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Correlates of Hepatitis C Serostatus Disclosure in Rural Appalachian Kentucky

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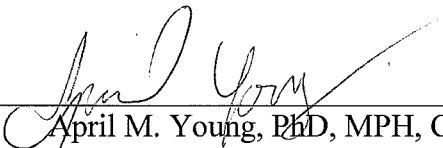
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CORRELATES OF HEPATITIS C SEROSTATUS DISCLOSURE IN RURAL
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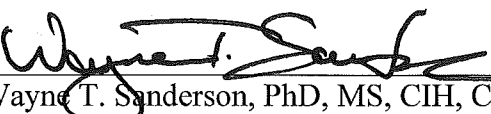
CAPSTONE PROJECT PAPER

A paper submitted in partial fulfillment of the
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Abstract

Aim: To identify demographic, behavioral, and interpersonal characteristics associated with hepatitis C (HCV) serostatus disclosure among adult, rural, high-risk people who use drugs (PWUD) in Appalachian Kentucky.

Methods: HCV antibody-positive participants (n=243), drawn from the fifth follow-up assessment of a longitudinal study of rural PWUD, completed interviewer-administered questionnaires eliciting demographic and interpersonal characteristics, risk behaviors, and information on HCV disclosure. Correlates of HCV disclosure were assessed using multivariate logistic regression.

Results: Most (69.1%) reported disclosing their HCV-positive status to at least one of their social referents (current or past sex partners, current or past injection drug use (IDU) partners, family, friends, or spouse), but few told the people with whom they inject drugs (3.8% disclosed to current, and 1.4% disclosed to past IDU partners). In multivariate analysis, adjusting for confounders and time since HCV diagnosis, older age (AOR=0.96, 95% CI [0.93, 1.00]) and lifetime history of drug treatment (AOR=0.39, 95% CI [0.22, 0.69]) were associated with decreased odds of HCV disclosure.

Conclusions: While most participants reported HCV disclosure, the almost complete absence of disclosure to current or former injection drug use partners was concerning. Although further research is warranted, it is clear that interventions are needed to encourage HCV disclosure among those most at risk of transmitting, or becoming infected with, HCV.

Introduction

Current estimates suggest that at least 3.5 million individuals (range 2.5 million – 4.7 million)¹ are infected with hepatitis C virus (HCV) in the United States, making HCV the most common blood-borne infection in the United States. The Centers for Disease Control and Prevention (CDC) estimates that nearly 30,000 incident cases of acute HCV occurred in 2013 in the United States.² Between 2006-2012, state surveillance data from Central Appalachia (Kentucky, Tennessee, Virginia, and West Virginia) demonstrated a 364% increase in the number of acute HCV infections among persons ≤ 30 years old.³ Among those cases of acute HCV in Central Appalachia with identified risk information, injection drug use (IDU) was reported in almost three-fourths of cases (73%).³ HCV is primarily transmitted through percutaneous exposure to contaminated blood. As a consequence, IDU is the leading means of HCV transmission in the United States.^{4,5} Despite the existence of national screening recommendations based on risk factors and birth cohort, many individuals are unaware that they are infected with HCV. Several recent studies suggest that a substantial proportion (40-85%) of HCV-positive individuals are unaware of their infection status.⁴ One study found that among persons who inject drugs (PWID), 72% of those who were HCV-positive were unaware of their status.⁶

Individuals with both acute and chronic HCV infections are often asymptomatic.^{7,8}

Consequently, many HCV-infected individuals never seek testing. These factors contribute to the substantial lack of awareness of serostatus among HCV-positive individuals, which places risk partners (particularly people with whom they inject or share injection equipment) of infected individuals at risk of unwittingly acquiring HCV. Although highly successful curative treatments

have been developed in recent years, these medications are prohibitively expensive.⁹ Among high-risk populations (such as PWID) that frequently lack access to health insurance or healthcare, reliance on curative medical treatment to stop the spread of HCV is not yet a viable and scalable prevention strategy. Primary prevention of HCV infection is the most desirable public health approach to reducing morbidity, mortality, and the economic burden associated with HCV infection.

