

Social barriers to pre-exposure prophylaxis uptake within sexual and gender minorities in the UK

DISCUSSION

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ABSTRACT

Background: Pre-exposure prophylaxis (PrEP) is a biomedical tool taken by HIV-negative individuals to prevent HIV transmission. (1) HIV prevalence is disproportionately high for transwomen and Afro-Caribbean men who have sex with men (ACMSM). (2, 3) This suggests that maximising PrEP uptake could be fundamental in curbing HIV prevalence, thus social barriers inhibiting its uptake warrant a deep understanding. The aim of this critical inquiry is to develop an understanding of PrEP social barriers faced by ACMSM and transwomen in the United Kingdom (UK).

Methods: The following databases were used for this critical inquiry: JSTOR, PubMed, and Web of Science. Out of the 30 studies identified as potentially relevant, 10 studies were included in the review.

Results: PrEP social barriers identified include: stigma, insufficient awareness, non-adherence, and suboptimal patient-provider relationships. (4-12) Social situations can lead to fear of PrEP stigma, deterring ACMSM from PrEP uptake. (4) A homophobic upbringing and racism could shield these individuals from PrEP awareness and adherence. Insufficient PrEP awareness, transphobia and the all-consuming oppression transwomen face may reduce PrEP access for transwomen. (9) Intersectionality could explain the heightened PrEP social barriers faced by transwomen and ACMSM. (4, 9, 10, 13)

Conclusion: Social barriers to PrEP uptake are enhanced amongst ACMSM and transwomen due to intersectionality. Continued training on intersectionality and sexual and gender minorities (SGM) health are essential for enhancing patient-PrEP provider relationship, and reducing discrimination from sexual health services. (14) Incorporation of SGM sexual health in sex education may alleviate the PrEP stigma ACMSM and transwomen face. Increasing policy representation of transwomen may

INTRODUCTION

Sexual and gender minorities (SGM) are a group of people who embody a variety of sexual orientations and genders (Figure 1). (15) SGM have faced historical challenges, including but not limited to the AIDS epidemic and infringements of their civil rights. (1) These widespread social issues continue to be a burden for SGM and contribute to health inequalities. The socio-economic inequalities they suffer from lead to restricted health care access, under-representation in policies, social isolation, and has also been attributed to a heightened risk of contracting COVID-19. (1)

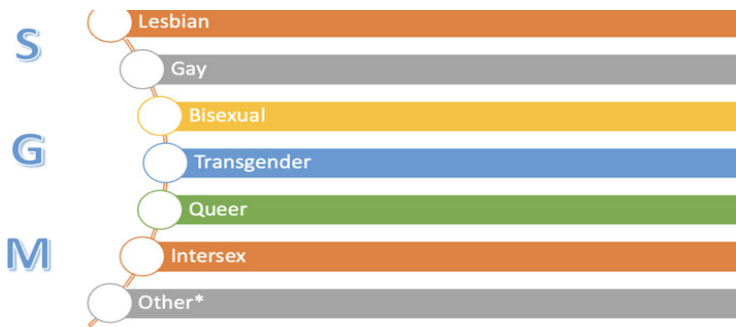


Figure 1: Adapted from Blondeel et al. (15)

*Other includes queer, asexual, men who have sex with men, questioning, two-spirit, gender variant.

Pre-exposure prophylaxis (PrEP) is an effective oral drug combination used by HIV-negative people to prevent HIV contraction. (17) As well as its biomedical potential, it can have psychosocial benefits like sexual liberation. NHS England was the last NHS system in Great Britain to commission PrEP (Figure 2). (18) Before its widespread commissioning in England, PrEP was only accessible via the IMPACT trial or if privately funded. (18) However, the trial did not sufficiently consider high-risk groups (sex workers, transwomen, and Afro-Caribbean men who have sex with men (ACMSM)) in their study demographics, raising issues on equitable access to PrEP for minorities. (19)

Health inequalities disproportionately affect transwomen and ACMSM. (1, 2, 20, 21) Coupled with high prevalence of depression and anxiety, the World Health Organization (WHO) reported that transwomen are 49 times more likely to have HIV than the non-transwomen population. (2) Despite this, there is a lack of awareness of PrEP amongst transwomen. (9, 10) According to the National AIDS Trust, the proportion of Black Africans and Caribbeans having late HIV diagnoses were 52% and 40% respectively, yet they only receive 28.7% and 2.8% of HIV specialist care in the United Kingdom (UK) respectively. (3)



