Beyond Viral Suppression: Adherence Challenges and Unmet Needs in People With HIV in the UK (Positive Perspectives 3 Study)

P079

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Key Takeaways

- The global Positive Perspectives 3 study explored the experiences and needs of people with HIV; this analysis focuses on 349 adults with HIV receiving ART in the United Kingdom
- Most participants trusted their HCP (70%) and were satisfied with their HIV medication (73%), yet 50% felt they did not get to discuss important topics during appointments and over half reported suboptimal overall and mental health (54% each)
- Over half (59%) reported suboptimal adherence, with 28% intentionally missing doses (35% aged <30 years vs 9% aged ≥60 years); only 65% overall had been told by their HCP that they had virologic suppression (44% aged <30 years vs 88% aged ≥60 years)
- These findings highlight unmet needs beyond virologic suppression in people with HIV in the United Kingdom; closing communication gaps and increasing shared decision-making may support person-centered care and long-term adherence

Plain Language Summary

- Positive Perspectives 3 is a worldwide study that asked people with HIV about their health, their HIV medicine, and their care; here, we looked at the answers from 349 adults in the United Kingdom
- Most people trusted their HIV doctor or nurse and were happy with their HIV medicine, but many felt important topics were not discussed during appointments, and about half said their overall health and mental health were not as good as they could be
- More than half missed doses or did not take their medicine as prescribed in the past year; younger people were more likely to skip doses on purpose and less likely to have been told their virus was under control
- These findings show that, even when HIV is treated, many people still have unmet needs; better conversations with their care team and more say in treatment decisions could help

Introduction

- As people with HIV require lifelong antiretroviral therapy (ART), improving quality of life requires optimizing treatment experience beyond virologic suppression alone, including shared decision-making and person-centered care[1,2]
- Shared decision-making empowers individuals to participate in treatment decisions, driving treatment adherence and satisfaction and in turn influencing health-related quality of life[1]
- Despite overall treatment success, unmet needs persist in person-centered care, patient–healthcare professional (HCP) communication, and treatment burden, including ongoing adherence challenges[1,2]
- The Positive Perspectives 3 (PP3) study is a global, cross-sectional survey co-designed with community representatives aiming to capture the experiences of people with HIV across 29 geographic areas[3]
- Here, we explore the perspectives and needs of people with HIV on ART in the United Kingdom, including those related to engagement with care and HCPs, treatment, and adherence

Methods

- The PP3 study comprised an anonymous cross-sectional survey administered digitally or via paper across 29 geographic areas
- This analysis focuses on adults with HIV in the United Kingdom receiving ART who were recruited via patient-support groups
- Self-reported data, including relationships with HIV care providers (ie, HCPs), treatment satisfaction, and treatment adherence, were analyzed
- Suboptimal treatment adherence was defined as reporting any non-adherence behavior (mistakenly or intentionally missing a dose, not following prescription, or taking extra medication) as occurring "sometimes," "often," or "always" in the last 12 months
- Suboptimal health was defined as reporting "fair," "poor," or "very poor" in response to rating overall health, mental health, sexual health, or physical health in the past 4 weeks
- Descriptive data were summarized with descriptive statistics (means, medians, and percentages, where applicable)
- Multivariable Firth bias-reduced logistic regression analysis was used to identify predictors of suboptimal adherence and estimate adjusted odds ratios (aORs)

Results

Participant Demographics

- Among 349 participants, 40% (139/349) were female and 26% (89/349) identified as gay; median (range) age was 36 (22-107) years (Table 1)
- Most participants were taking oral ART (95% [330/349]) and the remaining were on long-acting injectable ART (5% [19/349])
  - Of those on oral ART, 42% (139/330) were on a once-daily single-tablet regimen, 20% (65/330) were on a once-daily multi-tablet regimen, and 38% (126/330) reported taking other oral regimens

