Done by Adolphe Majyambere

In collaboration with Kigali Hope Association

Completion Year: 2017

ACKNOWLEDGEMENT

We would like to thank Kigali Hope Association (An organization of HIV-positive young

people) for ideas and support in data collection. This study is a result of the provided support

by making available the members to be interviewed and two peers who volunteered by who

assisting in data collection process.

We also thank the authorities of health facilities, interviewed care providers, counselors and

two senior staff from mental health and HIV/AIDS national
programs.

Adolphe Majyambere

SUMMARY

Several studies showed that HIV-positive youth and adolescents constitute a high-risk group

for mental and behavioral disorders
worldwide.

For young people and adolescents, it is obvious is that mental and behavioral disorders are

potentially preventable when properly and timely done.

A naturalistic cross sectional, descriptive study was done in health facilities. The main objective of this study was to assess the feasibility of mental and behavioral disorders primary prevention for HIV-positive adolescents and young adults through HIV/AIDS services.

In total, 112 adolescents and young adults aged between 14 and 25 were interviewed, 58.9% were males while 41.1% were females. Six health care providers and two policy makers were also interviewed.

Results from the study shows that among the needs of adolescents and young adults for prevention of mental behavioral disorders, there are; 1) communication and HIV status disclosure properly done to the children and adolescents; HIV disclosure counseling was qualified by all participants as an important component to prevent later mental and behavioral disorders. 2) The majority (66.9 %) of the participants were being followed up in by HIV care and treatment for more than 6 years including 15.2 % who have been enrolled for more than 15 years, continuous medical and psychosocial care were qualified as important element for prevention of mental and behavior disorders.

Lack of clear policy and guidelines, lack of trained and specialized staff, limited social support and insufficient skills for family members to support affected youth and adolescents are key identified weakness and

threats.

Finally, we come up with a model named: *“Model for prevention of mental and behavioral*

disorders among the adolescents and youth infected by HIV”. The model proposes

interventions at three levels; 1) policy and guiding documents, 2) clinical practices and 3)

family and community involvement.

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CHAPTER ONE: INTRODUCTION

1.1. CONTEXT AND PROBLEM STATEMENT

In Rwanda, the prevalence of HIV is 3% in the general population. Among the youth, the HIV prevalence is 0.6 % for those between 15 and 19 years old while it is 1.5% of the youth between 20 and 24 years old [1].

Mental health and HIV/AIDS are closely interlinked; mental health problems, including

substance-use disorders, are associated with increased risk of HIV infection and AIDS and

interfere with their treatment, and conversely some mental disorders occur as a direct or

indirect result of HIV infection [2].

On the other hand, HIV/AIDS imposes a significant psychological burden. People with HIV

often suffer from depression and anxiety as they adjust to the impact of the diagnosis of being

infected and face the difficulties of living with a chronic life-threatening illness, for instance

shortened life expectancy, complicated therapeutic regimens, stigmatization, and loss of

social support, family or friends. HIV infection can be associated with high risk of suicide or

attempted suicide. The psychological predictors of suicidal ideation in HIV-infected

individuals include concurrent substance-use disorders, past history of depression and

presence of hopelessness
[2].

The comorbidity of mental illnesses and increased psychological distress among HIV-

positive individuals is substantially higher than in the general population. Studies in both low

and high-income countries have reported higher rates of depression in HIV-infected people

compared to HIV-negative control groups
[2].

The level of distress often seems to be related to the severity of symptoms of HIV infection

and coping styles and learnt resourcefulness may shape the experience of depressive symptoms and the ability to care for oneself [2].

Although the problematic of mental health conditions associated to HIV is not yet explored enough in Rwanda, data from a study done in one of the health centers in the capital city show a high rate of depression among HIV-positive attending HIV care and treatment services. According to the author, the prevalence of depression among people living with HIV/AIDS who participated in the study was 41.7%. The percentage of depressed participants is in the range between 31.83 and 52.18% (CI of 95%). This means that almost a half of people living with HIV in the present study scored positive for depression, thus confirming that there is a high prevalence of depression among people living with HIV/AIDS attending a selected primary health care centre in Kigali [3].

The significant prevalence of depression among children living with HIV in Rwanda reflects a critical need to advance mental health care in this population. 25% of children aged between 7 and 14 had a diagnosis of depression based on the clinical interview [4].

Mental health comorbidities can negatively affect disease management in adolescents with chronic illnesses [7].

Adolescents living with HIV have additional risk factors that aggravate their susceptibility to

mental illness. Many may experience increased vulnerability due to loss of family and may

have to live independently, with relatives or in care. These adolescents are often exposed to

environments of poverty and violence and consequently experience other traumatic events

[8].

Living with a chronic illness, particularly one associated with stigma, discrimination and

social isolation, further impacts on one's mental health. Additionally, prolonged exposure of

the central nervous system to untreated HIV during developmental years can cause

neurocognitive disorders such as impaired motor skills, language difficulties and verbal and

memory impairment [8].

Mental illness and substance abuse are important co-morbidities. The disclosure and

declaration of HIV status to self and family is challenging and guilt in sexually infected

adolescents and tendency to blame parents if vertically affected need special consideration

and proper counseling [8].

In Malawi, in a study done for 562 adolescents (mean age, 14.5 years [SD 2.0]; 56.1 %

female), the prevalence of depression was 18.9 %
[12].

Mental and behavior disorders among the young people and adolescents have a negative

impact on HIV management including adherence to care and treatment program. It is

important to address mental health issues in adolescents living with HIV, as there is a risk of

delayed initiation and poor adherence to antiretroviral treatment
[8].

In a study we previously carried out in Kigali for adolescents and youth infected by

HIV/AIDS (double orphan, maternal orphan, paternal orphan, non-orphan), the rate of non-

adherence to antiretroviral treatment of each orphan category was 59.3%, 44.9%, 46.7%, and

49.7%, respectively [9].

An adolescent is an individual who gets infected with HIV once but stays infected and affected

for life [14].

Adolescents living with HIV experience numerous psychosocial stressors over an extended

period of time. These may be related to the initial diagnosis and disclosure of their HIV

status; the emotional and financial strain of long-term care and adherence to treatment;

coping with stigma and discrimination; distrust of health care providers; fear and experience

of legal consequences and abuse/violence (in the case of many key populations);

bereavement related to the death of loved ones or apprehension about their own possible

death; and concerns around emerging sexuality and desire for relationships and families of

their own [16].

Research in a number of international settings indicates that HIV-affected children (i.e. those

with HIV-positive caregivers) are at risk for a range of mental health problems, including

depression, anxiety and social problems due to disrupted parent–child relationships, fear and

misinformation [25].

Globally, antiretroviral therapy has exerted a dramatic impact on the mortality of perinatally

HIV-infected children. From 2001 to 2012, AIDS-related pediatric mortality declined by

64%. In high-resource settings, the mean age at death has doubled from 9 to 18 years

between 1994 and 2006 among the perinatally HIV-infected population [29, 30].

Similarly, in Africa, an increasing number of perinatally HIV-infected children have reached

adolescence. Although perinatally HIV-infected children are living longer, more efforts are

required to improve their mental health and their quality of life [31].

In general, middle childhood and early adolescence are periods crucial for mental health,

regardless of sero-status. In 50% of all depression cases, the first signs of the disorder appear

by the age of 14 years [32].

In Rwanda, HIV services have had tremendous achievements and progress. Now, Rwanda

has one of the highest rates of antiretroviral treatment coverage in Africa [5]. These achievements should contribute to boost mental health programs including prevention of mental and behavioral disorders focusing on most at risk groups.

In a study we recently published, done on 475 perinatally HIV-infected children aged between 7 and 14 years, of all children, 22% had symptoms of depression. Among those who had depressive symptoms (*n*= 105), 49% had never received psychological support [40].

