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## Social Networks, Stigma, and Hepatitis C Care among Women Who Inject Drugs: Findings from A Community Recruited Sample

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### Abstract

This study explores the role of perceived HCV stigma and social networks on HCV care among people who inject drugs (PWID) of both sexes, and solely among women who inject drugs (WWID). Data were from 269 HCV positive PWID, community-recruited through street-based outreach in Baltimore, MD. We defined HCV stigma based on participants' perceptions of treatment by others and their need to conceal their HCV status. Among WWID, HCV stigma was linked with decreased odds of undergoing liver disease staging (aOR = 0.33, 95% CI: 0.13,0.85) or to have attempted to get the HCV cure (aOR = 0.39, CI: 0.16,0.97), these associations were not evident in the overall sample with both sexes. Social network characteristics were significant correlates of HCV care in the overall sample, and these associations were stronger among WWID. WWID with more HCV positive social network members had higher odds of an HCV-related healthcare visit in the prior 12 months (aOR = 4.28, CI: 1.29,14.17) and to have undergone liver disease staging (aOR = 2.85, CI: 1.01,8.05). WWID with more social network members aware of the HCV cure were more likely to report an attempt at obtaining the HCV cure (aOR = 5.25,

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CI: 1.85,14.89). Our results suggest complexity in the role of social networks and stigma on HCV care.

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## Introduction

Advances in treatment have made Hepatitis C virus (HCV) infection curable for over 95% of infected patients with few side effects, yet HCV rates have increased three-fold in the United States (US: Ryerson et al., 2020; Zelenev et al., 2018). People who inject drugs (PWID), have HCV infection rates of 50–90% but are less likely to engage in HCV care than other individuals infected with HCV (Ryerson et al., 2020; Williams et al., 2021). Among PWID, women who inject drugs (WWID) are a smaller yet growing population, have unique social and economic conditions, and may face more barriers to HCV care compared to their male counterparts (Ryerson et al., 2020; Williams et al., 2021; Esmaeili et al., 2017).

For PWID, especially WWID, a significant barrier to HCV care engagement is stigma, the collective association of negative perspectives to behaviors or actions deemed unacceptable (Williams et al., 2021; Milne et al., 2015; Crapanzano et al., 2019). Stigma may manifest in three modalities: 1) social, reflecting the collective societal marginalization of a group of people according to a common behavior or characteristic; 2) self, or the individually internalized societal negative view toward a behavior or characteristic; and 3) systemic, which is the use of rules and regulations to negatively and disproportionately impact a group of people with a shared behavior or characteristic (Crapanzano et al., 2019, Livingston et al., 2011). While HCV treatment is recommended for all PWID regardless of current drug use, PWID may avoid health care systems due to systemic stigmas, such as refusals of care, internalized stigma, such as shame, and social stigma, including verbal abuse (Grebely et al., 2017; Norton et al., 2017; Ward et al., 2021; Biancarelli et al., 2019; Cunningham et al., 2018).

PWID, particularly WWID, navigate compounded stigma modalities, overlapping social disadvantage, and experience disparate access and engagement in health care (Williams et al., 2021; Leung et al., 2019; Grebely et al., 2017; Latkin et al., 2013a) and additional stigma due to substance use, gender, homelessness, and race (Shirley-Beavan et al., 2020; Medina-Perucha et al., 2019; Jones et al., 2019; Bowleg, 2012; Evans et al., 2018). Specific to substance use and gender, WWID are further stigmatized due to perceptions of drug use being antithetical to traditional caregiving roles, especially as parents (Meyer et al., 2019). In addition, WWID face marginalization due to gendered social norms within drug-using networks, as norms in drug-using networks dictate that males purchase, prepare, and administer drugs, leaving females with less control of drug-using behaviors (Shirley-Beavan et al., 2020; Medina-Perucha et al., 2019; Meyer et al., 2019; Iverson et al., 2017; Mayock, Cronly, & Clatts, 2015). The impact of the increased marginalized status of WWID have been linked with decreased access to harm reduction services, utilization of substance use treatment, have higher incidences of HIV, and have an increased need for associated services offered compared to their male counterparts (Staton et al., 2021; Larney et al., 2015; Iverson et al., 2017; Salleh et al., 2020; Meyer et al., 2019; Springer et al., 2015; Iverson et al., 2017).

