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Research methods

Developing a patient-reported experience questionnaire with and for people who use drugs: A community engagement process in Vancouver's Downtown Eastside

Michelle Olding[a,b,*], Kanna Hayashi[a,c], Lindsay Pearce[d], Brittany Bingham[c,d,e], Michelle Buchholz[c,f], Delilah Gregg[g,h], Dave Hamm[h], Laura Shaver[h,i], Rachael McKendry[e], Rolando Barrios[e], Bohdan Nosyk[c,d]

[a] British Columbia Centre on Substance Use, 400-1045 Howe Street, Vancouver, BC, V6Z 2A9, Canada
[b] Interdisciplinary Studies, University of British Columbia, 270 2357 Main Mall, Vancouver, BC, V6Z 1Y6, Canada
[c] Faculty of Health Sciences, Simon Fraser University, 8888 University Drive, Burnaby, BC, V6Z 1Y6, Canada
[d] British Columbia Centre for Excellence in HIV/AIDS, St. Paul's Hospital, 608-1081 Burrard Street, Vancouver, BC, V6Z 1Y6, Canada
[e] Vancouver Coastal Health, 520 West 6th Ave, Vancouver, BC, V5Z 4H5, Canada
[f] Drawing Change, Vancouver, BC, Canada
[g] Western Aboriginal Harm Reduction Society, Vancouver, BC, Canada
[h] Vancouver Area Network of Drug Users, Vancouver, BC, Canada
[i] BC Association of People on Methadone, Vancouver, BC, Canada

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ABSTRACT

People who use drugs (PWUD) frequently have complex health care needs, yet face multiple barriers to accessing services. Involving PWUD in health service design and evaluation can enhance the quality of data collected and ensure policy and practice improvements reflect the expressed needs of the population. However, PWUD remain largely excluded from the evaluation of health services that directly affect their lives, including development of patient-reported experience measures (PREMS) that have gained prominence in health services research and clinical practice. Detailed descriptions of PWUD participation in survey design are notably absent in the literature. In this commentary, we present a case that demonstrates how PWUD can contribute meaningfully to the development of questionnaires that assess patient-reported health care experiences. We describe the development, implementation and outcomes of a process to engage local drug user organizations in the evaluation of a redesign and reorientation of health service delivery in the Downtown Eastside (DTES) neighborhood of Vancouver, Canada. Through this process, participants contributed critical elements to the design of a patient-reported experience measure, including: (1) identifying unmet service needs in the neighborhood; (2) identifying local barriers and facilitators to care; (3) formulating questions on cultural safety; and (4) improving structure, language and clarity of the questionnaire. We highlight lessons learned from the process, reflecting on the strengths, challenges and ethical considerations associated with community-based approaches to questionnaire development. The workshop model presented here illustrates one flexible and promising approach to enabling meaningful participation of PWUD in questionnaire development.

Introduction

In Canada and globally, people who use drugs (PWUD) frequently have complex health care needs related to substance use, including co-occurring infectious diseases (e.g., HIV, viral hepatitis), cardiovascular disease, substance dependence and mental health conditions (Degenhardt & Hall, 2012; Urban Health Research Initiative, 2013). However, PWUD also face substantial barriers to accessing care, often delaying care due to stigma and discrimination experienced within the health care system (Neale, Tompkins, & Sheard, 2008). Indigenous

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[*] Corresponding author at: B.C. Centre on Substance Use, 400-1045 Howe Street, Vancouver, BC, V6Z 2A9, Canada.
E-mail address: molding@cfenet.ubc.ca (M. Olding).

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peoples[1] in particular experience poor access to appropriate care and a disproportionate burden of disease and substance-related harm (Gracey & King, 2009). These health disparities are rooted in colonial policies and perpetuated by ongoing institutionalized racism, entrenched poverty, social exclusion, interpersonal discrimination and inequitable social policies and practices (Allan & Smylie, 2015; Browne et al., 2011; Goodman et al., 2017; Tang & Browne, 2008). Primary care, substance use and mental health services have historically developed and operated separately in North America, posing additional barriers to comprehensive and continuous care (Rush, Fogg, Nadeau, & Furlong, 2008). Within this context, PWUD frequently access care from multiple sources (Nosyk et al., 2014), and rely heavily on emergency services (Fairbairn et al., 2011; Hansagi, Engdahl, & Romelsjö, 2012; Kerr et al., 2004; Palepu et al., 1999); this fragmented care delivery has been associated with poorer medication adherence and health outcomes (Nosyk et al., 2015).

Regional health authorities are increasingly promoting integrated care models as a way to improve accessibility and quality of services for PWUD with complex needs (Carey et al., 2013; Crowley, Kirschner, & Health and Public Policy Committee of the American College of Physicians, 2015; Health Canada, 2002; Korthuis et al., 2017). This has been the case in Vancouver's Downtown Eastside (DTES), a neighborhood that has long been home to a large illicit drug use scene. Here, the Vancouver Coastal Health Authority (VCH) is undertaking a redesign of health services aimed at improving health outcomes for residents of the DTES through greater coordination and continuity of care. Launched in 2016, the 'Downtown Eastside Second Generation Strategy' (DTES-2GS) plans to establish integrated care teams within three community health clinics; partnerships with private clinics to coordinate care for clients accessing private clinics; a new low-barrier addiction clinic with rapid access to opioid agonist treatment; and staff competency training on Indigenous cultural safety, women's needs, trauma-informed care, harm reduction fundamentals and pain management. In addition, VCH has allocated funding away from some existing services (including a low-barrier drop-in center for PWUD) and toward development of a new integrated health care center.

