Economic burden and mental health of primary caregivers of perinatally HIV infected adolescents from Kilifi, Kenya

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Abstract
Background: Eighty per cent of perinatally HIV infected (PHI) adolescents live in sub-Saharan Africa (SSA), a setting also characterized by huge economic disparities. Caregiving is crucial to the management of chronic illness such as HIV/AIDS, but the economic costs and mental disorders borne by caregivers of PHI adolescents often go unnoticed. In this study, we evaluated economic costs, coping strategies and association between economic cost and mental health functioning of caregivers of perinatally HIV infected adolescents in Kilifi, Kenya.

Methods: We used a cost of illness descriptive analysis approach and mental health was assessed using the Patient Health Questionnaire (PHQ-9). Cross-sectional data were collected from 121 primary caregivers of PHI adolescents in Kilifi using a structured cost questionnaire. Economic costs (direct costs and indirect costs) were measured from primary caregivers’ perspective. We used descriptive statistics in reporting the results of this study.

Results: Average monthly direct and indirect costs per primary caregiver was Ksh 2,784.51 (USD 27.85). Key drivers of direct costs were transportation (66.5%) and medications (13.8%). Total monthly costs represented 28.8% of the reported caregiver monthly earnings. Majority of the caregivers borrowed resources to cope with high economic burden. About 10.7% of primary caregivers reported depressive symptoms. Caregivers with positive depression screen (PHQ-9 score ≥10) had high average monthly direct and indirect costs. However, this was not statistically different compared to costs incurred by caregivers who screened negative for depressive symptoms.

Conclusion: Our study indicates that HIV/AIDS is associated with a significant economic burden for caregivers of adolescents living with HIV. These high economic burdens seem to negatively influence the mental health of caregivers of adolescents living with HIV. Results underscore the need for developing economic empowerment and social support programmes that reduce the economic burden of caring for perinatally infected adolescent. These efforts may improve the mental health and quality of life of caregivers of adolescents living with HIV.

Background
Despite the comprehensive implementation of strategies to prevent vertical transmission of HIV,
millions of children and adolescents in sub-Saharan Africa (SSA) are still perinatally infected [1]. In 2017, 36.9 million people were living with HIV around the world [2]; 2.1 million of them were adolescents aged between 10 and 19 years majority of whom reside in SSA [3, 4]. Over 80% of HIV infected adolescents acquired the infection through mother to child transmission [5]. Nevertheless, the advent and upsurge in the uptake of antiretroviral therapy (ART) in settings such as SSA has led to reduced HIV/AIDS-associated mortality and increased life expectancy [6, 7]. Most perinatally infected children are now surviving to adolescence and early adulthood [8].

Perinatally HIV infected (PHI) adolescents, like any other adolescents, require care which contributes to measurable costs on their caregivers [9]. With increased longevity, a primary caregiver often a family member, assumes the long-term role of caring for the infected young person throughout their developmental span. The caregiver has to adapt to the costs and stresses of caregiving demands. In settings such as SSA where healthcare services are often out-of-pocket [10, 11], most of caregiving burden falls solely on primary caregivers of PHI adolescents. Of growing concern is that these caregivers are bearing more than their “fair share” of costs of caring for their adolescents. The costs seem to be hidden or overlooked as they are not well captured on official records; hence, the development of evidence-based policy is hindered.

Family expenditure on HIV/AIDS may increase substantially due to high level of long-term investment costs [12]. Although drugs for HIV/AIDS are free for patients at public health facilities in many parts of the world. Some services incur a charge such as hospital admission or diagnosis of comorbid disease conditions [13]. Evidence suggest that caregivers are burdened by the costs of other components of care, such as medicine and treatment for opportunistic infections [14]. Additional costs include non-medical costs such as transport costs. The recurring expenses of accessing healthcare services and opportunity costs of time spent at the health facility for regular clinic visits and treatment of comorbid disease conditions may provide obstacles for PHI adolescents and their families [15]. The costs often have impoverishing effects on some households and hinder PHI adolescents from getting necessary care [16]. Furthermore, the costs may result in catastrophic health expenses in the context of fragile economic balance and low insurance coverage [17].
To meet the costs of illness caregivers of PHI adolescents, adopt coping strategies such as sale of assets and borrowing [18–20]. Such strategies can help to cope with immediate economic burden; however, they can also be potentially ‘risky’ for their future financial wellbeing. The selling of livelihood assets, for instance, reduces the caregiver’s/or family’s ability to generate future income [21, 22]. There exists a vast body of literature on economic costs of HIV in Kenya and other African countries. However, economic costs faced by caregivers of adolescents living with HIV have received relatively little attention.

