Original article

Voices of persons living with intravenous drug-related soft skin tissue infections seeking wound treatment: a qualitative descriptive study

ABSTRACT

Background People who inject drugs (PWID) may be referred to emergency services for treatment of wound infections or skin and soft tissue infections (SSTIs), such as cellulitis, abscesses and sepsis.

Methods This qualitative study examined the perceptions and experiences of 20 adults who accessed emergency department/s (ED) for advanced wound treatment and antibiotics. Community-based participant interviews explored their experiences and perceptions of care. A thematic analysis was conducted.

Results Findings characterise the perceptions and experiences of people with SSTIs in EDs, and include: early discussions with clinic physicians, nurses, family/friends who advised them to seek ED care; perceptions of being 'less than'; stigmatisation; the perception of being blamed or having intentionally causing the wound; underassessed pain and withdrawal management; and the importance of ED staff education on pain and withdrawal management.

Discussion Participants described accessing community and ED services for their wounds in three provinces. They described reluctance to attend ED when advised and instead self-managed wound care. Participants outline suggestions for improving ED care, including improved prevention and education to better prepare teams to address pain management and withdrawal risk.

Keywords drug use, PWID, skin and soft tissue infections, abscess, patient stories.

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BACKGROUND

People who inject drugs (PWID) and develop a skin and soft tissue infection (SSTI)[1] each have a story to share including wound self-care and the journey of seeking emergency department (ED) services.[2,3,4] Seeking healthcare is not straightforward for PWID who have SSTIs,[5] as they come up against systemic discrimination, stigma and barriers (risk of withdrawal, dope-sick), while interacting with staff and waiting for care.[6,7] In the first part of this community-based study we learned that clients prefer to engage in self-care treatments for abscesses and delay seeking wound care treatment from formal healthcare providers, such as acute care, emergency departments (EDs).[4] Therefore we sought to understand their perceptions and experiences, when they were advised to attend ED for advanced wound care treatment.

PWID living with SSTIs may go to significant efforts to hide their wound(s) from primary care providers, employers, friends and family. Prior to seeking formal health care, many initiate self-care under less than clean/sterile conditions (such as draining abscesses) and manage wounds with a range of home-made dressings.[7-11] Once a SSTI develops, accessing health care can be critical and people often delay seeking treatment until symptoms worsen (such as fever, pain, increased drainage). In addition, some do not receive treatment until they become

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seriously ill, leading to sepsis (a dysregulated immune response to infection, which may or may not involve septicaemia).[12] Overall, PWID who develop SSTIs experience a significant increase in morbidity and mortality.[13,14] .

THE IMPORTANCE OF STORIES

In this study, we share stories of PWID that move us at the personal and community levels.[15] We specifically collected teaching stories focused on people who may not have a voice in the healthcare system. Coles (1989)[16] states stories are at the heart of being open to listen and to think about how we can be and deliver healthcare responsibly . Stories can encourage us to consider how we can reduce barriers for PWID with SSTIs.[17] Stories are opportunities for us to care for marginalised and medically vulnerable people in innovative ways.[6,18] Therefore, we sought to explore the experiences and perceptions of PWID in the community when they sought SSTI care.

METHODOLOGY

In this study, PWID (n=20) who have or had SSTIs participated in semi-structured interviews[3] conducted in a place of their preference. Qualitative descriptive methodology was used to support researchers staying "close to their data and to the surface of words and events".[19, p 334] Trustworthiness elements included reflexivity activities (such as journals and field notes) and review of the transcripts and themes for accuracy.[20,21]

Adults, aged 18+, were recruited from a walk-in primary care clinic (PCC) with a harm reduction focus. We explored their journey when seeking and or trying to access health care for wounds (such as dressings and oral or intravenous antibiotics). A $20 gift was given to each participant upon completion of the 20–60 minute interviews; 18 interviews were audio-taped and two had handwritten notes. Data was transcribed verbatim and anonymised. University research ethics and the harm reduction centre teams approved the study. We did not have ethics approval in place to interview the ED teams.

