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Negative experiences of pain and withdrawal create barriers to abscess care for people who inject heroin. A mixed methods analysis

Phillip J. Summers^{a,b,*}, Julia L. Hellman^{b,c}, Madison R. MacLean^d, Vaughan W. Rees^c, Michael S. Wilkes^b

^a Department of Global Health and Population, Harvard T.H. Chan School of Public Health, 665 Huntington Avenue, Building 1, Boston, MA 02115, USA

^b UC Davis School of Medicine, 2315 Stockton Blvd, Sacramento, CA 95817, USA

^c Department of Social and Behavioral Sciences, Harvard T.H. Chan School of Public Health, 677 Huntington Avenue, Kresge Building, Boston, MA 02115, USA

^d Department of Health Sciences, Bouvé College of Health Sciences, Northeastern University, 360 Huntington Ave., Boston, MA 02115, USA

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ABSTRACT

Background: Skin and soft tissue infections (SSTIs) are prevalent among people who inject heroin (PWIH). Delays in seeking health care lead to increased costs and potential mortality, yet the barriers to accessing care among PWIHs are poorly understood.

Methods: We administered a quantitative survey (N = 145) and conducted qualitative interviews (N = 12) with PWIH seeking syringe exchange services in two U.S. cities.

Results: 66% of participants had experienced at least one SSTI. 38% reported waiting two weeks or more to seek care, and 57% reported leaving the hospital against medical advice. 54% reported undergoing a drainage procedure performed by a non-medical professional, and 32% reported taking antibiotics that were not prescribed to them. Two of the most common reasons for these behaviors were fear of withdrawal symptoms and inadequate pain control, and these reasons emerged as prominent themes in the qualitative findings. These issues are often predicated on previous negative experiences and exacerbated by stigma and an asymmetrical power dynamic with providers, resulting in perceived barriers to seeking and completing care for SSTIs.

Conclusions: For PWIH, unaddressed pain and withdrawal symptoms contribute to profoundly negative health care experiences, which then generate motivation for delaying care SSTI seeking and for discharge against medical advice. Health care providers and hospitals should develop policies to improve pain control, manage opioid withdrawal, minimize prejudice and stigma, and optimize communication with PWIH. These barriers should also be addressed by providing medical care in accessible and acceptable venues, such as safe injection facilities, street outreach, and other harm reduction venues.

1. Introduction

In the United States, the number of people who inject heroin (PWIH) has been increasing over the past decade (National Survey of Drug Use and Health, 2016). Skin and soft tissue infections (SSTI) are a common and potentially life-threatening condition associated with injection drug use (Binswanger et al., 2000; Ciccarone et al., 2016; Summers et al., 2017). SSTIs also pose a substantial burden on health systems and are often the most expensive cause of hospitalization among people who inject drugs (PWID) (Stein and Sobota, 2001; Takahashi et al., 2010; Tookes et al., 2015). Furthermore, SSTIs are an acute and generally progressive condition that—without prompt, appropriate care—can quickly become severe and may develop sequelae, including

sepsis, endocarditis, septic emboli, or necrotizing fasciitis, which may further increase morbidity and health care costs for PWID (Gordon and Lowy, 2005).

PWID frequently present to health providers, especially emergency departments, (Degenhardt et al., 2011; Kerr et al., 2005) and have higher rates of hospitalization and mortality compared to matched cohorts of non-drug-users (Binswanger et al., 2008). For a variety of structural, financial, and personal reasons PWIDs often have limited access to primary or urgent care (McCoy et al., 2001). Because of real or perceived limits on access to care to the formal health care system, PWID often resorts to potentially harmful self-care behaviors (Fink et al., 2013; Pollini et al., 2010; Smith et al., 2014). While there is evidence that pain, withdrawal symptoms, and asymmetrical power

* Corresponding author at: 2315 Stockton Blvd, Sacramento, CA 95817, USA.

E-mail address: pjsummers@ucdavis.edu (P.J. Summers).

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dynamics between providers and PWIH create a “risk environment” of hospitalization, contributing to risk of leaving against medical advice or using illicit substances while hospitalized (McNeil et al., 2014; Merrill et al., 2002), but the role of these factors in health-seeking behaviors has not been explored. While many barriers arise from structural impediments—geography, access, cost, and insurance status—little research has been done among PWID to understand the role of social constructs, patient perceptions, and other underlying psychosocial barriers to early and ongoing engagement with care. In particular, PWIH confront additional, modifiable issues in the health care setting, namely increased tolerance to opioid pain medications normally given to reduce pain during and following surgical procedures and the unpleasant symptoms of opioid withdrawal when their addiction is not considered an active medical problem.