As stipulated by the World Health Organization, integration of mental health into HIV/AIDS initiatives and programs in countries presents an opportunity to improve the health of people with HIV/AIDS [1].

Integration of mental health prevention in existing chronic disease control programs:

Integration of mental health in chronic diseases management especially in HIV /AIDS services was recommended by the World Health Organization as a key strategy to boost mental health services. The expansion of AIDS treatment initiatives in resource-poor settings provides an opportunity for integrating mental health care into HIV treatment [27].

The WHO recommends that attention to the psychosocial needs of people living with HIV

should be an integral part of HIV care. This includes assistance with employment, income,

housing, informed decision-making, coping with illness and discrimination, and prevention

and treatment of mild and serious mental health problem
[28].

In one operational study done in Ethiopia on integration of mental health prevention and care

in HIV primary health care HIV services, results show that, after training, the health care

providers at the pilot HIV clinics-initiated provision of mental health services, supported by

ongoing mentorship by the program's mentors. Results from the initial group of participating

37 health centers, from January to June 2014, are described below; the case managers

screened 17,484 clients, of whom 5.4 percent (944) clients were identified with suspected

mental health problems. Of these, 82 percent (773) were referred to the HIV clinic's nurse or

health officer for further assessment. The HIV clinic nurses and health officers diagnosed 616

clients with mental health problems. Among this group, the most common diagnosis was

anxiety (33 percent), followed by depression (31 percent), and memory loss/dementia (14

percent) [33].

The argument for integrating mental health care into primary health care is not only due to a

limited number of mental health professionals, but also to a certain number of benefits such

as reduced stigma for people with mental disorders, improved access to physical health care,

improved prevention and detection of mental disorders, better treatment and follow up, better

human rights protection, better health outcomes and improved human resource capacity.

Although there are benefits, there are also many challenges to integrating mental health care

such as the integration of mental health care into primary health care that requires investment

in staff training to detect and treat mental disorders, consistent availability and affordability

of psychotropic medications which is necessary and difficult in many settings, health care

providers' time which is further stretched and adequate supervision of primary care staff to

ensure quality and sustainability of mental health care
[33].

In Rwanda, the Ministry of Health initiated a program focusing on management of HIV and

mental disorders co-morbidity, through the HIV/AIDS and mental health national programs.

The program is now at the level of general
hospitals.

The core question is how prevention of mental and behavioral disorders can be done for

adolescents and young adults infected by HIV as one of the most at risk

groups.

Based on facts and real needs of users, this study will contribute to improve the mental and

behavioral disorders prevention component on that official
program.

1.2. STUDY INTEREST AND MOTIVATION

Our study was inspired by the intertwine relation between HIV and Mental Health and is aimed to

improve mental health in one of the most promising and vulnerable group: adolescents and

youth. The study is motivated by a scientific interest for a subject which is less explored and

documented in Rwanda.

Moreover, there is a researcher's particular interest to contribute to the improvement of mental

health and HIV services provided to adolescent and youth in
Rwanda.

By this study, we will contribute to finding better ways to improve mental well-being of

adolescents and youth infected by HIV through integration of mental and behavioral disorders

prevention in existing HIV care and treatment
services.

Prevention of mental disorders among children and adolescent is feasible. According to the

authors, specific interventions to increase resilience in children and adolescents through parenting

and early interventions, and programs for children at risk for mental disorders such as those

who

have a mentally ill parent or have suffered parental loss or family disruption, have also shown to

increase mental well-being and decrease depressive symptoms or the onset of depressive

disorders [10].

For example, in recent years, researchers and policy makers have recognized the importance of

focusing on prevention efforts for depression. Prevention requires a paradigm shift from

traditional disease models, in which symptoms are treated when they emerge, to a proactive focus

on mental health and on maximizing protective factors while reducing risk factors for mental

illness [13].

The aim of this study is to assess the feasibility of mental and behavioral disorders prevention

among the HIV-positive adolescents and youth in general hospitals' HIV services in Kigali-

Rwanda.

The focus for the study is primary selective prevention. Selective prevention targets individuals

or subgroups of the population whose risk of developing a mental disorder is significantly

higher than average, as evidenced by biological, psychological or social risk factors [10].

1.3. OBJECTIVES OF THE STUDY:

1.3.1. General objective:

The overall objective this study is to assess the feasibility of mental and behavioral disorders primary prevention among HIV-positive youth and adolescent integrated in general hospital HIV services.

1.3.2. Specific objectives:

- Assess the needs for prevention of mental and behavioral disorders among adolescents and youth infected by HIV
- Identify strengths , weakness, opportunities and threats for HIV services to integrate prevention of mental and behavioral disorders among adolescents infected by HIV
- Analyze existing national policies, plans, guidelines and tools on how they respond to the matter of mental and behavioral disorders among the HIV-positive adolescents and youth in order to inform the key stakeholders (policy makers, health care providers , users and the community)about prevention of mental an behavioral disorders among youth and adolescents infected by HIV
- Review literature and documentation about the best practices on mental health prevention and care among the HIV-positive young adults and adolescents
- Propose an integration model for mental and behavioral disorders prevention within HIV services targeting HIV-positive adolescents and youth.

CHAPTER TWO: METHODS

2.1. STUDY DESIGN

This study is a naturalistic, cross sectional, descriptive study that targeted both direct and indirect

beneficiaries. By direct beneficiaries, we mean the HIV-positive adolescents and young adults

and indicted beneficiaries are health care providers and policy makers. The study was carried out

in three general hospitals. The three general hospitals in Kigali were selected by convenience

criteria to perform the study.

In addition to the questionnaire addressed to HIV-positive adolescents and young people,

interviews with health care providers and policy makers from both Mental Health and HIV/AIDS

national programs were made.

2.2. RESEARCH QUESTIONS:

The study research questions are the following:

- What are the specific needs for HIV-positive adolescents and youth aged between 14 and

  25 years vis à vis prevention of mental and behavioral disorders in Kigali city general

  hospitals?

- What are the strengths, weaknesses, opportunities and threats in existing HIV services to

  and mental health programs to integrate prevention of mental and behavioral disorders for

  adolescents and youth infected by HIV in the Kigali city general hospitals?

- What are the available / lacking information in the national documents to guide the

  integration of mental and behavioral disorders among the HIV-positive adolescents and

  youth?

- What can be proposed as a model for prevention of mental and behavioral disorders

  among adolescents and youth infected by HIV in the Kigali city general hospitals?

2.3. STUDY POPULATION:

This study targeted HIV-positive adolescents and youth aged between 14 and 25 years old, enrolled in HIV care and treatment services in three general hospitals located in Kigali City. Health care providers and policy makers were also interviewed.

2.4. SAMPLING AND DATA COLLECTION METHODS:

A random sample was done for adolescents and youth who attended the clinic during a two weeks period from 26 September to 8 October 20016. The final sample comprised 112 participants. The interviews were conducted by selected and recruited experienced peers in the health facilities.

HIV/AIDS counselors from the health facilities were also recruited as focal points responsible for selecting eligible cases and eventually provide support if needed.

Interviews were done for health care providers from HIV and mental health services within the three health facilities (six respondents). In addition, we conducted interviews with policy makers on both HIV and mental health national programs (two informants).

During the data collection period, we interviewed all individuals who meet the inclusion criteria and attended the HIV clinics.

Inclusion criteria

Participants were adolescents and young adults meeting the following criteria:

1) to be HIV-positive and aware of his /her HIV status ,

2) to be aged between 14 and 25 years old
and

3) to be willing to respond to the questionnaire.

