

PAIN AMONG PEOPLE LIVING WITH HIV: A QUALITATIVE STUDY OF IMPACT, AND STRATEGIES FOR SELF-MANAGEMENT

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BACKGROUND: Pain is the most frequently reported symptom among people living with HIV. Prevalence is estimated between 54-83% (1), which is higher than the general population. Living with pain and HIV can result in depression, anxiety, psychological distress, and posttraumatic stress (2). People living with HIV and pain are more likely to have reduced retention in primary care, adherence to ART, virologic suppression, quality of life, and increased mortality (3,4). The WHO recommends self-management for managing chronic pain. Self-management support is when health professionals, teams and services work in ways that ensure that people with long-term conditions have the knowledge, skills, confidence and support they need to manage their condition(s) effectively in the context of their everyday life (5).

AIM: To understand the barriers to pain management for people living with HIV and how that can inform a pain self management intervention.

METHODS:

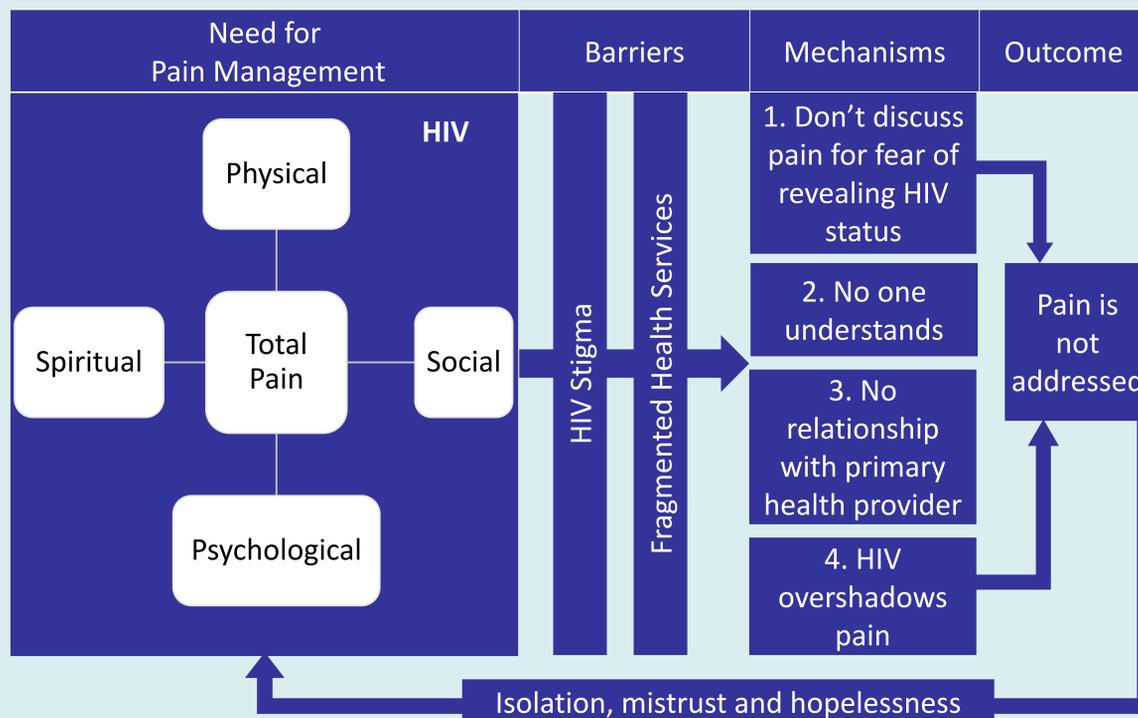
Study Design	Cross-sectional, qualitative, semi-structured focus group interviews
Inclusion Criteria	Adults with a known HIV diagnosis and have experienced ongoing pain for at least 3 months without ongoing injury
Recruitment	Purposive sampling of self-selecting participants and organisations from the UK-CAB message boards (an online forum for people living with HIV and HIV treatment advocacy).
Patient Public Involvement (PPI)	Individuals and organisations contacted our PPI Rep who referred participants to the study. Our PPI Rep reviewed the topic guides and study materials and co-facilitated focus group interviews with researchers.
Analysis	Thematic analysis using a framework method

