ORIGINAL RESEARCH

Lived experience of people living with HIV in Blantyre, Malawi: an exploratory qualitative study

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Abstract

Background
People living with the Human Immunodeficiency Virus (HIV) encounter a range of complex challenges that impact their physical, psychological, and social well-being. The combined effects of these challenges significantly impact their daily functioning. Despite the relatively high prevalence of HIV in Malawi, there is limited knowledge on how the challenges experienced by people living with HIV correlate with their societal participation and performance of activities.

Objectives
This study aimed to explore the lived experience of people living with HIV and how the challenges experienced impact societal participation and activity performance.

Method: A qualitative exploratory study design was used. Fourteen participants were purposefully selected for the study, with an equal number of males and females. The data was gathered through semi-structured interviews and manually analyzed using thematic analysis.

Results
It was found that participants faced discrimination, stigma, depression, anxiety, and worries. The study participants associated their taking of antiretroviral therapy with physical impairments such as dizziness, leg pain, yellow eyes, and fatigue. The physical impairments hampered participants' ability to walk, work, conduct business, perform household chores, and care for children.

Conclusion
This study identified the difficulties that people living with HIV faced in their communities and how these challenges impact societal participation and performance in activities. There is a need for a holistic approach to managing these challenges and making referrals to specialized professionals.

Keywords: stigma, discrimination, work, participation, and living with HIV.

Introduction and Background

Globally, the life expectancy of people living with the Human Immunodeficiency Virus (PLHIV) has increased due to the advancement and availability of combination antiretroviral medication (ART)[1]. At various points in their lives, they have encountered psychological, social, emotional, and physical challenges[2–4]. Fear of the reaction of society to disclosing one's HIV status to others was linked, on an individual basis, to psychological discomfort, anxiety, and HIV stigma[5]. Depression is the most common mental health diagnosis among people living with HIV worldwide[6]. They deal with social stigma at the community level, which leads to self-isolation, social isolation, and loneliness, which results in restricted participation or complete withdrawal of social activities[2,7].

Restrictions in social activities participation are associated with mental and physical impairments related to HIV illness and side effects of HIV medication[4]. The common physical impairments reported by PLHIV in the world include; gastro-intestinal side effects such as diarrhea, general body weakness, headaches, chronic fatigue, and pain[3]. These impairments affect an individual's participation in sexual activity and performance of household chores[4]. Hence, it contributes to reduced motivation, feelings of social isolation, and difficulties in maintaining work and intimate relationships[2]. PLHIV in African nations has reported similar issues. A study in Western Africa by Charlotte et al. found that older PLHIV in the West are more likely to face physical function restrictions due to the consequences of HIV illness, increasing their risk of disability[8]. Many HIV-positive individuals mention experiencing physical difficulties due to side effects of their medication, including dizziness, headaches, and soreness, which limit their ability to perform daily tasks like self-care[9]. In addition, PLHIV also faces mental and emotional difficulties such as psychological suffering, stigma, discrimination, anxiety, and depression[10,11]. Consequently, fear of discrimination and psychological distress negatively affected youths living with HIV. As a result, they stopped taking HIV medications, lost focus in class, and fell behind in class, which also resulted in poor academic performance[10,11].

The World Health Organization's International Classification of Functioning, Disability, and Health (ICF) serves as a framework for delineating health and disability[12]. The ICF model explicates how an individual's health issue interacts with contextual elements, dividing into functioning and disability (covering bodily structure, functions, activities, and participation) and contextual variables (encompassing environmental and personal factors) (ICF)[13]. People living with HIV (PLHIV) face challenges aligning with different ICF components, sometimes resulting in complications from the interaction of one or more components. Similar challenges are evident among PLHIV in Malawi. Esther et

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al.'s study highlighted how adolescents with HIV experience stigma at home due to discrimination, leading to school bullying and subsequent sadness[14]. HIV-positive youth face frequent hospitalization, impacting school performance, class repetition, and learning difficulties, although the study doesn't specify the impact on daily activities[15]. Pregnant women with HIV grapple with perinatal depression and acceptance of the HIV diagnosis, where stigma is directly linked to depression, though the study doesn't detail its effects on work, business, and household chores[16]. Physical and psychological impairments resulting from dysfunctions in the body's functioning can impose constraints on activities and participation.

