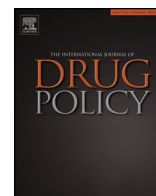




ELSEVIER

Contents lists available at ScienceDirect

International Journal of Drug Policy

journal homepage: www.elsevier.com/locate/drugpo

Research methods

“We’re giving you something so we get something in return”: Perspectives on research participation and compensation among people living with HIV who use drugs



Alexandra B. Collins^a, Carol Strike^b, Adrian Guta^c, Rosalind Baltzer Turje^d,
Patrick McDougall^d, Surita Parashar^{a,e}, Ryan McNeil^{a,f,*}

^a BC Centre for Excellence in HIV/AIDS, Vancouver, BC, Canada

^b Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada

^c School of Social Work, University of Windsor, Windsor, ON, Canada

^d Dr. Peter AIDS Foundation, Vancouver, BC, Canada

^e Faculty of Health Sciences, Simon Fraser University, Burnaby, BC, Canada

^f Department of Medicine, University of British Columbia, Vancouver, BC, Canada

ARTICLE INFO

Article history:

Received 22 February 2016

Received in revised form 11 June 2016

Accepted 14 September 2016

Keywords:

HIV/AIDS

Drug use

Research compensation

Research ethics

Canada

ABSTRACT

Background: Compensation for participating in research has been a fundamental element of the research apparatus despite concerns about its impact on incentivising participation. Researchers and research ethics boards acknowledge that compensation may prompt structurally vulnerable populations, such as people who use drugs (PWUD), to engage in research primarily out of financial need. Thus, institutional restrictions around compensation have been implemented. This study explores the ethical implications of compensation practices aimed at ‘protecting’ structurally vulnerable people living with HIV (PLHIV) who use drugs within the context of individuals’ lived realities.

Methods: We draw on five focus groups conducted in 2011 with 25 PLHIV who use drugs and access a community-based HIV care facility in Vancouver, Canada. This analysis focused on participants’ perceptions of research compensation, which became the central point of discussion in each group.

Results: Participants viewed research as a transactional process through which they could challenge the underpinnings of bioethics and bargain for compensation. Research compensation was thus critical to attracting participants and positioned as a ‘legitimate’ form of income. Participants’ medicalised identities, specifically living with HIV, were fundamental to justifying compensation. The type of compensation (e.g. gift card, cash) also significantly impacted whether participants were fully compensated and, at times, served to exacerbate their structural vulnerability.

Conclusion: Research compensation is critical in shaping structurally vulnerable populations’ participation and experiences with research and can further marginalize individuals. Practices surrounding research compensation, particularly for drug-using and HIV-positive populations, need to be evaluated to ensure participants are equitably compensated for the expertise they provide.

© 2016 Elsevier B.V. All rights reserved.

Introduction

Research compensation has been a fundamental, albeit controversial, element of the health research apparatus for decades (Dickert & Grady, 1999). For structurally vulnerable populations, compensation remains highly contentious despite a wealth of

literature exploring its tenuous impact on research (Festinger et al., 2005; Fry & Dwyer, 2001; McKeganey, 2001; Pandya & Desai, 2013; Permuth-Wey & Borenstein, 2009; Ripley, Macrina, Markowitz, & Gennings, 2010). Structurally vulnerable populations, such as people who use drugs (PWUD) and people living with HIV (PLHIV), occupy marginalised positions within larger social hierarchies based on socio-structural inequities (e.g. drug criminalisation, racism, poverty, sexism), as well as institutional structures (e.g. policies, regulations) (McNeil et al., 2015; Quesada, Hart, & Bourgois, 2011). Researchers and research ethics boards recognise that compensation incentivises participation (Ripley et al., 2010)

* Corresponding author at: BC Centre for Excellence in HIV/AIDS, 608-1081 Burrard Street, Vancouver, BC V6T 1Z1, Canada.

E-mail address: rmcneil@cfenet.ubc.ca (R. McNeil).

and may prompt PWUD and other structurally vulnerable populations to engage in low or high-risk research primarily out of financial need (Dickert & Grady, 1999).

As a consequence, there are persistent concerns that research compensation for the broader research enterprise, including socio-behavioural and biomedical research, might increase vulnerability among structurally vulnerable populations (e.g. undue risk-taking to access compensation) (Dickert & Grady, 1999; Macklin, 1981; Slomka, McCurdy, Ratliff, Timpson, & Williams, 2007) or, in the case of PWUD, lead to increased drug use following participation (Davidson & Page, 2012; Ritter, Fry, & Swan, 2003; Seddon, 2005). This dynamic has also led to concerns about the capacity of these populations to provide voluntary informed consent (Beauchamp & Childress, 2009; Grady, 2001), thus endangering participants' voluntary involvement. Individuals who choose to participate in research largely due to compensation may not be able to refuse or withdraw from the study, even when confronted with potential risks (Faden & Beauchamp, 1986; Grady, 2001). These concerns have prompted institutional restrictions by ethics boards around compensation (i.e. limiting compensation to reimbursement of incidentals, degree of risk) (Ackerman, 1989) or low monetary value of research compensation. Such limitations have subsequently led some researchers to provide little or no compensation for research participation, despite a range of possible approaches (e.g. monetary, gift cards) (McNeill, 1997; Permuth-Wey & Borenstein, 2009; Reiser, 2005). While there is important scholarship supporting concerns about research compensation, there is a need to explore the impact of different types of compensation on structurally vulnerable populations' voluntary consent and how it shapes research-related interactions in order to better inform the ethical framework around compensation.

