



Research paper

Perceptions of genetic testing and genomic medicine among drug users

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ABSTRACT

Background: Genetic testing will soon enter care for human immunodeficiency virus (HIV) and hepatitis C virus (HCV), and for addiction. There is a paucity of data on how to disseminate genetic testing into healthcare for marginalized populations. We explored drug users' perceptions of genetic testing.

Methods: Six focus groups were conducted with 34 drug users recruited from syringe exchange programmes and an HIV clinic between May and June 2012. Individual interviews were conducted with participants reporting previous genetic testing.

Results: All participants expressed acceptance of genetic testing to improve care, but most had concerns regarding confidentiality and implications for law enforcement. Most expressed more comfort with genetic testing based on individual considerations rather than testing based on race/ethnicity. Participants expressed comfort with genetic testing in medical care rather than drug treatment settings and when specifically asked permission, with peer support, and given a clear rationale.

Conclusion: Although participants understood the potential value of genetic testing, concerns regarding breaches in confidentiality and discrimination may reduce testing willingness. Safeguards against these risks, peer support, and testing in medical settings based on individual factors and with clear rationales provided may be critical in efforts to promote acceptance of genetic testing among drug users.

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Introduction

The promise of genomic medicine is that individual level genetic information can be used to tailor and optimize prevention and treatment interventions (Downing, 2009; Gerretsen, Muller, Tiwari, Mamo, & Pollock, 2009; Hutchison, 2010; Moonesinghe, Jones, Honore, Truman, & Graham, 2009). Genetic testing is already in use for hereditary disorders common to specific racial/ethnic groups (e.g., sickle cell disease in African Americans). More recently, specific genes have been associated with excess rates of disease (e.g., *BRCA* in breast cancer; *CCL3L1* and *CCR5* in HIV) (Ahuja et al., 2008; Kulkarni et al., 2008), reduced treatment response (e.g., *IL28B* in hepatitis C virus (HCV) treatment, *EGFR* in lung cancer) (Suppiah et al., 2009), or with resistance to chronic infection (e.g., *CCR5* in human immunodeficiency virus (HIV); *IL28* in HCV) (Ahuja et al., 2008; Kulkarni et al., 2008). Individual genetic information may

allow optimization and personalization of medical care, including more precise pharmacotherapy.

Genomic medicine will likely affect clinical management of HIV and HCV infection, drug treatment and other conditions. Pharmacogenomics, the study of the influence of the genome on an individual's response to a drug, is already beginning to guide treatment for HIV and HCV (Ahlenstiel, Booth, & George, 2010; Fellay et al., 2002). In HIV care, testing for HLA-B*5701 is routinely performed to assess for the safety of using the antiretroviral agent Abacavir. For HCV treatment, *IL28B* testing is used to guide treatment decisions and predict treatment responses for interferon-based treatment. Interferon lambda-4 genetic variants affect HCV clearance and seem to impact the response to treatment with direct acting antiviral agents such as Sofosbuvir (Meissner et al., 2014). *IL28B* and other genetic testing may remain important in individualizing HCV treatment regimens (Holmes, Liu, & Wagner, 2011). A number of genetic variants have been identified which appear to influence both the risk of addiction to specific substances and to influence response rates to specific drug treatment pharmacologic agents (Haile, Kosten, & Kosten, 2008). No genetic

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tests have yet entered routine addiction medicine care however some have been marketed direct-to-consumers, raising ethical concerns (Mathews, Hall, & Carter, 2012; Meissner et al., 2014; Shields, 2011). As it is likely that more genetic markers with better predictive utility will be identified, more data are needed on how best to incorporate genetic testing and pharmacogenomics into systems of HIV, HCV, drug treatment and related health care for marginalized population such as drug users, including members of racial/ethnic minority groups.

Marginalized groups such as drug users, particularly those who are also members of racial/ethnic minority groups, experience substantial health disparities with respect to access to and engagement in care and clinical trials. Medical mistrust may contribute to such disparities in general, and specifically with respect to HIV (Bogart, Wagner, Galvan, & Banks, 2010; Katz et al., 2004; Masson et al., 2009; Verschaeve, 2008; Washington, 2008). Questions arise related to potential repercussions of genetic testing, for example, regarding privacy and confidentiality issues with employers and with health, life and disability insurance. Drug users are more likely than the general population to have had prior arrests and incarcerations, and therefore may have heightened concerns about use of medical genetic testing for forensic purposes. In addition, genetic testing is sometimes clinically advised based on gene prevalences which may vary by race/ethnicity or on associations of race/ethnicity with a specific disease or treatment response (Mallal et al., 2008; Phillips, 2006; Rauch, Nolan, & Martin, 2006; Suppiah et al., 2009; Tanaka et al., 2009). Categorizing DNA samples by racial categories is a commonly employed practice in forensics and law enforcement (Bamshad, 2005; Cho & Sankar, 2004).

