication, but they were saying that due to how my liver levels were and it wasn't progressing that my viral load was low, that they couldn't get clearance to get the medication for me. But once I started talking to X, he got the paperwork from them and stuff he's like ‘no, you can get it, it's just we have to go different routes in order to get it.”’ (Age 35-45, white, man) While another stated “I was glad to hear on the news a year ago that they were gonna start giving it free to people with Hepatitis C and people didn't have to worry about being denied anymore.” (Age 55+, black, woman)

**HCV Awareness**

Hepatitis C awareness campaigns positively impacted engagement in care for many participants. Participants expressed that they learned about the availability of Hepatitis C treatment via the media, primarily television advertisements. For many participants, this prompted them to seek care for their infection. One participant said, “Seeing the commercials on television, how I
found out about it, there was commercials on tv here, get treated for Hep C, go to your doctor. I seen it on television, like oh, wow, this is cool, I went to the doctor.” (Age 46-55, white, man) Another participant expressed “I been wanted to do was get myself checked out and you now get healthy...But I never knew where to go or how to go about doing it until I started hearing about y’all will take care of us with this and stuff like that, hearing commercials on it and stuff like that. Y’all will help us and stuff like that. That's why I am here now to try to get help for my Hepatitis C.” (Age 55+, black, transgendered woman)

Participants also expressed that people are not knowledgeable of Hepatitis C and that improving Hepatitis C awareness is extremely important to facilitate engagement in care. One participant said “People, even though they see the commercial about the medication, they don't see how many people are actually affected by it.” Participants also discussed that people do not know that Hepatitis C is relatively common and suggested that providing information about how many people have the disease would facilitate engagement in care. As expressed by the following statement, “I just hope that they would come out in the opening and go on television or the radio anything that can broadcast the social media or anything to let people know that to go get checked for this. Just like they do it for HIV, they can do it for HC too.” (Age 55+, black, woman) Another participant said, “I actually noticed recently that you all are doing way more advertisements about treatments on TV, there's billboards. Personally, I think you all are doing an awesome job at trying to get out there, and letting people be aware that it's not just them. It's all over. I think you all are doing a very good job.” (Age 36-45, white, woman)

Several participants expressed that patient outreach would be a good way to increase awareness of Hepatitis C. One participant expressed “I don't know if they even heard about it on the news that they giving it free now to people with Medicaid. Let them know reach out to them,
send out letters or try calling” (Age 55+, black, woman) Another participant mentioned “Like I said earlier, you know we need this to put out to social media, on tv things like that…The black community and any community needs to be put out there cause this is something a lot of people walk around with. And they don't know this will kill you, this goes to the live.” (Age 55+, black, man)

**Discussion**

This study explored the barriers and facilitators to engagement in HCV care among patients attending a community clinic in a large metropolitan area. Supportive of the social-ecological model, this study's key findings suggest a complex interaction between patient, provider, healthcare system, and structural factors, making it challenging for individuals to engage in care for Hepatitis C (McLeroy et al., 1988). This study found that patient-level factors—including inadequate insurance coverage, limited knowledge, and competing priorities- served as barriers to engagement in Hepatitis C care. Previous researchers have reported similar findings (Adams et al., 2018; Sims et al., 2017; Trooskin et al., 2020). In contrast to previous research, mental illness was not found to be a major barrier to engagement in HCV care among patients in this study ((Masson et al., 2020; Rogal et al., 2017; Trooskin et al., 2020).

Similar to other studies, provider-level factors such as stigmatizing experiences with providers and limited patient education were barriers to HCV care (Bass et al., 2018; Dowsett, Coward, Lorenzetti, MacKean, & Clement, 2017; Patel et al., 2019). Like what previous researchers have found, the study findings demonstrated that fragmented healthcare services and the geographic location of the healthcare facility might serve as a barrier to individuals seeking care for their HCV infection (Falade-Nwulia et al., 2019; Masson et al., 2020). Moreover, this study corroborated other studies in demonstrating that the insurance reimbursement restrictions
and the lack of effective linkage to care programs of the correctional system serve as barriers to HCV care at the broader structural level (Jessop, Bass, Gutierrez, & Gashat, 2019; Litwin et al., 2019; Ocal & Muir, 2020). This study adds to the growing evidence that facilitators for engagement in HCV care include having the desire to achieve a cure and having a regular primary care provider (Bass et al., 2018; Makarenko et al., 2019). Additionally, the study also found that supportive services (i.e., transportation, rehabilitation services), support from family and friends, and the presence of comorbidities act as facilitators to engagement in Hepatitis C care (Falade-Nwulia et al., 2019; Litwin et al., 2019; Masson et al., 2020). Finally, this study also adds to the few available studies that reported that optimism regarding Hepatitis C care— including gratitude for the receipt of treatment, achievement of care milestones, and the desire to get healthy- as facilitators to engagement in care (Jessop et al., 2019; Patel et al., 2019). Though this study is one of a few existing that explored the barriers and facilitators to engagement in Hepatitis C care during the DAA era, several limitations exist. Recruitment occurred at only one community health center in an urban area, though across several locations in the GNO. Moreover, a convenience sampling method was used increasing chance of selection bias. Finally, the sample for this study was primarily black, male, and publicly insured, thus, limiting the generalization of these findings to the broader population.

Additionally, this study only recruited patients that came into the clinic to seek care, excluding those that may have yet to engage in care. Patients who have yet to engage in care may report different factors that affect their decision to seek care. Despite the limitations, this study is one of the few which provides detailed, rich information on barriers and facilitators of HCV care among high-risk, mono-infected individuals living in an urban area during the DAA treatment area.
These findings have implications for understanding barriers and facilitators to HCV care that can guide policy and intervention development. The study findings underscore the importance of health education and treatment accessibility. There is a need to scale up HCV awareness campaigns, focusing on HCV morbidity and mortality messaging. It's imperative that policies, which improve the accessibility of treatment, such as the Medicaid subscription model, be implemented nationwide. Furthermore, these findings suggest that addressing stigma and discrimination at both the system and provider level is crucial to ensuring successful care engagement. Lastly, these findings suggest there are still significant efforts needed to successfully engage incarcerated persons and persons who inject drugs into care and treatment. Future studies should investigate effective ways to target these populations.
References


Appendix A

Participant Screening Questionnaire

HCV Study

Patient Eligibility Screening and Demographic Questionnaire

Participant Code: ____________________________

Researcher Name: ____________________________

Date of Interview: ___________

Please Note: If you are pregnant and/or HIV positive, you are not eligible for the study.

1. How old are you? [CHOOSE ONE]
   __ Less than 18 years of age
   __ 18-24
   __ 25-35
   __ 36-45
   __ 46-55
   __ older than 55 years

2. What is your race? [CHOOSE ONE]
   __ black or African-American
   __ white or Caucasian
   __ Other (please specify)

3. Are you Hispanic? [CHOOSE ONE]
   __ Yes
   __ No

4. What is your gender? [CHOOSE ONE]
   __ Man
   __ Woman
5. What is your education level? [CHOOSE ONE]

   ___ Did not graduate high school
   ___ High school graduate or equivalent (e.g. GED)
   ___ Some college
   ___ College Graduate
   ___ Graduate or Professional School
   ___ Other (please specify)


   ___ Orleans Parish
   ___ Jefferson Parish
   ___ St. Bernard Parish
   ___ Plaquemines Parish
   ___ St. Tammany Parish
   ___ Other (Specify) ________________________________

7. Have you ever been diagnosed with chronic Hepatitis C infection by a provider or other health care professional? [CHOOSE ONE]

   ___ Yes
   ___ No
   ___ Don’t know
Appendix B

Patient Interview Topic Guide

Opening statement

Thank you for taking the time to talk with me. I would like to find out more information about your experience living with Hepatitis C. In addition, I would like to understand your perception about the healthcare experience and managing the disease. Do you have any questions before we begin?

1) Please tell me about the time you found out you had Hepatitis C? (Probe the following if not answered in the initial response)
   a) When did you find out you were infected with Hepatitis C?
      i) Where were you?
      ii) Who told you? How did he/she tell you?
      iii) What made you decide to get tested?
      iv) At that time, what information were you given about Hepatitis C?
   b) How did you feel when you first found out you had Hepatitis C?

2) Please share any beliefs you had/have about Hepatitis C (Probe the following)?
   a) What did you know about Hepatitis C at the time you found out you had been infected with the virus?
   b) What did you know about the medication for Hepatitis C at that time? (e.g., health beliefs, duration, effectiveness, medication side effects)
   c) How did your thoughts about Hepatitis C affect the way you felt about having the disease?

3) What made you decide to get care for the Hepatitis C infection?

4) Explain how you chose the doctor for your Hepatitis C care?
a) What is important to you when you visit the doctor about Hepatitis C?