Evaluating the impact of these service changes is challenged by the limited availability of client reported data on health care utilization and health care experiences in the DTES. Patient reported experience measures (PREMS), such as the World Health Organization (WHO) Survey on Health and Health System Responsiveness, provide promising tools for assessing patient's perceptions of care received during a recent health care experience (Valentine et al., 2003). However, existing measures of patient experience are not designed to address the distinct health care needs, perspectives and experiences of PWUD. With few exceptions (Madden, Lea, Bath, & Winstock, 2008; Neale et al., 2016), PWUD are rarely meaningfully involved in the development of health service questionnaires, despite calls from drug user organizations for more involvement in research design (Australian Injecting and Illicit Drug Users League (AIVL) (2003); Canadian HIV/AIDS Legal Network, 2006; Consumers' Health Forum (CHF), and (NHMRC) (2001); Vancouver Area Network of Drug Users, 2018a, 2018b). Detailed descriptions of PWUD participation in questionnaire design are largely missing in health services literature, raising questions about the extent of community involvement in community-based projects. The exclusion of PWUD from health service research and evaluation is methodologically and ethically problematic given evidence that service-user involvement can enhance the quality of data collected and ensure that evidence best meets the needs of affected communities (Hayashi et al., 2012; Neale et al., 2016; Shannon et al., 2007).

To address this gap, we partnered with three local drug user organizations to develop a patient-reported experience questionnaire. We outline the development, implementation and outcomes of this community engagement process, including the strengths, challenges and ethical considerations associated with community-based approaches to questionnaire development.

Project conceptualization and development

An academic research team based at the BC Centre for Excellence in HIV/AIDS (BC-CfE) and British Columbia Centre on Substance Use (BCCSU), partnering with representatives from VCH Aboriginal Health Strategic Initiatives, proposed to undertake a comprehensive, multidimensional evaluation of the DTES-2GS, focusing on access to care and quality of healthcare delivery. The BCCSU (formerly known as the Urban Health Research Initiative) runs three prospective cohort studies of over 3000 community-recruited PWUD in Vancouver, Canada (Strathdee et al., 1998; Wood, Stoltz, Montaner, & Kerr, 2006, 2009). When linked with health administrative databases, these cohorts provide an ideal infrastructure to evaluate clinical outcomes of the DTES-2GS. However, bi-annual questionnaires administered to participants currently collect limited data on patients' experiences navigating the health care system. One of our core objectives, as such, was to develop a supplemental questionnaire to assess health care access and non-clinical quality of care.

Our community partners included three peer-led organizations of PWUD which are based in Vancouver's Downtown Eastside (DTES) and have long-standing research partnerships with the BC-CfE and BCCSU. The Vancouver Area Network of Drug Users (VANDU) is the largest peer-based drug user organization in Canada, organizing since 1997 to improve the lives of PWUD through peer support, education and advocacy (Kerr, Douglas, Peeace, Pierre, & Wood, 2001; Vancouver Area Network of Drug Users, 2018a, b). The Western Aboriginal Harm Reduction Society (WAHRS) is a group of urban Aboriginal PWUD focused on developing support, education and training programs that reflect values of Aboriginal people. The BC Association of People on Methadone (BCAPOM) is a peer-based support and advocacy group for people receiving methadone and other forms of opioid agonist treatment.

The academic research team approached the community groups in October 2016 to share initial plans for an evaluation of the DTES-2GS and to request their involvement as community partners. Members of the board of directors provided support for the project and expressed interest in being actively involved in designing the study. It was imperative to the community partners that they not merely be consulted but be active participants with meaningful influence over the research process. Toward this end, we secured financial support to carry out a workshop series with members of the community partners to identify issues that these organizations would like addressed in the evaluation and refine development of a patient-reported experience questionnaire. Specifically, the workshops aimed to identify:

1. What are the main unmet needs in the DTES?
2. What are the barriers and facilitators to care in the DTES?
3. What are important elements of a positive health care experience for PWUD accessing services in the DTES?
4. How can existing patient-reported experience measures be adapted to reflect a local understanding of health service quality?
5. How do Indigenous PWUD conceptualize 'culturally safe' care? That is, what do participants consider important for establishing an environment free of discrimination and racism, where people feel safe when receiving health care (First Nations Health Authority, 2015)?

The academic research team undertook an iterative and collaborative process with the community partners to plan the workshop series. An initial list of domains for the questionnaire were identified by the

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[1] The terms 'Indigenous' and 'Aboriginal' are used interchangeably throughout this paper to describe the Indigenous peoples of Canada inclusive of those who identify as First Nations, Métis and Inuit. Aboriginal peoples are defined in the Constitution Act of 1892 as inclusive of these three groups. These terms are used in this paper with acknowledgement of the great diversity of cultures, languages and traditions that exist among Indigenous Canadians.