Figure 2: Adapted from Terrence Higgins Trust (18)

Social barriers to PrEP uptake continue to be an omnipresent challenge in the UK. (4, 5, 10-12, 22) A non-exhaustive list of barriers include stigma, non-adherence, lack of risk perception, insufficient awareness, and a suboptimal patient-provider relationship. These barriers can co-exist and have different weightings for various groups within SGM. (4, 10, 22) Poor PrEP uptake can increase HIV transmission, worsening its prevalence amongst SGM. (23) This threatens WHO's efforts of ending HIV transmission by 2030. (2) The lack of improvement in HIV prevalence amongst SGM will continue to fuel HIV stigma as the social aftermath of the AIDS epidemic prevails to this day. (1)

PrEP gap is a term given to the difference between the proportion of MSM on PrEP and the proportion of MSM who would likely take PrEP if given access. (24) In a survey to MSM across 50 countries in Europe and Central Asia, the EMIS-2017 report found the PrEP gap in the UK to be 20%. (25) Another finding was that 96.5% of HIV-negative MSM in Europe and Central Asia had never heard of PrEP (N=112939). In 2019, HIV transmission in MSM still made up nearly half of the national mode of transmission in the UK, while 84% of trans people accessing HIV care were transwomen. (3) The EMIS-2017 report findings (25) and HIV transmission statistic in the UK (3) necessitate holistic approaches in tackling barriers to PrEP uptake. Breaking social barriers through challenging social behaviours and expectations is thought to have been successful in controlling HIV transmission in the United States (US). (26) It is therefore fundamental to identify social barriers to PrEP uptake in the UK.

RESULTS

PrEP stigma

PrEP stigma refers to prejudice against those taking PrEP, for example associating it with being promiscuous or HIV-positive. (4, 13) After the IMPACT trial in England, Turner et al. found a statistically significant 4.6% rise in STI rates (N=3407), through a retrospective study amongst MSM. (27) Hildebrandt et al. conducted a nationwide survey (N=738) looking at the effects of HIV lifestyle stigma on public perceptions of PrEP funding. (11) The mean level of support for PrEP public funding in the lifestyle stigma group (those who are reminded of lifestyle factors associated with contracting HIV) is 3.73 (N=105), whereas the control group had a mean level support of 3.86 (N=115). When compared to each other, no statistical difference was found (p=0.38).

Witzel et al. investigated PrEP barriers amongst Black MSM Londoners and discovered that some participants refuse PrEP as they do not want to fulfil stereotypes. (4) One participant highlighted the stigma against Black MSM that they are “promiscuous and dominating”. Nakasone et al. conducted semi-structured interviews to assess PrEP attitudes of Afro-Caribbean transwomen, and established PrEP stigma to be a heavier burden for them, (10) consistent with Witzel et al. (4) Two respondents were fearful towards institutional stigma and racism when accessing sexual health services (SHS) (N=21). This is in addition to their worry about people finding out they are on PrEP and associating this with having HIV. Rael et al., who conducted focus groups to amass attitudes to PrEP use, had similar findings for transwomen in the US (N=18). (13) A transwomen sex worker described an experience of a client confronting her about her PrEP medication, demonstrating the stigma associated with PrEP use. She mentioned that PrEP use could deter her clients, and be destructive to her career.

PrEP adherence

Young et al. discussed PrEP acceptance amongst MSM and African communities in Scotland. (22) PrEP stigma determines the level of PrEP adherence of participants. “Fear of being caught on PrEP” may lead to PrEP non-adherence. The lack of privacy, and a sudden change in environment when taking PrEP can intensify this fear. Furthermore, a disruption to their daily routine may lead to forgetting PrEP intake. An example of this is visiting families for holidays or changes in a work schedule. Meanwhile, third parties have been found to be beneficial for PrEP adherence if they are aware that a participant is on PrEP. (6) Grov et al.’s participants conducted semi-structured interviews to identify strategies used by MSM to maintain PrEP adherence, and 13% of participants (N=103) reported that third parties, who are aware and supportive of them taking PrEP, can give them daily reminders for PrEP use. A multivariable analysis used by Mannheimer et al. identified factors affecting PrEP adherence amongst MSM (7) and showed disparities in PrEP adherence between White MSM and AC-MSM. When compared against each other, the odds ratio for PrEP adherence was 0.29 (CI: 0.13-0.66, p<0.0033), showing that

White MSM had better PrEP adherence. Even after adjusting for other factors linked to PrEP adherence, results remain statistically significant.

