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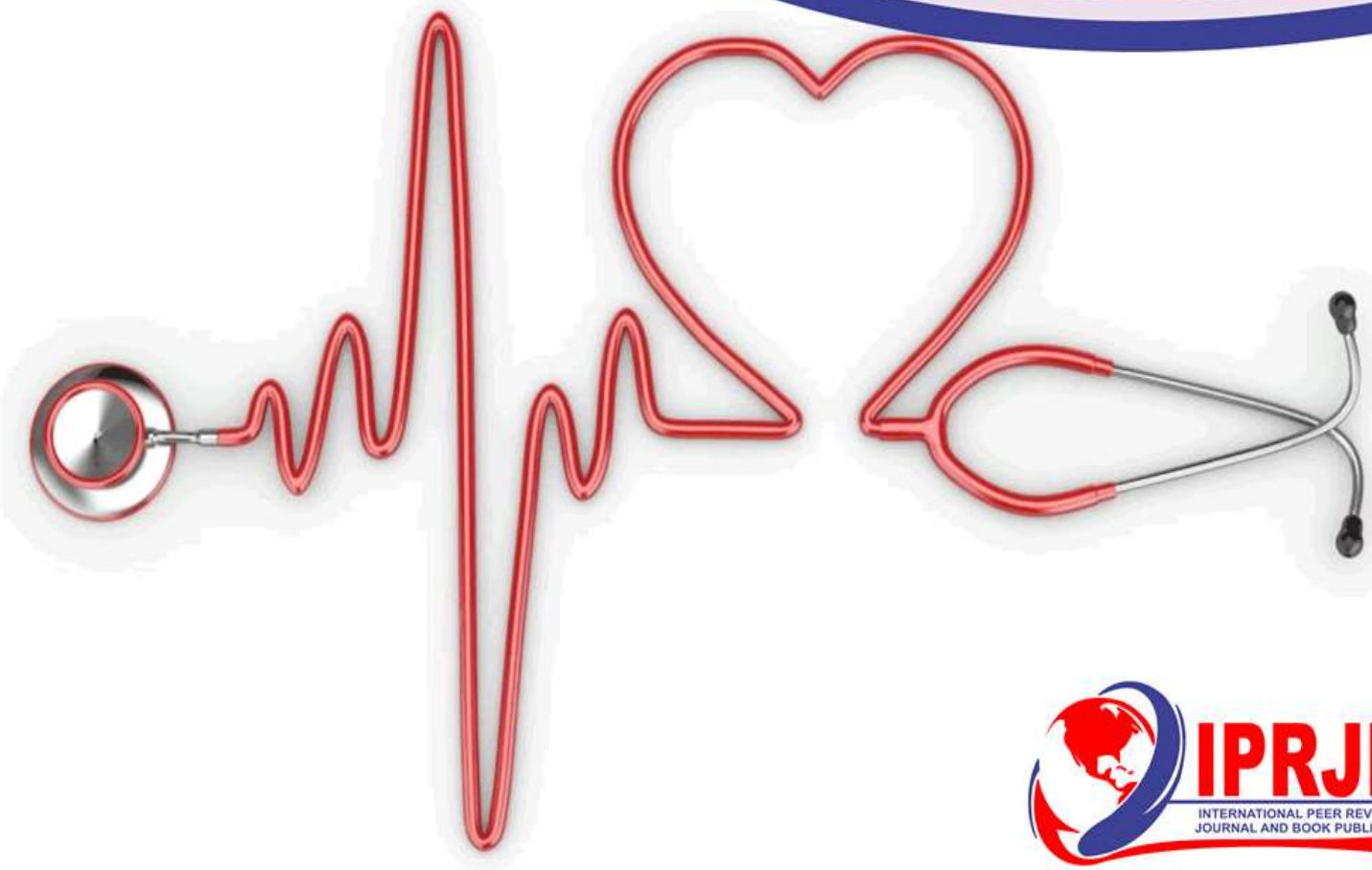

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EFFECT OF CAREGIVERS' HIV DISCLOSURE TRAINING ON PEDIATRIC HIV STATUS DISCLOSURE AND ART ADHERENCE IN HOMABAY COUNTY, KENYA: A COMPARATIVE LONGITUDINAL STUDY.

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Abstract

Purpose: The study objective was to establish the effect of HIV disclosure training on children's HIV status disclosure and on ART adherence.

Methodology: This was a comparative longitudinal study in ten health facilities in Homabay County with 860 non-disclosed HIV positive children on ART aged 6-10 years between 2016 to 2018.A randomized sample of 430 caregivers was trained on HIV status disclosure while another 430 caregivers not trained. All caregivers then performed HIV status disclosure to their HIV positive children, and children's disclosure and adherence to ART status established. We used semi structured questionnaires, FGDs and KIIs for data collection and IBM SPSS version 20, logistic regression, chi-square and Nvivo software for data analysis.

Results: Mean child age was 8 years for both groups, 35 and 37years for caregivers in control and intervention respectively. 409(95%) interventional caregivers had good overall knowledge on disclosure process compared to control (116(27%). Longitudinal viral suppression increased in both groups; intervention group 345(80.2%) to 384(90.1%), control (279(64.9%) to 296(70.1%). Trained caregivers were 2 times (OR-2.369) likely to disclose children's HIV status. Disclosure training had significant effect (P<0.05) on child's adherence. Children of trained caregivers were nine times (OR-9.145) likely to have good adherence. Level of education of caregivers (p=0. 035) and knowledge of care givers on the disclosure process (p=0.05) were significantly associated with ART adherence. Disclosure knowledge and lack of disclosure skills were cited in FGDs and KIIs as the major facilitator and barrier to disclosure and ART adherence respectively.

