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# Normalised pain and severe health care delay among people who inject drugs in London: Adapting cultural safety principles to promote care



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#### ABSTRACT

In the United Kingdom, increases in premature mortality among the intersecting populations of people made homeless and people who inject drugs map onto the implementation and solidification of fiscal austerity policies over the past decade, rather than drug market fluctuations and trends as in North America. In this context, it is crucial to explore how poverty, multi-morbidity and care delay interplay in exacerbating vulnerability to mortality among an aging population of people who use illicit drugs. The mixed methods Care & Prevent study generated survey data with 455 PWID and in-depth qualitative interviews with a subsample (n = 36). Participants were recruited though drug treatment services and homeless hostels in London from October 2017–June 2019. This paper focuses on qualitative findings, analysed thematically and contextualised in relation to the broader survey sample. Survey participants report an extensive history of rough sleeping (78%); injecting-related bacterial infections (65%) and related hospitalisation (30%). Qualitative accounts emphasise engagement with the medical system as a 'last resort', with admission to hospital in a critical or a "near death" condition common. For many severe physical pain and debility were normalised, incorporated into the day to day. In a context of everyday violence and marginalisation, avoidance of medical care can have a protective impetus. Translation of cultural safety principles to care for people who inject drugs in hospital settings offers transformative potential to reduce serious health harms among this population.

# 1. Introduction

Deaths among the intersecting populations of people who inject drugs (PWID) and those made homeless in the United Kingdom (UK) have risen exponentially over the past decade (ONS, 2019a, 2019b). UK surveillance data demonstrate increases in mortality, morbidity and health system burden associated with injecting-related infections (Public Health England, 2019), but provide little insight into the contextual and social relations informing health harm risk and treatment access. This paper draws on mixed method data generated for the Care & Prevent study with 455 PWID, many of whom report rough sleeping and injecting-related hospitalisation, to explore the dynamics of medical care seeking and avoidance among the most marginalised. Sample demographics are comparable to those of PWID represented in UK surveillance data (Doran et al., 2020). Findings presented focus on qualitative accounts, from a subsample of survey participants, to illustrate both the severity of health harms incorporated into daily lives and the structures that inform care delay.

The UK is not the only context for a dramatic rise in drug-related deaths. The drug overdose crisis in North America is well documented, with deaths rising from 38,329 in 2010 to 70,237 in 2017 (National

Institute on Drug Abuse, 2020). This due in part to changes in opioid prescription availability and use and contamination of the black-market heroin supply with the potent synthetic opioid fentanyl (Ciccarone, 2019). Over a similar period, 2012–2018, opioid-related deaths doubled in the UK, with the 14% increase in drug-related deaths from 2017 to 2018 larger than that of the previous three years combined (Office for National Statistics, 2019b). Deaths specifically involving heroin use increased by 12% to 1206 in 2018, with the highest proportion occurring among those aged 40–49 years old. While the scale of this increase pales in comparison to the overdoses decimating North American populations, its causal factors warrant close examination.

Unlike North America, the UK black-market drug supply is relatively stable and rarely contaminated with high strength opioids such as fentanyl. Increases in morbidity and mortality appear to map the implementation and solidification of fiscal austerity policies, first instigated in 2010 by the coalition Conservative government, rather than vagaries in illicit drug use and supply. Since this time there has been a steady increase in hospitalisations for serious injecting-related infections (Lewer et al., 2017) and deaths among growing populations of people made homeless. In 2018, 726 deaths were registered for homeless people, the highest annual increase to date. Of these, 294

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deaths were attributed to drug poisoning (Office for National Statistics, 2019a). Mortality statistics require cautious interpretation, particularly when informed by Automatic Cause Coding Software. This system, used since 1993, captures specific terms on the death certificate (Office for National Statistics, 2019b). For people who use illicit drugs regularly, drugs are likely to be recorded if evident in the environment but may not have contributed to or caused a fatality. For many, the causes of death are both more mundane and multifaceted. A recent populationbased cohort study of 6683 people who use heroin in London, for example, reports premature mortality as mostly due to common noncommunicable diseases such as cancer (Lewer et al., 2019). Noted are disparities in cancer management and outcome between the cohort population and those not recorded as using drugs. While the cohort population were twice as likely to die from cancer, they were half as likely to have a hospital admission for cancer treatment, indicating barriers to timely presentation, diagnosis and care.

In this context, it is crucial to unpack how poverty, multi-morbidity and care delay interplay in exacerbating vulnerability to mortality among an aging population of people who also use drugs. This necessitates a shift of focus from individual practice and drug supply as crucial points of intervention, to the systems and structures that can render health care access problematic for the most marginalised. People who use illicit drugs and those who are unstably housed, face myriad barriers to health care access, many of which are well documented. These include feeling marginalised, judged, medicalised and/or criminalised in relation to drug use (McCall and Pauly, 2019); being stigmatised due to wound odour or appearance of homelessness (Varley et al., 2020); struggling to navigate unfamiliar environments and unequal power relations with medical professionals (Harris et al., 2013). A nascent qualitative literature on delayed care seeking for injecting-related skin and soft tissue infections (SSTI) notes the impact of prior negative experiences of care (R. Harris et al., 2018; Phillips et al., 2013; Small et al., 2008). For many, hospital attendance is associated with pejorative treatment and intense embodied discomfort (unrelieved drug withdrawals and/or pain). Restrictive opening hours and competing priorities create additional barriers to timely attendance (Small et al., 2008). Dunleavy et al. (2019) emphasise the role of individual awareness and recommend that educational interventions 'emphasise the unacceptable consequences of SSTI' to promote timely care access as a means of stigma avoidance.

