

**National University of Rwanda
School of Public Health**



University Avenue:
B.P 5229, Kigali Rwanda
Tel: +250 585 166
Fax: +250 500 014
Email: infosph@nursph.org
Web site: www.nursph.org

**THE CONTRIBUTION OF SUPPORT GROUPS ON
ADHERENCE TO CARE AND TREATMENT AMONG HIV
POSITIVE CHILDREN AGED BETWEEN 7 AND 15 YEARS
Cross-sectional study conducted in the HIV clinic of CHUK
Kigali, Rwanda
June 2011-May 2012**

**Dissertation prepared and presented by Esperance MUKAMANA in
order to Obtain Master's degree in Public Health**

Kigali, August 2013

Director: Prof. Dr NTAGANIRA Joseph

Excellence in education and Service to the people

Dedication

To our Almighty God who created us, strengthened us in our entire life and, in addition to all other great actions, has given us capacity to achieve this important work

To our regretted parents, sisters and brothers, who helped us embracing the world and growing up but cannot physically join the enjoyment of this great achievement as they were killed during the genocide perpetrated against Tutsi in Rwanda. We hope they can feel we are very grateful to them and hoping they are rested in peace of their Creator

To our dear lovely family, colleagues and friends who supported us during the course of our study

To anyone who contributed in any way or another for us to have had this work completed

This dissertation is dedicated.

Esperance Mukamana

ACKNOWLEDGEMENT

We praise the Almighty God with deep gratitude for this great achievement we have experienced in our life.

The development and production of this important work has involved many people of varying levels of expertise in the area of pediatric HIV care treatment and support. The process has been possible because of their collaborative effort and support.

Our profound acknowledgement is addressed to the National University of Rwanda/ School of Public health authorities and staff members, especially the management team and academic members, for the wonderful training given to us.

We direct our particular gratitude to the Professor Joseph NTAGANIRA, who accepted supervising our work in addition to his multiple responsibilities. His unconditional and constructive advices will never be forgotten. The result of this scientific work is a fruit of his unreserved and collaborative effort.

We owe sincere gratitude to our lovely family, the colleagues and friends who had always supported us in varied ways during the course of our studies.

We can't stand acknowledging our classmates, MPH intake 3 evening students as well as MPH intake 5 day students, for the experience we shared and the hardships we underwent together during the time of our studies at NUR/SPH.

May the Almighty God bless you all.

Esperance Mukamana

LIST OF ACRONYMS

- AIDS** : Acquired Immunodeficient Syndrome
- ANECCA** : African Network for the Care of Children Affected by AIDS
- ART** : Antiretroviral treatment
- CHUK** : Central Hospital University teaching of Kigali (Centre Hospitalier Universitaire de Kigali)
- DHS** : Demographic health survey
- EGPAF** : Elizabeth Glaser Pediatric AIDS Foundation
- EMTCT** : Elimination of Mother-to-child Transmission of HIV
- FHI** : Family Health International
- GOR** : Government of Rwanda
- HIV** : Human immunodeficient Virus
- IHDPC** : Institute for HIV and other diseases prevention and control
- NGO** : Non-Governmental Organization
- OI** : Opportunistic Infection
- PEPFAR** : (US) Presidential Emergency Plan for AIDS Relief
- PMTCT** : Prevention from Mother-to-child Transmission of HIV
- RBC** : Rwanda Biomedical Center
- UK** : United Kingdom
- UNAIDS** : United Nations against HIV and AIDS
- US** : United States
- USA** : United States of America
- USAID** : United States of America for International Development
- WHO** : World Health Organization

LIST OF TABLES

Table 1: Socio-demographic characteristics of the study population

Table 2: Participation to support groups and age at disclosure

Table 3: Age at disclosure and year of enrollment into support groups

Table 4: Follow up of adherence to ART

Table 5: Reasons to attend HIV clinic compared to Socio-demographic characteristics

Table 6: Reasons to attend HIV clinic compared with age groups at disclosure and number of appointments at ART pharmacy

Table 7: Missed support group sessions compared to socio-demographic factors

Table 8: Missed support group sessions compared with the number of visits to HIV clinic per month

TABLE OF CONTENTS

Dedication	i
ACKNOWLEDGEMENT	ii
LIST OF ACRONYMS	iii
LIST OF TABLES	iv
TABLE OF CONTENT	v
EXECUTIVE SUMMARY	1
CHAPTER I. INTRODUCTION	4
1.1. BACKGROUND AND RATIONALE	4
1.2. DEFINITION OF CONCEPTS	5
1.2.1. HIV (human immunodeficiency virus)	5
1.2.2. ART (Anti-retroviral treatment).....	5
1.2.3. Adherence to care and treatment.....	5
1.2.4. Defining the support group	6
1.3. <i>PROBLEM STATEMENT</i>	6
1.4. <i>CHOICE AND INTEREST OF THE STUDY</i>	8
1.4.1. Personal interest	8
1.4.2. Scientific interest	8
1.5. <i>OBJECTIVES OF THE STUDY</i>	9
1.5.1. Main Objective.....	9
1.5.2. Specific Objectives	9
CHAPTER II. LITERATURE REVIEW	10
2.1. <i>WORLD SCALE AND DEVELOPED COUNTRIES</i>	10
2.2. <i>AFRICA</i>	11
2.3. <i>RWANDA</i>	12

2.3.1. Support group model as recommended by the national guideline on HIV and AIDS care and treatment.....	13
2.3.2. Organization of support groups	13
2.3.3. The role of the counselor:	14
2.3.4. The support group model from the HIV clinic of CHUK.....	14
2.4. LOGICAL FRAMEWORK.....	15
CHAPTER III. RESEARCH METHODOLOGY.....	16
3.1. RESEARCH DESIGN.....	16
3.2. POPULATION OF THE STUDY	16
3.3. CRITERIA OF EXCLUSION.....	16
3.4. SAMPLING	16
3.5. VARIABLES	16
3.5.1. Dependant variable	16
3.5.2. Independent variables	17
3.6. DATA COLLECTION AND ANALYSIS.....	17
3.7. ETHICAL CONSIDERATION.....	17
3.8. CONSTRAINTS AND LIMITATIONS TO THE STUDY	17
CHAPTER IV. RESULTS.....	19
4.1.1. Socio-demographic characteristics of the study population	19
4.1.2. Participation to support groups and adherence to care and treatment	20
4.2. BIVARIATE ANALYSIS.....	22
4.2.1. Reasons to attend the HIV clinic compared to Socio-demographic characteristics of the participants.....	22
4.2.2. Reasos to attend the clinic compared with the age at disclosure and number of missed appointments	23
4.2.3. Missed support groups sessions compared with socio-demographic factors	23
4.2.4. Comparison of missed support group sessions with the number of visits to HIV clinic per month	24

CHAPTER V. DISCUSSION.....	26
5.1. AGE.....	26
5.2. SEX.....	28
5.3. HAVING PARENT OR NOT.....	28
CHAPTER VI. CONCLUSION AND RECOMMENDATIONS.....	30
6.1. CONCLUSION.....	30
6.2. RECOMMENDATIONS.....	31
REFERENCES.....	34

ABSTRACT

This quantitative, cross-sectional study was carried out within pediatric HIV care and treatment clinic of CHUK, for a period of one year (From June 2011 to May 2012) focusing on *the contribution of support groups to adherence on care and treatment among HIV positive children aged between 7 and 15 years.*

It was conducted on a sample of 104 children. Data were collected from the clinic, using an anonymous questionnaire that was administered to participants.

Children were provided with a written informed consent form before using the questionnaire, children's parents and guardians signed it after reading and understanding it well.

Objectives of the study

Main Objective

To evaluate the contribution of support groups, to improving HIV positive children's health through a better adherence to care and treatment program within HIV clinic of the CHUK.

Specific objectives

- Measure the exposure of HIV positive children to support groups over 12 month;
- Analyze the adherence status of those children to care and treatment, especially considering the records related to their follow up over 12 months;
- Measure socio-demographic variables that led to success or failure of adherence on care and treatment program for HIV positive children.