Data collection instruments:

A questionnaire was used to collect data from the participants for social demographic information

and the assessment of needs. We developed the used questionnaire based on key needed

demographic information related to the study. Inspired by other studies and official documents,

we came up with a check list of specific needs of adolescents and young adults infected by HIV

vis à vis prevention of mental and behavioral disorders and developed the questionnaire

accordingly.

2.5. LITERATURE AND DOCUMENT REVIEW: POLICY DOCUMENTS ANALYSIS

In this study, literature review was done in two
steps:

Step one: review of published studies, official documents and reports on mental health

prevention for youth and adolescents in general and for those infected by HIV/AIDS. In addition,

we consulted published articles and documents describing prevention of mental and behavioral

disorders in general and specifically those related to prevention among the children, adolescents

and young adults infected or affected by HIV/AIDS or other chronic diseases.

Step two: The second step for literature review was dedicated to the review of the existing

national official document. For this, we set up a check list composed by questions related to the

needed information. The overall objective of this exercise was to make analysis on the national

policy, guidelines, protocols and tools vis à vis prevention of mental and behavioral disorders

among the HIV-positive adolescents and youth.

2.6. STATISTICAL ANALYSIS PLAN:

Statistical descriptive analysis of socio-demographic information and assessed needs was done

using SPSS-Version20.

2.7. SWOT ANALYSIS:

This was done to enumerate strengths, weakness, opportunities and threats for prevention of

mental and behavioral disorders in HIV services specifically for adolescents and youth infected

by HIV. This helped to know what is existing and on what the prevention interventions can be

based. This combines both structures, human and financial resources aspects.

2.8. ETHICAL CONSIDERATIONS:

Protection of intimacy and confidentiality for the respondents was ensured following adequate

and consensual procedures. Provided responses did not influence health care delivery to

participants. Again, a consent form was proposed to respondents for free and voluntarily

participation to the study. For adolescents under 18 years, parents or guardians were consulted to

give consent for the participants.

Briefly, the table below summarizes how the objectives were responded by answering to the

research questions, methods and data collection instruments that were used (table 1):

Table 1: Research questions, objectives, methods and data collection instruments:

Research questions	Objectives	Methods	Data collection tools
1. What are the specific needs for HIV-positive adolescents and youth aged between 14 and 25 years vis à vis prevention of mental and behavioral disorders in Kigali city general hospitals?	Assess the needs for prevention of mental and behavior disorders for adolescents and youth infected by HIV.	-Interviews with adolescents and youth	Questionnaire.
What are the strengths, ıknesses, opportunities and			Questionnaire.

threats in existing HIV and mental health programs to integrate prevention of mental and behavioral disorders among youth and adolescents in the Kigali city general hospitals?			gration of mental and avioral disorders among the -positive adolescents and th?	
engths, weakness, s and threats for HIV integrate prevention and behavioral among adolescents HIV.	-SWOT analysis	- Documentation review	nal es and ond to the ehavioral IV- d youth.	- Documentation review
	-SWOT analysis	- Documentation review		- Documentation review
		-SWOT analysis questions		-Interview with policy makers
		-SWOT analysis questions		-Interview with policy makers
		-SWOT analysis questions		- Documentation review checklist
		-Interview guide for care providers		- Documentation review checklist
		-Interview guide for care providers		- Documentation review checklist
		-Interview guide for policy makers		-Interview guide for policy makers
		-Interview guide for policy makers		-Interview guide for policy makers
		-Interview guide for policy makers		-Interview guide for policy makers
3. What are the available / lacking information in the national documents to guide the		-Documentation review checklist	Vhat can be proposed as a del for prevention of mental behavioral disorders among lescents and youth infected HIV in the Kigali city general pitals? ew of	

ument and best inspire an integration evention of mental ral disorders among itive youth and - Propose a model n of mental and isorders prevention HIV-positive .		checklist - Documentation review checklist
	-Literature review -Literature review	-Interview guide for policy makers -Interview guide for policy makers -Interview guide for policy makers
	-Interview with policy makers -Interview with policy makers	
	- Documentation review checklist - Documentation review	

CHAPITER THREE: RESULTS

3.1. Socio-demographic characteristics and specific needs for the adolescents and youth infected by HIV

3.1.1. Socio-demographic characteristics:

In total, 112 adolescents and young adults aged between 14 and 25 years old were interviewed. Among them 66 (58.9%) were males while 46 (41.1%) were females.

Most of the participants were aged between 18 and 21 with a proportion of 48.2%. 24.1 %

were aged between 14 and 17 while 27.7 % were between 22 and 25 years old.

The majority were protestant with 58.9%. Catholics represent 30.4 % while muslims were

6.3%.

For education level, more than a half (56.3%) completed or were attending their secondary

school, 9.3 % completed or are having university education while 20.5% completed or are in

the primary level education.

The majority of the interviewed adolescents and youth (97.3%) were not yet married while

2.7% were single parents. For occupation, 60.7 % of the respondents were student, 15.2%

had income generation jobs while 24.1% were unemployed. The loss of parents is one of the

situation affecting adolescents and youth infected by HIV. In this study, more than a half of

(50.9 %) lost one of their parents while 23. % are double orphans.

The table below summarizes that socio-demographic data for the respondents (table 2):

TABLE 2: Social and demographic characteristics (N=112)

VARIABLES FREQUENCY PERCENTAGE

SEX

F 46 41.1

M 66 58.9

Total 112 100.0

Age

14-17 years old 27 24.1

18-21 years old 54 **48.2**

22-25 years old

Total

27.7

100.0

100.0

31

112

27.7

RELIGION

Catholics 34 30.4

Protestants 66 58.9

Muslims 7 6..3

Others 5 4.5

Total 112 100.0

EDUCATION LEVEL

Not educated 4 3.6

Primary 23 20.5

Post primary 11 9.8

Secondary 63 56.3

University 11 9.8

Total 112 100.0

MARITAL STATUS

Married 0 0.0

Single 109 97.3

Single parents 3 2.7

Divorced 0 0.0

Total 112 100.0

OCCUPATION

Income generating job 17 15.2

Unemployed 27 24.1

Students 68 60.7

Total 112 100.0

ORHANS vs NON ORPHANS

Double orphans 26 **23.2**

Have only mother 54 **48.2**

Have only farther 3 2.7

19.6

Non orphans 19.6

Missing data 6.3

22 7 6.3

Total 112 100.0

18

3.1.2. Needs for HIV-positive adolescents and young adults vis à vis prevention of mental and behavior disorders:

The needs of HIV-positive adolescents and young adults might be identified according to

different aspects.

For this study, we focused on needs that are linked to prevention of mental and behavioral

disorders. In other words, we assessed specific elements needed for prevention of mental and

behavioral disorders among the HIV-positive youth and adolescents.

3.1.2.1 Communication of the HIV status to children and

adolescents:

HIV disclosure counseling is an important component of mental and behavioral disorders prevention among the adolescents and young adults infected by HIV especially those who acquired the virus from their mothers. The time to tell the child his status is an important element.

Data below show at which age the interviewed adolescents and youth were informed about their HIV status. Most of them were informed about their HIV status at late age. The majority (53.6%) were informed when they were between 11 and 14 years old. Some cases were obliged to wait until the age of 15 and above to be communicated their HIV status. Most of the participants who were informed about their HIV status at late age were double orphans (66.7 %) of those who were informed at 15 years and above. This means that double orphans are likely at risk for a delayed information about their HIV status.

Below is a table showing when HIV status was communicated to the respondents:

TABLE 3: Age of HIV status disclosure to children and adolescents

Age at HIV disclosure	Frequency	Percentage
Before 7 years old	1	0.9
Between 7 and 10 years old	42	37.5
Between 11 and 14 years old	**60**	**53.6**
15 years old and above	9	8.0
Total	112	100.0

Who did the HIV disclosure to adolescents and youth?