Common physical impairments reported by PLHIV include shortness of breath, muscle weakness, and joint discomfort[17]. Manyozo et al (2020) evaluated the WHO ICF in PLHIV in Malawi and reported that mental function deficits were the most affected domains, but they did not specify how these impairments influenced HIV-positive individuals' participation restrictions and activity limitations[18]. It is important to understand the connections between these challenges because individuals living with HIV are viewed holistically as such and may present with body functioning impairments associated with participation restrictions and activity limitations. Previous studies have shown that PLHIV faces various challenges, including psychological distress, stigma, discrimination, and physical impairments. However, there is a paucity of literature that explores the interactions between these challenges and their impact on social participation and activity limitations among PLHIV in Malawi. Therefore, this study aimed to explore the lived experiences of PLHIV in Blantyre, Malawi, and how these constraints interact with participation restrictions and activity limitations.

Methodology

Study design

A qualitative exploratory study design was used to explore the lived experiences of PLHIV. The participants were interviewed using a semi-structured interview guide that was based on the study objectives.

Study Objectives

The main objective of this study was to explore the lived experiences of PLHIV in Malawi. The specific objectives were to explore the psychosocial and physical challenges faced by PLHIV and to explore how these challenges impact their societal participation and performance in activities.

Setting

The study was conducted at Queen Elizabeth Central Hospital (QECH), and participants were recruited from the Umodzi Family Centre (Light-house ART Clinic) at QECH in Blantyre, Malawi. The Centre offers inpatient and outpatient critical services, as well as a "one-stop shop" that includes HIV testing and treatment, tuberculosis screening, and targeted reproductive health services. The clinic offers free ART and serves as a referral site for patients from other health facilities in Blantyre and the surrounding area. The Umodzi Family Centre was selected because it is the main referral clinic in the southern region of Malawi and has been in operation for more than seven years.

Sampling

The study population consisted of people living with HIV who were receiving ART at the Umodzi Family Centre. Purposive sampling was used to identify and select participants with research-related experiences[19]. A sample size of 14 was also considered adequate because evidence suggests that 10 to 12 interviews are sufficient to reach conclusions[19,20]. The 14 participants were purposefully selected, with 7 males and 7 females. The participants were between the ages of 18 and 60 years and were in the first, second, and third stages of HIV infection according to the World Health Organization (WHO) classification[21].

Data collection method

The study employed face-to-face, in-depth interviews, which were conducted to collect data. All the participants were purposefully selected at the Umodzi Family Centre while registering for their routine consultations. To identify participants, the clerk accessed participant records in the electronic register. The researcher approached participants who met the inclusion criteria face-to-face during the clinic visits to inquire about their willingness to participate in the study. Those who agreed were led into a separate room within the clinic, where the purpose of the study was explained. Before taking part in the study, participants were given information sheets and signed consent forms. The interviews took place in a private room within the clinic.

To collect qualitative data, we utilized a semi-structured interview guide designed based on the study objectives, and we validated it through a preliminary study before the main investigation. This technique proves useful for gathering data when exploring participants' experiences. Demographic data (including age, gender, marital status, occupation, type of occupation, ART, and HIV durations) was collected using a pre-interview questionnaire. The principal investigator (TM) conducted all in-depth interviews, recording them audio-wise, while a research assistant took handwritten notes throughout the interviews, each lasting between 30 and 60 minutes. Data saturation was achieved by the 13th interview, prompting the conclusion of data collection after conducting 14 interviews. Saturation was determined when participants began reporting the same information in consecutive interviews. The research was conducted between March and June 2020.

