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Perspectives and Experiences of Caregivers of Pediatric Patients on Effects of Reduced HIV Care Funding

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Abstract:-

Background: The Human Immunodeficiency Virus (HIV) infection remains as the most significant public health issue in the world today. Most treatment programs are sponsored through grants and donations since the cost of care is extremely high. The support programs too have changed with more focus on in country home grown interventions. The experiences and perspectives of caregivers of the children living with HIV/AIDS shades light on the possible challenges resulting from the loss of traditional sources of funding for treatment and social support. The researchers sought to outline the experiences and opinions of those who cared for juvenile patients living with HIV/AIDS at Kisii Teaching and Referral Hospital (KTRH).

Methods: A cross-sectional qualitative design with a phenomenological approach was used. In-depth interviews (IDI) were conducted on participants who provided consent and met the inclusion criteria. Potential participants were selected using purposive sampling approach method from in-patient and Comprehensive Care Centers (CCC). The IDI audio files were converted into a Microsoft text document, and then the text file was imported into the R version 4.0.2 program for thematic analysis.

Findings: Eight respondents that included both men and women were interviewed and all had attained high a minimum of high school education. The move from a robust donor supported HIV care to decreased funding, according to all respondents, is marked by great difficulty. The lack of adequate funding has resulted in the suspension of nutritional supplementation programs and a drop in the interval of drug distribution from six months to two weeks and negatively affects adherence for clients who face challenges with repeated travels to hospital to refill doses of treatment.

Conclusion: It was observed that a significant financial and social disruption was encountered due to the reduction in HIV care funding as evidenced by the caregivers taking up the role to fill gaps in care that includes out-of-pocket payments for drugs, supplements, consultation and laboratory services. Most of these services initially were supported 100 percent through donor programs. The inadequate donor support for HIV/AIDS programs hindered the comprehensive care of children living with HIV and raised caregiver costs thus putting a strain on the family support system.

Key words:- *Funding, HIV/AIDS, Pediatrics, Caregivers, Perspectives, Program.*

I. INTRODUCTION

HIV is still a dominant global public health disease affecting most people including children. Globally, roughly, 2.8 million children are HIV positive with 90% of these population coming from the Sub-Saharan Africa and those who are orphaned are estimated to be 13.4 million (Short & Goldberg, 2015a); (UNICEF, 2015).

HIV treatment needs long-term plans in terms of the cost of therapy being a long enduring condition (Volberding & Deeks, 2010). It also requires a well-supported specialized system for it to be successfully managed (World Health Organization, 2020).Notwithstanding, some noncommunicable diseases like diabetes and cancers related to HIV infection and adverse effects of some of the treatment regime emerge (Adeyemi et al., 2021). With ageing the disease progression become significant and proper approach in terms of treatment and care is important (Kasaie et al., 2020)

In Sub-Saharan countries, approximately 1/3 of the income per household earned yearly is spent on HIV and Tuberculosis associated morbidities(Teweldemedhin et al., 2018). A comprehensive approach that is inclusive of both non-medical and medical approaches like socio-economic sustenance and poverty reduction is key when it comes to eradication of these diseases (Assebe et al., 2020). Material Hardship which is an indicator of poverty has been linked with deterioration of socio-economic and health inequalities with impacts of food insecurity and irregular access to health services(Masa & Chowa, 2019). House hold members of HIV affected families with material hardship have been found to be heavily taxed in terms of health care costs(Short & Goldberg, 2015b). Financial resources will help in improvement of health infrastructure for care integration, promotion of ART adherence and retention in care, overcoming stigma inhibiting access to care among other logistics geared towards HIV prevention and treatment (Nachega et al., 2021)

Primary caregivers of children living with HIV are frequently exhausted and short on funds to fulfill their responsibilities(Kidman & Heymann, 2016). The social (Lentoor, 2017), economic (Katana et al., 2020), and psychological strain can sabotage continuity of care and treatment to children infected with HIV as well as those

