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Patient-reported outcomes reveal disparities in HIV care: migrants in Sweden experience lower adherence and more side effects

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ABSTRACT

Migrants in Europe are disproportionally affected by HIV and often experience poorer health outcomes, including lower rates of viral suppression. Integration of patient-reported outcome measures (PROM) in routine HIV care is recommended to improve health-related quality of life. In Sweden, a PROM questionnaire has been implemented in routine HIV care. The aim was to investigate differences in PROMs between migrants, defined as individuals born abroad, and Swedish-born people with HIV (PWH). This is a cross-sectional registry-based observational study including adult PWH who completed PROMs in 2020. Multivariable logistic regression models were used to analyze associations between patient characteristics and PROMs. Of 7766 PWH in the national cohort, 2145 (27.6%) individuals completed PROMs of whom 53.3% were migrants. Missed doses of antiretroviral treatment (ART) were associated with being born abroad, aOR 1.94 (95% CI 1.4–2.7), and WHO birth region Africa aOR 2.71 (95% CI 1.8–4.1) and Americas aOR 2.60 (95% CI 1.6–4.3). Experience of ART side effects was more common among migrants 14% vs 10.2% $p = 0.01$, borderline significant in the adjusted analyses aOR 1.35 (95% CI 0.97–1.89) $p = 0.08$. Migrants were nearly twice as likely to report satisfaction with their physical health. Both groups felt equally involved in their HIV care and experienced high satisfaction with HIV care (94.5% of migrants and 95.7% of Swedish-born) with a trend for migrants being less satisfied aOR 0.65 (95% CI 0.4–1.1) $p = 0.08$. Further research is needed to understand underlying factors of disparities in PROM to enable improved treatment adherence and equitable healthcare outcomes.

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HIV; migrants; patient-reported outcomes; adherence; side effects

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SDG 3: Good health and well-being; SDG 10: Reduced inequalities

Introduction

The number of migrants worldwide is increasing, and the largest population of international migrants reside in the European Region (McAuliffe & Oucho, 2024). Migrants are disproportionally affected by HIV and accounted for 47% of new HIV diagnoses in the European Union 2024 (European Centre for Disease Prevention and Control (ECDC) and WHO Regional Office for Europe, 2025). These elevated numbers likely reflect both higher HIV prevalence in certain countries of origin and the social and structural conditions experienced after migration, being most pronounced among individuals from sub-Saharan African nations and subpopulations such as asylum seekers and pregnant women (Santoso et al., 2022). In Europe migrants with HIV have poorer health and ART outcomes (Segala et al., 2024), including higher rates of late diagnosis, AIDS defining conditions, comorbidities, treatment discontinuation and loss of follow up, compared to native-born (Ross et al., 2018; Segala et al., 2024). In high-income countries, migrants may

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encounter various barriers to accessing healthcare services, including poorer access to prevention opportunities and HIV treatment (European Centre for Disease Prevention and Control (ECDC) and WHO Regional Office for Europe, 2023; Saracino et al., 2014).

Sweden has a high proportion of migrants among people living with HIV (PWH) compared with other European countries (European Centre for Disease Prevention and Control (ECDC) and WHO Regional Office for Europe, 2025), with 67% of PWH in Sweden being migrants (Carlander et al., 2023). In Sweden, healthcare is primarily publicly funded and HIV care, including ART, is provided free of charge for all people living with HIV, including migrants and undocumented individuals (Swedish Parliament, 2004). However, migrants living with HIV may still face challenges related to language barriers, unfamiliarity with the healthcare system, discrimination, and social exclusion, which may affect their experiences of care and support (Mehdiyar et al., 2016). Almost all migrants with a known HIV diagnosis in Sweden receive ART and according to the Swedish National HIV registry (InfCareHIV), in 2023, 93.5% of migrants met the treatment goal of HIV RNA <50 copies/ml, compared to 95% of Swedish-born individuals (Carlander & Mattsson, 2025).

Patient reported outcomes (PROs) provide the patients' perspective on their health and well-being, complementing objective markers such as HIV viral load and CD4-cell count. Patient-reported outcome measures (PROMs) are recommended in HIV care to enhance person-centered approaches and to identify unmet needs (Ambrosioni et al., 2026; European AIDS Clinical Society (EACS), 2025; Kall et al., 2020). Since 2011, an electronic validated PROM health questionnaire has been used in routine clinical HIV care in Sweden, to enhance person-centered care and assess PROMs, such as adherence and experiences of side effects (Marrone et al., 2016). Despite disparities in health outcomes, little is known regarding differences in PROs among PWH of different geographic origins and the aim of this study was to investigate PROs and satisfaction with HIV care in migrants and Swedish-born with HIV in Sweden.

Materials and methods

Design

The study was conducted as a cross-sectional cohort study, based on data from the National Quality Registry InfCareHIV.

Participants

Inclusion criteria were individuals living with HIV in Sweden 18 years and older who answered a self-reported PROM health questionnaire, from January 1st to December 31st, 2020.