Data management

To maintain confidentiality, the participants were identified using secret identification codes. The audio files were stored in a locked file on a password-protected computer, and the transcripts were kept in a locked cabinet in the Physiotherapy department within the hospital.

Data analysis

TM manually analyzed the data using thematic content analysis. This is the process of analyzing and extracting meaning from the experiences and realities of participants and assigning codes, themes, or patterns 19. She transcribed the transcripts verbatim from Chichewa to English and back. TM double-checked the transcribed text with the audio recordings to avoid missing any data. She repeatedly read the transcripts and listened to the audio files to become familiar with the information provided by the participants. Words with similar meanings were categorized to create codes. The meaning was assigned to the group of codes that were developed, which unearthed themes.

Trustworthiness

The process of ensuring that qualitative results are credible, transferable, dependable, and confirmable is known as trustworthiness[23]. In this study, it was incorporated through a member check. Participants were called over the phone (due to COVID-19 restrictions, face-to-face interactions were prohibited), and data were read to participants for verification. This procedure was used to ensure the credibility of qualitative findings by determining whether the results were accurate and resonant with participant experiences[24,25]. For code validation, raw transcripts were sent to a second author with expertise in HIV-related research to analyze and develop codes independently of the PI. The codes and transcripts developed by the second author and PI were sent to the third author, who is an expert in qualitative data analysis, to validate the codes (to group for similarity and differences). The validated codes were then returned to the PI for theme development. Multiple coders in qualitative research aid in the production of rich data analyses that could not be produced by a single researcher.

Ethical considerations

Permission to access participants was obtained from the hospital director, QECH, and ethical approval was granted by the Human Research Committee of the University of the Witwatersrand, South Africa (M190976) and the Kamuzu University of Health Sciences Research Ethics Committee, Malawi (P.11/19/2888). Written approvals from the hospital director, the manager of Umodzi Family Centre, and written consent from the participants were obtained.

Participants' confidentiality and privacy were observed. The participants were informed that their participation in the study was voluntary and that they would not be paid any money. However, the participants were given $4.9 (MK 4000) for refreshments and transport reimbursement. The raw data was kept confidential and will remain inaccessible to the public even after the study has been published and will be destroyed after five years.

Results

The study's results unveiled the challenges encountered by individuals living with HIV in Blantyre, Malawi, and how these challenges impact societal participation and activity performance. The social, demographic, and clinical characteristics of participants were as follows: seven males and females, respectively; nine people were married, two were divorced, and three were single. Five of the participants were in the age group 18-30, four in the 31-43 age group, and five in the 44-60 age group. Seven of the fourteen individuals worked, three were self-employed, and four were unemployed. All of the participants were in the second stage of HIV infection, according to WHO criteria. The findings were organized into three overarching themes and corresponding subthemes that emerged from the analysis of their experiences. These themes encompassed Psychological, Social, and Physical experiences.

Psychological Experience

Under this theme, the findings highlighted subthemes of discrimination, depression, stigma, anxiety, and worries.

Discrimination

Participants spontaneously mentioned discrimination when asked about their experiences post-HIV diagnosis. Many faced discrimination from relatives, to the extent of separating cooking utensils in the kitchen. A participant expressed concerns about self-discrimination among HIV-negative friends, citing a personal example: "*....in the group of those who are not HIV positive, you begin to discriminate against yourself while your friends do not discriminate against you.*" (MP.M)

Depression

Students in boarding schools discussed their experiences, with one participant attributing depression to the fear of discrimination due to ART treatment. This participant, born with perinatal HIV, blamed themselves, impacting academic achievement and health: "*Another issue was that I was in boarding school at the time and was afraid of discrimination. I didn't want people to know I use ART because I was afraid, they would judge me... This affected me, and I became depressed*," said the participant (MP. E).