Framework: This study was framed in the Provincial Opioid Use and Overdose Framework, as it emphasis the prevention, treatment and the development of appropriate harm reduction care services across the drug use spectrum.[22] Current provincial statistics reflect the urgent need for ongoing harm reduction services related to growing opioid deaths.[23]

Analysis: Data was coded concurrently using qualitative software and hand coded. Themes are presented in story format and participant exemplars are presented to support each theme.[20]

RESULTS

In this study 20 persons in the community were interviewed. Eleven identified as male and nine as female. Their age range was 18–69 years. They had each lived with one or multiple SSTIs (neck, arm, wrist, knee, lower leg, foot). Participants shared stories from EDs in Alberta, Ontario and Nova Scotia. They said their SSTIs developed from: missing an injection, injecting into soft tissue, being injected by another, using non-contaminated/contaminated drug supply, and insect bites. Participants shared experiences of multiple abscesses and some included admission to the hospital and critical care. They shared details of receiving oral and intravenous antibiotics. From the data analysis the following themes emerged.

IMPORTANCE OF EARLY CLIENT DISCUSSIONS WITH HEALTH CARE PROVIDERS

Prior to attending ED, participants described multiple conversations (back-and-forth) with physicians and nurses when advised them to go to ED for advanced wound treatment. Participants reflected and stated, they were "wasting precious time while trying to decide to go to the ED" (P10,12) over days/weeks. For example, a client may leave a clinic and go directly to the ED, some go to ED with or without a friend/peer advocate, some go but don't stay in ED for care due to the triage process and the wait times. Some clients do not go to ED at all and come back to the PCC seeking more complex wound care for a worsening wound(s) days/weeks later. In this study, four clients managed the demands of participating in an ED visit and returned to the PCC for ongoing intravenous (IV) antibiotics and wound treatment.

EXPERIENCES OF BEING "LESS THAN"

Upon arrival, participants in ED perceived themselves as being treated as "less than". Reports were based on their current/past drug use, fear of drug withdrawal, past ED visits, and whether they had come and gone from the triage area while waiting to be assessed. Participants shared:

> They do they do not care about you. They treat you with disrespect, you're not allowed to have any pain medications, you're not allowed to pretty much do anything (cigarette). They treat you like the lowest scum of the earth. I don't like how the system is. When you go to the ED you should get help, but because I was shooting up at the time, because of my wound they treated me like shit, garbage. They gave me the oral antibiotic and just put me on my way. I was telling them that I wanted to stay, that I don't feel good, I don't want to do this anymore, and they made me leave. (P1)

> The worst thing is, I've been to a lot of hospitals across Canada — some are worse than others. They penalise you. It's like they're racist against me because I'm a needle head. I'm sorry to say that, but that's how they say it." (P2)

> They kind of put you on the back burner. They don't tend to you at all. They don't really treat you like a human being; they just treat you like a junkie. I find that affects the healthcare that you get. It's like they don't really want to help you. There's a lot of stigmas when it comes to that. Even when I'm doing good and I go to the ED, they look back at my chart and the other times I was there for abscesses and drugs, stuff like that. Right off the bat, I'm in for a rough ride. I wish something could be done about that. I think everybody should get the same healthcare, whether you're on drugs or not. (P10)

It's your fault. You caused it.

Participants described over-hearing statements from ED staff such as "it is your fault, or you caused this" (P19, 20). A participant shared: "You know when you're asking for help and no matter what you say, everything is coming out negative. I ask: can I get a pain medicine? They reply 'well you shouldn't have smoked that meth' and walk away". (P2) Another related the following:

> I ended up with three blood infections. I was in rough shape, which was really bad for me because I'm already sick to begin with. I ended up going to ED by ambulance. I didn't know how extreme an abscess could be, without knowing it was already into the blood system. I had all the intentions of coming for care, but I kept putting it off and then boom it just hit, it knocked me out like a ton of bricks; then I needed care! I've had abscesses before and I've taken them out myself, this time when I was trying to take it out myself some of it got into the bloodstream. I got them from dirty coke. Looking back at it now, I wasn't doing it properly because when you get it, you have to get it all in the beginning because if you're squeezing it all day for 2 or 3 days, that's how the infection ends up in your bloodstream … I just thought it would just heal over after time. (P7)

Another shared:

> Some of my wounds are pretty bad, and I have to go to the hospital for lancing. Normally when I get them that bad, it's pretty serious. I had one in my arm once and I lost all mobility in my arm and the swelling went all the way up to my shoulder. The doctor actually said, he cursed at me and said, do you want to lose your arm? Once he started cursing at me, I realised that it was pretty serious stuff. It was a hydromorphone miss; it got bad fast. It was one of the first ones I ever got. I didn't even know you could get them when I first starting using IV drugs. After that incident I tried being more careful, but if you're using IV's, it's impossible. You're going to screw up sooner or later you're going to be too buzzed out and it's going to happen. (P10)

I know someone who died or nearly died

Participants shared that when they were told the wound was their fault, they thought of their friends/peers who had, or had nearly, died from a similar issue. Several shared the emotional pain when attending wakes or funerals for friends who had died.