5) Please describe your experiences with the doctors you have visited to get care for Hepatitis C infection (Probe the following)
   a) Describe your most recent experience

6) What is the relationship like with your doctor? (Probe the following)
   a) How does she/he communicate with you?
   b) How does she/he give you information about your care?
   c) How is he/she sensitive to your needs?

7) Please discuss the trust you have in your doctor to treat you for Hepatitis C.

8) Describe how you balance everyday life (tasks and activities) with visiting the doctor for Hepatitis C care (Probe the following)?
   a) What are some things that make it difficult for you to attend your scheduled Hepatitis C appointments or take your medicine?
      i) Discuss transportation, income, housing, social support, access to doctor, insurance, other health conditions, other service needs)
      ii) Health care system (e.g. facility, appointments, clinic environment, access to other services)
      iii) Cost of treatment and insurance restrictions
   b) What are some things that make it easier for you to attend appointments or take your medicine? (e.g. transportation, income, housing, social support, access to doctor, insurance, other health conditions, other service needs)
      i) Health care system (e.g. facility, appointments, clinic environment, access to other services)
ii) Cost of treatment and insurance restrictions

9) How has COVID 19 pandemic affected your ability to get care for your Hepatitis C?
   a) Access medication

10) Please explain how services for Hepatitis C care could be improved (Probe the following).
    a) What is working?
    b) What is not working?
    c) What do you think should be done to improve them?

Closing statement

We have come to the end. Thank you again for agreeing to talk with me. I really appreciate your willingness to help with this research project. Is there anything else you would like to comment on or add to what we talked about during this discussion?
# Appendix C

## Table 1 Participant Characteristics

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Appendix D

Figure 1 Social-Ecological Model of the Barriers and Facilitators to Engagement in HCV Care
Chapter 5: BARRIERS AND FACILITATORS TO ENGAGEMENT IN HEPATITIS C CARE FROM THE PROVIDER PERSPECTIVE

Introduction

Chronic Hepatitis C (HCV), also known as the silent killer, is the most common bloodborne illness in the United States. Approximately 2.4 million people are living with chronic HCV in the United States. Chronic HCV is the leading cause of liver disease, including cirrhosis and liver cancer (Hofmeister et al., 2019). An estimated 5-25% of people with chronic HCV infection will develop cirrhosis, and an estimated 1-4% will progress to liver cancer (Seeff, 2002). In the United States, HCV is the primary reason for liver transplantation, and if left untreated, HCV can even lead to death. In 2018, more than 15,000 people died of HCV-related causes (Prevention, 2020). This number is believed to be an underestimation as data indicate that most HCV-related deaths go undocumented on death certificates (Mahajan et al., 2014).

The number of people living with chronic HCV has steadily declined, mainly attributed to all-cause mortality among the baby boomer population, a group historically with the highest HCV prevalence (Hofmeister et al., 2019). However, the number of new cases of chronic HCV continue to rise, particularly among younger people (Ryerson et al., 2020). The rise of chronic HCV infection among the younger population has been primarily attributed to the prescription opioid epidemic and the increase in injection drug use, the leading risk factor for HCV infection (Zibbell et al., 2018). Among all HCV cases with available injection drug use information, 67% reported injection drug use in 2019 (CDC, 2021).

In Louisiana, HCV is a significant health problem, with approximately 50,000 people living with chronic HCV in the state (Rosenberg et al., 2018). Alarmingly, the number of new chronic HCV cases in Louisiana has increased 222% between 2014 and 2018, with more than 9,000 chronic HCV cases reported in 2018 (Louisiana Department of Health, 2019). Injection
drug use is the primary risk factor for HCV infection in Louisiana. An estimated 80% of new HCV cases are acquired through injection drug use (Louisiana Department of Health, 2019). In Louisiana, lower-income individuals, Medicaid enrollees, and the incarcerated are disproportionately infected with chronic HCV (Louisiana Department of Health, 2020).

Curative therapy is available to treat chronic HCV infection. Until recently, a combination of pegylated interferon and ribavirin was considered the standard of care (Ward & Mermin, 2015). The combination pegylated interferon-ribavirin therapy consisted of a painful injection, 24–48-week treatment durations, harsh side effects (e.g., depression, flu-like symptoms), and only a 37-41% curative rate (Dusheiko, 1997; Manns et al., 2006). In 2011, the Food and Drug Administration approved a new therapy for chronic HCV, direct-acting antivirals (DAAs), and in 2014 an all-oral DAAs therapy became the standard of care for chronic HCV infection (Ward & Mermin, 2015). Compared to the old therapy, DAAs have much shorter treatment durations (i.e., 8-12 weeks), fewer side effects, and nearly 100% cure rates (Feld et al., 2015; Ward & Mermin, 2015). Though curative treatment is available, only a small percentage of people living with chronic HCV infection is cured. Among all people living with chronic HCV in the United States, only an estimated 37% received treatment, and 37% were cured in 2018 (Chhatwal et al., 2019).

Louisiana public health officials have made eliminating HCV a public health priority and set an ambitious goal of eliminating HCV by 2024 (Louisiana Department of Health, 2019). Engagement in care is critical to ensure the state reaches its goal of eliminating the virus. Supportive of the social-ecological model, prior research suggests that multilevel factors influence engagement in HCV care. Specifically patient, provider, health care system, and structural-level factors. The SEM is a theory-based framework that is used to understand the
complex interplay between the individual and environmental factors on health behavior. The SEM posits that individual behavior affects and is affected by multiple levels of influence and that the relationship between the individual and his/her environment is reciprocal (McLeroy, Bibeau, Steckler, & Glanz, 1988). Within this framework, neither individual nor environmental factors are mutually exclusive in their influence on engagement in HCV care, but rather their interaction

Patient-level factors such as treatment beliefs, stigma, and instability factors have been found to influence engagement in HCV care (Adams et al., 2018; Litwin et al., 2019; Patel et al., 2019). Though DAAs are now the standard of care, inadequate knowledge about HCV treatment may cause these perceptions to persist among persons living with chronic HCV infection (Adams et al., 2018). Individuals whose disease status is due to engaging in a stigmatized behavior (e.g., PWID), fear being judged negatively by providers. As “self-protection” from stigma and discrimination, some infected individuals choose not to seek care and treatment for HCV (Masson et al., 2020; Patel et al., 2019). This study corroborates finding which reported that instability factors such as homelessness and food insecurity, are barriers to engagement in care (Colasanti et al., 2017; Noska et al., 2017).

Additionally, provider-level factors, including training and cultural sensitivity can influence engagement in HCV care. A survey analysis of infectious disease physicians in North America found that a substantial proportion (61%) of providers did not feel they had not received adequate training to evaluate, treat, and manage HCV in clinical practice (Chastain et al., 2015). Persons living with chronic HCV infection have reported provider insensitivity related to drug using behavior as a barrier to accessing care. It is important that providers understand drug-using identity to facilitate linkage and retention in care among this high-risk population (Rich et al.,
Researchers also have found that influential factors at the health care system level include fragmented healthcare services and access and availability to healthcare (Falade-Nwulia et al., 2019; Litwin et al., 2019; Sherbuk et al., 2020).

Moreover, structural factors, including criminalization of drug-using behaviors and the high cost of treatment have been found to influence HCV care outcomes (Akiyama, 2020; Brad Sears, 2020). Patients have reported criminalization of drug using behavior as a barrier to linkage and retention in HCV care. Patients who inject drugs fear being arrested or charged with a crime if they disclose injection drug using behavior, making it less likely they will link to or remain in care (Ford & Bressan, 2014). The high cost of treatment serves as a major barrier to accessing and remaining in HCV care (Litwin et al., 2019; Rogal et al., 2017).

Given the significant role healthcare providers play in ensuring successful engagement, understanding their perspectives is vital to improving HCV engagement in care outcomes. In this chapter, I will present the findings from the qualitative study that explored the perspectives of a diverse group of health care providers to gain an in-depth understanding of the barriers and facilitators of engagement in HCV care in the Greater New Orleans region. This information will be useful in designing interventions to facilitate engagement in HCV care in the area. Thus, helping to achieve Louisiana’s target of eliminating HCV by 2024.

Methods

A qualitative study was conducted to explore the perceptions of a diverse group of healthcare providers regarding the barriers and facilitators of engagement in HCV care in the Greater New Orleans area. A qualitative research design was the appropriate choice for this particular study because it allowed for exploring a topic that has not been widely studied. It also supported the use of methods, which resulted in collecting detailed, rich information to
adequately answer the research questions and provide information necessary to guide future descriptive or explanatory studies. The study gained approval from Tulane University Institutional Review Board.

Setting

The study was conducted in the Greater New Orleans area. Participants were recruited from various HCV healthcare agencies, including community clinics, a state university, and a pharmaceutical company.

