RESEARCH

Validity of Injecting Drug Users' Self Report of Hepatitis A, B, and C

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OBJECTIVE: To test the validity of drug users self-reports of diseases associated with drug use, in this case hepatitis A, B, and C.

DESIGN: Injecting drug users (n = 653) were recruited and asked whether they had been diagnosed previously with hepatitis A, B, and/or C. These self-report data were compared to total hepatitis A antibody, hepatitis B core antibody, and hepatitis C antibody seromarkers as a means of determining the validity of the self-reported information.

SETTING: Anchorage, Alaska.

PARTICIPANTS: Criteria for inclusion included being at least 18-years old; testing positive on urinalysis for cocaine metabolites, amphetamine, or morphine; having visible signs of injection (track marks).

INTERVENTION: Serological testing for hepatitis A, B, and C.

MAIN OUTCOME: Findings indicate high specificity, low sensitivity, and low kappa coefficients for all three self-report measures.

RESULTS: Subgroup analyses revealed significant differences in sensitivity associated with previous substance abuse treatment experience for hepatitis B self-report and with gender for hepatitis C self-report.

CONCLUSION: Given the low sensitivity, the validity of drug users, self-reported information on hepatitis should be considered with caution.

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ABBREVIATIONS: HAV = hepatitis A virus; HBV = hepatitis B virus; HCV = hepatitis C virus; HIV = human immunodeficiency virus; IDU = injection drug user; STD = sexually transmitted disease.

INDEX TERMS: hepatitis; injection drug use; infectious diseases; self-report; validity.

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Many major national substance abuse treatment outcome studies, sexually transmitted disease (STD) prevention programs, publicly-funded drug treatment and prevention projects, and other substance abuse-related programs rely heavily, if not exclusively, on information gathered via drug users' self-reports. Often major policy or intervention decisions are made based on the data obtained from such studies or efforts. Given that self-report is a commonly used tool for collecting information on drug use, sexual behaviors, STDs,

and other high-risk behaviors commonly encountered in injection drug using populations, it becomes important to determine the accuracy or validity of the responses provided by participants prior to interpreting data. Validity can be hampered either by under- or over-reporting by respondents.

Individuals who inject drugs may over- or under-report information for a variety of reasons. For example, given that the information being collected, e.g., drug use, sexual behaviors, and STD information, is often perceived as socially stigmatizing, injection drug users (IDUs) may feel uncomfortable reporting the behavior, leading to under-reporting.[1] On the other hand, drug users may over-report behaviors if they feel excessive reporting will be advantageous for them, e.g., by helping them gain enrollment to an incentive-based research project or priority for admission to a substance abuse treatment program.[2] Many other variables, such as intrinsic motivation to complete a research or diagnostic interview, failure to recall past events, fear of legal reprisal, insufficient description of reported events, and cognitive impairment may bias the validity of self-reported information collected from IDUs.[3-5]

The accuracy and validity of drug users' self-report is of special concern when the information being collected is disease or health-related. The lifestyles of IDUs place them at great risk for contracting sexually transmitted diseases and other infectious diseases that are transmitted through close interpersonal contact and poor living conditions.[6] Diseases of primary concern are human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), hepatitis A (HAV), B (HBV) and C (HCV), and STDs, e.g., chlamydia, gonorrhea, herpes, and syphilis, all of which have a high prevalence among injecting drug users and have the potential to spread to the general population.[7-9] The risk to both IDUs and the general population highlights the importance of having accurate information about the disease histories of IDUs.

Studies that have compared self-report information from IDUs regarding existing infectious diseases such as oral and genital herpes or syphilis with laboratory analysis found low correlations between these two sources of information.[7,10] Such findings contrast other studies that reported high levels of validity of self-report when inquiring about more general information about high-risk behaviors, e.g., injecting practices or sexual behaviors.[11-13] One possible explanation for this discrepancy may be that infected individuals may have experienced symptoms or received a diagnosis months or years before data about infection were collected, introducing the possibility of recall error. Alternatively, validity of self-report information on STDs may be influenced by the social stigma surrounding such infection.[13]