Although several studies have focused on the mental health, wellbeing and quality of life of caregivers of PHI children and adolescents [23, 24], they did not simultaneously evaluate caregiver’s economic burden and its association to mental health. In this study, we set out to evaluate the economic burden, coping strategies and mental health of primary caregivers of perinatally HIV infected PHI adolescents from Kilifi, Kenya.

Methods
Study setting
We carried out this study at the Centre for Geography Medicine Research-Coast at the Kenya Medical Research Institute (CGMRC-KEMRI) located in Kilifi County, Coastal Kenya. It was part of a baseline phase in an on-going longitudinal larger Adolescent Health Outcome Study (AHOS) between January and July 2018.

Kilifi County has an estimated population of 1.4 million by 2016, of whom, 61% are rural dwellers, and 22% are aged between 10 and 20 years [25]. Kilifi is termed as a “moderate HIV county” with 4% HIV prevalence, and 6000 (19%) of people living with HIV are adolescents and youth aged 15–24 years [26]. About a third of Kilifi County is covered by Kilifi Health and Demographic Surveillance System (KHDSS) nested in the KEMRI-Wellcome Trust Research Programme. The local economy of the KHDSS and Kilifi county residence is mainly subsistence farming.

Study design
This was a cross-sectional study nested in a larger adolescents’ health outcome study (AHOS). AHOS is an ongoing longitudinal study aimed at examining neurocognitive and mental health outcomes of 12–17 years old adolescents in the context of HIV. In this sub-study, we recruited primary caregivers
accompanying PHI adolescents participating in the parent study. PHI caregivers were recruited through sequential sampling from eight HIV treatment and care clinics in Kilifi County. Recruitment was done by a trained research assistant in liaison with local field worker and community health worker at the HIV treatment facilities. An adolescent living with HIV using ARVs has regular visits to the HIV specialized clinic for comprehensive care including ART refill, treatment for routine medical check-up, counselling services or nutritional advice (when recommended).

Data collection
We collected data using survey cost questionnaire/tool developed by adapting costing items from different existing tools [27, 28]. The items included information on direct and indirect costs incurred and coping cost strategies for PHI caregivers. The survey cost questionnaire was translated from English to Swahili and then back-translated to ensure accuracy and coherence. We piloted the tool with 12 participants from an HIV specialized clinic in Kilifi. We further revised the questionnaire based on feedback and results from the pilot phase. Data from the pilot phase were not analysed in the sub-study. The final version of the tool was later designed in a tablet platform using Research Electronic Data Capture (REDCap) [29].

Economic burden measures
We applied a cost of illness approach and measured direct costs, indirect costs and coping strategies from the primary caregivers’ perspective, i.e. we sort to elicit the economic costs incurred and paid for by the caregivers.

Direct cost: Average direct costs were measured by combining all the average out-of-pocket medical and non-medical costs for the PHI adolescent, caregiver and person accompanying PHI adolescent (other than the caregiver). These included administrative costs (registration and consultation, cost for diagnostic tests, medicine, food, accommodation/bed, travel and miscellaneous expenditure at the time of treatment visit. Besides the regular visits to the HIV specialized clinics, individuals living with HIV sometimes visit other healthcare providers for general treatment. In this study, the direct costs from regular visits and other healthcare provider visits were analysed. The average costs from these visits within the month of the interview was measured and assumed to be equivalent to the direct
monthly costs due to HIV/AIDS in this study.