InfCareHIV and the PROM questionnaire

The InfCareHIV registry monitors over 99% of people with diagnosed HIV in Sweden and additionally functions as an integrated clinical decision support tool in HIV care (Carlander et al., 2023). The registry contains data on antiretroviral treatment (ART), biomarkers, and socio-demographic characteristics but lacks information on parents' country of origin. In this study, migration experience is defined as being born abroad, consistent with the European Centre for Disease Prevention and Control (ECDC) definition of being a migrant (European Centre for Disease Prevention and Control, 2024). The InfCareHIV registry includes a PROM health questionnaire designed to assess factors important for health, treatment outcomes and to facilitate person-centred care (Supplementary file 1). Developed in collaboration with physicians, psychologists, nurses, and patient representatives, it includes PROs on self-reported physical and mental health, sexual life, and experience of ART side effects, adherence and patient reported experiences of HIV care (Carlander et al., 2023). Questions on satisfaction with physical health, psychological health, and sexual life were adapted from the Life Satisfaction Questionnaire (LiSat) developed by Fugl-Meyer et al. (Fugl-Meyer et al., 1991). The items measure individuals' subjective evaluations of their current well-being rather than objective health status. Participants rated their satisfaction with physical health, psychological health, and sexual life on a six-point Likert scale ranging from very dissatisfied to very satisfied. Adherence to ART

is measured by the patient reporting the number of missed doses in the last week. The questionnaire also includes patient-reported experience measures (PREMs) assessing patients' perceived involvement in planning and realization of their HIV care and treatment, as well as their satisfaction with quality of HIV care (Carlander et al., 2023).

The aim is to offer the PROM questionnaire annually in clinical care and it is performed at the clinic's computer, on paper, or at home through the Swedish healthcare system's dedicated website. The PROM questionnaire is available in ten languages, with professional interpreters used if necessary. Individual responses are visually presented in their medical charts through the InfCareHIV decision tool, facilitating discussions with healthcare providers (Carlander et al., 2023).

Selection of variables and PROM questionnaire items

The PROM questionnaire was performed online before a planned health care visit or during routine HIV follow-up appointments. The following independent variables were selected from the InfCareHIV registry: age, sex at birth, country of birth, probable mode of HIV transmission, years since first-ever positive HIV test, years since arrival to Sweden, years since initiation of ART, current plasma HIV RNA (irrespective of ART duration), CD4 cell count (current value, nadir). The variables used from the PROM questionnaire as dependent variables were: self-reported satisfaction with physical, psychological, and sexual health, missed doses; experience of side effects, feeling involved in planning and realization of HIV care and treatment and satisfaction with quality of HIV care.

Data analysis

Questionnaire responses for each variable were analyzed for the entire cohort and differences between migrant and Swedish-born individuals with HIV. Descriptive analysis and differences for the entire cohort and between migrants and Swedish-born individuals regarding following sociodemographic data were described: sex at birth, age, probable mode of HIV transmission, migrant status. The birth regions were categorized according to the WHO's regional classification (World Health Organization (WHO), 2025). Missing data were presented but not imputed.

Responses to questions 1–3 (self-reported satisfaction with physical, psychological, and sexual health) were dichotomized based on reference literature (Fugl-Meyer et al., 2002) into satisfied (very satisfied, satisfied) and dissatisfied (quite satisfied, quite dissatisfied, dissatisfied, very dissatisfied). Responses to adherence to treatment (question 4: missed doses) were dichotomized as adherent (0 missed doses) or non-adherent (1–2 missed doses and >3 missed doses). Responses regarding feeling involved in planning and realization of HIV care and treatment were dichotomized as feeling completely involved (completely agree) and not feeling completely involved in planning HIV care (do not agree at all, agree poorly, agree partially). Responses regarding satisfaction with quality of HIV care were dichotomized as satisfied (very satisfied, satisfied) and dissatisfied (quite satisfied, quite dissatisfied, dissatisfied, very dissatisfied). The response to this question is hidden at individual level in the graphic display, results only reported at group level for the caregiver.

For comparisons between groups, Fisher's exact test was used for dichotomous variables, Chi-square test for non-ordered categorical variables, Mantel-Haenszel Chi-square trend test for ordered categorical variables, and Mann-Whitney U-test for continuous variables. Univariable and multivariable backward logistic regression models were employed to analyze associations between patient characteristics, clinical data, and health questionnaire questions with binary outcomes. A significant multivariable model was selected through backward stepwise regression, forcing adjusted for age, sex and migrant/Swedish into the model and keeping all other independently significant variables (For univariable analyses, see Supplementary Table 1). Additionally, similar analyses for PROM variables as outcomes were performed stratified by country of birth (categorized as Swedish-born vs migrants or WHO regions). Hosmer-Lemeshow goodness-of-fit test was used for calibration and test for goodness-of-fit in the multivariable logistic regression models, where a non-significant p-value indicates good fit. The predictive ability of the models was described using c-statistics (area under the ROC curve), where a value ≥0.70 indicates a good (acceptable) model, ≥0.80 a commendably good model, and ≥0.90 an exceptionally good model. Results from logistic regression were

Table 1. Responses of the PROM questionnaire in 2020 for migrants, Swedish-born and all PWH.