In the United States, hepatitis A is one of the more commonly reported, vaccine-preventable diseases. IDUs have a higher prevalence of HAV than the general population.[14] HAV may be transmitted by injection but fecal contamination of the illicit drugs or the poor hygienic conditions common to IDUs are more likely to be the transmission route.[15] Hepatitis B is the most common cause of acute and chronic liver disease and a significant public health problem in the U.S. and all regions of the world.[16,17] HBV is transmitted through sexual encounters, blood-to-blood contact, and from an infected mother to her infant.[16] Hepatitis C has recently emerged as a major public health concern. HCV is transmitted through blood-to-blood contact and from infected mother to her infant.[18] Because injection drug users often engage in high-risk behaviors that facilitate transmission of infectious disease such as needle sharing and unsafe sex practices, they are at high risk for contracting HAV, HBV, and HCV.[19,20] Indeed, IDUs account for most new HCV cases reported in the U.S.[18] The high risk of hepatitis transmission among IDUs highlights the need for valid information about HAV, HBV, and HCV infection status. Accurate assessment of hepatitis incidence in this population can assist public health professionals and researchers create better plans to decrease the risk and incidence of infection.

Prior research has found limited validity for self-report HBV data and has not explored HAV and HCV self-report. Fisher, Kuhrt-Hunstiger, Orr, and Davis found low levels of validity for self-report of hepatitis B infection.[21] However, high levels of validity for self-report of no infection were found, indicating valid self-reporting of individuals who are not infected with HBV.[21] In the current study, the accuracy of IDU's self-reported information on HAV, HBV, and HCV infection was compared with actual serostatus as obtained through serological blood testing. Further, participant gender, ethnicity, and history of substance abuse treatment were considered as possible moderating variables of self-report validity. Primary methods used to determine validity of the self-report data were sensitivity and specificity. Sensitivity is defined as "the ability of a test to identify correctly those who have the disease"; specificity refers to "the ability of a test to identify correctly those who do not have the disease".[22]

METHOD

Participants

The total sample consisted of 497 male and 156 female injection drug users participating in a National Institute on Drug Abuse (NIDA) project designed to evaluate the effectiveness of a needle exchange program in reducing the incidence of blood-borne infections. Criteria for inclusion in the study were being of age 18 years or older; possession of picture identification; testing positive on urinalysis for cocaine metabolites, amphetamine, or morphine; having visible signs of injection; and self-report of recent injection. Of the participants, 363 (56%) were Caucasian, 135 (21%) Native American/Alaska Native, 122 (19%) African American, 23 (4%) Hispanic, 6 (0.9%) Asian American, and 4 (0.6%) Other. Ages of the participants ranged from 18 to 66 years with a mean age of 38.0 years (SD = 7.9). Relative to prior substance abuse treatment, 245 (37%) reported no prior treatment, 82 (13%) reported outpatient treatment (including in prison and methadone maintenance), and 326 (50%) reported both outpatient and inpatient treatment. There were no reports of inpatient treatment without outpatient treatment.

Risk behavior assessment (RBA)[23]

As part of their involvement in this research project, participants were administered the Risk Behavior Assessment, a structured interview developed by the Community Research Branch of NIDA in collaboration with the Cooperative Agreement for AIDS Community-Based Outreach/Intervention Research Program grantees. Trained interviewers read items to participants that requested information about demographics; HIV risk behaviors, such as drug use, needle sharing, and sexual behaviors; drug treatment history; health history and status; and work and income. The RBA has been demonstrated to have very good reliability and validity for HIV sexual and drug use questions.[2,9,24,25] In addition, reliability for items pertaining to work and income was found to be good.[26] For the current study, the RBA question of interest was, "How many times have you been told by a doctor or nurse that you had hepatitis B?" The 48-hour test-retest reliability for this question is 0.91.[21,24] Self-report of HAV and HCV was obtained using a supplemental questionnaire that asked "How many times have you been told by a doctor, nurse. or health counselor that you have hepatitis A?" and "How many times have you been told by a doctor, nurse, or health counselor that you had hepatitis C?"

Hepatitis serostatus

As part of their regular participation in the needle exchange project, participants received pretest serological counseling for hepatitis A, B, and C, and HIV. Blood was then drawn by a certified phlebotomist. Blood samples were tested for HAV, HBV, and HCV seromarkers. The test for hepatitis A was the HAVAB® EIA enzyme immunoassay of total antibody; for hepatitis B core antigen was Corzyme® enzyme immunoassay; and for hepatitis C, the Abbott HCV EIA 2.0 enzyme immunoassay for antibody was used.[27,28,29] Participants were considered to be infected with HBV if the test results were core (Anti-HBc) positive. Core antibody is a life long marker that indicates past exposure to HBV.