Stigma is a well-established structural barrier to healthcare utilization (Paquette et al., 2018). Stigma, as systemically embedded and un/consciously enacted during health care interactions (McCall and Pauly, 2019), is key to understanding care delay – but also the way in which people account for it. Data drawn on in this paper include participant accounts similar to those reported by Dunleavy et al. (2019). Offered, however, is a different reading. One that considers each narrative as multiple rather than singular – as providing firstly an anchor and protection against the weight of perceived judgement (akin to a 'front-stage' presentation of self, Goffman, 1956) which can then give way to a more fragile 'back-stage' account. As elaborated in the discussion, these narratives of care delay can be seen to speak both to normative expectations of what it is to seek care and be a responsible citizen as well as reflecting the violence imposed by this discourse and the structures that support it.

Thinking with, as well as about, care (Puig de la Bellacasa, 2017) requires not only critique of the structures and violences perpetuating morbidity and mortality among the most marginalised, but engagement with the concerns of those tasked to provide care. Following Pauly et al. (2015), I close by reflecting on the transferability of cultural safety principles from nursing care with indigenous populations to care for people who use illicit drugs. Thinking with cultural safety requires consideration of the way in which dominant cultural expectations of care seeking and systems of health care can be experienced as unsafe by marginalised populations. This necessitates a shift of view from an individualised focus on dependant drug use as a moral or medical

affliction to consideration of drug use as relational, as a culture, that – as with indigenous cultures – requires recognition of inequity and structural modification to facilitate improved health care access and outcomes

### 2. Methods

Care & Prevent, a mixed-method study, explored SSTI prevention, risk, care and sequelae among PWID. Data generation methods comprised a researcher-administered computer-assisted survey, urinalysis for proteinuria and qualitative interviews. Study rationale and methodology details are published (Harris et al., 2018). Participants were eligible if they were over 18 years old and had a history of injecting psychoactive drugs. Recruitment took place through specialist drug services, homeless hostels and day centres across London. The study followed a convergent design; quantitative and qualitative data generation were concurrent, with qualitative interviews continuing for an additional three months to extend and explore survey findings. This paper focuses on presentation of qualitative data and analyses.

Questionnaire data were generated from October 2017 to March 2019 with 455 PWID in London, of whom a subsample were invited to take part in a qualitative interview. Qualitative data were generated from October 2017 to June 2019. Interview participants were purposively sampled for variation in age, gender, injecting history and experience of SSTI. Interviews were of 60–120 min in duration, audiorecorded with consent, and conducted in a private room at a recruiting service, a café or the participant's home. Qualitative interviews were undertaken by the author, who has a history of injecting drug use. Where appropriate, this history was disclosed to participants and/or decerned by them (see Harris, 2015). Interviews were conducted in a conversational style, informed by a topic guide addressing life history, drug use trajectory, injecting and living environments; health issues and care practices.

Qualitative data generation aimed to explore how participants experienced, understood and accounted for injecting-related injuries and infections; how these impacted on health and wellbeing; and the contexts and social relations in which health care practices were enacted or constrained - both in relation to SSTI and more broadly. Analysis followed steps outlined for convergent design projects whereby each dataset is initially analysed separately using the appropriate qualitative and quantitative analytic methods, with results compared to inform the direction and questions asked of further analyses and data generation (Creswell and Clark, 2011). Final triangulation of mixed-methods data prioritised complementarity (findings greater than the sum of their parts), while also attentive to convergence and dissonance (Farmer et al., 2006). Survey analysis for example, highlighted an association between severity of infection and the time taken to seek healthcare. As reported in detail elsewhere (Wright et al., 2020), 60% of survey participants with an SSTI reported taking five or more days to seek medical advice after first noticing symptoms. This duration has been used as a measure of care delay (Hope et al., 2015) and reflects medical guidance that care should be sought immediately for bacterial infections (NHS, 2018). Early indications of these findings informed a qualitative focus on understanding the contexts of care delay, as reported in this paper.

Audio-recorded interviews were transcribed verbatim and entered into NVivo 12 for data management and analysis. Qualitative analysis was informed by constructivist grounded theory methods (Charmaz, 2013) with data analysed as generated in order to inform the direction of subsequent interviews, coding, case selection, memo and theory generation. Given a constructivist orientation, analyses were attuned to the construction of narrative accounts – as informed by the context of the interview encounter, the positionality of the interviewer (as an 'exinjector'), as well as social norms and expectations of what it is to care for the self and seek care. A strict demarcation of 'findings' (data) from 'discussion' (interpretation) can reify a false binary between the voice of the participants and that of the author, obscuring the co-construction

of accounts generated through embodied and verbal interaction (Harris, 2015). As such, analytic presentation of empirical data intertwines with the authors voice and interpretation.

Analysis began alongside data generation, initially through field and memo notation. The first five transcripts were line-by-line open coded by the author, using process or gerund codes (Charmaz, 2013). In consultation with team members, inductive open codes were consolidated into focused codes. These formed the basis of a coding frame, comprising 13 'first-level' codes or categories. The coding frame was entered into NVivo and two researchers coded the same four interviews against the 13 categories before the author coded independently. Second-stage coding comprised inductive open coding of the data in each category to inform analytic interpretation and theme development. The first level 'seeking, avoiding and receiving care' category for example, comprised six second level codes: finding a tipping point; navigating hospital systems; negotiating medical care; practicing selfcare/constraints against this; accounting for care delay. This paper comprises data from the "accounting for care delay" code. Inductive analysis of this code generated two orientating concepts, time and hope, which structure findings reported here. In this way, analysis has been an iterative yet systematic process, conducted inductively with attention to consistency as well as movement toward abstraction and theory generation.