While drug-using social networks may contribute to additional marginalization for WWID, overall, the social networks of PWID are an important factor in eliminating HCV (Latkin et al., 2013). Modeling data suggest that in social networks of PWID with an HCV prevalence 60%, treating 10% of network members annually would likely eliminate HCV among social network members within ten years (Zelenev et al., 2018). Furthermore, prior research indicates that having a social network member in HIV treatment increases HCV treatment utilization among HCV positive PWID; however, receiving HCV-related health information from a network member significantly decreases the likelihood of HCV treatment (Falade-Nwulia et al., 2019). This counterintuitive finding suggests that information shared within social networks may be mixed and may promote or dissuade certain health-seeking behaviors. While research indicates social networks and stigma can influence HCV-related behaviors, sex/gender differences in social network-related influences on HCV care needs further exploration, particularly how social factors differentially impact HCV treatment uptake. As such, this study evaluates the association of perceived HCV stigma and social network HCV characteristics on HCV care among PWID and specifically among WWID.

## Materials and Methods

### Study Overview

Data were from baseline surveys of 269 HCV seropositive PWID recruited (2016 – 2019) from impoverished neighborhoods in Baltimore, Maryland, through street-based outreach, advertising, and respondent-driven sampling (Dayton et al., 2019). Study participants were recruited for an intervention to increase access and adherence to HCV treatment. Our study location, Baltimore, MD, is ranked second in PWID per capita in the US, with this population having HCV rates of up to 80% (Keen et al., 2014); thus, respondent-driven sampling is effective for recruiting large samples of PWID. Moreover, antiviral treatment uptake among eligible PWID is low (Harris & Rhodes, 2013). As part of the intervention, recruited participants were connected with the Johns Hopkins HCV clinic for further testing and treatment. The eligibility criteria for this sub-study were being 18 years of age or older, a lifetime history of injection drug use, a positive HCV antibody test but never being cured of HCV, and informed consent. Participants who did not have a history of injection drug use, did not have an HCV seropositive test, reported ever being cured of HCV, did not meet other eligibility criteria, or could not provide informed consent were excluded from this study. Data were collected by trained research personnel through a combination of audio computer-assisted self-interviewing (ACASI) and face-to-face interviews on items about substance use, HCV status, HCV treatment utilization, and related issues. These interviews were approximately an hour in duration, and interview items have been used in multiple studies among PWID (Jones et al., 2022; Schneider et al., 2021; Dayton et al., 2019). All participants received remuneration of \$20 for their time, and all study protocols were approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

### Measures

**Perceived HCV Stigma:** Participants were asked, “Thinking about having Hep C, how much do you feel that you need to hide it?” (not at all, just a little, somewhat, very much)

and “How often do people behave negatively toward you once they learn about your Hep C status?” (never, rarely, sometimes, often). We created a binary stigma variable from these measures denoting participants’ perception of being stigmatized (somewhat/very much need to hide diagnosis AND/OR sometimes/often treated negatively). The perceived HCV stigma measure was adapted from previous drug use stigma items, which has been shown to have a strong internal consistency and predictive validity (Cronbach’s alpha of 0.93) (Latkin et al., 2010; Latkin et al., 2013).

*Any HCV Care* in the past 12 months Participants were asked, “In the past year, how many times have you seen a doctor about your Hep C?” (Recoded as any vs. no visits).

**Inability to obtain HCV treatment:** Participants were asked, “Have you tried to get the Hep C cure but have been unable to?” (Yes/No).