> I had an infection, and I went through wound treatment for about nine months. I think it was that hard because I'm a user right, so I am in and out of the hospital. It didn't help that they gave me such a hard time there. When I first went there to triage, me and my friend, we we're both sick and he died four days later. (P17)

> You know the whole time you are trying to get care in ED you are thinking of your buddies. If the abscess is bad enough, I would go. Yet, the other day my buddy had one — a line — that was so bad. My friend didn't have a choice but to go to ED. He was sick, and it was bad, he was going septic. Until they go septic, they don't go to the hospital. He nearly died. (P9)

LACK OF TRANSPORTATION, WAITING AND RISK OF WITHDRAWAL

Transportation to and from the ED was challenging. Rides to ED occurred using a taxi with costs covered by the PCC, having family or friend drive, by bus or hitchhiking. They stated a lack of transportation hindered their attendance and return visits to EDs (P6,12,13,15).

Upon arrival at ED, participants describe waiting in triage as very stressful, with fear and risk of withdrawal as the biggest concern.

> Sitting in the ED is an issue. Fortunately for me I only need to dose 4mg of Dialudid daily. There are people who use a lot more frequently than that, so sitting in the ER for seven hours is not an option, they are going to end up in withdrawal or go outside for drugs. I know people who avoid the hospital simply because it doesn't fit their dosing schedule. They would have to try and sneak in their meds and use. (P12)

During the ED waiting time clients describe being anxious (P5,14) and some leave the ED and then come back a few hours later. Some had staff ask if they were seeking drugs. (P4,12) Others described being told they would be re-triaged if they left the ED and came back, thereby making the wait longer. One described "I went back-and-forth to triage over 36 hours, I slept for 15 hours in the waiting room, then I got care" (P10). Another described "waiting 16–17 hours" (P2). Another stated once they got through triage "they waited another three hours in the room alone" (P3). One participant perceived his ED wait as worse because he was a IV user (P2). Another stated they were hungry and needed a cigarette. "I just needed to eat, I was so hungry and had no money for the vending machines, I just had to eat, I am pregnant; they gave me some food and water". (P10)

A participant who successfully navigated the ED shared the following:

> I hate going to the ED, sometimes I have to wait long times, like for this here area [shows researcher scars], it's healing now but it got badly infected, my arm went really huge, and the infection almost went to my bloodstream, had to stay in the hospital for like a week. It's better now, it started as a small bruise then it went really bad; I was in a lot of pain. I've been taking antibiotics though, finally it's all better now. I delayed care as I don't like waiting. My girlfriend she forced me to stay. I just hate the waiting part. Knowing you're in pain and it hurts, just hoping you'd get put in right away, that's the only part I don't like. (P3)

Another said: "good behaviour" mattered:

> I know going to the ED is not the greatest, you wait a long

time. Depending on what happens they either take forever, or they help you right away. It depends on your behaviour, I guess. If you give them s### behavior, they're going to be s### to you. If you give them good behavior, they're going to be good to you. It's that simple. (P4)

LACK OF COMPASSION, PAIN MANAGEMENT AND HUMAN TOUCH

Participants described lack of compassion, being in pain, and care being bereft of human touch and shared:

> They were going to try and make me walk. I was telling them that my hand was swollen like a balloon. I told them I was an IV user, and they told me to walk downstairs. I said I can't, and they said you need to get up and walk. I said: "Then I guess I'm going to die right here". I was at the ER for one night. They gave me oral antibiotics for the abscess and then told me to get up ... I was telling them that I want help, I really wanted help. I'm not doing good, I need help. I don't feel good and I begged them. They said, you have to go. Then I asked can you get me a cab fare back to the shelter. So, I went back to the shelter, puked and smoked more meth because what am I going to do about my pain; my pain was never addressed. (P1)

