

Using economic adherence support clubs (EASCs) to improve viral suppression and care of children living with HIV

Background

Globally, Africa accounts for the highest number of children living with HIV (Avert, 2019). HIV/AIDS remains among the leading causes of mortality among adolescents. Children living with HIV are more likely to die compared to other age groups of people living with HIV. In 2016, 120,000 children died due to AIDS related deaths worldwide (Avert, 2016). Although this is a significant reduction of mortality among children living with HIV/AIDS by 62% from 2010, it is not acceptable that the children should not have to live to their full potential (Avert, 2019). Children living with HIV continue to have poor outcomes globally and especially in Sub Saharan Africa due to a number of factors including lack of access to testing for HIV. This implies that those who are HIV positive will not be able to know their status and therefore start medication early on so as to have a prolonged life.

The prevalence of HIV among children living in Uganda is 0.5% which approximates to 95,000 children living with HIV currently (Uganda Population-Based HIV Impact Assessment (UPHIA), 2017). Over the years, the HIV response has seen improvements leading to reduced morbidity and mortality. There has been a decline in the number of AIDS related deaths in Uganda among children from 2010 to 2018 by 66%. A proportion close to the global figures. However, this is not acceptable especially if the country is to achieve the UNAIDS targets of 95 people knowing their status, 95% of those that know their status are on lifelong Anti-retroviral therapy and of those on ART, 95% are retained in care by 2030. Successes have been achieved by the country through strengthening the prevention of mother to child transmission services, HIV testing among children as well as improving access to ART and improvements in monitoring and retention in care.

Despite the battles won along the way, a number of challenges still exist that are hindering the country from achieving epidemic control. For instance, access to HIV testing especially in the rural setting may sometimes be a challenge. HTS; is the gate way for the continuum of care and therefore without knowing ones' status they cannot access treatment. Access to treatment is still a challenge with only 47% children accessing ART (Avert, 2020). Lifelong ART aims at improving the quality of

life of those living with virus through maximum suppression of virus in the body. However, the viral suppression among children remains low at 39.6%. Viral load is now the mainstay of monitoring people living with HIV. For children, monitoring is done routinely every after six months according to World health Organisation (WHO) HIV guidelines adopted by the Ministry of health of Uganda.

According to AVERT (2019), a number of factors contribute to ART adherence and therefore viral suppression among children. These are inclusive of unpalatability of the most of the pediatric dose formulations, unavailability of age appropriate pediatric ART formulations. Furthermore, children are solely dependent on their parents or guardians to access health care services and therefore ART. As they are solely dependent on their caregivers for treatment support, it is imperative that the caregivers are fully supported psychologically and socioeconomically in order to ensure improved outcomes among children in HIV care. In a study conducted by Nasuuna et al (2018), caregivers cited economic hardships including lack of transport and food experienced in caring for children living with HIV which bred for poor suppression and lost to follow up from HIV care. Therefore, Brewin Foundation(BF) set out to support caregivers of children living with HIV through a locally This locally owned, self-sustainable model has not only improved children's viral load and clinic attendance but also improved the financial independence of their female caregivers.

Methods

Study design and setting

Community based intervention involving a cohort of female caregivers of children in HIV care were selected from Mityana Hospital and Bulera health center III. Participants were enrolled into economic adherence support clubs (EASCs) following voluntary sign up from the respective health facility during the pediatric HIV clinic days. **Participant selection**

A total of 25 female caregivers were selected to take part of this intervention. They all had children living with HIV and in care. Participants were only selected after voluntary sign up of the caregivers with the children's counselor in the respective

health facilities. Participants signed up to be part of the clubs following awareness during the pediatric clinic day in which health education is routinely conducted. A total of 15 and 10 caregivers signed up to be part of the clubs in Mityana Hospital and Bulera Health center III(HCIII) respectively. Following enrollment into the clubs, caregivers of the children were set to have trainings in income generating activities (IGA) as well as communication with the children.