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who are critically sick leading to poor outcomes (Oyeyimika et al., 2021)**.**The high incidence of HIV infection in Sub-Saharan Africa has been linked to historical, political, economic, and cultural factors and so the coping strategies like education, voluntary counseling and testing, community involvement, care, treatment and support of the affected persons are employed (Lau & Muula, 2004). Consequently, external support is needed as the countries in Sub-Saharan Africa are unable to effectively produce adequate resources to efficiently improve on revenues from the government (Remme et al., 2016). In Ethiopia, spending cuts led to elimination of numerous HIV prevention and care programs as well as those that support orphans and vulnerable children(OVC)(Kates et al., 2016). According to a recent study, compared with no disruption, a 6-month interruption in the supply of antiretroviral therapy (ART) medications for HIV-infected individuals receiving treatment would be projected to result in a 1.63 times greater spike in HIV-related mortality over a 1-year period (Jewell et al., 2020).

The health system in Kenya has a concerted donor landscape. It has been reported that 4 donors fund almost 90% of all aids that come from the external sources (K. McDade et al., 2021). Reduced funding led to inability to maintain programs that considerably increased the introduction of HIV+ treatment of children from 43% to 93% with a surge in a number of new infections (UNAIDS-KENYA, 2018). In 2020, hit with a scarcity of cotrimoxazole and resulted to anxiety amid patients who had lost their incomes as well and depended on well-wishers for food aids (Osweta, B, 2021),.

Sub-Saharan countries have economic constraints however, some have tried domestic and innovative financing to manage HIV and related complications(Atun et al., 2016).Coping strategies used by caregivers depend on both internal and external strengths(Mujjuzi et al., 2021).Consequently, acceptance, positive reframing , emotional support in religion, substance use and venting(Oyeyimika et al., 2021), borrowing with friends, reduction of meals and borrowing with institutions(Lopera et al., 2011) avoidance and self-distraction(Ahmed et al., 2021) have been utilized by caregivers to cope with caregiving burdens. Regarding, children living with HIV infection, it is crucial that the opinions and experiences of caregivers in the African context are adequately documented (E. Asuquo et al., 2017).

II. METHODS

- **Design**: The researchers adopted a cross-sectional qualitative design to describe the perspectives and experiences of caregivers of pediatric patients on reduced funding of HIV/AIDS care programs obtained through in-depth interviews. A descriptive phenomenological strategy was adopted aiming at gaining a deeper understanding and describe thoughts, emotions, and actions of caregivers in the wake of reduced funding of HIV Care.
- **Study Site:** The study was carried out at Kisii Teaching and Referral Hospital (KTRH). This facility is the main teaching and referral hospital in Kisii County, Kenya with a bed capacity of 700. The hospital offers both outpatient and inpatient services for people from South Nyanza and the surrounding Counties.
- **Study Population:** The target were caregivers of pediatric patients on treatment for HIV infection in pediatric wards and the Comprehensive Care Centre in (KTRH). We included all caregivers of pediatric patients living with HIV/AIDS who agreed to take part in the study; those who had been taking care of the patient for over 6 months continuously; those identified as the next of kin in the files of patients and have consistently been taking care of them. Caregivers who had mental challenges and not concerned with to time, place, and person; those with symptoms of Covid 19, those who could not express themselves in either English or Swahili and those who had not attained the age of 18 years were excluded from the study.
- **Sampling:** The participants were selected using a non-probability purposive sampling technique from inpatient and comprehensive care facilities in (KTRH). Using the participant information and consent form, the researcher enlightened the possible volunteers who met the requirements about the study. Informed consent was obtained and a consent form was signed by each participant after they expressed their awareness of all the study's information and participation requirements.
- **Ethical Considerations:** The Joint Kenyatta National Hospital and University of Nairobi Ethics and Review Committee gave approval for the study. The recorded data was secured by keeping under lock and key to maintain confidentiality and protect Participants' personal identifiers. The designated Counseling rooms at the pediatric wards and Comprehensive care center were used as interview spaces. There was no monetary or any form of direct benefits given to participants.
- **Data management:** Data collection tools were validated through pretesting and interviewers were trained to ensure quality data capture. Professional transcription of data was done. Data was analyzed using **R** version 4.0.2 software. Qualitative data was run and the resultant outputs were examined.