Participants

A purposive sampling method was used to recruit five HCV care providers for semi-structured interviews based on their job roles. Recruitment occurred from December 2021 to April 2021. To be eligible for the study, providers had to be an adult professional (18 years and older), a current provider of HCV care and treatment services, or assisted in navigating the federally funded health care system process in New Orleans and have worked in the field for at least 12 months. Eligible providers included physicians, nurse practitioners, care coordinators, and peer navigators. Suggestions from the an advisory committee and the former Louisiana Department of Health HCV Coordinator helped to identify providers for the study. Providers were contacted via phone and email to invite them to participate in the study. A follow-up email was sent in five days if the provider did not respond to the initial email. Providers had the option of meeting in-person at a safe location (i.e., personal office) or via Zoom, a video-conferencing platform. To ensure the safety and security of the Zoom interviews, a unique passcode was issued to each participant. The unique passcode restricted access to the interviewee only. Interviews were scheduled with the HCV providers at a time that was most convenient for them.

Procedures
All five HCV care providers elected to conduct interviews via Zoom. Three days before the scheduled interview, providers were sent an email with the study consent script and Zoom invitation link. Providers were instructed to review the consent information before the interview. On the day of the interview, before the interview began, any questions that the provider had were answered and obtained informed consent verbally. All of the interviews were conducted by the principal investigator. An interview guide was developed to direct the semi-structured interviews with providers. A comprehensive review of the literature on barriers and facilitators to engagement in HCV care was used to establish the interview questions. The interview guide consisted of open-ended questions designed to elicit in-depth responses. The provider interviews explored: 1) Perception of the factors that affect linkage and retention in HCV, 2) Their specific role in facilitating linkage and retention in HCV care, 3) Experience caring for and treating patients with HCV, 4) Strengths and weaknesses of the health care system in ensuring patients access and remain in care, 5) HCV stigma and discrimination, and 6) Suggestions on how to improve linkage and retention in HCV care.

A consultation with two HCV care providers assessed content validity, clarity, and cultural sensitivity of the topic guide before data collection. The interview guide was then pilot tested with one HCV provider and modified based on the feedback from the pilot interview. The interviews lasted approximately 45-60 minutes and were recorded using the Zoom recording function. Only the audio recording was kept on file, and all other Zoom interview files were deleted. Participants were not compensated for their time.

**Data Analysis**

A social-ecological framework guided the design and analysis. The principal investigator and a research assistant transcribed the interviews verbatim. The transcripts were entered into
ATLAS.ti version 8 (Berlin, 1989) for coding and analysis. The analytic process began with a thorough reading of the interview transcripts as they were transcribed. As interviews accumulated partial summaries of each interview guide question were developed. A base set of theoretical concerns from SEM were present, but the interviews were read to explore respondent characteristics, treatment status and the range of responses and any social and behavioral factors that emerged.

As the interviews were read, a coding scheme was developed to identify underlying issues, themes, and events relevant to the analysis. The coding scheme adopted the integrated approach proposed by Hsieh and Shannon (Hsieh & Shannon, 2005). This scheme was applied to the transcripts. The development of the coding structure was an iterative process. This deductive approach to code development consisted of developing preliminary codes before the transcripts were reviewed and assigning codes. The preliminary codebook incorporated well-known concepts from the social-ecological framework. Though a preliminary codebook was developed, data were not forced into the predetermined categories. The initial codebook only served as a guide and evolved as data collection continued, and new codes, or modifications of existing codes were identified. Thus, an inductive approach to the development and application of codes was used. The inductive approach drew from Grounded Theory, to cross-check the applicability and meaning of initial codes, attempting to avoid wrongly assigning codes to the data to fit predetermined concepts or a theoretical framework (Creswell, 2007). The process continued throughout data collection as the emerging codes were developed and improved to fit the data.

Results

Participant Characteristics
Five HCV care providers were interviewed for the study. Table one (Appendix A) describes participant characteristics. Participants represented the various key roles involved in delivering care and services to patients with HCV. Specifically, participants represented federally qualified health centers, a harm reduction center, a national pharmacy services organization, and a large university healthcare system. Participants’ job titles included a lead infectious disease physician, infectious disease care coordinator, linkage to care coordinator, a senior pharmaceutical sales executive, and a nurse practitioner who also serves as associate professor of a Health Policy and Systems Management Program. The participants had extensive experience providing HCV care services, with years of experience ranging from 2 to 30 years. HCV care providers’ experience included providing direct clinical care to HCV patients, tracking HCV patients and assessments, and patient navigation. Additionally, participants’ experience included developing and analyzing state and institutional health policy, creating insurance reimbursement systems, and serving as a liaison between the pharmacy and provider to facilitate the HCV treatment prior authorization process.

Key Findings

According to the providers, multi-level factors influence the decision to engage in care after a positive HCV diagnosis. The major themes are presented within the social-ecological framework: patient-level, provider-level, healthcare system-level, and structural level. Appendix B provides a social-ecological model of the barriers and facilitators to engagement in HCV care.

Patient-Level

**HCV Beliefs.** Participants indicated that patients’ beliefs about the severity of HCV infection, influenced their decision to engage in care. More specifically, participants expressed that patients believed HCV was not serious, specifically due to the asymptomatic nature of the
disease. As expressed by one provider “Some people come in and you know are nonchalant they said it's not hurting me so apparently, I must be fine.” (Lead Infectious Disease Physician, 15 yrs). Another provider stated, “I am going to say it's more like some of the patients don't really think it's really. They don’t' believe that it could get really bad.” (ID Care Coordinator, 5 yrs).

Participants expressed educating clients on the effects HCV, but many still do not believe it’s a major concern as indicated by the following statement “You are talking to them you are explaining to them the risks and what to do and what not to do. Either they don't understand it, or they are not engaged…they just really and truly not caring.” (ID Care Coordinator, 5 yrs)

Additionally, participants noted that some patients are fearful to find out the severity of their disease provider indicated “I think also, some people know that it's serious and don't want to know where it is with them. Like they're not necessarily feeling anything, or they are starting to feel impacts of reduced liver function. It's like they're tired or things like that, they, they're a little bit scared to find out more, and to find out what damage is irreversible.” (LTC Coordinator/Patient Navigator, 2 yrs)

Conversely, some participants stated that the deadly nature of the disease is a motivating factor for engagement in HCV care. One provider said “…just having that diagnosis, sometimes people, just being afraid, just being scared. Sometimes those are strong motivating factors. Knowing that sometimes Hepatitis C can lead to cirrhosis of the liver, to liver cancer, sometimes leading to death, the potential of needing a transplant. Sometimes those are motivating factors to wanting to get treated early.” (LTC Coordinator/Patient Navigator, 2 yrs). Another provider added “People are very afraid they’re very anxious, they think that they may immediately die from the disease.” (Lead Infectious Disease Physician, 15 yrs)
Participants also noted that patients believe viruses cannot be cured, thus making HCV incurable. One provider expressed “Because they think…like you can't cure viruses. We can't cure this one…there's a lot of conspiracy theories. Why have they been able to do this with hepatitis C and not HIV? And you kind of have to explain why it's a different virus and you know, it works differently. That's why we can treat this one.” (NP/Associate Professor, 30 yrs) Another provider stated “So many folks have had it for so long, without thinking that a cure was accessible. There are some people who are just like, yup, I'm going to die., which is, I think, really disheartening.” (LTC Coordinator/Patient Navigator, 2 yrs)

Participants also believed that the patients are hesitant to engage in care because of the beliefs about the side effects of treatment, particularly those beliefs related to the old standard of care. One provider described his experience working during the old HCV therapy era. As shown in this statement “At an organization I worked with many, many years ago, we were treating hepatitis C with interferon, high dose. I've had some experience working with patients, you know, back in the olden days, where they received interferon three times a week and were sick as a dog and had very little success rate.” (Senior Pharmaceutical Sales Executive, 5 yrs) Another provider expressed, “I definitely get a lot of questions from people who have heard like interferon horror stories. Am I going to be really sick? Like is this going to take forever. I think there is a lot of fear about side effects and being really intense on the body that comes from past medication regimens.” (ID Care Coordinator, 5 yrs)

**Drug Use and Mental Illness.** Participants indicated that current drug use and mental illness are significant barriers to HCV care. Furthermore, participants described difficulties with retaining in care patients who are using substances. For instance, one provider expressed, “We have a lot of people that come in here, either they have had some alcohol or drugs, and you can
smell it… I explain to them what Hepatitis C is and the damages that it can cause. You know we do the fibro scan. I emphasize the importance of getting an ultrasound done and they still are just, it’s kind of hard to keep up with those patients.” (ID Care Coordinator, 5 yrs) Another provider stated, “We will have patients that are actively using drugs and sometimes when they’re actively using drugs and the drugs have really caused them to become nonfunctional pertaining to taking care of themselves as well as keeping a job, then that can act as a severe barrier for that person, who uses drugs and who’s addicted.” (Lead Infectious Disease Physician, 15 yrs)

