

# Correlates of Health-related Quality of Life in Primary Caregivers of HIV Infected and HIV Exposed Uninfected Adolescents at the Kenyan Coast

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## Research

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## Abstract

**Background:** Mothers and other primary caregivers play a crucial role in looking after HIV infected, and HIV exposed uninfected adolescents in sub-Saharan Africa. Daily caring may expose these caregivers to adverse states of health. Unfortunately, very few studies have examined their health-related quality of life (HRQoL) despite the additional risk of poor health outcomes. Our study documents the HRQoL profile, and associated factors in primary caregivers of perinatally HIV infected, perinatally HIV exposed but uninfected and HIV unexposed/uninfected adolescents aged 12 – 17 years at the Kenyan Coast.

**Methods:** This was a cross-sectional analysis of 485 primary caregivers: 195 of perinatally HIV infected adolescents, 128 of perinatally HIV exposed but uninfected adolescents and 162 of HIV unexposed/uninfected adolescents. All caregivers completed a self-report measure of HRQoL, depressive symptoms, and parenting stress. They also provided their sociodemographic information and that of the participating adolescents. We used one-way analysis of variance (and its non-parametric version) to assess statistical differences among the groups. Linear regression analyses were used to identify correlates of HRQoL among caregivers.

**Results:** Linear regression analyses indicated that depressive symptoms, increasing age of caregiver, and caring for an HIV exposed adolescent were significantly associated with reduced HRQoL at both the RAND SF-36 overall and sub-scale level. Having a professional job relative to subsistence farming was the only factor associated with improved overall HRQoL. At subscale level, higher socioeconomic status correlated positively with HRQoL (*within the limitations due to emotional problems domain*) while being a grandparent, and level of education (*physical functioning domain*), and parenting stress (*vitality domain*) were negatively associated with HRQoL. Moreover, caring for a male adolescent (*vitality domain*) and increasing adolescent age (*pain domain*) was associated with declining HRQoL.

**Conclusions:** Caregivers in this sample, especially those who are ageing, at risk of mental ill-health, and taking care of HIV exposed adolescents, appear to be vulnerable. Inclusive and multi-component interventions tailored to the caregivers' psychosocial and mental needs will potentially enhance their quality of life. Longitudinal studies are also needed to understand the underlying mechanisms and longer-term implications of the correlates of caregivers HRQoL identified in the present study.

## Background

By the end of 2018, approximately 1.6 million adolescents (10–19 years of age) were living with HIV worldwide, the majority (89%) of whom were from sub-Saharan Africa (SSA) (1); thus, the health-related quality of life (HRQoL) of these adolescents, as well as that of their caregivers, is of public health importance. Overall, this adolescent age group represents a mixture of young people perinatally infected with HIV and those more recently infected. Unlike in the early 2000s, when perinatally infected children had high mortality during infancy, and poor survival beyond childhood, the era of potent antiretroviral therapy (ART) has registered a dramatic survival of HIV infected children, with many getting into adolescence and adulthood (2). Amidst this unprecedented breakthrough in HIV care, the SSA region still experiences challenges in providing long-term care and support for the many HIV infected adolescents (3) as well as those perinatally exposed to maternal HIV but uninfected who have been shown to have substantially higher morbidity and mortality compared with children born to uninfected mothers (4).

In the current era of widespread effective HIV treatment and improved life expectancy, most of the primary caregivers of HIV exposed adolescents in SSA are young biological parents, frequently mothers who are HIV infected themselves (5, 6). Typically, such caregivers assume the total care of these adolescents with limited formal and informal support systems (7, 8). The majority of the existing literature on caregiving of HIV exposed children and adolescents in SSA depicts it as burdensome with serious economic, psychological, and social strain (7–9) and often associated with suboptimal child outcomes (10). However, other studies suggest that caregiving in the context of HIV is associated with intrinsic and extrinsic rewards, including emotional and psychological well-being, better health status, higher satisfaction and higher quality of life among the carers (11, 12).

Health-related quality of life (HRQoL) has emerged as a salient indicator of HIV care and an essential target for HIV-related research, aimed at expanding the continuum of service(13). HRQoL is a multidimensional measure of subjective overall health and well-being, including mental, social, and physical aspects of functioning (14). Among HIV infected individuals, research has shown that HRQoL can be affected by several sociodemographic, psychosocial, and biomedical factors (14). Both cross-sectional and longitudinal studies have consistently shown that social support, increased physical activity, higher socioeconomic status, better nutrition and virologic recovery are associated with improved HRQoL in people living with HIV (14). On the other hand, comorbidities (such as depression), stigma, drug and substance use have been associated with declining HRQoL (14). Unfortunately, the evidence base on HRQoL among HIV exposed adolescents, and their caregivers in SSA is insufficient and poorly documented. The few studies attempting to examine the HRQoL of caregivers of HIV exposed children and adolescents have focussed on isolated components of HRQoL (mostly socioemotional well-being) (10, 15–19) without documenting the correlates of HRQoL. Many of these studies tend to aggregate the HRQoL outcomes for carers of HIV exposed children and adolescents respectively, despite the apparent differences in their care needs (10, 11, 15–20). Adolescents living with HIV are widely recognized as vulnerable and may face challenges with HIV, including disclosure, peer pressure, stigma, school-related concerns, poor retention in care and medication adherence (21). The HIV exposed but uninfected adolescents may also face certain challenges such as orphanhood, living with and caring for sick household members (22). At times, these adolescents may also experience elevated vulnerability for engagement in risky behaviours (23). For caregivers, many have to bear the costs of care and treatment for family with little or no support, and sometimes provide care while ill and coping with the unique demands of adolescent caregiving. Optimizing the care for these caregivers, therefore, requires an understanding of the factors that contribute to their HRQoL. This knowledge will help healthcare providers and policymakers to devise evidence-based interventions and guidelines for improving the quality of care and wellbeing for both the HIV exposed adolescents and their caregivers.