**Liver Disease Staging:** Participants were asked, “Have you ever had a liver scan? That is where they used a machine to assess the amount of damage to your liver.” (Yes/No).

**Social Network HCV Characteristics:** Participants were asked, “How many of the people that you know have ever tested positive for Hep C?” and “How many of the people that you know, know there is a cure for Hep C?” The items were dichotomized into half or more vs. less than half of the networks.

**Sociodemographic Characteristics:** We used self-reported biological sex (male/female), race (Black/White), age, homelessness (yes/no), educational attainment (less than high school, high school/GED, some college+), health insurance (yes/no), employment status (unemployed/employed), and relationship status (in a relationship/single).

## Statistical Analyses

Our analytical sample included N=269 HCV seropositive PWID who reported on HCV care items. We excluded participants who were ever cured of HCV, those who reported their race as other than Black or White due to small sample size (N=18), and those with missing race information (N=13). We used logistic regression to assess the relationship between HCV-related stigma, social network HCV characteristics, and HCV care, adjusting for sociodemographic characteristics. Using Stata 17, we examined correlates for going to HCV-related doctor’s visits in the past 12 months, ever undergoing liver disease staging, and being unable to receive HCV cure, using the overall sample of PWID, as well as specifically among WWID.

## Results

The mean age of our analytical sample was 47 (SD 10.5) (Table 1). Over a third of the sample were female (38%), and identified as White (41%), the majority self-identified as Black (59%), and nearly all had public or private health insurance (92%). Among our sample of HCV positive PWID, 49% had ever received liver disease staging, 36% had previously tried to obtain HCV treatment but were unable to, and 68% had an HCV-specific healthcare visit in the past year. Under half of the sample perceived being stigmatized due

to their HCV status (44%). Almost half of the participants' social networks were aware of a cure for HCV (49%), while less than half (43%) reported HCV infection in greater than 50% of their social networks.

The multivariable logistic regression model assessing correlates of HCV-related doctor's visits in the past 12 months (Table 1) revealed that having a greater proportion of HCV positive social network members increased the odds of engagement in care (adjusted Odds Ratio [aOR] = 2.26, CI: 1.24, 4.11). The association between HCV positive social network members and having an HCV-related doctor's visit appeared to be strengthened among females (aOR = 4.28, CI: 1.29, 14.17). We found that White PWID in our sample were approximately 70% less likely to have seen an HCV care provider in the past year compared to Black individuals when we assessed all PWID and when we assessed only WWID (Full PWID Model: aOR = 0.30, CI: 0.15, 0.58; WWID Model: aOR = 0.27, CI: 0.08, 0.91). We found no significant associations between HCV stigma and HCV-related healthcare visits.

Significant associations between HCV stigma, social network HCV characteristics, and liver disease staging were evident for WWID, though no significant correlates for liver disease staging were evident when assessing males and females concurrently. HCV seropositive WWID who reported perceived stigma were significantly less likely to have undergone liver disease staging (aOR = 0.33, CI: 0.13, 0.85) than WWID did not report HCV stigma. Being in a relationship was associated with being less likely to have undergone liver disease staging among WWID (aOR = 0.33, CI: 0.12, 0.95). WWID who reported HCV infection in over 50% of their social networks were nearly three times as likely to have undergone liver disease staging compared to those with lower proportions of HCV positive network members (aOR = 2.85, CI: 1.01, 8.05).

Lastly, results revealed that PWID who attempted but were unable to get the HCV cure had significantly greater proportions of their social networks who knew about the HCV cure (aOR = 2.58, CI: 1.42, 4.67); this association appeared to strengthen among WWID (aOR = 5.25, CI: 1.85, 14.89). Among WWID, older age significantly increased the likelihood of an unsuccessful attempt to obtain the HCV cure (aOR = 1.05, CI: 1.00, 1.12), while perceived stigma significantly decreased the odds of an unsuccessful attempt (aOR = 0.39, CI: 0.16, 0.97).