III. RESULTS

A. Socio-Demographic characteristics of participants

The researchers recorded perspectives and experiences to saturation levels from participants. Majority of the participants were mothers and fathers who formed the most direct linkage to children with HIV/AIDS and thus understood more deeply how reduction of funding affected them. Participants had varied occupation levels of which farmers composed of 50%, teachers 37.5% and community service 12.5%.

B. Perspectives of participants on HIV/AIDS funding

To effectively access the theme that touched on perspectives of caregivers and reduced funding, certain specific codes were used. Some of the notable codes included 'worries,' 'views,' 'concerns,' 'transition problems,' and 'opinions.' From these codes, the following themes related to caregivers' perspectives on reduced funding for HIV/AIDS programs were identified.

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Categories	Frequency	Percentage
Gender		
Male	2	25%
Female	6	75%
Age		
30-35 years	4	50%
36-40 years	0	0%
41-45 years	3	37.5%
46-50 years	1	12.5%
Level of education		
High school certificate	3	37.5%
College Education	5	62.5%
Occupation		
Farmer	4	50%
Teacher	3	37.5%
Community health worker	1	12.5%
Family role		
Mother	6	75%
Father	2	25%

Table 1: Demographic Information of participants

➢ *Theme 1- Transition Problems*

The first theme that related to perspectives of caregivers was transition problems or issues that emanated from the reduced funding regime and the consequent taking over by the government agencies. All the respondents asserted in one form or the other that the transition from a robust donor funding of HIV/AIDS regime to a reduced one had significant challenges.

- **Sub-theme 1. Lack of preparedness by the Kenyan Government**

One of the respondents with a HIV/AIDs child who had previously benefited from donor funds for instance asserted that:

> *"I see there is still a challenge for the Kenyan government to oversee this project. I don't see it being as successful as when the donor agencies were in charge of the HIV/AIDS projects. If I compare the government only without any outside support, it's still a challenge" (respondent 002, 2021).*

The respondent is here comparing the donor funded regime against the present government control and sees a significant gap. Part of the reason for the gap is attributed to lack of preparedness by government agencies to deal with the issues that the HIV/AIDS program sought to address.

This is best elucidated by another respondent speaking on the transition problems noted that:

> "*Most county governments are not prepared for the transitioning in case there's a changeover. This means that maybe we will be affected in such a way that we will not get all the services that we used to get when the donor funding was there" (respondent 007, 2021).*

The same respondent offers a succinct elaboration of the lack of preparedness when she observes that:

> *...like now they're now implementing "partners are changing hands." Yet, the new incoming partner has not stepped on the ground but the outgoing partner has already left. And the gap has been left there between offering the services like there's a continuation but some of the services are not being done" (respondent 007, 2021)*

- **Sub-theme 2. Comparison of before and after reduced funding**

The respondents identified and contrasted issues before and after funding. The responders provided a more comparative account of what had previously occurred prior to the funding drop and what has since taken place. For example, a caregiver who also serves as the mother of an infected child recounted what she saw, saying:

> *"Before when we'd been offered support by other NGOs, you'd be given drugs for two months then you come back and get a month supply but nowadays, according to this transition, drugs nowadays are issued that only lasts for two weeks supply and you are asked to come again. The problem is, if the child's school is far away, one has to come many times to the hospital to access the drugs" (respondent 002, 2021).*

She continues saying that:

> *"With my firstborn, we'd be given food supplements to help add weight if you see the child has a deficiency, the child would be given and they'd take it. Nowadays those things are no longer available. Now they affect the child that when you give them drugs, they see them as something bitter. If you don't give*

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them something sweet afterwards, they view taking them as a challenge" (respondent 002, 2021).

- *Theme 2. Frequency of drugs disbursement*

Reduced funding had reduced the regularity of disbursement of drugs from six months to just 2 weeks supply while others asserted that it reduced from 3-month supply to a month supply depending on availability, stability of the patient and distance they were from the facility.