Most of the HIV status disclosure to the children and adolescents was done by health care providers. Near a half of respondents (49.15%) were informed about their HIV status by health care providers while 43.8% were informed by their parents. Only 7.1% were informed by other close family members. The role of both care providers and parents is very crucial in the HIV disclosure process. Results are captured in table below:

TABLE 4: Who did the HIV disclosure to the children and adolescents?

Who disclosed the HIV status	Frequency	Percentage
Parents	49	43.8
Health care providers	**55**	**49.1**
Other family members	8	7.1
Total	112	100.0

Appreciation of how HIV disclosure was done:

Adolescents and youth who were interviewed in this study appreciated the way the HIV status

was communicated to them. The majority of participants (69.6 %) appreciated how the disclosure

was done while 30.4% did not appreciate the way they were communicated their HIV status.

Below is the table describing the appreciation of the HIV disclosure process:

Table 5: Appreciation of HIV disclosure process:

Appreciate how HIV disclosure was done	Valid	Yes	78	69.6
		Total	112	100.0

ent Valid Percentage

69.6

100.0

Reasons mentioned by interviewed adolescents who didn't appreciate the HIV disclosure

process include the fact that they were too young to understand the message (41.7%), the

message which was not clearly communicated (25.%) and the fact that proper disclosure was

done after a longtime of lies (33.3%).

However, all adolescents and young people agreed that HIV status disclosure counseling done

properly can help to prevent mental and behavioral disorder.

Most of the interviewed participants were able to openly disclose their HIV status to other

people (60.7 %) while 39.3 % didn't tell anybody. Near a half of those who disclosed their

status (45.5%) were given support from friends and relatives.

3.1.2.2 Services provided to adolescents and youth

Most of the adolescents and young people have been enrolled in HIV care and treatment services

for more than 6 six years (82.1%) and almost half have been followed up for more than 11 years

(47.3%). Below is a table describing the duration of follow up in HIV care and treatment

services.

TABLE 6: Duration in HIV care and treatment services:

	ency	Percentage
Number of years in HIV Care and treatment services		
1-5 years	20	17.9
6-10 years	**39**	**34.8**
11-15 years	**36**	**32.1**
15 years and above	17	15.2
Total	112	100.0

Among the services offered to beneficiaries, most of them mentioned the following packages:

1) Medical care + HIV education sessions + support groups + life skills and the plan for

future

(21.4%)

2) Medical care + Free of charge medical services / health care insurance+ HIV education

sessions + HIV education sessions + Nutrition+ Individual Counseling and Psychotherapy+

Support group+ Income generating activities + School fees and/or materials + Life skills and

the plan for future (19.6 %)

3) Medical care + HIV education sessions + Individual Counseling and Psychotherapy+ support

groups (12.5%)

4) Medical care + Free of charge medical services / Health care insurance + HIV education

sessions + Individual Counseling and Psychotherapy
(12.5%).

Medical care combined with individual counseling and psychotherapy was qualified by the

participants as the most important components that help to manage and cope with their HIV status

(49.1%). Generally, medical and psychosocial services were qualified by participants as services that

are strongly contributing to prevention of mental and behavioral disorders for the age group. The

majority of respondents (72.3%) agreed while 27.7 % think that the two kinds of services are not

enough to prevent mental and behavioral
disorders.

Among the recommendations made, there is; 1) to put in place a particular follow up system for HIV-

positive young people and adolescents (9.8%), 2) to increase the frequency and variation of activities

for support groups and 3) reinforcement of diet and nutrition services (8%).

3.1.2.3 Support from friends and families:

Even if there is a proportion of adolescents and young people who didn't openly disclose their

HIV status (39.3%), it is important to highlight that nearly all respondents (92. %) recognized the

role of friends and families in prevention of mental and behavioral disorders for adolescents and

young people infected by HIV. However only 52.7 5% agreed that the family members are trained

and prepared to provide support to them in order to prevent mental and behavioral disorders.

Among the training topics proposed by respondents there are; 1) how to live with an HIV-positive

young person (33%), 2) diet and nutrition (8%), 3) and counseling skills (6.3%).

3.1.2.4 Perceived stigma and needed support:

The majority of participants (83%) stated that they have never experienced any kind of

stigma or discrimination. Even if the rate of stigma and discrimination is low, some of the

adolescents and youth fear to be stigmatized and avoid to disclose their HIV status to other

people (39.3%). One of the positive elements is that the majority of those who openly talked

about their HIV status were given more support (71.8%).

3.2. Objective two: Assessment of the weaknesses, forces, threats and opportunities

Information was collected from health care providers in HIV and mental health services in the

three general hospitals in Kigali. The table below describes the key strengths, weaknesses,

threats and opportunities for HIV services to integrate prevention of mental and behavioral

disorders for adolescents and youth infected by
HIV.

The table below captures the information collected from six health care providers and two

program managers. The table summarizes the strengths, weaknesses, opportunities and threats for

HIV and services to integrate a component for prevention of mental and behavioral disorders

focusing on adolescents and youth infected by
HIV.

Table 7: Presentation of strengths, weaknesses, opportunities and threats:

Strengths	Weaknesses
▪ Existence of both HIV and mental health services in the hospitals ▪ Lack of enough and well trained and /or specialized staff	▪ Inter-service program aiming integration of Mental Health and HIV services ▪ Lack of appropriate communication materials
▪ Multidisciplinary teams in some health facilities	▪ Guidelines are not clear enough on prevention of mental and behaviors disorders
▪ Treatment of most of mental disorders especially depression and anxiety	

- Lack of enough counseling rooms
- Regular follow up system for HIV-positive adolescents and youth in HIV services
- Lack of social support in the package for some health facilities
- Counseling in HIV services but focusing on cases with symptoms
- Limited means to do home visits
- Support groups for adolescents and youth
- Regular follow up is not well done especially in mental health services
- Home visit and outreach services
- Care and treatment are not standardized for all health facilities
- Financial support including transport facilitation for adolescents and youth in some health facilities
- Internal fundraisings are organized in some health facilities to support adolescents and youth activities

Opportunities Threats

- HIV services have external fund donners interested in care of adolescents and youth
- Financial aid is decreasing
- Heavy workload
- Health facility authorities valued HIV and mental health services
- Clinical supportive supervisions by central level experts
- Family members have limited skills in mental health and developmental aspects for adolescents. This causes law service demand and late consultations
- Families and the community don't understand their role in prevention of mental and behavior disorders

By looking at the findings from the SWOT analysis, it is clear that the general hospitals have

many forces and opportunities on which can be based the integration of mental and

behavioral disorders prevention. Some of the needed mental disorders prevention

interventions are already in place in some health facilities. The most important element to

reinforce is standardization and documentation of the interventions set with clear objectives

and monitoring and evaluation system. In addition, some health facilities have innovations

and initiatives that can guide policy makers to translate them into clear guiding documents.

3.3. Objective three: Analysis of policy and other guiding documents

The table below summarizes information contained in the national documents to guide the

implementation of mental and behavioral disorders among the HIV-positive adolescents and

youth.

TABLE 8: Analysis of policies of other national guiding documents

N°	Name of document	Is the documents clear on the topic (Yes / No)	Findings /Comments
	. Third Health Sector Strategic Plan 2012-2018		ח sector plan highlights mental health as one

of the main aspects of diseases control but has no

adolescents and psychosocial in for HIV management

single detail on what to do for mental disorders

but mental health prevention does not appear

prevention

anywhere

2. Rwanda HIV national strategic plan

- Insufficiency of adolescents and youth friendly

2013-2018

services is highlighted among the key challenges.