Stigma

Married female participants revealed ostracism from acquaintances upon learning about their HIV-positive status. One participant felt underappreciated at work due to physical changes resulting from ART, leading to low self-esteem and inhibiting job-related social events: "*After I was diagnosed with HIV and experienced side effects from the ART I was receiving, they simply changed it to 8A. 8A turned my eyes yellow, so when my coworkers noticed the change in the color of my eyes, they knew I was on ART and began gossiping behind my back.*" (FP. D)

Anxiety and Worries

Some participants expressed fear of living with HIV in the community, with one participant anxious about questions regarding their status, worsening their concerns and anxiety. Another participant, a mother, felt like a burden to her family due to financial difficulties: "*As I go about my daily life, I run into a lot of problems. Because of my current situation, I live an anxious life. This life requires someone to be doing some business to support the change that I am experiencing... If my relatives notice that my body is changing, they become concerned, asking what is wrong with me, which makes me anxious and worried.*" (FP. B)

Social Experience

This theme revealed subthemes of social support and facilitators of HIV medication adherence.

Social Interaction

Discrimination varied between rural and urban areas, with participants experiencing more discrimination in rural settings. However, some participants could live with their families without fear of discrimination, receiving encouragement and support to use ARTs: "*Now, when I returned from the village and moved to town, there were no problems here. I was chatting with people, and we could do anything in the community together, such as attending a funeral or doing community service.*" (MP. F)

Facilitators of HIV Medication Adherence

Participants found that disclosing their HIV status to family and friends improved ART adherence due to the encouragement and support received. "*My parents encouraged me to take the medication (ART) without forgetting.*" (FP. A)

Physical Challenges

Participants detailed significant physical challenges associated with living with HIV, encompassing dizziness, leg pain, yellowing of the eyes, and chronic fatigue.

Dizziness

Dizziness emerged as a prevalent and persistent symptom, disrupting daily life and work. Participants reported experiencing dizziness during the initiation of ART and regimen adjustments. This enduring symptom impacted work, business engagements, and household responsibilities.

A participant shared the impact on work: "*When I am working and I feel dizzy, it means I need to leave the customer. If someone else is waiting, it means that they will wait. If I find any customers that day, I only end up helping two.*" (FP. B)

Tasks at home became challenging: "*At home, I was failing to wash and cook, so I would find someone to help me.*" (FP. D)

Leg Pain

Leg pain hindered mobility and well-being, with participants reporting numbness affecting their ability to walk effectively. Persistent leg pain resulted in an extended inability to perform work-related activities for some participants. A participant described enduring leg pain: "*...because I feel too much pain, especially leg pains, I find it difficult to sleep.*" (FP. B)

Yellowing of the Eyes

Observable changes in eye color, specifically yellowing, became a visible marker of HIV status, leading to workplace stigma. Participants recounted their experiences, highlighting the challenges associated with this side effect.

A participant shared workplace experiences: *"My eyes turned yellow, and people who knew about ART recognized me; they could tell I was on ART by looking at my eyes."* (FP. D)

Chronic Fatigue

Chronic fatigue emerged as a pervasive concern affecting work punctuality, daily tasks, and overall well-being. Participants expressed the ongoing challenges associated with exhaustion.

A participant explained the impact on daily life: *"At work, it was difficult for me to carry books; I was tired, and I was sometimes late to work because of my tiredness. It meant that I needed someone to help me with the household chores."* (FP. W)

Chronic fatigue contributed to anxiety: *"Because of my current situation, I live an anxious life. This life requires someone to be doing some business to support the change that I am experiencing."* (FP. B)

