DR. SOPHIA SCHROEDER (Orcid ID : 0000-0001-8611-7346)

PROF. CARLA TRELOAR (Orcid ID : 0000-0002-8230-0386)

DR. TIMOTHY R. BROADY (Orcid ID : 0000-0002-4341-1868)

PROF. MARGARET HELLARD (Orcid ID : 0000-0002-5055-3266)

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HEALTH SERVICE UTILISATION AND EXPERIENCES OF STIGMA AMONG PEOPLE WHO INJECT DRUGS IN MELBOURNE, AUSTRALIA

Authors:

Filip Djordjevic[1,2], Kathleen Ryan[1,3], Jack Gunn[1], Loren Brener[4], Daniel O'Keefe[1,2], Bridget Draper[1,4], Sophia Schroeder[1,5], Judy Gold[1,5], Carla Treloar[4], Tim Broady[4], Paul Dietze[2], Margaret Hellard[1,3,4,6,7], Alisa Pedrana[1,4]

[1]Disease Elimination Program, Burnet Institute, 85 Commercial Road, Melbourne, Victoria, Australia, [2]Behaviours and Health Risks Program, Burnet Institute, 85 Commercial Road, Melbourne, Victoria, Australia [3]Department of Infectious Diseases, The Alfred and Monash University, 85 Commercial Road, Melbourne, Victoria, Australia, [4]Centre for Social Research in Health, The University of New South Wales, Sydney, Australia, [5]School of Public Health and Preventive Medicine, Monash University, [6]Peter Doherty Institute for Infection and Immunity, 792 Elizebeth Street, Melbourne, Victoria, Australia, [7]School of Population and Global Health, University of Melbourne, 207 Bouverie Street, Carlton, Victoria, Australia

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Corresponding author: Filip Djordjevic, 85 Commercial Road, Melbourne, Victoria, Australia, filip.djordjevic@burnet.edu.au

Conflicts of Interest

PD has received an investigator-driven grant from Gilead Sciences for unrelated work on hepatitis C and an untied educational grant from Reckitt Benckiser for unrelated work on the introduction of buprenorphine-naloxone into Australia. He has served as an unpaid member on an Advisory Board for an intranasal naloxone product. MH receives funding from Gilead Sciences and Abbvie for investigator-initiated research.

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Abstract

While the testing and treatment of people who inject drugs (PWID) in Australia is a priority for local hepatitis C (HCV) elimination efforts, perceived stigma related to injecting drug use (IDU) has been identified as a major barrier for PWID engaging in health services. We used data from the EC Experience Cohort study to explore associations between IDU-related perceived stigma and the number of different health services accessed by PWID in Melbourne, Australia. Data from the baseline questionnaire were used. Primary outcome was self-reported experience of stigma due to IDU (never, rarely, sometimes, often, always) in the previous 12 months. An ordinal logistic regression model assessed the association between stigma experienced and the number of different health services used (1-2, 3-4, 5-6, 7-10 different services) adjusted for recent IDU and key socio-demographics. Between September 2018 and February 2020, 281 participants were recruited from four health services. Sixty-nine percent were male, median age was 42, 83% reported past month IDU, 34% had never tested/tested >12 months, 8% tested negative <12 months, 43% were HCV positive but not treated, and 16% had been treated. Those accessing 5-6 services had 2.2 times greater odds of experiencing stigma (95% CI 0.86-6.65) compared to those using <5 services, and those reporting 7-10 services had 2.43 times greater odds of experiencing stigma (95% CI 0.85-6.92) compared with those accessing <7 services. In conclusion, experiences of stigma may not necessarily be a barrier for PWID to access health services, but high rates of health service use may further expose, exacerbate or exaggerate stigma among PWID. Further examination of how stigma may be in/directly impacting on hepatitis C treatment uptake is important and place-based interventions aimed at reducing stigma experienced by PWID may be needed.

Keywords

Stigma, Barriers, People who inject drugs, Primary care, Injecting drug use

Significance Statement

The research presented in this paper uses baseline data from the Burnet Institute's Eliminate Hepatitis C (EC) Experience cohort study to explore how the number of different health services accessed by participants in the past 12 months is associated with self-reported stigma experienced in the 12 months prior to interview. The findings presented are of interest because they indicate a potential rise in experiences of stigma for participants that reported accessing more different services. We discuss potential explanations for these findings, as well as potential measures that could address stigma experienced by PWID in community and health service environments.