Unique contribution to theory, practice and policy: The findings provide evidence – based interventions that will guide caregivers, the Ministry of Education and Ministry of Health on how and when to disclose to a child his own HIV status. Disclosure culminates into behavior change which is anticipated to enhance the reduction in the spread of HIV to the next generation and it is one way of sustaining the fight against HIV and AIDS.The study recommends all children in the age bracket of 6-10 years be disclosed to their own HIV status in order to increase their level of adherence to ART.

Key words: *Caregivers, paediatric, HIV Disclosure, ART Adherence, HIV disclosure Training*

INTRODUCTION

Pediatric HIV is the infection of HIV in children below <15 years with a global burden of 1.7 million children infected with the disease (United Nations Programme on HIV/aids. UNAIDS, 2021).In Kenya, 6% of children below <15 years live with the disease, while Homabay county is the second county mostly affected with the disease with a prevalence of 20.7%. Global and regional countries including Kenya, have reported low rates in pediatric HIV status disclosure, with no study focusing on training caregivers on the disclosure process (Amankwah-Poku et al., 2021; Doat et al., 2019; Guta et al., 2020; Turissini et al., 2013; Vaz et al., 2011).

Anti-retroviral therapy is a lifesaving treatment for people living with HIV. A dramatic reduction in HIV-related morbidity and mortality has been recognized in countries where ART has been made widely available (Mykhalovskiy et al., 2014).Therefore, it's no doubt that there are positive prospects that scaling up ART and adherence especially by HIV positive paediatrics would eventually enable the world to achieve an HIV and AIDs free generation(Ministry of Health, 2016).However, by the end of 2012, only 9.7 million people in low and middle income countries (LMICs) were receiving ART(CDC, 2014).This was only 65% of 15 million target for LMICs that was adopted by 189 United Nations member states(CDC, 2014).

Adherence to treatment protocol is exceedingly important in ensuring that drug efficacy does not fail with time. Adherence by children who are HIV positive is highly dependent on them knowing their HIV status, which can only happen by a disclosure process facilitated by their caregivers. The World Health Organization (WHO) recommends that children be informed of their HIV status at ages 6 to 12 years and full disclosure of HIV/AIDS be offered in a caring and supportive manner at about 8 to 10 years (WHO, 2011). Disclosure of HIV status is usually done by health care providers in the case of adults. In the case of children, however, disclosure is done by caregivers facilitated by a healthcare provider(WHO, 2011).In Kenya, HIV status disclosure should follow a confirmed laboratory HIV testing following NASCOP 2015 HIV testing guidelines (NASCOP, 2015). The obvious benefits of disclosure of one's HIV status is the reduction in the risk of transmission of HIV infection associated with the use of successful ART (NASCOP, 2015). Adherence to HIV care and treatment is pivotal for suppression of viral replication and upsurge of viremia. Among children living with HIV, adherence is highly dependent on them knowing their HIV status, which can only be done through a disclosure process facilitated by their caregivers. It has been recognized that efforts to increase the availability and accessibility of treatment should accompany disclosure (NASCOP, 2015).

Disclosure can be defined as a declaration of a person's HIV status.Disclosure can be partial i.e. giving information about what is happening in the body without naming the disease. It can also be full in which case both the name of the virus and the disease are declared. . Disclosure can also be inhibited by lack of HIV education(Marianne & Amy, 2001). Pre-disclosure of person's HIV status at testing facilities is often preceded with counseling in order to prepare the client psychologically for the outcome of the test (Ministry of Public Health and Sanitation, 2008). However, such pre-disclosure activities have only been practiced with adults but seldom with children. Recently the Kenyan Ministry of Health through NASCOP (NASCOP, 2018) released guidelines on use of antiretroviral drugs for treating and preventing HIV infection. In the guideline, it's recommended that adolescents should be counseled about the potential benefits and risks of disclosure of their own HIV status and that the youths should also be empowered and supported to determine when, how and to whom to disclose. The guideline also recommends that all HIV positive children irrespective of their age, CD4 cell count, WHO

clinical staging or co-infection, should start ART immediately an HIV positive diagnosis is established.

Sub-optimal adherence can lead to treatment failure and subsequent need to switch patients to 2nd or 3rd line ART (NASCOP, 2018). It can also lead to the emergence of drug resistant strains of the virus and enhanced transmission during risky sexual behaviors(NASCOP, 2018). Disclosure should follow a confirmed laboratory HIV testing following NASCOP 2015 HIV testing guidelines(NASCOP, 2015)

Statement of the Problem

According to WHO 2013 update on HIV treatment (World Health Organization, 2013), there are multiple treatment and preventive benefits of initiating ART earlier. However, most pediatrics positive of HIV had not benefited from ART because their HIV status had not been disclosed to them. It's therefore imperative that pediatric HIV status disclosure is done early enough to allow for timely enrolment by such children into ART program.

Limited work had focused on the effect of disclosure of a child's own HIV status on children's adherence to HIV treatment. Additionally, such studies had failed to explore how incorporating a child's caregiver in the disclosure process would impact on an HIV positive child's treatment adherence. According to WHO, (WHO, 2011) document that offers guidelines on HIV disclosure counseling for children up to 12 years of age, lack of disclosure affects the wellbeing of the child particularly on issues like access to paediatric HIV treatment, care and adherence to treatment. In Homa Bay County, it is evidenced from literature that up to 83% of children living with HIV and AIDs were not on ART by the end of 2014 and this could be partly that they were not aware of their HIV status simply because no one did the disclosure process. Lack of disclosure impedes children's adherence to ART, which could prolong the lives of these children. It is important that HIV positive persons adhere to ART treatment protocol. Lack of adherence usually leads to intermittent increase in viremia and this may increase the chance of the development of resistant strains of HIV consequently resulting into therapeutic failures. In the long run, Homa Bay County's future would be bleak as a result of an ailing youth population. This will affect the socio-demographic and economic development of the county in the near future. Due to the large number of children in Homa Bay County who were in need of ART in 2014, disclosing to them of their own HIV status would be a positive step in the prevention of HIV and AIDs presently and in the future. Incorporating children in the disclosure process is indeed a way of developing a pool of experts on disclosure that can be of use for the future generation.