Additionally, participants perceived that mental illness makes it challenging for patients to engage in care for HCV. One provider expressed “I find that I want to say about 60% of our patients they have some type of mental issues and that is also a barrier. That you know because the patients are not really quite there. It is challenging for them to keep up. They can only absorb so much. They can only do so much.” (ID Care Coordinator, 5 yrs) This provider also mentioned that some patients with mental illness are committed to care, but they lack the support they need to succeed. As indicated by the following statement “We do have some patients that despite their, their illness they try, and they are very committed to getting their treatment, they're very committed to doing what the doctor asks them to do. However, we do have some that they have mental problems and they do have supposedly a worker that helps, but honestly, I don't see where, that support is really helping. (ID Care Coordinator, 5 yrs)

Participants also described difficult experiences keeping patients with mental illness engaged in care. One provider expressed, “I can't get back in touch with him. I have no idea how many pills he's taken…You know, and it's because of his mental illness. I have so many of my patients with hepatitis C that have significant mental illness. Look, those are the ones you remember, because that's the difficult ones. I've got a bunch of others who've taken treatment are
fine, cool, and great. But the ones that are really difficult are the ones who have these underlying mental illnesses.” (NP/Associate Professor, 30 yrs)

Transportation. Participants identified transportation as a major barrier to engagement in HCV care despite multiple care locations, as indicated by this statement, “We have to maintain the patients every six months, we have to do an ultrasound, we have to make sure that we are following these patients every two months, on a monthly basis, to make sure their platelets are good…Transportation plays a big part on a lot of these patients. Even when we were offering services at five different locations, transportation was a big issue for a lot of our patients.” (ID Care Coordinator, 5 yrs). Another provider expressed, “I think what is very important. If a person doesn't have transportation that can be a barrier.” (Lead Infectious Disease Physician, 15 yrs)

One participant mentioned that their facility provided transportation, but funds are limited. They stated, “We have a program here, where the patients, we can offer them transportation, we can offer a cab to pick them up and bring them home. There's only so much that we have in funds that we can only do it so many times.” (ID Care Coordinator, 5 yrs).

Instability. Participants mentioned that housing instability and food insecurity made it difficult for people to engage in care. One provider stated, “There are those competing things. Those social determinants of health, transportation, food, housing, sometimes those things can be competing issues. We see that a lot. So, yeah, we do have to compete with that.” (Lead Infectious Disease Physician, 15 yrs)

Additionally, participants discussed how other instability factors, such as not having a phone, made it challenging for patients to keep up with their HCV care. For instance, one provider expressed “I think across the board, for patients without phones, that kind of imposes a bunch of other barriers of not necessarily being able to use like lift, because they won't be able to
communicate the driver or know exactly like I can tell them the car is coming at 10 but they're not gonna know what kind of car they don't know like who the driver is. And just like having access to a clock, having access to reminders.” (LTC Coordinator/Patient Navigator, 2 yrs)

**Other Care and Supportive Services.** Participants indicated that seeking care for other ailments is a facilitator for engaging in HCV Care. As expressed by one provider, “To be honest with you, most of them have gone into care because they went in for something else...I haven't necessarily seen patients who came in specifically, I've got Hepatitis C, and I need treatment.” (NP/Associate Professor, 30 yrs)

Additionally, participants also mentioned that patients would be motivated to engage in HCV care as a means to access social support services, including case management and medication-assisted therapy for drug addiction. As one provider said, “Starting hepatitis C care, is kind of like what brings them into our system to start accessing other services, including case management, that's also a really big ask that people have, like, assistance with housing. And like food stamps, and other things that case management can help. But case management is only available for patients getting physical health care...Hepatitis C, it is kind of just the lowest hanging fruit. We do a lot of treatment for people who are interested in Suboxone, which is a service we provide as well. Okay, so there are a lot of folks who are like, I want to start Suboxone. And anything else we do, I'm here. But that's not like what brought them here.” (LTC Coordinator/Patient Navigator, 2 yrs)

**Desire to Get Well.** Participants mentioned that the patients’ desire to be cured was a motivating factor for engaging in HCV care. “I think for some folks, like getting hepatitis C cured is the biggest motivator, they're ready to be done with it ready to move forward and feel like they're in a place in their life where they have the stability to address that.” (LTC Coordinator/Patient Navigator, 2 yrs)
Navigator, 2 yrs) Another provider expressed, “I think that just about every patient that comes in, you know they are trusting that they will be cured. They all come with the hope and trust that the cure is going to be there.” (ID Care Coordinator, 5 yrs)

Additionally, participants discussed the desire to live as a motivating factor. As indicated by the following statement, “The fact that people come in and they want to live for their family, they have kids, they have family members that they need to be healthy for, so I think a lot of those things are motivating factors.” (Lead Infectious Disease Physician, 15 yrs) Another provider stated “Most of them have either had patients, had either had family or people that they personally know that passed away from cirrhosis or cancer, so they are a little afraid and pretty much, they want to live.” (ID Care Coordinator, 5 yrs)

**Provider-Level**

**Patient-Provider Relationships.** Participants emphasized the importance of the patient-provider relationship in engaging patients in HCV care. Providers discussed how stigmatizing attitudes, specifically due to drug-using behavior, with providers hindered HCV care engagement. As stated by this provider, “I think something that is a barrier before people, like, even reach out about starting care is just past experiences, negative past experiences with healthcare providers, usually around some combination of drug use…I think a lot of people who use drugs can feel really dehumanized by provider conversations.” (LTC Coordinator/Patient Navigator, 2 yrs).

Participants described how relationships built on respect, kindness, and compassion helped to facilitate engagement in Hepatitis C care. One provider said, “You know, I um, I think it's so important that we are empathetic to what the patient is going through. We have to be patient; we have to be knowledgeable of what we are telling the patients. (ID Care Coordinator, 5 yrs) This provider went on to say, “I think patients are looking, you know I find that a lot...they are not only
looking for respect, but they are also looking to be understood. To not be judged.” (ID Care Coordinator, 5 yrs).

Participants also discussed how a provider’s availability impacts engagement in care. Another provider stated, “I try to just be available for folks to kind of come back when they're ready to come back. So I've had patients who I've worked with for like a year and a half before they attended their first appointment. Because they weren't ready, they had other stuff going on, they weren't interested in starting care, maybe they did go to their first appointment, but they never actually took months. So we try to let people know that like, we're here for them, even if this kind of adherence doesn't end up happening right away.” (LTC Coordinator/Patient Navigator, 2 yrs)

Another provider discussed treating patients with respect and ensuring confidentiality as a way to make patients feel comfortable. As expressed by the following statement, “You know this is a doctor's visit. There is patient doctor confidentiality, we try to educate them.” (Lead Infectious Disease Physician, 15 yrs)

Heavy Workload. Participants discussed that the lack of staffing makes it difficult for them to do their part in facilitating engagement in care. One provider stated, “It would really be up to us, or up to me to call and make that appointment but sometimes I can’t because I am in clinic with Dr. X. There's only so much that I can move on my end but hopefully that's changing soon.” (NP/Associate Professor, 30 yrs) Another expressed “I mean, physicians are stretched very thin. And you know, not only physicians, but mid-level providers are stretched very thin today, they don't have the time to be on the phones with the insurance companies getting reauthorizations doing the initial prior authorization.” (Senior Pharmaceutical Sales Executive, 5 yrs)

Patient Education. Participants believed educating patients on HCV plays a critical role in facilitating engagement in HCV care. One provider said, “Believe it or not a lot of patients have
a lot of questions, um and I, I do my best and I feel that I am educated enough to go into details.” (ID Care Coordinator, 5 yrs) Another provider indicated, “We just try to get patients education and understanding about the disease, it's process, and then we try to figure out where they are in the stage of their disease and tell them what they should expect from treatment as well as management based upon their own personal evaluation with the disease.” (Lead Infectious Disease Physician, 15 yrs)

One provider expressed that providing HCV education to patients can be challenging due to the complicated medical jargon and the lack of understanding may serve as a barrier to care. As indicated by the following statement, “I think sometimes it's the terminology. Unfortunately, I don't know another way of RNA detected, or RNA not detected, or you need a viral load, you know. I believe the terminology we may use; they may not understand. I try to explain it the best I can. Unfortunately, I don't have another word for genotype Fibro scan, they get that fibro scan confused with an ultrasound. I'm like no, the fibro scan is just going to give us a number, an idea, but ultimately the ultrasound is going to give us a picture of the liver and what's in there. So, I want to say, it's not understanding the terminology.”