Ethical approval for this study was granted by the London Bridge Research Ethics Committee, the Health Research Authority [17/LO/0872], and the London School of Hygiene & Tropical Medicine Observational Research Ethics Committee [12021]. All participants provided written consent; all names used are pseudonyms. Participants received a £10 voucher for the survey and £20 for qualitative interview.

# 3. Participants: SSTI risk and demographic context

The survey sample comprised 455 people with a history of injecting drug use. Demographics align with characteristics of PWID recorded in national surveillance data (Doran et al., 2020); predominately male (75%, n = 341), of White ethnicity (74%, n = 336) and a mean age of 46 years. The primary drug injected was heroin, either alone (44%, n = 199) or in combination with crack cocaine (49%, n = 255). Two thirds (63%, n = 284) report injecting in the last 12 months, with 79% (n = 360) currently receiving opiate substitution therapy (OST). On average, participants commenced injecting at 25 years old, with 42% (n = 192) injecting for over 15 years. Only 6% (n = 26) report full or part time employment. Lifetime history of street homelessness was high, at 78% (n = 355), with 207 (45%) reporting current rough sleeping or hostel accommodation. Most participants had experienced an SSTI (65%, n = 296), leading to hospitalisation for 46% (n = 137). Most (70%, n = 206) sought medical care for an SSTI, with the majority primarily using accident and emergency (A&E) hospital services (72% n = 149/206). As noted above, 60% (n = 124) took five or more days to seek care, of whom 46% (57/124) took ten days or more.

Qualitative interview participant demographics largely aligned with those of the survey sample. Of the 36 consenting to interview, 28 were men (78%), 29 identified as White British (81%), with an age range of 21–62 years (mean 46). Just over half (58%, n = 21) had been injecting for 15 or more years, with 20 (56%) reporting femoral vein injection. Of those injecting in the past 12 months (75%, n = 27) most (89%, n = 24) primarily injected heroin and crack cocaine in combination. Experience of street homelessness was overrepresented, with all but one (97%, n = 35) reporting a history of rough sleeping. Participants were asked about their primary accommodation over the past 12 months. The majority (64%, n = 23) were unstably housed (hostel, street homeless, jail/prison, sofa surfing) of whom six (17%) were currently rough sleeping. A history of SSTI was reported by 26 (72%), of whom 15 (58%) experienced a related hospitalisation.

These demographic data provide context to SSTI risk. SSTI tend to impact the most marginalised: those who are homeless or unstably

housed, who live with multi-morbidities and economic insecurity (Coull et al., 2014). Bacterial infection risk is informed by a complex interplay of injecting practice (rushed injecting, compromised hygiene), injecting environment (poor lighting, hygiene, privacy), social and power relations (being injected by another, sharing equipment), service access (injecting equipment, wound care, injecting advice), policy environment (drug prohibition, abstinence-orientated services) and vein viability (physiology, duration injecting, drug solution acidity). Difficulty accessing damaged peripheral veins in the arms can necessitate a transition to subcutaneous or intramuscular (IM) injecting or use of more dangerous veins in the neck (jugular), groin (femoral) or legs. This exacerbates bacterial infection risk, with femoral and lower limb injecting potentiating venous insufficiency, deep vein thrombosis and chronic leg ulceration. Abscesses and cellulitis are among the most common injecting-related SSTI. Both are traditionally treated with antibiotics, which if actioned quickly can enable swift resolution. Medical guidance emphasises urgency in seeking care for cellulitis, to prevent invasive infection (NHS, 2018). Abscesses can require incision and drainage, which if performed in a non-medical setting can exacerbate infection. Systemic infections, such as septicaemia and endocarditis, are potentially fatal and require specialist inpatient intervention.

### 4. Living with injecting-related injury and illness

Participant accounts of living with injecting related injury and illness provide insight into the contexts informing SSTI risk as well as care delay. Homelessness, subcutaneous and femoral vein injecting are mentioned by many – not as explanatory, but as a backdrop to lives in which illness is often incorporated and medical care eschewed. Many accounts shock with a visceral intensity and highlight complications unforeseen by the author. Four male participants, for example, spoke of blood spontaneously erupting from their groin, indicating an injury arising from femoral injecting:

It was mad, like I was homeless and the right side [of the groin] would just randomly, out of nowhere, it would just burst with blood, like blood everywhere! Literally everywhere, within ten seconds my entire trousers would be covered in blood. (Lee)

All emphasise a large volume of blood and its sudden, unexpected, occurrence; injecting-related injury made visible in the context of their daily lives:

I was on my way down here [drug treatment service] and it [my groin] haemorrhaged, it was like I'd been shot. Blood everywhere. Blood everywhere, you know? (Ryan)

Apart from one man whose groin haemorrhaged in a café and was rushed by ambulance to hospital, medical care was not sought. Ryan turned back from the drug service: "I went back home ... I had to get home to get changed and jump in the bath and different clothes and all that". Lee refused help from his dealer:

He turned up in a car and just as he turned up it burst ... he was like, what the fuck man, what's going on! And I said, oh nothing-nothing. He was like, come on, get in, I'm taking you to hospital and that. Even the dealer was like worried about it. But I was like, no-no.