Introduction

The advent of direct-acting antivirals (DAA) has revolutionised treatment for hepatitis C virus (HCV). Compared to interferon-based treatment, DAAs are more effective (95% cure rate), have fewer side effects, a shorter treatment duration and are taken in tablet form[1]. In 2016, DAAs were made available in Australia, enabling access to treatment at low-cost to patients in primary care settings[2]. Injecting drug use (IDU) is the most commonly reported risk factor to HCV infection in Australia[3], and many HCV treatment programs in Australia are aimed at people who inject drugs (PWID)[4].

By the end of 2019, around 82,000 people had received DAA therapy in Australia, equivalent to 44% of the estimated chronic HCV population in 2016[1]. Encouragingly, treatment uptake appears to be proportionately higher for PWID than for others living with HCV. However, rates of uptake have declined in recent years, and unless barriers to testing and treatment are addressed, it is unlikely that elimination will be achieved by the WHO target of 2030[1,2].

One such barrier reported among PWID is the experience of stigma and its impact on accessing services[5]. PWID are marginalised members of society whose drug use practices and potential links to criminal activity are heavily stigmatized[6]. This stigma is associated with poor psychological wellbeing and physical health[6]. Specific to the healthcare setting, stigma has been shown to prevent PWID from seeking help or disclosing important, but stigmatised, health information, to health professionals, which in turn could impact the care they receive [7,8]. The experience of stigma among PWID may also negatively impact access to needle and syringe programs (NSPs)[9] and intention to seek HCV care [5].

Especially problematic is that healthcare settings have been found to be a prominent source of stigma for this population [7,10,11].

It is also important to note that stigma experienced by PWID in healthcare settings is not limited to drug use practices. In a critical review of HCV-related stigma, Harris et al. discuss the way stigma is 'embodied in and 'built' through physical or institutional structures'[12 (p. 9)]. This might manifest itself in the form of flagging and infection control procedures that are visible to the patient and go beyond what is necessary for controlling HCV infection, the absence of safe or dedicated spaces to disclose HCV status, a lack of HCV expertise in general health staff and an absence of specialist HCV staff[12].

This paper presents an investigation of the relationship between reported levels of IDU-related stigma and health service utilisation.

Methods

Participant sample

Data were drawn from the EC-Experience cohort study - a prospective, longitudinal cohort of current or historical PWID that aims to track progression through the HCV care cascade over time and to identify potential barriers and enablers to completing HCV treatment. Participants were recruited via four community health services that provide HCV care in Melbourne, Australia, including three community health services targeting PWID with attached primary NSP, and one private GP clinic with a high caseload of patients receiving opioid substitution therapy (OST). At each study site, approximately 70 participants aged over 18 years were recruited. Recruitment targets across three key stages of the HCV care cascade were as follows; n=30 not engaged in HCV testing (never tested or tested more than 12 months prior to recruitment); n=30 diagnosed with HCV, but not currently engaged in HCV treatment; and n=10 currently on or completed HCV treatment. The sampling rationale was to allow for sufficient statistical power to assess predictors of progression through the different stages of the care cascade. The 10 participants at each site who had initiated or completed HCV treatment were included as a comparison group. All participants gave informed consent before their participation in the study and ethics approval was obtained from the Alfred Hospital Human Research Ethics Committee on 18 August 2018.

Study data

This study draws on cross-sectional baseline data from 281 EC-Experience interviewer-administered interviews conducted between September 2018 and February 2020 (recruitment is ongoing). Two participants were excluded from the demographics and final analysis due to missing data on IDU-related stigma and education level.

Analysis strategy

The primary outcome for this analysis is self-reported experiences of IDU-related stigma. Using a previously developed tool for indicating stigma, participants were asked how often they had experienced IDU-related stigma in the past 12 months on a five-point Likert scale (never, rarely, sometimes, often, always)[13]. Ordinal logistic regression was performed to assess the statistical association between more frequent experiences of stigma and exposure variables. The primary exposure variable of interest was the number of different health services accessed in the previous 12 months. Interviewers read out a list of 10 service types, asking if the participant had accessed any listed health and/or community services (GP clinic, OST prescriber, drug and alcohol service, housing service, pharmacy, community health service, hospital (emergency, inpatient and outpatient counted separately), NSP and mental health service). The number of services accessed was categorised into 1-2, 3-4, 5-6 and 7-10 different services to create categorical groups for statistical analysis. The ordinal model also included gender (male/female); age (18-29, 30-39, 40-49 and 50+ years old); and past month IDU (yes/no) as potential confounders. Gender and recent IDU were chosen as potential confounders because it was expected identifying as female and actively injecting could increase levels of reported stigma[14].

