



ASSOCIATIONS OF HEALTH-RELATED QUALITY OF LIFE AMONG ADOLESCENTS LIVING WITH HIV IN INDIA

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ABSTRACT Health related quality of life (HRQOL) studies in general and in HIV, in particular, have been rare in Indian adolescents and have been mainly undertaken in western countries. Further, HRQOL studies mostly merge adolescents with children or adults and thus fail to identify priorities specifically for adolescents. Adolescents living with HIV are an inadequately studied vulnerable group with poor quality of life not only in physical but also psychological domain and need medical care as well as support from community. Our study a cross-sectional, observational questionnaire-based study, conducted at ART clinic of a tertiary care hospital, Delhi was aimed to fill this gap by assessing the quality of life of adolescents living with HIV and to assess the factors associated with Health related quality of life using WHOQOL-BREF. In our study score was highest in psychological domain and lowest in environment domain. Female gender and poor nutritional status were found to be associated with the poor Health related quality of life. Our study emphasizes the need for adherence to HAART regimens, gender equality, reduced inequalities and adequate nutritional support in national programs to achieve zero hunger with special focus on adolescents living with HIV can go a long way in improving their health-related quality of life.

KEYWORDS : adolescents living with HIV, health related quality of life, associations, gender equality, reduced inequalities, zero hunger.

INTRODUCTION:

More than 70 million people have been infected with HIV over the last few decades. The advent of highly active antiretroviral therapy (HAART) has transformed HIV from a veritable death sentence to a chronic manageable disease. HAART has enabled the survival of children living with HIV onto adolescence. Adolescents contribute to 5% of the total people living with HIV (PLHIV) and account for about 11% of global incidence of HIV. Owing to committed and sustained focus on women of reproductive age group the incidence of vertically transmitted HIV is on a decline and that due to sexual and intravenous drug abuse amongst adolescents is on the rise. HIV is the leading cause of death among adolescents in sub-Saharan Africa and global data has shown no improvement in mortality rates since year 2017 in this vulnerable section of PLHIV according to UNICEF data 2022.

WHO defines adolescents as any person between the age group of 10 and 19 years. (World Health Organization, 2016) There are 1.2 billion adolescents in the world today, making about 16 percent of the world's population and 22% of Indian population. Adolescence is a critical phase in human development where an individual goes through physical, psychological, social and cognitive development and during this transition they face challenges of education induced stress, loss of family support, peer induced risk behavior and become vulnerable to early sexual debut, substance abuse, trafficking, violence, etc. and are at risk of acquiring HIV. (Masquillier, Wouters, Loos, & Nöstlinger, 2012) In India, other factors like lack of sexual education, early marriages, inaccessibility to safe sexual measures like condoms also come into play.

Adolescents living with HIV face disease-related problems like low self-esteem due to social stigma, depression, anxiety, deficits in cognition, school absenteeism, suicidal ideation, violent behavior, many opportunistic infections due to immunocompromised state and malnourishment. Medical interventions and the need to adhere to life-long ART could also interfere with mental and physical resilience and their overall quality of life (QOL).

Sensitization to perceptions of HIV infected adolescents is essential to promote psychosocial health and facilitate the transition to adulthood and for a comprehensive assessment of the overall impact of HIV infection on QOL. CD4 counts used to be the most commonly used tool for assessing the quality of life of people living with HIV. To comprehensively assess the overall impact of HIV infection on the lives of adolescents living with HIV (ALH), health-related quality of

life (HRQOL) measures are being increasingly preferred as more efficient alternatives to traditional clinical assessments of health. (Masquillier et al., 2012) HRQOL studies in general, and in HIV in particular, have been rare in Indian adolescents and they still are under-represented in research studies and clinical trials and thus fail to identify priorities specifically for adolescents. Our study was aimed to fill this gap by assessing the HRQOL of adolescents living with HIV using the WHOQOL-BREF and to assess the factors associated with HRQOL so that health services may be modified accordingly.

