Global Survey to Evaluate Engagement in Care and Treatment Experiences of People With HIV

P163

Xavier Guillaume[1], Robin Barkins[2], Marcel Dams[3], Nomfundo Eland[4], Maureen Owino[5], Carlos Saucedo[6], Yun-Chung Lu[7], Amina Omri[1], Alissar Moussallem[1], Larkin Callaghan[8], Michael Bogart[8], Connie Kim[8], Megan Dunbar[8]

[1]Oracle Life Sciences, Paris, France; [2]To Restore, Unite, Support, and Transform, Los Angeles, CA, USA; [3]Aidshilfe NRW e.V., Cologne, Germany; [4]Emthonjeni Counselling & Training, Cape Town, South Africa; [5]York University, Toronto, ON, Canada; [6]Agenda LGBT, A.C., Mexico City, Mexico; [7]We As One Association, Taiwan; [8]Gilead Sciences, Inc., Foster City, CA, USA

Conclusions

- Among all survey participants, 35% reported delayed initiation (>30 days) of HIV treatment, highlighting opportunities to support or improve rapid initiation of treatment
- The majority of participants who were receiving oral or injectable antiretroviral therapy for the treatment of HIV did not report challenges with treatment adherence, with 86% and 81% reporting no difficulty in taking their medication, respectively
- Participants identified treatment effectiveness, reduced side effects, and long-term safety as top considerations for adhering to or switching HIV medication
- Overall, participants reported high levels of satisfaction with their HIV treatment

Plain Language Summary

- People with HIV can live as long as those without HIV and have a high quality of life when they take medication to treat the virus
- Things like stigma (shame), discrimination, or not being able to see a doctor can cause a lag time to finding out someone has HIV and getting treated, which can lead to poor outcomes
- Understanding what people with HIV go through is important for helping them to have good long-term health
- This study asked 1250 people with HIV in 9 countries about their experiences and challenges they faced
- Most people who answered the questions said they did not have problems taking their medication and were happy with their HIV treatment
- Some people started their HIV treatment late, according to today's guidelines

Introduction

- Advances in antiretroviral therapy (ART) have enhanced HIV treatment effectiveness and accessibility, allowing people with HIV (PWH) to achieve a normal life expectancy and high quality of life if viral suppression is maintained[1-3]
  - The introduction of long-acting injectable therapy has further expanded treatment options for PWH[4]
- Stigma, discrimination, and socioeconomic challenges can disrupt engagement in care for PWH, resulting in late diagnoses, delayed initiation of ART, poor adherence, and reduced viral suppression[5-7]
- Understanding the experiences of PWH in the current era is vital to enhance engagement in care and achieve long-term treatment success[8]
- This study used an online survey to assess the perspectives of PWH on barriers to and facilitators of care, with a particular focus on treatment initiation, treatment adherence, and preferences for and satisfaction with HIV treatment options

Methods

- In this multinational, observational, cross-sectional study, a quantitative, 45-minute survey was conducted online using a multimodal approach involving patient communities/databases; patient panels; referrals from patient advocacy groups, physicians, and other patients; and social media targeting
  - This survey is ongoing, with a goal of recruiting 2500 PWH
  - Here, interim results are reported for 1250 participants from surveys conducted between 13 May 2024 and 16 July 2024
- The survey was codeveloped by investigators and community advocates who represented the survey countries (Canada, France, Germany, Italy, Japan, Mexico, South Africa, Spain, Taiwan, the United Kingdom, and the United States) and translated into local languages
- Survey questions assessed the experiences of PWH across the HIV care cascade and included sociodemographic information, sociobehavioural characteristics, clinical characteristics, HIV diagnosis and care, HIV treatment and preferences, and treatment success
  - The survey included the 10-item HIV Treatment Satisfaction Questionnaire (HIVTSQ) status version,[9,10] which is used to assess treatment satisfaction at the start of treatment or following treatment switch. It can be used to compare treatment satisfaction between different ART regimens within a holistic picture of patient-centric care. The HIVTSQ is scored on a 6-point ordinal scale, with a total score between 0 (lowest satisfaction) and 60 (highest satisfaction)
- Participating PWH were ≥18 years of age, had a self-reported diagnosis of HIV, resided in 1 of the survey countries, and could complete the survey in 1 of the local languages
- Descriptive statistics were used to summarise the data, with continuous/discrete variables presented as counts, means, and standard deviations (or medians, minima, and maxima) and categorical variables presented as frequencies and percentages

Results

- Among the total population (N = 1250), the mean (SD) age was 41.4 (11.8) years and the majority of participants identified as male (66%). Most participants were receiving treatment for their HIV (92%), with the majority receiving 1 daily oral pill (67%; **Table 1**)