**Provider Support.** The provision of support specifically to those providers who lack knowledge about HCV care and treatment, was highlighted as an important factor to facilitate engagement in HCV care. Participants discussed ways of providing support through direct consultation or using via telemedicine. As one provider said “Dr. X, and Dr. X who's our infectious disease lead, and Dr. X who is our chief medical officer are all like really engaged in helping other providers, like navigate this treatment as well. And hepatitis C is pretty straightforward. Treatment path goes. So even for folks who might not have treated hepatitis C before, you definitely want all of our providers to feel empowered to embark on that care, and
know that they have a whole team behind them if they have any questions about best practice.”
(LTC Coordinator/Patient Navigator, 2 yrs). Another provider stated, “It's so easy. I mean, it
really is. So there's really not a whole lot of trouble…I think it's gotten to the point that if there
isn’t enough providers throughout the state…you can do telemedicine visit.” (NP/Associate
Professor, 30 yrs)

One provider believed it was their responsibility to educate providers on how to care for
HCV patients. They said, “My job is to educate providers and get people linked to care, give
appropriate treatment and improve access. So there's no barriers to care or treatment when we do
have an effective cure.” (Lead Infectious Disease Physician, 15 yrs)

Participants also described training and mentorship experiences, which improved their
HCV knowledge, and made them effective at providing HCV related services. One provider stated,
“When the highly active drugs first came out for Hep C, my boss at the time asked me, he says,
can you learn Hep C, and I learned it from the ground up. I spent many, many weeks in, in clinics,
you know, rounding with doctors and learning a little bit about it and, you know, going back and
going back and doing prior authorizations and taking classes getting CES, you know, etc.” (Senior
Pharmaceutical Sales Executive, 5 yrs) Another provider said, “It was mandatory for me to attend
at least four...what is it called...four different trainings. We read a lot on it. I used to attend every
study there was with Ochsner with different people, we used to do ECHO in Houston with Baylor
University. The training that I received, it has been great. It has been great, otherwise I would not
know what I know about that.” (ID Care Coordinator, 5 yrs)

**Provider Hesitancy.** Participants expressed that some providers are reluctant to treat
Hepatitis C, which may impact care for HCV patients. The reluctance of some providers to care
for HCV is due to the lack of confidence in their ability to treat patients. As indicated by the
following statement, “I think most providers are not willing. I just think that they're not It’s not what they want to do. And I think they're afraid if they open up that door, they're afraid of the some of the patients who are really difficult, and then they get frustrated because they couldn't fix it, because it's so fixable.” (NP/Associate Professor, 30 yrs) Another provider expressed “I think it really depends on the providers comfort, okay. Some of our providers who treat Hep C are not infectious disease doctors.” (LTC Coordinator/Patient Navigator, 2 yrs)

In contrast, participants perceived managing HCV infection as an “easy” process that any clinician should be able to handle. As stated by one provider, “It's so easy. I mean, it really is. So there's really not a whole lot...And so I try to communicate back to the provider like, this is really easy. You can do it yourself. You don't need to send them to me.” (NP/Associate Professor, 30 yrs) Another provider indicated, “You know, it's so easy these days. It's so easy, you know basically in many cases, a one pill, once a day regimen for 12 weeks. And most of our patients when they take this therapy, they don’t have any side effects at all. So, it's very, not just for me but for someone who may not even be specializing in infectious disease, treatment these days is so simple so easy, less side effects, very effective, that everybody should be confident, rather if you are board certified in infectious disease or not as far as treating this particular illness with the therapy that is out there now.” (Lead Infectious Disease Physician, 15 yrs)

**Healthcare System-Level**

**Care Coordination.** Participants expressed that care coordination is an integral part of facilitating engagement in HCV care. Participants described their role in coordinating care for patients, which usually included scheduling appointments, tracking lab assessments, and organizing transportation. “I like to have control of the schedule. I make sure that I schedule most of his appointments. I am going to say 95% of the time, I am the one scheduling the appointments.”
(ID Care Coordinator, 5 yrs). Another provider stated, “I coordinate transportation for people who
need a ride into the building to access care, and they might have other health care requests that I'm
helping coordinate as well. So on those kind of avenues, I'm like working with providers and
patients to get folks into appointments.” (LTC Coordinator/Patient Navigator, 2 yrs)

Participants also discussed having staff on site, who’s primary role was to coordinate care
for patients. Specifically, their role was to assist with the Medicaid and the therapy approval
process. One provider stated, “something that has been really amazing in the work that I do is that
we have people on site who do Medicaid applications with clients. So if someone is eligible for
Medicaid, but isn't enrolled, they can just apply and we'll have an eligibility specialist who walks
them through the application and is able to see when it is approved, or to help with any additional
documents. So that's been really helpful.” (LTC Coordinator/Patient Navigator, 2 yrs) Another
provider expressed, So, you know we have a team, we have a team that works within our our
facility that helps people get connected to Medicaid if they qualify for it. If they don't qualify we
have our team, or infectious disease team who will help that person get on a patient assistance
program to help get them their medication for free.” (Lead Infectious Disease Physician, 15 yrs)
Moreover, a provider emphasized that the care coordination process is important, since the process
is difficult for some patients to navigate. “A lot of people, like I said, the population that we serve
are people that maybe didn't get an education, or they just don't know how to get around the system.
So, it's very difficult for them to say, okay, I am going to call, I am going to apply for Medicaid,
or I am going to call and get you know, I am going to go ahead and bring you the paperwork.” (ID
Care Coordinator, 5 yrs)

Patient outreach was identified as an important part of care coordination. Participants
described experiences of consistently reaching out to patients to get them in care. As indicated by
this provider, “I want to say it's persistence, because although you may call them three times, send letters, we continue to monitor them. Patients that were loss to follow up back in 2016, you know, they may get a phone call. Hey, you know, I am calling back from whatever… I try to encourage them to seek treatment…we are starting to see a lot of our old patients coming out.” (ID Care Coordinator, 5 yrs) Another provider stated, “You know Ms. X helps out with that, what she does, she has a log of everyone who has tested positive, who needs access to therapy. Often times she will reach out to those particular patients right there in our facility, when other providers find people who are positive, they know to refer to us so that we can get them on therapy. So the newly diagnosed are referred, those out of care, we have a patient care coordinator who tries to reach out to them to get them back into care so they are treated and cured.” (Lead Infectious Disease Physician, 15 yrs)

Supportive Services. Participants expressed that providing supportive services, such as transportation, medication delivery, and other social services positively impacted engagement in HCV care. One provider stated “We try to have other structures in place to try to combat that. You know if there is some food insecurity, we have social workers who can help connect that person to a food. And having housing issues a social worker will try to help get that person in placements. if there's transportation issue, if a person has Medicaid, Medicaid will actually help get that person to the appointment. We try to eliminate a lot of those competing factors so that we can make sure we take care of the health of the patient.” (Lead Infectious Disease Physician, 15 yrs) Another provider said, “Usually, medications are mailed to the patient. So it's really, fairly easy. (NP/Associate Professor, 30 yrs)

Additionally, participants expressed that the provision of mental health services is important to facilitate engagement in care for patients with mental illness. One provider expressed
I think accessing like behavioral health support is important…frequently one of the top healthcare goals for patients, and sometimes is a bigger healthcare goal, for hepatitis C care. And so we have as FQHC, we can offer like therapy and psychiatry.” (LTC Coordinator/Patient Navigator, 2 yrs) Another provider said, “We are federally qualified health care center, but we provide comprehensive care. So, we do primary care, infectious disease care, we also do mental health care. We have psychiatrists, psychologists, Licensed clinical social workers. So even though I am treating Hepatitis C, if I see that there is mental health care that needs to be done with that patient, it's a matter of me going right down the hall doing a warm handoff and referring that patient to mental health care.” (Lead Infectious Disease Physician, 15 yrs)

Despite the extreme need for mental health services, participants emphasized that the lack of services in the area made it challenging to care for patients with mental illness. As indicated by this statement, “We don't have the resources to treat them. But he needs to have someone go to his house and do mental health services. There's nobody around to do that.” (NP/Associate Professor, 30 yrs) Another provider stated, “That system is pretty overburdened, as I think most places in the city that accept Medicaid are not there. So, I can do, I can make some limited counseling sessions available, but it's not as robust as I would hope. And that as patients are potentially looking for.” (LTC Coordinator/Patient Navigator, 2 yrs)

**Clinic Environment.** The clinic environment was identified as having a major impact on facilitating engagement in HCV care. Participants discussed how a toxic clinic environment will make patients feel uncomfortable and less likely to come in for care. One provider described an experience of a patient who was the source of ridicule and judgement upon entering the clinic. “I had a client who, like, she was like using the bathroom and taking like a long time. And the nurse said to like another staff member, like unknowingly in my earshot, some like really disrespectful
things about her like, calling her a junkie, assuming that she used heroin, even though he had not met the patient yet and done any, like drug history with her. So it's like you don't know if this is drugs, you don't know what those drugs are like, these are assumptions you're making based on her appearance. You feel comfortable saying this… you as like a white male nurse about this, like black woman you have just met based on her appearance and taking a long time to go to the bathroom.” (LTC Coordinator/Patient Navigator, 2 yrs)