*Indirect costs (productivity loss):* We examined the loss of productive working time by the caregiver due to illness of PHI adolescent. Productivity cost was defined as the inability to carry out normal daily activities (paid and unpaid), and their valuation in United States Dollar (USD). Normal activities were defined as formal and informal work carried out by the caregiver. To calculate productivity losses, the inability to work, we divided into absenteeism and presenteeism. Absenteeism was defined when the caregiver was unable to carry out normal daily activities at all due to adolescent illness. On the other hand, ‘*presenteeism*’ was defined when the caregiver reduced efficiency in work where he/she could work some hours, but not the whole day [30]. The summation of absenteeism and presenteeism was termed as ‘productivity loss’ and their monetary valuation was termed as ‘productivity cost’ in this study. Two aspects were considered: i) the days which losses were experienced; ii) the extent to which work efficiencies were affected in hours. Valuation of productivity losses in this study is presented as Gross Domestic Product (GDP) per capita of Kenya (USD 4.11) in a day, according to 2017 World Bank report [31]. Valuation using per capita is preferred because this approach values time loss for the rich and the poor people by an average of the whole society [27].

*Mental health assessment*

The 9-item Patient Health Questionnaire (PHQ–9) [32] was also administered to the caregivers to assess their mental health functioning. The PHQ-9 is a screener and provides an indicator of depressive symptoms severity. 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. As a measure of severity of depressive symptoms, mild symptoms of depression are interpreted as PHQ–9 total score of 5–9, minor and moderate depressive symptoms equate to PHQ–9 total score of 10–14 and 15–19 respectively, and severe depressive symptoms equate to PHQ–9 scores of 20 or more. In this study, we used a cut off of ≥10 to indicate a positive screen for depressive symptoms. This cut-off maximizes the sensitivity and specificity in a study conducted in SSA [33]. PHQ–9 has proved to be reliable on primary healthcare setting with a Cronbach alpha of 0.86 from its original validation [34]. PHQ–9 and socio-demographic data was collected from the parent study.
Statistical analysis
Descriptive statistics were used to present caregiver’s socio-demographic characteristics, caregiving costs, coping strategies and mental health. Means and medians on continuous data and proportions on categorical data. Mean (average) costs were mainly reported because total cost, which is relevant and vital to society, can be directly estimated from mean cost [35–37]. However, we also used the Shapiro-Wilk test to test for normality. Median values were also reported, and Mann-Whitney U test was used where applicable. Data were analysed using R version 3.4.3 [38].

Results
A total of 124 caregivers of PHI adolescents were approached to participate in this sub-study. Two caregivers did not seem to comprehend the questions and one had an adolescent who had refused to take medicine for a period of two years. These caregivers were excluded from the study. Consequently, analysis involved responses of 121 caregivers who successfully completed the questionnaire. Table 1 highlights caregiver’s socio-demographic characteristics. Most of the caregivers were female (86.0%) and biological parents of the adolescents (62.8%). The mean age of the caregivers was 46 years (SD=12.42 and 41 (33.9%) had no formal education. Majority of the caregivers (98.3%) were not in employed professional occupation and were mainly in farming (38.0%) and business ventures (39.7%). Less than a quarter of the caregivers (9.1%) reported to have an active subscription with the National Hospital Insurance Fund (NHIF), a government-run health insurance coverage system in Kenya. This insurance cover in Kenya partly absorb some of the costs but not full HIV/AIDS treatment [39]. However, none of the caregivers registered with NHIF reported to use this cover to seek healthcare for adolescents living with HIV.

Table 1: Caregivers’ socio demographic characteristics (N=121)
| Characteristics                          | Frequency (n) | Percent (%) |
|-----------------------------------------|---------------|-------------|
| Caregiver                               |               |             |
| Mother                                  | 64            | 52.9        |
| Father                                  | 12            | 9.9         |
| Relative                                | 45            | 37.2        |
| Sex                                     |               |             |
| Female                                  | 104           | 86.0        |
| Male                                    | 17            | 14.0        |
| Age (years)                             |               |             |
| < 20                                    | 3             | 2.5         |
| 20-29                                   | 16            | 13.2        |
| 30-39                                   | 23            | 19.0        |
| 40-49                                   | 40            | 33.1        |
| Above 49                                | 31            | 25.6        |
| Unknown                                 | 8             | 6.6         |
| Caregiver’s Education level             |               |             |
| No education                            | 41            | 33.9        |
| Partial primary                        | 36            | 29.8        |
| Primary graduate                       | 25            | 20.7        |
| Partial high school                    | 6             | 5.0         |
| High school graduate                   | 10            | 8.3         |
| Tertiary                                | 3             | 2.5         |
| Marital status                          |               |             |
| Never married                           | 16            | 13.2        |
| Married                                 | 68            | 56.2        |
| Separated                               | 4             | 3.3         |
| Divorced                                | 0             | 0.0         |
| Widowed                                 | 33            | 27.3        |
| Occupation                              |               |             |
| Farmer                                  | 46            | 38.0        |
| Trader/Business                         | 48            | 39.7        |
| Casual laborer                          | 10            | 8.3         |
| Professional                            | 2             | 1.7         |
| Others                                  | 15            | 12.4        |
| Health insurance                        |               |             |
| Yes                                     | 11            | 9.1         |
| No                                      | 110           | 90.9        |