Methodology

We have used an anonymous questionnaire to collect data. We also consulted medical files and different registers to complete our information on appointment keeping for pick-up of drugs, clinical and immunological data such as viral load measurements were also collected. Geographical, socio-demographic variables such as age, gender, education level and other relevant variables were also considered. After gathering all needed information, data entry was done through SPSS 16.0. The analysis was conducted according the above mentioned objectives. Pearson Chi-Square test was used to analyze frequencies of variables.

Results

The study was applied to 104 HIV positive children who attend support groups within the HIV/AIDS clinic of CHUK. According to our study results, 76.9% of them come regularly to the HIV clinic to pick their drugs and attend support group sessions. Regarding drug pick up, 86.5% didn't miss any appointment for the 12 months. Of 88.5% who were eligible for viral load measurement and for whom this laboratory test was done, 77.9% present a good outcome, which includes 44.2% of undetectable viral load and 34.7% of viral load below 1000 viral copies per ml among all regular support group members.

Conclusion and recommendations

The support groups are key for patient to have and maintain a good adherence on care and treatment of HIV and AIDS. The HIV positive children are more enthusiastic, collaborative, responsible and confident when taking drugs knowing the reasons and the importance of doing so and this is helpful for parents/guardians too.

Based on experience from CHUK, the Rwandan Ministry of Health through RBC, its partners and all concerned stakeholders should put more emphasis on psychosocial support program at all health facility levels.

For other researchers

- To extend the research in number of clinics, in both urban and rural areas, considering all ages of HIV positive patients and comparing clinics implementing support groups and those without this intervention;
- To explore and know the reason why psychosocial support interventions are not as considered as other HIV clinical services, while they consist a pillar of adherence to care and treatment.

CHAPTER I. INTRODUCTION

1.1. BACKGROUND AND RATIONALE

The human immunodeficiency virus (HIV) epidemic is affecting millions of men and women, adults and children around the world. Although tremendous efforts have been made to mitigate the problem in terms of prevention, care and treatment, an important part of the program is yet to be strengthened in order to improve HIV positive patients' lives.

Around 94% of these patients have access to ART [1], but treatment success does not depend only upon the fact of drug's availability, but also essentially depends on patients' adherence to that treatment. This requires a joint effort of both patient and care provider, so that like persons, patients can have a normal life where HIV is no longer a killing disease but a chronic one.

Regarding HIV positive children, most of them are infected from their mothers and managing their problems is difficult, especially when they are not aware of their HIV status. This affects negatively their adherence to care and treatment as well as their entire day-to-day life.

One of the good ways to help them is to provide all explanations related to HIV infection and treatment, but most importantly to support them as they go through disclosure process including affective and emotional support as well as regular follow up.

Considering that good adherence constitutes a pillar to sine qua none condition to care and treatment [1], the RBC/IHDPC has included in the HIV/AIDS care and treatment protocol, the psychosocial care and support program for HIV positive patients, particularly to support and maintain them with a good adherence to ART among other objectives.

Among the main components of the psychosocial support program for HIV positive patients, the support groups are the most helpful because they bring together many patients, where they support each other by exchange of life experience, so people can learn from each other how to avoid isolation, how to combat stigma and discrimination, etc; so that they can live normal life like other citizens.

1.2. DEFINITION OF CONCEPTS

1.2.1. HIV (human immunodeficiency virus):

It is the virus that causes acquired immunodeficiency syndrome (AIDS). This virus passes from one person to another through human blood and fluid, and by sexual contact. In addition, infected pregnant women can pass HIV to their baby during pregnancy or delivery, as well as through breast-feeding [1].

1.2.2. ART (Anti-retroviral treatment):

It is a combined treatment to mitigate HIV infection's magnitude on patients' health, helping to reduce the number viral numbers or viral load.

1.2.3. Adherence to care and treatment:

“One must know that most treatment failures are mostly due to poor adherence.”[2]

To adhere means to comply with the instructions and any other given guidance, advices and indications provided by qualified agent(s), health care providers in this case.

Some people may use this term to denote compliance or observance but the adherence is preferred because it gives people right to actively participate in the actual implementation of process.

In HIV care and treatment program, adherence is an informed respect of treatment prescription instructions given to the right patients, including the right times to take right drugs, and it includes the respect of diet restrictions, medical consultation and drug supply appointments, laboratory test schedules, follow up counseling including support groups.

Similarly, the World Health Organization mentions that adherence should not be limited to taking medications, but also encompasses numerous health-related behaviors that extend beyond taking prescribed pharmaceuticals. In addition, the term instructions may imply that the patients become a passive acquiescent recipient of an expert's advices, opposed to an active collaborator to the treatment process [3].

1.2.4. Defining the support group

If we disaggregate the word psychosocial into two parts, we will have the following:

Psycho: mind (unique feelings, thoughts, understanding and believes that an individual has on a given situation).

Social: Interpersonal relationships and anything that goes on in the natural environment.

The World Health Organization (WHO) defines psychosocial support for HIV positive persons as a process to address the ongoing psychological and social problems of HIV infected individuals, their partners, family members and caregivers. [3]

Support group in HIV services (definition and description):

A mechanism where people meet on regular basis, to listen each other, exchange life experiences and challenges, sharing difficulties' burden and different ways to mitigate those problems as well as lessons learned; in order to improve lives.

Within the HIV health services, the support groups are organized and conducted differently according to the nature and magnitude of the problems that people are facing (HIV positive persons, orphans, widows, etc), the age groups, sex, marital status, etc.

1.3. PROBLEM STATEMENT

According to UNAIDS report of 2008, globally 33.4 million (31.1 million–35.8 million) people were living with HIV as of 2008[4]; 2.1 million (1.2 million–2.9 million) of them were children under 15 years, and about 15.7 million (14.2 million–17.2 million) [4] were women. Every day, over 7,400 persons become infected with HIV and about 5,500 persons die from AIDS, mostly because of inadequate access to HIV prevention care and treatment services. Globally, AIDS-related illnesses remain one of the leading causes of death and are projected to continue as a significant global cause of premature mortality in the coming decades.[5]

In African continent, the sub-Saharan side is the most affected. Comparatively to people's age, HIV-infected infants frequently present with clinical symptoms in the first year of life [5]. Without effective treatment, an estimated one third of infected infants will have died by one year of age, and about half will have died by two years of age. While progress has been made in preventing

new HIV infections in infants and children, greater efforts are yet needed to effectively scale up preventive interventions as well as care and treatment.

Among the common obstacles these countries are facing are limited HIV screening and early diagnosis of children with previous history of HIV exposure, especially for children born to HIV positive women; the inability to diagnose HIV infection early in the lives of newborns and infants severely limits their ability to access ART as well as limited human resources at local hospitals to cater for the demand for HIV and AIDS treatment therapy. According to the World Health Organization, there is insufficient advocacy and understanding that ART is efficacious in children; limited local human and technological capacity to treat HIV in children; financial constraints hinder successful progression of programs aimed at HIV treatment.

Nowadays, HIV-infected infants and children can survive to adolescence and adulthood. This is a result of effort made by country governments in collaboration with some nongovernment organizations (NGOs) such as International HIV/AIDS Alliance; Clinton Foundation-HIV and AIDS initiative; Elizabeth Glazer Pediatric AIDS Foundation (EGPAF); African Network for the Care of Children Affected by AIDS (ANECCA); Baylor International Pediatric AIDS Initiative, etc [6].

However, a significant gap is remaining through developing world; approximately 180,000 children in Kenya are living with HIV, and slightly more than 40,000 children are the only ones having access to ART. Most of these children have been infected all of their lives through mother-to-child transmission, yet parents and caregivers in Kenya often do not tell their children that they are HIV-positive until they reach adolescence [7].

The Government of Rwanda (GOR) has made a tremendous effort to address this issue, together with the support of the donors and implementing partners, to prevent and treat HIV infection and AIDS illness. Enrollment into care and treatment program have been initiated in 2003 and progressively increased over the time, and currently all patients in need can have access to treatment. Although significant progress was achieved in HIV/AIDS prevention, care and treatment interventions, remarkable gap is still present; a number of children enrolled is far lower (9%) comparing with the adults (91%) [8] from the beginning of the program to date and this means that a pathway is still long to achieve suitable objective.