PROCEDURE

Participants were recruited using targeted sampling and snowball sampling that integrated various efforts including word of mouth, flyers posted on bulletin boards at homeless shelters, and the use of outreach workers.[30,31] Participants were informed of eligibility requirements and the purpose of the study before enrollment was granted; informed consent was obtained prior to the first interview. Urine samples were acquired to determine eligibility for participation in the study. After obtaining informed consent, the RBA was administered and pretest counseling was provided. Blood samples were then obtained and sera tested for HIV and hepatitis. Following completion of the interview, participants were paid for their participation. Later, participants returned to obtain their serological test results and received posttest counseling. Of the 653 participants, 477 were tested for hepatitis A, 550 for hepatitis B, and 558 for hepatitis C.

Statistical analysis

Sensitivity and specificity

The serostatus of the individual was used as the true indicator for disease, while the self-report from the RBA or supplemental hepatitis questionnaire were referred to as the clinical tests. Sensitivity of the self-reported information was calculated as the proportion of participants who tested positive for a given seromarker who also self-reported having been told that they had that disease. Specificity of the self-reported information was calculated as the proportion of participants who tested negative for a given seromarker who self-reported that they had never been told they had that disease.

Subgroup analysis

Previous research indicates variables such as gender, ethnicity, and previous treatment involvement may influence the va-

lidity of information self-reported by injection drug users.[21,32] Data from the participants in the current study were examined on the subgroup level to determine whether the variables of gender, ethnicity, and previous treatment experience influenced the validity of the responses. Subgroup analysis was performed using a series of binomial tests of proportions, comparing within gender, ethnicity, and previous treatment experience. Analyses based on ethnicity included only the three groups with adequate sample sizes Native American/Alaska Native, Caucasian, and African American.

Table 1. Hepatitis self-report and serological results

HAV		Serological	
		Positive	Negative
Self-report	Positive	21	10
	Negative	134	312

HBV		Serological	
		Positive	Negative
Self-report	Positive	67	15
	Negative	152	316

HCV		Serological	
		Positive	Negative
Self-report	Positive	69	5
	Negative	225	259

Kappa

The reliability or agreement between self-reported infection and serological results was analyzed using Cohen's kappa.[33] Kappa measures agreement between two variables beyond that expected to occur by chance alone, and is commonly used in validity studies.[2] A maximum value of 1.00 indicates perfect agreement. As obtained Cohen's kappa distributions can be affected by imbalances in marginal totals as were found in the current analyses, two other indices are provided to help clarify the actual reliability of the items being analyzed.[34,35] These two indices are p_{pos}, observed proportion of positive agreement and p_{neg}, observed proportion of negative agreement.

RESULTS

Sensitivity and specificity

Table 1 provides the results of self-report and serological testing. Of the 477 participants with a baseline HAV blood test, 31 reported having previously been told that they were infected with HAV, for a prevalence of 6.5%. Serological testing revealed 155 participants as HAV positive, for a true prevalence of 32.5%. Of the 155 participants who tested positive for HAV, 21 reported that they had been told they were infected with HAV (sensitivity = 13.5%). Of the 322 participants who tested negative for HAV, 312 reported a doctor or nurse had never told them they were infected with

Table 2. Sensitivity and specificity for HAV by subgroup

	Sensitivity	95% Confidence Interval	Specificity	95% Confidence Interval
Total	13.55	8.59 – 19.96	96.89	94.36 – 98.50
Gender				
Male	12.07	6.76 – 19.42	97.67	94.99 – 99.14
Female	17.95	7.54 – 33.54	93.85	84.99 – 98.30
Ethnicity				
African American	2.78	0.07 – 14.53	100.00	93.28 – ——
Caucasian	21.92	13.08 – 33.14	95.92	92.12 – 98.22
Native American/Alaska Native	9.68	2.04 – 25.75	96.72	88.65 – 99.60
Prior treatment				
None	9.68	3.64 – 19.88	99.21	95.69 – 99.98
Outpatient	15.00	3.21 – 37.89	97.30	85.84 – 99.93
Inpatient	16.44	8.79 – 26.95	94.94	90.27 – 97.79

HAV (specificity = 96.89%). Of the 550 participants with a baseline HBV blood test, 82 reported having previously been told that they were infected with HBV, for a prevalence of 14.9%. Serological testing revealed 219 participants to be HBV positive, for a true prevalence of 39.8%. Of the 219 participants who tested positive for HBV, 67 reported that they had been told they were infected with HBV (sensitivity = 30.59%). Of the 331 participants who tested negative for HBV, 316 reported a doctor or nurse had never told them they were infected with HBV (specificity = 95.47%). Of the 557 participants with a baseline HCV test, 74 reported having been told that they were infected with HCV, for a prevalence of 13.3%. Serological testing revealed 293 individuals to be HCV positive for a true prevalence of 52.70%. The sensitivity of the HCV self report was 23.5%, with 69 of the 293 infected individuals self-reporting their HCV positive status. Specificity was 98.0%, with 258 of 263 correctly reporting their HCV negative status.