RESULTS:

BARRIERS TO PAIN MANAGEMENT FOR PEOPLE LIVING WITH HIV

SAMPLE CHARACTERISTICS

39	Participants
6	Focus Groups
61%	Women
79%	Black African
18%	MSM
18%	Outside London
55	Mean Age



Don't Discuss Pain:
"I haven't told anyone [about my pain]. I don't discuss it with family or friends. It's not something I want to do cause then it's 'where's this pain coming from?' And I don't want to get into all that."
- White man, identifies as MSM

No Relationship:
"Not everyone who lives with HIV has disclosed their status to the GP, so there is that trust. Everyone wants a GP who understands, and when you go there, to talk about the pain, you want a person who understands. The next time [...] you don't see the GP that you have started to explain, [you] see another person."
- Black heterosexual woman

No One Understands:

"Another pain is that people don't understand. That pain is the pain of people looking at you differently when you are HIV positive. The pain, when people cannot understand, what HIV is all about. [...] People don't tend to realise it, but it is a pain that is so difficult. The pain that I cannot sit somewhere that I cannot sit somewhere and tell somebody I am HIV positive, and it is taken normally that I am sick, and it's another sickness like any other thing."
- Black heterosexual man

HIV Overshadows:

"I feel like people like us with HIV, every time we go to see the professionals- the doctors, my HIV status overshadows all my sufferings. As soon as they've seen 'oh you are HIV' they are no longer concentrating on what I want to say to them. [...] Which means I am not getting much help because the time is finished when they are done asking about my HIV."
- Black heterosexual woman

CONCLUSION: Participants felt they were not receiving enough support from health services and their social circles to effectively self-manage their pain. Participants were particularly vulnerable to social isolation, as they felt they must hide or mask their pain to avoid HIV stigmatisation and discrimination. They stated that GPs are not adequately addressing pain due to time restrictions and a lack of knowledge about HIV. Many participants said they did not have relationships with primary health providers. This made it uncomfortable for them to continuously disclose their HIV status to new providers. Some participants felt HIV consultants did not help them with pain as they were more focused on their patient's life expectancy than on their quality of life. Participants said their pain not being addressed made them feel hopeless and mistrust the health system.

RECOMMENDATIONS:

- ✓ Create pain self-management services that are specifically for people living with HIV, so participants feel safe from stigma and discrimination.
- ✓ Inform people living with HIV on the source of their pain as not all pain is HIV related. Pain is common in the general population so people living with HIV should feel able to discuss their pain with family and friends and health professionals whom they have not disclosed their HIV status to.
- ✓ Educate people on how to present their pain and improve communication with doctors to get the most out of appointments.
- ✓ Raise awareness among health professionals that pain among people living with HIV is common, underreported and poorly addressed.
- ✓ Focus on improving people living with HIV's mental health and reducing social isolation as this can positively affect a persons total pain experience.

REFERENCES:

1. Parker R, Stein DJ, Jelsma J. Pain in people living with HIV/AIDS: a systematic review. Journal of the International AIDS Society. 2014;17:18719.
2. Scott W, Arkuter C, Kioskli K, Kemp H, McCracken LM, Rice ASC, et al. Psychosocial factors associated with persistent pain in people with HIV: a systematic review with meta-analysis. Pain. 2018;159(12):2461-76.
3. Sabin CA, Harding R, Bagkeris E, Nkhoma K, Post FA, Sachikonye M, et al. Pain in people living with HIV and its association with healthcare resource use, well being and functional status. AIDS. 2018;32(18):2697-706.
4. Merlin JS, Zinski A, Norton WE, Ritchie CS, Saag MS, Mugavero MJ, et al. A conceptual framework for understanding chronic pain in patients with HIV. Pain Pract. 2014;14(3):207-16.
5. A practical guide to self-management support:Health Foundation 2015.



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