Participants emphasized that patients should feel safe and comfortable when coming in for care. One provider said, “Being kind of like the first stop for a lot of folks, just with her schedule, availability, she is really amazing and has very, like strong standards for how everyone is interacting with her patients. And when we were in the building in person, she also practices the way our X building setup is that the waiting room and lobby is in a different space that's a little more private, a little like, it feels more comfortable in a lot of ways.” (LTC Coordinator/Patient Navigator, 2 yrs) Another provider stated, “We try to create an environment where they can be honest and share what they are doing and let them know this is a safe zone. You know, we are not going to, of course, discriminate against them in any type of way.” (Lead Infectious Disease Physician, 15 yrs)

One participant expressed the importance of a supportive team, not just the individual, in ensuring patients feel safe and comfortable in the clinic space. This provider said, “Strengthening the entire agency to show up like that. Definitely is like the biggest goal moving forward…No matter how great their patient navigation experiences or their doctor experiences, if a nurse is shitty, the front desk is mean, like that minutes of negative interaction can just unravel so much.” (LTC Coordinator/Patient Navigator, 2 yrs)
Facility Protocol. Participants described procedures at their facility that helped to make
the process of HCV care easier for patients. Specifically, participants described the ease of
rescheduling and quick appointment turnarounds. As said by this provider “We try to make things
as easy and accessible as possible. If a patient has missed a visit, we try to get them in, within a
week's time if they want to reschedule. So, when we see that a person really wants to be treated
for Hepatitis C and the opportunity door is there. We try not to close that door. We try to get people
in as soon as possible.” (Lead Infectious Disease Physician, 15 yrs)

Additionally, participants mentioned making accommodations by allowing telehealth visits
and walk-in appointments. As indicated by one provider, “To making sure the patient is following
up with, you know, their appointments, their bloodwork, with many patients we have even
attempted to, ok, you are having difficulties getting to the clinic, let's do a telephone visit.” (ID
Care Coordinator, 5 yrs) Another provider said, “So if they start and then stop taking it, and we
can't get in touch, like you can, especially before COVID, like walk-in, we'll get you resituated.”
(LTC Coordinator/Patient Navigator, 2 yrs)

Addressing burden of the requirements for HCV care was identified as one way a facility
aimed to improve engagement in HCV care. Participants described the difficulty patients had with
keeping up with the multiple appointments and required labs. As indicated in the following
statement, “So something I am seeing with patients who are transferring from other facilities
specifically, is that the providers at those facilities are still requiring a lot of testing and lab work.
Sometimes sobriety requirements before the patient can even start hepatitis C care. I actually had
a patient who works at X transfer her care out of X to us because she felt that the testing burden
was essentially a waste of her time, which we also believe, which is why our process is really
different. And that has been the barrier people are having at X as well. It's like fibrosis screenings
being required, like very frequent lab work.” (LTC Coordinator/Patient Navigator, 2 yrs) This provider went on to describe a rapid care process that their facility implemented to eliminate those barriers:

“Well, we our goal is to have like beginning labs, and that first appointment for patients who might have more complicated health care needs their second appointment two weeks later. So this is either for patients who have multiple chronic health things going on or just need more like emotional support in the process. In that case, they would do a two-week appointment. And then everybody does a one-month appointment. So there's first appointment one month appointment and end of care appointment. And for patients having concerns about their medication or more questions who need more support, those can be more frequent. But it's really the bare bones of it is that three appointments structure...we would get labs at all three of those appointments.” (LTC Coordinator/Patient Navigator, 2 yrs)

**Structural-Level**

**Accessibility of Treatment.** Participants expressed that improvements in HCV treatment accessibility has facilitated engagement in care. Participants reflected on the difficulties patients encountered in the past accessing treatment due to the high cost and rationing restrictions. One provider said, “When the highly active agents first came out, it was much more difficult to get those to go through, because it was a new process. The insurance companies were putting their hands up because of the cost of the medications.” (Senior Pharmaceutical Sales Executive, 5 yrs) Another provider said, in the five years that I have been doing it, at first it was the medications. Because the price is so high, it's ridiculously high.” (ID Care Coordinator, 5 yrs)

Moreover, participants emphasized that the implementation of the subscription model has made accessing treatment for patients with Medicaid much easier. As indicated by the following
statement, “Because it was so expensive, many of our patients who were on Medicaid could not receive treatment unless they were having severe stages of the disease. I think in the past that was really barrier to care, the finance, the cost of the medication but because of the new subscription model through Medicaid, uh the access to treatment is a lot easier.” (Lead Infectious Disease Physician, 15 yrs) Another provider added, “In some areas, such as Louisiana, because they do have that subscription model to pay for the therapy… Medicaid was always the absolute hardest, just to get approved. It went from night and day in Louisiana, because, you know, we went from not being able to get anything approved to everything just going through with the subscription model.” (Senior Pharmaceutical Sales Executive, 5 yrs)

In addition to the subscription model, participants expressed that patient assistance programs have made accessing HCV treatment possible for people who may not have Medicaid. As indicated by the following statement, “It is a little challenging for the people that don't have Medicaid… I think that for those patients that cannot get Medicaid or don't have Medicaid, we need to make it a little easier for them to be able to qualify for the patient assistance program.” (ID Care Coordinator, 5 yrs) Another provider stated, “Now everyone once in a while we will get patients that don't have any coverage at all. They don't have private they don’t qualify for Medicaid. Well Gilead has their patient assistance program who will help patients get those medications for free if they don't qualify for Medicaid and they don't have private insurance. So most if not everybody that comes through our facility with a diagnosis of Hepatitis C is able to have access to therapy.” (Lead Infectious Disease Physician, 15 yrs)

Participants reported that the ease of treatment reimbursement restrictions has helped to facilitate engagement in HCV care. One provider stated, “There were many obstacles put up in the past, whether it be a patient who doesn't have advanced disease, they wouldn't treat, or if a
patient had alcohol abuse, they wouldn't treat. They were requiring a specialist to write the prescription; a lot of those requirements have been lifted with the therapies becoming more common.” (Senior Pharmaceutical Sales Executive, 5 yrs)

**Discrimination.** Imbedded discrimination against drug-using behavior, race, and housing status was identified as a major barrier to engagement in HCV care. As indicated by the following statement, “It is innate, and they don't, they don't see it. And it's because it's the way they have been trained. And they have never learned anything else. It is an innately racist system.” (NP/Associate Professor, 30 yrs). Another provider stated, “So, people have had bad experiences in places like X and just like trying to start primary care. And we know that like across the board, there are a lot of like deep systemic issues in healthcare. Like low income, and like black and brown folks become uncomfortable with healthcare systems, and for the folks I'm working with, that is compounded with their experience as a person who uses drugs, and often their experience of being unhoused.” (LTC Coordinator/Patient Navigator, 2 yrs)

Additionally, participants discussed how “discriminatory” policies, such as criminalization of drug use, has hindered engagement in HCV care. As expressed by provider three, “There is a lot of fear and mistrust from a lot of my clients around accessing medical care. And not just that they think they need to be sober or abstinent from drug use to start treatment, but that they're just really worried that there will be like criminal repercussions for disclosing drug use to a provider. So, a lot of fear and mistrust. That keeps people from reaching out for any kind of health care.”