To address pain a participant shared:

> Here's another trick that I learned that really pisses them off, it has worked in my favour as long as you can withstand the attitude you're going to get after. When they refuse to treat my pain I tell them, okay, because you refuse to treat my pain, I would like that documented. They don't like it. Sometimes it doesn't work, and you won't get anything. I'm so sick of being dismissed, especially being female. But then the next nurse comes in, talks with me, and I get pain management; why does it vary so much? (P10)

Participants described the need for reassurance, which they had thought would br provided through a reassuring touch to the hand or arm by the care provider. Three participants shared that "no one touched my arm to reassure me" (P1,16,19). A person stated, "you know when you are sick, you are just looking for a bit of compassion, just a bit of touch; and they would not touch me" (P.1)

> Here is how I see it. I am the dreg of society. When they finally got to see me after 18 hours, two doctors came in and was leaning up against the wall. I asked him why he was there, and he said because he likes 'gross things', and I was like – what is your problem? Do you think this is a joke? It's not a joke, and I didn't get this from shooting up if that's what you're thinking. Anyways, I tried to cut it and drain it myself and I did drain out some of it, but it just got bigger and bigger, so I had to go to back to the ED. I was in so much horrible pain, I just had to go to ED. When I did go, thankfully I had a fever, so I only had to wait 18 hours. If I didn't have a fever, I probably would've had to wait three days ... I was supposed to go back up there everyday to get my dressings changed but they call everybody else in from triage, before they'll see me. But I come here to the clinic, and they know you a little better and they try to help us more. They take care of us. I like that. (P14)

Another said:

> Remember, people are people. I don't know but they should seriously have to do something about it. They should treat people equally. Just because they don't have health care insurance like rich people, it shouldn't determine the pain meds. A regular guy who works shouldn't be getting Dilaudid 4s when the guy with track marks is only getting Dilaudid 1s. It's stupid, they are in the same amount of pain, or more. (P20)

I THINK I AM RED FLAGGED

Participants described the importance of having an advocate when attending EDs. (P1,14,15) They described a deep sense that "they were red-flagged as a drug-user" (P15) or "made to feel like crap" (P3) or just ignored because "I am in pain with the abscess" (P6). One stated:

> My friend and I went to the ED. They were insisting we has the flu when we both knew what was wrong with us, drug sickness. I told them I wasn't leaving, and they told me I had the flu and to go home. I told them that I was dying, and I would die if they didn't run some tests. I wouldn't leave and I was arguing with the triage RN and then they ran some tests and sure enough, the doctor gave me four bags of IV fluid. I was trying to speak up for my friend, but he said to let it go. Two days later he was airlifted to the critical care centre and another two days later he died. That was hard. (P9)

> I got red-flagged. In the shelter I got my first abscess from a spider bite on my arm and my second on my buttock. I went to the ED, and they did not take me seriously. I ended up leaving. It was not an injection site. I know the risks are higher among IV drug users ... I had gone to the ED and was told to have a seat; the triage RN didn't even look at it even though I was more than willing to show it, they said that's fine you can show the doctor. I waited seven hours and was not seen, so I left. The next day, I was staying at the shelter again, so I felt like I was taking a turn for the worse like I was on the verge of going septic. So, I came down to the PCC, and I believe it was the street nurse who I showed it to. She took pictures and sent them to the doctor, that I was at risk of going septic, where is the humanity? (P12)

Another participant emphasised the importance of friends:

> You know, I have seen it because I've sat with buddies in EDs who've went there for wound treatment. I'm looking at the triage nurse, and you can just feel their body language and you can just see their faces — they're right rude. I think it's kind of hit or miss maybe. Maybe not every nurse or doctor are like that, but from what I've seen and heard that's my experience at the hospitals. I don't want to say they don't care but I want to say that we're pretty close to the bottom of the list when it comes to things like that. (P.16)

Finally, participants discussed the need for trust-filled relationships when seeking wound treatment. They described the importance of all staff being able to examine skin, wounds and infection and understand pain and withdrawal risks. Participants who completed their first IV antibiotic treatment in ED and received the next IV antibiotic dose in the PCC setting were grateful for ease of access and respect. A participant said: "The street nurses advocated for me to get IV antibiotics set up at the clinic with the community home care nurses. I started coming to the PCC everyday for my IV and dressings." (P7) Another said: "I would prefer to come to the PCC. They always provide me care ... they're amazing" (P8) A participant explained the following:

> I recently had a 2cm wide abscess from Wellbutrin on my leg, which I needed immediate attention for, or I would have lost my leg. I came to see the street nurse. She helped me in more ways than I could possibly say. She sent me home with all of the tools to do care at home until I got to the ED, and I continued to come back for follow-up care. (P11).