LITERATURE REVIEW

Benefits of Paediatric HIV Disclosure

According to WHO 2013 update on HIV treatment (World Health Organization, 2013), there are multiple treatment and preventive benefits of initiating ART earlier. However, most pediatrics positive of HIV had not benefited from ART because their HIV status had not been disclosed to them. It's therefore imperative that pediatric HIV status disclosure is done early enough to allow for timely enrolment by such children into ART program.

According to the WHO (2013) HIV treatment update (World Health Organization, 2013), there was a threefold increase in the number of primary health facilities providing HIV care and treatment for children in Kenya, Lesotho, Mozambique, Rwanda and the united Republic of Tanzania. However, there were comparatively small numbers of people being treated at the health facilities meaning that the increase in the number of health facilities providing HIV care

and treatment did not translate into large gains particularly in the number of children receiving ART. This therefore underscored the need of devising strategies to increase the number of children positive of HIV who are enrolled into ART program. Disclosure of paediatric HIV status would enable counties to increase the number of children positive of HIV being enrolled into ART program and reduce the number of children born of HIV. Early diagnosis and timely care and treatment can prevent many AIDS related deaths among children living with HIV.

The MoH (2018) ARV guidelines (NASCOP, 2018) recommends initiating ART immediately for all children younger than 10 years of age who are diagnosed with HIV; the challenge arises when such HIV positive children are transiting childhood to adolescence and eventually adulthood. They would be expected to take control of their sexual development and responsible behaviour. Based on this argument their HIV status needs to be disclosed.

Benefits of Adherence to ART

By the end of 2012, only 9.7 million people in the world over were receiving ART in low and middle income countries (World Health Organization, 2013). This was only 65% of 15 million target that was adopted by 189 united Nations Member states in June 2011 at the General Assembly High- Level meeting on AIDS in New yolk (UNGA, 2011). WHO (2013) reported that there was an increase in the number of people who were on ART globally by 1.6 and predicted that at the noted increase, the 15 million target of people to receive ART by the end of 2015 was achievable. Nevertheless without concerted efforts towards pediatric HIV status disclosure, it would be difficult to meet the UN target. A gain it's argued that 22 countries with high HIV burden of which Kenya was one of the countries had been put on a global plan towards the elimination of new HIV infections among children by 2015; this would only be achieved if there were plans to disclose HIV status of children who were just about to enter into their a adolescent phase of physiological development (UNAIDS, 2011).

The preventive effect of ART on onward HIV transmission had been confirmed in clinical trials as reported by (Cohen, 2011) and in routine program settings (Tanser, 2013). Therefore it's of no doubt that there were positive prospects that scaling up ART uptake and adherence especially by HIV positive paediatrics would eventually enable the world to achieve an HIV and AIDS free generation. This is the same argument put by (US-PEPFAR, 2013).

Recruiting paediatric positive of HIV into ART program is recommendation by WHO (WHO, 2013) and WHO strongly believes this strategy would enable them in achieving AIDS free generation. Riding on the framework of community strategy and using the proposed CDC paediatric HIV status disclosure process, the current study conducted an intervention that trained caregivers of HIV positive paediatrics on Paediatric HIV status disclosure so that this knowledge would assist them in disclosing to such paediatrics of their own HIV status. This intervention was anticipated to influence positive behaviour change among HIV positive paediatrics transiting into their adolescent phase of physiological development.

Barriers Affecting Disclosure Process of One's HIV Status

A study by Mburu and colleagues (Mburu et al., 2014), identified three main barriers to disclosure of HIV status: local norms that deter parents from communicating with their children about sexuality; fear of HIV stigma; and an underlying presumption that adolescents would not understand the consequences of an HIV diagnosis on their lives and relationships. One surprising finding that emerged in Mburu and colleagues (2014) study was that in rare cases, open family conversations about HIV did not help adolescents come to terms with an HIV diagnosis. The study also revealed that disclosure of HIV status would strain sexual relationships, although it did not always lead to rejection.

A study conducted in South Africa at Chris Hani Baragwanath Hospital established that primary caregivers of children with HIV did not disclose HIV status to their children, despite the fact that these children often asked questions about their illnesses. The reasons that they gave for not disclosing included fear of stigma, lack of knowledge and skills, and emotional unpreparedness. They also felt uncomfortable discussing HIV and illness with children (Kouyoumdjian*et al*., 2005). Trust in people to disclose ones HIV status has been reported in other studies as an overarching barrier (Arnold *et al*., 2008; Obermeyer *et al*., 2011). Importantly, the act of disclosure requires the HIV-positive person to trust that he or she will not be ostracized, criticized, stigmatized or rejected after the event. A study by Letteney and colleagues (Letteney & Laporte, 2004) identified stigma as a barrier to disclosure of one's HIV status. In other similar studies (Kmita*et al*., 2002; Waugh 2003; Kouyoumdjian*et al*., 2005) common barriers to disclosure included fear of rejection or loss of respect, negative emotional reactions from their children, and inadvertent disclosure to others by them.