**COVID-19 Pandemic.** Participants emphasized that the COVID-19 pandemic affected the systems, which facilitated engagement in HCV care. Specifically, the increased use of telehealth appointments which made attending appointments easier. One provider said, “It can be an issue, with them physically coming to the clinic. but during the pandemic of 2020, what really helped us
out as far as engaging patients, and helping our patients become compliant with their healthcare visits is telehealth, telemedicine, you know if there's an issue with them…not being able to come into the appointments physically, then maybe we can turn that into a telehealth visit, that way they can keep their appointment for that particular clinic visit.” (Lead Infectious Disease Physician, 15 yrs)

In contrast, participants discussed how the pandemic negatively impacted some health systems that were in place, specifically as it relates to linkage to care programs for some of the most vulnerable groups. As stated by one provider, “Now because of the subscription model, Rebekah Gee, who is formerly the Health Secretary for the state, her whole negotiation was to get people treated and cured who have Medicaid and for the prison population also. Hopefully the entire prison population should be treated. Now, what put a halt to some of that was the pandemic, the COVID-19 pandemic.” (Lead Infectious Disease Physician, 15 yrs) Another provider stated, “So before COVID, and during COVID are looking a little bit different…Having every single step supportive resulted in like the best retention and care we could give. And I think COVID has broken that down a little bit in our ability to have all those pieces of the team together.” (LTC Coordinator/Patient Navigator, 2 yrs)

**HCV Awareness.** Participants discussed the lack of knowledge and expressed the need for increased HCV awareness. One provider emphasized that improving HCV awareness will help to facilitate engagement in care as expressed in the following statement, “I think the main thing is just letting people know that the access out there is available, and you know if a person has that diagnosis they should seek care, seek treatment, and you know, it should be very effective with curing the disease and I think people need to know that and that will continue to make a big difference in our state as far as eliminating Hepatitis C.” (Lead Infectious Disease Physician, 15 yrs)
Another provider expressed issue with the HCV health education campaigns. Specifically, the lack of messaging targeting people who use drugs. This provider stated, “There is a real fear and avoidance of addressing drug use in communities that inject drugs, when talking about Hep C, and kind of those marketing materials, those like flyers. There were some focus groups actually at X for our participants to give feedback on like Hep C cure marketing materials, once the Medicaid change happened. And patients were all just kind of like, yeah, I know it's cured. Like, I know, I can cure it. Like, that's not my question. My question is, can I currently inject drugs and get this treatment?” (LTC Coordinator/Patient Navigator, 2 yrs)

**Discussion**

Providers who hold various roles in providing HCV care and services were interviewed to understand better the factors affecting HCV care engagement. Our findings suggest that factors across all levels of the social-ecological model (i.e., patient-level, provider-level, healthcare system-level, and structural level) affect engagement in HCV care in the Greater New Orleans area. Consistent with other studies, this study identified significant patient-level barriers to HCV care, negative beliefs about HCV care and treatment, drug use and mental illness, lack of transportation, and competing priorities (Adams et al., 2018; Rogal et al., 2017; Trooskin et al., 2020). The providers also identified patient-level facilitators including gaining access to other care and supportive services and the desire to be cured and live.

The study findings also indicate that provider-level barriers, including heavy workload, provider hesitancy, and negative relationships with patients, hinder HCV care engagement. Previous researchers have reported similar results regarding the impact of the patient-provider relationship and reluctance to treat Hepatitis C (Bass et al., 2018; Rogal et al., 2017). Our study found that providers feel their workloads, do not allow them time to complete tasks which will
facilitate engagement in HCV care. This finding adds to the growing evidence on provider-level barriers from the HCV care provider perspective as research is limited on this outcome. Similar to other studies, providers in this study identified providing patients with HCV education as a facilitator of engagement in HCV care at the provider level (Bass et al., 2018).

In line with other researchers, a toxic clinic environment was a significant barrier that providers discussed at the healthcare system level (Zuckerman, Carver, & Chastain, 2018). HCV care providers also identified structural-level facilitators, including care coordination, providing supportive services, including mental health services, and accommodating facility procedures as having a positive effect on HCV care engagement as reported in other studies (Falade-Nwulia et al., 2019; Litwin et al., 2019; Masson et al., 2013; Trooskin et al., 2020).

At the structural level, the improvement in HCV treatment accessibility due to the “Netflix” subscription model to pay for treatment and ease of insurance reimbursement restrictions was highlighted as a significant facilitator of engagement in HCV care, particularly among Medicaid enrollees. This study is the only one, to my knowledge, that has reported a real-world positive effect of the “Netflix” subscription model on engagement in HCV care from the provider perspective. Structural discrimination, lack of HCV awareness, and the effects of the COVID-19 pandemic hindered engagement in HCV care. These findings, specifically those related to discrimination and the lack of HCV awareness, are similar to other studies which reported factors influencing engagement in HCV care (Dowsett, Coward, Lorenzetti, MacKean, & Clement, 2017; Masson et al., 2020). To my knowledge, this study is one of the first to report on the effects of the COVID-19 pandemic on HCV care engagement.

To date, this study is one of the few to report from the providers’ perspective of the barriers and facilitators to engagement in Hepatitis C care during the DAA therapy era. The
COVID-19 pandemic and change in healthcare facility protocols, affected recruitment for this study. Though the sample size is small, HCV care providers were purposefully selected to ensure the views of critical providers are represented in the study. In conclusion, we identified many important multi-level factors that affect engagement in HCV care. HCV care providers proved to be an essential resource for information regarding the barriers and facilitators to engagement in Hepatitis C care. Including the provider perspective is imperative for the development of effective HCV care engagement policies and interventions.
References


Appendix A

Table 1: Participant Characteristics

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<th>Participant No.</th>
<th>Job Title</th>
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Appendix B

Social-ecological Model of the Barriers and Facilitators of Engagement in Hepatitis C Care from the Perspective of the Provider
Chapter 6: Conclusion

Summary of Findings

This study provided a better understanding of the perceptions regarding barriers and facilitators to linkage and retention in Hepatitis C care. Additionally, this study identified effective strategies to enhance engagement in Hepatitis C care. Patients and providers agreed that patient-level factors, including other pressing issues (i.e., comorbidities, social services), HCV knowledge and beliefs, and the desire to get healthy, help facilitate engagement in Hepatitis C care. Furthermore, the study found agreement among patients and providers regarding patient-level barriers to care, including instability factors and transportation. Though patients and providers discussed drug use during the interviews, there was a difference in the drug use context. For instance, patients in this study discussed drug use as the top priority and chose not to seek care until they were ready to stop doing drugs. In contrast, providers discussed drug use in the context of adherence and the ability to understand health and care processes after having engaged in care. Both groups discussed drug use as being a cause for discrimination when trying to seek healthcare. At the patient level, patients' perceptions differed from providers in reporting that signs and symptoms, peer and family influences, social support impact the decision to seek care. Providers expressed that mental illness was a significant barrier to engagement in care, which was not discussed among patients.

Both patients and providers believed that negative patient-provider relationships were a significant barrier to engagement in HCV care at the provider level. Providers and patients both discussed the need for patients to feel accepted and respected during their interactions with providers. Provider education was discussed during interviews with both patients and providers stating that provider education impacted HCV engagement in care. However, although patient education was expressed as a factor in HCV interviews among providers, dissimilar to patients,
providers did not note their lack of effort in providing patient education. One finding identified during the patient interviews was the providers' lack of concern or urgency about a positive Hepatitis C diagnosis. Providers did not reveal this attitude during their interviews. Though providers in this study felt confident in their own ability to treat or care for persons with Hepatitis C, they stated that provider hesitancy as a barrier to HCV care. Additionally, providers emphasized that a heavy workload made it difficult for them to assist patients with coordinating their care or navigating them through the system.

At the healthcare system level, both patients and providers believed that an inviting experience while seeking healthcare is imperative to facilitate engagement in care. Patients reported feeling unaccepted and discriminated against while seeking care, and many reported negative experiences with care providers in the past. Providers added that it's essential the clinic space be inviting and comforting for patients for successful care engagement. Accommodating facility protocols and supportive services, including mental health services and care coordination, were believed to be vital to successful HCV care engagement for both patients and providers. Patients differed in their perceptions by noting that barriers at the structural level included fragmented health care services served as barriers to engagement in care. Providers did not discuss these factors during their interviews.

At the structural level, providers and patients agreed on all but one factor. Providers noted that the COVID-19 pandemic impacted care engagement both positively and negatively. Whereas patients did not express that the COVID-19 pandemic had an impact on HCV care engagement. Figure 1 shows the comparison between patients and providers.
<table>
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<td>Instability factors</td>
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The study findings suggest significant improvement in HCV care engagement, primarily due to the increased accessibility to the new DAA therapy. However, despite this improvement in accessibility, major systemic issues persist, which continue to make HCV care challenging for some of the most vulnerable. Moreover, the findings demonstrated that HCV knowledge and awareness are low in the community. Patients reported not knowing enough about HCV and the associated care and treatment. Additionally, patients who injected drugs believed they needed to be off drugs before starting treatment; some reported being told by their providers. Research supports successful HCV treatment in people who inject drugs, with studies reporting high adherence and cure rates comparable to people who do not inject drugs (Eckhardt, Scherer, Winkelstein, Marks, & Edlin, 2018). Patients believed that widespread awareness campaigns would improve engagement in HCV care. Researchers have reported positive effects of widespread awareness campaigns improving knowledge and dispelling misconceptions of disease prevention, care, and treatment, thus, facilitating engagement in HCV care (Helsper et al., 2017). One key finding of the study was the revelation that HCV campaigns were void of
messages which specifically addressed care and treatment in people who inject drugs. Studies have demonstrated that to be effective; health officials should tailor health awareness campaigns to the target population (Helsper et al., 2017). A one-size-fits-all approach does not work. Effective HCV awareness campaigns must include targeted messages for PWID and their providers to increase knowledge of HCV care and treatment PWID to stop the spread of HCV (Helsper et al., 2017). Specifically, health education should dispel the myth of having to be clean or sober in order to start treatment and be cured.