DISCUSSION

This community-based study was conducted in a small, eastern Canadian city and this may have had a bearing on the findings. Twenty participants shared stories of seeking advanced wound assessment and treatment for injection related wounds in EDs in three provinces where they travelled for family and employment. Nevertheless, the data collected revealed rich information of individuals experiences and perceptions of seeking wound treatment in EDs.

Participants in this study described the basic risks of engaging in self-wound care, including infection, sepsis and death.[3,4,7] Participants also were aware of the importance of basic wound cleansing and covering the wound.[24.] Participants described the need for more client preventative education and access to necessary wound care supplies. For example, in this study the participants could access five day a week basic wound care services at the primary care walk-in PCC; run by nurses; this program supports access to supplies.[3] But for clients in need of advanced wound care, infection management with intravenous medication and complex wound assessment it is necessary for clients to attend ED for a comprehensive assessment, testing and scans.

Prior to attending ED for advanced wound treatment, most participants described having multiple conversations with community-based clinic physicians, nurses, pharmacists, peer workers/advocates and family members all who advised them to attend ED for advanced wound treatment (such as scans, blood work, IV antibiotics). Participants often described the risks of infection, they describe a deep sense of dread when being advised to go to ED for wound treatment. Their decisions were coloured by stories of friends, peers who died or almost died from similar wound-related sepsis events. As well, they feared withdrawal, lack of treatment or compassion related to withdrawal and being "dope-sick".[3,p11] This was similar to accounts in the literature, where participants described multiple reasons for not going or leaving the ED.[7] Delays in going to the ED included participants worrying about: the stigma of drug use; being in pain; being identified as drug seeking; fear of withdrawal; loss of work; travel costs to/from the ED; previous trauma and being further marginalised.[2,3,7,25-27]

Similar to accounts in the literature, participants perceived being impatient with the EDs triage processes and wait times; they admitted that if they needed to use a drug, if their pain was not managed and if they might withdraw[28,29] they would leave the ED, and upon leaving not all would return.

Finally, participants perceived ED staff as having a negative stigma of PWID. They believe that regular and repeated education would help staff understand that SSTIs are not self-inflicted and not all are seeking drugs. Participants perceive ED staff' beliefs influenced the way they triaged and subsequently treated. Participants believe ED staff attitudes and biases result in delays in wound care and increase risk of infection/sepsis. They perceive themselves to less than and thereby left at the end of the ED triage list.

CONCLUSION

Participants identified areas for improvement. They believe that IV antibiotics could be managed in community clinics where trust-filled relationships exist. Participants state regular and repeated pain and withdrawal management education programs should be offered to ED staff,[28,29] thereby reducing stigma and discrimination.[2,3,4] They discussed the need for more research to understand whether seeking ED care for wound related issues was the best fit for people with mental health and addictions issues. Overall, participants recommended education as key to prevention and improvement of wound care and related infections in EDs. They also acknowledged that the challenges and demands in any ED are many, and that financial and staffing constraints complicate access to timely wound treatment.

CLINICAL IMPLICATIONS

There are limitations to this study that should be acknowledged. Further research is needed to gain the perspectives of ED staff triaging and managing client care. This study was based on the stories of 20 participants who agreed to share their perceptions during the study period. Similar to previous literature, it is possible that clients attend ED directly for drug injection-related wounds that are not included in this community based study.[30]

Emergency department (ED) staff were not interviewed as this qualitative, community-based study focused exclusively on capturing the experiences and "teaching stories" of PWID, as they sought care for SSTIs. This kept the lived experiences of people navigating wound care and ED services at the forefront. The dissemination plan is to share findings with ED staff and potentially follow up with their perspectives on the insights gained in a future study. Funding to meet, interview and analyse the findings with ED staff is not currently available.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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