In Kenya, the situation is not different. To our knowledge, no study has examined the HRQoL of caregivers of HIV exposed adolescents in the country. The few studies investigating caregiving in the context of HIV have addressed issues such as the evaluation of support groups for guardians of orphans and vulnerable children (24), HIV-related stigma (25), HIV status disclosure (26), the prevalence of anxiety and depression among caregivers of HIV-infected children (27). Therefore, the current study seeks to expand the evidence base on the HRQoL among primary caregivers of HIV exposed adolescents residing in the rural settings of Kenya. Specifically, we aim to examine the status of HRQoL among 195 caregivers of perinatally HIV infected adolescents (PHI), 128 caregivers of perinatally HIV exposed but uninfected adolescents (PHEU) and 162 caregivers of HIV unexposed/uninfected adolescents (HUU). We hypothesised that the HIV serostatus of both the caregivers and participating adolescents would negatively influence caregivers HRQoL. In this study, HIV exposed adolescents refers to both PHI and PHEU adolescents.

## Methods

### Study design and setting

This was a cross-sectional analysis of the first wave data of an ongoing descriptive longitudinal study, the Adolescent Health Outcomes Study (AHOS), conducted between November 2017 and October 2018. The study was conducted at the Centre for Geographic Medicine Research-Coast at the Kenya Medical Research Institute (CGMRC-KEMRI) located in Kilifi County. With about 1.4 million people, most of the residents in Kilifi county are rural dwellers (61%) (28). Moreover, nearly half of this population is composed of children below the age of 15 years (29). By the end of 2017, Kilifi county had an overall HIV prevalence of 4%, and approximately 2,511 adolescents (10–19 years) living with HIV (30).

### Participants and recruitment procedures

Primary caregivers of PHI and PHEU adolescents (12–17 years) were recruited using sequential sampling of all families attending specialized HIV clinics from eight HIV treatment and care clinics within Kilifi County. Recruitment was carried out by a trained research assistant in collaboration with experienced healthcare workers attached to the participating HIV treatment facilities. Additionally, some of the primary caregivers of PHEU adolescents were recruited by conducting home visits to families affected with HIV within their community with the help of a community health worker stationed at an HIV clinic. On the other hand, primary caregivers of HUU adolescents were randomly sampled among different households within the Kilifi Health and Demographic Surveillance System (KHDSS) using the KHDSS population register (31).

The caregivers had to be the participating adolescents' primary carers and willing to accompany them for assessments. Carers of PHI adolescents (the majority of whom were biological mothers), needed to have fully disclosed their HIV status to the participating adolescents. They also needed to be aware of their own HIV status. The HIV status of PHEU adolescents was confirmed by checking the maternal medical records (antenatal care cards) which confirmed HIV infection of the mother during pregnancy. Recent medical records of the adolescent (if available) were also used to verify the status. The selection was limited to caregivers who willingly shared their HIV test results at the time of their pregnancy with the participating adolescent. The HIV status of primary caregivers was not ascertained by HIV testing in the current study. Among caregivers of perinatally exposed adolescents (the majority of whom were biological mothers), their status was confirmed by checking the maternal medical records (antenatal care cards) which confirmed HIV infection of the mother during pregnancy. For the remaining caregivers, we used HIV screening questions (last time a participant took an HIV test, the results, and whether they are on antiretroviral treatment) to ascertain this. More details of the study procedures are described elsewhere (32).

### Measures

Several measures were utilised in the main study. In this present study, we focused on only the specific measures that are relevant for the assessment of HRQoL and plausible correlated factors as described below.

### Sociodemographic and socioeconomic information

Data on caregivers' age, sex, education level, marital status, occupation, religion, and relationship to the participating adolescent was recorded. Caregivers' socioeconomic status was measured using an asset index that has previously been used in Kilifi (33). Additionally, information on adolescents' age, sex, current educational level, grade retention, and orphanhood status was captured and ascertained in the presence of their caregiver and from other records, including birth certificates. We also measured adolescents' mid-upper arm circumference, head circumference, height and weight following recommended procedures (34, 35). Height (in metres) and weight (kgs) were used to generate body mass index (BMI).

### Caregivers' mental health assessment

*Depressive symptoms:* The Patient Health Questionnaire (PHQ-9) was used to assess caregivers' depressive symptoms (36). This is a self-report depression severity measure, which has been applied in multiple cultural settings yielding good psychometric properties. The measure is scored on a 4-point Likert scale from '0' (not at all) to '3' (nearly every day) with total scores ranging from 0 to 27. PHQ-9 has previously been used in the study setting in Kenya, yielding good psychometric properties (37). This tool was translated and back-translated into Swahili using WHO guidelines then pre-tested in the study setting before being used in the current study. In this study, its internal consistency was 0.86 (95% confidence interval: 0.83–0.89). For analysis purposes, we used the continuous scores of the tool. Increasing scores on the measure translate into increasing depressive symptoms.

### Parenting stress

*The parental stress scale (PSS)* was used to measure the levels of stress experienced by caregivers (38). It has 18 self-report items which take into account both positive and negative aspects of caregiving. Respondents agree or disagree on various items about their typical relationship with their child on a 5 – point Likert scale from '0' (strongly disagree) to '4' (strongly agree) with total scores ranging from 0 to 72. The higher the score, the higher the measured level

of caregiving stress. This tool was translated and back-translated into Swahili using World Health Organization (WHO) guidelines then pre-tested in the study setting before being used in the current study. In the present analysis, its internal consistency was 0.78 (95% confidence interval: 0.75–0.81). For analysis purposes, we used the continuous scores of the tool.

## Health-related Quality of life

We assessed HRQoL using the RAND 36-Item Health Survey 1.0 (39). This is a generic measure of self-reported HRQoL assessing 8 health domains, namely: i) *physical functioning* (10 items assessing a respondent's ability to engage in activities of daily life); ii) *bodily pain* (2 items assessing bodily pain and its interference with normal activities); iii) *role limitations due to physical health problems* (4 items assessing the impact of individual's physical health on their ability to perform on the job, around the house); iv) *role limitations due to emotional problems* (3 items assessing the impact of individual's emotional health on their ability to perform on the job, around the house); v) *emotional well-being* (5 items that assess symptoms of mental health problems); vi) *social functioning* (2 items assessing whether social activities have been limited by health); vii) *energy/fatigue* (4 items); and viii) *general health* (5 items assessing respondent's perception of their general health, resistance to illness, and health outlook). This measure has been previously used in the current study setting (40, 41). Scoring the tool follows a two-step process. Firstly, pre-coded numeric values are converted to percentages using a predetermined scoring key with a high score defining a more favourable state of health. In the second step, items in the same domain are averaged together to create the 8 different scale scores. Final scores in the different subscales range from 0–100. In the current study, this measure yielded an internal consistency value of 0.88 (95% confidence interval: 0.86–0.89)