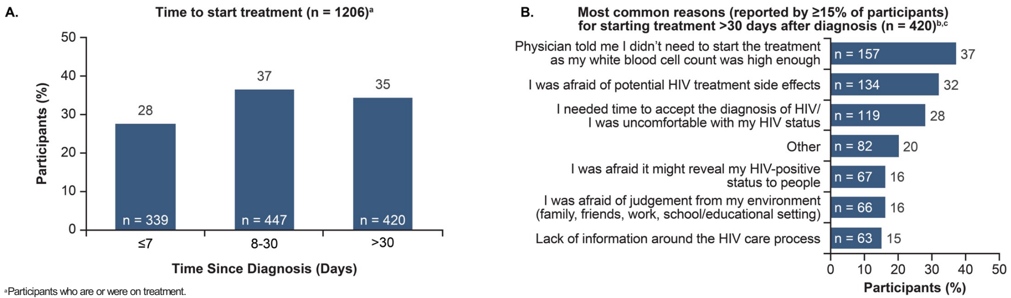
Table 1. Demographic and Clinical Characteristics

Characteristic	Participants (N = 1250)
Gender, n (%)[a]	
Male	831 (66)
Female	380 (30)
Other	39 (3)
Age, years, mean (SD)	41.4 (11.8)
Country, n (%)	
United States	336 (27)
United Kingdom	186 (15)
South Africa	175 (14)
Canada	129 (10)
Italy	111 (9)
Mexico	108 (9)
Germany	96 (8)
Japan	69 (6)
Taiwan	40 (3)
Subpopulation, n (%)[b]	
MSM	560 (45)
People who use drugs	381 (30)
Cis women	366 (29)
Older people with HIV (≥50 years of age)	314 (25)
Uninsured/underinsured	152 (12)
BIPOC MSM	130 (10)
Time since initiation of first ART, years, mean (SD)[c]	10.1 (9.1)
Receiving ART at the time of survey completion, n (%)	1154 (92)
Type of ART treatment taking at the time of survey completion, n (%)[d]	
1 daily oral pill	774 (67)
>1 daily oral pill taken at the same time of day	215 (19)
>1 oral pill taken several times a day	50 (4)
Injections only	42 (4)
Injections and oral pills	67 (6)

[a]Gender as identified by participants.
[b]Subpopulations overlap, and participants could be in multiple subgroups; thus, percentages may not sum to 100%.
[c]n = 1206.
[d]n = 1148.
ART, antiretroviral therapy; BIPOC, Black, Indigenous, and people of colour; MSM, men who have sex with men.

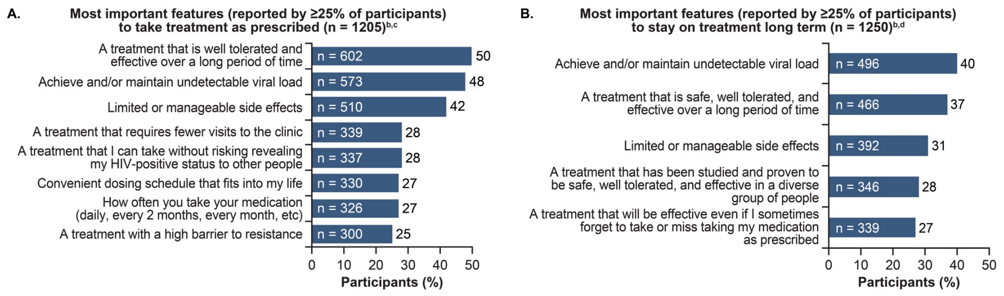
- Among the 1206 participants who started ART, similar proportions initiated treatment ≤7 days since diagnosis, 8 to 30 days since diagnosis, and >30 days since diagnosis (**Figure 1A**)
- Common reasons for delaying the start of treatment >30 days included physician recommendation based on white blood cell count, fear of potential side effects, and needing time to accept the diagnosis (**Figure 1B**)
- Among the total population, 31 (2%) participants never discussed treatment with a physician. The most common reasons for not discussing treatment (reported by ≥20% of participants) were fear of judgement from health care professionals (26%), fear of judgement from family/friends/work/school (23%), difficulties getting to the hospital/clinic (23%), and fear of potential side effects (23%)
- Most participants did not report adherence challenges with oral ART in the past month (890/1039 [86%]) or with injectable ART in the past 6 months (88/109 [81%])
- The most commonly cited barriers to taking HIV treatment as prescribed were the financial cost of treatment, clinics and pharmacies not having the appropriate medications, and fear of revealing HIV-positive status
- The most commonly cited facilitators were support from family, friends, or community; support or medication counselling from health care providers; and other support services
- The most important treatment features to motivate participants to take treatment as prescribed (**Figure 2A**) and to stay on treatment long term (**Figure 2B**) were that the treatment was safe, well tolerated, and effective over a long period of time; allowed PWH to achieve/maintain an undetectable viral load; and reduced side effects
- The most common reason for switching HIV treatment was physician suggestion (**Figure 3A**)
- The most important features participants identified for why they might choose to switch treatment were achieving/maintaining an undetectable viral load, reducing side effects, and long-term tolerability and effectiveness (**Figure 3B**)
- The overall median HIVTSQ score was 51.0/60 (**Table 2**)
- The median score for bictegravir/emtricitabine/tenofovir alafenamide (B/F/TAF) was 55.0/60, which was higher than the overall median score
- When excluding B/F/TAF, the median HIVTSQ scores for all other regimens (n = 908) and all other oral regimens (n = 799) were both 50.0/60

