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Perceived quality of life and its optimal drivers in people living with HIV, beyond HIV viral suppression in South Africa

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ABSTRACT

Viral load suppression is the goal in current HIV treatment efforts. This was a cross-sectional descriptive qualitative study of 41 purposively selected adult participants, achieved through data saturation. Guided in-depth interviews were conducted to subjectively evaluate QOL and its related drivers among virally suppressed PLHIV in the Eastern Cape province of South Africa. Thematic analysis was employed to identify key themes emerging from the interview responses. Participants consistently evaluated their QOL as improved, acceptable, or excellent, based on their psychological, physical and social wellbeing. Commonly cited drivers for the perceived QOL were positive social relationships, better access to healthcare services and positive self-efficacy, whilst perceived benefits of ART adherence and viral suppression were improved productivity and increased life expectancy. Multidisciplinary interventions are worthwhile where policies and programs must deliberately seek to address QOL determinants and aspirations of PLHIV, apart from targeting viral suppression through medications alone.

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Viral suppression; perceived quality of life; drivers of optimal quality of life; People living with HIV

Introduction

Viral suppression is a critical indicator of antiretroviral therapy (ART) success in the treatment and prevention of HIV. Viral suppression has been reported to influence quality of life improvements in people living with HIV (PLHIV),

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through interaction of several factors at individual, family, community and societal levels (Schalock, 2014). Perceived or self-rated quality of life and related drivers of optimum quality of life among PLHIV who are virally suppressed are important for understanding the interaction between viral suppression and observed individual functionality and wellbeing.

The UNAIDS defines viral suppression as a reduction in the amount of HIV in the human blood to less than 200 copies per milliliter, usually due to ART (UNAIDS, 2024). The associated benefits may include improved social and physical functionality, psychological wellbeing and consequently better self-evaluated life (perceived/self-rated quality of life) (Lazarus et al., 2016). Therefore, the significance of measuring perceived quality of life and related determinants in virally suppressed PLHIV lies in that they are based on felt/experienced benefits/improvements on psychological wellbeing and physical and socio-economic function. Given the increasing proportion of PLHIV accessing ART, viral suppression has become a critical goal to achieve, wherein perceived quality of life and related drivers of optimum quality of life are key in sustaining these positive gains in PLHIV (Lazarus et al., 2016).

Optimum quality of life is a self-rated status achieved when a person feels their needs or what is important to them have been met, according to their level of understanding (Abera et al., 2010). Studies conducted elsewhere have consistently shown a positive correlation between viral suppression and perceived improved/acceptable/excellent quality of life in PLHIV (Cho et al., 2020; Lazarus et al., 2016). The often-mentioned drivers of perceived quality of life were perceived benefits and social determinants such as demographic characteristics (self-system factors, race, income levels, level of education, geographical location, psychological wellbeing and social and physical function), access to supportive environments for accessing better health care and living a healthier lifestyle, and related policies (Karram et al., 2024). Determinants of quality of life are known to be personal and contextual, showing marked variations according to the mentioned social determinants (Karram et al., 2024; Santos et al., 2018). It is, therefore, important to generate context-specific evidence to support interventions aimed at supporting viral suppression and improving quality of life in PLHIV.

Statistics on HIV show that in 2023, about 30.7 million (77%) out of 39.9 million PLHIV were on ART, with 72% of them virally suppressed globally (UNAIDS, 2024). The increasing number of people on ART naturally signifies the need for strengthening programs aimed at improving viral suppression and its associated influences, such as perceived quality of life and related drivers. South Africa is ranked as the most unequal country globally, with poor HIV health outcomes included (Greenwood, 2018). As part of South Africa, the Eastern Cape province recorded the worst HIV-related indicators in the country (Hui, 2023). In 2020, approximately 58%

of PLHIV in the province were virally suppressed. This figure is significantly lower than the World Health Organization's target of 90%, as well as below South Africa's national average of 66% and the global average of 73% in the same period. It's worth noting that the global average for viral suppression is projected to rise to 83% by 2025 (Hui, 2023).