Furthermore, the adherence problem exists in children and adults. We still observe a number of patients with far low adherence rate and high viral load, numerous lost to follow up cases, dropout and abandons. Among the main reasons for this issue is a lack of accurate care and support services, especially the support groups as well as enough and qualified human resources to implement them. This is the key component of HIV positive children's care, in addition to disclosure process which is the starting point for psychosocial care, and it comes to support children emotionally and providing clear information that help them to positive living, including adherence to HIV care and treatment.

When parents and caregivers fail to talk to children and tell them about their HIV status, it hinders children who normally are willing to be part of their care and treatment plan and implementation. Delaying disclosure can confuse children and leave them with feelings of isolation, mistrust, and anger against their parents or guardians once their diagnosis is known. Many children report feeling relieved once they are told their diagnosis, and most express the wish to have been told earlier [9]. To ease the difficulty of disclosure to children, it is essential to view disclosure as an ongoing process rather than a one-time event. A child's age and developmental status, as well as a variety of family factors, should drive the process.

Research question

Do support groups contribute to adherence on care treatment among HIV positive children?

1.4. CHOICE AND INTEREST OF THE STUDY

1.4.1. Personal interest

Our personal experience as health professional, the research in HIV and AIDS is of great importance. The children constitute a group of people who become vulnerable to HIV infection without any kind of responsibility or risk behavior. Moreover, in the recently past years children were not fully touched by care and treatment programs. Our Personal interest of this study was to put more emphasis on HIV positive children, focusing on importance of using support groups to help them adhering on care and treatment program.

1.4.2. Scientific interest

When children take medicines without knowing why they are taking them, they are likely to refuse or abandon their treatment. In addition, we know that support groups constitute one of the ways to educate children on HIV and AIDS, OI as well as respective drugs including why and how they are taken. Therefore, we wanted to assess and document the added value of these support groups on HIV care and treatment program among HIV positive children enrolled and followed up within the HIV clinic of CHUK; so that we can contribute to improving the stated program around the country and beyond.

1.5. OBJECTIVES OF THE STUDY

1.5.1. Main Objective

Evaluate the contribution of support groups, as part of general psychosocial, to improving HIV positive children's health through a better adherence to care and treatment program within HIV clinic of CHUK.

1.5.2. Specific objectives

- Measure the exposure of HIV positive children to support groups over 12 month period (June 2011-May 2012);
- Analyze the adherence status of those HIV positive children to care and treatment, especially considering the records related to their follow up over 12 months;
- Measure socio-demographic variables that led to success or failure of adherence on care and treatment program for HIV positive children.

CHAPTER II. LITERATURE REVIEW

2.1. WORLD SCALE AND DEVELOPED COUNTRIES

Psychosocial care and support for HIV positive children is recognized as an important part of HIV program interventions, complementing the medical treatment. This synergy comes to enhance holistic approach to patient treatment, care and support, to support ART adherence and help achieve clinical goals. In addition, interventions should be tailored to the patients' needs as much as possible, focusing to the specific situation of the child (based on development stage, disease presentation, and home/family circumstances) and adapted over time as the child matures and his or her needs evolve [9]. Support groups and individualized counseling are critical approaches for helping children in process with difficult feelings and experiences, as well as build skills to fend off internalized stigma. Programs also highlighted having consistent, positive messaging on HIV (e.g., that it is not a death sentence, that children can lead normal lives and should plan for their future) as being crucial to ensuring a confident, hopeful child; such messaging should be reinforced by all influential individuals in the child's immediate sphere [9].

Worldwide, roughly 17.5 million (14.6 million–20.9 million) children under the age of 18 have lost one or both parents due to AIDS, and more millions have been affected, with a vastly increased risk of poverty, homelessness, school dropout, discrimination and loss of life opportunities. These hardships include illness and death. Of the estimated 2 million (1.7 million–2.4 million) people who died of AIDS-related illnesses in 2008, 280,000 (150,000–410,000) them were children under 15 years old [10]. There is no cure for HIV infection. However, early infant diagnosis is critical. When ART is administered as early as possible in the course of infection, it can help children living with HIV lead longer, healthier lives, and among the strategies to tackle this issue is the ART supported by psychosocial support care [11].

Although support groups can help children have a better adherence to ART and live positively with HIV, barriers also exist, either related to the patients' day-to-day life or to the health system; that lead to numerous obstacles to adherence on treatment. A study conducted by the Department of Neurosciences, University of California, San Diego, La Jolla, California among 120 children of average age of 12.8 years has shown that the most frequently reported barrier by either the

caregiver or youth was “forgot.” There were varying degrees of agreement between child and caregiver on the following barriers: “forgot,” “taste,” “child was away from home,” “child refused,” and “child felt good.” Children who knew their HIV status were more likely to report logistical barriers, such as scheduling issues. Children with a biological parent as their caregiver were more likely to report regimen problems or fear of disclosure as a barrier [12].

2.2. AFRICA

The Sub-Saharan Africa remains the region most heavily affected by HIV. Psychosocial support care is important for all programs that provide treatment, care, and support for children living with HIV and their families, including those that focus on clinical management of pediatric HIV (e.g., ART programs, and palliative care programs) and others that prioritize support for orphans and vulnerable children. Among these challenges of operating in high HIV prevalence and resource-constrained settings, programs in South Africa and Uganda are incorporating promising practices within the way they structure and deliver psychosocial support services. Those practices include: 1) addressing basic household needs and; 2) expanding the continuum of care services [13].

In Mozambique, a prospective cohort of 122 HIV-infected children commenced on ART, adherence was measured monthly during the first year of treatment by medication return (MR) for both syrups and tablets/capsules [14]. The same study was also conducted in Cape Town, South Africa demonstrated evidence that excellent adherence to ART is possible in African infants and young children and the relatively simple low technology measure of adherence by MR strongly predicts viral response. Better socio-economic status and more palatable regimens are associated with better adherence [15].

Approximately 180,000 children in Kenya are living with HIV, and slightly more than 40,000 children are the only ones having access to ART. Most of these children have been infected all of their lives through mother-to-child transmission, yet parents and caregivers in Kenya often do not tell their children that they are HIV-positive until they reach adolescence [16].

In Uganda, a qualitative study conducted, examining HIV serostatus and treatment disclosure practices and findings reinforce the idea that HIV disclosure is a process, not a one-time event.

Interviewees do always anticipate both positive and negative outcomes of disclosure, including financial and emotional support, stigma, discrimination and rejection [17].

2.3. RWANDA

In Rwanda, where prevalence of HIV infection is 3% according to DHS 2005 and DHS 2010 [18], since 1983 when the first case of HIV has been discovered, there was no way to manage such problem. The program to prevent and treat HIV infection and AIDS illnesses started slowly in 2003 in CHUK with support of ESTHR project and was scaled up since 2004, HIV and AIDS program supported by PEPFAR, Global Fund and other donors till present, where HIV service coverage is 430 sites [19].

Over the time, enrollment into care and treatment program have been progressively increased; the epidemiological update on HIV in Rwanda showed that adult number was increased from 8,815 in 2004 to 114,995 in 2012 whereas in children the number has augmented from 468 in 2004 to 8,880 in 2012 [19]. This raise of number was result of the great effort and emphasis that the Government of Rwanda (GOR) has put in the area of HIV prevention, care and treatment together with its different stakeholders including donors and implementing partners. The National Prevention of Mother-to-Child Transmission (PMTCT) program has significantly contributed to reduce the number of new HIV infections, and its current strategy aims the elimination of Mother-to-Child Transmission (EMTCT). The purpose of this strategy is to reduce the new HIV infection to 2% and below. As obvious, those who unfortunately become HIV positive are timely enrolled into care and treatment program and are regularly followed up to enhance their adherence to ART.