Both men got on with their lives as best they could, Lee self-managing his wound for a week until it stopped discharging blood:

I covered it and I held it for about ten minutes and in that ten minutes I'd go like that [pressing down] and it would just [gushing sound] but then after about ten minutes I moved the towel away and it had stopped.

Accounts of incorporating injecting-related injuries and infections into the day-to-day were common. Systemic infections and illnesses, ranging from pneumonia to endocarditis and septicaemia, were also incorporated or ignored for as long as possible. This could lead to

hospital admission in a 'near death' state, as Jade relates:

I got really, really sick and I noticed that my side was hurting me and I couldn't catch my breath, I had to breathe three times before I could get one breath, I had pneumonia and I went home ... stayed in my bed for a couple of days ... I wouldn't go to the hospital still, I just thought it was just a fever and I would get over it, but then I started spitting up blood .... she [friend] called the ambulance, it took me, I don't even remember, I was delirious, when I got to the hospital the doctor said if you didn't come in the night, you would have died, you would not have been here to talk about it, they would have picked your body up from your house.

When asked "what stopped you going in earlier on that occasion?", Jade replied: "I don't know, I'm just not a person that, I have to be dying before I'll go to the hospital, I think that's what it is with me." This answer gives little away. Jade attributes hospital avoidance to her personality, a stoic resolve. As illustrated across accounts, attributions of personal culpability and will (both strong and weak) are commonly called on by participants when first asked to make sense of care delay.

Marie, for example, repeatedly cites 'laziness' when speaking of the three years she lived with painful abscesses on her buttocks before seeking medical care. This 'laziness' is situated in a context of long days generating money on the street:

Probably about three years [before seeking care], because I was still sitting on the street begging ... I was sitting on cold, I was sat there for 12, 14 hours a day ... year in year out. So basically, all that pressure on the sores and there is no blood circulating ... and just basically nothing was working, in my body.

When Marie finally sought care, it was at a critical state – necessitating surgical debridement of each buttock, with risk of limb amputation. She reflects on those years and why she did not seek help: "there wasn't time, I just thought what's the point, what's the point, there wasn't any point." This poverty of time and hope repeats through and across participant narratives. Marie's words are well placed to frame an exploration of care delay as well as its narrative structure.

# 5. Understanding care delay: time

# 5.1. 'There wasn't time': taking care of business

Marie sat for 12–14 h a day on a cold concrete footpath in order to generate money through begging, day in day out, for more than ten years. She had a flat where she would go to sleep and prepare her drugs. "There were needles everywhere ... needles even in the skirting, the boiler cupboard". She eschewed the facilities that a home could afford, citing poor 'hygiene' as a reason for infection: "I never had a mirror ... my hands were always dirty, imagine being a beggar on the street, my hands were always dirty, I never ever bathed". Despite increasing pain and discomfort, her focus was clear:

It's just the abscesses one after the other after the other and it started getting worse and it started building up and going down, and building up and going down and eventually I had no bum ... All I can remember at the time was thinking I need money, I need money. And that was it ... That's where my focus was just getting £120 to £140 a day.

It can be hard to make sense of such a story, particularly in the context of Marie's former life. She demonstrates her past through photographs – I saw a well-travelled personal trainer, a dedicated long-distance swimmer. This life is now a memory; Marie's temporal orientation is necessarily short term. The generation of money to alleviate sickness creates the new rhythm of her life.

This rhythm is pressing and, as Bourgois writes, structuring; "ironically, opiate addiction creates order out of what appears at first sight to be chaotic lives that have spiralled out of control" (2010:240). The

quest for bodily intensity and relief provides a self-contained purpose: it is "the first thing you think of when you wake up and the last thing you think of when you go to sleep" (Dean). Preble and Casey (1969) provide a seminal account of illicit drug use as a 'career', as an active "taking care of business" on the street. Unlike most legitimate professions the street hustle provides few opportunities and protections for time out. The money has to be made – and in the case of generating £120–140 a day – it is a full-time job. Time poverty, more than material poverty, runs through participant's narratives like a mantra. Their days are busy and purposeful; despite physical pain, medical care is not a priority:

"When have I got time for hospital?" (Jav)

I ain't got time for nothing except for drugs innit? (Kirsty)

"Who's going to wait [at A&E] four hours?" (Dev)

"I was too busy ... I was in a lot of pain ... I didn't have time" (Jade)

I'm going to be kept in [hospital] for days on end, like oh no! (Lee)

You ain't got time to run around [seeking care] if you need to make money and go and score and stuff like that. (Dean)

This is often a false economy, saving time in the now heightening chance of hospitalisation in the future. As injecting injuries progress into complex health problems, what was most feared becomes inevitable. Realising this, the imperative is to ward against withdrawal in the hospital setting; further exacerbating delay.

### 5.2. 'I wait to the last minute': stockpiling for hospital

Fear of being admitted to hospital without adequate OST provision, illicit drugs, or the money to purchase drugs while an inpatient, precluded medical engagement for many. Even when participants expressed a strong intent and desire to access care, the requisite money or drugs needed to be sourced and stockpiled first. Given the demands of living on the streets, this goal was often just out of reach. Jade tells of another episode when the large abscess on her arm became too painful to bear: "as long as I didn't have the money I wasn't going to the hospital, [although] I needed to go". When she finally got to A&E, hospitalisation was unavoidable. Lack of timely OST provision then precipitated her self-discharge with a large unhealed post-operative wound:

They give you a dose of Methadone in the hospital but you have to wait for the doctor to consent, so I'm waiting days, by the time I wait for the doctor I'm sick as a dog so I end up checking myself out to go and get drugs because I needed drugs because I'm kicking like Bruce Lee ... I felt like I was going into convulsions, so I leave ... sick as a dog, arm bandaged up, I have to go out and find some money to get high, thank God that I found something.