Serostatus disclosure has been described as a cornerstone of primary prevention strategies related to human immunodeficiency virus (HIV) transmission between sexual partners.^{10,11} HCV disclosure can similarly serve as an important preventive public health measure for HCV infection. Disclosure of HCV allows the social contacts of an infected individual the opportunity to make informed decisions regarding engaging in risk behaviors, thus potentially reducing HCV transmission risks. Research indicates that individuals who believe their injecting partner is HCV-positive are more likely to practice safer injecting habits (i.e., not inject with someone else's used needle/syringe).¹²

While there have been numerous efforts to determine correlates of HIV disclosure,^{10,11,13-15} comparatively less research has been published investigating the factors associated with disclosure of HCV. Additionally, studies examining disclosure of HIV more frequently focus on serostatus disclosure among sexual partners; findings from this research may not be applicable to understanding disclosure of HCV status given that sexual transmission of HCV is rare¹⁶ and percutaneous transmission through shared needles or injection equipment among PWID is most common.^{4,5,8} Similarly, the fact that HIV disclosure is mandatory in many settings¹⁷ while HCV

disclosure is not suggests that the factors impacting HIV disclosure may differ from those impacting HCV disclosure.

Social stigma surrounding disease status disclosure, particularly of infectious diseases perceived as being acquired through stigmatized risk behaviors (e.g., illegal drug use), can negatively impact access to health care, employment, and social support.¹⁸ HCV disclosure has been described in the literature as a complex and emotionally difficult endeavor, with fear of a negative reaction, rejection, or stigmatization commonly cited as barriers to HCV-positive status disclosure.^{18,19} Studies among current PWID also found that PWID perceive HCV infection as inevitable and ubiquitous,²⁰ and suggested that this fatalistic attitude could result in ambivalence about the need for HCV disclosure.²¹ Results from a cross-sectional survey in Australia revealed that individuals who reported being advised by someone at the time of diagnosis to tell no one or only close family members disclosed their HCV-positive status less widely than those who did not receive the same advice,²² suggesting that social influences may have a profound impact on an individual's disclosure practice.

Much of the published literature related to HCV disclosure has been conducted internationally, primarily among PWID in urban settings,^{18-20,22-26} and most of the studies anecdotally report correlates of HCV disclosure rather than focusing on disclosure as the primary research outcome. Relatively little is known about factors that influence HCV-positive disclosure among high-risk populations in rural settings. Appalachian Kentucky is an economically disadvantaged region that suffers from worse mortality rates among young and middle-aged adults than many less developed countries.²⁷ A recent study demonstrated that annual increases in acute HCV

incidence among young (≤ 30 years) PWID in the United States were at least twice as high in rural jurisdictions as urban jurisdictions.²⁸ The largest increases noted in the study were in rural jurisdictions in or nearby Appalachian counties.²⁸ When considered in combination with the recent significant increase in acute HCV infections among persons ≤ 30 years in Kentucky, Tennessee, Virginia, and West Virginia,³ the data suggest that Central Appalachia is a current epicenter of HCV incidence in the United States. The purpose of this analysis is to identify demographic, behavioral, and interpersonal characteristics associated with HCV serostatus disclosure among rural, high-risk drug users in Appalachian Kentucky.

Methods

Study Design

Data were collected from drug users ($n=415$) completing their fifth follow-up assessment in the ongoing, longitudinal Social Networks among Appalachian People (SNAP) study. The overall goal of the SNAP study is to analyze risk factors for HIV, HCV, and HSV-2 in the context of drug users' social networks. Participants ($n=503$) were recruited through respondent-driven sampling^{29,30} between November 2008 and September 2010 from an Appalachian county in eastern Kentucky (explained in detail elsewhere³¹). Respondent-driven sampling has previously been shown to be an effective technique for the recruitment of rural drug users.³² The original participants, or seeds, were recruited through outreach workers, community informants, and flyers posted at the study site, and had a lifetime history of IDU. Once the seeds completed their baseline interviewer-administered questionnaire, they were given three coupons and asked to recruit drug-using peers (irrespective of injection status).