. Guideline for psychosocial care and

support for people infected and /or

affected by HIV/AIDS

eline highlights important elements that

Psychotherapy, psychosocial counseling and home

contribute to mental health prevention such as HIV

visit are as key stipulated interventions but not

status disclosure, support groups and group/

specifically for adolescents and youth

indi

psy

How

sim

disc

you

3. National Mental Health Policy in

- Mental health policy has a general component of

Rwanda

mental disorders prevention but information and

strategies focusing on youth and adolescents mental

disorders prevention is not available

. Guideline for mental disorders

roposed for mental and behavioral disorders

4. National strategic plan for mental

- No special focus on prevention of mental and

health 2001-2015

behavior disorders among the adolescents and youth

management

prevention

. National protocol for management of

mental health disorders

ny prevention component

5. Rwanda National Health Research

Agenda 2014- 2018

- Priority research topics are mentioned including

0. HIV disclosure tool for children and

adolescents infected by HIV

important tools that contributes to mental

mental health but none focusing on adolescents and youth

health prevention by its methodic way to proceed

6. National Guidelines for Prevention

- The guideline has important components on

and Management of HIV, STIs &

Other Blood Borne Infections.

Edition 2013

HIV

set

in a

anti

11. Guideline for HIV management

component for care of adolescents but prevention of

o Mental health is considered as an important

mer

ado

among the adolescents

3.4. Objective three: Model for prevention of mental and behavioral disorders among

the adolescents and youth infected by HIV

Considering the literature review and information collected through interviews done with care

providers , policy makers and data collected from adolescents and youth , it is easy to conclude

that mental and behavioral disorders prevention for HIV-positive adolescents and youth can be

addressed while working on three levels : policy and guiding documents, clinical practices and

family/community level (chart 1) :

3.4.1. Levels of the model:

3.4.1.1 Policy and guiding documents:

Policy and guiding documents development is the startup point for any program and intervention. Mental and behavioral disorders prevention for adolescents cannot be done if policies are not clearly considering that aspect as an important one. While the policy is developed, it has to be translated into a strategic plan, guidelines, protocols and tools to guide the implementation.

From the information collected in this study, there are several initiatives and interventions

done in the general hospitals specifically for adolescents and youth. Some of the

interventions are contributing to the prevention of mental and behavior disorders for the

adolescents and youth but still, there is a need to clearly incorporate this aspect in the mental

health and HIV/AIDS policies, strategic plans, guidelines, protocols and tools. The

Chart 1: Model for mental and behavioral disorders prevention for HIV-positive

adolescents and youth

importance of having clear guidance documents in to set up standardized services as well as

monitoring and evaluation
mechanisms.

The model highlights also the reciprocal linkage between policy development and clinical

practice experience. Policies orient the clinical practice on one hand, and on the other hand

clinical practice experience is needed to inspire policy development. SHEKHAR S., et al,

reminded that in their article. “Because of their knowledge base, mental health professionals

need to advise public health planners and programme developers on the possibilities of

initiating prevention interventions or integrating mental health components into existing

programmes. The possibilities for this role are enormous, since most countries and

communities have public health and social programmes that can serve the cause of prevention

of mental disorders. Even if no changes are needed, an awareness that the programme may be

having an impact on prevention of mental disorders helps to reinforce the need for the

programme to be continued or expanded
[10].

Inter-service collaboration is a key element for their success of this model through a well-

structured referral system, regular case and information sharing meetings. One touching

example is a case where the hospital HIV services staff organized a fundraising involving

care providers and hospital authorities to collect some money to respond to raised social

support needs for HIV-positive adolescents and
youth.

SHEKHAR S., et al confirmed that, in many cases, mental health professionals need to take

an active role in initiating prevention programmes. This role can be as a leader or as an active

collaborator, especially in an intersectorial programme. Some of the most effective

prevention programmes have been initiated by mental health professionals working in close

collaboration with other professionals. [10]

3.4.1.2 Clinical practices:

The clinic is the place not only where mental and behavioral disorders can be diagnosed and

treated but also prevented. More than 80% of interviewed adolescents and youth has been being

followed up in the HIV care and treatment services for more than six years. For this purpose, the

proposed model gives power to the clinic setting for not only the management of symptoms but

also provide services that promote resilience and copying strategies to neutralize risk factors

for the normal development of the HIV-positive adolescents and youth. Interventions like HIV

disclosure counseling timely and properly done have positive impact on adherence to

antiretroviral treatment and the general health outcomes for children and adolescents.

An important question is how to know what approach to use to make sure adolescents and youth

are served with preventive services. Among the strategies to achieve this is the set up youth

friendly services equipped with multidisciplinary well trained teams to implement the minimum

package clearly defined in the guidelines using appropriate tools. Again, inter-services

connection and collaboration is needed to manage cases that may require more advanced and

specialized care services.

Screening of mental and behavior disorders including alcohol and drug abuse

Prevention of mental and behavioral disorders among the HIV-positive adolescents and

youth, clinical practices should comprise systematic screening of mental and behavioral

disorders including alcohol and drug
abuse.

The World Health Organization recognizes that Mental illness can take many forms,

especially in adolescents as they go through emotional, social and physical changes. Most

commonly, adolescents experience depression and anxiety disorders. Other mental health

issues that are prevalent in adolescents include behavioral and psychiatric problems such as

attention deficit hyperactivity disorder. Alcohol and other substance use, which is common

during adolescence, can contribute to increased risk of mental health problems. Additionally,

adolescents affected by trauma e.g. rape, abuse or other forms of violence can experience

long-term anxiety and depression in addition to the physical effects of trauma [8].

The World Health Organization recommends to address mental health issues in adolescents

living with HIV as mental illness increases adolescents' vulnerability to engage in risk-related

behaviors, including substance use or risk-associated sex.
[8]

The model proposes the systematic screening of mental and behavioral disorders for

adolescents and youth infected by HIV as the key component for prevention as well as care

and treatment.

Linkage between clinical practices and support from the family /community:

In addition to the health facility based clinical services, the role of care providers is important

when extended to the interventions targeting the family members and the community. The

modal proposes the link between the two settings and their reciprocal enrichment.

SHEKHAR S., et al, proposed that another way mental health care providers can assist in

prevention efforts is by initiating prevention interventions in family members of those taking

mental health care. Preventive approaches for children of parents with a diagnosed mental

disorder, who are particularly at risk, can be highly effective but unfortunately not applied

often. Mental health professionals need to balance their role of providing much needed care

to the patients who are under treatment with preventing future need for care among their

families [10].

3.4.1.3 Family and community involvement:

The role of family members and the community in prevention of mental and behavior

disorders is crucial. Safe and supportive environment free of any kind of stigma is a key

protective factor for adolescents and youth infected by HIV. Conclusions from a qualitative

study showed that, HIV+ adolescents in South Africa experience similar concerns to those in

high-income countries, socio-emotional coping may be compromised by increased levels of

loss due to the late roll-out of antiretroviral treatment and challenges to caregiving contexts

including poverty, stigma and minimally supported foster care arrangements. There is a need

for mental health promotion programmes for adolescents to adopt an ecological approach,

strengthening protective influences at the individual, interpersonal, community and policy

levels [36].

Most of the interviewed participants recommended that family members should be coached by

health care providers in supportive counseling of children, adolescents and youth infected by

HIV.

Parent management training programmes have also shown significant preventive effects, like

the "The Incredible Years", which provides a behaviorally-based intervention that increases

positive interactions between the child and the parent, improves the child's problem-solving

behavior and social functioning, and reduces conduct problems at home and school. The

programme uses videotape modelling methods and includes modules for parents, school

teachers and children [10].