Table 1. Demographics and Baseline Characteristics

Parameter	Overall population (N=349)
Age, median (range)	36 (22-107)
Sex assigned at birth, female:male, n (%)	138 (40):209 (60)
Gender identity, n (%)[a]	
Male	201 (58)
Female	139 (40)
Non-binary	4 (1)
Transgender	3 (1)
Prefer not to answer	1 (<1)
Sexual orientation, n (%)	
Heterosexual/Straight	209 (60)
Gay	89 (26)
Bisexual	39 (11)
Lesbian	6 (2)
Other	2 (1)
Pansexual	2 (1)
Asexual	1 (<1)
Prefer not to answer	1 (<1)
Ethnic group (reported by ≥10% of participants), n (%)	
White/Caucasian	86 (28)
English	53 (17)
African	39 (13)
Financial condition	
Stable/Comfortable	133 (38)
Financial difficulty	179 (51)
Missing	37 (11)
Time from diagnosis to start of HIV medication, n (%)[b]	
≤1 month	223 (64)
>1 month to 12 months	78 (22)
>1 year to 5 years	25 (7)
>5 years	21 (6)
Non-HIV comorbidities, n (%)	
0	107 (31)
1	30 (9)
≥2	212 (61)
Polypharmacy (≥5 concomitant non-HIV medications), n (%)[c]	263 (80)

[a]Missing data (n=1). [b]"Don't know/Can't remember" (n=2). [c]Missing data (n=21).

Engagement With Care and HCPs

- Most participants reported high trust (70% [222/315]) and comfort discussing sensitive personal topics (71% [223/315]) with their HCP; however, only 65% (205/315) were satisfied with their involvement in treatment decisions (Table 2)
- Communication gaps remained; 58% (182/315) of participants saw room for improvement in care coordination between HCPs, 50% (157/315) realized post-visit that they did not discuss important topics, and 52% (165/315) felt completing a form for their HCP ahead of their appointment would be helpful
  - Many also struggled to raise concerns when unprompted (36% [112/315]) or felt unheard by their HCP (33% [105/315]), and 25% (78/315) reported not being asked about side effects at their last visit

Table 2. Participant Perceptions of HCP Communication and Shared Decision-Making (N=315)[a]

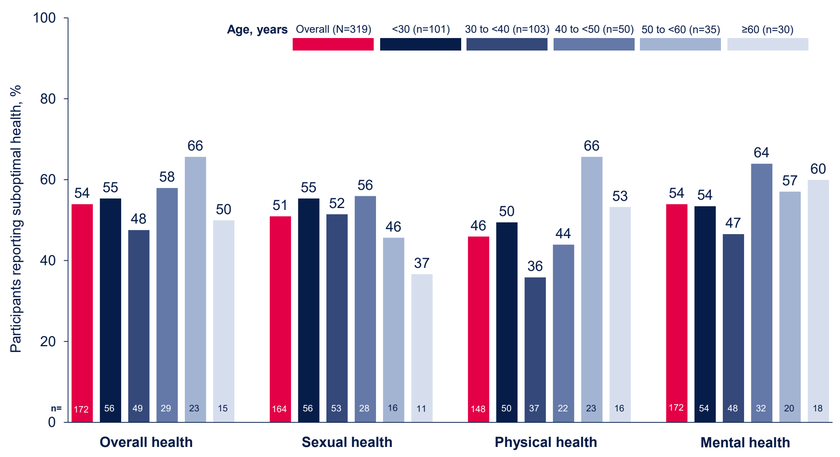
Enablers of shared decision-making		Ongoing communication gaps and unmet needs	
71% (n=223)	were comfortable discussing personal aspects of life with their HCP (eg, sexual health)	**58%** (n=182)	see room for improvement in inter-provider coordination of overall care
70% (n=222)	trust their HCP to meet their health needs	**52%** (n=165)	would find it helpful to complete a form for their HCP ahead of appointment
66% (n=207)	feel encouraged by their HCP to ask questions	**50%** (n=157)	realized post-visit that important topics were not discussed
65% (n=205)	were satisfied with their involvement in treatment decisions	**36%** (n=112)	find it hard to raise worries unless specifically asked
62% (n=196)	feel their HCP helps deal with feelings of uncertainty about health	**33%** (n=105)	sometimes feel unheard by their HCP
62% (n=196)	had treatment satisfaction assessed by their HCP	**25%** (n=78)	did not have their HCP ask about side effects during last visit
57% (n=180)	have access to their HCP at any time		

[a]Missing data (n=34).

