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“I know my body better than anyone else” Perspectives of people who inject drugs on antimicrobial treatment decision making for serious infections

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Patients with IDU-associated infections desire autonomy, respect, and patient-centered care.

“I know my body better than anyone else”

Perspectives of people who inject drugs on antimicrobial treatment decision making for serious infections.

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Introduction

- Few studies have examined the perspectives of patients with lived experience regarding outpatient treatment options for injection drug use (IDU) associated infections.
- We sought to better understand the perspectives of both community partners with lived experience who work with people who inject drugs (PWID) and hospitalized patients with IDU-associated infections on shared treatment decision making.

Methods

1. Semi-structured interviews were conducted with N=10 patients hospitalized with IDU-associated infections and N=6 community partners in the Portland, Maine region.
2. Interviews focused on substance use history, experiences with infections and hospitalization, and perspectives on discussing outpatient alternatives with a physician.
3. Interviews were transcribed and deidentified.
4. Three authors analyzed interview transcripts and coded them following a process of iterative categorization, then identified and evaluated themes.

Results

Theme Types	Summary of Themes
Hospitalization - reasons to stay	Hospital as a bridge to substance use disorder (SUD) treatment; refuge or protection from triggers; caring staff
Hospitalization - reasons to leave	Experiencing stigma; feeling restricted or trapped; inadequate pain or withdrawal symptom management
Outpatient treatment options	Antimicrobial efficacy; housing and transportation resources; self-efficacy; available social support
Patient decision making	Importance of autonomy; impact of SUD on decision making; including patients in conversations; focusing on patient goals

Discussion

- Patients value their health outcomes in making treatment decisions, but also factor in other considerations.
- Including patients in shared decision making may decrease the likelihood of self-directed discharge by reducing experiences of stigma and better aligning care with patient goals

Representative Quotes

Negative hospitalization experiences:

“...I just got lied to and I don't like it when they lie to me. And a few other times I just was in a lot of pain and I didn't, wasn't getting treated the way I should. And, I just know that I hit the street and you do better. So, I leave and go get high and feel better.” (Jason, 48)*

Hospital as a place of refuge:

“There's no way that I could be home right now and not trying to get heroin or some sort of pain med on the street, which is never what it's said to be anymore. So it's better that I'm in here. [...] But being in here at least I know what's being put in my body and they're able to monitor me. So it's safe.” (Chris, 36)

Importance of patient autonomy:

“I know my body better than anybody else. I'm the one who's lived in it for 42 years. But once I got to talk to [the doctor] and stuff, I started feeling a lot better. He made me feel like he really listened, like he really cared, it gave me some reassurance.” (Jennifer, 42)

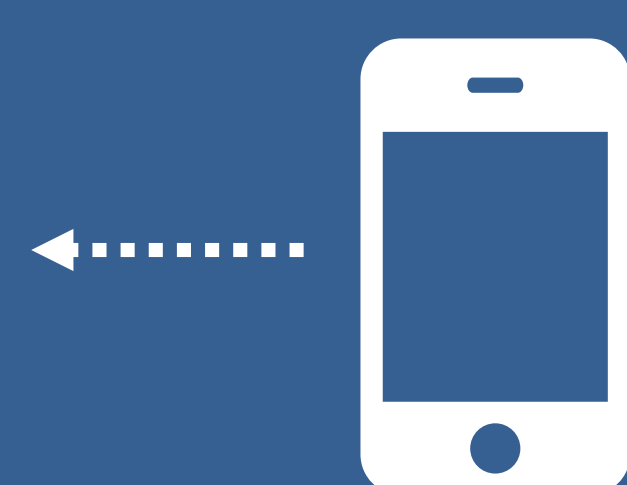
Harm reduction:

You don't have to [stop using drugs]. But you do need to be told, ‘We don't care if you're using or not. We want to help you to get rid of the infection.’” (Samantha, 30)

*Participant names were changed for privacy.

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