Whereas these strategies have been used in a variety of settings to improve adherence rates, none has proved effective by its self in all settings, and the most effective interventions have been complex in nature, labor intensive, and costly to the health-care system. Because adherence is determined by multiple factors, a multifaceted approach to enhance adherence is encouraged. Current strategies advocated by WHO to achieve high levels of adherence to ART in resource-limited settings focus on patient education through counseling, enhancing caregiver support by encouraging treatment “buddies,” and disclosure to other trusted members of patients’ networks [20]. Support groups and individualized counseling are among critical and proven approaches for helping process for children with difficult feelings and experiences, as well as build skills to fend

off internalized stigma: “*My counselor helped me see that whatever they said, I had the power to take it or not, let it affect my life or not*” (youth in Uganda).

The Rwandan pediatric guidelines on HIV and AIDS care and treatment advise disclosing a child’s HIV-positive status when the child is seven to eight years-old using a visual tool with cartoon drawings, which has been developed specifically for children, to provide them with information on the HIV, OIs and other related diseases, the ART including its importance in their body as well as adherence to this treatment.

2.3.1. Support group model as recommended by the national guideline on HIV and AIDS care and treatment

The support groups are implemented to support adherence of patients to ART. The importance of the support groups is to facilitate interpersonal relationships; to help group members or participants to have a better understanding of HIV and AIDS as well as other related infections such as opportunistic infections (OIs) and sexual transmitted infections (STIs), to understand the ART including its advantages and the potential side effects of ARVs and how they may be managed as well as how good they should behave as living with HIV; to allow them know themselves become more affirmative (have the self-esteem) and more responsible for their own decisions.

Support groups help them become more expressive and open to others; to permit each participant to share his/her own experiences so that they can support each other and avoid isolation and stigma.

2.3.2. Organization of support groups

Aspects to cover during group counseling session are the following and not limited to:

- Ensure free consent of each and every participant;
- Constitute groups: group patients with similar problems and in the same categories;
- Respect the rhythm, the choice and the personality of each participant;
- Establish group norms: (punctuality, confidentiality, mutual respect, timing, etc).

2.3.3. The role of the counselor:

The counselor's role is to guide the discussion, according to the selected topic and helping participants to respect the pre-established regulations, to facilitate the group interactions, to help clients get answers to different questions they may have, to support participants emotionally or according to any other situation as well as to stimulate the participation of everyone as appropriate.

2.3.4. The support group model from the HIV clinic of CHUK

The idea of support group establishment came in March 2003, with a cohort of 40 patients, including 32 adults and 8 children, and the clinic began its interventions in Kigali University Teaching Hospital (CHUK). The first support group of HIV positive children was formed in 2005 with 24 children. The total number of enrolled active children at time of our first contact to the HIV clinic of CHUK was 476 and was disaggregated into 3 support groups of children.

Those children are distributed in support groups according to their group ages as follows:

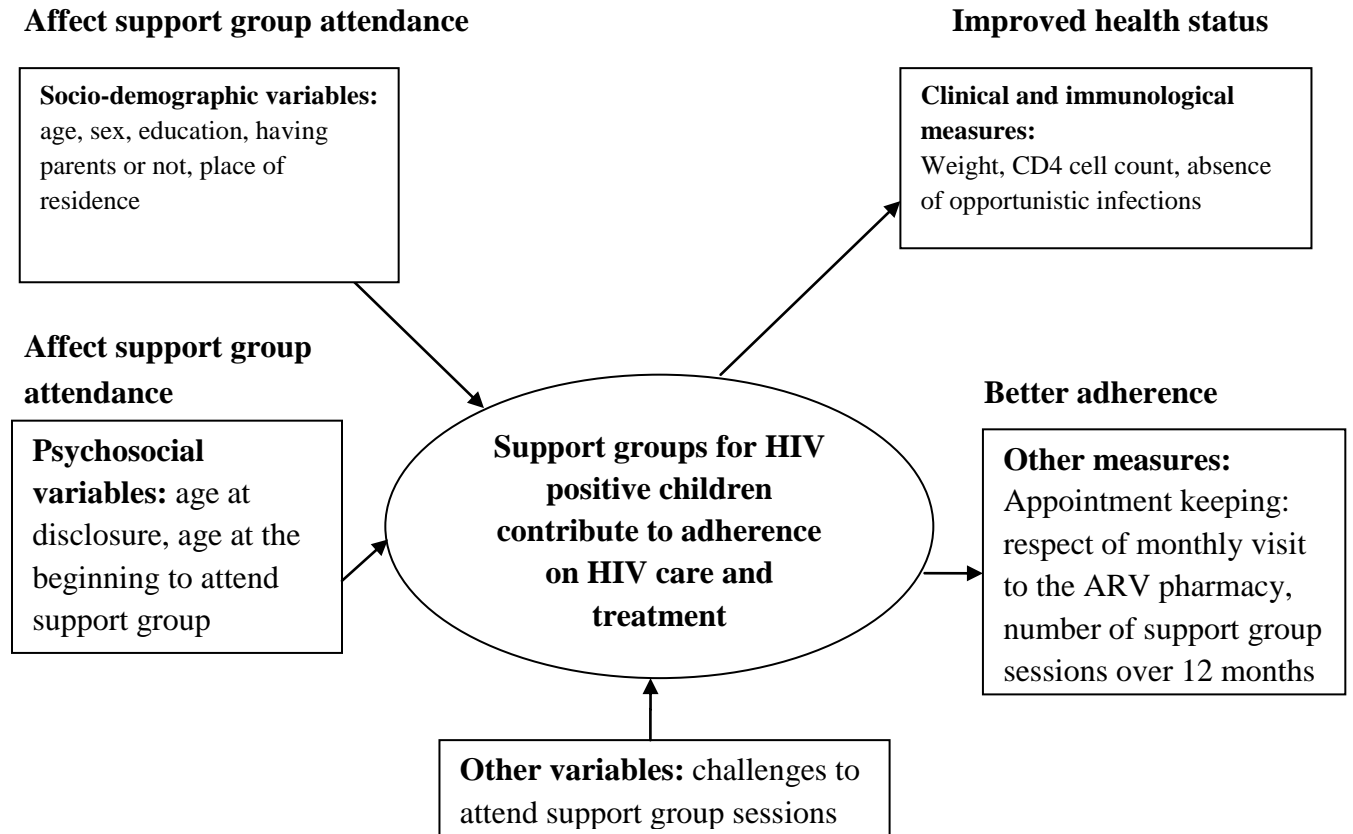
- Group 1: 7 to 12 years: 80 (46 boys and 34 girls);
- Group 2: 13 to 15 years: 53 (28 boys and 25 girls); and

The 3rd and 4th groups are composed by the adolescents and are in transition, moving from pediatric to adult treatment department.

These groups meet on monthly basis, one after another, mostly on Saturdays, because the normal working days are busy with high workload that cannot allow care providers enough time to facilitate those groups, and also because the children attend schools during the week.

2.4. LOGICAL FRAMEWORK

The following logical framework was designed to summarize the above provided information, showing the cause-of-effect relationship between the different variables of the study, and how they influence positively or negatively the contribution of support groups for HIV positive to adherence on HIV care and treatment.



CHAPTER III. RESEARCH METHODOLOGY

3.1. RESEARCH DESIGN

This is a quantitative, cross-sectional study.

3.2. POPULATION OF THE STUDY

This study is focused on HIV positive children followed in support groups as component of the national psychosocial support care program and in support groups. The study was conducted among 104 HIV positive children (62 girls and 42 boys), who are followed in care and treatment program in the HIV clinic of CHUK over the last 12 months. They are aged between 7 and 15 years and subdivided into two age groups: group 1 composed by 55 children, aged between 7 and 12 years and group 2 that is composed by 49 children, aged between 13 and 15 years.

3.3. CRITERIA OF EXCLUSION

The children aged below 7 years old and those who are above 15 years were not be considered. Those who were not yet enrolled in June 2011 and those who don't participate in support groups were not part of our study. Because of limited capacity of the researcher, the study could not be able to consider children living with disabilities.

3.4. SAMPLING

Considering the size of the study population, the entire number of children followed into support groups and meeting the above mentioned criteria was considered.

3.5. VARIABLES

3.5.1. Dependant variable

Support groups well conducted for HIV positive children, contribute to their good adherence on care and treatment program.