Studies looking at PrEP adherence amongst transwomen reveal additional challenges. (9) In the US, trans-specific factors affecting PrEP acceptability were studied by Sevelius et al. through focus groups and individual interviews. They found that transwomen had a lower power to negotiate PrEP. A respondent described the limited selection they have for dating so when it comes to sex, they are more likely to be submissive to their partners and engage in riskier sexual activities. Ultimately, this may explain their struggle to take PrEP regularly.

Owens et al. conducted a qualitative study investigating PrEP adherence determinants amongst MSM. (8) All respondents (N=34) believed that quality of PrEP information given by providers affects adherence. Some thought that an in-depth instruction on PrEP use increased PrEP adherence for them, as opposed to being given an “abrupt instruction” to take it daily. Others believed that having a good and long relationship with providers has aided PrEP adherence. Similarly, Sevelius et al. established that transwomen found PrEP access easier from trans-informed providers due to reduced PrEP stigma. (9) In contrast, others were deterred from PrEP access due to transphobia from other patients in SHS, as well as providers.

PrEP awareness

Frankis et al. conducted a study to understand PrEP awareness amongst Scottish MSM. (12) Their findings supported the EMIS-2017 report; (25) 33% of participants were unaware of PrEP (N=690). (12) To evaluate factors affecting PrEP awareness, they used a bivariate regression analysis to display the factors enhancing PrEP awareness (Table 1).

| Ameliorating factors to PrEP awareness | Odds ratio | Confidence Interval | p-value |
|--|------------|---------------------|---------|
| Having a degree | 3.49 | 1.80-6.77 | P<0.001 |
| Exposure to the gay community | 1.69 | 1.21-2.36 | P<0.002 |
| Had STI test in the last year | 1.85 | 1.33-2.58 | P<0.001 |
| Had HIV test in the last year | 2.33 | 1.67-3.26 | P<0.001 |
| Always/sometimes talked about HIV with unprotected anal sex (UAS) partners | 1.85 | 1.09-3.13 | P<0.023 |

Table 1: Adapted from Frankis et al. (12)

The ameliorating factor, ‘always/sometimes talked about HIV with unprotected anal sex partners’, has significantly increased PrEP awareness. From Table 1, regular engagement with SHS increased PrEP awareness. Nonetheless, PrEP awareness may not necessarily be positively correlated with PrEP use, as Frankis et al. found (OR=1.03, CI: 0.74-1.42, p<0.873). (12) This was consistent with Walsh et al. who claimed that there is little evidence for the associa-

tion between PrEP awareness and PrEP use. (29) Furthermore, Nakasone et al. supports this claim for transwomen. (10)

PrEP awareness is particularly low in ACMSM. (4, 10, 22, 29) Witzel et al. found that Black MSM struggle to have conversations about SGM sexual health with their families. (4) Not only that, Black MSM reported experiences of offline and online racism amongst SGM communities. Racial isolation was explored by Nakasone et al., where they discovered that Black transwomen in Glasgow struggle to access sexual health support from the White-dominated community. (10) Conversely, transwomen in London found it comfortable to access support from an ethnically diverse community. However, the main finding was most respondents were unaware of PrEP campaigns. Those who were PrEP-aware mentioned that it would help if PrEP campaigns were inclusive of BAME role models and transwomen, consistent with another study. (13)

Sevelius et al. found that only one transwoman knew about PrEP (N=30). (9) Respondents believed that differences in awareness is due to poor self-eligibility, lack of trans-inclusive PrEP activism, and PrEP threatening their femininity. They viewed PrEP to be exclusively for white gay men who are safe, and financially stable in life. Many felt they did not fit these criteria, leading to lower PrEP uptake. Nearly all of the participants highly valued femininity and perceived the intake of a 'masculine' product to demean their identity, making PrEP access uncomfortable and challenging for them. Regarding trans-inclusive PrEP campaigns, participants felt that transwomen are "an addendum" to MSM representation and believed they should have more representation.