PROM Questions	Migrants performing PROM 2020 (*n* = 1132) *n* (%)	Swedish- Born performing PROM 2020 (*n* = 993) *n* (%)	PWH performing PROM 2020 (*n* = 2145) *n* (%)	Tests between groups *p*-value Sweden vs abroad
Satisfaction with physical health				
Not satisfied	359 (31.9%)	446 (45.5%)	812 (38.2%)	
Satisfied	765 (68.1%)	535 (54.5%)	1312 (61.8%)	<0.0001
Missing data*	8	12	21	
Satisfaction with psychological health				
Not satisfied	390 (34.9%)	359 (36.5%)	755 (35.6%)	
Satisfied	729 (65.1%)	625 (63.5%)	1368 (64.4%)	0.46
Missing data*	13	9	22	
Satisfaction with sexual life				
Not satisfied	443 (42.9%)	502 (54.6%)	954 (48.4%)	
Satisfied	590 (57.1%)	418 (45.4%)	1018 (51.6%)	<0.0001
Missing data*	99	73	173	
Being on ART?				
Yes	1119 (99.2%)	983 (99.4%)	2122 (99.3%)	
No	9 (0.8%)	6 (0.6%)	15 (0.7%)	0.80
Missing data*	4	4	8	
Experiencing side effects				
Yes	152 (14.0%)	97 (10.2%)	251 (12.2%)	
No	935 (86.0%)	856 (89.8%)	1809 (87.8%)	0.01
Missing data*	45	40	85	
Doses missed last week				
No doses missed last week	927 (83.8%)	893 (92.3%)	1839 (87.9%)	
One or more doses missed last week	179 (16.2%)	74 (7.7%)	254 (12.1%)	<0.0001
Missing data*	26	26	52	
Feeling involvement in planning and realization of HIV care and treatment				
Not completely involved	193 (17.8%)	194 (19.9%)	389 (18.7%)	
Completely involved	894 (82.2%)	780 (80.1%)	1692 (81.3%)	0.23
Missing data*	45	19	64	
Satisfaction with quality of HIV care				
Not satisfied	61 (5.5%)	42 (4.3%)	104 (4.9%)	
Satisfied	1058 (94.5%)	942 (95.7%)	2019 (95.1%)	0.25
Missing data*	13	9	22	

*Missing data or chose not to answer the question. Missing data is not included in column percent.
PROM, Patient-reported outcome measure; PWH, People living with HIV; ART, antiretroviral therapy

presented with adjusted odds ratios (aOR) and 95% confidence intervals (CI). An alpha level of 0.05 was used as the significance level. Statistical analyses were performed in the software program of Statistical Analysis System version 9.4 (SAS Institute Inc, Cary, NC, USA).

Ethical considerations

The Swedish Ethical Review Authority approved the study (2021–03956; 2022–05624-01). All patients included in the study received both written and verbal information about the InfCareHIV registry and provided verbal consent to be included. The study was conducted in accordance with the Declaration of Helsinki (World Medical Association (WMA), 2024).

Results

Patients' characteristics

Of 7766 individuals living with HIV registered in the InfCareHIV in 2020, a total of 2145 PWH completed the PROM questionnaire of which 53.3% (1132) were migrants and 46.7% (993) were born in Sweden (origin missing, $n = 20$) (Supplementary Table 2). The most common regions of origin were the African Region (46.7%) followed by the European Region (20.5%). Among migrants the most common way of HIV transmission was heterosexual sex (54.8%) followed by men who have sex with men (33.4%). The migrant respondents were significantly younger (46 years vs 55 years, $p < 0.01$), more often women (44.4% vs 12.6%, $p < 0.01$), and had heterosexual transmission as the most common mode of transmission compared to the Swedish-born respondents (Supplementary Table 3).

Adherence to ART

Overall, 12.1% (254/2145) PWH reported missed doses of ART during the past week. For migrants, 16.2% (179/1132) reported missed doses, compared to 7.7% (74/993) of the Swedish-born (Table 1). In the multivariable model, adjusted for age, gender and country of birth, among all individuals responding to the PROM, being a migrant was associated with a higher likelihood of reporting impaired adherence (≥1 missed dose of ART during the past week), aOR 1.94 (95% CI 1.39–2.69), compared with individuals born in Sweden. For every ten years of age increase, the risk of missing doses decreased, aOR 0.70 (95% CI 0.60–0.81). Satisfaction with psychological health 0.66 (95% CI 0.49–0.90) and satisfaction with sexual life, aOR 0.69 (95% CI 0.50–0.94) were associated with reduced risk of missed doses. Impaired adherence was associated with origin (according to WHO regions), highest for individuals born in the African region, aOR 2.71 (95% CI 1.8–4.1) and the American region aOR 2.60 (95% CI 1.6–4.3) (Figure 1).