METHODS:

This cross-sectional survey was conducted at an anti-retroviral clinic of a tertiary care hospital. Sixty-four consenting participants in the age group of 10-19 years who were on antiretroviral treatment for six months or more, were clinically stable and had a parent or accompanying caregiver were recruited. Those with physical disabilities, other significant concurrent illnesses, those residing in orphanage or group homes or without a caregiver were excluded from the study.

Informed written consent was obtained from parents/caregiver of adolescents aged 10 to 17 years and directly from the participants aged 18 years of age and above. Verbal assent was taken from participants 10 and 11 years of age and written assent from participants between 12 to 17 years. The study was approved by the Institutional Ethics Committee.

Data on demographic characteristics of the adolescents and their families were obtained from face to face interview. Disease specific data like mode of acquisition of HIV, length of time since diagnosis of HIV, age at ART initiation, duration on ART, current ART regimen, current and baseline CD4 cell count and plasma HIV viral load etc. were extracted from review of medical records. Details of substance abuse, adherence to treatment (last 30 days by recall), school absenteeism (last 30 days by recall) were also recorded in addition to height and weight of the study participants.

All participants were administered the WHOQOL-BREF in the language of choice i.e., Hindi or English. The WHOQOL-BREF consists of 26 items that produce a generic HRQOL score across 4 domains i.e. physical (7 items), psychological (6 items), social Relationships (3 items) and environment (8 items). In addition, it includes questions around overall perception of QOL and health which are analyzed separately. (Skevington, Lotfy, & O'Connell, 2004) The

instrument was made culturally appropriate for Indian adolescents by replacing the item on 'Are you satisfied with your sexual life' with 'Are you satisfied with the respect you receive from others'. (Agnihotri, Awasthi, Chandra, Singh, & Thakur, 2010) The responses to items were recorded on a 5-point Likert scale. This score was transformed to a 4-20 scale according to the standard procedure defined in the WHO QOL user manual.

The statistical treatment included descriptive presentation of frequency tabulations for categorical variables, and means, standard deviations and inter-quartile ranges for continuous variables. The WHOQOL-BREF scores of participants were recorded in different domains. Mean scores were reported across different categories of risk factors. WHOQOL-BREF scores in individual domains were used as the outcome variable to develop linear regression models for individual associations. Analyses were performed using Stata software (version 13.0, Stata Inc., USA).

RESULTS:

The present study included 64 adolescent PLHIV with mean age of 14.5 years with 35 (54.6%) males. Fifty-nine participants (92%) lived with a family member, ten (16%) were married and parents of 52 (81%) participants were currently married, four (13%) were separated, two (3%) divorced and two (3%) were double orphans. Mean family income was Rs. 15421.8 ± 13861.6 (approx. USD 185 + 166) and 20 (31%) were from middle socio-economic class of BG Prasad revised social class scale 2022. (Pentapati & Debnath, 2023) Fifty-one (79.6%) were currently attending school and all of them were financially dependent and unemployed. The primary mode of acquisition of HIV was vertical transmission with mean time of HIV diagnosis being 69.12±44.63 months and mean age at ART initiation being 113±49.3 months. The median duration on ART was 60 months (IQR 24, 96 months) and fifty (78%) were adherent to treatment. Mean CD4 count at base line was 574.2±371.2 cells per cubic ml and current mean CD4 count was 745±460 cells per cubic ml and 54 (84.3%) achieved viral suppression. Thirty-eight (59.3%) were underweight and thirty-nine (60.9%) were stunted while the mean BMI was 17.44 kg/m².

The mean domain score was highest in psychological (15.12) domain followed by physical (14.84), social (14.80), and environment domain (14.57). The domain scores and their comparison with regional sample of mixed ages and age based normative scores are as shown in Table 1.