Subgroup analysis

Tables 2, 3, and 4 provide the results of the analyses examining possible differences in sensitivity and specificity when broken down separately by participant gender, ethnicity, and prior treatment experience. For self-report of HAV, no significant differences were revealed in sensitivity or specificity relative to gender, ethnicity, or treatment experience. Significant differences in sensitivity for self-report of HBV were associated only with previous substance abuse treatment experience, with a greater proportion of participants infected with HBV with previous inpatient substance abuse treatment experience (46/118 = 38.98%) reporting HBV infection than participants without previous drug treatment (11/70 = 15.71%), $p < .05$. No significant differences in specificity were revealed between outpatient and inpatient treatment. No significant differences were revealed in sensitivity or specificity relative to participant gender or ethnicity. For HCV, significant differences in sensitivity were revealed only between women (28/75; 37.33%) and men (41/218; 18.81%), with women having greater sensitivity scores, $p < .001$. No differences in specificity of HCV self-report were found with respect to gender, and there were no differences in sensitivity or specificity with respect to ethnicity or treatment experience.

Kappa

As revealed in Table 5, kappa statistics were all consistently very low, with overall statistics ranging from .13 to .28, indicating low reliability. The p_{pos} and p_{neg} provide more detailed statistics regarding kappa statistics and reveal the same pattern as identified by sensitivity and specificity, that is, low probability of accurately reporting positive results and high probability of accurately reporting negative results.

DISCUSSION

As indicated by the low sensitivity, results from the current study revealed a significant discrepancy between IDUs, self-reported HAV, HBC, and HCV infection status and the results of serological testing for markers of infection with the corresponding hepatitis virus. Specifically, the results revealed self-reported prevalence to be 6.5% for HAV, 14.9% for

Table 3. Sensitivity and specificity for HBV by subgroup

	Sensitivity	95% Confidence Interval	Specificity	95% Confidence Interval
Total	30.59	24.56 – 37.16	95.47	92.64 – 97.44
Gender				
Male	26.75	20.01 – 34.39	95.91	92.80 – 97.94
Female	40.32	28.05 – 53.55	93.55	84.30 – 98.21
Ethnicity				
African American	25.00	12.12 – 42.20	93.55	84.30 – 98.21
Caucasian	32.81	24.78 – 41.67	96.15	92.24 – 98.44
Native American/Alaska Native	26.19	13.86 – 42.04	94.29	86.01 – 98.42
Prior treatment				
None	15.71	8.11 – 26.38	98.68	90.84 – 98.40
Outpatient	32.26	16.68 – 51.37	91.89	78.09 – 98.30
Inpatient	38.98	30.14 – 48.39	96.13	91.77 – 98.57

HBV, 13.3% for HCV, as compared to true prevalence of 32.5%, 39.8%, and 52.7%, respectively. This significant discrepancy, or low sensitivity of self-report, indicates that IDUs' self-reports of hepatitis infection are biased underestimates and should only be used for estimating a lower bound of the true prevalence of infection.

Although sensitivity of self-report regarding infection with a hepatitis virus is low, specificity of self-report was high. Those participants who reported having never been told by a doctor or nurse that they were infected with a given hepatitis virus were very accurate in reporting this information, as indicated by specificity rates that ranged from 95.5% for HBV to 97% for HAV to 98.1% for HCV. The high specificity findings support other findings regarding self-report by drug users that suggest that self-report tends to be valid when the variable of interest is one of which the drug user has direct knowledge.[2,24,36-39] For example, individuals who have used illicit substances in the previous 48 hours are likely to provide reasonably valid self-report of recent drug use because of their direct and recent knowledge of the use.

Two major issues may explain the low sensitivity of self-reported hepatitis infection. First and foremost, infected individuals may not have been aware of their actual serostatus. Such lack of awareness is likely given that the IDUs in the current study may have poor access to healthcare due to their low socioeconomic status, i.e., 46% reported having earned less than $500 in the last 30 days. Due to inaccessible healthcare, participants may have been less inclined to seek medical assistance when the initial symptoms of hepatitis infection appeared and may never have been diagnosed. Further, symptoms of hepatitis infection are often flu-like, including nausea and fatigue, symptoms that may be interpreted by an IDU as withdrawal symptoms. When experiencing these symptoms, the individual may choose to wait for the symptoms to pass or to self-medicate through the use of illicit substances. Finally, individuals using illicit substances may refrain from seeking medical care altogether simply for fear of possible legal consequences for their drug use.