Individuals eligible for study participation were at least 18 years old, resided in Appalachian Kentucky, and had used prescription opioids, cocaine, heroin, or methamphetamine to get high in the prior 30 days. All participants received copies of the consent form and provided signed documentation of informed consent. Participants were compensated for their time (\$50), and those seeds whose coupons were redeemed (i.e., by a peer who was eligible for, and completed the baseline interviewer-administered questionnaire) received an additional \$10 per redeemed coupon. Participants completed interviewer-administered surveys and HCV testing approximately every six months. For the baseline assessment and the first three follow-up visits, trained study staff tested participants for antibodies to HCV using the Home Access test (Home Access Health Corporation, Hoffman Estates, IL), explained in detail elsewhere.³³ For all subsequent visits participants were tested using the OraQuick HCV rapid antibody test.³⁴ All participants were provided with their test results, either in person or by telephone, and pre- and posttest counseling was provided according to CDC guidelines. Participants who tested positive for HCV were provided with information about local healthcare resources for additional testing and treatment. The Institutional Review Board at the University of Kentucky approved the study protocol.

A total of 415 participants (82.5% of the original sample) completed the fifth follow-up assessment. Participants lost to follow-up were less likely to be unemployed ($\chi^2=9.70$, $p=0.002$) than those retained in the study, but were otherwise not significantly different from those remaining in the analysis in terms of demographic characteristics or HCV serostatus. For the fifth follow-up assessment (3.8–5.3 years since participant enrollment), questions were added to

examine whether participants who had tested HCV antibody-positive at baseline or at any point during the study (n=243) had disclosed their HCV-positive status to others. Specifically, participants were asked, “After testing positive (here—at this location) for hepatitis C did you tell (please check all that apply): [your current sex partner, past sex partners, current injection drug use partners (people you inject with), past injection drug use partners (people you inject with), family member(s), close friend(s), spouse (if married)].”

To assess correlates of HCV disclosure, a dichotomous variable was created to indicate whether or not participants disclosed their HCV-positive status to anyone. Dichotomization was necessary because the limited number of participants disclosing to most of the identified person-type categories did not provide sufficient power to identify statistically significant differences in demographic, behavioral, or interpersonal characteristics between those HCV-positive individuals who had disclosed or had never disclosed their HCV-positive status by person-type.

Demographic, behavioral, and interpersonal data were also obtained through the interviewer-administered questionnaire. Demographic characteristics included gender, age (years), race, education, marital status, and unemployment. Additional characteristics, including lifetime history of IDU, lifetime history of drug treatment, and time since HCV diagnosis (years), were also assessed. Finally, interpersonal characteristics included whether the participant: was dependent on someone else for the majority of their support, self-reported spending most free time alone (rather than with family or friends), and had significant periods experiencing serious problems getting along with others during his/her lifetime. The latter interpersonal characteristic was assessed with the question, “Have you had significant periods in which you have

experienced serious problems getting along with your [mother, father, brothers/sisters, sexual partner/spouse, children, close friends, neighbors, co-workers] in your life?” Data were dichotomized to a negative response if participants denied serious problems with all possibly identified social referents, and to an affirmative response if participants acknowledged serious problems with any of the possibly identified social referents. The resultant covariate is hereafter referred to as ‘social conflict.’