## Data analysis

Initial data checks were conducted, and all missing values noted. Box plots and histograms were plotted to assess the normality of continuous variables. For categorical variables, proportions and percentages were generated to explore their distribution. One-way analysis of variance (ANOVA) was used to identify group differences on normally distributed continuous variables. At the same time, the Kruskal-Wallis H test was utilised to identify group differences on skewed continuous variables. Pearson's chi-squared test was utilised to identify group differences in categorical variables. Fisher's exact test was used for categorical values which have some of their cell values less than 5. Univariable linear regression analyses were conducted to identify correlates/factors associated with the HRQoL variables among caregivers. All factors from the univariable analysis having a P-value  $\leq 0.20$  (42) were then entered into a multivariable linear regression model to examine the independent correlates through a backward elimination process, in which the largest P-value was excluded till all remaining variables make significant contributions to the final model by considering the t-test and F test. We tested for model assumptions for all the linear regression models used in the analysis (linearity, homoscedasticity, normality). Multicollinearity was checked using variance inflation factor. After these analyses, we also conducted exploratory analyses using generalized linear models to assess whether having sibling pairs in the sample had any impact on statistical independence in our results. This was essential because our sample of adolescents had 75 sibling pairs, however, the results were very similar in both scenarios.

## Results

### Sample characteristics of the caregivers

A total of 485 caregivers, taking care of 558 adolescents, participated in this phase of the study (see Table 1). The sample of adolescents comprised of 75 sibling pairs, hence the mismatch with the number of caregivers. The mean (range) age of the caregivers across the sample was 43.5 (13–78) years. The majority of these caregivers were biological mothers of the participating adolescents (343; 71.61%). Close to half of the caregivers across the sample were HIV infected (228; 47%), a majority (415; 85.6%) were females, about two thirds (321; 66.2%) were married and living with their spouses, three quarters (364; 75.1%) were Christians while a majority (420; 86.6%) had up to a primary level of education. A substantial proportion of the caregivers (193; 39.8%) depended on seasonal subsistence farming for their livelihood, and a similar proportion (211; 43.5%) were small scale traders. Groupwise, caregivers of PHI adolescents were more likely to be non-biological parents, have a higher body mass index (BMI), and be in professional employment compared to caregivers of both PHEU and HUU adolescents. Moreover, caregivers of PHI and PHEU adolescents were more likely to be older, seropositive, and living single compared to caregivers of HUU adolescents. We did not find differences in sex and socioeconomic status among the different caregiver groups. Table 1 gives a detailed description of the sociodemographic characteristics and other related variables of the caregivers with their statistical tests of difference.

### Sample characteristics of participating adolescents

Slightly more than half (296; 53.1%) of the participating adolescents across the sample were female, with a mean (range) age of 13.7 (11–17) years. Groupwise, PHEU adolescents were more likely to be younger compared to both HUU and PHI adolescents. On average, the adolescents had spent 5.4 years in school across the sample. Both PHI and PHEU adolescents were more likely to be orphans, compared to HUU adolescents. Besides, PHI adolescents were more likely to present with lower mid-upper arm circumference (MUAC) and BMI (see Table 2).

Table 1

Sample characteristics of primary caregivers of perinatally HIV infected, perinatally HIV exposed but uninfected and HIV unexposed/uninfected adolescents  
(N = 485)

	Whole sample (n = 485)	Caregivers of HIV unexposed/ uninfected adolescents (n = 162)	Caregivers of HIV exposed uninfected adolescents (n = 128)	Caregivers of HIV infected adolescents (n = 195)	Statistical difference
Sample characteristic	Mean (SD) or Median (IQR) or n (%)	Mean (SD) or Median (IQR) or n %	Mean (SD) or Median (IQR) or n %	Mean (SD) or Median (IQR) or n %	
Sex of caregiver					
Female	415 (85.6%)	132 (81.5%)	115 (89.8%)	168 (86.2%)	0.1
Caregivers mean age (years) [OM = 2]	43.5 (11.1)	41.1 (10.1)	44.8 (10.3)	44.6 (12.1)	0.002
Caregiver's level of education					
None	159 (32.8%)	68 (42%)	40 (31.3%)	51 (26.2%)	
Primary Level	261 (53.8%)	82 (50.6%)	78 (60.9%)	101 (51.8%)	< 0.001
Secondary Level	48 (9.9%)	10 (6.2%)	10 (7.8%)	28 (14.4%)	
Tertiary Level	17 (3.51%)	2 (1.2%)	00 (0%)	15 (7.7%)	
Caregiver's marital status					
Never married	22 (4.5%)	1 (0.6%)	4 (3.1%)	17 (8.7%)	
Married	321 (66.2%)	142 (87. %7)	67 (52.3%)	112 (57.4%)	< 0.001
Widowed/Divorced	142 (29.3%)	19 (11.7%)	57 (44.5%)	66 (33.9%)	
Caregiver's occupation					
Farmer	193 (39.8%)	82 (50.6%)	45 (35.2%)	66 (33.9%)	
Small scale trader	211 (43.5%)	63 (38.9%)	62 (48.4%)	86 (44.1%)	
Casual labourer	63 (13%)	13 (8%)	21 (16.4%)	29 (14.9%)	< 0.001
Professional	18 (3.7%)	4 (2.5%)	0 (00%)	14 (7.2%)	
Caregiver's Religion					
Christianity	364 (75.1%)	112 (69.1%)	97 (75.8%)	155 (79.5%)	
Islam	64 (13.2%)	18 (11.1%)	21 (16.4%)	25 (12.8%)	0.01
Traditional	57 (11.7%)	32 (19.8%)	10 (7.8%)	15 (7.7%)	
Caregiver's HIV Status					
Seronegative	257 (53.0%)	160 (98.8%)	30 (23.4%)	67 (34.4%)	< 0.001
Seropositive	228 (47.0%)	02 (1.2%)	98 (76.6%)	128 (65.6%)	
Caregiver's mean Body Mass Index (BMI)	23.2 (5.3)	22.9 (4.0)	21.9 (4.7)	24.2 (6.3)	< 0.001
Caregiver's mean socioeconomic status score	1.7 (1.6)	1.5 (1.3)	1.5 (1.3)	2.0 (1.8)	0.08
Caregiver's median depressive symptoms	6.0 (3.0–8.0)	5.0 (3.0–8.0)	6.0 (3.5-9.0)	7.0 (4.0–9.0)	0.07
Caregiver's median parenting stress score	64.0 (56.0–70.0)	65.0 (59.0–71.0)	60.0 (55.0–68.0)	64.0 (57.0–71.0)	0.03
Notes: % are column percentages; SD – Standard deviation; OM – Observations missing					