Conceptual Framework

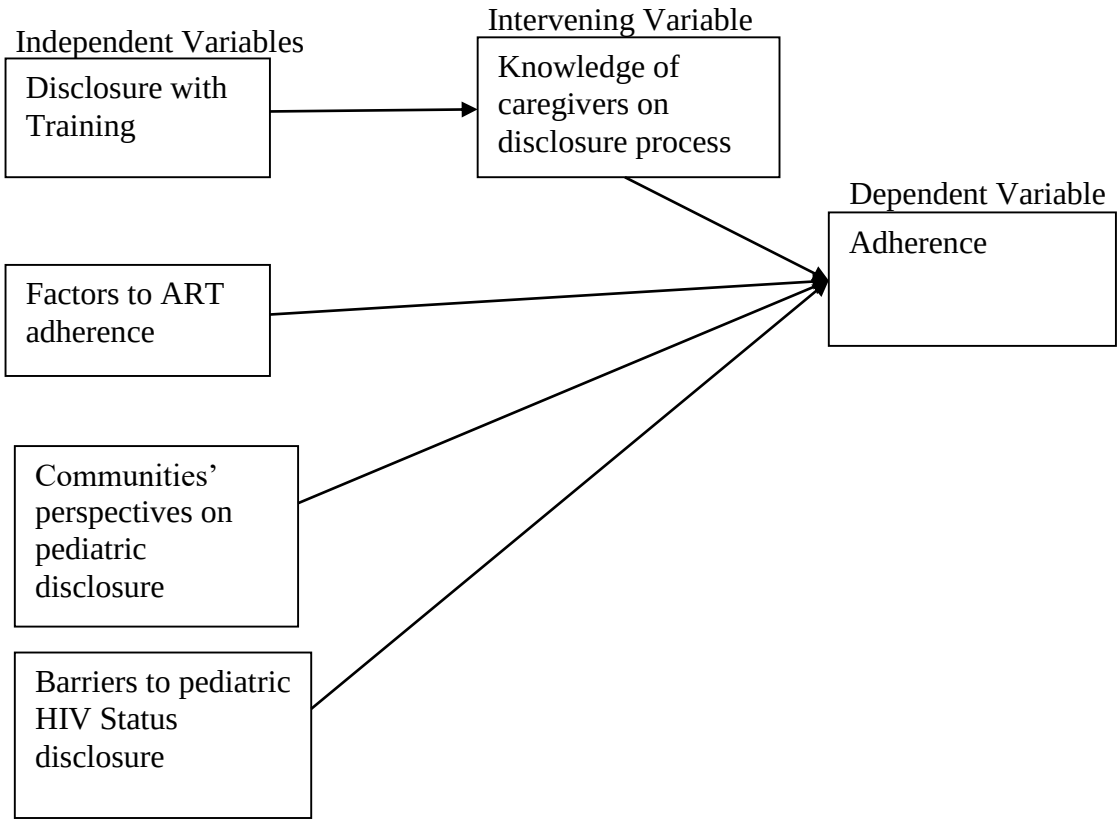

Figure 1: Conceptual Framework

METHODOLOGY

Study Sites

The study was conducted across 10 comprehensive care centres in high volume health facilities in six sub-counties of Homabay County namely; Homabay Township Sub County, Ndhiwa Sub-county, Kasipul Kabondo Sub-county, Kabondo Sub-county, Rangwe Sub-county and Rachuonyo North Sub-county. Both Sub-counties and health facilities were purposively selected for the study.

Study Design

The study used a comparative longitudinal study design where caregivers of non-disclosed HIV positive children aged 6-10 years were randomized into intervention and control groups. The intervention group was taken through HIV status disclosure training while the control group received no training.

Study Population

The study focused on children aged 6 - 10 years on ART, non- HIV status disclosed, plus their caregivers. This is the age that falls within the recommended age by the World Health Organization (WHO, 2011) and the Kenya Ministry of Health (National AIDS and STI Control Program (NASCOP), 2011)as appropriate for HIV status disclosure in children.. Children aged 6 - 10 years are considered to have developmental cognitive and some level of comprehension.

Inclusion Criteria

The children were HIV positive, 6-10 years, on ART and residents of Homabay County. The caregivers were of children who were HIV positive, residents of Homa Bay County for the last three months before and 1 year after recruitment into the study to allow for participation in the follow up that was carried out after 12 months. Participants must voluntarily consent/ascent to participate in the study without being coerced.

Exclusion Criteria

Participants not of sound mind at the time of recruitment and during subsequent follow ups.

Study Limitation

The study focused on training caregivers of HIV positive children on HIV status disclosure process but we realized that gap in HIV status disclosure knowledge also existed among some service providers (healthcare workers at the comprehensive care centres).

Sample Size Determination

A representative sample size at a confidence level of 95% and an error margin of ± 5% was determined from a population of 16, 500 HIV positive non-disclosed children who were on ART in Homa Bay County. This resulted into a sample of 391participants (Yamane, 1967). A total of 10% of the calculated sample size was added to buffer for losses to follow ups, withdrawals and missing participants and therefore the corrected sample size was 430.

$n = N/ (1+N (e^2)$

Where n = the sample size

N= total population (16,500)

e = level of precision or error margin (0.05)

n = 16, 500/ (1+16, 500 *(0.05)*(0.05)

= 16, 500 /35.3625

=391 (+10% of the calculated sample size), the new corrected sample size was 430.

Because the study had both children and caregivers and also experimental and control groups, the control arm had 430 HIV positive children and their caregivers from records of non-disclosed HIV positive children aged 6 -10 years attending EGPAF,s supported ARV centers in Homa Bay County. Similarly, the experimental group had another 430 HIV positive children and their caregivers from records of non-disclosed HIV positive children aged 6-10 years attending EGPAF's supported ARV centres in Homabay County.

Table 1: Sampling procedure for the Intervention Arm

Health Facility	Sampling Frame (Non Disclosed Population 6-10 years)	Sample size
Homabay County Referral Hosp.	198	198/473x430=180
Kendu Sub County Hospital	99	99/473x430 =90
Rangwe Subcounty Hospital	49	49/473x430 =45
Kandiege Level 4 Hospital	52	52/473x430 =47
Ndhiwa Sub-county Hospital	75	75/473x430=68
Total	473	430

Table 2: Sampling Procedure for the Control Arm

Health Facility	Sampling Frame(Non Disclosed Population 6-10 years)	Sample size
Kabondo Subcounty Hospital	98	98/451x430 =93
Kasipul Sub County Hospital	174	174/451x430=166
Othoro Level 4 Hospital	80	80/451x430 =76
Ober Level 4 Hospital	54	54/451x430=52
Nyang'iela Health centre	45	45/451x430 =43
Total	451	430

We used simple random sampling method to proportionately select the 860 non-disclosed HIV positive children aged 6 to 10years, from EGPAF's supported health facilities in six Sub-counties of Homa Bay County. The children were then paired to their caregivers who were then tasked with the responsibility of disclosing to them their HIV status.