Again, adolescents and youth need to be taught about life skills including sensitive issues related

to the future life such as marriage, how to have children etc. This model proposes also a specific

package for orphans due to multiple losses, and critical socio-economic situation. For that

reason, vulnerability to mental and behavioral disorders is higher. Services like parenting and

other kind of social support (education and free of charge medical insurance for example) are

necessary for that specific group
[10].

In one family based intervention study done in one rural Rwanda district, results showed that

interventions targeting families contribute to prevention of mental and behavioral disorders

among the HIV- affected adolescents. According to caregivers, youth protective factors of

family connectedness, good parenting, child pro-social behavior and caregiver social support

improved significantly from pre-intervention to post-intervention, and changes were

sustained and showed continued improvement at the 6-month follow-up. In addition,

caregiver-reported youth perseverance/ self-esteem was higher at 6-month follow-up than at

pre-intervention. Youth-reported social support and parental use of harsh punishment also

improved significantly from pre- to post-intervention and improvements were sustained at 6

months of follow-up.

The number of children who scored in the clinical range for depression decreased from five

of 32 (15.63%) at baseline to four of 31 (12.90%) at post assessment, to three of 33 (9.09%)

at follow-up. The number of children whom caregivers rated in the clinical range for

depression decreased from five of 37 (13.51%) at baseline, to three of 34 (8.82%) at post

assessment, to zero of 34 at follow-up. According to caregivers, youth-internalizing

symptoms (depression, anxiety/depression and irritability) also improved from pre-

intervention to 6-month follow-up. There were no reported improvements in youth conduct

problems or functional impairment [25].

This model is built on the principle that prevention of mental and behavioral disorders does

not only consist on reducing symptoms but rather put in place a framework that help in both

promotion of protective factors and reduction of
symptoms.

An article on prevention of mental disorders among the adolescents highlighted that, in recent

years, researchers and policy makers have recognized the importance of focusing on

prevention efforts for depression. Prevention requires a paradigm shift from traditional

disease models, in which symptoms are treated when they emerge, to a proactive focus on

mental health and on maximizing protective factors while reducing risk factors for mental

illness. In general, a review of the literature indicates that prevention programs utilizing

cognitive behavioral and/or interpersonal approaches, and family-based prevention strategies,

are most helpful [26].

For the American National Research Council and Institute of Medicine, Prevention

emphasizes the avoidance of risk factors; promotion strives to promote supportive family,

school, and community environments and to identify and imbue in young people

protective

factors, which are traits that enhance well-being and provide the tools to avoid adverse emotions and behaviors [13].

3.4.2. Cost implication for the model:

Considering the current available resources and the structure of HIV and mental health services in general hospitals in Kigali, this modal doesn't have a big budget implication. Rather, it requires more restructuration, coaching, supervision and guiding documents (guidelines, protocols and tools).

Data collected from participants, interviews done with health care providers and policy makers as well as the SWOT analysis show that adolescents and youth have access to many

services that, if well reorganized and standardized, can contribute better to the prevention of

mental and behavioral disorders among the adolescents and youth infected by HIV without

great funding need. However, one of the three hospital is lacking a psychologist in the team.

Furthermore, some funds should be oriented to training, clinical supportive supervision,

mentoring and the development of guiding document and tools.

The World Health Organization recommends that primary health-care providers,

including

HIV counsellors, can be trained to recognize and treat common mental and substance-use

disorders and refer patients to specialized services when warranted. Such providers need to

be properly trained and supported by adequate supervision, and the process of referral to

mental health services needs to be an integral part of the health infrastructure [1].

After identification of HIV-positive adolescents and youth needs, the American Academy of

Pediatrics report (2014) proposed a similar package. Pediatrics proposed a response to those

needs grouped into four categories: 1) Youth friendly services: composed by elements related

to HIV disclosure, confidentiality and stigma, denial and coping with diagnosis of HIV

infection , case management, multidisciplinary and comprehensive care in the medical home.

2) Structural program elements: including addressing barriers to health care, access to mental

health services, alcohol and drug treatment, transportation to health care settings and housing

as well as peer-to-peer counseling. 3) Social media: as a mean of communication and

reminder to improve adherence to antiretroviral treatment. 4) Advocacy: advocate for

resources that are necessary to provide optimal care for HIV-infected adolescents and young

adults to include social support, rehabilitation, education, and access to basic necessities,

including stable housing, without which the best medical care may prove ineffective

[34].

CHAPITER FOUR: DISCUSSION:

Socio-demographic factors for Mental and behavioral disorders prevention

A sample of 112 was considered for this study. Males represent 58.9 %, while females represent 41.1%. There is a predominance of the adolescents and youth aged between 18 and 21 years old with 48.2% of all respondents. With antiretroviral treatment, children who were perinatally infected by HIV have now the chance to live longer until the adolescence and adult age.

Similarly, in the United State of American, many children infected with HIV perinatally

have

survived into their second or third decade of life with antiretroviral treatment [34].

In our study, most of the interviewed adolescents and youth (65.1%) are doing or had

competed their secondary and/or university education level studies. This is a good sign that

HIV-infected adolescents and young people in Rwanda have access to basic education. This

can be considered as a mental health protective factor.

The American pediatric academy confirms that graduating from school is a major milestone

for all youth [34].

Students living with HIV have a right to equal access to education and the opportunities that

education creates. Being able to remain in school and pursue an education represents

normalcy and the maintenance of hopes and ambitions for the future. It also allows

adolescents to acquire the life skills they need to manage peer pressure, form relationships,

make good decisions and achieve their goals. Schools can also serve as important partners for

health services in meeting the needs of adolescents for information, testing, support and

referral for appropriate services [8].

There is sufficient evidence indicating the efficacy of interventions in reducing risk factors,

increasing protective factors, preventing psychiatric symptoms and new cases of mental

disorders. Macro-policy interventions to improve nutrition, housing and education or to reduce economic insecurity have proven to reduce mental health problems [10].

In other words, education provides to marginalized children and youth affected by HIV epidemic with a window of hope and opportunity for a future free from poverty, disease and disparity [37].

Most of the interviewed HIV-positive adolescents and youth have lost at least one of their parents (74.1%) including the double orphans (23.2%). The psychological wellbeing of the orphans infected by HIV is a big concern. Prevention of mental and behavioral disorders among the orphans by HIV should be given more attention.

In a study done among HIV-positive adolescents in Kenya, for mental health, orphan status was associated significantly with emotional problems, depression symptoms, exposure to traumatic events, and intrusion and arousal symptoms of PTSD. Orphan status also was significantly associated with less social support [15].

In a study done in Uganda , more orphans, than non-orphans had more common emotional

and behavioral problems e.g. more orphans reported finding “life unfair and difficult”

(p=0.03); 8.3% orphans compared to 5.1 % of the non-orphans reported having had past

suicidal wishes (p=0.30) and more reported past “forced sex / abuse” (p=0.05). Lastly, the

orphans' social functioning in the family rated significantly worse compared to the non-

orphans (p= 0.05). Qualitatively, orphans, compared to non-orphans were described as

“needy, sensitive, and isolative with low confidence and self-esteem and who often lacked

love, protection, identity, security, play, food and shelter
[38].

The same study recommended setting up a national policy and support services for orphans

and other vulnerable children and their families, a national child protection agency for all

children, child guidance counselors in those schools with many orphans and lastly social

skills training for all children [38].

Delay in HIV disclosure for children /adolescents and prevention of mental and

behavioral disorders

HIV status disclosure for adolescents and youth is not only an important step in management

and prevention of mental and behavioral disorders but also a matter of right. In this study, we

observed that HIV disclosure was delayed in most of the cases. The majority of participants

were informed about their HIV status between 11 and 14 years (53.6%). A certain number of

them (8%) were even obliged to wait until the age of 15 and above.

