

Assessment of HIV Related Disabilities among People Living with HIV Who Are on ART. A Cross Sectional Survey in Blantyre Urban, Malawi

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Abstract

Background

Despite improvements in survival, persons living with HIV experience a range of physical, cognitive, mental and social health-related challenges. Among adult persons living with HIV in Malawi, the prevalence of disability and associated risk factors are not known. This study was designed to assess the prevalence of impairments, activity limitations and associated risk factors among adults living with HIV in Blantyre urban, Malawi.

Methods

We conducted a quantitative cross-sectional study among adult persons aged 18 years and older living with HIV and on ART receiving their care at five government run health facilities in Blantyre urban. We used the WHO's International Classification of Functioning, Disability and Health (ICF) for data collection. The ICF provides a unified, standard language and framework for the description of health and health-related states. The College of Medicine Research Ethics Committee (COMREC) approved the study and written informed consent was obtained from study participants. Descriptive statistics were used to summarize the data. Univariable and multivariable logistic regression were used to assess association between presence of disability and selected factors. Odds ratios (OR) and their 95% confidence intervals were calculated.

Results

Of the 277 participants enrolled, 225 (81%) were female and 52 (19%) were male. The mean age of participants was 37 years (std. dev 9.5). Impairments in mental functions (43%) and sensory functions and pain (40%) were the most prevalent among the study participants. Energy and drive (18%), memory (14%) and sleep (13%) were the most affected mental functions. Socio-demographic characteristics were not significantly associated with occurrence of the mental function impairments.

Conclusions

Our study highlights the level of impairments among person living with HIV especially mental health impairments, sensory functions and pain. Integrated health services including mental health screening and care, physical rehabilitation into all HIV testing and treatment settings are very critical to improve service delivery but also general access to rehabilitation by persons living with HIV.

Background

The roll out and availability of antiretroviral therapy has changed the prognosis of HIV from what was inescapable death to a chronic manageable condition[1],[2]. Many of the estimated 35 million people currently living with HIV worldwide are expected to live almost near normal life expectancies[3]. While the rapid expansion in antiretroviral therapy access in low and middle income countries has resulted in

dramatic declines in mortality rates, many people living with HIV face new or worsening experiences of disability[3].

The World Health Organization (WHO) considers disability as an umbrella term for long-term physical, mental, intellectual or sensory impairments. It is defined as difficulties encountered by an individual with regard to human functioning that are categorized as impairment, activity limitation and participation restriction. It arises as result of an individuals' interaction with a health condition which hinders their full and effective participation in society on an equal basis with others. The link between HIV and disability is thought to be due to the direct action of HIV, its secondary conditions and/or side effects of ART medications used for treatment, which may lead to impairments in a wide range of areas such as cognition, vision, hearing, mental health and musculoskeletal functioning [4]. Many People Living with HIV (PLHIV) encounter activity limitations (e.g. in self-care, mobility) and participation restrictions (e.g. employment, schooling) due to these impairments, especially when combined with modifiers such as poor access to care and rehabilitation and stigmatization [5][6]. Adequate management of HIV infection invites a shift to function and social participation outcomes and not only the clinical indices[7]. Using the international classification of function disability and health, reports from South Africa, Brazil and India highlight the high level of disablement among adults living with HIV, and that up to 65% live with some form of body impairments[8],[9]. A study conducted in 2014 and 2015 compared levels of functioning and disability among PLHIV in South Africa and the United States reported that disability was present at 51% in South Africa compared to 86.6% in the United States[10]. In Nigeria, a study conducted among 360 adults showed that two out every three PLHIV, although rated mild, it affected the participants quality of life significantly[11]. Findings from British Columbia show a high prevalence of disability among people with HIV exists, with over 80% having experienced at least one impairment, activity limitation or social participation restriction[2]. The implications of HIV-related disabilities are of global importance in HIV care especially in the era of improved longevity for individuals infected with HIV [3][8][9]. This is further demonstrated by Mugisha et al (2016) in Uganda[14] when they note that chronic conditions present among older adults have been shown to affect their functioning, and has since called for a revision of the health policy in Uganda to address these critical health care needs.

The burden of HIV in Malawi

Malawi is among the countries worst affected by the HIV epidemic, with 10.6% prevalence in the 15–49 year old population and 3% among adolescents[15]. Current estimates put the number of PLHIV in Malawi at about 1,000,000 and it was anticipated that this number will increase largely as a result of increased survival among PLHIV as a result of the scaled up and integrated ART and PMTCT program[15]. Malawi aims to diagnose **90%** of all persons that are infected by HIV- provide antiretroviral therapy (ART) for **90%** of those diagnosed, and achieve viral suppression for **90%** of those treated by 2020[16],[17]. By 2016, the country had 72.7% of people living with HIV knew their status, 88.6% of these are on treatment and about 90.8% of those on treatment have achieved viral suppression. Due to increased accessibility to ART many individuals infected with HIV are therefore expecting to live near normal life expectancies[18],[19].