## Discussion

This study assessed the association between social network HCV characteristics, HCV stigma, and HCV care. Overall, care-seeking rates were suboptimal. Of particular concern is that 36% of participants tried to obtain the HCV cure but could not. Reasons underlying unsuccessful attempts to obtain the HCV cure were beyond the scope of this study; however, the inaccessibility of the HCV cure in the US and globally has been well documented (Ward & Mermin, 2015; Norton et al., 2017; Barber et al., 2020). Inaccessibility of HCV curative treatment is attributed to structural stigma in the form of past insurance requirements in the US, which required the cessation of drug use before HCV treatment (Martinello et al., 2017; Norton et al., 2017; Falade-Nwulia, Irvin, & Merkow, 2019). Furthermore, the lack of affordability of these drugs, with costs ranging as high as \$83,000 to \$150,000 per treatment,

has led to stringent reimbursement policies, contributing to inaccessibility (Ward & Mermin, 2015; Barber et al., 2020).

Among WWID, we found that having more HCV positive social network members was strongly associated with HCV care engagement. This finding may suggest that social support within a social network may attenuate the stigma of HCV care engagement. Contrastingly, WWID with greater proportions of social network members knowledgeable about the HCV cure, had increased odds of reporting an inability to receive the HCV cure. The former association suggests positive diffusion of information among network members, while the latter implicates structural barriers and systemic stigma, inhibiting receiving treatment. This finding shows promise that social network-based interventions may have the potential for positively impacting outcomes among WWID. Framing HCV-related treatment/interventions as a social responsibility, such as bringing peers along to get tested/treated, may be especially beneficial for females. Prior research has found that PWID whose friends/partners were concerned about their HCV were five times more likely to seek HCV treatment than those without concern from their support system (Falade-Nwulia, Irvin, & Merkow, 2019).

We also found that perceived HCV stigma was associated with a decreased likelihood of undergoing liver disease staging among WWID. These results suggest that the additional impact of HCV stigma, along with other forms of stigma (e.g., drug use stigma), that PWID face is complex--and may differentially impact behavior among sexes. We also found that among WWID, those who felt stigmatized because of their HCV had lower odds of unsuccessful attempts to obtain a cure. Because our sample was limited to PWID not cured of HCV, the likely explanation for this result is either WWID with perceived HCV stigma, compared to women who do not, are less likely to attempt to obtain the HCV cure or are currently on HCV medications. Strategies to reduce stigma include the utilization of harm reduction programs to test for HCV, developing public health awareness campaigns, increasing accessibility by providing integrated care, and reducing referrals to hard-to-access offsite care (Grebley et al., 2017; Milne et al., 2015; Cook et al., 2014). Furthermore, creating women-focused harm reduction sites and engaging with community groups that serve PWID may increase access and uptake of HCV treatment (Grebley et al., 2017; Milne et al., 2015; Cook et al., 2014).

In addition to social network characteristics and stigma, race and relationship status were linked with HCV care engagement. While White PWID of both sexes was less likely to report HCV-related visits, females in relationships indicated decreased odds of ever undergoing liver disease staging than their single counterparts. Our findings are comparable to those on other related infectious diseases such as HIV and stigma. Specifically, women living with HIV, who have worse clinical outcomes compared to men living with HIV, report multiple sources of stigma, particularly from healthcare workers, and its negative impact on their likelihood to engage in health services (Turan et al., 2019; Sangaramoorthy, Jamison, & Dyer, 2017; Knowlton et al., 2011). Moreover, women living with HIV and with partners have been shown to have worse clinical outcomes (e.g., adherence to antiviral medications) than women without partners (Knowlton et al., 2011). This finding parallels our findings that women with partners were less likely to have undergone liver disease staging than

women without partners. Our findings, along with the above studies, suggest couple-based interventions to improve the health outcomes of women who use drugs and have related infectious diseases such as HCV/HIV.