Economic costs

The average monthly cost per caregiver was Kenyan shilling (Ksh) 2,785.51 equivalent to United States Dollar (USD) 27.85, with direct costs being Ksh 1,671.98 (USD 16.72) and indirect costs being Ksh 1,112.5 (USD 11.13) (Table 2). Total cost incurred by participants in this study was Ksh 336,926 (USD 3369.26). For both average and total costs, direct costs constituted 60.05% and indirect costs 39.95%. The main key drivers of direct costs were transportation (66.5%) and medications (13.8%). The study found that the average number of days a caregiver was completely unable to carry out normal activities due to illness of PHI adolescent in a month (absenteeism) was 1.78. The average number of days lost due to sub-optimal work efficiencies was 0.92. Therefore, average productivity
loss in a period of one month was a total 2.7 days. Average productivity costs were calculated by multiplying average days lost by the caregiver in a month with per capita GDP in Kenya as of the year 2017. Thus, average productivity costs due to caregiving in a month were Ksh 1,112.53 (USD 11.13) (Table 2).

Average total costs were calculated by summing direct costs and productivity costs (indirect costs) due to HIV/AIDS in a monthly period. Thus, the average total monthly costs per caregiver was Ksh 2,784.51 (USD 27.85), which was 28.8% of the average caregiver’s monthly income.

Table 2: Economic cost to caregiving for perinatally HIV infected adolescents

| Cost component                      | Mean monthly costs per caregiver | Median (USD) | Proportion of total costs |
|-------------------------------------|---------------------------------|--------------|---------------------------|
|                                     | Kenyan shilling (SD) | USD\(^a\) (SD) |                           |
| Direct costs                        |                                  |              |                           |
| Administrative costs                | 39.34 (95.74)                  | 0.39(0.96)   | 0.00                      |
| Diagnostics                         | 53.72(168.73)                  | 0.54(1.69)   | 0.00                      |
| Medicine                            | 231.14(427.21)                 | 2.31(4.27)   | 0.00                      |
| Other                               | 0.00(0.00)                     | 0.00(0.00)   | 0.00                      |
| Subtotal                            | 324.20(565.06)                 | 3.24(5.65)   | 0.50                      |
| Direct non-medical cost             |                                  |              |                           |
| Travel                              | 1111.49(931.43)                | 11.11(9.31)  | 8.00                      |
| Food                                | 233.79(270.36)                 | 2.34(2.70)   | 1.55                      |
| Bed charges                         | 2.50(27.39)                    | 0.03(0.27)   | 0.00                      |
| Subtotal                            | 1347.78(1104.25)               | 13.48(11.04) | 9.50                      |
| Total direct costs                  | 1671.98(1221.76)               | 16.72(12.22) | 12.00                     |
| Indirect costs (Productivity costs\(^b\)) |                          |              |                           |
| Absenteeism                         | 733.69(725.98)                 | 7.34(7.26)   | 4.11                      |
| Presenteeism                        | 378.84(122.83)                 | 3.79(1.23)   | 3.79                      |
| Total indirect costs                | 1112.53(753.05)                | 11.13(7.53)  | 8.78                      |
| Grand Total Cost                    | 2784.51(1492.33)               | 27.85(14.92) | 25.48                     |