Jade also purchased bandages from a pharmacy, dressing and cleaning her wound until it healed. These bandages afforded a protective and concealing barrier; vital for the continuance of street-based sex work: "tricking, you know what I'm saying, no man wants to see this ... I'm really trying to keep it hidden."

This need and prioritisation (of money generation and drug supply, over medical care) sits uncomfortably with normative expectations of what it is to care for the self. People who use drugs are not immune to these expectations, often internalising judgement for failing to meet them. Ross' initial narrative of care delay also references time, but in a way that is both self-depreciating and abstracted – he is the ubiquitous irresponsible 'junkie':

When I had endocarditis it was like the worst pain .... of course I'm a junkie so I wait until the absolute last minute to go to hospital but then as soon as I went to hospital they pulled me out the line, the nurse said, he's septic, I was turning yellow and then I was there for five weeks .... I was still using when I obviously had this endocarditis, I was still using and it got to the point where I couldn't

breathe and when I'm using I procrastinate, everything's tomorrow, everything, I'll sort myself out [with drugs] and that's why.

When asked to talk more about this time, fear enters the picture:

Severe pain [for three weeks] and then when I'd have a hit of heroin it would work, it would stop the pain for about two minutes and then I'd be back in pain and then I had a fever and then eventually my girlfriend phoned the ambulance, at the time ... Scared, it's the fear of the not having drugs at the time and that sounds pathetic. ... I wasn't on the script, no.

For Ross, there is some shame attendant on admitting fear, 'it sounds pathetic'. The first narrative, while depreciating, demonstrates agency. Procrastination is purposeful, 'I'll sort myself out'. In the second, he is rendered vulnerable – potentially unable to sort himself out and without the legitimation of an OST prescription to obtain relief from opiate withdrawal through the hospital system.

Having an OST prescription in place did not, however, assuage anxieties about seeking care – particularly if hospitalisation appeared imminent. Ray spoke of living on the streets with swollen painful leg, waiting "to payday so I can go into hospital with a few bits [drugs], you know, and in case they don't give meth[adone] or whatever". But when he woke one morning unable to walk, hospitalisation became inevitable:

It turned out I had a blood clot in my groin and just above my knee, under the thigh and this bit here was fluid, oh, all the blood clots were infected with streptococcus ... my leg was just really big and swollen and then when I started getting the treatment all these ulcers started appearing all over my leg, I'm like, oh, oh, fucking hell.

Elaborating on how his leg came to get this bad, Ray notes fear of discrimination and of opiate withdrawal:

Mainly because how I have been treated at the hospitals, which is just like fucking dirt you'd find on your shoe, but I would say it was equal parts of that, and also being scared that I was going to be rough [sick] ... because if they didn't [give] me Methadone, like someone's said he [doctor] won't do it unless he would have to, and if you don't know your rights, but yeah, it was that that really scared me more than anything, was being sick [in withdrawal] in a hospital. (Ray)

In this scenario agency is limited; Ray is dependent on and vulnerable to a rigidly bureaucratic system. Continuity of prescription care is not guaranteed for those on OST, particularly at the hospital local to many participants. Here, current protocol states that a laboratory urinalysis result must be obtained before OST is dispensed, even when the patient's prescription is verified by their pharmacist and/or drug treatment centre. By the time the laboratory results are back, some will have self-discharged.

# 6. Understanding care delay: hope

# 6.1. 'What's the point': poverty of expectation

The incorporation of pain and debility into daily life is a viable option when there is little hope for any meaningful help, or sense of worth that this help is deserved. Ian makes sense of delay for injecting-related conditions in these terms:

You look at the world and say if I become ill there must be something out to get me otherwise I wouldn't be ill, and that's why they don't go for treatment, because they think I'm not winning, I'm losing, because I'm losing this is going wrong, it's going to keep going wrong.

Here, 'care', might lead to something more detrimental – for a perceived 'self-inflicted' condition, treatment could be punitive or cause additional harm:

It's being so scared at turning up at the hospital and when they've got an ulcer, somehow that just turns it into "oh we're going to cut your hand off", seriously, it's scared. People just are very scared to turn up at a hospital. (Ian)

As Ian intimates, resisting medical care can have a protective impetus. Anticipating harm or thwarted agency in an unfamiliar and potentially hostile system, many incorporate debility or practice self-care. Dan avoids perceived iatrogenic harms by attending to his own abscesses: "if you go to hospital they will lance it and that leaves a scar".

Potential scars to be avoided are not only physical but emotional. Participants were alert to signs of negative judgement, and often had their own well honed. Ryan, one of the men who did not seek care for a femoral haemorrhage, accounts for his injury in these terms:

That's when the trouble started, when I started using my groin ... it was never getting time to heal, it was that many hits, it was like cutting myself slowly, very slowly, and it's never healing, the blood's gone into your leg quicker than I was able to get it out. (Ryan)

Ryan's account, of 'cutting myself slowly', evokes self-harm and personal culpability. This is potentially magnified in the context of femoral injecting. Often positioned as 'a last resort' or boundary not to be crossed (Rhodes et al., 2006), groin injecting and its associated complications can weigh heavy on the conscience. Given the weight of a personal boundary crossed, exposure to the judgement of others may also be avoided at any cost.