> *"Sometimes I go to the hospital to get the drugs. I find that I don't get a three months' supply of drugs as before and I'm issued a two weeks supply" (respondent 004, 2021).*

> "*We used to be given three months' supply of drugs, but now we get only a month's supply. (respondent 008, 2021).*

A caregiver who is also a teacher and a mother remarked that the two-week supply and in some cases a one-month supply instead of a six-month supply is difficult for caregivers especially because it raises the traveling expenditures necessary to get those drugs. She said that:

> *"It becomes a challenge to us, doctor, because we used to go to the health center to pick the drugs for three months' supply, it'd be long before we go back to pick more. In the process we'd have saved fare if we were coming from far. So, this one-month supply of drugs becomes a challenge because of the short interval and therefore we are unable to afford fare to travel to pick the drugs because they get used up fast" (respondent 008, 2021).*

- *Theme 3. Lack of support for continuity of care*

The 49-year-old mother asserted to reinforce the point about the lack of blood tests, that:

> *"… there was this thing about the transition where you'd be issued with drugs. A child was supposed to have a blood test every six months but it's no longer available nowadays. Since the onset of the Covid-19 pandemic, they say that there'll be no more blood tests. Now it's almost one year. …If the child's health has deteriorated, and you want them to do a check up to find out what's up; if they test let's say like the kidney, you'll be forced again to pay" (respondent 001, 2021).*

> "*...They used to follow up on how we live and how we take our food, and our drugs when our food was exhausted, they'd give us more supplies. But these days they don't follow up. "(respondent 007, 2021).*

- *Theme 4. Unavailability of nutritional supplements*

On the issue of absence of nutritional supplements due to less funding, respondents noted that*;*

> *"We'd be given food supplements to help add weight if you see the child has a deficiency…. Nowadays those things, the food supplements, are no longer available" (respondent 002)*
>
> *"We used to be given food and given drugs. But these days we're only given drugs. We don't even have fare to go to the clinic" (Interview 005, 2021)*
>
> *"If you watch the kids, they've missed out on things like nutritional support. They lack supplies, thus they don't have access to healthy food. "(respondent 001)*

C. Experiences of caregivers as a result of reduced funding for HIV/AIDS programs

To effectively access the theme that touched on experiences of caregivers on reduced funding, certain specific codes were used. Some of the notable codes included 'experience,' 'happening,' 'what you do.'

- *Theme 1. Joblessness and homelessness*

The respondents responded on what the reduction of funds has meant for parents and the child alike. One of the respondents offered an elaborate response on this when she said:

> *"Yes, well, for example we had pediatric mothers who used to be attached to the clinic and they were being given a stipend every month. However, they were laid off because of the transitions, because of the reduction of funds. Now, they don't have another source of income. Before someone gets to build themselves up again and get to the place they were before becomes tough. Life becomes very difficult than bearable. In fact, some of them have gone to the streets. They're now street children; street parents because they cannot afford to pay rent (respondent 007, 2021).*
>
> *:" ...like now without funds, the people who were employed as counsellors tracing drug defaulters lost their jobs and so difficult reaching this group" respondent 001*

According to the respondent, reduced funding has led to loss of jobs for caregivers as well as taking them to street life with experiences of tight budget concerns as reported by one of the caregivers who indicated that:

> *"To get here in Kisii to access drugs, I use Ksh 150; to and from I use Ksh. 300. Ksh 300 to and from, when you're with the child, you must use and additional Ksh 300. My income is low, so I see it's difficult to visit the clinic as required" (respondent 002, 2021).*

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➢ *Theme 2. Child health care deterioration*

Others who responded discussed the impact of the cut in funding on child care. One of the caregivers who has been working with a child with HIV/AIDS for more than 5 years observes that:

> *"...when a child fails to take his drugs properly his viral load doesn't decrease, you find he has a high viral load because he doesn't get drugs" (respondent 005, 2021).*

> *"We used to be given food supplements, especially for children who are malnourished, that used to boost with immunity, but now there are no supplies. Many of these children are so weak as they cannot eat well too" (respondent 008)*

Essentially, the child's health has worsened as a result of the less funding and has aggravated the negative practices on post funding reduction among caregivers.