DISCUSSION

Results show that transwomen and ACMSM may face stronger social barriers to PrEP uptake than other SGM groups. (4-10, 12) The rise in STI rates after the IMPACT trial (27) may strengthen public perception that PrEP encourages promiscuity. This may deter SGM from accessing PrEP, to prevent enacted PrEP stigma on top of other SGM discrimination. Although there is evidence showing positive attitudes towards PrEP funding, (11) further studies are required to support this finding. It is necessary to break associations between PrEP use and 'having HIV', and this can be done through general public education. PrEP non-adherence amongst ACMSM (7) may demonstrate how health inequalities affect PrEP use. For instance, they may have a more demanding occupation (30) meaning they de-prioritise PrEP adherence.

One may assume that intersectionality, a term describing the interlinked nature of social categorisations, may account for the reinforced social barriers ACMSM face. (4) The interactive effects of religion and ethnicity may affect the PrEP awareness of ACMSM. Belonging to a homophobic family may explain the insufficient PrEP awareness due to lack of conversation on MSM sex. (4) Another possible effect of this is intensifying internalised homophobia. This may explain PrEP non-adherence, as those who conceal their

SGM identity from friends and families may find it more challenging to take PrEP in private. (5) PrEP non-adherence, due to lack of privacy at home, may worsen amidst COVID-19 restrictions. It may benefit individuals if PrEP was taken less frequently and away from home. Studies could look at the possibility of administering a single dose PrEP injection in a clinical setting. (29) Finally, SGM familial acceptance may influence PrEP adherence as support from third parties may benefit them through PrEP adherence reminders. (6)

A further effect of intersectionality is exemplified through transwomen. (10) Afro-Caribbean transwomen in London were more comfortable accessing sexual health support from peers than Glasgow counterparts. This could be due to fear of transphobia (8), and the differences in ethnic diversity of the two cities. Intersectionality suggests that being racially excluded in society, coupled with experiences of transphobia may both contribute to a weaker social network which may lead to insufficient PrEP awareness, and therefore not being able to access it.

A good patient-provider relationship has the potential to boost PrEP adherence. (8, 9) SGM may be too anxious to consult with a new provider due to PrEP stigma, and fear of disapproval after 'coming out' again. Transwomen may have additional struggles of dealing with transphobia from providers, and other patients. It can be suggested that MSM and transwomen may benefit from consulting with a familiar health care professional. Those who talked about HIV with their UAS partners had greater PrEP awareness. (12) This may be due to having a mutual understanding of safe sex practices resulting in the empowerment of autonomy. The lower power status of transwomen results in a reduced ability to negotiate safe sex. (9) This may demonstrate that transwomen are disproportionately affected by insufficient PrEP awareness due to the impacts of social oppression. Another reason is that transwomen are more vulnerable to domestic violence, (20) meaning their lack of sexual health autonomy may be exacerbated. Increased PrEP awareness alone may not aid uptake as various studies found no link between increased PrEP awareness and increased PrEP use. (10, 12, 31) This suggests that even if SGM are PrEP aware, aforementioned social barriers may be more influential, and confounding this association; further studies are required to confirm this assumption. Risk perception of individuals to HIV could influence the weak link between the two variables.

Insufficient PrEP awareness amongst transwomen is explained by preconceived ideas that PrEP is only for MSM. (9) Transwomen being 'an addendum' to gay and cis-women-specific PrEP campaigns may contribute to this misapprehension. The motivations for this may include lack of understanding of trans-specific health needs, lack of societal trans-visibility, and under-estimating the risk of transwomen to HIV. Overall, this under-representation may explain the insufficient data available on transwomen health issues, (1) meaning that identifying the needs of transwomen across the nation may be difficult. Campaigns must also encourage transwomen to access support if suffering from domestic violence. (9)

This may also combat the lower power of transwomen to negotiate safe sex.