Understanding how research compensation practices shape individuals' participation is particularly relevant in the context of PLHIV who use drugs, as such constraints can deter their participation in research that may be of benefit to them or their communities (Bell & Salmon, 2011; Permuth-Wey & Borenstein, 2009). Moreover, concerns regarding the impact of compensation on structurally vulnerable populations (e.g. exploitation, undue inducement), particularly PWUD, have not been fully accounted for in the literature. Although limited, previous work has documented the impact of research participation and compensation on the lives of PLHIV and PWUD to address the ethical concerns of respect, beneficence, and justice (Fisher, 2004; Russell, Moralejo, & Burgess, 2000; Semaan, Santibanez, Garfein, Heckathorn, & des Jarlais, 2009), as well as concerns of undue inducement or increased vulnerability (Festinger et al., 2005; Slomka et al., 2007). For example, Russell et al. (2000) highlight the need for an expanded interpretation of ethical principles in relation to structurally vulnerable research participants, while Semaan et al. (2009) underscore the need to uphold ethical principles in research with people who inject drugs. Additionally, Festinger et al. (2005) demonstrated how neither amount nor type of compensation significantly impacted drug use or perceptions of coercion for PWUD participants. Similarly, Slomka et al. (2007) found that structurally vulnerable PWUD dismissed concerns that compensation impacted their drug use or risk-taking. Additional studies have sought the perceptions of research participation and compensation of PWUD (Barratt, Norman, & Fry, 2007; Davidson & Page, 2012; Fry & Dwyer, 2001). One study found differences between research ethics board regulations and how people who inject drugs (PWID) understand their participation (Davidson & Page, 2012). While ethics boards framed participation as a voluntary act, participants viewed their research involvement as an income-generating opportunity (Davidson & Page, 2012). Another study identified a range of motives for participation among PWID (Fry & Dwyer, 2001). While economic gain was

included, findings highlighted how participation was motivated by more than personal benefit.

Whereas these studies have highlighted the role research participation and compensation play in the lives of PWUD, there remains a need to explore how participants rationalize their involvement in research, particularly around their intersecting identities (e.g. HIV status, drug use). Identities are comprised of various characteristics, such as class and race, which intersect at the micro-level and often reveal larger socio-structural inequities (Bowleg, 2012; Kelly, 2011). For structurally vulnerable populations, HIV status and drug use can be additional social identities of particular relevance. As such, it is necessary to interrogate the rationale and theory that forms the basis of bioethics – ethics applied to health-related fields and medicine, including research – by examining the broader macro- and micro-contexts (e.g. power structures) in which it is practiced (Benatar, 2006; Hedgecoe, 2004; Murray & Holmes, 2009). It is especially important to explore the ethical implications of compensation aimed at 'protecting' structurally vulnerable PLHIV who use drugs in the context of individuals' lived realities.

We undertook this qualitative study to explore the perspectives of structurally vulnerable PLHIV who currently or formerly used drugs regarding research participation and compensation. We sought to generate insight into the ethics of research compensation and how current approaches impact participants, particularly within the context of structural vulnerability. Ultimately, we aimed to better understand what constitutes 'equitable' research compensation for drug-using populations, including those living with HIV.

Methods

We draw upon data collected during five focus groups conducted with PLHIV who use drugs recruited from the Dr. Peter Centre (DPC), a community-based HIV care service in Vancouver, British Columbia (BC). The service includes a 24-hour specialised nursing care residence and low-barrier integrated day health program operating under a harm reduction approach. Focus group discussions were conducted to understand the perspectives of DPC clients on research participation in order to inform future research activities at the centre.

Eligibility and participant recruitment

All DPC residents and clients were eligible to participate in this study, and there were no other inclusion criteria. Posters containing information about the focus groups were posted at the DPC, and instructed interested individuals to sign up for focus groups at the front desk. Prospective participants were provided with an appointment card stating the date and time of the focus group for which they had signed up. Enrolment remained open until the final focus group session, after which it was determined that saturation had occurred. A total of 25 DPC clients and residents signed up for, and participated in, the focus group discussions (see demographics in Table 1).

Data collection

Focus groups were conducted in a meeting room at the DPC over the course of two days in July 2011, and were facilitated by an experienced qualitative researcher (RM). Prior to commencing each group, the facilitator used a research information sheet to explain the purpose of the study, highlighting the need for participant input to develop research relevant to, and respectful of, the experiences of residents and clients of the DPC. The facilitator then answered any questions, and obtained verbal and written

Download English Version:

<https://daneshyari.com/en/article/5120866>

Download Persian Version:

<https://daneshyari.com/article/5120866>

[Daneshyari.com](https://daneshyari.com)