For women, drug use alone carries this weight. To be known as a woman who injects is to face social abnegation and potentially risk claim to a mothering role. Kirsty fears what might happen if she doesn't attend hospital for an injecting related injury: "Could turn into blood poisoning, you can die. I don't want to die, I've got children", but for now she will not seek care. She explains why:

Like scum innit? ... Course you're gonna get treated like that. It's obvious they're gonna treat you like that, if you're on drugs. It's horrible really because you're scared to tell them [that you inject].

Participant accounts of being turned away, accused of drug-seeking and experiencing shame and stigma when care seeking are multiple; too many to elaborate here. They demonstrate however, that the hope and worth required to seek care are often negated by the very services tasked to provide it.

For those unable to hide their injecting practices or associated injuries, perceived judgement extends beyond medical disclosure. Alex attunes to reactions of others in the hospital waiting room, where he occasionally goes to get his ulcers dressed: "when you go into the A&E smelly legs and that, it's fucking embarrassing man, having to sit there and people looking and you know, yeah, it's horrible." Participants with chronic leg ulcers had little control over the pervasive 'outing' of odour – conveying the abjection of an untended wound or unwashed body. Sai describes:

sitting on the bus and people were going [inhales] because you could smell pus coming out the leg ... these were ulcers and abscesses or abscesses that turned into ulcers sort of thing.

He rarely sought care but "just plodded along, got my drugs" - debility and pain incorporated into the day to day. There is a resistance here. Unlike Alex, Sai does not speak of experiencing shame but displays quiet stoicism, continuing to sit on the bus, to live his day-to-day life in the face of others disquiet.

# 6.2. 'What's the point': normalised pain and resistance

Participants were no strangers to pain. Indeed, delaying care for injecting-related injury necessitates living with often severe physical pain and debility. For many, this pain was normalised, incorporated into the day to day. Katy describes living with the pain of cellulitis as

"part and parcel". Dean speaks abstractly of seeking help, but he has grown used to living with debility:

Just my health doesn't, it doesn't seem to bother me, like, that I'm not well ... I can't breathe sometimes, I struggle to get to the chemists to pick my Methadone up ... I should get my lungs checked out, as well, they're bad and, as I say, I've got an abscess.

Dean also points to his thigh, noting it had been severely swollen and painful for some time. When asked if he'd consider seeking medical advice, he replied:

I don't know, it just doesn't seem that important to me. Oh, it hurts, like fuck, it's very painful. Yeah, I should, I might, yeah, I'll give it a go. I know, it's dreadful, ain't it, what we do to ourselves.

'What we do to ourselves' is inclusive – the interviewer, as peer, is incorporated into a shared understanding of self-inflicted injury; of the perverse interplay between self-preservation and destruction that injecting can entail. It is an understanding also, that this pain is just one of many.

For participants living on the streets, the violence and pain of exclusion were ever present. Present in the hostile architectures of partitioned benches and blue lit public toilets, in the restrictions and inadequacies of defunded 'helping services', in the casual brutality of passers-by. As Jeff demonstrates: "I've been set alight sleeping bags, I've been battered, nearly kicked to death, I've had it all." Violence, as part of the fabric of everyday life, necessitates a hard exterior to enable survival. For some, a hard exterior predominated in the interview encounter. Lenny pulls up his shirt to show a torso scarred with knife and bullet wounds; demonstrating a hard-won reputation on the streets. Later, he makes a poignant plea for help:

Because I'm on the streets they're saying oh well you just stick there, basically ... since I come out of the coma I've had no housing, they just kicked me out of the hospital ... no psychiatric help like for my mental health, nothing really, no support what so ever. I'd go anywhere, anywhere at all [for housing]. I'm trying, trying, but no, no one's catching me, no one's holding me no life-line.

For those in accommodation, life may be no easier. Some have escaped homes marred by years of domestic violence or still suffer from the pain of having children taken away. In this context, health harms can also become normalised, as part of a larger picture of harm – in which death can sit as a viable option. Drug injecting can take the self to the limits of experience. Some, in pushing at those limits, play with the possibility of no return:

I've had big hits ... like some fucking convulsions with it ... it was like you were riding a surf board to death ... fucking scary ... because you're so close, mate, you can feel it, feel death looking down right at me, poking in your back. (Dev)

Lenny embodies his desperation, gesturing at a broad scar circling his neck, with the words: 'I'd just had enough, I wanted to give up, I slit my own throat September gone'.

Embodied pain can also be considered as a site of resistance – a demonstration of agency in constrained circumstances. Lenny, for example, slit his throat in a public place. Initially refusing to enter an ambulance he made the journey standing: "I lay down for no one in this life, seriously". At the hospital, as soon as the last stitch was put in his neck "I walked out". Marie incorporates injecting related injuries into her daily life, stating:

I think it was just fuck it I don't care, do you know what I mean, I think it was like basically I cut my arms, so what, never wear short sleeves again, so what, I've got an abscess on my bum, so what, it's never ever going to get better, so what, you know what I mean. (Marie)

Ben is 21, with many years living on the streets. He was excluded

from a hostel bed, until raped while rough sleeping. This violation afforded him a hostel placement. He is defiant; prepared to suffer further losses to get away from the streets:

My mindset of just standing up and not giving a fuck, you know, even if I lose my leg at least I'll get a Council flat ... I'd rather lose a leg than stay on the streets my whole life. Definitely. I'd rather lose both legs and be in a wheelchair.

This account shocks. It both makes visible and resists a normative reification of bodily integrity. For Ben, at only 21, there are more important things at stake than keeping his legs.