Interventions designed to increase viral suppression rates in PLHIV on antiretroviral therapy (ART) could benefit from considering the perceived or self-rated quality of life and associated factors among those who are virally suppressed. Research on perceived quality of life and its related drivers in virally suppressed PLHIV is essential for developing targeted interventions that promote or maintain viral suppression. This study examined what PLHIV perceived as optimal drivers of their quality of life after achieving viral load suppression during ART.

Methods

Study design and setting

The study employed a qualitative descriptive cross-sectional approach on PLHIV who were virally suppressed. This study was conducted from eleven cluster-selected health facilities situated in four adjacent health districts in the Eastern Cape province. The province is a predominantly rural coastal province with a population of more than seven million (StatsSA, 2022). The province has a high unemployment rate among its predominantly (85.7%) Black population (StatsSA, 2022).

Participant selection

Study participants were obtained from a database of virally suppressed adults between January – June 2023. Purposive sampling was employed to select study participants from an existing dataset of individuals who had consented to participate in further HIV-related studies. This dataset was managed by the South African Medical Research Council, in collaboration with Walter Sisulu University as part of the Research Capacity Development Initiative (MRC-RFACC 01–2014, SAMRC Project Code: 57009 ref. HDID12663_SB23), at which the main author (ZBN) and the supervisor (TRA) were the co-investigators. Data were collected until data saturation was achieved with 41 study participants, consisting of 61% females and 39% males. Viral suppression was verified from patient registers prior to enrollment into the study.

Data collection

Data was collected using a standardized in-depth interview guide, based on qualitative research principle of achieving data saturation to determine

sample size. These interviews solicited information on perceived quality of life and related driving factors in this population of HIV virally suppressed individuals. All in-depth discussions were tape recorded, supported by interview notes and session summaries, where necessary. All interviews were conducted by trained researchers using the native language for comfort and better understanding among participants. The interviews took place at the participants' homes or health facilities, depending on their preferences, and each lasted between 20 to 30 minutes.

Data management and data analysis

In-depth interviews data were recorded and transcribed verbatim onto a word processing document from audio recordings, and triangulated with notes and summaries. Transcriptions were done by a fluent IsiXhosa speaking research assistant and were then translated to English as forward translation and back to IsiXhosa (native language) as backwards translation. This was done to yield textual data for thematic analysis using Nvivo version 15[®]. Thematic data analysis was conducted by members of a multi-disciplinary team in Nvivo 15[®]. Thematic analysis involved familiarization with the data, generation of initial codes, development of emerging themes, revision of emerging themes, definition of emerging themes and writing-up of the report. Utterances, concepts and themes were independently searched for from within the qualitative data. Transcribed and translated statements were sent for confirmation to a panel of multi-discipline (medical doctor, social worker, health scientists, social scientists) researchers and some of the participants to avoid distortion and misrepresentation. Measures to ensure trustworthiness of the qualitative data were applied following recommendations of Lincoln (1985) study. Study results were presented according to main themes, using verbatim quotes to support the themes.

Results

Participants characteristics

A total of 41 virally suppressed participants aged between 30 and 59 years responded to the in-depth interviews before data saturation was achieved. Participants' characteristics are presented in [Table 1](#).

Emerging themes

Themes that consistently emerged from the in-depth interview data were categorized into two, namely: perceived quality of life and drivers of

Table 1. Demographic characteristics of study participants (n = 41).

Variable	Frequency	Percentage (%)
Gender		
Female	25	61
Male	16	39
Employment		
Unemployed	25	61
Formally employed	8	20
Self-employed	5	12
Retired	3	7

optimal quality of life. Results are summarized using a saturation grid in Table 2.