Trainings were conducted in a homestead of one of the signed up caregivers following their consent. IGAs trained included urban farming with main emphasis on vegetable farming, vaseline production with local herbs as well as making snacks. Caregivers were then encouraged to take up the IGAs on individual and group basis. Urban farming was the most taken at individual basis. By both groups of the care givers from the two health facilities. In addition to having the trainings, the caregivers were required to at least meet once a month under the supervision of one of the organization staff. This was a platform for the caregivers to discuss adherence issues they face while caring for children living with HIV and how they can overcome. Furthermore, caregivers were encouraged to save monthly from their generated income which they can build on eventually to grow their businesses. The club leadership included a chairperson, treasurer and secretary elected by the group members.

Data collection and analysis

Outcomes expected from this intervention included viral suppression for the children who were non suppressed and full clinic attendance. In addition, improvement in the psychosocial wellbeing and socioeconomic status of the caregivers and consequently the children were expected. Viral load bleeding was done routinely while appointment dates were recorded in the Facility appointment books. Caregivers received pre- reminder calls a week prior to their clinic day and also on the day before so as not to forget to come to the facility. They were also encouraged to come with children for clinical monitoring regarding their nutrition status as well as the routine clinic check-ups. If the child was due for the viral load at any one point during the project time, they were bled and results were awaited. Children who were non suppressed continued to receive their intensive adherence counselling (IAC)

sessions routinely to ensure that they were able to suppress at the end of the IAC sessions.

Ethical considerations

Following registration of the caregivers into the EASCs, consent forms were administered to the caregivers in English. This was done by the children's counselors after thorough explanation of the work to be conducted and possibility of having their pictures taken and shared with other people. All caregivers gave their consent and either signed off with hand written signature and for those who could not write, a thumb print was obtained.

Results

Characteristics

All caregivers enrolled into the project were female with youngest being 18 years and the oldest being 67 years. Five of the 25 caregivers were HIV negative. Of the 20 HIV positive caregivers, 4 were non suppressed while 16 were all suppressed. The children of the caregivers were 29 in total all below 15 years of age. Some of the care-givers had more than one child in care as can be seen by the greater number of children compared to the caregivers in the EASCs. Of the twenty-nine children, 8 were suppressed at the time of the formation of the clubs.

Both groups of care givers that were trained in IGAs and selected leaders for their groups including the chairman, secretary as well as a treasurer. Caregivers from Bulera HCIII embarked on vaseline production as a group. On individual basis, they started on urban faming using old sacks as well broken containers including buckets at home to grow. Caregivers from this facility ensured to meet every last Thursday of the month at one of the caregivers home. Meetings enabled them to save from their IGAs as well peer to peer support among caregivers.

The caregivers of Bulera HCIV currently have 400,000 Ugandan Shillings equivalent to \$115 saved as a group from vaseline production. On the other hand, caregivers from Mityana Hospital were focused on individual IGAs with main emphasis on urban farming as well as snacks production. They set out to meet on every third Sunday of the month in which to discuss their saving schemes and provided peer to peer support. Mityana caregivers have successfully saved 546,000 approximately \$156 to

date. The suppression rate of the children currently stands 75% for children compared to the baseline suppression rate of 28%. No children were reported to have missed any appointments during the time of the project. None of the Caregivers have cited lack of food as main barrier to adherence during the time of the project.

Below is a table displaying the sociodemographic characteristics of participants in the project

Table 1

Variable	Baseline	Baseline viral load suppression (Children)		Baseline viral load suppression (Caregivers)		Month 6 viral suppression	
	N	Suppressed N(%)	Non suppressed N(%)	Suppressed N(%)	Non suppressed N(%)	Suppressed N(%)	Non suppressed N(%)
Sample (Caregivers)	25	-	-	(16)80%	4 (20%)	-	-
Sample (Children)	29	8 (28%)	21 (72%)	-	-	22 (75%)	7(25%)
Median Age (Caregivers)	30						
Median Age (Children)	8						
Education of caregivers	-						
Primary	17						
Secondary O' Level	5						
Secondary A 'level	3						
University	-						
Marital status	-						
Married	6						
Separated	13						
Widowed	7						
Employment status	-						
Unemployed	14						
Self employed	7						
Employed	4						
Perceived future financial status							

Uncertain	19						
Secure	6						
Area of residence	-						
rural	11						
Peri-urban	14						
Urban	0						