### 7. Discussion

Participant accounts evidence a double narrative in relation to care delay. For many, the first response attributes causality to the self: I was 'lazy'; 'I needed to score'; 'all I cared about was getting high'; 'I procrastinate'; 'that is just the way I am'. Listening more, another story emerges. One of fear: fear of opioid withdrawal; of being hospitalised without guarantee of OST continuation or adequate pain and withdrawal management; fear of punitive treatment, such as excessive and scarring surgical interventions. One of mistrust: mistrust of authority; of 'helping services' that perpetuate the shame and disappointment of exclusion. One of time and resources: of having each minute consumed by money generation pressures. One of hope, limited in a context of everyday violence. These accounts are also of self-protection. Claims of agency, being busy and having low expectation, can provide a sense of purpose and protect against the pain of disappointment. Avoidance of medical institutions can protect against further emotional and physical assaults. To frame care delay as self-protection, in the context of bodily deterioration and progressive health complications, is anathema for many. The surface narrative - of individualised responsibility and deficit – is one attuned to normative expectations of what it is to seek care. As elaborated below, a reading of these accounts at face value only can act to perpetuate a violence - and thus entrench barriers to care.

# 7.1. Everyday and embodied violence

Participants' narratives illustrate the interplay of contextual, relational and embodied influences on accessing and engaging with medical care. Everyday violence – interpersonal, structural and symbolic – plays a role in both normalising embodied pain and creating a protective impetus to avoid engaging with medical systems. DeVerteuil (2015) frames violence as harmful, as inhibiting self-development and self-expression; as contingent and contextual, linked to social and collective structures; and as processual, including through interplay with space and place. Manifestations of violence can be explicit, physical assault/interpersonal violence for example, but also implicit. Structural violence, for example, as embedded in social norms and structures and its unquestioned internalisation, symbolic violence (Bourgois, 1998). These everyday violences both constrain and enable certain sorts of subject formations and ways of interacting with medical systems and care.

Structural and symbolic violence are mutually supporting – their interplay is cyclic. The influence of this cycle on access to and uptake of medical care among marginalised populations is documented (Parkin and Coomber, 2009). Of interest are analyses that incorporate expressions of agency, ingenuity and resistance into the symbolic/structural violence interplay. Gamlin (2013) for example, highlights structural violence as a barrier to health service access among indigenous Huichol migrants in Mexico, including for maternity care. In order to protect their health and survival the Huichol expand and draw on 'authoritative knowledge', a cultural resource of practices and beliefs, to provide dignity and meaning to practices such as giving birth in a field. These acts, while protective, are inevitably denigrated as animalistic by the dominant culture, perpetuating discrimination and the need to protect

through avoidance of dominant health systems. Participant accounts of self-care, including through stockpiling illicit drugs to take into hospital, illustrate a similar cyclic dynamic. Stockpiling of drugs or money for hospital is an agential stand to 'make safe' an inhospitable space. It acts to mitigate the structural violence of medication denial, but if uncovered is denigrated as 'animalistic'. Discharge may then be enacted, either by the hospital or the patient – particularly if pain medication is not forthcoming. This agency is limited, covert. Participants rarely, if ever, directly challenged hospital procedures or enlisted an advocate to argue for their rights. Here, seemingly 'self-destructive' acts (care delay, taking illicit drugs into hospital) can be meaningful, protective, in contexts of structural violence and constraint, Yet, the symbolic violence these contexts produce both demarcates the extent of agency enacted and the protective potential it entails.

Bourgois (2010) details with nuance the interplay of interpersonal, structural and symbolic violence in the lives of the most marginalised. His accounts illustrate how for PWID, homeless in the United States, care avoidance protects against the structural violence of hospital systems where surgical debridement is experienced as excessive, pain relief denied, and discharges abrupt and unsupported. Bourgois and Gamlin do not position structural violence as wholly deterministic - it acts in concert with agency, rather than subsuming it. It is crucial, however, not to romanticise resistance, to overstate agency. Protective strategies, while agential, may not always be effective - particularly when underpinned by symbolic violence. The bravado of care avoided because 'I was too busy', 'I have to be near death, that's me', both protects against and obscures the role of structural and symbolic violence in normalising pain and suffering for many. These and similar narratives can be seen, drawing on Goffman's (1957) dramaturgical framing, as 'front-stage accounts' - alert to social context and audience expectations. They protect through assertions of agency, however self-depreciating.

An isolated surface reading of such accounts can further enact violence by solidifying self-depreciating or responsibilising narratives into actionable recommendations for behaviour and altitudinal change. Dunleavy et al. (2019) draw on qualitative accounts, similar to those of the London participants, to recommend interventions promote "awareness of the unacceptable social or physical consequences of SSTI" as this can foster "a sense of personal responsibility and agency" toward SSTI care among PWID. If we consider claims of personal responsibility and culpability for 'self-inflicted' SSTI as one among multiple narratives, we can also see how awareness and internalisation of judgements around the "unacceptability" of SSTI can enact a symbolic violence, precluding care seeking rather than facilitating it. As noted earlier, participants were alert to signs of negative judgement, and often had their own well honed. Shame in relation to 'unsightly' or odoriferous infections as well as the means of their acquisition, does not require magnification through educational campaigns. For some participants, shame manifest in accounts of low self-worth and treatment deservedness, for others it necessitated avoidance of any structures or systems likely to re-inscribe negative judgement.