Participant Perceptions of Health and Current ART Regimen

- Over half of participants (54% [172/319] each) had suboptimal overall and mental health, followed by suboptimal sexual (51% [164/319]) and physical health (46% [148/319])
- Suboptimal health perception was prevalent across all age groups (Figure 1)
  - Suboptimal overall health was lowest among people aged 30 to <40 years
  - Adults aged <50 vs ≥50 years had higher rates of suboptimal sexual health
  - Adults aged ≥50 vs <50 years had higher rates of suboptimal physical and mental health
- Female and male participants reported comparable health perceptions across domains; 6 of 7 participants who were non-binary or transgender reported suboptimal sexual and mental health

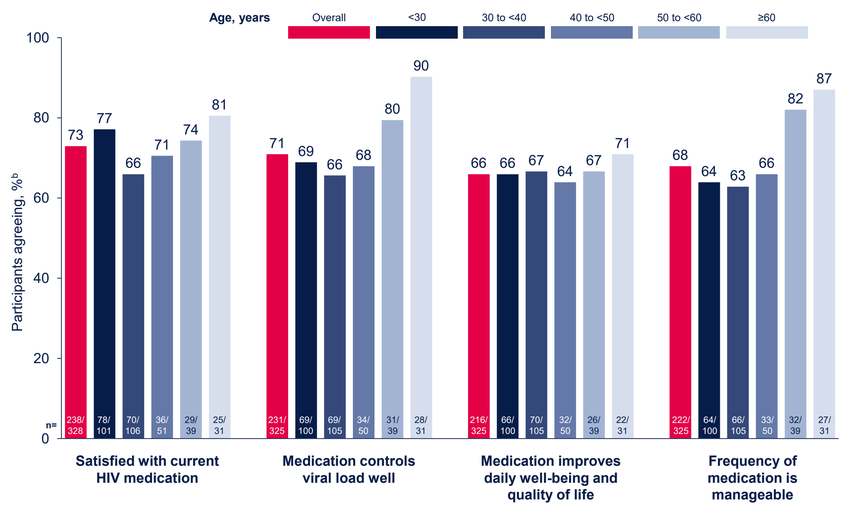
Figure 1. Health Perception Ratings by Age Group in Participants With Suboptimal Perceptions of Health (N=319)[a]



[a]Missing data (n=30).

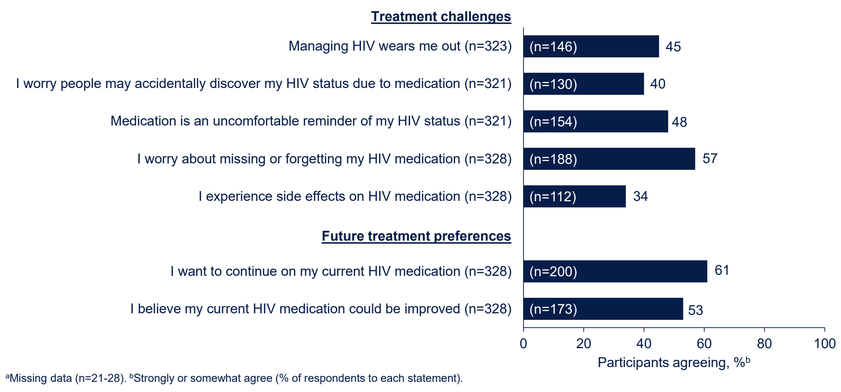
- Over half of participants (58% [187/323]) feared the health effects of HIV as they get older, rising from 53% (54/102) among those aged <30 years to 78% (28/36) among those aged 50 to <60 years
- Most participants were satisfied with their HIV medication (73% [238/328]) and agreed it controlled their viral load well (71% [231/325]; Figure 2)
  - Agreement rose with age for viral load control (aged <30 years, 69%; aged ≥60 years, 90%) and manageable dosing frequency (64% vs 87%, respectively); female and male responses were similar
- Despite most participants reporting positive treatment effects, many experienced ongoing treatment burden; over half (53% [173/328]) believed their medication could be improved and a third (34% [112/328]) reported side effects (Figure 3)
  - 57% (188/328) worried about missing or forgetting doses, 48% (154/321) found their medication an uncomfortable reminder of their HIV status, and 45% (146/323) said managing HIV wears them out
  - 39% (128/328) expressed a desire to discontinue their current medication (20% disagreed with continuing their current medication; 19% were neutral)