Discussion

This model set out to not only improve the viral suppression and retention in care in the short interim but also for the caregivers of the children living with HIV/AIDS to have a more secure financial future. Baseline viral suppression was at only 28% compared to 75% suppression rate at six months. This was attributed to improved adherence among the children. Increased availability and accessibility of food; a perceived barrier to many caregivers to adherence to ART, gave the children a chance to respond better to adhering to ART than before. Food insecurity that has been cited in several studies (Kalichman et al, 2014 and Nasuuna et al, 2019) as one of the barriers to adherence to ART and consequently to poor viral suppression. In their study, Kalichman et al (2014) found that families that were food secure were more likely to be adherent to ART and therefore better outcomes. Thus it was imperative that the model improves the financial independence of the caregivers of the children in order to improve food security which is seen as a marker for poverty.

There was observed timely clinic appointments and consequently better clinic monitoring and conducting timely interventions including timely viral load testing from baseline results compared to the ongoing project. This was attributed to the availability of transport to come to the facility on time. Evidence by Nasuuna et al (2019) has shown that the lack of transport to come to the facility was a major barrier to keeping appointments and consequently retention in care. The caregivers were motivated to come to the facility at the appointed time as they were able to meet up with each other. This gave them a chance to sell off their products including the vaseline derivatives at the facility thus earning themselves an income. This in turn offered peer to peer support and forged friendships among the caregivers thus contributing to social cohesion and self-confidence. The increased source of

income for the caregivers gave them a chance to have transport to come to the facility when they were due.

The uniqueness of this model hinged on the fact that caregivers started up the IGAs on their own without being given initial capital such that they would value the work they are doing. Cash transfers are now popular in many HIV programs as is mentioned in a review by Richter et al (2009). However, these pose a risk of causing dependence among the recipients and thus a continuous cycle of poverty. This model on the other hand aimed at ensuring sustainability as it was community led. It was also unique in the sense that the model provided a platform for the caregivers to discuss adherence issues for their children and finding solutions within themselves. This boosted the care-givers' confidence in supporting their positive children. Shortcomings of this model however included the lack of financial literacy. Thus without the support on how to secure their financial future, caregivers and their children were still one step away from poverty.

Conclusion

Supporting families of children living HIV to be financially independent should be put into consideration in HIV programs as most of the adherence issues stem from markers of poverty and thus contribute to poor outcomes. Scaling up of this community led self-sustainable model has the potential to improve many more lives of children living with HIV. Thus more funding should be directed in community led activities such as these to ensure ownership.

References

Avert (2020) *HIV and AIDS in Uganda*. Available at: <https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/uganda> (Accessed: 20 February 2020)

Avert (2019) *children, HIV and AIDS*. Available at: <https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/uganda> (Accessed: 20 February 2020)

Kalichman, S.C., Hernandez, D., Cherry, C. *et al*. Food Insecurity and Other Poverty Indicators Among People Living with HIV/AIDS: Effects on Treatment and Health

Outcomes. *J Community Health* **39**, 1133–1139 (2014).

<https://doi.org/10.1007/s10900-014-9868-0>

Nasuuna, E., Kigozi, J., Muwanguzi, P.A. *et al.* Challenges faced by caregivers of virally non-suppressed children on the intensive adherence counselling program in Uganda: a qualitative study. *BMC Health Serv Res* **19**, 150 (2019).

<https://doi.org/10.1186/s12913-019-3963-y>

Richter, M.L, Sherr, L., Adato, M., *et al.* Strengthening families to support children affected by HIV and AIDS, *AIDS Care*, 21:sup1, 3-12 (2009) DOI: [10.1080/09540120902923121](https://doi.org/10.1080/09540120902923121)

UPHIA (2017) summary sheet: preliminary findings. Available at:

[https://www.afro.who.int/sites/default/files/2017-](https://www.afro.who.int/sites/default/files/2017-08/UPHIA%20Uganda%20factsheet.pdf)

[08/UPHIA%20Uganda%20factsheet.pdf](https://www.afro.who.int/sites/default/files/2017-08/UPHIA%20Uganda%20factsheet.pdf) (Accessed 12 August 2017)