

Stigma related to HIV pre-exposure prophylaxis use among men who have sex with men in Wales: a mixed methods study

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HIV PrEP IN WALES

- Oral HIV PrEP has been available in Wales through the NHS since July 2017
- Primarily used by men who have sex with men (MSM)
- Stigma may influence PrEP uptake, use, and persistence...

MEASURING STIGMA

- Stigma – a distinguishing characteristic that differentiates individuals and serves as a basis for their social devaluation
- Associated with poor mental health, lack of engagement in care, poor health outcomes
- Three primary forms are enacted, anticipated, and internalised stigma
- Stigma can operate at intrapersonal, interpersonal, and structural levels
- Lack of valid and reliable measures for PrEP-related stigma
- This makes it difficult to measure success of interventions aiming to address PrEP-related stigma

WE AIMED TO DESCRIBE

1. An adaptation of the HIV stigma scale for PrEP users
2. Experiences of PrEP users in Wales with regards to different forms and levels of stigma associated with PrEP use

WHAT WE DID

- Mixed methods study of individuals accessing PrEP through four sexual health clinics in Wales
- Adapted items from “personalized stigma” and “disclosure concerns” subscales of HIV stigma scale by Berger et al (2001)
- Item content validity reviewed by author team and stakeholders
- Piloted in sexual health clinics prior to implementation
- Construct validity (confirmatory factor analysis) and internal consistency (Cronbach’s alpha)
- Deductive framework analysis for qualitative interview data

PrEP STIGMA SCALE ITEMS

- Items scored on 4-point Likert scale (strongly disagree to strongly agree)
- Items 1 to 5 reflect personalised stigma, items 6 to 12 reflect concerns around sharing PrEP use info with others

1. I have lost friends by telling them that I take PrEP
2. I have been hurt by how people reacted to learning that I take PrEP
3. I have stopped socialising with some people due to their reaction when learning that I take PrEP
4. People I care about stopped speaking to me after learning that I take PrEP
5. I regret having told some people that I take PrEP
6. I am very careful whom I tell that I take PrEP
7. I work hard to keep my PrEP use a secret
8. In many areas of my life, no one knows I take PrEP
9. Telling someone I take PrEP is risky
10. I worry about people discriminating against me because I take PrEP
11. I worry that people will assume that because I take PrEP I have sex with lots of people
12. I worry that people will assume that because I take PrEP I am HIV positive

WHAT WE FOUND

- 60 PrEP users included in survey study, 21 interviewed. All MSM, 88% White British
- 5/18 “personalized stigma” items adapted
- 5/10 “disclosure concerns” items adapted, 2 items added (7 items in total)
- Items demonstrated good construct validity (93% total variance explained)
- Cronbach’s alpha for each subscale was 0.85 and 0.90
- Correlation between subscales was 0.4
- Some floor effects for personalised stigma subscale
- Interviews suggested missing items, greater specificity, inter-relationships between different stigma forms, connections with HIV-related stigma, and influence of the media

ENACTED

When I was with my ex-partner, he was on PrEP as well ... but it does have that little paranoia affect, like why are you on PrEP? But I'm also on PrEP as well. There's a reason why they're on PrEP, and you think it's because they're sleeping around, but then I'm on PrEP for my reasons.

I think on the whole the support from the clinic was fantastic and the lady just spoke to you like a human being ... She was really caring and she really asked the right questions and was really supportive.

ANTICIPATED

It [taking PrEP to prevent HIV] tells people [about] my sexual activity.... So again I think it's ... wanting to be discreet about ... the kind of sexual activity I have. Fundamentally I'm gay but I'm not out... So I don't want that to be common knowledge.

I live in an area where everything is quite communal. So you got to the chemist, okay you might not know the pharmacist himself, but it's that you know the staff the other side of the desk or whatever, so, you know although there is a level of confidentiality it always gives you that doubt of actually what they're sharing with friends and family or whatever.

INTERNALISED

[I was] kind of thinking I was going to be ... sort of off the rails so to speak and being a bit promiscuous on the rebound ... that's how I got onto it ... [Initial impression of the type of person who takes PrEP] Very promiscuous ... putting yourself at risk all the time of getting HIV.

HIV-RELATED STIGMA

I think it's [PrEP] prompted a conversation around HIV, in terms of, well, if somebody is [living with HIV and with have a viral load which is] undetectable, they say that they're the best people, I say the best, the safest people to have sex with, because they're on top of their sexual history, they know what their viral load is, and they're on treatment for it [HIV]. So they're probably so much more conscious than what anyone else would be in terms of their sexual history.

ROLE OF MEDIA

When it was being covered on the news, I remember a lot of arguments by the public were “Why should we pay for someone to basically do whatever they want sexually, and we pay for this pill so they can do that?”

CONCLUSION

Our measure had good psychometric properties but additional items may be useful. Further work is needed to develop this scale, validate it in a larger sample, and determine the extent to which it remains a valid measure in different demographic groups.