Table 2  
Sample characteristics of participating adolescents (N = 558)

	Whole sample (n = 558)	HIV unexposed/ uninfected adolescents (n = 200)	HIV exposed uninfected adolescents (n = 157)	HIV- infected adolescents (n = 201)	Statistical difference
<b>Sample characteristic</b>	Mean (SD n (%))	Mean (SD) or n %	Mean (SD) or n %	Mean (SD) or n %	
<b>Relationship with caregiver [OM = 5]</b>					
Biological mother	398 (72.0%)	163 (82.3%)	124 (78.5%)	111 (56.4%)	
Biological father	61 (11.0%)	28 (14.1%)	12 (7.6%)	21 (10.7%)	< 0.001
Grandparent	36 (6.5%)	00 (0.0%)	13 (8.2%)	23 (11.7%)	
Another relative	47 (8.5%)	6 (3.0%)	8 (5.1%)	33 (16.8%)	
Sibling	11 (2.0%)	1 (0.5%)	1 (0.6%)	9 (4.6%)	
Mean age (years)	13.7 (1.6)	14.1 (1.6)	13.3 (1.4)	13.8 (1.5)	< 0.001
<b>Adolescent Sex</b>					
Female	296 (53.1%)	104 (52.0%)	88 (56.1) %	104 (51.7%)	0.7
Mean number of schooling years [OM = 14]	5.4 (2)	5.6 (1.6)	5.3 (2.1)	5.3 (2.2)	0.3
<b>Grade retention [OM = 4]</b>					
No	311 (56.1%)	103 (51.8%)	102 (65.4%)	106 (53.3%)	0.02
Yes	243 (43.9%)	96 (48.2%)	54 (34.6%)	93 (46.7%)	
<b>Orphan Status</b>					
Both parents alive	375 (67.2%)	181 (91.4%)	96 (60.8%)	98 (48.5%)	
One parent alive	141 (25.3) %	17 (8.6%)	57 (36.1%)	67 (33.2%)	< 0.001
Both parents deceased	42 (7.5%)	00 (0.0%)	05 (3.2%)	37 (18.3%)	
Mean Mid Upper Arm Circumference (MUAC) [OM = 20]	21.1 (2.8)	21.5 (2.6)	21.1 (2.6)	20.5 (2.9)	0.001
Mean Body Mass Index (BMI) [OM = 18]	17.5 (2.5)	17.7 (2.2)	17.5 (2.5)	17.3 (2.8)	0.04
Mean Head circumference [OM = 18]	53.3 (1.6)	53.3 (1.7)	53.2 (1.6)	53.2 (1.6)	0.03
Notes: % are column percentages; SD – Standard deviation; OM – Observations missing					

#### Health-related quality of life profile of caregivers

Caregivers of HUU children had significantly higher HRQoL scores than the other caregivers in the overall HRQoL domain. For all the HRQoL subscales (except energy/fatigue and social functioning domains), caregivers of HUU adolescents had significantly higher mean HRQoL scores compared to caregivers of both PHEU and PHI adolescents (see Table 3). Caregivers of PHI and PHEU adolescents had similar mean overall HRQoL scores. Additionally, caregivers of PHI adolescents reported significantly lower mean HRQoL scores across all subscales (except for physical functioning, emotional wellbeing and general health domains) than caregivers of PHEU adolescents. Across the sample, the largest mean quality of life deficits was observed in energy/fatigue (– 46.9%), pain (– 36.3%), social functioning (– 34.7%) and emotional wellbeing (– 32.7%). Table 3 summarizes a break-down of these results, and Fig. 1 gives a graphical distribution of the mean HRQoL across the caregivers.

Table 3  
Health-related quality of life profile among the caregivers (N = 485)

Variable	Whole sample (n = 485)		Caregivers of HIV unexposed and uninfected adolescents (n = 162)		Caregivers of HIV exposed but uninfected adolescents (n = 128)		Caregivers of HIV infected adolescents (n = 195)		P- value
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	
Overall HRQoL	75.0 (14.7)	79.2 (67.1– 85.8)	78.9 (11.4)	81.8 (72.6–87.2)	72.9 (15.9)	78.1 (65.0–85.3)	73.0 (15.6)	77.1 (63.5 – 84.4)	< 0.001
Physical functioning	92.7 (18.7)	100.0 (100.0– 100.0)	97.6 (8.3)	100.0 (100.0– 100.0)	89.7 (22.6)	100.0 (92.5– 100.0)	90.7 (21.2)	100.0 (100.0– 100.0)	0.02
Role limitation due to physical health	75.6 (35.1)	100.0 (50.0– 100.0)	81.2 (31.5)	100.0 (50.0– 100.0)	76.0 (35.7)	100.0 (50.0– 100.0)	70.8 (36.8)	100.0 (50.0– 100.0)	0.05
Role limitation due to emotional problems	73.2 (36.9)	100.0 (33.3– 100.0)	82.5 (31.8)	100.0 (66.7– 100.0)	69.0 (39.7)	100.0 (33.3– 100.0)	68.2 (37.7)	100.0 (33.3– 100.0)	0.003
Vitality (Energy/fatigue)	53.1 (16.1)	50.0 (40.0– 65.0)	53.8 (14.4)	50.0 (40.0–65.0)	54.4 (17.3)	50.0 (45.0–65.0)	51.7 (16.6)	50.0 (40.0– 65.0)	0.2
Emotional well-being	67.3 (18.1)	68.0 (52.0– 84.0)	68.7 (18.4)	72.0 (48.0–84.0)	63.6 (17.9)	60.0 (48.0–80.0)	68.5 (17.7)	72.0 (56.0– 84.0)	0.03
Social functioning	65.3 (20.0)	62.5 (50.0– 75.0)	65.1 (20.2)	62.5 (50.0–75.0)	65.9 (19.9)	62.5 (50.0–75.0)	64.9 (20.0)	62.5 (50.0– 75.0)	0.8
Pain	63.7 (24.3)	65.0 (45.0– 77.5)	67.7 (23.6)	67.5 (45.0–90.0)	63.1 (24.2)	61.3 (45.0–77.5)	60.7 (24.5)	55.0 (45.0– 77.5)	0.04
General health	77.4 (16.5)	85.0 (70.0– 90.0)	83.0 (12.2)	90.0 (80.0–90.0)	74.0 (17.6)	77.5 (62.5–90)	75.1 (17.7)	80.0 (65.0– 90.0)	< 0.001