Our study should be contextualized within several limitations: the reliance on self-report data, the use of liver scans as a proxy for liver disease staging, cross-sectional study design, nonrandom sample, lifetime outcome variables, a smaller sample size of WWID, a limited measure of stigma, and while antibody tests reveal a history of HCV, it cannot delineate current HCV infection or reinfection. Furthermore, 15%–25% of HCV infections resolve spontaneously, without medical intervention, with newer data suggesting even higher proportions (Schillie et al., 2020). Despite these limitations, this study boasts a relatively large sample size of a community-recruited and highly marginalized population, the assessment of HCV-related stigma, and the often-overlooked sex-specific models.

Our findings underscore the importance of female-specific and social network-based interventions to increase positive outcomes for HCV infection, particularly among WWID. Such strategies include health services with a strong commitment to nonjudgmental approaches, reducing systemic treatment barriers, and engaging with underserved communities to increase awareness of treatment options within marginalized populations' social networks (Milne et al., 2015). Additional research on the complexities of HCV stigma modalities and their impact on HCV cure is needed.

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**Table 1:** Multivariable Logistic Regressions Predicting HCV Care among HCV Seropositive PWID

	N (%) or M (SD)	HCV Care (Yes: 180, 68%)		Liver Disease Staging (Yes: 114, 42%)		Unable to get HCV Cure (Yes: 97, 36%)	
		Full Sample (N=262) aOR (95% CI)	WWID (N=100) aOR (95% CI)	Full Sample (N=266) aOR (95% CI)	Females (N=100) aOR (95% CI)	Full Sample (N=266) aOR (95% CI)	WWID (N=101) aOR (95% CI)
Age	47 (10.5)	1.00 (0.96, 1.03)	1.00 (0.94, 1.06)	1.00 (0.98, 1.03)	0.95 (0.90, 1.01)	1.02 (0.99, 1.05)	1.05 (1.00, 1.12)
Female Sex	101 (38%)	1.45 (0.81, 2.59)	---	0.73 (0.43, 1.24)	--	1.47 (0.86, 2.55)	
Homeless	137 (51%)	1.09 (0.61, 1.95)	0.94 (0.34, 2.62)	1.03 (0.61, 1.75)	0.65 (0.25, 1.71)	1.16 (0.66, 2.02)	1.43 (0.55, 3.73)
Stigma	118 (44%)	1.25 (0.71, 2.17)	0.89 (0.33, 2.37)	0.77 (0.47, 1.28)	<b>0.33 (0.13, 0.85)</b>	0.95 (0.55, 1.62)	<b>0.39 (0.16, 0.97)</b>
Race							
Black	160 (59%)	REF	REF	REF	REF	REF	REF
White	109 (41%)	<b>0.30 (0.15, 0.58)</b>	<b>0.27 (0.08, 0.91)</b>	0.79 (0.43, 1.48)	0.34 (0.10, 1.23)	0.51 (0.26, 1.01)	0.80 (0.26, 2.45)
In a relationship	68 (25%)	0.85 (0.45, 1.61)	2.86 (0.88, 9.27)	0.56 (0.30, 1.02)	<b>0.33 (0.12, 0.95)</b>	1.26 (0.69, 2.33)	1.28 (0.49, 3.44)
Networks aware of HCV Cure	170 (64%)	1.22 (0.68, 2.21)	0.99 (0.35, 2.84)	1.08 (0.65, 1.78)	0.51 (0.19, 1.36)	<b>2.58 (1.42, 4.67)</b>	<b>5.25 (1.85, 14.89)</b>
>50% of Network HCV Positive	116 (43%)	<b>2.26 (1.24, 4.11)</b>	<b>4.28 (1.29, 14.17)</b>	1.20 (0.71, 2.04)	<b>2.85 (1.01, 8.05)</b>	0.93 (0.53, 1.63)	0.56 (0.21, 1.49)