Ethics Approval and Consent to participate:

Ethics approval was granted by the Maseno University Ethics Review Committee (Ref: MSU/DRPI/MUERC/00386/17).Informed consent/ascent was obtained from caregivers of the children before participating in the study. Participation into the study was on voluntary basis. Information generated out of the study was treated as confidential and stored in pass worded computers that was only accessible by the principal investigator.Caregivers of the eligible children who were willing to participate in the study were given full explanation of the study and its importance. They were also informed of the data collection procedures which involved audio recording of focus group discussions (FGDs) and key informant interviews. There were no foreseeable risks attached to this study.

Caregiver's HIV Status Disclosure Training:

Before the training, baseline information on viral load (used as proxy to ART adherence) was gathered from non-disclosed HIV positive children aged 6-10 years in February 2016 as a basis for comparison with end-line viral load.

The Centre for Disease and Control implementing partners, led by EGPAF, had come up with pediatric disclosure guide , an extract of the Kenya ART guideline 4th edition (National AIDS and STI Control Program (NASCOP), 2011) with some additional information in it which looked at disclosure eligibility for both caregiver and children (ages 6 – 10 years); child and caregiver readiness for disclosure, the execution of disclosure and post disclosure assessment. The CDC partners disclosure guideline (not published at the time of the study execution but later got published in 2018) (Glaser, 2018), was used for the disclosure training in this study, has components that ensure re-assurance; comfort of caregiver and the child during disclosure; safety, which is defined by the presence of conduciveness of the disclosure environment, location of disclosure room that must not be near open windows; absence of portable equipment that can be used to execute violence. The guideline also has sections that are meant to assess the knowledge of a child on basic HIV and AIDS information, knowledge of disclosure and benefits associated with disclosure.

According to CDC partners' pediatric disclosure guideline (Glaser, 2018), the following have been identified as benefits associated with disclosure of own HIV status namely: enhanced adherence to treatment, increased co-operation from the child in terms of adherence, promotion of communication, enhanced risk reduction and promotion of positive living by HIV positive pediatrics.

Disclosure training was conducted to caregivers in the intervention group as a routine procedure for three monthly clinic visits at the caregivers psychosocial support groups in their respective health facilities by the peer counsellors and psychosocial counsellors. The control group received routine adherence sessions and taught benefits of HIV status disclosure. After the training of caregivers on disclosure process, both group caregivers performed disclosure to their HIV positive children, and a period of 12 months was allowed between disclosure and end-line follow up to establish the effect of disclosure training on children's adherence to ART and children's HIV disclosure rate.

Child HIV Status Disclosure Checklist

Table 3: Paediatric Disclosure Checklist

Name of the Facility_____ Name of the child _____

DOB_____Sex_____Caregiver'sname______CCC No_____

Task 1. **Assess the child for disclosure eligibility**	**Date task 1 executed:**		**Facilitator's name:**
Child has met the age criteria (between 6 and 10 years)	Yes	No	
Child and caregiver knowledgeable on the benefits of disclosure (Yes/No)	Yes	No.	
Caregiver willing to disclose to the child	Yes	No.	
Task 1 Comments:			
2. Assess the child and caregiver for readiness	**Date task 2 executed:**		**Facilitator's name:**
Child or caregiver free from severe physical illness, trauma, psychological illness or psychiatric illness?	Yes	No.	
Child have consistent family, peer support or social support	Yes	No.	
Child demonstrates interest in the environment and playing	Yes	No.	
Assess what the child already knows about the medicines and illness and address needs and concerns	Yes	No	
Assess functional school engagement by the child (consistent attendance, interacts well with the school community, able to freely discuss school activities	Yes	No.	
Is the caregiver ready to disclose to the child?	Yes	No.	
Assess what the caregiver has communicated to the child-	Yes	No.	
Task 2 Comments:			
3. Execute disclosure: done guided by caregiver and supported by Health care worker in the clinic	**Date task 3 executed:**		**Facilitator's name:**
Reassure both caregiver and child and assess their comfort and safety	Yes	No.	
Invite caregiver to disclose using the simplest language the child can understand	Yes	No.	
Observe immediate reactions of both child and caregivers and address concerns or negative reactions	Yes	No.	
Invite questions from the child and revisit benefits of disclosure	Yes	No.	
Explain care options available to the child and caregiver	Yes	No.	
Conclude session with reassurance to both child and caregiver	Yes	No.	

Task 3 Comments:

Child disclosure was done using a disclosure checklist, a tool that guided the disclosure process as shown in table 3 above. Both group caregivers conducted children's HIV status disclosure facilitated by healthcare providers at the health facilities.

Data Collection Process

Baseline Survey

A baseline survey was done to establish the adherence level of HIV positive children in Homa Bay County before disclosure of their own HIV status. The children recruited into the study had recent viral load results recorded in their files a month to three months to the survey.

Both qualitative and quantitative methodologies were employed. A pre-test study was carried out in two randomly selected interventional and control health facilities in Homabay county. Data collection instruments used by the investigator were semi-structured, interviewers-administered questionnaires, Key Informant Interviews and focused group discussions. We used semi structured questionnaires to collect quantitative data from 860 participants and the questionnaires were available in both English and Dholuo translations. The questionnaires collected participants' socio-demographic profiles, caregivers' knowledge on disclosure process and effect of disclosure on ART adherence. FGD collected data on caregivers' disclosure process, factors facilitating and hindering paediatric disclosure and ART adherence before and after disclosure training. FGD discussants were caregivers of the children. Four adult FGDs (2 control, 2 intervention), comprising of 12 males, 12 female caregivers were conducted. Genders in each group (Control and Intervention) were 6 females, 6males. Key Informant Interviews focused on viral load status of HIV status disclosed and non disclosed children, relationship between adherence and viral load, contribution of caregivers disclosure training to treatment adherence and viral load, barriers to HIV status disclosure and treatment adherence. Key Informant Interviews were conducted with health care providers at the comprehensive care centres. The interviews comprised of (3 females, 3males) giving a total of 6 informants.