Notes: HRQoL – Health Related Quality of Life; SD – Standard Deviation

#### Correlates of HRQoL among primary caregivers across the sample

In the univariable linear regression analyses, all variables except sex and grade retention of participating adolescents were significantly associated with the subscale and overall HRQoL scores of the caregivers (at  $p < 0.05$ ). Apart from grade retention, the other variables met the set a priori significance level of ( $p < 0.20$ ) in some of the HRQoL subscales for consideration in the multivariable linear regression analyses. Details of the univariable analyses are presented in Supplementary Table 1.

In the multivariable linear regression analyses, increasing depressive symptoms among caregivers was strongly associated with declining overall ( $\beta = -2.00$ , 95% CI - 2.3, - 1.7;  $p < 0.001$ ) and subscale HRQoL (Table 4). Likewise, increasing age of caregivers was significantly associated with decreasing overall ( $\beta = -0.2$ , 95% CI - 0.3, - 0.1;  $p < 0.01$ ) and subscale (physical functioning, role limitations due to physical health and social functioning) HRQoL (Table 4). Similarly, caring for a PHEU adolescent was significantly associated with declining overall ( $\beta = -3.7$ , 95% CI - 7.3, - 0.2;  $p < 0.05$ ) and subscale (general health) HRQoL. This was also the case for a caregiver taking care of a PHI adolescent which was associated with a reducing overall ( $\beta = -4.8$ , 95% CI - 8.0, - 1.5;  $p < 0.01$ ) and subscale (role limitations due to emotional problems, energy/fatigue and general health) HRQoL (Table 4). On the other hand, having a professional job relative to small scale subsistence farming was strongly associated with improved overall HRQoL ( $\beta = 8.6$ , 95% CI 2.5, 14.7;  $p < 0.01$ ). We did not find evidence of an association between caregivers' HIV status and HRQoL both at the overall and subscale levels.

A few other variables were also associated with an increase or a decrease of HRQoL at the subscale level. Being a grandparent relative to a biological mother among caregivers was significantly associated with reduced HRQoL in the physical functioning domain ( $\beta = -15.6$ , 95% CI - 24.1, - 7.6;  $p < 0.001$ ) and pain domain ( $\beta = -12.1$ , 95% CI - 21.9, - 2.4;  $p < 0.05$ ) (Table 4). Likewise, a unit increase of an adolescent age was significantly associated with a 1.6-point reduction in quality of life scores in the pain domain. Also, caring for a male adolescent relative to a female one was associated with a reduction of HRQoL in the vitality (energy/fatigue) domain ( $\beta = -2.9$ , 95% CI - 5.5, - 0.3;  $p < 0.05$ ). Furthermore, a unit increase in parenting stress among caregivers was associated with a 0.3-point reduction in quality of life scores in the vitality (energy/fatigue) domain. Besides, having higher educational achievement was associated with reduced HRQoL scores in the physical functioning domain. A unit increase in caregiver's socioeconomic status was associated with a 2.3-point improvement in HRQoL in the role limitations due to emotional problems domain.

Table 4  
Multivariable linear regression analysis of correlates of HRQoL among caregivers

<b>β-coefficient (95% CI) of HRQoL domains and overall scale as dependent variables</b>									
Independent variables	Overall HRQoL	Physical functioning	Role limitations due to physical health	Role limitations due to emotional problems	Energy/fatigue	Emotional wellbeing	Social functioning	Pain	General health
Participating adolescent's age								<b>-1.6**</b> (-3.0; -0.3)	
Participating adolescent's sex									
Female					Ref				
Male					<b>-2.9**</b>				
					(- 5.5; -0.3)				
Participating adolescent's head circumference					<b>0.9*</b>				
					(- 0.1; 1.7)				
Participating adolescent's orphan status									
Not one									Ref
Partial orphan									1.0 (- 2.4; 4.4)
Full orphan									<b>5.97*</b> (- 0.01; 12.0)
Participating adolescent's HIV Exposure									
Unexposed uninfected	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Exposed-Uninfected	<b>-3.7**</b> (- 7.3; -0.2)	<b>-5.0*</b> (- 10.8; 0.8)	0.4 (- 9.1; 9.9)	<b>-8.9*</b> (- 18.6; 0.8)	-1.5 (- 6.3; 3.3)	<b>-3.3*</b> (- 7.8; 1.23)	3.3 (- 2.3; 9.0)	-0.1 (- 7.8; 7.7)	<b>-5.8**</b> (- 10.6; -1.0)
HIV infected	<b>-4.8***</b> (- 8.0; -1.5)	-3.1 (- 8.9; 2.7)	<b>-6.8*</b> (- 15.4; 1.8)	<b>-11.5**</b> (- 20.3; -2.7)	<b>-4.8**</b> (- 9.6; -0.1)	0.2 (- 3.9; 4.3)	1.6 (- 3.5; 6.8)	-2.0 (- 9.7; 5.6)	<b>-6.6***</b> (- 11.3; -1.9)
Caregiver's HIV status									
Seronegative	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Seropositive	-0.04 (- 2.9; 2.8)	0.6 (- 4.7; 5.9)	-1.8 (- 9.4; 5.9)	<b>-1.5*</b> (- 9.3; 6.3)	<b>-3.0*</b> (- 1.4; 7.3)	0.1 (- 3.6; 3.7)	-0.6 (- 5.1; -4.0)	-3.9 (- 10.8; 3.0)	-2.0 (- 5.9; 2.0)
Table 4 continued									
Independent variables	Overall HRQoL	Physical functioning	Role limitations due to physical health	Role limitations due to emotional problems	Energy/fatigue	Emotional wellbeing	Social functioning	Pain	General health
Adolescent's relationship with caregiver									
Biological mother		Ref			Ref			Ref	
Biological father		3.1 (- 2.8; 9.1)			0.8 (- 3.8; 5.3)			-1.2 (- 8.3; 5.9)	