Several studies have reported disability estimates among children living with HIV (CLHIV), however, there has not been a similar report on disability prevalence and associated factors among adult PLHIV in Malawi. Research from a study conducted in 2013 in Malawi suggests higher prevalence of disabilities among pediatric patients with HIV where Devendra *et al*[20] looking at impairments, activity limitations and participation restrictions, reported a 33% disability prevalence among children with HIV in Lilongwe compared to 7% in their controls. Hrapcak *et al*[21] in 2016 reported that hearing loss was more common among pediatric patients living with HIV and this affected their social functioning and school participation. There is growing evidence of disability experience among adult PLWHIV in other countries, this knowledge is lacking in Malawi. The revised Malawi National HIV Policy highlights the need to redefine strategies based on best evidence instituting multidisciplinary approach. To better inform this new approach to HIV care, there is urgent need to understand the prevalence of disability among the adult PLHIV in Malawi. This study therefore was designed to fill this knowledge gap.

Methods

Study design

We conducted a quantitative cross-sectional study among adult patients diagnosed with HIV patients across five public health facilities in Blantyre urban, Malawi.

Study setting

The study was conducted at five public health facilities in Blantyre urban: The facilities include Zingwangwa, Limbe, Ndirande, Bangwe, and Chilomoni. These health facilities are normally managed by a clinical officer as the in-charge, nurse, pharmacy technician, psychosocial counselor. The services offered include HIV testing and counselling, ART administration, adherence support services through psychosocial counselling and viral load monitoring.

Study population and sample size estimation

Participants were recruited into the study if they were living with HIV, based on their previous HIV test results obtained in the health passport book, were on ART at least for 3 months, as evidence suggests a 3 months window as a mean time to achieve a biological effect, including viral load suppression, following ART initiation[22], aged 18 years and above. Participants were also recruited if they were attending their out patient clinic within Blantyre urban at the stated government run health facilities and were able to understand the study aims and consent properly. Data were collected from March to August 2018. Participants were recruited consecutively from each health facility. Sample size was calculated using both the Leslie and Kish formula for descriptive studies and for comparing two proportions using sample size calculator in Stata 14. The larger minimum sample size required based on both these methods was

taken as the sample size for the study. Based on 90% study power, a precision estimate of 0.05, an estimated disability prevalence of 50%,[10] the sample size of 259 was required.

Ethical considerations

The study was reviewed and approved by the College of Medicine Research Ethics Committee (COMREC), (certificate number P.04/18/2388). Permission to conduct the study was granted by the Director of Health and Social Services (formerly District Health Officer) for Blantyre district. To ensure privacy and confidentiality, codes were used on the questionnaire instead of participants' names. Informed consent was obtained from participants, and where participants were illiterate a witness was invited to help explain the purpose of the research project during informed consent process. Research assistants were trained on the purpose of the study and all ethical requirements for the study.

Data collection and instrumentation

Data were collected through semi structured interviews using the International Classification of Function, Disability and Health (ICF) checklist. ICF provides a unified, standard language and framework for the description of health and health-related states[23]. The ICF contains a series of over 1,800 codes serving as the uniform terminology and standard to describe and measure an individual's health, disabling conditions, or both within each component of the framework[24]. An alphanumeric system is used in the ICF coding scheme with the letters b, s, d and e denoting the components of Body Functions, Body Structures, Activities and Participation, and Environmental Factors, respectively. Table 1, shows an outline of the ICF checklist with the domains, categories and subcategories that were used in this study. For instance, the column for subcategory level 2 lists examples of some of the subcategories in level 1, but not the full list (see: www.who.int/classifications/icf/training/icfchecklist.pdf). In addition, the checklist has a section for demographic data, including patients' age, gender, level of education, years of formal education, current occupation, and medical diagnosis, and risk assessment was measured against these factors. The ICF has been reported to be a reliable tool in assessing health, social and environmental challenges faced by persons living with HIV [8],[25]. Table 1 shows the ICF framework indicating the interaction between a health condition, body functions and structure and contextual factors to produce a functional outcome.