A second possible explanation for the low sensitivity of self-report may be that participants may have had external or internal motivations to under report infection. A possible external influence may have been the perception of denial as socially desirable and admission as socially stigmatizing. Internal factors may have included a motivation to get through the interview more quickly, difficulty recalling past events, or cognitive impairment. Given the nature of the information being reported by the participant, social desirability is a likely external factor. For example, hepatitis B is considered by many to be a stigmatized sexually transmitted disease. To avoid this stigma, participants may underreport HBV. Regarding internal factors, recall bias can have significant effects on self-reported information, particularly if the event of interest occurred more than 30 days prior to the interview. Further complicating recall among IDUs is the possibility that the participant may have been under the influence of illicit substances either at the time of notification of hepatitis infection or during the interview conducted for the current study.

Table 4. Sensitivity and specificity for HCV, by subgroup

	Sensitivity	95% Confidence Interval	Specificity	95% Confidence Interval
Total	23.55	18.81 – 28.83	98.10	95.62 – 99.38
Gender				
Male	18.81	13.85 – 24.64	98.12	95.26 – 99.49
Female	37.33	26.43 – 49.27	98.00	89.35 – 99.95
Ethnicity				
African American	23.81	12.05 – 39.45	100.00	94.13 – ——
Caucasian	25.52	19.52 – 32.30	95.80	90.47 – 98.62
Native American/Alaska Native	20.93	10.04 – 36.04	100.00	94.79 – ——
Prior treatment				
None	17.31	10.59 – 25.97	98.25	93.81 – 99.79
Outpatient	25.00	13.19 – 40.34	100.00	84.56 – ——
Inpatient	27.59	20.50 – 35.62	97.64	93.25 – 99.51

Individuals who were previously enrolled in either outpatient or inpatient substance abuse treatment and were HBV seropositive had higher sensitivity rates. This finding may be accounted for by the fact that individuals in drug treatment are commonly required to have a physical examination during the process of enrollment into the program. In such a physical examination, the healthcare professional will typically include questions about symptoms that might indicate possible HBV infection. Further, given the high prevalence of blood-borne pathogens such as HBV and HIV among drug users, screens for these pathogens are often included in such a physical examination. In the absence of symptoms, these blood screens may detect HBV seromarkers or elevated liver enzymes that could indicate possible HBV infection. For all of these reasons and others, those participants with previous substance treatment experience may be more likely to have been told they were infected with HBV, resulting in more accurate self-reporting of HBV infection.

The fact that it is not clear whether sensitivity of self-report is low because participants denied their infection status or were unaware of it is the most significant limitation to be considered when interpreting the results of this project. Future research will need to address this issue. One possible method for doing so would be to recruit participants from a previous research project in which serostatus testing and feedback was conducted and report about each participant. Another means would be to recruit participants from clinics at which they had been notified of their hepatitis serostatus.

Although it appears that the IDUs in the current study reported accurately when they were aware of infection, it would appear that awareness or knowledge of infection is limited, at least in this population. These findings highlight the need for increased efforts at providing hepatitis testing as part of the enrollment process for substance abuse treatment and outreach services to out-of-treatment drug users. The need for such increased efforts is strengthened by the very high rates of hepatitis infection revealed in this study, rates that are significantly higher than would be suggested if relying strictly upon self-report data.

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Table 5. Cohen's kappa, p_{pos}, and p_{neg}, broken down by subgroup

	HAV			HBV			HCV		
	kappa	p_{pos}	p_{neg}	kappa	p_{pos}	p_{neg}	kappa	p_{pos}	p_{neg}
Total	.13	.23	.81	.29	.45	.79	.21	.38	.69
Gender									
Male	.13	.21	.82	.26	.40	.80	.17	.31	.70
Female	.14	.28	.77	.34	.55	.74	.31	.54	.67
Ethnicity									
African American	.03	.05	.75	.21	.37	.79	.27	.38	.79
Caucasian	.23	.33	.85	.32	.47	.79	.18	.40	.61
Native American/Alaska Native	.08	.17	.80	.24	.39	.79	.25	.35	.80
Prior treatment									
None	.12	.17	.82	.14	.25	.80	.16	.29	.72
Outpatient	.15	.25	.80	.25	.45	.74	.18	.40	.57
Inpatient	.14	.26	.81	.38	.54	.79	.24	.43	.70

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