β-coefficient (95% CI) of HRQoL domains and overall scale as dependent variables										
Grandparent		<b>-15.6***</b> (-24.1;-7.6)		3.0 (-3.2; 9.1)				<b>-12.1**</b> (-21.9;-2.4)		
Other relative		-1.8 (-8.2; 4.6)		<b>6.0**</b> (0.7; 11.3)				-2.4 (-10.7; 5.9)		
Sibling		5.2 (-6.6; 17.0)		<b>10.7**</b> (1.1; 20.3)				-1.6 (-16.4; 1.)		
Caregiver's religion										
Christianity								Ref	Ref	
Islam								<b>5.4*</b> (-11.5; 0.6)	<b>-3.14*</b> (-7.24; 0.95)	
Traditional								4.3 (-2.2; 10.7)	<b>4.4*</b> (0.01; 8.9)	
Caregiver's educational level										
No formal education		Ref		Ref		Ref		Ref	Ref	
Primary		-1.2 (-4.9; 2.5)		-1.4 (-8.3; 5.4)		-0.4 (-3.7; 2.8)		-1.4 (-5.3; 2.6)	-2.8 (-5.9; 0.4)	
Secondary		<b>-7.3**</b> (-13.4; -1.2)		<b>-9.9*</b> (-21.2; 1.5)		<b>3.8*</b> (-1.7; 9.2)		3.9 (-2.6; 10.4)	-1.9 (-7.2; 3.3)	
Tertiary		-3.6 (-14.5; 7.3)		<b>13.0*</b> (-5.6; 31.5)		5.0 (-4.8; 14.7)		4.5 (-6.1; 15.1)	<b>5.8*</b> (-2.2; 13.7)	
Caregiver's BMI				<b>0.6*</b> (0.1; 1.2)						
Caregiver's depressive symptoms (PHQ-9 scores)		<b>-2.0***</b> (-2.3; -1.7)	<b>-1.2***</b> (-1.6; -0.7)	<b>-3.8***</b> (-4.6; -4.0)	<b>-4.0***</b> (-4.9; -3.2)	<b>-1.5***</b> (-1.8; -1.1)	<b>-2.4***</b> (-2.8; -2.0)	<b>-1.8***</b> (-2.3; -1.3)	<b>-2.4***</b> (-2.9; -1.8)	<b>-1.3***</b> (-1.7; -1.0)
Table 4 continued										
<b>Independent variables</b>	<b>Overall HRQoL</b>	<b>Physical functioning</b>	<b>Role limitations due to physical health</b>	<b>Role limitations due to emotional problems</b>	<b>Energy/fatigue</b>	<b>Emotional wellbeing</b>	<b>Social functioning</b>	<b>Pain</b>	<b>General health</b>	
Caregiver's socioeconomic score	0.5 (-0.2; 1.3)	-0.2 (-1.3; 1.0)	0.5 (-1.5; 2.5)	<b>2.3**</b> (0.1; 4.4)	0.5 (-0.5; 1.4)	<b>0.9*</b> (-0.1; 2.0)	-0.1 (-1.4; 1.1)			
Caregiver's parenting stress (PSS scores)					<b>-0.3***</b> (-0.4; -0.1)					
Caregiver's age (years)	<b>-0.2***</b> (-0.3; -0.1)	<b>-0.2***</b> (-0.4; -0.04)	<b>-0.3**</b> (-0.6; -0.04)				<b>-0.2**</b> (-0.3; 0.0)			
Caregiver's occupation										
Subsistence Farmer	Ref							Ref		

<b>β-coefficient (95% CI) of HRQoL domains and overall scale as dependent variables</b>										
Small scale Trader	0.2 (- 2.2; 2.6)					<b>-2.4*</b> (- 5.6; 0.8)			2.4 (- 2.1; 6.9)	
Casual labourer	1.8 (- 1.7; 5.3)					<b>3.8*</b> (- 0.7; 8.3)			<b>6.8**</b> (0.2; 13.3)	
Professional	<b>8.6***</b> (2.5; 14.7)					2.9 (- 6.0; 11.7)			6.2 (- 6.8; 19.2)	
n of the final model	483	477	480	485	461	485	483	477	484	
R-squared for the final model	36.3%	19.6%	21.1%	21.9%	24.4%	29.7%	13.3%	19.4%	17.4%	
<b>Notes:</b> * p < 0.20; ** p < 0.05; *** p < 0.01; <b>Bolded</b> – some level of significance; <b>HRQoL</b> – Health-related Quality of Life; <b>BMI</b> – Body Mass Index										

## Discussion

Optimal caregiving is essential for adolescents to thrive. In the current study, we set out to document the HRQoL status of primary caregivers taking care of HIV exposed adolescents in a rural area of coastal Kenya. Our results show that in the current era of highly active ART, most caregivers of HIV exposed adolescents are biological parents, often their mothers, unlike in the earlier years of the epidemic where many were ageing grandmothers (5, 6). Overall, the HRQoL of caregivers in this sample was within the average level. However, our sample presented large HRQoL deficits in vitality (energy/fatigue), pain, social functioning, and emotional wellbeing domains. These domains highlight the important HRQoL targets that can be plausibly prioritized for interventions seeking to improve the quality of life of caregivers of HIV exposed adolescents in the study setting. A closer examination of these domains indicates the critical need for addressing the mental and psychosocial needs of these caregivers.