Perceived quality of life

Participants consistently reported positive perceptions of their life, self-rated as improved, acceptable or excellent, based on felt or experienced improvements on their physical and social function and psychological well-being:

Since I started on ARVs, I feel that my quality of life is excellent. I am happy because I'm now feeling good and virally suppressed, I can now work for my children and see them grow. (Female, 40 years Old, Interview 8)

My health has improved very well since I started taking my ARVs [antiretroviral drugs]. I take my ARVs as recommended [by healthcare workers], I was told that I am now HIV negative [virally suppressed] because of the medication, and I feel that my life is excellent. I am now [physically] fit, I go to work and take care of my children, I no longer feel as sick as I used to, and I am not stressed. I experience some minor ailments that are common to anyone, but overall, I am satisfied with my life. (Female, 55 years Old, Interview 19)

Look at me now can you tell that I am sick? You see? I don't see any difference on how I am feeling with my life right now compared to when I was HIV negative, I don't see any difference, I'm not sick, I am not stressed. I just feel like any other healthy person, I am happy that the medication worked well for me, and I am satisfied. (Male, 45 years old, Interview 23)

It's just that I am also diabetic, so I take medication for diabetes too and get sick from time to time. However, I feel that my life has improved a lot, I am now HIV negative [virally suppressed] because of this [ART] treatment, so I say minus one problem." (Female, 36 years old, Interview 2)

Drivers of optimal quality of life

Optimum quality of life among the virally suppressed participants was found to be mainly influenced by several drivers. Predominantly mentioned drivers of optimum quality of life were self-system/self-efficacy, positive social

relationships, income, healthy diet and lifestyle, better access to healthcare services, and perceived benefits of ART adherence and viral suppression (increased life expectancy, improved psychological wellbeing and physical and social function, improved productivity and satisfaction with life):

I live for my kids! I am happy that I have adhered to [ART] medication, and I am now HIV negative [virally suppressed]. I feel happy and satisfied with my life because I can now work for and take care of my kids and see them progress academically. I am not stressed because they cheer me up all the time, encourage me to take my medication, and give me all the support I need. ... Family is all you need when you have this condition. (Female, 39 years old, Interview 4)

It is all about how you take it. When I tested HIV positive, I told myself that I must [consistently] take the medication [as prescribed] for it to work. I can say that I am strong because I never gave up or got stressed about it ... and I believe in God too, so I know I am not alone. Now, I am feeling satisfied with my life because I have accepted my situation, I trusted the medication, and I am now fit and happy. (Male, 45 years old, Interview 20)

With this condition [HIV positive status], the most important thing is to accept it and take ARVs as recommended. That is what I had to do, and now see, I am HIV negative [virally suppressed] and fit. I am satisfied with my life because I can work for myself and my family, and make money [income]. We were taught to eat good food, stay fit [physical fitness] and avoid alcohol. Now eating healthy [foods] requires money, and I am happy that I can afford to buy [healthy] foods because I am fit and can go to work to earn money. That alone makes me feel that my life has greatly improved since achieving viral suppression. (Female, 40 years Old, Interview 8)

I am happy and satisfied with my life because I can work and make some money now. The medication has greatly improved my health [helped me to achieve viral suppression] and my life. I take my medications, I go to work and earn money, I exercise, I eat good [healthy] food as advised [by healthcare workers], I don't smoke or drink, ... and now see how healthy I am. I feel happy to live a normal life [due to viral suppression] like this. (Female, 59 years old, Interview 15)

I do not feel like I am living with HIV anymore, because I feel strong and healthy. It is all because of the excellent services I get from the hospital. Apart from the medication, they [healthcare workers] also give us [treatment] advice and check on us? The support [from healthcare workers] is so great, and it makes me feel safe and loved. Now I know I can live longer and healthier, work for my children and see them grow. (Female, 37 years old, Interview 1)

When I was initiated into treatment, I called my kids to pray together as I was going to take the treatment for the first time. The reason was that those who were initiated before me had visual hallucinations; some said they were seeing snakes and all those unreal things, but I did not see those. Spirituality and family support are extremely important for [treatment] success and how one feels [about life], and it's working [well] for me. (Female, 55 years old, Interview 10)

I told myself that HIV has no power over me, and I will live longer no matter what. I could have died [of HIV] a long time ago, but I am alive today because I am spiritually strong, and my strength comes from God. The journey has not been easy,

though. Back in the days when I was sick, people were dying of HIV right by my side, in my community and at my workplace; they were dying. I couldn't attend their funerals since I was on the sick bed, but because of my spirituality and right attitude, I am here, fit and happy today. I think others died because of their mindsets and beliefs – they would go to traditional doctors [and were given traditional medicine] and avoid taking ARVs, whilst I was taking my medication and praying. You know, so it is very important to pray, God can uplift you [physically and emotionally], and now feel happy and satisfied with my life. (Female, 59 years old, Interview 22)