For migrants, in the adjusted model, increasing age was associated with better adherence to ART, aOR 0.73 (95% CI 0.61–0.87) and more years living with HIV aOR 1.30 (1.03–1.63). For Swedish-born individuals satisfaction with psychological health was associated with missed doses (Table 2).

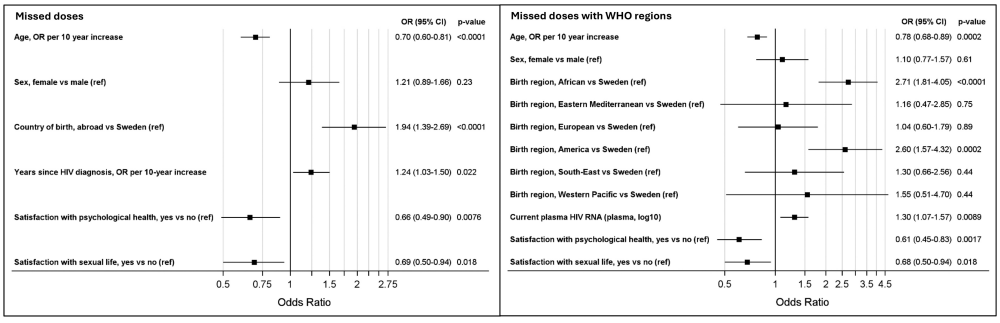

Figure 1. Multivariable logistic regression analyses for associations between selected variables and missed doses and multivariable logistic regression for associations between selected variables and missed doses with WHO regions.

Table 2. Multivariable logistic regression analyses of associations between selected variables and adherence to ART among migrants and Swedish-born individuals.

Selected variables	Migrants	Swedish-born
	Association with adherence to ART OR (95% CI)	Association with adherence to ART OR (95% CI)
Age, per 10 years increase	**0.73** (0.61–0.87)	**0.82** (0.67–1.00)
Sex, female vs male (ref)	1.14 (0.82–1.58)	0.78 (0.78–1.65)
Years since HIV diagnosis, per 10 years increase	**1.30** (1.03–1.63)	
Satisfaction with psychological health, yes vs no (ref)		**0.50** (0.31–0.82)
Experienced side effects, yes vs no (ref)		1.83 (0.95–3.51)

Bold ORs represent statistically significant associations (95% CI excluding 1.0).

Self-reported side effects

Overall, 12.2% (251/2145) of PWH reported side effects from ART. Of the migrants living with HIV, 14.0% (152 of 1132) reported experience of side effects from ART compared with Swedish-born, 10.2% (97 of 993), $p = 0.01$ (Table 1). For all individuals higher CD4 nadir count was associated with lower aOR of experienced side effects 0.90 (95% CI 0.82–0.98). Additionally, satisfaction with physical health, aOR 0.58 (95% CI 0.42–0.79), sexual life aOR 0.69 (95% CI 0.51–0.96), while feeling involved in HIV care planning aOR 0.53 (95% CI 0.38–0.75) were associated with less self-reported side effects (Figure 2).

For migrants, side effects was associated with poorer physical health, aOR 0.43 (95% CI 0.30–0.61), and feeling less involvement in HIV care planning, aOR 0.64 (95% CI 0.41–0.98). For individuals born in Sweden a higher CD4 cell count, aOR 1.13 (95% CI 1.03–1.23), satisfaction with sexual life aOR 0.47 (95% CI 0.26 –0.83) and feeling less involved in HIV care planning 0.26 (95% CI 0.15–0.46) were associated with reported side effects (Table 3).

Self-reported satisfaction with physical, psychological and sexual health

The proportion of all individuals responding to the PROM questionnaire, who reported being satisfied with their physical health, was 61.8%. Migrants rated their physical health better than Swedish-born individuals, with 68.1% of the migrant group being satisfied with their physical health, compared to 54.5% ($p < 0.01$) among the Swedish-born respondents (Table 1).

In the adjusted multivariable logistic regression analyses migrants were nearly twice as likely to be satisfied with their physical health. Among migrants, satisfaction with physical health was positively associated with psychological and sexual health and feeling involved in HIV care planning while lower satisfaction with physical health was associated with older age and the experience of side effects (Figure 3). Among Swedish-born individuals, as for migrants, satisfaction with physical health was positively associated with psychological and sexual health. For Swedish-born, heterosexual mode of HIV transmission was associated with lower self-reported physical health (Table 4).