3.5.2. Independent variables

The following independent variables have been leveraged:

Socio-demographic variables:

- 1) Age (consider age-groups), 2) Sex, 3) Attending school or not, 4) having parents or not, 5) parents/guardians were educated or not.

HIV program related variables:

- 6) Age at disclosure, 7) children know the reasons why they attend the clinic every month or not, 8) Number of visits to the clinic every month, 9) Appointment keeping (consider monthly visit to ARV pharmacy and see how many missed appointments per month), 10) Viral Load (VL) measurements (how many children have undetectable and how many have detectable VL).

3.6. DATA COLLECTION AND ANALYSIS

The data collection was processed using an anonymous questionnaire for participants. Additional patients' information was obtained through the review of patient files. Quantitative data collected were entered and analyzed under SPSS 16.0 software. The Pearson Chi-square test was also used to test the colleration between the different tested variables as mentioned within the chapter of study results.

3.7. ETHICAL CONSIDERATION

Prior to conduct the data collection, we requested for approval of our study by ethics committee of CHUK and we obtained it. The informed consent was also obtained from all children's parents and guardians, who signed it after reading and understanding it well, and the confidentiality was respected. In that order, numerical identification was used, to keep the questionnaire anonymous enough.

3.8. CONSTRAINTS AND LIMITATIONS TO THE STUDY

The comprehensive psychosocial support to enhance adherence to care and treatment is an important topic that could interest broader research perspectives.

For the financial reasons and time constraints, the current research could realize such achievement, the reason why it was only focused on the support groups as one of the main psychosocial support

program components. Because of this constraint, the research was conducted in only one health facility as there was no capability to compare with others and in different ways.

A population of 104 participants is too small to come up with findings that inform decision making. An example is that all children covered by our study adhere to ART at around 80%. This confirms our statement that *support groups contribute to adherence on care and treatment*, but with limitation to the validity of the study because we could not show the other aspects of the psychosocial support program. Our first objective was to be able to conduct a comparative study, targeting as many health facilities as possible, making a comparison between health facilities where support groups sessions are conducted and those where the services is not offered, conclude on the findings and make recommendations.

We could not even make comparison of HIV positive children enrolled into support groups from both urban and rural areas, or those from urban area but from more than one health facility. Finally the current research was conducted among HIV positive children aged between 7 and 15 years, followed in the HIV clinic of CHUK; by looking at implementation of support groups and gathering information about children's experience on that intervention and then we formulated the recommendations.

CHAPTER IV: RESULTS

4.1. DESCRIPTIVE ANALYSIS

4.1.1. Socio-demographic characteristics of the study population

To begin with, this is the descriptive presentation de of the study population. The study population is composed by HIV positive children, aged between 7 and 15 years. Their total number is 104, including 62 females (59.6%) and 42 males (40.6%). Of them 45.2% have both parents, 16.3% have fathers only, 26% have mothers only and 12.5% are totally orphans. A percentage of 77.7% attend school regularly and most of them perform well, 21.1% of them attend school irregularly (with some absences) and only 1% doesn't go to school (has dropped). Among them, 85.6% have their parents/guardians educated and 14.4% have parents/guardians who are not educated. The illustration is with the following table.

Table 1: Socio-demographic characteristics of the study population

Variables	N	%
Sex	N=104	
Male	42	40.4
Female	62	59.6
Age groups	N=104	
7-12 years	55	52.9
13-15 years	49	47.1
Have parents or not	N=104	
Have both parents	47	45.2
Have father only	17	16.3
Have mother only	27	26
Orphans for both parents	13	12.5
Attending school	N=104	
Regularly	81	77.9
With some absences	22	21.1
I have dropped	1	1
Parents/guardians educated	N=104	
Yes	89	85.6
No	15	14.4

4.1.2. Participation to support groups and adherence to care and treatment

a) Support groups

From our findings, 78.8% of participants know the reason why they attend the HIV clinic and 21.2% did not know it or were hesitating. We also obtained some results on the reasons given by the participants for them to attend the HIV clinic as detailed with the following table.

Table 2: Participation to support groups and reasons to attend

Variables	N	%
Know why attend clinic every month	N=104	
Yes	82	78.8
No	22	21.2
The reasons to attend the clinic	N=104	
Because I have HIV	45	43.3
To learn how take well my drugs	32	30.8
To play with others	1	1
I don't know	3	2.9
N/A	22	21.2
Other	1	1

With the following table, as continuity of support groups, we have the information regarding the age groups of the children when they have gone through the disclosure process, the time for enrollment into support groups. The results show that 67.3% of them were aged between six and eight years, while 32.7% were aged between nine and eleven years.

Table 3: Age groups at disclosure and enrollment into support groups

Variables	N	%
Age groups	N= 104	
6-8 years	70	67.3
9-11 years	34	32.7

b) Adherence to care and treatment

Our study found that during the period of 12 months, 76.9% have to visit the clinic for one to two times a month, while 13.5% came for more than two times a month, especially when they were sick. Of them, 9.6% do not remember how many times they have to come to the clinic per month. Regarding the missed appointment on ARV pharmacy, 86.5% did not miss any appointment during the 12 month period, whereas 13.5% have missed one to two appointments.

Concerning the viral load measurement, the results showed that 77.9% of patients have viral suppression below 1000 viral copies and 22.1% have viral load measured as above 1000 copies. This last result is a condition to review the entire treatment plan including change of ARV regimen. The following table is showing what is above mentioned.

Table 4: Follow up of adherence to ART

Variables	N	%
Number of visits at the HIV clinic per month	N=104	
1-2 times	80	76.9
More than two times	14	13.5
Don't know/don't remember	10	9.6
Missed appointments to ARV pharmacy per month	N=104	
0	90	86.5
1-2 times	14	13.5
VL results (presented into groups)	N=104	
Undetectable VL (less than 40 copies/ml)	46	44.2
Between 41 and 1000 copies/ml (accepted as VL suppression too)	35	33.7
VL above 1000 copies/ml (considered as detectable VL)	23	22.1

4.2. BIVARIATE ANALYSIS

4.2.1. Reasons to attend HIV clinic compared to Socio-demographic characteristics of participants

The following table shows the importance of considering the ages while taking care of HIV positive children. It is also to highlight a very significant P-value (P-value = 0.000) when looking at the ages of the children and whether they know or not why they attend the HIV clinic every month. Considering the age groups to illustrate this, we find the group aged between 13 and 15 years to be the one knowing very well the reason why they attend the clinic every month (93.9%), while the one aged between 7-12 years to know it at (34.5%).

However, we have found the children having both parents not to have a considerable percentage of those who don't know the reason why they attend the clinic (34.0%) while those of them who are totally orphans all (100%) know that reason. Having educated parents was seen as important aspect: of those who have educated parents, 66% knew why they were attending the HIV clinic while 33% didn't know that reason. Those of them who have non educated parents were minority (N=14) but most of them knew that reason (93.3%).

Table 5: Reasons to attend HIV clinic compared to Socio-demographic characteristics

Socio-demographic variables	Know why attending the clinic every month		Chi2	P-Value
Sex	Yes	No	0.003	0.955
Male	33 (78.6%)	9 (21.4%)		
Female	49 (79.0%)	13 (21.0%)		
Age groups	Yes	No	12.551	0.000
7-12 years	36 (65.5%)	19 (34.5%)		
13-15 years	46 (93.9%)	3 (6.1%)		
Have parents	Yes	No	9.718	0.021
Have both parents	31 (66.0%)	16 (34.0%)		
Have father only	15 (88.2)	2 (11.8%)		
Have mother only	23 (85.2%)	4 (14.8%)		
Orphans for both parents	13 (100%)	0 (0%)		
Parent/guardian educated	Yes	No	2.206	0.138
Yes	68 (76.4%)	21 (23.6%)		
No	14 (93.3%)	1 (6.7%)		

4.2.2. Reasons to attend the clinic compared with the age at disclosure and number of missed appointments

Comparing the age groups at disclosure and the number of missed appointment to ART pharmacy, we found that 65.7% of those aged between six and eight years at disclosure to know why they attend the clinic every month and 34.3% do not know that reason. The P-value is very significant on this variable (P-value = 0.000). Regarding the second age group (aged between nine and eleven years), they know that reason at 97.1% and only 2.9% do not know that reason. Regardless of the age groups, among those who have not missed any appointment to art pharmacy, 81.1% know the reasons to attend the HIV clinic, while 18.9% do not know that reason.