This study revealed that discrimination, particularly against PWID, permeates the system from the structural to the patient level, serving as a barrier to engagement in HCV care. Providers reported that housing status and race compound some patients' experiences of discrimination. Patients perceived that they would be discriminated against due to their drug-using behavior and positive HCV status. Additionally, patients feared disclosure of disease status and injection drug use, and delayed care. Several researchers have reported on the detrimental effects of negative societal perceptions surrounding stigmatized behaviors (e.g., injection drug use) and stigmatized conditions (e.g., HIV, HCV) on engagement in care (Muncan, Walters, Ezell, & Ompad, 2020).

Study participants highlighted the unwelcoming feeling of traditional healthcare facilities and being mistreated when seeking care. Several studies have reported that experiences of institutional discrimination were associated with poorer health outcomes, including reduced engagement, among people who inject drugs, racial ethnicities, and the homeless (Couto et al., 2020). Participants in this study reported having experienced stigmatizing attitudes from providers and did not engage in HCV care to avoid those negative experiences. Researchers have reported the importance of the patient-provider relationship in facilitating engagement in HCV care (Falade-Nwulia et al., 2019; Trooskin et al., 2020).
Both providers and patients expressed the detrimental effects of societal discrimination on engagement in HCV care. The media and political context shape societal perceptions. The promotion of negative perceptions and stereotypes of PWID in the media and criminalization policies against drug use continue to fuel discrimination against people who inject drugs. Thus, hurting HCV engagement in care. Raising awareness and understanding about HCV would help to reduce the stigma surrounding the disease. Additionally, implementing policies that employ harm reduction and drug rehabilitation instead of criminalizing drug help to change societal perceptions surrounding drug use and people who inject drugs (Muncan et al., 2020). With rates of HCV infection among PWID are steadily rising it is essential that public health efforts target PWID to reduce the burden of HCV (Ryerson et al., 2020).

Providers expressed that mental illness was a significant barrier to engagement in Hepatitis C care, and supportive services, such as mental health care, were crucial to ensuring successful engagement HCV care. There's a high prevalence of mental illness among persons living with Hepatitis C, particularly those with substance abuse issues (Spradling et al., 2018). Several studies have reported mental illness as a barrier to linkage and retention in Hepatitis C care (Spradling et al., 2018). The provision of mental health care services would help to improve engagement in Hepatitis C care (Spradling et al., 2018; Yarlott et al., 2017). Despite this fact, providers emphasized the inadequacies of Louisiana's mental health care system, making it difficult for them to provide the care that some of their patients needed. Providers highlighted the inadequacies in the mental healthcare system. Louisiana ranked 45 in the nation for mental healthcare in 2020 (Mental Health America, 2020). Limitations in the mental health care system have been attributed to structural racism and stigmatization of mental illness, resulting in health care cuts and the closing of mental health institutions.
Additionally, the study highlighted the lack of an efficient linkage to HCV care programs for incarcerated and recently released individuals. The majority of patients reported a history of incarceration, with many of them have expressed that they did not receive treatment while behind bars. Also, these patients reported that they did not receive any information regarding HCV care and treatment and had to navigate the healthcare system themselves, causing a delay in care. This information is concerning due to the high rates of HCV among incarcerated persons. HCV prevalence in the correction facilities is 10 times that of the general population (Akiyama, 2020). Studies have reported the necessity of effective linkage to care programs for incarcerated populations to reduce HCV burden in this group and prevent loss to follow-up upon release (Zampino et al., 2015). In the past, funding for these programs was limited, making access to HCV treatment difficult. However, in Louisiana, the proposed implementation of the Netflix model in correctional facilities, is expected to improve access to HCV care treatment for all people, including those that are incarcerated. It’s imperative that systems are put into place to ensure efficient execution and that it reaches all that are incarcerated.

**Evidenced-Based Recommendations for a Comprehensive Model to Facilitate Engagement in HCV Care in the Greater New Orleans Area**

The findings of this study highlight the complex interplay between factors at the patient, provider, healthcare system, and structural levels that influence engagement in HCV care. Based on these findings, evidence-based recommendations utilizing a multi-level approach to facilitating engagement in HCV care were developed. These recommendations aim to address the social conditions, healthcare system, provider, and patient factors to improve engagement in HCV care in the Greater New Orleans area. The list of recommendations are found below:

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**Evidence-Based Recommendations for a Comprehensive Standard of Care Model**
• Advocate for the continued support of sustainable policies, which increase accessibility to HCV care and treatment for all, including correctional facilities (Littlejohns, Smith, & Townend, 2019; Pollack Porter, Rutkow, & McGinty, 2018)

• Advocate and support policies to prioritize mental healthcare by increasing funding and creating more mental health infrastructure. (Littlejohns et al., 2019; Pollack Porter et al., 2018)

• Advocate for and support policies for the decriminalization of drug using-behavior and implement harm reduction and drug rehabilitation strategies (Muncan et al., 2020)

• Scale-up HCV awareness campaigns, specifically targeting PWID
• Messages should target high-risk groups and inform of treatment success in PWID
• Tailor health education materials to specific target groups, especially PWID and involve PWID in the design and evaluation of health education materials (Helsper et al., 2017)

• Implement care coordination and patient navigation upon release of people from jail or prison (Akiyama et al., 2019)

• Utilize a multi-disciplinary approach to care. Care teams should include case management to identify and address social needs (i.e., housing, food, transportation), behavioral health practitioner, care coordinator, peer navigator, and pharmacist (Boodram et al., 2020; Ford, Johnson, Desai, Rude, & Laraque, 2017; Masson et al., 2013; Naidjate et al., 2019)
• Implement long-term outreach program for patients who are loss to follow-up (Webster et al., 2020)
• Utilize financial incentives to encourage engagement, if resources allow (Norton et al., 2019)

• Integrate HCV care into non-traditional healthcare settings (harm reduction centers, medication-assisted therapy facilities, homeless shelters) (Adamson et al., 2020; Burton, Voluse, & Anthony, 2019)

• Adopt accommodating facility protocols, such as easy rescheduling and telehealth appointments (Khoja, Ali, & Feroz, 2021)

• Build HCV care and treatment capacity of healthcare providers by task shifting, training all relevant staff on HCV care and treatment process, and implementing Project ECHO, telementorship with HCV specialists (Beste et al., 2017; Kattakuzhy et al., 2017)

• Implement mandatory cultural competency training for all facility staff, not only those that provide direct HCV care services. Cultural competency training should include firsthand experiences from stigmatized groups, especially PWID (Bielenberg, Swisher, Lembke, & Haug, 2021)

• Adopt a patient-centered communication approach (B. Q. Tran, 2021)

**Future Research**

The findings of this dissertation highlight a number of areas for research. The systematic review identified best practices for linkage to and retention in HCV care; however, the availability of quality studies eligible for the review was severely lacking. Future studies should evaluate linkage to and retention in HCV care strategies, specifically those targeting PWID,
homeless, and incarcerated populations, utilizing more rigorous methods. Moreover, future research should determine the extent that state and local institutions incorporate best practices to facilitate engagement in HCV care, in the Greater New Orleans area.

Additionally, this study sample was majority baby boomer age. The HCV epidemic is shifting, with chronic HCV cases exponentially increasing in younger age groups. Future studies should explore the barriers and facilitators to engagement in care among younger populations to inform the design of effective linkage to and retention in HCV care interventions targeting this group. Moreover, participants in the study expressed challenges with seeking care at correction facilities or upon release from prison or jail. Future studies should evaluate linkage to HCV care processes of correction facilities, identify gaps, and inform the design of more effective strategies to link to and retain HCV care. Lastly, future research should assess and develop standardized linkage to and retention in HCV care outcome measures to better inform on the effectiveness of interventions.

**Conclusion**

The Centers for Disease Control and Prevention has made the elimination of Hepatitis C a priority, by setting a goal to eliminate Hepatitis C by 2030 (CDC, 2020). Similarly, Louisiana has adopted a Hepatitis C Elimination Plan, which set an even loftier goal by aiming to eliminate Hepatitis C by 2024 (Louisiana Department of Health, 2020). There has been some progress in addressing Hepatitis C in the US with the decline of HCV prevalence. However, Hepatitis C remains a major health problem as the number of new HCV infections are increasing exponentially, especially among young people.

This study is one a few that has provided an in-depth understanding of the barriers and facilitators to linkage to and retention in HCV care during the new DAA treatment era. The
findings from this study revealed that despite notable improvement in DAA treatment access, systemic issues, continue to make it challenging for individuals to engage in HCV care. In order to make progress towards achieving the national and state HCV elimination targets, state and local institutions must adopt a multi-level evidence-based approach to address the barriers to engagement in HCV care.
References