Among all who responded to the PROM questionnaire, 64.4% reported being satisfied or very satisfied with their psychological health. There were no statistically significant differences between Swedish-born and migrant individuals regarding satisfaction with self-reported psychological health, 63.5% and 65.1%, respectively (Table 1). In the adjusted multivariable logistic regression model, several factors associated with satisfaction with psychological health were shared between Swedish-born individuals and migrants

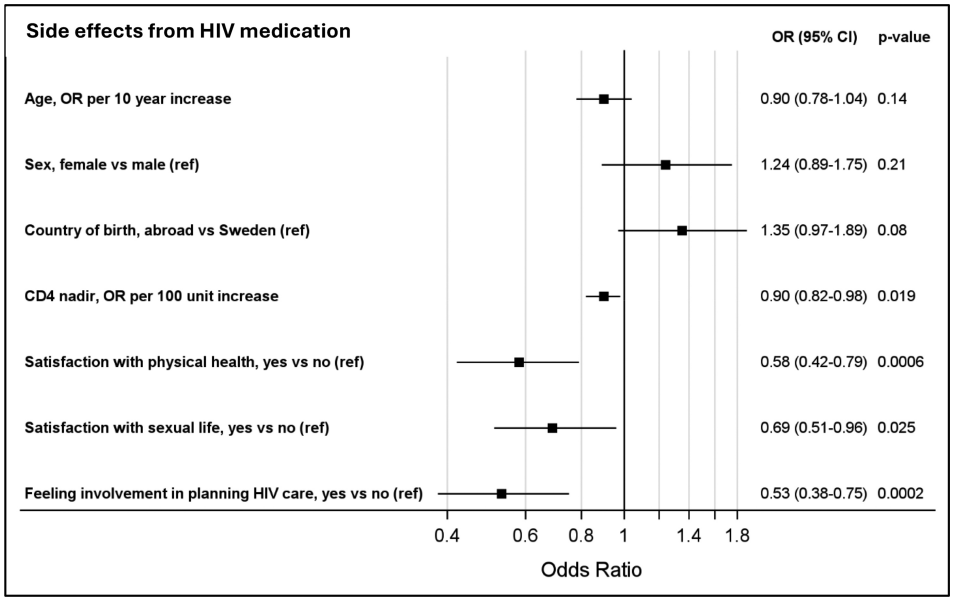

Figure 2. Multivariable logistic regression analyses for associations between selected variables and side effects from HIV medication.

Table 3. Multivariable logistic regression analyses of associations between selected variables and self-reported side effects among migrants and Swedish-born individuals.

Selected variables	Migrants Association with self-reported side effects OR (95% CI)	Swedish-born Association with self-reported side effects OR (95% CI)
Age, per 10 years increase	0.98 (0.84–1.16)	1.16 (0.92–1.47)
Sex, female vs male (ref)	1.21 (0.84–1.74)	0.93 (0.39–2.20)
Current CD4 values, per 100-unit increase		**1.13** (1.03–1.23)
Satisfaction with physical health, yes vs no (ref)	**0.43** (0.30–0.61)	
Satisfaction with sexual life, yes vs no (ref)		**0.47** (0.26–0.83)
Feeling involvement in planning and realization of HIV care and treatment, yes vs no (ref)	**0.64** (0.41–0.98)	**0.26** (0.15–0.46)

Bold ORs represent statistically significant associations (95% CI excluding 1.0).

(Figure 3). In both groups, older age, satisfaction with physical health, sexual life, and higher perceived quality of HIV care were associated with a greater likelihood of reporting satisfaction with psychological health (Table 4).

The proportion of respondents who were satisfied with their sexual life (with or without a partner) was 51.6%. Migrant individuals reported higher satisfaction with their sexual life, at 57.1%, compared to 45.4% ($p < 0.01$) among Swedish-born respondents (Table 1). In the adjusted multivariable logistic regression, the likelihood of being satisfied with one's sexual life decreased with increasing age for both groups (Figure 3). Women were more likely than men to report satisfaction with their sexual life, and satisfaction in one's sexual life was also positively associated with higher levels of self-reported physical and psychological health and feeling involved in HIV care planning. Additionally, sexual satisfaction was negatively associated with a longer duration since HIV diagnosis for Swedish-born (Table 4).

Involvement in planning and realization of HIV care and treatment and satisfaction with quality of HIV care

No statistically significant differences were found between Swedish-born and migrant individuals regarding feeling involved in their HIV care, with 82.2% of migrant respondents and 80.1% of Swedish-born respondents feeling completely involved in their HIV care and realization of their HIV care (Table 1). Results for adjusted multivariable analysis regarding in planning and realization of HIV care and treatment for all PWH, migrants and Swedish-born are presented Figure 4. Factors associated with feeling involved in planning and realization of HIV care and treatment, were satisfaction with physical health, sexual life, not experiencing side effects and being satisfied with quality of HIV care. For migrants, satisfaction with psychological health, sexual life and being satisfied with quality of HIV care were associated with feeling involved in planning HIV care. This result was equal for Swedish-born, with the additional factors of higher age, years since HIV diagnosis, and not experiencing side effects associated with feeling involved in HIV care.