Table 1
An outline of the International Classification of Functioning, Disability and Health (ICF) checklist

Domains	Subcategory level 1	Subcategory level 2
Impairments of body function (b)	b1: Mental b2: Sensory b3: Voice and speech b4: Cardiovascular, hematological and respiratory systems b5: Digestive system b6: Genitourinary b7: Neuromuscular-skeletal b8: Skin and related structures	Examples of b2 sensory functions: b2-10: Seeing b2-30: Hearing b2-35: Vestibular b2-80: Pain
Impairments of body structure (s)	s1: Nervous system s2: Eye and ear s3: Voice and speech s4: Cardiovascular and respiratory s5: Digestive s6: Genitourinary s7: Movement	Examples of s1 nervous system structures: s1-10: Brain s1-20: Spinal cord and nerves
Activity limitation and participation restriction (d)	d1: Learning and applying knowledge d2: General tasks and demands d3: Communication d4: Mobility d5: Self-care d6: Domestic life d7: Interpersonal relationships d8: Major life areas d9: Community and civic life	Examples of d4 mobility activities: d4-30: Lifting and carrying objects d4-40: Fine hand use d4-65: Moving around using equipment d4-70: Using transportation d4-75: Driving

	First qualifier (fq): Extent of activity performance in normal environment	
	Second qualifier (sq): Extent of activity without assistance	
Environmental factors (e)	e1: Products and technology e2: Natural environment and manmade changes e3: Support and relationships e4: Attitudes e5: Services systems and policies.	Examples of e2 natural environment and manmade changes: e2-25: Climate e2-40: Light e2-50: Sound.

Data management and analysis

Data were entered into Microsoft excel spreadsheet for cleaning and then exported into STATA version 14 (StataCorp, College Station, TX, USA) for analysis. Data were summarized using proportions for categorical variables while continuous variables were summarized using means and standard deviations. Univariate and multivariate logistic regressions were used to summarize associations and assess risk factors for impairments, activity limitations and participation restriction; this assessment was restricted to factors contained in the ICF tool, these largely included age, employment status, marital status and education status. The Alpha level of significance was set at 0.05.

Results

We invited 277 participants to participate in the study across all the five health facilities of Zingwangwa (82), Limbe (42), Ndirande (55), Bangwe (42) and Chilomoni (56). Among these, 225 (81%) were female and 52 (19%) were male. The mean age of participants was 37 years (std. dev 9.5) with the range 18 to 78 years old. A total of 189 (68%) were married and only 40 (14%) were in formal employment. The majority of the participants (126, 45%) reported highest level of formal education as primary school (126, 45%), secondary school (111, 40%) level training. Table 2 summarizes patient socio-demographic characteristics.

Table 2
Socio-demographic characteristics of study participants, Blantyre, Malawi N = 277

Variable	Attribute	Frequency, n (%)	
Gender	Male	52	(19%)
	Female	225	(81%)
Age (mean, 37 years (std. dev 9.5)	< 50	250	(90%)
	≥ 50	27	(10%)
Marital status	Single	88	(32%)
	Married	189	(68%)
Educational status	None	17	(6%)
	Primary	126	(45%)
	Secondary	111	(40%)
	Tertiary	23	(8%)
Occupation status	Formal employment	40	(14%)
	Non formal	237	(86%)

Impairments of body functions

Table 3 presents a summary of impairments in body functions. Mental functions were most affected, affecting 118 (43%) patients with energy and drive (18%), memory (14%) and sleep (13%) disturbances as the most affected mental functions. About 40% of the participants reported having sensory problems including pain experience (20%) and vestibular functions (19%) impairments.

Table 3
impairments of body functions disintegrated by system, Blantyre, Malawi N = 277

Domain	Persons experiencing impairments		Confidence intervals
	N	(%)	
Mental functions	118	(43%)	103(37%) 136(49%)
Sensory functions and pain	111	(40%)	94(34%) 127(46%)
Functions of the cardiovascular, hematological, immunological and respiratory systems	66	(24%)	52(19%) 80(29%)
Functions of the digestive, metabolic and endocrine systems	70	(25%)	55(20%) 86(31%)
Genitourinary and reproductive functions	17	(6%)	8(3%) 24(9%)
Neuromusculoskeletal and movement-related functions	50	(18%)	36(13%) 63(23%)
Functions of the skin and related structures	31	(11%)	19(7%) 42(15%)

Activity limitations

We found low levels of activity limitations and participation restriction among the people living with HIV. Interpersonal interactions (4%) including intimate relationships and family relationships and mobility (3%) were the most affected domains. Domains of general tasks and self-care were not affected among the participants. Table 3 presents a summary of the activity limitations and participation restrictions by domains.