Analysis

Logistic regression was used to explore associations between HCV disclosure and demographic, behavioral, and interpersonal characteristics. All analyses were conducted using SAS software, version 9.4 (SAS Institute; Cary, NC, USA).³⁵

A confounding analysis was completed to aid in covariate selection for the final model. Changes in the estimated, unadjusted odds ratio between independent variables identified as being associated with disclosure in the literature (e.g., gender and education)^{22,26} and through univariate logistic regression analysis (e.g., lifetime history of drug treatment) and HCV disclosure were examined in the presence and absence of other covariates that could act as potential confounders. Confounding was considered present if the estimated, unadjusted odds ratio changed by more than 15%. The confounding analysis identified lifetime history of drug treatment as a positive confounder of the association between HCV disclosure and both gender and education. Consequently, lifetime history of drug treatment was required to be in the final model. Covariates in the initial multivariate model included gender, age, race, education, marital status, unemployment, dependence on someone else for majority of support, lifetime history of

IDU, spend most of free time alone, social conflict, lifetime history of drug treatment, and time since HCV diagnosis. The final model was derived through manual backward elimination with $\alpha_{\text{critical}}=0.05$, and included age, lifetime history of drug treatment, and time since HCV diagnosis.

Respondent-driven sampling weights were not applied to the data because rather than calculating population estimates of HCV disclosure, this study focused on correlates of HCV disclosure in this sample of rural, high-risk drug users. Collinearity within the model was assessed in both the full and final models using the %COLLIN_2011 macro.³⁶ Covariates did not exceed a condition index of 30 in either the full or final model, indicating that multicollinearity was not present in either multivariate model.

Results

Participant Characteristics

Participants (n=243) were primarily male (57.2%), white (93.0%), and had at least a high school education (54.3%). The mean age was 33.8 years (range 20.5-56.5). While all participants were HCV antibody positive, only 32.9% sought confirmatory testing, and only 4.9% sought treatment for HCV. Among those who sought confirmatory testing (n=80), the majority (85.0%) reported testing positive on the second test and being told they have HCV. Most (77.0%) tested HCV-positive for the first time within the SNAP study. The median duration since HCV diagnosis was 8.8 years (IQR 5.9) and 4.2 years (IQR 1.4) for participants who tested positive prior to entering the study and during the study, respectively; the overall mean duration since HCV diagnosis was

5.0 years (range 0.4-22.3). Demographic, behavioral, and interpersonal characteristics are presented in Table 1.

HCV-positive Status Disclosure and Correlates

Most participants (69.1%) reported disclosing their HCV-positive status to at least one of their social referents (Table 2). Individuals who disclosed their HCV-positive serostatus most commonly disclosed to current sex partners (63.7%), family members (51.8%), close friend(s) (13.7%), or past sex partners (9.5%). Few participants disclosed to current IDU partners (3.8%, calculated among 72 who reported injecting within the past six months), spouses (if married) (2.9%), or past IDU partners (1.4%, calculated among 215 who reported ever injecting drugs).

Results from unadjusted logistic regression analyses are presented in Table 1. Estimated, unadjusted odds ratios, 95% confidence intervals, and *p*-values are provided to show associations between covariates and HCV-positive status disclosure. None of the demographic, behavioral, or interpersonal characteristics assessed were significantly associated with HCV disclosure.

Lifetime history of drug treatment was significantly associated with non-disclosure of HCV-positive status. Participants with a lifetime history of drug treatment had 60% lesser odds of disclosing their HCV-positive status than those participants who had no history of drug treatment (odds ratio [OR]: 0.40; 95% CI [0.23, 0.70]). Of note, there was no evidence of a dose-response relationship between weeks spent in drug treatment in the prior year and HCV disclosure (data not shown in table).

Table 3 presents the results from the final multivariate logistic regression model (n=243). Adjusting for all other covariates in the model, age ($p=0.043$) and lifetime history of drug treatment ($p=0.001$) were independently associated with HCV-positive status disclosure. Time since HCV diagnosis ($p=0.782$) was maintained in the final model to control for the effects of varying duration of serostatus awareness. Holding all other covariates constant, a one year increase in age corresponded to a 4% reduction in the odds of disclosing HCV-positive status (AOR: 0.96, 95% CI [0.93, 1.00]). A lifetime history of drug treatment corresponded to a 61% reduction in the odds of disclosing HCV-positive status compared to participants without a history of drug treatment, adjusting for the other covariates in the model (AOR: 0.39, 95% CI [0.22, 0.69]).