Regarding satisfaction with the quality of HIV care, 94.5% of migrants and 95.7% of Swedish-born PWH were satisfied, showing no statistical differences between the two groups (Table 1). Results for adjusted multivariable analysis regarding satisfaction with quality of HIV care for all PWH, migrants and Swedish-born are presented in Figure 5. Satisfaction with physical health, psychological health, and feeling involved in planning HIV care were positively associated with satisfaction with quality of HIV care. For migrants, satisfaction with physical and psychological health and feeling involved in HIV care was associated with higher satisfaction with quality of HIV care. For Swedish-born years since first ART, satisfaction with psychological health and feeling involved in planning HIV care were associated with satisfaction with quality of HIV care.

Table 4. Multivariable logistic regression analyses of associations between selected variables and satisfaction with physical, psychological and sexual health among migrants and Swedish-born individuals.

Selected variables	Migrants			Swedish-born		
	Association with satisfaction of physical health OR (95% CI)	Association with satisfaction of psychological health OR (95% CI)	Association with satisfaction of sexual life OR (95% CI)	Association with satisfaction of physical health OR (95% CI)	Association with satisfaction of psychological health OR (95% CI)	Association with satisfaction of sexual life OR (95% CI)
Age, per 10 years increase	0.88 (0.76–1.02)	**1.16** (1.00–1.35)	**0.78** (0.68–0.89)	0.91 (0.80–1.05)	**1.45** (1.25–1.67)	**0.80** (0.69–0.92)
Sex, female vs male (ref)	0.91 (0.65–1.26)	**0.59** (0.38–0.91)	**1.69** (1.27–2.25)	1.24 (0.70–2.19)	**0.49** (0.30–0.82)	**2.40** (1.48–3.88)
Country of birth, migrant vs Swedish-born (ref)	**1.83** (1.42–2.35)	0.91 (0.70–1.17)	1.01 (0.80–1.27)			
Years since HIV diagnosis, per 10 years increase						**0.76** (0.64–0.90)
Probable mode of HIV transmission						
Heterosexual vs men who have sex with men/bisexual (ref)		**2.23** (1.42–3.51)		**0.56** (0.38–0.85)		
Intravenous drug use vs men who have sex with men/bisexual (ref)		2.48 (0.59–10.38)		0.63 (0.27–1.45)		
Other modes of transmission vs men who have sex with men/bisexual (ref)		**2.05** (1.14–3.71)		1.21 (0.42–3.46)		
Satisfaction with physical health, yes vs no (ref)		**6.51** (4.71–9.00)	**2.15** (1.55–2.98)		**6.01** (4.32–8.36)	**2.29** (1.66–3.17)
Satisfaction with psychological health, yes vs no (ref)	**6.14** (4.43–8.52)		**3.49** (2.54–4.79)	**6.26** (4.47–8.77)		**3.58** (2.50–5.12)
Satisfaction with sexual life, yes vs no (ref)	**1.98** (1.42– 2.75)	**3.34** (2.43–4.58)		**2.35** (1.70–3.24)	**3.47** (2.43–4.94)	
Experienced side effects, yes vs no (ref)	**0.50** (0.32–0.77)					
Feeling involvement in planning and realization of HIV care and treatment, yes vs no (ref)			**1.73** (1.20–2.50)	**2.35** (1.59–3.49)		**1.61** (1.08–2.39)
Satisfaction with quality of HIV care, yes vs no (ref)	**4.58** (2.18–9.62)	**1.97** (1.00–3.88)			**3.44** (1.38–8.60)	

Bold ORs represent statistically significant associations (95% CI excluding 1.0).

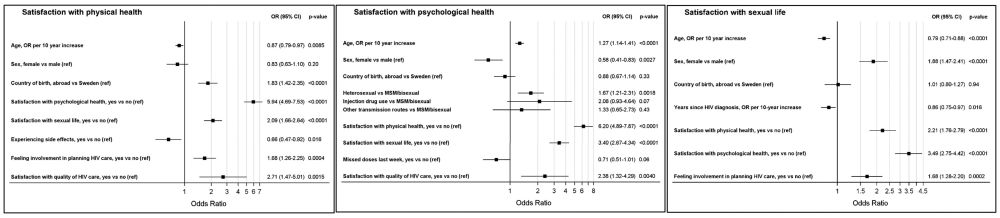

Figure 3. Multivariable logistic regression analyses for associations between selected variables and satisfaction with physical health, psychological health, and sexual life for all PWH.

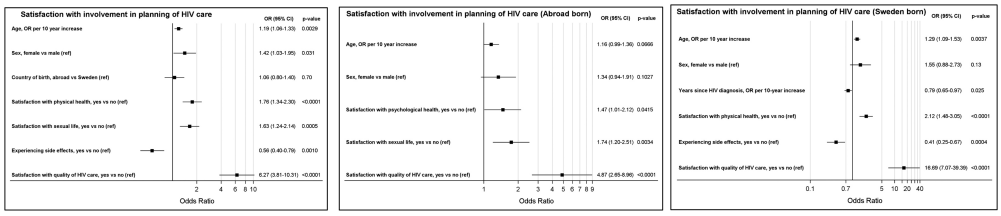

Figure 4. Multivariable logistic regression analyses for associations between selected variables and satisfaction with involvement in planning and realization of HIV care for all PWH and stratified by migrants and Swedish-born.