Trained enumerators i.e. peer & psychosocial counsellors and clinicians at the comprehensive care centres administered the questionnaires to caregivers of the HIV positive children on each clinic visit for six months until the required number (860) of study participants reached. Each facility had a trained research assistant (clinician in charge of the CCC) who oversaw the data collection process. They verified the completeness of the data (cleaned the data) on site at the end of the day.

Data Analysis

The IBM Statistical Package for Social Sciences version 20 was used for the analysis of the quantitative data. The quantitative results were presented using tables. Pearson's chi-square was used to compare adherence between experimental and control groups after disclosure training of caregivers. Logistic regression model was used to determine significant factors associated with ART adherence and to model the relationship in two groups (those adhering to ART and those failing adherence to ART). A significance level of 5% was used in performing all the tests. Statistical significance was tested at a p-of ≤ 0.05 and odds ratios at 95% confidence interval. Qualitative data were thematically analysed using Nvivo software and results presented as narrations or quotes.

Variable Measurement

Viral load was used as the proxy for ART adherence. The outcome variable was viral load measured as either adhered (<1000 copies/ml of blood) or failed adherence (>1000 copies/ml of blood).Viral load level of less than < 1000 copies/ml of blood implied good adherence to ART, while viral load level above >1000 copies/ml of blood implied failed adherence to ART

RESULTS

Socio Demographic Characteristics of Caregivers and Children

Table 4: Socio-demographic characteristics of the study participants:

Variable	Category	Intervention(%)	Control (%)
Age of caregiver	18-25	20(4.6)	45(10.4)
	26-35	198(46)	207(48.1)
	36-45	143(33.2)	130(30.2)
	46-55	42(9.7)	39(9.0)
	Above 55	27(6.2)	9(2.0)
Mean Age		37.2	35.0
Sex	Male	58(13.3)	93(21.6)
	Female	372(86.7)	337(78.4)
Level of education caregiver	None	11(2.6)	33(7.7)
	Primary incomplete	146(34)	74(17.2)
	Primary complete	139(32.4)	112(26)
	Secondary incomplete	58(13.5)	101(23.5)
	Secondary complete	65(15.2)	90(20.9)
	Tertiary	11(2.3)	20(4.7)
Level of education Household Head	None	9(2.1)	19(4.4)
	Primary incomplete	108(25.1)	65(15.1)
	Primary complete	124(28.8)	98(22.8)
	Secondary incomplete	61(14.2)	85(19.8)
	Secondary complete	113(26.3)	104(24.2)
	Tertiary	15(3.3)	59(17.7)
Marital status of participants	Single/never married	11(2.6)	22(5.1)
	Married	272(63.3)	257(59.8)
	Divorced	8(1.9)	12(2.8)
	Separated	16(3.6)	10(2.3)
	Widowed	123(28.6)	129(30)
Size of household	1 –2	29(7.0)	10(2.0)
	3—5	195(45.0)	205(48.0)
	6 and Above	206(48.0)	215(50.0)
Age of a child	6	52(12.1)	71(16.1)
	7	66(15.3)	92(21.5)
	8	87(20.2)	96(22.4)
	9	108(25.1)	82(19.2)
	10	117(27.2)	89(20.8)
Mean age		8.40	8.06
Sex of child	Male	203(47.2)	263(61.2)
	Female	227(52.8)	167(38.8)

A total of 860 non-disclosed HIV positive children aged 6-10 years plus their caregivers participated in the study. The mean ages of the children in both control and intervention groups were 8 years respectively. Children in the control group comprised of more males (61.2%) than

those in the intervention group (47.2%), while the intervention group had more female children (52.8%) than control group (38.8%).

Mean ages of caregivers in the study were 35 and 37 years for control and intervention groups respectively. The study had more male caregivers in the control group (21.6%) than intervention group (13.3%), while female caregivers were more (86.7%) in the intervention group than in the control group (78.4%); Table 4 shows the socio-demographic characteristics of the study participants.

Knowledge of Caregivers on HIV Disclosure Process in Homabay County

Knowledge on HIV positive status disclosure process was comparatively measured after the training of caregivers in as shown in table 5 below.

Table 5: Caregivers knowledge on HIV status disclosure process

Variable	Knowledge	Intervention (%)	Control (%)
Conditions for Disclosure	Poor	0	257(59.8)
	Good	430(100)	173(40.2)
Process of disclosure	Poor	0	358(83.3)
	Good	430(100)	72(16.7)
Materials for disclosure	Poor	70(16.3)	408(94.9)
	Good	360(83.7)	22(5.1)
Persons required for disclosure	Poor	60(14.0)	145(33.7)
	Good	370(86.0)	285(66.3)
Appropriate Age of Disclosure	Poor	1(0.2)	154(35.8)
	Good	429(99.8)	276(64.2)
Individual person to disclose	Poor	0	2(0.5)
	Good	430(100)	428(99.5)

The overall knowledge on disclosure process was determined using the six knowledge areas. A score of 4 or more out of 6 was considered as good knowledge. Most caregivers 409(95%), in the interventional group after training, displayed good overall knowledge on HIV disclosure process as compared to control group where only 116(27%) had good knowledge. Most caregivers in the intervention group, had good knowledge on conditions and procedure of disclosure 430(100%), process of disclosure 430(100%), materials needed for disclosure 360(83.7%), persons required for disclosure 370(86.0%), appropriate age of disclosure 429(99.8%) and individual person to disclose 430(100%) as compared to the control group after HIV disclosure training.