Discussion

The study investigated the subjectively evaluated quality of life and related drivers in virally suppressed PLHIV in Eastern Cape province of South Africa and made the following observations: participants consistently perceived their quality of life as improved, acceptable or excellent, emanating from experienced improvements to their psychological wellbeing and physical and social functions; and optimum quality of life was driven by self-system factors (such as attitudes, beliefs, self-efficacy), positive social relationships, income, healthy diet and lifestyle, better access to healthcare services, and perceived benefits of ART adherence and viral suppression (increased life expectancy, improved psychological wellbeing and physical and social function, improved productivity and satisfaction with life). Individuals living with HIV are part of society, which influences their behavior and how they perceive their lives. They are intrinsically intertwined with society and cannot be defined outside of it. Insights in this study are better clarified using selected constructs of Bandura's Health Belief Model (Addo et al., 2022).

Study participants generally perceived their quality of life positively, and this emerged from all the individual interview feedback. The perceived benefits of treatment adherence that lead to viral suppression are associated with several advantages, including a higher perceived quality of life, enhanced productivity, improved physical and social functioning, and better psychological well-being (Ohrnberger & Hauck, 2022). Existing research evidence shows that viral suppression is significantly associated with reduced viral transmission through sexual intercourse, injuries through sharp objects and mother to child during pregnancy, labor, delivery and breastfeeding (Bavinton et al., 2018; WHO, 2023). The relationship between viral suppression and perceived quality of life is, however, more complex than this study could manage to critically examine due to the inherent limitations of qualitative studies.

Being a qualitative study, the study sought to generate data on perceived drivers of optimal quality of life among PLHIV following viral suppression, based on their levels of understanding of their needs. The perceived quality of life is known to be affected by several factors such as individual factors

(age, gender, race, socio-economic status, level of education, efficacy, disease history) and other variables apart from individual factors, which can vary by person and context (O'Brien et al., 2023; Sangbana, 2020). Barriers posed by stigma have frequently been identified in recent history as a primary driver; however, participants in the present study did not address this issue in their reflections. As observed from the study, participants mostly based their quality-of-life evaluations on comparisons between their life experiences before and after achieving viral suppression, not considering experiences before they had HIV. Viral suppression represented efficacy, allowing individuals to be more economically productive, physically healthier, and socially functional. This shift in quality of life was much more meaningful than their experiences prior to achieving viral suppression, regardless of any other life aspirations they may have had.

This study agrees with existing research that measurements of perceived quality of life should take a holistic approach, rather than focusing solely on clinical HIV-related parameters (Lazarus et al., 2023). This perspective acknowledges the coexistence of HIV with other communicable and non-communicable diseases and conditions. It is important to consider the interplay between HIV and mental health, as this relationship can significantly affect the perceived quality of life for PLHIV (Christopher et al., 2020; Nkporbu, 2017). For example, previous studies have shown that individuals with both HIV and non-communicable diseases or other comorbidities report a lower perceived quality of life compared to those without additional health conditions (Christopher et al., 2020; Nkporbu, 2017). A study in Canada emphasized that a multi-team-based model comprising different disciplines for the continuum of care is essential for delivering an effective long-term HIV program that can maintain a good quality of life for PLHIV (Liddy et al., 2019). A holistic approach must ensure that the continuum of care addresses social, environmental, economic, and mental well-being, enabling PLHIV to lead a normal and quality life while maintaining their suppressed viral load.