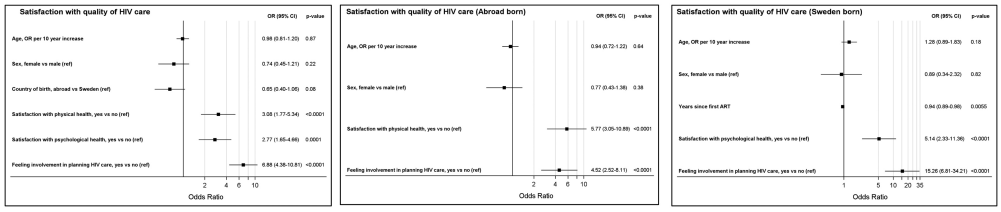

Figure 5. Multivariable logistic regression for associations between selected variables and satisfaction with quality of HIV care for all PWH and stratified by migrants and Swedish-born.

Discussion

In this national registry study, we investigated disparities in patient-reported outcome measures within routine clinical care between migrants and Swedish-born individuals with HIV in Sweden. The study found significant differences in PROMs between these groups, particularly in ART adherence and the experience of ART side effects.

Being a migrant was associated with a significantly higher likelihood of reporting impaired ART adherence. Among migrants originating from Africa or the American WHO regions, one in five reported at least one missed dose during the previous week. These findings align with recent data describing adherence challenges for migrants in the HIV care process (Goupil de Bouillé et al., 2025) and poorer treatment outcomes among migrants from Africa, when comparing HIV outcomes across different WHO regions (Segala et al., 2024). Even though Sweden was one of the first countries to achieve UNAIDS' three "95–95-95 goals" (Lundgren et al., 2024), disparities in virological outcomes have been found between migrants and Swedish-born individuals (Carlander & Mattsson, 2025). A previous study on PROM in routine clinical care demonstrated a strong correlation between self-reported adherence to ART and treatment outcomes, specifically the proportion of individuals achieving viral suppression (Marrone et al., 2016). In this present study, self-reported adherence was not directly compared with virological outcomes, as not all respondents to the PROM questionnaire had been on ART more than six months or had treatment interruptions, thus not expected to be undetectable. The finding that missed doses last week were associated with more years living with HIV may reflect treatment fatigue linked to continuing medication use. A systematic review by Sarma et al. (Sarma et al., 2023) reported a negative association between adherence and overall medication burden. Also, the same review demonstrated that older people with HIV tend to be more adherent to ART than younger individuals, which aligns with our findings where optimal adherence was associated with older age (Sarma et al., 2023). A systematic review investigating migrants´ adherence to the HIV care process (treatment adherence, retention in care and virological outcome) in high-income countries showed that migrants from sub-Saharan Africa were the most likely to encounter difficulties in adhering to the HIV process but concluded that origin is a too simple categorization for explaining more complex patterns (Goupil de Bouillé et al., 2025). Rather, different intersecting social and cultural determinants could influence adherence to HIV care processes, including life events during the migratory journey, exposure to violence, level of health literacy, educational level, social precariousness, loneliness, administrative insecurity, social representations of the healthcare system and health and living conditions in the host country (Goupil de Bouillé et al., 2025), and may thus impact adherence to ART. This underscores the complex interplay between adherence, HIV duration, age, and other contextual factors, including sociodemographic characteristics. Further research is needed to explore how underlying factors, such as low health literacy, exposure

to violence, and social positions impact adherence in the Swedish context. Such evidence is essential to inform the development of targeted interventions, including patient education, aimed at improving adherence among people living with HIV.

In the PROM questionnaire, migrants with HIV reported a higher level of self-reported ART side effects compared to their Swedish-born counterparts. ART side effects may be associated with poorer adherence to ART (Li et al., 2017), but this study did not find this association. However, in a previous larger study of PROM the HIV cohort during 2011–2017, the association between self-reported side-effects and ART adherence was found (Mellgren et al., 2020). Since then, the proportion of individuals reporting ART-related side effects in the Swedish cohort has declined from 32% in 2011 to 6% among Swedish men and 10.5% among migrant women in 2024 (Carlander & Mattsson, 2025; Mellgren et al., 2020).

Although the prevalence of ART side effects in the cohort has declined, the association between experiencing ART side-effects and not feeling involved in HIV care persisted from previous studies (Mellgren et al., 2020). Patients who felt completely involved in their care had approximately half the odds of reporting side effects. This association may reflect better communication about ART and patients' experiences of side effects, underscoring the importance of person-centred care. Social vulnerabilities have been suggested as contributing factors of dissatisfaction with care (Préau et al., 2012). Moreover, the concept of ART side effects, as defined by individuals, extends beyond the conventional biomedical framework, typically measured and reported in pharmaceutical studies (Mellgren et al., 2020). Side effects can encompass for example fear of accelerated ageing, anxiety about unknown long-term effects, and the perceived impact of ART on social life (Mellgren et al., 2020) and patients' beliefs may predict reporting of ART side-effects (Horne et al., 2019). Both migrants and Swedish-born reported high levels of feeling involved in their HIV care planning (82% and 80% respectively) and also very high satisfaction with quality of HIV care (95% and 96% respectively), with a trend for migrants being less satisfied. For migrants, access to free HIV care and ART may be an improvement from previous experiences still, there may be a need for more time in the patient-physician encounter (Mehdiyar et al., 2016).