- **Sub theme 1- Out- of pocket cost expense**

The respondents spoke of refreshments, fare withdrawal and blood test subsidy prompting them to create a budget for them.

> *"Like earlier on, we would have all the tests for free but now we pay for all the tests but in the past the donor would cover it" (respondent 001, 2021).*

The caregiver keeps saying that:

> *"In the past we'd do tests including kidney function to gauge if the drugs are causing the kidneys any harm. But since the transition, it has been now on the parents. And when they go to the lab and are asked to pay say Ksh 1000 for the tests, yet some even Ksh 200, they can't afford it. They used to be free of charge." (respondent 001, 2021).*

It was said by another respondent that:

> *"For example, my child here has had lots of "missed appointments. Sometimes it's time to pick drugs, and we don't have a fare to come to pick the drugs. Earlier on, Nuru ya Watoto, a funded program for children, would give us fare to the clinic. But now it's not available. We have to budget for it" (respondent 005, 2021).*

> "*I must use the fare to go from my home to the hospital. A two weeks interval! You see I use a lot of money unlike when I'd get a two or three...months' supply of drugs. And now that I am a low-income earner!" respondent 008,2021*

> "*There are things the children were used to begin given like refreshments when they come to the clinic, they can cannot get them anymore like some used to be given even money as transport reimbursement for them to come to the clinic which is not there anymore" respondent 007,2021.*

➢ *Theme 3. Reduced HIV funding and access to education*

According to one of the fathers who participated in the interview, he was more worried about school fees and how the transition had affected them by saying:

> *"In the past we'd be supported even in paying school fees. However, since the changes occurred, I've never gotten that support in payment of school fees. I have two children whose school fees has not been paid so I'm affected" (respondent 005, father, 2021).*

> *"The government should reinstate the earlier program which would serve us food wise and some school fees and few school items. When I could get some money, I could contribute to clearing school fees and in buying some food at home. But now that is not provided. Some of my children are not going to school because am not able to afford all these things" (respondent 008,2021)*

It is clear that financial assistance given to parents in some way lessened the financial burden of the children's school expenses. Lack of these assistance prevented them from receiving HIV care and accessing educational opportunities.

➢ *Theme 4. Reduced funding and Nutrition*

Others who responded to the survey discussed their experiences with the food they consume. The care-giver aged 35 years indicated that:

> *"We used to be given plump nuts, weighed and height measured and if they got your child's weight was amiss from the graph they used at the clinic, they would inform you that you needed nutritional intervention. You'd be given plump nuts and flour. But these days all these are gone. We don't know how it happened. So, these days we fend for ourselves, we're only recommended what to get. The nutritionist gives us a list, only tells us to buy omena, buy that and that and they don't want to know if we reside in town or in the upcountry. It's difficult. It's true; they don't care if you have the money" (respondent 005, 2021)*

For instance, a different respondent who was questioned made a forceful observation about the problem of the victims' lack of nutritional support and their experience of hunger. In this regard, she pointed out:

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"Many deaths have resulted, especially among children, because they lack the support that they'd get from the donor, regarding drugs, nutrition and much more. And for these drugs, ARVs, you cannot take them on an empty stomach! These drugs need one to eat properly for them to work effectively. Taking these drugs on an empty stomach contributes to affected children dying. And now, many deaths have resulted but we are quick to attribute all deaths to Covid-19. But you may find that the child could have been infected with HIV but failed to get proper nutrition, and as soon as they took the drugs, the immunity got further compromised" (respondent 001, 2021).

*"*About *the food, we can't tell how the children are doing. We used to be given some food but nowadays is not provided. We just eat what's available, not proper nutrition (bora chakula tu si chakula bora) the children suffer...and sometimes we sleep hungry and the drugs don't go well with someone who doesn't feed properly" (respondent 008,2021).*

- *Theme 5. Loss of training opportunities for HIV positive children and their caregivers*

The training that was available prior to funding reductions and the lack thereof are two crucial experiences that are contrastively portrayed. According to one caregiver who has had AIDS for 22 years had this to say:

"...I thank God because I have children. I have 1 out of 6 who is affected by HIV. For us we were able to get the teachings earlier on and know how to handle the children. Back then when the organizations were powerful. They'd even pay us a visit in the rural areas, in our homes and offer us advice. But now we don't have an organization that does that anymore" (respondent 001, 2021).