In this study, subjectively evaluated optimum quality of life was consistently influenced by perceived benefits of ART and viral suppression, self-system factors, social relationships, income, diet and lifestyle, and health system factors. This aligns with psychology and social science, which state that wellbeing is a person's overall state encompassing physical, social, emotional, and psychological aspects of life that are inextricably linked (Karram et al., 2024). Some studies have established a stronger association between a stronger self-system (on personal beliefs, perception, self-efficacy and behavior regulation) and higher perceived quality of life, and vice versa (Galárraga et al., 2013). Stronger relationships and associated emotional support from family and friends have also been found to be important influences of

optimum quality of life, that are closely linked to personal aspirations for living longer to stay connected with significant others (Christopher et al., 2020; Galárraga et al., 2013; Nkporbu, 2017; O'Brien et al., 2023).

The ART adherence, viral suppression, optimum social and physical function, and psychological wellbeing can therefore be considered as means to an end of living longer to fulfill one's aspirations. Hence from patients' perspective, ART adherence and viral suppression may not be viewed in terms of the shortcomings or the possible harm they may bring, but according to the overall benefits that are connected to the end (living longer to attain personal aspirations such as seeing one's children grow and succeed) *visa vis* the possible harms. Identified individual and external conditions in which a person lives in/with that determine their quality of life together reported to form part of drivers of optimum quality of life (WHO, 2025). For instance, in this study family and friends (social relationships) were found to play a significant role of providing emotional support needed for motivating adherence with ART, consequently contributing to viral suppression. Inextricably, adherence to ART by the patient is also in itself a means to an end, motivated by desire to live longer and be with family and friends that one values. In the same way, a stronger self-system, (better) income, healthier diets and lifestyle, and stronger health systems can be seen as facilitating factors or means to an end, that can strengthen/enable one to access ingredients required for a longer life to attain aspirations more successfully (Safreed-Harmon et al., 2019). Hence, in essence, the most effective strategic approach in HIV management is through a holistic approach aimed at building/strengthening personal/community skills; and undertaking strong advocacy to putting in place a public policy for ensuring supportive/enabling environments required for promoting maximum and productive life expectancy in PLHIV so that they can achieve their aspirations (Forsythe et al., 2019; Safreed-Harmon et al., 2019). This approach can surely contribute to optimum quality of life in PLHIV through a holistic approach, other than focusing on improving/achieving clinical outcomes alone, such as viral suppression.

Conclusion

Viral suppression may contribute to improved perception on quality of life among PLHIV, but focusing on viral suppression alone is not sufficient. Therefore, treatment success and quality of life must not be measured based on clinical outcomes such as viral suppression alone. Treatment success efforts must also consider the extent to which available interventions are holistic to address physical, economic, social and psychological aspirations of PLHIV is worthwhile. Holistic interventions are worthwhile, where interdisciplinary and intergovernmental policies and programs deliberately

seek to address QOL determinants and aspirations of PLHIV, apart from targeting viral suppression through pharmaceutical approaches alone. Qualitative studies on perceived quality of life can further be improved by deliberately guiding participants' responses to address other factors that could affect a person's perceived quality of life such as those overlooked by this study (mental health issues and other diseases).

Strengths and Limitations

The study was conducted with a homogenous population. The use of commonly spoken local language during interviews allowed participants to express their perceptions freely and eloquently. Conducting interviews in spaces preferred by participants also facilitated maximum participation in the study. The study focused on participants with suppressed viral load only. Conducting an analysis of the role of these perceived quality of life influences, though worthwhile, was outside the scope of this study. Moreover, assessing these factors would require a larger sample size and quantitative approaches to confidently establish associations, which was beyond the study aim and design. Again, though there were indications that some participants may have been living with other conditions, the generated qualitative data did not show negative evaluation by those who reported to be living with other condition(s)/disease(s) in addition to HIV. This might in part be due to "pain discounting", where participants might have felt that having a suppressed viral load and sickness from another condition was better than having an unsuppressed viral load and that condition, which could undermine their functionality more. Moreover, outcomes that are subjectively evaluated can best be determined by the individual's level of understanding, rather than any other conditions that are beyond specific research skills.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

Ethics

The study ethical principles were guided by the Helsinki Declaration and Ethical approval 093/2022 of Walter Sisulu University Faculty of Medicine and Health Sciences Human Research Ethics Committee and NICR 2023 10498 from the University of Stirling.

Informed Consent

All participants signed a written informed consent prior to all data collection and recordings.

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