Table 6: Reasons to attend HIV clinic compared with age groups at disclosure and number of missed appointments at ART pharmacy

Variables	To know why attending HIV clinic every month		Chi2	P-value
	Yes	No		
Age groups at disclosure			12.313	0.000
6-8 years	46 (65.7%)	24 (34.3%)		
9-11 years	33 (97.1%)	1 (2.9%)		
Number of missed appointments	Yes	No	2.056	0.152
0	73 (81.1%)	17 (18.9%)		
1-2	9 (64.3%)	5 (35.7%)		

4.2.3. Missed support groups sessions compared with socio-demographic factors

The following table is showing a slight difference when comparing sex disaggregation and the fact of missing any support group sessions, female were found to have missed fewer sessions than male. Considering the age groups, we curiously found the younger children to have missed fewer sessions than older. For those having parents or not and those attending school or not we found no difference either. And consequently there is no P-value signification.

Table 7: Missed support group sessions compared with socio-demographic factors

Variables	Missed support group sessions between June 2011 and May 2012		Chi2	P-value
	Yes	No		
Sex			5.005	0.025
Male	27 (64.3%)	15 (35.7%)		
Female	26 (41.9%)	36 (58.1%)		
Age groups			5.613	0.018
7-12 years	22 (40%)	33 (60%)		
13-15 years	31 (63.3%)	18 (36.7%)		
Have parents			0.156	0.984
Have both parents	23 (48.9%)	24 (51.1%)		
Have father only	9 (52.9%)	8 (47.1%)		
Have mother only	14 (51.9%)	13 (48.1%)		
Orphans for both parents	7 (53.8%)	6 (46.2%)		
Attend school			1.801	0.406
Regularly	39 (48.1%)	42 (51.9%)		
With some absences	13 (59.1%)	9(40.9%)		
I have dropped	1 (100%)	0 (0%)		

4.2.4. Comparison of missed support group sessions with the number of visits to HIV clinic per month

According to the table below, when we observe the impact of having to attend HIV clinic and the missed sessions to support groups, we found a big difference between those attending for one to two times and those attending for more than two times a month. However, among those who attend for one to two times, a slight difference was highlighted regarding the issue of missing support group sessions or not. Among those who attend the clinic for more than two times, only 28.6% do not miss their support group sessions. The third category is composed by those who do not know or do not remember how many times they have to go to the clinic. Also here the P-value is not significant (P-value = 0.255).

Table 8: Missed support group sessions compared with the number of visits to HIV clinic per month

Variables	Missed support group sessions between June 2011 and May 2012		Chi2	P-value
	Yes	No		
Number of visits to the HIV clinic per month			2.734	0.255
1-2 times	38 (47.5%)	42 (52.5%)		
More than 2 times	10 (71.4%)	4 (28.6%)		
Don't know/remember	5 (50%)	5 (50%)		

CHAPTER V. DISCUSSION

The descriptive analysis characterizes the study population as being composed 104 individuals. As in most of all populations in Rwanda, the number of females is greater than males {62 (59.6%) versus 42 (40.4%)}. Among them, 12.5% are orphans while others have at least one parent. Of them, 77.9% attend school regularly, 21.1% have some absences at school and only 1% has dropped out. All of them had had completed the disclosure process at the age of 11 years, with subdivision of age groups of six to eight (6-8 years) for one group and from nine to eleven (9-11 years) for the second group of age at disclosure.

Furthermore, through the bivariate analysis, we have used the Pearson Chi square test, to identify association between different variables of our study, and then we found that not all variables are associated with the implementation of support groups, to enhance adherence to care and treatment. Among the factors that influence that association ($P\text{-value} \leq 0.05$), the age (especially age at disclosure), sex and the fact of having parents or being orphans to be associated with the implementation of support groups.

5.1. AGE

Participants who were aged between seven and twelve (7-12 years) were likely to have less knowledge of the reasons to attend the HIV clinic; those who responded as don't know that reason were at 34.5% (65.5% know that reason) whereas the same response (don't know the reason to attend the HIV clinic) for those aged between 13-15 years is at 6.1%; which means that they know that reason at 93.9%. Here we have a very strong association and the $P\text{-value} = 0.000$. Regarding the age at disclosure; the same analysis has found that those who have disclosed very early (the guidance says the disclosure has to be conducted at age of seven to eight; [1] and the first age group in our study is between six and eight), are likely to have less information than those who disclosed at age of 9-11 years why on the reason they come to the HIV clinic every month. The first group know that reason at 65.7% while the second knew that reason at 97.1%.
 $P\text{-value} = 0.000$.

These findings match with the formative study conducted in the US on “the role of disclosure in relation to assent to participate in HIV-related research among HIV-infected youth” [20].

The age at the beginning of disclosure process is important because it helps children having enough information regarding the HIV status, accepting it and being part of their own day-to-day life including care and treatment plan and implementation.

Moreover, a study conducted by the Department of Neurosciences, University of California, San Diego, La Jolla, California [12] has shown that when the ethical barriers including stigma and discrimination are removed (through a timely disclosure process), children can communicate easily between their parents/guardians, as well as the caregivers; children themselves are responsible of their own treatment plan implementation. Per this study, children with an average age of 12 years used to report that parents/caregivers have forgotten as reasons for not have taken their ARVs and the same study has revealed these children to be among those who didn't have a good disclosure process.

In Africa setting, this leads us to highlight the WHO recommendation to achieve high levels of adherence to ART in resource-limited settings, focusing on patient education through counseling, enhancing caregiver support by encouraging treatment “buddies,” and disclosure to other trusted members of patients' networks [20].

Another qualitative study conducted in Uganda in 2009, has expressed the importance of the disclosure process that is conducted at the age that children are able to understand, share living experience of HIV and AIDS, and then contribute to their day-to-day treatment. The disclosure process should be introduced at the age of 7-8 years old [16]. This statement also is in convergence with the Rwandan guidance on comprehensive care and treatment for persons infected with HIV and AIDS [1], indicating that disclosure process should be initiated at the age of 7-8 years and this what is in current practice across all health facilities that can offer support group sessions.

The same statement was also affirmed by children's parents—this information was provided to us by the caregivers during our interview with them. For the children's parents/guardians, the support groups came as response to remove the burden of numerous questions they were asked by their children; and some of these questions were humiliating vis-à-vis their children. For others it was

not a matter of humiliation but it was emotionally hard to express themselves to the children, especially when they hard to explain children how they were born with infected by HIV.

Through support groups, there is a way to provide detailed explanations to children regarding this, provide enough information on HIV and AIDS as well as the care and treatment practices. The provision of information removes the fear and anxiety, stigma and discrimination which frequently result in unstopped conflicts with their parents/guardians. It also makes them confident, and in their return, they understand their reason to continue normally their day-to-day life. Therefore, they feel responsible and accountable for their own treatment plan and implementation, which make them courageous and believe in a better future.

5.2. SEX

The sex has an influence of having a bigger number of girls than boys and it was shown as associated with the attendance to support groups, the boys tends to have missed more support groups sessions than girls, with a slight signification of P-value. (P-value = 0.025). However, when looking at the variable of knowing the reason to attendance the HIV clinic, we find no difference other than just having a bigger number of girls than boys; P-value = 0.955 (not significant) because although that difference in effective number exists, the percentage was found same for girls and boys regarding those who know the reason to attend the HIV clinic or not. This goes together with our experience in HIV care and treatment in general, because even in adult HIV positive patients, we find a greater number of women than men seeking health care services, responding to guidance, etc.

5.3. HAVING PARENTS OR NOT

Being orphan is a big challenge in children's life; in addition to be living with HIV becomes a serious burden to their day-to-day existence and activities. Our study has shown 66.0% to know why they attend the HIV clinic and 34.0% don't know that reason. Of our participants, only 13 out of 104 are totally orphans but surprisingly they are ones who knew at 100% the reason why they go to the HIV clinic every month. P-value = 0.021.