There is a large body of evidence showing that HIV infected adults are generally at risk of poorer quality of life outcomes than demographically-comparable HIV uninfected counterparts partly because of social circumstances, relationship issues, comorbidities, and stigma in addition to their underlying infection (43, 44). However, few studies have examined the effect of caregivers' and care recipients' HIV serostatus on the carer's HRQoL in SSA. In our study, only the HIV status of the care recipients predicted HRQoL among the caregivers in adjusted models. Contrary to our initial hypothesis, caregivers' HIV serostatus was not associated with HRQoL. This finding could perhaps be an indication that the distress arising from caring for an HIV infected adolescent has more negative impact than the carer's own status on the HRQoL. Indeed, a recent qualitative exploration of the challenges faced by adolescents living with HIV in the same study setting identified several challenges that the adolescents face including poverty, poor mental and physical health, unsupportive school system, high levels of stigma, problems with HIV disclosure, and medication adherence (45). Arguably, such challenges could be taking a toll on the caregivers HRQoL; however, more studies are required to understand the role of these factors on the caregivers' HRQoL. Our observation could be further explained by the significant economic burden that caregivers of HIV infected adolescents are likely to face in their caregiving roles. Indeed, a recent cross-sectional study in the same study setting documented significant economic burden (especially for transportation and medication costs) among caregivers of perinatally HIV infected adolescents (46). However, it could be that some of the adult carers are HIV uninfected and yet taking care of HIV infected adolescents or even vice-versa whereby an HIV infected carer is taking care of PHEU adolescent who poses fewer challenges, he/she (adolescent) is disease-free. This discrepancy of HIV serostatus could have limited the effects on the overall HRQoL outcomes.

Another key finding from the present study was the predictive effect of depressive symptomatology on HRQoL (overall and all subscales) among caregivers. Our finding on worsening HRQoL with an increasing burden of depression is consistent with the results of a recent cross-sectional study which examined the impact of cognitive and mental health outcomes on the HRQoL of a low literacy adult population in the same study setting (40). Besides, there have been several reports of poor psychosocial and mental health outcomes in both HIV exposed and HIV unexposed individuals in our study setting (40, 45, 47–49). High rates of untreated depressive symptoms, perhaps because of HIV-related stigma and difficulties in accessing care, could explain why it is such a strong predictor of HRQoL in this sample (49). Untreated depression could result in impaired economic productivity, reduced ability to perform work and social roles, loss of relationships, physical decline, and problem-solving deficits for the caregivers, hence negatively impacting their HRQoL (50).

Among caregivers' sociodemographic factors, only socioeconomic status correlated positively with HRQoL while age, education level, and relationship with adolescents influenced HRQoL negatively. Similar to findings from other developing countries, having a professional job relative to subsistence farmers (many of whom are likely to be unemployed) was associated with improved overall HRQoL (51). Arguably, individuals in formal employment are more likely to have higher educational level, enjoy higher wages and better working conditions and work environments compared to those without professional employment, thus less likely impacted by high caregiving burden (as may be the case for carers of HIV infected adolescents (46)), hence the improvement in their HRQoL. Better socioeconomic status has long been associated with good health outcomes in the literature (14). Individuals of higher socioeconomic status are likely to have a more enlightened attitude towards disease management, better health-seeking behaviours, and more likely to be employed hence easily access healthcare services, which could invariably enhance their HRQoL. In our study, a unit increase in socioeconomic status score was associated with 2.3-point improvement in HRQoL in the role limitations due to emotional problems domain.

We also found out that having secondary level education relative to lack of formal education was strongly associated with reducing HRQoL in the physical functioning domain. The reason for this observation is not well understood; more detailed studies (with larger samples) are needed to explore the impact of educational status on HRQoL. We also noted that a unit increase in caregivers age was associated with declining overall, and subscale (physical functioning, role limitations due to physical health and social functioning) HRQoL. A study in Namibia did not find any association between age and HRQoL (18). However, this study had a smaller sample size (n = 97), composed of general caregivers (not of HIV exposed adolescents), did not adjust for the caregivers' HIV status, and most of them had a chronic illness that prevented them from working. Our finding could potentially be due to the direct effect of ageing on caregivers (reduced muscle mass) which has been linked with lowered muscle strength, reduced maximal aerobic exercises, and decreased bone density (14, 52). It could also be related to HIV treatment factors such as adherence, viral suppression, among others. However, these factors were not measured in the current study. Moreover, cumulative exposure to risk factors, including sedentary lifestyles, loneliness usually associated with reduced physical activity could also play a role in our observation. Related to this finding, we also observed that being a grandparent relative to a biological mother was associated with a reduced quality of life in the physical functioning and pain domains. Older caregivers (many of whom are grandparents) are likely to experience an excess risk of caregiving burden, child behavioural difficulty, weakened support systems, geriatric syndromes (e.g. impaired mobility, somatic symptoms such as chronic pain) which are likely to harm their health outcomes (53, 54). In Uganda, however, older caregivers of HIV exposed people were more likely to report better health compared to those without caregiving responsibility (11).

Among child characteristics, we found out that caring for a male adolescent influenced caregivers HRQoL negatively. Likewise, the increasing age of adolescent was associated with a decline in caregivers HRQoL in the pain domain. In this cohort, both male sex and increasing age are risk factors for poor adolescent health outcomes such as multiple health risk behaviour (32). Thus, it is plausible that the care for adolescent males involves various sources of distress for the carers, and these have implications for the carers HRQoL. Also, this period coincides with multiple adjustments for the growing adolescent and the caregiver such as disclosing the HIV status to the adolescent, handling sexuality issues for the adolescent (e.g. forming relationships) and how to manage the potentially elevated risk of HIV-associated psychosocial problems. Such adjustments could partly explain the decline in caregivers HRQoL, especially in the absence of adequate psychosocial support to the caregivers on coping positively (55, 56). This could also be partly explained by an increasing caregiving burden in the caregiver as the child grows. It may translate into more needs for adolescent in terms of food, educational requirements such as school fees, and active parenting issues (such as disciplining issues) and others. Nonetheless, we cannot make firm conclusions regarding the role of these factors in the current analyses; more research is needed to explore them further, particularly within the context of qualitative studies.

## Strengths And Limitations

To our knowledge, this is among the few studies in SSA that have documented the quality of life of caregivers of HIV exposed adolescents in the present era of effective ART. The study has few strengths. First is has a relatively large sample size. Secondly, the inclusion of two comparison groups; caregivers of PHEU and caregivers of HUU adolescents enabled us to adequately compare HRQoL outcomes across the 3 groups of caregivers in the same setting. Thirdly, all the study measures were adequately adapted and validated before use in the local population, yielding good psychometric properties. However, given our study's cross-sectional nature, we cannot make any causal inferences on the observed associations. Additionally, the use of self-report interviewer-administered measures may have led to under-reporting or over-reporting of outcomes such as depressive symptoms and HRQoL in the caregivers.