We conducted a secondary descriptive analysis to examine whether experiences of stigma varied by types of services providers. Participants were asked how often they had been treated poorly or differently to other people at a service in the previous 12 months, differentiated by four service provider types: nurses, GPs, specialists at hospitals and NSP or community health workers. The aforementioned Likert scale responses were used, with an additional 'have not seen this service provider in the past 12 months' option.

Results

[Table 1 to be placed here]

Of the 281 participants, most were male (69%) and aged 30 and above (96%, Table 1). When asked how often they had experienced IDU-related stigma in the past 12 months, the most common response was 'never' (31%), followed by 'sometimes' (30%) and 'often' (17%).

As shown in Table 1, participants who reported accessing five or more health and social services had greater odds of reporting more frequent IDU-related stigma. However, this association was not significant in the adjusted model. While those accessing 3-4 services had slightly lower odds of experiencing stigma more frequently (aOR 0.86 95% CI 0.38- 2.46) compared to those using 1-2 services, the adjusted odds increased in step when compared to 5-6 and 7-10 services. Being female and reporting recent IDU showed a significant increase in odds of reporting IDU-related stigma in the adjusted model.

In the secondary descriptive analysis, experiences of stigma were least commonly reported in relation to engagement with NSP and community health workers, with 93% of participants reporting 'never' experiencing stigma from these healthcare providers. Stigma experiences at the hand of GPs, nurses and specialists were reported at similar proportions with between 66% and 71% of participants reporting 'never' experiencing stigma from these providers. However, between 4% and 8% of participants reported experiencing stigma 'often' or 'always' from these healthcare providers.

Discussion

This study provides a preliminary analysis of the association between the experience of IDU-related stigma and health service utilisation. Results suggest increased levels of self-reported IDU-related stigma were associated with a higher number of different healthcare services accessed in the 12 months prior to interview. While this association did not remain significant in the adjusted model, an increase in odds of stigma coincided with a higher number (five or more) of services accessed. Multiple studies have previously demonstrated that stigma is associated with an adverse effect in help-seeking behaviour and health service engagement for PWID[5,7]. In contrast to this previous work, our analysis suggests that PWID who access a greater number of health services are more likely to experience stigma at higher frequency, compared to PWID who access fewer services.

There are myriad reasons that could explain the relationship (albeit non-significant) between the higher frequency experience of stigma and the utilisation of multiple community and health services. PWID often experience varied and complex presentations such as poor physical and mental health and poverty[6]. Many of these factors are subject to societal stigma and marginalisation in and of themselves, and this stigma may be compounded for individuals facing numerous stigmatised issues. For example, an individual experiencing homelessness and poor mental health, who also injects heroin may need to access an NSP, an OST prescriber, a housing support worker and a mental health support worker. Having multiple health and social issues likely increases the need to access multiple services, some of which aren't specifically focused on supporting PWID. A consequence is the probability of being exposed to stigma increases in the very individuals who are most vulnerable and require multiple supports – further compounding the issue of stigma in this group. Stigma experienced by PWID has been associated with poor physical and psychosocial health[6], meaning the very experience of stigma may lead individuals to require greater support and service access. This pattern could be especially exacerbated for individuals needing clinical support, as clinical settings are a prominent source of stigma for PWID [7,10,11]. This narrative is partially supported by our results where stigma was more commonly reported from nurses, GPs and clinical specialists, than it was from NSPs and community-health workers (i.e. services directed towards PWID). Finally, for some individuals, it may be the experience of stigma that drives the utilisation of multiple services. Whilst it might be expected that the experience of stigma may cause an individual to disengage from services entirely, it may also be that individuals who experience stigma at a particular service eschew that service in favour of another (as Biancarelli et al[7] pointed out), which in turn opens the opportunity for the experience of stigma from a new source.