Strengths and limitations

All studies reviewed were conducted from 2012 onwards after the approval of PrEP (18). A notable critique for studies are their applicability to ACMSM and transwomen. Excluding studies specifically looking at ACMSM, 50% (N=103) and 94% (N=33) of participants recruited by Grov et al. and Young et al. were white, respectively (5, 6). This suggests that claims regarding PrEP adherence may be weaker for ACMSM, creating uncertainties on whether they face the challenges of privacy and support network, or lack thereof on PrEP adherence. Oppositely, Mannheimer et al. recruited 10% white MSM (N=176) in the USA, (7) meaning the representative claim of black MSM having a lower PrEP adherence, compared to their white counterparts, may be transferrable to the UK.

The use of focus groups and individual interviews by Sevelius et al. (9) ensures the expression of personal opinions, dissimilar to the sole reliance on focus groups by Young et al. (5) and Rael et al., (13) which may have led to opinions being swayed by more dominating participants. However, Sevelius et al. conducted their study in the US; (9) and British transwomen may face different challenges with PrEP adherence. Both Nakasone et al. and Witzel et al. are the first to conduct their research in the UK (4,10) so finding consistent studies to support PrEP social barriers for Afro-Caribbean SGM was difficult. This means the finding's reproducibility cannot yet be confirmed. Furthermore, Nakasone et al. recruited participants through SHS (10) so participants may be more PrEP aware, and accepting of PrEP. This suggests over-estimation of claims, posing an issue on the representativeness of results to other transwomen in the UK.

CONCLUSION

This review aimed to deepen understanding of social barriers to PrEP uptake amongst SGM, in particular transwomen and ACMSM. ACMSM may find PrEP stigma a greater social barrier to PrEP uptake due to the racial stereotypes they wish to avoid being associated with. (4) This may lead to individuals abstaining from PrEP use to avoid the consequences of PrEP stigma. PrEP campaigns encouraging safe sexual liberation could build confidence in PrEP uptake amongst MSM. This is particularly pivotal for ACMSM and transwomen who are under-represented in existing PrEP campaigns. (9,10,13)

Intersectionality has aided the understanding of the PrEP social barriers faced by ACMSM. (4, 5, 10) Exposure to homophobia, racism and internalised homophobia may intensify PrEP stigma, insufficient PrEP awareness, and PrEP non-adherence. Discrimination against SGM may be curbed by integrating SGM sexual health, and SGM acceptance in heterosexual-focussed sex education delivered at schools. Ultimately, education aim to reduce PrEP stigma, and boost PrEP uptake amongst ACMSM.

Transwomen continue to suffer from insufficient PrEP awareness and PrEP non-adherence despite being at higher risk of HIV. (9,

13) Their continued experiences of social oppression (20) could explain these strengthened social barriers to PrEP uptake. Alleviating the social oppression of transwomen through governmental policies may lead to increased PrEP uptake. Discrimination from SHS and PrEP providers may form a combined barrier to PrEP uptake for transwomen and ACMSM. (8, 9) An in-depth instruction of PrEP use by familiar providers may benefit PrEP adherence for transwomen patients. Providers, as well as future providers, could benefit from continued awareness of SGM-specific health needs. Awareness of intersectionality and its effects on ACMSM and transwomen patients could better prepare providers for consultations.

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APPENDIX A

METHODOLOGY

REPORTING TEMPLATE

| Criteria | For example... |
|--|--|
| Databases searched | JSTOR, PubMed, Web of Science |
| Search criteria | 'Pre-exposure prophylaxis' OR 'HIV prevention tool' AND 'Stigma' OR 'Awareness' OR 'Adherence' OR 'patient-provider relationship' OR 'transwomen' OR 'Black, Asian, Minority Ethnic' OR 'Afro-Caribbean men who have sex with men' |
| Inclusion criteria | Studies conducted from 2012; studies conducted on transwomen; studies conducted on Afro-Caribbean MSM; studies conducted in the UK and USA; |
| Exclusion criteria | Studies conducted on heterosexual men and women; studies conducted on biomedical barriers; studies not written in English |
| Number of journal articles identified from databases | 85 |
| Number of abstracts screened and identified as potentially relevant | 30 |
| Number of journal articles included in the review | 10 |



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