Table 1: Comparative Domain Scores

Domain	Mean of study population	Mean of regional sample of mixed ages (Skevington et al,2004)	P value	Mean of age-based scores (Skevington et al,2004)	P value
Physical	14.8	15.9	0.0035	15.6	0.036
Psychological	15.1	14.2	0.0065	14.8	0.36
Social	14.8	13.9	0.0520	14.9	0.79
Environment	14.6	12.1	<0.0001	14.4	0.57

Legend for the table: P values marked in bold are < 0.05, which is considered statistically significant.

Our participants had poor QOL in physical domain both in comparison to WHOQOL-BREF domain scores for regional sample for mixed ages and age based normative scores and poor QOL in psychological domain compared to regional sample of mixed ages. Our participants had better QOL in environment domain on comparison with regional sample for mixed ages. (Skevington et al,2004)

Comparison of various associations in each of the domains is as shown in table 2.

Table 3: Multivariable Analysis Of Sociodemographic Characteristics With Domain Scores

Sociodemographic characteristics	Physical domain	Psychological domain	Social domain	Environment domain
Age				
Univariate	0.9(-0.1-1.9)	0.6(-0.6-1.7)	0.4(-1.0-1.8)	0.3(-0.8-1.5)
Multivariate	0.5(-0.7-1.6)	-0.2(-1.5-1.0)	-0.7(-2.1-0.6)	-0.5(-1.7-0.6)
Sex				
Univariate	-1.7(-2.7- -0.8)	-1.9(-2.9- -0.8)	-2.5(-3.7- -1.2)	-1.7(-2.7- -0.6)
Multivariate	-1.2(-2.3- -0.2)	-1.4(-2.5- -0.2)	-2.2(-3.5- -0.9)	-1.6(-2.7- -0.6)
Present educational status				
Univariate	1.4(0.2-2.7)	1.0(-0.4-2.5)	1.5(-0.15-3.2)	0.8(-0.6-2.2)
Multivariate	1.2(-0.1-2.5)	0.6(-0.8-2.1)	0.5(-1.1- 2.1)	0.07(-1.3-1.4)

The multivariable analysis of association of sociodemographic characteristics with domain scores is as shown in table 3.

Statistically significant association was found with sex (males performing better than females) in all domains; weight for age (those underweight performing poorer) in psychological, social and environment domains. Psychological domain is associated with adherence to therapy with participants with less than target adherence (95%) performing better than their counterparts. No association was found with age, time since diagnosis, HIV viral load, CD4 count and BG prasad social classes.

Table 2: Associations Between Domains As Per WHOQOL-BREF And Demographic Variables

Variable	Number N=64 (%)	Physical domain	Psychological domain	Social domain	Environment domain
Age					
10-14 Years	26 (40)	14.5	14.9	14.6	14.4
15-19 Years	38 (60)	15.4	15.5	15.1	14.8
P Value		0.09	0.3	0.5	0.6
Sex					
Male	35(55)	15.6	15.9	15.9	15.3
Female	29(45)	13.9	14.1	13.5	13.6
P Value		0.0006	0.001	0.0002	0.002
Present educational status					
Studying	51(80)	15.1	15.3	15.1	14.7
Not studying	13(20)	13.7	14.3	13.6	13.9
P Value		0.02	0.16	0.07	0.25
ART Regimen					
First line	57(89)	14.7	14.9	14.6	14.3
Second line	7(11)	16.1	16.6	16.8	16.4
P Value		0.08	0.08	0.04	0.02
CD4 Count					
350 or less	21(32)	14.7	14.6	14.7	14.5
More than 350	43(68)	14.9	15.2	14.9	14.6
P Value		0.8	0.38	0.82	0.89
HIV Viral load					
1000 or less	54(84)	14.8	15.1	14.7	14.4
More than 1000	10(16)	15	15.3	15.5	15.7
P Value		0.80	0.80	0.40	0.09
Weight for age					
Less than -1 (underweight)	38(59)	14.1	14.3	13.7	13.9
-1 or more	26(41)	15.8	16.3	16.3	15.6
P Value		0.001	0.0006	0.0001	0.002
Adherence to ART:					
95% or more	50(78)	14.7	14.8	14.6	14.3
Less than 95%	14(32)	15.2	16.2	15.6	15.7
P Value		0.46	0.05	0.25	0.03
Time since diagnosis					
0-5 Years	31(48)	14.7	14.9	14.5	14.4
>5 years	33(52)	15.4	15.8	15.6	15.1
P value		0.2	0.2	0.2	0.3
BG Prasad social classes					
I (Upper class)	7	15.7	17.1	16.6	16.3
II (Upper middle class)	15	15.7	15.7	15.7	15.1
III (Middle class)	20	14.6	14.9	14.3	14.2
IV (Lower middle class)	13	14.4	14.5	14.3	14.1
V (Lower class)	8	13.9	14.1	14.1	14.0