Results from a study done is South Africa show that older child age was a determining factor

for HIV disclosure to children, 22 (37.2%) learned of their HIV diagnosis between 11 and 16

years. The mean age of disclosed children was 10.6 years [39].

While there is little evidence that disclosure causes psychological harm and research suggests

that it may actually be beneficial for a young person's mental wellbeing. A study done in

Zimbabwe showed that learning about their HIV status is still one of the most difficult life

events for adolescents living with HIV/AIDS [21, 22].

Despite these facts, the World Health Organization's guidelines for HIV status disclosure are

limited to children under the age of twelve. Even though, many perinatally-infected children

are not disclosed their HIV status until they are adolescents [23].

The American Academy of Pediatrics encourages the disclosure of HIV infection status to

school-aged children [17]. Timely and properly done HIV disclosure counseling is an

important element in prevention of mental and behavioral disorders for perinatal HIV infected adolescents and youth.

In addition, a study done in the United States of America concluded that there was also no significant difference between time trends in quality of life scores before and after disclosure of HIV status, suggesting that diagnostic disclosure to children should not be delayed for fear of a negative impact on quality of life [35].

However, a particular attention should be put on double orphans. In this study, most of those with late HIV disclosure (66.7 %) at the age of 15 years and above were double orphans. At the family and community level, the proposed model suggests a particular social support to orphans infected by HIV.

HIV long-term follow up and integration of mental and behavioral disorders prevention:

More than 82.1 % of interviewed adolescents and young people have been adhering to the

HIV care and treatment services for more than 6 years including those who are being followed up for 15 years and above (15.2%). These figures show a high retention rate and prolonged duration for follow up in HIV care and treatment services for perinatally infected adolescents and youth. For that reason, HIV care and treatment service is a better place to integrate prevention of mental and behavioral disorders among the adolescents and youth infected by HIV. While preventing and managing mental and behavioral disorders, there will be a double gain. On one hand, the infected HIV-positive adolescents and youth will develop a positive mental health and on the other hand, HIV prevention, care and treatment will be well managed.

The biopsychosocial approach is particularly important to the management of HIV infection.

Successful prevention and treatment cannot occur in the absence of well integrated psychosocial approaches. Mental health workers, either directly or in consultation with other providers, have an important role to play in ensuring that these services are well-conceptualized and meet the mental health needs of those who use them [18].

While interviewing adolescents and youth, results showed that medical services combined with psychosocial counseling and psychotherapy services are essential. They were appreciated and qualified by the participants (49.1%) as key pillars in prevention of mental

and behavior disorders.

The World Health Organization recognizes that psychosocial support can help patients as

well as their caregivers gain confidence in themselves and their coping skills. It can increase

patients' understanding and acceptance of comprehensive HIV care and support services,

encourage adherence to HIV treatment, and equip them with skills to make informed

secondary prevention decisions. Such support can also help prevent adolescents living with

HIV adopting risk-associated behaviors or from developing more severe mental health

problems [8].

Caregivers also benefit from support that acknowledges the stress they are under and

validates their concerns about their children or charges, while enabling them to learn how to

cope with the adolescent's developmental and health needs
[8].

In addition, integration of HIV into mental health services provides opportunities for

identifying individuals at risk of HIV infection, introducing HIV prevention and detecting

those who are infected and providing them with appropriate HIV treatment and care. Mental

health services should ensure access to voluntary and confidential HIV testing and

counselling for those at risk [1].

Role of family members and the community support:

The role of family members and the support from the community is crucial for prevention of

mental and behaviors disorders among the adolescents and youth infected by HIV.

Participants recognized that role of family members and the community in prevention of

mental and behavioral disorders (92%). However, participants declared that family members

don’t have enough skills and training to support them. This was confirmed by the

interviewed health care providers and policy
makers.

While developing and implementing a mental health prevention program, it is important to

tackle on the family and community dimension. For most adolescents, families remain the

primary, trusted source of emotional, material and practical support. They have an important

role to play in encouraging and supporting an adolescent to live positively with HIV,

beginning with disclosure of the adolescent's HIV status if they have not yet done
so [8].

As children become adolescents, families and other caregivers are key partners with health

providers in supporting a child's transition from pediatric to adult services. However, the

potential benefits of family support can only be gained when an adolescent agrees for their

family to be involved. Health care providers should assess family dynamics and, when

appropriate, encourage adolescents to allow family members or other supportive adults to

play a role in supporting their positive living. As part of goal setting and planning with adolescents, they should be allowed to specify ways in which they want their families to

support them and issues they prefer to address on their own. In general, health care providers should always respect an adolescent's wishes in this regard [8].

Management of stigma and discrimination:

Some of the interviewed adolescents and youth declared they have been ever stigmatized (17%). Most of the adolescents were reluctant to disclose their HIV status to other people.

Only 39.3% were able to openly talk about their status to others. This can be interpreted as a sign of fear to be stigmatized and discriminated.

Considering the negative impact of stigma and discrimination on development of a positive mental health for adolescents and youth, community interventions should focus on promoting activities against stigma and discrimination. As it has been proved in different studies, confronting HIV stigma and managing disclosure of HIV status to others may significantly impact mental health function [19, 20].

Health care providers must also be alert to situations where there is a potential for violence

against the adolescent, which is an issue in some families. In these cases, social and

protective services must be engaged to ensure that the adolescent is safe and remains in care

[8].

Policy and guidance documents:

Although the problematic of mental and behavior disorders among the adolescents and youth

infected by HIV is well documented, analysis done on national guiding documents for both

HIV and mental health programs shows that prevention of mental and behavior disorders is

not clearly stated in the documents**.** The starting point to manage the situation is the

development and the definition of the issue in national policies, strategic plans, guidelines,

protocols and others guiding documents. As highlighted by the responsible of community

mental health and rehabilitation in the national mental health program, prevention of mental

and behavior disorders could not be possible if that component is not clearly defined in the

policy and other reference documents.

HIV /AIDS national guiding documents highlight adolescents and youth infected by HIV as a

particular category and psychosocial care services are well documented. However, a clear

guidance is needed to define the concept and the package of interventions aiming to promote

protective factors for the HIV-positive adolescents and
youth.

LIMITATIONS AND FUTURE DIRECTIONS:

This study was done for a limited age range category and a limited location. Only the

adolescents infected by HIV aged between 14 and 25 were considered. If time and means

allowed, it could be better to cover the entire categories of adolescents and youth infected by

HIV.

The fact that we only considered urban general hospitals causes some limitations. It could

cover even other health structures and countrywide. Again, it could be more interesting if the

proposed model was tested but due to limited time and resources, this could be a subject to

more broad studies.

Further studies can focus on extension of the study to other more wide age ranges with a

sample considering urban and rural realities. However, the results and the proposed model

can be used as a pilot program that can be tested, extended and implemented in all general

hospitals countrywide.

Further researches can also explore the impact of mental health determinants on antiretroviral

adherence as well as on general health outcomes for adolescents and youth infected by HIV.

CHAPITER FIVE: CONCLUSIONS:

Due to successful HIV care and treatment in Rwanda, most of the children who born with

HIV can live longer and many are now adolescents and young adults. The current challenge

is how to help them to live positively with the virus and control the mental and

behavioral

risk factors including the HIV related
stressors.

The fundamental question is how to develop resilience among the adolescents and youth who

most of them born with HIV. Again, how the existing services are taking into consideration

this important matter and how feasible the integration of mental and behavioral disorders

prevention in existing HIV care and treatment services? With the needs assessment done

with the direct beneficiaries, it is easy to conclude that mental and behavioral prevention is a

must.