Figure 2. HIV Medication Benefits and Satisfaction by Age Group in Participants With Suboptimal Perceptions of Health (N=325-328)[a]



[a]Missing data (n=21-24). [b]Strongly or somewhat agree (% of each group).

Figure 3. Participant Perspectives on HIV Medication: Challenges and Treatment Outlook (N=321-328)[a]

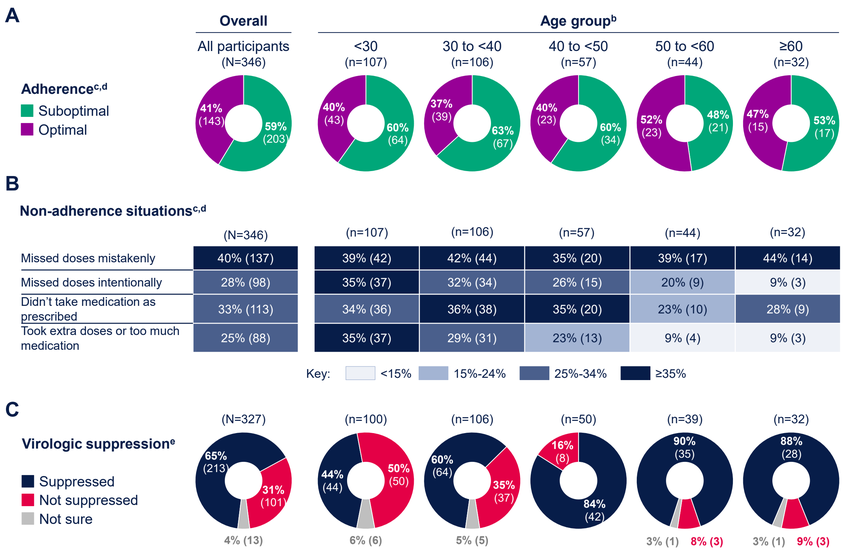


[a]Missing data (n=21-28). [b]Strongly or somewhat agree (% of respondents to each statement).

Adherence to ART

- Over half of participants (59% [203/346]) reported suboptimal adherence in the previous 12 months, and 28% (98/346) intentionally missed doses (Figure 4A-B)
  - Intentionally missing doses and taking too much medication decreased with age (aged <30 years, 35% for both; aged ≥60 years, 9% for both), whereas mistakenly missing doses was similar across age groups (35%-44%)
  - Suboptimal adherence was more common among female than male participants (66% [91/137] vs 54% [108/200])
- Suboptimal adherence was similar among participants on long-acting (58% [11/19]) and oral (59% [192/327]) ART
- Only 65% (213/327) reported that their HCP had told them they had virologic suppression, ranging from 44% (44/100) of those aged <30 years to 90% (35/39) of those aged 50 to <60 years (Figure 4C)