Table 4
Activity limitations and participation restrictions among people living with HIV, proportion affected by domain, N = 277

Domain	Participants with activity limitations	Confidence interval
	N (%)	%
Learning and applying knowledge	2 (0.7%)	0.00 – 0.02
General tasks and demands	0	-
Mobility	7 (3%)	0.01 – 0.04
Self – care	0	0
Domestic life	4 (1.4%)	0.00 – 0.03
Interpersonal interactions and relationships	11 (4%)	0.02 – 0.06
Major life areas	0	
Civic life	2 (0.7%)	0.00 – 0.02

Mental functions and associated factors

Among the impairments reported, mental function impairments were the most affected domain of all the bodily functions reported by up to 43% of all participants. We could not run a regression analysis on the activity limitations to assess risk factors as there were very few participants that experienced these outcomes and could lead to unstable standard errors during analysis, however we explored factors that could be associated with mental function impairments in our population. Mental function impairments experienced were not significantly different among study participants as regards their age, gender, education level, marital status and occupation status. Table 5 below shows results from a univariable and multivariable logistic regression.

Table 5
 Results from Univariable and Multivariable logistic regression analysis for mental health impairments

Factor	Unadjusted OR (95%CI)	Adjusted OR (95%CI)
Gender		
Female	1	
Male	1.09 (0.59 – 1.99)	1.18 (0.61 – 2.25)
Age		
<50 years	1	
≥50 years	0.65 (0.27 – 1.50)	0.60 (0.25 – 1.48)
Marital Status		
Not married	1	
Married	1.68 (1.00 – 2.85)	1.59 (0.92 – 2.74)
Education level		
None	1	
Primary	0.73 (0.03 – 2.03)	0.60 (0.21 – 1.71)
Secondary	0.61 (0.22 – 1.69)	0.49 (0.17 – 1.44)
Tertiary	0.39 (0.11 – 1.43)	0.34 (0.09 – 1.31)
Employment status		
Formal employment	1	
Non-formal employment	1.45 (0.72 – 2.92)	1.30 (0.62 – 2.71)

Discussion

This study highlights a high level of impairments especially in the mental functions (43%), sensory functions and pain (40%) among persons living with HIV in Blantyre urban, Malawi. The mental functions most affected include: sleep disturbances, energy and drive and intellectual functions. Very few people reported activity limitations which were mainly in the area of mobility (3%) and interpersonal interactions and relationships (4%). This therefore highlights the need to strengthen mental health services for PLWHIV in Malawi. Collins et al [26] in their systematic review on relevance of mental health to HIV and AIDS care and treatment programs in low and middle income countries, report a wide range of depression experience among persons living with HIV in 13 reviewed studies, rates ranged from 0–63%. Although in this study, demographic characteristics were not significantly associated with mental health experience among our participants. Collins et al further reported that family relationships and social support, having

a serodiscordant spouse, AIDS in a spouse and HIV related worries and stressors were significantly related to mental health illness. In 2019, Remien et al[27], reported that rates of mental health problems are higher among both people vulnerable to acquiring HIV and PLWHIV, compared with the general population and our findings are adding to this valuable report in the Malawian context. Unfortunately, mental health impairments increase risk for HIV acquisition and for negative health outcomes among PLWHIV at each step in the HIV care continuum. The high prevalence of impairments and activity limitation among people living with HIV has been attributed to HIV itself, the medications they use and other HIV related conditions [1]. Similarly, in our study the high prevalence of impairments could be due to the same factors. The reported low level of activity limitation in our study could be due to the design of the study and the setting (outpatient) where participants were recruited as they come from home to receive their medication at the health facilities. It has been reported that, patients that are hospitalized or undergoing institutional based rehabilitation are likely to present with high levels of impairments and activity limitations [9].

Similar results have also been reported by Myezwa et al[8] using the ICF among patients with HIV attending outpatient services in South Africa. However our results indicate a close to 20% less impairments compared to those reported in South Africa. Furthermore, among study participants in this study, pain experience (20%) and vestibular functions impairments (19%) were some of the most reported impairments of body functions. These results highlight the need to comprehensively review and manage patients with HIV beyond the routine HIV markers of viral load, CD4 count to including individual functional assessments. With increase in life expectancy due to accessibility to HIV medications coupled with high prevalence of impairments and activity limitations, rehabilitation will become an integral component of HIV care [8].

Digestion (11%) and weight maintenance (13%) were the most common reported impairments within the domain of the functions of the digestive, metabolic and endocrine systems which was prevalent in 25% of our study participants. However, Myezwa et al in 2008[8] reported 2 times more impairments at 44% prevalence related to this domain among patients with HIV who sought outpatients services in South Africa. This variation could be explained by the self-reporting of illness and disability experience as the concept of illness varies depending on how the individual understands it [28]. These variations in proportions affected are reflected in impairments related to the neuromusculoskeletal systems, Myezwa et al in 2008 reported a 27% prevalence among outpatients compared to the 18% reported in our study[8].