Effect of HIV disclosure training on knowledge of disclosure process

Table 6: Effect of HIV disclosure training on knowledge of disclosure process

Group	Variable	Category	Proportion (%)	Logistic regression
Control	Overall knowledge	Poor knowledge	314(73)	OR-2.369 SE-0.109 DF. 1 P<0.05
		Good knowledge	116(27)	
Intervention		Poor knowledge	21(5%)	
		Good knowledge	409(95%)	

Table **6** shows logistic regression analysis and proportional comparison of knowledge among caregivers in the control and intervention group to determine the effect of HIV disclosure training on knowledge of disclosure process. Trained caregivers were two times more likely to disclose children's HIV status (OR -2.369).

Change in ART Adherence

Viral load was used as the proxy for ART adherence. We compared baseline and end-line viral Load levels among HIV positive children of trained and untrained caregivers in Homa-Bay County.

Table 7: Level of viral load in the intervention and control group both at baseline and end line evaluation

Variable	Viral load of child	Baseline		End line	
		Control (%)	Intervention (%)	Control (%)	Intervention (%)
Viral load	Adherence(<1000copies/ml)	279(64.9)	345(80.2)	296(70.1)	384(90.1)
	Failed Adherence (>1000copies/ml)	151(35.1)	85(19.8)	126(29.9)	42(9.9)

The viral load was categorised as adherence (<1000copies/ml) and failed adherence (> 1000copies/ml). The proportion of children who adhered to ART increased in both control group 279(64.9%) to 296(70.1%) and intervention group 345(80.2%) to 384(90.1%). This study result was supported by *KII4: "In children less than 10 years, viral suppression is fairer. From 10-14years, viral load is not so good, is not well. 14-19 years viral load is worse. Viral load suppression is good and that it is fairer in early adolescents and worse in late adolescents. In late adolescents, viral load is worse because of the issue of disclosure, disclosure was captured late. Many children who are now 14 years and above, were not disclosed to at the right time that is what has caused the viral load to be worst in late adolescent."*

Chi Square Test for End line Viral Load

Pearson's Chi-square test was used to statistically compare adherence between intervention and control groups by comparing viral load levels. The Pearson Chi-square also tested the hypothesis that there is no significant difference in the viral load levels to ART dose regimen between intervention and control groups.

Table 8: Chi-Square for viral load between the Control and Intervention group

	Category	Type Intervention	Control	P-value
The end-line viral load of patient	Viral load > 1000 copies	42(25.0%)	126(75.0%)	<0.0001
	Viral load < 1000 copies	384(56.5%)	296(43.5%)	
	Missing	4(33.3%)	8(66.7%)	
	Total	**430(50.0%)**	**430(50.0%)**	

The study established that there was a significant difference in the viral load levels between intervention and control groups due to a p-value less than <0.0001 at 95% level of confidence. The null hypothesis was therefore rejected and concluded that there is significant difference in the viral load levels between intervention and Control groups. This further implied that the difference in the viral load levels for the two groups was not by chance and therefore a strong evidence for rejection of the null hypothesis. This implied that training of caregivers on the disclosure process improved the viral load levels for children living with HIV in Homabay County.

Effect of HIV Disclosure Training on ART Adherence

Table 9: Effect of HIV disclosure Training on ART Adherence among HIV positive children

Group	Variable	Category	Proportion (%)	Logistic Regression
Control	Viral load	Failed adherence(>) 1000copies/ml	126(29.3)	SE-0.106 DF-1 P-<0.05 OR-9.145
		Adherence (<1000copies/ml)	296(68.8)	
Intervention		Failed adherence (>) 1000copies/ml	42(9.8)	
		Adherence (<1000copies/ml)	384(90.1)	

Table 9 shows a logistic regression analysis to determine the effect of HIV disclosure training on ART adherence among HIV positive children. This was done by comparing the viral load outcomes for the children after the training for control and intervention groups while controlling for all the socio-demographic characteristic of respondents. Disclosure training had significant effect on ART adherence of children. Children whose care givers were trained (intervention group) were nine times likely to have good adherence to ART (suppressed viral load). These results were borne out by KII4 "*quite a number of pediatrics are adhering because when we look at their viral loads, most of them are adhering, only a few are failing adherence. Pediatric adherence to ART has been improving overtime due to intensified adherence teachings before and after ART initiation. She added that HIV status disclosure to children has also played a role in improving adherence to ART since children know the reasons why they are taking medicines".*

HIV status disclosure also increased child individual responsibility to take medication as was supported by KIIs and FGDs. "*Caregivers training help them understand the relationship between viral load and adherence, this makes them deliver right information to the child and the child will adhere to the medication (KII8)". "After disclosure, I felt relieved, the child takes his medicines in time, on Saturdays, older child sometimes goes to pick the medicines even alone, it has made our work easier" (FGD1,R2). "After disclosure, adherence improved, no stigma, no fear, they keep good clinic appointments, they take medicines well" (FGD1, R1). "He takes his medicines well as compared to before" (FGD4, R6),"The children didn't know that they had a serious health condition, but disclosure process made them know the reality of their HIV status, making them adhere to their medicines better as compared to before the disclosure"(KII7).Similarly, "HIV status Disclosure has really done it for me. I used to struggle answering questions here and there on reasons why these medicines are taken daily, he understood quite well that these medicines are taken daily in order to live long, children should be told their HIV status so as to understand the reasons they should be taking their medicines daily", (FGD 4, R6).*

Factors associated with adherence to treatment.