Discussion

The study explored the experiences that people living with HIV face and how these experiences impact societal participation and the performance of activities. The experiences were divided into three categories: psychological, social, and physical. The data demonstrated that discrimination and despair had a negative impact on the health and education of HIV-positive youngsters. Fear of being discriminated against by classmates contributed to ART default, hence frequent illness and hospitalization, resulting in poor health outcomes. The findings on ART default related to discrimination and anxiety were consistent with those of Kaunda et al. and Kimera et al.[15,27]. Youths with prenatally acquired HIV were living an unhappy life, resulting in inadequate focus and poor performance in school. These findings are comparable to those of Kimera et al.'s study, which found that youth felt depressed and did not value education, contributing to low academic performance and increased dropout rates[27]. The study results highlighted that some participants were being stigmatized at work, at home, and in their communities. Physical changes such as jaundice (yellow eyes) worsen the situation by causing feelings of low self-esteem and devaluation, which contribute to workplace self-isolation. The finding agrees with the study done by Twinomugisha et al., in Uganda[28] that stigma produces difficult working conditions marked by loneliness and isolation.

Furthermore, the outcomes of this study suggest that anxiety hinders workplace social activity involvement. Apart from the stigma, women displayed indicators of mental illness such as anxiety and stress. These worries were related to financial restrictions and illness. Worries, despair, anxiety, and psychosis, on the other hand, have been linked to the side effects of ART[16,29,30] in numerous studies. In contrast to our findings, LeMaster et al.[16] identified abandonment by a husband, stigma, and raising children as major sources of anxiety. Nevertheless, it must be pointed out that women were also more anxious due to the twin burdens of HIV and postpartum depression. For most participants, living in their communities presented both positive and negative experiences. Despite disclosing their positive status, some of the participants had a positive experience living in the community. They were encouraged and supported by family members, which helped them stay in ART care. These findings are in tandem with those of Carbone et al.[31] and Chirambo et al.[32], who found that family and community support are the most important facilitators of ART adherence. Our findings support previous findings and recommend that social and family support should be included as a non-pharmacological intervention to help PLHIV in Malawi.

Physical impairments such as dizziness, leg pain, and foot numbness hampered participants' movement in the current study. Mobility is involved in tasks such as transportation, financial management, shopping, home maintenance, and prescription acquisition, according to instrumental activities of daily living (IADLs). These are activities that an individual needs to live an independent life in a society[33]. According to Albert et al.[34], decreases in mobility resulted in a decrease in the performance capability of IADL and activities of daily living (ADL). These refer to activities that people do regularly, such as bathing, toileting, transferring, and eating[35]. Physical disabilities hinder social interaction and functional mobility[36].

According to the current study, household chores were the most affected home activities, followed by participation in work and business. The findings are similar to recent findings that demonstrate housekeeping is the most compromised activity in HIV-positive older individuals[37,38]. Furthermore, the study found that exhausted participants had difficulty executing their obligations at work and caring for children at home. They required assistance from family members to participate in domestic duties. In PLHIV[39], fatigue impairs physical activity and mobility performance. As a result, there is a need for early detection of psychological, social, and physical issues experienced by PLHIV and to refer them to suitable specialists.

Limitations

This study, while making meaningful contributions, acknowledges certain methodological considerations. The inclusion of participants spanning a wide age range, although offering a comprehensive perspective, may have constrained the depth of insights into age-specific variances. It should also be highlighted that the study did not fully explore the variations in challenges faced by different age groups. Furthermore, the manual analysis conducted by the primary researcher might have added bias and caused limitations to the transferability of the data during the analytical phase.

Conclusion and recommendation

This study found that people living with HIV face problems that impact societal participation and the performance of daily activities. They face prejudice, stigma, despair, anxiety, and concerns. These psychological difficulties have a significant impact on social interaction, academic achievement, and adherence to ART. Furthermore, those who experience physical symptoms because of ART side effects have difficulty performing daily activities, mobility, and household duties. Early detection of these issues will allow for prompt referral to a specialized facility for treatment. The authors recommend further research to investigate the experiences of HIV-positive youth in Malawian boarding schools.

Conflicts of interest

The authors declare no conflicts of interest.

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