There is no shortage of evidence documenting negative attitudes and stigma held by health care providers and the general public towards PWID, but the implications for experienced pain and withdrawal in the health care setting have not been evaluated (Lang et al., 2013; Lloyd, 2013; van Boekel et al., 2013). While the barriers to care for chronic conditions affecting PWIH, including Hepatitis C and HIV (Treloar et al., 2013; Zeremski et al., 2013; Sarang et al., 2013) have been addressed in the literature, SSTIs have received minimal attention. Further, the barriers to SSTI care and the perspectives of PWIH regarding the roles of pain and withdrawal in their health decision-making by the SSTIs have not been addressed. We investigated the care-seeking experiences of PWIH with a history of SSTI, to understand factors associated with delayed care, including perceptions of health provider attitudes, perceptions of care they received, their experiences of pain control and withdrawal symptoms, and other structural barriers that may exist within the health care system, from the perspective of PWIH. A mixed-methods approach—including both qualitative and quantitative elements—was selected to provide generalizability and depth to our findings.

2. Methods

2.1. Setting and design

This mixed-methods study is a primarily qualitative study with quantitative follow-up, according to the Priority-Sequence Model (Morgan, 1998). The two components were 1) semi-structured interviews conducted with N = 12 PWIHs and 2) a structured survey administered to N = 145 PWIHs recruited from two urban areas in the USA: greater Boston, MA and Sacramento, CA, USA. This study's research question emerged during the initial qualitative phase of a larger study regarding abscess risk factors, previously published by this group (Summers et al., 2017). Once the themes were identified during these key informant interviews, the survey questions were expanded in response to this inquiry to understand trends and provide confirmation of the qualitative findings in the greater population of PWIH in these cities (Morgan, 1998).

2.2. Qualitative methods

The researchers gained access to the study population after volunteering with the partner harm reduction agencies over the course of months-to-years, building mutual trust and understanding with staff and clients. The study was conceptualized, designed, and implemented with expertise, feedback, and guidance from the staff at these partner agencies. In particular, the harm reduction staff was instrumental in identifying a purposive sample and quickly facilitating rapport with potential participants. The two cities, Boston and Sacramento, were chosen because of the relationships established in the harm reduction communities there during the corresponding author's training. Interviews were conducted by two researchers using a semi-structured interview script to assure mutual understanding of the interview goals

and open-ended questioning style. The interviews covered injection practices, experiences and understandings of skin infections, and behaviors around the care of abscesses, including health care experiences. Our sampling strategy maximized information-rich cases within the confines of our study resources by purposefully seeking a diverse sample. The needle exchange staff, who possessed a familiarity with the study populations, assisted in recruiting a purposive group of participants with varied viewpoints based on age, gender, type and duration of use, experience with SSTIs, and knowledge of local drug culture, which served to maximize information-rich cases and validate the findings across these perspectives. Prior to obtaining verbal consent, participants were informed on the purpose and components of the study using a standardized script and were specifically assured that all responses would be de-identified and recordings deleted to maintain anonymity, additionally, there would be no positive or negative ramifications of their participation in the study. Participants were included if they were actively used heroin based on self-report. This allowed us to explore topics of interest that were unique to PWID who are dependent on opioids, specifically withdrawal and difficulty with acute pain control due to opioid tolerance. Participants were excluded if they did not speak English or reported that they were under 18 years old.

The theoretical model we employed is most consistent with two previously described models describing health-seeking behaviors. The Health Belief Model (HBM) of health-seeking behaviors describes perceived severity, susceptibility, benefit, barriers, and cues to action. Perceived barriers are the most influential dimension of this model (Janz and Becker, 1984), which is consistent with our hypothesis, though no studies to date explore HBM in the context of PWID. The Conceptual Model of Medical Care Avoidance proposed by Taber et al., (2015) based on National Cancer Institute data and the Crisis Decision Theory (Sweeney, 2008) describes the response to negative events (i.e., a health event) as “first by appraising the severity of threat, next by identifying available response options, and lastly by evaluating available response options”. They describe the roles of four factors: perceived need to seek care, “traditional barriers to care”, personality traits, and “unfavorable evaluations of seeking medical care”. The latter category included themes such as physician factors, organizational factors, and affective concerns including pain and other aversive symptoms, which fits nicely with the concept of medical care avoidance we explored in this study. In order to be deterred by these unfavorable assessments of health care options, the patient must first acknowledge a need, then identify options, overcome the traditional barriers, and ultimately decide that possible benefits of engaging in health care do not outweigh their negative expectations of this interaction.

Interviews lasted approximately one hour, were conducted in a private room within the harm reduction agencies, recorded digitally, and transcribed verbatim by the researchers. Transcriptions were sent to a third researcher for coding and category formation using a general inductive approach, in which analysis is determined both by the research objectives (deductive) and through familiarity and analysis of the raw data itself (inductive). This approach is useful for condensing varied, raw data into categories and themes, which can then be linked to research objectives and, ultimately used to develop theories about the underlying processes (Thomas, 2006). Transcripts were read several times to identify themes and categories, after which a coding frame was developed, and the transcripts were coded according to this frame. Coding was performed using color codes and memoing in Microsoft Word and Excel. As new codes emerged, the coding frame evolved and transcripts were reread according to this structure. Open coding stopped once no new codes emerged. At this point, the iterative process was used to develop broader categories, which, through discussion, were expanded into larger, key themes. Through this iterative process of developing codes, categories, and themes, a Thematic Analysis approach was employed to develop the findings presented below (Vaismoradi et al., 2013). Due to the study design and limitations saturation was not specifically achieved through ongoing interviews.

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