## Conclusions

The results of the present study draw attention to crucial implications for healthcare providers and policymakers. First, primary caregivers, especially those taking care of HIV exposed adolescents at the Kenyan coast are vulnerable regardless of their own HIV serostatus. This highlights the crucial need for inclusive and multi-component interventions tailored to the caregivers' physical, psychosocial, and mental health aspects to meaningfully enhance their quality of life and that of their adolescents. Family-based programmes addressing, for instance, household psychosocial risk factors would be beneficial in this setting. Secondly, it is worthwhile to focus more intensive support to caregivers with an elevated risk of mental health problems, those who are ageing, those living in the poorest households, and those with poorer health states. Properly designed epidemiological/longitudinal studies are urgently needed to understand the underlying mechanisms and longer-term implications of the correlates of caregivers HRQoL identified in the present study.

## Abbreviations

**AHOS** – Adolescent Health Outcomes Study

**ANOVA** – Analysis of variance

**BMI** – Body Mass Index

**CI** – Confidence Interval

**CGMRC** – Centre for Geographic Medicine Research, Coast

**HIV** – Human Immunodeficiency Virus

**HRQoL** – Health-related Quality of Life

**HUU** – HIV unexposed uninfected

**IQR** – Interquartile Range

**KEMRI** – Kenya Medical Research Institute

**KHDSS** – Kilifi Health and Demographic Surveillance System

**MUAC** – Mid-upper arm circumference

**OM** – Observations missing

**PHEU** – Perinatally HIV exposed but uninfected

**PHI** – Perinatally HIV infected

**PHQ-9** – 9-item Patient Health Questionnaire

**PSS** – Parental Stress Scale

**RAND-SF 36** – RAND 36-Item Short Form Survey questionnaire

**SD** – Standard deviation

**SERU** – Scientific Ethics Review Unit

**SSA** – Sub-Saharan Africa

**WHO** – World Health Organization

## Declarations

**Ethics approval and consent to participate:** Permission to conduct the study was sought and granted by the Kenya Medical Research Institute Scientific and Ethics Review Unit (KEMRI/SERU/CGMR-C/084/3454). We also sought approval from the Kilifi County Government, Department of Health Services (HP/KCHS/VOL.VIX/80). All participants provided written informed consent for their participation.

**Consent for publication:** Not applicable

**Availability of data and materials:** No additional data are available. Anyone interested in accessing the data reported in this article is free to write to the Data Governance Committee of the KEMRI Wellcome Trust Research Programme who will review the application and advise as appropriate, and ensure that uses are compatible with the consent obtained from participants for data collection. Requests can be sent to the coordinator of the Data Governance Committee using the following email: [dgc@kemri-wellcome.org](mailto:dgc@kemri-wellcome.org).

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**Authors' contributions:** AA, CRN and GS conceptualized the study. AA, CRN, DS and PNM designed the study. DS and PNM supervised data collection. PM and CN designed study questions for tablet administration and managed the study data. EC and VAK participated in data collection. PNM and PM analyzed the data. PNM, AA, CRN, and DS contributed to the interpretation of the data. PNM wrote the first draft of the manuscript. All authors critically reviewed subsequent versions of the manuscript and approved the final version for submission.

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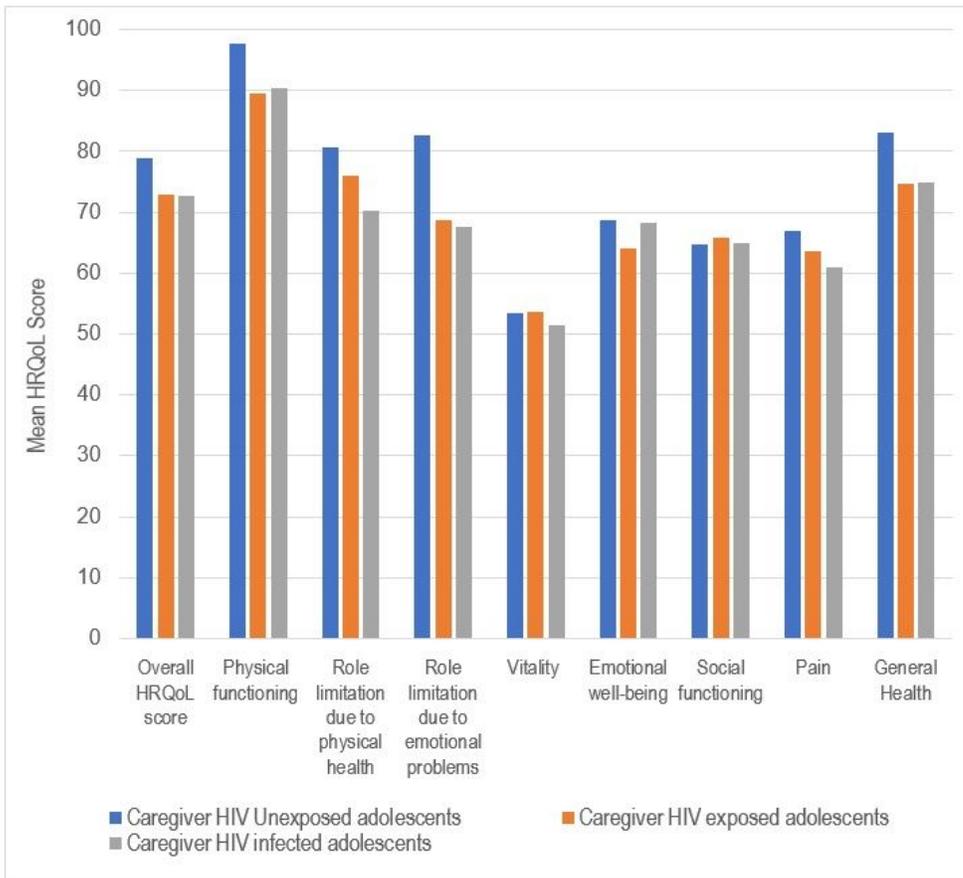
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## Figures



**Figure 1**

Graphical distribution of the mean HRQoL scores across the three groups of careivers

## Supplementary Files

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