\(^a\)USD – United States Dollar; 1.00USD equivalent to Kenyan shilling 100.4 (Central Bank of Kenya monthly interbank exchange rate, August 2018)

\(^b\) Absenteeism (days caregiver was completely unable to work), Presenteeism (The decrement in performance associated with the caregiver remaining at work while impaired by adolescent health problems, hours lost converted to days). Valuation done using per capita GDP in 2017 (Ksh 411/day) (World Bank data[31])

\(^c\) Percentage computed by diving the total cost from the cost component item by the grant total cost and multiplying the result by 100

Coping strategies

Adolescent’s caregivers were asked on their coping behaviours that have an effect on minimizing the impact of costs on caregiver’s families due to illness. We also inquired about any amount of money raised from different sources to support treatment over a period of four months. Caregivers indicated
use of combined coping strategies, as shown in Figure 1.

Caregiving costing and mental health outcomes

Based on a cut-off score of ≥10 on the PHQ-9, thirteen (10.7%) primary caregivers of PHI adolescents screened positive for depressive symptoms (Table 3). It was observed that direct, indirect and total costs of caregiving for PHI adolescents were higher among caregivers with a positive screen for depressive symptoms compared to those without depression symptoms (although not significant).

Table 3: Caregiving costs in USD per caregiver and mental health outcomes

| Cost categories | No depressive symptoms (score<10) n = 108 | Depressive symptoms (score ≥10) n = 13 |
|-----------------|---------------------------------------------|----------------------------------------|
|                 | Mean costs (SD) | Median costs (IQR) | Mean costs (SD) | Median costs (IQR) |
| Direct Costs    | 16.32 (12.19)  | 11.60           | 19.46 (12.66)  | 19.20             |
| Indirect Costs  | 10.76 (7.44)   | 8.65            | 13.84 (7.99)   | 14.30             |
| Total Costs     | 27.21 (14.87)  | 23.86           | 34.01 (14.62)  | 40.24             |

*Mann-Whitney tests on non-normal cost data

USD: United States Dollars, SD: Standard deviation, IQR: Interquartile range

Discussion

This study examined the economic burden and mental health of primary caregivers of perinatally HIV infected (PHI) adolescents, using data from 121 primary caregivers. This is especially important, as limited research has been done around economic burden and mental health of caregivers of PHI adolescents from SSA, yet SSA carries the biggest burden of HIV [40]. We found that caregivers of PHI adolescents experienced a high economic burden, and in some cases, applied catastrophic coping strategies, also known as risk or stress level coping strategies. Additionally, we observed that caregivers with depressive symptoms had a higher economic cost burden compared to those without though this costs difference, although this was not statistically significant.

The economic burden for the caregivers interviewed was high, representing approximately a quarter of their monthly income. This economic burden is likely to contribute to lowered quality of life for the caregiver [41–43] as funds for other important family expenditure and investment may become scarce. The highest burden was associated with travel costs to attend clinic and then followed by
costs of purchasing drugs largely for opportunistic infections and other health conditions. These results have a two-fold implication on policy planning for health care. First, the need to avail paediatric HIV care closer to community settings will be important to reduce the travel costs to patients and their families. Secondly, ARVs need to be provided alongside other required treatment plans to reduce the caregiver costs and expenditures on purchasing of drugs.

Productivity loss is an important economic burden in the context of HIV and surprisingly few studies have investigated productivity loss in sub-Saharan Africa. We noted there were studies related to productivity losses due to HIV/AIDS on adult population in other countries. A study in Nepal [27] reported lower but comparable productivity costs. Higher productivity costs in our study might be due to the following reasons: i) the specialised HIV clinic is located far from most care recipients, and ii) poverty with most adolescents as they lack access to balanced diet which is required to keep them healthy. This may affect their immune system, making them vulnerable to opportunistic infections. Hence it leads to loss of productivity by the caregiver since much time is spent on taking care of a sick adolescent rather than performing normal income-generating activities.