Prior work examining the acceptability of genetic testing for guiding clinical care has focused on community knowledge of genetics (Akinleye et al., 2011; Catz et al., 2005; Etchegary et al., 2010; Jonassaint et al., 2010; Long, Thomas, Grubs, Gettig, & Krishnamurti, 2011; Morren, Rijken, Baanders, & Bensing, 2007; Murphy & Thompson, 2009; Suther & Kiros, 2009; Thompson, Valdimarsdottir, Jandorf, & Redd, 2003; Vadaparampil et al., 2011). These studies found that greater genetic literacy and higher socioeconomic status were associated with more positive attitudes towards genetic testing. The acceptance of genetic testing may require some degree of genetic literacy; disparities in genetic literacy may pose barriers to the equitable delivery of genetic testing-informed medical care (Wang et al., 2009). Racial/ethnic minorities, specifically Black/African Americans and Latino/as, demonstrated the least genetic literacy and the most mistrust of genetic testing (Long et al., 2011; Murphy & Thompson, 2009; Suther & Kiros, 2009; Thompson et al., 2003; Zimmerman et al., 2006). These considerations highlight the need for improved understanding of the beliefs and attitudes of drug users, particularly racial/ethnic minority drug users, toward genetic testing and toward the use of individual genetic information in medical care and drug treatment.

There are a paucity of data regarding attitudes and perceptions of genetic testing among illicit drug users (DUs), or among people living with HIV/AIDS and/or hepatitis C. Focus groups can be used to identify common perceptions of the risks and benefits of genetic testing (Goodman, Lehman, & Otero, 2009). This study addresses these knowledge gaps by exploring DUs' (including drug users with HIV and/or HCV) (1) experiences with genetic testing, (2) attitudes towards genetic testing to guide treatment of HIV/AIDS and/or HCV or other conditions, (3) attitudes towards genetic testing to guide treatment of drug misuse, and (4) attitudes towards basing decisions to do genetic testing on patients' race/ethnicity. To the best of our knowledge, this paper presents the first data available on perceptions of genetic testing among DUs.

Methods

Focus group participants were recruited from two different settings: an HIV primary care clinic and syringe exchange programmes (SEPs). Specifically, we conducted three focus groups at one HIV clinic, one with non-Hispanic Black participants, one with Hispanic participants, and one with non-Hispanic white participants. We also conducted focus groups with participants recruited from three different needle exchanges: including a Hispanic focus group at an SEP in the Bronx, a non-Hispanic white focus group at an SEP in Manhattan, and a non-Hispanic Black focus group at an SEP in Brooklyn. Each focus group was homogeneous with respect to race/ethnicity in an effort to increase participants' comfort in talking about racial/ethnic issues. Focus groups were conducted between May and July 2012.

Eligibility criteria for the focus groups included: age ≥ 18 years; self-identifying as either non-Hispanic Black, non-Hispanic white, or Hispanic; having used illicit substances, including cannabis, during the past 12 months; being a NYC resident; and speaking English.

Participants were recruited through staff referrals from among persons currently receiving services at the study sites and who met the eligibility criteria. Each participant was assigned a "unique pseudonym" and was compensated \$25 for their participation.

Focus groups were moderated by a PhD level ethnographer (CGA) and used a semi-structured focus group guide. Focus groups began with an introduction about genetic testing and the use of genetic testing for hereditary conditions, such as sickle cell disease. A focus group guide was used to steer discussions; the process of question development was iterative, based on grounded theory methodology (Auerbach & Silverstein, 2003; Glaser & Strauss, 2009). The focus group guide covered themes such as general perceptions and understandings of genetics and genetic testing, past experiences with genetic testing, genetic testing based on race/ethnicity, and participant attitudes towards the implementation of genetic testing in routine medical care (with an emphasis on HIV, HCV and drug treatment).

We also conducted semi-structured individual interviews with 3 focus group participants who reported past experiences with genetic testing. Each individual interviewee was provided with \$20 cash stipend for his/her time.

Data collection

At the beginning of each focus group, participants completed a brief sociodemographic questionnaire. Genetic testing-experienced participants were asked a range of questions about their genetic testing experiences and any changes in attitudes and perceptions towards genetic testing based on these experiences. Since participants kept a unique pseudonym, we linked each interview with the sociodemographic survey completed at the beginning of the focus group.

Qualitative data analysis

Focus groups and interviews were digitally recorded to ensure accuracy of the information captured, with resultant mp3 files stored in password protected databases. Focus groups and interviews were transcribed verbatim. All data was hand-coded by the ethnographer. "Hand coding" refers to a coding process that is performed through in-depth review and re-review of the transcripts, rather than by use of a computer program (Patton, 2002). Transcripts were coded, compared and analysed paying particular attention to emergent themes common to all focus groups. Grounded theory analytic techniques were used to seek patterns in the data and to develop emergent hypotheses about them (Glaser & Strauss, 2009). Potential emergent themes were identified by the

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