Participants spoke of incorporating severe, painful and progressive injecting-related injuries into the day-to-day. This incorporation of debility is notable, given already stressed bodies - often active, covering many miles, inadequately nourished and used as a protective barrier - against hard pavements, hostile architectures and the casual violence of passers-by. This reading, of pain as incorporated, might seem at odds with participants' daily investment in alleviating pain (with drugs) and the prominence of drug withdrawal in accounts of care delay. Withdrawal is both complex and deeply familiar; embodied and incorporated into habitual practice. With each injection, withdrawal is averted - the pervasiveness of a habit tied, in part, to the power to alleviate this pain. As Ray says: "being sick is one of the scariest things in the world to be ... the worst thing is it's knowing that there's something that can make you better." Through the alleviation of withdrawal, participants can enact control. In the medical setting that control is potentially lost. Control over hospitalisation might be minimal, and if hospitalised, pain management and withdrawal alleviation are at the mercy of medical practitioners. It is understandable therefore, why many wait until they have additional money or drugs before seeking care. And, how difficult it is to obtain this surplus supply while living hand to mouth on the street.

### 7.2. Care and cultural safety

So, what can be done? Here, it is important to think with care. To, as Puig de la Bellacasa (2017) cautions, not enact a crude "eulogy of margins", offering nothing but a corrosive critique of "the power of the centre" (as a focus on structural and symbolic violence might intimate). But to engage also, with opposing or 'centrist' concerns. A case example is the hospital system. What are the matters of concern that animate those who insist on laboratory testing for evidence of OST, before allowing this to be provided? What alternatives can be offered that also speak to and alleviate these concerns? To this end, the author is a member of the 'DUG' (drug user group), instigated by staff at a London hospital in response to concerns about inpatient use of illicit drugs and absences from the wards to procure drugs. Ward nurses report finding it difficult to cope and worry about disruption to treatment regimens and patient recovery. Protocol deems that OST can only be provided after inpatient laboratory urinalysis to mitigate against perceived risk of drug-drug interactions and opioid overdose. For this hospital, to forego a test at all is to risk liability, even when prescription verification is provided by the pharmacist and/or the prescriber. To treat these concerns with care has involved consideration of alternative technologies, such as point of care testing, to enable prompt OST provision. At the same time, broader conversations can be had that act to humanise PWID and alert providers to the constraints that they, as well as the ward nurses, face.

Care is necessarily practice-based. Care, as an ethical political practice, requires practical engagement with situated material conditions (Mol, 2008). If we attune, for example, to the environments, relationships and rationalities informing risk and protective practice, we are better placed to imagine how these could configure differently to enable preventative and timely health care access. A first step is recognition. Recognition of the daily violences confronting PWID and how these impact on both the experience of, and ability to attend to, bodily pain. Bourgois writes: "Abscesses ... broken bones, opiate withdrawal symptoms and the potential for violent assault are constant features of their lives. But temporary exhilaration is also just around the corner" (2010: 239). These are lives that could be read as impoverished of alternative forms of meaning, of hope, of acceptable exhilarations. However, this is to do a disservice. Recognising habitual drug use as an affective quest for intensity, for exhilaration - alongside the impacts of its disavowal - can provide a lens through which to honour the stories of people who, even if ambivalently, dedicate themselves to this way of

McCall and Pauly (2019) detail the myriad ways in which people who use illicit drugs can feel unsafe in accessing healthcare. They propose the transferability of cultural safety principles to nursing practice with people who use drugs. This approach aims to foster practitioner reflection on the impact of power imbalance and inequitable social relationships in health care, including in relation to personal attitudes and beliefs:

Cultural safety is about recognizing that as a health care worker you come from a position of privilege and power. The goal of cultural safety is to reduce the tendency for health care practices that cause patients to feel unsafe and powerless (McCall and Pauly, 2019: e3).

Arising in the New Zealand nursing context, with a focus on enhancing care for Maori patients (Ramsden, 1993), cultural safety principles have been adopted, from the mid-1990s, to address inequity in care for a range of socially, economically and politically marginalised populations (Gerlach, 2012). Reflecting on transferability of these

principles to PWID, Pauly et al. (2015) note their structural violence and intergenerational trauma-based origins and thus, their applicability beyond care for indigenous populations. Beneficial outcomes have been noted by practitioners adopting cultural safety principles with PWID, including at the Canadian supervised injecting facility, INSITE (Pauly et al., 2015). In the UK context, cultural safety for PWID would ideally incorporate recognition of the need for safe injecting equipment in hospital settings. Coupled with a more flexible and trusting approach to pain and withdrawal management, extending needle and syringe provision to inpatient care provides a powerful message of trust and acceptance. This is crucial, not only to enhance care access, but also to combat the negative health impacts of low self-worth and shame. In this way, meaningful practices of cultural safety can interrupt cyclic processes of structural and symbolic violence and provide a window for care.

### 8. Conclusion

By studying peoples experience of living with injecting related injuries and infections I consider the ways their lives intersect with structural forces to explore and understand the factors underpinning care delay and refusal. This necessitates an understanding of care delay as protective for some and as normalised for others, in a context of structural and symbolic violence. It is short-sighted, and potentially harmful, to frame care delay for injecting related injury in relation to individual responsibility and cognition. We must attend to the social structural factors that necessitate a numbness to pain and debility among the most marginalised. Cultural safety offers a lens to consider how dominant cultural expectations of care seeking and systems of health care can be experienced as unsafe by marginalised populations. Fearless translation of cultural safety principles to care for PWID in hospital settings offers transformative potential to reduce serious health harms among this population.

# Declaration of competing interest

None.

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