Regardless of the underlying explanation, experiences of stigma in health services may impact willingness to disclose certain practices such as IDU for fear of being further stigmatised or discriminated against[7,8]. Like this study, Wilson et al[15] reported that study participants recruited from NSPs described higher levels of stigma from general healthcare workers as compared to NSP workers. To address stigma stemming from these healthcare workers, the ways in which providers interact with patients with a history of IDU could be improved. Interventions such as online training modules and integration of peer workers have been shown to be effective in reducing stigma and encouraging PWID to engage with health services, respectively[16,17]. Our finding of participants experiencing less stigma from NSP and community health workers also demonstrates a need for more low-threshold and integrated care targeted towards substance use. Also on a systemic level, the Joint United Nations Programme on HIV/AIDS (UNAIDS) recommends decriminalisation of drug use and possession[18]. It is argued that such an approach would reduce stigma and discrimination that currently 'hampers access to health care, harm reduction and legal services.[18]

The findings relating to gender and stigma are consistent with literature reporting that women experience greater stigma than men because they are possibly perceived as 'bad women', in differentiation from standard gender-role expectations[14]. Additionally, participants who did not report recent IDU may have reported less IDU-related stigma because it has become easier for them to 'pass' as someone who does not inject drugs[19].

The main limitation of this study is its small sample size, particularly in the reference category of the exposure variable of interest. There were no data collected on how often each service was accessed, nor which practitioners were seen at different services, which could have provided a more detailed account of service utilisation. Service type was not differentiated in the analysis, which would have allowed for a more detailed analysis. Participants were asked about HCV-related stigma, however, given that we recruited participants based on HCV status, we chose not to use this as the outcome for analysis. Finally, the cross-sectional baseline data does not show how differences in exposure and outcome can change over time; longitudinal data collection is ongoing and further analyses are planned once this data is available.

While previous studies suggest that stigma may limit healthcare utilisation, we found that PWID who reported a higher frequency experience of stigma were accessing multiple healthcare services. Analysis also showed that PWID may experience greater stigma when engaging with GPs, nurses and specialists; whilst NSP and community health care workers were associated with lower levels of experienced stigma. In response, some PWID may choose not to disclose their IDU status when receiving healthcare for fear of stigmatisation, thereby impeding optimal healthcare. Evidence-based interventions such as stigma training for health service staff and integration of peer worker should be explored to potentially reduce the experience of stigma among PWID presenting at health services.

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Table 1. Characteristics of sample and results of ordinal logistic regression to assess association of number of different health services on higher levels of stigma. N=281

	N (%)	OR	95% CI	aOR	95% CI
Gender					
Male	195 (69)	reference		reference	
Female	86 (31)	1.72	0.97-3.09	1.7	**1.07-2.76***
Age					
18-29	11 (4)	reference		reference	
30-39	94 (33)	2.11	0.56-7.95	1.84	0.61-5.54
40-49	110 (39)	1.28	0.35-4.66	1.01	0.33-3.05
50+	66 (24)	0.73	0.20-2.73	0.74	0.23-2.34
IDU past month					
No	48 (17)	reference		reference	
Yes	233 (83)	2.43	1.29-4.59	2.38	**1.30-4.36***
Services accessed past 12 months					
1-2 services	19 (7)	reference		reference	
3-4	109 (39)	1.60	0.61-4.16	0.86	0.38-2.46
5-6	109 (39)	3.54	1.32-9.50*	2.20	0.86-6.65
7-10	43 (15)	2.91	0.95-8.85*	2.43	0.85-6.92
IDU-related stigma					
Never	87 (31)				
Rarely	33 (12)				
Sometimes	83 (30)				
Often	48 (17)				
Always	30 (11)				
HCV cascade status					
Never tested	22 (8)				
Tested negative >12m ago	74 (26)				
Tested negative <12m ago	21 (8)				
Tested positive, not treated	120 (43)				
On or finished treatment	44 (16)				
Employment status					
Full time	11 (4)				
Part time/casual	17 (6)				
Not employed	253 (90)				
Level of education					

Primary to 9	96 (34)
10 to 12	141 (50)
Post-school qualification	44 (16)
Aboriginal and Torres Strait Islander status	
Aboriginal	31 (11)
Country of birth	
Australia	230 (82)
Other Country	51 (18)

*Significance level p<0.05 OR=Odds Ration aOR=Adjusted Odds Ratio