

Introduction

- The life expectancy of people living with HIV (PLHIV) and rates of viral suppression (VS) have improved dramatically across the United States over the past 25 years.
- However, PLHIV who are virally suppressed continue to report significantly lower health-related quality of life (HRQL) than the general US population.¹

Objectives

- The current study was conducted to further understand current unmet needs and determinants of HRQL among PLHIV in the U.S.

Methods

Study Design

- This study involved a sequential quantitative-qualitative study design, comprising a cross-sectional survey and three virtual focus groups (FGs). The survey aimed to establish some baseline understanding of patient well being that the FGs could further explore, including possible solutions for improving HRQL among PLHIV.

Participant Population

- Participants were eligible to participate in either elements of the study if they were at least 21 years old, self-reported a diagnosis of HIV, and had a smartphone with access to the internet.
- Recruitment was conducted through several social media platforms, including Facebook, for the quantitative survey and through a recruitment vendor's patient database who specializes in HIV research for the qualitative study.

Measures

- The survey was completed on a mobile application downloaded directly to the participants' device. Questions included sociodemographic and clinical sections and the Functional Assessment of HIV Infection (FAHI), where higher scores indicate better HRQL. FG participants completed a sociodemographic and clinical web survey.

Analyses

- Study data were summarized using descriptive statistics. Differences in respective scores were evaluated using analysis of variance (ANOVA). FGs were audio recorded and transcripts from the groups were coded in ATLAS.ti using a thematic coding approach.

Results

Demographics

- The quantitative survey was completed by 1,226 PLHIV (≥50 years old: 41.6%; male: 81.0%) and 22 PLHIV (≥50 years old: 33.3%; male: 52.4%) participated in the FGs. One FG participant did not complete a demographic form. Key sociodemographic characteristics are presented in Table 1 for each sample.

Results (continued)

Table 1. Participant Demographic Characteristics

Sociodemographic Characteristics	Survey (N=1,226)	Focus Groups (N=21)
Sexual Orientation		
Heterosexual	212 (17.3%)	10 (47.6%)
Homosexual	938 (76.5%)	9 (42.9%)
Bisexual	61 (5.0%)	2 (9.5%)
Other	14 (1.1%)	-
Race/Ethnicity¹		
Hispanic or Latino	196 (16.0%)	5 (23.8%)
White	654 (53.3%)	12 (57.1%)
Black	319 (26.0%)	7 (33.3%)
Other	57 (4.6%)	3 (14.3%)

¹Not mutually exclusive

Survey Findings

HRQL

- The FAHI total and domain scores from the quantitative survey are presented in Table 2.
- Emotional well-being was significantly higher among older (age ≥50) survey participants compared to younger participants (age <50) (difference score: 3.0; p < 0.005). The FAHI total score and other domain scores were comparable by age group.
- PLHIV residing in metropolitan statistical areas (MSAs) reported better physical, emotional, functional and global well-being than PLHIV in non-MSAs (p < 0.005 for all domains).

Table 2. FAHI Scores

FAHI Scores	Survey (N=1,226)
Total Score (max score: 176), mean (SD)	113.4 (32.0)
Cognitive Functioning (max score: 12), mean (SD)	7.5 (3.0)
Social Well-Being (max score: 32), mean (SD)	18.1 (8.0)
Emotional Well-Being (max score: 40), mean (SD)	26.0 (9.2)
Physical Well-Being (max score: 40), mean (SD)	29.1 (8.5)
Functional and Global Well-Being (max score: 52), mean (SD)	32.7 (10.8)

Results (continued)

Qualitative Findings

HRQL

- FG participants described emotional challenges (e.g., depression, anxiety and feeling overwhelmed), physical, and social (particularly around dating and stigma) impacts of living with HIV.
 - "But I think the one thing that we sometimes or a lot of times miss is the mental state of individuals when it comes to the quality of life because taking (HIV medication)... that's a job in itself to deal with...so I think mental health is really at the top of the list for a lot of people."
- FG participants stated socioeconomic status and insurance coverage can improve HRQL for PLHIV. Availability of support was also reported as leading to improvement in HRQL, mentioning PLHIV living in MSAs had more access to programs.
 - "...The fact that I hardly have any money coming out of pocket for my medical is a blessing. I mean, that alone gives me a great deal of peace of mind...so, I feel my quality of life is pretty good."

Proposed Solutions for Improving HRQL

- Possible solutions for addressing unmet needs for PLHIV emerged from the FG discussions, including increasing availability of emotional support programs, low-income housing, quality healthcare and HIV tailored medical advice (especially in rural areas), as well as representativeness in communication about HIV.
 - "...I'd say that making sure that people have access to services, individuals that are in more urban areas or suburban areas are going to have a lot more access to services than folks that are more rural and so, therefore the issues might be the opportunity to get there..."
- More support may be needed for participants who do not qualify for programs but still need assistance.
 - "...That's something I personally find that I have had to struggle with because I am a single woman...I make a decent amount of money for my age group because I don't have children. I don't qualify for things but yet I'm still struggling."

Limitations

- Recruitment was based on convenience sampling which may have resulted in under-representation of Black and Hispanic individuals compared to the US PLHIV population.

Conclusion

- Life expectancy for PLHIV has improved significantly, yet PLHIV still experience significantly reduced HRQL.
- The results of this study confirm there are still unmet needs which adversely impact HRQL among PLHIV in the US. Potential areas for focus and possible solutions from the patient-perspective were identified.

References

- Evans T, Cutts K, Lykopoulou K, Ferrer PE, Swinburn P. The Real-World Insights of People Living with HIV Shared Through Electronic Devices (RISE) Study. JHPOR. 2021 (1).