Legend for the table: P values marked in bold are < 0.05, which is considered statistically significant.

ART Regimen				
Univariate	1.4(0.2-3.1)	1.6(-0.2-3.5)	2.3(0.1 -4.4)	2.1(0.3- 3.8)
Multivariate	0.3(-1.5-2.1)	0.2(-1.4-1.8)	1.1(-1.1-3.3)	0.8(-1.0-2.6)
CD4 Count				
Univariate	0.1(-1.2-1.5)	0.7(-0.8-2.2)	0.2(-1.6-2.0)	0.1(-1.4-1.6)
Multivariate	-0.3(-1.7-1.0)	-0.04(-1.5-1.4)	-0.6(-2.3-1.0)	-0.5(-1.9-0.9)
HIV Viral load				
Univariate	0.2(-1.3-1.6)	0.2(-1.4-1.8)	0.8(-1.1-2.7)	1.3(-0.2-2.9)
Multivariate	0.4(-0.8-1.7)	0.5(-0.9-1.9)	1.3(-0.3-2.8)	1.7(0.3-2.9)
Underweight (nutrition)				
Univariate	1.7(0.7-2.7)	2.0(0.9-3.1)	2.5(1.3- 3.8)	1.7(-0.7- 2.8)
Multivariate	0.9(-0.1-2.0)	1.3(0.2-2.5)	1.8(0.5-3.1)	1.3(0.2-2.4)
Adherence to ART				
Univariate	-0.5(-1.7-0.8)	-1.4(-2.8- -0.005)	-1(-2.6-0.7)	-1.5(-2.8- -0.1)
Multivariate	-0.9(-2.2-0.3)	-1.9(-3.3- -0.5)	-1.1(-2.6-0.4)	-1.5(-2.8- 0.2)
Time since diagnosis				
Univariate	0.7(-0.5-1.9)	0.8(-0.003-0.02)	1.1(-0.5-2.7)	0.7(-0.6-2)
Multivariate	0.4(-0.7-1.5)	0.4(-0.8-1.7)	0.7(-0.7-2.0)	0.4(-0.8-1.5)

Legend for the table: Abbreviations: ART, Anti-Retroviral Treatment; HIV, Human Immunodeficiency Virus

Univariate and multivariate logistic regression analysis of sociodemographic variables with domain scores

Data in bold are statistically significant

DISCUSSION:

In our study, participants reported better quality of life score in psychological domain followed by physical and social domain with poorer quality of life in environment domain. We found that males had significantly good quality of life in all domains compared to females which represents the discrimination, social stigma and lack of support often experienced by female and highlights the need for gender equality and reduced inequalities. Weight for age was associated with psychological, social and environment domain with participants who are underweight performing poorly which highlights the importance of zero hunger and the measure to ensure adequate nutritional support in national programs to achieve the same. Adherence to ART was found to be associated with psychological domain with participants with less than target adherence having good quality of life which can be due to good perception of QOL leading to decreased need to adherence. No association was found with age, time since diagnosis, present educational status, ART regimen, HIV viral load and CD4 count.