This experience is in accordance with the findings from a set of abstracts put together by Save the Children UK from several African countries, e.g. Malawi, Uganda, Tanzania, Zimbabwe, Botswana, Mozambique, South Africa, etc in “Growing up with HIV in Africa” [31]. According to these findings, there is a growing body of literature that suggests that children who are orphaned and also HIV sero-positive experience psycho-social distress and significant challenges to their well-being.

However, another study has shown that children can continue their normal life even with HIV and being orphans. This is with support of *coping strategies*, which consist in the ability to find, even in a new and unusual situation, an appropriate reaction to the challenges one is facing. It is defined as cognitive and behavioral efforts responding to specific stresses that exceed the usual capabilities or resources of a person [32]. These results are confirmed with our study findings, where we found children to have only one parent or no parent to have a lower number of participants who don't know the reasons why they attend the HIV clinic every month. Those who don't have any of both parents were the ones knew those reasons at 100%.

Considering all of these parameters, we articulate that a good HIV care and treatment have to be always associated with the psychosocial support program. The caregivers evaluate everyone's readiness to go through the disclosure process and join the support groups. In addition, there is a national guideline for psychosocial support program to support adherence to ART, as part of the national protocol for HIV and AIDS care and treatment in Rwanda [1]. The HIV clinic work hand in hand for to share responsibilities and provide complementary and continued care and support for HIV positive children.

As a final say to the results of our research, this brings us to a confirmation of our statement that *“the support groups contribute to enhance adherence to care and treatment among HIV positive children aged between 7 and 15 years”*.

CHAPTER VI. CONCLUSION AND RECOMMENDATIONS

6.1. CONCLUSION

Support groups are among the key strategies for a good adherence to care and treatment for HIV positive adults and children. Particularly, children who are enrolled into support groups have opportunity to learn new life skills, including reproductive health and also to know more about HIV and AIDS, including its prevention and treatment as well. Children can participate in their treatment plan and implementation.

Both parents and children like the support group program, in such a way that children understand they can leave a normal life like others and invest for a better future. Parents find support groups as an easy way to help children know what happened to them, support them to go through disclosure process and respond to numerous questions asked by children about how they have acquired the HIV, who is responsible for the infection and also about their future. On the clinic's side, especially regarding the adherence to HIV care and treatment, the health care providers find easy to work with children who are in support groups more than those who are not; the reason why the support group model is recommended to other health clinic where it is not currently implemented.

However, the children still have a number of questions regarding their future life, including when curative treatment will be available, when they will finish taking ARVs, whether they will go to university and finish their studies, etc.

Therefore, children have made some recommendations, including reinforced follow up that goes until their homes, clinics would work with their parents/guardians to provide them with more and detailed explanations about their children's life style and how they can support them better.

6.2. RECOMMENDATIONS

The findings from our study on *the contribution of support groups on adherence to care and treatment among HIV positive children aged between 7 and 15 years*, allow us to confirm the statement. Some of the positive points are highlighted, including easing 1) the disclosure process

for both parents and care providers but also for children; 2) support groups constitute a learning process for children and parents; 3) children can share life experience and support each other; 4) they understand the magnitude of having HIV, the importance of a lifelong treatment; 5) children can assume their responsibilities regarding their treatment plan supported by their parents/guardians; 6) generally, from the clinic's records, children have good treatment response and this constitute success for the health facility as well as for the health system in general.

However, there are also areas of revisiting the model, including the 1) teaching materials that are not well adapted to Rwanda context and culture; 2) support groups sessions are conducted during the week ends because during working days care providers are busy with other health service provision activities but this obliges children to come for may times a month. This bring us to the fact that generally speaking the psychosocial support care is not given enough weight from the health care services “just people think about it after everything else is fine or when patients have psychosocial problems specifically”. Because of this, care providers are not given enough time to this service that was proven to be an extreme importance; 3) the model should include enough time for parents/guardians, to empower them with skills and necessary support so that in their return they can be more supportive to the children while outside the clinic.

Therefore, our recommendations would be directed to different entities and persons as follows:

a) To MOH and RBC:

- Our research found the support group program to be a key for good adherence to HIV care and treatment and people living with HIV appreciate it, especially children and their parents/guardians. We therefore recommend its reinforcement and extension to national level as it is only working well in some health facilities;
- Review the teaching materials and to accommodate the needs of children living with disabilities (example: during the course of our study, one of the study population was among those living with disabilities and it was not very easy to work with him);
- Find strategies to increase HIV/AIDS care and support budget, for the health facilities to be responsive to specific needs of children, including some of them who cannot always find transportation fees.

b) To CHUK and other health facilities:

- Reinforce the program in a way to be more supportive to specific cases that require special attention, including those in need of home visit, people living with disabilities in addition to HIV;
- Each health facility should be able to provide psychosocial support for HIV positive patients, especially for children in order to facilitate and maintain good adherence to care and treatment;
- Review the organization of the clinic, to accommodate the support groups sessions within the normal working days, instead of conducting them during the week ends.

c) To children's families:

- HIV positive children are like any other children in terms of day-to-day life but also need more attention than others because of their fragility of HIV living body. We thereby encourage families (parents/guardians) to be more responsible and supportive to their children and help them to adhere to care and treatment program, and also work closely with health care givers at health facilities anytime they have concerns or do not understand anything; in order to improve children's life.

d) To other stakeholders:

- Some organizations including NGOs and civil society organizations have in their strategies to support children in need including orphans and vulnerable children, and HIV positive children are among them. We are strongly recommending them to support them especially help find school fees and materials, so that HIV positive children can dream their future like others.

e) To other researchers:

- To extend research to more than one clinic, considering all ages of HIV positive patients and comparing clinics implementing support groups and those without this intervention; and then present the results;
- To explore and know the reason why psychosocial support interventions are not as considered as other HIV clinical services, while they consist a pillar of adherence to care and treatment;

- Many people including our study population ask questions about curative treatment of HIV. We therefore encourage researchers to investigate more about that topic and find out whether this is something that people can believe and be expecting for the future and what is being done nowadays.

REFERENCES

1. RBC, Guidelines for the provision of comprehensive care to persons infected by HIV in Rwanda, 2009
2. UNAIDS, Prise en charge psychosociale des personnes infectées et/ou affectées par le VIH/SIDA report, 2008
3. World Health Organization , Adherence to long-term therapies: evidence for action; 2003
4. UNAIDS Report on the Global AIDS Epidemic 2010
5. UNAIDS and WHO, AIDS Epidemic Update, 2009
6. Foster, G (2005). Bottlenecks and Drip-feeds: Channeling resources to communities responding to orphans and vulnerable children in southern Africa. Save the Children UK.
7. Dorothy Mbori-Ngacha: Follow-Up and Adherence Management for Children and Adolescents Living with HIV, University of Nairobi, Department of Pediatrics and Child Health, Kenya
8. TRACNet report, October 2009
9. ADISTAR –one: Meeting the psychosocial needs of children living with HIV in Africa, , Technical brief, June 2011
10. UNAIDS statistics, 2008
11. www.who.int/hiv/pub/paediatric/paed-prelim-summary; consulted on April 27th 2012.
12. Ashley L. Buchanan, MSa, Grace Montepiedra, PhDa, Patricia A. Sirois, PhDb, Betsy Kammerer, PhDc, Patricia A. Garvie, PhDd, Deborah S. Storm, PhDe, and Sharon L. Nichols, PhDf + Author Affiliations: Barriers to Medication Adherence in HIV-Infected Children and Youth Based on Self-and Caregiver Report
13. Mary-Ann Davies et al: Adherence to antiretroviral therapy in young children in Cape Town, South Africa, measured by medication return and caregiver self-report: a prospective cohort study
14. Literature Review Report: Regional Children’s HIV Treatment Literacy Toolkit for Communities, South Africa HIV and AIDS dissemination Service.
15. Journal review: human rights watch: <http://www.hrw.org/news/2010/12/01/kenya-support-disclosure-hiv-status-children>; consulted on April 13th 2012
16. HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: a qualitative study, 2009.