Most of the adolescents have mental and behavioral vulnerabilities. Results from this

assessment study revealed that current and available resources in the three general urban

hospitals are enough to integrate mental and behavioral disorders. Therefore, clear polices,

plans, guidelines, protocols and tools are needed to guide the implementation of mental and

behavioral disorders for the adolescents and youth infected by HIV. In addition, available

evidences on mental health issues among HIV-positive adolescents and youth can be

translated and inspire current policies, plans, guidelines and protocols updates and

or/development.

Integrating mental health and behavioral disorders prevention in general hospitals is a real

need. Mental health and HIV/AIDS national programs should consider prevention of mental

and behavioral disorders as an important component to improve the well-being of HIV-

positive adolescents and
youth.

Moreover, a restructuration of the care and treatment services is necessary in a way that

existing interventions are reorganized and standardized. The proposed model is essentially

based on what is existing but, in a broader way, considering other dimensions involved in

mental health prevention such as policy and other guiding documents development, clinical

practices, family and community involvement.

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APPENDIX

1. Questionnaire for the adolescents and youth

N° of the responde

M/F

001 Sex M------1 F-----2

N° of the medical file: 002 Age Date of birth : ---------

003 Religion Catholic : ----------1

Protesta

Health Facility/ FOSA: ----------

Muslim :

PART ONE : Demographic characteristics

N° Question Category /response

Other (specify) ----------4

004 Education level Not educated : ----------1

Primary : ----------2

Post primary : ----------3

Secondary : ----------4

University : ----------5

Other (specify) ----------6

005 Does he have parents? None ------1 Only mother -------2 Only farther --

--3 Has both -----4

006 Marital Status Single :----------1

Legally married : ----------2

Not regally married : ----------3

Divorced :------4 Widow/Widower ----------5

007 Occupation Income generating job : ----------1

Unemployed :----------2 Student ----------3

008 Do you have chidden? If yes, how many? Yes : ---------1 No : --------2

Number of children :---------

PART TWO : Information on medical and psychosocial services

HIV DISCLOSURE

009 At which age were you informed about your HIV

status (HIV disclosure)
1) Before 7 Y.O 2) 7- 10 Y.O 3) 11- 14 Y.O

5) a

010 Who informed about your HIV status Parents ---------1

Health care providers : ----------2

Other : ---------3 (specify)----------

011 Do you appreciate the way your HIV status was communicated to you?

If Yes , explain how

If No, explain why
Yes :----------1 No :----------2

If no, what do you think was not good for you?
Yes ----------1 No:----------

---

012 Do you think a good HIV disclosure counseling can help youth and children to prevent mental

(trauma) and behaviors disorders to children?

013 Did you inform someone about your HIV status

If yes, what were the reaction?
Yes :---------1 No:----------2

1) Surprised

3) Stigmatizing

4) Other : (specify)----------

OTHER MEDCIL AND PSYCHOSOCIAL SERVICES

014 For how long have you been enrolled in HIV care and treatment services?
Number of years: ----------

015 What are the services are you gaining from your health facility
1) Medical (ART, prophylaxis , treatment of OIs)

016 What services that you think are most important to help to manage and cope with your HIV status? (By order of importance)
1) ----------
2) ----------
3) ----------

2) Free of charge Medical services/mutuelle de santé

3) HIV education sessions

4) Nutritional services

5) Individual Counseling and psychotherapy

6) Support group

7) IGAs

8) School fees and/or materials

9) Life skills including sensitive issues like (trauma) marriage and the future?

017 Do you think the medical and psychosocial services provided to you are enough to help you to cope with you HIV status?

If no, what can you recommend to improve the services that can help to prevent mental

10)

and behavior disorders for youth and adolescent

infected by HIV?
Yes :----------1 No :---------2

PART THREE : SUPPORT FROM FRIENDS AND FAMILIES

018 Do you think the support from friends and family is important to help young people to cope and

prevent mental and behavior disorders
Yes :----------1 No :---------2

019 Are your family members enough trained and prepared to offer the support you need?
Yes:----------1
No: ----------2

020 What would you propose as education topics that your family member can be trained in to be able to

support you better?

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021 Have you ever experienced stigma related to HIV?

If yes, what kind of stigma did you experienced?
Yes :---------1 No :---------2

---

022 If yes question 021 is true, how does it disturb your copping strategies?

---

023 What do you think can be done for your siblings avoid stigma related to HIV? (at school, at home, in your village)

II. Interview guide for Health Care Providers:

Questions for health care providers in HIV and Mental Health services:

1. Identification of the health care provider:

NAME FH/FOSA SERVICE QUALIFICATION EXPERIENCE GAINED

TRAININGS

2. How do you understand the concept of mental and behaviors disorders prevention

among the HIV-Positive adolescent and youth?

3. What are the main mental and behavior disorders that are generally observed among

the adolescents and youth infected by HIV/AIDS?

4. How do you appreciate prevention of mental and behavior disorders for the

adolescents and youth infected by HIV? Do you think it is feasible and how?

5. Are the policies, guidelines and tools clear about the activities that are needed to

prevent mental and behavior disorders among the adolescents and youth?

6. What do have as activities that you think are contributing to the prevention on

mental and behavior disorders in your current services (HIV or mental health)?

7. What are the challenges that your service is facing in the management of mental and

behavior disorders for adolescents and youth infected by HIV?

8. How do you appreciate the role of the family members in prevention of mental and

behavior disorders for the youth and adolescents infected by

HIV?

9. What are strengths /resources that are available for your services to respond to the

need of young adolescents and youth infected by HIV vis à vis prevention or

decrease mental and behaviors
symptoms?

10. What are the weaknesses for your services to respond to the need of young

adolescents and youth infected by HIV vis à vis prevention or decrease mental and

behaviors symptoms?

11. What are the threats for your services to respond to the need of young adolescents

and youth infected by HIV vis à vis prevention or decrease mental and behaviors

symptoms?

12. What are the opportunities for your services to respond to the need of young

adolescents and youth infected by HIV vis à vis prevention or decrease mental and

behaviors symptoms?

13. Do you have any particular recommendation that could help to integrate mental and

behavior disorders prevention in the comprehensive HIV
services?

III. Interview guide with the policy makers:

1. Is the concept of mental and behaviors disorders prevention among the HIV-

   Positive adolescent and youth clearly defined in the national HIV / mental health

   policy?

2. What are the main mental and behavior disorders that are generally observed

among

the adolescents and youth infected by HIV/AIDS?

3. How do you appreciate prevention of mental and behavior disorders for the

adolescents and youth infected by HIV? Do you think it is feasible and how?

4. Are the policies, guidelines and tools clear about the activities that are needed to

prevent mental and behavior disorders among the adolescents and youth?

5. What are the examples of activities that you think are contributing to the prevention

on mental and behavior disorders in your current services (HIV or mental health)?

6. What are the challenges that your service is facing in the management of mental and

behavior disorders for adolescents and youth infected by HIV?

7. How do you appreciate the role of the family members in prevention of mental and

behavior disorders for the youth and adolescents infected by HIV?

8. What are strengths /resources that are available for your services to respond to the

need of young adolescents and youth infected by HIV vis à vis prevention or

decrease mental and behaviors symptoms?

9. What are the weaknesses for your services to respond to the need of young

adolescents and youth infected by HIV vis à vis prevention of mental and behavior

disorders or decrease mental and behaviors
symptoms?

10. What are the threats for your services to respond to the need of young adolescents

and youth infected by HIV vis à vis prevention of mental and behavior disorders or

decrease mental and behaviors
symptoms?

11. What are the opportunities for your services to respond to the need of young

adolescents and youth infected by HIV vis à vis prevention of mental and behavior

disorders or decrease mental and behaviors
symptoms?

12. Do you have any particular recommendation that could help to integrate mental and

behavior disorders prevention in the comprehensive HIV
services?