Our results indicate that migrants with HIV report greater satisfaction with their physical health compared to Swedish-born individuals. Among migrant respondents, nearly 70% rated their physical health as good or very good, whereas the corresponding figure for Swedish-born respondents was 55%. This is in line with the so-called "healthy immigrant effect", that migrant individuals may exhibit better health than the populations of their host countries at the onset of migration, except for refugees who resided in refugee camps prior to migration (Gee et al., 2004). This phenomenon is explained by the fact that migrant individuals are often younger, stronger, and healthier, enabling them to cope with the challenges of migration.

In contrast, we found no differences in psychological health between migrants and Swedish-born. However, a qualitative study of migrants with HIV in Sweden showed that their life situation was highly impacted by HIV stigma (Mehdiyar et al., 2020). In Sweden, migrants reported that social and structural factors such as language barriers, precarious legal status, and anti-immigrant sentiment further complicate health access, and may foster late diagnoses and delayed treatment, and that these compounded challenges contribute to psychological distress and weakened social support (Nkulu-Kalengayi et al., 2022). Additionally, it is well described that migrants with HIV may face intersecting layers of discrimination and stigma due to their migration status, race, socioeconomic background, and HIV status (Jackson-Best & Edwards, 2018) (Mellini et al., 2024). Stigma can also manifest in healthcare settings through discriminatory practices and lack of culturally competent care, discouraging individuals from seeking treatment and adhering to ART (Bor et al., 2021), and poorer treatment outcomes (Logie et al., 2018). It is possible that intersectional stigma affecting migrants with HIV in Sweden is a part of our findings of lower adherence and higher experience of side effects, which need to be further explored.

Strengths and limitations

Registry-based studies have limitations including risk of potential biases. In this study, there is a risk of selection bias as the group who responds to the questionnaire may have better health or is more engaged with healthcare services compared to non-respondents. Respondents may overestimate their health status due to social desirability or subjective interpretation, for example, impaired adherence may be more common than this study demonstrates.

Another consideration is that the study lacks information on socioeconomic status, factors that are known to impact health outcomes. All individuals who had performed PROM irrespective of ART duration were included, and this limits the study from assessing PROM in relation to viral suppression since not all had been on ART continuously for six months to be estimated undetectable.

A strength in this study is the high number of respondents that were migrants and that data is national and collected from PROM integrated in routine HIV care. The number of individuals who had been offered the opportunity to respond to the PROM questionnaire was lower in 2020, the first year of COVID-19 pandemic, where 28% performed PROM compared to 38% the previous year (National Quality Registry InfCareHIV, 2019), however the decline rate for performing PROM was only 5.2%.

Data were collected during 2020, coinciding with the COVID-19 pandemic. There were no differences in societal or healthcare restrictions for migrants or Swedish-born persons, and routine HIV follow-up care continued throughout this period. However, some physical visits were replaced with digital consultations according to the circumstances and health needs of the individual. The questionnaire was administered in connection with regular clinical visits or completed digitally, the broader societal circumstances associated with the pandemic may have influenced participants' experiences and perceptions.

Conclusions

This national study on patient-reported outcomes among people with HIV demonstrates differences in adherence and experience of side effects in migrants compared to Swedish-born individuals, differences that may affect ART outcomes and long-term health. The study supports the use of PROMs in HIV care to identify unmet needs in heterogeneous HIV populations. Further research is crucial to understand underlying factors to enable improved treatment adherence, reduced side effects, and equitable healthcare outcomes.

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Author contributions

Ewa Carlsson Lalloo: Conceptualization, Formal analysis, Investigation, Methodology, Validation, Visualization, Writing – original draft, Writing – review & editing. **Johanna Brännström**: Methodology, Validation, Writing – review & editing. **Manijeh Mehdiyar**: Conceptualization, Validation, Writing – review & editing. **Christina Carlander**: Methodology, Resources, Validation, Writing – review & editing. **Åsa Mellgren**: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Validation, Writing – review & editing.

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ÅM has received honoraria for lectures and advisory board from GSK ViiV outside of this work. JB has received honoraria for advisory boards from GSK Viiv, Gilead Sciences and Merck Sharp & Dohme, all outside the scope of this article. CC has received honoraria, paid to her institution, for lectures and advisory boards from GSK Viiv, Gilead Sciences and Merck Sharp & Dohme, all outside the scope of this article. ECL has received honoraria from GSK Viiv and Gilead Sciences for lectures, all outside the scope for this article.

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