On comparison with age based normative data collected from WHOQOL working group by Skevington et al significant difference in means by independent samples unpaired *t*-test was found in physical domain with our participants reporting lower QOL. On comparing with regional sample of mixed ages our study participants reported better QOL in environment domain and poorer QOL in physical and psychological domain.(Skevington et al., 2004) The poorer physical domain scores in both comparisons are a reiteration of the pain, discomfort, energy levels and health problems of adolescents who are living with HIV. The good QOL in environment domain may be due to good socioeconomic status and living conditions of our participants.

Enimil et al in a mixed method study on quality of life of adolescents living with perinatally acquired HIV evaluated HRQOL using WHOQOL-BREF in 2016 among 40 adolescents in 2015 at Kumasi, Ghana.(Enimil et al., 2016) The study reported good quality of life in physical domain followed in sequence by social, environment and psychological domains. Compared to international age based normative data they reported lower quality of life in all domains and on comparison regional sample of mixed ages also reported lower quality of life in physical and psychological domain but not in social and environment domain. This differs from our study reporting only poorer QOL in physical domain and psychological domain. This difference may be because of difference in living conditions, social acceptance, low stigma, parental support, and good virological suppression in our study participants.

Sanjeeva et. al. in a cross-sectional study in 2018 on transition of children with perinatally acquired HIV infection into adulthood evaluated HRQOL in 107 participants more than 18 years of age using WHOQOL-BREF in South India.(Sanjeeva et al., 2019) They reported poor quality of life in physical domain followed by psychological domain with higher quality of life in social domain followed by environment domain in contrast to our study which showed better

QOL in psychological and physical domain. Our participants were younger, likely to have had a limited understanding of disease and were living with their parents as compared to the older participants included by Sanjeeva et. al. The good QOL in physical domain may be due to better immunological status of our patients as reflected by their viral suppression and CD4 counts. In addition, Sanjeeva et al had also reported that educational status was associated with social and environment domain, socioeconomic status with physical domain and reported no association with sex. However, we find a significant association of the performance with sex in all domains and no association with educational status and socioeconomic status.

Wig et. al. in a cross-sectional study on impact of HIV/AIDS on the quality of life evaluated HRQOL using WHOQOL-BREF in 2006 among 68 horizontally HIV infected adults in Delhi.(Wig et al., 2006) They found that quality of life in social and psychological domain was better than environment and physical health domains. We report similar results in our participants. However, Wig et al had reported that educational status and socioeconomic status are associated with psychological domain in contrast to results.

Nutritional status is associated with all domains of QOL in our study with those underweight performing poorly. Iheme studied Health-related quality of life and nutritional status of people living with HIV/AIDS in South-East Nigeria and showed a positive correlation between subjective global assessment derived nutritional status (*determined by nutritional intake, weight change over past one-month, gastrointestinal symptoms and functional capacity*) with BMI and overall QOL.(Iheme, 2023) They showed inverse association between height for age with general QOL and psychological domain.

Our study involves participation of adolescents under care of ART services. Few studies have focused on this vulnerable group. With inclusion of several sociodemographic and treatment variables and their associations with HRQOL our study provides insight for tailoring management of this chronic medical condition for adolescents living with HIV. However, a cross-sectional design does not allow us to observe temporal changes in domain scores or report causality. Longitudinal case-control studies are required to assess impact of disease on HRQOL and for estimating change of HRQOL with increasing age and changing sociodemographic structure. Impact of interventions aimed at improving quality of life should be studied. Lack of literature on adolescents living with HIV warrants further studies assessing the quality of life outcomes and their associations to structure appropriate measures.

CONCLUSION:

Adolescents living with HIV are a unique and vulnerable group with poor quality of life not only in physical but also psychological domain and need medical care as well as support from community. Emphasis on adherence to HAART regimens, gender equality, reduced inequalities with adequate nutritional support in national programs to achieve zero hunger with special focus on adolescents living with HIV can go a long way in improving their health-related quality of life.

Disclosure Statement:

Authors and coauthors do not have financial or non-financial competing interests.

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