Discussion

To the author's knowledge, this is the first study of its kind to quantitatively assess correlates of HCV serostatus disclosure among rural drug users. The purpose of this study was to identify demographic, behavioral, and interpersonal characteristics associated with HCV disclosure among high-risk drug users in Appalachian Kentucky. Notably, 30.9% of participants did not disclose their HCV-positive status to anyone. Among individuals who did disclose their serostatus, disclosure to those social referents potentially at greatest risk for infection through percutaneous transmission was rare (3.8% among current, and 1.4% among past IDU partners, respectively). Overall, the results of this study suggest that older age and lifetime history of drug treatment are associated with a decrease in the odds of HCV disclosure.

An association between age and disclosure has previously been identified in the HIV literature,^{37,38} but not in the HCV literature. A recent study found that older adults (≥ 50 years old) were less likely to disclose HIV than younger adults (20-39 years old).³⁷ Post-hoc, gender-stratified analyses in this study revealed that age was associated with HCV disclosure *only* among women ($p=0.006$). These data suggest that older women are less likely as a group to disclose their HCV-positive status than younger women, while age does not significantly influence male disclosure patterns. The reasons for this are likely multifactorial, but may be related to a greater perception of social stigma surrounding drug use among older women compared to younger women or even men. A small, qualitative study of older (≥ 50 years of age) HIV-positive women in the southeastern United States supports this hypothesis: the women reported being reluctant to disclose their status because they viewed it as more shameful at their older ages.³⁸

The *negative* association between lifetime history of drug treatment and HCV disclosure had not been identified in previous literature, and was an unexpected and novel finding of this study. Although the nearly three-fold decrease in odds of disclosure among those with a lifetime history of drug treatment seems counterintuitive, it is possible that individuals whose drug treatment was court-ordered (as was the case in 52% with a lifetime history of drug treatment in the study) were more reluctant to disclose their HCV-positive status out of fear that it would be seen as an admission of prior or current drug use, which could violate their probation. Additionally, individuals who successfully completed drug treatment may have a new social identity of being abstinent, and might consider HCV disclosure irrelevant in their current milieu. The result suggests that interventions aimed at increasing HCV disclosure should partner with drug

treatment providers to clarify misperceptions among patients of the potential consequences and benefits of disclosing one's HCV serostatus.

This study is not without limitations. These data are cross-sectional; consequently, inferences about causality or temporality are not possible. Second, as a result of the small sample size, the analysis may have lacked the statistical power to detect small differences among some of the covariates, potentially increasing the probability of type II error. Third, the homogeneity of this rural, Appalachian sample may limit generalizability of the results to more diverse urban or rural population groups. Similarly, the fact that this study population is in the midst of an acute HCV epidemic^{3,28} may limit its generalizability beyond other settings experiencing increased acute HCV incidence. Fourth, behavioral and demographic data were self-reported and subject to recall and social desirability bias. Of note, HCV serostatus was *not* self-reported, and this was a strength of the study. Fifth, information about disclosure in particular relationships (such as duration of relationship or frequency of interaction) was not available. However, it does not appear that the tendency to disclose to sex partners is related to frequency of contact, and on average participants reported injecting more frequently in the prior 30 days than having sex. Finally, serostatus in this study was based on HCV antibody testing rather than RNA testing; antibody testing does not necessarily correlate with active HCV infection. However, a prior random sample of HCV antibody-positive participants from the study cohort revealed that 69% were HCV RNA-positive,³⁹ suggesting a high potential for transmission and reinforcing the importance of HCV disclosure, particularly to injection risk partners.

Despite these limitations, this study provides important insight into demographic, behavioral, and interpersonal correlates of HCV serostatus disclosure among high-risk drug users in rural Appalachia. Most striking was the almost complete absence of disclosure to current or former IDU partners, the social referents theoretically at highest risk of HCV infection given the efficiency of percutaneous transmission. Current post-test counseling guidelines for HCV testing do not mention disclosure.⁴⁰ Incorporating educational messages related to the importance of HCV disclosure into post-test counseling might help curtail the further spread of HCV. Findings from this study suggest that messages targeted at older women should be prioritized since this group was identified as being especially hesitant to disclose HCV status. Partnering with drug treatment providers on interventions may represent another method to encourage HCV disclosure as a normative behavior among those most at risk of transmitting, or becoming infected with, HCV.