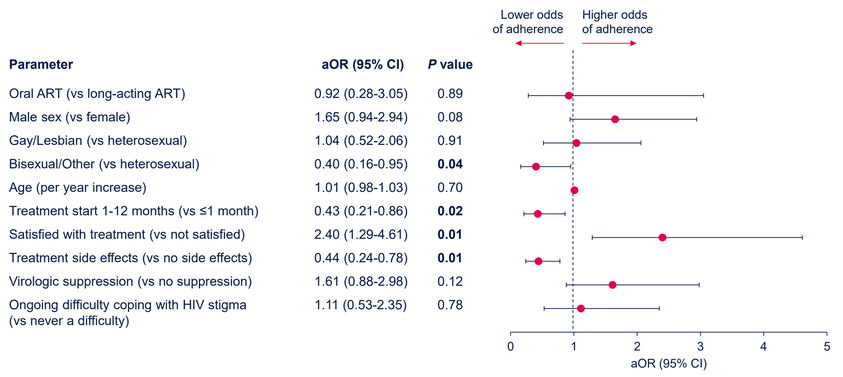
Figure 4. Adherence to ART and Virologic Suppression by Age Group (N=327-346)[a]



[a]Missing data/Prefer not to answer (n=3-22). [b]Percentage within each group. [c]Missing data (n=3). [d]Reporting "always," "often," or "sometimes" in response to non-adherence events in the last 12 months. [e]As described by main HCP; excludes prefer not to answer (n=2) and missing data (n=20).

- In logistic regression analyses, bisexual/other sexual orientation (aOR, 0.40; *P*=0.04), treatment start times between 1 and 12 months prior to the survey (aOR, 0.43; *P*=0.02), and presence of treatment side effects (aOR, 0.44; *P*=0.01) were associated with lower odds of treatment adherence, while treatment satisfaction (aOR, 2.40; *P*=0.01) was associated with higher odds of adherence (Figure 5)

Figure 5. Factors Associated With Adherence to ART: Multivariable Logistic Regression[a]



[a]Multivariable Firth bias-reduced logistic regression model (N=113 complete cases [45 adherent, 68 non-adherent]). Variables were selected using cross-validated Elastic Net penalization to optimize model fit and eliminate non-predictive factors (eg, polypharmacy, stigma, treatment start, treatment side effects, mental health, education level, employment status); age, sex, and regimen were forced as standard confounders, while intersex was removed due to sparse data. aOR <1 indicates lower odds of adherence relative to the reference group; bold *P* values are statistically significant (*P*<0.05).

Conclusions

- Most participants in the United Kingdom reported trust in their HCP and comfort discussing sensitive topics, but satisfaction with treatment decision involvement was lower, communication gaps persisted, and over half perceived their overall and mental health as suboptimal
- Although most were satisfied with their current ART, over half believed it could be improved and nearly 2 in 5 did not express a desire to continue treatment
- Suboptimal adherence was common, particularly among younger participants and women; younger participants reported intentionally missing doses more often, while missing doses by mistake was similar across age groups
- Only two-thirds had been told by their HCP that they had virologic suppression (ranging from <50% in those aged <30 years to 90% in those aged 50 to <60 years)
- Bisexual/Other sexual orientation, treatment initiation within the past year, and presence of side effects were independently associated with lower odds of adherence, while treatment satisfaction was associated with higher odds of adherence; these initial findings generate valuable hypotheses for future investigation
- Study limitations include cross-sectional design, self-reported measures, and recruitment via patient-support groups, which may limit causality, accuracy, and generalizability
- These findings highlight unmet needs beyond virologic suppression in people with HIV in the United Kingdom
  - Routinely exploring reasons for adherence challenges, alongside closing communication gaps and increasing shared decision-making, including proactively supporting opportunities to articulate day-to-day barriers, are crucial for ensuring person-centered care and improving long-term adherence

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References: 1. Okoli et al. *AIDS Behav*. 2021;25:1384-1395. **2.** de los Rios et al. *AIDS Behav*. 2021;25:961-972. **3.** Patel et al. NPhA 2024; Los Angeles, CA.

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