It is worth noting that the government of Kenya gives a monthly transfer cash payment of Ksh 2000 (USD 20) to primary caregivers of Orphans and Vulnerable Children (OVC) [44]. This programme was set up as a way to provide a financial buffer for caregivers of OVC. However, our observations point out to the potential weakness of this public health intervention in Kenya. First, in this study, most caregivers fulfilled the criteria to receive the cash transfer, but only three caregivers reported the cash transfer as their source of income. We hypothesize that the low uptake of the cash transfer may result from low awareness or bottleneck bureaucratic measures one must undertake to access to the fund. There is an urgent need to understand this barrier and propose measures that will ensure equity is maintained in the distribution of support funds to caregivers of orphans and vulnerable children.

Caregivers of PHI adolescents in our setting applied various coping strategies to meet the need of those under their care. However, some of the reported coping mechanisms are detrimental to the economic wellbeing of the family. For instance, the sale of family assets or borrowing (especially with a high-interest rate) risk long-term economic hardship for the caregiver and/or family [21, 22]. On the
other hand, children missing exams and school affects future economic wellbeing of the adolescents and his/her family. These results provide further impetus for the development of more economic empowerment programmes for caregivers of PHI adolescents to save the family from spiralling into poverty.

Nearly 11% of these primary caregivers screened positive for depressive symptoms. Even though not statistically significant, high direct costs and indirect costs (productivity costs) burden were observed in caregivers with depressive symptoms compared to those without. Similar trend was observed by Harmanci and Cetinkaya [45], who reported a significant association between mental health and economic burden. We hypothesize that our study was not adequately powered to detect the difference. For instance, we had only 13 people screen positive for depression while in Harmanci and Cetinkaya, their number of screen positives were 92. Future work with larger sample size need to examine these associations in greater detail.

The results of this study should be interpreted within the context of some limitations. We undertook a cross-sectional study with a small sample size; we cannot assume that the economic burden applies to the larger caregiver population of adolescents living with HIV in Kenya. In addition, the data were derived from self-reported caregivers who needed to recall their past caregiving costs. Therefore, we cannot rule out the possibility of response and memory bias.

Conclusions
Although ARV drugs have been fully subsidized in HIV comprehensive care centres in Kenya, caregivers of PHI adolescents are still paying a considerable amount of money (relative to their incomes) when seeking care for their child. These high economic burdens may potentially contribute to a vicious cycle of poverty, poor mental health for the caregivers and reduced educational opportunities for adolescents. It is therefore recommended that a further review on the financial support for families caring for perinatally infected adolescents be undertaken to ensure long-term health of the affected adolescent is guaranteed and consequently better economic growth from productive individuals and households.

Declarations
Abbreviations
AIDS: Acquired immune deficiency syndrome; PHQ: Patient Health Questionnaire; ART: antiretroviral therapy; PHI: Perinatally HIV infected; CGMRC-KEMRI: Centre for Geography Medicine Research-Coast at the Kenya Medical Research Institute; HIV: Human Immune Virus; AHOS: Adolescent Health Outcome Study; KHDSS: Kilifi Health and Demographic Surveillance System; REDCap: Research Electronic Data Capture; NHIF: National Hospital Insurance Fund; USD: United States Dollar; OVC: Orphans and Vulnerable Children; GDP: Gross Domestic Product

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Author Contribution

PVK, AA, & JJ conceptualized the study.

PVK, AA & JJ designed the study

PVK, AA, PM, & JJ designed and developed study tools.

PVK, PM, MKN & DS contributed to data collection
PVK, PM, & JJ contributed to data analysis

PVK, AA, PM, MKN, DS, CN, & JJ contributed to the interpretation of the data

PVK wrote the first draft of the manuscript

AA, PM, MKN, DS, CN, & JJ critically reviewed the manuscript.

All authors have read and approved the submitted manuscript.

Competing Interests
The authors declare that they have no competing interests.

Consent for publication
Not applicable

Ethics approval and consent to participate
This study was approved by Scientific and Ethics Review Unit (SERU) of the Kenya Medical Research Institute (KEMRI/SERU/CGMR-C/084/3454). All caregivers were above eighteen years and gave a written informed consent. Participation in the study was voluntary and anonymous.

Availability of data and material
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 advice 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.

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Figures
Figure 1

Coping strategies Caregivers applied various combination of coping strategies hence the graph shows an aggregate combination percentage of each coping strategy from the caregivers.