Table 10: Factors Associated with ART Adherence for HIV Positive Children after the Disclosure Training of Primary Caregivers

Variable	Category	B	S.E.	P-value	OR	95% C.I. OR	
						Lower	Upper
Age of care giver	18-25						
	26-35	0.768	0.68	0.259	2.155	0.568	8.171
	36-45	0.138	0.614	0.822	1.148	0.345	3.821
	46-55	-0.096	0.614	0.876	0.908	0.272	3.028
	Above 55	0.222	0.629	0.724	1.249	0.364	4.285
Sex of care giver	Female						
	Male	0.303	0.298	0.308	1.354	0.756	2.426
Level of education-caregiver	None						
	Primary incomplete	1.402	0.941	0.136	4.064	0.643	25.688
	Primary complete	0.788	0.748	0.293	2.198	0.507	9.532
	Secondary incomplete	1.224	0.691	0.076	3.401	0.879	13.164
	Secondary complete	0.432	0.689	0.53	1.541	0.4	5.942
	Tertiary	0.702	0.65	0.28	2.017	0.565	7.206
Level of education-Head of household	None						
	Primary incomplete	-1.197	0.951	0.208	0.302	0.047	1.946
	Primary complete	-0.635	0.569	0.265	0.53	0.174	1.617
	Secondary incomplete	-0.851	0.487	0.081	0.427	0.164	1.109
	Secondary complete	-0.819	0.478	0.087	0.441	0.173	1.125
	Tertiary	-0.866	0.411	**0.035**	0.421	0.188	0.942
Marital status caregiver	Single, Never married						
	Married	-0.007	0.585	0.991	0.993	0.316	3.124
	Divorced	-0.253	0.238	0.286	0.776	0.487	1.236
	Separated	0.066	0.684	0.924	1.068	0.279	4.08
	Widowed	-0.833	0.685	0.224	0.435	0.113	1.664
Occupation of caregiver	Informal employment	-0.632	0.430	0.141	0.531	0.229	1.233
	Formal employment	0.577	0.456	0.206	1.781	0.728	4.354
	Others	0.232	0.527	0.660	1.261	0.448	3.544
Sex of the child	Male						

	Female	-0.066	0.207	0.751	0.936	0.624	1.404
Knowledge on Disclosure	Poor knowledge						
	Good knowledge	1.047	0.235	**0.05**	2.849	1.799	4.516

Table 10 above shows logistic regression analysis for factors associated with ART adherence of HIV positive children after the disclosure training of primary caregivers. All socio-demographic factors showed no significant relationship except level of education of the household head p=0. 035. Similarly, knowledge of care givers on the disclosure process was significantly associated (P<0.05) with ART adherence. Children of care-givers with good disclosure knowledge were three time more likely to have good adherence to ART. In addition to socio-demographic factors, other factors associated with adherence to treatment were revealed in the FGDs and KII. These factors included: training of caregivers and children; *"The many teachings we get from support groups help us to adhere to medication" (FGD1, R2),"Most of these children start treatment at an early age, so if you will have captured caregivers training at an early age as they continue with treatment then it becomes easier"(KII 7).*Comparable sentiments also came from KIIs*: "Children who know their HIV status, tend to own their treatment and therefore it is easier for them to suppress" (KII5).*In addition, *"Caregivers' training help them understand the relationship between viral load and adherence, this makes them deliver right information to the child and the child will adhere to the medication" (KII2).*

In terms of predictors of adherence to ART, one KI indicated that age of the child is associated with adherence to treatment*;"In children less than 10 years, viral load suppression is fairer, from 10-14years, viral load is not so good, is not well. 14-19 years' viral load is worse. Adolescents are usually left on their own. They feel they are not sick so they stop taking drugs "(KII4).*

Barriers to HIV Status Disclosure and ART Adherence.

Most untrained caregivers 306(71%) felt that disclosure was complex and difficult and were concerned that they did not have the necessary skills to disclose and so requested counsellors and clinicians to disclose to their children their HIV status on their behalf. Inadequate knowledge among caregivers on disclosure process is likely to impede disclosure rate as was reported among the FGD participants: *"It was really difficult and uncomfortable because I didn't know what to tell the child. I consulted with the clinician what to tell the child then the clinician told me what to do" (FGD3,R2)."I disclosed to the child his HIV status. I started from the point of his hospitalization which came as a result of increased red germs in the body" (FGD3)."If one has inadequate knowledge on disclosure, it becomes difficult to approach the child because the child might ask questions that you will not be in a position to answer" (FGD2,R6).* Comparable sentiments also came from KIIs: *"The difficult part is that we do not know how to approach them and what to tell them about their status. (KII4).*

CONCLUSIONS AND RECOMMENDATIONS

Conclusion

This study concludes that caregiver's HIV disclosure training is an important predictor of both ART adherence and viral suppression in children for there were significant differences on the level of adherence to ART and viral suppression between the control and intervention group.Additionally, the study further concludes that lack or untimely training of caregivers on HIV status disclosure impedes HIV status disclosure among children by caregivers.

Recommendations

The study recommends that all children in the age bracket of 6-10 years to be disclosed to their own HIV status by their caregivers in order to increase their level of adherence to ART. This recommendation is based on the findings that children whose care givers were trained (intervention group) were nine times more likely to have suppressed viral load. This will reduce cases whereby the children refuse to take drugs without knowing the purpose of the drugs as it was witnessed among those HIV positive children who had not been disclosed their own HIV status.

The study also recommends the Ministry of health of Homa Bay County to offer door to door monitoring of adherence to ART by HIV positive children as well as providing the ARVs to them on regular basis at their homes. This will in the long run improve adherence to ART through eliminating the need to travel to the health facility which is associated with stigma and lack of transport among other barriers.

The study further recommends caregivers of HIV positive children to be trained on various HIV status disclosure aspects such as the appropriate time to disclose child's own HIV status, what is involved in child reassurance before a disclosure session, what needs to be prepared for a paediatric disclosure session and who should be involved during paediatric disclosure. This recommendation is based on the finding that caregivers, who were trained on HIV status disclosure, disclosed to more children their HIV status than untrained caregivers.

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