Actually, another caregiver supported the issue of training and said that:

"Another challenge we've experienced in taking care of children is "health education". You know in the past, we used to be grouped according to the age of the child and then we're taught. Through education, the child knows the importance of taking his drugs, and what the drugs do to reduce the viral load. Nowadays we don't have health education; we don't have those programs where we'd meet up, now we are troubled." (respondent 005, 2021).

"*I'd wish that these programs had counselling for children of the adolescent age like before. They talk to them, teach them and organize things like fun activities" (respondent 004,2021)*

IV. DISCUSSION

Caretakers who are closely related to children living with HIV/AIDS and a deeper understanding of how the reduction in funding affects them were polled about their perspectives and experiences. The results above indicate that the study was able to access qualitative data from a cross-section of respondents based on the gender, age, occupation, level of education, and family roles of the respondents. This improves the results' reliability, dependability, and confirmability.

Caregiver stress is exacerbated by the constraints brought on by reduced funding, burdens characterized by medicine shortages, the withdrawal of nutritional supplements, and high associated costs. This agrees with the literature asserting that a child's psychological, mental, and physical wellbeing are strongly influenced by the mental health of caregivers(Murray et al., 2017) and those of studies on the mental health of caregivers of critically ill patients that are restricted to population in English-speaking high-resource countries.

A systematic analysis of the effects of pediatric critical illnesses on caregivers and families revealed that the family had unmet demands and pressures, therefore health professionals should be aware of this to make sure they are included in the treatment of the sick child(Shudy et al., 2006). Further, the outcomes agree with (E. F. Asuquo et al., 2017) who conducted a study on the encounters of informal caring of PLWHIV by women. It was established that care giving strains mostly in women due to poverty, joblessness, singlehood coupled and being sole family breadwinners. In addition, the study found that they had a greater risk of contracting HIV in addition to physical stress and mental health issues. The literature demonstrates that Kenya's health system has a concentrated donor landscape, with four donors funding nearly 90% of all external aid (the United States, the Global Fund to Fight AIDS, Tuberculosis and Malaria, the United Kingdom, and Gavi, the Vaccine Alliance). The transition challenges identified by the caregivers are consistent with this literature (K. K. McDade et al., 2021).

According to analysis of the viewpoints and experiences of the caregivers, they have considered the severity, action cues, susceptibility, and benefits related to the wellbeing of their children in the wake of the drop in donor financing. This suggests that the results are consistent with the Health Belief Model, which aims to clarify and anticipate wellbeing practices and provides the basis for interventions to increase awareness of health risks, improve perceptions of individual risk, encourage actions to reduce or eliminate the risk, and increase confidence in one's ability to make the necessary changes (Green et al., 2020) (Chin & Mansori, 2019)

V. CONCLUSION

The study outcome indicated a substantial transition challenge evidenced by the caregivers taking up the role to fill gaps in care due to "reduced funding" that includes out-of-pocket payments to pick drugs, buy supplements, consultation, and laboratory services. Most of these services initially were supported 100 percent by donors. The lack of donor support for HIV/AIDS programs hindered the care of HIV positive children and raised caregiver costs, which exacerbated the bad experiences caregivers had with children after financing. But because it is a reality for them, others have turned to other means of survival, albeit with difficulty.

VI. RECOMMENDATIONS

A multi-sectoral partnership of community-based organizations, non-governmental organizations, and county health facilities should develop guidelines for resource mobilizations to support funding HIV programs. In addition to reducing and managing HIV/AIDS cases, particularly in youngsters, this will also make it easier for caregivers to handle the crisis. The government, through its non-governmental organization, would prioritize empowerment initiatives that would aid parents of children with HIV/AIDS in becoming self-sufficient. To analyze the same constructs as the current study, a quantitative study should have components like questionnaires, observation schedules, and document analysis.

- **Study limitation:** Single site study findings cannot be generalized
- **Declaration of interest**: There was no conflict of interest in this study.

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