17. Rwanda DHS 2010 and Rwanda epidemiological update 2010
18. World Health Organization: Anti-retroviral therapy for HIV infection in infants and children: towards universal access (Recommendations for a public health approach); 2010 revision.
19. TRACNet Report, Rwanda Biomedical Center 2012
20. Corneli A, L. Vaz, J. Dulyx, S. Omba, S. Rennie, F. Behets. 2009. The role of disclosure in relation to assent to participate in HIV-related research among HIV-infected youth: a formative study. *J Int AIDS Soc*
21. Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, Seventh Edition. © 2003 by Saunders, an imprint of Elsevier, Inc. All rights reserved.
22. National University of Rwanda: Course of research methods
23. National University of Rwanda: Course of operational research
24. <http://data.unaids.org/publications//RC-pub02/pc606-invfuture>: Investing in the Future: psychosocial support for children affected by HIV/AIDS; consulted on November 30th 2011.
25. <http://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2011/november/20111121wad2011report/>; consulted on November 30th 2011.
26. http://www.aidstarone.com/sites/default/files/promising_practices/g3p_docs/CampHope.FinalReport.19Oct09; consulted on Nov 30th 2011
27. S. Naar-King; C. Arfken; M. Frey; M. Harris; E. Secord & D. Ellis (2006): Psychosocial factors and treatment adherence in pediatric HIV/AIDS, *AIDS Care*; 18:6, 621-628; USA, 2007
28. Mary-Ann Davies^{1,2*}, Andrew Boulle², Tanzeem Fakir¹, James Nuttall¹ and Brian Eley¹ et al: Adherence to antiretroviral therapy in young children in Cape Town, South Africa, measured by medication return and caregiver self-report: a prospective cohort study, 2008
29. Siu GE, Bakeera-Kitaka S, Kennedy CE, Dhabangi A, Kambugu A., HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: a qualitative study
30. Arrive´ E, Dicko F, Amghar H, Aka AE, Dior H, et al., HIV Status Disclosure and Retention in Care in HIV Infected Adolescents on Antiretroviral Therapy (ART) in West Africa, March 2012
31. Save the Children UK, Growing up with HIV in Africa, abstracts presented between 2008 and 2012
32. Psychosocial support for orphans and other children made vulnerable By HIV and AIDS. A conceptual framework, Department of Social Development, Republic of South Africa, 2010

33. Care for orphans, children affected by HIV/AIDS and other vulnerable children.
A strategic framework, FHI, 2001
34. UNAIDS: Together we will end AIDS, 2012
35. <http://pediatrics.aappublications.org/content/129/5/e1244.full>; Consulted on May 18th 2012
36. <http://www.biomedcentral.com/1471-2431/8/34>; Consulted on May 18th 2012
37. <http://www.plosone.org/article/info:doi%2F10.1371%2Fjournal.pone.0018505>; Consulted on May 18th 2012
38. http://regist2.virology-education.com/2ndHIVPed/docs/O_16Butler.pdf; Consulted on May 18th 2012

APPENDIXES

Appendix I: Questionnaire for HIV positive children followed up in support groups

Part I : Socio demographic information gathering		
N°	Questions	Answers
1	Sex	M-----1 F-----2
2	Age	Birth date -----
3	Place of residence	Sector----- District-----
4	Do you have parents?	Yes (both of them):-----1
		Yes (only father): -----2
		Yes (only mother):-----3
		No : -----4
5	Do you attend school?	Yes (regularly) :-----1
		Yes (with some absences):-----2
		No (I have dropped) :-----3
		No (I have never been at school) :-----4
6	Are your parent(s)/guardian(s) educated (any education level)?	Yes :-----1
		No : -----2
Part II : Information on adherence to care and treatment		
7	Question about disclosure: do you know why you are attending this clinic every month?	Yes :-----1 No :-----2
8	If yes, what is the reason?	Because I have HIV-----1 To learn how take well my drugs-----2 To play with others-----3 I don't know-----4
9	Age at disclosure: Since when are you aware that you are HIV positive?	Since (Month/Year) :-----/-----
10	a) For how long have you been attending support groups?	Since (month/Year):-----/-----
	b) How many sessions did you attend since then (also look at the patient register)?	Number of sessions:----- Number of sessions due-----

11	How many times do you usually have to come at the clinic per months?	Number of visits : one-two times-----1 More than two times:-----2 Don't know/remember :-----3
12	**Appointment keeping: check from the patient's file and see how many appointment he/she responded to versus the due number of appointments	Number of missed appointments:-----1 Number of appointments due:-----2
13	**CD4 cell counts: check the first (at enrollment in care and treatment program) and last CD4 cell numbers from the patient's file	First CD4 cell counts : -----1 Last CD4 cell counts: -----2
14	** Weight: check the first weight at the enrollment and last weight from the patient's file	Weight at the enrollment: -----1 Last weight:-----3
16	What is the formulation of your drugs (look at them if possible and consult file too)	Syrups-----1 Pills-----2
17	What are your strategies to remember taking your doses?	Radio-----1 Watch with alarm-----2 Family members remind me-----3 Other (specify)-----4
18	Have you missed any support group sessions?	Yes (number of missed sessions): -----1 No (skip the following 2 questions):-----2
19	What are the obstacles to attend support groups sessions (reasons why you have missed sessions)?	Transportation fees-----1 Parent/Guardian not always available-----2 I was sick-----3 Other (specify)-----4
20	What would you propose to address them?	----- ----- -----
21	Do you have any questions for me?	----- ----- -----

Thank you

** Information to be collected from patients' file without asking question to them

Appendix II: Consent form to be used before talking to support group members (to be signed by parents/guardians)

Introduction

My name is _____ and I am a student at National University of Rwanda.

I am here to collect some information about your attendance to support groups. In order to conduct a study on the “*contribution of support groups to adherence on care and treatment among HIV positive children*”, I will ask you some questions about your participation to support groups and other related to adherence to care and treatment program in this clinic. The results of our interview and data collection will be compiled with those from other children in this clinic and used to better understand the current situation in this clinic and to determine the contribution of support groups to adherence on care and treatment that could be recommended to other health facilities.

I am not recording you, your name or any other information that could be linked to you.

The responses you give me are confidential and will be summarized with the responses of other clients in this clinic and will serve to improve service provision.

Thank you.

Consent

I, _____, after reading and understanding the above statement, accept that my child provides the needed information.

Parent's signature _____ Date ____/____/____

=====

Icyemeza ko abagize amatsinda batanze amakuru ku bushake gisinywa mbere yo kuganira nabo

Intangiriro

Nitwa: _____ nkaba ndi umunyeshuri muri kaminuza nkuru y'u Rwanda.

Ndi hano kugira ngo mumpe amakuru ku byerekeye uburyo muhura na bagenzi banyu mu matsinda mukaganira ku byerekeye ubuzima bwanyu. Mu rwego rw'ubushakashatsi turimo gukora ngo tugaragaze umusanzu w'ibiganiro mu matsinda y'abana babana na virusi itera SIDA mu gukurikirana neza gahunda yo kuvurwa no kwitabwaho, ndibukubaze ibibazo byerekeye iyo gahunda ndetse n'uburyo ibafasha kugira ngo mubashe gukomeza kubaho neza. Umusaruro w'ikiganiro cyacu n'amakuru uza kumpa bikazakoreshwa kugira ngo twumvaneza uko iyo gahunda ikora ndetse n'uburyo andi mavuriro yabigiraho. Sindibufate amajwi, amazina yawe cyangwa andi makuru yaba akwerekereyeho.

Ibisubizo uza kumpani ibanga kandi bizashyirwa hamwe n'iby'abandi bo muri ri vuriro kugirango ribashe kurushaho gutanga serivisi nziza.

Ndabashimiye.

Kwemeza ko amakuru atanzwe ku bushake:

Jyewe _____, maze gusoma no kumva neza ibyanditse haruguru, nemeye ko umwana wanjye atanga amakuru akenewe.

Umukono _____ Itariki ____/____/____