Figure 1. Summary of Timing of HIV Treatment Initiation After HIV Diagnosis



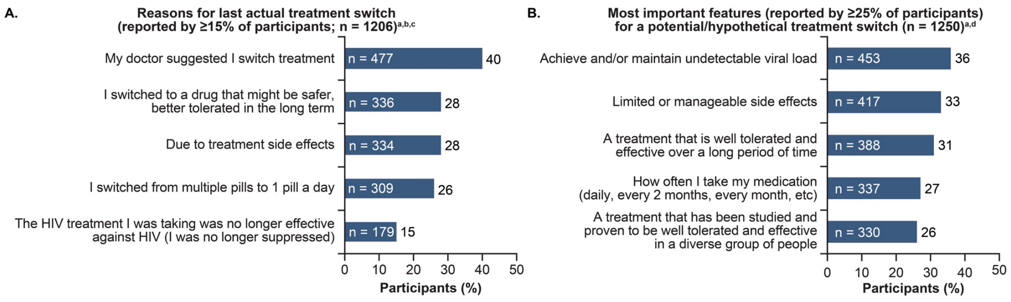
[a]Participants who are or were on treatment.
[b]Participants could have selected multiple responses; thus, percentages may not sum to 100%.
[c]Participants with delayed start of treatment >30 days.

Figure 2. Summary of the Most Important Features for Treatment Adherence and Persistence[a]



[a]Participants were asked to rank the top 3 treatment features, among 13 possible responses, that would be most important to motivate them to take treatment as described and stay on treatment long term. Features selected by ≥25% of participants are shown.
[b]Participants could have selected multiple responses; thus, percentages may not sum to 100%.
[c]Participants who are or were on treatment (n = 1205; 1 participant was excluded because of missing data).
[d]All participants (N = 1250).

Figure 3. Summary of the Reasons and Most Important Features for Treatment Switching



[a]Participants could have selected multiple responses; thus, percentages may not sum to 100%.
[b]"Other" was reported by 4% of participants.
[c]Participants who are or were on treatment.
[d]Participants were asked to rank the top 3 treatment features, among 13 possible responses, that would be most important in switching HIV treatment.

Table 2. Summary of HIV Treatment Satisfaction Questionnaire Scores

	Overall (n = 1148)[a]	B/F/TAF (n = 240)	All Other Regimens[b] (n = 908)	All Other Oral Regimens[b] (n = 799)
HIVTSQ score, median[c]	51.0	55.0	50.0	50.0

[a]Among the 1154 participants who were receiving treatment, 6 did not answer the HIVTSQ survey.
[b]Excluding B/F/TAF.
[c]The HIVTSQ is a validated 10-item questionnaire scored on a 6-point ordinal scale, with a total score between 0 (lowest satisfaction) and 60 (highest satisfaction).
B/F/TAF, bictegravir/emtricitabine/tenofovir alafenamide; HIVTSQ, HIV Treatment Satisfaction Questionnaire.

Limitations

- In this cross-sectional study, analyses for the interim results reported here were not stratified by time since initiation of ART
- Results may have been impacted by participant recall bias

References: **1.** World Health Organization. HIV and AIDS. Accessed 9 September 2024. https://www.who.int/news-room/fact-sheets/detail/hiv-aids. **2.** Cohen MS, et al. *N Engl J Med*. 2011;365:493-505. **3.** Rana AI, et al. *Drugs*. 2020;80:535-45. **4.** US Department of Health and Human Services. Guidelines for the use of antiretroviral agents in adults and adolescents with HIV. Accessed 10 September 2024. https://clinicalinfo.hiv.gov/sites/default/files/guidelines/documents/adult-adolescent-arv/guidelines-adult-adolescent-arv.pdf. **5.** Mugavero MJ, et al. *Clin Infect Dis*. 2013;57:1164-71. **6.** Katz IT, et al. *J Int AIDS Soc*. 2013;16:18640. **7.** Genberg BL, et al. *Soc Sci Med*. 2009;68:2279-87. **8.** Lazarus JV, et al. *HIV Med*. 2023;24:8-19. **9.** Woodcock A, Bradley C. *Qual Life Res*. 2001;10:517-31. **10.** Woodcock A, Bradley C. *Value Health*. 2006;9:320-33.

Acknowledgements: This study was funded by Gilead Sciences, Inc. We extend our thanks to the survey participants. Medical writing support was provided by Katherine Townsend, PhD, of Lumanity Communications Inc., and was funded by Gilead Sciences, Inc.

Disclosures: **XG**, **AO**, and **AM** are employees of Oracle Life Sciences and were commissioned by Gilead Sciences, Inc., to conduct this study. **LC**, **MB**, **CK**, and **MDu** are employees of and may own stocks or stock options in Gilead Sciences, Inc. **RB**, **MDa**, **NE**, **MO**, **CS**, and **Y-CL** have no conflicts to report.

Correspondence: Megan Dunbar, megan.dunbar2@gilead.com

HIV Glasgow; November 10–13, 2024; Glasgow, UK