Compared to impairments of body functions, activity limitations and participation restrictions were less common among persons living with HIV attending out-patient clinics in urban Blantyre. In our study, interpersonal interactions and relations (4%) and mobility (3%) were the most reported activity limitations and participation restriction (Table 4).. A similar study conducted among children at the Malawi Baylor College of Medicine reported a higher prevalence of disability among HIV positive children (33%) compared to HIV negative control (7%), however it is important to note that most of the children in this study were also reported to have comorbid conditions that may have influenced the finding[20].

Despite the variations in prevalence of disability on different domains from different settings, our estimates are relatively low compared to those reported in India and South Africa[8],[28]. A recent assessment of disability in a cohort of people living with HIV in the United States using the WHODAS (World Health Organization Disability Assessment Schedule) questionnaire reported a 52% prevalence of disability among people living with HIV compared to our findings in this study[30]. This variability could be due to the different instruments used and the settings are inherently different which can affect the disability experiences and perception. Across all these settings, the variability is high in terms of impairments in body functions and activity limitations and participation restrictions, measurement differences within the individual studies need to be considered as the studies used different tools, setting of the studies need to also be considered as they varied significantly in terms of health services organization and structure and patient socio-demographic profiles all of which may affect the individual study estimates. These results agree with estimates reported from recent studies which have seen a significant increase in the number of older adults living with HIV[26][31][32].

Our study adds to the body of knowledge for HIV care in Malawi highlighting emerging issues to improve care. It further highlights the need to look beyond limited clinical markers like CD4 counts, viral load and symptoms of HIV disease towards a comprehensive functional assessment and management to improve quality of life among patients living with HIV. The findings agree with findings from the HIV disability study conducted among children living with HIV in Lilongwe, Malawi where a high magnitude of disability was reported demonstrating the need for rehabilitation services among people living with HIV in the era of improved longevity.

At macro level, HIV policy implications are important to also consider. The Malawi national strategic plans recognize that HIV remains a significant challenge in the country and requires a revision of strategies based on both emerging and best evidence instituting multidisciplinary approach towards HIV response[33]. Similarly, with the emergency of HIV long terms survivors, the South African national strategic plan on HIV/TB/STI 2017–2022 duly recognize the need to address health needs of this population and have included rehabilitation as a critical component in HIV care[34]. The aging HIV population with new disability experiences including those with mental health impairments will require particular attention to address chronic HIV syndrome in the face of comorbidities that increase with age such as hypertension and diabetes[35]. Recently, population level interventions including exercise have become popular interventions to avert some of the HIV associated impairments and limitations. Researchers in Canada are evaluating the impact of community based exercise program with the aim of reducing disability and enhancing health living[30].

Study Limitations

One of the limitations to our study is that we did not consider the effect of ART regimen which could potentially affect the presence or absence of body impairments and activity limitations. We did not also collect data on co-morbidities which could further help explain the impairments and disability phenomenon presented in this paper. Further research should assess these important factors and their

role in disability experience among patients with chronic HIV infection. There is also need to review evidence for health promotion among HIV survivors. Finally, the study was facility based which may have been affected by selection bias in favor of those that only made it to the clinics during the survey time.

Conclusion And Recommendations

Our study highlights the level of impairments among person living with HIV who participated in this study. We further report a high proportion of participants experiencing mental health impairments. The necessary screening tools and efficacious treatments to treat mental health problems among people living with are available. Integrated health services including mental health screening and care, physical rehabilitation into all HIV testing and treatment settings would not only strengthen HIV prevention and care outcomes, but it would additionally improve global access to mental healthcare and the general rehabilitation services. Health care workers and the health systems should also be proactive in identifying and managing impairments among people living with HIV in order to enhance treatment outcome during care of persons living with HIV

Declarations

Author contributions

SM, NT, ASM conceptualized the project, data collection was led by SM. SM in consultation with NT, ASM and GK analyzed the data. All authors contributed to the development and revision of the manuscript and approved the final version.

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Ethical approval and consent to participate

The study proposal was reviewed and approved by the College of Medicine Research Ethics Committee (COMREC) on May 29, 2018 - (certificate number P.04/18/2388). Written Informed consent was collected before conducting any study related procedures.

Consent for publication

Not applicable

Competing interests

Adamson Muula is a member of the editorial board for the BMC public health journal, otherwise the rest of the members declare no conflicting interests.

Availability of data for the study

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request

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