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Table 1. Demographic and behavioral characteristics of sample and univariate associations with HCV disclosure (n=243)

Characteristic	Total n (%)	Disclosed HCV-positive status, n (%)	Crude OR	95% CI	p-value
<i>Demographic</i>					
Male	139 (57.2)	92 (54.8)	0.72	(0.41, 1.26)	0.251
Age (years), mean (SD)	33.8 (7.8)	33.2 (7.5)	0.97	(0.93, 1.00)	0.054
White	226 (93.0)	158 (94.1)	1.63	(0.59, 4.45)	0.344
High school graduate	132 (54.3)	90 (53.6)	0.91	(0.52, 1.57)	0.726
Currently married	46 (18.9)	35 (20.8)	1.53	(0.73, 3.21)	0.260
Unemployed	106 (43.6)	78 (46.4)	1.46	(0.83, 2.54)	0.188
<i>Interpersonal</i>					
Spends most of free time alone	71 (29.2)	49 (29.2)	0.99	(0.55, 1.80)	0.979
Social conflict	31 (12.8)	20 (11.9)	0.79	(0.36, 1.74)	0.552
Dependent on someone else for majority of support	83 (34.2)	58 (34.5)	1.05	(0.59, 1.88)	0.857
<i>Other characteristics</i>					
Lifetime history of IDU	215 (88.5)	144 (85.7)	0.34	(0.11, 1.01)	0.052
Lifetime history of drug treatment ^a	105 (43.2)	61 (36.3)	0.40	(0.23, 0.70)	0.001**
Time since HCV diagnosis (years), mean (SD)	5.0 (3.5)	5.0 (3.7)	0.99	(0.92, 1.07)	0.764

HCV=Hepatitis C virus; OR=Odds ratio; CI=Confidence interval; SD=Standard deviation

^a Drug treatment includes methadone detoxification, methadone maintenance, Outpatient Drug Free, residential treatment, non-methadone detoxification, and 12-step programs (Alcoholics Anonymous/ Narcotics Anonymous)

** $p < 0.01$

Table 2. Person-types to whom participants disclosed HCV-positive status (n=243)

Category	Disclosed HCV-positive status, n (%)
Current sex partner	107 (63.7)
Family member(s)	87 (51.8)
Close friend(s)	23 (13.7)
Past sex partner	16 (9.5)
Current injection drug use partners (n=72) ^a	2 (3.8)
Spouse (if married) (n=46) ^b	1 (2.9)
Past injection drug use partners (n=215) ^c	2 (1.4)

^a Calculated among the 72 participants who reported injection drug use in the past 6 months

^b Calculated among the 46 participants who were married

^c Calculated among the 215 participants who reported ever injecting drugs

Table 3. Multivariate analysis of correlates to HCV disclosure (n=243)

Characteristic	Adjusted OR	95% CI	p-value
Age	0.96	(0.93, 1.00)	0.043*
Lifetime history of drug treatment	0.39	(0.22, 0.69)	0.001**
Time since HCV diagnosis	1.01	(0.93, 1.10)	0.782

OR=Odds ratio; CI=Confidence interval

* $p < 0.05$

** $p < 0.01$

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Biographical Sketch

Megan Hofmeister earned her Bachelor of Science degree in biology from the University of Virginia, followed by a Master of Science degree in Biohazardous Threat Agents and Emerging Infectious Diseases from Georgetown University. She completed medical school at the University of Kentucky and an Internal Medicine internship at Ohio State University. Currently, Dr. Hofmeister is the Chief Resident in General Preventive Medicine at the University of Kentucky, and is completing her Master of Public Health degree with a primary concentration in epidemiology.